SPRING 2006 ISSUE 216

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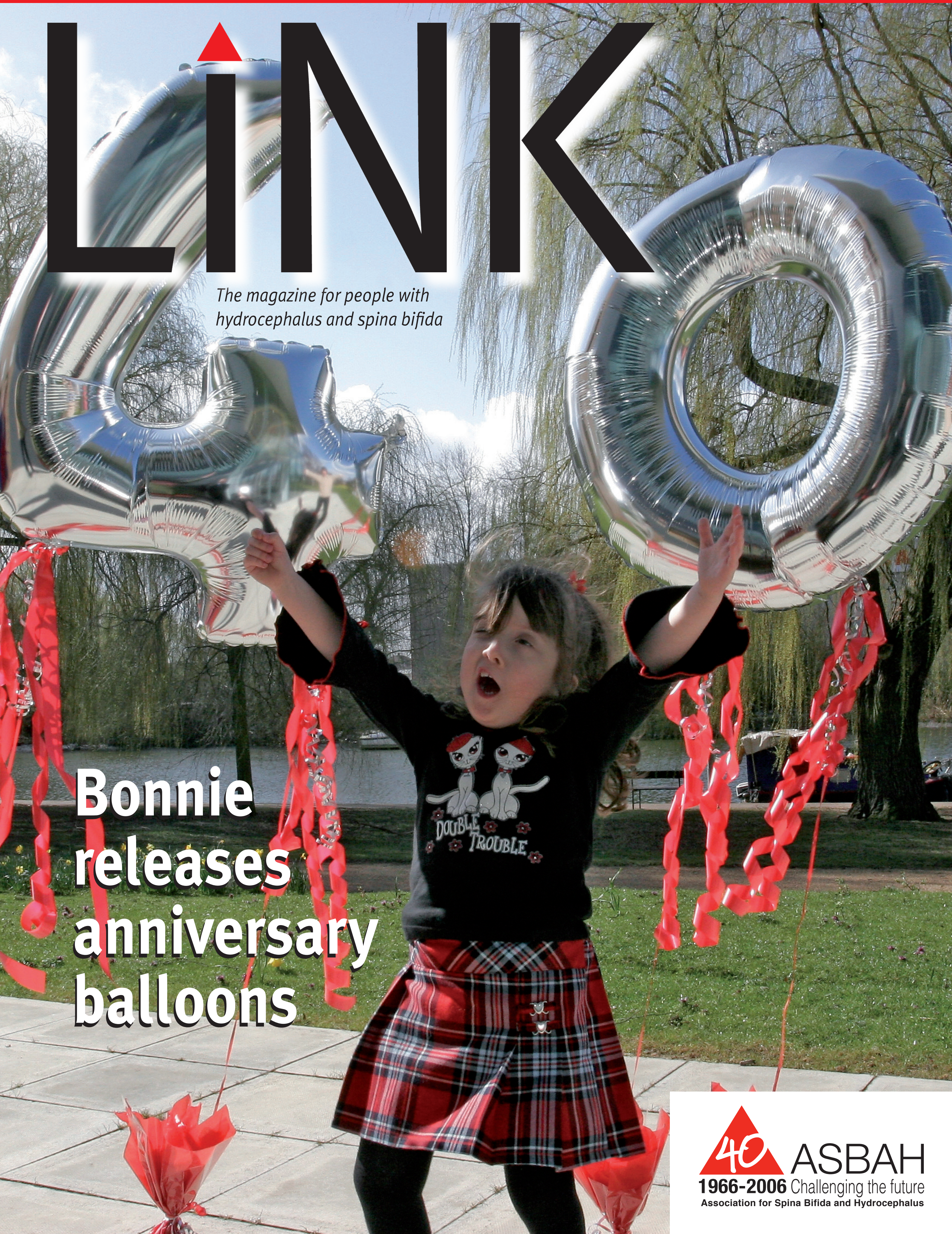
LINK

The magazine for people with hydrocephalus and spina bifida



Bonnie releases anniversary balloons

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

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Peter Farrall writes

As I write, the sun has finally come out from behind the clouds after the long, cold winter.

But the past couple of months have been such a hectic time for ASBAH that we've hardly had time to grumble about the weather.

On pages 6 & 7 you'll read about the generous grant from the Big Lottery - worth £224,000 over three years – to fund the Helpline and Information Service.

Other news items include the latest on the campaign to fortify white flour with folic acid (page 15) and a new genetic research programme (page 26)

To tie in with ASBAH's 40th anniversary celebrations we have spoken to several *Link* readers who have their 40th birthday this year (pages 16 & 17). There's also coverage of the balloon release and a message from ASBAH's Chairman, Richard Astle.

In the fundraising section we talk to two people from organisations which are long-time supporters of ASBAH, plus there's news of our runners in the London Marathon.

On page 23 Graham Webb, MBE, talks to *Link* about how he went from being a 15-year-old drop out to heading a multi million dollar hair care company, despite secret medical problems caused by spina bifida.

As you read this we'll be busy working on the summer issue. So if you have any stories or ideas you'd like us to include, please get in touch.

Best wishes,
Peter

Peter Farrall
Assistant Director
(Marketing and Communications)
peterf@asbah.org

Patron:
HRH The Duchess of Gloucester GCVO
President: Jeffrey Tate CBE

ASBAH's mission is to work with people with spina bifida and/or hydrocephalus, their families and carers to promote individual choice, control and quality of life

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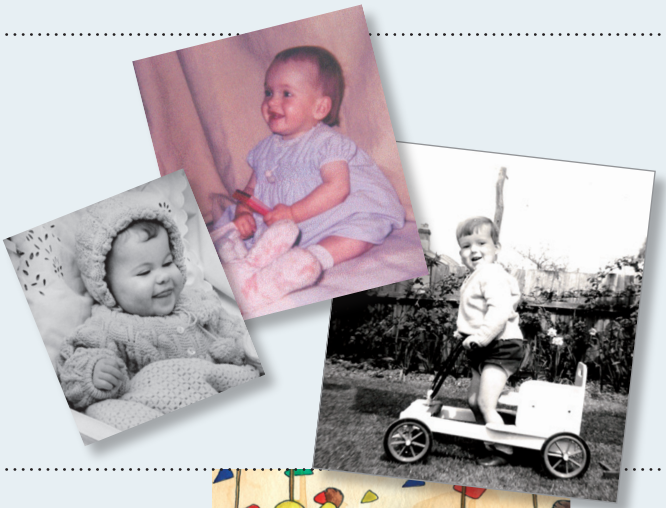


ASBAH'S FLYING HIGH

The April skies of Peterborough were filled with almost 3000 red balloons and two giant four and zero silver balloons to mark the forty years ASBAH has been in service.

With so many balloons to release, ASBAH Chairman Richard Astle asked five-year-old, Bonnie Serdecki, from Stamford, Lincolnshire, to help him free the balloons.

The spectacle is one of a number of sponsored balloon races ASBAH organises throughout the year to raise money and April's event is hoped to raise around £130,000.

Let's hope there's a strong wind to blow the balloons further than France, Germany or Poland, which have all had an ASBAH balloon land in their part of the world.

Good luck to all the organisations and businesses that have sponsored a balloon, the most well travelled balloon will earn its sponsor a case of champagne. If you or your company wishes to sponsor a balloon, the next race is the special 40th Anniversary balloon race which will be released in Peterborough on June 10th as part of ASBAH's 40th anniversary celebrations.

Contact Tom Logan, ***toml@asbah.org*** or ring 01733 555988 for further details.

From the Chairman...

I am delighted and honoured to continue as Chairman in ASBAH's 40th Anniversary year.

I know you are all familiar with ASBAH's distinguished history during which many tens of thousands of individuals and families have received a huge range of support and help from ASBAH advisors.

But I am also conscious of the difficulties that so many families have experienced over the years and it is gratifying to know that the ASBAH team has always been there for them.

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

The 40th anniversary year is not just a time for looking back, but also the perfect opportunity for us to take stock of ASBAH's position. We can look forward to the many challenges facing our service users and their families and examine how ASBAH can respond to those challenges.

ASBAH has just completed its new 5 year Strategic Plan to 2011 which reaffirms its commitment to service users. The Plan will ensure that ASBAH continues to give the advice, help and direction they and their families need to ensure they can get the most out of life.

After much discussion we also recently put together our response to the National Service Framework for Long-Term Neurological Conditions. For the first time in government policy, these conditions are identified as worthy of attention and quality services. It may only be words on paper at the moment, but it gives us a definite goal to work towards both, nationally and locally.

Almost three quarters of our affiliated local associations have now signed up to ASBAH's 'Compact' to ensure that both locally and nationally, ASBAH is able to have a bigger voice on behalf of all of our service users.

One particularly exciting piece of news in our 40th year is the £224,000 award from the Big Lottery Fund to create and run, for three years, our national Helpline and Information Service. This helpline will mean that everyone affected by spina bifida or hydrocephalus will benefit from an additional source of information and support. Local associations can play their part to ensure that details of the Helpline are there, at the point of diagnosis in their area. The Helpline will make ASBAH accessible to more people than ever before.

With our adviser network, our website and soon, our Helpline, ASBAH's service provision to individuals, families and carers; and to medical, education and other professionals has never been greater.

But a charity is only as effective as the people within it and I know that without the ongoing commitment and professionalism of the local associations, ASBAH staff and trustees, we could not achieve our aims. So I give my grateful thanks to you all.

My thanks also go to the trusts, companies and individual donors who give the huge financial support which enables ASBAH to carry out its vital work.

So ASBAH can not only enjoy celebrating this milestone anniversary year, but just as importantly, with all your help, we can all look forward to an even more successful future.

Richard Astle, ASBAH chairman

40th year messages of support

I am delighted to send my congratulations to ASBAH as your celebrate your 40th anniversary, and to wish you well in the future.

Over the last 40 years ASBAH has helped to improve the lives of many thousands of people affected by spina bifida and hydrocephalus.

Generations of individuals and families have cause to be grateful for the support and advice you have provided. These achievements do credit to all those involved.

May I pay tribute to ASBAH for your work to date. I am sure you will go from strength to strength.

David Cameron
Leader of the Opposition

I know that ASBAH does a wonderful job in helping individuals and families affected by spina bifida and hydrocephalus.

This support means so much to the families and I join with others in congratulating you on 40 years of dedicated service.

Gerald Howarth MP
Shadow Defence Minister

In the words of a very old song. ASBAH has ‘been together now for forty years and it don’t seem a day too much’. Congratulations on reaching ruby status, and from all of us who’ve been on the receiving end of ASBAH’s work, heartfelt thanks.

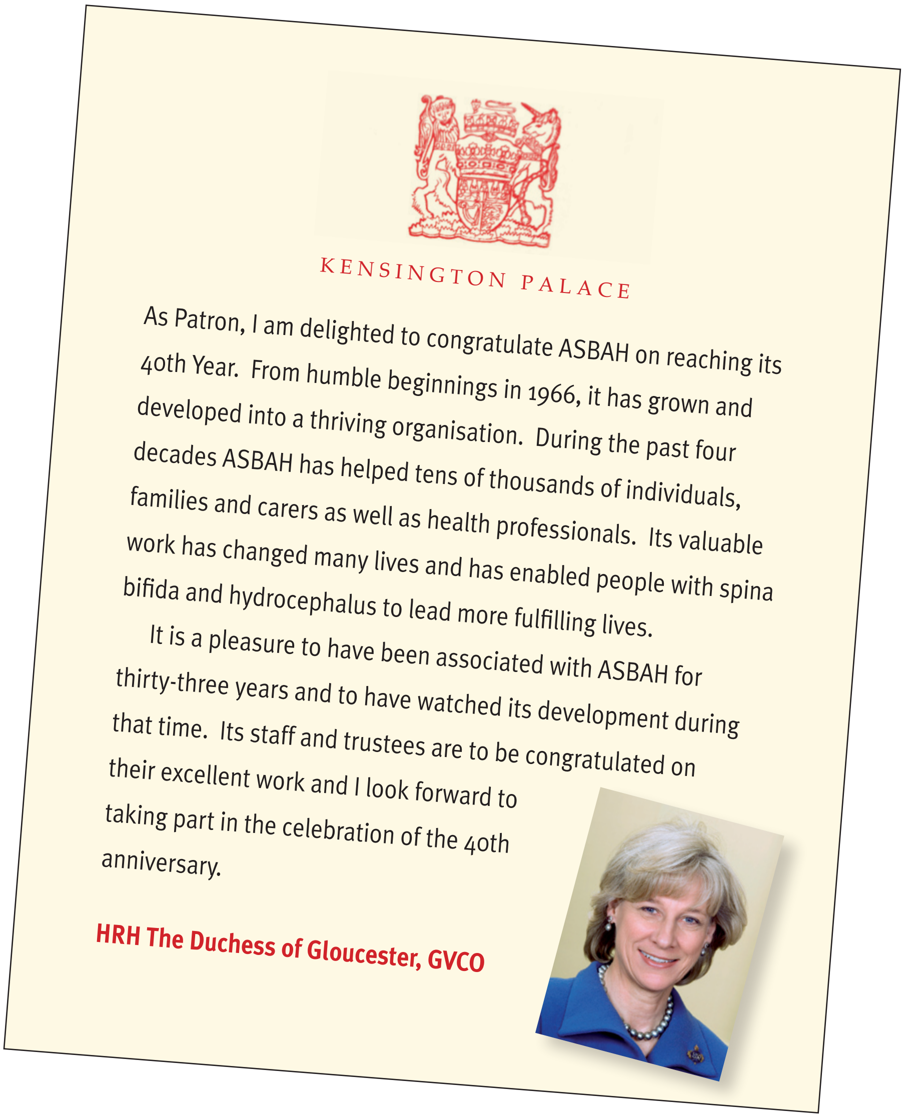
Michael Aspel

Congratulations on your 40th anniversary – 40 years of invaluable work supporting and advising not only those with spina bifida and hydrocephalus, but the whole family.

You have also raised awareness of the problems and difficulties of living with these conditions. Peer support must make a huge difference and much has been accomplished.

Here’s to the next 40 years!

Lady Darcy de Knayth



KENSINGTON PALACE

As Patron, I am delighted to congratulate ASBAH on reaching its 40th Year. From humble beginnings in 1966, it has grown and developed into a thriving organisation. During the past four decades ASBAH has helped tens of thousands of individuals, families and carers as well as health professionals. Its valuable work has changed many lives and has enabled people with spina bifida and hydrocephalus to lead more fulfilling lives.

It is a pleasure to have been associated with ASBAH for thirty-three years and to have watched its development during that time. Its staff and trustees are to be congratulated on their excellent work and I look forward to taking part in the celebration of the 40th anniversary.

HRH The Duchess of Gloucester, GVCO

I warmly congratulate ASBAH on its 40th anniversary. The experience and depth of research gained over these 40 years enables the Association to meet its long-standing commitments to providing advice and expertise to individuals, families and carers affected by spina bifida and hydrocephalus.

This support enables thousands across England, Wales and Northern Ireland to overcome difficulties presented by these two conditions and, as a result, enjoy a better quality of life.

I wish you every success for the next 40 years and beyond.

Best wishes
Paul Burstow MP

ASBAH do amazing work in providing information and advice in all aspects of health relating to spina bifida and hydrocephalus.

I found your advice valuable when I was pregnant with my daughter Carys. You were always willing to listen to the concerns I had and your advice was a great support to me at all stages of my pregnancy.

I would like to send my best wishes to everyone at ASBAH. Keep up the good work.

Best wishes
Dame Tanni Grey Thompson

Helpline ready for take off thanks to the Big Lottery

ASBAH has made a huge step towards its Helpline and Information Service Appeal target thanks to a massive grant from the Big Lottery Fund.

News of the funding – worth £224,000 over three years - was announced in March to the delight of ASBAH staff.

Now the team is working to get both the technology and staff ready for the proposed project start date of I June 2006.

The funding will now allow ASBAH to ensure that details of its services are present at every point of diagnosis of either spina bifida or hydrocephalus.

Spina Bifida
Hydrocephalus
HELPLINE
0845 450 7755
Local rate call

This could be at the point of an ante-natal scan, at the time of a premature birth or later in life when normal pressure hydrocephalus is diagnosed or a spina bifida occulta affected spine begins to cause problems.

Over the years ASBAH knows that on many occasions families say that they only learn of ASBAH and their support from a chance remark by medical staff or referral from someone else.

Now ASBAH will have the resources to reach out to everyone affected by spina bifida or hydrocephalus.

Mary Malcolm, Assistant Director (Services) told *Link*: “Everyone was obviously thrilled to hear that we’d been given funding for the Helpline and Information Service.

“There is a lot of work to be done to meet our proposed launch date, but it is a very exciting time.

“The technology and systems are already in place so the first major task will be to recruit staff and decide on a location for the office.

Mary added: “We initially plan to recruit and train two part-time staff to man the Helpline.”

The operators will be expected to deal with a huge variety of calls, providing help and support on all aspects of spina bifida and hydrocephalus - from antenatal enquiries, health and social care, education, transition to independence, through to bereavement support. Medical queries will however, be passed on to the medical advisers.

Some of their work is expected to be sign posting – using the extensive database to give callers contact details of ASBAH area advisers and local agencies or organisations who can directly help.

Mary said: “The Helpline will be a fantastic addition to the broad range of services ASBAH already offers. Whenever people pick up the phone we want to make it as easy as possible for them.

“A one-to-one conversation can do so much to allay people’s fears and put their minds at rest. Knowing that there’s someone at the end of the phone can be reassuring.”

Mary added: “We imagine that the majority of calls that come through to the Helpline will be quick queries or questions where our operators will be able to point them in the right direction for the help they need.

“But until it is up and running, we can’t make too many assumptions – it’s really a case of wait and see.”

HELPLINE LAUNCH - 1ST JUNE 2006

Supported by
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BIG LOTTERY FUND

Helpline appeal background...

The Helpline and Information Service appeal was launched on GMTV by soccer star Danny Mills in 2003.

Thanks to Danny's efforts the Appeal funds got off to a flying start.

Speaking of the Big Lottery Fund grant, Danny said:

"ASBAH's fundraising efforts won't stop - whilst the Big Lottery Fund is an enormous boost - we still need to raise over £40,000 per year to see the Helpline continue beyond the three year period of the grant."

We are delighted that Danny - as Patron of the Helpline Appeal will still continue to help us raise money to ensure that it continues into the future.

To make a donation to the Helpline Appeal visit *www.asbah.org*

"As a parent I have called ASBAH many times when I needed help, information and support. They are the only people I have found that have been able to offer specific advice. ASBAH is just brilliant!"

Sue Tucker from Huntingdon, whose three-year-old daughter, Emma, has hydrocephalus.

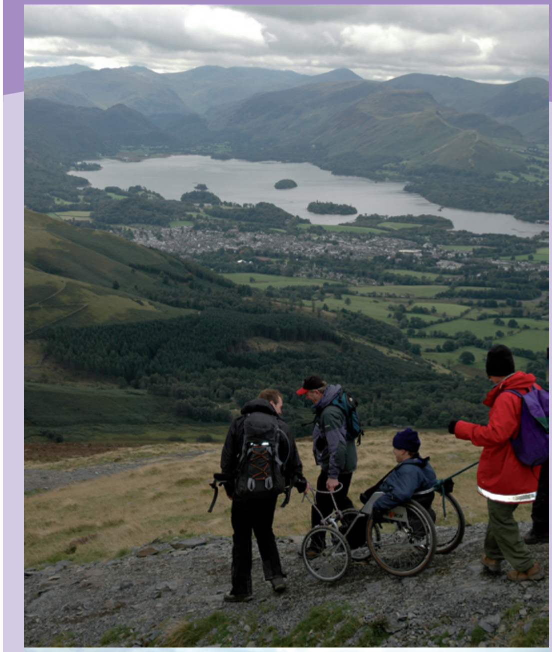
"Not only would the Helpline provide an all round information and back-up support for us but also will be an invaluable resource for Oscar's care team, friends and other family members."

Tamsin Olney from Leighton Bromswold, whose son, Oscar, aged 2, has hydrocephalus.

"The Helpline is great news for service users like me and compliments the services provided already by ASBAH. Moreover, it will offer me and my friends, family and care workers an opportunity in which to share issues about spina bifida and hydrocephalus anonymously. Being able to speak to someone direct is reassuring and offers a feeling of comfort."

Jason Merrill

HELPLINE LAUNCH - 1ST JUNE 2006



ON THE UP

Congratulations to Lee Rollings from Lincoln, who reached the summit of Skiddaw mountain, raising £1,160 for ASBAH in the process.

Lee, who has spina bifida, achieved his ambition to reach the summit of the fourth highest mountain in the Lake District with the help of a team of 12 volunteers who pulled his wheelchair up the 3054 foot ascent.

He said; "I had a great day but at times it was very scary, especially on the way down where I was leading the party and the others acted as my 'brakes'."

It took just under two hours to reach the summit and, according to Lee, the weather was good at the start but visibility reduced to less than 50 meters and the wind chill factor was considerable.

We think Lee is amazing, not just for his fundraising efforts, but for accomplishing a life long dream. Well done Lee. - Everest next year then?

Hitting a high note for ASBAH

Young Jack McLean and fellow students at Manchester's Middleton Popstars Academy are hoping to pull in the crowds at a special concert aimed at raising funds for ASBAH.

Keen singer Jack, 14, who has hydrocephalus, joined the academy five years ago and has since taken part in many workshops and performances across England and Europe.

The young singing star has already won several competitions singing pop classics including Robbie Williams and U2 covers.

Mum Liz said his involvement with the group has helped him overcome some of the difficulties caused by his hydrocephalus.

She explained: "When Jack reached school age he began to exhibit many of the common difficulties faced by youngsters with the condition.

"But being involved with Middleton Popstars has helped to raise his self-esteem, self-confidence and self-worth."

The family moved from Manchester to Llandudno, North Wales, three years ago, but are happy to make the long journey to rehearsals.

Liz, project administrator at Middleton Popstars, added: "We have received a great deal of support from ASBAH, particularly from advisers Marcia and Jill in Manchester and North Wales and from education adviser, Joanne.

"With their ongoing support Jack has been able to maintain his placement at mainstream schools. For this we will be eternally grateful."

The concert, Sounds of Soul, will raise funds for ASBAH as a thank you for their help and Liz hopes *Link* readers will be able to come along to the event on 26 May 2006 at the Middleton Civic Centre, Manchester. Tickets cost £5, (£4 concessions), family ticket £12 (two adults and two children).

For more information call project manager Anne Marshall on 0161 653 7747.

What a cracking idea! A giant egg for ASBAH

Cornish chocoholics crossed their fingers that they had bought the lucky ticket to win what is believed to be the biggest Easter egg in the UK.

Tickets for the eggstraordinary creation sold at £1 each and raised a total of £631 for ASBAH.

St Ives-based County Confectionery produced the impressive egg which is 2ft wide; 3ft tall with a waist line of 79 inches and weighs in at a massive 32kg.

It took a total of five hours to make from pouring the chocolate into the mould to adding the hand decorated flowers.

According to statistics the average British chocoholic eats 10kg of chocolate a year so this could keep them munching for sometime.

Roy Stuart, co-founder of the confectionery company, was one of the team behind the fabulous handmade egg.

He said: “Producing a chocolate egg this size wasn’t without teething problems such as packaging and moving it around. But we did it.

“We decided that this year we would like to support ASBAH as they are a fantastic charity which we are very pleased to have been able to help.”

ASBAH strikes lucky in lottery

ASBAH is set to benefit from the new online lottery which is expected to prove a strong rival to the National Lottery.

Monday is operated by Chariot lottery- which is chaired by Tim Holley, the former Camelot chief executive officer behind the National Lottery – launched in April, Monday is selling weekly lotteries on behalf of a number of charities.

Monday allows the lottery players to choose the registered charity benefiting from their lottery ticket purchases, and nearly 70 charities – including ASBAH - have signed up.

Players will have a better chance of winning prizes and Chariot will give a bigger contribution to the nominated charities than the National Lottery.

monday
THE CHARITIES LOTTERY

The range of charities, both big and small, will get 30% of every ticket sold - more than five times what they receive from National Lottery tickets. It is hoped that up to £150 million a year will be raised for these causes.

Each week five charities will benefit from ticket sales, and when purchasers buy a £1 ticket, they will nominate which of these they would like to support.

It is expected that each charity will feature five times each year.

Donna Treanor, Assistant Director (Fundraising) told *Link*:

“We’re delighted that ASBAH is to be included in the new Monday lottery.

ASBAH has signed up for the initial two years, so we will benefit from the proceeds of ten Monday Lottery draws.

“It is expected to be very popular because people who buy tickets online will know that considerably more will go direct to the nominated charities.”

A recent survey conducted by Chariot found that 8 out of 10 people would prefer National Lottery money to be donated to a UK charity of their choice.

Chariot Managing Director Craig Freeman said: “In 2003 a tiny article deep in a Sunday paper referred to our idea to launch a fairer lottery. We were not named and none of our contact details were given. Nonetheless over a thousand people tracked us down and got in touch. They wanted to know more, such was their dissatisfaction with the National Lottery.

“Two years later the company formally launched. Amongst our team are a number of the key people who launched Camelot. They saw in Chariot an opportunity to redress the balance by launching a lottery that benefits players and charities alike.

“The final concept is a fairer lottery that both effectively raises money for charities and offers players better odds and better prizes for matching fewer numbers. Jackpot winners are guaranteed every week.”

For more information about Monday, log on to ***www.playmonday.com*** *- or use the link from* ***www.asbah.org***

RUNNING

On the run

ASBAH's very own 'A' Team went on the run in April, pounding the 26-mile London Marathon course.

The team of four men, who all live in France, were voted to do their bit for ASBAH's 40th anniversary celebrations by running the gruelling 26-mile race.

The team - all in their forties – were led by Andrew Corrigan, the son-in-law of Teresa Cole, ASBAH's Assistant Director of Services until her retirement in 1999. Andrew's wife also worked for ASBAH at Five Oaks for two years during the 1980's.

Andrew said: "ASBAH and other charity work is often a topic of conversation when I'm talking to my friends in France, and three of them agreed to join me on the London Marathon run to celebrate ASBAH's 40th anniversary.

"The 'A' Team, as we've called ourselves, is made up of me, Phillipe Renault and brothers Christian and Serge Dussuyer, both of whom have run several marathons."

Andrew added: "My aim is to survive the marathon and cross the finishing line in one piece - within 4 hours if possible - as well as raising awareness of ASBAH's work in this anniversary year.

ASBAH wished the team best of luck on their marathon run.

If you would like to support the team, log on to ***www.justgiving.com/acorrigan*** to view their team page.

Just Giving brings in funds

Eight fabulous fundraisers are now listed on ASBAH's page on the popular Just Giving website.

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

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

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

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

Currently on the ASBAH pages are:

charity made easy
justgiving.com

Andrew Corrigan and his team	**- the London Marathon**
Jaynie Phillips	**- five races in 2006**
Susie Clapham	**- British 10km London Run**
Badenoch & Clark	**- Dress Down Friday**
Caroline Cashman & friends	**- 3 Peaks Challenge**
John Richardson	**- London – Brighton Bike Ride**
Megacycle	**- ASBAH's annual money-spinning event**
Helen Braid	**- in memory of daughter Alexandra, who died in December 2001, aged 18 months.**

For more information about ASBAH fundraisers, log on to www.justgiving.com/asbah/raisemoney

Runners needed

ASBAH is on the hunt for keen runners to tackle the British 10km London Run – the third largest road race in the UK.

The run, now in its sixth year, is a popular choice with charities because unlike the London Marathon, it does not charge charity runners more to take part.

The event, on Sunday 2 July, will attract hundreds of runners, including many of the world's finest athletes and celebrities.

The London Run begins on Piccadilly by Hyde Park Corner, passing Trafalgar Square onto the Victoria Embankment, where it follows the Thames to St Paul's Cathedral.

From there the route winds around the City of London before following the Thames back to the finish on Whitehall.

Ian Morley, ASBAH's events fundraiser said that each year ASBAH is forced to turn away people who ask for a place in the London Marathon.

"Competition amongst charities for places in the London Marathon is fierce," he explained.

"But this year ASBAH has places available in the British 10K London Run as well as in the Great North Run and South Run. We hope that people will come forward to run for us."

Anyone interested should contact Ian at ASBAH on: 01733 421328.

ASBAH has places available in the following:
- **British 10K London Run**
- **Great North Run**
- **Great South Run**

STAR SUPPORTERS

In the first of a new series meeting regular ASBAH supporters, *Link* talks to Flight Sergeant Jerry Hudson from RAF Wittering.

Stunning cakes, baked and iced by talented chefs at RAF Wittering, have raised hundred of pounds for ASBAH over the years.

The cakes have become a regular feature at the Royal Pigeon Racing Association annual British Homing World Show where they are raffled off to raise cash for ASBAH.

Flt Sgt Jerry Hudson from the base near Peterborough, has organised the cake creation for the last two years and is keen for the tradition to continue.

ASBAH's Donna Treanor with Peter Bryant, General Manager, of the Royal Pigeon Racing Association at The British Homing Pigeon World Show, 2006.

Jerry, who was posted to Basra at the end of February, is no stranger to charity work.

He was awarded an MBE last summer for services to the force and the community.

The father of two is a keen fundraiser, and during his three years at RAF Wittering, headed a group responsible for supporting a range of charities.

He told *Link*: "It was a great surprise and honour to be awarded the MBE. I certainly wasn't expecting it. I enjoy my charity work; it gives me the chance to give something back to the community.

"But I am really just a front man with a great team behind me. We all certainly enjoy creating the cakes for ASBAH and it is great to know that they always raise so much money. "

Ian Morley, ASBAH's events organiser, explained: "The first cake made by the staff of Wittering was for our 25th Anniversary, 15 years ago, when a member of staff introduced us to the station commander.

"After this initial cake we re-established contact again in 2004. Their kind support has continued since then and the cakes have proved extremely popular with the pigeon fanciers."

But Jerry, 44, says that he couldn't do his charity and community work without the help and support of his family – wife Angela and sons Daniel, 10 and Alex, 8.

When he returns from Basra in June, Jerry will relocate to RAF Kinloss, near Inverness, on promotion to Warrant Officer.

But he added: "The support RAF Wittering gives ASBAH doesn't end here. I intend to pass the mantle to someone else so the fundraising continues. Baking a cake once a year for ASBAH isn't any hardship to us and the money it brings in helps a great cause."

(Right) Flt Sgt Jerry Hudson

Pigeon power gives ASBAH a flying start

Gareth Picken (left) and Peter Bryant (right) meet Peckish the pigeon.

It was a chance suggestion that introduced ASBAH to its largest single sponsor, the Royal Pigeon Racing Association (RPRA).

Back in 1973, the RPRA organised it's first ever British Homing World Show. It was decided that should there be any profit then the proceeds should be donated to charity.

One of the stewards had a young grand-daughter with spina bifida, so he put ASBAH's name forward.

Now, 33 years on, the RPRA is ASBAH's largest single sponsor, and has donated more than £440,000 from profits of its annual shows.

"...the RPRA is ASBAH's largest single sponsor..."

It's a huge amount which has gone a long way in helping ASBAH carry out its valuable work, and hundreds of people have benefited over the years.

Peter Bryant, General Manager of the RPRA and show manager, is delighted that the relationship continues, and is justifiably proud of the impressive amounts his organisation raises each year.

Peter, who joined the RPRA in 1999 after leaving the RAF, knew very little about pigeons when he joined the Cheltenham-based team... but proved a fast learner.

"I think there were quite a few people who were sceptical about my appointment, they thought it should only be a pigeon man in this job" he admitted. "It was a steep learning curve for me, but I relish a challenge and I put my life and soul into the job."

As well as dealing with routine day-to-day matters to keep Britain's 37,000 pigeon fanciers racing, the RPRA team put in a huge amount of time and effort setting up each annual show, which takes months of preparation.

When the event was launched at Doncaster Racecourse in 1973, it was a small event which largely attracted pigeon fanciers from the Doncaster area and North Midlands.

As the years passed the event grew in size, attracting thousands of visitors from home and abroad, each year raising more cash for several grateful charities.

Peter explained: "The British Homing Pigeon World Show is really the Crufts of the pigeon world. It's a huge event which is held over a weekend in January. It takes almost a year to organise each show, and we attract fanciers from the USA, South Africa and most of Europe, such is the popularity of the show"

Since 1977 the show has been held at Blackpool's Winter Gardens, and the RPRA has, on average, around 2,500 pigeons on display.

"We attract between 180 to 200 trade stands and profits from their fees, along with the entrance price, usually amounts to around £100,000, which is all donated to charity.

"Unfortunately attendance was slightly down this year because of Avian Flu concerns but we were still able to present a £10,000 cheque to ASBAH."

Everyone at ASBAH is very grateful to the British Homing World Show of the Year for its unceasing support over the years and gives its thanks for every penny of the £440,000 which has been donated over the past 34 years.

Our hero

Teenage swimming sensation, Rebecca Harding who has spina bifida, was named this year's 'Star of South London' at the 'Our Heroes Awards 2005'.

The sporty thirteen-year-old, from Brockley in London, was nominated for the award by her swimming club after bagging numerous swimming and athletic achievements as well was earning a potential place in the Great Britain squad for the 2012 Paralympics.

Rebecca's efforts come after recovering from a major operation and amazing her family and friends by being back in the water after just one month. Perhaps it was the thought of winning a Paralympic gold medal that spurred her on but one thing's for sure, she's certainly a star in our eyes too.


Anita Dobson presents Rebecca with her 'Star of South London' award

TRIBUTE:
Robert Pollard

Robert Pollard, 23, from Mount Hawke in Cornwall, died peacefully in his sleep in March.

Regular *Link* readers may remember Robert from *Link 208* when he was featured after winning a prestigious photography competition for the Sunday Telegraph. Robert also contributed to *Link 202*, where he wrote about a luxurious cruise holiday he had been on with his parents.

His adviser Lyn Young said of Rob, "He was great fun and very lively, the double of his dad. He was a larger than life character and made the most of everything. He will be greatly missed by all who knew him."

Mobility Roadshow

If the article on the Flying for the Disabled (*Link 215*) whetted your appetite, you can learn more about flying scholarships at the Mobility Roadshow, Kemble Airfield, near Swindon on 8 - 10 June.

Flying Scholarships for the Disabled will be on Stand B15 where disabled people can apply for a flying scholarship for 2007. Buy a raffle ticket and you could also win a fabulous prize

The Mobility Roadshow is the world's largest outdoor mobility event – it's the motor show for disabled people – and admission is free.

It aims to give anyone with a mobility problem - drivers, passengers, adults or children - the chance to see what is available to help solve that problem and try out and evaluate the options in a "no pressure" environment.

For more information about the roadshow check out the website at ***www.mobilityroadshow.co.uk*** *or call 0870 770 3222.*

Learn more about flying scholarships for the disabled at ***www.toreachforthesky.org.uk***

HOSPITAL ART ATTACK

Having your art work displayed in public is an honour for any artist, especially if you've only been painting for six months, but that's exactly what's happened to Elizabeth Battye from Milton Keynes.

Elizabeth, who has hydrocephalus and spina bifida, attends a weekly art class in Neath Hill. When the class was asked to take part in the 'Freedom' exhibition at Milton Keynes hospital to brighten up the walls, Elizabeth got busy painting and created three pieces of abstract art, all of which are now on display.

According to Elizabeth's mother, Margaret, attending the art course and seeing her own work exhibited has given Elizabeth a real boost in confidence and was thrilled to see her paintings on the hospital walls.

Where are you now?

Your Voice, ASBAH's disabled adult user forum, is on the hunt for any adults who have been involved with ASBAH during its 40 years.

You may have been connected to the national organisation or been a member of your local association, or attended the LIFT activities. Alternatively you may have received support from ASBAH staff.

Whatever your story, we would love to hear it. How has life been for you? How have services and facilities changed throughout your life?

You could also let us know if there is anyone you have lost touch with that you would like to make contact with again.

We would particularly like to know if you would be interested in attending a reunion event.

We can't promise anything, but you never know what could happen if you mention someone who might also be reading *Link* and reads your story.

Please send your stories to Barbara Robinson, Your Voice Co-ordinator at **barbarar@asbah.org** Tel 01733 555988 or write to her at ASBAH, ASBAH House, 42 Park Road, Peterborough PE1 2UQ. A selection of the best stories received will be published in a future edition of *Link*.

We realise that people reading *Link* may have lost loved ones or friends over the years.

If this is the case, please accept our sympathy, but if you feel able to, you could offer them a great tribute by telling us their story.

> **Whatever your story, we would love to hear it. How has life been for you?**

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To book your place, please contact:

Barbara Robinson
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Telephone: 01733 555988

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

Fortification campaign moves a step closer to victory

A simple scheme that could prevent more than 300 cases of spina bifida a year is finally being considered by the Government.

The Food Standards Agency (FSA) has sanctioned a 12-week consultation exercise alongside extensive consumer research to ask the public whether they would back the addition of folic acid to white flour.

But campaigners – including ASBAH – are disappointed that the FSA still has failed to recommend the mandatory fortification of flour.

The addition of folic acid to flour is compulsory in several countries including the United States, where the incidence of neural tube impairments in babies has fallen by one third.

Chief Executive, Andrew Russell has long stressed the importance of adding the ingredient to some types of flour most commonly found in bread and other foods.

In a letter to The Times, Andrew said: "Sadly the Food Standards Agency (FSA) has not yet recommended the mandatory fortification of flour with folic acid as a public health measure to prevent spina bifida.

"At its Board meeting on 6 April, it decided to carry out a public consultation without favouring the scientifically recommended option to fortify flour with folic acid.

"Two government scientific committees have considered this issue in detail. One reported in 2000, and the other produced a preliminary report earlier this year.

"Both recommended fortification and considered that this was an effective and safe method of preventing spina bifida. "

He added: "It is hard to understand the FSA Board's hesitation on this issue. Surely it should be a champion of effective public health action and proper nutrition, not a barometer of public sentiment reflecting the minority who feel that such sound public health practice infringes personal liberty.

> **"I can scarcely think of something so simple, inexpensive, effective and safe that could improve the health of children that is not used."**

"We continue to urge the FSA Board to look at the science, consider the public interest and show leadership.

Britain's Food Standards Agency rejected expert advice to fortify flour three years ago amid fears it could delay diagnosis for people with Vitamin B12 deficiency.

That argument was discussed by Prof Nicholas Wald, Director of the Wolfson Institute for Preventative Medicine, in a recent ITN interview.

He said: "I can scarcely think of something so simple, inexpensive, effective and safe that could improve the health of children that is not used.

"It's so important to take folic acid before pregnancy. Once the woman finds out she is pregnant it's too late for the vitamin to have a preventative effect."

His backing was echoed by the influential Scientific Advisory Committee on Nutrition which also recommended that the benefits were clear and that there were no significant risks.

Even if flour is fortified, for women planning to become pregnant, it will still be important to take a daily tablet giving an additional supplement of folic acid.

Women who have a close relative with spina bifida or who have previously had a pregnancy affected by spina bifida, should consult their doctor to get the correct level of supplement.

In the last issue of Link we asked readers who will celebrate their 40th birthday in 2006 – ASBAH's 40th Anniversary year – to get in touch. A big thank you to those of you who did write in and we'd still love to hear from anyone else who is celebrating the landmark birthday this year.

Happy 40th Bir

Carolyn McCarthy

I was born on a wet January in the local hospital in Stamford, the town I live in 40 years later!

Within 24 hours of birth I was transferred to Addenbrooke's for surgery to close up my spine and a fortnight later I was one of the youngest person until then to have a valve fitted for possible hydrocephalus. Touch wood, I have never had any problems relating to this.

Over the years I have seen specialists in Sheffield, London and Liverpool, as well as locally.

There were various operations done in Sheffield on my legs and ankles to get me into callipers, but these weren't successful. I eventually decided to stay in the wheelchair.

I was fairly stubborn as a child and rarely allowed my sb/h to get in the way of anything I wanted to do. My parents and two older brothers were always there if I came up against something which was difficult. But I found over the years that you get round most things one way or another.

I went to an ordinary infants school where the children didn't treat me any differently.

I went to an ordinary infant's school where the children didn't treat me any differently, and then on to Lonsdale College in Stevenage, Hereward College and then a local college to study child care.

I now live in a flat near my parents, who look after my elderly and very cranky cat. I am a voluntary worker at a day centre for elderly, housebound people, and do secretarial work for them as well.

I am now single after losing my fiancée to Multiple Sclerosis in 2005. I don't have any children after deciding at an early age that it wasn't something that I wanted.

I think attitudes towards disability are improving, albeit slowly, and even adults who I always found rather wary when they saw the wheelchair, were fine once they started to relax and get to know me.

Dave Blake

The past couple of years have been a time of reflection for Dave Blake, who hits the Big 40 later this month.

Dave, from Southampton, left full-time employment 6 months ago after suffering from stress and depression, which he believes may have been caused by, amongst other things, his time at mainstream schools.

Dave, who has spina bifida and hydrocephalus, said: "It was always assumed that I would attend a mainstream school and while it seemed OK at the time, looking back I often wonder if I wouldn't have been better off at a special school.

"It wasn't that I was bullied, or singled out at all, I just felt that I was at a disadvantage. I always had to work twice as hard as anyone else, and I was very slow at writing – I still am. Also, although I walk with the aid of sticks, I was excluded from certain activities, such as sport.

"My disabilities were always played down and I lived the life of an able-bodied child.

"I hated school, without really knowing why and left as soon as I could at the age of 16, with 5 'O' Levels.

"Looking back I wonder if, had I continued my education, would I have improved my employment prospects?

"I do feel that my disability has prevented me from fulfilling my potential

rthday

and although I would like to study to become a web designer, my partner and I have a mortgage and other financial commitments, so it would be very difficult to leave work to go back to college.

Dave has worked as a telephonist for most of his working life, with Hampshire Police for 15 years, and for the last 15 months, for NHS Direct.

"I only work part-time at the moment, "he added, "my health has to come first. As I've got older my priorities have changed and I have had to accept my limitations."

Linda Corbett

If you were 40 in Denmark, you would be having a "round birthday". As far as I can gather, this also applies to 50, 60, 70 etc and is just a nice way of saying you have reached a bit of a milestone.

Being 40 crept up on me really, and whilst I didn't suddenly start to feel old the minute I hit the milestone birthday, I have to admit that those anti-ageing beauty products look better value for money than they used to!

Even worse, I have started talking about the "good old days" as though being 20 was heaps better than being 40, and I get all nostalgic when people start reminiscing about things like children's classic tv programmes (and I still have my pink knitted Clanger somewhere!) but was life really that much better?

When I was a teenager, hospital stays were measured in months not weeks, and even so, my 4 months in Rivelin Valley was considered fairly feeble when compared to many of the other inmates.

Fairly feeble also summed up my success in finding a job; my first paid employment was just a series of extended temporary contracts, as the company did not want to give me permanent staff benefits.

...and I still have my pink knitted Clanger somewhere!

For the first 10 years of my working life, I had employment contracts which severely reduced certain benefits such as life assurance, just because the word "disabled" appeared on the job application form, even though they had little or no evidence to suggest that I might use any of these benefits.

The problem was (and often still is) that employers, like a lot of the general public, have stereotyped ideas about disabled people and they therefore used to ask stereotypical questions. For example "what would you do if there was a fire?" (leave the building perhaps?) or the old favourite, "how would you get something from the top shelf of a cupboard?" - to which the theoretical answer was always ask a colleague; in practice I usually balanced on the wobbly step stool or mountaineered up the front of the cupboard if no-one was looking.

Does the Disability Discrimination Act have the teeth it needs to give everyone the same rights? Well it certainly put a stop to the silly questions about whether I was a mobile fire hazard.

As regards to benefits, next week I start a new job and I have not even been asked to go for a medical, and I will have full BUPA cover, a good pension and my own parking space (although my rights don't extend to the blue badge spaces in supermarkets which still get taken by people who labour under the misconception that selfishness is a disability).

Who knows, maybe by the time I arrive at my next round birthday, things will have improved. However I also have a sneaking suspicion that the fight against the seven signs of ageing may have got more expensive!

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Tell your story

At ASBAH we're always looking for people to tell their story to help us in our work promoting awareness of spina bifida and hydrocephalus.

Your experiences of these conditions can be put together as case studies which we can use in a variety of ways.

They can be put out to the media when we're looking to publicise new initiatives or could be used on leaflets or in *Link* as real life experiences to back up medical articles.

If you are willing, we may also ask you to speak to a journalist on certain issues you feel strongly about.

We do have a number of people who are willing to help, but as always, we're looking for more volunteers.

You could write your story and send it in. Or you may find it easier to speak to one of our *Link* reporters on the telephone. Of course you will see the finished article and have chance to change anything you aren't happy with.

We always respect your right to privacy and will always check with you before passing your information on to a journalist... and we'll never put any pressure on you to do an interview. You and you family will always come first.

If you can help, please contact Peter Farrall on 01733 555988 or email him at ***peterf@asbah.org*** or write to him at the ASBAH address shown on page 3.

Sam hits the headlines

Perfect in our eyes

When routine tests revealed there was a problem with her unborn baby, one mum knew that termination would never be an option

Sam Copeland, 37, from Crewe, Cheshire, was shocked to learn her unborn child had the neural tube defect spina bifida. But she and husband Mark, 37, were both determined to go ahead with the pregnancy. They're now the proud parents of baby Elisabeth, 1.

Sam Copeland is the perfect example of how ASBAH have been able to use her story to raise the profile of spina bifida and hydrocephalus.

Sam, whose third child, Beth, was born with spina bifida and hydrocephalus last February, told her story to ASBAH for inclusion in *Link*.

Several months later Prima Baby magazine approached ASBAH asking if we could put them in contact with a family who had a baby with spina bifida.

Sam was asked to see if she would be interested in talking to Prima Baby. She was, and the family, from Crewe in Cheshire, were interviewed for the 'Perfect In Our Eyes' feature in the March issue of the magazine.

Sam said: "We were thrilled with the coverage. I was a little apprehensive about what the article would say, but it was accurate and was written in a very positive way."

Alongside the interview Prima Baby ran a column giving more information about spina bifida and also ASBAH's contact details.

The coverage ASBAH received from this article is invaluable and of course mother-to-be and new mothers of babies with spina bifida and/or hydrocephalus reading the Prima Baby article now know where to turn to for practical help. So everyone's a winner.

Elisabeth…one year on

We know time flies, but it hardly seems possible that baby Elisabeth Copeland is one year old.

Elizabeth, who was born on 16 February 2005, is the long-awaited baby of Sam and Mark Copeland, from Crewe in Cheshire.

Link readers may remember the feature we ran in 2004 where Sam talked about her feelings after discovering at a routine 16-week scan, that the baby she was carrying had spina bifida.

Ignoring medical advice, Sam and Mark decided to continue with the pregnancy, and were thrilled when Elisabeth - known as Beth at home - was safely delivered.

It's been a tough year, and the family, which includes Laura, 17, and David, 14, couldn't imagine life without their gorgeous girl.

Sam said: "Beth is such a smiley, happy baby, and she has already brought us so much joy. She is one of those babies that everyone seems to fall in love with. She's been through so much already, but she is very tough and takes everything in her stride."

It's been a tiring 12 months for Sam and Mark too. "Beth had so many operations early on that we were just running on adrenalin," Sam said. "When things finally settled down we had time to really think about things and it did take us some time to come to terms with the fact that we have a disabled child.

"Beth may be my third child, but I often feel like a complete novice. It's been a steep learning curve for me but we have had some great support from family, friends and ASBAH."

Shunts are, in fact, difficult to break or dislodge and most sports – with few exceptions – should be encouraged.

Enjoying sport

By Rosemary Batchelor, ASBAH medical adviser

Many parents and teachers worry that, if a child with hydrocephalus joins in with the games and sports that their friends enjoy, damage to the shunt is likely to follow.

Rosemary Batchelor

Children can run and jump, trampoline, do forward rolls and use the apparatus in the gym. However, they may need help with balancing and should not hang upside down (eg, from wall bars) for any length of time.

Those with lumbar peritoneal (LP) shunts should avoid twisting actions as in aerobics and some dance.

They can play all non-contact sports like rounders, track events and cross-country running.

If the child with hydrocephalus has short-term memory problems, they may need frequent reminders of the rules and will need encouraging to wait their turn.

Again, be aware that sports where the player twists at the waist, such as golf, for example, will be unsuitable if they have an LP shunt.

Care should be taken by children with ventriculo peritoneal (VP) or ventriculo atrial (VA) shunts when drawing back the bow string in archery ~ hold the bow on the opposite side of the neck to shunt catheter.

Common sense should prevail when looking at contact sports. On the football field or netball court, special care should be taken if a child with a VP shunt is hit hard in the abdomen by a ball. Although damage to the distal (lower) catheter is highly unlikely, it must be considered if pain persists or signs of shunt malfunction develop.

Activities where the players are grabbed round the neck must be avoided, judo or using the tackling bags in rugby training, for example.

Swimming is excellent exercise; people with shunts can scuba dive but deep sea diving is not advisable and there are sailing and water sports clubs with special facilities for disabled people.

Whatever sport your child decides they would like to do, they should follow the general safety advice for that sport.

So helmets must be worn for any where injury to the head may occur such as horse riding, cycling, climbing, and canoeing.

If "off the peg" helmets do not fit, there are manufacturers who make special order and large helmets. Contact information@asbah.org or phone the Information department at 01733 555988 for help.

Children with hydrocephalus, like all children, should be encouraged to try a variety of games and sports. They will never know that they can play if they aren't allowed to try ~ within sensible limits, of course!

Most things are possible with imagination and care. If in doubt, ask ASBAH or your neurosurgeon for advice.

There will always be those with unrealistic ambitions who will need gently steering towards a sport more suited to his age and capabilities. A 10 year old will not be a Formula 1 driver but may have a talent for go-cart racing!

Most things are possible with imagination and care. If in doubt, ask ASBAH or your neurosurgeon for advice.

Benny's Team Wins

Benny Bear's loyal gang of followers will be pleased to hear that a new book will soon be available.

'Benny's Team Wins' is the fifth story in the series about the cuddly bear with hydrocephalus.

The latest tale, sponsored by shunt manufacturer, Codman, sees Benny off to a weekend sports camp with his classmates, and despite looking forward to the adventure, Benny has a few last minutes nerves about whether having a shunt will prevent him from taking part in some of the activities.

Helen Fernandes

After hearing some sensible advice from Nurse Diane at the hospital, "no judo or rugby scrums", he sets off for his weekend away.

Of course he has a thrilling time, and after being made captain of the Red team, leads his group on assault courses, skateboarding sessions and cross country, among other activities.

Helen Fernandes, Paediatric Neurosurgeon at Addenbrooke's Hospital, Cambridge, has written the foreword.

She said: "This latest Benny Bear book sees Benny enjoying himself at camp, happily joining in all the sporting activities with his classmates.

"I hope that this will allay natural anxiety in parents and allow their children to be adventurous, normal boisterous play will not damage a shunt.

"Children with hydrocephalus (whether treated by shunt or ETV) can safely take part in most sports that their friends enjoy and their parents should be supporting them.

"Look how successful Benny is. There is no reason why many children with hydrocephalus can't be as well."

'Benny's New Shunt' will first be available as a series of downloadable pdf's from ASBAH's website – ***www.asbah.org*** from mid May.

Benny Bear in Japanese *- Sonoe Tsukumo pictured above is the secretary of the Japan Spina Bifida and Hydrocephalus Research Foundation. Together with the president of the foundation, Satoru Matsumoto M.D., Sonoe translated 'Benny Gets Better' into Japanese.*

Graham Webb MBE

Graham Webb MBE, went from being a 15-year-old drop out to heading a multi million dollar hair care company, battling medical problems he kept secret.

It wasn't until Graham was 33 that spina bifida occulta (tethered cord syndrome) was finally diagnosed and he finally had some answers about the condition he'd struggled with.

Graham, who lives with wife Mandy and their four children in Kent, is a keen supporter of ASBAH's work.

Here Graham, 59, talks to *Link* about his life and why he was prompted to write his autobiography.

"I didn't come from fashionable beginnings. I grew up in South London, which was only a few miles from the heart of London, but light years away from it in style and attitude.

> **"When I was 15 my school teachers pronounced me "bone idle" and were more than happy to see me leave."**

My mother told everybody that I was the healthiest baby around. But the truth was that I had an undiagnosed case of spina bifida and which made my childhood a kind of torture.

At school I was the boy with "funny feet" who had lots of embarrassing accidents. My feet fell outwards and my toes were clawed.

I was incontinent, and it was a kind of shame I carried inside myself, hiding it from my parents as much as possible.

School was an ordeal. Even today one of my vivid memories of childhood is the dread I felt when school uniforms went from winter's black shorts to the white shorts of spring.

With white shorts it was harder to ignore the constant dribbles and I became adept at pretending that I hadn't noticed that my shirt tail was hanging out. I learned to carry my satchel in a camouflaging position.

I lived with a kind of shame I kept from everyone. The easiest way for me to deal with it was to keep it a secret.

"When I was 15 my school teachers pronounced me "bone idle" and were more than happy to see me leave.

After school I sent out 62 job application letters for sales jobs and received 62 rejections. The only person who would take me on was a barber who was looking for an apprentice.

I opened my first hairdressing salon in my early twenties but even though my career was taking off, my condition deteriorated.

By my early thirties I owned a string of salons – and it was only then that someone took my problems seriously. I was playing squash with a GP and he noticed that I had to keep stopping to visit the toilet. After the match he said, very nicely, "Do you need to see me professionally?"

He referred me to an urologist at Kings College Hospital, who referred me to a neurologist. I was put through a series of horrific tests before finally being diagnosed with spina bifida occulta. I had the textbook case – a little dimple on my lower back where the neural tube had failed to close properly.

That same year, 1980, I had neurosurgery, but unfortunately it didn't end my incontinence. Eventually I discovered ASBAH, who gave me some invaluable advice.

Finally, in 1997, eight years after I had launched the Graham Webb hair product line, I found a surgeon who offered to reshape my bladder neck. After the operation I was taught to self-catheterise. It revolutionised my life.

Two years later I had surgery on my feet in America, and after several months "off my feet" and lots of physiotherapy I was at last able to walk more normally.

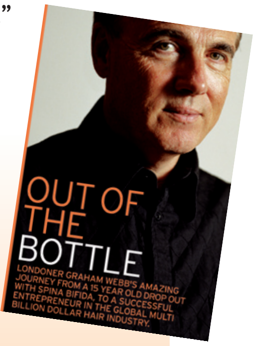
I will be eternally grateful to several surgeons, including Mr Julian Shah, urologist, who changed my life.

I sold my hair product range to Wella in 2002 – we were number 4 in America at that time – and I am now their Goodwill Ambassador doing meets and greets and book signings. I am also a corporate speaker for all kinds of organisations and companies around the world.

I wrote my autobiography, *Out Of The Bottle*, because part of me wanted to look back over my shoulder and assess the stumbles and leaps I've made in my life.

I hoped my story will help people, not just those with spina bifida, but would-be entrepreneurs too.

The reaction to my book has stunned me. I never for one moment imagined that I would now be on my fourth edition. The book seems to be empowering so many people – not only those with spina bifida – but those facing other challenges. It's also inspiring would-be entrepreneurs too."



Graham Webb's autobiography, Out Of The Bottle, costs £17.99 and is available from his website, ***www.grahamwebb.co.uk****; all the profits go to charity.*

Graham Webb will be a speaker at the opening session at the ***International Federation for Spina Bifida and Hydrocephalus 17th International Conference in Helsinki from June 29 – July 2, 2006.***

The theme of the conference is "Access" and the subject will be discussed from different perspectives – physical, attitudinal and medical and from different stages in people's lives.

A variety of doctors will give lectures on the services they provide for people with Spina Bifida and/or Hydrocephalus. Adults and young people with Spina Bifida and/or Hydrocephalus and their families from different countries will also outline their experiences and ideas.

For more information about the International Conference, check out the website ***www.congrex.fi/sbh2006/***

In the next issue of LINK: Kathryn Baldock explains how botox cured her incontinence

Linda's line

Whilst tracing his family tree, Andrew discovered that his relations have not moved very far over the last 200 years - 10 miles eastward to be precise. At that rate, the Corbett's will have reached Essex by the end of the next century!

Nowadays we want to go further than the next village or town and if you are heading into London, that generally means taking the train and as you probably already know, the old slogan "let the train take the strain" is a complete load of twaddle for anyone with a mobility problem.

For a start, before you can even get on the train, you have to navigate your way round the self-service ticket machine. Last time I went up to London with Andrew for a hospital appointment, we ended up with the wrong ticket because I lost my balance and accidentally jabbed the super-sensitive screen with my finger. (As the ticket was cheaper, I didn't bother to complain!)

Assuming you can get onto the platform, there is then the scramble to get onto the train itself. In several London stations, they don't even announce which platform your train is leaving from until a few minutes before departure, resulting in the human equivalent of a stampede across the Serengeti during rush hour. You will not be surprised to learn that I invariably end up last in this race and am therefore forced to play "hunt the seat" once I am on board.

This is always a game of two halves, played between the smart suited businessmen who have already commandeered a seat (and promptly hide behind very large newspapers), and the well intentioned but equally seat-less passengers who are determined to make sure you get a seat whatever the cost to your dignity. It is quite within the rules to give pointed stares at the people hogging the seats directly under the "please give up this seat if someone needs it" notice, but I have to say it doesn't often work.

Sometimes you can engage your fellow passengers in a sympathy vote, but that one works better when you have someone with you - my good friend Richard has been known to say in a very loud voice "shame no-one wants to give up their seat isn't it?" which usually shifts all but the stubborn. As a solo traveller, an entertaining alternative is to trample on as many feet as possible each time the train lurches forward out of the station. (Don't say sorry - it ruins the effect).

And finally, get your own back on the seat hoggers when you get off the train. Take a ludicrously long time getting off and try and block as much of the exit as possible for as long as you can. If anyone barges past, just shout "this wouldn't happen if I'd got a seat!"

LINK

the lifestyle magazine for people with hydrocephalus and spina bifida

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Charities respond to welfare proposals

There has been a cautious response from charities and disability rights organisations to the government's plans to get one million incapacity benefit claimants back into work.

The Welfare Reform Green Paper, "A new deal for welfare: Empowering people to work" was unveiled by Work and Pensions Secretary John Hutton. It is aimed at moving the country closer to Labour's ambition of an 80% employment rate, and could save £7 billion a year.

The proposals are aimed at reducing the number of new claimants, providing more help to those receiving Incapacity Benefit to return to work, and giving greater support to the most severely sick and disabled.

But organisations representing disabled and older people say reforms of incapacity benefit need to be properly funded.

They also believe that employers must make suitable work available and lose their preconceptions about giving jobs to older and disabled people.

The proposals include giving individual counselling, training and advice to sick and disabled people to help them back to work.

It will be compulsory for claimants assessed as able to work to take part in these schemes. Those who refuse to take part could lose as much as £10.93 a week in payments, rising to £21.86 for a second refusal.

Claimants who refuse to take part in back-to-work schemes risk losing part of their benefits.

An estimated 2.7m people currently claim incapacity benefit, resulting in an annual bill of £12.5bn. From 2008 it will be renamed the Employment and Support Allowance.

The Disability Rights Commission (DRC) has described the reforms as a "step in the right direction". But Chairman Bert Massie says he wants to see more detail in order to be sure that the proposals really will improve opportunities for disabled people.

A spokesman for Scope said: "The government appears to have ignored the fact that, despite the Disability Discrimination Act, there's still widespread discrimination against disabled people in the job market."

What they think

A number of disabled rights organisations and charities – ASBAH included - have been consulted by the Government on the proposed welfare reforms.

An ASBAH committee, headed by Mary Malcolm, Assistant Director (Services) is now studying the Green Paper before making its recommendations.

The committee is made up of a range of people, including two area advisers and members of Your Voice, ASBAH's adult user forum.

Here two people from the committee talk about their concerns.

Mary Malcolm, ASBAH Assistant Director (Services)

"In theory I think the reforms could be a good thing, but only if they are properly handled. Every individual is different so the resources need to be in place to examine each case on its own merits.

"Many disabled people are unable to find a job to suit them. Those who are employed tend to work in public services departments. Often employers do not give disabled people a fair chance, and of course access can be a problem too.

"I think it is great that disabled people are being encouraged to work, because employment can boost self-esteem and feelings of self-worth. But it has to be the right job.

"I am concerned that advisors in job centres will be properly trained to help the disabled find work that is suitable for them. People with hydrocephalus only, for example, could find it difficult to do certain work, depending on the way they are affected by the condition, but if they are given the support and their condition is understood they are extremely capable of holding down responsible jobs.

"The welfare reform suggested by the Green Paper can only work if the government deals with issues such as these.

Angela Lansley, area adviser for the Merseyside & Lancashire region.

"I believe that any attempts to increase the number of disabled people engaging with work will have to make it really worthwhile financially to leave the safety of benefits.

"At present, many of our service users, other than those in professional jobs, are working for little more than if they stayed at home. Reform of housing and council tax benefit, with a significant increase in the amount of disregarded income, could be crucial here.

"Disabled workers have to know that the system – including the new ESA, housing benefit and tax credits - can respond quickly and efficiently to changes of circumstance as they move in and out of work. This is not the case at present.

"Pressure on employers to comply with the requirements of the DDA, quick and easy access to workplace support, flexibility in working arrangements are all vital.

"I have particular concerns about support for some of our service users who have hydrocephalus and mild - moderate cognitive or learning difficulties. They may pass the Personal Capability Assessment test but find it difficult to cope with the demands of the modern, target-driven workplace."

Air your views

The government's Green Paper, "A new deal for welfare: Empowering people to work", can be downloaded from the Internet, at ***www.dwp.gov.uk/aboutus/welfarereform***

If you would like to have your say, email ***welfarereform@dwp.gfi.gov.uk***

Understanding genetics - can you help?

A new website is being created to help nurses, and other healthcare professionals learn about genetics and help them understand the effect genetic conditions have on people's lives.

The project called *'Telling Stories: understanding real-life genetics'* will collect around eighty stories from individuals, families and health professionals who are affected with different genetic conditions, or have a particular story to tell about their experience in caring for people with a genetic condition.

The stories will be collected as video clips, sound recordings and written accounts of people's experiences.

Running the project is a team from the University of Glamorgan, University of Plymouth, the Wales Gene Park and the Genetic Interest Group.

Project leader, Professor Maggie Kirk said: "This website will help the nursing professions to understand more about how living with a genetic condition can affect a person and their family's life. Being able to understand a patient's viewpoint will help a nurse to care for their patient."

> **"Being able to understand a patient's viewpoint will help a nurse to care for their patient."**

The team is now looking for volunteers who themselves, or a family member, have a genetic condition, or perhaps work with someone with a genetic condition. Your experiences are valuable, whether they're good or bad.

If you are interested in taking part you'll be asked to sign a form of consent and you'll be free to leave the project at any time, without giving a reason.

You'll be asked to tell your story, either by writing it yourself or by talking to someone on the team. Your personal details will not be added to the information you give.

Interviewers are specially trained and you do not have to talk about anything you feel uncomfortable with.

Experiences will be edited and posted on the website of the NHS National Education and Development Centre, with links to explain more about the condition and group support contacts.

For more information contact Telling Stories Project Manager, Ms Kalbir Kaur-Mann (Project Officer), School of Care Sciences, University of Glamorgan (GT 7213), Pontypridd. CF37 1DL.

Alternatively call Kalbir on 01443 483141 or email: **kkaurman@glam.ac.uk**

SRHSB - 49th Conference Review

Medical adviser Gill Yaz was one of a group of ASBAH representatives who attended the 49th conference of the Society for Research into Hydrocephalus and Spina Bifida (SRHSB) in Barcelona last year.

Here Gill writes about some of the research topics presented at the four-day conference held at the Vall d'Hebron Hospital.

The SRHSB is a society committed to promoting and sharing research on spina bifida and hydrocephalus. The papers and presentations from this conference were of a very high standard, and covered a vast range of subjects from embryology to family relationships.

It is very difficult to pick highlights from such a quantity of exciting new work, but here are some which I hope will be of interest to *Link* readers.

Young people and weight gain

Professor Shurtleff from Seattle presented some fascinating work he has done with young people with spina bifida, around weight gain, a major concern for many of my service users.

He has studied the measurements used to determine if people are overweight (BMI) and found that measuring arm span in people with spina bifida gave a good indication of how tall they may have been had not spina bifida resulted in shorter leg length etc.

Using arm span to calculate BMI meant many of the young people in his clinic were less overweight than had been thought.

However, weight gain remained a serious problem. Prof Shurtleff discovered that young people involved in wheelchair sports were far less likely to be overweight than those who did not.

Young people with spina bifida who walked but were unable to participate in sports were likely to gain weight and the Professor urged all young people to be active and to develop a positive view of wheelchair use, even if only to participate in sports.

His work on weight reduction showed that people with spina bifida needed significantly less calories to maintain their weight than those without, some needed approximately half the recommended allowance!

Young people lost weight well with a very low calorie diet, carefully supervised in his clinic, which improved their health, independence and self-esteem enormously.

Family relationships

A team from the University of Nijmegen in the Netherlands looked at the quality of family relationships in families with a child with spina bifida.

They found that while many parents found raising their child very satisfying, they reported their marriages as being less intimate, possibly as they became a ‘team of carers’ rather than a couple.

It reminded me how important it is for all couples to make time for their relationship, and try hard to find someone who can baby-sit sometimes.

MRI during pregnancy

Prof Griffiths from Sheffield continues his research into MRI during pregnancy if spina bifida is diagnosed on ultrasound scan; he showed that a great deal of extra information could be gained from MRI, especially when the original ultrasounds reported difficulties viewing the baby and uncertainties over the diagnosis

NPH research

Exciting research into Normal Pressure Hydrocephalus was presented by Dr Klinge from Hanover, and Drs Czoznyka from Cambridge. Progress continues apace as the role of a very large protein (beta amyloid) in NPH and Alzheimer’s is studied, and links between the two conditions are discovered.

VA shunt infections

Dr Bayston’s team from Nottingham highlighted the very important issue of VA shunt infections. As VA shunts are used less often nowadays, doctors are becoming less and less familiar with the complications which may arise from long-standing shunt infections, such as shunt nephritis. A case was presented showing how a person with very serious renal problems recovered quickly when the VA shunt was replaced.

Attention spans in children

Dr Vinck from the Child Neurology Centre in Nijmegen, the Netherlands, presented a study looking at attention in children with spina bifida and hydrocephalus.

When the children were given tests to do using a pen and paper their attention was significantly worse than when the same tests were given on the computer. The study concluded that having to do something physical, such as handwriting, interfered with the children’s attention, and that attention in itself was not affected.

Brain development

Research into hydrocephalus development in animal models is progressing rapidly.

Dr Rodriguez team from Chile discussed their findings of antibodies against the development of a protein needed to support the aqueduct, and thinning of the lining of the ventricles in hydrocephalus, which could affect the way the brain develops.

The team has also identified some abnormal chemicals secreted into the CSF which could also affect brain development.

Adults with spina bifida

Dr John Mazur gave the Casey Holter Memorial Lecture on the very important subject of adults with spina bifida. He gave a fascinating talk on the history of the care of children with spina bifida and hydrocephalus, and how research has benefited those who are now adults. Dr Hunt’s Cambridge cohort study continues, shedding much needed light on the effects of the conditions as her group enter their middle years.

Details of the research papers presented at the 49th conference can be found at ***www.cerebrospinalfluidresearch.com***

SRHSB
50th
Annual Meeting
Cambridge 2006

The 50th Annual Scientific Meeting of the Society for Research into Hydrocephalus and Spina Bifida will take place at Queen’s College, Cambridge, from August 30 - September 2, 2006, headed by Professor John Pickard and the Academic Neurosurgery Unit.

VP shunt info needed - can you help?

ASBAH’s Honorary Consultant in hydrocephalus, Dr Roger Bayston (pictured below), hopes ASBAH members can help him with his new research study on VP shunts.

The new project follows on from his successful research into VA shunts which was boosted by many valuable contributions from people on ASBAH’s database.

A letter and questionnaire was mailed to ASBAH members in November to people who ASBAH believed have, or at some stage had a VA shunt.

Dr Bayston said: We know little about how shunts behave except what we learn from hospital patients, that is when things go wrong.

“We need to be able to advise people correctly on shunt-related questions, and to do this we need to know how shunts behave over time.

“We have carried out a survey of people in the community with VA shunts that drain into the heart, and we are very grateful for the extremely helpful replies that we received.”

Now he needs information from people who have a VP shunt fitted to help him with the second part of the study.

Dr Bayston explained: We now wish to gather information from people with VP shunts that drain into the abdomen.

“Seeking information from shunted people of all ages in the community rather than those in hospital will give us a more realistic picture of shunt behaviour.

“We will ask only five or six questions, and you will be able to add any comments of your own about your experiences with your shunt.”

A random sample of service users with a VP shunt will be contacted in the next month.

Going for Gold

Young swimmer Thomas Brown is making a splash in the swimming world, and he's set his sights on a paralympic gold medal.

In the past six months the 15-year-old has taken the swimming world by storm, and the future looks even brighter for the boy from East London.

Thomas, who has spina bifida, has seen his life dramatically change since scooping medals at the national finals last year.

In January he competed for England in Holland, winning a gold medal in the 50m Butterfly and three bronze medals in the 50m Backstroke and Front Crawl and Individual Medley.

Now he is one of 16 athletes in the country to be accepted on the World Class Start programme, which grooms the elite for international success.

> **“I am so proud of what Thomas has achieved, both in the swimming pool and out.”**

Top swimming coach Michelle Weltman has taken him under her wing as his personal trainer and Thomas now fits in early morning sessions as well as training after school with the Newham Swimming Club.

Mum Barbara said: “His achievements have been fantastic. I took Thomas swimming when he was a baby, because I wanted him to be able to swim for safety reasons and because it is good exercise.

“But when he was 9 I found it hard to find a swimming club to take him because they only accepted able-bodied children.”

When Thomas was 13 he stopped swimming because he was self-conscious about the scar on his back.

But thankfully for the national team, he took up the sport again 12 months later, and has gone from strength to strength.

Barbara explained: “Thomas can walk but uses a wheelchair when his muscles get tired or he has back pain. This means he has great upper body strength which obviously helps, especially when swimming butterfly and front crawl.

“It's a great form of physio for his legs as it makes him use all his muscles, without putting too much strain on them.”

Thomas's successes have also boosted his self-esteem. “He is so much more confident,” Barbara added. “Swimming is everything to him and he is determined to go for gold at the 2012 London Paralympics, although he'll do his best to win a place in the Beijing 2008 Paralympics too.

“He trains so hard. His coaches work him like a dog, which is the way it has to be if you want success. The downside is that he isn't concentrating on school work so much, which of course is still important.”

But despite his hectic schedule, Thomas still finds time to continue his involvement with the Association for Wheelchair Children.

He is an ambassador for the charity and loves working with children to boost their wheelchair skills and their confidence.

“Thomas has always believed that having a disability shouldn't stop you doing the things you want to,” Barbara added. “His motto is “Believe and you'll achieve”, which makes him such a good role model for the children.”

His work with the Association for Wheelchair Children earned him the coveted Newham Citizen of the Year Award. Big-hearted Thomas promptly donated £50 of the £100 prize money to the Association for Wheelchair Children.

Barbara added: “I am so proud of what Thomas has achieved, both in the swimming pool and out. He's got a great team of people behind him, helping him to realise his dream of paralympic glory.”

Letters

We welcome letters for publication, which should be sent to: Editor, Link, 42 Park Road, Peterborough, PE1 2UQ.

The editor reserves the right to edit letters, so please keep them short.

I recently received the last issue of *Link* with the 1966 cover. I've still got the original.

My daughter Denise would have been 40 this year, on 26 February, but she sadly passed away on 19 August 2005.

We did belong to the Staines and Hounslow local association until it closed last year.

Reading the first issue of *Link* again and the recent issue really shows how things have changed for the better. Thank you to everyone at ASBAH.

Mrs J Thompson

I am writing to let you know how much I enjoy reading *Link*. I am nearly 82 years old and was born with spina bifida. I was operated on at Ashton-under-Lyme Infirmary at ten days old.

They didn't know much about spina bifida then, but I must say they did a good job as I have been able to walk and dance up until almost ten years ago. I am in a wheelchair now but I am still very independent.

I had two children, a son, who is now 58 and a daughter who died twelve years ago with leukaemia.

She left two children, a daughter and a son, who is now 34 years old, who has spina bifida and hydrocephalus. He has always used a wheelchair or crutches.

My granddaughter is such a kind person and does her best for us both, even though she is busy with her own three children. She really is marvellous

I wish all the people at ASBAH and the team on *Link* the very best of luck with all your work.

Jean Nizankowski, Bognor Regis

Holiday let

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

ISLE OF WIGHT ASBAH - HOLIDAY BUNGALOW

Fully-furnished and equipped two-bedroomed bungalow. Beautiful area. Wheelchair-accessible. Site facilities, shop. Local indoor heated pool. Transport advisable. Excellent rates. Offers early/late season. **Details: Mrs S Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF Tel: 01983 863658,** *www.iwasbah.co.uk*

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

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

TRENERRY LODGE, CORNWALL

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Details: Angela Parsons tel: 01872 553755
www.babatrenerry.co.uk

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

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Home with a heart for disabled travellers! Spacious, luxury, adapted bungalow situated on 18 hole golf course. 3 double bedrooms-sleeps 6, 2 bathrooms (Mangar bathlift installed). Custom furniture, patio & conservatory, cable TV. Telephone. Free Country Club membership. 24 hour 'on-call' management company. 15 minutes from Orlando Airport; 20 mins Disney. For current availability contact paraplegic owner. **Sue Fisher, 5 Park Lane, Broughton Park, Salford M7 4HT. Tel/Fax: 0161-792 3029 or email:** *rita.sue.fisher@ntlworld.com* **website:** *http:homepage.ntlworld.com/susan.fisher33*

ROPERS WALK BARNS, MOUNT HAWKE, CORNWALL

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

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

Diary dates

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

Let's Talk Spina Bifida

Monday 19th June 2006

Liverpool.

An informal day for the parents of young children. As numbers will be limited, priority will be given to those from the Northern Region. But, if you live outside the region, let us know if you would like to be considered if any vacancies arise.

For details and bookings contact:
Angela Lansley - 0151 733 8392
email angelal@asbah.org or
Elizabeth Miers - 01490 450360

……

Summer Experience

Monday 7th to Thursday 10th August 2006.

Kepplewray Centre Lake District , Cumbria.

If you are 12 - 16 years old and would like to know more about this residential activity course, please contact Joan Pheasant at the Northern Regional Office on 0113 255 6767.

Please e-mail the editor (link@asbah.org) dates of your events for the next issue of Link by Friday 23 June 2006, giving the name of event, purpose, location, date, cost (if applicable), contact name, phone no. and email address.

Classified rates

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

Cheques and postal orders should be made payable to 'ASBAH'. Classified adverts for the next issue of *Link* should be submitted by Friday 23rd June 2006

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Blaine Harrison

If you're out of touch with today's rock scene then you can be forgiven for not being familiar with the Mystery Jets.

The group, which recently took part in the prestigious NME Awards Tour with the Arctic Monkeys and Maximo Park, is fast heading for commercial success after releasing their debut album, *Making Dens*.

They're receiving plenty of coverage in the national press too, for the unusual line-up which includes Henry Harrison, 55, father of the leader singer and keyboard player Blaine. And while most sons are keen to shake off parental influence as soon as possible, Blaine, 20, believes there are no age limits in rock.

> **"It was a bit strange when Dad was trying to get to sleep in the back of the tour bus and we wanted to stay up all night. But if I wanted to rebel against my Dad, I would have gone to work in a bank!"**

Henry started the group when Blaine, who has spina bifida, was 8, encouraging him to perform on stage to gain confidence and show the world that having a disability shouldn't be a barrier to following your dreams.

"Music was something we could all do together," Henry said. "I thought my time had gone, but there was no reason I shouldn't be in the band."

As the group grew with the addition of Blaine's friends, Henry encouraged the youngsters to explore all rock and not be limited by one particular style. Even now the Mystery Jets aren't keen to be linked to any one music scene.

Their album, *Making Dens,* has been in the music press as a "wilfully barmy creation which has delighted and baffled reviewers in equal measure." It is made up of a lively mix including Little Bag of Hair, which details Blaine's memories of hospital treatment.

But Henry says he never had any initial ambitions for the band. Fame and fortune were never a motivation.

"It wasn't about making a living or getting famous. To me it was just good fun and a good way to spend time with Blaine. Funnily enough Blaine and Will were the ones with the rock 'n' roll dream."

The group hails from Eel Pie Island, near Twickenham, a small village in the middle of the Thames, which has a long musical heritage. The Eel Pie Hotel – mentioned in Dickens' *Nicholas Nickleby* – became a retreat for poets and artists, and in the Sixties resounded with performances of Pink Floyd, the Rolling Stones and The Who.

Blaine Harrison - with keyboard

Henry and Blaine, who have lived there since the mid-Nineties, are fast becoming Eel Pie Islands most famous export... and least popular residents after a series of free concerts last summer.

After welcoming audiences of up to 600 at a time to their boatyard gigs, neighbours complained to the local authority, who promptly issued the group with a noise-abatement order.

Blaine said: "I guess you can't blame them, but it is a shame as our music has

always been bound up with the place in which we make it."

So instead they took their music to their fans with a highly successful and largely self-financed Eel Pie Revue tour.

Last year brought support slots with Bloc Party and Futureheads before they took part in the prestigious 2006 NME tour, which catapulted the Kaiser Chiefs to fame.

Blaine said: "It was a bit strange when Dad was trying to get to sleep in the back of the tour bus and we wanted to stay up all night. But if I wanted to rebel against my Dad, I would have gone to work in a bank!"

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✓ *Upholds the quality standards of the ASBAH Local Association Compact*

Local Association secretaries requiring changes to this list should contact:
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