Together

Inside this issue:

Inspirational Athlete – Natalie Povey

Star of *Born to be different* – Emily Speirs

All the latest news

Plus lots more …

Issue two 2011

association for
spina bifida
hydrocephalus
ability beyond disability
Registered Charity Number 249338

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Welcome to the latest edition of *Together* magazine, the first I have had the pleasure to edit in my role as ASBAH's new Marketing and Communications Officer.

The past few months have been hectic as I have travelled the country getting to know colleagues and meeting some inspirational families and members, and I hope you enjoy the news, information and feature articles we have included in this issue.

This issue is the last to be published under the ASBAH name, the next *Together* will be published under our new name – read all about this exciting development on page 7.

One of the things our younger members have been telling us is that the organisation needs a more up to date image and more for them, so as well as a smart new name and logo we have introduced the Benny Bear Club - see page 6 and contact us if you'd like to join.

Finally, *Together* is about all of us together; if there is anything you'd like us to feature, specific information you'd like to see, or a view you'd like to share, then please contact me at toms@asbah.org - I'd love to hear from you.

Tom Scott,
Editor

Tom Scott

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Submission dates for Autumn Edition
Register of interest to submit by:
26th August 2011
Final date for submissions: 16th September 2011
Publication date: 30th September 2011

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Textphone Service: 01733 421395
info@asbah.org www.asbah.org

Please let us know if you are happy to receive future mailings by email as this saves on postage and helps the environment. Email: info@asbah.org

Registered charity number 249338

ASBAH launches health and well-being survey

As a result of the many changes to health and social care services, and the post-code lottery in getting the services, ASBAH's Adult Members' Council (AAMC) is leading on a nationwide survey into the health and well-being of our members.

The aim of the survey will be to:

- Identify the issues and challenges faced by children and adults living with SB/H in looking after their health and well-being
- Provide evidence of the needs and support our members require at each stage of their lives - as babies, children, and teenagers and into adulthood
- Find out which areas of England, Wales and Northern Ireland are providing the services you need and which are not
- Use the findings to develop ASBAH services AND to campaign for improved services, that are 'fit for purpose', no matter where you live

The membership survey will be launched over the next few months and all members will have the opportunity to contribute by email, post, telephone or face-to-face discussion.

In the meantime, please email Kate Thomas at katet@asbah.org or telephone 01656 864102 with any comments, questions or ideas for the survey.

Remember - the more responses we have, the better! We will use the research to talk to GPs, consultants, hospital departments, management in the health and social care services, Members of Parliament and Assembly Members in Wales and Northern Ireland, local councillors and many more.

Together we can make change happen!

Blue Blobbers Visit

Everyone at ASBAH House was delighted to welcome the Blue Blobbers group as they made their way up to Peterborough to find out more about the work at Head Office and pay a visit to the Cathedral … via Queensgate Shopping Centre!

Whilst the group were here we took the opportunity to throw a Benny Bear Birthday Bash and invited Rebecca Chisnall (see page 13) to enjoy the food and fun too. Everyone from the group had a good time and it was great for us all to get to know each other better.

Benefits watch

ASBAH staff are observing carefully the various changes in welfare benefits and want to be sure that we remain aware of the effects of these on our members. We would value hearing from members about their experiences, good and bad of using the current benefits system. Do you understand the system or does it continually confuse you? Are you concerned about the changes and what they might mean? Do you think the Government operates a fair system? Do you have tips or advice for other members or do you need more help and support? Would you like to see more information on ASBAH's website and if so what would you like to see?

If you'd like to feed in your views or comments informally please e-mail info@asbah.org

Family events

Family Day

The sun shone on 17 April in Wales to provide a wonderful day for ASBAH Cymru's Family Day in Sully.

Families arrived alongside friends and people from the local community to have fun. Activities provided included bouncy castles, arts and crafts, face and arm painting and a visit from Benny Bear!

The day itself drew visitors from as far afield as Fishguard and Whitland and we received 100% positive feedback when asked if they enjoyed their day.

We have received interest from families to stage another weekend event. If you are interested, we would be keen to hear more. Feedback on where to hold the event, what to include, how much to charge etc will help us to shape a day that will be beneficial to everyone.

Please email katet@asbah.org with your thoughts.

> "I just wanted to say thank you to yourself and everyone else at ASBAH Cymru for organizing today's fun day. Megan came home full of beans after meeting Benny the Bear, driving a fire engine, making a fantastic Easter craft egg and bouncing on the bouncy castle. It has just taken us an hour to persuade her to go in the bath as she did not want to wash her face paint off."
>
> *Rachel Crutcher*

The wet and the wild

ASBAH CEO Jackie Bland joins NWASBAH for family fun, at the Nell Bank Centre.

My first visit to a full blown Local Association event didn't start too well – my SatNav dumped us on top of a hill in the Yorkshire Moors and there was no sign of the Nell Bank Centre where, I was told, NWASBAH members would be enjoying a day of outdoor activities.

Thankfully helpful volunteers using good old fashioned mobile phones guided me and my family off the hill and into the midst of an extremely lively and happy family day.

Children dunked for tadpoles in the specially adapted ponds, just the right height for a junior wheelchair, whilst elsewhere toddlers met chickens and teenagers indulged in a full blown water fight using fully accessible water weapons. Whilst parents and volunteers shivered in a sharp May breeze, clothes and wheelchairs got wetter and wetter as the fight approached a frenzy.

Thankfully piping hot Yorkshire fish and chips arrived just in time to avoid mass frostbite and everyone enjoyed lunch together. The children dried out whilst trying their hands at card making and sewing.

It was a charming event, beautifully organised by NWASBAH volunteers and I am very grateful to have been invited and to observe first hand the value of such family days organised at local level.

Perhaps the memory that will stay with me longest is a conversation between two little girls who had just met. They climbed out of their wheelchairs and were crawling up the slide in the adventure play area. 'I have to crawl', said one, inching up a little at a time, 'because I have spina bifida.'

'Really'? said the other one, inching up behind her and smiling in surprised delight, 'so have I!'

The Benny Bear Club

Benny's Blog – What a busy bear!

The Benny Bear Club now has its very own blog! With being such a busy bear, Benny expressed a wish to share his news with everyone so we gave him his own blog.

If you have pictures from events that Benny attended or if you would like to send pictures, stories or poems about yourself or Benny to feature on the blog then please email them to:

BennyBear@asbah.org

Benny is really looking forward to getting to know you through the blog – look out for all his news and updates over the coming weeks …

www.bennysblog.co.uk

Benny Bear

Welcome to the home of the Benny Bear Club.

Be Brilliant!

Superstar!

Who is Benny?

BennyBear

Peterborough, United Kingdom

Benny Bear is a special bear, he has a shunt to help

Monday, 25 July 2011

My little flower

Hello Everybody!

Well, it's been a while since I last wrote on my blog - I've been such a busy bear!

Last week was such a fun week, I don't know where to start.

To begin with I got a letter from a beautiful girl call Daisy. I was delighted to hear that, after having her shunt fitted at 11 weeks old, Daisy is getting on brilliantly. However, the best part of Daisy's letter was to hear that she carries her Benny Bear teddy EVERYWHERE!

Here is a photo of Daisy and her Benny, don't they look happy!

JOIN THE BENNY BEAR CLUB - Press the link below:

JOIN HERE

Written by Jack Kelemen (aged 4 with SB & H)

"I love Benny Bear and he makes me laugh when he dances. He was so funny at the Surrey picnic and he gave me a great big bear hug!"

Busy Bear!

Christmas Cards

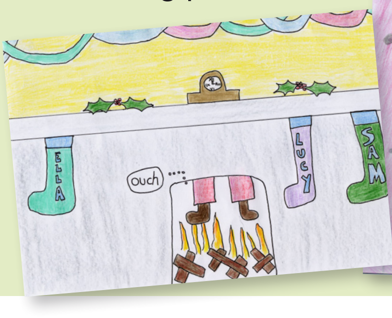
In the last issue of *Together* we launched the 2011 Christmas Card Competition, asking you to design the card that we will be selling this year.

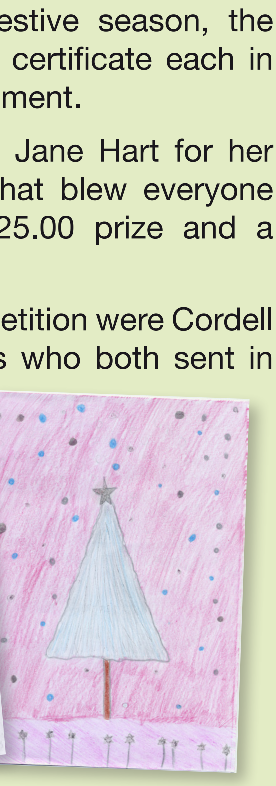
We were delighted with the response and, after much deliberation, we can announce that the grand-prize winners are twins Ella and Lucy Thomas, aged 9 from Melton Mowbray. Ella has hydrocephalus and submitted the very funny picture of Santa getting a bit hot in the chimney!

Their beautiful artwork will bring a cheer to every household in the festive season, the girls receive £50.00 and a certificate each in recognition of their achievement.

Our second prize goes to Jane Hart for her unique Christmas scene that blew everyone away, Jane receives a £25.00 prize and a certificate.

The runners up in the competition were Cordell Hindley and Rachel Unnes who both sent in great designs to the competition – thank you all for taking part!





New name for our charity

Chief Executive Officer Jackie Bland explains a historic decision made by Trustees

Shine

Spina bifida • Hydrocephalus

Information • Networking • Equality

Formerly The Association for Spina Bifida and Hydrocephalus (ASBAH)

In a significant voting decision for this organisation ASBAH Members came together for an Extraordinary General Meeting on May 12th and decided to change the name of this charity.

The new name and logo (shown above) are the result of months of work and consultation to find a name and image which will take us all forward and enable people with spina bifida and hydrocephalus to find a stronger national voice. Our full name will now be the words **Spina bifida**, **Hydrocephalus** followed by three key words that represent what members tell us is most important about our work – **Information**, **Networking**, and **Equality**.

Together these words make the acronym **SHINE** – an easy-to-remember, accessible word which funders and members of the public find it easier to relate to when we first introduce ourselves.

Our charity number and what we do remains the same, but we aim now to build a bright new image and a bright new future for our organisation.

The official launch of SHINE will be celebrated with an open day and launch ceremony at our national headquarters here in Peterborough, at a special event in Northern Ireland and with an open day at our Leeds office. If you are keen to celebrate with us and have been active in ASBAH in the past, or can help show VIP visitors the value of the charity's work then contact us at info@asbah.org and tell us why you'd like to be there to help launch the new name.

Shine

Information – helping members and others understand and manage their conditions.

Networking – building a strong community of people who share similar life experiences.

Equality – working towards a better deal for those with spina bifida / hydrocephalus

Campaign

When ASBAH launched the Go Folic! campaign in March, we wanted to find new ways to inspire women to take folic acid BEFORE they get pregnant. At present, many women only take it AFTER they find out they are pregnant and this is too late.

So, how can we help more women to take it at the right time? One way is to spread the word via the press and several newspapers have already featured our campaign. Thanks to Vitabiotics, which sponsors Go Folic!, we even had national adverts on the day of the Royal Wedding, wishing the happy couple a happy and healthy marriage along with our key message about folic acid (Vitamin B9).

Go Folic! has also been featured on many internet sites and we are working to increase our web presence. To gain maximum impact, we are making three films to be shown on the web and passed on via email, facebook etc.

The first film shows how an embryo develops in the early weeks after conception and why a lack of folic acid may cause birth defects, such as spina bifida. By bringing this 'invisible' stage of pregnancy to life, we can make the need for folic acid feel more real to women.

In the next video Zoe Burnay, whose daughter Hattie has spina bifida, tells her personal story. Zoe's pride in her daughter, combined with her openness about the challenges spina bifida brings, will touch a chord in many people who might otherwise just think 'it won't happen to me'.

Our third video brings humour to the campaign, by creating a cheeky cartoon character called 'Folic Fred'. We won't spoil the joke by telling you how Fred gets our message across ... but we're sure he'll be a big asset to the Go Folic! campaign!

We aim to have all three films ready by Autumn. If you sign up for the newsletter at **gofolic.co.uk**, we will send you an email as soon as the films are out and keep you updated on this exciting campaign.

Review of Literature

As part of the ongoing development of the organisation, all of ASBAH's written materials are being reviewed to see which publications are useful, which need to be refreshed, and what we need in terms of brand new literature.

With this in mind we would like to hear from members, staff and anyone else that benefits from the various leaflets, booklets, magazines and internet sources of literature.

You can let us know which of these are particularly useful to you and tell us what you would like to see produced in the future.

New membership officer

We are pleased to announce that we have had been successful in securing the £250k grant from the Big Lottery which will fund our membership scheme.

The new scheme will increase communication between ASBAH and its members and help us to work more closely together. We also aim to ensure our message is out there for everyone who needs us and therefore we expect our membership numbers to increase.

To achieve this we have recruited a Membership Development Officer who will also work closely with ASBAH's Adult Members Council. Many of you will already know badminton player Gobi Ranganathan. Gobi, who has spina bifida, will take up this role from early September – we look forward to welcoming him to the organisation.

NPH Awareness Pilot Campaign

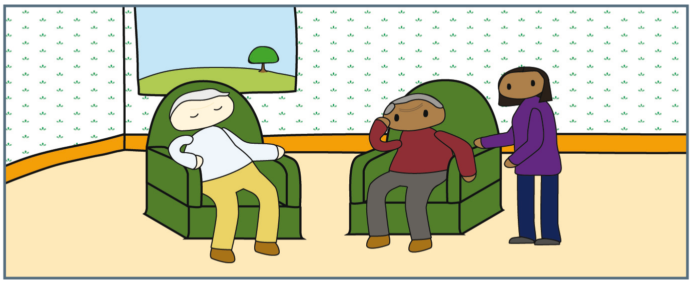
This Summer ASBAH is running a pilot awareness campaign in the Bristol area to alert people to a little-known condition called NPH (Normal Pressure Hydrocephalus). NPH mainly affects people over sixty. Symptoms can include difficulty walking, short-term memory loss and urinary incontinence.

It is very important that people with NPH get an early diagnosis as this gives them the best chance of successful treatment. Yet, because the condition is not well-known, many people with NPH can go undiagnosed or misdiagnosed for a long time. ASBAH is running this pilot, sponsored by Codman, to see if, by raising awareness, we can help turn this situation around.

The Bristol School of Animation has created a special film for ASBAH about NPH. This animation is being shown every 20 mins on TVs in the waiting rooms of local GP surgeries. It will be viewed by over 250,000 people this way and reach even more people via YouTube.

Richard Edwards, a neurosurgeon at Frenchay Hospital, says treatment can be life-changing: 'In some cases, where nursing home admission previously seemed inevitable, patients are delighted to find that, thanks to the treatment, they are able to remain living in their own home.'

Carole from Bristol, who has NPH, says: 'I was lucky that I was diagnosed before my condition really deteriorated. Even so, I had already had some dangerous falls. Once I fell backwards on to my car, another time I fell in the garden and just managed to crawl back into the house.'



'Thank goodness my GP heard about NPH and recognised the symptoms in me and so I got treatment. I am able to get out and about safely again. I hate to think that there are people out there with similar symptoms without knowing why.'

Julia Cross, whose husband has NPH, has been distributing leaflets on NPH to help raise awareness: 'I want everyone to know the symptoms of NPH as this will help people to get an early diagnosis. The doctors at Frenchay Hospital helped my husband and this campaign should mean they will help more people in future.'

To view the animation and the leaflet, just click on the NPH banner on ASBAH's home page. Copies of the NPH leaflet are available from ASBAH.

Carers want more support

More than 400 carers responded to our Carers Survey in the last edition of Together, providing a valuable insight into the lives of parents, family members and friends who provide support for our members with spina bifida and hydrocephalus.

The survey, funded by the Department of Health, revealed that 28% of our carers work as well as undertaking their caring roles while 34% felt that their caring commitments prevented them from working. Seventeen per cent of carers responding were above retirement age. Almost a quarter of carers said that they needed more support.

Among the concerns held by carers, transport and opportunities to socialise rated highly, so too did the need for more information on health information and support networks.

ASBAH is grateful to all those who responded and is looking to develop a special area on its new website for carers, providing information and signposting services as well as looking at how it can include more support for carers.

Paralympic dreams

Tom Scott introduces an inspirational ASBAH member.

Natalie Povey is an example to us all. Strong, determined and modest to the last, her rapid achievements as a Para-dressage rider are nothing short of outstanding.

Natalie, 22, from Wrexham, North Wales, has spina bifida which affects the use of her lower limbs. She is able to walk with the use of crutches and uses a wheelchair, though this does little to stop her being highly active and independent.

It's hard to believe, in light of such rapid success, but Natalie only started riding six years ago. After being advised to start riding by her physiotherapist, Natalie soon engaged with the sport on more than a recreational level. In this short space of time she has quickly progressed into a position whereby she is now knocking on the door of the Paralympic squad for London 2012.

Seeing Natalie prepare and care for her horse, Westpoint First Lady – or 'Fizz' as she is better known – quickly tells you a lot about the character of this young woman. Overcoming minimal use of her legs due to her spina bifida, Natalie demonstrates complete self-discipline in providing for all Fizz's needs.

However, it is when Natalie is in the saddle that you really see her giftedness in action. At the recent British Para Dressage National Championships *Together* joined Natalie to see what is involved in a day's competition at the top level of the discipline.

Natalie Povey – Athlete Profile:

- Born: 13/12/1988
- Lives: Wrexham, North Wales
- Coach: Grace Mew
- Horse: Westpoint First Lady or 'Fizz'
- Riding for: 6 years

Natalie spends the morning readying Fizz and is soon ready to warm up. After being assisted into the saddle by her father Martin, Natalie is in command of her mare who stands 15.2 hands

What is dressage?

- Type of horse riding event
- Originally designed to show a horse's capability on the parade ground in a military setting
- Today the dressage 'test' consists of a series of movements performed in an enclosed arena of 20x40 metres
- The horse is guided through set movements which must be completed at specific points in the arena
- The judge or judges sit at one end of the arena and assess the rider's performance
- The maximum score for each movement is 10, however any score above 6 is good
- These collective marks are then combined with a score for the performance of the horse and rider together and a percentage is given
- No one has ever scored 100% for a complete test

tall. Fizz is of a lively nature and, after 15 months hard work with Natalie and trainer Grace Mew, she still requires a frim hand.

This is a task Natalie is more than able to tackle. During her first 'test' at this year's British Para Championships, Fizz was determined to do her own thing, but Natalie was more than a match for the feisty Fizz and kept her on the straight and narrow in the Hickstead arena.

After watching the young Welsh woman it is hard to believe that Natalie only started riding at the age of 15. She is utterly composed in the saddle and currently has one main goal – to make the Paralympic GBR Team for London 2012.

Natalie is keen to share that she is not from a 'horsey' family and that she has brought her parents along on her exciting journey as she aims for Paralympic glory. It is the combination of support from her parent's, the Team GBR World Class Development Squad, and ASBAH's Fit for Success programme, which has enabled Natalie to pursue her dream, in spite of the financial challenges that come with equestrian sports.

Earlier this year, having read an article in the first edition of *Together,* Natalie applied for a Fit for Success grant from ASBAH in order to help her progress as a Paralympic rider and she was successful in receiving a grant for £1000 to assist her with her sport related costs. Since gaining this support Natalie has continued to develop and has recently been reselected for the World Class Para Equestrian Development Programme 2011-2013.

As a disabled athlete Natalie is able to achieve a level of freedom that her spina bifida can otherwise restrict. As she says herself, "Para Dressage is my life and without my horse I would be lost, riding gives me a freedom that my disability can sometimes restrict.'

You can learn more about Natalie and keep up to date with all her news by visiting her new website – **www.nataliepovey.co.uk**

What is the Fit for Success programme?

- Fit for Success was launched in 2009 to promote more physical activity for people who have spina bifida and/or hydrocephalus
- It aims to support high profile athletes with spina bifida/hydrocephalus, such as Natalie, to overcome any barriers to fulfilling their true potential and becoming role models for others to achieve better health and fitness
- It also supports people with spina bifida/hydrocephalus as they engage with sport and physical activity to achieve their own goals
- By promoting physical activity and good health throughout **ASBAH's** membership, it aims to educate people about how to stay healthy in order to live fitter, healthier, longer lives.

Christmas Cards

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

Each pack of 10 cards and envelopes comes with a traditional Christmas greeting inside.

Carols in the snow

Welly Xmas

Hiding in the snow

Garden Robin

Kings

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Contemporary trees

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Carols in the snow		£3.40	
Penguins		£2.30	
Garden robins		£2.80	
Hiding in the snow		£2.80	
Contemporary trees		£2.80	
Kings		£3.40	
Welly xmas		£3.40	
Number of packs		**Postage per pack**	
1		£0.70	
2		£1.40	
3		£2.10	
4		£2.40	
10		£3.15	
Over 10 packs		FREE	

Total order *(inc. postage and packing)* £ ☐

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

☐ Cheque/Postal order made payable to ASBAH enclosed

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

Focus on funds

We are delighted to have been chosen as the ‘Sainsbury’s Local Charity of the Year’ for the Bretton store near our Peterborough Head Office.

The partnership was launched in store on 1st July with a Summer Fun Day (although the enthusiastic staff had already managed to raise £200 prior to the official launch).

Benny Bear made a special guest appearance, although the star of the day was undoubtedly local ASBAH member Rebecca Chisnall who is 2 and has spina bifida and hydrocephalus. She spent the day making new friends, charming customers and helping us raise over £600 on the day.

A massive thank you to Sainsbury’s staff for helping us.

JustTextGiving
You can now give, and encourage others to give, by text message! Simply text **ASBH11 £1** (or £2, 3, 5, 10) to **70070**
It couldn’t be easier and you can use if for all your fundraising events or initiatives.
For more info see justtextgiving.com/asbah

Please keep an eye out for opportunities within your local stores such as Sainsbury’s and Waitrose, and nominate ASBAH where you can. These local partnerships are great for raising funds for ASBAH and also raising awareness of what we do.

Are you one of the 30 million adults in the UK…

…who have not made a Will? If so, then you might want to take advantage of a unique opportunity being offered to all of us within the ASBAH community.

We are pleased to announce that Ambrose Appelbe, a long-established and well-respected London law firm, is generously offering ASBAH members, supporters and staff 15 minutes of free telephone support from their team of professionals with expertise in Will writing. By calling 020 7242 7000 and asking for either Lucie Sleeman, Leah Parry or Felix Ambrose, you will have 15 minutes free of charge and without obligation to ask any questions relating to making or amending your Will.

Having worked with ASBAH in the past, Ambrose Appelbe know how much we rely on gifts left to us in Wills to keep our services going so they have also offered a discounted rate for clients wishing to mention ASBAH in their Will.

Planning for when we are no longer here may seem morbid or seem so far in the future that we don’t need to think about it just yet. The harsh reality is that if you pass away without making a Will, there are certain rules which dictate how your money and possessions should be allocated which will almost certainly not be the way you would have wished.

Knowledge gives you control, and knowledge gives you options. A correctly prepared and executed Will can enable you to safeguard the future. A free 15 minute call to Ambrose Appelbe may be all that is needed to enable you to obtain peace of mind.

Emily Speirs - 1000%

Tom Scott speaks with Emily's mum, Rachael, and reflects on the story of a remarkable young member.

Many readers will have watched the recent episode of the Channel 4 series *Born to be different* featuring the inspirational Emily Speirs. The programme, which has followed a group of disabled children from birth to their present age of 10, details the obstacles faced by disabled children and their families and how they seek to overcome them.

Whilst each of the children featured demonstrate a formidable capacity for living full lives in the face of severe disabilities, there is nonetheless something very special about young Emily.

Emily was born with spina bifida and, soon after she was born, underwent the first of many operations. The programme offers an intimate insight into the life of the Speirs family and shows their extraordinary resilience as they continue to support one another.

The focus of this episode was particularly striking because it detailed the emotional journey of Emily gaining more control of her continence. As viewers we were reminded of scenes from a previous series in which Emily insisted that she was happy to stay in nappies long-term. This, however, has now all changed as Emily continues to mature and seeks to increase her levels of independence.

It is from this point on in the programme that we hear the term 'knickers' used frequently – for all Emily really wants is to be able to dress like her friends and take some control over her day-to-day toileting.

Of course this, for someone experiencing the physical realities of spina bifida, doesn't happen easily. Having already endured serious operations in her young life, Emily has to once again undergo a procedure so that her bladder and bowel functionality can be improved.

It is not a decision that the family took lightly, and Emily herself needed four years to come round to the idea. As a young child she was unaware of the possible stigma attached to wearing pull up nappies long term, but, as she starts to think about secondary school in the future, there is a realisation that it is necessary to take as much control as possible of her bladder and bowel.

Although Emily acknowledges her fear in going ahead with the operation, she approaches it bravely saying in her joyful tone, **'I really want the operation now and I'm going to sing 'This could be the greatest day of our lives as it's my favourite song by Take That … because it will be the greatest day of our lives, because I'll be in knickers finally.'**

However, before the song can be sung, Emily has to undergo 5 hours of reconstructive surgery to enlarge her bladder and manipulate her appendix so that she can begin to control her own bowel. We watch as the family wheel Emily down the corridor at the Royal Manchester Children's

Hospital and say their emotional goodbyes before Emily goes for anaesthetic.

For Emily's Mum, Rachael, being a nurse doesn't make the ordeal any easier and we witness the heartbreak of a mother letting her daughter undergo life-changing surgery in the hope of a better future. Rachael speaks openly throughout the programme and at one point shares her thoughts on the lives of children who must spend long periods in hospital, **'Kids with disabilities spend a lot of time in hospital, I think to a degree they're robbed of their childhoods.'**

Rachael spoke to *Together* after the programme had aired and, whilst many disabled children like Emily do encounter such a loss of quality time during childhood, it was reassuring to hear of the support the Speirs family have known from the point of diagnosis onwards.

Having been told that their growing baby had spina bifida in March 2000, Rachael and her husband Richard returned home and started searching the internet for more information on a condition they were unfamiliar with. Although this was overwhelming to begin with, the couple pulled together and, with some help from ASBAH in the early stages, they have maintained this resolve, a fact to which Emily's character testifies each time she appears on the screen.

It is this positive image of Emily that we are reminded of throughout the recent series of *Born to be different*. As the operation to improve Emily's continence ends, and the process of learning to self-catheterise and wash out her bowel begins, we continue to see her high-spirited personality shine. There are still tears and there is no rushing the time it takes for her new bladder to heal, Richard reflects, **'We were ready for the operation, we knew that was going to be tough. But then you come home and you think everything is going to be easy now, but it wasn't.'**

Despite the steep learning curve it becomes immediately apparent that Emily's operation was a wise decision. Emily is asked: 'Do you think it's been worth it?' to which she replies: **'Out of 100% worth it, I think it's been, erm, 1000% worth it!'**

The final episode in the series takes us a year further on in Emily's life and we get to see the incredible change in her life as a result of the operation. She is able to look after her own continence and is becoming increasingly independent.

In the final scenes of the show we see Emily away from home for two nights on a school trip. Rachael, although acknowledging the difficulty in letting Emily go, highlights the significance of the event, **'The whole reason she had the operation was so she could live her life independently. The operation was, without a doubt the best thing we ever did … apart from have her.'**

Adult members council

Hello Everybody - Here is news about some of the activity your ASBAH ADULTS MEMBERS COUNCIL has been involved in over the last few months.

The Chairperson, Lisa Cain, attended the successful launch of the Go Folic! Campaign at a Parliamentary Reception and was one of the speakers alongside the Public Health Minister Anne Milton, MP and ASBAH CEO, Jackie Bland.

Lisa also attended the Surrey and Greenwich ASBAH AGM, letting local associations know about us, our new role within ASBAH, and what we as a group hope to achieve over the next three years. And as if that wasn't enough Lisa was also a part of the conference in Belfast hosted by Cathy McKillop, Director of Northern Ireland ASBAH.

The NI conference ran over two days, the first was targeted at professionals and the second at adults with SB/H. Over twenty members attended. Lisa ran the age 30+ forum with NI member Beverly Whyte. There were also sessions on living with disability from Marcia Collins and more on healthy living and stress management with Ruth Balmer.

We were delighted to welcome actor David Proud, best known for his role as Adam Best in Eastenders. David, who has spina bifida, has succeeded in acting at the highest level and offered great encouragement to the adults in attendance.

Most of the council attended the group's induction day at ASBAH house in April, where the group met most of the staff and found out more about their roles within ASBAH. This was a very worthwhile exercise in which we found out how we could all work together for the good of everyone involved.

The Grandparent's Day, which was held at the Peterborough United Football Ground, saw a great response and we met with Grandparents from near and far.

The main speaker on the day was Paul Chumas, Consultant Paediatric Surgeon at Leeds General Infirmary. Mr Chumas used his expertise to give valuable insights into what spina bifida and hydrocephalus are and got a great response from the grandparents.

Rosemary Smith, who's grandson has spina bifida and hydrocephalus, gave a great talk on being a grandparent detailing the stages in her grandson's life.

Also giving talks were Elizabeth Miers, ASBAH Area Adviser speaking on *Supporting Your Child*, Gill Yaz, Health Advisor, and the team from ASBAH House, Monica Evans, Paul Dobson and new kid on the block Tom Scott. Tom took photos on the day which you can see by logging on to www.facebook.com/asbah.charity. Now, if you were hoping to see one of myself, well Tom got a lovely picture of my back – maybe he thinks I only have a face for radio!

We will also have AAMC representative Geraint Catherall in attendance at the 'Hydrocephalus: the hidden disability' event in Exeter on Thursday 8th September 2011.

So, all in all I hope you can see that we are now so much more involved in the life of the organisation. Finally on behalf of the AAMC and I'm sure everyone at ASBAH, I would like to extend our condolences to Rosemary Batchelor, Principal Health Adviser at ASBAH and Jon Burke, AAMC Committee member, on the passing of their respective fathers.

Michael Bergin,
Communications Officer, AAMC

Programme of events

2011 August	Family Day Birmingham Nature Centre 16th 10-3pm For further information contact: Geraldine Long 01789 763090
	London Group – monthly - Sunday afternoon For further information contact: Hilary Franklin 0208 4419967
September	York Drop in - for Adults and Parents. Every 2nd Wednesday 1 - 3pm Low Moor Community Centre, York YO10 4JG For further information contact: Denise/Sylvie 0113 255 6767
	Hydrocephalus the Hidden Disability 8th 10 – 4pm Exeter. For further information contact: Lynne Young 01726 861062 Angie Coster 01308 426372
October	London Group – monthly on Sunday afternoon 24th – Bowling For further information contact: Hilary Franklin 0208 4419967
November	London Group – monthly on Sunday afternoon 7th Shopping For further information contact: Hilary Franklin 0208 4419967
December	London Group – monthly on Sunday afternoon 19th Christmas Lunch For further information contact: Hilary Franklin 0208 4419967
2012 March	Family Opportunity Weekend Friday 16 –Sunday18 March Britannia Hotel, Leeds For further information contact: Denise/Joan 0113 255 6767

ASBAH's Lifelong Opportunities Programme

presents

Hydrocephalus – the hidden disability

association for spina bifida hydrocephalus
cymdeithas spina bifida hydrocephalus

Registered Charity Number 249338

A conference offering information about hydrocephalus to parents and professionals.

Exeter

Thursday 8th September 2011

10am – 4pm

For more information please call:
Lynne Young – 01726 861062 or
Angie Coster – 01308 426372

contact us

As well as our national office, based in Peterborough, ASBAH has five regional teams of community advisers covering England, Wales and Northern Ireland, you can contact them via our helpline number or direct as follows:

association for
spina bifida
hydrocephalus
ability beyond disability

National office:
42 Park Road, Peterborough PE1 2UQ
Tel: 01733 555988
Textphone: 01733 421395
Fax: (01733) 555985

Email: info@asbah.org
www.asbah.org

North of England & West Midlands:
64 Bagley Lane, Farsley,
Leeds LS28 5LY Tel: 0113 255 6767
Fax: 0113 236 3747
Email: nro@asbah.org

Eastern region:
42 Park Road, Peterborough, PE1 2UQ
Tel: 01733 421309 Fax: 01733 555985
Email: ero@asbah.org

London and South:
209 Crescent Road
New Barnet, Herts EN4 8SB
Tel: 020 8441 9967
020 8449 0475
Email: lasr@asbah.org

Northern Ireland:
ASBAH, PO Box 132
Cushendall BT44 0WA
Email: niro@asbah.org

association for
spina bifida
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Pen-y-Bont ar Ogwr
CF31 9LD Cymru
Ffôn: 01656 864102
Ebost: wro@asbah.org

www.asbah.org


SpeediCath® Compact
NEW
CATHETER
FOR MEN
Available from
01 February 2011
Designed for discretion

Transylvanian Challenge

13th – 18th September 2012

TREK FOR ASBAH

Fundraise for

association for spina bifida hydrocephalus
ability beyond disability

www.asbah.org/treks

Discover Romania on this amazing trekking adventure. The route will take you into the rugged Piatra Craiului National Park where you will encounter the magnificent views and wildlife, pass through traditional villages and experience the majesty of Count Dracula's 'Bran Castle'. Up mountains and through gorges this is a very challenging but rewarding expedition, where you get a fascinating glimpse of life in this almost untouched corner of Europe.

For full details please contact Cerys Long
01733 421329 or email **cerysL@asbah.org**

Registration Fee: £250 per person
Min. Sponsorship £1750 per person

PETERBOROUGH

run the 2011 Great Eastern Run

for association for spina bifida hydrocephalus ability beyond disability

Sunday 9th October 2011

option 1

Great Eastern Run
Half Marathon

option 2

Great Eastern Run
4k Fun Run

ASBAH will pay your entry fee when you commit to raising a minimum sponsorship of
£150 for the half Marathon or **£50 (£30 under 16's) for the Fun Run**

Half Marathon
- Great event with real fitness challenge
- Raising significant sums for the people ASBAH supports

Fun Run
- Suitable for children* and families
- Easy to train for
- Low fundraising target

*Children under 8 must be accompanied by an adult

We'll equip & support you
You'll receive:
- a breathable running vest
- personalised sponsorship forms
- training advice
- fundraising tips
- online giving facilities

Disabled athletes
The Great Eastern Run caters for disabled athletes in both races, so go on,
GET INVOLVED!

We'll see you at the end!
See you at our marquee after the finish line for:
- complementary drink & snack
- celebrating together with other ASBAH competitors
- place to meet family & friends

To run for ASBAH contact Ian Morley on
01733 421328 or email: ianm@asbah.org