SUMMER 2010 ISSUE **232** **THE MAGAZINE OF THE**

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spina bifida
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link

Building the ASBAH community

Building more of a community for ASBAH

by Jackie Bland, CEO

In just over a year now as Chief Executive of ASBAH it has become very clear to me how much people value the services of our advisers and helpline, especially when there are particularly difficult issues to be dealt with. I have received the message loud and clear that these services are vitally important and should be protected even in these times when funding is scarce.

However, I have also noticed that ASBAH has much less to do with its membership than many other voluntary organisations, in fact it hasn't really got a 'membership' at all. In many ways we have become so focused on the challenges that people face, that we have perhaps neglected to build our community in other ways.

In the letters I receive from people and in recent discussions with the new 'Your Voice' committee, as well as in discussions with parents and local associations**, it is clear to me that ASBAH could be much more of a community than it currently is.** It could be in contact with people more often, it could encourage more peer contact and support. Those people who are currently 'registered' with the charity could be listened to more and have more influence over what it does and how it is run.

I am also hearing from people with both spina bifida and hydrocephalus that they want us to be campaigning more about the issues that matter to them, and that they want to be involved in those campaigns.

To respond to this feedback we are working on plans to make ASBAH a full membership organisation. Membership will be free, and all those currently registered with the charity will automatically become members and from then on be in regular contact with us through mailings, updates, special web pages, and in many other ways as the scheme develops.

At the moment we are still consulting all those with a stake in ASBAH about this, because it's important that any membership scheme is what people really want. The Your Voice Committee has already agreed to move forward in developing such a

scheme and plans to consult the wider YV membership. At their meeting in May, the Committee were asked 'What would you want as a member of ASBAH?'. Among their responses were: *regular updates, information, a more attractive organisation for young people, better promotion of ASBAH and the disabilities themselves, peer support, a sense of community, leaflets in different languages, ability and power to change things, a more visible organisation, lobbying at all levels, membership benefits, opportunities to get involved, a large annual event.*

And these were just a few! It won't be possible to do everything at once but feedback like this gives us a valuable new direction for the organisation and **I want to work with colleagues to create a vibrant, energetic, influential membership in the interests of everyone involved with ASBAH.**

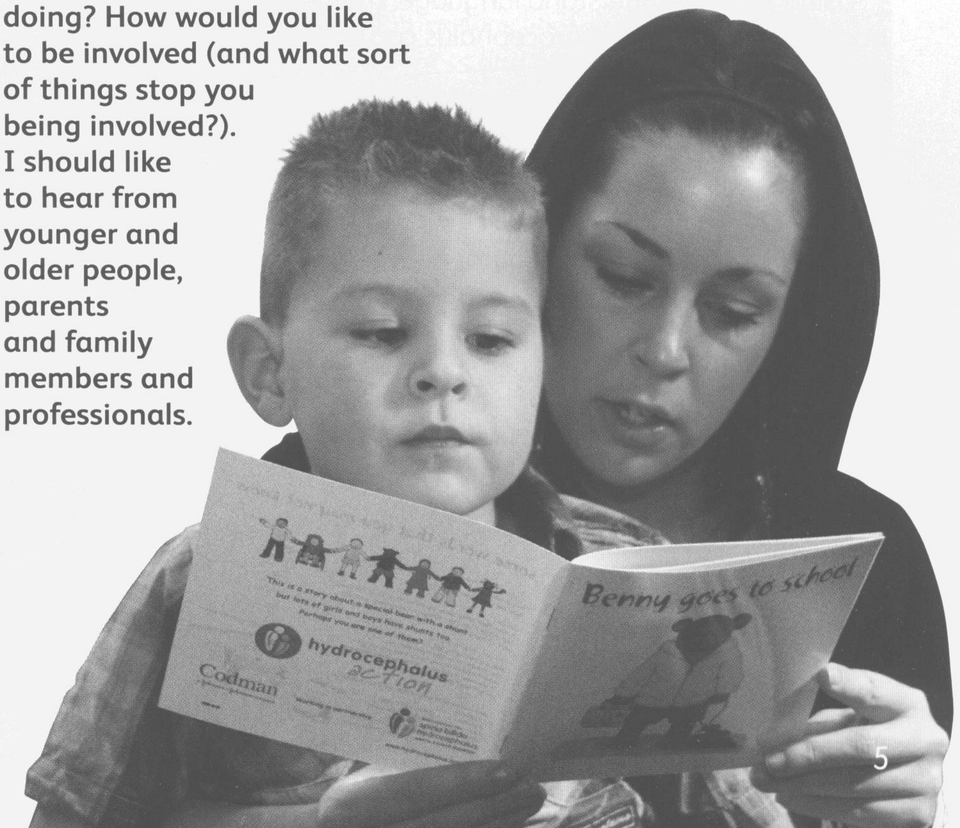
The idea is that the new membership will have a number of different categories –Youth, Adult, Family (parents, carers, other family members). Within the Youth Section it has been suggested that we could have a 'Benny Bear' Club to interest and involve our youngest members. It is also planned to have an Associate Membership which health and social care professionals, and other interested parties, could join.

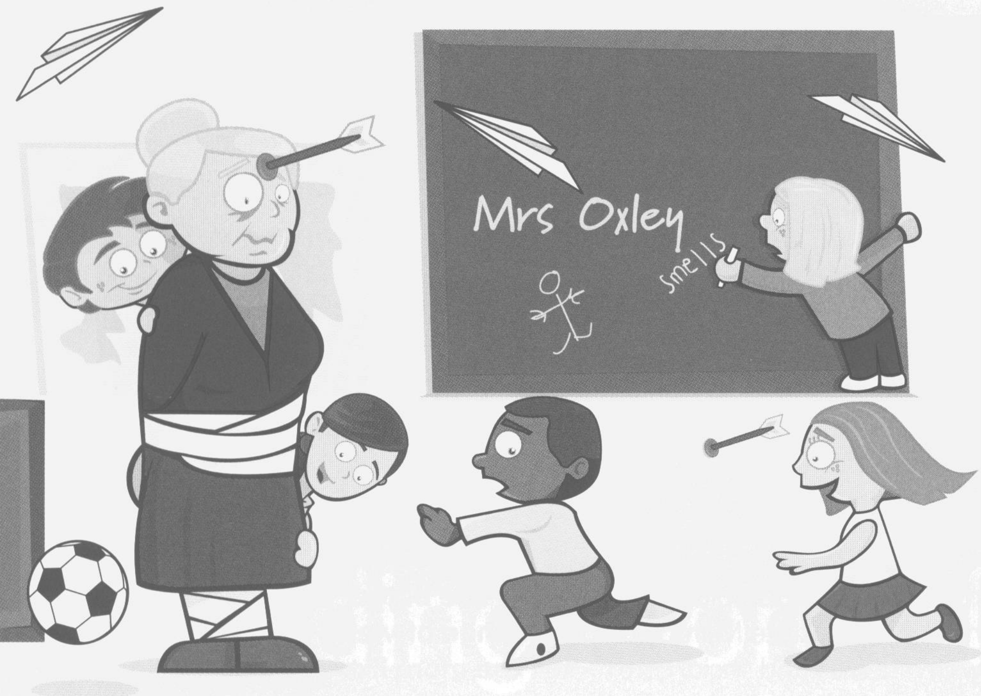
We hope to launch this membership later in the year once funding has been secured and ASBAH's Board of Trustees has approved the final shape of the scheme.

Before that, however, I would like to hear from *Link* readers, and anyone else associated with ASBAH, what you would like as a member of ASBAH. What is important to you? What would you like to see the organisation doing? How would you like to be involved (and what sort of things stop you being involved?). I should like to hear from younger and older people, parents and family members and professionals.

The bigger and wider the range of views we receive, the more likely it is that we can create a really useful, meaningful membership for everyone who wants to be a part of ASBAH in the future.

To let Jackie know your views you can email her direct at: jackieb@asbah.org or ring the helpline number and leave a message for her. Of course, you can also write to: Jackie Bland, CEO, ASBAH, 42 Park Road, Peterborough PE1 2UQ





> "I found the book easy to understand and I liked the bright pages and pictures. I liked the section about planning and organising because it was colourful and didn't have too much to read.
>
> I loved the tips because it was easy to see what the main points are. There are lots of ideas to make learning easier."
>
> **Jess, 9 years old.**

Hydrocephalus and Learning

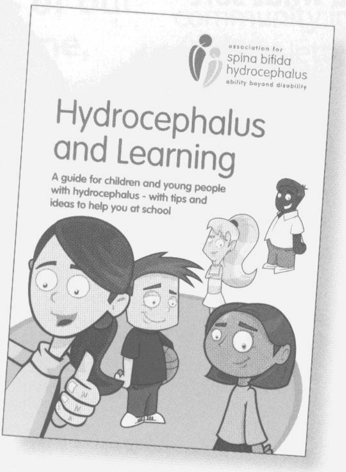
Our latest publication, Hydrocephalus and Learning, aimed at helping children and young people at school, is now available.

The 16-page booklet has been produced by ASBAH's education advisers and Dr Sophie Thomas, a Clinical Psychologist.

Using easy-to-understand language, the booklet explains how hydrocephalus can affect the ability to learn. Young people with the condition can find it difficult to organise themselves for lessons or to plan their work.

The book is packed with practical tips and hints and how to explain to teachers and friends about hydrocephalus.

You can order a copy of Hydrocephalus and Learning online or by phoning the helpline number - 0845 450 7755 - or by emailing *helpline@asbah.org*



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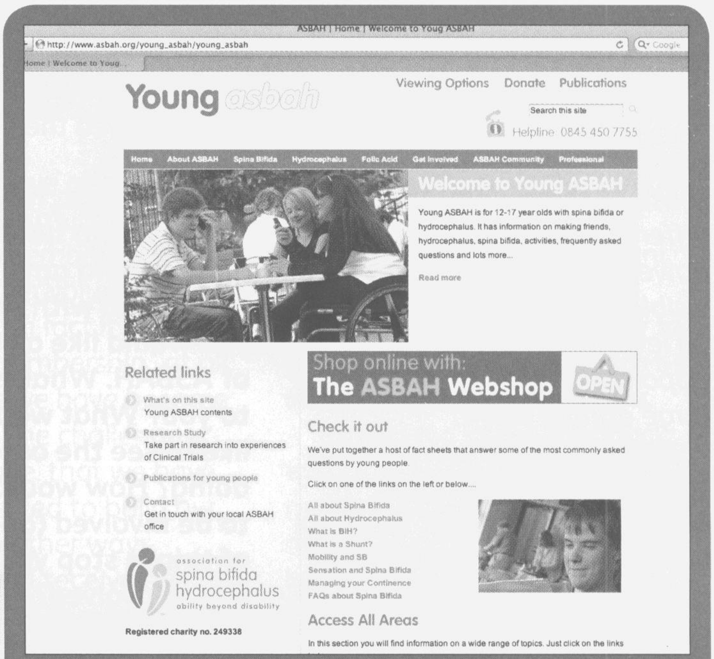
Hydrocephalus and Learning

A guide for children and young people with hydrocephalus - with tips and ideas to help you at school



ASBAH | Home | Welcome to Youg ASBAH

http://www.asbah.org/young_asbah/young_asbah

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Welcome to Young ASBAH

Young ASBAH is for 12-17 year olds with spina bifida or hydrocephalus. It has information on making friends, hydrocephalus, spina bifida, activities, frequently asked questions and lots more...

Read more

Related links

What's on this site
Young ASBAH contents

Research Study
Take part in research into experiences of Clinical Trials

Publications for young people

Contact
Get in touch with your local ASBAH office

association for
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Registered charity no. 249338

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The ASBAH Webshop
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Check it out

We've put together a host of fact sheets that answer some of the most commonly asked questions by young people.

Click on one of the links on the left or below....

All about Spina Bifida
All about Hydrocephalus
What is BIH?
What is a Shunt?
Mobility and SB
Sensation and Spina Bifida
Managing your Continence
FAQs about Spina Bifida

Access All Areas

In this section you will find information on a wide range of topics. Just click on the links

Young ASBAH goes live

Our new website for 12 – 17 years olds with spina bifida and/or hydrocephalus is up and running.

Young ASBAH is packed with information on making friends, hydrocephalus, spina bifida, activities, frequently asked questions and lots more...

We're keen for our young members to play an active role in their website too and welcome your submissions. Contact us at the usual *Link* address.

See it your yourself at: ***www.asbah.org/youngasbah***

Nominate **ASBAH** at work

Many employers adopt a Charity of the Year so we're asking all our service users, families and friends to take the opportunity to nominate ASBAH at work.

We know from experience that company 'Charity of the Year' arrangements can bring in very valuable funds.

The decision about which charity to choose is often based on employee nominations which frequently benefits the larger organisations that have higher profiles - with smaller charities being overlooked.

We would like to encourage everyone in the ASBAH community to ask their employer to consider us when reviewing their charitable activities for the coming year. Get family and friends to ask theirs too!

Martine Austin, ASBAH's new corporate relations officer, said: "If you don't feel comfortable about asking the question directly, please feel free to call me.

"You could always write a short letter to the relevant person telling them about us (we would be happy to help you with this), or simply ask if you can put up one of our posters in the company staff room, coffee area, or on a notice board. It all helps.

"Don't forget to point out that helping a smaller organisation like ASBAH means that any support they give will have a much greater impact."

Martine is also looking for influential/high profile individuals that may be able to support one of ASBAH's forthcoming campaigns – so if you know of someone who fits the bill... please get in touch.

If either you or your employer require any further information, materials/posters etc, please contact Martine Austin on 01733 421349 or email *martinea@asbah.org*.

CHARITY OF THE YEAR

Tony's nomination gets the vote

Tony Nero, who has a part-time position at the Passport Office in Peterborough, put forward ASBAH for the coveted Charity of the Year title.

With help from a member of ASBAH's fundraising team, he submitted an application letter, plus printed information about ASBAH, to the charity committee.

In January he was delighted to hear that ASBAH had been chosen as the Passport Office's charity for 2010.

Now he's supporting the many fundraising events and has donated one of his paintings as a raffle prize.

Tony told *Link*: "ASBAH was nominated by two other members of staff at the Passport Office which I know helped my application.

"Staff do a lot of different fundraisers every year, from raffles and cake sales to sweepstakes, so I was really pleased that ASBAH was selected."

Arty ASBAH raises £300

Peterborough shoppers with an eye for art enjoyed a chance to view and buy originals at our special fundraising exhibition.

The event, at our Peterborough head office, was set up by artists Shaun Pitchers and Tony Nero, who donated 15% of the proceeds from every sale to ASBAH.

A special VIP viewing was also held and attracted guests including the Mayor of Peterborough, city councillors and leading people from the local business world.

The exhibition raised more than £300 for ASBAH, with £252 being donated from sales and a further £77 from the raffles and sales of badges.

Tony, who works as a designer in ASBAH's marketing department, said: "Thank you to everyone who made it to the exhibition and to all who helped on the day and sold raffle tickets.

"The exhibition was very successful in helping to raise awareness and funds for ASBAH, as well as being a great opportunity for Shaun and me to show our work."

For further details and to see examples of the artists' work go to **www.tonynerobrushworks.com**

What now for Special Needs education

You may recall a news item which featured on both TV and in the papers, in the run up to the general election when the father of a young boy with spina bifida questioned David Cameron on the Conservative's policy on the education of children with special needs.

Jonathon Bartley told Mr Cameron of his two-year struggle to get his son Samuel, who has spina bifida and hydrocephalus, into mainstream school and said he believed that the system was biased against getting disabled children into mainstream school.

He told Mr Cameron: "You are not representing the needs of children in mainstream education. You want to segregate disabled children."

Mr Cameron, then leader of the Conservative Shadow Cabinet, said as a father of a disabled child himself he was "passionate" about helping them to get the education which was right for them.

"We want a better balance and to give the choice to parents," he told Jonathon Bartley. "At the moment statementing is done by Local Authorities. We think it should be provided by someone separate.

"We think that if parents prefer their child to go to a mainstream school they should have that; if they feel their child would do better in a special school, they should have that."

In an interview with Sky News Jonathon Bartley said he was worried that there won't be the resources to support children with special needs.

Now Britain is led by a Tory-Lib Dem coalition government. Its 'The Coalition: our programme for government' states: "We believe the most vulnerable children deserve the very highest quality of care. We will improve diagnostic assessment for school children, prevent the unnecessary closure of special schools, and remove the bias towards inclusion."

Source: ***http://libdems.org.uk/siteFiles/resources/PDF/Government/Coalition-Programme.pdf***

Link would be interested to hear from parents about how the change of government affects their choices in the education of their child.

Marmite's Moomite Auction raises thousands for ASBAH

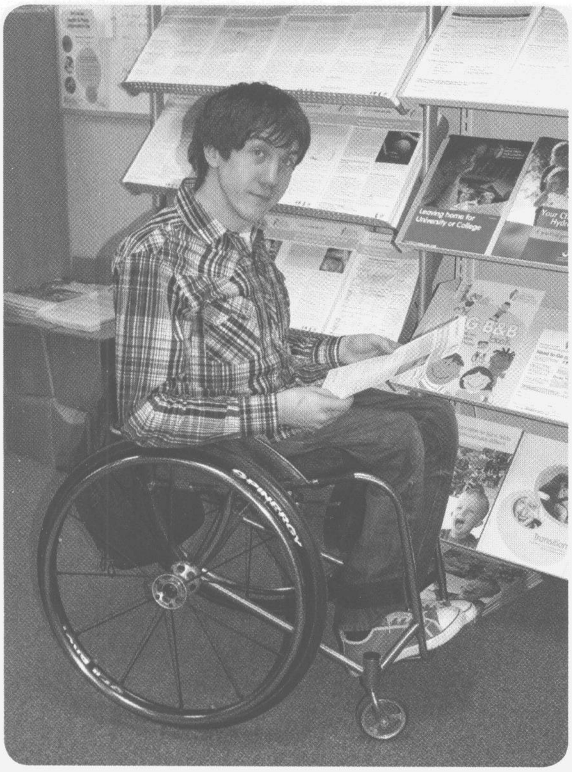
A piece of exclusive art by popular artist Caroline Shotton was auctioned on eBay by Marmite to raise funds for ASBAH.

Bidding for the original painting was fierce with the winning bid reaching £2,969, which was donated to ASBAH, as Marmite's preferred charity.

The painting, entitled Moomite, features quirky cows on the iconic Marmite jar label, but in a comical take on Salvador Dali's famous surrealistic piece, 'The Persistence of Memory'.

Jackie Bland, Chief Executive of ASBAH, said: "The relationship we have with Marmite is excellent. They are very proactive and thoughtful as to how they can work to benefit ASBAH and ensure that the essential services we provide are maintained.

"In just a matter of months, Marmite has helped raise thousands of pounds for ASBAH, since we became their preferred charity. I would like to say a big thank you to all those people at Marmite who helped in the latest fundraising exercise and look forward to continuing our relationship with this iconic brand."



TV star visits ASBAH

Actor and ASBAH Patron David Proud paid a visit to ASBAH House to meet staff.

David, who plays Adam Best in the BBC's EastEnders, made a return visit to the Peterborough offices where he did work experience after leaving school.

David, who has spina bifida, said: "ASBAH helped me when I was younger and now, they help even more people."

"ASBAH has supported thousands of people in some shape or form over the years and I'd urge as many people as possible to make contact, irrespective of the complexities surrounding the issue."

Staff told *Link*: "It was lovely to meet David. He was very relaxed and chatty, and was very interested to hear about the work we do. Of course we picked up a little showbiz gossip too!"

To check out the images from the tour, click: ***www.facebook.com/DavidProud***

Danny's marathon challenge raises over £12,000

ASBAH Patron and former England footballer Danny Mills completed the Brighton Marathon in a wheelchair in an impressive 2 hours, 43 minutes raising more than £12,000.

His efforts have also helped promote ASBAH in the national media and raise awareness.

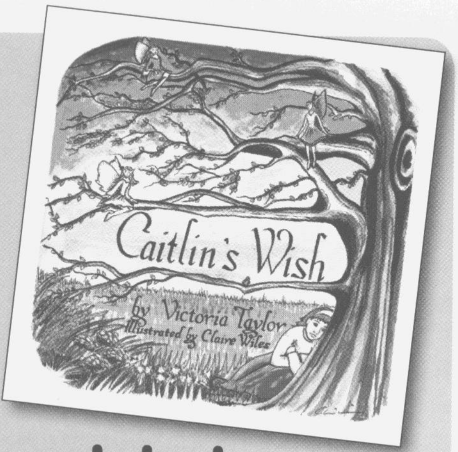
His training for the 26.2 mile event began on 20 October last year and he said: "A big part of the challenge was to adapt to training in a wheelchair and using different muscles to the ones I used as a professional footballer."

But the gruelling training paid off as he crossed the finish line almost 30 minutes faster than he had hoped.

Danny said: "It was tough but the crowds were fantastic although I got a puncture to the front tyre for which I had no spare, only 9 miles into the race. Fortunately I was able to continue to the end without it making too much difference.

"At around 20 miles everything was sore - fingers, arms, shoulders, back, and my legs were numb, but all I could think about was making it across the line.

"There was no way I was going to fail or let down everyone that helped make this possible. But most importantly I wasn't going to let down all those who have so generously sponsored me."



Story book helps young carers stay positive

A new story book aimed at children who have a disabled family member helps young carers to see the positives in their life rather than dwelling on the negatives.

Caitlin's Wish was written by Victoria Taylor for her daughter, Adele-Caitlin, when she found it hard to come to terms with her father's disability.

When Adele-Caitlin was two years old her father was diagnosed with Intracranial Hypertension (IH). Being so young she just accepted the situation.

It was only when she went to school that she started to compare her life with others and realised that her life was different. She felt sad and isolated by her situation, but was too young to access any support.

Inspired to try and make a difference, Victoria wrote the magical fairytale (with a twist) with young carers in mind.

Caitlin's Wish helped Adele-Caitlin to view her life from a different perspective and she realised that disability and illness can affect anyone at any time in their life.

She learned to think of the things that her father could do now, rather than dwelling on what he couldn't do anymore.

Victoria has now published the book in the hope that it might help other children.

Caitlin's Wish is available to order now, published by Author House and can be purchased at from the Author House website price £10.99.

www.authorhouse.co.uk/bookstore

For more information on Caitlin's Wish please go to ***www.caitlinswish.co.uk***.

Royal visitor for clinic

Patients at Multi-Disciplinary Clinic for Spina Bifida & Hydrocephalus got a royal surprise when ASBAH's Royal Patron, HRH The Duchess of Gloucester, paid a visit.

The Duchess met staff and patients during the 50-minute long tour of the department at the Chelsea and Westminster Hospital.

ASBAH adviser Gill Yaz, who attends each clinic, held once a fortnight, was on hand to meet her.

Gill said: "The Duchess expressed a wish to see the clinic for herself on a working day and she was extremely well informed and interested.

"She met the staff members and the consultants who work there on an ad hoc basis. It was a lovely surprise for the patients who were booked in and one, Carol Weatherby, was asked to present the Duchess with a bouquet."

The Multi-Disciplinary Clinic cares for approximately 500 patients a year from a wide geographical area.

It provides a 'one-stop' health check-up for patients living with spina bifida and hydrocephalus, drawing on the expertise of a range of multi-disciplinary staff. Patients can expect to be seen once a year for an annual MOT.

ASBAH has supported the clinic since it was first established. Health Adviser Gill Yaz attends all clinics to give advice to patients and their carers on social and support issues, and to make contact with their local key worker to provide ongoing support.

Where are they now?

Elisabeth Copeland

We know the years fly by but we couldn't believe it when we heard that Elisabeth Copeland (or Beth as she's called) had started school.

Link readers may remember the feature we ran about her parents Sam and Mark who talked to *Link* when a 20-week routine scan indicated that Beth had spina bifida and hydrocephalus.

The couple were determined to remain upbeat and looked forward to the birth of their already much-loved daughter.

Beth was born on 16 February 2005 and after a tough few months, the family – which includes Laura (now 21) and David (now 18) – settled down to their new life.

Five years on, the family have moved house, Laura has finished university and married, David is off to university and Sam is completing the second year of her Food Industry Management degree course. Life is hectic, as Sam continues to teach an evening class at a local college and is still making wedding cakes.

She took time out from baking 160 cupcakes to talk to *Link*…

Sam's story

"A lot has happened in the last few years. Life has certainly been a rollercoaster for the whole family.

The first few months were difficult as Beth was going in and out of hospital regularly, but gradually things got easier.

Beth is a real joy and everyone who meets her loves her. She's bossy, headstrong, full of fun, bright as a button and is very happy at school.

The first mainstream school we looked at didn't have the facilities she needed but we are very happy with the school we found.

> ***"Of course I have had wobbly moments but I tell myself to shut up moaning and get on with it. There are many parents who have had it much harder than us."***

She has one-to-one support and the teaching assistant Natalie, who worked with Beth at nursery, is now supporting her at school which we are delighted about because they get on so well.

In the early days we were hopeful that she would have some leg function, but unfortunately she hasn't. Luckily she's always been very mobile in her wheelchair so gets around really well. She'd love to join a wheelchair dancing group but we haven't been able to find one in our area.

We're a tight-knit family and have always tried to be very positive, even when things have been tough. Of course I have had wobbly moments but I tell myself to shut up moaning and get on with it. There are many parents who have had it much harder than us."

J-U-M-P
Jacobs Unique Memory Pot

J-U-M-P

Beth was filmed on her big day as a bridesmaid at big sister Laura's wedding thanks to the J-U-M-P charity, which works to capture memories for the families of disabled and terminally ill children.

Sam said: "J-U-M-P do a wonderful job, and give you the feeling that your child is the most special child ever.

"The DVD they did for us was wonderful and records some very special memories for us all."

You can see a trailer for the charity (which features the Copeland family) by going to: **http://link.brightcove.com/services/player/bcpid29605477001?bclid=0&bctid=58006384001** Alternatively visit the charity website at: **www.j-u-m-p.org**

Information day boosts fitness drive

The Fit for Success initiative gained more momentum at a special information day for disabled people in the Peterborough area.

The event at ASBAH's head office, gave visitors the chance to learn more about what sports are available in the area and meet local sporting stars.

Gobi Ranganathan, Britain's number one seed wheelchair badminton player, and teenager Alice Rush, a county swimming champion and an aspiring paralympian, chatted to visitors and encouraged them on their quest to improve their health and fitness.

Other guests included the Peterborough MP, the Mayor of Peterborough and Gillian Beasley the Chief Executive of Peterborough City Council.

Exhibitors, including Sailability, Disability Sport Peterborough, Sports Performance Buddy Ltd, Grasshopper Golf Buggies, Unity Stars, a Special Needs Cheerleading Squad, and other disability sport related organisations, were on hand to answer questions and give out information.

ASBAH Chief Executive Jackie Bland said: "Staying fit and healthy is one way of getting the best out of life when living with spina bifida and/or hydrocephalus.

"We want to support all those people with spina bifida/ hydrocephalus who want to achieve more in terms of their health and fitness - from small changes such as eating a healthier diet to training for a major event."

Find out more about Fit for Success by visiting the website at ***www.asbah.org***

Andy hits the fairways

As a child, Andy Brittles, who has spina bifida, had little chance to get involved with sport.

But these days sport plays a large part in Andy's life - both at work and at home. He's the National Delivery Manager for the Playground to Podium scheme which aims to identify and nurture young disabled athletes.

When time - and the weather – allows, you'll find him on the fairways, indulging in his passion for golf.

"Unfortunately work has taken over in the past year and I don't get to play as often as I'd like," Andy told *Link*. "And I have to admit that I am a fair-weather golfer. It isn't so appealing in the wind and rain."

Andy took up the sport in 1983 following a leg amputation. "The ability to play golf does depend on the severity of your disability," he said, "although there are some golf courses which allow wheelchair users, I am lucky in that I am fairly mobile."

He is a member of the Helsby Golf Club near his home in Cheshire, where he has spent many happy hours perfecting his swing.

"I love the sport. It's very sociable and is always a challenge. You don't necessarily need a handicap to suit your disability either and are treated on an equal footing, which I like."

Anyone for golf?

Golf is becoming more accessible for people with physical disabilities thanks to the work of the Disabled Golf Society.

The charity covers all types and ages of disabled golfer, irrespective of gender or ability, and aims to bring together disabled golfers and help them to enjoy golf on a level playing field... or in this case a level golf course!

If you're thinking of taking up the sport check out its website - a one stop location for the sharing of information and advice and special discounts on equipment including such essentials as golf buggies and their relevant adaptations.

For more information go to ***www.disabledgolfsociety.com***

You can email the society at ***info@disabledgolfsociety.com*** or call on 01666 503918. Membership is free.

The Handigolf Foundation
www.handigolf.net

The Handigolf Foundation promotes golf for disabled people, often wheelchair users, and hires out electric buggies from which all shots are played. It also offers access to full-size golf courses which allow these buggies on to tees, fairways and greens. Membership is free.

For more information contact the Secretary, Mr Ray Lee on 01424 814324 or email him at: ***rayndpam@hotmail.com***

High seas adventures open to all

If you've ever watched Pirates of the Caribbean and longed to experience the thrill of life on a tall ship... then the Jubilee Sailing Trust (JST) should be your first port of call.

JST is keen to encourage more people with spina bifida and/or hydrocephalus to enjoy a unique experience on one of its two vessels, the Lord Nelson and Tenacious.

These are the only two tall ships in the world designed and built to enable people of all physical abilities to sail side-by-side as equals.

On board everyone can be involved in almost every activity from taking the helm, setting sail and keeping watch... regardless of your physical ability and previous sailing knowledge.

JST offers a range of voyages to people aged 16 years and over, from Day Sails to give you the chance to get a flavour of what it's like to be on board, through to voyages of a week and longer.

The JST subsidises the costs on every voyage to make their adventures as affordable and inclusive as possible and offer extra bursary funding for those who might struggle to afford the full cost.

For more information about the Jubilee Sailing Trust go to its website at ***www.jst.org.uk*** or call 0123 8044 9108 to request a brochure.

If you do sign up for one of JST's life-changing adventures, be sure to let us know.

ASBAH Patron, actor David Proud, took a trip on a JST voyage around Scotland's Western Isles in 2002 when he was 19.

His experiences were filmed as part of the BBC's Wish You Were Here holiday programme. At the end of the week David said: "It was an amazing time. When I think of what I've achieved and the personal things I've battled with it makes me wonder what I can achieve in the future. It has shown me a different kind of strength.

"To be able to share an experience like this is fantastic. You can do everything on an equal level... it's just a shame the rest of the world can't be like this."

"The Jubilee Sailing Trust provides a challenging yet safe environment where people can participate together as equals in the same team regardless of their physical status.

It gives people the confidence to keep challenging perceptions and prejudices and to reach their potential whatever that might be."
Dame Tanni Grey-Thompson, Paralympic Olympic Gold Medallist and JST Vice Patron

"I loved every last minute of my time aboard the Lord Nelson, from meeting lots of new and brilliant people to learning new skills. I have been inspired by what I and other people have achieved."
Laura Whittington

"The only way to truly understand is to just go and do it. Get on the ship, climb the rigging, do the dishes, helm the ship. Long after the salt in my clothes, tan, and bruises have faded I will take with me all that I have learnt, experienced and achieved."
Mary Estall

"Beyond doubt, sailing on the Lord Nelson was one of (if not the) best things I have ever done. It was a once in a lifetime opportunity."
Katy Fair

Enjoy sailing... whatever your ability

Sailability is a national programme to encourage and support people with disabilities to take up the sport. Backed by the RYA (Royal Yachting Association) it is available at many sailing sites around the country.

Sailing is one sport which enables able-bodied and disabled sailors to take part on equal terms. Sailability claims to make it possible for you to sail, whatever your disability and you don't need any previous experience.

The Sailability group run by a team of volunteers at Peterborough Sailing Club has opened the popular sport to people with disabilities and took part in ASBAH's first Fit for Success open day – to explain how accessible sailing is.

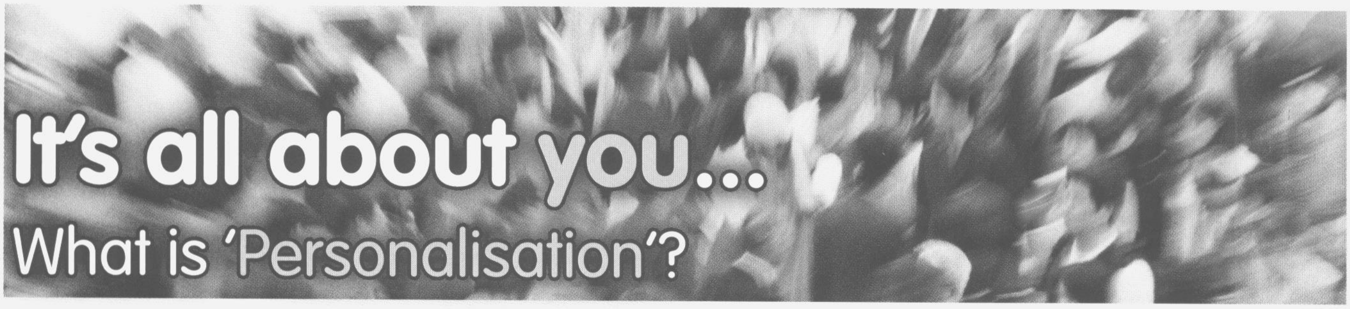
The popularity of Peterborough Sailability, has soared since its launch in 2006, with disabled adults and children taking to the waters of the local country park at Ferry Meadows lake each week.

The club has RYA qualified supervision and all safety equipment is provided.

The Peterborough club meets every Tuesday and Thursday from April to October, with a fee of £4 per person, though fees and meeting times will vary at different Sailability Clubs.

You can find the nearest sailing centre to you by visiting the RYA Sailability website at:

Contact Website: ***www.rya.org.uk/sailability***
Email: ***info@ryasailability.org*** Phone: 023 80604243



It's all about you...

What is 'Personalisation'?

You might already be using 'personalisation' to obtain social care services or you might be thinking about doing so. But how do you qualify and what does it mean?

Personalised care or self-directed support (SDS), is about people being in control of the support they need to live their life as they choose.

How it works varies in different authorities. Councils determine 'eligibility' and many will only offer SDS to those whose needs have been assessed as 'substantial' or even 'critical'.

Northamptonshire County Council (NCC) told *Link* how they do things and explained some of the basics of self-directed support.

Sarah Lee Richards (Transformation Manager) told us that NCC see this method of delivering services as enabling recipients to live life as ordinary citizens, able to use the same services as non-disabled people.

The process is based around the individual, with a person-centred assessment, to look at a person's whole needs as well as risks to their independence.

The individual then has a personal plan and a personal budget to get the support they need.

This doesn't mean they have to do it all by themselves or employ all their own carers/personal assistants etc. You can take the 'DIY' route and employ your own staff and spend your budget flexibly or, at the other end of the scale, you could ask your care manager to commission the services you require on your behalf.

There can be lots of options in between, which you, your family and friends might find more suited to your individual situation and there is help out there to guide your decisions.

How does it work?

Step 1: Self-assessment

In NCC the first step is self-assessment and finding out the costs of support.

Step 2: Plan own support

You work out how to use the money to meet your needs in the way that suits you best

Look at all sorts of paid and unpaid support

Write a support plan (or seek assistance to write one) that meets the Local Authority's checklist, that meets your outcomes and is within the Personal Budget

Step 3: Agree the plan with the local authority and any other funders

Step 4: Manage your personal budget or get help to manage it

There are different ways of doing this – from direct payments to the individual, or family, who then pay for their social care; to the account being held by the local authority. The latter does limit choice as local authorities may only offer services they can provide, from an approved list.

Step 5: Organise Support

– such as recruiting staff, buying equipment etc, though a lot of this might have been covered in the planning stage

Step 6: Live life!

If all goes well, the outcome of personalisation will mean you being able to have independence, choice and control so that you can get on with enjoying your life.

Step 7: Review and learn

– looking at what has worked and what hasn't and if you have achieved what you wanted from self-directed support.
Lessons learned – SDS can deliver great outcomes and although it can be hard work getting organised most people feel it is worth it. Getting the planning right is the most important step to achieving successful SDS.

This model is based on that of Northamptonshire County Council and other councils' way of implementing personalisation will vary. For more information, see the links below or speak to your ASBAH adviser

Further info:

SDS for me

www.sds4me.org.uk - information on support planning and a national forum where you can discuss issues around SDS

in Control

www.in-control.org.uk lots of information about SDS as well as a publication – Basic Guide to Self-Directed Support

My style

By Lisa Cain

Fashion means different things to different people. People would probably describe my style as 'smart casual'.

Clothes are my main extravagance. To me looking smart and presentable is just as important as looking fashionable, if not more so. When I feel good about what I'm wearing it makes me feel good about myself and therefore is a great confidence boost to my self- esteem.

I always wear trousers as I think they are more practical when getting in and out of cars and my wheelchair.

I buy trousers in plain colours as I feel patterns draw attention to my legs and that would make me feel self-conscious. I do have one leg longer than the other, so usually have to shorten trousers!

My Dad used to work in the fashion industry so I tend to rely on him to do alterations for me. But you can buy iron-on tape which is a quick and easy way to shorten things yourself.

Jeans are good because you can turn the bottoms up which is a cheats way around the problem. I try to buy jeans with elasticated waists as they are far more comfortable when sitting down.

I buy most of my trousers in M&S as they come in different lengths and if you find they don't have an accessible changing room in your local store you can take items home – as long as you return them within 28 days.

I do have a couple of key pieces which I wear for certain occasions, a smart suit which can be dressed up or down when I need to make a good impression, such as at meetings or functions.

I also have a black, short-sleeved jacket which I wear in the summer and with different colour t-shirts or blouses underneath and create a totally different look very easily.

When buying a jacket I tend to look for a short style with a button-up front and not waisted. Small collars are good as large ones tend to gape and swamp me.

I also tend to buy jackets in black or navy as I find sleeves tend to get dirty from pushing my chair and in washable fabrics if possible, as dry cleaning can cost a fortune!

Tops are my weakness. After losing a lot of weight about three years ago, with advice from ASBAH health adviser, Rosemary Batchelor, I can now buy designer labels from Debenhams – Betty Jackson, Jasper Conran, John Rocha... Their knitted tops and blouses aren't as expensive as you may imagine.

I would recommend mail order from Boden – great clothes in designs and colours which are unusual and of a very good quality. The staff are friendly and returns are free.

When first shopping with

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them you might like to buy two different sizes to check which fits you best as I find, with all companies, clothes come up in different sizes, despite what it says on the label. Boden also have a great range of accessories.

I can't feel my feet and they are different sizes so shoes and boots are a problem. I have to wear flat-heeled lace-ups (sorry Gok – can't get my feet into knee-high boots).

The last pair of shoes I bought were Correspondents (black and white) and a good fit... so I bought them in beige and white too ready for the summer. I tend to do this when I find something suitable.

Handbags – I always buy shoulder bags for safety reasons as I live in London, and ones which aren't too big so I can put them down the side of my chair.

Hair – I like to have a good cut and tint as this enhances your appearance and completes your look.

Fashion disasters... too many more than I care to remember, but ones which stick in my mind are:

Slip-on shoes which I loved and insisted on buying but which wouldn't stay on my feet!

A designer handbag which I bought on holiday in a sale. Now I'm home it doesn't seem suitable as the straps are too short and I'm unable to return it.

Editor's note – our thanks to Lisa for her personal tips and recommendations. If there are any guys out there who would like to tell us their fashion secrets please get in touch. Email us at *link@asbah.org*

Looking great after a weekend by the sea

Adult members of ASBAH headed for beautiful Brighton for a themed weekend - 'Looking Good Feeling Great' and came away doing just that

The two days were packed with workshops and talks on a wide range of subjects ranging from positive thinking and confidence building, to independent living and relationships.

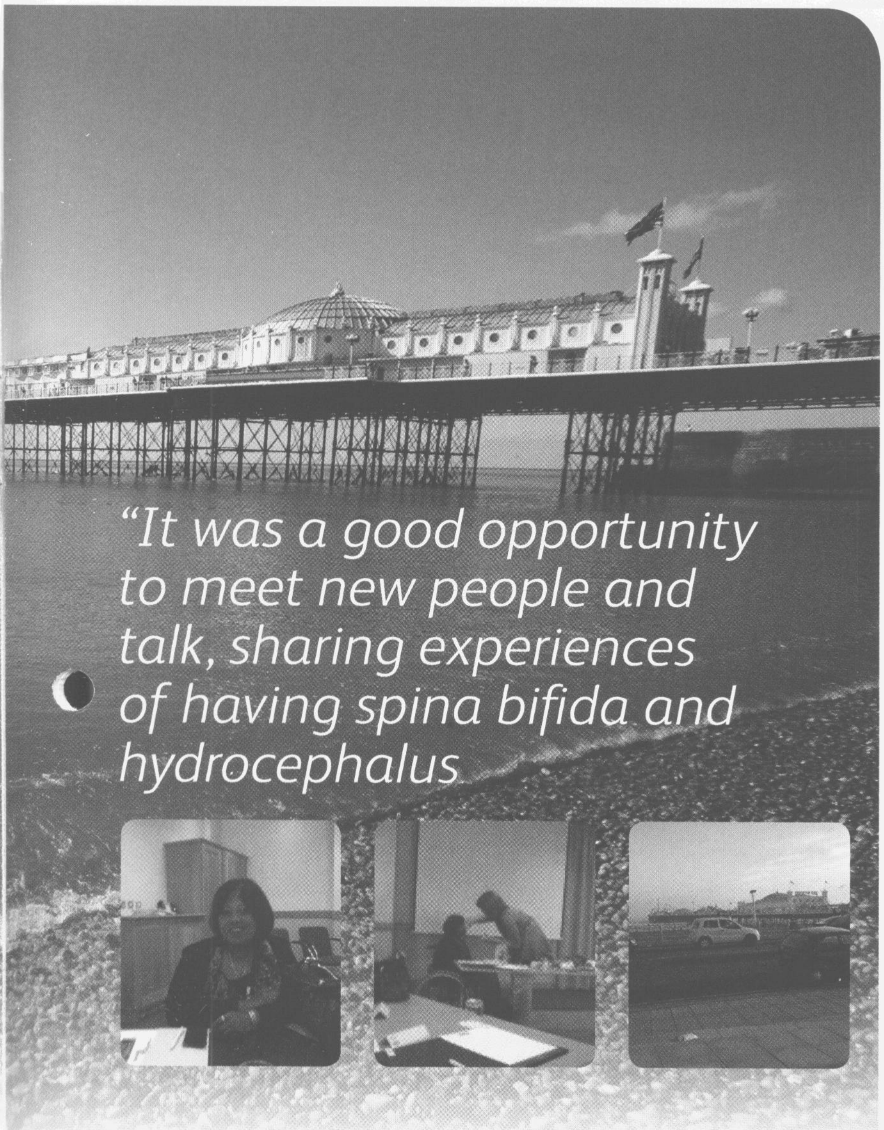
There were also sessions on fashion, exercise and nutrition, plus time with a Body Shop consultant who gave make-up and aromatherapy demonstrations.

Mark Harris, the group's development officer, said: "We had 25 members of our Your Voice group at the weekend who enjoyed listening and participating in workshops such as Tai Chi and 'Indian Head Massage... plus a trip to Brighton pier in the sunshine.

"The feedback forms were very positive, with comments such as "very informative, interesting and well presented", "the speakers were really enthusiastic", and "very relaxing and enjoyable". We're all pleased it went so well."

One new YV committee member, Sita Patel, said: "The weekend was a great eye opener for me as it was the first such weekend I had attended.

"It was a good opportunity to meet new people and talk, sharing experiences of having



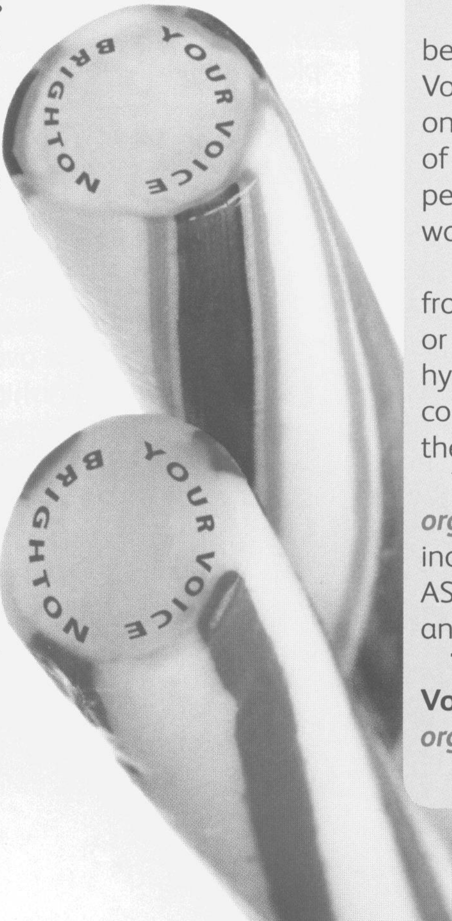
> “It was a good opportunity to meet new people and talk, sharing experiences of having spina bifida and hydrocephalus

spina bifida and hydrocephalus – seeing how people dealt with situations differently.

“I believe that these events are paramount to the development of the individuals that they are aimed at.”

Sita, who works for the NHS at the Ealing PCT (West London), added: “The weekend gave me a lot of insight and understanding that “I’m not alone” - there are people out there, sharing the same views and facing similar hurdles.

“Since the weekend, it has been nice that we have all been able to come away; gaining new friends and I have stayed in touch with most of the members who shared this weekend with me.”



YV newsletter out now

The latest edition of the YV newsletter, Your Voice Your Choice, is now available to download from the ASBAH website.

The four-page publication includes a range of articles including interviews with YV members, Natasha Rainey and Lisa Cain, who talk about their lives.

There’s also an article by ASBAH Chief Executive Jackie Bland who explains how the ASBAH team will be reviewing the ways in which ASBAH communicates with its user groups - in particular with those who have the disabilities themselves.

She said: “What we want to achieve is a vibrant, modern organisation that truly listens to the views of disabled people and includes them centrally in its work and development.

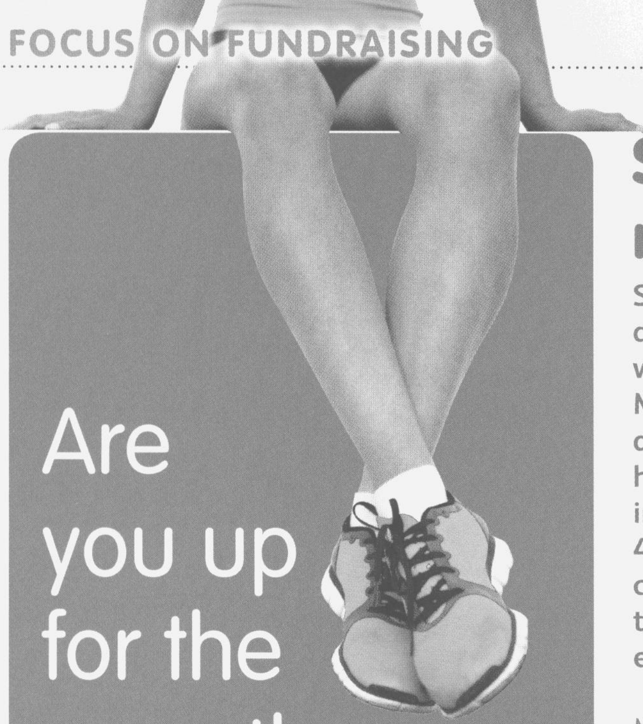
“It may well be that Your Voice, with its current name, form and structure, is no longer the most effective way of achieving these aims.”

Over the coming months Jackie will be consulting fully with the new Your Voice Committee to hear their views on how we can create a membership of people who are meaningfully and permanently involved in how the charity works and develops.

Jackie is interested to hear directly from any current Your Voice members, or any adults with spina bifida or hydrocephalus, who would like to contribute ideas and comments about the way forward.

You can e-mail her at **Jackieb@asbah.org** or write in to share your views about inclusion, involvement and equality at ASBAH, or in the wider communities and society in which we live.

To download your copy of Your Voice Your Choice, go to: www.asbah.org/yourvoice



Are you up for the marathon challenge?

This year we cheered on three runners who pounded the streets in the 29th London Marathon raising money for ASBAH.

The runners who had been lucky enough to secure ballot places collected more than £2,400 for us... with more cash still coming in.

ASBAH Running Co-ordinator Ian Morley said: "Initially we had four runners but, regular Team ASBAH runner, Jude Gale sustained a hip injury whilst training and was told by her GP not to run until she was advised that it was safe to do so.

"In the spirit of charity running Jude has now signed up for the Great North Run and will carry her sponsors from the London Marathon across to this popular event in South Shields. This gives her five months to get back into training."

For more information about running for Team ASBAH go to our online fundraising pages: ***www.asbah.org/get-involved*** or contact Ian Morley on 01733 421328 or email ***ianm@asbah.org***

Speedy Sascha runs up more than £1,000

Sascha Osborn was doubly delighted with her London Marathon success after romping home in an impressive 3 hours 49 minutes and collecting more than £1,000 for her efforts for ASBAH.

Sascha, Divisional Manager at Capita Education Resourcing in London, signed up for a ballot entry last April after running the Sheffield Half Marathon and in October was surprised to hear that she'd secured a place.

"I know so many people who have entered the London Marathon ballot for years without success, so I didn't expect to get lucky," she said.

"I told my parents that I'd like to run for a charity and we agreed that ASBAH would be a good choice. My twin brother Sam had spina bifida, and died when he was a week old. I have always wanted to do one big thing for charity in his memory."

Sascha started a Runners World 16-week training plan in January, following it religiously... and her efforts paid off.

"The race went really well," she said. "I started quite slowly because it was so crowded but after a while I decided to speed up a little.

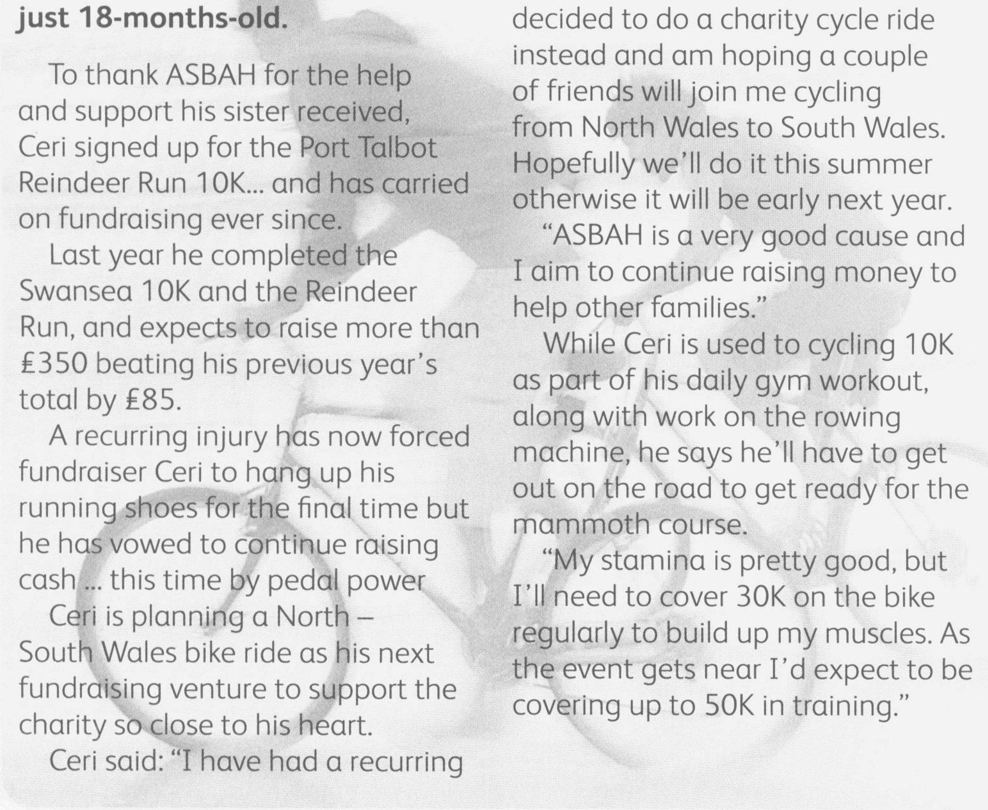
"I did get a stitch at mile 17 but I ran through it and at mile 22 I realised that if I pushed myself I could get a sub 4-hour time. Also, the faster I went the quicker the whole thing would be over!"

She crossed the finishing line in a fantastic 3 hours 49 minutes and said: "I was delighted with my time. During my long training runs I'd thought that there was no way I'd run the 26.2 miles faster than 10-minute mile speed. But it must have been the buzz on the day and the cheering crowds that pushed me on."

Sascha was delighted by the generosity of friends and colleagues who supported her efforts.

She added:"There's still some money to come in so hopefully the total I've raised for ASBAH will be even higher."

Fundraiser Ceri turns to pedal power



Ceri Parker, from Aberdare in South Wales, began supporting ASBAH in 2006, in memory of his young nephew. Sion was born with spina bifida and hydrocephalus, and died in December 2004 when he was just 18-months-old.

To thank ASBAH for the help and support his sister received, Ceri signed up for the Port Talbot Reindeer Run 10K... and has carried on fundraising ever since.

Last year he completed the Swansea 10K and the Reindeer Run, and expects to raise more than £350 beating his previous year's total by £85.

A recurring injury has now forced fundraiser Ceri to hang up his running shoes for the final time but he has vowed to continue raising cash ... this time by pedal power

Ceri is planning a North – South Wales bike ride as his next fundraising venture to support the charity so close to his heart.

Ceri said: "I have had a recurring tendon injury for the last two years and I've been told that if I continue to run, it will just get even worse. It is a weakness that will never really improve.

"I've always cycled on the exercise bikes at the gym so I have decided to do a charity cycle ride instead and am hoping a couple of friends will join me cycling from North Wales to South Wales. Hopefully we'll do it this summer otherwise it will be early next year.

"ASBAH is a very good cause and I aim to continue raising money to help other families."

While Ceri is used to cycling 10K as part of his daily gym workout, along with work on the rowing machine, he says he'll have to get out on the road to get ready for the mammoth course.

"My stamina is pretty good, but I'll need to cover 30K on the bike regularly to build up my muscles. As the event gets near I'd expect to be covering up to 50K in training."

"Although I am unable to run for this amazing charity any more, I would urge those that are capable to try it.

"It's a great experience and a wonderful way of raising much needed money for ASBAH.

"There are so many local races wherever you are from, from 1 mile to 27 miles - it doesn't matter how experienced you are at running, there is a race out there for you and ultimately a race for ASBAH."

Chris's marathon effort raises £1,800

Living in the Middle East isn't conducive to marathon running, but mechanical engineer Chris Dale didn't let the high temperatures put him off.

Chris, who has lived in Doha in Qatar since July 2009, completed the gruelling Dubai Marathon raising £1,800 for ASBAH.

He said: "When I was two-years-old my mother lost a baby through spina bifida so raising money for ASBAH was on the recommendation of my mum – and I effectively did it for her and my dad.

To read the full story go to ***www.asbah.org/get-involved***

Ryan puts on the glitz

An ASBAH Star Supporter is continuing to prove her fundraising prowess.

Zoe Burnay, from Mother Advertising in London, enlisted the help of colleague Ryan for a second time and thanks to his chutzpah... collected £857.50 for ASBAH.

Zoe, whose daughter Hattie, seven, has spina bifida and hydrocephalus, has recruited family, friends and colleagues during the past few years, raising thousands of pounds.

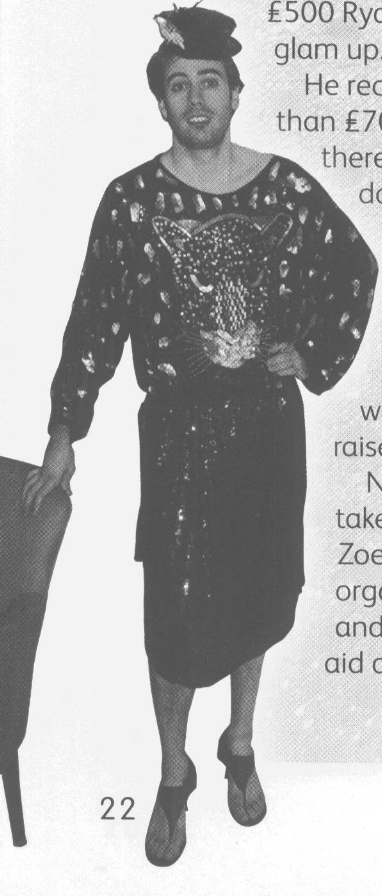
She said: "ASBAH has been a great support from the beginning of Hattie's life and we all have a great deal of respect for all the work it does. My whole family is involved with fundraising to help ASBAH continue providing such fantastic support."

TV producer Ryan - who had his head shaved for last year's fundraiser - volunteered to dress as a woman for the entire day.

Staff members were asked to make a pledge ... if they totalled £500 Ryan agreed to glam up.

He received more than £700 in pledges so there was no backing down. After sitting in client meetings in high heels, a dress, make up and a hat, Ryan was delighted to raise £857.50.

Never one to take things easy, Zoe is now busy organising a raffle and an auction in aid of ASBAH.



The Smiths' new bid to boost ASBAH's funds

Delighted by the fundraising success of his sponsored walk last year, Shaun Smith is now putting all his energies into a charity auction to give another boost to ASBAH.

Accrington Stanley FC has kindly donated the use of its clubhouse for the evening on 28 August and Shaun and wife Dawn are busy drumming up support for the event.

The family, from Oswaldtwistle in Lancashire, raised almost £4200 for us last year on a 12-mile sponsored walk which saw Shaun donning a Benny Bear costume for the entire trek.

"It's our way of saying thank you to ASBAH for its support when our youngest, Harrison, was diagnosed with hydrocephalus.

"Our charity work raises money to help ASBAH continue its work and also increases awareness about hydrocephalus. The more people know about the condition the easier it will be for Harrison."

> *"It's our way of saying thank you to ASBAH for its support when our youngest, Harrison, was diagnosed with hydrocephalus."*

So far the couple have organised a number of donations to be auctioned off including memorabilia from Blackburn Rovers, a Gold Day pass at Oulton Park, signed promotional goods from EastEnders and much more.

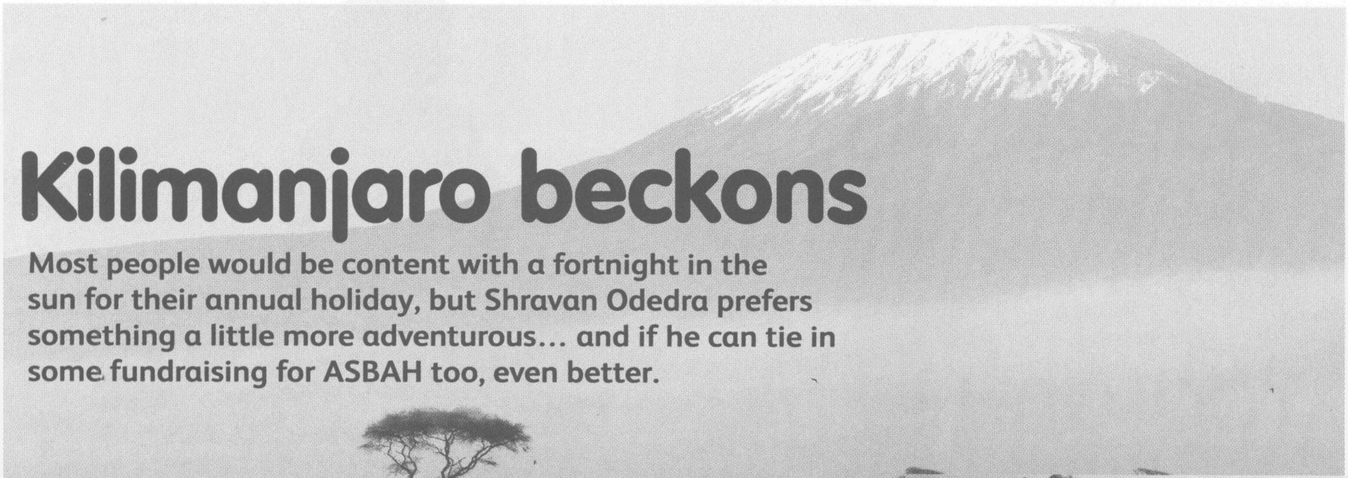
"Tickets for the family evening have gone on sale and the price will cover supper. We've got activities such as face painting for the children and a local DJ has very kindly volunteered his services free of charge for the night," Shaun added. "It should be a really good night and hopefully will raise a lot of money."

If anyone wishes to purchase tickets they are on sale from Shaun at £5 each or £15 for a family ticket.

Contact Shaun by emailing him at *familyguy@fsmail.net*

Kilimanjaro beckons

Most people would be content with a fortnight in the sun for their annual holiday, but Shravan Odedra prefers something a little more adventurous… and if he can tie in some fundraising for ASBAH too, even better.



Shravan, a digital designer for a London-based advertising agency, trekked along a section of the Great Wall of China in 2008, raising £1,420 for ASBAH in the process.

Now he's planning to undertake a Kilimanjaro Charity Trek in September and hopes to collect even more funds.

Shravan, 31, said: "Trekking along the Great Wall of China was incredible, but now I'm looking for a greater challenge.

"This Kilimanjaro trek will be much tougher but I enjoy pushing myself to see what I can achieve."

He also plans to up the stakes in his fundraising and has already started on his campaign.

Shravan has first-hand experience of hydrocephalus as his brother, Ram-Krishan, 21, was born with the condition.

"By fundraising for ASBAH I'm also helping to increase awareness and understanding of hydrocephalus," Shravan added.

"When I tell people what I'm fundraising for no-one really seems to know much about ASBAH so I'm putting in a lot of time promoting the cause too."

He has booked a place on the trek with Skyline, one of the leading charity events organisers. "I did the China trek with Skyline and it went very well, so I thought I'd try out something else," Shravan explained.

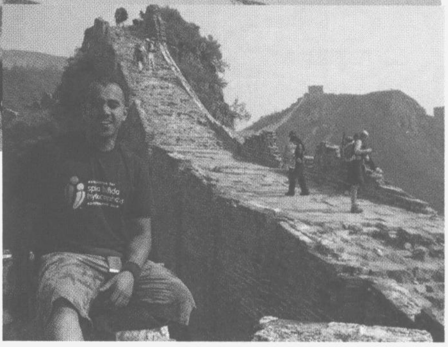
"Kilimanjaro will be much tougher and there's the high altitude to consider too. I've already begun training with gym work and lots of walking with weights at the weekends.

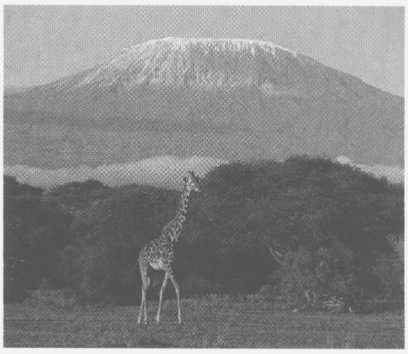
"I'm really excited about the trip especially since my family originated from that area. If I can get the extra time off work I hope to stay for a few more days to visit friends."

Shravan's fundraising drive has begun in earnest too, with sponsorship plus bucket collections at supermarkets and underground stations. "I need to raise a lot of money but I've got more than enough enthusiasm for the job," he said.

You can follow Shravan's fundraising progress at ***www.justgiving.com/shravan-odedra***

There are rules about where you can do charity collections so if you're thinking of doing a collection for ASBAH please get in touch with our fundraising department first. Contact: ***cerysl@asbah.org*** tel: 01733 421329





Kilimanjaro Charity Trek

At 5,895m Kilimanjaro is Africa's highest mountain and is one of the largest volcanoes to ever break through the Earth's crust. It's also one of the largest free-standing mountains in the world.

The charity trek takes place over 10 days and the group will enjoy a wide range of experiences from the tranquility of the jungle, breathtaking glaciers and views that others will only dream of.

For more information about Skyline's overseas events go to: ***www.skylineoverseas.co.uk*** or call: 020 7424 5511

Some advice for parents from ASBAH's senior health adviser, Rosemary Batchelor

Programmable CSF shunts in children

An increasing number of children with hydrocephalus are now being treated with programmable/adjustable CSF shunts.

These shunts can offer a more accurate way of controlling fluctuating changes in intracranial pressure, but they bring their own problems as they can be accidentally reprogrammed after close contact with magnets.

Instances where this has occurred include:

- A child who leant his head against the magnetic catch on a kitchen cabinet
- A teenager using "Patient line" headphones whilst an inpatient in hospital
- Children leaning their heads on fridge magnets
- A child in school whose classmates regularly placed magnets over the metal part of his shunt valve and who was too afraid to report it
- A nursery class child who lay on the floor to play with a "Brio" train set and whose magnetic couplings came into contact with his valve
- A little girl whose family fish tank had a magnetic cleaner – she liked to rest her head against the tank as she enjoyed the buzzing sensation from the filter mechanism.

People have also reported their shunt has been accidently reprogrammed at airports where they were required to walk through the security gate which contains magnets.

Symptoms of shunt malfunction can include:
drowsiness, nausea or vomiting, head pain, photophobia, irritability and seizures.

Problems can also occur when shunt valves come into contact with quasi medical magnets such as magnetic pillows, bracelets etc.

Small children with programmable shunts need protection when magnets are in use in their social or school setting.

They should be closely supervised if playing with toys that contain magnets and prevented (as should their friends) from putting the magnets anywhere near their shunt valve.

They should not lean against cupboards, drawers etc that may have a magnetic closure

There should always be an adult present if there are magnets around.

The child needs to be made aware that he/she must be careful when playing with toys that include magnets.

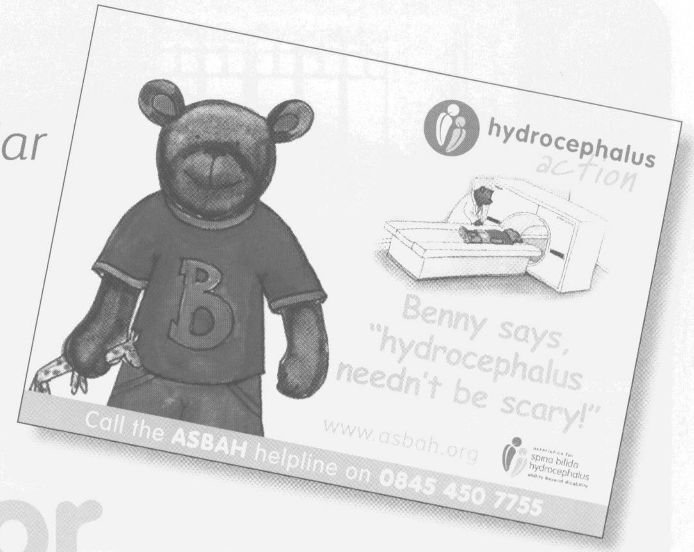
If a child known to have a programmable shunt shows signs that could indicate shunt malfunction after unsupervised play with magnetic toys, his/her neurosurgeon should be informed.

Symptoms of shunt malfunction can include: drowsiness, nausea or vomiting, head pain, photophobia, irritability and seizures.

The manufacturers of programmable shunts say that in theory they are resistant to most magnets including the older MRI scanners - in practice this is not always so.

For further information contact ASBAH and ask to speak to a health adviser – also see ASBAH's shunt alert card.

> "Benny Bear remains as popular as ever and we hope the new posters will help to reassure children before their scan."



New look for Benny Bear poster

Our new Benny Bear poster could soon be appearing in a hospital near you.

The A4 design, showing Benny having a MRI scan, is aimed at reassuring children and promoting ASBAH with details of our website address and contact number.

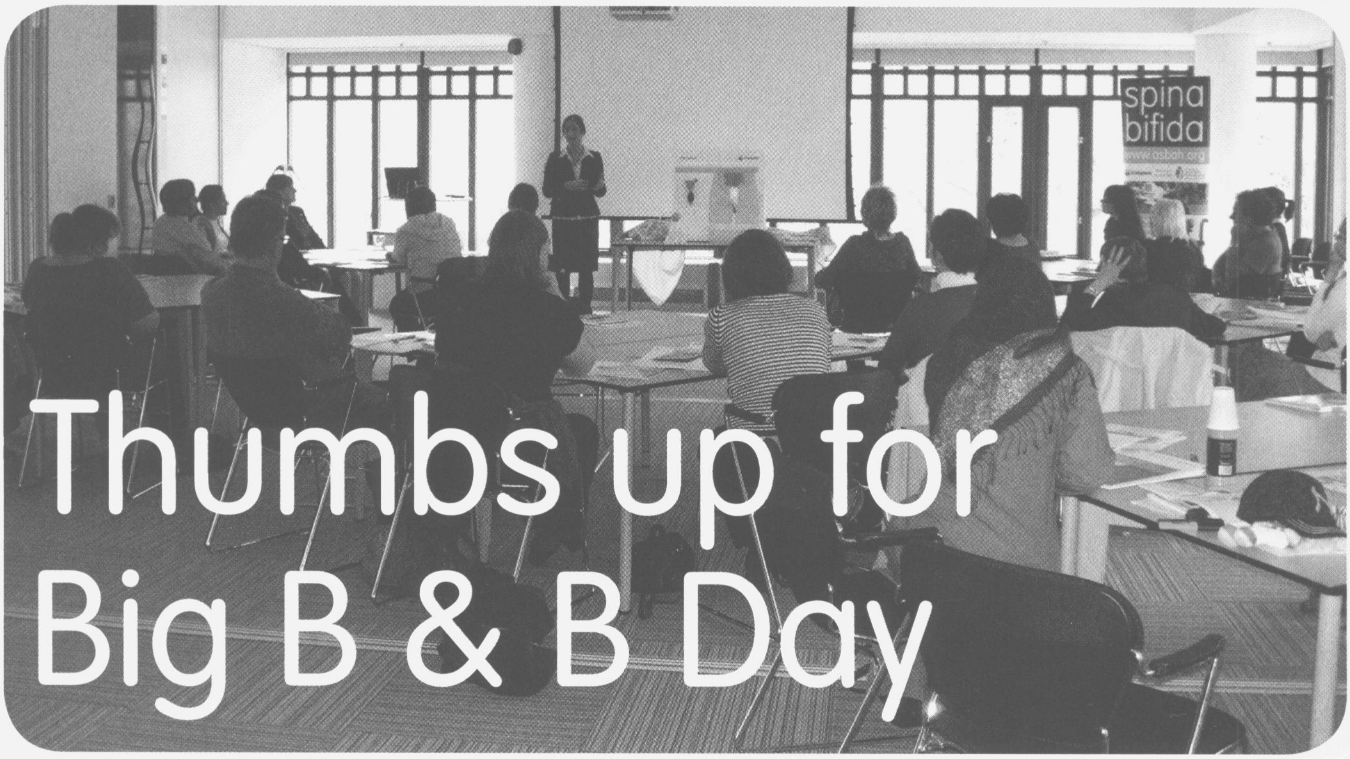
Marketing and communications manager Gill Winfield said: "Benny Bear remains as popular as ever and we hope the new posters will help to reassure children before their scan.

"We know that the bright designs appeal to both children and parents, and they continue to prove a successful way of promoting ASBAH."

Last year mother Louise Colver contacted ASBAH after spotting a Benny Bear poster in the hospital where her young daughter Grace was having a shunt fitted.

She made a note of the website address and looked up ASBAH as soon as they could.

If you would like one of the new Benny Bear posters to put up in the hospital or clinic you or a member of your family uses, call the helpline number to request one - 0845 450 7755.



Thumbs up for Big B & B Day

Parents were delighted by the excellent advice and information they picked up at our first B & B Day.

The event, aimed at giving parents all the information they need about bladder and bowel management, was part of ASBAH's new Life-Long Opportunities Programme.

Led by ASBAH's senior health adviser Rosemary Batchelor and continence adviser Gill Yaz, the day included the latest information on bladder and bowel care, options for management and advice on how to involve the child in decisions.

Lively presentations were given by a mix of professionals and parents and everyone came away feeling that they had learned a lot.

The presentations included:

- *Latest information on bladder and bowel care*
- *Options for management*
- *'What worked for our child' presentation by a parent.*
- *Enjoying an 'ordinary' life.*
- *How to involve your child in decisions*

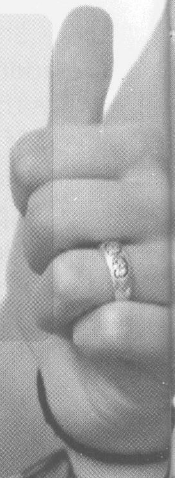
The event was held at Coloplast in Peterborough, which kindly donated a meeting room for the event.

Gill Yaz told *Link*: "We know many parents want to improve their child's quality of life through good continence management and we were pleased the day went so well. We had 34 parents from around the country attending and their feedback was very good.

"There was a variety of speakers on a range of subjects so we felt there was plenty for them to think about and discuss.

Gill added that if there is an opportunity to hold another similar information day the team is very keen to take it.

Don't forget that parents or adults can always contact our health advisers with any questions about continence management. There's also a wealth of information on our website at ***www.asbah.org***.



What the parents thought...

"As parents of an 11-year-old daughter we found the event most worthwhile both in terms of the information received and for the opportunity to meet a wide range of people including parents, doctors, ASBAH representatives and Coloplast staff.

"All were unanimous that bowel management presents one of the biggest challenges for parents and children alike and to hear so much advice and options was fantastic.

"The overriding impression we had on leaving the event was just how important it is that everyone received regular, reliable and consistent information regardless of which part of the country one happens to reside in.

"It was fantastic to be able to share and receive the knowledge in the room."

John & Sall Stone

"We know many parents want to improve their child's quality of life through good continence management and we were pleased the day went so well."

"We thoroughly enjoyed the day. It was so nice to go somewhere where everyone had similar issues. Hearing the mothers speak and having the opportunity to speak to them was really helpful.

"Sharing experiences helps build knowledge of other areas of support - we were given contacts of other specialists we can approach which we didn't know before."

Amanda Fall

We thought there was a good mix of professional urology and "how it really is" from parents. The day was well worth going to."

Philip and Katrina Nice

Bryn hits the road to take ASBAH to the people

Area adviser Bryn Roberts is fulfilling his ambition to take ASBAH out to the people.

Bryn, who joined the Advisory service in Wales in September 2008, covers the extensive North Wales area, working out of his office on Anglesey.

Conscious that people in rural pockets in the south of the area may be deterred from making the long journey, Bryn launched a pilot scheme offering outreach sessions once a month.

Based at the Centre for Integrated Living (CIL) in Porthmadoc, Bryn is available from 10am – 2pm, to provide the usual adviser service.

The three-month pilot scheme began in March and after initial success, has been extended for a further three months. The outreach service will then be evaluated and its future decided.

Bryn explained: “If you live in the outer reaches of the area, it can be difficult to reach our office.

“When I came to the position it was always my aim to get out and meet as many people as possible, and to encourage new faces to make use of the services we offer.

“I sent details of these outreach sessions to everyone on our database and have re-established contact with several people.

“Being based at the CIL has also led to me meeting a couple of people with spina bifida and hydrocephalus who have never had any dealings with ASBAH at all.”

He said the service is about quality rather than quantity. “I see an average of two people in one session, helping them to complete Disability Living Allowance forms, for example, so its time well spent.”

Bryn added: “I hope to use this model of service in other areas of my patch, to engage with both new and existing members.”

“When I came to the position it was always my aim to get out and meet as many people as possible, and to encourage new faces to make use of the services we offer.”

Summer fun for young people

There has been a rush to snap up places on ASBAH's Barnstondale Challenge 2010, part of the Life Long Opportunities Programme.

The four-day residential course, to be held at Barnstondale Centre in Barnston in July, is open to 12 – 16 year olds with spina bifida and/or hydrocephalus.

It's an exciting chance for young people to enjoy new experiences, face outdoor challenges, make new friends and, above all, have a great time.

Northern Region manager Joan Pheasant said: "Barnstondale Challenge will be a teenager residential with different activities to those happening at the Summer Experience, but with the same fun outcomes and friendly staff and helpers."

Contact NRO at *nro@asbah.org*

Tel: 0113 255 6767

Meet our new advisers

Emma Enfield

Emma Enfield has been appointed the new adviser for Lincolnshire following Linda Knight's retirement.

Emma, who combines her new role with her part-time job as occupational therapist, is settling in to her dream job very quickly.

"Linda was my manager when I started out as an OT in 1995," she explained. "We kept in touch and I always thought how lucky she was to work for ASBAH. The job sounded so rewarding and interesting."

When Emma heard Linda was retiring she applied for the part-time position and was thrilled to be offered the job.

"I feel so lucky," she said. "My area of expertise is spinal injuries and with ASBAH I have been given the chance to specialise even further. I hope people across ASBAH will make use of my OT knowledge too."

Joanna Pietrzak

Joanna Pietrzak is the new adviser for the Greater Manchester area.

Joanna, who has held several positions, decided to put her Social Work degree to good use once more and applied for the ASBAH vacancy.

She said: "Earlier in the year I decided to find a role that I would be suited to and could feel passionate about. I was extremely pleased to spot the advertisement for ASBAH's Adviser vacancy in the newspaper soon after and it seemed like everything had fallen into place.

"Fortunately, I was offered the post following interview and have not looked back. It is proving to be the best role I have had and I hope this will be the case for many years to come."

When not working for ASBAH, Joanna spends time renovating her home - "I can work my way around B & Q blindfold" – and walking with her Border Collie named Angel.

Elaine Adams

Elaine Adams has taken over from Jenny Green as the new adviser for Coventry, Warwickshire and Solihull.

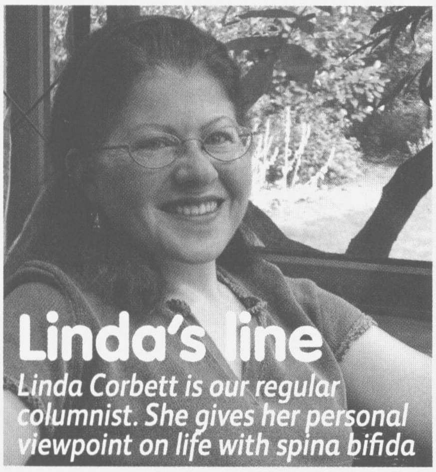
Before joining ASBAH in February, she worked for six years as a personal tutor, at Hereward College in Coventry, gaining valuable experience supporting students with a wide range of disabilities including spina bifida and hydrocephalus.

While at Hereward, she successfully achieved the CPCAB certificate in counselling skills and the NVQ Level 4 in Advice and Guidance.

Elaine has previously worked throughout the country in print journalism and public relations including two years as national public relations officer for the British Association of Social Workers.

She has extensive experience in the university sector, both as a lecturer at Bournemouth University and currently in student support with the Welfare and Disabilities Office at Coventry University.

She has also had sales and marketing support roles with companies in different industry sectors. Her interests include reading crime fiction, the Titanic (she is a member of the British Titanic Society) and visiting antique fleamarkets to search out bargains!



Linda's line

Linda Corbett is our regular columnist. She gives her personal viewpoint on life with spina bifida

I am not where you think I am. You will have to take this on trust but I am currently not sitting in my conservatory scribbling away, but am 2,000 km in a south-east-ish direction on the island of Cyprus.

The weather is hot, the food is lovely and the swimming pool is just reaching a useable temperature. Not that I can swim, but it looks nice, and having spent the last few days watching Andrew splash around in the pool it has given me a very good idea.

With the new Government and a change in Disability Minister (now Maria Miller from Basingstoke), she is bound to need some new ideas and initiatives to prove that she is not just a repeat of the previous incumbent, so I have come up with an excellent new idea for her to pilot – free holidays in the sun for all disabled people.

Doubtless the DWP will start chortling on about cost at this point but really, the economic advantages are staggering if looked at carefully. For example, before we left for Cyprus, we were freezing to bits in the UK.

Well I was, as I have very poor circulation and feel the cold. A lot. A week in the sun will therefore save us the cost of having the heating going full blast for a whole eight days.

There are loads of other health benefits to being in this part of the world. For instance my doctor always used to recommend the odd glass of red wine to aid circulation, and of course everyone knows that it is cheaper to buy wine abroad because that's where it comes from in the first place.

Then there is the matter of exercise which is meant to be really, really good for you. I personally don't do all that much but after traipsing round what felt like 100 miles of Heathrow Airport, I reckon I have clocked up around three months worth of exercise in just getting out of the country.

That must be several million calories all by itself! Obviously during your holiday, you will also be able to avail yourself of your private swimming pool as it won't be full of oiks and other tourists. And I am informed that even waving your legs in the shallow end counts as exercise, thereby reducing the likelihood of heart disease in the future (and more cost saving for the health service).

Out in the clean sea air, you will probably find that any respiratory problems are much reduced – I use my asthma inhaler a lot less on holiday – so that is more cost saving for either you or the Government, depending on who pays for your prescriptions.

Clearly you need to take into account any airline strikes or lurking volcanic ash clouds but the whole thing could become very popular in the future. ASBAH could even buy their own holiday property on Cyprus although in the interests of fairness, the senior management team should probably manage the rota, possibly on a first come first served basis. (Jackie - as it was my idea, I am bagsying the first week of May 2011).

Diary dates

Contact your regional office for further information on any of the events below

Northern Region: York Drop-in 2010

Where: Low Moor Community Centre, Bray Road, Fulford, York YO 10 4JG
When: Second Wednesday each Month: 14 July; 11 August; 8 September.
Time: 10.15-12 noon

For further information: contact: Sylvie Bailey (Adviser for North Yorkshire ASBAH), ASBAH House North, 64 Bagley Lane, Farsley, Leeds. LS28 5LY. Tel: 0113 255 6767 or email **sylvieb@asbah.org**

Dunstable Support Group

For people with spina bifida and/ or hydrocephalus and their carers. Please come whenever you can. While there is no crèche, young children are always welcome.

Where: Disability Resource Centre, Poynters Road, Dunstable.
When: Usually on the second Monday of each month.
Time: 1 – 3pm

For further information contact Valerie Bottoms on 01582 757745

Surrey Local Association Summer Picnic

When: Sunday 18 July, 3.30pm onwards
Where: Old Pheasantry, Merrywood Grove, Lower Kingswood, Tadworth KT20 7HF, a large country house with gardens and a play area for children.

For further information contact Angela Bailey on 01293775775 or email her at **angela@asbah.org**

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For details of Local Associations contact your regional office or ASBAH Helpline or visit www.asbah.org

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