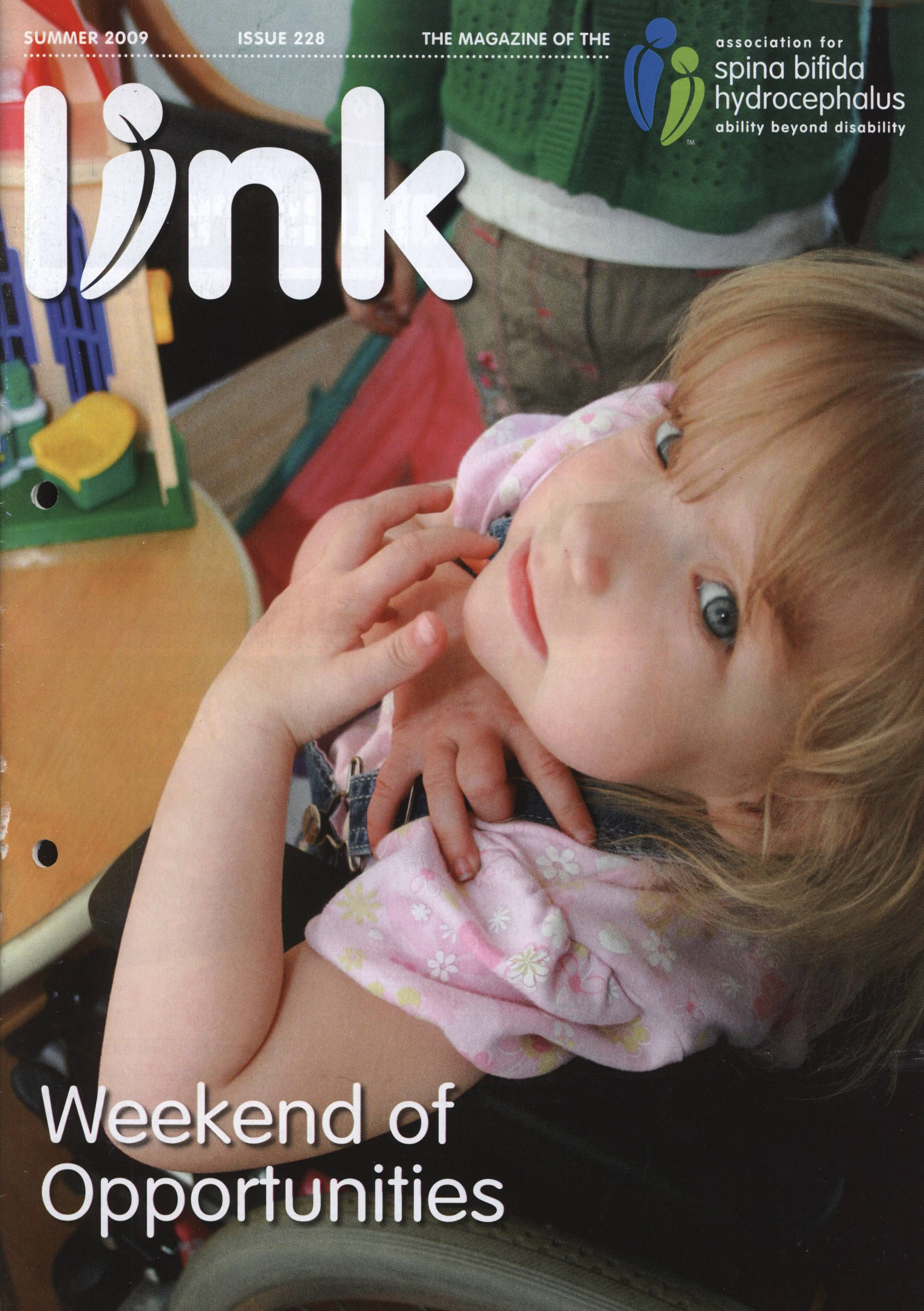
SUMMER 2009 ISSUE 228 THE MAGAZINE OF THE

association for spina bifida hydrocephalus
ability beyond disability

link



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Cardiff

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- Skiing
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- Transport
- Direct Payments and personal assistants
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Mark Harris
ASBAH House
42 Park Road
Peterborough PE1 2UQ
Email: markh@asbah.org
Telephone: 01733 421322

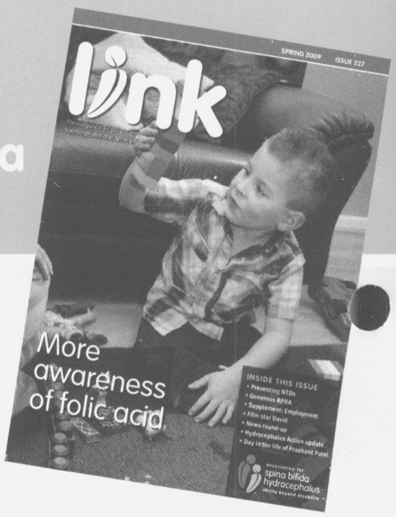
association for spina bifida hydrocephalus
ability beyond disability

Registered charity no.249338

Your Voice newsletter 'Get Your Copy' see page 5 for more details

link

the magazine of the association for spina bifida and hydrocephalus



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Link is published quarterly
(Winter, Spring, Summer and Autumn)

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Association for Spina Bifida and Hydrocephalus
Registered charity number 249338

Welcome to the summer issue of *Link* which you'll notice has a slightly different look. We still have the varied mix of news, features and events but the larger print size should make it all easier to read.

We asked readers training to gain a place in the Paralympics to get in touch and are delighted to be able to feature some of the hopefuls in this issue – all putting in maximum effort to achieve their dreams. The efforts of all those taking part in fundraising for ASBAH are recognised and we find out what makes people climb mountains, run marathons or dance and sing their hearts out to raise vital funds for us.

Our special feature looks at keeping healthy in mind and body and ideas on gentler ways of getting fit than our paralympians and fundraisers! If there are topics you would like to see covered in future special features you can email or write in with your ideas.

Also in this issue is a round-up of ASBAH news from the regions but we are always pleased to hear your news or views on what you read in *Link*. Do keep in touch.

Gill Winfield

Gill Winfield
Editor

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Registered charity number 249338
ISBN 1360-323X

Designed and produced by
Bluestation Communications

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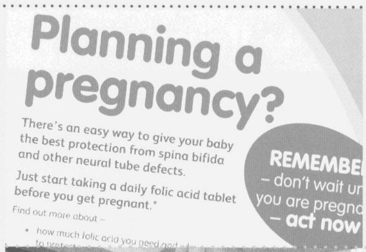
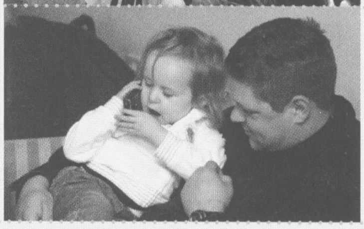


Planning a pregnancy?

There's an easy way to give your baby the best protection from spina bifida and other neural tube defects.

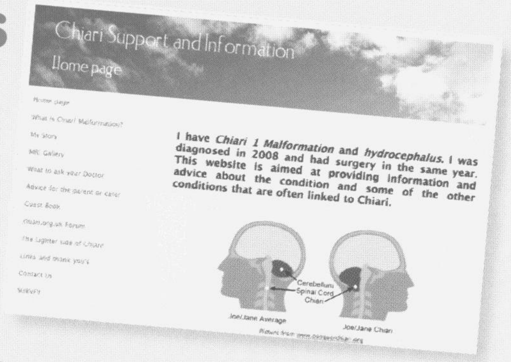
Just start taking a daily folic acid tablet before you get pregnant.*

Find out more about –



Alison goes online with Chiari experiences

Alison Palmer has tapped into her personal experience to create a website to help others learn more about Chiari malformation.



Chiari Support and Information

Home page

Home page
What is Chiari Malformation?
My Story
MRI Gallery
What to ask your Doctor
Advice for the parent or carer
Guest Book
chiari.org.uk Forum
The lighter side of Chiari
Links and thank you's
Contact Us
Survey

I have *Chiari 1 Malformation* and *hydrocephalus*. I was diagnosed in 2008 and had surgery in the same year. This website is aimed at providing information and advice about the condition and some of the other conditions that are often linked to Chiari.

The mother of three, from Southport, was diagnosed with Chiari malformation and hydrocephalus in 2008 after suffering headaches and neck pain. It took several operations and more than a year before she was able to even think about getting her life back on track.

She told *Link*: “I decided to create a website for people with Chiari and their carers because what happened to me came as a huge shock. After the diagnosis I was expecting to have six weeks off work and then get back to normal.

“I had my most recent surgery to fit a VP shunt last year and although I am still in some pain, I am starting to get my life back together.”

Alison, who worked with pupils who have been excluded from mainstream school, said: “I don’t know if and when I’ll be able to go back to work but I am hoping to finish my degree by Christmas.”

She added that her condition has had a big impact on her three children, Nicholas, 12, and twins Nathan and Cerys, 9.

“I am a single mother so I arranged for someone to look after them for my first surgery. But when I kept going back into hospital for up to three and a half weeks at a time I don’t think they thought I would come out.”

The content of this site is my understanding of the condition based on the research I have carried out and about my experiences of having Chiari.

The website, which also formed a module of Alison’s degree, has information about Chiari malformation, a section about what to ask your doctor, a survey and a forum as well as two personal stories.

Alison added: “As I had so many complications my story is not a positive one but it’s an honest one. There is another personal story on the website by a lady I met who did have a better experience than I did.

“I must also make it clear that I do not have any medical training. The content of this site is my understanding of the condition based on the research I have carried out and about my experiences of having this condition.

“I am pleased with the end result and I think writing everything down has helped me to come to terms with what I have gone through. I hope the website helps others and I’d be delighted if others sent in their story.”

Check out the website at ***www.chiari.org.uk***

Folic acid awareness – how you can help

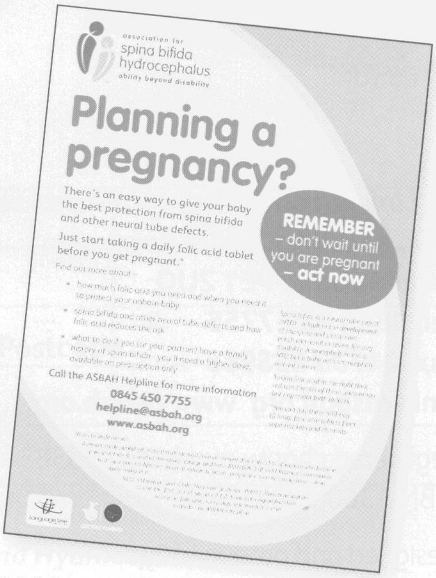
Have you spotted an ASBAH poster advertising folic acid awareness in your GP surgery? If not, perhaps you can help.

Earlier in the year ASBAH mailed out posters - which highlight the importance of taking a folic acid supplement if you are planning a pregnancy - to all GP surgeries in England, Wales and Northern Ireland.

If you can’t see a poster displayed, please request one from the ASBAH helpline and ask your surgery to display it – and help raise awareness of folic acid.

The distinctive posters give information about how a deficiency in folic acid is a major risk factor for neural tube defects (NTDs), such as spina bifida, and gives ASBAH’s helpline details for more information.

The importance of folic acid is also highlighted on the ASBAH website with the help of Professor Sir Nicholas Wald from the Wolfson Institute of Preventive Medicine and mother Sonia Reains, whose son Dylan has spina bifida.



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Planning a pregnancy?

There’s an easy way to give your baby the best protection from spina bifida and other neural tube defects.

Just start taking a daily folic acid tablet before you get pregnant.*

Find out more about...

- how much folic acid you need and when you need it to protect your unborn baby
- spina bifida and other neural tube defects and how folic acid reduces the risk
- what to do if you (or your partner) have a family history of spina bifida - you'll need a higher dose, available on prescription only

Call the ASBAH Helpline for more information
0845 450 7755
helpline@asbah.org
www.asbah.org

REMEMBER
– don’t wait until you are pregnant
– act now

Vitamin research may reduce rates of hydrocephalus

A team of researchers believe taking a special vitamin supplement during pregnancy could prevent hydrocephalus.

Tests on rats showed a combination of folates dramatically reduced the rates of hydrocephalus and continued to work after the condition had started to develop.

But the research, published in the Journal of Neuropathology and Experimental Neurology, is still at a very early stage.

The team from the universities of Manchester and Lancaster hope to get permission to start clinical trials in pregnant women with babies diagnosed with hydrocephalus.

The supplement itself is not currently available, so they are seeking the support of a pharmaceutical company willing to produce it as a pill.

The research team also say they have shown it is the chemical composition of cerebrospinal fluid - rather than the fluid itself putting pressure on the brain - which causes the problems.

Lead researcher Jaleel Miyan said: “Cerebrospinal fluid is not a liquid which simply cushions the brain and carries chemicals around it. It is actively produced and transported and plays an essential biological role in developing the brain.”

The combination of supplements appeared to stimulate this process.

Although women are already advised to take folic acid before conceiving and in the early stages of pregnancy, to help prevent spina bifida, this does not appear to promote brain cell growth in the same way as the combined supplement.

Dr Imogen Montague, a spokeswoman for the Royal College of Obstetricians and Gynaecologists, said the study was “potentially very exciting.”

“There are so few things we can currently do to decrease the incidence of birth defects so these findings are really to be welcomed.

“But we do have to be cautious about the results - extrapolating results from rats may be problematic, any general use[of the new supplement] would still be a long way off.”

ASBAH health adviser Gill Yaz said: “Dr Miyan’s research is at a very exciting stage. We certainly hope the clinical trials are approved, and we are watching developments with great interest.”

Get your copy

The latest issue of the Your Voice newsletter – Your Voice, Your Choice – is now available online at *www.asbah.org/yourvoice* and is packed with the latest news and information from ASBAH’s group for adults with spina bifida or hydrocephalus.

To get hold of your copy or for more information about Your Voice contact Mark Harris, YV development officer on 01733 421322 or email him at: ***markh@asbah.org***

Online newsletter

***Link* readers may not be aware that our local association quarterly newsletter is also available online.**

Visit ***www.asbah.org/ASBAH+Community/localassociations/connectbulletin***

The June issue includes:

- Transition support update
- Parents views on services for disabled children
- New equipment website

Discount on Blue Badge Atlas

***Link* readers have been offered a 30 per cent discount off the new Concise UK Road Atlas for Blue Badge drivers.**

The latest version of this useful 256-page guide is the official journey planning tool for Blue Badge holders offering plenty of help and advice to make your journey smoother.

Included are details of accessible accommodation, on-street parking rules for every UK council, petrol stations and accessible toilets plus shopmobility locations.

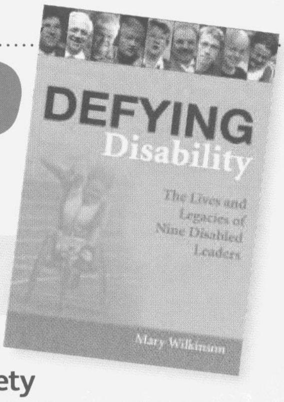
It also features 60 town centre plans with blue badge bays, accessible toilets and accessible car park information.

To buy the guide for £9.99 inc p&p (usual cost £13.98) go to ***www.thepieguide.com/shop***, click on the Concise UK Atlas and complete your details. Alternatively you can call 0844 847 0875. Allow 3 – 5 working days for delivery.

Review

Defying Disability

by Mary Wilkinson



Published by Jessica Kingsley Publishers
Price: £17.99

Defying Disability is essentially a short biography of nine disabled people from a variety of backgrounds and with differing problems, who have all gone on to become national figures and achievers in their own field.

Given that this is a book about disability, it could very easily have gone down the personal "triumph over tragedy" route but it has not. Instead, it highlights how each person set about changing their own life, whether through sport, broadcasting, business, politics or campaigning, and in the process made a difference to the lives of many others.

The book also provides an insight into the world of disability politics, and how the disabled population are now demanding a greater say in how their own lives are managed - a position neatly summed up by the campaigner Rachel Hurst as "Rights, not charity". Through the differing viewpoints of each individual, "Defying Disability" invites you to consider whether it is society itself that is responsible for the limitations and barriers faced by disabled people.

There are a lot of acronyms in this book but don't be put off - this is not a dry and dusty academic volume. The actions and opinions of these outspoken people will challenge your perceptions of disability and achievement, and will ultimately enable you to form your own opinion on where you stand in the disability debate.

Keep up to date with equality

The Government's Equality Bill should remove some of the problems that form a barrier for equality and achievement for everyone in Britain.

When it was published, in April, the Bill was welcomed by the Equality and Human Rights Commission.

It includes a host of measures designed to tackle inequality and discrimination, and help Britain become a fairer society.

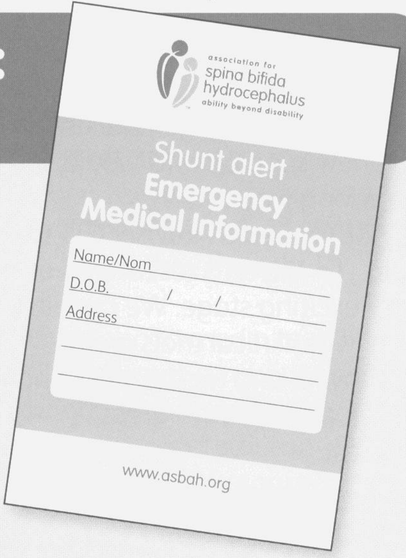
The plans include simplifying legislation, improving public services and extending protection to a wide range of groups facing discrimination.

Trevor Phillips, Chair of the Equality Commission, said the Equality Bill "is about how everyone, from whatever background, can live wholly fulfilled lives – in their communities as well as workplaces."

The Commission's role will be to ensure it works in practice through policy development, guidance, influencing and enforcement work.

For more information go to: *www.equalityhumanrights.com* and click on the Equality Bill link.

Shunt passports: now available



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Shunt alert
Emergency
Medical Information

Name/Nom
D.O.B. / /
Address

www.asbah.org

ASBAH's helpline is often asked for information about hydrocephalus, in foreign languages, to take when travelling abroad. So those of you who are planning an overseas trip will be pleased to hear that we have produced the new shunt passport, for adults or children with hydrocephalus, to take on holiday.

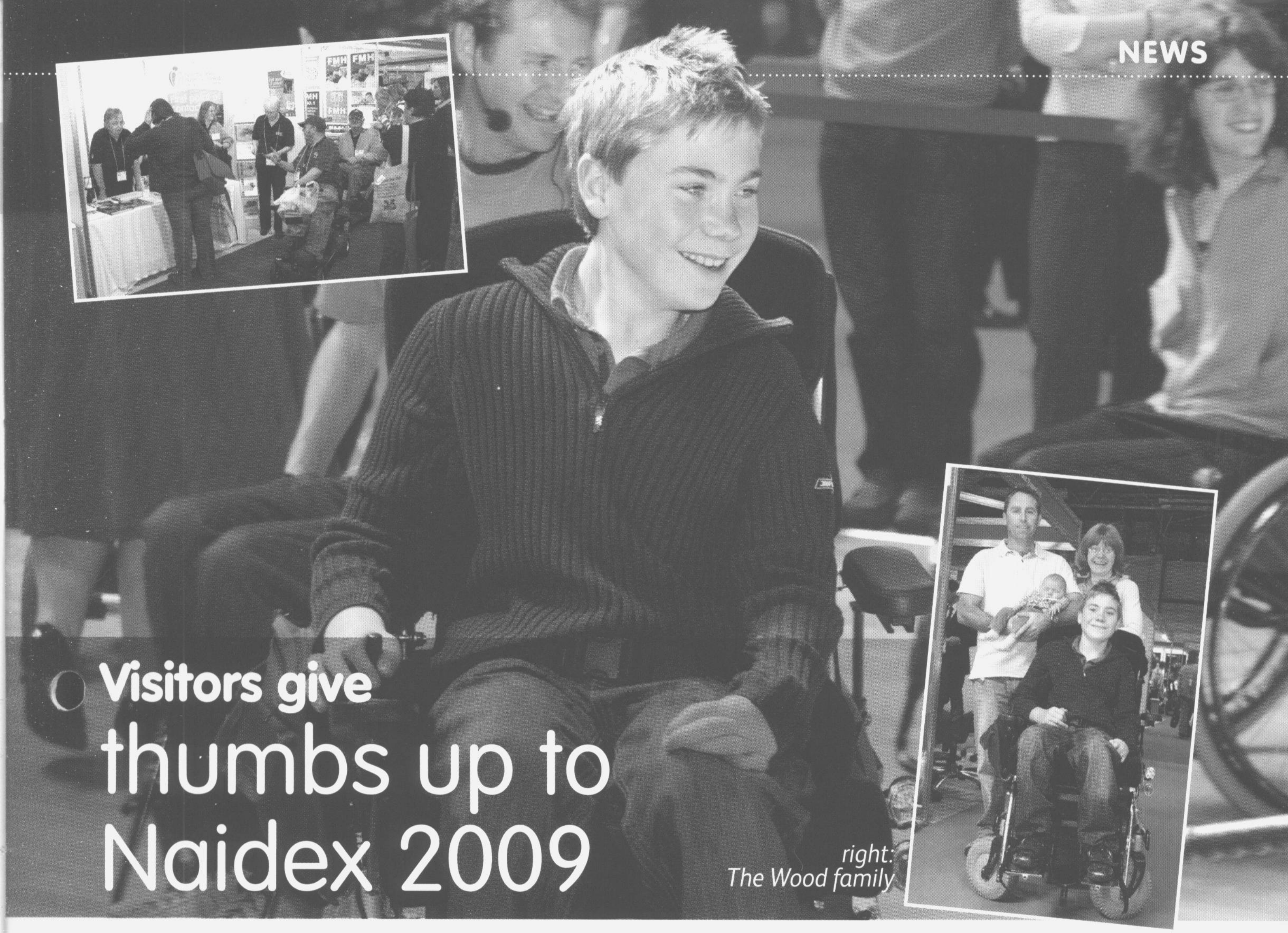
The passport contains information about hydrocephalus including symptoms of shunt failure, just like the shunt alert cards currently available in English.

There will be space in the passport for important information about you (or your child), including the type of shunt you have and when it was fitted, the name of your local hospital and neurosurgeon, along with contact details.

This information is in English but also in seven other languages from the most common holiday destinations: Spanish, French, Portuguese, Italian, German, Greek and Turkish.

Helpline manager, Linda Lewis, said: "We hope that people with hydrocephalus thinking about travelling overseas will find these new shunt passports put their mind at rest about explaining the condition to medical staff if the need arises."

The shunt passports can be ordered from the helpline or the website, cost £7.00 inc p&p. Telephone: 0845 450 7755 *www.asbah.org*



right:
The Wood family

Visitors give thumbs up to Naidex 2009

Staff from ASBAH were among the 350-plus exhibitors showcasing at Naidex 2009, the UK's leading homecare, disability and rehabilitation exhibition.

The three-day event, at Birmingham's NEC, attracted thousands of visitors keen to view the latest products and services to enable independent living and meet representatives from a variety of support organisations.

> **"We go to Naidex most years as there's always plenty to see. This time we were looking at wheelchairs as I need a lighter model."**
> ***Wendy Letts***

On show was everything from wheelchairs and stair lifts, children's equipment and clothing to beds and continence aids. Visitors picked up plenty of information and advice from the experts too.

The crowds included *Link* readers Mariann and Colin Wood and their son Cameron, 13, who has spina bifida.

The family, from Hereford, recently moved house and are currently planning an accessible conversion to enable Cameron do more for himself.

Mariann said: "Cameron's physiotherapist suggested we went to Naidex to have a look at what products are available which might be useful to us.

"We didn't see any of the infra-red activated products which we were really looking for, but the room sets gave us quite a few ideas.

"We also spotted lots of small gadgets which we knew would help Cameron to be more independent, which is so important now he's almost 13."

While Cameron enjoyed looking at the gadgets and gizmos on show, what really caught his eye was the Whizz-kidz section – where he got the chance to try out his dancing skills plus wheelchair basketball.

Mariann said: "Cameron plays Boccia, floor lacrosse and curling with other children with disabilities, but this was the first time he'd really got together with lots of other wheelchair users. He had a great time."

Cameron added: "It's a great event with lots of useful information about products that will be helpful to me as I get older and gain more independence."

Put the dates for Naidex 2010 into your diary now, April 20th–22nd 2010 at the NEC Birmingham.

Newlife wheelchair for Ashley

The future's looking brighter for two-year-old Ashley James-Jenkins after her parents secured £10,000 funding for a much-needed wheelchair.

They applied to the Newlife Foundation for Disabled Children charity and were delighted to be awarded a wheelchair grant.

Her father, Ryan, told *Link*: "The new wheelchair is specially designed for Ashley and with adaptations, will be suitable for her until the age of ten."

The wheelchair is fully electric, with a seat which lowers to the ground. It has given Ashley the mobility and freedom she needs to get around and play with older brothers Saul, Nicky and little sister Maddie.

"We can't thank Newlife enough. They were so helpful and friendly from the start and the whole process was hassle-free for us."

Ryan also praised the family's ASBAH adviser, Margaret Stanton. "We haven't received a great deal of help locally, but Margaret has been fantastic from the day we first got in touch," he said. All our family would like to thank Margaret for sorting out every problem we have had. She really goes beyond the call of duty every time."

Newlife Foundation
for Disabled Children,
at: Newlife Centre,
Hemlock Way, Cannock,
Staffordshire, WS11 7GF.
Tel: 01543 462 777
www.newlifecharity.co.uk

"The seminars were useful and informative and all the children had a wonderful time making friends with children of similar abilities and ages."

Joe and Satomi Folkett, parents of Lamar, 4, who has spina bifida.

Neurosu[illegible]on Paul Chu[illegible]as

Opportunities

Families from the Midlands and North of England forged new friendships at our Opportunity Weekend in May.

Ten families – with a total of 21 children – enjoyed the action-packed weekend at the pretty seaside resort of Lytham St Annes, three miles south of the bright lights of Blackpool.

The weekend included several workshops for parents run by ASBAH staff, while their children were kept entertained.

Family activities including trips to the beach and Blackpool Zoo were also arranged to make their stay a memorable one. There was evening entertainment with a clown and magician for the children, followed by a cabaret.

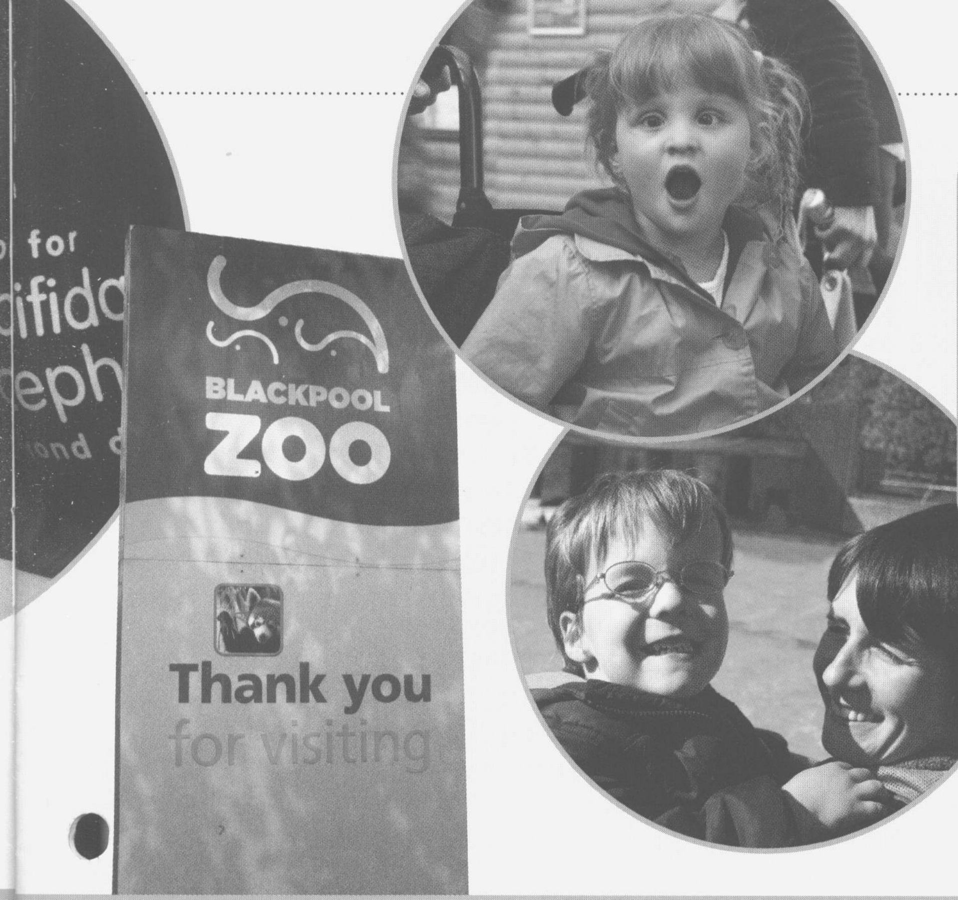
Two external speakers also gave talks - Neurosurgeon Paul Chumas, about spina bifida and hydrocephalus "Current thinking", while Rosemary McCrearey from the Department of Work and Pensions (DWP) covered all benefits related issues.

The information they received gave them more confidence and made them feel much more positive about their child's future.

David Isom, Eastern Region Manager, was one of the organisers of the weekend. He said: "Everything went extremely well and the feedback we received was excellent.

"The parents felt it was so valuable to meet others who had children with spina bifida and/or hydrocephalus. It was a great chance for their children to make friends too.

"They found the workshops really useful and what they thought they knew about the conditions beforehand was very different to what they came away with. The information they received gave



weekend

them more confidence and made them feel much more positive about their child's future."

David praised the St Annes Hotel staff who, he said, "couldn't have been more helpful. Nothing was too much trouble for them."

The facilities were fully accessible in every aspect so the families could relax and enjoy themselves completely.

David added: "We sent out flyers about the weekend to a number of families and received 45 applications. From the information they gave we shortlisted ten, which was a very difficult task.

Our funding

Our fundraising team worked especially hard to gain grants to pay for the Opportunity Weekend.

Trust Fundraiser Helen Dow said: "This event would not have been possible without the fantastic financial support we received from the Four Acre Trust, the Harbour Charitable Trust, Next Retail Ltd and the Good Neighbours Trust."

St Annes Hotel

St Annes is a sea-front hotel with stunning sea views. The hotel offers holidays for people with disabilities and special needs, and their carers, friends and families.

All rooms have ensuite bathrooms, are wheelchair accessible, and contain all the specialist equipment you might need during your holiday.

For more information go to ***www.bondhotel.co.uk/index.php/bond-hotel-st-annes*** or call 01253 341218.

"We thought the weekend was brilliant and as a family we certainly got a lot out of it. It was good to speak to other parents and children and to find that they experience the same problems and have similar concerns.

"We made a lot of special friends over the weekend and hopefully plan to meet up again later in the year.

"All the ASBAH staff were really approachable and friendly, and both John and I learnt a lot from the workshops & talks. We now feel much more confident and knowledgeable about talking to medical staff and the school."

Helen Wilkinson, mother of Caitlin, 5, and Abi, 2, who both have spina bifida, and Rebecca, 12.

Well-being

Getting the most out of life is a lot easier if you are feeling healthy and happy. But taking good care of yourself can sometimes be a challenge. Here, ASBAH's health advisers, give their advice for keeping in tip top condition.

Skin

What does skin do?

The skin has 3 main functions – protection, regulation and sensation.

Protection:

- from harmful ultraviolet rays by producing melanin
- acting as a barrier to prevent damage by chemicals or knocks and bumps
- stops moisture from entering the body and uncontrolled loss of fluid from the body
- acting as a "reservoir" for vitamin D which is vital to maintain good teeth and bone growth
- from infection by producing cells which heal wounds

Regulation of temperature: by sweating, by opening of the blood vessels in the heat and closing them when cool.

Sensation

To touch, pain and temperature via the nerve cells contained in the skin. Damage to these nerve cells [neuropathy] means that the sensitivity to pain is decreased – or sometimes non-existent – and this is something that particularly affects people with spina bifida amongst other conditions (e.g. diabetes)

Taking care of your skin

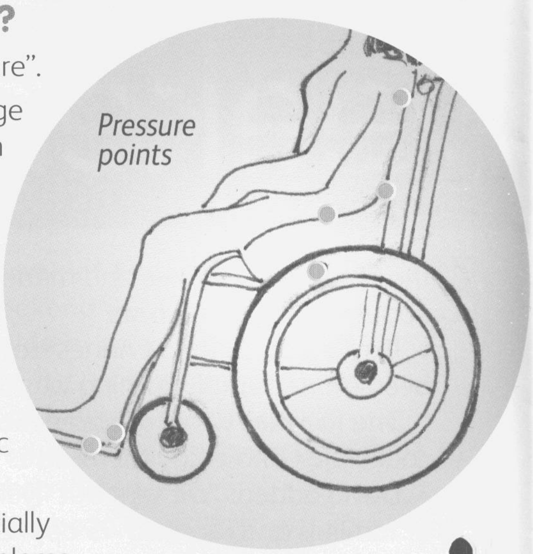
As people age, the skin becomes less elastic and thinner and is consequently less resistant to damage.

For people with spina bifida, these changes are particularly important as a minor injury [from pressure or from a scrape] can result in a pressure ulcer [sore] which are notoriously difficult to heal.

Pressure ulcers are a significant cause of poor health and the importance of avoiding them is graphically illustrated by the case of Mark Weatherall who died from complications of pressure sores aged just 43 - his widow Claire warned of the dangers in *Link* issue 225.

So what can you do to help?

As ever, "prevention is better than cure".



- Keep as mobile as possible – change your position to relieve pressure on your skin – especially where your bones are more prominent.

  Wheelchair users can release pressure by pushing straight up, leaning from side to side, bending forward over your knees, tilting back in your manual chair or reclining the seat of your electric wheelchair
- Keep skin clean and dry - be especially careful if you have continence problems
- Inspect vulnerable areas [bottom, heels, toes, thighs, back] for redness. If it occurs - find out what is causing the problem and do something about it. For example, if it's due to hard seams or tight clothing change for more suitable clothes
- Wear good fitting shoes and socks – so that these don't rub your skin
- Keep your wheelchair cushion in good condition and wrinkle free
- Keep your weight down – obesity will increase skin problems
- Eat a good diet which includes protein and vitamins (especially vitamin C)

Most important, value, care for and respect your skin and if, despite all your best efforts, you do develop a sore seek treatment promptly!

For more information see ASBAH's Pressure Sores Information sheet – available from the website or via the helpline.

Stay safe in the sun

A suntan means your skin has been damaged by the sun.

Most non-melanoma skin cancers are caused by long term exposure to the sun and if you burn easily you are at more than average risk from another type of skin cancer called malignant melanoma.

It is the ultraviolet light UVB in sunlight that damages skin cells and it is important to wear a sunscreen to filter out these harmful rays.

What the sun protection factor (SPF) means

The sun protection factor of a sunscreen tells you how much of the sun's harmful UVB rays are filtered out. If you use

- Factor 15 – only 7% of the harmful rays will get through
- Factor 30 – only 4% of the harmful rays will get through
- Factor 60 – only 2% of the harmful rays will get through

So, it is sensible to use a high factor sunscreen because this gives you much more protection than a lower one and experts recommend at least a Factor 15 sunscreen.

Applying sunscreen

It is important to apply your sun cream often enough and thickly enough. You must apply it thickly. If you put it on too thinly you won't get as much protection as it says on the bottle.

Use golf ball sized dollops for small children. You need to put it on about 30 minutes before you go out in the sun and reapply it every two hours (or more often if it has been washed, rubbed or sweated off).

SunSmart advice – staying safe in the sun

Applying a sunscreen won't automatically protect your skin from damage, they are just one way of protecting yourself against the sun.

The best advice is to keep out of the sun when it is hottest, cover up with hats and t-shirts and make sure you never burn.

Many parents find the sunscreen T-shirts (available from Boots and other high street retailers) are useful for smaller children.

- This information was provided by Cancer Research UK. *www.cancerhelp.org.uk*

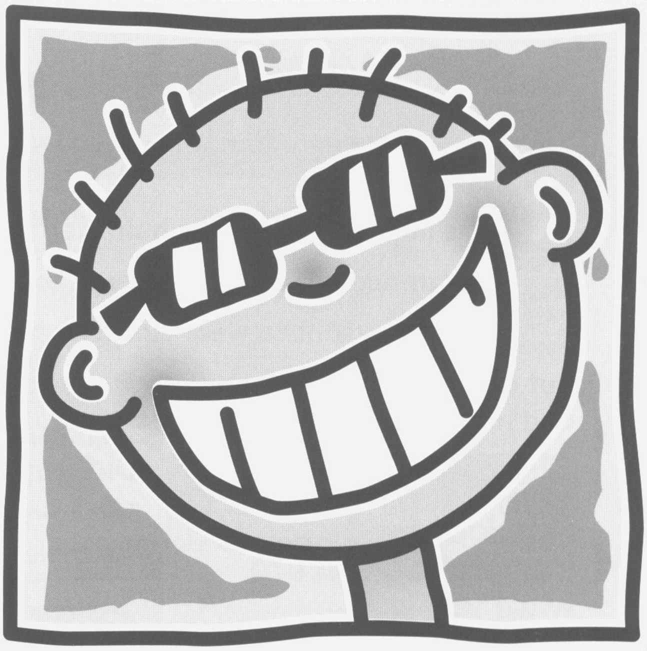
For more information check out:
www.netdoctor.co.uk
www.Which.co.uk/Sunscreen-Reviews

Don't forget your glasses...

Prolonged exposure to UV rays, especially UVB, can cause cancer of the cornea, cancer of the eyelids, cataracts and even blindness

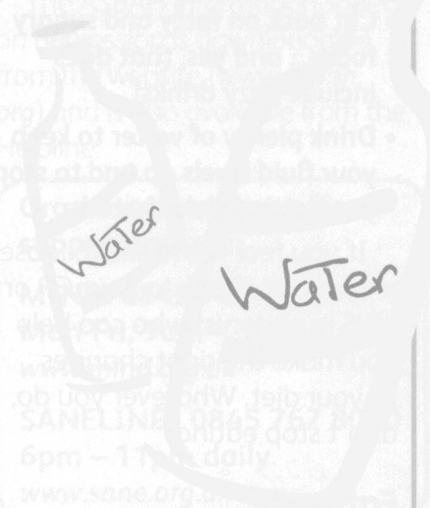
It is also believed that 80 per cent of damage occurs before the age of 20, so if you are buying for children look for sunglasses that still protect.

Make sure they are not toy sunglasses and that the UV protection is the same as for an adult pair.



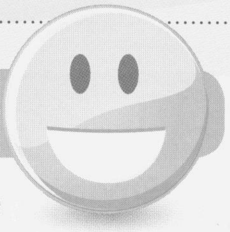
Keep well watered

Remember to keep well hydrated in the heat. Drink plenty of fluids, especially when working or playing in the sun. If you can, try to schedule physical outdoor activities for the cooler parts of the day.



Staying hydrated is particularly important for people with hydrocephalus. If you become dehydrated you may suffer headaches which can mimic shunt problems.

Start young to get fit



YAWN... here we go again. Yes we know you've heard it all before.

Yes it's important to eat a balanced diet
Yes it's important to get plenty of exercise
Yes it's important to wear sun screen.

But a good diet and exercise makes you feel and look good – and no one can argue with that!

Diet

Fabulous food (remember, you are what you eat)

Obesity means kids and adults who carry 20 per cent extra body weight. This extra weight could cause serious health problems at some point later in life such as arthritis, cancer, heart disease, stroke, diabetes and depression – not nice!

- **Eat a balanced diet including plenty of fresh fruit and veg**
- **Cut back on fatty and sugary foods... and yes, that does include fizzy drinks!**
- **Drink plenty of water to keep your fluid levels up and to stop you getting dehydrated**

If you feel you'd like to loose a few kilos, speak to your GP or NHS nutritionist who can help you make the right changes to your diet. Whatever you do, don't stop eating!

Eat well

Check out the Food Standards Agency website for practical healthy eating advice for children, from toddlers to teenagers. *www.eatwell.gov.uk/agesandstages/children*

Did you know?
In the UK right now, one in five children are obese.

Did you know?
The number of obese children has tripled in the last 20 years.

Exercise

Keeping fit & having fun

Being fit is easy really – it just means using your body for something else besides sitting on the sofa.

Any activity that gets you slightly out of breath and gets your heart pumping can help to keep you fit, in shape and looking good.

Exercise is particularly important for wheelchair users who can become overweight more easily because they use fewer calories than those who walk. This can lead to pressure sores – yes, even in children!

Continence

If you have continence issues read our Russell and Millie books which will help you to understand and cope with your continence. The books come in two versions, 'Russell' for boys, and 'Millie' for girls and show how continence problems affect Russell and Millie's lives.

For your copy call the helpline on 0845 450 7755.

Did you know?
Keeping fit can reduce your chances of getting some serious health problems like heart disease and obesity.

Smart Summer Skin Care

- **Even on cloudy days the sun's rays can burn your skin – so always wear a sun scream with a high protection factor during the summer months.**

*** Take special care at the hottest time of the day – 11am – 3pm**

- **Stay in the shade**
- **Cover up & wear a hat and sunglasses. Sunscreen t-shirts are great for younger children.**
- **Stay cool**

Did you know?
Several severe sunburns in a child (under the age of 18) doubles the risk of skin cancer later in life.

Did you know?
Sunburns can also age the skin – so if you don't want to look like your Grandma when you're 30 – cover up!

Continence

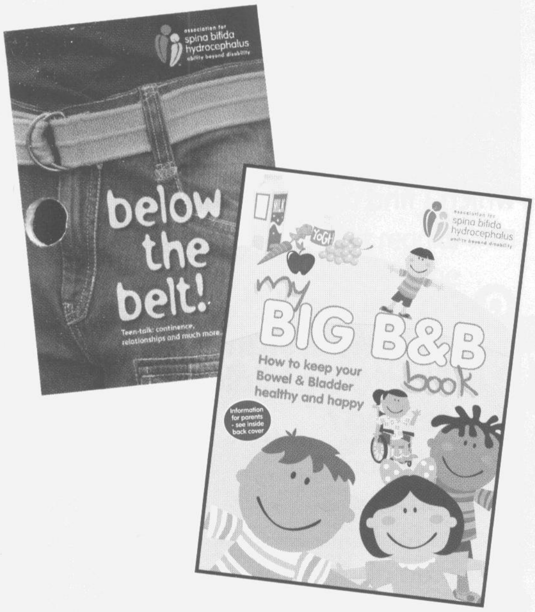
Below the belt

Continence, especially bowel continence, seems to be the thing about spina bifida which bothers people more than anything else.

- **Understanding how your bowel and bladder work can help you make choices about how you manage your continence.**
- **Drink plenty of water and eat a varied diet... plenty of fruit, veg and cereals really help.**
- **Get hold of a copy of ASBAH's Below the Belt booklet – it'll tell you all you need to know about continence... and other**

stuff to help you survive the teenage years.

- **If you're younger – aged between 5 – 8 years – ask for a copy of ASBAH's My Big B&B Book.**
- **Don't be shy; you can speak to an ASBAH continence adviser if you need more help. She won't be embarrassed; she's heard it all before.**



For copies of Below the Belt and My Big B&B Book call the ASBAH Helpline on 0845 450 7755.

Check out the website at *www.asbah.org* for information sheets on a range of healthy living topics.

Taming the black dog of depression

We often use the expression "I'm feeling depressed" when we're feeling sad or miserable about life. Usually these feelings pass in due course.

But if the feelings are interfering with your life and don't go away, it could be a sign that you're depressed in the medical sense of the term.

Depression shows up in many different ways. Some of the symptoms include:

- **Having difficulty sleeping and waking early**
- **Feeling tired and lacking energy**
- **Feeling low-spirited for much of the time, every day**
- **Being preoccupied with negative thoughts**
- **Experiencing a sense of unreality**
- **Thinking about suicide.**

At its most severe, clinical depression can be life-threatening, because it can make people suicidal or simply give up the will to live but there are lots of things which can help make people with depression get better.

What can I do to help myself?

Fighting negative attitudes - try to recognise the pattern of negative thinking when you are doing it, and replace it with a more constructive activity.

Activity is good for the mind - get physical for at least 20 minutes a day. Exercise stimulates chemicals in the brain called endorphins, which can help you to feel better.

Caring for yourself - do things that will improve the way you feel about yourself. Pay attention to your personal appearance and set yourself goals that you can achieve. Look after yourself by eating healthily - tobacco, alcohol, or other drugs, can make you feel worse.

Self-help groups - it can be helpful to share experiences with others who are experiencing the same thing you are.

For more help and information about depression consult your GP.

The ASBAH information sheet on depression is downloadable from the website (***www.asbah.org***) and is also available from the Helpline.

Organisations that offer support include:

MIND: 0845 766 0163
Mon-Fri, 9am – 5pm.
www.mind.org.uk

SANELINE: 0845 767 8000
6pm – 11pm daily.
www.sane.org.uk

How I cope with depression: Anna's story

Anna Thompson is a talented musician, who plays piano, euphonium, tenor horn, trombone and guitar. She lives with husband Stewart and their two dogs.

Anna, who has spina bifida and arrested hydrocephalus, taught music in schools after graduating from university.

But depression has led to her giving up her teaching career, apart from a few private piano lessons for friends, and she now volunteers for her local church instead.

Anna had 'the 'blues' in her teens but first experienced full-blown depression in January 2008.

Anna told *Link* how depression affects her and how she copes:

continued over page

continued from previous page

Anna Thompson

"My first real bout of depression was completely devastating. I woke up every day wishing I hadn't. I felt completely alone and I cut myself off from all my friends and most family. I hardly slept, I lived off chocolate buttons for about three months, and I cried or sat alone a lot."

Q Did your GP help?

I consulted my GP after about two weeks and she was absolutely fantastic, putting me on anti-depressants and sending me for counselling. She insisted I went back to see her every other week, then every month.

Q Do you think something triggered your depression?

Yes, my brother is a successful dancer in London and he had his first real 'break' in a pantomime in December 2007 where he starred alongside such celebrities as Mickey Rooney and Les Dennis.

The whole family went to see him perform one weekend and I was hit very hard by the realisation that I would never reach that level of success and I felt like a complete failure.

Q How does depression affect you now?

After that initial 'breakdown,' things did eventually get better but I have never felt the same since. I still get good days and bad, but I've learnt to adjust my day accordingly.

Anything could trigger another bout. Very often I won't recognise that I'm on a down spell until it becomes very obvious. My husband spots it much quicker than I do.

I get very dark thoughts, severe tiredness, sleeplessness, crying over anything and everything and loss of interest in anything. I hide at home as much as I can until it lifts again.

Q What support do you get?

I am so lucky to receive such wonderful support from everyone around me. I speak to my parents daily and my friends and in-laws are all fantastic.

Stewart is my angel from heaven. Despite having a very busy job and other musical commitments, he takes extremely good care of me and makes sure I am looking after myself.

I also have a very tight group of friends around me whom I love very much. When I am depressed, they form a cocoon around me and are 'on call' if you like, 24/7 in case I need them.

I take anti-depressants every day now. These are adjusted as needed depending on my level of depression and have kept me afloat.

Q Are there things you can do to help yourself when you feel that you are heading towards another low?

It takes me a while to reach out for help when I am depressed, but once I have I find it a great relief and start on the road to recovery. I cancel my commitments so I can concentrate on myself. I make sure I get enough rest and sleep and fresh air. I am a practicing Christian so I have great belief in prayer and ask God for help, which I find a great comfort to me.

Q Do you feel that other people understand what it is like to be clinically depressed?

Some do, some don't! I do think that some people view it as an excuse for laziness, that I'm not bothered about them or that I am seeking attention.

Q What would you say to someone else who is experiencing severe depression for the first time?

The first thing I have to say is that it is really important that you understand that **IT WILL ALL BE OK**.

As people with a disability, we have a lot of emotional issues to deal with as a result of living in an able-bodied society.

It is very important to talk through your worries, fears and feelings with someone you trust. The Samaritans can help if you can't talk to anyone face-to-face, but unless you get things out of your mind, I feel they just eat away at you. Talking certainly aids the healing process!

Your continence

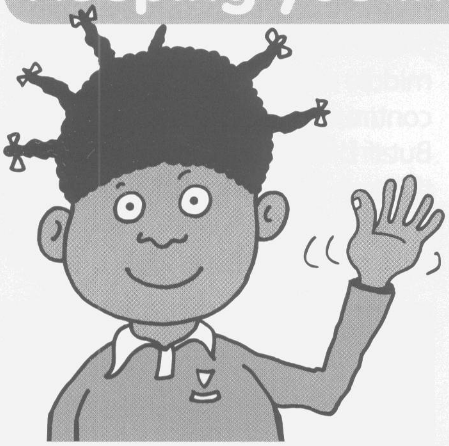
Good bladder and bowel management can improve quality of life for people with spina bifida.

Needing to go too frequently, or very urgently, interfers with everyday life, while chronic constipation can leave you feeling lethargic and grotty.

- Caring for your bladder and bowel at the same time is important, as each can affect the other; an overloaded bowel can stop your bladder emptying completely, and a full bladder can stop your bowel from working.
- Empty your bladder at regular intervals to help prevent urine infections which can make you very ill and cause kidney or bladder stones. Bladder stones can make infection more likely, and so the problem grows.
- If your bladder is small and 'twitchy', it is very important to empty it to keep the pressures down and prevent reflux of urine back up to the kidneys. This will cause permanent damage to the kidneys, and affect your long-term health.
- Take your medication regularly.
- Regularly emptying your bladder, and a good routine with your bowel, can reduce leakage of urine and faeces. Leakage left on your skin can easily cause sores, especially if you can't feel your skin getting sore. Leakage can leave you feeling less confident and even mean you miss out on activities.

Find out what might improve things - if you have not had a continence review for some years, you may not be aware of some of the exciting new developments. Talk to an ASBAH health adviser about the options. The helpline can put you in touch with advisers. Tel: 0845 450 7755; email: ***helpline@asbah.org*** or ask your regional ASBAH office *(see page 31)*.

Keeping you informed on continence issues



Need continence advice? We can help with a range of information including:

- 15 information leaflets on continence issues from toilet training to surgical interventions, tests and procedures, catheterising and even diet and continence.
- My Big B&B Book - An activity book for children to take control of their continence from an early age.
- Russell and Millie – books to help children with spina bifida understand and cope with their continence. They come in two versions, 'Russell' for boys, and 'Millie' for girls and show how continence issues affect Russell and Millie's lives.
- Below the Belt - a practical guide for teenagers on issues relating to continence, relationships and much more...

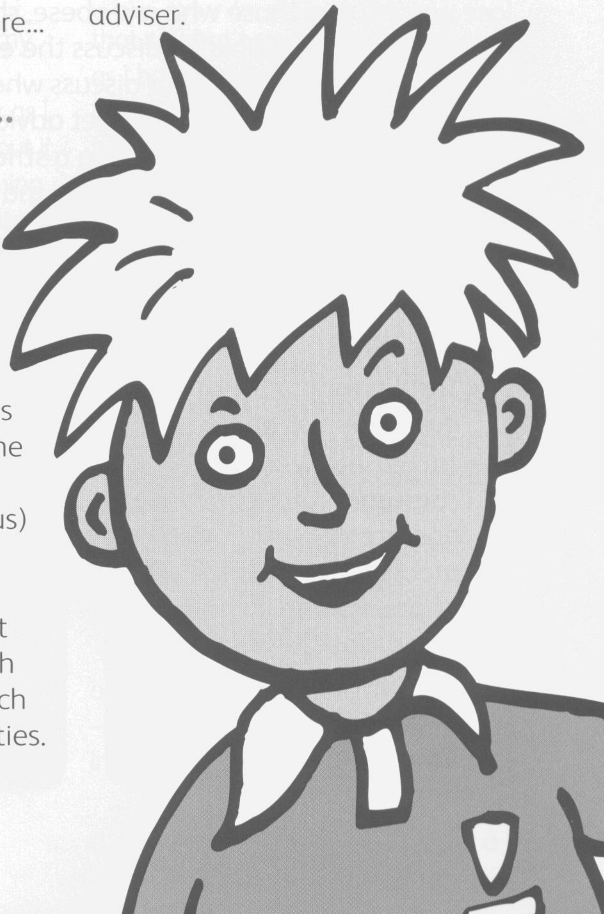
And don't forget your... Need to Go Card

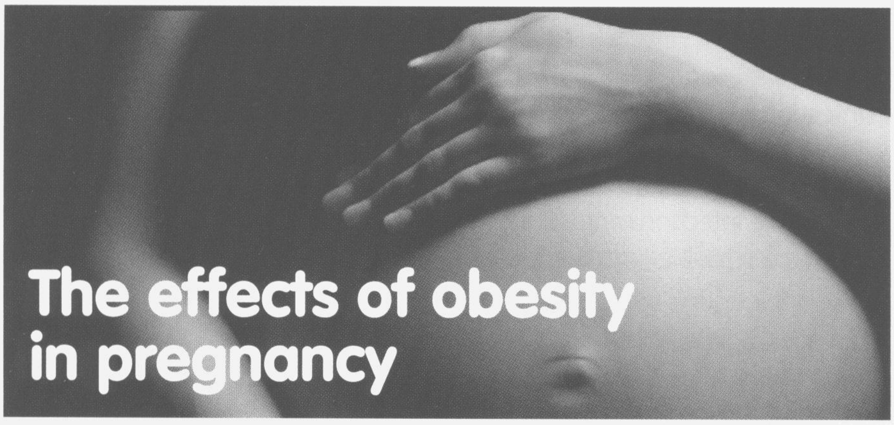
It's a free continence card launched by ASBAH to help those with spina bifida or hydrocephalus access toilet facilities more easily.

The pocket-size laminated card, entitled Need to Go, has the message "Please Help. The person holding this card has spina bifida (or hydrocephalus) and needs to use the toilet urgently".

These cards should make it easier for holders to approach staff in stores and shops which don't have public toilet facilities.

Go to: ***www.asbah.org/Spina+Bifida/continence/continenceinformation*** for continence information, or call the helpline on 0845 450 7755. Email: ***helpline@asbah.org*** - they can also put you in touch with an adviser.





The effects of obesity in pregnancy

Obesity during pregnancy can pose a risk to the health of an unborn child, research has shown.

Dr. Judith Rankin, Reader in Maternal and Perinatal Health at Newcastle University, has been involved in The Maternal Obesity and Pregnancy Outcome (MOPO) project.

She said: "There is concern about the outcome of such pregnancies. Links between obesity, diabetes and hypertension and other risks are already known."

"Studies also suggest there is an association between maternal obesity and NTDs (neural tube defects including spina bifida) and cardiac anomalies.

"As a woman's Body Mass Index increases, serum folate decreases so an overweight woman may need higher doses of folic acid than a woman of a normal weight."

Dr Rankin concluded "Action is needed now to deal with the problem of obesity in pregnancy, with the sensitivities of all involved carefully considered."

Of course, we would all like to be our ideal weight but it is not always easy to achieve. Rosemary Batchelor, ASBAH senior health adviser, suggests that women who are finding it difficult to lose weight, and those who are obese, should see their GP pre-conceptually, if possible, to discuss the effects of their extra weight on pregnancy. They can also discuss whether they need to take a higher dose of folic acid and get advice on healthy eating. But Rosemary advises against starting a strict weight loss diet during pregnancy: it is not a good idea and may harm the baby.

Possible increased risk of complications, including:

- **risk of miscarriage**
- **Insulin resistance and gestational diabetes**
- **Increased need for caesarean sections and greater risk during procedure, increased risk of pre-eclampsia and blood clotting disorders**
- **Increased blood loss during labour**
- **Wound infection**

In some cases maternal obesity has been associated with a higher risk of:

- **Increased birthweight**
- **Low Apgar scores which indicated problems with circulation and breathing**
- **Infant birth trauma**
- **Stillbirth**

Helping hands

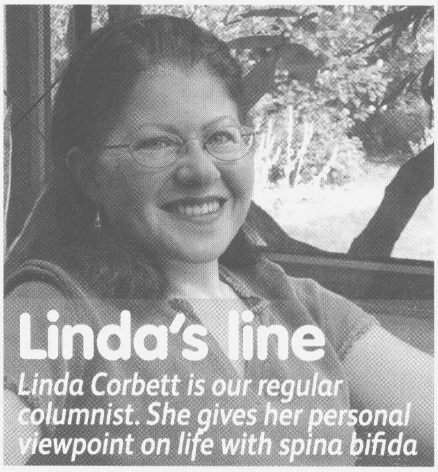
***Link* readers who have experienced a lack of understanding about how hydrocephalus can affect performance at work will be interested to hear how Daniel Machell overcame this problem.**

Daniel was forced to look for a new job when the company he had been with for seven years went into liquidation two years ago.

He found a position as a salesman in a furniture store in Colchester but the company became concerned about his performance.

Daniel told *Link*: "I have a problem with my short term memory and this was creating problems for me. If I am in the middle of doing something I can continue without any problem. But if I'm distracted in any way, the task I was originally doing just sails out of my head."

Daniel's ASBAH adviser, Val



Linda's line

Linda Corbett is our regular columnist. She gives her personal viewpoint on life with spina bifida

I have always prided myself on being able to write clear, concise, English, that makes perfect sense, and does not end up sounding like one of those amusing extracts from church magazines or letters to the council. As an example of the sort of things I mean:

make light work for Daniel

Meyer Hall, paid a visit to the store and suggested contacting the Workstep scheme which put Daniel's employer in touch with Tara Vinyard and Zsuzsi Szabo from SCOPE Employment Services, who have since been working with him.

She said: "They commissioned a psychologist to do an assessment - this recommended some support for his dyslexia/ dyspraxia type problems and he has been getting one-to-one help."

I have learnt ways to prompt my memory and if I do make an occasional mistake, my colleagues know why and are understanding.

Daniel said he had always tried to use a notepad as a memory aid but it didn't always work for him. "If my train of thought was broken, I didn't know what to write," he said. "I was given an audio notepad instead which is much better for me."

His boss, Mick Fisher, asked Val for a staff training session on hydrocephalus to help colleagues to understand why Daniel had these problems.

Val said: "Tara, Zsuzsi and I did a session with the other people who were supporting Daniel. The feedback was positive – some of his colleagues were very interested and wanted to know more."

Linda Knight, ASBAH's adviser for Lincolnshire, who is an occupational therapist, also paid Daniel a visit and spent a morning making recommendations about special seating for him.

Daniel said: "Things are so much better for me at work now. I have learnt ways to prompt my memory and if I do make an occasional mistake, my colleagues know why and are understanding.

"The support I have received from everyone has been fantastic."

"For those of you who have children and don't know it, we have a nursery downstairs"

or…

"Our kitchen floor is damp. We have two children and would like a third so please send someone round to do something about it"

So imagine my horror when I discovered (too late) that I had written something equally as daft on my recent application for Disability Living Allowance!

Having been turned down before by the DWP, this time around I enlisted the help of our excellent adviser Angela, who has a great deal of experience in this field (or possibly minefield). This is because she knows what needs to go on the form and has an objective view of what is classed as assistance. A good example is my kitchen step, which is essential for reaching the worktops and cooker as I am only 4'3" tall. I don't think about it as an aid – it is just an everyday thing that Andrew occasionally bumps into in the kitchen and the guinea pigs hide underneath to evade capture.

Similarly, Angela knows how to answer some of the more tricky areas on the form which to my way of thinking are just plain idiotic. For example "What would you like to be doing?" Well that would depend on how much money the Government wanted to give me, wouldn't it? Actually, I would quite like to be retired on my own personal Caribbean Island but I don't think DLA benefit stretches that far.

In fact, in my case, it would seem that it doesn't stretch anywhere at all as I have just been turned down again, presumably because the Government has now run out of money having shelled out for endless expense claims from our MPs, details of which are now available thanks to the Freedom of Information regulations. Perhaps I should just cut out the middle man and send my next bill for shoes to my MP? Of course it doesn't have to stop at essentials and if the Government would like to chip in towards the cost of a cleaner, gardener, chauffeur etc I would be more than happy to follow the example our MPs have set for the rest of the country.

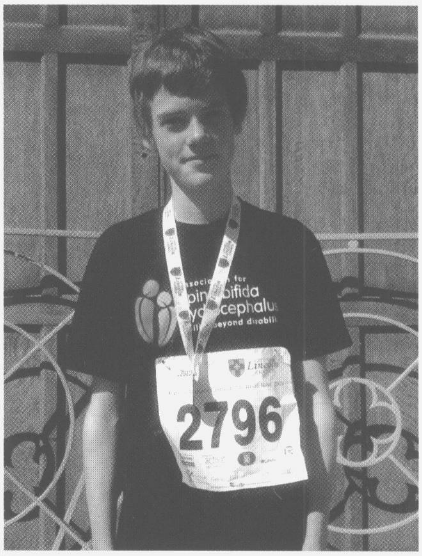
And for those still waiting to find out what I wrote on the DLA form – sorry, that is currently classified information!

Fantastic fundraisers

With all the fantastic fundraising efforts of our members it's hard to tell the full stories of each one in *Link's* pages. Instead, we are including a brief summary of the latest endeavours, with more details and photos on our website. And every issue we will focus on a different area of fundraising, letting you know how you can get involved and the support ASBAH can give to fundraisers. This time we take a look at running - from fun runs to marathons. So why not think about joining in – visit our website and click on Get Involved for more details. If you're more 'armchair' supporter than action man, please take a look at the energetic escapades at *www.asbah.org/get-involved* where you can donate online with the click of a button.

Jack's perfect 10

How long would it take you to run 10 kilometres? 15-year-old Jack McLean was aiming to dash across the finish line in an hour when he took part in the Lincoln 10k road race in March 2009.



Jack, who was diagnosed with hydrocephalus when he was four-months-old, was raising money for us by running with his mum Vicky and dad Alastair. He wanted to say thank you for the help and support ASBAH has been able to give to his mum and dad.

Jack's mum told us that the information the family got from ASBAH at the time Jack first became ill has been the biggest help. "ASBAH let us know so much about Jack's condition and answered any questions we had," she said. "It wasn't just help with the present, it was hope for the future, too."

After becoming ill again when he was 13 and undergoing a complete shunt revision, Jack decided that he wanted to raise some money for ASBAH. After signing up for the Lincoln 10k road race, Jack started to do some training runs to get used to pacing himself for the big event.

On the day, Jack was lucky with the weather and enjoyed warm, sunny conditions. He ran at a steady pace, with his parents, for most of the race, before speeding off to the finish on his own, crossing the line almost exactly on target!

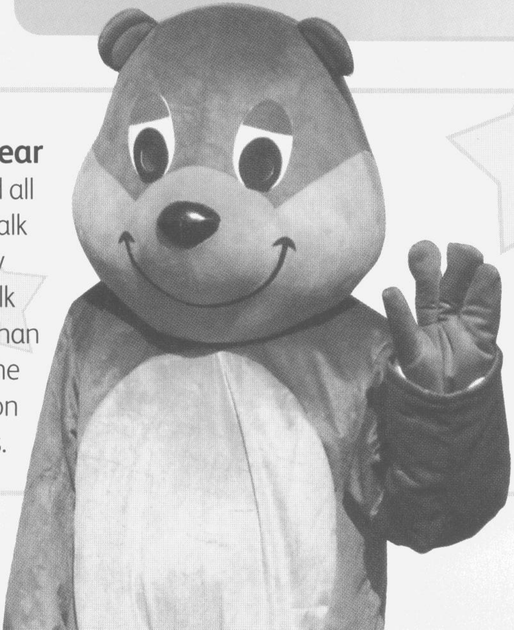
Through his Justgiving sponsorship page, Jack raised a brilliant £810 for us. Thanks, Jack, and very well done.

London Marathon

Thanks also to Claire Luscombe and John George Wright who raised £455 and £638 respectively

From Burnley to Blackburn as Benny Bear

Shaun Smith had a Benny Bear costume shipped all the way from China especially for a sponsored walk organised by his wife Dawn. Shaun was joined by 79 friends and family on the taxing 12.5 mile walk along the canal side and has so far raised more than £3,000 for ASBAH. The family chose to donate the money to us as their eight-month-old son Harrison has recently been diagnosed with hydrocephalus.



Rockin' it for ASBAH

Jed Langley and his mum Linda, from West Yorkshire, organised a charity music event at Batley Carr WMC to raise money for ASBAH. They chose us because Jed was born with spina bifida and they wanted to give something back.

Firefighter faces the heat to complete London Marathon

Enfield firefighter, Ian Rapley, should be used to facing extreme heat given his daily job tackling fires but running the marathon tests even the fittest of people.

It was around the 13- mile mark that the pain started to set in. Ian experienced stomach cramps and pain in his feet but, the crowd was fantastic and spurred Ian on. After 22.5 miles, he caught a glimpse of family and friends which gave him a boost to finish the race in an incredible four hours, 47 minutes.

Reaching the finishing line was an emotional moment. Ian said: "When I crossed the line it was an amazing feeling, it was so emotional I just burst into tears."

To date Ian has raised £1,116 to thank ASBAH for the help given to the family of his great nephew Luke who has hydrocephalus. Ian said: "I would like to say a massive thank you to everyone who sponsored me."

Persistence pays off in fundraising bid

For someone to have the tenacity to apply to do the London Marathon, six years running, in order to get a chance to compete is very special.

Crispin Flowerday, from Cambridge, did exactly this and joined the 35,000 other runners in this year's event.

Crispin chose to run for us because his sister, Leonie has spina bifida and hydrocephalus. As Leonie has grown up we have helped both her and her mum, with support and information.

Training for the day was a great challenge, and an injury in February meant he had to take nearly a month off! Given this, the fact that Crispin managed to finish the race in just over four hours is an amazing achievement.

So far Crispin has raised a fantastic £1,500 for ASBAH. He said: "I found people very generous. I have managed to raise a great amount of money by sending just one email out to my friends. Thank you to everyone who sponsored me and to those who came to support me on the day."

Running for ASBAH? We can help.

ASBAH is always delighted to give our help and support to anyone wanting to take part in a run and raise funds for us.

We will send you a fundraising pack containing all you need to get going, including sponsorship forms and guidance on how to set up your very own online donation page with justgiving.com -which makes raising money easier than ever. We'll provide a breathable ASBAH running vest that you can wear to show that you're taking part in the event for our benefit.

We're also considering a scheme for the London Marathon to refund anyone who wins a ballot entry and would like to raise money for ASBAH. Contact Ian Morley for more information ***ianm@asbah.org***

Telephone 01733 421328

GREAT MANCHESTER, NORTH AND SOUTH RUNS
'Places Available'

A great finish with a sniffle

Alex Dennis from Bristol finished the 'Run Bristol' 10k race on 10 May in an hour and 19 minutes, even though she was full of cold! She raised £320 for us through sponsorship from friends and colleagues.

Football fundraising fun in York

York postal officers raised almost £500 by competing in a charity football match. Mike Boyes, York West's delivery office manager, organised the event after colleague Lynne Cammidge asked if they would raise money in aid of ASBAH as her three-year-old granddaughter has hydrocephalus.

***You can read more about these fantastic fundraisers by visiting** www.asbah.org/get-involved*

Why fundraisers do it for ASBAH

"We wanted to say thank you for the help and support ASBAH's been able to give to our mum and dad. It wasn't just help with the present, it was hope for the future, too."

"ASBAH has been lovely, and really helpful when things have not been so good."

"I'd just like to thank ASBAH for all of the hard work that you do. I'm sure that the people you're helping must feel truly thankful for your efforts."

"I was born with spina bifida and I wanted to give something back after all ASBAH's help."

"My great nephew has hydrocephalus and ASBAH has helped him and his parents, throughout his life."

Cambridge Quilters' raffle

The Cambridge Quilters group is hoping to tuck away some money for ASBAH with the raffle of a specially made quilt.

The group will be drawing the raffle at its exhibition at Grantchester Village Hall, near Cambridge, at 3.30pm on Sunday 6 September.

The Quilt Show, which runs from Friday 4 - Sunday 6 September, is open to the public, who can enjoy tea and cakes with the group between 10am - 5pm, or 4pm on Sunday.

The ladies of Cambridge Quilters nominated us as one of their supported charities in recognition of the help that we've been able to give to member Moira Neal, whose daughter Claire has a shunt. "ASBAH has been lovely, and really helpful when things have not been so good," said Moira.

If you would like to have a chance of winning the beautiful quilt, you can buy raffle tickets costing £1 each by calling Harriet Wilson on 01223 870830.

Sorry, Robin!

In the last issue of *Link*, we told you about the fantastic fundraising efforts of Robin Pettit. We'd like to apologise to Robin for calling him Robert in the article and hope that we can tell you more about his great work for us in the future… with the right name!

Strictly come fundraising

A group of school children put their best feet forward to take part in a dance competition inspired by the popularity of ballroom dancing on TV. The event was organised by Anastasia Castiglione, founder of the Castellano School of Spanish Dance. Anastasia has hydrocephalus and she saw an opportunity to combine her love of dance with raising money for ASBAH.

On the run

Louise Metson recently fulfilled a life long ambition when she ran in the London Marathon, raising £1,800 for ASBAH in the process. Louise was running in memory of her baby nephew, Luke.

STAR supporter

Shaun Gillam

Completing a challenge like the Great South Run is an achievement that many people would only expect to fulfil once in a lifetime. Our Star Supporter, Shaun Gillam, has completed three momentous challenges in aid of ASBAH to date, and he has more planned in the future.

Shaun, from Hedge End in Hampshire, was inspired to support us after his daughter, Angel, was born with hydrocephalus back in 2006. Shaun told *Link* that the Gillam family has received a great deal of support and information from ASBAH throughout the last few years, and that they make use of a number of the services available. Shaun said: “Angel is doing very well and is a happy and active little girl.”

Back in July 2007 Shaun completed a gruelling bike ride from John O’Groats to Lands End. Shaun roped in his good friend Rob Wallis and the pair managed to complete the 951-mile journey in just 16 days.

As you can imagine, a challenge like this requires an awful lot of training and preparation. Shaun’s training began about six months before the event itself and consisted of cycling around 150 miles per week, over the course of three or four days.

ASBAH would like to congratulate Shaun on all of his fantastic achievements. We look forward to hearing more about his future fundraising plans.

Even with all of this training Shaun couldn’t prepare for some of the challenges that they had to overcome during the course of the 16 days. These included no less than three punctures, and trying to read a map whilst cycling. In total this event raised a super £2,800.

Next on the list was the Great South Run in October 2008. Shaun teamed up with his brother Richard to run this race raising £365.00.

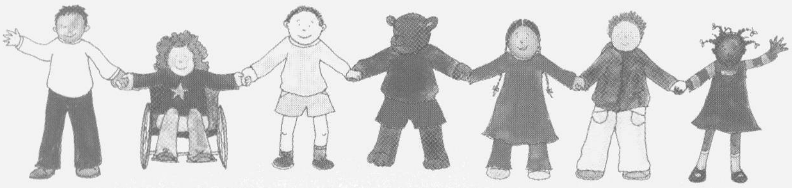
Most recently Shaun tackled the Three Peaks Challenge. This event is notoriously difficult and involves climbing the three highest peaks in the UK: Ben Nevis in Scotland, Scafell Pike in England and Snowdon in Wales, and all in just 24 hours!

Shaun was joined by six friends who were also up for this challenge: Rob Wallis, Mark Wright, Ryan Cox, Steven Ashton, Noel Haines and Ian Knott. They were blessed with good weather as the sun shone down on them. The team completed the challenge in 25 hours which we think is a wonderful achievement. Funds raised for this event currently stand at £1,100 but this amount is set to rise.

Shaun has got a few months to rest and recuperate from this latest challenge before he competes in the Great South Run again next October.

All together Shaun and his supporters have raised a whopping £3,900 for ASBAH and no doubt there will be much more to come as Shaun shows no signs of slowing down.

Codman - Working in partnership with ASBAH



Benny Bear reaches out to Grace

The popular Benny Bear books and posters have introduced many people to ASBAH who might otherwise have been unaware of how we can help.

The Benny Bear materials are sponsored by Codman – working in partnership with ASBAH to raise awareness and understanding of hydrocephalus.

Mother Louise Colver and husband Gary spotted a Benny Bear poster in the hospital where their young daughter Grace was having a shunt fitted.

They made a note of the website address and looked ASBAH up as soon as they could.

Louise said: “My brother ordered the set of Benny Bear books for us and Grace has already started looking at them.

“Although she is too young to understand the words, she enjoys the pictures and I’m sure they’re the reason why ‘bear’ was one of her first words!”

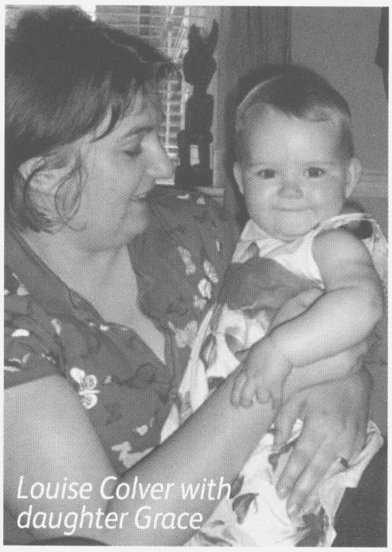
Grace’s story

“Grace was diagnosed with meningitis at just two weeks old; she had a very rare form of meningitis called citrobacter which caused huge absesses to form in her brain.

This was a very scary time for all of us, but after six weeks in hospital on IV antibiotics Grace was sent home.

She had to return to hospital a week later for an MRI; we didn’t realise at the time but one of the things they were looking for was evidence of hydrocephalus.

At the same time as her scans were being reviewed at Nottingham hospital we noticed that Grace’s head was growing rapidly and called our health visitor to check her head circumference.



Louise Colver with daughter Grace

After speaking to specialists, at Nottingham, we were asked to take Grace in the next day so that she could be assessed with a view to having a ventriculo-peritoneal shunt fitted.

At that point I thought that a shunt was a temporary device to drain the fluid from her brain, I didn’t realise that Grace’s hydrocephalus was likely to be a lifelong condition.

Things were explained in more detail at the hospital; one of the nurses showed us an outline of a child with a shunt attached so that we could see what one looked like and where it would go.

Leaving Grace in the preparation room for her operation was very hard but we could stay with her until she was asleep. When the operation was over a nurse took us down to recovery and I remember running the last few steps because I recognised her cry.

The worst point in Grace's journey was probably when, nine days after having her first shunt inserted, she became ill through a shunt infection.

The shunt had to be removed and a temporary drain inserted whilst the infection was treated. Thankfully within a week the infection had completely cleared and a second shunt was inserted.

One more blip; we spent Grace's first Christmas in hospital after another suspected shunt infection but it turned out to be a normal childhood virus and we came home on Boxing Day, just as Grace was about to turn four-months-old.

Grace is now 19-months-old and brings such happiness to everyone in her life. Although she was a little bit late achieving head control she is now developing really well and achieving all her milestones.

She is the friendliest, most sociable little girl I've ever known. We couldn't be more proud of her!

We are also very thankful to all the hospital staff who have helped Grace and we're very glad that ASBAH exists to support us along the way if we need it."

Louise Colver, Grace's mother

KEY POINT

- Benny Bear introduces family to ASBAH
- Grace had meningitis which led to hydrocephalus

Hannah helps young medics

A young *Link* reader has been helping medical students learn more about hydrocephalus.


Hannah Meadway

Hannah Meadway, 12, who has a VP shunt, was asked by her paediatric consultant at Hull York Medical School (HYMS) if she would volunteer to be a 'patient' as part of the students' year 4 exams.

The consultant said that Hannah, from Sproatley in East Yorkshire, would give the young medics valuable experience as they rarely saw patients with hydrocephalus.

After discussion with her parents, Paul and Joanne, and twin sister Beth, Hannah agreed to take part.

Paul said: "Two medical students examined Hannah and they were assessed by three doctors.

"Neither of the students diagnosed her condition, although one did come close. But neither of them realised she had a shunt."

Paul added that the family thought the experience was really worthwhile, raising awareness at a key level.

Paul added that the family thought the experience was really worthwhile, raising awareness at a key level.

"We would encourage anyone with hydrocephalus to volunteer as a 'patient' for medical exams," he said.

"All it took for us was a few hours out of our day. It is confidential and travelling expenses – plus tea and biscuits – are supplied. Hannah thought the experience was so worthwhile that she has volunteered to be a 'patient' again on 10 July.

"I'm sure any local medical school would welcome contact from *Link* readers to give its students valuable experience."

hydrocephalus action

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

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

Coloplast - Working in partnership with ASBAH

Compact catheter provides a solution

Evie with mother Caroline

Heavy snow nearly deterred Caroline Toombes from attending a Coloplast market research meeting... but both she and daughter Evie are delighted she made the effort to get there.

Caroline got chatting to another mother who trains children how to self catheterise and she told her about the SpeediCath Compact catheter. Caroline returned home with some product samples assuming it would take weeks to persuade her seven-year-old daughter to use the new product.

She said: "We talked about it and to my surprise, Evie was very keen. Instead of taking weeks to build up to it she tried almost immediately and managed to insert it herself the first time. with me holding a mirror for her.

"Of course there have been considerable ups and downs since and sometimes she loses confidence, but I feel very positive because we have started on the path towards independence, which I certainly didn't expect at this stage.

"I encourage Evie to self-catheterise twice a day, but I never push her, and at weekends, or if over tired, she takes a break."

Caroline explained that the previous system of catheterisation Evie had used was tricky – as water had to be added and the catheter was slippery to hold.

"Evie was first catheterised at the age of three-and-a-half, and it was a nightmare because it could take up to half an hour, every two hours. My son was 18 months old at the time so he needed lots of attention too."

Evie was born with tethered cord, although this wasn't diagnosed until she was one, at a routine hospital check up.

A doctor who was examining a mark on her foot looked at what appeared to be a small birthmark at the base of her spine, thought it might be an indication of tethered cord syndrome. An MRI scan confirmed his suspicions (lipomylomeninigocele) and Evie was operated on two months later.

Caroline said: "Thankfully Evie is mobile but nerve damage affected her bladder which means she needs to use a catheter.

"Now Evie is more confident and I finally feel like there is light at the end of the tunnel. I know it is partly due to Evie maturing with age, but Speedicath Compact has had a very positive impact on the whole family's life.

"It has also changed our outlook on holidays and days out, as the SpeediCath Compact is easy to use."

Catheterising a young child for the first few months can be a tough challenge for both the parents and child.

"We tried everything but what worked for Evie was a personal CD player with her favourite Kylie album on. We called it her 'magic music'. Very quickly it took her mind off what was happening and she relaxed. It was only a small thing but gave us a tool to make the whole process so much easier.

"Evie's school carer has been hugely instrumental in assisting her progress and worked closely with the family to build on the initial achievement of self catheterisation."

If you have any questions relating to the SpeediCath Compact catheter, or would like to receive a sample to try, then please contact Charter Healthcare on 0800 220 622.

Thumbs up for new activity book

If you have a child aged 5-8 years then ASBAH's new continence activity book could help them take control of their continence routine.

The colourful eight-page 'My Big B&B Book' will help children learn more about how to keep their bowel and bladder ('B&B') healthy

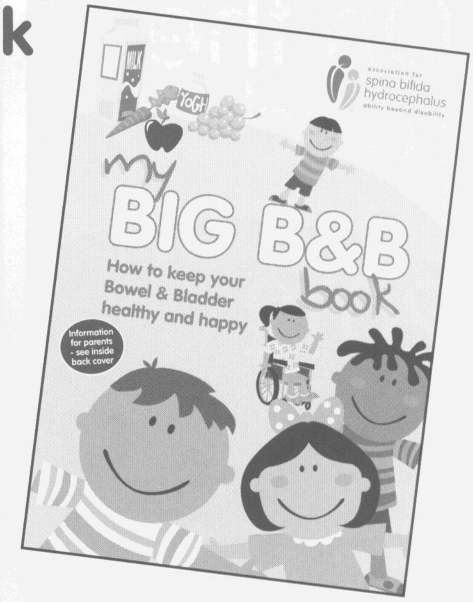
It has a section where they can fill in details about their own continence routine, word searches and a multi-choice quiz section, all aimed at helping them understand the importance of their continence management.

Easy-to-understand advice on diet is included and at the back of the book are four daily routine charts for the children to complete.

ASBAH's continence adviser Gill Yaz believes personal continence management is an area which parents and carers should address as early as possible.

"By encouraging young children to become involved from an early age, personal continence care becomes part of their life so they get used to the idea of taking complete control in their teen years," she said.

The Big B&B Book has been sponsored by Coloplast and is available free (p&p is £2.00) through the ASBAH Helpline. Call 0845 450 7755.



Review

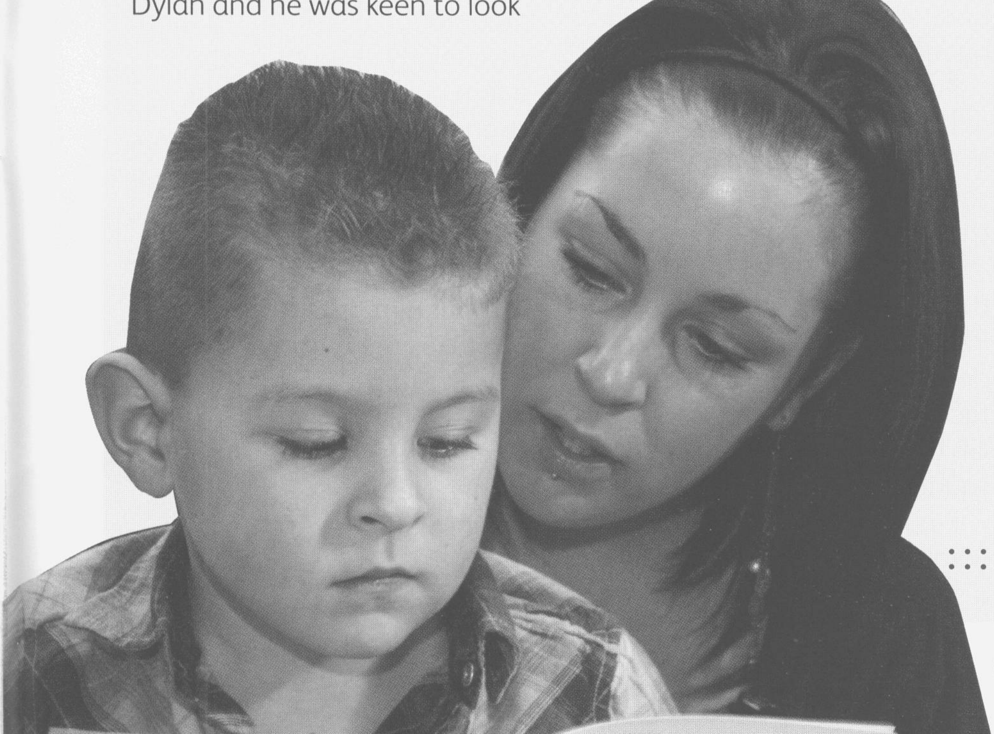
ASBAH sent a copy of My Big B&B Book to mother Sonia Reains, whose young son Dylan, six, has spina bifida and hydrocephalus.

Sonia, who features in the new folic acid film clip on the ASBAH website, said: "Dylan loved the book and I thought it was really good too. It was colourful and attractive to Dylan and he was keen to look at it and show it to people. He thought it was great because it was about things he could relate to.

"I felt it explained things really well and helps to reinforce what I say. It's a fun way for him to learn more about bowel and bladder issues and to realise that other children have continence issues too.

"I think it is very important for parents to emphasise the importance of good continence routines as early as possible. The earlier they start the easier it is for the child."

"Dylan knew from very early on that he needed to eat well and keep clean. He understands that if he does not keep a good routine he is more likely to soil."



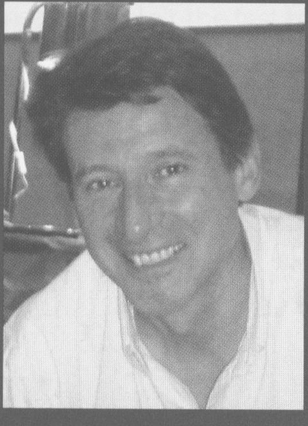
Dylan and Sonia Reains

On the road to London 2012

Sebastian Coe, Chair of the London Organising Committee of the Olympic Games and Paralympic Games (LOCOG), said "I had the pleasure of being in Beijing for the Paralympic Games last year and watched with admiration as Paralympics GB athletes won 102 medals – 42 of them gold – and finished second on the medal table behind only the hosts, China.

"It is exciting to think that London in 2012 is the next port of call for the ever-developing Paralympic Games, a place where Britain's Paralympic athletes can once more show their extraordinary talent and inspire future generations to take up sport.

"The BT Paralympic World Cup, held in Manchester in May, was a significant stepping stone for many athletes aiming to compete in London and beyond."



Pippa targets 2012

Pippa Britton

It was a chance remark, 19 years ago, that set archery star Pippa Britton on the road to the winner's podium, when husband Nigel suggested she went out once a week to socialise.

She joined an archery club and, after a few years, decided to compete seriously. For the past nine years she has been a strong player in the GB squad and has a clutch of world championship gold, silver and bronze medals for her efforts.

Pippa, who has spina bifida, was delighted to secure a place in GB's 11-strong Beijing archery squad and said: "It was a huge thrill.

"I'm very privileged to be at the peak of my sporting career in my 40's. Age isn't really a defining factor in our sport. In fact at Beijing we had the oldest GB competitor in the archery squad – he was 63!"

Pippa described the Beijing Paralympics – where she put in a solid performance to finish fifth - as "the most amazing experience".

She said: "It's an incredibly emotional experience: the pride at the opening ceremony, the thrill of representing your country and the sheer adrenalin of competing.

"There's also a wonderful feeling of community because the athletes live together, quite isolated from the outside world."

Beijing was the first Paralympics allowing the use of a compound bow, which Pippa uses.

Pippa developed curvature of the spine (scoliosis) at the age of 12 and underwent major surgery in 2006. With the support of coach, Tim Hazell, she returned to full fitness to secure three world records.

Now she is training for 2012 but still suffers a great deal of pain which interferes with her training schedule.

"Some weeks it's very frustrating because I can only manage around 30 minutes training, and my coach settles for that," she explained.

Pippa's physical training consists of shooting and she swims for general fitness. Her preparation also includes sports psychology sessions as she's a firm believer that mental strength plays a vital role in achieving success.

She has great support from husband Nigel. "I don't think I could have achieved so much without him," she told *Link*. "He takes me to tournaments, runs the house when I'm away, pays the bills and often cooks my dinner. He's an absolute treasure."

Louise Hunt

Louise aims to net gold

Wheelchair tennis star Louise Hunt is currently ranked 59 in the world in the women's category and is number five in the junior world ranking.

Louise combines studies on her B Tech Sports Science college course with travelling the world to compete in international tournaments.

Here she tells her story...

"I was born with spina bifida which wasn't picked up during my mum's pregnancy, so when I was born it was a bit of a shock to everyone.

My parents were told I would be lucky to survive, and that if I did I would never even sit up. Well, shows how much they knew because here I am, 17 years later, achieving things the doctors could have never imagined.

A lot of credit must go to my parents for all the belief, dedication and encouragement they've given me.

Today, my life revolves around sport – namely wheelchair tennis – and I travel all over the world, including places like Brazil, Italy and Israel, competing in international tournaments every year.

I currently play in 10-15 tournaments a year, which keeps me away from home for around 3-4 months of the year. I do get a bit homesick. I train on average 5-6 days a week, exhausting, but so worth it.

My ultimate aim is to compete in the 2012 London Paralympics and win a medal for Great Britain. I went to the Beijing Paralympics with a 2012 wheelchair tennis squad to gain experience for London 2012.

This squad was picked by the Great Britain Tennis Federation and is for the athletes they believe can win medals in four years time.

My sport has brought me so many opportunities and experiences and has also given me confidence, a great social life and a thirst for life.

I have met many celebrities and members of the royal family, including the Queen, who I also played in front of at the opening of the National Tennis Centre.

I have had several TV appearances, one of which was on Blue Peter which was so cool; I had my own dressing room and everything.

I think it's so important to believe in yourself no matter how able or disabled you are. I wish all disabled people would try to get involved in things, whether it is in sport, music or even just simply socialising and integrating more.

You cannot change who you are but you can control what you do with your life.

I can't believe how lucky I am but I could not have done it without my friends and family."

Swimmer Sam's going for gold

Five years ago, we ran a special feature in *Link* about a10-year-old swimming star who won four gold medals at the Junior Nationals.

Recently, his mum Sharon told us that Sam, now 15, is aiming to swim for Great Britain in 2012.

Sam is on the British Swimming World Class Pathway Programme which identifies athletes with the potential of achieving a place at the 2012 games.

He trains with the Mid Beds Swim Squad seven times a week and fits two land training sessions into his packed schedule.

Sam has represented Great Britain twice at the Danish Open, bringing home gold, silver and bronze medals. He also holds four British and two European Records.

Sam qualified last year for the Beijing Paralympic Trials in Sheffield and was swimming alongside many of the Beijing medallists.

Mum Sharon said: "Sam didn't start swimming until the age of six when we took him for one-to-one swimming lessons, mainly to keep him active and to overcome his fear of water."

Sam, who has spina bifida and uses a wheelchair, attends a main stream high school near the family's Luton home, where he is achieving good grades.

His parents Sharon and Rob have treated Sam the same as his brother and sister, encouraging him to try new things and face new challenges.

Sport for all

There's no doubt of the huge benefits of sport and exercise for everyone, able bodied or disabled.

Regular exercise improves your health and fitness levels, brings a sense of well being and achievement ... and helps you to get out and about in the community.

The athletes featured in *Link* are an inspiration to us all, but very few of us are able to achieve that level of success.

But every form of exercise is good for the mind and body, and even if you are overweight and out of shape, once you find a sport you enjoy, improvements are quickly seen.

Today there are more opportunities than ever for disabled people to access an organised sport and the London 2012 Paralympics is helping to promote accessible sport across the nation.

Enjoying sport if you have hydrocephalus

If you have a shunt you do have to be careful about what activities you take part in, but shunts are difficult to break and most sports – with few exceptions – should be encouraged.

If in doubt, ask ASBAH or your neurosurgeon for advice.

For full guidance, for adults and children with hydrocephalus, read the Enjoying Sport article on on our website at: ***www.asbah.org/ASBAH+Community/livingwithhydrocephalus/enjoyingsport***

This article also appeared on page 20 of *Link* 216. If you do not have access to the internet or would like a printed copy of the feature, contact the helpline on 0845 450 7755

The English Federation of Disability Sport (EFDS) is the national body responsible for developing sport for disabled people in England. It works closely with several national disability sports organisations.

One of the aims of EFDS is to raise public awareness of sport for disabled people. EFDS also develops education programmes to increase the number of coaches working with disabled people.

For more information go to: ***www.efds.co.uk*** or contact the EFDS on 0161 247 5294

The Inclusive Fitness Initiative (IFI) is working to ensure that disabled people gain equal access to gym-based physical activity. It has built up a network of over 180 inclusive facilities across England.

The Inclusive Fitness Mark (IFI Mark) quality mark accreditation scheme awards the IFI mark to facilities across the whole of the United Kingdom if they fulfil certain conditions.

DisabledSport.co.uk is trying to build a useful resource for anyone who wishes to know about venues near them which offer good accessibility for wheelchairs, and also changing facilities which are adapted for different disabilities.

Go to: ***www.disabledsport.co.uk***

Other useful contacts:

Disability Sports NI (DSNI) – Northern Ireland's main disability sports organisation.
www.dsni.co.uk
Tel: 02890 387 062

WheelPower (formerly known as The British Wheelchair Sports Foundation) is the national organisation for British wheelchair sport.
www.wheelpower.org.uk
Tel: 01296 395 995

Riding For The Disabled Association
www.rda.org.uk
Tel: 08456 581 082

Your local council – its leisure or social services department should have details about facilities, sports clubs and other initiatives in your area.

Right: Wendy Letts with Vienna and husband Peter

After nearly five long years of hoping for a baby, Wendy and Peter Letts are now living their dream.

Wendy Letts

Daughter Vienna made her appearance last November, four weeks ahead of schedule, and although she was small, weighing in at a petite 3lb 6oz, she was perfect.

The couple, from Oldbury in the West Midlands, married five years ago and always hoped to start a family.

Wendy, who has spina bifida, and Peter, who uses a wheelchair following a spinal injury at the age of 21, didn't give up hope and were delighted to discover, in February 2008, that Wendy was pregnant.

Wendy, who is able to walk with the aid of crutches, said: "I had a good pregnancy and worked all the way through, keeping on my feet apart from at work. I work in the office at a van depot and my boss was worried for me when I had to go into the yard and asked me to use my wheelchair.

"Peter and I agreed early on that I wouldn't have any of the tests apart from scans," she added. "Whatever will be will be, was our motto.

"Yes I was born with spina bifida but I've grown up to lead a normal life. We felt that if our child was born with a disability we would instil the philosophy of 'getting on with life' into them too."

Wendy went into labour four weeks before her due date and although she planned to have a natural birth, the baby was in distress so she had an emergency caesarean.

Baby Vienna was healthy but spent two weeks in the neonatal unit because she was so small. Wendy also needed a three-week stay in hospital after suffering internal bleeding and blood clotting problems.

Back home things settled into a comfortable routine and the family life Peter and Wendy had always dreamed of.

"The only problem I have is getting Vienna up and down the stairs," Wendy said. "We have a stair lift and when Vienna was tiny I would slip her into a papoose to go upstairs.

"Now she's bigger and wrigglier I can't manage because my balance without crutches is poor, so I have to leave that to Peter for the moment.

"We also have a pushchair which attaches to the front of my wheelchair so I can get out and about. Apparently these pushchairs aren't made any longer and we struggled to find one, which is incredible because it is so useful."

Wendy plans to return to work in August. She added: "That way one of us will be with Vienna most of the time and our families are close by if we need any help."

News from ASBAH managers around the country

Eastern Region held another successful forum meeting in April where local ASBAH associations came together to swap news, views and ideas.

I'm pleased to report that funding from Northamptonshire County Council and Lincolnshire County Council have been negotiated for 2009/10.

One of our regional advisers, Colette Torrance and Helpline manager Linda Lewis manned ASBAH's stand at the Primary Care Exhibition, in May, where a lot of interest was shown in our poster on folic acid. Over 250 health professionals visited the stand over the two days of the show.

The next forum meeting will be addressed by ASBAH's Chief Executive, Jackie Bland.

Dave Isom, Regional Manager

Northern Ireland held a workshop with senior representatives of the five education and library boards (ELB), earlier this year. We are working with representatives of the ELB regional strategy group and are the first voluntary organisation to have this level of contact. It provides a strong connection into the education system.

We have held three information sessions for 10-14-year-olds, 15-17-year-olds and 18+. We also ran information sessions for professional social care staff

Jackie Bland, ASBAH's Chief Executive, visited NI in April and met all staff and representatives of the NI Association.

Cathy McKillop,
Regional Manager

Northern Region. April saw Northern Region manning a stand at the SEN Fair in Grimsby. It had many visitors and was good networking for the staff that attended. We will be present at further events, including: Disability Awareness Day in Warrington on12 July and Kidz Up North, on 26 November and would be delighted to see any *Link* readers attending these events.

Joan Pheasant,
Northern Regional Manager.

South East Region. The region had a stand at Kidz South in Reading in June.

Sharon Saville, one of or area advisers, has nearly completed her Level 3 NVQ in advice work. This was funded by Train to Gain - a Government-funded agency.

The region is changing its name to London and the South, to better reflect the area we cover.

Jo Francis, Manager,
London and the South

Wales. The Wales Office closed on 14th April after nine years. Bryn Roberts, North Wales Adviser, is working from a local County Voluntary Services Office and I will be working part-time from home, until my retirement as Wales Regional Manager, on 30 September.

The Wales Team, Trustees and members of Local Associations welcomed Jackie Bland, ASBAH CEO, to Wales in April to celebrate the work done so far, and to input into planning for the future of ASBAH in Wales.

Elin Ifan,
Wales Regional Manager

Midlands and South West

Geraldine Long and Jenny Green (area advisers in the Midlands) were involved in manning the ASBAH stand at Naidex, see page 7.

At the beginning of June, Ann Gillard (adviser for Bristol and Somerset) and Margaret Stanton (adviser for South EastWales) received a royal visit at ASBAH's stand at the Mobility Roadshow from our Patron, HRH The Duchess of Gloucester, when she toured the event.

Ann Gillard and Margaret Stanton meet HRH The Duchess of Gloucester

Diary dates

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

Dunstable Support Group

For people with spina bifida and/or hydrocephalus and their carers.
Meets: 1–3pm, usually on the second Monday of each month.
Where: Disability Resource Centre, Poynters Road. Dunstable.
Dates for 2009:
13 July 14 Sept 12 Oct
Please come whenever you can. While there is no crèche, young children are always welcome.
Contact: Valerie Bottoms on 01582 757745

Suffolk / Norfolk Spina Bifida / Hydrocephalus Support Group

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

Where: Roydon Village Hall,
High Road, Roydon,
Nr Diss, Norfolk.

For further details please contact Margaret & Alan Twyford on 01728 860916 or by email *twyfords@aandmtwyford.plus.com*

Northern Region: York Drop-in 2009

Where: Low Moor Community Centre, Bray Road, Fulford, York YO10 4JG.
When: Second Wednesday each month:
11 August (TBC)
9 September
Time: 10.15am – 12 noon.
For further information please contact the Northern Region office on 0113 255 6767
or email *nro@asbah.org*

ASBAH AGM 2009

Date: Saturday 26 September 2009
For more details please contact Lyn Rylance at ASBAH by calling 01733 421356
or email *lynr@asbah.org*

Eastern Region Forum

Date: Saturday 17 October 2009
For further details please ring 01733 421309.

Please contact the editor (Link@asbah.org) with dates of your events for the next issue of Link by Friday 14 August 2009.

Regional contacts

ASBAH East
42 Park Road
Peterborough PE1 2UQ
Tel: 01733 421309
Fax: 01733 555985
Email: *ero@asbah.org*

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

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

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

ASBAH N. Ireland
PO Box 132
Cushendall
Belfast BT44 0WA
Tel: 0845 450 7755
Email: *niro@asbah.org*

For details of Local Associations contact your regional office or ASBAH Helpline or visit www.asbah.org

Holiday lets

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

ISLE OF WIGHT ASBAH - HOLIDAY BUNGALOW

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

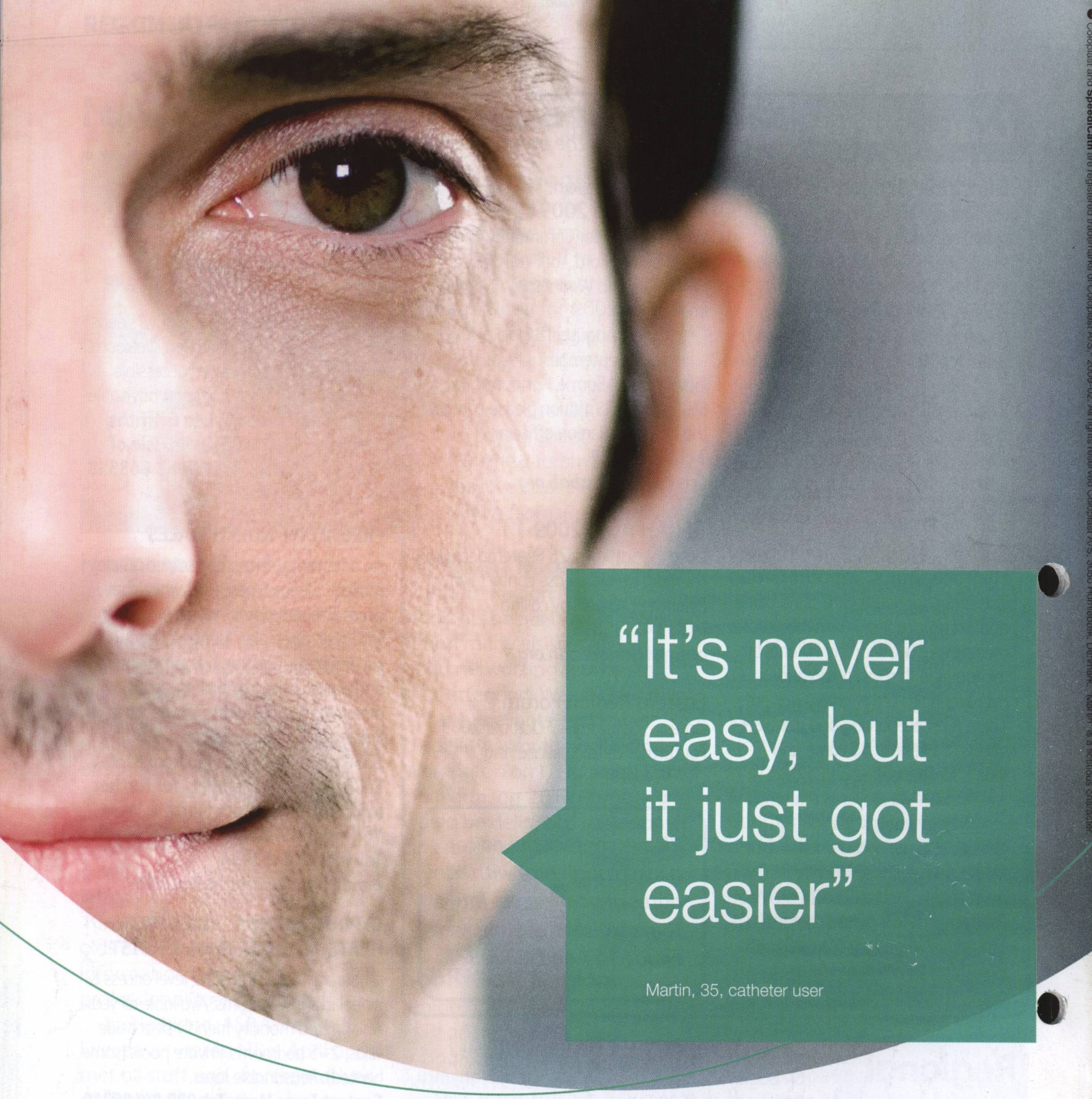
PRESTATYN, NORTH WALES

An adapted caravan for disabled holiday makers. Sleeps 6 people (2 wheelchair accessible bedrooms), wheel-in shower with seat, open plan lounge, dining, kitchen area. Caravan has ramp access and is overlooking a children's play area in a site adjacent to the beach at Prestatyn. Costs are between £130-£350 pw for members and from £150-£425 pw for non-members; **for further information contact North & West Yorkshire ASBAH, c/o ASBAH North Tel. 07989 2453994
e-mail** *nandwyasbah@aol.com*

CYPRUS, PAPHOS - VILLA WITH HEATED INDOOR POOL & HOIST

4 bedroom Villa Ampelitis, level access & wheel-in shower rooms. Available all year. Also limited mobility friendly beachside villas, 2 - 5 bedrooms. Private pools (some heated). Reasonable rates.
**Contact Irene Hare. Tel: 020-84406219
Email:** *irene@sundancevillas.co.uk*
www.sundancevillas.co.uk

ASBAH Helpline
0845 450 7755


"It's never easy, but it just got easier"
Martin, 35, catheter user