WINTER 2010 ISSUE 230 THE MAGAZINE OF THE

association for
spina bifida
hydrocephalus
ability beyond disability

link

Adviser services: your stories

We need your old/unwanted mobile phones!

Got a new phone for Christmas? Please don't forget to recyle any old or unwanted mobiles to help raise funds for ASBAH.

Simply call Cerys on 01733 421329 for a freepost envelope to recycle your phone or ink cartridge, or visit the website at:

www.asbah.org/get-involved/fundraising+ideas/Recycling

to find out more.

Send us your unwanted mobile phone to recycle and you will be helping us to help disabled children and adults

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Every phone you send will raise up to £10 for ASBAH

Spina Bifida & Hydrocephalus Helpline 0845 450 7755 (Local Rate Call)

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In this last issue of 2009 we look back at how our advisers have helped families and individuals – whether it's assisting them through a difficult process such as an employment tribunal, liaising with a child's school, supporting young people becoming independent – or being there for new parents. And we remind readers of the many ways in which our health, education and community advisers can help you throughout the year.

Looking forward to 2010, our new columnist, Miranda, gives hints and tips on keeping fit, Your Voice give details of two exciting events they are planning for the spring, and we tell you about a new research project looking for participants.

I'd like to take this opportunity to wish you all a healthy and happy new year and hope to hear from more of you in 2010 about what you would like to see in *Link* magazine in the future.

Gill Winfield

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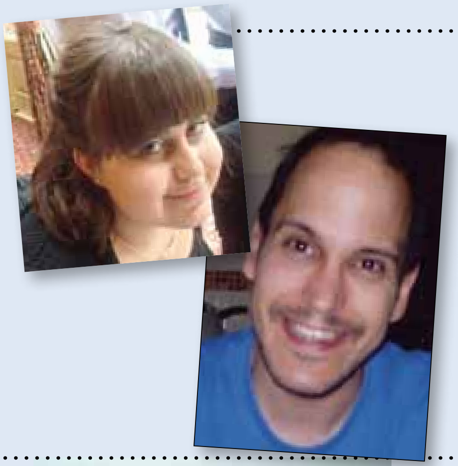

Danny's wheelchair challenge

ASBAH Patron, Danny Mills, will take on the biggest challenge of his life when he tackles the inaugural Brighton Marathon... in a wheelchair.

In addition to the rigorous training needed to complete the 26.2 mile course on 18 April 2010, he also plans to spend a week living as a wheelchair user.

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

"It won't be easy, but I want to show how everyday things we take for granted can be a lot more difficult when you are a wheelchair user," he said.

"Wheelchair marathon racers show how a wheelchair can be fast and efficient on the course, but what should also be a good way to get about in everyday life can be limited by the environment and other people's attitudes to disability."

Danny, who recently launched ASBAH's *Fit for Success* initiative, (see pages 6 and 7 for the latest update), added: "Hopefully my efforts will show just how difficult the training is for our aspiring Paralympic athletes and the extra dedication they need to reach the top."

He also hopes his marathon effort will raise thousands of pounds for ASBAH and the National Association of Disabled Supporters (NADS).

Danny said people will soon see him doing part of his training in and around the streets of Harrogate, his home town.

"I'm going to try and avoid some of the really steep hills but I'm expecting at times there will be adverse reaction to me getting in people's way.

Martin's music brings Christmas cheer for ASBAH

Musician Martin Stanyer has recorded a charity Christmas tune in memory of his baby sister, who died from complications of spina bifida when she was five weeks old.

Although Elizabeth died before Martin was born, he grew up knowing of the sister he had lost.

This year, 30 years after her death, Martin, from Stafford, was inspired to write and record a festive song, to raise awareness of spina bifida and to raise funds for ASBAH.

Martin, 25, who performs under the name Naked Sunday, said: "I was brought up seeing photographs of Elizabeth and my mum and dad talked about their memories of her.

"It had a big effect on me and now it has been almost 30 years since she died, I thought it was time to do something."

When *Link* spoke to Martin in November, his comedy song – Pull My Cracker – had already raised £400.

He said: "The song is full of innuendo, but it is completely clean. I am selling the CDs

We love it!

An exciting new partnership is developing between ASBAH and the iconic high street brand Marmite.

Marmite MD Matt Burgess phoned ASBAH Chief Executive, Jackie Bland, in October - to say that Marmite would like to adopt ASBAH as its ‘preferred charity’ – definitely welcome news for lifetime Marmite worshipper Jackie.

Yeast extract is high in folic acid and B vitamins so naturally something ASBAH would want to promote as part of our campaign to encourage all women who might become pregnant to get the right range of vitamins and supplements.

Major high street brands having the confidence to support ASBAH and promote our name and central messages immediately raises the profile of our cause

Marmite has already really helped us by agreeing to support ASBAH Patron Danny Mills in his wheelchair challenge to the tune of £5,000, as well as producing a Marmite Christmas Card with 50 per cent of the profits coming to ASBAH.

We will also benefit from sales of a Paddington Bear puppet which Marmite produced following a successful advertising campaign in which the Marmalade loving bear became a Marmite lover for a while.

Other ideas are in the pipeline and the association is causing a real buzz around staff and supporters of ASBAH.

Matt Burgess explained the company’s decision to offer support: “ASBAH is a very effective charity doing outstanding work and we are proud to be able to support that work and make a contribution.

“Marmite is a naturally rich source of folic acid and has a long heritage of talking to mums about being ‘rich in b vitamins’ - so it felt like a very natural partnership.”

“This is exactly the kind of partnership we are looking for,” commented Jackie Bland.

“Major high street brands having the confidence to support ASBAH and promote our name and central messages immediately raises the profile of our cause and gives others the confidence to help. I am very grateful to all staff at Marmite for their enthusiasm and encouragement.”

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through a music shop in Stafford; the owner, Eric Furze, has been really supportive.

“A few copies have also been sent out to Germany to an army sergeant who contacted me through Facebook. His son has hydrocephalus so he thought it would be good to send them out as Christmas cards. My song has been played on Forces Radio so I may even get more sales in the run up to Christmas.

“It’s all about raising awareness of spina bifida and hydrocephalus” he said. “ASBAH is one of the many less well-known charities so I’m delighted that it is getting a lot of coverage through Pull My Cracker.

“Elizabeth’s death affected the whole family, but my mum in particular. The interest in the song has helped her to come to terms with her loss and she’s pleased to know that her baby isn’t forgotten.”

The run up to Christmas has been a hectic one for Martin who has played several gigs, throughout Staffordshire, in the hope of selling more CDs.

“The song has really captured people’s imagination and it has been a really worthwhile thing to do. Hopefully the money I raise will really help to change someone’s life.”

You can view Martin singing Pull My Cracker online, at: ***www.youtube.com/watch?v=NVtGSQZi2JI*** or view the Facebook site - Facebook group called: Christmas song pull my cracker by Martin Stanyer - at ***www.facebook.com***

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 such as eating a healthier diet and becoming more active, 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.

With Miranda's help you'll be *Fit for Success*

Meet Miranda Adams our new columnist who will be encouraging you to improve your fitness.

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

In the first of this new series she talks about how to find a sport or form of exercise you'll enjoy... and how to motivate yourself to get started.

Just look at me now

Today, fitness instructor Miranda Adams is a picture of health.

The energetic 27-year-old karate Black Belt finds the time for five gym sessions a week, in addition to the 20 hours she works with disabled people at Peterborough's Bushfield Sports Centre.

But until the age of 11, Miranda relied on a wheelchair to get out and about because her legs were too weak to carry her.

She was born with hydrocephalus and, as a child, underwent several shunt operations. Complications left her with poor mobility and little strength.

Although she gradually stopped relying on a wheelchair, Miranda did little exercise until she left school.

She said: "I tried karate at the age of 17 because I wanted to learn how to defend myself. I loved it so much that it quickly became a passion. I'd never done any sport or exercise until then.

"The more I did, the fitter and stronger I became and I started adding gym workouts to my training. There's no doubt about it, sport has transformed my life."

After the birth of her son Daniel, eight years ago, Miranda began training to become a fitness instructor and she now specialises in working with disabled people who come to her by referral from their GP.

She's seen first-hand how exercise improves strength and stamina... not to mention giving a big boost to confidence and self-esteem.

"It benefits everyone," she said, "and no matter what your disability, there will be something out there for you.

"You need to find a form of exercise that you enjoy and need to believe in yourself, no matter what you are physically able to do. Everyone can progress and achieve."

The sports centre where she is based has a range of equipment designed for disabled people, although she admitted that few areas have this facility.

Miranda Adams

Miranda added: "I count myself very lucky and I think, because I was so weak throughout my childhood, I really appreciate what I can do now. Every time I speak to my mum she tells me how proud of me she is.

"Through my work and my personal experience I know how becoming fitter transforms lives, and I love to encourage and motivate others.

"I hope *Fit for Success*! encourages many others to get active."

Miranda's column

Starting out on the path to fitness

Top tips for starting a healthy exercise routine

Find something you'll enjoy – this may be gym workouts or a particular sport, try out different things that are suitable for you until you find something you really like doing.

Focus on your strengths. We all have our own strengths so choose something which best suits yours. For example. if you have a stronger upper body, choose something which enables you to focus on that. This will increase your self-confidence and skill level.

Try to get into a good routine of regular exercise sessions.

The best way to maintain exercise, as part of your lifestyle, is to make it part of your daily routine. It then becomes a habit, which you feel you want and need to do because it makes you feel good.

An example of a good gym exercise routine when starting out:

10 minutes on an arm cycle/ treadmill at a pace that makes you feel warm and raises your heart rate slightly.

- Chest press - 2 sets of 10 repeats
- Seated row – 2 sets of 10 repeats
- Shoulder press – 2 sets of 10 repeats
- 20 minutes on arm cycle/ treadmill at pace which makes you slightly breathless and perspire
- Cool down for the last five minutes on your chosen exercise machine for your heart rate and breathing to return to resting level.
- Cool down stretches – stretching the muscles you have used in your workout will help to decrease build up of tension in the muscles as well as improve flexibility.

(This routine should be performed 2-3 times per week with rest days in between; cardiovascular exercise can be performed up to 5 times a week, ideally at duration of 30 – 40 minutes)

Remember that everyone's ability and fitness level is different, however, everyone has the capability to do some form of exercise.

Always have an instructor show you how to perform the exercises properly for the first time

Starting and maintaining a regular exercise routine will help you to improve your:

- **Cardiovascular fitness**
- **Muscular strength and tone**
- **Functional independence**
- **Self confidence**
- **Outlook and mood.**

In the next article, we will look at the importance of a healthy diet and at how to continually progress with your exercise routine and fitness levels.

Good luck with your healthy new start!

Fit for Success Grant

Alice Rush

Our first grant, under the *Fit for Success!* scheme, has been presented to Alice Rush, a young swimmer who has her sights firmly set on the 2016 Paralympics.

Alice, 12, has spina bifida and hydrocephalus and has had more than 25 operations including shunt revisions and orthopaedic surgery.

Her parents first took her swimming at the age of two but Alice would make herself sick in the car park in a bid to have the lesson cancelled.

Mother Vicki said: "After many changes of teachers we finally found one who managed to get Alice over her fear of water.

"As she learnt to swim she developed a natural swimming style and began to enjoy the sport and her confidence blossomed. "

Alice joined the City of Cambridge Swimming Club's disability squad two years ago and she was encouraged to swim competitively.

Vicki added: "As her training sessions have increased, her fitness level has improved, she is able to maintain a healthy weight, and understands the benefits of healthy eating.

"These benefits have also helped her be more active physically, she is able to power herself in her wheelchair for longer distances."

Children are often judged by their sporting prowess and until Alice began swimming she was always the little girl that 'tried' but you didn't really want her on your team!

Now her peers can understand that she may not be the fastest on land but they certainly want her in their team in the water.

Cricketers support *Fit for Success*

We were simply bowled over when our new *Fit for Success* campaign received a most welcome financial boost with a £275 donation from a charity cricket match.

Graham Saville – husband of East Sussex adviser Sharon - organised the 'fun' event between two rival Old Boys teams.

Sharon, who served cream teas to the 22 players, said: "The match ended with a barbecue and raffle, with a number of kind donations from all the players."

"They decided the proceeds of the raffle should be donated to charity and in view of this sporting venture, it was relevant to ASBAH's new *Fit for Success* campaign."

The raffle raised £275, £50 of which was raised from a signed Sussex County cricket bat, which was kindly donated through a friend.

Sharon added: "Both teams were told about *Fit for Success* and they agreed that they would like the money to be used towards funding equipment or training for an athlete of ASBAH's choice"

John flies high with FSD

Soaring into the skies at the controls of a light aircraft is an experience that most of us will only be able to dream of.

But thanks to the pioneering work of Flying Scholarships for the Disabled (FSD), the skies have been opened up to more than 300 disabled people.

One man who recently rose to the challenge is John Hayes, 44, who has spina bifida. This is his story...

John Hayes' parents were told he would probably not make it though his first night.

Thankfully the doctor's diagnosis was wrong, but John's life has not been an easy one.

In 1992 he had to have major bladder surgery and an emergency colostomy. Peritonitis was also diagnosed and he believes that had his fiancée, Joanne, not been constantly at his bedside he would have died.

Joanne's love and care pulled him through; they married and her support did much to renew his confidence until, sadly, she died of cancer just a year later. John's world fell apart and without counselling and the help of his parents he believes he would still be in a very dark place.

In his application form for a flying scholarship, John wrote: "I think the challenge of learning to fly would build my morale and confidence and I would certainly like the opportunity to try. It will be hard I know and I may not succeed, but if I don't try I will never know".

Successful applicants are sent on courses which are run both overseas in South Africa, and in the UK at Lasham and Goodwood.

John was awarded a scholarship at Goodwood which was provided through the fundraising efforts of servicemen and staff at RAF Marham.

Applications for a flying scholarship are obtainable from *www.toreachforthesky.org.uk* or by telephoning 0844 578 4 578.

Teenager Karl Hassell is looking forward to a holiday of a lifetime after winning a coveted place on his school's arctic expedition.

Arctic adventure beckons

Karl, 13, from Newark in Nottinghamshire, will be joining six other pupils from Fountaindale School on the two-week trip to Iceland in June 2010.

The children, who range in age from 11 to 17, have a variety of disabilities and are undergoing several training sessions to ensure that they have the skills they will need during their adventure.

Karl, who has spina bifida and hydrocephalus, recently underwent bladder surgery - which he had previously been reluctant to agree to - in order to enable him to be more independent in time for the trip.

His mother Helen said: “All of the children who got through the selection process are incredibly excited and it has been a big motivator in encouraging them to learn new skills and to take more responsibility for themselves.

“I've already noticed a big difference in Karl. He's always been very active and sporty but now he's working on his fine motor skills such as learning to tie his own shoe laces.”

Karl Hassell

The arctic adventure is a curriculum-based educational trip which includes an environmental and cultural study as well as plenty of travel around Iceland. The youngsters will feed their findings back to their classmates via email and webcams.

Helen said: “Karl found his last years at mainstream primary school difficult but Fountaindale has been perfect for him. It used to be a real battle getting him out of bed every morning but now he's up and ready, raring to go.

“The attitude is very much let's look at what we can do instead of focussing on the children's limitations and it is incredible what can be achieved when the will is there.”

> *“On the very first training weekend we already started to see signs of what these young people could achieve when given the opportunity to help themselves rather than being helped by others.*
>
> *“These skills are important to help them achieve their maximum functional potential and a trip like this is a brilliant way to motivate them.”*
>
> ***Sarah Bacon, physiotherapist***

Hoo-kOn stand makes life easier for Karl

A revolutionary portable and lightweight IV drip stand helps Karl Hassall to live more independently.

Karl, 13, uses The Hoo-kOn, a stand which enables bags of intravenous drugs or fluids and monitoring equipment to be securely attached.

It was invented by community healthcare staff in Wolverhampton and was specially designed for use in the community.

Karl will be making good use of the Hoo-kOn to support the equipment he needs for bowel irrigation. Priced at £125.64, it is easily stored, being in its own holdall and is easy to clean and very quick to assemble. It is lightweight and meets infection control requirements.

For every Hoo-kOn IV Stand purchased, the manufacturers MDTi, will make a donation to ASBAH – at no additional cost so when ordering please ensure that you write ASBAH after your name.

Further details about the stand can be found at *www.mdti.co.uk*.

Help with computer skills

UCanDoIT teaches people with physical and sensory disabilities a range of computer skills, on a one-to-one basis, in their own homes.

Over the past 10 years, nearly 3,000 learners with over 80 different disabilities, have learnt with the charity.

Tutors are trained to teach use of specialist software - such as screen readers, and hardware - such as switches, for learners who may be unable to use a standard keyboard or mouse and will operate the computer with their feet.

The charity strongly believes that learning on a computer which has been tailored to the needs of a disabled individual ensures a better learning experience and a greater chance of success.

This also allows the student to practice at times that suit them rather than when a learning centre is available.

One of their learners recently said: "UCanDoIT has opened a new world to me and given me so much to look forward to.

UCanDoIT
Behind a Computer Everyone is Equal

"I have new friends and the knowledge to look for things on the internet rather than having to ask anyone to do it for me - now I do it myself. It means so much."

The course usually consists of 10 lessons and will cover mainly internet and email skills. This includes using the web for searching, shopping, joining groups and forums.

The charity hopes that learners will gain the skills to enhance their independence, and to enjoy being part of a wider community.

There is a small cost per lesson for people on a low income and this works on a sliding scale. All UCanDoIT tutors are CRB checked.

If you would like to know more about UCanDoIT please contact: telephone/Minicom 020 7730 7766 email: *enquiries@ucandoit.org.uk* **or visit the website at** *www.ucandoit.org.uk*

Research project – can you help?

The Spina Bifida Genetics Research Project is enrolling mothers in a study to determine if genetic variations in folic acid metabolism account for an increased risk of having a child with spina bifida.

From the results of the study, it may be possible to develop a test that can identify at-risk women prior to conception. They could then be treated by their physicians the same way as women who have had a child with spina bifida – with high dose folic acid supplementation.

Participants in the study are asked to complete a brief online survey and provide a DNA sample using a simple 'at-home' saliva collection kit.

For more information and to enroll in the SB Genetics Research Project, please go to the website at *www.sbgenetics.org* and select ENROLL.

Upon completion, participants may choose to receive a £10 gift card or to have SB Genetics donate £10 to their designated spina bifida organisation.

ASBAH teams up with Action on Elder Abuse

Our Helpline is running a one-year partnership with Action on Elder Abuse (AEA) who work to protect, and prevent the abuse of, vulnerable older adults.

It is hoped that this collaboration will help to direct people to the most appropriate, helpful and effective advice.

For more information about Action on Elder Abuse go to *www.elderabuse.org.uk* or call: 0808 808 8141

Have you got what it takes to go for gold?

The UK Talent Team, in partnership with ParalympicsGB, is seeking sportsmen and women with the potential to become Paralympic champions in 2012. They are looking for individuals who may have undiscovered talents in a number of Paralympic sports.

If you can answer yes to the following questions, then they want to hear from you!

- ***Do you have an impairment?***
- ***Do you have a UK Passport (or are you eligible for one)?***
- ***Are you aged between 15 and 35 years old?***
- ***Do you have a sporting background in any sport?***
- ***Do you have the desire, commitment and determination to win?***
- ***Are you up for a once in a lifetime opportunity?***

To find out if you have what it takes to win gold in London 2012 apply online at ***www.uksport.gov.uk/pages/paralympic_potential***

The closing date for applications is MONDAY 11 JANUARY 2010, so don't delay. Sign up now!

Hat trick of gold medals for Gobi

Gobi Ranganathan, Britain's number one wheelchair badminton player, recently enjoyed his most successful tournament to-date winning a hat trick of gold medals.

Gobi, who has spina bifida, competed in the Irish Leg of the Four Nations Disabled Badminton Championships.

After winning last year's Singles and Men's Doubles titles in Belfast, he had to compete for both those and the Mixed Doubles title in this year's competition, which was held in Dublin's ALSAA Sports Complex.

A delighted Gobi told *Link*: "I came away from Dublin having completed a badminton hat-trick. I retained the Men's Singles title, regained the Men's Doubles Title, and won the Mixed Doubles title for the first time. I certainly didn't envisage winning three gold medals."

He added: "As always, my performance and results couldn't have been achieved without help from my family, friends and various organisations which have supported me throughout the year."

Now Gobi has his sights set on a successful 2010. He is due to play at the French International in Toulouse in April, the European Championships in Switzerland in May, plus the Four Nations Championships in Glasgow and Manchester.

"I hope I can follow on from this year's success and keep climbing up the World Rankings," he said.

ASBAH advisers... here when you need them

As many of you know, our advisers offer wide-ranging support.

Hundreds of families and individuals through England, Wales and Northern Ireland have relied on their adviser for information, advice and, sometimes, simply a shoulder to cry on.

These hard working professionals provide essential support offering simple, impartial advice and sometimes life-changing information.

The advisers also work with professionals such as teachers, health staff or social workers and colleagues from other organisations, to ensure that they are aware of the possible effects of spina bifida and hydrocephalus.

Our advisers offer their support, confidential information and advice on:

- *Folic acid and pregnancy*
- *Medical conditions and treatment*
- *Staying healthy*
- *Bowel and bladder issues*
- *Benefits, finances and funding*
- *Education*
- *Living independently*
- *All aspects of relationships and social life*
- *Local services*
- *A listening ear…and much more*

Maintaining expertise

Lynne Young, Community Adviser for Cornwall and the South West said: “ASBAH recognises that we have to build up a vast knowledge base, and provides us with regular ongoing training, to ensure that we develop and maintain expertise in spina bifida and hydrocephalus, enabling us to inform and assist other professionals in giving the best possible service.”

Lynne Young

New leaflet

Our new adviser leaflet introduces our adviser services and will be used to help raise awareness across the country.

The new leaflet gives a broad overview of how our advisers can help, with details of how to contact your adviser on the back.

What my adviser means to me...

“My local adviser Ann Gillard gave us lots of information and the support we badly needed. She was happy to answer every little question we had and it was so reassuring to know that she was there.”
Hayley Horsley, mother of two-year-old Joshua

"Gill taught me to deal with what is happening right now."

Gill's support brings continuing comfort to the Kelly family

Julie Kelly had no idea that her new baby Cody had spina bifida. He was born with a lump on his back which doctors believed could be a cancerous tumour. When the lump was thoroughly checked out two weeks later, to Julie's shock, spina bifida was diagnosed.

Julie, from Berkshire, talks about how her adviser Gill Yaz has provided wonderful support during the last four years and how she has helped the family move on with their lives and understand his condition.

Julie's story

"The last four years since Cody's birth have been a bumpy ride to say the least. Being told that Cody had spina bifida came as a huge shock.

"I had all the routine tests during my pregnancy, including an amniocentesis which was recommended because I was an older mother at 36. The results were all fine and with three daughters, my husband and I were very excited to have a boy.

"We knew nothing about spina bifida and didn't know what to do or think. It was a horrendous time.

"I called ASBAH and was put in touch with Gill Yaz. I must have been on the phone to her for two hours the first time we spoke. My mind was spinning with questions – some of them ridiculous like 'will Cody get married?', 'will he be able to have children?'

Gill Yaz

"In the early days Gill taught me to deal with what is happening right now, and not to worry about the future. That was very valuable advice which I try and stick to.

"So much of the medical information meant nothing to us but she has sat down and talked us through it. Similarly she has helped us complete forms which we didn't understand.

"Gill attended meetings at Cody's nursery and the mainstream school he will be attending next September, and helped me to understand his rights. We are so grateful to her for everything.

Today Cody is a wonderful part of our family and the spina bifida label is only used in hospital. He is a real character and is adored by everyone."

Cody Kelly

What my adviser means to me...

Gill was wonderful then and has been so ever since. I feel like she is our angel who came in our hour of need and is there for us when we need her. I can ring her any time and she calms me down and together we work things through.
Julie Kelly, mother of Cody, 4 years old.

“...at long last, someone was on her side.”

Lynne helps to turn Rebecca’s life around


Rebecca

Lynne Young, community adviser for Cornwall, first met Rebecca in January 2007 after her parents, contacted our helpline for advice.

Rebecca, who has hydrocephalus and cerebral palsy, was experiencing difficulties at school and was extremely unhappy with her life in general.

Lynne paid a visit to Rebecca’s home, to see if she could work with the family to improve matters for Rebecca, who was 15 at the time.

Lynne said: “Rebecca was really struggling at mainstream school so I visited her school and provided advice and information to teachers.

“She was also extremely unhappy as she had no friends and had been the victim of bullying at school.

“To try and tackle these problems I arranged for Rebecca to be referred for counselling. I also made a referral to Adult Social Care to ask for an assessment, to provide her with a community care assistant, to assist Rebecca to access leisure activities.”

Lynne said: “Rebecca confided that her life was unbearable as she was again being bullied.”

After making a referral to Early Support and arranging for a Team Around the Child (TAC) meeting, through the Common Assessment Framework, Rebecca and her parents asked Lynne to take on the role of lead professional.

The first meeting addressed funding for a residential placement at National Star College, counselling sessions, benefits and access to leisure facilities.

In July 2009 Lynne was thrilled to hear that Rebecca had been granted funding to enable her to attend National Star College.

“Rebecca’s mother got in touch with me in September to let me know that Rebecca was extremely happy at National Star College, which is obviously wonderful news,” Lynne added.

Parents’ story

“When we contacted Lynne we were desperate to find help for Rebecca. Her time at mainstream primary and secondary schools had been difficult because she received very little specialised support, regarding help in learning, and was bullied throughout.

A Connexions adviser informed Rebecca that she would be unlikely to secure funding for an out of area college and would have to travel a daily three-hour round trip, by taxi, to attend a college in Cornwall for her chosen subject.

When Rebecca left mainstream school she was not offered any advice about specialised colleges out of her local area. Rebecca was forced to accept courses that were not suitable, within her local education authority. After completing a 12- month period on an Animal Care Pathfinders course, which she found to be unsuitable, difficult, and at times unbearable, she decided to look further afield, for something more accessible and in line with her skills. By looking online, Rebecca found National Star College and arranged to go for a visit on one of their open days. Following her visit she decided that this college could offer all she was looking for, and

What my adviser means to me...

“My adviser has been a tower of strength, supporting me through some of Dylan’s long stays in hospital, visiting me and putting me in touch with other families affected by spina bifida and hydrocephalus.
Sonia Reains, mother of Dylan, 6 years old.

more. On applying for a place at National Star College, Rebecca found herself submerged in a pool of funding bureaucracy.

"When Lynne got involved it was a huge relief to us all. Just having a friendly face at some of the interminably long meetings was a help in itself.

"She was incredibly organised and I know what has been achieved for Rebecca is because of Lynne driving it all forward.

"When Rebecca met Lynne she felt that at long last, someone was on her side.

"Rebecca is thriving at National Star College – in fact she's a changed girl. She's experiencing a positive education for the first time and she's delighted. She is growing in confidence and developing her independent living skills.

"It is a huge weight off our minds too. We feel, for the first time in years, that she is safe and enjoying a fulfilling learning experience that will provide her with the essential tools and knowledge for independent living and access to employment."

National Star College

National Star College in Cheltenham is an independent specialist college working with learners who have physical disabilities and associated learning difficulties. For more information call 01242 527631 or check out the website at ***www.natstar.ac.uk***

> *"...we learned ways which would help me to remember information more easily."*

Revision tips help Megan make the grade

Megan Gilbert

Megan Gilbert is a bright and able student currently studying three A Levels at Strathearn grammar school in Belfast.

But in the run up to her GCSE's last summer, Megan, who has spina bifida and hydrocephalus, felt she needed additional support to make sure she got her grades, so she contacted her ASBAH education adviser.

Megan and Catherine McCurry (education adviser for Northern Ireland) explain how they worked with the school's Special Education Needs co-ordinator (SENCO) to ensure Megan did as well as possible.

Catherine explained:

"I initially talked to the school's SEN co-ordinator, Rosie Brown, to see where the school thought Megan needed support.

The first thing I usually do is explain how the pupil's condition may affect their learning. We then work to come up with a learning strategy which will help.

In Megan's case she has short-term memory problems and sometimes has difficulty in recalling information.

She is a lovely girl who is extremely popular and she has consistently worked very hard at school. The strategies we came up with did help and, as we progressed, everyone noticed that she was gaining in confidence and self-esteem.

After her mock GCSEs Megan was predicted to achieve six C grades but when the final results came out in the summer, everyone was thrilled to hear that she had two Bs and four Cs.

Megan attended one of the ASBAH study days to talk about the support she had received and how it had helped her. She was wonderful and a great inspiration to everyone."

Megan said:

"My hydrocephalus means that I have short-term memory problems and I have difficulty retaining information... which is obviously a problem in class.

In study periods, my assistant goes through everything I've just learned and we use little cards with the relevant points on them. We go over these again and again until I can remember them.

My assistant will then ask me questions about the lesson and then ask me the questions in a slightly different format.

This technique really helped and I feel much more confident in class. The extra support has made a real difference to my learning and I'm using the techniques in Sixth Form."

What my adviser means to me...

"The helpline put me in touch with my adviser who visited us and gave us so much support. Without her I don't know what we would have done."
Lorna Korbel, mother of Evie, 5 months

> *"I'm convinced that I won my case because of Moira's input."*

Tribunal victory for Steven

A letter of support from his ASBAH adviser saved Steven Pringleton months of worry in his fight to get the benefits he is entitled to.

Steven, 45, was made redundant last year during an extended spell of sick leave.

He had experienced severe headaches and dizzy spells for months, but was finally forced to take time off work after he had a fit in the street and fell, bumping his head.

Steven, from the North East, said: "For weeks I was unable to doing anything. My speech was poor and I found it hard to even move, let alone walk. At one stage I actually thought I was going to die."

> **Steven phoned the ASBAH Helpline and was put in touch with his local adviser, Moira Foggo.**

After an initial misdiagnosis, Steven was given neurological tests which revealed he had hydrocephalus – probably since birth.

Steven explained: "I underwent an ETV operation last year which was successful, but I am still struggling and I have had two fits in the last six months. I would like to work but I have limited abilities now so I don't know what work I could actually manage.

"After three months of handing in sick notes to the Department for Work and Pensions (DWP), I attended a work assessment.

"This was conducted by a qualified DWP healthcare practitioner whose opinion judged, without hospital or doctor's medical records, that my hydrocephalus does not cause me any physical or mental disabilities!

"My benefit was stopped because the DWP believed I was now fit enough to do any kind of work, despite handing in sick notes and being unable to work while I was made redundant.

"I was unhappy with this decision because I was still far from well and I appealed."

Steven phoned the ASBAH Helpline and was put in touch with his local adviser, Moira Foggo.

Moira said: "The DWP had sent a doctor out to assess Steven and judged he was fit for work.

"It was clear to me that this was not the case - Steven had all the traits of hydrocephalus.

"When the date for Steven's tribunal came through, I offered to write to the DWP to explain what hydrocephalus is and how it affects Steven's ability to work.

"We were all thrilled when he won his case almost immediately. Now I am helping Steven to apply for Disability Living Allowance (DLA) to ensure he gets what he is entitled to."

Steven told *Link*: "I am very grateful to Moira for her help. At the start of my illness I was rushed to hospital suffering from speech loss, fits, severe headaches and dizziness.

"I was too ill to record these events and they were also unrecorded by my doctor.

"Moira's conversation and letter to the DWP filled in the blanks for this period which crucially resolved the outcome of the independent tribunal.

"Up until this point, my fits were never mentioned. As soon as this was made clear the tribunal ruled in my favour.

"I'm convinced that I won my case because of her input. It was very reassuring to talk to her and have her on my side."

What my adviser means to me...

"I contacted ASBAH when my husband and I began thinking about starting a family. I really wanted reassurance that it was OK to go ahead.

"I called the helpline which put me in touch with Geraldine, my local adviser, who put my mind at rest.

Wendy Letts, mother of Vienna, 10 months

> *“Linda has been a great help to me for the last seven years.”*

Linda provides a helping hand to Adam

Lincolnshire adviser Linda Knight has worked with Adam Simmons from Stamford since she first took over the area in 2002.

During the past seven years she has had regular contact with Adam, now 33, helping him with a range of issues ranging from finding independent accommodation to budgeting.

Adam, who has hydrocephalus, admits that at one stage his life was spiralling out of control and without Linda he doesn’t know how he would have coped.

Linda’s story

“I first met Adam when he was trying to learn to drive. Unfortunately, because of his hydrocephalus, his poor spatial awareness meant this was never going to be possible.

Linda Knight

“We kept in touch and I was later asked to help Adam with his budgeting. He had built up a sizeable debt and he was gambling more and more, which obviously added to the problem.

“With the help of me and his parents, Adam worked hard to get his life back on track and sort his finances out. I put him in touch with Gamblers Anonymous and supported him on a very regular basis.

“He still struggles with budgeting. To begin with he will laugh off his debts, then when he realises he has seriously overspent he feels very depressed and can’t see a way out of his problems.

“Adam was keen to leave home and had been on a council waiting list for many years, without any success. A single man living in a comfortable family home meant that he remained low down on the list.

“Both his parents and I wrote letters of support and finally, two years ago, he was offered a lovely ground floor flat by Axiom Housing Association.

“Adam is a hard worker but recently lost both of his jobs and now we’re working to find him new employment.

“He is a very likeable and sociable young man but the side-effects of his hydrocephalus mean that people who don’t understand the condition do not understand why he sometimes behaves as he does.

“I always make sure that I am completely upfront and constructive in my comments. Sometimes Adam might not like what I say but he does listen.

“His parents do get involved if he is having difficulties and if they call me, I always keep Adam in the picture to reassure him that we’re not talking behind his back.”

Adam Simmons

Adam’s story

“Linda has been a great help to me during the last seven years and it is very reassuring to know that I can call her with any problems. She understands me and is never judgmental, so I feel I can be honest with her.

“Several years ago I had got

continued over page

What my adviser means to me...

“The support my adviser, Lynne, has given me has been indispensable. I don’t know what I would have done if that support hadn’t been there. ASBAH has been extremely helpful.”
Casey Bottono, student.

continued from previous page

into a lot of debt. Everything was spiralling out of control and I was drinking and gambling money I didn't have. I had several bank loans which were increasing all the time because of the high interest rate and I thought I'd never pay them off.

Linda helped me with my budgeting and gave me the support I needed to pay my debts off. When I made my final payment it was a huge relief to me.

I had been on the council housing list for around 15 years, and I had almost given up on ever leaving home. My parents had written several times but it wasn't until Linda got involved that I was offered a housing association flat.

At the moment I am job hunting again and Linda is helping me to find a suitable position.

I am very grateful to her for all the help she gives me."


Adam Simmons

Maternity information gap

A new UK study shows that physically disabled people, embarking on parenthood, often struggle to get the necessary help and information they need to prepare for the birth.

The study, carried out by the UK based information charity for disabled parents, Disability, Pregnancy and Parenthood International (DPPI), aimed to develop understanding of the information needs of physically disabled parents who use maternity services and investigated the scope of existing provision.

The participants revealed a lack of awareness and knowledge, among many maternity and health professionals, on integrating disabled parents' need for information and access to maternity services, with their needs as disabled people.

Parents noted that many professionals knew little about the specific needs arising from their disability and found it difficult to obtain information on how their medication might affect their baby.

Hidden disabilities were often overlooked, with assumptions being made that people had no access needs.

Lack of knowledge of how, for example, particular birth positions might impact on parents with physical disabilities was also highlighted.

One mother with scoliosis said: "I wanted to have an active birth, but I ended up in stirrups, flat on my back on the bed. As a result my back pain was much worse afterwards."

The report also revealed how negative attitudes still persist among health professionals including pressure to terminate a pregnancy because of health problems and pressure to have tests to assess if the baby has any disabilities;

Maternity professionals and health professionals working with physically disabled parents/mothers-to-be were also approached to describe the main issues they faced.

One midwife said: "Due to lack of time it was difficult to spend more time with disabled mums teaching them normal mothering skills like feeding and holding."

To read the report in full go to ***http://www.dppi.org.uk/projects/episurvey.php***

The DPPI is seeking to address some of these issues through the development of two guides for physically disabled parents – one on pregnancy and birth and the other on early baby care.

The guides aim to provide information to parents, including where to go for further help, in order to empower them to make choices about their pregnancy, birth and caring for their new baby.

While aimed at the parents themselves, it is anticipated that these guides can be shared between the parents and professionals to help increase awareness and understanding amongst professionals of the needs of disabled parents.

These guides – were published in October - with input from physically disabled parents, maternity and other health professionals.

Foetal anomaly screening symposium

This symposium, held in partnership with FASP [the NHS Foetal Anomaly Screening Programme] at Aston University, Birmingham was a follow on from the one held at the Royal College of Obstetricians in London, in 2008.

There are no guidelines in the UK for a pathway for obstetricians and sonographers to follow when spina bifida has been diagnosed at the 20 week pregnancy scan. This means that care of the mother, information giving and correct referrals, to assist the parents in making decisions is, at best, patchy.

Some women, we heard, get very good treatment with the diagnosis given sensitively, a quick referral to a foetal medicine consultant and to a paediatric neurosurgeon, an intra-uterine MRI scan, support offered by specialist midwives and the family signposted to ASBAH.

Jackie Bland

In other maternity units, very little information about spina bifida may be available and the information that is given is presented in a negative way. There may be no other professional advice or input offered and a bleak picture painted about the likely quality of life for the baby; termination of pregnancy is offered as the “best outcome”.

This symposium gathered people involved in the care of women who find that their unborn baby has spina bifida.

It was chaired by Professor Jenny Hewison who is Professor of Health Psychology and a member of the FASP steering group.

Jackie Bland, ASBAH CEO, gave the ASBAH perspective; her accounts of cases from the Health Advisers demonstrating, in most cases, how poor care can be. It was a powerful message followed by a video presentation by Sarah, the mother of Logan who has spina bifida and hydrocephalus, and a personal statement accompanied by photographs of Lorna and her baby, Evie, who has the same conditions.

We heard from Pat Ward, the Director of FASP and Professor Peter Soothill, Consultant in Foetal Medicine at Bristol.

They were followed by Professor Paul Griffiths whose research in Sheffield is supported by ASBAH, who showed how much more detail can be seen on a MRI scan when compared to an ultrasound scan.

Ms Maria Cartmill, a neurosurgeon from Nottingham, explained the Nottingham care pathway, which she instigated there.

For the afternoon session we were allocated to discussion groups where we aired our opinions about how an ideal care pathway should look.

All agreed that there is a lot of work to do ranging from better training of sonographers and midwives to identifying which medical professionals should be involved in the prenatal care of the mother (whatever decision she makes about the outcome of the pregnancy),

FASP has taken the information from the meetings and hopes to use this to formulate a National Care Pathway, which we hope will be in force by 2011.

By ASBAH senior health adviser, Rosemary Batchelor

Fantastic fundraisers

The sky's the limit for daring fundraisers

Agreed, it's not for everyone, but charity parachute jumps and skydives are popular ways for the more adventurous to raise cash for their favourite charity.

ASBAH has received thousands from thrill-seeking fundraisers over the years, all keen to experience an extra adrenalin rush while raising money.

Parachute jumps, paragliding, skydiving and hang-gliding are becoming more popular with fundraisers, who know that a tougher challenge can encourage more financial support from family, friends and colleagues.

But such extreme activities should not be undertaken lightly. Always book your sport through a recognised centre which has an excellent safety record.

ASBAH directs many people towards Skyline, but there are lots of other recognised organisations around the country which set up similar events.

Daring skydive raises £3,171

Grandad Geoffrey Laughton, persuaded work colleagues to nominate ASBAH as their chosen charity for their annual fundraising event, as a thank you for the support his young grandson had received.

His daring colleagues at RWE Npower, Drax Power and Royle Recruitment voted to test their courage with a skydive... raising £3,171 in the process.

Geoffrey was delighted with their efforts for ASBAH, which gave his daughter Sharon and son-in-law Steve Senior help and advice, after their son Jacob was born with spina bifida and hydrocephalus in 2007.

Sharon explained: "Jacob was diagnosed with the conditions when I was pregnant and we received a lot of support from ASBAH, particularly my local adviser Julie Turnbull. She was a great help to us."

Jacob, who is now two, has come on in leaps and bounds, with the help of his two sisters, the help of his physio, Julie Hudson, and using splints, he is now able to stand up and walk holding on to the furniture."

Sharon explained that, while her father organised the event, he was unable to skydive himself, and instead cheered his nine colleagues on from the ground, at Hibaldstow Aerodrome, Brigg.

"The idea for the skydive actually came from his work mates," she added. "I don't think any of them had done it before but they enjoyed themselves so much that they're talking about doing it again.

"We're really proud of them all and are very grateful to them and RWE Npower, Drax Power and Royle Recruitment for their generous donations and raising so much for ASBAH."

The Great North Run

Jump with Skyline

Skyline is the largest organiser of sponsored charity jumps in the UK working with well over 1,500 charities.

The company was founded 14 years ago, specialising purely in organising parachute jumps for first-time jumpers.

Today, more than 7000 people a year make their first time jump with Skyline. Many of these jumps are made for charity and to-date Skyline jumpers have raised £4.5million for over 1,500 charities.

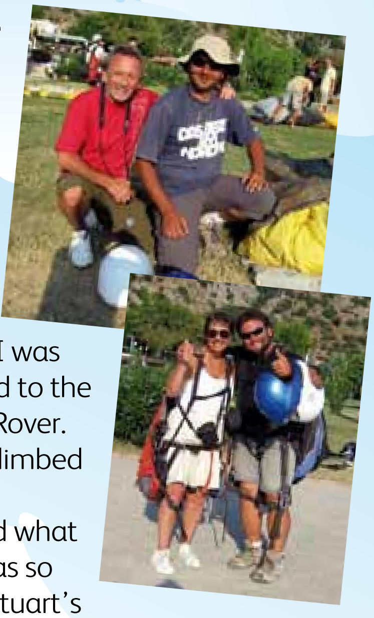
By raising a minimum sponsorship amount (starting from just £360) you can receive your skydive for free!

For more information check out the website ***www.skylineparachuting.co.uk***

Alternatively call Skyline on: 020 7424 5500.

Fundraising flights raise £295

A Cheshire couple faced their fears to raise £295 for ASBAH from a tandem paraglide.



Anne and Stuart Simpson were keen to support ASBAH in memory of their son Paul, who had spina bifida, and died at the age of 14.

They did their paraglide from the 6500ft Badadag Mountain in southern Turkey, although the jump had to be postponed for several days due to poor weather conditions.

Anne said: "To be honest I wasn't sure that I was going to go through with it. Our group travelled to the top of the mountain in an open-topped Land Rover. Everyone was chatty to begin with but as we climbed higher and higher, we grew silent.

"We were strapped into the harness and told what to do at the launch, and then we were off. I was so busy concentrating that I completely missed Stuart's take off.

"Stepping off a 6500 feet high mountain was an extraordinary feeling, but it was a wonderful experience. There was a real sense of peace over the mountains and the views were incredible. Before I knew it we were landing on the promenade. Apparently landing is the tricky bit, but we were fine."

Anne explained that they had always wanted to fundraise for ASBAH, but until now, the right opportunity had never arisen.

Paul

"We had so much to be grateful for during our son Paul's lifetime and ASBAH played a significant part in educating and supporting us throughout his wonderful 14 years of life," she said.

"We were very proud of him, and his influence throughout his lifetime has left an indelible mark on us and many others, even some 11 years on.

"It was our nephew Ollie, who was very close to Paul, who suggested we used the paraglide to raise funds. It was a lovely suggestion and we are very grateful to everyone who supported us."

Ailie Tonkin & Jude Gale

You can see more of our fantastic fundraisers by visiting www.asbah.org/get-involved

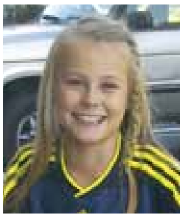
Ian Clark

Adrenalin junkie Jimmy jumps for ASBAH

Self-confessed adrenalin junkie, Jimmy Tolley, realised a dream when he added parachute jump to the list of extreme sports he'd tackled.

Jimmy and three friends signed up for the jump from Hinckley Airfield ...and then decided to combine the fun with fundraising.

ASBAH proved the perfect choice as Megan, the eldest daughter of Jimmy and partner Tracey Perkins, has spina bifida occulta. Friend Chris Tomkins, who also jumped, has a 19-year-old niece with hydrocephalus.


Megan

Tracey explained: "Jimmy had always wanted to do a parachute jump. In the past he's done shark diving in South Africa and a helicopter flying lesson. When he and his friends signed up he thought it would be a great way to raise some money."

While Tracey didn't fancy tackling the jump herself, she played her part by collecting sponsorship money... £1,600 to date.

She said: "Jimmy and his mates camped near the airfield the night before and jumped at 8.30 the following morning.

"They did tandem jumps with an instructor because they hadn't done the necessary training to jump alone, although Jimmy would have preferred to jump solo. He said it was fantastic but was all over too quickly."

While Jimmy jumped, Tracey stayed at home, worrying whether the jump would go to plan.

She said: "I have to admit that I was very nervous that something would go wrong. All those horror stories you read about came to mind and I was relieved when they all returned home safely.

"We're all delighted with how much has been raised for ASBAH. I'm very proud of them and very grateful to everyone who made a donation."


Ed Jamieson (left) and James Kinsey

"The Great North Run was a fantastic experience. I'd always wanted to try a half marathon and it didn't disappoint. As my sister has hydrocephalus I was really pleased to have been able to raise around £2,000 to help ASBAH.

Alexandra was diagnosed with late-onset hydrocephalus at the age of nine. She is now in her first year at Warwick University.

Many thanks to Elizabeth Miers at ASBAH for all the help over the years. I am glad to have had the opportunity to give something back."

James Kinsey, Cheshire

Running up thousands for ASBAH

Well done and thank you to all our runners who took part in the Great North Run 2009.

This time, 27 people tackled the gruelling 13.1 mile course from Newcastle to South Shields to raise funds for ASBAH.

The Great North Run, which took place on 19 September, is one of the most prestigious half-marathons in the world and attracted 54,000 competitors, including elite athletes, celebrities and fun runners.

They tackled the undulating course in blazing sunshine, cheered on by an estimated 30,000 spectators.

The ASBAH runners were greeted at the finish by ASBAH's running co-ordinator Ian Morley, and his wife Val, who often volunteers to help on these occasions, as well as Joan Pheasant, North of England and West Midlands Regional Manager.

The team were on hand to offer congratulations and goody bags providing a much needed drink and sugar fix.

Ian said: "The 2009 Great North Run was ASBAH's most successful year of involvement yet.

"So far we have received sponsor money amounting to £7,500, with more to come"


Gilly and Charlie Martin

Triumph for Charlie

"My son Charlie, 24, has hydrocephalus and had been unwell with a shunt problem from December 07 until fairly recently.

He always said that he would like to run a marathon and when he was bedridden last year he vowed that when he got better he was actually going to do something about it.

He had less than three months to train and the training runs only exacerbated his fatigue.

But we did it and we crossed the line together in two hours 18 minutes - holding hands - at exactly the same time as the Red Arrows flew over the finish line - perfect timing.

We have been in contact with ASBAH since Charlie was age four, often in times of worry when things weren't going so well. So to run for ASBAH was an obvious choice for us. To date we have raised a total of £2,126."

Gilly Martin


Malcolm Henderson


Kelly Bailey & Helen Arnold


Mikey McGhee & Kelly Duguid

Neuroscience Nurses' Meeting

By ASBAH senior health adviser, Rosemary Batchelor

I was invited, along with my colleague, health adviser Gill Yaz, to speak to a group of neurosurgical theatre managers at Codman's offices in Wokingham.

The event was designed to teach the 23 delegates more about hydrocephalus and how it affects the individual and their family.

The delegates, who came from 15 units in England and Ireland, were joined by members of Codman's sales team.

CustomBone

The programme, arranged by Codman's trainers, was designed to show the theatre managers aspects of hydrocephalus outside the operating theatre experience.

Usually they don't see patients following surgery and Codman felt it was useful for them to learn about what happens when patients leave theatre to highlight the human side of their work.

Mark Attenborough, Codman Training Manager launched the meeting with a lively and informative presentation on "How a shunt works", and was followed by Dr Hugh Richards who presented data from the Shunt Registry - which holds information on every operation for shunt, ETV or EVD in the UK.

Dr Hugh Richards

There were talks from Lindy May, Nurse Consultant from Great Ormond Street Hospital, who spoke on Shaken Baby Syndrome, and from her colleague Sue Chapman.

Steve Allen, Neuro Theatre Manager from Alder Hey Hospital, took us on a virtual tour of Liverpool's new intra-operative MRI theatre suite – the only one in Europe and very space age with its blue glass wall and equipment costing £3 million.

Debbie Quirk, also from Alder Hey, presented a case study of a girl with hydrocephalus caused by a head injury who needed a hole in her skull repairing with a material called CustomBone. The results were spectacular!

The guest speaker was Jay Jayamohen, Paediatric Neurosurgeon from Oxford John Radcliffe Hospital, who talked about oncology and tumours.

Jay Jayamohen

We also learnt about CSF pathophysiology from Jenny Sacree, from Bristol's Frenchay Hospital, and heard about pain management and about the NICE guidelines for patient safety.

Gill Yaz explained what ASBAH is and what services we offer to people with hydrocephalus, and my talk, "Hydrocephalus FAQs", ran through the questions our health advisers are asked and which theatre staff probably never hear.

It was a varied and interesting programme which also left time for us to talk among ourselves, to renew old contacts and make new ones.

hydrocephalus action

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

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

Hydrocephalus book reaches Romanian families

The ground-breaking Your Child and Hydrocephalus book is now available to professionals and families in Romania.

The book, first published by ASBAH in 2004, has been translated into Romanian and was printed by the Romanian Spina Bifida and Hydrocephalus Association (RSBHA) this summer.

Adriana Tontsch, President of the RSBHA, said: “When the printers sent over the first pages for approval it was a very moving moment for us. This book is the first real information material families and health professionals in Romania have had.”

More than 400 children died without anyone really noticing...except us.

In Romania, around 600 children each year are born with spina bifida and hydrocephalus.

The RSBHA has organised surgery for 176 children in recent years, but as Adriana explained: “More than 400 children died without anyone really noticing... except us.

“Parents and families with children who have hydrocephalus and spina bifida are not given detailed information about the conditions or further development of the patients, which was the reason why we decided to translate the book and publish it.”

The material in the book was donated to the Romanian association by ASBAH and was translated into Romanian with the help of a mother whose child had surgery in October 2008.

It took her three months to translate it with the final corrections being made by a Romanian teacher.

In July the book was launched at a special presentation attended by health professionals including Prof. Dr Nicolae Ianovici, President of the Romanian Society for Neurosurgery, representatives of the Ministry of Health, the press and families affected by hydrocephalus.

The first book was presented to 11-year-old Andrei Dumitrache, one of the lucky few in Romania who had surgery in Vienna 11 years ago.

The RSBHA has had 1000 books printed which are being distributed to parents, health professional and youth welfare organisations.

Adriana added: We would not have been able to publish this book without all the help of ASBAH. We would like to thank everyone involved.”

Carole Sobkowiak

Carole Sobkowiak, one of the co-authors of Your Child and Hydrocephalus, told Link: “I first met Adriana at a Flour Fortification Initiative (FFI) meeting on folic acid in Bucharest last October and was very impressed with the efforts she was making to establish a National Centre in that City.

“As she has said the book is exactly what they were looking for and it has been painstakingly translated. It will enable the Romanians to establish treatments and its guidelines will be used in conjunction with child development programmes.”

Your Child and Hydrocephalus is a practical guide for parents and is still available from ASBAH, call the Helpline 0845 450 7755 for details of how to order a copy or visit the publications area of our website at ***www.asbah.org***

Advice for school nurses

ASBAH health adviser, Gill Yaz

Our health adviser Gill Yaz recently contributed to a feature in a leading nursing magazine.

Gill's article appeared in the British Journal of School Nursing (BJSN), which is published for school nurses and other professionals involved in the health and social care of school age children.

In the article Gill talked about the importance of working to achieve bowel continence and the impact faecal incontinence can have on children's wellbeing.

During the 1990s she worked in a school for children with physical disabilities.

Several of the young people had faecal incontinence, which she was convinced could be improved.

She said: "I brought the subject up with their parents saying that it would be fantastic if we could get their child out of pads.

"But I had no idea that I was up against years of negative messages from professionals, telling parents their child would always be 'doubly incontinent'. Sometimes this began at birth, based only on the received wisdom concerning the diagnosis.

"Once the belief became entrenched, it proved virtually impossible to change the mindset of the parent."

> **I had no idea that I was up against years of negative messages from professionals telling parents their child would always be 'doubly incontinent'**

Gill believes that it is important for school nurses to be well informed on bowel management to work effectively with parents in helping implement an adequate bowel care regime as soon as possible.

"Bowel management is now, on the whole, tackled far more actively than previously, but the value in giving positive messages to parents, at all stages, regarding bowel management should not be underestimated," she added.

"Everyone working with school-aged children wants to improve their life chances, to see them enter adulthood secure, confident and ready to take their place in society. Work towards bowel continence will help to make this happen."

ASBAH's My Big B&B Book is just one of the publications we've produced, with support from Coloplast, to help children establish a good bowel and bladder routine. The Big B&B activity book is to encourage children from around 5 to 8 years old to take an active part in their continence management. The book is free for children with spina bifida (£2 post & packing charge applies). For details of this and other information contact the ASBAH helpline on 0845 450 7755 or visit the continence area at ***www.asbah.org***

Coloplast

Coloplast and ASBAH are working in partnership to campaign for an increased awareness of bladder and bowel health and to support ASBAH's members and families in their efforts to live a full and satisfying life.

An interview with Martin Beynon

Continence – the importance of an annual review

At ASBAH we always stress the importance of continence care to ensure both a good quality of life and general good health.

This issue we talked to Martin Beynon, Marketing Manager and Clinical Education Lead at Coloplast, about the issues surrounding continence assessments.

Martin said: “It’s really important for anyone with continence issues to have an annual review even though the chances are that their bowels and bladder will be fine.

“Sometimes, even though they may not be aware of any symptoms, there can be underlying problems which only a health professional will pick up.

“If the patient uses intermittent catheterisation, they may not be doing it regularly enough, which increases the risk of Urinary Tract Infections (UTIs), and can lead to serious kidney problems.

“If you go to your GP with a UTI they are likely to prescribe antibiotics which will clear up the current infection but won’t address the underlying problems.”

In its recent review of payments for continence products, the Department of Health suggests that an annual review might be an effective option to ensure that the products patients are using are the most suitable for their needs.

Most people with spina bifida will already have access to continence support through advisers in the community, continence nurses at the hospital or clinic they attend, and of course ASBAH’s own adviser service can provide vital information.

Continence care is very much better in general, but people with continence issues can still feel very isolated

In today’s NHS patients don’t have to wait to be referred by their GP to a specialist continence nurse, they can have direct access.

“Many people will have had access to continence services from an early age,” Martin explained, “and it is vital that they retain contact so their condition and function is assessed each year.”

He added that annual reviews also enable users to learn about new products which may be more suitable for their needs.

“New products are regularly being introduced on to the market and if a patient is introduced to a product which is better suited to them, or easier to use, that can have a massive impact on the quality of their life.

“We know that people get used to a product or learn to live with it, and can be reluctant to try something new, but a change can make a real difference.

“A new product could mean fewer incidents of leakage, for example, which gives people a real confidence boost and the freedom to get out and about more. It really can transform their life.

“Continence care is very much better in general, but people with continence issues can still feel very isolated.

“In society generally it’s still a taboo subject but having access to continence services means they do have someone they can talk to freely and honestly.”

Your Voice
presents

Open to all adults (aged 18 and over)

Ageing Disgracefully

Join us at this event and learn how to age disgracefully!

Date and venue:

Friday 26th March to Sunday 28th March 2010
(Closing date for applications: 26th Feburary 2010)
Jury's Inn Hotel, Eyre Street, Sheffield

Discussion, activities and speakers on:

- Housing possibilities for the future
- Health aspects of ageing
- Keeping Fit and active
- Financial issues as we progress in life
- Support at home as our needs change
- Social activities as we get older

Comments from a past event:

"Very informative and positive....."

"It was very informative and told me what I needed to know"

"The presenter was excellent...."

"Fun, easy going afternoon session, well presented"

Cost:

£95: Delegate rate includes two nights' accommodation & breakfast, lunch on Saturday and Sunday, evening meal on Friday and Saturday, optional trip to local shopping centre.

£35: Day rate (Saturday).

Looking Good Feeling Great

Date and venue:

Friday 23rd April to Sunday 25th April 2010
(Closing date for booking: Monday 15th March 2010)
Jury's Inn, Brighton, East Sussex

Sessions on:

- Positive Thinking
- Confidence Building
- Independent Living
- Relationships
- Fashion
- Body Shop/ Aromatherapy
- Exercise and Nutrition

Comments from a past event:

"Was unsure whether or not to come, but glad I did!"

A very good mix of listening and doing, well balanced"

"I loved it, it was interesting, fun, very enjoyable and relaxing"

Cost:

£110: Weekend rate: includes accommodation, workshops and meals

£35: Day rate (Saturday 31st only): includes workshops and lunch

Delegate rates are highly subsidised by Your Voice.

Book NOW

For further information on both events and to reserve your place, contact: Mark Harris
YV Development Officer, ASBAH, 42 Park Road, Peterborough PE1 2UQ
Email: markh@asbah.org **Telephone: 01733 421322**

Tony Murphy, manager of the Patient Advice and Liaison Service (PALS) for The Walton Centre NHS Foundation Trust in Liverpool.

Tony Murphy

The Walton Centre is a dedicated neuroscience hospital. Patients and relatives can get in contact directly in person, by telephone or email, to talk about concerns and issues. Tony has worked for PALS for almost seven years.

Prior to working for PALS, Tony worked for the Multiple Sclerosis Society for three years and volunteered for the Motor Neurone Disease Association for 10 years, already having had some insight and empathy for people with neurological conditions.

When asked what his day entailed, Tony told *Link*: "I am often in just after 7am. Recently, a female patient and her husband whom I had been supporting, was being discharged to a hospice at 9am and I called to see if everything was going to plan. I also offer to see folk who may not have visitors; due to the distances involved for relatives travelling to the centre, or because relatives just can't afford the cost, or get off work, or other family commitments prevent them from afternoon visiting."

PALS are able to point people to the help ASBAH offers. Tony explains: "About five years ago, after chatting to a woman with a shunt, it dawned on me that most of our patients with hydrocephalus do not carry a Shunt Alert card. I designed posters which are liberally spread throughout the Trust and over 500 people with a shunt have since asked us for an application form.

> **About five years ago, after chatting to a woman with a shunt fitted, it dawned on me that most of our patients with hydrocephalus do not carry a Shunt Alert card.**

"When people come for an application form, I often pick up on other issues of emotional or practical support etc. I help those where I can and normally sign-post them to the local ASBAH advisers in our area.

"A lot of my callers are those who've developed hydrocephalus later in life, for example, as a result of a brain tumour but obviously there are those who call in and say, 'I've had the same shunt since I was three-days-old and I'm now 36!' We also hand out ASBAH's information leaflets on shunts and hydrocephalus and work closely with ASBAH advisers."

Why not pay a visit to the Walton Centre, they are a centre of excellence for adult neurosciences. Survey feedback on their care and treatment yields very high levels of satisfaction with doctors, nurses and other staff. Tony added: "Several of our neurosurgeons, like Mr Paul May and Mr Connor Mallucci, are household names amongst people affected by hydrocephalus. At the moment we are developing a lot of written information on our web site ***www.thewaltoncentre.nhs.uk*** – check this occasionally and see what's new."

If you would like to contact Tony for further information about his services and how PALS may be able to help you, please call 0151 529 6100 or email: ***tony.murphy@thewaltoncentre.nhs.uk***

News from ASBAH around the country

Halloween fun at family day

Northern Region's

fun-filled family day was a chance for people from around the area to meet up and make new friends.

The well-organised event, held on 31 October at Wakefield's National Coalmining Museum, attracted 15 families which included 31 children.

The children were kept busy making Halloween masks and soap, face painting and playing games. They also enjoyed meeting the pit ponies and children aged five years and above were taken on trips down the mine.

Meanwhile the adults – including grandparents - had the opportunity to attend two morning discussion sessions.

One, "We've been there!" featured a panel of three adults with spina bifida and hydrocephalus and one parent of a child with spina bifida and hydrocephalus.

They gave a brief run down of their experiences and then opened the session for questions and general discussion.

The other session was led by a panel of ASBAH advisers, who answered questions and held a discussion with the group. The afternoon offered a group on 'Making time for the family and yourself".

Northern Region manager Joan Pheasant, who organised the day, said: "All of the sessions buzzed with chat and the parents actively supported each other. Many friendships were forged and contact details exchanged."

She added: "Our aim was to offer an informal day where parents and children had the chance to meet up and learn from each other.

"Everyone seemed to gain a lot from it and the feedback has been extremely positive."

London and South region

Introducing two new members of staff:

Angie Coster will be the new adviser covering Dorset, Hampshire, Isle of Wight, South Wilts, Berkshire and Oxfordshire. Angie will be working 28 hours per week, Monday to Thursday.

Angie has a social work background, including working with children with disabilities and has more recently worked as a regional care adviser for the Motor Neurone Disease Association and on the Alzheimer's Society Helpline. Angie began work with us on 7 December 2009.

Hilary Franklin will be joining us as the new North and West London adviser in the new year. Hilary has worked for the NHS as a speech and language therapist and is looking forward to working in the voluntary sector. She begins work on 12th January 2010.

Diary dates

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

Dunstable Support Group

For people with spina bifida and/or hydrocephalus and their carers.
Meets: 1–3pm, usually on the second Monday of each month.
Where: Disability Resource Centre, Poynters Road. Dunstable.
Please come whenever you can. While there is no crèche, young children are always welcome.
Contact: Valerie Bottoms on 01582 757745

Northern Region: York Drop-in 2010

Where: Low Moor Community Centre, Bray Road, Fulford, York YO10 4JG.
When: Second Wednesday each month:
13 Jan 10 Feb 10 Mar 14 Apr
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***

Your Voice is hosting an 'Ageing Disgracefully' event. Friday 26 Mar - Sunday 28 Apr 2010 at Jury's Inn in Sheffield. More information contact Mark Harris on 01733 421322 or email ***markh@asbah.org***

Your Voice is hosting a 'Looking good, feeling great' event. Friday 23 Apr - Sunday 25 Apr 2010 at Jury's Inn in Brighton. More information contact Mark Harris on 01733 421322 or email ***markh@asbah.org***

Suffolk / Norfolk Spina Bifida / Hydrocephalus Support Group

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

Where: Roydon Village Hall,
High Road, Roydon,
Nr Diss, Norfolk.
10.30am-12.30 on the following dates for 2009/2010:
7 Jan 4 March
For further details please contact ASBAH East on 01733 421309 or email ***ero@asbah.org***

Please contact the editor (Link@asbah.org) with dates of your events for the next issue of Link by Friday 26 February 2010.

Eastern Region Forum

Date: Saturday 20 March 2010
Where: ASBAH House, Peterborough
Time: 11am
Guest speaker, Jackie Bland, ASBAH Chief Executive.
Buffet lunch available and free car parking.
For further details please contact ASBAH East on 01733 421309 or email ***ero@asbah.org***

Regional contacts

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

ASBAH East
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 84490475
Fax: 020 84406168
Email: ***sero@asbah.org***

ASBAH in Wales / ASBAH yng Nghymru
Tel: 01248 352886
Email: ***wro@asbah.org***

ASBAH N. Ireland
PO Box 132
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***

Holiday lets

For classified rates, please contact the *Link* Editor.
Email: *link@asbah.org*

ISLE OF WIGHT ASBAH - HOLIDAY BUNGALOW

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

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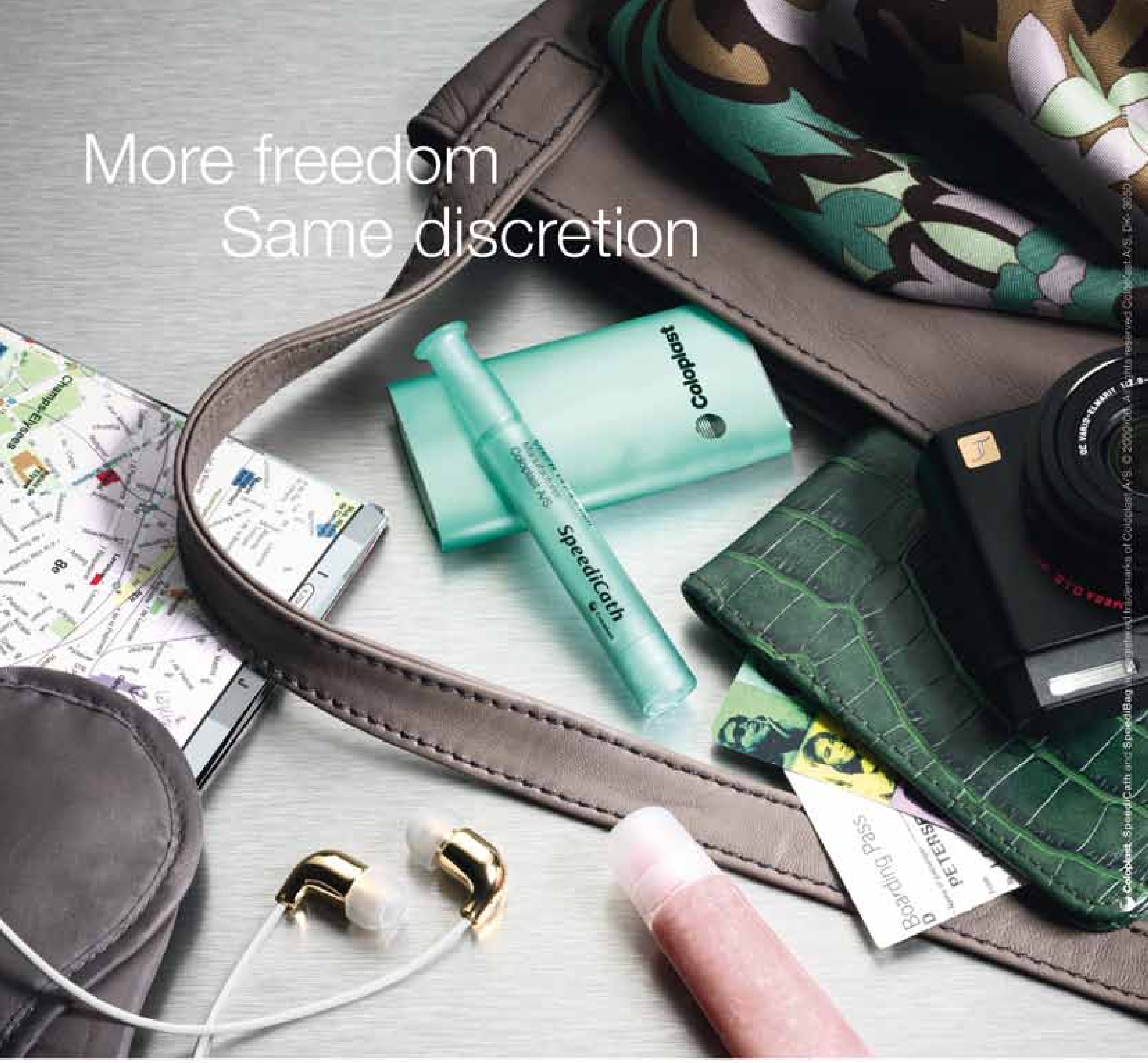
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