SPRING 2007 ISSUE 219

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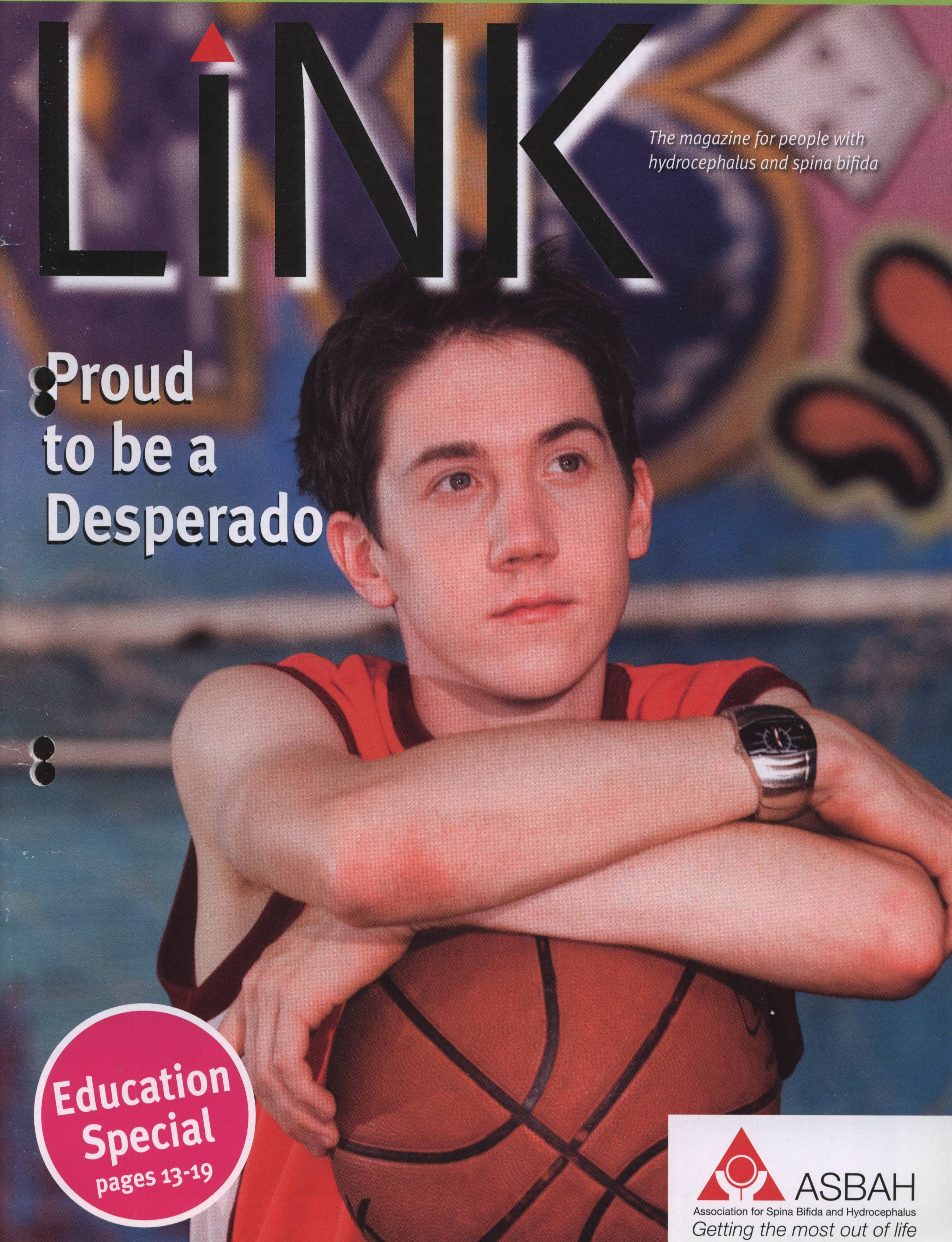
- Meet ASBAH's Telesales team
- New Your Voice committee
- Keith's drive to improve care services
- Hydrocephalus Action update
- News round-up
- China & Peru fundraising adventures

# LINK

*The magazine for people with hydrocephalus and spina bifida*



## Proud to be a Desperado

**Education Special**
pages 13-19

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

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

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

## You can help us make that difference!

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

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

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

# Forget-me-not
## *Memorial Fund*

**At ASBAH we receive many donations in memory of a loved one who has died.**

Friends and family often find it a fitting way to remember the person who has passed away.

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 our Fundraising team on 01733 555 988 or email donnat@asbah.org**

## Peter Farrall writes

Welcome to *Link* 219, the first issue of 2007.

As regular readers will know, ASBAH's 40th anniversary celebrations last year helped generate a host of fascinating articles.

We're determined to continue to develop and improve *Link* and have planned plenty of special supplements this year.

in this issue we focus on education with articles covering a wide range of topics from pre-school through to further education opportunities.

Anyone going into hospital will have concerns about "superbug" infections which are mentioned so frequently in the media. *Link* spoke to two experts in the field of infection control who give their valuable advice on what precautions can be taken.

On pages 21 & 22 you can read about the newly elected Your Voice committee, and find details about the exciting new Your Voice website.

As ever our fundraising pages are packed with news of people who have worked so hard to collect cash for us – some are regulars, others are new faces. But whoever they are, their efforts are really appreciated.

So all in all it's another packed issue. Many thanks to everyone who writes in with their news or story ideas. If we haven't been able to include your story this time, our apologies, but please do continue to write in. We couldn't put *Link* together without your help.

Best wishes,
Peter

Peter Farrall
Director of Marketing
and Communications
peterf@asbah.org

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**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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Designed and produced by Bluestation Communications

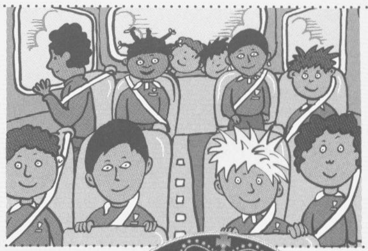
*Link* is published by ASBAH,
National Centre, 42 Park Road, Peterborough PE1 2UQ

*All Link enquiries to:*
Link, ASBAH, 42 Park Road, Peterborough PE1 2UQ
Tel: 01733 555988 Fax: 01733 555985
link@asbah.org www.asbah.org

*Subscriptions (four issues per year):* UK £6.80
All Europe by airmail £10.50
Rest of the world: by airmail £16.50,
by surface mail £10.50

Registered charity number 249338

ISBN 1360-323X



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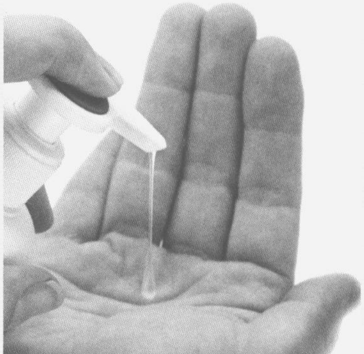
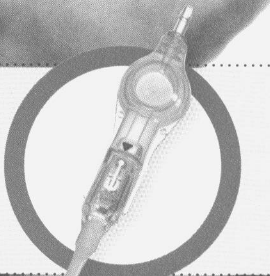
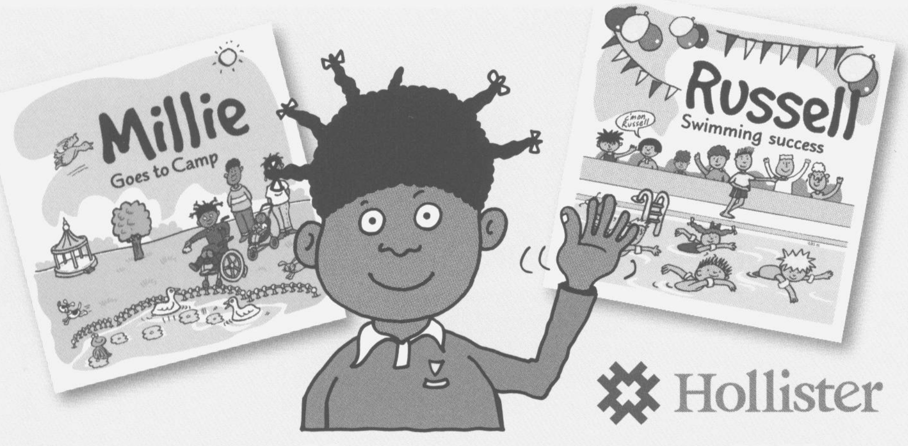






# Russell and Millie

## bring confidence to youngsters

**ASBAH has linked up with Hollister Ltd to produce a new series of books aimed at helping children with spina bifida learn more about continence problems.**

Hollister, a healthcare company which produces the Advance range of intermittent catheters, has sponsored the Russell and Millie books, launched this month.

The books, *Russell/Millie's Swimming Success* and *Russell/Millie Goes to Camp*, come in two versions – Russell for boys, and Millie for girls - and deal with bladder and bowel issues.

They are aimed at boys and girls aged between four and nine years, and show how continence problems affected Russell and Millie's lives.

With assistance and patience they learn to manage their continence, giving them the freedom and confidence to get on with their lives.

The books, written by Paula Thompson and Rosemary Batchelor, ASBAH's Medical Advisers, help to simply explain the medical facts, and how the child can make life easier for themselves.

In his foreword, Dr Malcolm Lewis, Consultant Paediatric Nephrologist at the Royal Manchester Children's Hospital says: "Children with spina bifida often have lots of difficulties and being incontinent can be one of their biggest battles to overcome.

"By reading about Millie and Russell I hope that they will understand that with help and some patience, they too can become clean and dry and live full and active lives just like any other child."

The books cost £3 (including postage) for the set of two books. Send a cheque payable to ASBAH to: ASBAH, 42 Park Road, Peterborough PE1 2UQ.

Please state clearly whether you require the version for boys or for girls.

# Top award for Charlotte

**If your head teacher calls your name out unexpectedly during assembly that usually means one thing... trouble.**

So young Charlotte Buckley got the surprise of her life when she was summoned to the stage to be presented with a Diana, Princess of Wales Memorial Award.


*Charlotte Buckley*

Charlotte, from Port Sunlight on the Wirral, wasn't even aware that she had been nominated for one of the prestigious awards which celebrate young people who have been brave, have overcome personal obstacles who are an inspiration to others.

Charlotte, 14, who has hydrocephalus, still has no idea who nominated her, although she strongly suspects it was one of her friends.

Mum Diane said: "It all came as quite a shock because I don't think Charlotte realises how much she has achieved. I think one of the main reasons she was nominated was for her work with the St John Ambulance Brigade.

"She joined around three years ago and attends weekly meetings as well as handling a lot of duties at weekends."

Charlotte was born 13 weeks premature, weighing a tiny 2lbs 2oz. She developed hydrocephalus at four months old, and was fitted with a shunt.

Diane explained: "Charlotte is lucky in that she doesn't have any physical side effects, but she does have short-term memory problems and she has to worker harder at school to compensate. Getting into Grammar School was a real achievement.

"It also means that she must take instructions one at a time, which often means she has to explain to teachers to make them appreciate her problems.

"But she doesn't let it get her down or hinder her in any way and we're all so proud of the way she gets on with her life."

# New web site to help the disabled

**Disability charity Leonard Cheshire is to launch a new web portal later this year aimed at all disabled people within the UK.**

It will feature information on a range of topics – including benefits, employment and access - and enable users to add their own experiences, comments, and to chat and blog online.

If you are interested in taking part in a pilot of the service this spring, please contact stephen.elsden@lc-uk.org

# New record for Jonathan

**Wheelchair racer Jonathan Smith beat off stiff opposition to clinch first place in his second Tesco Junior Great South Run.**

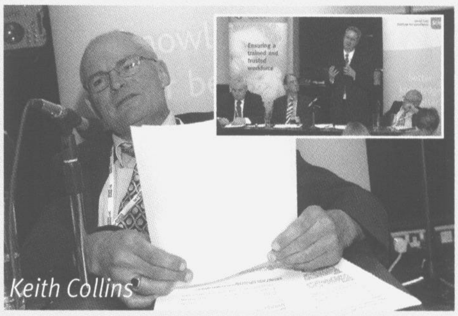
The fiercely contested annual Portsmouth race saw Jonathan, 15, knock more than a minute off his time, finishing in a fast 10.44 minutes... a new course record.

Jonathan from Kingston in Surrey has trained hard for the past year with Velocity Wheelchair Racing Club in Kingston.

He said: "I made a quick start but was held back by a strong head wind on the promenade. After that section I speeded up and maintained a fast pace until the final bend where I sprinted for the finish. "

He added his thanks to Surrey ASBAH for its encouragement and to Sports Aid for the funding he was granted.

# Keith meets MP in drive to improve care services


Keith Collins

**Former social worker Keith Collins discussed the failings of social services during an hour-long meeting with Ivan Lewis, Minister for Care Services.**

Keith, who has spina bifida, was invited to speak at the General Social Care fringe meeting at the Labour Party Conference last September.

But Ivan Lewis, who was due to attend, was delayed and missed Keith's speech.

So when the MP for Bury South was visiting Birmingham's Heartlands Hospital in November, he arranged to meet Keith to give him another chance to air his views.

Keith, from Birmingham, told *Link*: "Having retired from my post as a senior social worker due to deteriorating health four years ago, I soon found out what it was really like being a service user.

"How my perception of social services has changed during the past few years.

"Some service providers have made me feel humiliated by their lack of professionalism.

"I also gave Mr Lewis details of three other examples of people in the Birmingham area who have been failed by social services – and they are just the tip of the iceberg."

Keith's concerns include lack of continuity of care, inadequate training of care staff, difficulty in obtaining direct payments, issues around unmet need and escalating care costs.

He added: "When I started my career in social services I enjoyed my work and took pride in enabling others towards their goal of a better quality of life.

"That is why, when I became a service user, I expected to receive a first class service. Unfortunately this notion was shattered."

In his speech to the fringe meeting, which was attended by 50 dignitaries and MPs, Keith also discussed the advantages of local authorities as social service providers over independent agencies, best value and the need for better training of care staff.

He added: "An under-funded, unaccountable and poorly policed system is a serious danger to all vulnerable people.

"I was impressed that Mr. Lewis arranged the meeting specifically to discuss the concerns raised at the Manchester Conference.

"The more service users are able to share their experiences the better chance we have of developing a social care system where progress serves need."

# Opportunities for young people in the North West

**ASBAH, Irish ASBAH (IASBAH) and Inishowen Rural Development (IRDL) have teamed up to provide a unique service for young disabled adults in the North West of Ireland.**

The Gateway to Opportunities project targets physically disabled people between the ages of 18-30, living in isolated areas in Ireland including Coleraine, Derry/Londonderry, Limavady and Inishowen in County Donegal.

The project hopes to bring disabled young people closer together and provide a range of training and support opportunities aimed at improving their career prospects, self confidence and self esteem.

Irish football hero Packie Bonner, patron of IASBAH, launched the scheme on 18th January 2007, along with key speakers Colin Power, the Chief Executive of IASBAH, Sid McDowell CBE, Vice-President NIASBAH.

Sid McDowell said: "It's an exciting opportunity for young disabled adults throughout the North West region to take advantage of training and peer support in a relaxed and friendly setting. I'm confident that it will prove to be a positive and rewarding experience for all participants involved."

This Project has been funded through the Cross – Border Consortium under the EU Peace II Programme and part-financed by the UK and Irish Governments and is administered by CFNI through ASBAH and Irish ASBAH.

To find out more about the Gateway to Opportunity Project or to register – contact Julie McGrory on 0035386 600 2929 or email: Juliem@asbah.org

# Portage survey needs your help

**The National Portage Association is surveying parents who have received a portage service for their child to help improve services.**

Dr Fran Russell, who has a son with a learning disability, is compiling a report about Portage, a home visiting educational service for pre-school children with additional support needs and their families.

She would like to hear from people about their experiences, particularly if their Portage service stopped sooner than planned for any reason or if they decided not to use Portage.

If you think you can help, or know of a family who can, or would like to find out more please contact - Fran Russell – Tel 0113 2671337 (9am to 6pm Monday to Friday) or email fran.russell@talk21.com

Fran will ask you to either arrange to talk to you on the telephone or to complete a short questionnaire.

Any information you choose to share will be treated in the strictest confidence and you will not be identified in any report/s that are written.

# Disabled Parents Network

**As a disabled parent, you may feel isolated, on trial or having to prove you are a "good" parent.**

If you need extra help contact the Disabled Parents Network (DPN), a national organisation for disabled people who are parents or who hope to become parents, and their families, friends and supporters.

For more information contact DPN at www.disabledparentsnetwork.org.uk or write to Disabled Parents Network, 81 Melton Road, West Bridgford, Nottingham, NG2 8EN. Call 08702 410 450 for general enquiries.

# Help with your fuel costs

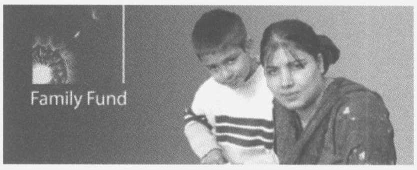
**It hasn't been advertised but one bright spark contacted Link to let us know that British Gas is giving discounts on fuel costs if you receive certain benefits.**

You can claim two payments of £30 towards your gas bill and two payments of £15 towards electricity – providing British Gas is also your electricity supplier.

To claim you must be in receipt of one of the following benefits: Disability Living Allowance, Attendance Allowance, Constant Attendance Allowance, Carers Allowance, Severe Disability Allowance, Council Tax Benefit, Housing Benefit, Income Support, Income Based Job Seekers Allowance.

Anyone wishing to claim should call the British Gas Helpline on 0845 601 2006.

# Get details of your day in print



**The Family Fund is looking for families to take part in its latest research project to create a 'Day in the Life' diary for use by families and health professionals.**

The charity hopes to publish a book showing how families with disabled children live on a day-to-day basis to help others gain insight into some of the issues such families face.

Family Fund is looking for around 200 responses so your diary entry really does count.

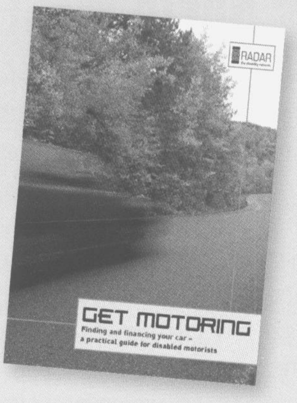
If you wish, all names can be changed in the final publication. Please indicate on the form if you wish to remain anonymous.

In order to take part, please download the diary sheet from their website at ***www.familyfund.org.uk*** and write down your experiences. You will also need to give details of your child's diagnosis and date of birth.

You can e-mail your response to maw@familyfund.org.uk or return it by post to: Research, Family Fund, Unit 4, Alpha Court, Monks Cross Drive, Huntington, York YO32 9WN.

# Top tips from new motoring guide

**If you are a disabled driver or passenger, get your hands on the new "Get Motoring" guide from disability rights organisation RADAR.**



The free guide gives you tips for getting the best deal on purchasing or leasing a car.

It addresses everything from driving lessons to potential depreciation values. As well as additional features specific to disabled motorists such as adaptations, VAT exemption, and the Motability Scheme, the publication simply explains other costs associated with getting on the road as encountered by all motorists

"Get Motoring" is free from RADAR by calling 020 7250 3222, textphone 020 7250 4119. "Get Motoring" is also available to download at ***www.radar.org.uk***

# Eager Beaver scoops award

**Young Thomas Asare-Sarpong's zest for life didn't go unnoticed at his Beaver pack where leaders awarded him the prestigious Beaver of the Year award.**

Thomas, who lives with Grandmother Kathy Shannon in Stainton, on the outskirts of Doncaster, scooped the coveted Jinks Award, for the Beaver who gets the most from his time with the Tickhill group.

Thomas, 8, who has spina bifida, relishes the weekly meetings, giving one hundred per cent effort to every activity.

Grandmother Kathy told *Link*: "Thomas is unbelievable. He wants to be the best at everything and doesn't think he's different to anyone else, which is a great attitude to have.

"He uses a K-frame or wheelchair to get around, but doesn't let them hamper him in any way.

*Thomas Asare-Sarpong*

"Joining Beavers was the first thing he's really done away from me, with the exception of school, and he's really enjoyed being independent. Now he's talking about camping trips when he moves up to Cubs."

**He does have a lot to deal with but he just gets on with it.**

Thomas and Kathy enjoyed another surprise in December when they were invited on a daytrip to Lapland to see Father Christmas, courtesy of Sheffield Children's Hospital.

Kathy added: "It was a magical experience and Thomas had a wonderful time. He does have a lot to deal with but he just gets on with it. He's a lovely boy and I'm so proud of him."

# 21 years of dedication

**Fundraiser Corrine Thomas has been praised for her unstinting work for more than two decades.**

Corrine, 86, has been one of the regular volunteers in the ASBAH charity shop in Gorseinon in South Wales for 21 years.

Shop manager Linda Morris has contacted the local council asking them to recognise Corrine's hard efforts over 21 years.

Linda said: "Corinne gives up every Tuesday, regardless of the weather or her health, to come in and help customers. She acts as a mother and friend to all the staff here and is extremely friendly and very good with our customers. She really deserves recognition for her work."

Corrine, a great-grandmother, said that she can hardly believe that she has been working in the shop for so long as the months and years have flown by.

"I enjoy helping out," she said, "It gets me out of the house and I like to go into the shop, meeting people and having a chat.

"We have a very good group of volunteers here; it's a really good crowd."

One regular customer said: "I think that too often the efforts of people like her go unrecognised. She really deserves a special mention for all the work she has done."

# Extra help for Leeds & Bradford

**The Leeds and Bradford local association is celebrating the appointment of three new members of staff.**

Duncan Stoke and Michaela Carter have been taken on to run groups with teenagers in Wakefield and Leeds/Bradford area with Nicola Boldy supporting adults in Leeds/Bradford.

Deputy Chairman Jo Baxter told *Link*: "We received funding from several sources, including Children In Need, which enabled us to employ additional staff.

We are thrilled to have them working with us to improve services for the people in our area."

The association, which celebrates its 40th anniversary this year, has gradually expanded its area in recent years following the closure of the Castleford and Pontefract, Huddersfield, York and Halifax associations. In view of these changes it is proposed that the association change its name to North and West Yorkshire Association for Spina Bifida and Hydrocephalus (NWY ASBAH).

And as part of its 40th year celebrations the group is planning a road show to promote itself around the areas and meet service users, old and new.

Jo, who has been with Leeds and Bradford for more than 36 years, said: "It will be a great way to get to know people in our new areas as well as meet up with our existing members."

Running such a large group is no mean feat, especially with a committee which is down to just five members.

But Jo remains positive and said: "We have a great committee and team of helpers but just need a few more people to help share the workload, particularly as our area has widened. We're keeping our fingers crossed that some volunteers will come forward at our AGM in March."

# Indesit's Christmas cash collection

**Staff at Peterborough's Indesit Company headquarters decided against sending Christmas cards to each other... but not because they lacked Christmas cheer.**

Logistics Replenishment Planner, Kim O'Brien suggested that staff in her department made donations to charity instead of sending cards to each other, and asked the team for suggestions.

ASBAH fundraising director Donna Treanor's nephew, Michael Belson, who works in the department forwarded details and ASBAH was subsequently chosen as the charity to benefit.

The kind-hearted employees agreed and their festive efforts raised £50 in the process. Many thanks to you all.

# Ian runs up £3200 for ASBAH

**In October, Ian Williams, 31, from Wales, ran the Abingdon Marathon and raised over £2,600 for ASBAH.**

Ian, who was born with spina bifida but had it corrected as a baby, ran the 26.2 miles around Abingdon and its surrounding villages. With the exception of two bridges over the Thames, the course is one of the flattest routes in the UK, and attracts a number of wheelchair athletes.

Completing the course in 4 hours and 44 minutes, he said: "I've been running regularly for the last two years, but marathon training takes a lot of commitment. I managed the first 18 miles quite comfortably, but the last bit was very tough".

Ian is a keen runner and this year will be entering the London Marathon. He has even made his own website ***www.fetcheveryone.com***, for anyone else who is interested in running.

# Jaynie races ahead

**In the third of our series meeting regular ASBAH supporters, *Link* talks to Jaynie Phillips from Manchester, who competed in six gruelling events to boost ASBAH's funds.**

**Manchester's very own superwoman took part in six tough races in her bid to raise money for ASBAH in 2006.**

Jaynie, from Didsbury, tackled six events ranging from 10K runs to triathlons throughout the summer months, raising more than £600 in the process... and she plans to do it all again this year.

Super-fit Jaynie decided to run for ASBAH after discovering, two years ago, that she has arrested hydrocephalus

**Super-fit Jaynie decided to run for ASBAH after discovering, two years ago, that she has arrested hydrocephalus**

"I was very surprised to discover that I've had it since birth. It hasn't caused me any problems at all as it occurred when I was a baby so my body was able to adapt.

"But ASBAH was very helpful in providing me with information when it was first diagnosed, so I thought it would be good to raise money for the organisation."

Jaynie began running several years ago, competing in 10K runs and then her first half marathon, the Great North Run. "Although I couldn't walk for a week afterwards, I loved it and I've done it for the past 3 years now," she explained.

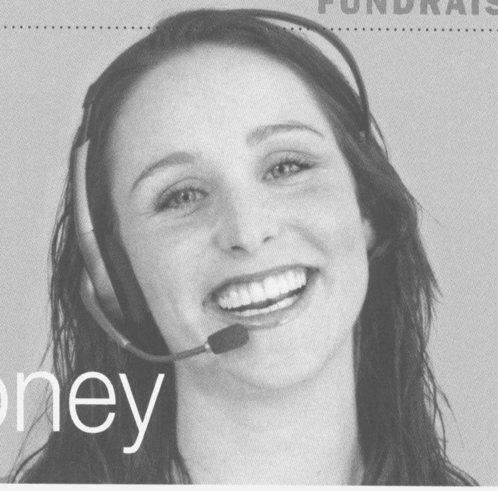
"Over the past few years I have watched my partner compete in the Olympic distance triathlons and always wanted to give it a try so last year I bought all the equipment I needed and gave the sprint distance a go - which is 750m swim in open water, 20k bike ride and 5k run.

"It is quite hard as you have to train for three sports. I found the swimming the hardest and up until Christmas 2005, I couldn't swim front crawl at all. Swimming in open water was really frightening at first and it wasn't until I was into my second race and the water had warmed up a bit that I became used to it.

"But nevertheless, after I'd done my first triathlon I became totally addicted. They are so much fun. My challenge this year is to do the Olympic distance."

2007 promises to be a hectic year for Jaynie as she recently took up the position as PA to the Company Secretary of a large media company after nine years in her previous job. She has also started a part-time teacher training course at University.

But she added: "I loved taking part in so many events last year and every race has been a personal best, so I've a lot to live up to this year. 10k is still my favourite distance but the Triathlon is my new passion and I hope to train hard and improve on my time."



# Small team generates **big** money

**Tucked away in ASBAH's Peterborough offices is a small but industrious department which generates nearly a million pounds each year.**

The Telesales department brought in an impressive £865,000 for the charity last year, by selling advertising in spring and winter brochures, a guide to ASBAH services and the ASBAH diary.

Other money-spinners are the regular balloon races, where companies and individuals sponsor a balloon. The one which travels the furthest wins a case of champagne. In the past, balloons have made it to Germany, Belgium and the Netherlands.

The department, made up of 14 telesales representatives and three admin staff under manager Tom Logan, was set up almost twenty years ago.

Unusually for offices of this type, it has a low turnover of staff, with the average employee staying on for at least 12 years.

Donna Treanor, Director of Fundraising, said: "There is a great sense of team spirit within the department. It's a small office and everyone gets on very well, which is so important for a happy and motivated team.

"ASBAH is a wonderful organisation to work for and I think this also contributes to the success of the department."

The representatives, who work 9am to 5pm, Monday to Friday, each have their own areas to cover. They keep in contact with existing supporters as well as cold calling, working their way through companies listed in the yellow pages.

Each rep can make between 200 and 300 calls a day, achieving on average, 20 sales from those calls.

Donna told *Link*: "It can be a thankless task and for the department to raise so much each year really shows how dedicated our staff are.

"These days there are more than 180,000 registered charities all trying to raise money, so competition is fierce.

"But ASBAH is unusual, if not unique, in that we run our own telesales department, whereas most charities employ an agency to do it for them.

"Keeping the department in-house means that we don't pay any commission to an agency, and we also have more control over the department."

Cold calling is the toughest part of the job, particularly when they ring someone who doesn't know anything about ASBAH, or indeed anything about spina bifida or hydrocephalus.

"They are a fantastic and very hard working team, and the money they bring in each year enables ASBAH to support many thousands of families and individuals affected by spina bifida and hydrocephalus.

"We are very grateful to the companies and individuals who do support ASBAH in this way."

**Brigitte Sargeant, team manager, who has worked for the department for 14 years.**

*"In this job it is essential to keep a happy disposition. If you feel negative about work or something in your personal life, that will come through in your voice and will be picked up by the person you are calling.*

*It can be tough at times, but like in any job, you become hardened to it and if you are unsuccessful with one call, it's a case of moving on to the next.*

*We do have set information about ASBAH which we use, but we tailor it to each person we're calling. One of the most important pieces of information is that we are calling direct from ASBAH so we don't need to pay any commission to an agency.*

*We all really appreciate the continued support of so many companies who take out adverts or sponsor balloons in our races. Without their help the department would not be able to raise so much cash for ASBAH"*

**Asif Shaheed, telesales representative**

*"Working in telesales is a number crunching exercise. You can make 100 calls without success but you keep on going and eventually meet your targets.*

*Of course it is easier calling existing supporters who know all about ASBAH and the valuable work it does.*

*It's a great department to work in – there's a really good team spirit. I worked for ASBAH from 1994 to 2001, and then joined another company because I fancied a change.*

*But I kept in touch with everyone and rejoined the team last year. Having great colleagues is a great motivator. Knowing about the many people ASBAH helps is also a great motivator."*

# More Monday money for ASBAH

**ASBAH has scooped £4,400 from its third draw of the Monday Lottery taking the total to date to more than £22,000.**

The next draw ASBAH will benefit from will be held on week beginning Monday 3 April.

If you fancy a flutter, visit Monday Lottery at ***www.playmonday.com*** to register.

*Zurich's Cares Committee has donated £1,210 to ASBAH thanks to a nomination from service user, Liam Parsons, who's baby daughter has spina bifida. Pictured from left to right are; Dawn Weale, Donna Treanor, Nick Hoyle, Liam Parsons and Sandra Skett*

*Many thanks to Neil Featherby for organising the Boxing Day Run in aid of the Danny Mills Helpline Appeal that raised £218.*

PETERBOROUGH

**MEGACYCLE**

**Charity Cycle Ride Weekend 2007**

**Saturday 30th June & Sunday 1st July**

For further information contact Ian Morley at ASBAH on 01722 421328 or email ianm@asbah.org

*Mr Burrows (Jake's teacher), Jake Norris, David Isom (ASBAH's Eastern Region manager)*

# Jake's blood money helps ASBAH

**Schoolboy Jake Norris donated £50 to ASBAH after clinching first prize in a fancy dress competition.**

Jake, aged 14, from Mansfield in Nottinghamshire won a £5 book voucher when he dressed as the 'Beachcomber Vampire' whilst on a family holiday at the Beachcomber Caravan Park in Cleethorpes.

When Jake went to collect his prize, the caravan sales representative said he would give Jake an extra £50 to give to a charity of his choice.

Jake, who has spina bifida and hydrocephalus, decided to give the money to ASBAH. The money will be used to help support a new Area Adviser who will be working in the Nottinghamshire area.

The cash was presented to David Isom, ASBAH's Eastern Region Manager, at Jake's school,The Brunts, in December.

……

# Mums the word!

**ASBAH has received a boost of £7,000 thanks to a donation from the Mothercare Charitable Foundation, following a plea by Mothercare employee Rosie Sweeting.**

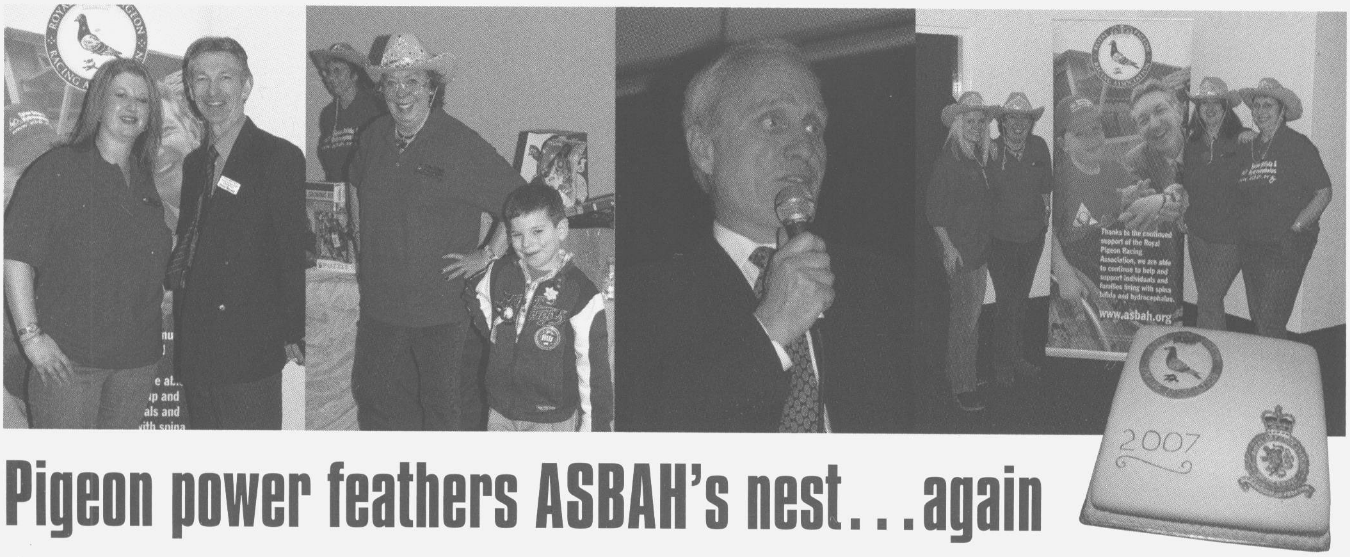
Rosie was inspired to take action after meeting seven-year-old Bradley Norman, who has hydrocephalus, and his parents, Rachel and Linden, who told her all about ASBAH's services.

Rosie gave the family advice on what Mothercare products would be most suitable and enjoyable for Bradley. A friendship developed and Rosie has since been down to Cornwall to visit the Norman family.

Each year, the Mothercare Charitable Trust selects a family 'Charity of the Year' and donates a considerable one-off sum of money. ASBAH had stiff competition from other registered national charities and research organisations and was lucky enough to be selected thanks to Rosie's unfaltering determination to argue its case.

Lynne Young, ASBAH Area Adviser said: "I am delighted that Mothercare chose to support ASBAH with such a magnificent donation, and would like to express my sincere thanks to Rosie Sweeting, from Mothercare, for all her hard work in ensuring that ASBAH beat all of the other charities that were put forward to benefit from Mothercare's charitable foundation.

"This huge donation will ensure that our services reach the many families that call upon ASBAH for advice and support."



# Pigeon power feathers ASBAH's nest...again

**Pigeon fanciers up and down the country came together for the British Homing World Show in January, and raised a fabulous £12,500 for ASBAH.**

The event, held at Blackpool's Winter Gardens, saw 22,149 visitors keen to check out the 1700 fancy pigeons and 2230 racing pigeons on display.

The show, now in its 35th year, is run by the Royal Pigeon Racing Association (RPRA), ASBAH's largest single sponsor. In the past 34 years the group has donated more than £460,000 from the profits of the annual event.

ASBAH's Chief Executive, Andrew Russell and Donna Treanor were among the visitors and were presented with the donation by Peter Bryant, General Manager of the RPRA.

Peter told *Link*: We were very pleased with the Show of the Year again; another great success despite the atrocious weather and high winds which we are sure may have dissuaded some people from attending.

"The new fancy display of pigeons was well received and added another attraction to the show so it really was a pigeon fest this year.

"Overall with attendance up we hope to make lots of profit, all of which will be winging its way to our favourite charities in the next 12 months."

# Skyline overseas events - fundraising adventures

**ASBAH has signed up to the Skyline overseas events scheme to encourage fundraisers keen on more adventurous ways to collect cash.**

Overseas challenge events are one of the most successful fundraising initiatives to have been introduced to the UK in recent years.

And in response to popular demand Skyline, a unique management events company, is increasing its exciting range of schemes.

In 2006 alone, more than 25,000 people took part in Skyline fundraising events, raising in excess of £4 million for over 1,500 charities.

Now people raising funds for ASBAH can sign up for an once-in-a-lifetime trek across China or Peru, or one of the many parachute jumps organised by Skyline in the UK.

The treks are suitable for people of all ages and all walks of life. Some people go with friends and family, but most don't know anyone on the trip and take the opportunity to make new friends.

Participants do have to raise a minimum amount of sponsorship - £2,500 for the China Trek, for example – but Skyline do suggest a range of money-spinners to help make fundraising fun and easy.

For more information about Skyline log on to ***skylinecharity.co.uk***

If you know someone interested in fundraising for ASBAH either with a parachute jump or by taking part in a China or Peru Trek, contact Ian Morley at ASBAH on 01733 421328.

### China Trek

*For a country with the largest population in the world, China remains largely untouched by the West. It is a beautiful country steeped in tradition, history and mythology.*

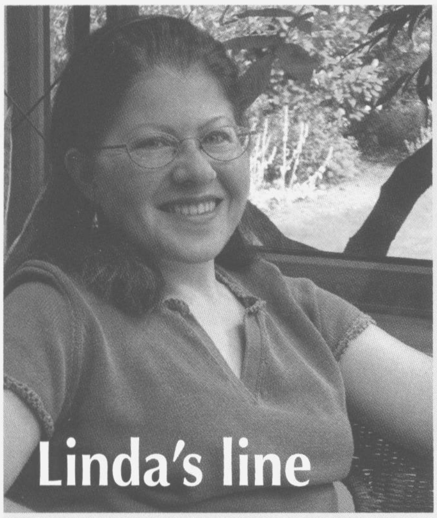
*The trek follows parts of the Great Wall of China where possible, up hill and into the valleys, enjoying the sight and sounds of the beautiful countryside.*

### Peru Trek

*Walk through the untouched Lares region of Peru, over high mountain passes, green valleys, tranquil mountain lakes and enjoy breathtaking views of the snow-capped Andean mountains.*

*The unforgettable trek ends with a visit to Machu Picchu, one of the worlds most important archaeological finds.*

***For further information, please contact Ian Morley at ASBAH on 01733 421328 or email ianm@asbah.org***



## Linda's line

**Does anyone know what the word is for people who pretend to be disabled just to take advantage of certain situations? If there isn't one there should be, because there seems to be a lot of them around at the moment.**

I suspect it's not because they wish to share the physical or social disadvantages which go with the territory, just the facilities thank you very much. You see them everywhere – parked in blue badge holder spaces at the supermarket (don't get me started on that one!), hogging the corner seat on trains, and now it has spread to my workplace as well. My current gripe is that the world and his wife seem to be using the disabled toilet, allegedly because the facilities are nicer.

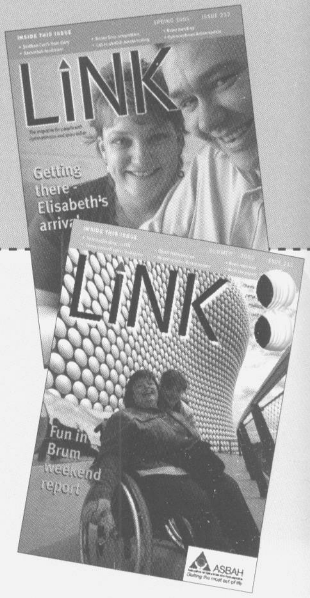
I have to admit that it does have proper brand name hand wash rather than that dodgy pink squirty stuff, and it doesn't have the same slightly chemical smell that the non-disabled toilets do (the ladies, that is, - market research does not extend as far as checking the gents). Even so, I don't expect to have to use the second-rate facilities when I am the token disabled person employed on the first floor (or any floor, come to that). To add insult to injury, or more accurately near-injury to insult, I was almost knocked over the other day when yet another pretender exited rather quickly, giving the door an excessive shove outwards into the corridor as I was passing.

To put the tin lid on it, last week I arrived early at work to find somebody had parked in the disabled badge holder's space. Now that really is my allocated space – number 22, Linda Corbett, first floor – and it is not up for negotiation. Following a swift investigation organised by yours truly, it transpired that our security guard couldn't park in his normal space and had plonked his car in the blue badge space thinking no one was using it.

You might not be completely surprised to learn that I was all in favour of an immediate public enquiry, hopefully culminating in a naming and shaming operation, but our receptionist thought it would be more appropriate if he was just asked to move his car. In my opinion, it would be more appropriate if he acquired a proper medical condition and then I might, just might, let him share my space. Very occasionally. Possibly at Christmas.

# LiNK

**the lifestyle magazine for people with hydrocephalus and spina bifida**



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*(Winter, Spring, Summer and Autumn)*

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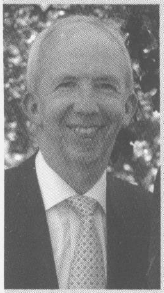
# Education

## SUPPLEMENT



A warm welcome to this special educational supplement in which I am sure you will find something of interest and use.

These are the types of issues we discuss at the Education Committee - not only discuss but also take action through ASBAH to try and improve the provision for our members

Enjoy the read!

**Neil Watts - Headmaster,**
**Northgate High School, Ipswich**
**Chairman, ASBAH Education Advisory Committee**

## Contents

## The Disability Equality Duty

By Joanne Grenfell
ASBAH Education Adviser

**The new Disability Equality Duty law, which came into effect in December 2006, means that all schools now have a responsibility to meet the needs of students, their staff and any visitors.**

One of the reasons this duty has been brought out is because, compared to able bodied students, disabled children are twice as likely to leave school without qualifications. There has been very little analysis of why this is and schools now have to monitor this to establish areas where disabled young people are underachieving.

The new law will also assist parents and staff as well as students by identifying those with a disability. For example some parents may not be attending parent's evenings because of genuine personal difficulties, such as not being able to walk far.

It will also mean that children who have a condition such as severe asthma will be classed as disabled even though they may not have any special needs.

Schools are also required to produce a Disability Equality Scheme, outlining their plan for actively promoting disability equality among pupils, parents and employees.

The new duty forces schools to think about attitudes and how to influence and change things for the better. If you would like more information about this visit the Disability Rights Commission website at www.drc.org.uk.

# Disability Rights for Pre-School Children

By Patricia Spencer
ASBAH Education Adviser

**One aspect of the Education Team's advisory work in recent months has been to identify exactly what rights very young disabled children have in the UK. Our job has been to investigate whether advances in Disability Discrimination legislation apply to children in their very early years.**

Many early years settings are most supportive of children with disabilities, working together with parents and carers to enhance their lives, but in some cases they are not aware of the importance of the recent legislation and the rights of all young children. Parents and carers need to be aware of the needs of their children, and be active in monitoring their childcare setting's approach to supporting young children with hydrocephalus and spina bifida.

Under Part 3 of the Disability Discrimination Act, early years settings not constituted as schools (this can mean nurseries, playgroups, family centres or childminders) must not refuse to provide a service, or offer a lower standard of service, or a service on worse terms to a child with a disability.

Local authorities, health care agencies, schools, and early education settings must not treat disabled children 'less favourably'. For instance, if a nursery refused to accept a child who had: continence problems linked to their condition; epilepsy and needed specific support for any seizures he/she may have whilst in nursery or had mobility and access needs.

Settings should actively make 'reasonable adjustments' for disabled children and be 'anticipatory', not waiting until a child with a disability is due to be admitted. That way, no excuse can be made that the setting cannot admit a child e.g. in a wheelchair, or with continence problems.

To see the full article please visit our website: www.asbah.org

# Managing Bowel and Bladder needs in schools and in the Early Years

By Patricia Spencer
ASBAH Education Adviser

**The Government acknowledges that children, especially those with continence issues due to disability, need to feel comfortable and confident whilst in school, nursery or playgroup. Poor continence is outside a child's control and affects not only their well-being, but also their health, behaviour, learning and the ability to participate fully in activities.**

Recognising the need for all educational establishments to have sufficient facilities, trained staff and individual care plans for children with such needs, the Government has produced legislations, recommendations and a White Paper, all of which provide guidelines for establishments to follow.

These should already be in place before the child attends the setting and topics include:

- Preserving the privacy, dignity and independence of each child, taking care to avoid risk of ridicule and bullying
- The agreement of a continence management plan or 'Continence Policy' at the assessment stage
- Staff training and communication with parents
- Planning, so that children with continence issues are considered in games and PE, swimming, school visits, drama, and music, as well as the main curriculum subjects
- Health and safety and child protection
- Ways of adapting timetables and systems to promote bladder and bowel health.

One thing to note is that nurseries, schools and playgroups are potentially discriminating, and therefore behaving unlawfully if they refuse to admit a child for a reason related to their disability, including concerns relating to continence. If this should happen, parents could contact ASBAH's Helpline to be put in touch with either an Education Adviser or a Medical Adviser for advice.

To see the full article please visit our website: www.asbah.org

# Behaviour

By Carol Rubinstein
ASBAH Education Adviser

**Many of the calls we receive are about behaviour. Unfortunately, as parents, our ability to manage our child's behaviour seems to be one of those things that identifies us as 'good' or 'bad' parents. As a result it can be very distressing when things seem to be going wrong.**

The first thing to remember is that all parents have difficulties with their child's behaviour at times. Secondly, we can't control children's behaviour but we can manage it.

Children with hydrocephalus typically have problems with understanding language, concentration, short term memory and processing information. All of these, potentially, can have an impact on behaviour. If you can't remember instructions then you won't be able to carry them out. If you have trouble transferring knowledge to new situations you may be able to do something in one place but not another. If you don't understand jokes your friends may think you're a bit 'odd'.

The impact that hydrocephalus can have on learning and behaviour varies with every individual. Some people may have very few problems whereas others may have many. It is important to remember that children with hydrocephalus often have a number of specific learning difficulties which may mean they learn in a different way and need different strategies to help them.

Human behaviour is extremely complicated and many experts have studied, analysed and argued over this for years. This has led to countless theories about how behaviour can be managed and in recent years numerous television programmes and books have been produced on the subject, which often make it look all too easy!

Parents, and teachers, often feel de-skilled when faced with a child who does not behave appropriately. This, in turn, can lead to the situation getting worse as parents get more and more frustrated and children feel more powerful but also less secure. This can make their behaviour even more extreme and in children and adults with developmental difficulties, it becomes even more complicated as they may not react in the way we would expect.

The good intentioned manuals and programmes purposely ignore individual circumstances and personalities and some would argue that these aren't relevant. However, it is very difficult to give a standard recipe for improving children's behaviour because every situation is different and may require different strategies. Yet there are ways that we can begin to work out what is going wrong and to put it right:-

- **Firstly, try to detach yourself from the situation. This is not easy but try to see it as 'a problem to be solved' and approach it 'scientifically'.**
- **Make a list of the behaviours which you are finding difficult, then prioritise them from the most to the least troubling.**
- **Concentrate on the behaviour at the top of the list and make a note of anything which might be relevant i.e.,**
  - When does it happen?
  - Where does it happen?
  - Is any other particular person involved?
  - How often does it happen?
  - What happens before?
  - What happens after?
  - How do other people react?
  - How does it stop?
  - You may need to observe for a few days to be sure that you have as much information as possible.
- **Then try to work out what the child is getting from this behaviour.**
  - Is it attention?
  - Do they enjoy the fuss?
  - Do they get their own way?
  - Do they avoid doing something else?

At this point you should have some ideas about what triggers the behaviour, how it stops and what the child gets from it. Now you are in a better position to try to change it but this will take time and a lot of patience. Your child may have been practising this behaviour for several years so it is unrealistic to expect it to stop immediately. You and your child will need to learn new behaviours to replace the one you want to stop.

*continued overleaf*

## Workshop

### Positive Behaviour Management – A Workshop for Parents

**This workshop is intended to help parents of children of any age understand and better manage their child's behaviour.**

It will cover:

- How children with developmental disabilities are different
- Observation techniques
- Modifying Difficult Behaviour
- Coping
- Positive Behaviour Management
- Social and Emotional Skills Training

**Time:** 10.30am to 3.30pm, Wednesday May 9th 2007
**Location:** ASBAH House, 42 Park Road, Peterborough PE1 2UQ

There will be a token charge of £5 per person to include lunch.

Unfortunately we are not able to cater for children during this day.

For further information contact Carol Rubinstein on 01733 421319

*continued from previous page*

When asked to advise on behaviour management I have on my list of strategies just four essentials;

### Routine

The more established a routine the less likely a child is to try to change it. You may need a 'going to school' routine, a 'what to do when you come home' routine, a 'bedtime' routine. In fact, wherever you notice a time that causes problems, try a routine.

Routines are particularly important for children with short term memory problems. Repetition enables them to remember what to do and allows them to be more independent.

### Consistency

This ties into routines but also includes how we respond to a behaviour. If we always ignore 'Johnny' when he shouts then eventually he will stop shouting, if we only ignore it now and again then he will learn that it works sometimes and he keeps trying.

### Positive not Negative

Look for the positive, ignore the negative – sometimes we have to make a real effort to notice the positives but when you do notice that your child is behaving appropriately, make sure they know you've noticed.

Reward good behaviour however small. Rewards can be anything that the child enjoys; a cuddle, five minutes playtime, music, just a smile. It doesn't have to be a present.

Try to ignore inappropriate behaviour as much as you can. If you have to intervene do it as calmly and as quietly as possible, avoid arguments and discussion.

Make instructions positive; 'This is what I want you to do', not, 'Don't do that"

### Make time

Try to make some time every day which is just for you and your child. It could be built into a routine, for example, at bedtime. It is important that this time is guaranteed, no matter what, even if you don't feel like it.

If your child doesn't feel like it, make it clear that this is special time and you are available if they change their mind.

These strategies may well help in curbing inappropriate behaviour but this is when the hard work really begins. Children need help in learning how to manage their own behaviour. Some children with hydrocephalus will need direct teaching of social skills because they find social interaction, understanding language, reading emotions and body language very difficult. They may need to learn how to manage their own emotions. What do you do when you are angry, frustrated, really excited?

Again, this is very child specific and not everything can be covered in the space of this article, however, ASBAH Advisers and Education Advisers will be pleased to offer advice.

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## Communication with Schools

By Carol Rubinstein
ASBAH Education Adviser

**Case Study**

Sharon Hodgson explains how communicating with her son Jonah's school helps him make progress. For the full story visit our website: www.asbah.org

**As schools have become more inclusive, staff have learned to deal with many difficulties facing students. However, teachers receive little training in Special Educational Needs and so many may never have heard of hydrocephalus or Spina Bifida.**

Effective communication between parents and staff can make an enormous difference to understanding and consequently to the child's welfare at school.

All children with special needs, either with or without a Statement must have tailored plans provided by the school to ensure their needs are met, including:

- **Accessibility Plan** – this outlines what the school is planning to do to make the building accessible to all
- **Care Plan** – for children with medical or personal care needs
- **Risk Assessment** – if there are health and safety considerations for a child in school
- **Individual Education Plan** – a regularly reviewed document aimed at children with identified special learning needs.

Parents should tell the school if there is anything on a plan which they disagree with and in the event of problems it is often useful to ask a third party to mediate - ASBAH Advisers or Education Advisers would be pleased to offer advice.

To see the full article please visit our website: www.asbah.org

# School Transport

By Joanne Grenfell
ASBAH Education Adviser

**Parents often worry about getting their child to and from school safely and reliably. The main duties regarding transport are placed on the local authority but schools will also need to be aware of these duties in order to be able to provide information and advise parents of their rights and responsibilities. The Education and Inspections Act will be implemented sometime this year so most schools will have a school transport policy or travel plan in place.**

In 1999/2001 one car in ten, in urban areas between the hours of 9am and 10am was taking a child to school. Most of these journeys were less then one mile and with the increasing concerns about the environment and increase in road accidents the Government is trying to encourage safer routes to school.

There are two documents explaining the plan called "Travelling to School: an action plan" and, "Travelling to School : a good practice guide". They set out what the Government intends to do to support schools and encourage those children who are able to take public transport safely, walk or cycle to school to do so. Ideas range from providing local school travel advisers who can offer specialist support to schools, provide grants for schools, offer car sharing schemes and help to organise "walking buses" or cycling groups. The plan also highlights that whenever possible children and young people with special educational needs should be encouraged to travel independently to school as well.

For more information visit www.dfes.gov.uk and look up "Education and Inspection Act 2006 Consultation on school travel guidance" or www.dft.gov.uk and search under young people or school transport.

# How Statementing is Changing

By Carol Rubinstein
ASBAH Education Adviser

**Case Study**

Christine Milton talks about the crucial role that parental input played in the compilation of her daughter Katie's Statement. For the full story visit our website: www.asbah.org

**Unlike days gone by when children with special needs automatically went to special schools, today's mainstream schools aim to include all children wherever possible.**

Statements of Special Educational Needs were introduced with the aim of ensuring an appropriate education for those children who needed special provision, whether in mainstream or in special schools. To get a Statement, children were assessed by an Educational Psychologist and other professionals. Statements provided re-assurance to parents and enabled schools to access extra funds for extra resources, equipment and staff.

Now schools have greater budgets to cater for children with special needs, local authorities have seen their budgets decrease. Now they only keep a small proportion of the education budget for centrally managed resources such as Statements, and this has led to a re-evaluation of their purpose.

As mainstream schools are now expected to cater for almost all children and they have a budget to reflect this, it follows that a Statement should no longer be necessary except for those children with the most complex needs. The criterion for assessment varies throughout the country but already, it is virtually unheard of for a child who may have a disability but no learning problems to have a Statement.

Parents concerned about how their child's education will be managed without a Statement should communicate with the school, noting that:

- schools must follow procedures when planning and providing an appropriate education for a child with special needs
- all children with identified special learning needs should have an Individual Education Plan.

Advice on how parents should monitor and contribute to their child's education is outlined in the section 'Communicating with Schools'.

To see the full article please visit our website: www.asbah.org

# Visiting Schools

By Joanne Grenfell
ASBAH Education Adviser

**Case Study**

Joy Clarke-Roberts discusses the benefits of regular visits to her daughter Amelia's school. For the full story visit our website: www.asbah.org

**When visiting a potential school parents should try to imagine whether their child would be happy there. It can be helpful to go with a list of questions, making the first visit to school without the child so that the head teacher or senior member of staff can be spoken to freely. Parents could invite their local ASBAH adviser or parent partnership officer for support.**

It is best to arrange a time to visit when children are in the school and if possible to meet with the staff who would be involved with the child. Parents should be given a school prospectus and have the special educational needs policy explained to them.

Some questions parents could ask...

- What is the general structure of the school day?
- How would the school deal with personal care matters relevant to the child?
- Are there any adaptations or equipment in the school which will help the child?
- How are the individual needs of children met in the classroom?
- How are parents kept informed about a child's progress?
- If needed, what support would the child receive at breaks and lunchtimes?
- Does the school have a parents group which meets often?
- How does the school deal with bullying and helping children make friends?
- Does the school need more information about hydrocephalus and/or spina bifida, would they like more input from an advisor or contact from an educational or medical adviser?

Exploring a potential school should go a great way towards helping a parent make up their mind, especially if they are made to feel welcome or perhaps see other children with similar needs to their child.

To see the full article please visit our website: www.asbah.org

# Person Centred Planning in Year 9 for students with a Statement of Educational Needs

By Joanne Grenfell
ASBAH Education Adviser

**In many Local Authorities the 'Transitional Review' in Year nine is now called the 'Person Centred' Review Meeting, which is much less formal. These meetings take place at an important stage, when future aspirations and career prospects are being considered and everyone has a voice, especially the young person themselves.**

At the meeting, which is managed by a trained facilitator, everyone is encouraged to ask questions. Some of the main points discussed at the meeting are what the strengths of the young person are and what they have achieved so far at school. It should be made clear what the important needs of the student are and discuss what they may be in the future. Also, what is working well for the student and what is not, so adjustments can be made accordingly.

The various professionals who have been involved with the student while they have been at school are also asked to comment and the student may invite a friend along, to contribute to the discussion and offer moral support. From this discussion, the facilitator will draw up an agreed Action Plan.

After the meeting, the agreed points of action will be circulated, along with who will take responsibility for doing what, and when it will be done.

The Person Centred Review Meeting is clearly different to the Transitional Review and seems to be getting increasingly popular for students. Those who attend the meeting have to work together to make ideas happen successfully, and commit themselves to a deadline to ensure actions have been followed through as promised.

To see the full article please visit our website: www.asbah.org

# Going to University

Name: Ben Edwards

Age: 22

Occupation: Student

**Case Study**

Barrister-to-be Ben Edwards spent three years studying law at Exeter University.

For any student, beginning a new life at University is a daunting prospect, but Ben, who has hydrocephalus, had additional concerns.

In the run up to both GCSE's and A Levels his shunt failed and his neurosurgeon tried various types before finding one – a programmable shunt – to suit.

But Ben, from Birmingham, was determined that his health scares would not deter him from his dream to study law, and arrived at Exeter University in September 2003 ready to take the first step on the career ladder.

Here Ben, who is studying on a Bar Vocational Course, talks about his time at University.

Going to University was a daunting experience; moving away from home, leaving my friends, starting in a new city. Daunting, but exciting as well. It was the beginning of a new adventure and I could be my own person.

Of course I was nervous about leaving home - I had to start doing my own washing, cooking, cleaning! My mum may nag, but boy did she do a lot for me.

I chose Exeter because it is a small campus university and the law department was very well known.

As I sometimes find it difficult to get my bearings I was worried that if I was in a big city, on my own, I would get horribly lost one day.

The first few weeks there were weird. Finding my way round was probably the hardest thing. I'm not very good at directions.

Life seemed a real emotional rollercoaster at times. But once I found a great group of friends, I had a great time. You grow up so quickly at Uni because there is no-one to hold your hand anymore. It's a steep learning curve yes, but worth it.

My hydrocephalus affects me on a daily basis. I suffer from regular headaches, which can be remedied by taking paracetamol but sometimes the headache niggles away all day. It's annoying, but I'm used to it now.

I have always been open about my condition, but 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.

I always carry a shunt alert card and made sure my housemates and friends knew about the card and are aware of the warning signs of shunt failure.

My hydrocephalus isn't serious enough for me to need additional help from the University to help me complete my studies. Help was available but students must ask for it and make sure they get it.

For me University was a great experience. I learnt a lot about myself and made some very good friends... ones I intend to keep.

I grew up, became more independent and learnt how to cook a mean 'spag bol'.

I began my Bar Vocational Course, the barrister training course last September, studying in London, so it was another big move and I'm back living in halls of residence again.

The course is the most difficult I have studied, but it's a great experience, and I know I am on the right path to get to where I want to be... a successful barrister.

So who knows? I may well be the next Lord Chancellor, or perhaps the next Tony Blair? One thing I can be sure of, I intend to be a major player within the judiciary system, so watch this space! Disability shouldn't get in our way, and I won't let it.

# Join in and have your say

## Get Your Voice Heard Online

**Your Voice now has it's own dedicated website and members can interact with other members by becoming a Forum member.**

Joining the Forum gives you the opportunity to have your voice heard on topics that matter to you. Membership also gives you access to regular news and information keeping you informed of Your Voice activities.

There are lots of reasons to join the Your Voice Forum, some of which are listed below:

- **Access to debates and the chance of having 'your voice' heard**
- **The strength of support from other members**
- **Regular news and information updates**
- **Access to our event programme**
- **Opportunities to meet and make new friends**

Joining the online Your Voice Forums couldn't be easier and, better still, membership is free. To access the Forums you must be a registered ASBAH service user and a YV member, over 18 years old and have spina bifida and/or hydrocephalus.

If you are not a registered ASBAH service user please contact Barbara Robinson, the YV Policy Officer, at barbarar@asbah.org or call her on 01733 421 322.

You can register for the forum online! All you have to do is log on to ***www.yourvoicegroup.org*** and go to the 'How to join YV' page where you'll find an application form – don't forget, some of the fields are compulsory and must be filled but these are indicated with a '*'.

Once you have submitted your completed form, an automatic email response will pop up to tell you that your application will be dealt with. You will then receive a confirmation letter in the post confirming your user name and giving you a password, along with details of how to log in to the Forums

For those of you who are new to online Forums, it might look a little daunting but don't be put off- it's easier than it looks! There is a detailed guide on the website to help you through it.

## Planned events: 2007

In addition to the 'Private Functions' events advertised below, two further weekend events are planned in 2007 – details of which will be updated on the website....watch this space!

**Event: Ageing**
**Location: to be confirmed**
**Date: July**
*For more information contact barbarar@asbah.org*

**Event: Housing and Financial Planning**
**Location: South East**
**Date: November**
*For more information contact barbarar@asbah.org*

*more Your Voice news on page 22*

### Your Voice presents

# Private functions

### Your questions answered about bladder and bowel management

**Open to all adults (aged 18 and over)**

## Dates and venues:

**South East Region**
**Saturday 21st April 2007**
Charity Centre, Stephenson Way, London
Guest speakers include:
Mr Julian Shah, Consultant Urologist

**Eastern Region**
**Saturday 28th April 2007**
ASBAH House, 42 Park Road, Peterborough
Guest speakers include:
Mr Williams, Consultant Urologist

***£20* *day delegate rate including lunch***

*Registered charity no.249338*

## Content includes:

- **Talk and Q&A session: With a consultant on bladder and bowel management**
- **Quality of Life issues: ASBAH continence adviser**
- **Exhibitors from product manufacturers**
- **Talk and Q&A session: With a stoma nurse/ nurse specialist on skin care**

*Details of the precise content to be confirmed for each venue*

*For further information and an application form contact:*

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

## Your Voice Advisory Committee 2007

**A new Your Voice Advisory Committee has now been elected following the elections in December 2006. Interest was high and the committee have been able to build a team with representatives from Wales, Somerset, Devon, London, Yorkshire and the Midlands and include some familiar faces as well as bringing in some new members.**

With a new 15-strong-team in place and the newly launched website, 2007 certainly looks like a very exciting year for Your Voice. In fact, you can visit the website now to find out more about Your Voice and all about the new committee members at www.yourvoice.org

Your Voice Advisory Committee elected members include:

***Carole Armour***
***Michael Bergin***
***Jon Burke***
***Lisa Cain***
***Geraint Catherall***
***Keith Collins***
***Amar Raj Singh Dugal***
***Charles Harper***
***Louise Iontton***
***Shaun Jennings***
***Mary King***
***Cathy Lunn***
***Paul Manning***
***Nick Woodward***
***Paul Zickel***

## Your Voice Questionnaire

Please help us to ensure that ASBAH's work continues to take your views into account by completing the confidential and anonymous questionnaire inserted in this magazine.

The objective of the questionnaire is to gather opinions of people with spina bifida and hydrocephalus. You don't have to answer all the questions and there are no wrong answers.

If you haven't received a questionnaire, you can download a copy off our website at ***www.yourvoicegroup.org***

# ETV got Josh back on the rugby pitch

*For a lucky few, an ETV operation is an alternative treatment for hydrocephalus.*

*Endoscopic third ventriculostomy (ETV) is a natural way of draining the CSF fluid from the brain which means a shunt does not have to be used.*

*The treatment, only suitable for a small percentage of hydrocephalus patients, has many advantages over shunting. Infection rates are low and ETV does not cause over-drainage problems which can lead to headaches.*

*Josh Pendlebury is one of the lucky few patients who was suitable for ETV and the removal of his shunt meant that he could once again play his beloved rugby.*

*Here his father Alan, from UpHolland in Lancashire, talks to Link about Josh's experience of hydrocephalus.*

"My son Josh was a normal nine-year-old, who loved sports to the extreme, spending much of his free time playing football, rugby and many other sports.

He was rushed into hospital with what we thought was a head cold but after 36 hours he was eventually diagnosed with hydrocephalus.

We knew nothing of the condition and it was a very frightening time for us all. Josh was rushed into theatre where he had a shunt fitted.

The hospital offered us little information or support so I tried to find more details on the internet. Of course the search engine threw up many daunting medical terms and scare stories, but then we found ASBAH.

From feeling completely alone and bewildered ASBAH offered us so much help and advice plus information about different treatments which are available. Suddenly our nightmares faded.

One of the treatments which was mentioned was the third ventriculostomy.

We approached the hospital about this but were told that this was an operation they could not perform.

I contacted another consultant at the hospital who said he could offer the operation if Josh was a suitable candidate.

We changed consultants just in time as Josh's shunt blocked and he was rushed in to hospital. The new consultant carried out an ETV and within two weeks Josh was home and starting to regain his life again.

Now Josh is 14 and is doing well at school and is still playing his beloved rugby. He currently plays for a successful team in Wigan and has gone for trials at Lancashire RUFC. Josh also plays golf and has just completed his PADI open water diving course. Sky diving next!

All the things that he couldn't have achieved without the help of ASBAH and Josh's consultant.

But I know that his life could have been so different if we had not found ASBAH."

## Enjoying sport

Josh Pendlebury has been given the all clear to play rugby because his hydrocephalus was treated by the ETV procedure.

Children who have shunts do have to be careful about what activities they take part in, but shunts are difficult to break and most sports – with few exceptions – should be encouraged.

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

*For full guidance read the Enjoying Sport article on page 20 in Link 216 (Spring 2006 issue) and on the ASBAH website www.asbah.org*

# Going into Hospital?

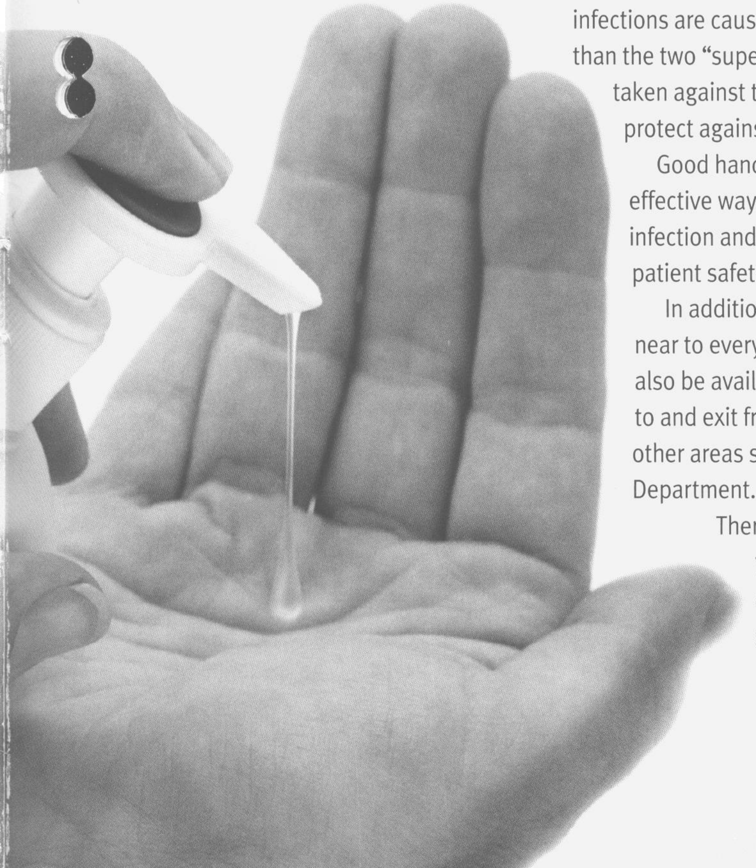
## Steps you can take to help avoid "superbugs"

**Anyone going into hospital these days must have concerns about the number of "superbug" infections. Current figures suggest that approximately 1 in 10 patients may acquire an infection whilst in hospital, but there are precautions you can take to help ensure that you are amongst the 90% or more who are not affected.**

### What are "superbugs"

"Superbug" refers to any bacterium or virus that either spreads very rapidly, or is resistant to a lot of antibiotics, especially if it also causes a lot of infections. There are two main ones that affect hospitals: MRSA and Clostridium difficile. Neither of these is new but they have become more common because of changes in medical practice. This is particularly true regarding use of antibiotics, and these are now being restricted in order to reduce the spread of these two infections.

**MRSA:** Staphylococcus is a family of common bacteria and many people naturally carry them in their noses and throats without any ill effects.



MRSA stands for methicillin-resistant Staphylococcus aureus and it is often resistant to many other antibiotics too. Other strains of S aureus might be resistant to several antibiotics too, but they remain sensitive to methicillin and therefore to other common antibiotics.

Antibiotics are not completely powerless against MRSA, and there are many that are effective against the usual strains of MRSA.

**Clostridium difficile:** This bacterium is carried by many people in small numbers in the bowel. If the balance of bacteria in the bowel is upset, such as by antibiotics, then C diff (as it is known) can take over and cause severe diarrhoea and sometimes serious bowel infection. It can also be picked up by people from lockers and other surfaces. The bug is extremely difficult to kill in the environment, being resistant to many disinfectants. It is also resistant to the alcohol in handrubs, and if there is a case of C diff on a ward then staff should be using soap or antiseptic detergent and water to wash their hands.

It is important to realise that most infections are caused by bacteria other than the two "superbugs", but measures taken against them will also help to protect against other infections.

Good hand hygiene is the most effective way to prevent cross-infection and is key to maximising patient safety.

In addition to being available near to every bed, hand gels should also be available at the entrance to and exit from every ward and in other areas such as the Outpatients Department.

There are a number of steps you can take to look after yourself if you are going into hospital:

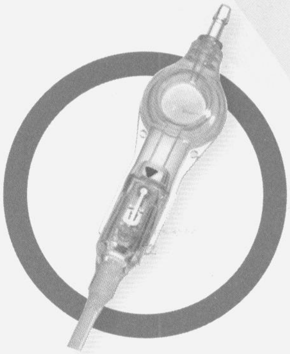
- *Pack your own anti-bacterial handwash but feel free to use the hospital hand gels. Handwipes are also useful if you are confined to bed.*
- *Wash your hands after using the toilet and before and after every meal*
- *Always clean hands before entering and when leaving wards etc and encourage your visitors to do the same.*
- *Limit the number of visitors you have at any one time.*
- *"It is ok to ask" – you have the right to ask a member of staff if they have cleaned their hands before personal contact.*
- *Keep belongings in the locker provided and send any unnecessary items home.*
- *Use wet wipes to clean your own locker top /bed table*
- *Visitors should not visit with dirty/muddy shoes; this helps keep the hospital clean.*
- *Visitors should not sit on beds, but use the chairs provided*
- *Visitors should visit only one patient, rather than going from patient to patient or ward to ward. Nor should they visit if they are feeling unwell or have had an infection in the past 72 hours.*
- *If you are prescribed antibiotics for use after leaving hospital, make sure you finish the full course.*

It is important to remember that the vast majority of people leave hospital better for the experience and without an infection, taking these simple steps can help ensure that you are one of them.

**Many thanks to Roger Bayston, Associate Professor at the School of Medical and Surgical Sciences, University of Nottingham and Christine Powell, Infection Control Sister at Peterborough and Stamford Hospitals, for providing the information for this article.**

**The full paper is available on the Asbah website *www.asbah.org***

# Codman Hakim™ Programmable Valve an adjustable shunt to treat hydrocephalus

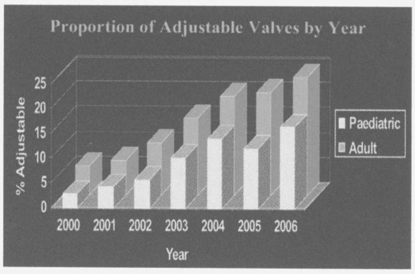


**CSF shunts fall into two categories: fixed pressure or programmable [adjustable].**

In fixed pressure shunts, the pressure is set at the time of manufacture: it cannot be altered.

In programmable shunts, the opening pressure is selected and set at the time of operation but can be altered by a neurosurgeon or nurse specialist using a specific electro magnetic programmer.

There are a number of adjustable shunts on the market at present and the neurosurgeon selects the one he feels is most suitable.



The three main adjustable valves widely used in the UK are the Codman Hakim, the Medtronic Strata and the Miethke Pro-GAVis.

Programmable shunts such as the Codman Hakim have been around for about 15 years and are growing in popularity (see graph). They now account for about 26% of the 2800 new valves implanted in the UK each year.

Figures from the UK Shunt Registry indicate that the revision rate of programmable valves is lower than that of conventional valves in the first 98 weeks of use [4.8% compared to 7.3%]. After that time, there is no significant difference.

## How does the Codman Hakim valve work?

The valve contains 10 tiny magnets and the opening pressure of the valve is adjusted by means of an external codified magnetic field in the programmer. The spring in the ball-spring mechanism of the valve sits on top of a rotating spiral cam [this looks rather like a spiral staircase], which contains a 'stepper' motor.

When a specific magnetic field is applied to the stepper motor, the cam will turn slightly thus increasing or decreasing the tension on the spring and changing the opening pressure of the valve.

The valve can be adjusted by 18 small increments, allowing the pressure to be tailored to an individual's requirements.

## Who needs a programmable valve?

People whose intracranial pressure needs change over time and those who may be susceptible to over or under drainage. Programmable valves are the treatment of choice for people with normal pressure hydrocephalus because they can be adjusted by small steps until the correct pressure for that person is found.

## How is the pressure changed?

The neurosurgeon will place the valve programmer [VPV] over the 'staircase' of the valve. The new Codman Mark 3 VPV senses the pressure in the valve and counts the 'click' changes when it is reset so that there is no need to conduct an x-ray for verification.

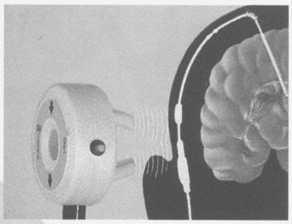
If the shunt is overdraining, the pressure needs to be adjusted upwards by 1-2 steps: for underdraining, it will be adjusted downwards.

**Your neurosurgeon will tell you what your pressure is and to what level s/he is adjusting it.**

## Can the valve be accidentally reset?

This is unlikely but, because the valve contains tiny magnets, there have been reported incidents of the settings being changed by contact with some magnetic items such as fish tank cleaners, magnetic toys, fridge magnets and magnetic pillows. Some valves reset when going through airport security gates or in MRI scanners.

The new Hakim valve is safe up to 3.0



*Positioning the valve programmer (VPV)*

Tesla. Most MRI scanners have a power of 1.5 Tesla but new more powerful scanners are starting to appear. However, it is still important that the setting is checked after exposure to MRI.

## Are programmable valves effective?

For carefully selected people programmable valves work well; not everyone will need or benefit from an adjustable shunt.

And it is important to remember that no shunt, however hi-tech, is free from the long-term complications of any other implant.

## Case Study

**Andrea Macleod, 37 from Worcestershire, has had a Codman programmable valve for three and a half years. Before that, she had a series of fixed pressure shunts - the first one in 1988.**

Andrea says: “I don’t really remember much about my fixed shunts but I know they didn’t work very well. This just seems to work.

“The fixed valves seemed to be wearing out really quickly and I seemed to be having my shunt replaced quite often. Since I’ve had the programmable valve fitted, I’ve had it reprogrammed once about a year after it was put in as it was overdraining and I was getting low pressure headaches and having terrible problems with my memory.

“Having it turned up was quick and painless – I didn’t know anything had been done! I wasn’t better right away but gradually my headaches went, and although my memory’s not brilliant it is much improved.”

**Having it turned up was quick and painless – I didn’t know anything had been done!**

Andrea said that, despite warnings that household magnetic items might change some settings on valves, she had not suffered any interference.

She added; “I’ve heard that that was an issue for some people, but its never caused me a problem”

Asked whether she believed her programmable valve was better than the fixed ones, Andrea said:

“Personally speaking it is beneficial. It doesn’t feel any different from any other shunt; I just know it keeps me well.”

*The valve programmer (VPV) unit*

# SRHSB publishes conference report

**Research papers from the 50th Annual Meeting of the Society for Research into Hydrocephalus and Spina Bifida (SRHSB) are now available online.**

Abstracts from 61 different presentations are listed on the website www.cerebrospinalfluidresearch.com and are also available in pdf format.

The meeting, held in the historic surroundings of Queens' College in Cambridge, brought together experts from different fields who share a common interest in hydrocephalus and spina bifida.

Delegates who attended the four-day conference were welcomed by Professor John Pickard, Chairman of the host committee and his organising team from the Department of Academic Neurosurgery.

Professor John Pickard delivered a presentation entitled Idiopathic Intracranial Hypertension, which covered the history and traditions of this difficult condition, to cutting edge science.

Carole Sobkowiak, in her presidential address, drew on a long and distinguished career helping children and families deal with physical disability. Carole, co-author of ASBAH's Your Child and Hydrocephalus book, stressed the importance of management from early infancy, and emphasised the relevance of posture and vision.

ASBAH staff were also involved in the proceedings by helping with the administration of the conference. Chief Executive, Andrew Russell, gave a presentation outlining ASBAH's efforts to promote the fortification of flour with folic acid.

The SRHSB now looks forward to its 51st Conference, which will take place in Heidelberg, Germany on 27-30 June 2007.

“Have you

# Asbah calls for folic acid to be added to flour

**ASBAH has urged the Food Standards Agency (FSA) to recommend folic acid be added to all white flour within the UK.**

The 13 week consultation, launched by the FSA at the end of last year, set out four options for improving the intake of the vitamin folic acid among young women in order to reduce the number of neural tube defect (NTD) affected pregnancies in the UK.

ASBAH has recommended that they opt for Option 4 which would see a small quantity of folic acid automatically added to flour, meaning most women wouldn't have to actively take a supplement. However, women 'at risk' of an NTD pregnancy should take the higher prescription dose of 5mg daily. 'At risk' includes those who have already had an NTD pregnancy and women with a close relative affected by NTD.

**Adding folic acid to flour, at the proposed level, would mean that about 300 spina bifida pregnancies a year would become normal pregnancies.**

Each year up to 1,200 pregnancies in the UK are affected by neural tube defects (such as spina bifida) – 85% of which result in termination. Taking folic acid, at the correct dose, could prevent about 75% of these affected pregnancies.

The vitamin is already added to flour in the USA, Canada and 37 other countries. Significant health benefits have been reported including reductions in heart disease and stroke and a dramatic fall in the number of spina bifida affected pregnancies.

ASBAH Chief Executive, Andrew Russell, commented: “We are hopeful that, after 10 years of campaigning, our voice is being heeded by the FSA. Many pregnancies are unplanned and therefore women don't take a folic acid supplement in advance. Adding folic acid to flour, at the proposed level, would mean that about 300 spina bifida pregnancies a year would become normal pregnancies.

“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 other three options being considered by the FSA are: continuing with the current policy of advice to women; increasing the effort to encourage young women to take folic acid supplements and, lastly, encouraging industry to fortify more foods with folic acid on a voluntary basis

The consultation closed on March 13 2007 and the FSA aim to investigate responses and produce a summary within the next three months. ASBAH has been invited to help with a private briefing of the FSA Board before it reports to the Health Minister.

# r say"

## Research study seeks volunteers

**Scientists are appealing for women who have experienced a neural tube defect pregnancy to take part in an important new study.**

Women planning a pregnancy are already encouraged to take folic acid before conception and in early pregnancy to prevent neural tube defects (NTD).

But scientists believe that the lack of another vitamin – inositol – may also cause the baby to develop spina bifida or even anencephaly, where the brain is largely absent.

Now the Medical Research Council has funded research led by Professor Andrew Copp at the Institute of Child Health in London.

The PONTI study – Prevention of Neural Tube Defects by Inositol – began earlier this year and ASBAH has agreed to help the team by asking women who have experienced a NTD pregnancy to join the study and perhaps take vitamin inositol (as well as folic acid) if they are planning another pregnancy.

Professor Copp said: "No dangers or side effects of inositol are known. It has been used in high doses to treat other conditions and is naturally widespread in many foods and some health supplements. No problems have ever been found."

**Anyone wishing to know more, or is considering taking part, should contact Rosemary Batchelor, ASBAH's senior health adviser, on 01733 421306.**

**You can find further details on the study website: *www.pontistudy.ich.ucl.ac.uk* or by emailing ponti@ich.ucl.ac.uk**

## Equality for Disabled People

**ASBAH will respond to a new consultation launched by the government's Office for Disability Issues (ODI) and hopes local associations and their members will air their views.**

The ODI was set up to ensure that government departments work together to help the Government's aim of improving life chances and achieving equality for all disabled people by 2025.

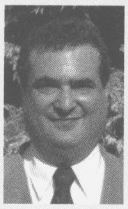
The Equality for Disabled People consultation is asking for views from disabled people, as well as carers, parents, young people and organisations, on what equality for disabled people means to them, and how progress towards greater equality can be measured.

ASBAH is now preparing its response and is keen to include the views of local association members and the Your Voice group.

To enable us to gather your views we will be mailing a summary of the consultation and questions to all local associations. Please look out for this and send us your replies, so that ASBAH's response contains a broad range of views.

*The Office for Disability Issues (ODI) will set an example for equal opportunities, and aims to be a model public sector organisation in internal practices, external relations and activities.*

*For more information about the Equality for Disabled People consultation log on to:* ***www.officefordisability.gov.uk/consultations/***



*"This consultation will enable the ODI to engage directly with disabled people and members of disability organisations to find out exactly what we as individuals think must be done to achieve the government's aim of equality for disabled people by 2025 and what we think are the most important areas of our lives that the ODI should focus on when measuring progress.*

*The ODI wants to hear from as many people as possible, of all ages and backgrounds and has expressed the hope that we can take some time to let them know what we think.*

*This is a golden opportunity for everyone involved with ASBAH to give their thoughts and opinions because they will inform and be incorporated in ASBAH's response."*

**Paul Zickel, ASBAH Trustee**

## Sign up to beat discrimination

**A European-wide petition to combat discrimination in all areas of everyday life of disabled people has been launched and needs your signature.**

The 1Million4Disability petition was set up by the European Disability Forum (EDF), to draw attention to how the European Union impacts on disabled citizens.

The International Federation for Spina Bifida and Hydrocephalus (IF) has been a member of the EDF since it began 10 years ago. Pierre Mertens, president of the IF, is a board member of EDF.

A spokesperson for the EDF said: "The European Union must respond to the call of at least one million citizens, as stated in the draft EU Constitutional Treaty so we must not miss this opportunity to raise our voices."

On 4 October 2007 the signatures will be officially handed over to the European Commission and the European Parliament.

To access the campaign website log on to ***www.1million4disability.eu/sign.asp?langue=EN***

There you can also download a printable version of the signature campaign.

# Continence and stoma products threat

**Representatives from the Bristol and District local association have voiced their concerns about government proposals regarding the pricing and delivery of continence and stoma products.**

A consultation paper published by the Department of Health, which closed last month, recommended proposals that would alter the way in which the government funds these products and services.

If these proposals are put into effect as they stand, it may no longer be viable for companies to supply certain products, regardless of whether a patient has successfully used a specific product for many years.

Patients will need to collect prescriptions from their GP and collect the products – often very bulky – from the chemist.

Kim Egan, assistant secretary at the Bristol and District group, who has spina bifida and hydrocephalus, wrote to her local MP voicing her concerns.

She said: "The government's proposals do worry people who think their present system could be altered."

Her mother, Sheila, one of the founder members of the Bristol local association added: "As a group we wrote similar letters to the ten MPs in our area. Everyone is very happy with the way the service operates at the moment and we have no wish to see it changed."

ASBAH service user Kate Sadler, who relies on home deliveries for her continence products, said: "Continence problems never seem to be seen as a disability by people in government, but they are. Home delivery of continence products is vital. It is convenient and discreet."

**All ASBAH service users can register their concerns over the proposals by signing an online petition to the Prime Minister, available on the 10 Downing Street website *http://petitions.pm.gov.uk/homedelivery***

# 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.*

**As someone who has both SB and H I have always known about your website, but have only been on there to look up specific things.**

However, I recently viewed it to do some research as part of my role as an equality and diversity consultant in an F.E college... and I was really impressed with what I found.

Having had the condition for all of my 21 years I didn't think there was much I had left to learn, but I found myself hooked for most of the morning.

I passed the website details on to my colleague and we now have a rich body of knowledge which we can refer to, not only in our dealings with students with Spina Bifida and Hydrocephalus, but other disabilities as well.

Thanks once again,

Tania Nurton
Learning Support Assistant and E and D consultant,
Abingdon and Witney College, Oxon

……

**I have read with interest the ASBAH web site and have found it very informative if not a little upsetting.**

I have had a shunt fitted for hydrocephalus since I was around 2 years old. Some of the information given has explained some thing that I experienced when I was growing up, but I did feel that a very glum picture has been painted. Please tell me if I am the only person with this condition that leads a very full and active life.

I have completed my education with 10 GCSE's A-C grade, 3 A-Levels and a diploma in Sports Therapy. I have been in full time employment since leaving college at 19 years old. I have only had 6 weeks off for a blocked shunt but I am fully fit now.

I am currently a Police Community Support Officer within the Police Service and I believe that I am doing a worthwhile job.

I live with my partner and have no adaptions for the condition. I ride a motor bike and hold a full car licence and have never let this stop me from doing the things that I want to do.

I think that success stories like mine should be shown so that parents with affected children can see that their children can have a chance to lead full and productive life.

Caroline Williams

*We hope that the information sheets cover all symptoms and outcomes that may be experienced by people with hydrocephalus.*

*Every person with hydrocephalus needs to be looked at on an individual basis. But everyone is entitled to be armed with clear, up to date information so that they are prepared for any difficulties that may arise. Not every person with hydrocephalus will experience all the symptoms.*

*Happily, there are many people with hydrocephalus living very ordinary, fulfilled and even adventurous lives - hopefully the positive articles in every issue of Link should help dispel any "glum" picture of the disability inadvertently painted.*

# 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 [illegible]iday makers. Each sleeps 6 people (2 wheelchair [illegible]essible bedrooms), wheel-in shower with seat, [illegible]n 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

[illegible]ening August 2005, single storey accessible [illegible]n converted to a high standard by family of [illegible]elchair 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:**

### Forget-me-not Conference

Meeting the challenges of spina bifida and/or hydrocephalus. A day for professionals and parents.
Venue: Tally Ho Conference Centre, Birmingham
Date: 17th May 2007
Time: 9.45am – 4pm
Cost: £10.00
For further information and/or application form please contact Geraldine Long 01789 763090, or email geraldinel@asbah.org or Jenny Green 01926 511 206, or email jennyg@asbah.org

### ASBAH Northern Region Summer Experience

For 12 to 16 year olds - Monday 13 August to Thursday 16 August 2007. Contact the Northern Regional office for more info.

### 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:
11 April, 9 May,13 June,11 July,
15 August, 12 September, 10 October,
14 November, 12 December.

### Summer Get Together

Venue: At the Secret Hills Discovery Centre, Craven Arms.
Date: Saturday 23 June
Time: 1:30 -4:00pm
More details from Elizabeth Miers on 01490 450294

### Your Voice Group events see p21

*Please e-mail the editor (link@asbah.org) dates of your events for the next issue of Link by Friday 11 May 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 11th May 2007

Please send to: Editor, ASBAH
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Tel: 01733 555988. Email: **link@asbah.org**

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# David Proud

# Proud to be a Desperado

**Link reader David Proud is enjoying new found celebrity status after playing a lead role in a ground-breaking children's BBC TV programme.**

David, from Peterborough, won a lead role in a new CBBC 10-part series, Desperadoes, about a wheelchair basketball team.

The programme, which was three years in the planning, is unique in that all the disabled characters are played by untried actors - many of them recruited from real-life wheelchair basketball teams. The cast includes paralympic wheelchair basketball player, Ade Adepitan.

> **It has been a very big learning curve as I have become very comfortable with my disability and I had to do a lot of research to be able to lose this comfort for the part.**

David, who has spina bifida, plays the role of Charlie, a 14-year-old who has a spinal injury which left him paralysed.

The series follows the highs and lows of Charlie as he comes to terms with his disability and joins a wheelchair basketball team which progresses through the Great Britain Wheelchair Basketball Association's Junior League.

Although David is no stranger to the small screen – he launched ASBAH's Helpline Appeal on GMTV with Danny Mills - his only acting experience was taking part in school drama and an A-level in theatre studies.

An acting coach was on set for the first five episodes to help the cast in their first major on-screen roles.

But David needed no extra tuition in learning wheelchair basketball skills, as he's been a keen player for years with Peterborough Phoenix, a national third division team in Stanground.

David, 23, said: "Playing the character of Charlie was a challenging role as he has suffered an injury and is suddenly thrust into an unknown world.

"I had to adapt myself to show an audience what it would be like to suddenly have to cope with a disability.

"It has been a very big learning curve as I have become very comfortable with my disability and I had to do a lot of research to be able to lose this comfort for the part."

When filming was completed last September, it was back to the day job for David, at Peterborough's Job Centre Plus.

David said: "It was very difficult settling back into my job. It all seemed very quiet and subdued after an exciting few months."

And after much soul-searching David resigned from his job in February and signed up with an acting agency.

He told *Link*: "I figured out that I can support myself for about six months if I do some temping too, so I decided to take a chance and see if I can make it as an actor. I really have to give it a go otherwise I'll regret it one day.

"Filming Desperadoes was such an exciting time from creating a new character to making friends with the rest of the cast. I hope the programme will open up many other avenues for me.

"To build a name for myself I would have to aim primarily for parts asking for disabled actors but would like to think that I would be able to compete for normal parts in productions.

"I have very high hopes for this series, as there has been a phenomenal response to the early assembly of the show. I hope that it will inspire the industry to employ more disabled actors."

Charlie Bethel, Chief Executive of the Great Britain Wheelchair Basketball Association commented, “We are so proud of everyone that took part in the drama. It was great to see how well our athletes seem to have adapted to acting.

“It is great to see the sport being portrayed in such a positive and dynamic way. It shows wheelchair basketball as a sport and one that can be played by everyone.”

# Contacting ASBAH

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**SHEFFIELD** ✓
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**TRAFFORD & SALFORD**
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**WARRINGTON & DISTRICT**
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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