SPRING 2010 ISSUE 231 THE MAGAZINE OF THE

association for
spina bifida
hydrocephalus
ability beyond disability

link

Meet running Ambassador Emma Hine

Get online

Visit ASBAH’s website at www.asbah.org for information on anything and everything connected with spina bifida or hydrocephalus.

The site is a great place to find out about the ASBAH community of individuals, families and friends, as well as professionals - and how we are sharing achievements, challenges and information on living with hydrocephalus, or spina bifida, and related issues.

Of course, you can also see the wide range of services – from direct support and information, to campaigning and research which ASBAH provides.

Find information, get the latest ASBAH news, read personal stories, see extended articles from *Link* magazine, get your views heard, get involved, contact our helpline, check out the events diary, order publications …and much more

Plus special sections for:

- **ADULTS with spina bifida or hydrocephalus**
- **PROFESSIONALS**
- **NEW! Young ASBAH – for 12-18 year olds**

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At long last we've seen the last of the snow (famous last words!) and can look forward to getting out and about in the spring with longer days and some sunshine, surely?

In this issue we've got features on taking up a new sport and wheelchair tennis, plus great ideas on how to look good with fashion tips from Gok Wan and *Link* reader Vicky Mason. On our fundraising pages we focus on running for ASBAH but are also looking for 'Friends' of ASBAH to attend presentations - no running involved in the latter!

But if the elements conspire against us, you can wile away the hours visiting our ever expanding website (where you can also read more *Link* stories), joining our new Facebook page or improve your fitness at the gym.

Whatever you get up to, why not let us know your views and ideas on what you would like to see in future issues of *Link* and on the wider world.

Gill Winfield

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Join our Facebook group

If you're a Facebook fan, make sure you join the new official ASBAH site.

We launched our Facebook group on 11 February and by the end of the month had attracted nearly 500 fans... not a bad start!

Even if you're not a social networking addict, it's still a great way for you to keep up to speed with what's happening at ASBAH and events we've got planned for the coming months.

We hope that individuals, families, carers, professionals and anyone with an interest in hydrocephalus or spina bifida and related issues will join our debates and help ASBAH reach out to a wider audience.

It will also be an easy way for everyone to get in touch with each other – although please adhere to the usual internet safety rules.

Facebook is a social networking website that is open to anyone over the age of 13 who has a valid e-mail address.

You'll find us at *www.facebook.com/ASBAH.Charity*

Education support extended thanks to Children In Need

ASBAH was thrilled to hear that we have been granted funding to the tune of £131,863 over three years to finance our national education adviser project.

Funding for the previous project, led by national education adviser Naomi Marston, came to an end in March when the existing three-year Children In Need grant finished.

Since 2007, ASBAH has supported children in primary education, developing strategies and supporting educators and parents. This has enabled 600 children each year to get the best out of their educational experience.

We will now be able to develop specific training material, which will inform educators and other professionals working with children in school, about the implications of hydrocephalus on learning.

Many are now moving from primary to secondary school and need continued support to make the most of the options available to them.

Fundraising Project Co-ordinator Helen Dow told *Link*: "We were delighted to hear in mid-February that our application for further funding had been confirmed. It is very exciting news for us and we are very grateful for Children In Need's support."

The project will now work with children aged 4 – 18, and its extended support programme will include helping children and their families who are facing transition, either from primary to secondary school or on the options available when leaving school.

Our evidence shows that without the support of ASBAH's education and community advisers to provide advice, information and practical support to educators and parents, correct strategies may not be put in place to assist with the learning difficulties associated with hydrocephalus.

Without this support these children and young people could be severely disadvantaged within their educational environment, resulting in long-term implications as they move towards adulthood, employment and independence.

National education adviser Naomi Marston said: "The news of further funding was fantastic, we will now be able to develop specific training material, which will inform educators and other professionals working with children in school, about the implications of hydrocephalus on learning, and useful strategies that may be implemented into the classroom environment".

Homing in on half a million

This year's Royal Pigeon Racing Association (RPRA) national show, held in Blackpool, reached a milestone in it's fundraising history.

Not only the pigeons were cooing as a cheque was presented to ASBAH which took the total sum donated to us, since the first show, to over £500,000.

Every year the RPRA has donated proceeds from the show to charity and ASBAH was chosen back in 1973 because one of the stewards had a grand-daughter with spina bifida.

ASBAH Deputy CEO, Colin Roberts, received a cheque for £25,000 at this year's show, held in the Winter Gardens at Blackpool, in January, which took the grand total raised for us to £500,000. Colin also presented the RPRA President, Les Blacklock, with a certificate to mark the occasion.

Colin said: "We have had fantastic support from the RPRA all these years and we are absolutely delighted that their continuing generosity enables us to provide services to many families affected by spina bifida and hydrocephalus both in Lancashire and throughout the country.

"We always enjoy going to the show, meeting familiar faces and new visitors, many of whom visit the ASBAH tombola which increases the funds raised but also gives the faniciers a chance to win a prize."

For many years the RAF, at Wittering, has made a special cake for the show and this year's cake, in keeping with the funds raised, was the biggest yet!

Danny Mills faces wheelchair challenge

ASBAH Patron Danny Mills took time out of his training schedule to update *Link* readers on what he sees as one of the biggest challenges of his life - tackling the inaugural Brighton Marathon... in a wheelchair.

Danny, the former England footballer, hopes his efforts will raise awareness of the daily challenges faced by wheelchair users – from accessibility problems to negative attitudes.

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. I was used to running on a daily basis but I obviously can't use my legs for the wheelchair challenge and have had to develop different techniques particularly with my arms.

I've run half marathons before and I was able to chuck a pair of trainers on and go out on the roads around my neighbourhood to put in the necessary miles. One of the difficulties I have faced for the challenge is the danger of training on the road in a wheelchair and I have had to use the track to build up stamina and technique. Another problem is getting a decent grip on the wheels of the chair when it's wet – so I'm praying for a sunny day on 18 April."

Danny hopes his marathon effort will raise thousands for ASBAH and the National Association of Disabled Supporters (NADS) – he's a firm believer that everyone should be able to get to football matches as easily and often as they choose.

To sponsor Danny's wheelchair marathon, please visit his Justgiving page at ***www.justgiving.com/***

IF's 21st International Conference

Experts from around the globe will converge on Dublin, in June, for the International Federation for Spina Bifida and Hydrocephalus (IFSBH) 21st international conference.

The World Congress will build on the success of previous conferences to further enhance understanding of spina bifida and hydrocephalus.

A range of speakers from a variety of related fields will address topical aspects and learn about the latest advances in treatment.

Among the speakers will be paediatric neurosurgeon Dr. Benjamin Warf (USA) and Dr. Timothy Brei (USA), a recognised expert in diagnosing and treating children with disabilities, who has spina bifida himself.

The distinguished line-up includes Dr Trudi Edginton (UK) and Mr. Pierre Mertens (Belgium). Also included in the programme will be personal accounts from Eli Skattebu (Norway) and John Fulham (Ireland).

George Kennedy, CEO, Spina Bifida and Hydrocephalus Ireland, said: "The Congress will maintain the quality of previous conferences by focusing on advances in intervention techniques and treatment while incorporating new and exciting features, such as Youth and Adult Forums and Insights breakout sessions.

All of this will take place in an environment which offers you opportunities to liaise with other people, families and carers affected by the conditions and with other experts and professionals."

The congress will be held at the four star Citywest Conference & Resort Hotel, situated just 15km west of Dublin, on 11 – 12 June.

For further information about the Congress and the programme of events go to:

www.ifsbhireland2010.com

Creative support for ASBAH

The walls of ASBAH's head office in Peterborough have been brightened thanks to the creative skills of two artists.

Shaun Pitchers and Tony Nero, who between them have more than 20 years of artistic experience, have set up an exhibition in the main conference room. They have offered to donate 15 % of the proceeds from any piece sold to ASBAH.

Tony, who works as a designer in ASBAH's Marketing department, said "I first exhibited in Peterborough in 2007 and my work was well received. Since then, I've been exhibiting locally.

"I feel that taking part in this exhibition is a great opportunity for Shaun and me to show our work and to help raise awareness and funds for ASBAH."

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

Dame Tanni Grey-Thompson made peer

Wheelchair racer and disability campaigner Dame Tanni Grey-Thompson has been appointed a non-party political peer in the House of Lords.

Baroness Grey-Thompson, who has spina bifida, has said she will focus her attention on the areas of sport, disability and youth.

She won a total of 16 Paralympic medals, 11 of them gold, across five Paralympic Games between 1988 and 2004.

In 1993 she received an MBE for services to sport, in 2000 the OBE for services to sport and in 2005 she was made 'Dame' Tanni Grey-Thompson DBE for her services to sport.

In an interview with the Daily Telegraph, she said: "I feel incredibly honoured to have been considered for this, and to have been accepted into the House of Lords.

"This is a day I will remember forever. But the hard work starts now - as I would really like to make a difference."

Since her retirement in May 2007, Dame Tanni Grey-Thompson has campaigned to raise the profile of disability athletics and is Chair of the Women's Sports and Fitness Foundation Commission on the Future of Women's Sport.

Martine's building links in Peterborough and beyond

Martine Austin is ASBAH's new corporate relations officer who will be working to build partnerships with both the local Peterborough business community and with national companies.

She has worked in the tele-sales department for 15 years selling balloons to businesses across the country, in ASBAH's virtual balloon races.

Her new role will see Martine developing creative and long-term partnerships with companies and businesses.

She said: "ASBAH is proud to be in Peterborough and is already indebted to the city companies for their support.

"I want to see 2010 as the year in which we really build on that and I am excited about exploring mutually beneficial partnerships."

Kidz North goes South

The popular Kidz Up North exhibition dedicated to disabled children and their carers, moves south in June when it opens in Reading on 24 June.

The event, which was run in the Midlands in March, is free to visitors and offers information on mobility, seating, beds, communication, access, education, toys, transport, style, sports, leisure and much more...

It's a great way to find out about the latest equipment and products and meet representatives from the 90 companies taking part.

The free seminars provide you with information on best practice, new research and good practical advice. For professional visitors, certificates of attendance are available to support continued professional development. Children and parents are very welcome to attend.

For further information or to order your free visitors' entry tickets contact the Exhibition Team at Disabled Living on 0161 214 5962/5959. Email *carmel.hourigan@disabledliving.co.uk*

Kidz South:

Thursday 24 June 2010
9.30am – 4.30pm
Rivermead Leisure Complex,
Richfield Avenue, Reading
RG1 8EQ

Kidz Up North:

Thursday, 25 November 2010
Reebok Stadium, Bolton

Moomite auction by Marmite

The nice people at Marmite have auctioned a piece of exclusive artwork, by popular artist Caroline Shotton, who is well known for her iconic whimsical images of cows.

The eBay auction went live on 19 March as *Link* went to press, with bidding starting at £500.

The money raised will be donated to ASBAH, as Marmite's preferred charity. We have already benefited from a range of projects including the sale of Marmite Christmas cards in London's Regent Street last December.

Artist Caroline is known for weaving cheeky cows into world famous pieces of art. Her previous paintings include her quirky take on the 'Mona Lisa' (Moona Lisa) and 'Girl with the Pearl Earring' (Cow with the Pearl Earring) which fetched from £3,000 to £6,500 each.

www.theposhpics.com

ASBAH'S on the ball

ASBAH is hitting the small screen and the national press thanks to the generosity of Peterborough United.

We are one of three charities chosen by the Championship club to be emblazoned on the front of the club's green away kit.

Peterborough United chairman Darragh MacAnthony kindly agreed for the football club's chosen charities to front the playing kit for the rest of the season.

He said: "We have been working closely with our three chosen charities for this season and this gesture will allow them to receive a lot of exposure between now and the end of the season and hopefully bring in much needed funding."

There was wide media coverage following the 4-4 draw with Cardiff City, where Peterborough wore a special one-off strip to raise awareness for the three charities.

The special kits worn on the day were auctioned off and raised £5,600 which will be split between the three charities – ASBAH, Sue Ryder Care and The Free Kicks Foundation.

ASBAH's Marketing & Communications Officer Shelly Bullard, said: "I hope that our association with POSH will create greater awareness of ASBAH's presence in Peterborough and also lead to greater fundraising for the services that ASBAH provides."

Fit for Success!

***Fit for Success!* is our exciting new scheme to help people with spina bifida and/or hydrocephalus make the best of their fitness – from making small changes to training for a major sports event.**

The campaign is backed by a host of paralympians and top-level athletes all keen to help others get the most out of life.

***Fit for Success* has 3 main aims**

- Promoting physical activity and good health throughout ASBAH's membership.
- Encouraging and supporting more people with spina bifida/hydrocephalus to engage with sport and physical activity and achieve personal goals
- Supporting high profile athletes to overcome any barriers they may encounter.

***Link* columnist Miranda Adams is full of advice and encouragement to those wanting to improve their fitness.**

Miranda, a Peterborough-based fitness instructor, is experienced in working with people with a wide range of disabilities – and has hydrocephalus herself.

In the second in her new series, Miranda writes about…

Continuing and progressing your exercise routine

Ideally every exercise routine should be updated every six to eight weeks. This is so that you don't reach a plateau, where your fitness levels and muscular strength and endurance no longer continue to improve. By updating your programme regularly you will continually improve.

There are various ways you can do this:

Cardiovascular training progressions

- Starting with the cardiovascular part of your routine, a good way to improve is to increase the resistance on your chosen exercise machine. Try not to overdo it, an increase of 1-2 levels is usually enough
- Secondly, increase your speed on your chosen machine - if you are covering a certain distance then try to decrease the time it takes to complete your distance each week, or look at your consistent speed and aim to increase this slightly each week
- If you find you are getting bored with the cardiovascular machine you are using then you can either change the machine or change the cardiovascular programme you have set on the machine. A good programme to use to improve fitness levels is interval training.
- Interval training is where you alternate regular intervals of high resistance and low resistance or high speed and low speed. These quick changes will train your cardiovascular system to respond quickly and really help to advance your fitness levels. You will only need to do 10 minutes of training like this, as part of your programme, to see improvements.
- Aim to do 30 minutes of cardiovascular training each session - you can increase this time also if you feel ready. However, if you are doing weights on the same day try not to overdo it on the cardio, 60 minutes is plenty.

Miranda Adams

Resistance training progressions

There are many ways you can work to progress your resistance training, most important is to regularly change and update what you are doing at a level that is suitable for you, this way you will always improve and hopefully enjoy what you are doing.

- Firstly, look at changing the equipment you are using to something slightly more unstable. For example, going from using a resistance machine to resistance tubing, pulleys or free weights.
- By using equipment that is less stable you will be engaging your core and abdominal muscles more, which helps with better movement and

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posture and also continence improvement.

- Secondly, or alternatively, if you don't feel ready to try free weights, increase to the next weight up and reduce the amount of repetitions (reps) you have been doing.
- If previously you were doing two sets of 10 reps, for example, when you increase your weight, you can now reduce your reps to a minimum of eight and up to a maximum of 12.
- Doing resistance training increases the necessary strength for everyday activities such as pushing a wheelchair or carrying items. It will also help to improve your self image and confidence.

The importance of a healthy and balanced diet

A healthy and balanced diet is important with any lifestyle and for any health and fitness goal. I will take you through some basic requirements to maintain a healthy diet and lifestyle.

- Having a healthy diet will also help you to see better improvements in your fitness and resistance training and help to increase your energy levels so that you can train more efficiently.
- It is true what they say breakfast is the most important meal of the day - make sure you always get a good healthy breakfast - something like wholegrain cereal and milk or yoghurt with a glass of fruit juice. Or poached egg on wholegrain toast.
- Eating regularly during the day is very important for effective metabolism and good energy levels - ideally eat a healthy meal or snack every four hours.
- Carbohydrates are important for your energy levels but remember to have them at regular meal times and preferably in the form of wholegrain varieties.
- Make sure you have plenty of protein in your diet. Protein is essential for muscle growth and repair.
- It is good to have protein within 20 minutes of your workout for muscular repair. Whey protein shakes are good for this and you can get these from most health shops and some supermarkets.
- Remember to keep well hydrated throughout the day and during your workouts.
- Remember your fruit and vegetable intake. 5-a-day is minimum, but more if you can. This is important for your daily requirements of vitamins and minerals which help your body function at its best.

Good luck with continuing and progressing your exercise sessions. Keep up the good work and remember to enjoy.

Next time we will look at additional types of exercise that may be beneficial and I will give some examples of suitable programmes and classes that you could try.

Playground to Podium

Playground to Podium is a dedicated initiative designed to identify and nurture young disabled athletes.

The scheme, developed by the Youth Sport Trust, Paralympics GB and UK Sport is designed to form a pathway which will take young disabled people from school PE classes to high level performance and competition.

And while the ultimate aim of this pathway is to produce Britain's next Paralympians and elite disabled athletes, it is also designed to ensure that all young disabled people are able to take part in high quality sports provision of their choice.

The scheme focuses on six sports: athletics; boccia; football; swimming; table tennis; and wheelchair basketball.

Playground to Podium also aims to:

- **train 3,600 teachers to recognise potential talent in young disabled people**
- **offer quality coaching to 22,500 young disabled people through partnership clubs**
- **introduce 2,000 disabled adults to high quality coaching in a community setting**

The scheme is currently identifying at least 15 young disabled people a year, per school sport partnership, who demonstrate a high ability in generic skills. They are invited to attend the County Athlete Assessment, coordinated by English Federation of Disability Sport and development centres.

Andy Brittles, National delivery Manager for the scheme said: "Over recent years there have been fewer numbers of talented disabled athletes emerging at the top end of the performance pathway in comparison with other countries.

"There was a need to review the performance structure underpinning our success as a country if we are to secure and improve on our current international standing and in the medal tables in 2012 and beyond."

For more information about Playground to Podium go to: ***www.sportengland.org/support__advice/playground_to_podium.aspx***

Anyone for tennis?

The Tennis Foundation is inviting applicants for a series of one and two day wheelchair tennis camps that will take place across Britain this year.

Camps for both juniors and adults are being held at tennis centres in Bolton, Loughborough, Swindon and Welwyn Garden City, with dates scheduled in March, May, August, September, October and December.

The Lord's Taverners is supporting the junior camps through its Wheelchair Tennis Junior Development Programme, a partnership initiative with the Tennis Foundation.

The events will be an ace way to try your hand at one of the most popular of paralympic sports, with expert coaching and the chance to try out purpose-built tennis chairs.

Similar camps have provided a launch pad for some of Britain's current crop of wheelchair tennis stars, including ASBAH'S Fit for Success supporter and current British women's No 3, Louise Hunt.

Louise, 18, is now a three-time women's doubles National champion, three-time International Junior Masters doubles champion and a former winner of a Lord's Taverners Sports Endeavour Award.

She said: "I went to several wheelchair tennis camps when I first started out in the sport and they were so much fun and I learnt such a lot.

"Taking part in sport is an excellent way to maintain a healthy lifestyle and is a great way to build confidence.

"The partnership between the Lord's Taverners and the Tennis Foundation has enabled these camps to take place and they are important from a sporting perspective, as well as being a sociable and fun way to make new friends and lead an active lifestyle," she added.

To find out more about the dates and locations and learn more about wheelchair tennis, go to the Tennis Foundation website. You can also download an application form.

Visit ***www.tennisfoundation.org.uk/disabilitytennis/wheelchairtennis***

Alternatively contact Becky Drew on 0208 487 7119 or email her at: ***becky.drew@tennisfoundation.org.uk***

More and more people are taking up tennis

There are some 10,000 public courts across the UK, why don't you make them free for social play?

Latest - Cramlington Park Achieves National Recognition

Wheelchair tennis

Wheelchair Tennis was founded in 1976 when 18-year-old Brad Parks, who was left paraplegic following an acrobatic skiing accident, first hit a tennis ball from a wheelchair and realised the potential of this new sport.

Still one of the fastest growing wheelchair sports in the world, wheelchair tennis integrates very easily with the able-bodied game since it can be played on any regular tennis court, with no modifications to rackets and balls.

Wheelchair tennis follows the same rules as able-bodied tennis as endorsed by the ITF, with the only exception being that the wheelchair tennis player is allowed two bounces of the ball.


Louise Hunt

Taking part in sport is an excellent way to maintain a healthy lifestyle and is a great way to build confidence.

Where are they now?

Over the years dozens of children have been featured in our literature - everything from information booklets and fundraising leaflets to *Link* magazine.
Many of their families are still involved with ASBAH and we thought it would be interesting to catch up with them and find out where they are now.

Mathew Bottoms, who has hydrocephalus, featured in the ASBAH book 'Hydrocephalus and You' when he was a young boy. His mother, Val, had submitted an article about Mathew and the family called, 'Make a little time for yourself.'

Mathew Bottoms

Mathew, now 20, lives with his parents and younger brother James at the family home in Dunstable.

Val's story

"Mathew had a brain haemorrhage when he was three-months-old which left him with hydrocephalus.

He has had long periods where his health has been settled but there have been a lot of up and downs too, in common with many people who have hydrocephalus.

The longest time he has had the same shunt for is 13 years – and even that wasn't completely trouble-free.

He has most of the classical hydrocephalus problems and he also had extremely delayed development.

Mathew attended a mainstream nursery and primary school, but it was when he was at his middle school that he began to experience real problems. Even though Mathew was statemented and had one-to-one support, he wasn't coping well. He was being bullied too.

We applied for Mathew to move to a special school for children with moderate learning disabilities, but the local authority offered him a place at a school which wasn't our choice. We appealed against the decision and went through a lengthy appeal process. Thanks to the fantastic support from ASBAH, Mathew was offered a place at the school we thought was perfect for him.

He was there from the age of 14 until 16 years and he then started a four-year Pathways course at Central Bedfordshire College in Dunstable, where we live.

The course has been perfect for him and he has learnt a lot of vital life skills as well as helping in the college coffee shop.

Part of the course has been animal care and we managed to get Mathew a place as a volunteer at the local dogs rehoming kennels. He works there one day a week and it has worked out very well. The owner has been very supportive and working gives Mathew a sense of purpose and a real confidence boost.

Now we're concentrating on finding something suitable for Mathew to do when he finishes college in the summer. It is important that he continues to learn and develop, doing something he enjoys."

I have been taught lots of life skills to help me do the jobs you have to do in everyday life.

Mathew's story

"I'm in the fourth year of my Pathways course. We do a range of different things every year. At the moment we're doing activities such as swimming, animal care and going into the community looking at shops.

I have been taught lots of life skills to help me do the jobs you have to do in everyday life.

On the course we have cookery lessons which includes making scones for the college coffee shop. Sometimes our group runs the coffee shop for a day with the help of our teachers. It's good fun.

I enjoy helping out at the animal rescue kennels because I love animals. I usually go on a Wednesday and help clean out the kennels and wash and refill the water bowls.

I also help out as a leader at Sea Scouts on a Friday night which is fun and do canoeing in a swimming pool on Tuesdays. I hope to start learning to do an Eskimo roll soon. I'm looking forward to doing that."

Matthew Coates, 12, was pictured on an ASBAH fundraising leaflet shortly after he started primary school.

Matthew Coates

Matthew, who was born with hydrocephalus, lives with his parents and elder brother James, 14, in Tockwith, North Yorkshire.

His mother, Sarah, an ASBAH trustee for the past seven years, gave *Link* an update of Mathew's life.

“Matthew has had almost five years with no shunt problems (touch wood) which has been wonderful, especially considering that in the first eight years he had had a total of 10 shunt revisions. Unfortunately, about two and a half years ago, he was diagnosed with epilepsy, following a series of absences. However, his medication is working well and he has been seizure-free for almost two years.

He continues to show traits which are typical of someone with hydrocephalus - such as being very literal, and having a short attention span, but I think that, in the main, Matthew has got off quite lightly.

He is very habitual which may be a side effect of his hydrocephalus, and which we can work to his advantage.

For example, Matthew has never forgotten to take his medication and often reminds me because I'm the one who has forgotten. His school bag is always packed the night before without any prompting from me.

He moved from the village primary school, which had 197 pupils, to a secondary school with 1800, so was a huge change. I was worried that he would struggle to find his way around and would have trouble relating to so many different teachers, but he has dealt with the move extremely well.

ASBAH's education adviser, Joanne Grenfell, has offered again to go in to the school to talk to teachers about Matthew and hydrocephalus, should they need any advice.

> **As a parent there are certain situations you can control but you can't wrap your child up in cotton wool, there are certain life skills they have to learn for themselves.**

English is a strong subject for him but he doesn't find maths easy, but I always tell him to do his best. He loves drama and is very good at entertaining people.

Matthew isn't that keen on sports but because of the medication he takes he does have a propensity to put on weight so I try to encourage him to keep active, from a health point of view – cycling, swimming, badminton and plenty of walking.

He travels to school by bus and if I think about the many things that could go wrong I would really worry.

As a parent there are certain situations you can control but you can't wrap your child up in cotton wool, there are certain life skills they have to learn for themselves – no matter how hard it is watching from the sidelines.

A recent quote from one of Matthew's teachers said ‘although you do not always find the work easy, you always try to do your best.’ As a parent I don't think you can ask for anything else.”

Matthew met HRH The Duchess of Gloucester at ASBAH's 40th celebrations in 2006

How to Look Good Naked… with a difference

The inimitable Gok Wan met three disabled women with zero body confidence in the last series of Channel 4's How to Look Good Naked.

He used every trick in his book, as well as learning a few new ones, to persuade these women to see just how gorgeous they are.

One of women to get the 'Gok' treatment was Tracy Warren from Leicestershire, who has been using a wheelchair since 2007.

Tracy admitted that, "I hate the way I look. There's not a thing I feel positive about. I have an arched back, twisted legs, big hands … I think I look awful."

It was a revealing moment for her trusted group of close friends, none of whom had a clue that Tracy's self-esteem was so low.

But luckily for Tracy her guardian angel – in the shape of Gok – was at hand, declaring: "You are going to be the hottest thing on a set of wheels."

After assessing Tracy's shape and what will work well for her in a wheelchair, the pair hit the shops to rifle through the racks. A new hairstyle and a make-over later, Tracy was ready for her photo shoot and even braved the catwalk.

She said: "It was an amazing experience. As someone in a wheelchair, I felt it didn't matter how I looked. I felt boring and unimportant.

"Since the show my confidence has shot through the roof. Friends and family say that they have seen a drastic change in my confidence. I like who I am today."

Missed the series?

You can view all three episodes of How to Look Good Naked…With a Difference, online at: ***www.channel4.com/programmes/how-to-look-good-naked/episode-guide/series-6***

What did you think?

Your Voice member Lisa Cain saw the show. She told *Link*: "It was a positive start to looking at fashion for wheelchair users but I was a little disappointed by the show.

"All three women were quite tall and slim which does make buying clothes easier. Unfortunately, people who have spina bifida tend to be shorter. I would have liked to have learnt more about how

clothes can be altered to make them more wearable.”

Do you agree with Lisa? Send in your comments and fashion tips by writing to the Editor at the usual *Link* address or email us at: *Link@asbah.org*

You’re looking good girl

You might use a wheelchair, but that doesn’t mean fashion doesn’t apply to you. Look for variations that will be practical and comfortable to wear. Some of Gok’s suggestions included:

- Don’t hide your disability under baggy clothes – they invariably make you look bigger than you are. Baggy, saggy tops will make you feel just that.
- Fitted tops are usually more flattering as they show off your silhouette.
- Look out for shorter versions of coats and jackets. Instead of a full-length trench coat – one of the season’s key looks – choose a shorter length trench.
- Pleated knee-length skirts in soft fabrics are easy to wear and look good when you are sitting down.
- Don’t forget to work those accessories – hats, scarves, sunglasses, beads, earrings, corsages… and a ‘to die for’ bag.
- Keep your eye on fashion trends. A feather mini skirt, the season’s must have fashion item might not work for you, but a feather-trimmed cardigan or handbag is more practical and keeps you bang on trend.

Gok says… “Don’t be afraid to adapt.”

- If buttons are difficult to undo, try using Velcro instead.
- Sleeves or trousers can be rolled up for a casual look if they’re too long to be practical.
- High-waisted jeans may be more suitable as they won’t reveal any lumps or bumps if your top rides up - but they can be restricting. You don’t need to be a skilled needlewoman to add elastic panels at the sides!
- Skinny jeans are flattering and by adding zips at the ankles they’ll be easier to put on.

Measure up

- Don’t shy away from the tape measure – get a friend to help measure you in all the right places.
- Knowing your shape will make buying clothes much easier, whether in the high street or online.
- If you are planning a visit to high street stores, check out their size guides online beforehand. You’ll know which size clothing to select before you hit the changing room.

Weightier issues

If you’re planning to shed a few pounds, don’t put off shopping until you’ve hit your target weight - make sure you’re looking good while you do it.

If you are overweight there’s no excuse for not looking stylish. Many of the high street shops offer ranges in larger sizes and stores such as Elvi and Evans have great ranges in store and online to choose from… in sizes up to 26.

Go online for inspiration

There are hundreds of websites where you can get inspiration on what’s hot this season. Guaranteed there will be some styles and fabrics not suitable if you’re using a wheelchair – but a lot will be fine, even if you need to adapt them in some way.

We tracked down three of the best….

Times Online: *http://women.timesonline.co.uk/tol/life_and_style/women/fashion*
Caron Franklin’s How to Look Good: *www.howtolookgood.com*
Guardian Fashion: *www.guardian.co.uk/lifeandstyle/fashion*

Shopping heaven

Have a good idea of what items and shapes you’re looking for before you leave the house – it will make life easier

Looking good

Anyone familiar with our Below the Belt book for teenagers will have spotted stylish Vicky Mason who was one of our models.

Vicky, who has spina bifida, loves buying clothes and accessories and says that using a wheelchair should not deter anyone from looking their best.

"I've always loved clothes and accessories – I've got hundred of pieces of big jewellery and I must have 100 pairs of dolly shoes."

Vicky, 19, from Spalding in Lincolnshire, said that she knows what shapes suit her and what things are practical – and if it isn't suitable, she's happy to adapt.

"I don't do much sewing myself but my Mum has always taken items to a dressmaker who will adapt them for me. For example, she will take the waistband off a pair of jeans and insert elastic so I get the look in a way which is more comfortable for me."

When we interviewed Vicky in February, she said leggings or jeggings, with a chunky belted cardigan, and snuggly Ugg boots were a favourite during the winter months.

Knowing what suits her makes shopping easier and Vicky's happy to cruise the clothing rails alone.

"I tend to head for Monsoon, River Island, Next and Dorothy Perkins, she said, "but unless I'm in the larger city stores, there never seem to be any disabled changing rooms.

"I usually take stuff to the till and explain that because there are no disabled changing facilities I will have to try the clothes on at home and return them if they are unsuitable. The sales assistants are generally shame-faced and say that's fine. But hopefully I'm getting the message across."

The way I look is very important to me. I feel much more confident when I look good and I don't think that being in a wheelchair means you shouldn't look your best.

Vicky's fashion tips for girls with a difference

Fed up with uncomfortable gaping jeans, dirty sleeves, and having to wear big baggy clothes? Worry no more… I'm here to help.

Jeans

Want to wear stylish jeans but find them too uncomfortable when you sit down all the time?

- Remove the waist band and replace with elastic.
- If larger sized jeans are too flared, have them slimmed down.
- If you prefer drainpipes but have difficulty getting them on, try this year's "in" look JEGGINGS or TREGGINGS. These can be dressed up for evening by adding a glitzy top and statement jewellery, finished off with a little pair of ankle boots. To dress them down they can be worn with Ugg boots or dolly shoes with a jumper and belt or a t-shirt.

Tops

Have the problem with baggy tops or dirty sleeves, then go for…………

- Try shorter sleeves for the summer which can also can be worn in the winter with a chunky, funky jumper and a wide belt accessorized with fashion jewellery.
- For a funkier look with a baggy knit, try wearing brightly coloured or patterned tights but never forget the belts and jewellery because the sack of potatoes look is not in!

Dresses

Want to look as glamorous as your girlfriends on that big night out but find that dresses are either too long and floaty or gathered round the waist… not a good look when you have to sit down all the time.

- Try to avoid long floaty dresses
- A good look for sitting down is a straight knee length dress that doesn't ride up.
- Another stylish alternative is a puffball dress that hides a multitude of sins!

Accessories are essential!

A pretty dress or a funky jumper is never complete without those chunky beads, false nails or big bangles. As for the scarves and handbags, well that goes without saying.

- If you have a boring jumper or t-shirt that you just don't know what to do with then always jazz it up with big fashion beads or a trendy scarf.
- Those big glamorous rings and bangles never look nice with unpolished short nails so get yourself down to your nearest salon and get those nails pampered and looking glam. A cheaper option is buying false nails from the shops - if you can't do it yourself it's just an excuse for a girly pamper night.
- Do you have a problem never knowing where to put your handbag when you are pushing yourself? Get yourself down to the shops and treat yourself to a glitzy bag that will go over your shoulder. That way you can still look stunning and be safe.
- If you've got one of those figures that you just want to show off but you've got lots of big baggy jumpers then just pop on a waist belt and you will be transformed.
- Remember, an everyday outfit can soon be glammed up with some funky, chunky beads.

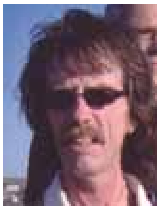
Getting involved

The results of the recent Your Voice election were announced in February with seven new faces joining the team.

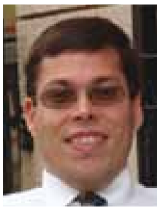
The 15-strong committee is made up of registered ASBAH members. The next meeting will be in May and will look at the future shape of involvement of adults, with the disabilities, in ASBAH.

Who's who on the new Your Voice Committee:

Carole Armour, Leicester
Carole's involvement with ASBAH spans 35 years - firstly with Sussex ASBAH and then as a committee member of Leicester ASBAH. She has been on the Your Voice steering group since 1993 and is an ASBAH Trustee.



Michael Bergin, Hull, East Yorkshire
Michael has, with a colleague, arranged a conference in the UK. He represented YV at the International Conference in Portugal. He also launched the 'Your Voice Your Choice' newsletter.



Jon Burke, Huddersfield, West Yorkshire
Jon works for a national charity advising local organisations on health and social care issues. He has represented ASBAH on the board of the International Federation of Spina Bifida and Hydrocephalus.

Lisa Cain, London (Redbridge)
Lisa has helped organise events in Manchester and Birmingham, as well as running various workshops. She has been Chair of the group and has attended conferences on behalf of YV. Lisa has been a Trustee for six years and Lead Trustee for London and South for four years.

Geraint Catherall, York, Yorkshire
Geraint has been a member of the Your Voice committee for the past three years and has been Chairperson. He is a regular at committee meetings and events.

Clair Coverdale, West Midlands
Clair enjoys finding out about new ideas and concepts to enable others to benefit from them. She feels strongly about rights for people with disabilities and would like to contribute to changing attitudes. Clair is a member of an ASBAH "Connect" group.

Amar Raj Singh Dugal, London (Harrow)
Amar enjoys sharing his experiences with others. He's an active member of the group, helping and contributing towards decision making and planning of events.

Amy MacGibbon, London (Islington)
Amy believes that society should be more familiar with hydrocephalus and spina bifida and their effects – in employment in particular.
She is looking forward to making suggestions on skills which could be offered to people with the conditions, to help improve their confidence in employment.

Paul Manning, Ceredigion, Mid Wales
Paul has been involved in organising events and was appointed a National Trustee. He is now Lead Trustee for Wales and is Chair of ASBAH Cymru.

Kevin Ogborne, Bristol
Kevin has wide and varied experience in employment and currently talks to school children about disability and his life experiences. He has also run training sessions for employees of Remploy. Kevin is now keen to use his experiences to help others.

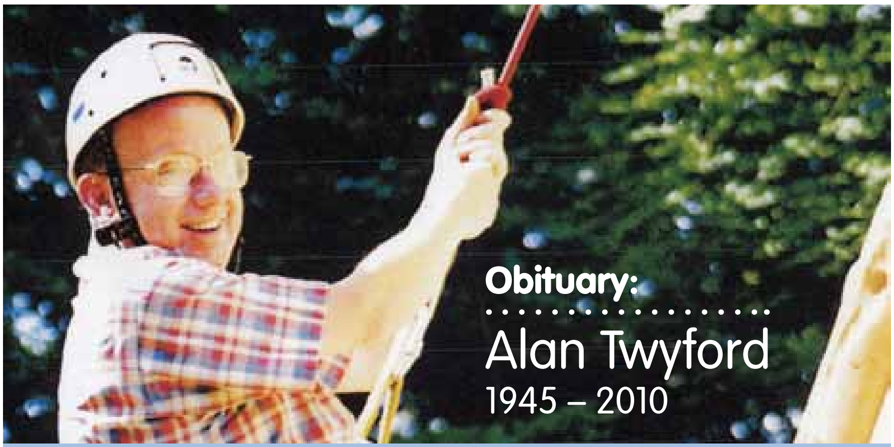
Elizabeth Potts, East Cheshire
Liz is looking forward to the opportunity to engage with others and help in making decisions to enrich the lives of others. She works part-time for the Disability Information Bureau and is an elected volunteer member for a local involvement network, primarily looking into health and Social Care concerns within the public sector.

John Richards, Milton Keynes – Bucks
John, an ASBAH adviser, has spent many years involved in charitable organisations, both for physically disabled people, and people who are visually impaired. His mission is to ensure that people with disabilities are given opportunities to obtain the skills and the means needed to achieve involvement in mainstream society.

Alison Robinson, North East England
Alison has worked in the voluntary sector for the past 30 years as a Trustee, honorary secretary, treasurer, and chairperson of various groups, including the Disabled Drivers' Association and Mobilise. She has a wide knowledge of physical disabilities, mobility and care matters.

Louise Turner, Ottery St Mary, Devon
Louise is currently studying towards two degrees - Sociology and Voluntary Sector Studies. During her studies she was diagnosed with hydrocephalus and had a 3rd ventriculostomy. Louise quickly learnt that living with a disability which is not always visible can add additional challenges.

Paul Zickel, London (Haringey)
A regular and active member of YV, Paul also chairs the Civil Service Disability Network, which meets regularly with MPs, Trade Unions, the All Party Paliamentary Disability Group and others who drive the disability agenda. Whenever possible he voices the views and concerns of YV and ASBAH.



Obituary:

Alan Twyford

1945 – 2010

Alan was born in Kingston Vale on 7th August 1945. He attended mainstream primary school until 11 and then went to Treloar's, a specialist school for physically disabled children, in Hampshire, until he was 18.

In September 1964, Alan began working for Surrey County Council at County Hall, Kingston, where he stayed for 41 years until he retired just before his 60th birthday.

He became involved with ASBAH's South London group at the age of 18 when he was still living with his parents. He became Secretary at the age of 22.

Alan met Margaret after she responded to a letter in *Link* Magazine. Alan then began writing to her and eventually went to visit her in 1968.

The couple were married in July 1971 and bought a bungalow in Tollworth, where they lived for 34 years.

Alan and Margaret decided against having children of their own, but after becoming involved in ASBAH's Independence Week, they met a teenager with spina bifida. She eventually became their foster daughter and spent weekends and school holidays with them. They later had a second foster daughter.

Alan became involved with Your Voice ASBAH, joined the Board of Trustees and was on the Services Committee. He was also Chairman of Surrey ASBAH.

The couple retired to Suffolk in 2005 and started up the Suffolk and Norfolk Spina Bifida and Hydrocephalus Support Group.

Friends and family have donated over £1,000 to this group since his death.

Tributes

"A gentleman who emanated warmth and enthusiasm. All who have worked and/or socialised with Alan will deem it to have been a privilege and it will be a very special memory of a remarkable gentleman."

Leonie Holgate
former ASBAH Specialist Adviser (hydrocephalus)

Alan was a kind and generous man, a devoted husband and a firm believer in ASBAH and what it stood for."

Jo Francis, Manager,
London and South region

Alan had a quiet but passionate belief in supporting ASBAH and informing everyone he met about spina bifida and hydrocephalus but just as importantly to me Alan was a true gentleman in every sense of the word and will be sadly missed."

David Isom
Manager, Eastern region

Could you be a Friend of ASBAH?

We are looking for individuals to take on a very special role – attending presentations to receive cheques on behalf of ASBAH.

Very often we don't have anyone available to collect the money raised by local groups and organisations and personally thank those involved for their hard work and generosity. Our advisers attend if they can, but often don't live in the local area.

So we're looking to create a database of volunteers across England and Wales who would be happy to represent ASBAH at cheque presentations local to them, give a short talk about our work and collect the donation. ASBAH will pay all agreed travel expenses.

Individual giving co-ordinator Cerys Long explained: "It isn't always possible for our advisers to attend cheque presentations. They simply live too far away for it to be practical.

"By having lots of Friends of ASBAH on file, we could approach someone who does live in the local area."

If you are interested in becoming a Friend of ASBAH contact Cerys on 01733 421329 or email her at: *cerysl@asbah.org*

Cerys will explain more about the role and will ask a few questions to see if this important role would suit you.

Anyone who accepts a position will be required to give a short talk (which will be supplied) about ASBAH and our work.

Meet ASBAH Running Ambassador Emma Hine

There's no doubt about it. Emma Hine is a superhero.

The young mother from Havant near Portsmouth – with the help of family and friends – has raised more than £20,000 for ASBAH since she first contacted us for support back in 2002 as well as broadcasting ASBAH wherever she can.

Her son Lewis, now 9, had a brain tumour when he was 17 months old and several weeks later was diagnosed with hydrocephalus.

The family got in touch with ASBAH and has received ongoing support from local and education advisers.

To say thank you and to make sure that similar support can be made available to other families in similar situations, Emma has thrown herself into fundraising activities – encouraged all the way by Lewis.

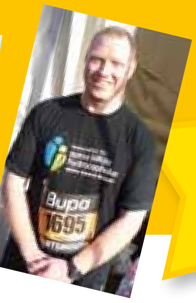
As well as special one-off events, a mainstay of their fundraising has been in the Great South Run.

In 2005 Emma and seven family members and friends donned superhero costumes and tackled the grueling 10-mile course through the streets of Portsmouth.

Since then their numbers have swelled to an impressive 22… all dressed up as 'Where's Wally' last year. Tired of watching from the sidelines, Lewis has put his best foot forward too, taking part in the Mini South Run.

Thank you for your efforts

A big thank you goes to all 72 runners who ran for ASBAH in the 2009 Great South Run. To date they raised £6,300… with more cash still coming in.



Great South Run… are you up for the challenge?

We are looking for 100 runners to take part in the 2010 Great South Run to raise funds for ASBAH.

The 10-mile race, held on Sunday 24 October, winds its way through the streets of Portsmouth, passing landmarks such as HMS Victory and the Spinnaker Tower.

The course is almost flat, with minimal slopes so it's perfect for novices or those looking for faster times.

Around 21,000 runners are expected to join in the fun and along with the thousands of fun runners, club athletes and charity teams, will be a mix of celebrities and elite athletes from around the world.

ASBAH's running co-ordinator Ian Morley said: "We have paid for 100 places in the Great South Run so entry will be free for our runners.

"We don't set a minimum amount to be raised by each runner but we hope that our runners raise as much as they can for us."

By signing up to run for ASBAH you'll receive a running pack with a personalized book of sponsor forms, full details on how to set up an online giving site plus an ASBAH breathable running vest.

ASBAH representatives will be stationed in the charity village at the finishing line, checking our runners have finished safely and providing a hot drink and a sugar fix.

Anyone interested in entering the Great South Run should contact Ian Morley on 01733 421328 or email: *ianm@asbah.org*

"In the past we had quite often talked about doing the Great South Run but never actually got round to doing it.

What finally prompted us was our son Aaron who took part in the children's event a couple of years ago with his friend Lewis Hine, who inspired us to do this run for ASBAH.

Being complete novices to running, all we knew was that it was going to be a challenge. But we were determined not to stop and to definitely finish.

Ten miles doesn't sound far when you say it but in reality, running it seemed endless. The run was tough, especially the first two miles, when you think, what have I let myself in for and then the last two miles when you know the end is in sight but you are battling the cold sea breeze and spray.

Despite all that, the sense of achievement was well worth the aches and pain experienced during the following days.

Would we do it again? Definitely but next time, an extensive training plan will play a vital role and an iPod with upbeat music to pace yourself, a must."

Lisa & Marcus Byrne

Lace up your running shoes… it’s a great way to help ASBAH

Running for charity is one of the most rewarding experiences you can have... whether you’re a seasoned runner or just starting out.

The feel good factor of meeting a personal challenge and raising much-needed funds for ASBAH make it an unforgettable experience.

You’ll see our running calendar on ***www.asbah.org/get-involved/fundraising+ideas/Running+for+ASBAH*** features some of the big BUPA Great Run events where we have guaranteed places.

Boost your training

Whether you’re a new or an experienced runner, there are plenty of ways to improve your running and motivation.

Training schedules, which range from beginner through to advanced level, can help you to keep on track while online training diaries are a great way to log your miles.

Check out the Train and Prepare area on the BUPA Great Run website at ***www.greatrun.org***

Runners World is another good website, with personalized training plans, plenty of good advice and details of planned races around the country at ***www.runnersworld.co.uk***

“The first few times I entered the Great South Run it was just to fundraise. Then last year I started to do some training. I only run between two and four miles three times a week but it made such a difference.

“In the 2009 run I knocked almost 30 minutes off my previous best and felt that I could carry on running at the end. Usually I’m exhausted and have trouble getting up and down the stairs for a few days.

“Now I get really irritable if I can’t run. It is a great stress reliever and gives me more energy.”

Emma Hine

How we can help

Run for Team ASBAH and we will give you all the support you need to make it a day to remember.

No matter what event you decide to do our support network will be with you every step of the way offering plenty of fundraising advice, training information, sponsorship forms, a quality running vest and online giving facilities.

If you take part in some of the larger races such as the Great South and Great North Runs we’ll even be on hand to greet you as you cross the finish line.

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

Run local

Many of our supporters enjoy taking part in the larger, more prominent running events such as the Great North Run to raise funds for ASBAH.

But there are hundreds of smaller events held in England and Wales each weekend which also provide you with the perfect opportunity to put your best foot forward for ASBAH.

Get in touch and let us know what event you have signed up for and you will receive all the usual support and encouragement from the ASBAH fundraising team.

Head out East for an unforgettable run

Great Eastern Run - the perfect 10!

What a great year to take part in the Great Eastern Run, a half marathon which takes place at 10:10am on 10/10/10 in ASBAH's home town of Peterborough.

Whether it's your first half-marathon, your first time in the Great Eastern or you're an established competitor, you'll get a real sense of personal achievement by running for ASBAH.

Great Eastern 4km Fun Run

If a fun run is more your thing, why not run for us in the 4km Event.

Suitable for all ages* and abilities, this fun run is a friendly event and a great way to raise money - for serious runners through to those competing in fancy dress.

*Children under 8 must be accompanied by an adult.

Whichever course you choose, ASBAH will be with you all the way and greet you at the finish in our marquee, with a drink and snack.

The Great Eastern has all the features you would expect of a well organised event including:

- ***Road based city centre course***
- ***Frequent water stations***
- ***Refreshments***

Festive proceeds boost our funds

Christmas Fair donation

ASBAH received a generous £500 donation from a school Christmas Fair after being nominated by parent governor Louise Gordon.

Louise, from Stockton-on-Tees in Cleveland, has become a keen supporter of ASBAH since she first contacted us last year.

Louise, who has two daughters, Bethany, 6, and Freyja, 4, gave birth to a son with severe spina bifida and hydrocephalus, on 4 May 2007.

Jacob was born two months prematurely, weighing just 12 oz, and only survived for 30 minutes.

She told *Link*: "After Jacob died I received no real support. I left hospital and that was it. Last year I felt strong enough to try and deal with my feelings and after a bit of research, found ASBAH and got in touch.

"I spoke to someone and was sent some leaflets which explained more about the conditions and that helped me to come to terms with my loss.

> **It was appalling to lose my baby and to be left to get on with things. I'd hate anyone else to suffer in that way.**

"Now I am determined to raise money to help ASBAH offer support to others who are in a similar position. It was appalling to lose my baby and to be left to get on with things. I'd hate anyone else to suffer in that way."

Louise, a parent governor at Harrow Gate Primary School, Stockton-on-Tees, where her daughters are pupils, put forward ASBAH at a meeting to decide where the proceeds from the Christmas Fair should be donated.

She was delighted when the committee wholeheartedly backed her suggestion and invited area adviser Sylvie Bailey to the school Christmas concert where she was presented with the donation.

Louise is now planning to take part in the Great North Run for ASBAH and is organising a 70s theme disco to raise more funds.

Proposed changes to children's neurosurgical services in England

Last year NHS Medical Director, Sir Bruce Keogh, asked the national Specialised Commissioning Group [NSCG] to develop a neurosurgical service that will deliver the best treatment for children with neurosurgical conditions and their families.

Mr Paul Chumas, paediatric neurosurgeon at Leeds General Infirmary convened a steering group with two "arms".

One was a working group of professionals including neurosurgeons, neurologists, intensivists, anaesthetists, oncologists, paediatricians and nurse consultants set up and chaired by Mr Ian Pople, neurosurgeon at Frenchay Hospital in Bristol. The second, a patients' representatives group, chaired by Mr Chumas.

Rosemary Batchelor, Senior Health Adviser and Gill Yaz, Health Adviser for London and the South represent ASBAH. Other groups represented are from various brain tumour charities and those concerned with the care of children with epilepsy, head injury and childhood cancer.

Mr Robert Hughes from "Anna's Hope" (a brain tumour charity) was elected as the liaison person between the two groups.

At present, there are 15 paediatric neurosurgical centres in England; the proposal is to reduce the number of these centres and concentrate children's neurosurgery in a smaller number of "super centres" offering world standard care - no decision has been made as to how many of these "super centres" there may be.

The pressures prompting the review of children's neurosurgical services include:

- *Some centres carry a lighter caseload than others; therefore some surgeons may not be getting enough experience with complex cases.*
- *The centres vary in the range of services they can offer.*
- *Of the 15 centres, only three offer 24/7 care by a paediatric neurosurgeon. In practice this means that if your child is admitted after 5pm or at weekends or holiday time, the likelihood is that any necessary surgery will be performed by an "emergency competent" adult neurosurgeon and not one who specialises in operating on children.*
- *Some centres are not ideal for the care of children – they may be seen in adult outpatient settings, there may not be appropriately trained theatre staff, there may be too few beds for children so neurosurgical patients are cared for in general paediatric wards rather than in those with specialist nurses and therapists.*

What will it mean?

We are working to make sure that children with hydrocephalus get the best possible care, although it may be different from the care they receive now. It is hoped that most should continue to be treated by their usual neurosurgeon but will have the advantage of seeing another specially trained consultant when theirs is away or unavailable.

Some families may have to travel further or rely on their local hospital for emergency care; help with travel arrangements for families and accommodation needs must be met, and there must be arrangements to transfer children to their neurosurgical unit quickly.

These needs have been highlighted in the National

Hydrocephalus Pathway which is being written by Paul Chumas and Rosemary Batchelor to address the needs of children with hydrocephalus who may have problems with their shunts or ETV and their families.

The Pathway also includes recommendations for adequate training of staff in A & E departments of district general hospitals, guidelines for training of junior neurosurgeons, and information for ambulance services including the air ambulance service.

What happens now?

Nothing is going to happen overnight; your children will not suddenly find themselves without a neurosurgeon. But change will happen and it is important that the transition goes smoothly, with every child having access to 24/7 specialised paediatric neurosurgical care in a "gold standard" centre rather than the less than ideal situation in England at present.

All 15 centres are in the process of being assessed; they will then all be asked to put in a bid to become a "super centre". Only after this will the decision be made by the NSCG on the number and siting of these centres.

For more information go to www.specialisedcommissioning.nhs.uk where you can see the draft service standards document "Safe and Sustainable Paediatric Neurosurgical Services".

If you would like to take part in an email questionnaire from the patient support group, please send your email address to ***helpline@asbah.org*** who will pass it on to Robert Hughes.

***Link* readers will be kept up to date with the progress of this review with the latest news and decisions when they happen.**

Codman - Working in partnership with ASBAH

Lecture tour in India

By Roger Bayston, Associate Professor, University of Nottingham; Chair, ASBAH Medical Advisory Committee & President, Society for Research into Hydrocephalus and Spina Bifida

In December last year, I and Dr Mark Luciano, a colleague from the Cleveland Clinic in USA, visited hospitals in five Indian cities, sponsored by Codman.

It was a hectic trip, visiting Delhi, Bangalore, Mumbai, Chennai and Lucknow in just one week.

We visited hospitals and also gave a series of lectures on hydrocephalus, shunting, external ventricular drainage, endoscopic third ventriculostomy and normal pressure hydrocephalus, including talks at the 58th Annual Conference of the Neurological Society of India and the 16th Meeting of the Chennai Neuro Society.

India is a country of contrasts – and that includes the quality of healthcare.

Unregulated and mostly unqualified "clinics" abound and "folk medicine" is still widely used especially in rural areas.

The institutions that we visited were well established and many dated from the time of the British Occupation. They were impressive and the medical staff were well-qualified, many having trained in the UK.

In one hospital a neurosurgeon, whom I had last worked with at Great Ormond Street in the 1980's, showed us round his unit which he had massively extended with Government funds to build a theatre, ward and intensive care complex worthy of any UK hospital. However, during one of the lectures that we gave, the electricity failed twice!

It might take a long time for most people in India to have easy access to a free health service, but there were clear signs that, at least in the major cities, good medical care was becoming more widely available.

Obituary Peggy Eileen Keeling 1921-2010

By Roger Bayston

"Peggy Keeling was a remarkable woman, who was a founder member of ASBAH, and was also involved in establishing the RICHARD Fund at Sheffield Children's Hospital.

Peggy was a dynamo whose energy was always directed to making life better for others, and her interests and abilities were legion.

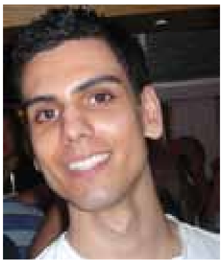
She was an extremely effective fundraiser and raised funds for LASBAH as well as for the RICHARD FUND and, in later years, for my research group to support our research into shunt infections.

It is partly due to this support that we were able to develop the anti–infective shunt that has now been shown to significantly reduce shunt infection worldwide.

Peggy will be long remembered for her important contribution, as well as her personality."

A fast, convenient and discreet home delivery service

This issue we meet Blair Cheekooree, Marketing Communications Manager at Coloplast, who talks about the benefits of healthcare home delivery services.



Blair Cheekooree

Blair told *Link*: "There is a growing need for users of healthcare products to have them delivered to their homes quickly and discreetly.

"At Coloplast we have a home delivery service called Charter Healthcare, which delivers all prescription continence and ostomy products direct to the user's home.

"Many customers want a fast, convenient and discreet service as they rely on their products on a daily basis and often want them delivered without anybody really knowing what they are."

The service delivers products within 24-48 hours, ensuring users never run out of products. Items are wrapped in plain brown packaging using a national courier, so discretion is maintained when the products arrive at the customer's house.

Convenience plays a big role in the delivery of products, so it is important to ensure customers don't have to wait in for deliveries.

Blair explained: "We can deliver products without the need for a signature on receipt of an order, so people can get on with their day and don't have to wait in. There's an option to give an alternative address for delivery, if the person is not at home, too.

"Many users have busy lives and may not remember or have time to order their products."

From this, Charter Health Care has developed a direct contact service, which means our Customer Care team will call the user regularly, usually once a month, to check if they need to order more products. This support ensures they never run out of products and is very popular with the majority of customers.

Blair added: "Along with reliable delivery, many people want more value from a home delivery service. We listen to what users want and respond in a way that really meets their changing needs.

"We have developed a range of complimentary items with users and health care professionals, which can be used alongside healthcare products."

Free items include wet wipes, dry wipes, scented disposable bags and a water spray. The popularity of these has grown considerably with our customers who can choose a selection to try with every order.

Home delivery has become more sophisticated in recent years, especially with online shopping.

Along with reliable delivery, many people want more value from a home delivery service, we listen to what users want and respond in a way that really meets their changing needs.

Charter Healthcare home delivery is also available on the internet through www.charterhealthcare.co.uk where users and health care professionals can log on and order products.

There is a lot of useful information on the website, but the huge advantage is products can be ordered 24 hours a day, 7 days a week. The online service reaches its first birthday in April and already has more than 3,000 users.

You can contact Charter Healthcare by telephone, 0800 787 132, Monday to Friday, 9am-6pm or Saturday, 9am-2pm. Alternatively, you can visit *www.charterhealthcare.co.uk*

Don't miss out on our Big B&B Day which will give parents all the information they need about bladder and bowel management.

The Big B&B Day – last chance to book

The event, part of ASBAH's new Life-Long Opportunities Programme, is open to parents who have a child under 12 years old who has spina bifida.

Led by ASBAH's senior health adviser Rosemary Batchelor and continence adviser Gill Yaz, the Big B&B Day will include:

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

Gill Yaz told *Link*: "We are very excited to present the first ever Life-Long Opportunities day. We know many parents want to improve their children's quality of life through good continence management, and we very much hope to welcome them to our Big B&B Day."

Where & When

The Big B&B Day will take place on:
Wednesday 5 May 2010
10am to 4pm
at Coloplast, Nene Hall, Peterborough, PE2 6FX.

There is no provision for children to attend this event. The Coloplast building is fully accessible with plenty of car parking spaces.

The cost is £5 per delegate which includes a light lunch.

If you would like to attend contact Lyn Rylance, ASBAH House, 42 Park Road, Peterborough, PE1 2UQ. Telephone: 01733 421356. BUT HURRY - closing date for applications is 14 April.

My Big B&B Book

This activity book, aimed at 5 to 8 year-olds, helps children understand the importance of their continence management.

The eight-page publication, sponsored by Coloplast, has a section where children can fill in their own continence routine, complete word searches and a multi-choice quiz section.

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

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

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

You can download the insert sheets from our website *www.asbah.org/Spina+Bifida/continence*

Alternatively, call the ASBAH Helpline to request a *My Big B&B book*.

News from ASBAH around the country

Eastern Region

- Eastern region staff were delighted to hear that our application for grant funding for our **Northamptonshire** adviser, Sharon Lapsley, has been approved by Northamptonshire Country Council for 2010/11.

- The county of **Buckinghamshire** is now to be provided its Area Adviser service by Eastern Region and not London and the South Region. The adviser is **John Richards**. John works part time but will be only too glad to help or to take referrals.

You can contact the Eastern Region office on 01733 421309.

- Area adviser **Linda Knight** bid a sad farewell to colleagues and service users in March when she retired after 11 years with ASBAH.

"It has been a wonderful and very rewarding job, with a lot of laughs along the way."

Emma Enfield has been appointed as the new adviser for Lincolnshire and joins the team in April.

London and the South Region

We now have a full complement of staff covering the region which has been expanded to include the **west country**.

Induction has been completed for **Angie Coster** and **Hilary Franklin** using the new induction process which is being piloted.

Wales

Kate Thomas joined ASBAH in July 2009 as the new Director for ASBAH Cymru, following Elin Ifan's retirement.

Here she writes about her first six months in her new role.

The 16th July 2009 was a day of great apprehension and one that changed my life forever.

It was the day of my interview for the role of Director of ASBAH Cymru. It turned out to be the same day that I was offered the job. I accepted… and haven't looked back since!

The first six months has been very much a time to explore exactly what ASBAH does, what services we provide to the individuals and families we work with, and to consider how the team in Wales can further develop the work we already do, to reach more people, making sure that information and support is available to make life easier and more fruitful, and frankly less of a battle at difficult times.

There has been much discussion, many meetings, mapping of services, developing links to health, social care and education people across Wales, fundraising information and project ideas.

Now it is time to start putting some of this planning into practice.

With the help of the three dedicated, very experienced area advisers across Wales, and with the advice and guidance of the ASBAH local associations and ASBAH Cymru members, we are taking our first steps to building on the services and support we already provide.

The support of colleagues across England and Northern Ireland has also been invaluable.

In the immediate future, our plans include the setting up of social groups for adults with spina bifida and/or hydrocephalus, in Swansea, North Wales and Mid Wales; and a parents' support group in South East Wales. Our area advisers will lead three of these groups. Paul Manning, the Chair of ASBAH Cymru Advisory Committee, has volunteered to lead the Mid Wales group.

Key projects for the next three years will focus on events and information days for children, teenagers and adults; we also want to expand our team of area advisers, promote the benefits of folic acid, and provide opportunities for individuals of all ages to engage in exercise and activities, should they so wish.

Of course, we need to find money to do all of this, so developing a funding plan is also high on my 'to do' list.

For further information on ASBAH Cymru, to find out about the social groups we are setting up or any of the other work we do, or to let us know about any fundraising you are doing for us, contact me, Kate Thomas, at *katet@asbah.org* or telephone 01656 864102. I'd love to hear from you!

BIG LOTTERY FUND

LOTTERY FUNDED

Northern Ireland

Big Lottery gives massive boost

Northern Ireland ASBAH has been awarded almost half a million pounds to fund a new project which will reach out to people across the country.

News of the fantastic £494,000 funding was released on 23 February and now the team are keen to set their plans in motion.

The grant will be used to fund the Getting the Break project which will improve the health and well-being, training opportunities, and confidence of a greater number of people with spina bifida and/or hydrocephalus, their families and carers.

The project will run a range of training/information programmes that will encourage people to learn new skills, improve their self-esteem and gain independence, including daily living skills, confidence building, speaking in public, an introduction to employment, IT skills and sport and recreation.

Cathy McKillop, director for ASBAH Northern Ireland, said: “The funding is fantastic news for everyone. The grant means we can more than double the amount we spend in Northern Ireland in each of the next three years.

“The Getting the Break project will be a very pro-active service geared to connecting with people and will complement the work we already do providing information and support on a range of issues.

The project will run a range of training/information programmes that will encourage people to learn new skill

“Very often, once people reach the age of 18, they don’t get in touch with ASBAH unless they need help or support, but we plan to reach people across the country.”

The Northern Ireland team aren’t wasting any time. A steering committee has already been formed, made up of NI Association representatives, adult service users and parents.

Staff are also recruiting for new positions to help handle the extra workload Getting the Break will create.

Cathy McKillop

Cathy added: “The funding has provided us with a fabulous opportunity and we intend to make the most of it. Getting the Break should have a huge impact here and will be a pilot for ASBAH as a whole.”

A spokesperson for the Northern Ireland local association (NIASBAH), which has six branches across the country, said: “This is a truly fantastic achievement and our warmest congratulations go to all those involved in the successful bid for this substantial funding.

“Putting in these bids is a complex and necessarily bureaucratic process and to win through after a lot of hard work is quite remarkable.

“This breakthrough provides a golden opportunity to develop a much closer and positive working relationship between the various ASBAH interests in Northern Ireland.”

Linda's line

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

I have recently had my annual employment medical which is a complete top-to-toe health check provided to all members of staff. It is a really good benefit to have, although the medical itself is preceded by a questionnaire of epic proportions, which would make some of the DWP efforts in form creation look positively feeble!

There were, however, a couple of flaws in this form, the first one being that the question "have you ever been in hospital or had an operation" only had three lines after it for the answer. Useless!

Luckily my hospital record is now on the computer in a handy printable page so the answer to that one was "see attached". The next problem question also required some careful answering, as the form went on to ask about how much exercise I did and how much alcohol I drank. The answer to that was "none" and "lots", however I have a sneaking suspicion that they were meant to be the other way round!

As many regular readers of *Link* will be aware, exercise is not my strong point. Don't get me wrong – I subscribe to the idea, but the execution leaves a bit to be desired and the pre-exercise risk assessment normally goes along the lines of:

Exercise = waving limbs around = strong likelihood of mishap.

Non-exercise = more time to watch a DVD and/or eat chocolate.

Generally option two wins.

All that has changed with the arrival of the medical results, which show that I have very high cholesterol and according to received advice (well, the opinion of my colleagues in the office actually) the answer is exercise. Bummer.

However, all is not lost as our household is now (since Andrew's birthday) the proud owner of a Nintendo Wii.

This handy gadget provides options for trying all sorts of different sports from the comfort of your own living room.

I am already getting quite good at some of the activities, and achieved a good score in the cycling by cutting across the corners, although I am still rubbish at Frisbee Dog. (Lest you are concerned about animal cruelty issues here, let me reassure you that you don't actually chuck the dog, he is just there to catch the Frisbee for you).

So, with any luck, by the time I come round to next year's medical I will be able to provide a more comprehensive answer to the exercise questions and am very hopeful that a combination of windsurfing, sky diving, cross country cycling and several rounds of Frisbee Dog should be enough to satisfy even the most demanding of medical practitioners.

Obituary Joan Carter 1922-2009 Shropshire and Mid-Wales ASBAH.

Joan was born in Herefordshire, but grew up in Birmingham, and was educated at Sparkhill Commercial School. She worked in the war torn rubble of the city, before marrying her Shropshire lad, Stan Carter, in 1949.

The couple worked and settled in and around the Craven Arms area and after 14 years, their only child, Sara-Ann, was born.

Sara-Ann had spina bifida and hydrocephalus and the frequent treks to hospitals began.

Joan was passionately committed to finding the best treatment for Sara and consequently understood the needs of other parents with similar problems.

She was instrumental in setting up the Shropshire and Mid-Wales group acting as Chair, Secretary and Treasurer from time to time.

Raising money became second nature to her. "Let's have a raffle" was her motto. **She was feisty, friendly, communicative, generous and fun-loving and never frightened to challenge "the powers that be".**

Funds raised helped to purchase an adapted holiday home in Wales, a parent's room in Alderhay Hospital as well as support to families.

Joan's indomitable spirit helped her through Stan's death, when Sara was three, and she determinedly sought the best opportunities medically, educationally and socially for Sara, never forgetting to support those in similar circumstances.

Although distraught when Sara died, aged 22, Joan continued her efforts for ASBAH members and never failed to see the funny side of life.

She spent her final years happily, in sheltered accommodation and working as a volunteer in a local cancer charity shop. She remained a devoted member of ASBAH.

Diary dates

Contact your regional office for further information on any of the events below. Please contact the editor (Link@asbah.org) with dates of your events for the next issue of Link by Friday.

Northern Region: York Drop-in 2010

Where: Low Moor Community Centre, Bray Road, Fulford, York YO10 4JG.
When: Second Wednesday each month:
12 May   9 June   14 July
11 August   8 September
Time: 10.15am – 12 noon.
For further information please contact Sylvie Bailey (Adviser for North Yorkshire ASBAH) at the NEWMO office on 0113 255 6767 or email ***sylvieb@asbah.org***

London and South Region will be having a stand at Kidz South – a free exhibition dedicated to disabled children, their families and carers, and the health care professionals who work with them.
Information on mobility, seating, beds, communication, access, education, toys, transport, style, sensory, sports, leisure and much more from more than 90 exhibitors.
Where: Rivermead Leisure Complex, Richfield Avenue, Reading, RG1 8EQ.
When: Thursday 24 June
Time: 9.30am – 4.30pm
For further information or to order your free visitor entry tickets contact the Exhibition Team at Disabled Living on 0161 214 5962/5959. Email ***carmel.hourigan@disabledliving.co.uk***

Suffolk / Norfolk Spina Bifida / Hydrocephalus Support Group

This group for adults with spina bifida and/or hydrocephalus and their carers meets every two months. Parents of teenagers with spina bifida and/or hydrocephalus are also very welcome. There is ample parking and disabled access at the hall. Do come and join us for tea/ coffee and a chat. Area adviser Val Meyer-Hall attends meetings whenever possible
Where: Roydon Village Hall, High Road, Roydon, Nr Diss, Norfolk.
When: 10.30am-12.30 on the following dates for 2010:
13 May   2 Sept   4 November

On July 1 a BBQ will be held in memory of Alan Twyford at 6pm-8pm. (More than £1000 in donations in remembrance of Alan have been sent to the Support Group).

A Norfolk and Suffolk parent network has been formed and several parents have requested the opportunity for their children to meet others with Hydrocephalus and/ or Spina Bifida. A fun children and family's day will be held on Sunday 25 July at Roydon Village Hall. More information about the day will be posted on the website closer to the day.

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

Regional contacts

North of England & West Midlands
64 Bagley Lane,
Farsley, Leeds LS28 5LY
Tel: 0113 2556767
Fax: 0113 2363747
Email: ***nro@asbah.org***

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Tel: 01733 421309
Fax: 01733 555985
Email: ***ero@asbah.org***

London and South
209 Crescent Road
New Barnet, Herts
EN4 8SB
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Email: ***sero@asbah.org***

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Cushendall
Belfast BT44 0WA
Tel: 0845 450 7755
Email: ***niro@asbah.org***

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

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Email: *link@asbah.org*

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