SUMMER 2007 ISSUE 220

link

The magazine for people with hydrocephalus and spina bifida

Family weekend a big hit

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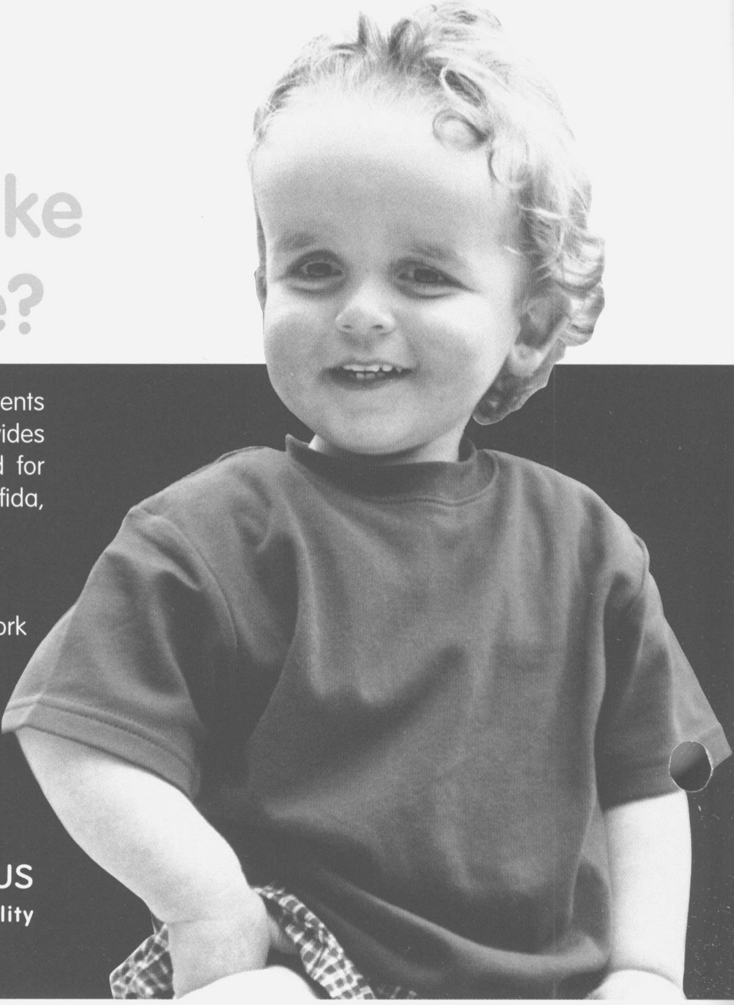
association for
spina bifida
hydrocephalus
ability beyond disability

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 421330

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

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ability beyond disability

Forget-me-not
Memorial Fund

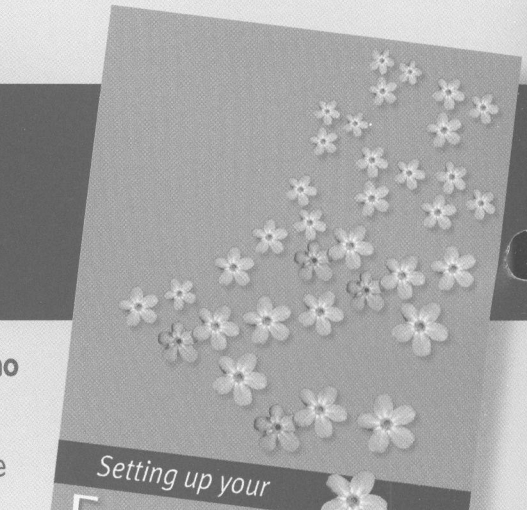
At ASBAH we receive many donations in memory of a loved one who has passed away.

Friends and family often find it a fitting way to remember someone special.

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

It really is so simple to set up as ASBAH handle all the administration and we'll send you regular updates with news about your fund.

To find out more call Jane Ayres at ASBAH on 01733 421330 or email janea@asbah.org



Setting up your
Forget-me-not
fund

association for
spina bifida
hydrocephalus
ability beyond disability

Registered charity no 249338

Peter Farrall writes

This summer issue of *Link* is a real mixture and we hope that you'll find plenty of articles that are relevant to you and your family.

ASBAH was thrilled to be able to hold another of its popular family weekends in April – the first for two years – thanks to generous grants from Dixons, the Cotton Trust and the D'Oyly Carte Charitable Trust. All of our 17 families who attended had a great time, learn't alot and many friendships were forged. Read all about the event on pages 20 and 21.

There's also the regular Your Voice page introducing the new committee members and revealing the results of the recent YV questionnaire.

Many readers will remember the Siobhan Corr's pregnancy diary which ran for three issues in 2005. On page 18 we catch up with Siobhan and see how she's adjusted to family life with her son Daniel.

The Codman pages (22 and 23) include some of the most frequently asked questions from parents about hydrocephalus. There is also plenty of good advice about how to tell someone that you have the condition.

Continence issues aren't something we have covered for some time, so to celebrate the new partnership between leading manufacturer of continence and stoma products Coloplast and ASBAH. *Link* will feature regular continence news. To start with we meet two people, an adult and a child, who talk about their experiences.

Please keep your stories and letters coming in. We couldn't put *Link* together without your help. Have a great Summer and we'll see you again in October.

Best wishes,
Peter

Peter Farrall
Director of 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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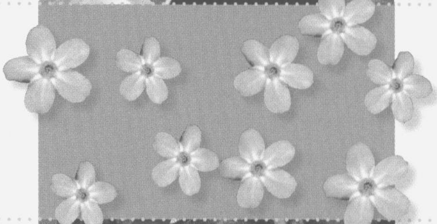


Helping carers into education

Family carers in the Eastern Region or Midlands can receive help returning to learning thanks to a new support programme.

By joining the Carers into Education project, carers aged 16 or over can access National Extension College courses at reduced rates. A range of courses are on offer including GCSEs, AS and A2s, vocational subjects such as book-keeping or child-minding, along with creative writing, counselling and study skills.

NEC courses are through distance learning, with no requirement to attend classes, so you can study where and when you choose. Studies can be fitted around caring responsibilities and carers will have the support of a subject tutor and a personal mentor. In addition, the NEC will work closely with your local Princess Royal Trust Carers' Centre to support you while you study.

Your personal mentor will maintain regular contact with you throughout your course, at times and in a format to suit you.

Don't miss the opportunity to finish that GCSE never completed, to learn that new language or to start on something new and exciting just for you.

For more details and information please contact: Sue Crowley, Carers into Education Manager, National Extension College, The Michael Young Centre, Purbeck Road, Cambridge. CB2 8HN . Tel. 01223 400387 or email sue.crowley@nec.ac.uk

IF CONFERENCE

A party of ASBAH representatives attended the annual conference of the International Federation for Spina Bifida and Hydrocephalus (IFSBH) at the end of May.

The theme for this years International Conference was Tomorrow, focussing on primary prevent of spina bifida and hydrocephalus, as well as the prevention of secondary disabilities.

ASBAH Chairman Richard Astle and Chief Executive Andrew Russell were among the delegates at event held in Kampala the bustling capital city of Uganda.

Jon Burke, a Your Voice member and ASBAH's representative with the IFSBH, also attended the three-day conference.

Leading medical experts from around the world gave a series of talks and presentations on subjects including mandatory food fortification worldwide. Talks and workshops about the treatment of spina bifida and hydrocephalus in Africa were also held.

For more information about the International Conference log on to ***www.ifglobal.org***

Extra investment to help learners

Provision for learners with disabilities or learning difficulties has been boosted by the launch of the first national strategy.

The Learning and Skills Council's (LSC) the organisation which aims to make England better skilled and more competitive, has pledged an additional £35 million by 2008 to support and develop new provision. Funding allocated to specialist colleges will be increased by 15 per cent to £181 million.

The Learning for Living and Work scheme will be a major step forward in the provision of quality post-16 provision across the Further Education sector.

It should also ensure equal opportunity for everyone to engage in learning and enhance their employability whatever their personal circumstances.

Bill Rammell the Minister for Higher, Further Education and Lifelong Learning, said: 'With the ever growing demand for world class skills we cannot let the situation persist where disabled people do not have equal opportunities for gaining qualifications."

Could you be an ASBAH trustee?

Would you like to join ASBAH's team of volunteer Trustees and help oversee the governance of ASBAH?

We are looking for Trustees who are passionate about ASBAH's work in supporting individuals, parents, carers and families. We are particularly seeking individuals who have experience in finance, business, marketing and communications or legal experience.

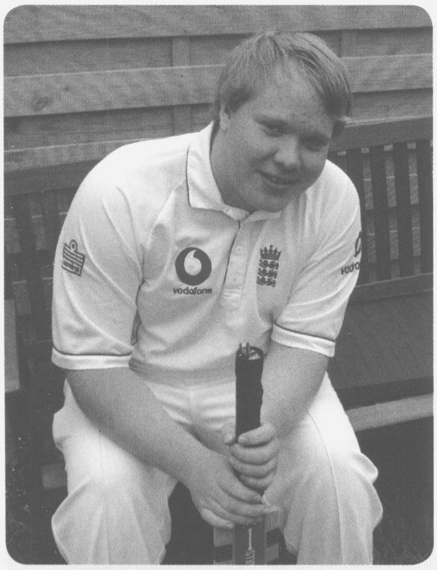
The Board meets four times a year in Peterborough. There are aadditional various sub-committees, conferences and events to which you will be invited. Although participation is voluntary, incurred expenses are reimbursed.

In return we can offer a chance to really make a difference in the lives of people affected by spina bifida and hydrocephalus and a chance to help the Board maintain direction, decisions and policies to ensure ASBAH's future success.

Applicants from black and ethnic minority communities will be especially welcome.

For an application pack apply to Brian Deffee, Company Secretary, ASBAH, 42 Park road Peterborough PE1 2UQ or email him on ***briand@asbah.org***

The Association for Spina Bifida and Hydrocephalus, ASBAH's Annual General Meeting will take place at ASBAH house, Peterborough on Saturday 22 September, when trustees will be elected.



Talented Nicholas plays for England Disabled Cricket team

Not many people get to play sport for England, but that's exactly what 16 year old Nicholas Chiddle from Hemel Hempstead did back in April this year, when he represented the England Disabled Cricket team.

Previously an active football player, Nicholas, who is an occasional wheelchair user, got into cricket because experts advised him to cut back on the footie due to the impact too much contact sport could have on his spina bifida. Cricket was an ideal option and as he was already interested in the game, Nicholas set to work, researching the Disabled England team on the internet and making contact to find out about the selection process.

He was indeed selected and now has his first game under his belt and another coming up soon. He said: "My first match was a very close one and provided me with really good experience. I scored six runs, played wicket keeper, took a catch and a run out and it was great fun. I've made some good friends and really enjoy the training sessions between matches."

Fortification campaign moves a step closer to victory

Folic acid should be routinely added to a food to reduce the number of children born with impairments such as spina bifida, food experts have ruled.

Members of the Food Standards Agency (FSA) board unanimously backed the measure following a 12-week consultation exercise, but the final decision will rest with the Government.

The announcement, made on 17 May by the FSA, came as welcome news to ASBAH, which has been campaigning for the mandatory fortification of flour with folic acid for many years.

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

We are delighted that the FSA board has taken the decision to recommend mandatory flour fortification to ministers

He said: "We are delighted that the FSA board has taken the decision to recommend mandatory flour fortification to ministers.

"It is a rare opportunity to benefit from a vitamin, and significantly improve public health. Now that the science has been listened to we look to health ministers to quickly implement this life saving measure."

The FSA's aim is to recommend to government that the widest possible range of flours be fortified, whilst preserving the consumers' choice to buy non-fortified flour if they wish.

Andrew added: "It is to ensure that the maximum number of women of child-bearing age benefit from the fortification, it is vital that the widest range of flour products are fortified.

"Whilst all women are at risk, research shows that it is the poorest and most educationally underprivileged women who are most at risk of a spina bifida pregnancy.

"Unfortunately relying on all women to plan their pregnancies and take a folic acid supplement in advance is unrealistic as a policy approach. Even when flour is fortified women planning a pregnancy should take a folic acid supplement."

At its open board meeting, the Board debated a range of options to increase folate intakes of young women in order to prevent pregnancies affected by NTDS such as spina bifida. Official figures state that there are 700 – 900 such pregnancies each year but ASBAH believes there are about 1200, leading to around one thousand abortions each year.

Mandatory fortification already takes place in more than 30 countries including the United States, Canada and Chile, where Neural Tube Defects rates have fallen by between 27 per cent and 50 per cent.

Fortification will be introduced in Ireland next year and is under discussion in Australia and New Zealand.

One study raised concerns that folic acid could mask the signs of vitamin B12 deficiency in elderly people, which can in severe cases lead to neurological damage. But there is no evidence of this happening when folic acid intake is 1mg per day or less.

Andrew added: "As hundreds of thousands of Americans have taken folic acid in supplements for decades, there is over a billion person-years of experience of folic acid supplementation, with no evidence of any harm from the vitamin, only benefits."

The FSA board rejected the measure five years ago due to lack of available evidence about possible risks and benefits, but a panel of UK scientific experts last year came out in favour of mandatory fortification.

First birthday celebrations for **Helpline**

What a difference a year makes! It hardly seems possible that 12 months have passed since ASBAH's Helpline was launched on 1 June 2006.


Linda Lewis

Since then Helpline manager Linda Lewis and operators Annie Kilsby and Dawn Stilwell have dealt with thousands of enquiries, providing support on all aspects of spina bifida and hydrocephalus. The Helpline also provides access to medical and educational advisers and, if necessary, support at a local level.

LOTTERY FUNDED

The majority of queries – 76 per cent – are made by telephone, with 17 per cent coming in by email, and 7 per cent by letter.

"We receive a real mix of enquiries," said Linda, "from parents and family members to health professionals and outside agencies calling on behalf of their clients."

Many calls are of a practical nature – Where can I buy suitable clothing? or Where can I get travel insurance? - while others are more sensitive, concerning emotional and relationship issues.

To enable the Helpline to deal with queries even more efficiently, the team are compiling a Knowledge Base, listing all relevant contacts under different headings.

Linda said: "It is a very time consuming project which will evolve over the years, but will make life easier for us in the long run."

She added: "There really is no knowing what a call will be about. The practical issues are usually straightforward. We can't always give people the answer they are looking for, but we will signpost them to someone who can help.

"When people need to talk about emotional issues, we are supportive but we can't counsel them. Sometimes it's just enough for us to listen to someone and that can make a big difference to their day.

"It is a challenging job, and like most helplines, sometimes we are so busy we could do with another pair of hands. But it is so rewarding. I go home at the end of the day and feel that I have made a difference to people's lives.

ASBAH's Helpline can be called on 0845 450 7755 Monday –to Friday at local call rates.

ASBAH service users are asked to keep their eyes peeled at hospital clinics and other places… in fact anywhere where they feel the Helpline should be advertised.

If Helpline details aren't on show, please contact us on 0845 450 7755 and let us know. We'll make sure information leaflets are sent out.

We know that the Helpline provides a vital service, and should be available to every individual and family affected by spina bifida and hydrocephalus.

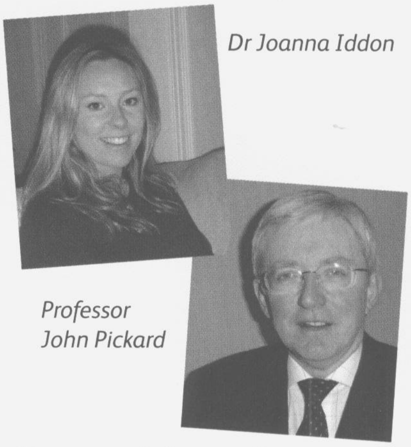
Help with your fuel costs

In the last issue of *Link* we included an article about British Gas giving discounts on fuel costs if you are in receipt of certain benefits.

One reader contacted us to let us know that although this offer had been running for the past two years, unfortunately it is now closed.

But bright spark Suzan Cain rang her own fuel provider, Southern Electric, and discovered that the company run a scheme called Energy Plus which gives a 20 per cent discount if a member of the household is in receipt of certain benefits.

So the message is if you, or someone else who lives at your address, receives benefits, give your energy supplier a call to see if discounts are available. It's certainly worth a try.


Dr Joanna Iddon

Professor John Pickard

Cognitive & Psychological Sequelae of Congenital Hydrocephalus:

Turning Theoretical Knowledge into Useful Clinical Intervention and Guidelines

ASBAH is funding a new research study of adults who have hydrocephalus, aimed at improving their health, social and psychological support. This study will be based at the Chelsea and Westminster Hospital in London, and will include people from a wide area of southern England. Some of the participants will also have spina bifida.

Detailed medical information will be built on through a range of neurological and neuropsychological tests, and the resulting information and the views of participants collated. It is hoped that coping strategies and interventions can be developed and recommended, resulting in an ASBAH publication aimed at improving the quality of life for adults living with hydrocephalus.

The project, which will be led by neuropsychologist, Dr Joanna Iddon and supported by Dr Richard Morgan and Professor John Pickard.

Incapacity benefit under review

Disability campaigners have warned that thousands of sick and disabled people could be deprived of incapacity benefits because of the radical review of the welfare system.

The Freud Report, 'Reducing Dependency, Increasing Opportunity', which was unveiled in March, was welcomed by the government as part of its plan to get more people back into work.

The report claims that in the past ten years nearly every targeted disadvantaged group has seen its "employment gap" fall. But while the active welfare state has worked for many people, it has also left many behind.

The new welfare reforms are aimed at getting this minority back into the workplace and moving the country closer to the government's ambition of 80 per cent employment.

Key to its success is to reducing the number of new claimants, providing more help to those receiving Incapacity Benefit to return to work and giving greater support to the most severely sick and disabled.

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They include giving individual counselling, training and advice to sick and disabled people, to help them back into employment.

It will be compulsory for claimants assessed as able to work to take part in these schemes. Those who refuse could lose out by a reduction in their benefits.

Under the welfare reform plans, Incapacity Benefit and Jobseekers Allowance will be scrapped and replaced with a single Employment and Support Allowance for those whose health affects their ability to work. This will be paid at different rates depending on the severity of the claimant's condition.

The Personal Capability Assessment (PCA) – the test of incapacity - will be revised with a new scoring system. This is to address a current gap in the assessment of cognitive and intellectual function in conditions such as autism spectrum disorder, acquired brain injury or hydrocephalus and to redress the existing bias against people with mental health problems.

New systems are to be piloted this year.

But the National Association of Welfare Rights Advisers (NAWRA) said the "whole essence" of the test had been changed.

NAWRA criticised the Department for Work and Pensions for using "legal experts" to draft the tests rather than experts in occupational and mental health, physical and learning disabilities.

But Jim Murphy, minister for Employment and Welfare Reform, said the draft regulations fully reflected the views of medical experts who were involved in the review.

Among NAWRA's criticisms, it said the draft regulations had increased the number of tests originally set by other experts and altered their severity.

It said original tests would be harder for people with physical problems but easier for those with mental health problems.

In an interview with the BBC "The whole essence of the test has changed,' said Judy Stenger, mental health welfare rights adviser.

"In fact there have been 70 changes made by DWP legal experts... all of which seem to make it harder for claimants to secure sickness status because of their mental health.

"Vulnerable claimants who would have been deemed unfit for work in the eyes of experts will now find themselves forced to negotiate the considerable challenges of survival as job seekers."

It is being said that those already claiming Incapacity Benefit will not lose out financially.

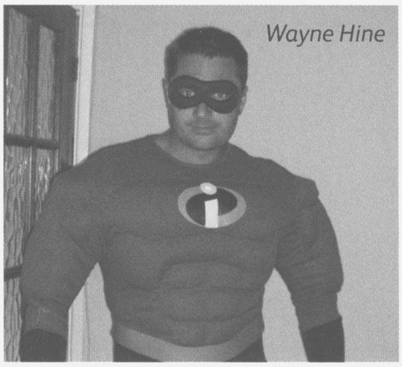
ASBAH adviser, Angela Lansley said: "A number of young people who claim benefit at 16 or 19 are put on Income Support rather than Incapacity in Youth Benefit (IB(Y)), often because some JobCentre staff know little about this non-contributory benefit.

Some ASBAH service users, who would be entitled to IB(Y), actually choose to stay on Income Support because it passports them to free prescriptions, eye and dental services and, if they are living with parents who are claiming housing benefit, may exempt them for the time being from paying a non-dependant contribution towards housing costs."

Angela suggested that this group of people should take independent welfare rights advice as to whether they should be applying for IB(Y) now.

There are long-term benefits to being on IB(Y), for example it is not affected by the income of any current or future partner and it could safeguard them when the new system of ESA is introduced.

Though fine detail is not yet available, further information about the proposed changes can be found on the Disability Alliance website at ***www.disabilityalliance.org*** or ***www.benefitsandwork.co.uk***



Superheroes weather the storm

Young Lewis Hine's very own band of superheroes endured tough weather conditions to run up an impressive £2059 for ASBAH.

The fabulous five-year-old fund-raiser, who has already collected thousands of pounds for ASBAH, persuaded Mum Emma and 20 other friends and family to tackle the 10-mile Great South Run course for the second year running.

Lewis chose all the spectacular costumes including Buzz Lightyear, Snow White and Tinkerbell. Dad Wayne donned as Mr Incredible with Emma slipping into her Batgirl gear again for the annual run around the streets of Southsea.

Emma laughed: "One of the highlights for Lewis was seeing me getting a piggy back on a giant teddy bear dressed as a fireman. What can I say, I was tired!"

She first contacted ASBAH when Lewis, who had a brain tumour removed in 2002, was diagnosed with hydrocephalus. Since then the family has received lots of support and information. Their ASBAH adviser also visited Lewis's school to teach staff more about hydrocephalus and possible side effects.

The Great South Run is just one event among many fundraisers Lewis and his family have joined in as a thank you to ASBAH and to help other families in similar situations.

But the 2006 run proved even more gruelling than expected with torrential rain and high winds.

Emma told *Link*:" The weather on the day was horrific and presented us with a whole new set of challenges. Mr Incredible discovered that a big padded muscle suit becomes not only wet and uncomfortable but extremely heavy too!

"We did many TV interviews on the day and again made it onto the Channel 5 programme. We also recorded a podcast for the Great South Run website, and gave ASBAH a mention. In fact we were so popular on the day at one point we were doing a live radio interview from the queue for the toilet."

Despite the terrible weather, the superheroes all completed the gruelling race and were welcomed back by ASBAH's Ian Morley and wife Val who were armed with ASBAH medals and survival bags.

Now the brave band of heroes, which has recently swelled to an impressive 40, is hoping to take to the streets of Newcastle later this year for the Great North Run. Good luck to you all.

Golf day fundraising drive

A host of golfers took to the fairways on 15 May to help drive funds at a charity golf day in Birmingham.

An impressive £4,000 was raised, at housing group, Midland Heart's 19th Annual Golf Day, for ASBAH with the proceeds going towards the Danny Mills Helpline Appeal.

The event, held at Kings Norton Golf Club, raised a total of £15,000, which was divided between ASBAH and Entrust Care.

Richard Farnell, Chairman of Midland Heart, thanked all the teams representing businesses from around the Midlands who competed for a host of prizes.

He said: "We all recognise the fantastic work of the chosen charities, on a local and national level, and how they improve the quality of life for many individuals that turn to them in times of need."

Auctionner David Barby with Richard Farnell, Chairman of Midland Heart

Northern Ireland has a tireless fundraiser

William Steenson who is Special Appeals Co-ordinator with ASBAH Belfast and District Branch has been an active fundraiser with ASBAH since 2005. In the past three years he has raised around £16,300 for ASBAH's Belfast and District Branch through collections at local supermarkets. Now William is concentrating his efforts to raise funds for ASBAH's Northern Ireland Regional Office and is working with two enthusiastic volunteers.

William told *Link* Magazine "I spent ten years actively fundraising for Co-Operation, Ireland's Peace Building Programme before making the move to ASBAH in 2005 as the Local Belfast Branch's Special Appeals Co-Ordinator to help transform the lives of those who are touched by spina bifida or hydrocephalus - we always have a lot of fun raising funds and it's a real thrill when, after an event, we are able to hand over a cheque to the Association to help the cause."

Forget-me-not fund **keeps their memory alive**

ASBAH's memorial fund scheme is proving a popular way for friends and family to pay tribute to loved ones who have passed away.

The scheme, launched last February, has already raised £8491- including Gift Aid reclaimed - to help others with spina bifida and/or hydrocephalus.

When ASBAH receives a gift in someone's memory, a Forget-me-not Memorial Fund can be created in their honour and family and friends often find this a fitting way to remember someone special who has passed away.

The Funds are flexible, allowing people to make donations in whatever way suits them best - whether this be by single donation or regular standing order.

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

ASBAH's Trusts & Legacies Officer Jane Ayres said: "A Forget-Me-Not fund is a really special and personal way to remember a loved one you have lost. It keeps their memory alive , whilst at the same time helping other families affected by spina bifida and hydrocephalus."

It really is so simple to set up and ASBAH will send you regular updates with news about your fund. You can also choose to set up your own personal Forget-me-not webpage at www.justgiving.com/asbah/raisemoney that can include photographs and personal messages. What better way to celebrate a life?

To find out more call Jane on 01733 421330 or email janea@asbah.org

Ceri runs up £150+

Ceri Parker's nephew Sion

Student Ceri Parker donned his running shoes to raise money for ASBAH in memory of his young nephew.

Sion, who was born with spina bifida and hydrocephalus, died two years ago when he was just 18 months old.

Ceri was determined to raise cash for ASBAH as a thank you for the help and support his sister received.

So he signed up for Port Talbot's popular Reindeer 10K Run, an annual Christmas event held in Margam Park in the South Wales town.

Ceri, who raised more than £150, said: "The support my sister received from ASBAH was very helpful so I wanted to repay that by helping to raise much-needed money so ASBAH can help other families in the same position.

"It was only the second time that I've taken part in a race, but I do enjoy going out for a run. My ambition is to do the London Marathon within the next five years."

Ceri, who is first year Psychology student at Swansea University, said there was a great atmosphere on the day.

He added: "I ran the race in 58mins which is a minute slower than last year, so I was a little bit annoyed that I didn't beat my Personal Best. But about 5 1/2 Km into the race I pulled a tendon in my left foot and I struggled to finish.

"But overall I was so pleased to finish because my sister and niece were at the finish line."

Thank you to...Whittlesea & District Lions

Cambridge based charitable organisation Whittlesea & District Lions has collected a fantastic £1,000 for ASBAH.

As well as holding stalls at numerous school fetes, money was raised through the club's big Christmas extravaganza, a fabulously decorated float which parades Santa through the streets each December.

President Pat Ash, whose ten year old granddaughter Ashley has spina bifida explained: "As president of the organisation, I was offered the chance to choose how a proportion of the money raised could be divided. Having had firsthand experience of the wonderful support they offer to families affected by spina bifida and hydrocephalus, I didn't hesitate to suggest ASBAH.

I think that the work ASBAH does is wonderful and my daughter Melissa has gained great strength over the years after receiving advice and support to help little Ashley. We are thrilled to be able to donate this £1,000 and delighted to think that in doing so, we can make a difference to other people's lives."

London Marathon runners raise £9,159 to date, with more to follow!

Once again, an amazing bunch of ASBAH supporters ran in the Flora London Marathon, raising £9,159 at the time *Link* went to press – well done to: Marie Bacon; Olly Chapman; Sarah Horton; Colin Howells; Sean Watters; Kim Lowe; Nadine Ornsby; Lucille Reed; Heather Boyd and Paul Burton. Also congratulations to Elini Panayi who completed the Mini Marathon.

This year's race took place on a very hot April day, making for challenging conditions for the runners. Marie Bacon who has Spina Bifida Occulta told *Link* what it was like to be part of the event: "I've only been running for a year, having joined a running club after looking for a new challenge. Through ASBAH I did the Great North Run back in October last year, but nothing could have prepared me for the daunting nature of the London Marathon. It was extremely tough because of the heat and at about 15 miles I really thought I might not make the finish – there seemed such a long way to go and I was really tired. But I fought on and after the 22nd mile I got this amazing second wind which carried me through to the finish line. I raised over £750 and would definitely do it again!"

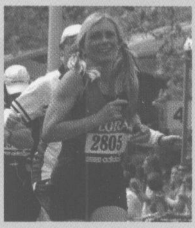
Marie Bacon

Olly Chapman

Sarah Horton

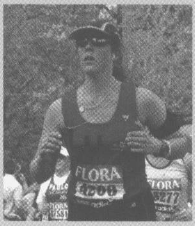
Colin Howells

Sean Watters



Kim Lowe

Nadine Ornsby



Lucille Reed

Heather Boyd

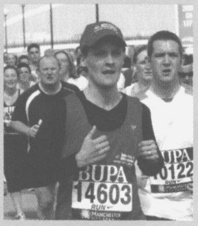
Paul Burton

> ***What a great day out. Tough going for a while but knowing how much people had sponsored me spurred me on. Was only gutted I did not see Borat! - Olly Chapman***

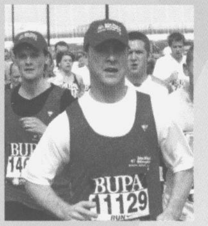
Great Manchester Run is such fun and raises £2,700 to date

Congratulations also to nine ASBAH supporters who took part in the 10km Great Manchester Run in May. Well done to: Nancy Turner; Simon Chambers; Paul Conner; Thomas McLoughlin; Claire Baldwin; Michael Bicheno; Pete Woodhead; Ian Morley and Emma Hine.

Ian, who works in ASBAH's fundraising office and is severely visually impaired, completed the race attached to running 'buddy' Emma Hine. Emma, from Porstmouth, whose son Lewis has hydrocephalus, explained what it was like to run the race as part of a twosome: "Running with Ian was actually easier than I thought it would be and the time went really quickly because we chatted on the way around. He was great company, the weather was good and we paced ourselves well, even managing a sprint finish. It was great fun and a day to remember!"

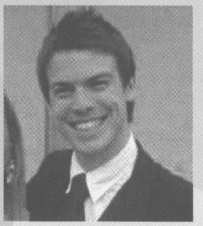


Nancy Turner

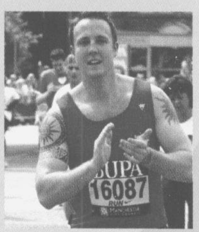


Simon Chambers

Paul Conner


Thomas McLoughlin


Claire Baldwin

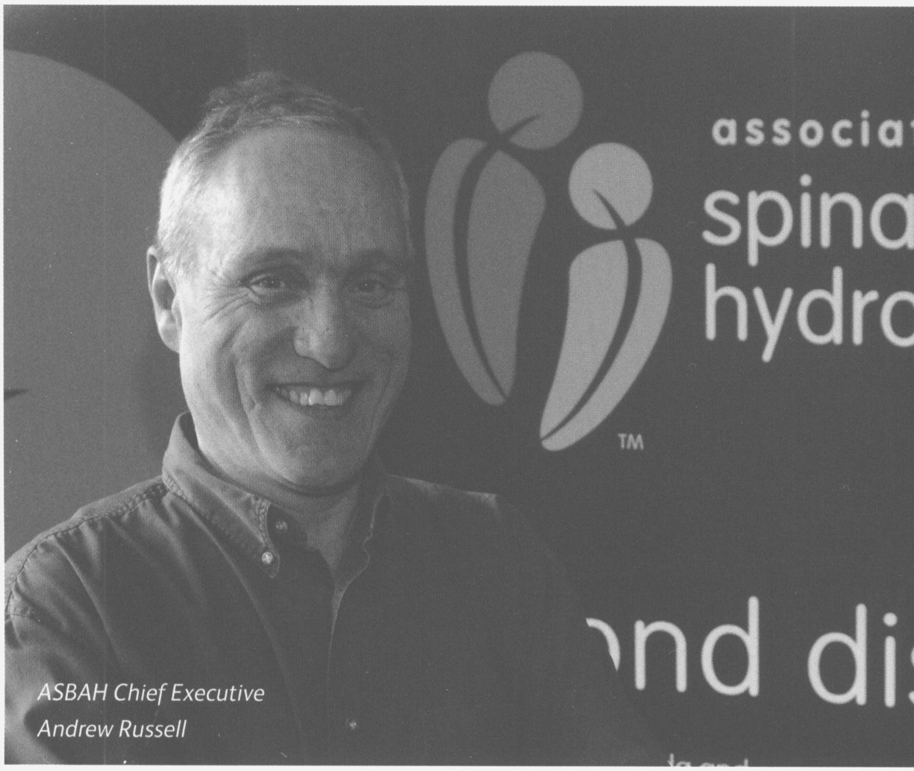


Michael Bicheno

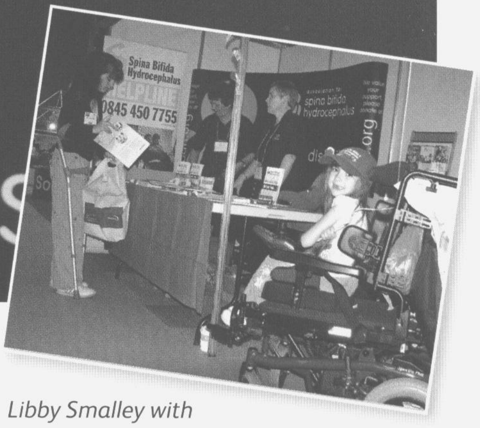
Pete Woodhead

Ian Morley

Emma Hine



ASBAH Chief Executive Andrew Russell



Libby Smalley with her mum Elaine Gordon visit the ASBAH stand at Naidex

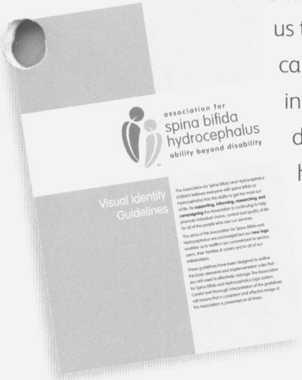
Introducing a new look... for the Association for Spina Bifida and Hydrocephalus (ASBAH)

2007 marks a change of look for the Association for Spina Bifida and Hydrocephalus (ASBAH). We're proud to announce the launch of a new logo, which, thanks to the generosity of our design consultants, has been created at minimal cost. The logo was officially unveiled in April at the Naidex exhibition at Birmingham's NEC, the largest event for the national homecare and disability market in the UK.

ASBAH Chief Executive Andrew Russell explains: "The aims of the Association for Spina Bifida and Hydrocephalus are unchanged, but our new logo enables us to reaffirm our commitment to service users, their families and carers and to all of our stakeholders. In essence, it demonstrates in a fresh way, the committed professionalism with which ASBAH delivers its many services to everyone affected by spina bifida or hydrocephalus."

The crisp, clean lines of the new logo are complemented by our new strapline, "**ability beyond disability**" which, once again, we feel sums up the Association's core belief that everyone with spina bifida or hydrocephalus has the ability to get the most out of life. By **supporting, informing, researching and campaigning**, the Association is continuing to help promote individual choice, control and quality of life for all of the people who use our services.

Peter Farrall, Director of Marketing and Communications for ASBAH told *Link*: "It's a tall order to sum up our values and services in a single visual way, but we feel that by using fresh and bright colours with a modern design, we have achieved this aim."


association for
spina bifida
hydrocephalus
ability beyond disability

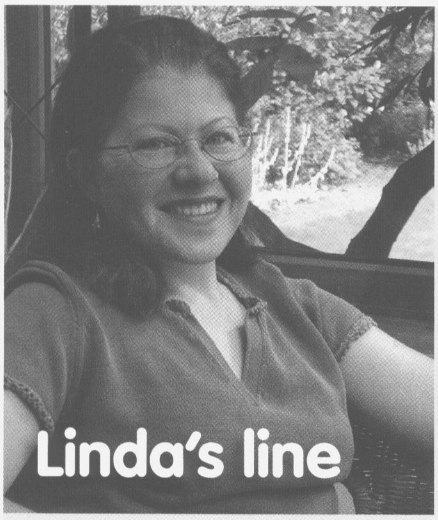
Visual Identity Guidelines

From now on, ASBAH Local Associations can also incorporate new logos, that echo the one used by the main Association. Whilst being sufficiently different, to help define our 'corporate' and 'local' brands. Local Associations who have signed up the ASBAH Compact, can request a special support CD pack, including an introduction to their new look; artwork for various applications like letterhead and compliment slips, plus a set of user-friendly guidelines on how to use the logo. If you would like further information, please contact Peter Farrall on **01733 421362** or e-mail: **peterf@asbah.org**


ability beyond disability
north & west yorkshire
association for
spina bifida & hydrocephalus

Local Association Pack

"We like the look of the new branding, which is certainly fresh and up to date. It's particularly good that the new identity for the Local Associations will be similar but at the same time distinctly different to the main ASBAH brand. We think it will have wide ranging benefits, not least in making everyone feel part of the overall ASBAH partnership."
- Jo Baxter, Deputy Chair of the North and West Yorkshire Local Association (formerly Leeds & Bradford)



Linda's line

It's only two years later than planned but we are finally getting our front garden done. Had I been able to remember where I put my original drawings, I would be able to tell you whether my badly drawn, not-to-scale, plans were heading for fruition or demolition but perhaps it is for the best.

The men who are doing all the work have come from Kosovo – not specially to do my garden, obviously – and so far, they have been working very hard. However it is fair to say that they have a novel approach to problem solving which is rather interesting from a spectator's point of view. Take for example the tree stump which is in the way of the new front wall; you could dig it out, pull it out (if you were strong) or hire a mechanical gadget to yank it out.

These guys found a length of armoured cable in our garage and tied one end to the tree stump and the other to the back of their car to see if they could tow it out. This reminded me very much of watching Pingu – you don't speak the lingo but in a strange sort of way you know what the characters are saying. In this case it was along the lines of "bummer, this isn't going to work". I don't have any qualifications in building or engineering but I could have told them that before they got started.

Today we had a consignment of bricks delivered – it's all go here, I can tell you. Before the hapless delivery man could leap back into his cab, the Pingu crew persuaded him to use his hoist and a bit of rope (also probably from our garage) to tug the tree stump out. It was some while later, after I had moved my car (precautionary action), put the washing on, made my lunch and sat down to eat it, that I heard some cheering which seemed to indicate that they had at last been successful. I'm pretending I'm not in at the moment.

The second problem today (why is it always on my day off?!) was the discovery of a blocked drain. It was on our property as well, so I had to phone up Thames Water and pay someone to come out rather urgently as according to the builder nothing was going down the drain. Nothing, that is, except my day off which is deteriorating rapidly, so if anyone else wants me I'll be in the back garden with some earplugs and a large glass of wine.

link

the lifestyle magazine for people with hydrocephalus and spina bifida

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(Winter, Spring, Summer and Autumn)

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Spina Bifida
SUPPLEMENT

Contents

What is spina bifida?

Spina Bifida, which literally means ‘split spine’, is a fault in the spinal column in which one or more vertebrae fail to form properly, leaves a gap or a split, causing damage to the central nervous system.

Spina bifida occurs when there is a failure of development of the boney canal which surrounds the brain and spinal cord. In the spine, the affected vertebrae have a defect at the back so that a boney ring does not completely surround the spinal cord.

The fault may occur in one or more of the vertebrae but it is most common around waist level.

There are three main types of spina bifida which will all be present at birth.

Spina Bifida Cystica (cyst-like)

The visible signs are a sac or cyst, rather like a large blister on the back, covered by a thin layer of skin. There are two forms:

1) Myelomeningocele

Myelomeningocele is the most serious and more common of the two forms of cystic spina bifida.

Here the cyst not only contains tissue and cerebro-spinal fluid but also nerves and part of the spinal cord. The spinal cord is damaged or not properly developed.

As a result, there is always some paralysis and loss of sensation below the damaged region.

The amount of disability depends very much on where the spina bifida is, and the amount of affected nerve tissue involved.

Bladder and bowel problems occur in most people with myelomeningocele, as the nerves come from the bottom of the spinal cord, so are always below the lesion.

It is also necessary to have intact nerve pathways to the brain for complete control and sensation.

2) Meningocele

In this form, the sac contains meninges (tissues which cover the brain and spinal cord) and cerebro-spinal fluid, which bathes the central nervous system. Development of the spinal cord may be affected, but impairment is usually less severe than myelomeningocele. Meningocele is the least common form of spina bifida.

Spina Bifida Occulta

This is a mild form of spina bifida which is very common. Estimates vary but between 5% and 10% of people may have spina bifida occulta.

It must be emphasised that, for the vast majority of those affected, having spina bifida occulta is of no consequence whatsoever.

Often people only become aware that they have spina bifida occulta after having a back x-ray for an unrelated problem.

However, for a few (about 1 in 1,000) there can be associated problems because the spinal cord has become tethered to the backbone.

These people may also have associated difficulties such as foot deformity, weakness in the legs, bladder infections and incontinence and bowel problems.

Often a child who is previously symptomless may experience difficulties during periods of rapid growth or at adolescence.

For more information about spina bifida see ASBAH’s information sheets on our website: *www.asbah.org*

Continence management

Many people with spina bifida have varying degrees of what is known as a neuropathic bladder and bowel – when damage to the nerves interferes with normal bladder and bowel working.

During childhood, annual checks should be carried out as a matter of course, particularly during puberty, which often brings about changes in bladder and bowel routines. Incontinence may get worse and management more difficult.

Automatic regular reviews often stop when individuals move from childhood to adult health services. They may only be seen if problems arise.

But as David Stott discovered, asking questions and seeking out the best consultant may take time, but it is ultimately worthwhile.


David Stott

Adult case study

Name: **David Stott**

Age: **49**

Lives: **Nelson, near Burnley**

"Looking back I must have had incontinence problems as a child as I didn't have much control over my waterworks. If I needed to go, I had to go immediately. I was given a key to the toilet at school so I could dash off whenever I needed to.

I went to mainstream schools and each year when I went into a new class, I'd have to explain my problem to the teacher. Thankfully the other children never really picked up on it so I wasn't teased.

I was quite mobile at school but later on I had to wear callipers on both legs after I experienced problems with a dropped foot which kept turning inwards.

I went into catering, which, with hindsight, wasn't the ideal career because I was on my feet all day.

My health problems got worse and my right leg was amputated because of very poor circulation in the lower leg.

Shortly after this I began to experience problems with my water works. I was told that I'd have to have a urostomy bag as there was no suitable alternative. But with an artificial leg, there was nowhere to strap the bag without affecting my balance.

After talking to ASBAH and people at a local charity for the disabled, I heard about various procedures which were worth investigating.

I wrote to several hospitals and was eventually seen by a consultant who was very optimistic that he could help.

I would encourage anyone with continence problems to seek as much advice as possible and not to take no for an answer.

The first operation I had was to create an artificial bladder, which enabled me to carry out intermittent catheterisation.

It made a huge improvement to the quality of my life, although there is a risk of infection so I do have to have a course of antibiotics on standby.

Later on, when I began to have bowel problems, I underwent antegrade continence enema (ACE).

A tube was created inside my body using my appendix and a stoma (small opening) was made at the lower right side of my tummy.

A catheter can be passed through the stoma and into the bowel, and once a day I put in about 2 litres of saline, which clears my bowel around 30 minutes later.

Having these two operations really improved things for me. I am more independent and confident, and can live a relatively normal life.

I would encourage anyone with continence problems to seek as much advice as possible and not to take no for an answer. I did work hard to find a consultant who could offer me alternatives, but it was worth the effort."

Child case study

Name: **Ashleigh Peacock**

Age: **10**

Lives: **Leeds**

"Ashleigh has Tethered Cord Syndrome and although she had a few problems with bladder incontinence when she was young, her condition has got slightly worse as she's got older," explained her mother, Melissa.

"She learned bladder control very quickly, although when she needed to go, she

We've never made an issue over Ashleigh's continence problems and I think our attitude has helped her. It certainly hasn't ever bothered her.

needed to go immediately. This was fine if we had a potty to hand, but if not, then she would wet herself. It was easier to keep her in 'Pull-Ups' until she was five.

"In the past few years her condition does seem to have worsened, although we were forewarned by ASBAH medical advisers when she was a baby that that this could be the case, so it didn't come as a shock.

"Ashleigh needs to go for a wee every hour. Her bladder doesn't seem to be able to hold out any longer – it's just how it works.

"She does have accidents at school but thankfully it doesn't seem to bother her. I must admit that her friends are wonderful – they'll walk behind her to the toilet so no-one sees the wet patch and the school staff are very supportive. They also monitor every accident, so we can see if the problem is getting worse.

"Luckily the school building is brand new and has great toilet facilities, plus a shower, so if Ashleigh has an accident, she just deals with it herself.

"She has always has a real aversion to hospitals and surgery and has shied away from any medical intervention such as urodynamic tests so far. Of course she may feel different later on. But she knows her own mind and I think it helps her to have some control over any treatment she has.

"One recent development is that an ultrasound scan suggested that she may not be emptying her bladder fully, which could lead to infections. Ashleigh began taking Oxybutynin Hydrochloride three months ago to help her bladder relax. Hopefully this will improve the situation.

"We've never made an issue over Ashleigh's continence problems and I think our attitude has helped her. It certainly hasn't ever bothered her, although that may obviously change in a year's time when she goes to high school."

Catherine speaks out against NHS targets

An ASBAH service user has seen first-hand how Government NHS targets are failing patients with long-term health problems.

Catherine Pocock, who has spina bifida, has experienced chronic foot and ankle problems for many years.

In October last year her orthopaedic consultant thought a second opinion from a more experienced consultant would be helpful, and referred Catherine to a surgeon renowned for his expertise in foot and ankle surgery.

Believing that the 13-week waiting time targets would apply, Catherine, from Exeter, became concerned in January that she hadn't heard any news.

A phone call to the hospital revealed that the waiting time targets relate only to GP referrals.

There are no targets for the length of time a patient must wait if a consultant has referred them to another consultant (a Tertiary Referral).

If people don't speak up nothing will ever change

Catherine, 43, told *Link*: "By this time I was in severe pain and I knew that the condition of my feet and ankles was deteriorating fast. It was clear that I would have to wait for months for an appointment.

"I was naturally very upset and frustrated, but I realised that many people must be going through similar experiences so I decided to take action."

After much research Catherine wrote to the Shadow Health Secretary, MP Andrew Lansley, voicing her concerns.

He replied: "Treatments which the Government doesn't set a target for are sidelined, with patients often waiting an unacceptably long period of time before receiving treatment."

Mr Lansley also asked if Catherine's case study could be included in a dossier being compiled by the Shadow Health team.

Catherine Pocock

Catherine also contacted her GP and local MP Ben Bradshaw, who both supported her case.

She said: "I found that people were mostly very understanding, but no-one seems to be able to do anything about the situation.

"Consultants must meet their targets so patients being referred from another consultant go to the back of the queue.

"I know that many people – particularly those with orthopaedic problems which aren't considered to be life-threatening – must experience the same problems as me.

"Unfortunately many people are still very trusting of the system and don't realise that they've been put on a back burner. In the meantime their condition deteriorates."

Thankfully Catherine was eventually given an appointment with the new consultant in May, who was "shocked" by the severe condition of her feet and ankles.

She said: "People should be treated according to need, not a target and it's a strange system where consultants aren't allowed to prioritise who goes on their lists. I'm only surprised that the situation hasn't received more publicity.

"It took a lot for me pursue this issue and at times I was exhausted by the effort, especially when, sometimes, it all seemed so futile. But if people don't speak up nothing will ever change."

If you have experienced similar problems and would like to voice your concerns, contact your local MP and Shadow Health Secretary, MP Andrew Lansley, at the House of Commons.
Email: ***lansleya@parliament.uk***

Getting back to work

It is important to identify your personal skills, strengths and abilities and to have realistic employment goals

For many people with disabilities applying for a job or returning to the workplace can be a tough prospect.

CV preparation and job applications can seem like a minefield if you've been out of the workplace for some time.

But ASBAH member Simon Wrigley, a Work Preparation Facilitator with Local Solutions, a Liverpool-based charity, has kindly provided some expert advice for job seekers.

Their set of information sheets – downloadable from both the ASBAH and Your Voice websites – cover all aspects of applying for a job, from preparing a CV and completing an application form to preparing yourself for an interview.

Simon Wrigley

"At Local Solutions we will work through the handouts with our clients. But people downloading them from the ASBAH website should still find them very useful," Simon told *Link*.

Simon, who has spina bifida, was one of the speakers at last year's Your Voice residential weekend, giving a general overview about employment matters.

He knows only too well how many people with disabilities have little confidence in their ability to get a job.

"Knowing how to put together a good CV or complete an application form is empowering," he said.

"It is important to identify your personal skills, strengths and abilities and to have realistic employment goals."

To download the information sheets go to **www.asbah.org**. If you would like a printed set write to: ASBAH Helpline, 42 Park Road, Peterborough, PE1 2UQ

Jo Pugh

Jo's career

Jo Pugh is a volunteer at ASBAH in Peterborough, helping out one day a week in the Helpline office, handling a variety of administration duties.

She has had several full-time jobs since graduating from Nottingham University and is a firm believer that a positive attitude is everything when it comes to job hunting.

Jo, who has spina bifida, said: "My disabilities aren't my primary focus in life. I don't use a wheelchair but I do have mobility and balance difficulties. But I accept how I am and get on with it.

"Your personal attitude also influences the way other people see you. My friends say that they completely forget I am disabled, which is the greatest compliment they could pay me."

Similarly Jo said she has never faced any obstacles when it comes to applying for jobs.

She said: "Again I think a lot of it comes down to attitude. My disabilities don't affect my ability to do a job so they aren't relevant. No-one should let their disability hold them back. Have confidence in yourself and get out there."

My disabilities don't affect my ability to do a job so they aren't relevant. No-one should let their disability hold them back

After graduating with a degree in Spanish and Portuguese in 1996, Jo taught English in a Spanish secondary school for 12 months, before joining Travelex, a worldwide money financial company. She worked there for five years using her language skills in a variety of roles.

She then worked for the NHS for two years implementing a new government initiative on patient choice in the Peterborough area.

For the past six months Jo has worked for herself, giving private Spanish lessons. The part-time hours have enabled her to fulfil a long-held ambition … to do voluntary work.

"I simply didn't have time before," she explained. "A full-time job leaves little time for anything else.

"I am thoroughly enjoying my days with ASBAH. I like the variety of work and the feeling that I am giving something back.

"I am a firm believer that if you would like to work, you should, and having a disability shouldn't hold you back. Focus on your positive attributes – everyone has their strengths and has something they can give."

Mobility for Ruth

The discovery of an old wheelchair in a cupboard at a physiotherapist's clinic gave Ruth Hadley a whole new perspective on life.

Ruth, 4, who has spina bifida and hydrocephalus, has no movement from the waist down, and at the age of 18 months old, she relied on being carried to get around the house.

But when the physiotherapist pulled out the battery-powered Comet and suggested the family gave it a try, there was no looking back.

"The Comet had a joy stick control and although we weren't sure how Ruth would manage, in just a few days she was happily moving around the house and could turn circles very easily," mum Deborah told *Link*.

"Unfortunately it also meant that because she was seated at a higher level, she could access the kitchen cupboards," she laughed.

"Ruth also managed to cause quite a lot of damage too, ramming the wheelchair at door frames."

Her elder brother Peter, now 6, had to learn to move his toys out of the way because Ruth had no respect for anything lying in her path.

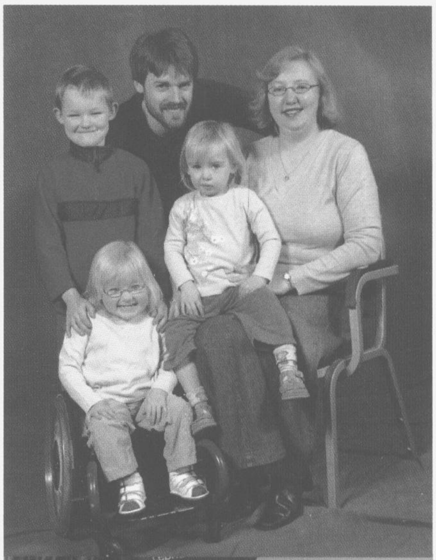
Deborah said: "The wheelchair gave Ruth a taste of independence for the first time and it was wonderful to see her being able to move around the house.

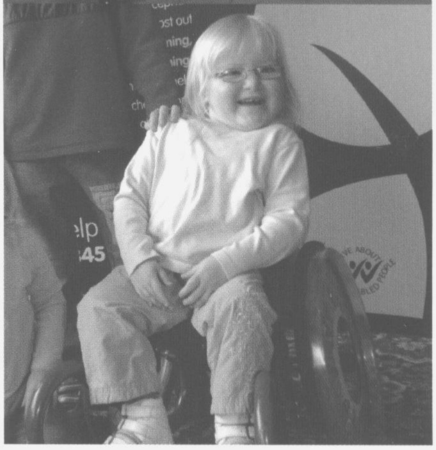
"I used to take her to a Mother and Toddler group, but because she wasn't mobile, Ruth had to either stay with the babies or sit on my knee. Once she had wheels she could go off and make friends independently.

"Ruth now has a lightweight self-propelled Mini chair. It is fine for in the house, at the playgroup and the library, but Ruth is quite small for her age and hasn't the strength or the stamina to use it for long periods of time."

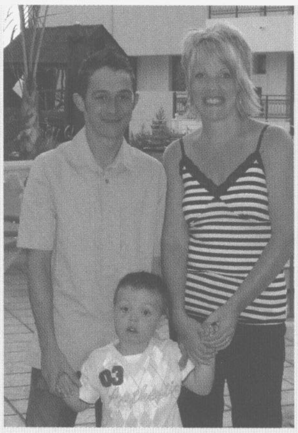
At home Ruth has a willing helper in the shape of her sister Catherine, who is two.

"They play very well together," Deborah added, "and Catherine will bring things to Ruth if she can't reach them. Of course she has also been known to run off with them in the other direction too, but on the whole they get on extremely well."





Tethered Cord



Marcus and Kerri with Mason

Mother Kerri Barrett thought the operation to improve her young son's tethered cord would be a straightforward procedure.

When surgeons suggested that Mason, now 4, would find an improvement in his mobility if he had the operation, Kerri and partner Marcus Howes, were keen to go ahead.

Kerri, from Thetford in Norfolk explained: "Mason was diagnosed with spina bifida occulta when he was ten months old. He has a very visible mark on his back and doctors recommended an ultra sound scan, and then a MRI scan which confirm their fears.

"It didn't cause Mason too much trouble, although he was rather clumsy and couldn't jump or run around as other two year olds.

"Surgeons suggested the operation because they felt it would make a big improvement to Mason's mobility.

I'd advise any parent in similar situations to contact ASBAH to get a better idea of the procedures involved

"We weren't given very much information but we were led to believe that it was a routine procedure and meant a short, three-day stay in hospital for Mason.

"But unfortunately it didn't go as planned. In fact it was the most frightening time of my life.

"After the operation Mason was supposed to lie still for 72 hours… but of course, like any lively three-year old it was difficult to keep him still.

"He split the stitches and fluid was leaking out – I was terrified. In all he had three operations and was hospitalised for two weeks."

But despite the family's experiences, the third operation was successful and Mason is now far more mobile.

Kerri added: "Of course we're thrilled with the results but I wish we had been better informed about what to expect and what could go wrong.

"I'd advise any parent in similar situations to contact ASBAH to get a better idea of the procedures involved, before they agree to surgery."

Tethered cord story....
See page 18 for Nina's Story

Tethered Cord - continued

Nina's story

"Tethered Cord and Erythromelalgia were just words to me in 2000. I didn't understand fully what was wrong with my deformed feet and I had no idea about, or understanding of, tethered spinal cords. Of necessity, I have become very familiar with many aspects of tethered cord syndrome and Erythromelalgia since then."

The condition of Nina Bunton's tethered spinal cord began to deteriorate in early 2000. After recovering from the shock of diagnosis and facing huge fears of disability, she tried to find information on the internet to learn more about the problem but very few UK sites with relevant information existed.

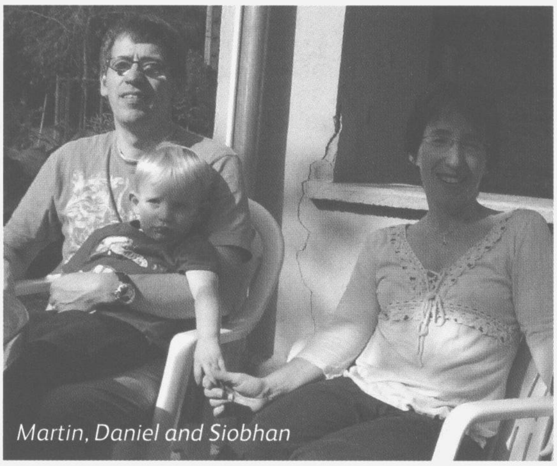
"Any details I could find were mainly aimed at medical professionals and were very technical in their language," she said.

So Nina created her own website based on her experiences of this condition and successful detethering surgery. It also consolidates information and resources she found in her internet searches.

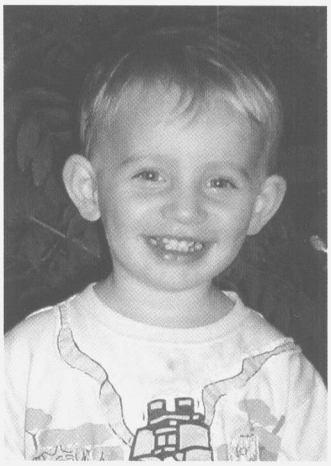
The feedback page is full of praise for the site, from people around the world, including leading neurosurgeons. Mr Ian Pople from Bristol's Frenchay hospital said: "This website will become a very useful resource for patients with TCS."

Nina added:" The website has no fancy gizmos but it should be a useful resource for people. I welcome feedback, advice, and personal stories that you feel happy about publishing."

Find Nina's website at ***www.btinternet.com/~tetheredcordresources/personal_story.htm***



Martin, Daniel and Siobhan



Rising to the challenge of parenthood

***Link* readers may remember reading Siobhan Corr's pregnancy diary during 2004.**

Siobhan, who has spina bifida, gave birth to Daniel in December that year and after four months maternity leave, returned to her teaching post four days a week at a secondary school in Bolton.

Here Siobhan, and her husband Martin, who works as a probation officer and is registered blind, talks about their experiences of parenthood.

"The initial worries that all parents have when they are expecting their first child can be exacerbated by disability. However, most of these barriers can be easily overcome, with some forward planning and with support from friends.

Many people are bemused at our attempts to "herd" Daniel as he learned to walk and at our efforts to climb up and down slides etc

"Generally, the public appear to be ambivalent about us as disabled parents. In this modern world, I think the public do accept that parenthood is not just about physical fitness…

"Many people are bemused at our attempts to "herd" Daniel as he learned to walk and at our efforts to climb up and down slides etc. A number of (mainly elderly) women have asked "Is he really yours?" and "Did you really give birth to him?" as they look on with some admiration.

"A fellow traveller on a plane to Toulouse congratulated us on our efforts to manage on and off the plane without any assistance from staff. Martin has become something of a pack horse! Me – an in-flight entertainer!

"As Daniel has learned to walk new worries have emerged. Due to my mobility problems, Daniel does have some restrictions which other children do not – for his own safety – he is learning that he must not run off, must hold my hand and that he will be restricted to his buggy if he does not follow these rules. Not unreasonable rules really!

"Within a confined space his movements are less restricted. It is important to balance the need to keep him safe with his right to a level of independence.

"At just 2 years old, he is learning that there are certain things that Mummy and Daddy cannot do– he does not ask me to carry him but instead says "sit down, sit on mummy's knee" and likewise rarely asks his Daddy to read him a story – Daddy does the rough and tumble play and all the carrying. However, our roles do complement each other and it aids the division of labour.

"More recently, we have started to experience some toddler tantrums. These present a potential challenge for me as I would struggle to quickly and quietly remove him from the situation in a public place.

"These tantrums are still one of many challenges to be met in the future…"

Disability affects family members in many different ways as Lisa-Marie Taylor from Loughborough knows only too well.

Lisa, 35, has spina bifida, hydrocephalus, Arnold-Chiari malformation and was recently diagnosed with fibromyalga.

Here Lisa and daughters Alysia, 13, and Bethany, 11 reveal how these conditions affect their day-to-day life.

How does disability affect day-to-day life?

Lisa's story

"Having these problems does get me down as I get tired very easily, but I still consider myself lucky as I can do pretty much what the average person can.

At the same time, living with these conditions isn't easy for any of us and we are all affected in small ways. Little things like getting out of a low chair or the bath, for example. The children laugh and say, "crank up the old granny", which I guess is their way of helping them cope.

When I was growing up I can't remember wanting to settle down and have a family. But I met Simon when I was 19 and that all changed.

Alysia and Bethany have always been aware that I am different from other mums. Not that I look any different physically, I just struggle a bit more than most.

I mainly suffer from tiredness and I get grumpy and shout at the girls and everyone around me. I hope they know I don't mean it. But when things get too much the girls go to their grandparents so we can all have some space.

I've been very lucky with my parents and my friends. They listen to my moans and groans and are very supportive. The girls also raise my spirits when I am down.

But I have met some people who have had a negative attitude. I was once told by a senior registrar that how I was at the time was about as good as it was going to get. I took on board what they said and have proved them wrong. That's the sort of person I am… no-one keeps this woman down!"

Alysia's story

"It can be scary. When Mum gets ill we never know if she is going into hospital and how long it will be until we see her again.

When I was eight Mum collapsed and was rushed into hospital. That scared and worried me because I didn't know if she would get better again.

But Bethany and I don't see our Mum as being any different to other mums. She treats us just the same as our friends' mums treat them.

My friends treat her the same as anyone else but they do look out for me when I am sad and when Mum is ill they cheer me up.

We have always done lots of activities and Mum has always been there, cheering us on and putting us first, despite however she was feeling. She may struggle a bit, but we love her as our Mum."

Bethany's story

"I remember Mummy being poorly and wondering if she would get better.

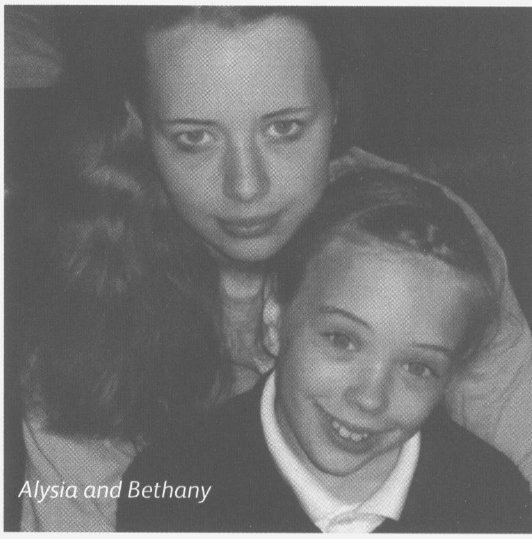
It has been harder for me and my sister growing up because not everyone has a mum who goes into hospital. It is scary when she's ill but I love her – she's my mummy.

I don't like to see her struggle or in pain. If my friends see she's having a bad day they do ask if she's OK."

For further information and advice please visit ***www.dppi.org.uk***

Lisa-Marie Taylor

Bethany and I don't see our Mum as being any different to other mums. She treats us just the same as our friends' mums treat them



Alysia and Bethany

Fun and delight on the Isle

Thanks to the support of a number of Trusts, ASBAH has been able to continue with its long tradition of Family Weekends. This year 17 families stayed from Friday afternoon to Sunday lunchtime at the Old Park Hotel at St Lawrence on the Isle of Wight, which boasts a range of family-friendly facilities and attractions nearby.

> **The Family Weekend is a fantastic way to give families not only the chance to 'get away from it all' for a few days, but also the opportunity to meet people who may have had similar experiences.**

Accompanied by their parents, the group was made up of 17 children aged six or under with spina bifida and or hydrocephalus and all their brothers and sisters, whose ages ranged from 4 months to 12 years.

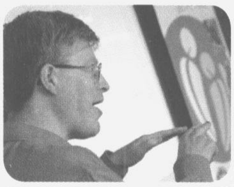
To care for the children were 20 ASBAH staff supported by Garry Rendle, a nurse from Great Ormond Street Hospital. The staff included Advisers, Specialist Medical and Education Advisers, Fundraising, Helpline staff , and members of ASBAH's management team.

They were joined by Carol Sobkowiak, Consulting Physiotherapist and member of ASBAH'S Medical Advisory Committee; Eric Ballantyne, Consultant Neurosurgeon from Ninewells Hospital, Dundee and Edward Lamb, UK Nationwide Manager from shunt manufacturer, Codman.

The children were divided into four age-related groups, each with their own group leader and individual programme. Whilst ASBAH staff looked after and entertained the children, the parents had their own programme of talks on a variety of practical subjects like behaviour, education and continence. Eric Ballantyne spoke on hydrocephalus, and was around all weekend to answer the parents' many questions. Ed Lamb gave a fascinating insight into how shunts work and Carole Sobkowiak explained the importance of early onset physiotherapy and, in the course of the weekend, did a mini physio assessment for each of the disabled children.

Saturday started with face painting for the 2-4 year olds, whilst the 5-7's had fun in the play room and the babies enjoyed some gentle play and snoozing. The brothers and sisters of the disabled children excitedly travelled in the minibus to the Island's Amazon World for a morning of animal spotting and fun.

After lunch it was all change and it was the 5 -7's turn for an excursion to Amazon World, the sibling group's turn to get arty and the 2-4's got on with some funky face painting with Donna, ASBAH's Fundraising Director.

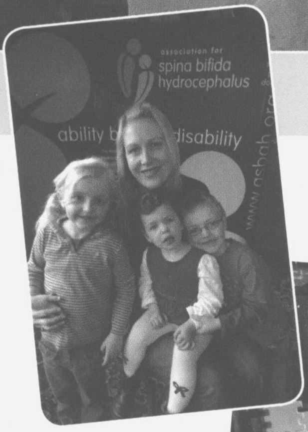


Eric Ballantyne

Consultant Neurosurgeon Eric Ballantyne, told *Link*: "I found the weekend very instructive in showing how the family as a whole interacts with their affected child. Usually in outpatients or the ward the environment is very artificial and there is little time available. The weekend allowed everyone to relax and showed how they live with these medical conditions. I found that some parents did not really understand hydrocephalus but they were relaxed enough on the weekend to ask very basic questions which perhaps they felt embarrassed or unable to ask in the clinic. The best bits of the weekend for me were the trip to Amazon World with the children and watching the youngsters having fun with the fabulous magician Cristo!"

On Saturday night, ASBAH staff acted as babysitters for the smaller children so that parents could enjoy a candle-lit dinner together with wine, courtesy of Codman, whilst the older siblings were enthralled by the tricks of Cristo the magician.

# of Wight



Sunday morning meant a trip by minibus to the beach for the siblings, followed by fun in the hotel adventure playground. A messy time in the art room and games in the hotel's gardens and mini assessments with Consulting Physiotherapist Carol Sobkowiak rounded off the activities.

All too soon it was lunchtime and time to say farewell, as the families headed back on the ferry to Portsmouth.

Rosemary Batchelor, ASBAH Senior Adviser, Health and Policy Issues, said: "The Family Weekend is a fantastic way to give families not only the chance to 'get away from it all' for a few days, but also the opportunity to meet people who may have had similar experiences. The sense of bonding and friendship was overwhelming and the atmosphere all weekend was so warm and positive it was a real wrench when it was time to go home on the Sunday. Everybody pulled together and an incredible amount of useful information was shared between the families, ASBAH staff and the medical experts."

Our thanks go to the Old Park Hotel, to Wightlink Ferries, to Amazon World and especially to Dixons, the Cotton Trust and the D'Oyly Carte Charitable Trust, whose grants made another successful weekend possible.

The Stoner family attended the Family Weekend with their two year old daughter Emma who has hydrocephalus. Jim Stoner said:

"The Family Weekend offered more information in a day and a half of seminars and workshops than we could possibly have gleaned from weeks of surfing websites. It proved to be a fantastic opportunity to meet other parents dealing with similar issues and to listen and learn from experts, safe in the knowledge that our children were safely enjoying themselves nearby. We felt privileged to be given the opportunity to participate and could not recommend this event highly enough to other parents (and siblings) of children with spina bifida or hydrocephalus. On behalf of all of the adults and children who attended, a huge thank you to ASBAH."

What the kids thought!

I think we should have more time for playing and watching badgers.

I have learnt how to make a chocolate biscuit.

I was happy to meet other children with hydrocephalus.

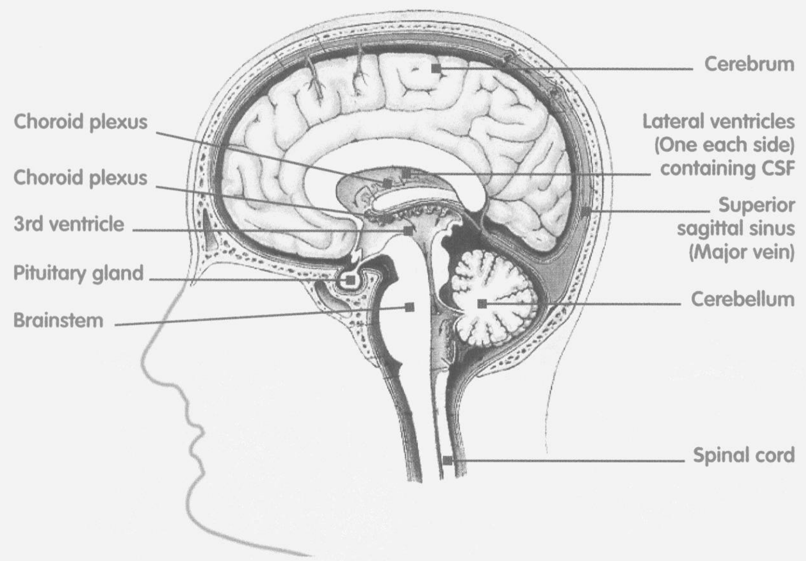
I enjopyed staying up late and watching the magician.

I liked going on the ferry.

I have learnt that no matter what people are like they are still people.

Going to Amazon World and having my face painted was fun.

I did not like nothing!



Cerebrum: The main part of the brain, in two halves one on each side (left and right hemispheres).

Cerebellum: The smaller part of the brain at the back of the head, involved in muscular coordination.

Ventricles: Connected spaces inside the brain, where CSF is produced. There are two lateral ventricles (one each side), a third ventricle and a fourth ventricle. CSF flows from here over the outside of the brain before being absorbed back into the bloodstream.

Choroid plexus: The organ that makes CSF.

Superior sagittal sinus: The major vein that runs over the centre of the top of the brain and collects CSF, draining it back into the central bloodstream.

Frequently asked questions about hydrocephalus

Families who have a child with hydrocephalus - or people who have hydrocephalus themselves - often have lots of questions that they perhaps do not want to ask their neurosurgeon or which only occur to them once they are at home discussing the hospital appointment they have just been to.

Below are just a few of the queries that ASBAH medical advisers are frequently asked. But do remember that everyone is different and only take the answers as a rough guide.

Paper answers are no substitute for talking things through with an adviser.

Q My baby is going to have a shunt. Will I be able to see it after it's done?

A No, the whole shunt is under the skin so once your baby's hair has grown properly and he/she has put on some weight, it won't be visible.

Q There's redness over my shunt and along where the tubing goes.

A Contact your neurosurgical unit if you have open access or see your GP to check for possible infection.

Q Will a mobile phone affect my shunt?

A No. If you are worried, use your mobile on the opposite side to your shunt. Of course it is sensible for anyone to use mobiles for short periods only.

Q Should my child be vaccinated?

A Yes. Your child should have all the vaccinations that other children have. If your child is travelling overseas, they will need exactly the same travel vaccinations as other travellers. If he/she has conditions other than hydrocephalus, see your GP for further advice. *See ASBAH's new vaccinations information sheet.*

Q Do I need antibiotics for routine dental treatment? My dentist says there's a risk of infecting my shunt.

A No. The only time you need antibiotics is if there is a dental infection such as a tooth abscess. If you have unnecessary antibiotics you increase your risk of developing resistance to them.

Q I have a VP shunt. Now I'm getting tingly hands, numbness in my face, sometimes I can't swallow. I'm frightened because I am always out of breath. No one knows what's wrong. Is it my shunt?

A Your symptoms could be related to your shunt. Make an appointment to see your neurosurgeon soon.

Q Can you really get an infection in a shunt that has been in for years?

A VA shunt infections can occur when the shunt has been in for many years. This does not apply to VP shunts – or any others.

Q I have a programmable shunt. Is it safe to go through the safety gates at airports etc?

A The shunt manufacturers assure us that the newer programmable shunts will not be affected. However, to be safe you should carry your shunt alert card and follow the airport advice for travellers with pacemakers which can also be altered by magnets.

Q I can't stop crying. I feel awful. Can't sleep. Stressed out. Why should my shunt make me feel like this?

A These are not symptoms usually seen with hydrocephalus. Go to your GP and explain how you feel. If you find this difficult, ask someone to go with you. People with hydrocephalus get other illnesses, just like anyone else.

Q I am a first aider. I'm told that Heimlich's manoeuvre will dislodge a VP shunt. Surely death by choking is a bigger risk?

A It is highly unlikely that you will damage the shunt. And you're right; the possibility of choking to death should outweigh any worries about the shunt.
In the unlikely event of having to perform this procedure on someone with a shunt, a neurosurgical check after recovery should allay any fears they may have.

Pituitary gland: A gland situated in the brain cavity but just behind the face. It is very important in secreting a large number of hormones that regulate body function and development. An example is growth hormone, and others are involved in sexual development.

Brainstem: A very important area connecting the spinal cord to the brain. It controls breathing and other vital functions.

Spinal cord: A complex trunk of nerves transmitting impulses to all parts of the body, allowing muscle movement, sensation and reflexes.

Q I have "arrested" hydrocephalus. Should I just forget I've got it?

A No, always keep in the back of your mind that you have had a diagnosis of hydrocephalus and be aware that, at some time, it could affect you again. So, if you experience headaches, visual disturbances (especially if accompanied by feeling sick or vomiting) remind your GP that you were diagnosed with hydrocephalus in the past so that he can refer you to an appropriate specialist.

Q Do children always vomit when their shunt goes wrong?

A No, every child is different. Most start by being very sleepy and sometimes difficult to wake. They may (but not always) have headaches, sometimes feel sick, often stop eating, are just "not right". You know your child best. If in doubt, contact your neurosurgical unit. They would rather you had false alarms than miss a potential problem.

Q Can we take our son on a plane or through Euro tunnel? He has an ETV.

A Yes. An ETV or shunt are not affected by either. Do make sure you declare his hydrocephalus to your insurers. Even the new E111 is insufficient to cover you for medical care should something happen while you are away. If the insurance company is going to charge you a lot more, contact ASBAH Helpline on 0845 450 7755 for suggestions of alternate companies.

Hydrocephalus – make sure people are in the know

Telling people that you – or your child - have hydrocephalus isn't always easy, but it is vital that certain people are aware of the condition and its possible side effects.

For a child with hydrocephalus it is important that schools, employers and anyone in loco parentis such as Cub or Brownie leaders, sports coaches and the parents of friends, know what to do in an emergency.

Teenagers and adults must make sure that they tell anyone that they spend a lot of time with such as friends, flatmates and colleagues.

Why?

- If you are unwell, they know who to contact.
- They can get assistance if you have symptoms of shunt problems
- If there is an accident, the emergency services need to know that you have hydrocephalus.
- Sometimes children will tell teachers or others in a position of responsibility things they don't tell their family. For example they might mention that they are experiencing sight problems or headaches. These may be important to act on if child has hydrocephalus.

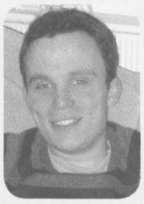
Who should tell them?

- Parents should tell schools before the child begins. Take along information sheets from ASBAH to help explain what hydrocephalus is.
- Sometimes it may be possible for an ASBAH adviser to visit the school.
- The child may like to tell his classmates why he/she has a scar on their head… the children will probably be fascinated especially if they can see a picture of a shunt.
- Tackling schools and employers directly will ensure everyone has the opportunity to ask questions and will avoid "Chinese Whispers".

Don't make a drama out of telling people; they will respond by accepting it just like they accept anything else about you. The more open you are, the less the likelihood of bullying.

Remember that hydrocephalus is part of what you are but doesn't have to be all you are.

I have always been open about my condition, but when I first went to university I didn't tell my flatmates for a few weeks. When I did, I found that they'd never heard of hydrocephalus. They were very understanding, and didn't treat me any differently. - *Ben Edwards*



Q What games can my daughter do at school now she has a shunt? The school don't want her to join in PE or anything.

A She can do almost anything – gymnastics (including forward rolls), netball, rounders, football, tennis, swimming (and diving) etc. Not judo or any other sport where she is grabbed round the neck. She only needs to wear a protective helmet when doing sports that require it i.e. riding, skate boarding, canoeing.

For further information for young children, read "Benny's team wins".

For more frequently asked questions please go to our website www.asbah.org If you have any questions you would like to ask our medical advisers, please call the Association for Spina Bifida and Hydrocephalus on our helpline, 0845 450 7755 (local rate call) or visit www.asbah.org

Wesley is the key to independence for Liz

Liz Potts is 44 years of age and has been in poor health since her thirties following the diagnosis of conditions including spina bifida and hydrocephalus.

Limited mobility was seriously affecting her independence until she partnered up with a new carer called Wesley. Wesley is no ordinary carer or helper – he is an assistance dog, provided by national charity Canine Partners which assists people with disabilities, helping them enjoy greater quality of life and independence and even sustaining education and employment.

Liz, who is married with two teenage sons, told *Link*: "It was love at first sight as soon as I was introduced to Wesley on the assessment and residential training courses I had to complete in order to be partnered with an assistance dog. He is a very large, beautiful and gentle golden retriever and we came home together in July 2006. Since then my life has been transformed and I have got my independence back. Wesley can pick things up, get things off shelves, pull off socks and is brilliant at laundry – he can halve the time it would take me to empty the washer or tumble dryer!

For more information please visit ***www.caninepartners.co.uk***

Your Voice presents

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Open to all adults (aged 18 and over)

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Reserve your place NOW

£90 ***delegate rate including two nights accommodation, breakfast and buffet lunch. Evening meals on the friday and saturday only.***

The delegate rate is subsidised by Your Voice

Discussion points and speakers on:

- **Arthritis/osteoporosis/ menopause & hrt**
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- **Aches & pains**
- **Keeping Fit**
- **Social & recreational issues**
- **Nutrition**
- **Financial issues**

Details of the precise content to be confirmed

For further information and to reserve your place contact:

Barbara Robinson
ASBAH House
42 Park Road
Peterborough PE1 2UQ
Email: barbarar@asbah.org
Telephone: 01733 421322

association for spina bifida hydrocephalus
ability beyond disability

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Get heard, get a voice.
Join 'Your Voice'

Your Voice, ASBAH's adult service user group, was set up in May 1992 to give all of ASBAH's adult service users the chance to play an active role in the development of ASBAH's policies, as well as a forum for training, meeting new people and having some fun.


Lisa Cain

Lisa Cain, chair of the group adds: "Your Voice is a great way of meeting adults with spina bifida and/or hydrocephalus. We organise meetings and events at different venues around the country, focussing on issues relevant to our members.

"The group is all about empowering the individual and promoting positive attitudes. We also lobby for comprehensive civil rights for all disabled people, with particular emphasis on those with spina bifida and/or hydrocephalus.

"To date the group has contributed to ASBAH policy and took a prominent role in shaping the Social Model policy and getting it adopted by the Board of Trustees. Members of Your Voice have also participated in international conferences organised by the International Federation for Hydrocephalus and Spina Bifida."

Recent meetings have included a weekend event in Leeds about getting into work and a weekend event near Cardiff which offered taster activity sport sessions . A series of events are planned including a talk about Ageing and Housing and Financial Planning.

If you are interested in joining YV please contact YV Policy Officer, Barbara Robinson on barbarar@asbah.org.uk or call her on 01733 421 322. Alternatively for more information and to complete an online registration form on the new YV website go to ***www.yourvoicegroup.org***

Committee Members

The 15 members of the YV Advisory Committee were elected by YV members in December 2006 and will serve a three-year term. They are as follows:

- Lisa Cain - *Chair, London (Redbridge)*
- Carole Armour - *Leicester*
- Michael Bergin - *Preston, East Yorkshire*
- Jon Burke - *Huddersfield*
- Geraint Catherall - *Leicester*
- Keith Collins - *Birmingham*
- Amar Raj Singh Dugal - *London (Edgeware)*
- Charles Harper - *Paignton, Devon*
- Louise Iontton - *Ilkley, West Yorkshire*
- Shaun Jennings - *Weston-super-Mare, North Somerset*
- Mary King - *Manchester*
- Cathy Lunn - *Sheffield*
- Paul Manning - *Aberystwyth, Mid Wales*
- Nick Woodward - *Surrey/Hampshire Borders*
- Paul Zickel - *London (Haringey)*

YV Your Voice - Join in

Your Voice goes online

Your Voice has recently launched its very own website at ***www.yourvoicegroup.org*** The site provides details of the latest news and events as well as opportunities to have **your** say about issues affecting people with spina bifida and/or hydrocephalus through the interactive forum discussion area.

We're looking for feedback

The Your Voice Committee is appealing to its members to get in touch with their bright ideas to help it plan the YV events calendar.

The Committee is looking for suggestions to make sure future information days cover topics that a wide range of members want to learn more about.

Three Continence Days were recently organised around the country following requests from several YV members, but were subsequently cancelled due to low numbers.

Events of this type are subsidised by the Your Voice budget and cancellations mean unnecessary costs are incurred... in this case £1,100.

To prevent this happening again the Committee would love to receive feedback to discover why the Continence Days didn't attract more interest and to find out what events would be well received.

Barbara Robinson, Policy Officer (Your Voice), said: "The Your Voice group is a team effort and the Committee is really keen to set up information days and other events that its members would enjoy.

"But to do that it needs to know what they would be interested in doing. So we're asking our members to get in touch."

Contact Barbara Robinson at ASBAH with your views on 01733 421322 or email her ***barbarar@asbah.org***

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Milicent Bagot: Le Carré's "Connie"

Friends and family of Milicent Bagot made donations to ASBAH totalling £550 in memory of the former senior MI5 officer.

Miss Bagot, who had hydrocephalus following a car accident during WW2, was a legendary figure in MI5.

Miss Bagot, who had three shunt revisions during her lifetime, was devoted to her secret work and knew more about the spread of communism than anyone else at the time.

Security sources always believed she was the model for Connie Sachs, the Soviet expert in the Le Carré novels, Tinker Tailor, Soldier, Spy and Smiley's People.

Harriet Greene, Miss Bagot's niece, said: "Aunt Milicent was always the soul of discretion so we knew nothing at all about her work. We all feel very, very proud of her."

She also warned MI5 bosses that Harold "Kim" Philby, the MI6 agent who was a Soviet KGB double agent, had been a member of the Communist Party

Milicent Jessie Eleanor Bagot was born in 1907, the daughter of a solicitor. She was educated at Putney High School and went on to read classics at Lady Margaret Hall, Oxford.

Her association with the intelligence service began in 1929 when she joined the counter-subversion section of the Metropolitan Police Special Branch as a registry clerk. Two years later her division was transferred to MI5.

By the end of the Second World War Miss Bagot had earned a reputation for her intimate understanding and knowledge of Communist affairs. She was awarded the MBE in 1949 in recognition of her knowledge and for her contribution to countering the threat it posed.

She also warned MI5 bosses that Harold "Kim" Philby, the MI6 agent who was a Soviet KGB double agent, had been a member of the Communist Party, alerting suspicions to his activities.

Milicent is remembered for her enthusiasm and energy, and for demanding one hundred per cent effort from her subordinates. One former colleague recalled: "As a boss she was a bit fierce, as a woman absolutely lovely."

In 1953 she was promoted to assistant secretary rank, in charge of all the Security Service's efforts against international communism.

On her retirement in 1967, she was advanced to CBE and the FBI director, J. Edgar Hoover, sent her a personal letter, expressing his appreciation of her work.

Miss Bagot continued to work for MI5 part-time and was involved in a number of research projects, including looking at pre-war communist records for leads to any spies who might still be active. She finally stopped working in 1976.

Milicent Bagot died in a nursing home on 26 May 2006 at the age of 99. A thanksgiving service was held at St Paul's Church, Knightsbridge on 9 October 2006.

ASBAH Fundraising officer Jane Ayres said: "We are always conscious that donations of this nature are the result of unhappy circumstances and we are extremely grateful to Miss Bagot's family for choosing to support ASBAH's work in memory of this great lady.

"The donations received from all those who gave at Miss Bagot's thanksgiving service will be used towards ASBAH's research projects."

NEW faces at ASBAH

Lisa Raman: Specialist Medical Adviser & Helpline team

Lisa Raman has joined ASBAH as specialist medical adviser, for the Eastern Region & the Helpline. As well as being part of the Helpline team, taking calls to advise people about various issues surrounding hydrocephalus and spina bifida, Lisa provides medical information and support for the ASBAH advisers working across counties including Nottinghamshire, Leicestershire, Derbyshire, Lincolnshire, Northamptonshire, Cambridgeshire, Bedfordshire as well as parts of Wales.

Lisa holds nursing qualifications in both the USA and UK as well a Masters degree in nursing, and is also a qualified neurosurgical nurse.

Belinda Smith: ASBAH Adviser

Say hello to Belinda Smith who joins the team of ASBAH advisers. Belinda, who has a background in occupational physiotherapy and mental health, will be covering Dorset, Wiltshire, Hampshire and the Isle of Wight. She told *Link* about her new role: "To me, being an ASBAH adviser seems to be all about helping people affected by hydrocephalus and spina bifida live the lives they want to lead. The advice and support my colleagues and I will offer to service users, health professionals, teachers and families, will hopefully go a long way towards helping people move towards achieving new goals, whether they want to gain new levels of independence, get help with physiotherapy to become more mobile or improve their health situation in some other way."

Collette Torrence: ASBAH Adviser

Welcome to Collette Torrence who joins as ASBAH adviser, covering the counties of Nottinghamshire, Derbyshire and Leicestershire. Collette has a nursing background, from Leicestershire North West PCT where she was a member of the rapid response team. *Link* asked her about her new role and she said: "I'm looking forward to transferring the knowledge I've gained from my previous nursing roles into my new position of ASBAH where I'll be helping those whose lives have been touched by hydrocephalus or spina bifida. Being part of a team that can make a difference and help someone make positive changes to their quality of life is really exciting and I'm ready for the challenge!"

Sylvie Bailey: ASBAH Adviser

Joining the nationwide network of ASBAH advisers is Sylvie Bailey, who is based at ASBAH's northern office in Leeds and covers North Yorkshire, Redcar and Middlesbrough. Sylvie has a varied background, in nursing, mental health and teaching, making her a very welcome addition to the team.

She told *Link* why she decided to join ASBAH: "When I heard that an adviser's role in my area had come up, I was excited because the various elements of the job encompass what I really want to do. I was looking for something challenging and this is it!"

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.

Our family recently had a fantastic holiday at Disneyland Paris thanks to exceptional service from EasyJet and staff at the resort.

When we arrived at Disneyland we took the free shuttle bus back to the hotel, but it was so crowded that it was a real struggle for us with Elisabeth in her buggy.

We asked at the hotel reception if we could book a taxi for the following morning.

In the event they arranged for a free mini bus with a ramp to take us there and back every day. We were also given a special Blue Pass so we could go to the front of the queue and get straight on the rides… and stay on if we liked.

When we went to watch the Parade, a member of staff spotted that Elisabeth was disabled so they lift her in the buggy on to the bandstand so she had a fabulous view. Minnie Mouse came over to see her and Tigger danced just for Elisabeth.

Everyone made such a fuss of her. It was wonderful. We'd all thoroughly recommend a trip there.

….***Sam Copeland, mother of Elisabeth, 2***

Happy 60th Birthday to... Cheryl Wilton!

ASBAH would like to wish a very HAPPY BIRTHDAY to Cheryl Wilton, a member of the Staffordshire Local Association.

Cheryl, who has spina bifida and uses a wheelchair, defied doctors, who didn't think she would even survive infancy. Sixty years on and, following a variety of challenges throughout her life, including the sad loss of her mother who had been her main carer, Cheryl leads a very fulfilled and independent life thanks to a personal Assistant and a strong network of good friends. Read more about Cheryl's amazing life in the next issue of *Link* magazine.

Holiday let

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

ISLE OF WIGHT ASBAH - HOLIDAY BUNGALOW

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

PAIGNTON, DEVON

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

PRESTATYN, NORTH WALES

Choice of two adapted caravans for disabled holiday makers. Each sleeps 6 people (2 wheelchair accessible bedrooms), wheel-in shower with seat, open plan lounge, dining, kitchen area. Caravans have ramp access and are overlooking a children's play area in a site adjacent to the beach at Prestatyn – a small market town on the North Wales coast within easy travelling distance of Rhyl, Llandudno, and Snowdonia National Park. Costs are between £95-£275 per week; **for further information contact North & West Yorkshire ASBAH, c/o Jo Baxter, 8 Staveley Court, Shipley BD18 4HF. Tel. 07989 243994, e-mail** *jo.baxter2@btinternet.com*

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

ROPERS WALK BARNS, MOUNT HAWKE, CORNWALL

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

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*

WANTED

Accommodation

One or two bed GFF with garden suitable for wheelchair user preferably Croydon/Hastings area but will consider anywhere suitable. If required, I have in return large one bed GFF, with wheel-in shower, private garden/shed/car park 10 minutes from Worthing town and sea front.
Further details contact Lisa on 07940 720920 or by email lisa.buck4@virgin.net

Accommodation

ILKLEY, WEST YORKSHIRE

Flat 1 Wharfedale. Three bedrooms, living room, kitchen, bathroom and toilet. Fully wheelchair accessible and on the ground floor. The person to hold the tenancy must have a disability and need housing related support. Care and support packages can be arranged with Bradford Social Services.
Contact: Mark Best, Tel/Fax: 01943 603013, or write to Five Oaks Housing Scheme, Ben Rhydding Drive, Ilkley LS29 8BD.

Diary dates

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

Megacycle 2007

Peterborough
Date: Saturday 30th June & Sunday 1st July
For further information contact
Ian Morley at ASBAH on 01733 421328 or
email ianm@asbah.org

York Coffee Mornings

Venue: Low Moor Community Centre,
Bray Road, Fulford, York YO10 4JG
Time: 10.15am - 12 noon
Dates: The second Wednesday of every month:
15 August, 12 September, 10 October,
14 November, 12 December

ASBAH Family Day

Date: Wednesday 1 August 2007
Time: 10am - 4pm
At: The Together Trust Centre, Schools Lane,
Cheadle, Manchester SK8 1JE
For further details contact: ASBAH House
North, 64 Bagley Lane, Farsley. Leeds. LS28 5LY
Tel: 0113 255 6767 Email: nro@asbah.org

Your Voice presents: AGEING DISGRACEFULLY

For more information see p24
Open to all adults 18+
Date: Friday 10 - Sunday 12 August
At: Jury's Inn, Birmingham
Reserve your place now.
Contact barbarar@asbah.org

ASBAH AGM

Date: Saturday 22 September
Time: 11.00am
At: ASBAH House, Peterborough
For more information contact lynr@asbah.org

Eastern Region Local Association Forum Meeting

Date: Saturday 13 October 2007
Time: 11.00 am start
At: ASBAH House, 42 Park Road, Peterborough
PE1 2UQ
Lunch and parking
Speaker: Linda Lewis Help Line
and Information Manager.
More information contact the
Eastern Region Office on: 01733 421309

Please e-mail the editor (link@asbah.org) dates of your events for the next issue of Link by Friday 14 September 2007, 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 14th Sept 2007

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The Concorde Wheelchair Dancers

Dancing their way onto the **small screen**

The Concorde Wheelchair Dancers have a simple philosophy – 'Dancing is for everyone. Don't let your wheels get you stuck in a rut – get out there.'

It's an attitude that has stood the Bristol-based group in good stead since its launch in the 1970s.

Many of its original members are still dancing with the group today, alongside newcomers, aged from 8 to 70 plus.

Chairperson Julia Hall has been involved with the group for more than 25 years. She told *Link*: “It's a great way to meet people and have fun, as well as being a good form of exercise.

“We attend competitions and festivals all over England and Scotland, travelling to places we'd probably never go to otherwise.”

We attend competitions and festivals all over England and Scotland, travelling to places we'd probably never go to otherwise

The group enjoyed a brush with fame when they hit the small screen in April as the subject of the BBC1 One Life documentary.

The programme was filmed competing at the National Wheelchair Dance Festival in Blackpool last November, where the group clinched six trophies and were voted Champions by the panel of judges.

“We had been trying to get our hands on one of the trophies for about 30 years, “explained Julia, “so we had a great celebration that night.

“But it was a bit weird having the cameras there, although when I was on the dance floor I was completely oblivious to them. But I have to admit that I certainly played up to the camera at other times,” she laughed.

Wheelchair dancing is believed to have originated in England in the 1960s, created as a means to teach new wheelchair users how to cope with their new form of transport.

As time went on it became more about the music and the dancing, with increasingly sophisticated structures and formations. Today waltzes, cha-chas, jives, 2-steps, sambas and contemporary rock are all among the Concorde's stylish repertoire.

There are several categories that the group competes in, namely Formation, Novelty, Disco, Ballroom and PHAB dancing, where a disabled person dances with an able bodied person.

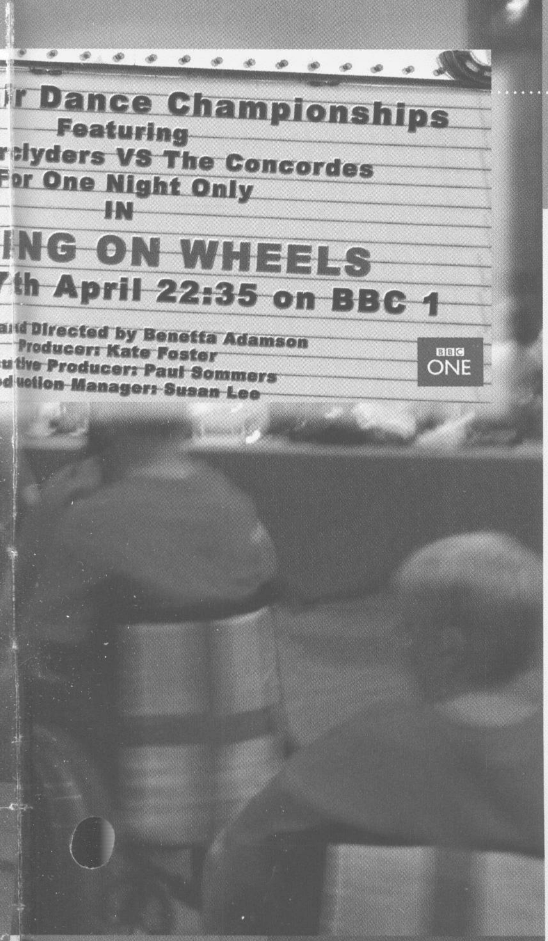
The Concorde group prefers team formation dances, generally with three or four couples. “We believe strongly in teamwork, and you need plenty of that for formation dancing,” laughed Julia.

“There are many dances and categories, so each person takes part in the dance they can manage,” she said. “The stronger, more experienced members prefer the faster ones such as the Latin American routines.

Julia added: “New members are always welcome. We're not interested in your disability, we're only interested in what you can do, and it is always lovely to meet new faces.”

The type of chair you use is no obstacle. The Concorde teams have two electric wheelchairs, one semi-powered chair and a whole host of manual chairs in various shapes and sizes.

If you fancy tripping the light fantastic with the Concorde Wheelchair Dancers contact Chairperson Julia Hall, on 01275 833541 or email *julia@wheelchairdance.co.uk*



The Wheelchair Dance Association was formed in 1974. At its peak more than 30 groups were members of the WDA. Today there are 12 in England and Scotland and no groups currently running in Wales.

But the WDA is keen to welcome interest from new teams. If you would like further information, or a start-up pack including scripted dances, a music cassette/CD and introductory leaflet (a fee will apply) contact Margaret Oliver MBE on 01637 860460.

Contacting ASBAH

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

Local Association secretaries requiring changes to this list should contact:
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Let's Celebrate Together!

This year marks Coloplast's 50th anniversary and there is a lot for us to be celebrating through 2007.

Coloplast was born from an idea presented by Elise Sørensen, a Danish nurse searching for a product that would help her sister who had undergone surgery. From that first day, we have been committed to listening both to the needs of the people who use our products and the healthcare professionals who work with them.

Innovation and quality are two of the key factors to our success in the Stoma care, Continence care and Wound care fields. At Coloplast, we always strive to develop and deliver products and services that will impact positively on people's daily lives.

As part of our celebrations, we would very much like the opportunity to meet some of our product users. If you would be interested in meeting a member of our team, please call Hayley Porter on **01733 392 060** or Martin Beynon on **01733 392 059**.

Working Together and Celebrating Success

Coloplast
together