SPRING 2005 ISSUE 212

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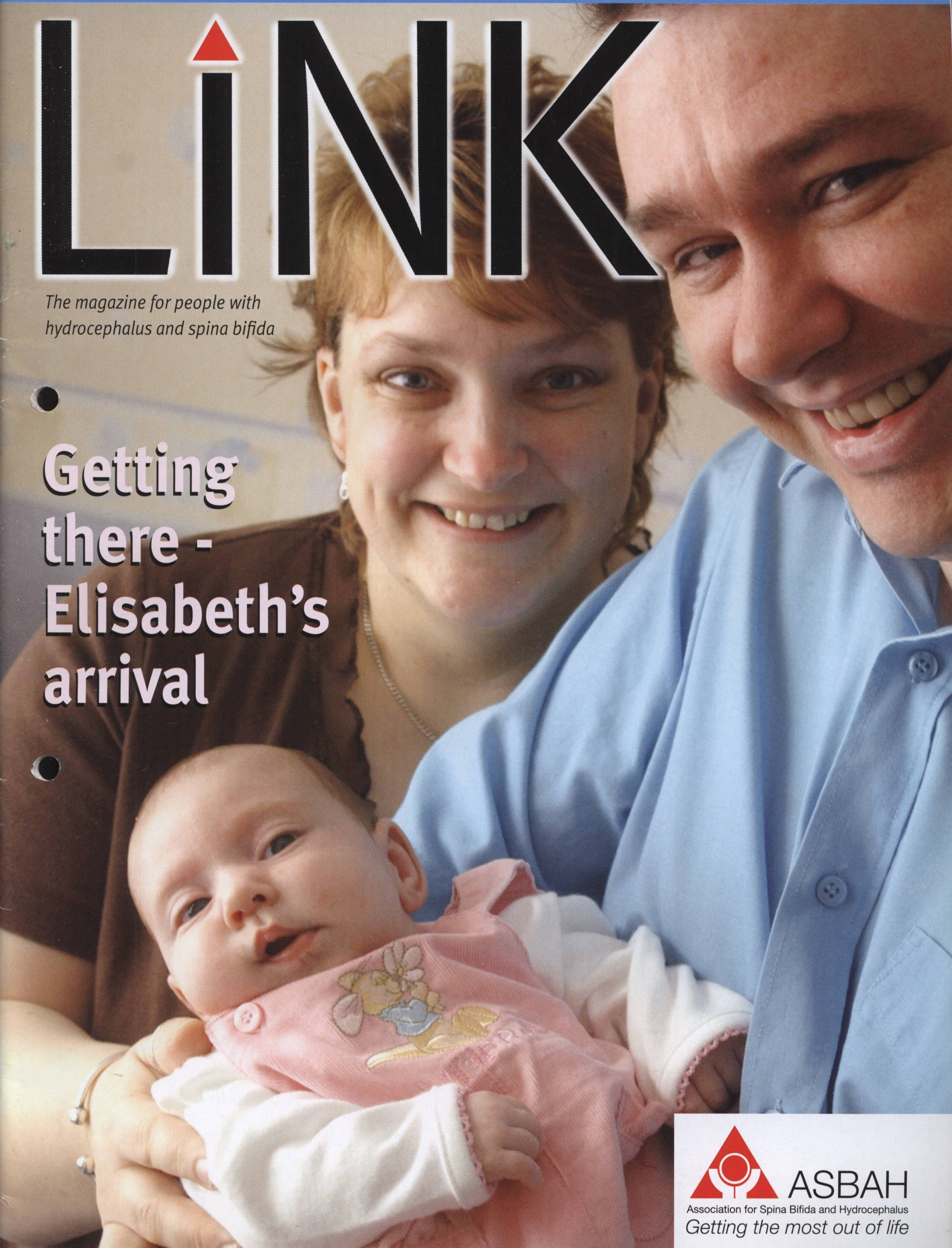
LINK

The magazine for people with hydrocephalus and spina bifida



Getting there - Elisabeth's arrival

ASBAH
Association for Spina Bifida and Hydrocephalus
Getting the most out of life

Peter Farrall writes

Welcome to the Spring *Link* which, as always, covers a wide range of issues which affect our readers and their families.

We are fairly family-focussed this issue, through accident rather than design, and are always on the lookout for material to suit our many adult readers. So if there's something you would like us to feature, please let us know and we'll do our best.

We had an excellent response to our interview with mother-to-be Sam Copeland in *Link* 211, which clearly struck a chord with many of you.

Turn to page 26 to meet baby Elisabeth and read Sam's diary about the first four weeks after the birth.

Talking of new arrivals, we catch up with Siobhan Corr for the last instalment of her pregnancy diary, and she reveals the ups and downs of motherhood since the arrival of baby Daniel in December.

We also focus on the Family Awareness Days, which tie in with our new *Your Child and Hydrocephalus* book, and report on the first event, held in Belfast in February. On page 19 we meet psychologist Hazel Bennett, one of the speakers at the Belfast Family Awareness Day, and a contributor to the *Your Child and Hydrocephalus* book.

On medical matters Professor Paul Griffiths from Sheffield's Royal Hallamshire Hospital talks about his ASBAH-funded research programme, page 25. We also report on a new study which suggests that adding folic acid to food is the most successful way of reducing neural tube defects.

Of course there are the usual news pages, fundraising stories and features to enjoy.

Enjoy this Spring issue and hopefully the weather will be suitably spring like too!

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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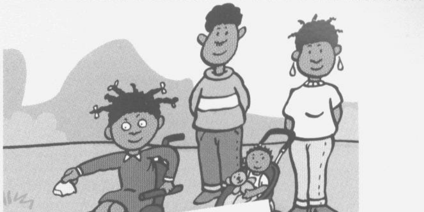

ASBAH Welcome to the Association for Spina Bifida and Hydrocephal
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Hydrocephalus
Hydrocephalus can occur in anyone, anytime but what are the causes and how is it treated?
Find out more

Spina bifida

Folic Acid
ASBAH is actively campaigning to introduce the compulsory addition

About ASBAH

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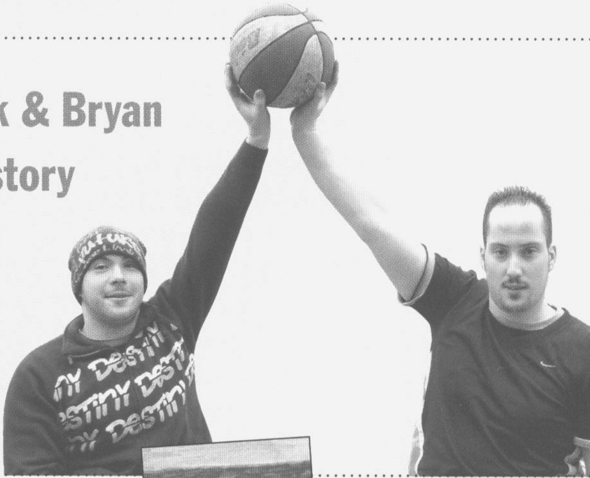

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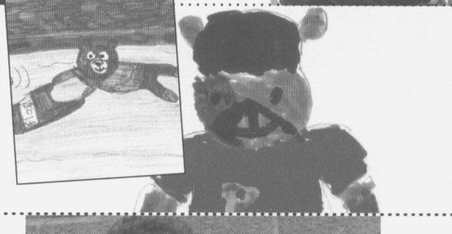
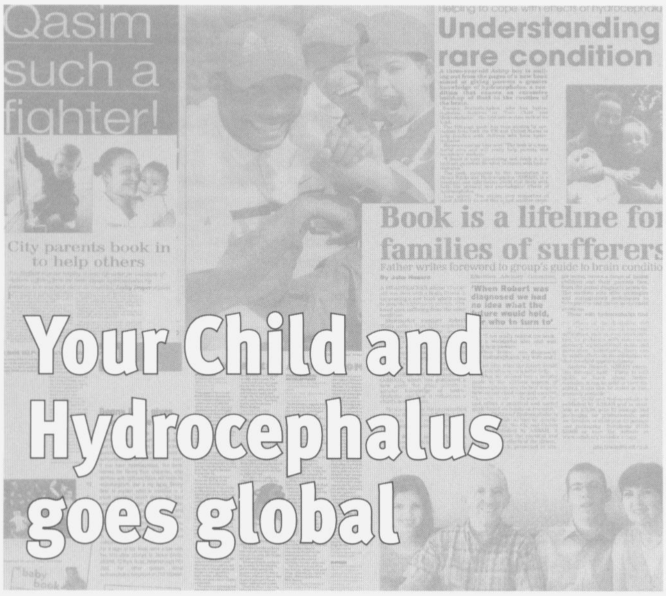




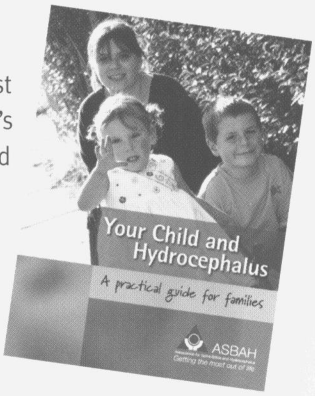
Your Child and Hydrocephalus goes global

Orders have flooded in from across the world for the new ASBAH publication, *Your Child and Hydrocephalus.*

More than 1,000 copies of the book have been sold since the 4 November launch, with the first internet order coming from Canada, just hours after it went on sale.

Copies of the book have been sent to all member countries of the International Fedaration for hydrocephalus and spina bifida – from Australia to Zambia, to highlight that there is a major new resource available for parents.

ASBAH in Germany (AsbH) have also been in contact with ASBAH as they are keen to have the book translated into German.



A widespread press campaign has also helped to publicise *Your Child and Hydrocephalus* and boost sales. Many newspapers in Britain's major towns and cities have carried reports, with plenty of additional interest generated by specialist healthcare and educational publications who have all favourably reviewed the book.

Peter Farrall, Assistant Director Marketing and Communications, said: "*Your Child and Hydrocephalus* is a major work for ASBAH and a valuable resource for parents and families with a child affected by hydrocephalus. We are delighted that the book is valued by so many families throughout the world

"We are particularly thrilled that Alder Hey Hospital in Liverpool bought a bulk supply of books to give out to medical staff and families. It is also very gratifying to hear that several local associations, including Somerset and North Wales, intend to supply the book to their families either free of charge or at a special reduced rate."

Your Child and Hydrocephalus *can be ordered from the ASBAH website www.asbah.org or from the ASBAH information section, 01733 555988. Price for* Link *readers and ASBAH families is £9.99 plus £2.00 p&p.*

ASBAH hits the road

ASBAH is going on tour with the Charter Continence Care Roadshow to help bring a wealth of information to people who need help with bladder and bowel management.

Charter
quality and care
Continence
Roadshow 2005

The Roadshow, an initiative by Coloplast, kicked off in Peterborough on 11 April and will visit 46 UK towns and cities during its 12-week tour.

On board, healthcare professionals will be on hand to provide any necessary support and advice, and will provide information about seven major charities, including ASBAH.

Visitors will also get the chance to take a look at the latest Coloplast products, including its full range of catheters, sheaths and bags. Information will also be available about the company's support services, which includes a 'to your door' service for all continence product needs.

A spokesman for Coloplast said: "We hope ASBAH members will join us at one of the locations and become involved in what the Roadshow has to offer. It will give them the opportunity to meet up and talk with national groups and the Coloplast team.

For further details on the locations of the Roadshow call Freephone 0800 783 1434.

Free tickets for carers

Disabled people who need someone to accompany them to the cinema can take advantage of a new scheme offering a free ticket for carers.

The Cinema Exhibitors' Association Card is a national card that can be used to admit your carer free of charge at participating cinemas. To apply for the card, you will need to meet one or more of the following criteria:

a) Be in receipt of the disability living allowance or attendance allowance.
b) Be a registered blind person.
c) Be a holder of a disabled person's rail card.

A processing fee of £5 is charged per card, and the card is valid for 3 years from the date of issue.

Application forms are available from cinemas supporting this card or you can download a form to print out from the website www.ceacard.co.uk

For information on participating cinemas check out the website or write to the following address: **Mr N Smith, The Card Network, The Technology Centre, Rossmore Business Park, Ellesmere Port, Cheshire. CH65 3EN. Tel: 0151 348 8020 or email: info@ceacard.co.uk**

Another honour for Tanni

Britain's best-known Paralympic athlete, Tanni Grey Thompson, was made a Dame Commander of the Order of the British Empire in the New Year Honours List.

The Cardiff-born racer, who won her 11th gold medal at the Athens Paralympics last summer, previously received an OBE and MBE.

Since she made her debut for Wales at the Junior National Championships aged just 15, she has become Britain's most successful wheelchair athlete ever.

In the 2000 Sydney Paralympics she hit top form, picking up four gold medals, after victories in the 800m, 100m, 200m and 400m.

Tanni, 35, took her Paralympic gold tally to 11 by winning the T53 100m and 400m in Athens.

Tanni, who has spina bifida, has also won the London Marathon on two occasions, and is looking forward to competing in the event again this April.

We wish her every success!

Emma ties the knot

Wedding congratulations go to ASBAH member Emma Lewis Thomas and new husband Enoch.

The couple, from Cardigan in West Wales, married at Llwinyrhwreld Chapel in Tegryn, after 12 years together.

Emma, who has been an ASBAH service user for the past ten years, was given away by her 15-year-old son Dafydd Win.

But the couple didn't get the chance to jet off on honeymoon, as Emma explained: "My father isn't well so I like to keep an eye on him and we've also got three dogs to look after. But it was a wonderful day. We invited around 50 guests and we all had a lovely time."

Meet Millie & Russell, ASBAH's latest creations

ASBAH is working on a new set of books to give children more information and confidence about continence issues.

The project, a partnership between ASBAH and Hollister, which manufactures continence products, introduces two new characters, Millie and Russell.

Two versions of each book are planned, one each for girls and boys, as they each experience different continence problems.

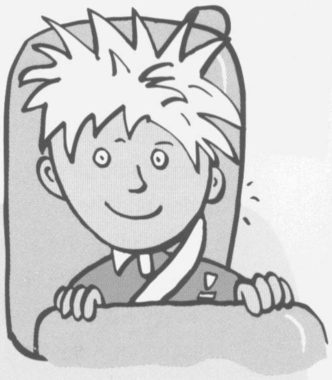
The first book of a series of four is centred around a camping trip, and reinforces that although children may have continence issues, they can lead a normal life, doing all the activities their friends do, without anyone knowing.

With words by medical advisers Paula Thompson and Rosemary Batchelor (author of the Benny Bear series), and illustrations by George Hollingworth, the books are expected to be popular with children aged eight years and over.

The foreword is written by Dr Malcolm Lewis, Consultant Paediatric Nephrologist, Royal Manchester Children's Hospital.

A spokesperson for Hollister Limited said: "We are very pleased to sponsor ASBAH's Millie and Russell books. We believe ASBAH are providing an invaluable tool for helping children, their friends and families to understand intermittent catheterisation and what it means to them."

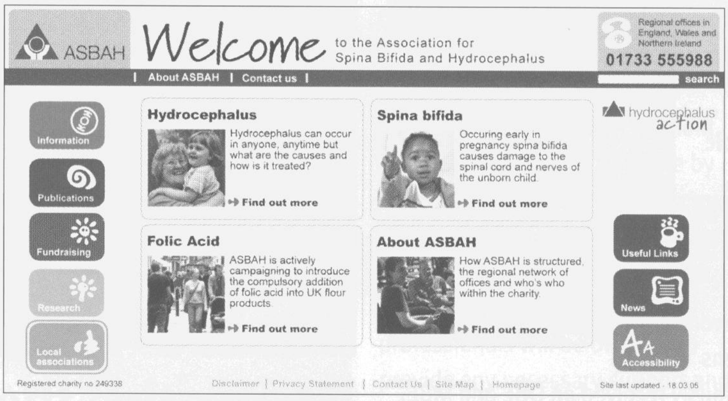
The first book, Millie goes to Camp, will be available in early May. Contact the Information department at ASBAH for further details, or check out the new-look ASBAH website www.asbah.org to order you copy.



(Bottom) Millie and her family feed the ducks

(Top) Russell takes a trip

ASBAH updates its website



Welcome to the Association for Spina Bifida and Hydrocephalus

Regional offices in England, Wales and Northern Ireland
01733 555988

Hydrocephalus

Hydrocephalus can occur in anyone, anytime but what are the causes and how is it treated?

Spina bifida

Occuring early in pregnancy spina bifida causes damage to the spinal cord and nerves of the unborn child.

Folic Acid

ASBAH is actively campaigning to introduce the compulsory addition of folic acid into UK flour products.

About ASBAH

How ASBAH is structured, the regional network of offices and who's who within the charity.

Registered charity no 249338

Site last updated - 18.03.05

With a new welcoming home page, the structure of the site has been redesigned to offer easier navigation throughout

If you're a keen user of the Internet, check out the new ASBAH website, due to be launched later this month.

The new-look site will be brighter and breezier, and easier to navigate than the current website.

As well as different imagery, the new ASBAH web pages will have more relevant information than before, with news stories, articles and factual pages updated regularly.

The site will also feature Local Association pages and an inter-active fundraising section. Users will also be able to order publications direct through the website.

Peter Farrall, Assistant Director Communications, said: "Websites are a dynamic medium – they are continually growing and expanding. It was time to look at the ASBAH site and see how it can better serve the thousands of people who visit it each week.

"With a new welcoming home page, the structure of the site has been redesigned to offer easier navigation throughout and to the library section where all of ASBAH's information sheets are available to download and print out. The site is also now fully accessible.

"At last we are able to offer a basic web page for each local association and I do hope that they send through information and details of their events and activities to put on it.

"The site is never finished and already we are considering new enhancements throughout the coming year to offer greater interactivity. It would be really good to get feedback about the new site," said Peter.

New adviser for Northamptonshire

Northamptonshire County Council

ASBAH has won a grant to employ a part-time area adviser in Northamptonshire.

The much-needed funding, agreed by Northamptonshire County Council in March, came as welcome news to Eastern Region and the Northampton local association as the area has been without a permanent adviser since 2001.

Maggie Nichols, secretary to the local association, said: "It is wonderful news and will make a huge difference to the work we do."

Northampton County Council did fund the part-time post from March 2004 for 12 months. The position was shared by area advisers Linda Knight and John Richards, who also cover the Hertfordshire, Lincolnshire, Bedfordshire and Milton Keynes areas.

Maggie added: " The advisers have done a fantastic job and it is now appropriate to be recruiting to fill the position with a dedicated area adviser for the county."

She added: "Having a professional adviser will make a big difference to the service we can provide. Everyone involved with the local association has family commitments which means we aren't always available to help as much as we'd like.

"We have found that families new to ASBAH in particular, often feel more comfortable talking to a professional, particularly about financial concerns.

"Advisers also know exactly who to contact for help in a wide range of matters, and the various agencies do respond better to their requests."

David Isom, manager of the Eastern region for ASBAH commented:

"The award from Northamptonshire CC for Strategic Funding is a 3 year award which amounts to over £50,000 worth of funding for this service.

"We can now plan to recruit an area adviser over the course of the next few months solely to cover Northamptonshire. This funding arrangement should prove to be a win, win, win, situation for ASBAH, the Northamptonshire local association, service users and professionals throughout the city council and across the county.

Lynne Jones, Commissioning and Contracts Manager for Services for People with Physical Impairments, Northamptonshire County Council added:

"Northamptonshire County Council has recognised the many benefits of having local ASBAH advisers within the County. ASBAH has formed an excellent working relationship with the Council and there is a shared understanding of the importance of people being able to access information, advice and support to enable them to live independent lives.

The three-year funding provides some stability for development and an opportunity to identify and respond to the previously unmet needs in Northamptonshire."

Tom Woodrow helping Carole Sobkowiak talk to parents at the Belfast Awareness Day

Hazel Bennett

Awareness Days voted a hit

Parents and professionals have been lavish in their praise of the first Hydrocephalus Action Awareness seminars.

The study days, launched in Belfast in February, were well attended by people keen to learn more about the various aspects of helping a child with hydrocephalus.

It is hoped that two Awareness Days will be organised for each region, plus one in the south west of England.

The one-day seminars, with practical workshops and talks, are designed to help parents and professionals get more from the new Your Child and Hydrocephalus book.

Rosemary Whalley, local adviser for Belfast, was the key figure behind the recent seminars, helped by the ASBAH team in Northern Ireland. Extra support came from the Royal Belfast Hospital for Sick Children's physiotherapy department.

The seminars attracted an impressive range of speakers including two of the authors of the book, Carole Sobkowiak and Hazel Bennett, Dr Hugh Richards from the UK Shunt Registry, neuro surgeon David McAuley, and Alex Best from Codman.

Rosemary said: "Both days were well attended and were extremely successful. We did an evaluation survey at the end of each day and comments were very positive."

Professionals attending included physiotherapists, community nurses, social workers and education specialists, and all highly rated the talks. They also suggested topics they would like to know more about for future seminars.

Rosemary said: "Around 40 parents attended and they found the speakers and practical workshops informative and helpful.

"They particularly enjoyed the talk given by Carson Quinn, an ASBAH service user who has hydrocephalus. It is always useful for parents to meet someone who knows what it is like to have hydrocephalus and to hear how they cope with the challenges which may arise."

She added: "Seminars like these complement the individual work we do with families and, if we have the resources, are something we would like to do more regularly."

Both days were well attended and were extremely successful

Venues and dates for forthcoming Awareness Days in England and Wales

Saturday 7th May	Banstead, Surrey
Saturday 14th May	Bristol
Wednesday 18th May	St Asaph, Denbighshire, North Wales
Monday 23rd May	Cardiff, South Wales
Saturday 18th June	Maidstone Kent
Monday 20th June	Liverpool
Saturday 2nd July	Royden, Norfolk/Suffolk Border
Saturday 17th September	Darlington

Please contact your regional office for more details and a booking form

Allied Vehicles is the UK's leading vehicle adaptation specialist, supplying a wide range of taxis, minibuses and wheelchair passenger cars throughout Britain and overseas. The company, based in the Possilpark area of Glasgow, is also the UK's first Peugeot and Citroen authorised specialist dealer for service, parts and warranty repairs.

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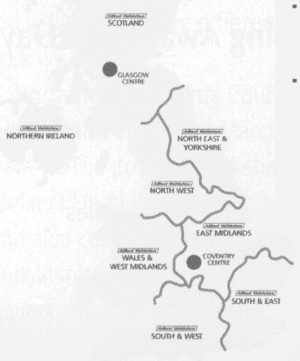
- **Free Nationwide delivery**
- **Dedicated customer care centre - open 7 days**
- **Wide range of wheelchair accessible vehicles**



- Allied Vehicles is the UK's leading specialist in vehicle adaptation.
- Our specially adapted manual cars, automatic cars, people carriers and minibuses are designed to make you more mobile and help enrich your quality of life.

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VCA Motability

0800 587 9608 **Allied Vehicles**
www.alliedvehicles.co.uk Driving For Perfection

The Automatic Choice in Accessible Vehicles

Two friends from Dunbar, Fiona Cullum and Robert Dignan have found a new lease of mobility thanks to their new cars from Allied Vehicles, the UK's leading supplier of wheelchair accessible cars.

Both Fiona and Robert are wheelchair users and previously shared the use of one vehicle. Recently, there has become a necessity for each of them to have their own vehicle and so they decided that the Allied Vehicles' Renault Autograph with automatic transmission is just what they need.

Fiona and Robert are involved in the East Lothian Care and Accommodation Project (ELCAP), which aims to provide services for people who require care and support in the activities of daily living, together with advice and assistance to others involved in their care.

ELCAP carers will drive Fiona and Robert in their new vehicles, helping them to get out and about whenever they need to.

Neil Nicolson from ELCAP, who assisted in the purchase of the vehicles said: "We had a lot of contact with Bob, our Mobility Adviser from Allied Vehicles. He couldn't have been better. First class! He had a total understanding of what Fiona and Robert need."

"Bob brought the vehicle to us and gave us a full demonstration so we could see how it operates and how it can benefit our clients," added Neil.

Allied Vehicles General Sales Manager, Peter Facenna, commented: "The Autograph is a relatively new addition to our growing range of specially-adapted wheelchair accessible vehicles.

"Based on the Renault Kangoo this model was selected both for its stylish looks and in response to customers keen to have the option of an automatic gearbox.

"I'm delighted that Fiona and Robert have chosen the Autograph and hope it will make a real difference to their mobility, thanks to the support of ELCAP."

Tel: 0800 587 9608 www.alliedvehicles.co.uk

Pigeon Power

The kind folk of the Royal Pigeon Racing Association (RPRA) certainly have something to coo about after feathering ASBAH's nest by some £15,000.

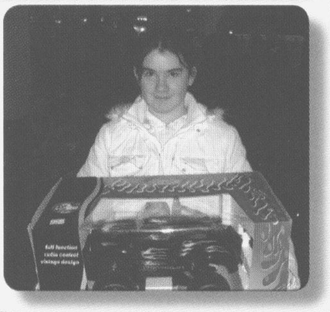
The RPRA's annual British Homing World Show 2005, held at the Blackpool Winter Gardens in January, saw around 30,000 people through its doors. With over 2,000 birds on display and 200 stands, there was plenty to see and do.

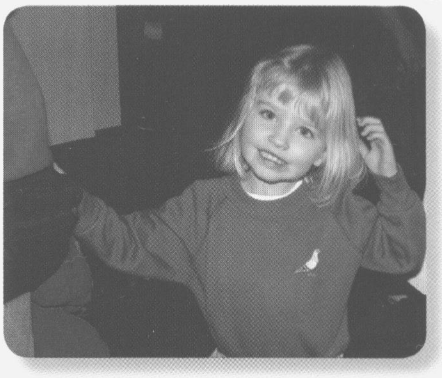
ASBAH's Executive Director Andrew Russell was among the visitors, and was presented with the money raised from last year's event.

Anne Walton who was ASBAH's area adviser in the North East also volunteered her time for the whole weekend, together with Husband Reg. Thank you both for continuing to help out year in year out.

Each year the show raises around £100,000 for charity, mainly through pigeon auctions, raffles and attendance fees and, for the 32nd year running ASBAH was one of the main beneficiaries.

ASBAH is very grateful to the RPRA committee, its general manager, Peter Bryant and to Mrs Mac and her team for all their hard work behind the scenes.





RAF Wittering Cake Bake

Service men and women from RAF Wittering have shown their generosity to ASBAH for the second year running.

They baked and iced a special cake that was presented to ASBAH at the Royal Pigeon Racing Association's British Homing World Show of the year in Blackpool in January.

The cake, which was the main prize in ASBAH's tombola at the show, raised more than £500 .

Bride's Big Day Donation

Newlyweds Susan Tucker & husband Richard chose an unusual route to fundraise for ASBAH.

Susan & Richard, whose daughter Emma has hydrocephalus, walked up the aisle on Christmas Eve.

Instead of wedding gifts, the kind-hearted couple asked guests to make a donation to ASBAH as a thank you for all the support they have received.

Thanks to the generosity of their guests, the couple were able to present ASBAH with £1,100.

Crafty Things

As if the handy folk of Billingborough, Lincolnshire, didn't have enough to do with preparations for Christmas, the crafty lot got busy making homemade items and gifts for a village craft fair, held in early December, in aid of ASBAH.

Eric Huff, treasurer of the Billingborough craft fair committee, organisers of the event, said: "This is an annual fundraising event and each year we choose a different charity to support. ASBAH was a unanimous decision because we like to pick charities that affect the lives of other people."

Lorraine, who is one of the committee members has spina bifida and nominated ASBAH after the support she received from her adviser, Linda Knight.

So, Eric and his fellow committee members put the local residents to work and asked them to create a bevy of crafty items to sell at the fair and, through a lot of hard work and handicraft, a grand total of £1,022 was raised from sales of raffle tickets

We would like say a big thank you the craft fair committee and everyone who contributed to the event.

You Bet

Keen golfer, David Deering, came up with a enterprising way to boost ASBAH funds by 'betting' he can beat his pals at the Sussex Golfing Society at a round of golf.

As captain of the society he arranges eight matches a month during April to October, were he places his bets against the other players. If he wins, they have to pay him but should he lose, the bet is passed back to the winner.

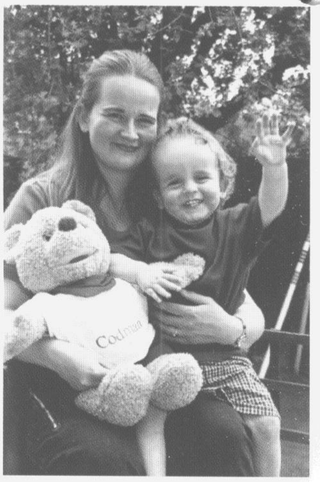
Luckily his fellow golfers are all charitable chaps and donate their winnings anyway – lucky for ASBAH!

The fundraising doesn't stop there though, for after the game the players retire to enjoy a well-earned meal where David hands out 'fines' to players who have done something foolish during the day.

Back in December, David also auctioned off an England shirt belonging to footballer, Rio Ferdinand, which raised a whopping £130!

We think David has found a truly entertaining way of raising money for ASBAH and thank him, and his kind-hearted pals, for being such good sports!

Lighten up!



A resourceful mother brought a touch of Christmas magic to her street and raised cash for ASBAH at the same time.

Lisa Nicholls-Sykes and neighbours from Ashby-de-la-Zouch, Leicestershire, decorated their homes in festive fairy lights and treated fellow neighbours to a Christmas street party and BBQ.

Lisa, who's son Barney has hydrocephalus, managed to cajole a further 20 homes along the street into adorning the front of their houses in all things Christmassy as well.

It was a sight to behold when the homes finally revealed all on 28 November 2004 at a big 'switch-on' street party – even the local press turned up to mark the occasion!

A grand total of £300 was raised for ASBAH and, such was the success of the event, Lisa and her neighbours are already preparing to do the same again next year. Good luck everyone and thanks for all your support!

Our thanks to Paul, Tamsin and Oscar Olney who in total gifted £970.59 to ASBAH following Paul's parachute jump, ASBAH's Shelly Bullard (left) receives the cheque.

DJ Tim visits ASBAH

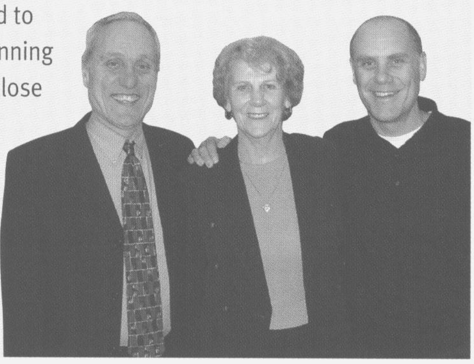
Radio 2 DJ Tim Smith and his mother Pat paid a visit to ASBAH to present another donation for the Carolyn Smith Memorial Fund and meet up with Executive Director Andrew Russell.

The money, a private family donation, will boost the ASBAH fund set up in memory of Tim's sister, Carolyn.

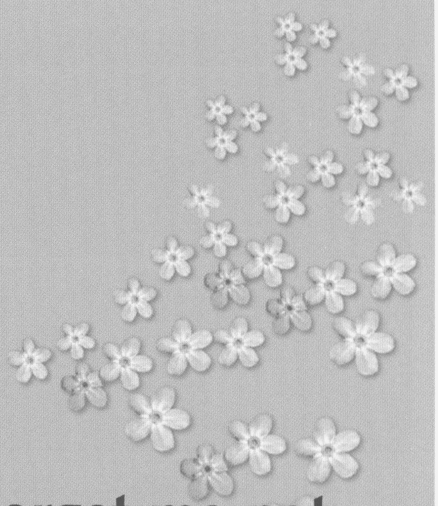
Carolyn, who worked for ASBAH as an accommodation officer and field worker (local adviser), died from a brain tumour in September 1991, aged 28.

Carolyn's family set up a memorial fund in her memory and decided that all donations to the fund should be used to help people with S B / H who are planning to live independently - a cause very close to Carolyn's heart.

Tim explained: "Raising money for the fund helps us to keep Carolyn's memory alive and reminds us how dedicated she was to her job."



Donna Treanor receives a cheque for £400 from Yaxley Fire Station in Peterborough



Forget-me-not fund keep their memory alive

ASBAH has launched a new memorial fund scheme to help family and friends pay a special tribute to a loved one who has died.

Relatives often find it comforting to send in donations in memory of the person who has passed away.

Now, when ASBAH receives a gift in someone's memory, we can set up a Forget-me-not Memorial Fund in their honour.

A web page in their name will be provided so friends, family and colleagues can make donations at any time. What better way to celebrate a life?

Forget-me-not Funds are flexible, allowing people to make donations in whatever way suits them best. It can be a single donation on a specific date, or monthly gifts by direct debit, whichever is more suitable.

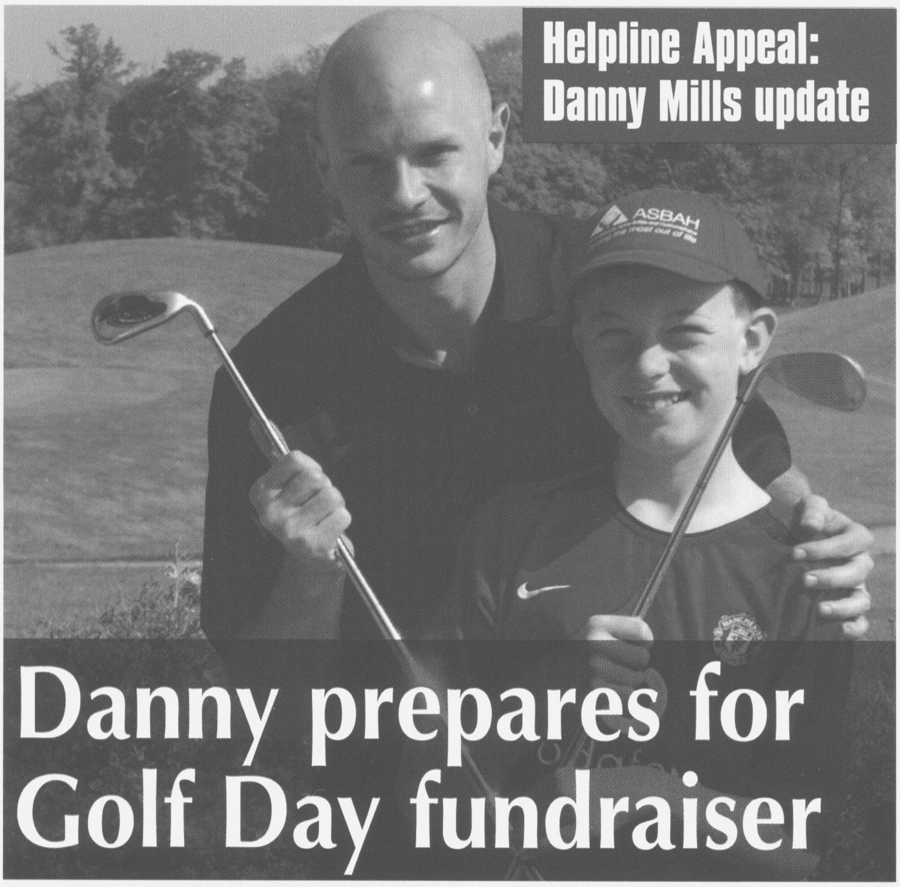
Donors can also take advantage of GiftAid to make their contributions worth almost a third more.

The funds are simple to set up and ASBAH will handle all the administration and send the family regular updates with news about their fund.

To find out more about Forget-me-not Funds, contact ASBAH's fundraising department on 01733 555988 or visit www.asbah.org

Helpline Appeal: Danny Mills update

Danny prepares for Golf Day fundraiser



Fundraising for ASBAH's Helpline Appeal is going from strength to strength.

As we went to press, its Patron, footballer Danny Mills, was preparing for the second Danny Mills Golf Classic.

The event, held at the Worsley Park Marriott Hotel and Country Club, Worsley Park, Manchester, saw a host of Premiership footballers on the fairways to boost the helpline funds.

It is hoped that the golf day has raised even more than last year's event, which brought in an impressive £33,000. We'll include a full report in the next issue of *Link*.

The helpline appeal is also set to benefit from the Touchstone Housing Association Charity Golf Day on 10 May at Kings Norton Golf Club in Birmingham.

The organisation, which manages 16,000 homes across the Midlands, has kindly agreed to split the proceeds from the day between ASBAH and some local Coventry charities. Danny will co-host the charity auction in the evening.

The Helpline Appeal received another welcome boost from Sportlink, which organised an unusual Boxing Day event.

More than 30 runners, made up of various sports personalities including ex-Norwich City footballer Daryl Hutch, and hardy local runners took part in the Sportlink Felthorpe Hare & Hound's Cross Country Run.

The run involved a 'hare', played by International athlete, Neil Featherby, and a pack of chasing 'hounds', played by pairs of runners.

The 'hounds' chased the 'hare' round a chilly 10-mile cross-country course set in the Norwich countryside. But the fleet-footed hare had the last laugh, crossing the finishing line 40 minutes before the first set of hounds.

First to limp home was ex-Middlesbrough player Greg Briggs, fellow hound, Mark Browne and boxer Jon Thaxton... minus his partner.

The day was huge fun for all those involved, and raised £300 for the Helpline Appeal. A big thanks to all the runners for enduring the frosty conditions to raise the money for ASBAH.

Good Sports

Never let it be said that the staff here at ASBAH aren't a sporty lot!

Donning sweat bands and vests, three of our most energetic employees, Shelly Bullard, Paul Dobson and Andrew Russell, took part in a wheelchair basketball challenge, in aid of ASBAH, the fourth member of the team was David Proud, always one to help out with our fundraising events,

Ten teams took part in the tournament, which took place on 27 January at Carre's Grammar School in Sleaford, and together raised around £400.

Much to the delight - and surprise - of Andrew and Paul, they made up one half of the winning team, and David won an award for the most skilled player on the court.

Thanks to everyone involved in the tournament and to Chris Hassell for organising the event.

The appointment... will help groups such as Your Voice to make sure their needs are met and supports their push for change.

Comic Relief boost for Your Voice

A £48,000 grant from Comic Relief will enable ASBAH to fund a Policy Officer post for Your Voice, the Association's disabled service user group.

The funding - which will cover the costs of the new position for three years - comes from the charity's *Fighting for Justice* programme. It helps groups such as Your Voice to make sure their needs are met and supports their push for change.

The new Policy Officer will manage and deliver a vibrant three-year programme under the *Fighting for Justice* banner.

It will include training courses to empower, educate, and improve the confidence of disabled people, and to ensure that their policy views are heard.

Another key objective for the post holder is to double the membership of Your Voice.

The Your Voice Steering Group was set up more than 11 years ago to give ASBAH's adult disabled users the chance to have an active input in the development of ASBAH's policies and the information it publishes. It also gives them the chance to speak up on significant issues which affect their lives.

The group meets up every two months for a committee meeting to discuss a range of issues and arrange new activities. These include residential and day courses on a wide range of themes, including assertiveness training, committee skills and mobility issues.

Twice a year Your Voice reports to ASBAH's trustees, enjoying a formal link with the decision-making part of the organisation.

For more information on Your Voice and, as an adult service user, how you can join, contact ASBAH on 01733 555988.

Your Voice presents

COME & HAVE SOME FUN IN BRUM!!!!

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Friday 20th May 2005 - Sunday 22nd May 2005

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- **Museums**
- **Yoga & Reikie**
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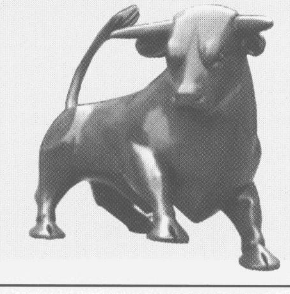

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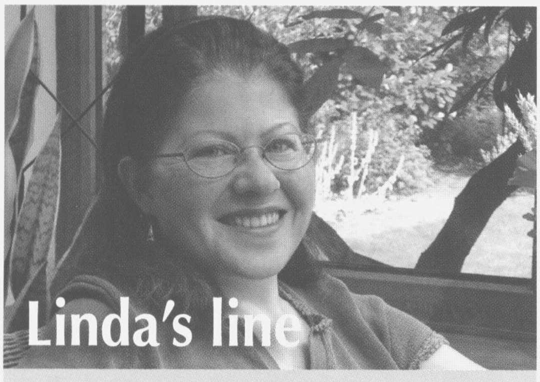
Cheques should be made payable to ASBAH and sent to: Jason Merrill, ASBAH House, 42 Park Road, Peterborough PE1 2UQ

ASBAH
Association for Spina Bifida and Hydrocephalus
Getting the most out of life



Linda's line

Ask anyone who goes fishing how big their best catch was, and you get an idea of how easy it is to get your scale wrong.

For those of us like myself who are not fishing enthusiasts, it's exactly the same principle as finding a spider in the bath - when it's squatting against your white enamel bath it looks like one of the extras from Jurassic Park, but put your multi-legged friend alongside a ruler (assuming you are brave enough to attempt this!) and the result will probably appear disappointing.

I am currently having lots of problems with scale as Andrew and I are trying to re-design our front garden. When we bought our house 6 years ago, the front garden was full of tatty overgrown bushes and, 6 years on... well, it's still got the same tatty overgrown bushes, so the project for 2005 is a complete front garden makeover. In the absence of Charlie Dimmock and the Ground Force team, we have had to come up with our own design and I can tell you this garden planning lark is not as easy as it looks on tv.

Having measured out the area and transposed the outline of the garden onto graph paper, we then started to draw on the features we wanted. Unfortunately, Andrew waited until my masterpiece was finished before pointing out that the space I had allowed for my car was only suitable for a vehicle with the turning circle of a scooter. This is probably because we have bought defective graph paper. However I concede that the reduced grass space was largely due to my over estimated tree trunk (which according to the scale had the girth of a 300-year-old oak tree). Now I know why I never pursued a career in map making!

Still, my Mum always says you can't be good at everything so perhaps we do need the Ground Force expertise after all. It shouldn't be too tricky for them, just a bit of grass, a small tree, a few bushes and parking for two cars. How difficult can that be?

Now all I have to do is arrange a weekend away...

Support pledged by Local Associations

Fifteen local associations will be working more closely with ASBAH after signing up to the Local Association Compact.

The agreement, which was put together after a year-long consultation with the 39 local associations, aims to bring all local associations together.

The network of 39 LA's throughout England, Wales and Northern Ireland is a vital resource for thousands of individuals and families affected by spina bifida and/or hydrocephalus and ASBAH is keen to provide support in a variety of ways.

ASBAH hopes the Compact will improve standards both at ASBAH and within the local associations, to benefit everyone involved, particularly those with SB/H, their families and carers.

ASBAH's Executive Director Andrew Russell said: " We are pleased that there has been such an encouraging early response to the Compact initiative.

"We appreciate that many local association committees will have met and perhaps wanted clarification on points or refer the Compact at the next meeting, so it is really positive that 15 have already signed up to the initiative".

Local Associations signed up so far include:

- ✓ *North Wales*
- ✓ *Leeds and Bradford*
- ✓ *Surrey ASBAH*
- ✓ *Thames Valley*
- ✓ *Sheffield*
- ✓ *Devon*
- ✓ *North Yorkshire*
- ✓ *Sussex*
- ✓ *Bristol and District*
- ✓ *Somerset*
- ✓ *Wirral*
- ✓ *South Wales*
- ✓ *Cannock and Walsall*
- ✓ *Kent*
- ✓ *Whitchurch (SALOP)and District*

Thames Valley Support for Compact

Thames Valley was one of the first local associations to sign up to the Compact.

Secretary Marina Sawyer said: "We have done everything we need to do to be part of the Compact and we welcome the on-going support of ASBAH, which gave us a lot of help when we were trying to get established.

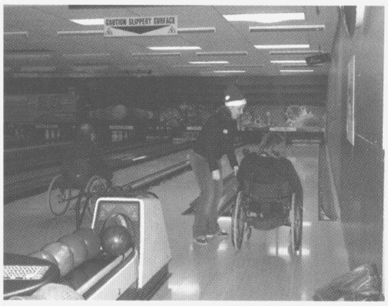
"I think the Compact is a very good idea. We're all using the same name so it will really help to have closer links and support."

Thames Valley ASBAH - one year on

February marked the end of a challenging but rewarding first year for the Thames Valley Local Association.

The group was set up by a small group of parents with children with SB and H together with members of the old Berkshire local association, which closed.

The long-term target of the new committee – headed by chairperson Sarah New – is to raise enough cash to fund a Berkshire/Thames Valley adviser.



But as secretary Marina Sawyer explained: “Getting started was much harder than we anticipated. None of us had ever done anything like this before so it’s been a steep learning curve for us.

“It took quite a while to register with the Charities Commission and establish a financial constitution that we didn’t have time to think about fund-raising or attracting new members.”

But the new group, which has ten members, has enjoyed several social events, including a day out at Wellington Court Park at Risley in Berkshire, and an adults-only bowling evening.

Marina added: “The social events are great but of course we must raise money to support ourselves. We were lucky in that the old Berkshire local association passed over their finances to us, so we did have a start-up fund, but now we need to raise more.

“It’s been difficult to organise any large fund-raisers because so many people are collecting for the Tsunami appeal. We have done small things such as placing collection boxes in local shops but we’re hoping to do more this year.”

Thames Valley Local Association holds its AGM on 18 April at 7.30pm at Hollister’s head office in Wokingham. All are welcome. For more information contact Marina Sawyer at 62 Chestnut Crescent, Shinfield, Reading. RG 2 9EJ or email: ***tvasbah@aol.com***

Sheffield Association 40 years on

Life for the Sheffield Local Association is much quieter these days... a far cry from the hectic early years when the association was getting established.

Secretary Barbara Clark was one of the founder members nearly 41 years ago, becoming involved through her son Martin, who had spina bifida and hydrocephalus.

Sadly Martin died 11 years ago, but Barbara has remained strongly involved with the committee.

She said: “I think people do still like to belong to an association and we continue to support our members in any way we can. But members today do not show the same enthusiasm and interest as they did 40 years ago.”

But as well as committee meetings, and a thriving newsletter written by John Antoszkiewicz, Sheffield still organises a popular annual Family Fun Day for old and young members, friends and colleagues.

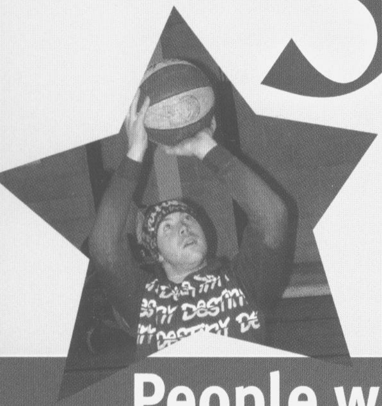
Last year’s well-attended event was held at the Sheffield and District Society of Model Engineers, with rides on the miniature trains, a bouncy castle and picnics to enjoy.

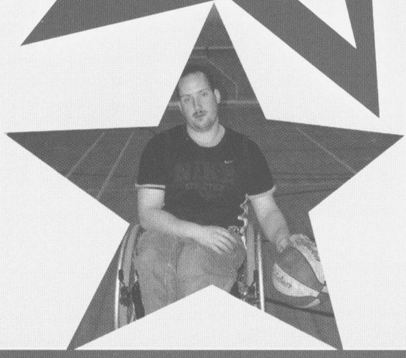
Barbara said: “In the early days we worked endlessly for the interests of those with spina bifida and hydrocephalus. Now the pace is much slower thanks to the efforts of others. In the 1960’s there was no Mobility or Attendance Allowances, we had to fight for everything.

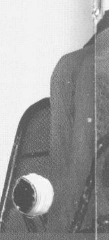
“Looking back over the 40 years, we have achieved many of our goals and we can be very proud of our achievements.

“We may not organise many social events, but all our members know that if they need our help and support, we are here for them.”

National Star College







People with disabilities hoping to study for a career sport are turning to the pioneering National Star Col

The Cheltenham-based college is a popular choice with students from around the UK, attracted by its first-class reputation for varied vocational, Entry and Pre-Entry level courses.

The acclaimed centre enables young people with disabilities to prepare for adult life through cost-effective, innovative programmes of education, training and independence, through a wide range of vocational courses.

> **At the core of the college's ethos is the ability to identify a student's potential and encourage its development to maximise quality of life, both now and in the future.**

The sports department is one rapidly expanding area with a variety of courses and activities to help students get the most out of their time at the college.

Kathryn Burgon-Watson, Sports Curriculum Co-ordinator, told *Link*: "At the moment we have 13 students – two of which are female- enrolled on the full-time vocational sports courses, all from a variety of backgrounds.

"Students come from mainstream or special schools and choose our sports courses for many reasons, including pursuing a career in sport, accessing specialist practical and curriculum sport or wanting to develop a variety of academic and sports related skills.

"There's a very lively atmosphere here, partly because there's a lot of emphasis on working in a group. Team work helps our students to gain in confidence and develop their communication skills."

The college, which has a total of 160 residential and day students plus a thriving Adult & Community Learning department, boasts a gym, swimming pool, golf course, basketball and badminton courts among its first-rate sports facilities.

Kathryn said: "Our courses include the City and Guilds Sport and Recreation Progression Awards which provide an introduction to academic and practical knowledge about the world of sport. Topics covered include health, nutrition, sports psychology, anatomy and facilities management, amongst others.

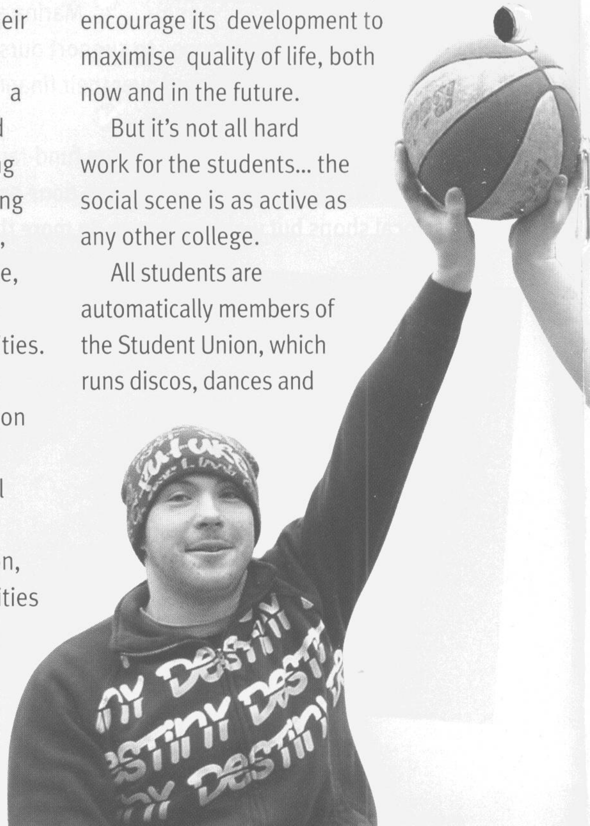
"We also run a Community Sports Leaders Award which teaches valuable skills in leadership, team building, coaching and event organising. It is a fantastic qualification for any budding coach."

Students at the college are supported by a strong team of therapists, education and residential facilitators and nurses.

At the core of the college's ethos is the ability to identify a student's potential and encourage its development to maximise quality of life, both now and in the future.

But it's not all hard work for the students... the social scene is as active as any other college.

All students are automatically members of the Student Union, which runs discos, dances and



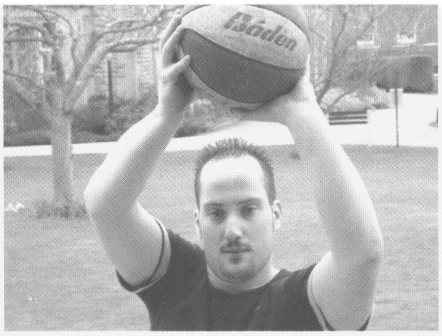
r in llege.

barbecues, among many other activities.

There are many other clubs offering a range of activities including art club, Duke of Edinburgh Award Scheme, fishing club, rifle shooting, boccia, drama workshop and concerts.

Kathryn added: “At the National Star College we have proved that independence for young people with disabilities is achievable.

“The success of our students shows that our approach to education is achieving substantial benefits and making a real difference in the lives of young people.”



Name: Mark Turner

Age: 21

Home town: Wolverhampton

My disability: Spina Bifida

My level of mobility: Independent (Manual Chair user)

The course I am attending: Sport and Recreation Progression Award Level One and Community Sports Leaders Award.

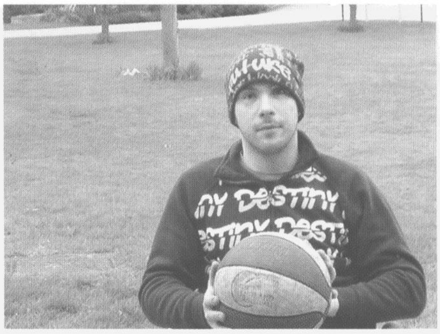
Why I chose this course: I like lots of different sports and know quite a lot about it, I want to gain good qualifications so that I can get a career in sport.

What I hope to get out of the course: I want to find out a lot more about sport and exercise, how to keep fit and healthy, learn about the human body and I would also like to learn how to teach and coach other people about sport and fitness.

I used to be a national junior power lifter and it helped me to see lots of countries and places I maybe wouldn’t have seen if it wasn’t for sport, it just proves that if you work hard and believe you can do it you can achieve a lot, I would like to be able to teach other people about how sport can help them too!

My thoughts about National Star College: I think it’s a good place, I could be here or sitting at home doing nothing – I’m learning a lot too. It gives me more chances to get involved in different sports and you can socialise with lots of new people too.

What I hope to do after National Star College: Hopefully I would like to work part time in sport, maybe working as a coach or working as a fitness instructor in a gym. It is also my dream to go to the Paralympics one day as a Power lifter. I would like to spend some time at home with my family in Wolverhampton and look for somewhere to live independently.



Name: Bryan Stevens

Age: 19

Home town: Aviemore

My disability: Hydrocephalus

My level of mobility: Independent (Manual Chair User)

The course I am attending: Sport and Recreation Progression Award Level Two

Why I chose this course: I chose the course because it was the closest one to home, which offered the best disability sport

What I hope to get out of the course: I want to gain qualifications, learn about different sports, meet new people and develop my basketball and athletics skills. At the moment I play basketball at national league division two for Bristol Pirates.

My thoughts about National Star College: I went to a mainstream school and had only met one person with a disability before I came to college, so coming to the National Star College meant I could meet and socialise with other people with disabilities, although it can be a bit protective for the more independent students at times.

What I hope to do after National Star College: I would like to work as a sports development officer for people with disabilities in the Scottish Highlands, and I would hopefully like to travel and play basketball in Ireland and America. I would also like to compete at international level in Basketball or Athletics one day.

National Star College

inclusive - innovative - inspirational

Are you *willing* to make a difference to his life?

Barney has hydrocephalus but, with ASBAH's support, he and his parents are looking confidently to the future. ASBAH supports and provides specialist advice throughout England, Wales and Northern Ireland for thousands of children and adults with hydrocephalus and spina bifida, making a positive difference to their lives.

You can help us make that difference!

We rely upon donations and legacies to enable us to continue our work with children like Barney. For further information please write to Jane Ayres at the address below or ring 01733 555988.

Association for Spina Bifida
and Hydrocephalus
42 Park Road,
Peterborough PE1 2UQ
email: janea@asbah.org
www.asbah.org

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LiNK

The ESSENTIAL magazine for people with hydrocephalus and spina bifida

ASBAH's magazine, Link, is an absolute lifeline!

Nici Picken
Gloucestershire

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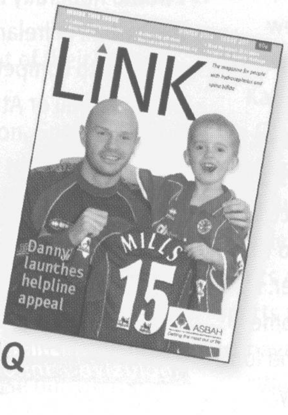

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Meet the expert

Hazel Bennett, *Psychologist*

***Link* meets up with Psychologist Hazel Bennett, a contributor to the *Your Child and Hydrocephalus* book and a speaker at the Family Awareness Days.**

When and why did you become interested in psychology?

I became interested in psychology during my A-Levels. I did some work experience in a local hospital and became more interested in the consequences of ill health for people, such as the distress it causes and the later implications for their quality of life, than the actual diagnosis and treatment. I began thinking about individuals and asking questions about why we do things, how our mind works and the processes that determine why similar situations effect people so differently. I found this area fascinating.

Where did you study for your Psychology degree and when did you graduate?

I studied at the University of Nottingham and graduated in the summer of 2003. Throughout my degree I was particularly interested in Clinical Psychology, which applies psychological principles to help us understand clinical problems, such as depression and anxiety

When did you begin work at the University Hospital, Nottingham, and how long were you there for?

I began working as an Assistant Psychologist at the University Hospital, Nottingham in October 2003. I was in post there for one year.

I believe you trained under the guidance of Arleta Starza-Smith. How much of an inspiration was she to you?

Arleta was my supervisor while working in Nottingham. I feel I was very fortunate to have had a supervisor who was not only a fountain of knowledge and experience but who was also so enthusiastic about the work we were doing and the children we were working with. She is a very supportive mentor and was and still is a huge inspiration for me.

When did you become involved in working with children with hydrocephalus and their families?

When I started working in Nottingham I was involved with children and adults with neurological conditions. Many of the children I saw at this point had hydrocephalus and my interest and involvement with these children and their families increased over the year.

In what areas do psychologists help children with hydrocephalus?

Clinical neuropsychologists have the skills to assess children's cognitive abilities (e.g. memory, processing speed, spatial processing) to determine their individual strengths and weaknesses. Depending on the outcome of the assessment and the nature of the individual child's difficulties they may then offer guidance, strategies and support in an attempt to help the child to reach their potential level of functioning. However, all departments differ in the nature of service that they offer and each child referred comes with an individual, complex set of needs.

When did you first become involved with ASBAH and to what extent do you think the charity helps children and adults with hydrocephalus, and their families?

I became involved with ASBAH after a few months of working in Nottingham when Arleta and I started to get involved with writing a chapter of the book 'Your Child and Hydrocephalus'. Since then I have become increasingly aware of the nature of ASBAH's work. I think the charity is an absolute saving grace for so many families and individuals with hydrocephalus. It is a huge source of information and support for the whole family, without which many people would feel very isolated, confused and distressed.

What is your current post?

I am currently working as an Assistant Psychologist with Leeds Adult Mental Health NHS Trust. I work in an Assertive Outreach Team, offering psychological support to people in the community with severe and enduring mental health problems.

How much of your work today is supporting children with hydrocephalus?

Due the nature of the route into Clinical Psychology, graduates need experience in a variety of areas before doctorate training. Unfortunately, therefore, I

Continued overleaf...

...Continued from previous page

Meet the expert

Hazel Bennett, *Psychologist*

do not work directly with children with hydrocephalus at present; however I am still in contact with ASBAH and am speaking at a number of their family awareness days this year. This is still an area of interest for me and I look forward to having the opportunity to come back to this field of work after my training is complete.

Do you find your job stimulating and satisfying?
Absolutely. I think that any job that involves meeting different people every day and offering them a source of support and hope for the future can only be stimulating and satisfying.

Are there any downsides to the job?
I guess as an assistant psychologist it is frustrating to work in each job for only one year. You just start to build up experience, skills and knowledge when you have to move on to the next post. It does mean, however, that you have a wide range of experience to equip you later as a trainee clinical psychologist.

What are your career hopes for the future?
I have applied for the 3-year Doctorate in Clinical Psychology and have interviews at the end of April. Following this training I will be qualified as a Clinical Psychologist and, at present, I plan to work in Paediatrics while maintaining my interest in research.

What are your interests outside of work?
I enjoy camping and cookery and attempt to make as much time for these hobbies as possible. I also try to keep fit through aerobics, walking and dance.

How do you relax?
Absorbing myself into a really good book or meeting up with friends and family is good escapism for me.

Chat rooms - your experiences

In *Link* 211 we highlighted the importance of safety when using Internet chat rooms.

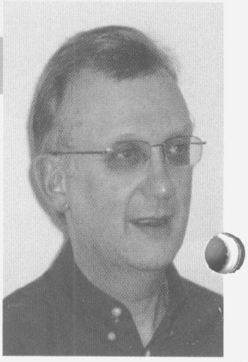
Mary Malcolm, Assistant Director, Services, said that many ASBAH members use the Internet as a way of talking to new people.

But she also voiced her concerns that chat rooms are a way for paedophiles and other dubious characters to get to know someone under false pretences.

“Many of our members do live independent lives, but they may still be very vulnerable,” she said.

This issue we meet two *Link* readers who have used the Internet to talk to new people, but have had very different experiences.

John's story



John Antoszkiewicz spent more than 20 years working as a singer in clubs and theatres around Britain.

Since retiring in 1997 through ill health, John, 55, became interested in computers and latterly, the Internet.

Three years ago he logged on to the popular icq website, which is used as a meeting place by millions around the world. Now he has many friends across the globe he is in regular contact with.

John said: “I looked at the chat rooms initially out of curiosity, but I found them a strange way of talking to people. Most of the conversations don't make much sense.

“Instead I completed a profile page, giving my age, background, interests, that sort of thing, and posted it on the site.

“Over the years a variety of people who share the same interests and outlook as me have been in touch. But we either use the Instant Messaging service or email each other.”

John, who is a member of the Sheffield Local Association, keeps in touch with people in Arizona, Canada, Michigan, Australia, Ankara, Rhode Island... as well as a few who are more closer to home in Norfolk and Staffordshire.

He added: “It's pleasant to have a chat to people, it's interesting to hear their experiences and it helps to pass the time. It's really the modern equivalent of pen pals and providing you use the system properly and safely, it can be a lot of fun.”

It's pleasant to have a chat to people, it's interesting to hear their experiences.

Chrissie's story

Chrissie also contacted Link after reading the article in our last issue, and shared her experiences.

“I split up with my partner last year and found myself living on my own for the first time, independent, but still vulnerable.

“A friend introduced me to internet dating and chatting and it seemed to work for her.

“Once I was on the internet I decided to give it a try, although unlike her, I don't use a wheelchair.

“It didn't work for me though. I used the chat rooms from April 2004 to January 2005 and have finally decided that enough is enough. I didn't find love, I just had bad experiences.

“I do feel isolated so I thought internet chatting would give me some company. But all it gave me is trouble. Some men I just chatted to, others I met. In my experience many men just use the chat rooms to harass girls.”

I didn't find love, I just had bad experiences.

Siobhan Corr's pregnancy diary

Weeks 20-40

Concluding our popular series, Siobhan Corr, who has spina bifida and hydrocephalus, opens the pages of her diary to share her experiences during the second half of her pregnancy, and the first weeks of motherhood.

22 July Our 20 week anomaly scan. The consultant explained that she would, in particular, be looking for indications that my baby had any structural abnormalities such as spina bifida or cleft palate etc. She measured the baby's head, it's limbs, studied its kidneys – all good indicators of spina bifida or hydrocephalus and confirmed all looked absolutely normal. She confirmed the sex of the baby for us.

20th August I awake with a sharp pain in my side. I suspect a UTI, but since infections can induce labour, I decide to ring the hospital, who advise me to come to triage for assessment. They confirm a UTI and I have to increase my dose of antibiotics for 7 days. Baby is well.

In addition, I am having considerable pelvic discomfort – sleeping and walking are becoming more difficult.

9th September I am referred to the senior physiotherapist at the hospital. She advises me to cushion my bed mattress, use a footstool to get in and out of bed and keep my knees together when getting out of chairs etc. I will have to sleep with 2 pillows from now on – 1 under my bump and 1 to protect my pelvis. I can take a small dose of paracetamol for the pain.

29th September I am 29 weeks pregnant and can no longer change my urostomy bag. I visit the practice nurse at my local clinic and she arranges for me to attend the district nurse every 3 days until I deliver my baby. My stoma has changed shape and size and I will have to see the stoma nurse for advice on new products.

30th September The anaesethetist discusses with me the options for pain-relief An epidural is ruled out, as it might prove problematic because of the location of my lesion. Drugs seem the best option!!! In the event of a Caesarian, I will require a general anaesethetic.

21 October My consultant has arranged for me to speak to a Urologist – in the event of a Caesarian, due to the position of my ureters, it would be best to do a mid-line incision – although, this would require a longer recovery. My Consultant is still keen that I should deliver normally (if possible).

5 December 6 days before my due date, I start to have niggling pains and after 8 hours, I go to hospital. I stay overnight for observation but am advised to go home to rest since I am not (officially) in active labour.

6 December I return, 6 hours later, in an ambulance. I am 5 cms dilated and require gas and air for the pain. They break my waters 4 hours later at 7cms and the pain then really intensifies – I require a small dose of diamorphine. 2 hours later, fully dilated, I start to push. However, over an hour later, I have still not delivered the baby and am tiring.

The doctor in charge assists with a Ventouse. Daniel James is born at 1.25 am on 7 December. He weighs 7 lbs 4 ozs.

The first few weeks...

I have this enormous sense of achievement, beyond anything else that I have achieved (graduation, promotion etc).

Martin and I enjoyed nearly a month together with Daniel before he had to return to work. This was a joyful time, never to be forgotten. However, it was not a true reflection of motherhood – the visitors soon stop coming!

I soon had to face up to the practical difficulties of motherhood – carrying him in and out of the car, bending down to bath him, lifting him on to and from his playmat etc.

All of these have required greater organisation and thought on my part to ensure his safety. Not having family close, has made things more difficult – a baby is not always good company! I have had to make real efforts to meet lots of other mums and this has provided me with support and a whole new social life which I had never contemplated – Music with Mummy, Gym tots, Mother and Baby groups etc.

I am determined to enjoy the remainder of my maternity leave with Daniel and that he should be fulfilled by this time together.

Codman - Working in partnership with ASBAH

Benny Bear Colouring Competition

Thank you to all the budding artists out there who entered our Benny Bear colouring competition.

We asked 5 – 10 year-olds to send in their pictures showing what adventures they would like to see Benny Bear enjoying this year.

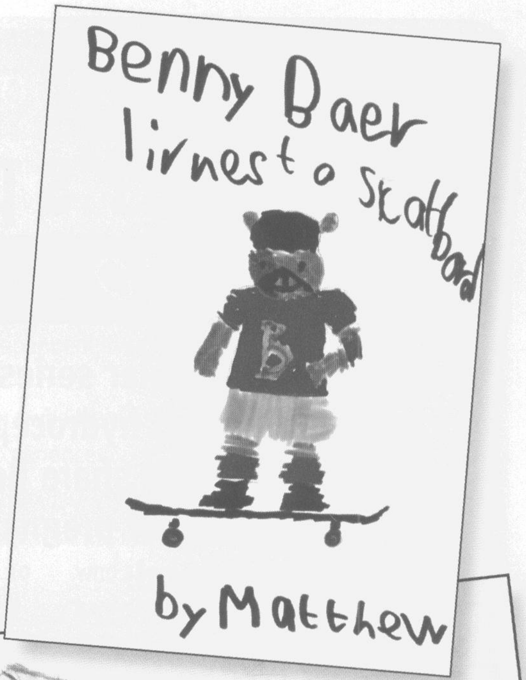
And the entries flooded in and have given author Rosemary Batchelor plenty of inspiration for the next books.

Ideas included Benny joining a football team, skateboarding, swimming and a camping trip to name just a few.

After much deliberation our judges voted Stephen Naylor, Fraser Cummins, Matthew Williams and Erin Walpole the four winners.

As well as their own Benny Bear teddy bear – the winners will be receiving a gift token to allow them to buy either new drawing materials – or new books to read.

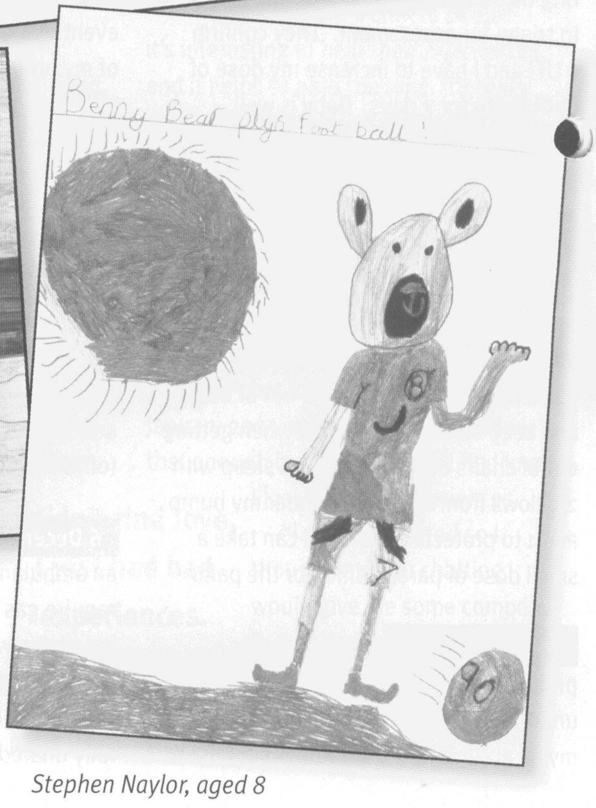
Well done to everyone who entered.



Matthew Williams, aged 6

Fraser Cummins, aged 6

Erin Walpole, aged 7



Stephen Naylor, aged 8

hydrocephalus action

Theatre Nurses visit Codman

Senior theatre nurses took a detailed look at how shunts are made during a visit to Codman's Switzerland factory.

The group of 30, from hospitals across the UK, also heard leading experts talk about hydrocephalus and the physical and psychological problems, which can result from the condition.

ASBAH's medical adviser Rosemary Batchelor and Peter Farrall, Assistant Director Communications, accompanied the nurses on the three-day fact-finding mission in March. They gave a presentation on the Hydrocephalus Action Awareness campaign – a partnership between ASBAH and Codman, and the new '*Your Child and Hydrocephalus*' book.

The speakers also included Liverpool-based senior theatre nurses Joan Grogan, from Alder Hey Hospital and Trish Byrnes from the Walton Centre, who spoke about the fitting of shunts in their respective hospitals.

Roger Bayston, gave a talk on Bactiseal and how it helps to prevent infection, and Sue McQueen OBE, head of infection control at Great Ormond Street, spoke about MRSA and how infection rates can be reduced.

Peter Farrall said: "Touring the Codman factory was incredibly interesting. It was fascinating to see how the shunts are made in highly sterile conditions, with such precision and accuracy ... which is especially impressive when you consider the size of a shunt and the importance of the job it does

"The factory is based in La Locle, which is known as Watch Makers Valley, as Cartier, Tissot, TAG Heuer, Swatch and many others, are based there. The area has a long tradition of very highly skilled, precise, detailed work."

Rosemary Batchelor added: "It was a very useful trip as many of the nurses only see patients on a clinical basis so they learned a great deal about hydrocephalus and its effects. We also handed out copies of the *Your Child and Hydrocephalus* book for them to take back to their units."

PROFILE

Roger Bayston

MMedSci FRCPath

Roger Bayston, ASBAH's Honorary Consultant in hydrocephalus, was one of the key speakers during the theatre nurses visit to the Codman factory.

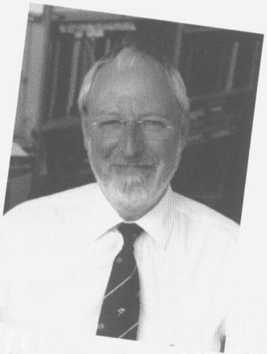
Roger, who is Senior Lecturer in surgical infection at the University Hospital, Nottingham, gave a presentation on Bactiseal and how it prevents shunt infection.

During his career Roger has carried out research into complications of hydrocephalus shunting, and particularly infection, resulting in more than 100 publications.

He was ASBAH's first ever Research Fellow, and during this time the groundwork was laid for his later studies into shunt infection.

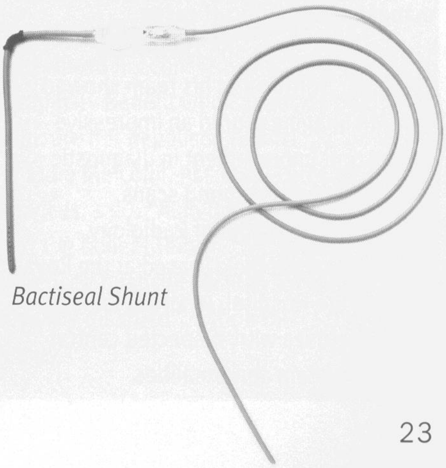
Since then Roger has devised a diagnostic test for shunt infections and introduced new national guidelines for the treatment of shunt infections.

He also developed the revolutionary Bactiseal shunt, which prevents infection by killing bacteria on contact.



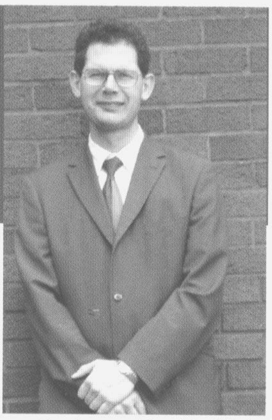
Roger Bayston

For many years Roger has been a member of ASBAH's Medical Advisory Committee, as well as a long-standing member and past Treasurer and Hon Secretary of the Society for Research into Hydrocephalus and Spina Bifida.



Bactiseal Shunt

Volunteers needed for new research study



Professor Paul Griffiths

Mothers-to-be carrying babies with suspected spina bifida are being offered the chance of an improved diagnosis as part of the new phase of an ASBAH-funded research study.

Professor of Radiology, Paul Griffiths is looking for volunteers to have MRI scans for detailed monitoring of foetal spine and brain abnormalities.

Local associations and ASBAH area advisers are being asked to speak to pregnant women carrying a baby, which has been diagnosed with spina bifida, who may be interested in having a more detailed scan.

Professor Griffiths, who is based in the Academic Unit of Radiology at Sheffield's Royal Hallamshire Hospital, has been carrying out in utero Magnetic Resonance Imaging (MRI) for the past six years.

His studies have revealed that in most cases of spine and brain abnormalities, MR imaging provides vital, detailed information that can help.

In a recent trial of 100 pregnancies, MRI scans gave a 48% improvement in diagnostic accuracy.

In his latest research series, which is part funded by ASBAH, Professor Griffiths plans to scan the foetuses at between 20 and 24 weeks. If the pregnancy continues, the women will be invited back for a repeat examination at around 30-32 weeks.

Any suitable mothers-to-be, whose unborn baby has been diagnosed as having spina bifida and who are interested in taking part in this research will be referred to Professor Griffiths via ASBAH's Senior Medical Adviser Rosemary Batchelor.

Professor Griffiths will then make contact with their obstetrician before arranging to see them. The referring hospital will not be charged for the MRI scan and ASBAH will cover the volunteer's travelling expenses to Sheffield. The information gathered by the MRI scan will be sent to the mother's obstetrician.

> **This important research has already pushed forward MRI techniques to provide far more information to expectant mums.**

Since the project was launched six years ago, more than 350 pregnant women have been scanned, as part of clinical work as well as research studies.

Now Professor Griffiths is looking forward to expanding his caseload after hearing that he has been awarded a £2 million grant to buy a second MRI scanner, purely for foetal imaging.

Professor Griffiths said: "We hope the new scanner will be up and running in 2006 and this will enable us to improve our capacity to take on more clinical cases and research studies.

Andrew Russell, ASBAH's Executive Director, commented, "This important research has already pushed forward MRI techniques to provide far more information to expectant mums. We want to see this work brought widely into clinical practice. I hope that many women prenatally diagnosed with a spina bifida pregnancy will consider going to Sheffield, as it will help the research and give further information to the patient."

MR imaging what are the advantages?

Magnetic Resonance Imaging (MRI) gives important extra information over ultrasound when assessing the severity of foetal abnormalities such as spina bifida and hydrocephalus. This information is often useful for mangement of difficult cases.

In a report published last year, Professor Griffths and his team showed that MR imaging scored an impressive 48 per cent improvement in diagnostic accuracy over ultrasound scans.

The Academic Unit of Radiology, University of Sheffield, based at the Royal Hallamshire Hospital, ran trials looking at 100 foetuses with suspected central nervous system abnormalities.

The foetuses were scanned by both ultrasound and MR imaging and the results were compared.

Professor Griffiths revealed: "Until now there have been few large studies which have performed detailed follow-up in order to confirm or refute the antenatal diagnosis.

"So we were very pleased when our study revealed that the MR imaging gave a 48% improvement in diagnostic accuracy."

In 35 of the 100 cases in the study, MR imaging provided extra information, which either changed the diagnosis, or provided additional information which could have altered management.

In 11 cases where MRI changed the diagnosis, the brain was described as abnormal on ultrasound but was shown to be normal on MRI.

Professor Griffiths said: "If we have achieved anything so far, we have been able to show that in a number of cases that termination of pregnancy was not necessary."

He added: "MRI is a powerful tool for investigating the foetal brain and spine. Having this detailed clinical information can alter management of the conditions, and also enables the parents to make a more informed choice.

The clarity of the images also makes it much easier for medical staff to explain to parents exactly what the abnormalities are."

Adding folic acid to food is the most successful way of reducing neural tube defects, a new report suggests.

The policy, used in America and Canada, has resulted in the number of neural tube defects falling by more than three quarters since folic acid fortification was introduced there in 1996.

The study, published in the British Medial Journal, also concluded that Government recommendations advising women to increase their intake of folic acid failed to reduce these birth defects in nine European countries and Israel.

Researchers looked at the incidence rates of neural tube defects in England and Wales, Finland, the Netherlands, Ireland, Hungary, Portugal, three regions in France, two regions of Italy and Israel.

They examined the incidence rates of neural tube defects before and after government's recommendations about taking folic acid supplements, in a study of 13 million births.

The researchers believe that government recommendations did not work because the majority of women either took no notice of them, or only did so for a short while after the publicity campaign.

By fortifying food – such as flour - with folic acid ensures that women get the necessary intake without having to think about it, the team concluded.

In 2000 the Committee on Medical Aspects of Food and Nutrition Policy recommended that the fortification of flour should be introduced in Britain. But the Department of Health consulted the Food Standards Agency to consider the issue.

Two years later the agency asked for more research to be carried out because of potential risks to the elderly. But Canadian research, published last September, detected no ill effects on the elderly, whose vitamin B12 deficiency can be masked by folic acid.

ASBAH's Executive Director Andrew Russell told Link that Britain now lags behind 30 to 40 countries that have added folic acid to food.

He said: "Around 100 babies are born every year with spina bifida, and many more are terminated early because the condition has been detected. That is not a good strategy when you can do primary prevention by adding folic acid to food."

Disability campaigners consider benefit changes

There has been a mixed response to the government's plans to reform the welfare system in a bid to get more sick and disabled people out to work.

The benefits, paid to almost 3 million sick and disabled people, are to be overhauled to remove disincentives to return to work.

The outline plans included scrapping Incapacity Benefit along with automatic rises in payments for claimants after six months and a year.

Most claimants are expected to receive the new Rehabilitation Support allowance of £55 a week, which will be topped up for those making efforts to return to work. Others with more severe medical conditions and disabilities will get the new Disability and Sickness Allowance.

Works and Pensions Secretary Alan Johnson said he wants to remove the "perverse incentive" for people who are able to work again to stay on Incapacity Benefit, which increases from just under £56 a week to £74 a week after a year.

In an interview with the BBC, disability campaigner Bert Massie, chairman of the Disability Rights Commission, gave a cautious welcome to the extra support to help people get back to work. But he also voiced his concerns that people on Incapacity Benefit who cannot do paid work are not penalised financially.

Mary Malcolm, Assistant Director, Services, said: "Alan Johnson has stated that the benefit reform "will provide enhanced financial security for the most severely disabled". I hope this is the reality."

Call to abolish means testing for Disabled Facilities Grant

A coalition of the UK's leading children and disability charities is campaigning for reform of the Disabled Facilities Grant (DFG) because it fails even the poorest families.

The action group, made up of 12 leading UK charities including Mencap, ASBAH, Barnardo's and Scope, is calling for MPs to abolish the means testing of the Disabled Facilities Grant.

DFG is a grant that is available to disabled people or families with disabled children to help pay for adaptations to their home such as a downstairs bathroom or a stairlift.

But the campaigners believe the means test is unfair and unworkable as there are many additional and hidden costs to bringing up a disabled child.

The group claims that families with disabled children are already among the worst off, as bringing up a disabled child costs on average three times as much as a non-disabled child.

A recent study showed that families caring for a disabled child face severe reductions in employment status, level of earnings, savings and pensions and incur many additional costs including equipment, transport and medical support.

The abolition campaign has attracted widespread support from voluntary groups, occupational therapists and parents.

More than 100 MPs from all parties have supported a petition calling on the Government to abolish the means test at the earliest opportunity.

Caroline Gordon, National Campaigns Officer at Mencap told *Link*: "The Office of the Deputy Prime Minister is currently reviewing the DFG process and is due to publish its report to Ministers in May 2005.

"We would welcome further support to ensure that the concerns of families around the country are listened to and acted upon. We would be happy to assist you in raising this issue in the House or to Keith Hill MP, Minister responsible for the DFG, or Lord Rooker, ODPM Minister in the House of Lords."

ASBAH's Executive Director Andrew Russell commented: "I'm hopeful this time. ASBAH has continually pressed on this issue, in a private meeting with the previous government's Housing Minister, and a meeting last year with the Prime Minister's Strategy Unit.

"It's disturbing that successive governments have failed to act, despite professing concern for disabled people and their families."

For more information about the campaign to reform the Disabled Facilities Grant (DFG), visit the Mencap website at ***www.mencap.org.uk/dfg***

Caroline Gordon can be contacted at Mencap on 020 7696 6021 or ***caroline.gordon@mencap.org.uk***

Welcome to

In the last issue of *Link* we met mother-to-be, Sam Copeland, who talked openly about her feelings for her unborn baby, who had recently been diagnosed as having spina bifida.

It was a difficult time for the family but on 16 February their wait was finally over... Elisabeth Ivy Copeland was born by Caesarean section at 11.50am, weighing in at a healthy 7lb 6oz.

Now Sam talks to *Link* about the tough first few weeks as she and husband Mark watched their new baby undergo six operations.

Sam and Mark were naturally upset when a routine 16-week scan last October revealed that their baby had spina bifida.

The couple, from Cheshire, had longed for a baby since they married in 1999. Sam, 35, already has two children – Laura, 15, and David, 12 - from her first marriage, who were adopted by Mark in 2003, and the couple wanted a third to complete the family.

The news that their baby had spina bifida was a great shock, but the support of relatives, friends and ASBAH, helped Sam and Mark prepare for the new – and much wanted - addition to the family.

And on 16 February their baby girl Elisabeth – or Beth as she's usually called – was born.

But the first four weeks of Elisabeth's life were tougher than Sam and Mark had anticipated, as they had to stand back and watch their new baby being taken to theatre five times in the first few weeks.

"It's been a rough time for all of us, but we finally feel that we're getting there," Sam told *Link*. "Worry is exhausting and the lack of sleep doesn't help either. But I feel much better in myself now and I finally feel that life is getting back to normal."

"And Beth is a real tough cookie. After every operation she's been wide-awake within the hour, waiting for her next feed. And already she has pushed herself up on to her knees when I've been trying to change her nappy."

Sam added: "The whole family has been through really stressful time, but Beth is so gorgeous that she's worth it all. Many thanks too to *Link* readers who have expresed their good wishes and support for us – we really appreciate it!"

he world baby Elisabeth

Sam's Diary - Sam shares some extracts from her diary written during the first weeks of Elisabeth's life.

Wednesday 16 February

Elisabeth was born by Caesarian section at 11.50am. I had said that I didn't want to see her back before it was operated on, but I did look. I was expecting it to be like an open bullet hole, but it looked like a [illegible]mp of jam.

Elisabeth was wrapped in cling film like a chicken and was taken to the children's hospital that afternoon. Mark followed the ambulance by car.

My ASBAH adviser Elizabeth Miers came to see me and was very supportive. It is strange being here without my husband and newborn baby.

Thursday 17 February

Elisabeth's back was operated on. The nurses told me that if I could get out of bed and eat some breakfast I would be able to go to the children's hospital to visit her. I was out of that bed like a bullet! I still felt very ill and had to use a [illegible]eelchair, but it was worth it.

Beth's operation went well.

Saturday 19 February

I was discharged from hospital. It is so lovely for Mark and I to be together at last with our baby.

Monday 21 February

I finally got the chance to cuddle Beth and breast-fed her for the first time.

Tuesday 22 February

Beth is very unsettled. At her MRI scan her kidney and bladder were very enlarged. She was given an intermittent catheter, which she'll need indefinitely, or even permanently.

Wednesday 23 February

As a doctor was showing me how to do the catheter, Beth moved her toes for the first time. I thought I was imagining it, but then she moved her feet. I was in a state of shock and delight.

Thursday 24 February

During a ward round Beth lifted her legs in the air. Everyone is thrilled.

Friday 25 February

Everyone is happy with Beth's progress and she is discharged from hospital.

Monday 28 February

Back at the children's hospital to have Beth's stitches removed. When the final stitch is taken out, CS fluid spurts out everywhere. I am devastated. I didn't know what it meant. Her back was stitched again with dissolvable sutures.

Tuesday 29 February

Beth's wound leaked again in the night. A CT scan shows that she does have hydrocephalus. In a strange way I am relieved because I won't keep looking out for the symptoms.

I spoke to Elizabeth Miers at 10.30am, and by noon she was with me on the ward. She is a great comfort. Beth's shunt was fitted and her back re-stitched. She was back on the ward by 3pm.

Friday 4 March

Everything is looking rosy. Beth is discharged from hospital again.

Saturday 5 March

As I changed a nappy, I noticed a wet patch on Beth's back. Back to hospital again. The shunt has failed so Beth went into theatre to have the shunt replaced and her back re-stitched. My feelings were very mixed, although I had been told that shunts fail sometimes, I was shocked that it failed after just four days. I felt completely out of my depth

Sunday 6 March

Beth was very unsettled all night. I noticed another wet patch on her back. It was an emergency dash to theatre to open up her back to find out where the leakage was coming from. The surgeon found a hole near the base of her spine and needed to repeat part of the original closure

Monday 7 March

CT scan shows that everything is OK but Beth must stay in hospital to rest and recover.

Wednesday 8 March

Everything is going well and Beth is gaining weight.

Monday 14 March

Beth is discharged and we can finally go home. I hope it will be for good this time. There are more than 100 new baby cards waiting for us and I am looking forward to having visitors. I hope we can put the past few weeks behind us and get on with life with our new baby.

Monday 21 March

Beth went to theatre to have stitches removed. After the last time I was a nervous wreck, but all seemed to go well.

Tuesday 22 March

WE ARE HOME AT LAST!!!!!

The Way Ahead

Wheelchair users in Milton Keynes worked with artist, Caroline Cardus, to speak out about their everyday experiences of access and integration for a nationwide exhibition.

Using the format of UK road signs, The Way Ahead presents their views in a humorous and thought-provoking way.

Caroline's work is motivated by personal experience of disability, and she hopes her art will promote discussion about the reality of disabled people's lives.

She said: "As an artist I believe in using my art as a medium to speak about my experiences, good and bad. I wouldn't change who I am, but sometimes I wish the world were different.

"The Way Ahead is an idea I had after feeling the European Year of Disabled People had passed me by with little impact on my everyday life.

"I wanted to produce a body of work that explored whether other disabled people felt optimistic or pessimistic about government legislation, or whether the changes they wanted to see were not covered by laws, by society's perception of them as fellow human beings."

The Way Ahead exhibition will be on show at Sheffield College Gallery, 10 – 25 May, and at Salisbury Arts Centre, 17 – 26 June.

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 was very saddened to hear of the death of Duncan Forrest, whose obituary I read in the last issue of Link.

Mr Forrest was my consultant at the Westminster Children's Hospital for the first nine years of my life.

He was a person of great warmth and had a real empathy for all the patients in his care and their parents.

He will be fondly remembered for the pioneering work he did in the field of spina bifida and hydrocephalus.

I will miss him.

***Judith Hayeem** - Harrow, Middlesex*

I was delighted to read about ETV in the last issue of Link, as my son was born with hydrocephalus, which was found during a routine scan at 18 weeks.

The consultant's advice was to terminate the pregnancy but my husband and I were not prepared to do this.

After 16 more scans to monitor head growth, our little boy was born naturally with no problems and at seven weeks old he had an endiscopic third ventriculostomy.

Our son is now two years old and a normal, happy little boy, although he has been slow at learning to walk, is nearly there now!

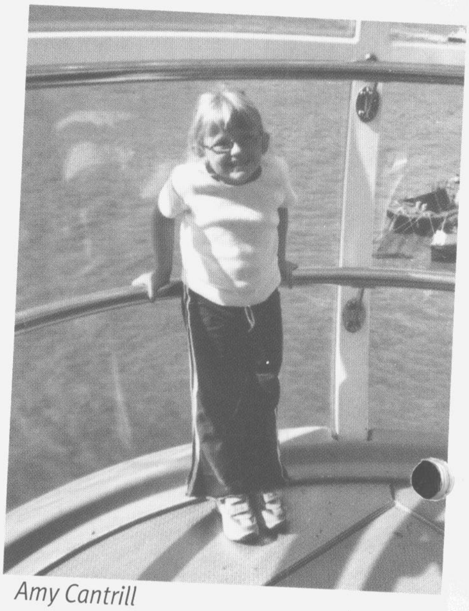
***Tracey Shirley** - Dursley, Glos*

Reading our interview with Sam Copeland in the last issue stirred many memories for Link reader Helen Cantrill.

Helen, from Somercotes in Derbyshire, contacted us to say she was in a similar situation five years ago.

She wrote: I also experienced the ignorance of some of the medical profession. It was presumed that I would want a termination as soon as it was found out that my daughter had SB.

Five years on, with a very happy, healthy and lively daughter, who has just a few SB related problems, such as intermittently catheterisation and some slight mobility issues. I am so very glad that I didn't take their advice.


Amy Cantrill

Life goes on no matter what and with love and a smile, most obstacles can be overcome or coped with and I send my very best wishes to Sam and her family.

I have been in contact with other families affected by spina bifida, and found it to be very useful. I would be pleased to hear from other families.

Helen Cantrill

If you would like to get in touch with Helen, contact Catherine Mayfield, medical adviser, Eastern region or send a letter or email to Link.

I would be interested in hearing from other people who have a programmable shunt, especially those who have travelled abroad. I am 23 years old and have spina bifida and hydrocephalus. I am going on holiday this year and am concerned that my programmable shunt will be affected.

***Lydia Blackmore** - Crawley, West Sussex*

Lydia can be contacted through The Editor, Link.

I would be interested to know the age of the oldest Link reader who has spina bifida. When I tell people that I am 80 years old, they always comment that I must be the oldest living person with spina bifida.

***Ms J 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 clubhouse, 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***

PAIGNTON, DEVON

Six Berth all electric wheelchair accessible caravan situated within a mile of the beach. Site facilities [illegible]ude 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. [illegible]s 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@baxterjo.freeserve.co.uk***

BERWICK COTTAGE, EAST HARLING, NORFOLK

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*

ORLANDO, FLORIDA

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*

TRENERRY LODGE, CORNWALL

Farm bungalow, mobility level 1 accessible. Sleeps 4, open all year. Short and long breaks. **Details: Angela Parsons tel: 01872 553755** *www.babatrenerry.co.uk*

For sale

MEYRA OPTIMUS POWER CHAIR, virtually new, £4,000 ONO. Tel : 01243 822410, can deliver within 100 miles of Sussex coast.

Diary dates

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

Eastern Region
Saturday, 2nd July - Royden, Norfolk/Suffolk
Hydrocephalus Awareness Parents day
(based on the *Your Child and Hydrocephalus* book)
Tuesday, 7th June - BIH Study day - ASBAH House

South Eastern Region
Saturday, 7th May - Banstead, Surrey
Saturday, 18th June - Maidstone, Kent
Hydrocephalus Awareness Parents day
(based on the *Your Child and Hydrocephalus* book)

Northern Region
Monday, 20th June - Liverpool
Saturday, 17th June - Darlington
Hydrocephalus Awareness Parents day
(based on the *Your Child and Hydrocephalus* book)

Wales
Wednesday, 18th May - St Asaph, North Wales
Monday, 23rd May - Cardiff, South Wales
Hydrocephalus Awareness Parents day
(based on the *Your Child and Hydrocephalus* book)

South West
Saturday, 14th May - Bristol
Hydrocephalus Awareness Parents day
(based on the *Your Child and Hydrocephalus* book)
Contact ASBAH, Peterborough for more details

ASBAH AGM, Peterborough
Saturday, 24th September

Please e-mail the editor (link@asbah.org) dates for the next issue of Link by Friday 10 June 2005, 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 17th June 2005

Please send to: Editor, ASBAH
42 Park Road, Peterborough PE1 2UQ.
Tel: 01733 555988. Email: ***link@asbah.org***

ASBAH offices

ASBAH
42 Park Road
Peterborough PE1 2UQ
Tel: 01733 555988
Fax: 01733 555985
Email: ***info@asbah.org***

ASBAH EAST
42 Park Road
Peterborough PE1 2UQ
Tel: 01733 555988
Fax: 01733 555985
Email: ***ero@asbah.org***

ASBAH NORTH
64 Bagley Lane,
Farsley, Leeds LS28 5LY
Tel: 0113 2556767
Fax: 0113 2363747
Email: ***nro@asbah.org***

ASBAH SOUTH EAST
209 Crescent Road
New Barnet, Herts EN4 8SB
Tel: 020 84490475
Fax: 020 84406168
Email: ***sero@asbah.org***

ASBAH IN WALES
4 Llys y Fedwen,
Parc Menai, Bangor,
Gwynedd LL57 4BL
Tel: 01248 671 345
Fax: 01248 679 141
Email: ***wro@asbah.org***

ASBAH N. IRELAND
Graham House
Knockbracken Healthcare
Park, Saintfield Road,
Belfast BT8 8BH
Tel: 028 90798878
Fax: 028 90797071
Email: ***niro@asbah.org***

"It just goes to show that if the shunt is working, anything can be achieved."

Matthew Carnelley

When Matthew Carnelley developed hydrocephalus as a baby, his parents prayed that he would be able to lead a normal life.

Thirteen years later the football-mad youngster is following in the boot-prints of northeast greats like Malcolm MacDonald and Alan Shearer.

He has made light of his condition, caused when he contracted meningitis, to be snapped up by Middlesbrough Football Club's Academy.

The midfielder, who joined the Premiership outfit just as ASBAH helpline patron Danny Mills left for Manchester City, is currently a key part of the Under-13 squad.

But his amazing achievements don't end there – he also has district cross country and 200 metre titles to his name.

Dad, Russell, summed up the teen star's amazing courage when he said: "As a baby we prayed he'd be able to lead a normal life...but now we feel we've got Superman."

Matthew chose Boro ahead of Newcastle, Hartlepool, York and his home town and favourite club of Darlington.

Russell added: "We chose Middlesbrough in the end because its training academy is close to Darlington.

"We were concerned that when Middlesbrough found out Matthew had a shunt they wouldn't be interested, but they've been very supportive. All the coaches have been informed of the symptoms of shunt failure."

Training sessions three nights a week from 5.30 to 7.30 means the trainee has to be organised to fit in his homework.

Matthew started playing aged five when he joined the Darlington Master Skills Academy, but admitted his parents were always wary.

"I developed good skills and fitness but mum and dad didn't want me to play in a competitive league," he said.

But as he grew in stature and his talent became more obvious he was directed to a local team, from where he progressed to represent the district.

Each Sunday is spent playing another club academy side, and Mathew admits his dream is to break into the first team and become the next Mark Viduka or Jimmy Floyd Hasselbaink.

Russell said: "He is as fit as any kid on the team. At a recent hospital check-up medical staff were concerned that his heart rate was too low, but it seems it is a result of his high level of fitness.

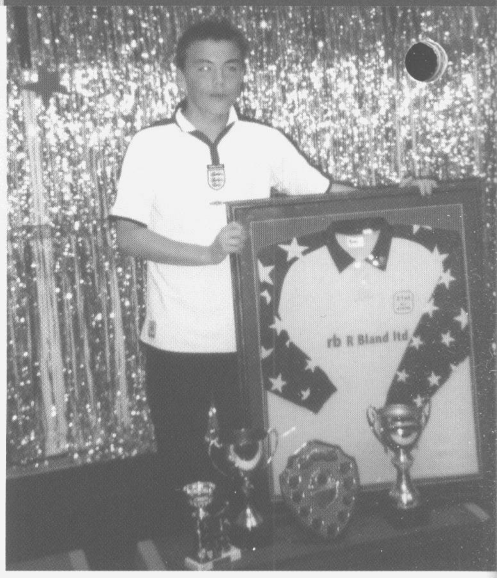
"It just goes to show that if the shunt is working, anything can be achieved."

Matthew, who has a 15-year-old brother Daniel, admitted: "Getting into the Academy was a dream come true. I was quite nervous to begin with but everyone is very friendly and I settled in quite well.

"I started training with them last April – just as Danny Mills was leaving - and signed up in August.

"It was nice to have offers from several clubs but Middlesbrough was one of the nearest and its Academy is one of the best in the country."

His ambition now is simple: "To fulfil my potential with Middlesbrough and enjoy my time there, but in the end become a professional."



Directory of independent local associations

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Tel: 0117-9777942

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BOLTON & BURY
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28 Gladeside
St Albans, Herts AL4 9JA
hamrock@supanet.com

KENT
Office address:
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c/o ASBAH North
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Tel: 01278 780946
peter.harling@telco4u.net

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Surrey SM3 9TS
Tel: 0208 641 7866

SUSSEX
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sasbah.office@tiscali.co.uk

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South Glamorgan
CF62 6SS
Tel: 01446 735714

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Mrs Elizabeth Graham
101 Coolreaghs Road
Cookstown
Co Tyrone BT80 8QN

NON-AFFILIATED ASSOCIATIONS

BEDFORD
Mr R C Simmonds
16 Parkstone Close
Bedford MK41 8BD
Tel: 01234-400068

CALDERDALE
Mr A L Crowther
12 Elm View
Huddersfield Road
Halifax HX3 OAE
Tel: 01422-341497

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Mr Ken Hall
17 Wallhouse Street
Cannock, Staffs
Tel: 01543-504847

CORNWALL
Mrs Liz Pollard
Ropers Walk Farm
Mount Hawke
St Agnes
Cornwall TR4 8DW
Tel: 01209-891632

DERBYSHIRE
Mrs A Hewitt
St Merryn, 20 Burley Hill
Allestree, Derby DE22 2ET
Tel: 01332-841893

DEVON
Tony Sprague
52 Lorrimore Avenue
Stoke, Plymouth
PL2 1HZ
Tel: 01752-550430
mailbox@dasbah.com
info@dasbah.info
www.dasbah.com

EAST ANGLIA
Mrs L Turner
7 Stow Gardens
Wisbech
Cambs PE13 2HS
Tel: 01945-466205

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Mrs R McCarthy
26 Brixham Gardens
Ilford, Essex IG3 9AX
Tel: 0208-594 1852

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Springfield,
Town Lane
Chale Green, Ventnor
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25 Royds Avenue,
Heysham, Morecambe
LA3 1PA

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Mr Allan Barratt
127 Limetree Road
Hucknall,
Notts NG15 6AW
Tel: 0115-953 7291
Fax: 0115-953 2081
(8am - 6pm)

OXFORDSHIRE
Mrs Shirley Dale
14 South Row, Chilton,
Didcot, Oxon
OX11 0RT
Tel: 01235 -834785

THAMES VALLEY
Mrs M Sawyer
62 Chestnut Crescent,
Shinfield,
Reading RG2 9EJ
TVasbah@aol.com

WESSEX
Mr T Poole
123 Gerrards Green
Beaminster,
Dorset DT8 3EA
Tel: 01308-862614

WHITCHURCH (Salop)
Mrs E Calder
Southfork, Sedgeford,
Whitchurch,
Salop SY13 1EX
Tel: 01948-663627

OTHER ASSOCIATIONS

SCOTTISH SBA
Chief Executive:
Mr Andrew Wynd
190 Queensferry Road
Edinburgh EH4 2BW
Tel: 0131-332 0743

IRISH ASBAH
Mairead Graham
Irish ASBAH
Old Nangor Road
Clondalkin, Dublin 22
Tel: 00 3531 457 2329

JERSEY
Channel Islands
Mrs Ursula Emmanuel
Priory Gardens
La Grande Route
de St Clement, St Clement
Jersey, JE2 6QQ
Tel: 01534 -853019

Association secretaries requiring changes to this list should contact:
LINK EDITOR, ASBAH, 42 PARK ROAD, PETERBOROUGH PE1 2UQ Tel: 01733 555988 Fax: 01733 555985

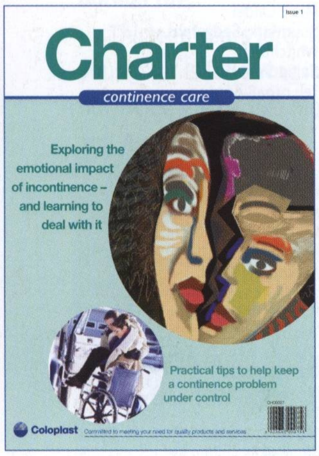
Charter

quality and care

Continence Roadshow 2005

Do you use any of the following to manage your bladder?

- Intermittent catheters
- Indwelling catheter
- Sheaths
- Night bags
- Leg bags


Issue 1

Charter

continence care

Exploring the emotional impact of incontinence – and learning to deal with it

Practical tips to help keep a continence problem under control

Coloplast Committed to meeting your need for quality products and services

If so, we would like to invite you to visit the **Charter Continence Care Roadshow**.

Between April and June, we will be visiting 46 locations across the UK, offering a wealth of information to individuals that require help with their bladder management.

On board, healthcare professionals will be available to provide any advice and support you may require and we will have information on hand from the major charities such as SIT, The Continence Foundation, *In*Contact, MS Society and ASBAH, together with information on local continence services.

You can also take the opportunity to learn about the latest products from Coloplast, including our full range of intermittent catheters, sheaths and bags. There will also be information on our support services, which includes **Charter Healthcare** – delivering a complete 'to your door' service for all of your continence product needs – and the newly launched *Charter Continence Care* journal packed full of advice and information.

To find the most convenient location for you to visit the Roadshow, please check the list of towns and cities we will be visiting below.

We look forward to seeing you on board.

Supported by:

Coloplast

Association for Continence Advice

ASBAH
Association for Spina Bifida and Hydrocephalus
Getting the most out of life

BAUN
BRITISH ASSOCIATION of UROLOGICAL NURSES

The Continence Foundation

*In*contact
www.incontact.org

MS
Multiple Sclerosis Society

SIT
Spinal Injuries Together

Royal College of Nursing
APPROVED

Peterborough	Monday 11 April
Leicester	Tuesday 12 April
Birmingham	Wednesday 13 April
Walsall	Thursday 14 April
Nottingham	Monday 18 April
Sheffield	Tuesday 19 April
Wakefield	Wednesday 20 April
Hull	Thursday 21 April
York	Monday 25 April
Middlesbrough	Tuesday 26 April
Newcastle-upon-Tyne	Wednesday 27 April
Edinburgh	Friday 29 April
Dundee	Tuesday 3 May
Aberdeen	Wednesday 4 May
Glasgow	Friday 6 May
Carlisle	Monday 9 May
Southport	Wednesday 11 May
Blackpool	Thursday 12 May
Liverpool	Friday 13 May
Manchester	Monday 16 May
Stoke-on-Trent	Tuesday 17 May
Oswestry	Wednesday 18 May
Conwy	Thursday 19 May
Belfast	Monday 23 May
Londonderry	Tuesday 24 May
Aberystwyth	Friday 27 May
Swansea	Tuesday 31 May
Cardiff	Wednesday 1 June
Gloucester	Thursday 2 June
Bristol	Friday 3 June
Truro	Monday 6 June
Plymouth	Tuesday 7 June
Exeter	Wednesday 8 June
Bournemouth	Thursday 9 June
Southampton	Monday 13 June
Salisbury	Tuesday 14 June
Portsmouth	Wednesday 15 June
Brighton	Thursday 16 June
Maidstone	Monday 20 June
Croydon	Tuesday 21 June
Stanmore	Wednesday 22 June
Oxford	Thursday 23 June
Milton Keynes	Monday 27 June
Northampton	Tuesday 28 June
Cambridge	Wednesday 29 June
Ipswich	Thursday 30 June

For further details on the location of the Roadshow, please contact Freephone 0800 783 1434