WINTER 2004 ISSUE 207 80p

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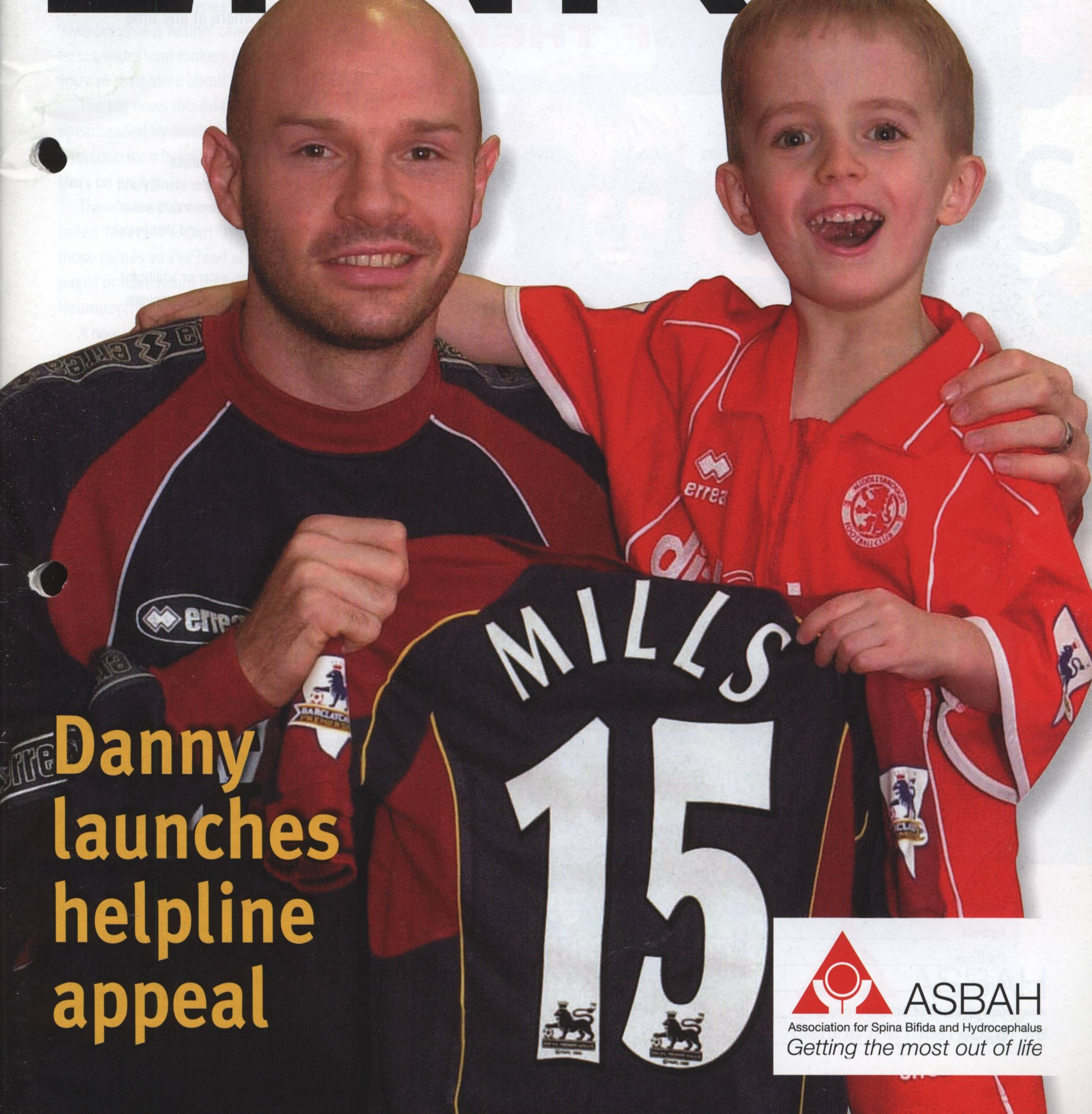
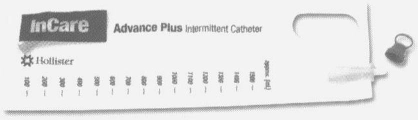
LINK

The magazine for people with hydrocephalus and spina bifida



Danny launches helpline appeal

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


InCare
Advance Plus Intermittent Catheter
Hollister

Peter Farrall writes

Yes, this is *Link* – the new look *Link*. Over the last few editions we've been improving the content. The time had come to look at the style, so that *Link* would be both a triumph of both content and style!

The new look also reflects the advances ASBAH has made in the last few years as a modern organisation whose number one concern is you. ASBAH is now more proactive at campaigning on your behalf. Our EastEnders campaign (News, p 4) is an example of this.

In fact in 2004 we'll be heightening hydrocephalus awareness through the new 'Hydrocephalus Action' campaign. We're joining forces with shunt makers Codman to do this, and you can read more about Codman on pp18-19.

The big news this edition is our new appeal spearheaded by footballer Danny Mills to raise £300,000 for a helpline for ASBAH. Read his story on pp 8-9.

There's another new feature in this issue. It's called 'Meet the expert' and aims to bring to life those names you've read about in our medical pages or have heard on the hospital circuit. Neuropsychologist Jo Iddon is our first subject.

A new year. A new *Link*. Go for it. Tell us what you think!!

Best wishes,
Peter

Peter Farrall
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(Marketing and Communications)
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Patron:
HRH The Duchess of Gloucester GCVO
President: Jeffrey Tate CBE

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

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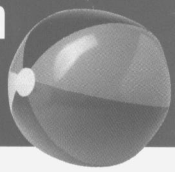

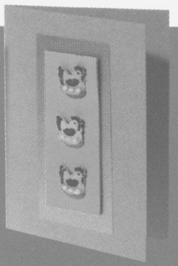

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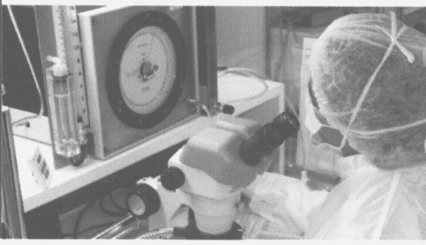

EastEnders tackles hydrocephalus

(see p 4)

Disability Discrimination Act and Schools

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

Autumn hydrocephalus campaign reaches millions

A first rate chance to promote normal pressure hydrocephalus came ASBAH's way in the autumn when Nana Moon from BBC's EastEnders was revealed to have the condition.

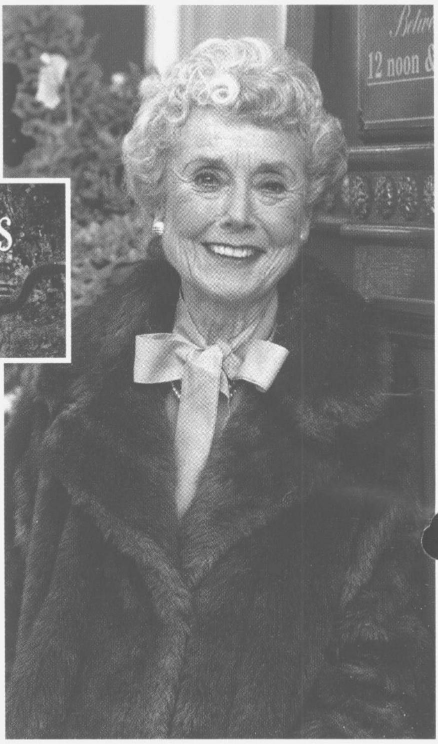
Working closely with the BBC, ASBAH capitalised on the story by alerting the media to this particular storyline and explaining what exactly normal pressure hydrocephalus (NPH) is. Other messages ASBAH wanted to get across were that NPH can be confused with dementia; that, unlike dementia, it can be treated (with a shunt operation); and that people suffering from hydrocephalus can lead a normal life if treated correctly.

The campaign involved the preparation of an initial briefing note for newsdesks to raise the issue; a follow-up press release was then sent out to coincide with the week in early November when Nana, played by Hilda Braid, was told that she had NPH. Case studies were then used to illustrate both the practical advantages and the success of a shunt operation.

The re-launch of the website (see p 13) was timed to coincide with the media campaign and dedicated information pages were prepared to mirror the media activity. A link to the BBC website was also set up, which in turn had a page on NPH supplied by ASBAH.

And the result? There was national newspaper exposure to more than four million people, as well as coverage on some key BBC local radio stations. All in all, nearly six million people learned about NPH though the campaign.

For more information on NPH see p22.



Nana Moon

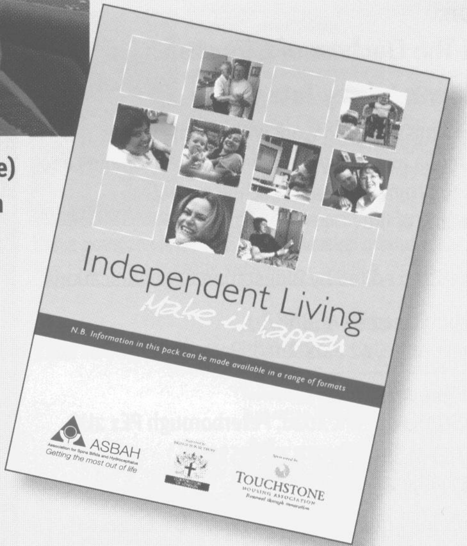
The Living in London Forum

Touchstone Housing Association Managing Director Stewart Fergusson (centre) after presenting Mark Simpson (left) and Andrew Hoey from Birmingham each with a new Independent Living Pack.

Touchstone, a member of the Keynote Group, has sponsored the publication of ASBAH's new guide, which was written by the Living in London Forum.

The whole project has been possible thanks to generous funding by the Bridge House Trust.

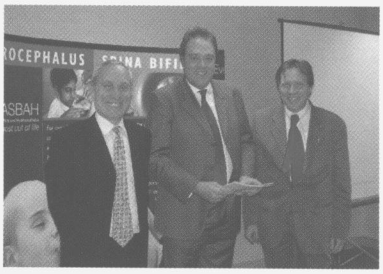
The pack, which comes in a handy loose leaf binder, deals with preparation for independent living, where to live, the support needed, housing options and the advantage of direct payments for assistance. It also has a self-help questionnaire about daily living.



The pack is available free of charge (however, donations are warmly welcomed!), except for p+p at £1.50, from ASBAH's information section. Email them at: info@asbah.org or call 01733 555 988.

(left to right)
1. Bo Hjelt (Sweden)
2. Runa Schoyen (Norway)
3. Eli Skattebu (Norway)
4. Trevor Capps (Australia)
5. Andrew Russell (UK)
6. Teije Dijk (The Netherlands)
7. Teresa Cole (UK)
8. Tinne Lotte (Belgium)
9. Pierre Mertens (Belgium)
10. Els De Clercq (Belgium)
11. Klaus Seidenstucker (Germany)
12. Aloysius Bakkidde (Uganda)
13. Kerrie Engel (Australia)

International group meets in Peterborough



(left to right) Andrew Russell, Richard Howitt MEP, Pierre Mertens

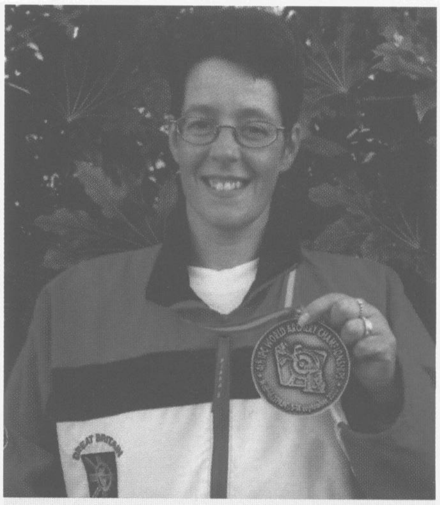
The board of the International Federation for Spina Bifida and Hydrocephalus (IFSBH or 'If') met in Peterborough in early December, made up of representatives from the national associations of Australia, Belgium, Germany, The Netherlands, Norway, Sweden, Uganda and the UK.

Andrew Russell said: "We are delighted that we in Peterborough have this opportunity to host the international federation. It is a chance for us all to compare notes in the campaign to help people with spina bifida or hydrocephalus get the most out of their lives."

'If' runs a number of projects around the world, including initiatives to improve health and social care in Africa.

Snooker dream comes nearer

The introduction of wheelchair snooker to Northern Ireland has come a step closer with the award of £1,815 by the Community Foundation for Northern Ireland (CFNI) to the man behind this dream, Mark Patton. Mark's pictured here with CFNI's Kate Campbell and Colin Kennedy.



Pippa's bullseye

Pippa Britton did it for Britain in September when she won silver at the 2003 World Archery Championships in Madrid. Newport-based Pippa, aged 40, was part sponsored both by ASBAH and SWASBAH, who gave her a £100 for a new set of bows. She was pipped to gold by an Italian who, with the last arrow, won by just one point.

Pippa, who has spina bifida, took up archery 12 years ago. She joined a local club and from there entered competitions all over the UK. She later succeeded in qualifying for the British team.

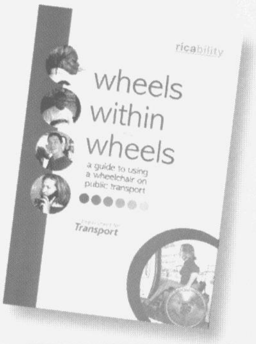
On how her family back home felt about her success, she said: "My husband was delighted. I think he phoned everyone we know!"

STOP PRESS

- An incredible £15,000 donation was made to ASBAH at the Homing World Show of the Year 2004 by the Royal Pigeon Racing Association. The full story will appear in the next issue of *Link*.

- Dr Spitz Holter, inventor of the shunt valve, died in December. A tribute will appear in the next issue of *Link*.

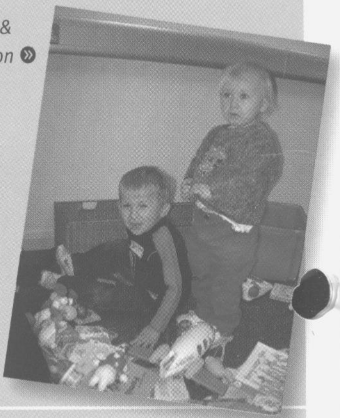
Wheelchairs on public transport



The charity Ricability has produced a guide to using a wheelchair on public transport. *Wheels within Wheels* tells you what you can expect from newer trains, coaches, buses and taxes. It has information on how you can find out where accessible services are running and gives tips on travelling in a wheelchair; it also lists the key dimensions of wheelchairs currently available in the UK and which of them will fit onto public transport. For a free copy send an A4-sized s.a.e. (56p) to: Wheels within Wheels, Ricability, 30 Angel Gate, 326 City Road, London EC1V 2PT. Ricability's tel no is 020 7427 2460. www.ricability.org.uk

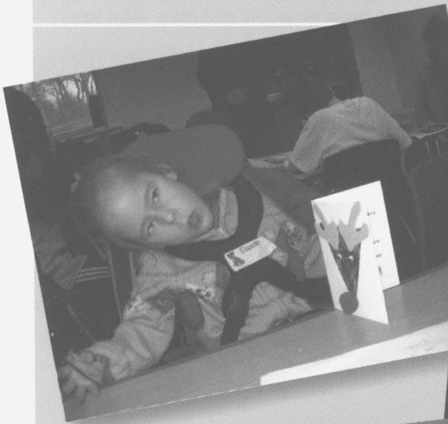

Amy Lilley and Chloe Osborne

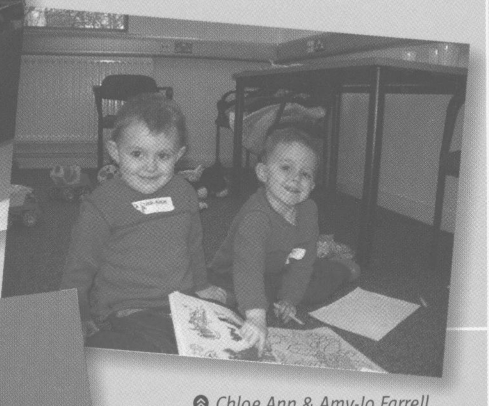

Emma Booth


David Poulston & Danielle Poulston

Northern Open day

ASBAH Northern Region took to the road again in November when it held an open day in Sheffield. Grandparents, parents, brothers and sisters and carers joined staff in an information sharing and fun day. There were discussions about education and health, as well as a benefits quiz and a session about caring for carers. Activities laid on for the children included mask, puppet and card making. The day was part funded by Sheffield Local Association.


Elspeth Austin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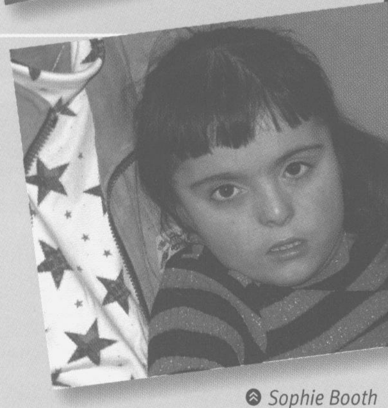
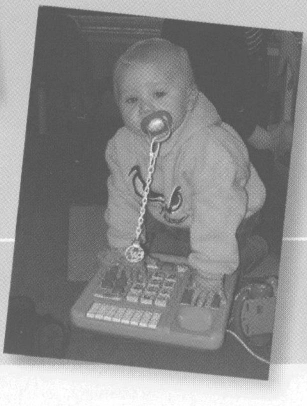

Sophie Booth


Jordan Poulston


Cathy Lunn, Emma Booth, Marcia Conroy & David Jackson

Peter's happy ending

Young Peter Harris's 2003 had a real low, but ended very happily with him becoming something of a star in his hometown of Great Yarmouth.

For Peter's mobility bike was stolen last October. Peter, 10, has spina bifida and has to wear calipers. But with the subsequent news of the theft in the local papers, the good townspeople of Great Yarmouth, spearheaded by Neville Thompson of Broadland Sport Club, raised enough money to replace it.

But before he was presented with the bike just before Christmas, he had a little task to perform: judging the best dressed Christmas window in the town's Victoria Arcade. He's pictured here outside the winning shop receiving a donation to ASBAH of £250 from Martin Green of the arcade's owners London and County.

Adam Scorey/©EDPpics2003

Midlands to Minehead

by Geraldine Long and Jenny Green

Last November a group of ASBAH service users made their way through West Country storms and motorway hold-ups to The Promenade Hotel, Minehead, for the weekend.

The hotel, run by Grooms Holidays, offered extremely comfortable, accessible accommodation. The staff made everyone feel welcome and the chef's excellent cuisine enticed even the non-breakfast eaters to tuck into hearty breakfasts. Lunches and dinners were so excellent that weight watching was impossible.

Due to unavoidable late arrivals and subsequent dining in shifts the first evening, workshops planned for the afternoon had to be abandoned. When everyone had finally arrived and had been fed we made our way to The Ship Aground for cut throat games of skittles and just a few drinks!

The next morning we awoke to calm weather and sunshine which lasted all weekend, allowing trips along the prom to see the sea and to buy souvenirs.

Stuart, our trainer, along with ASBAH staff, arranged workshops focussing on assertiveness, self-esteem, confidence building and spina bifida and/or hydrocephalus. Everyone contributed ideas and experiences and used a rare opportunity to share feelings with peers. It was amazing how the Magic Stick helped everyone to understand the benefits of communication and of working together as a team. Spaghetti and marshmallows will forever be linked to bridge building and group work!

Stuart, our trainer, along with ASBAH staff, arranged workshops focussing on assertiveness, self-esteem, confidence building and spina bifida and/or hydrocephalus.

The catchphrase of the weekend was "hydrocephalus moments," when memory and concentration lapse. The phrase, coined by one of the service users, was endorsed by everyone as totally appropriate.

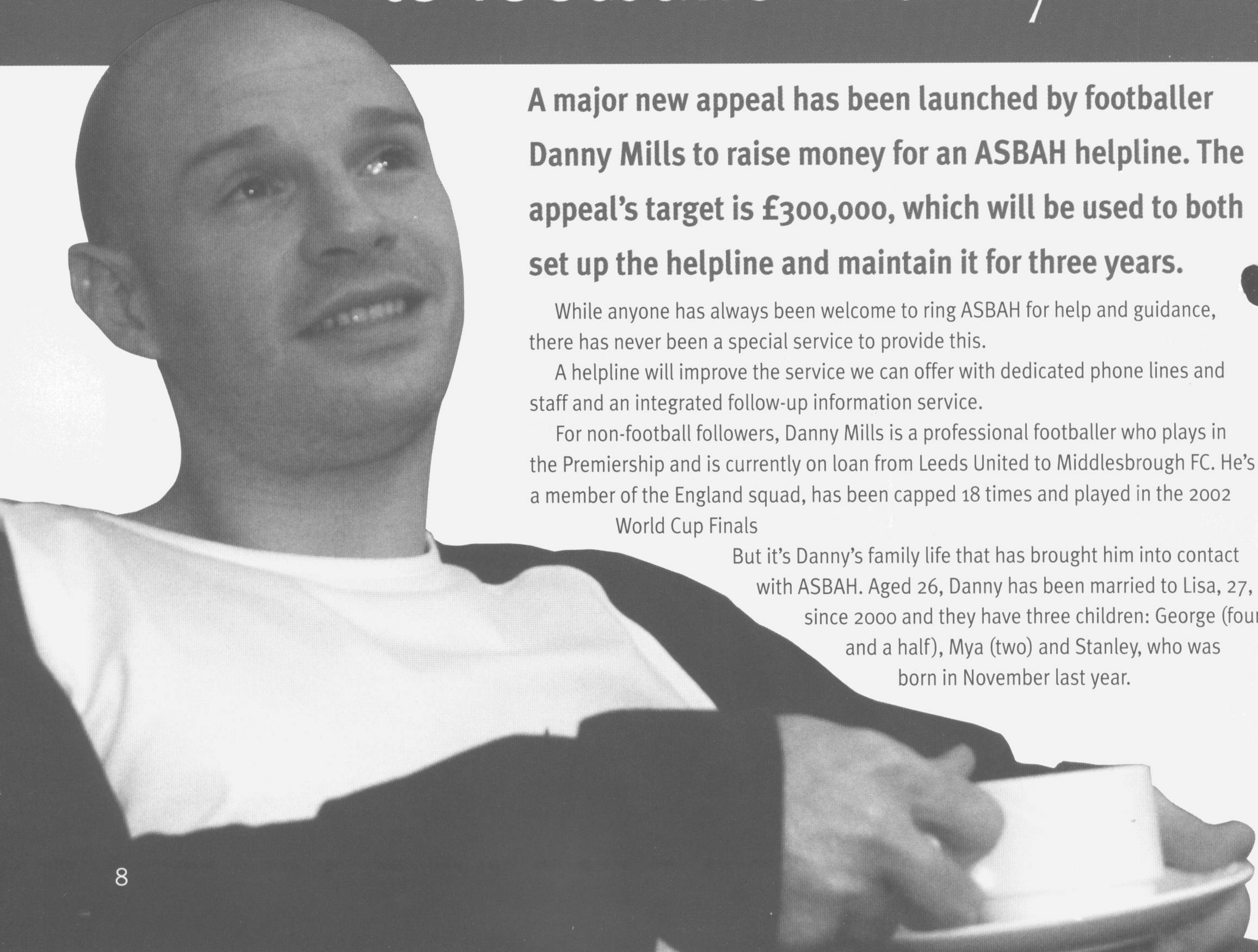
Volunteers came in to assist everyone who wanted help with hairstyling and make-up in preparation for a special evening on Saturday. After aperitifs in the bar we all tucked into a turkey and tinsel meal, followed by a sing song and presentation of awards. True to the spirit of Christmas, presents were found under the festively decorated potted plant. ASBAH advisers lacked the stamina of some people, who partied until the early hours!

Despite the celebrations of the night before we all met up for breakfast in the sunny dining room on another glorious day. The skills practised on Saturday were reinforced by further workshops, interspersed by bulletins on the progress of the England team in the Rugby World Cup.

All too soon it was time to leave. Promises were made to keep up friendships formed and plans were suggested for a reunion in 2004.

Thanks must go to the Leeds and Holbeck Building Society, the Birmingham Hospitals Saturday Fund and ASBAH for their generous support.

Helpline appeal kicks off thanks to footballer Danny Mills



A major new appeal has been launched by footballer Danny Mills to raise money for an ASBAH helpline. The appeal's target is £300,000, which will be used to both set up the helpline and maintain it for three years.

While anyone has always been welcome to ring ASBAH for help and guidance, there has never been a special service to provide this.

A helpline will improve the service we can offer with dedicated phone lines and staff and an integrated follow-up information service.

For non-football followers, Danny Mills is a professional footballer who plays in the Premiership and is currently on loan from Leeds United to Middlesbrough FC. He's a member of the England squad, has been capped 18 times and played in the 2002 World Cup Finals

But it's Danny's family life that has brought him into contact with ASBAH. Aged 26, Danny has been married to Lisa, 27, since 2000 and they have three children: George (four and a half), Mya (two) and Stanley, who was born in November last year.

DANNY MILLS ASBAH HELPLINE APPEAL

When Lisa went to hospital in 2002 for what was meant to be a routine scan during pregnancy, they were told that the child, whom they called Archie after discovering he was a boy, had spina bifida and hydrocephalus very severely and that he wouldn't survive. Everything then became a blur.

Danny subsequently contacted ASBAH and, on learning that there wasn't any helpline as such, realised that there was an urgent need for a dedicated service for people to access help, support and advice on all aspects of spina bifida and hydrocephalus.

Help will be accessible to anyone via the helpline on all aspects of spina bifida and hydrocephalus - from antenatal enquiries, health and social care, education, transition to independence through to bereavement support. Having access to the right advice and support will ease the stress and strain during a traumatic period and help them make the right decision.

Link met up with Danny just before Christmas and he filled us in on the story:

When did you decide to set up the helpline appeal?

It was really the middle of 2003, when we realised that Lisa was pregnant again and once we had got over the twenty week stage, which is the crucial point where in 2002 we found out that Archie wouldn't survive. That was a big, big critical point, we hadn't really told anyone that Lisa was pregnant until then.

Once we got over that I got on the Internet and looked around. For a long time I knew that I wanted to be involved in some sort of charity work. Doing the job I do it's always nice to help out in anyway I can. I was looking for a spina bifida and hydrocephalus charity and I came across ASBAH, I just picked up the phone and called them. I spoke to several people and they may have thought that it was a wind up to start with but I got put through to Donna Treanor, the Fundraising Manager. She had read a piece about me in *The Guardian* and was delighted that I wanted to help out.

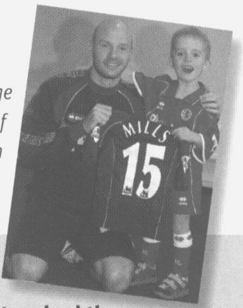
What do you hope the appeal will achieve in both the short term and in the long term?

Initially I got involved to raise money to set up the helpline, which is key. When we first found out about Archie we didn't know what to do or who to turn to; we thought there was no real support out there for us. In the long term: that we can raise awareness of the fact that there really is someone out there who will make a special effort to talk you through every situation - that qualified counsellors are always on hand to give expert advice and guidance.

The appeal has got off to a promising start with £1,000 raised from an auction on the Internet site ebay in December. Broadlands Radio (which covers Danny's home town of Norwich) also ran an appeal in December, Operation Santa Claus, which contributed £3,300. Other events are planned, including a celebrity golf day and gala dinner at the end of the current season where Danny plans to attract celebrities and sportsmen to help boost the fundraising effort.

If you would like to help Danny, you can donate by sending a cheque made payable to 'ASBAH' to our Peterborough address or by visiting our website at www.asbah.org.

Thank you.

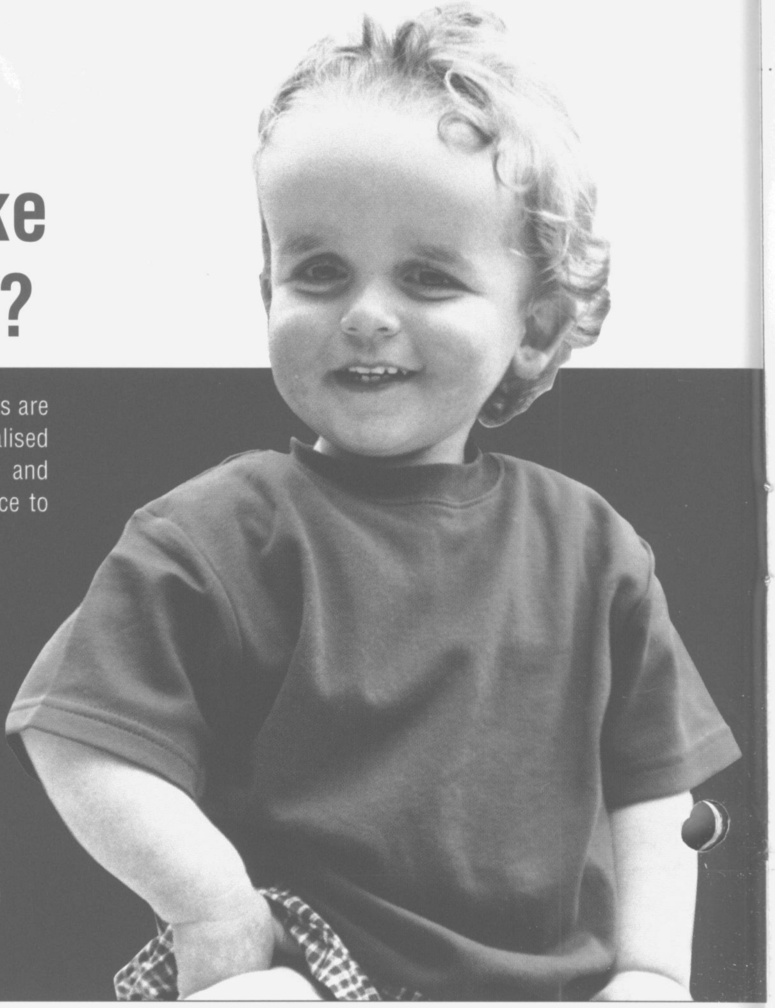


Cover image courtesy of Middlesbrough Evening Gazette

Danny's work for ASBAH has already touched the heart of little Michael Jones, four-and-a-half, who has congenital hydrocephalus. After reading about Danny's work for ASBAH in Boro's club magazine, Michael's parents, Alan and Sheila from Guisborough in Cleveland, wrote to him. In their letter they said that, because of the size of his head, Michael couldn't get the Boro strip over his head. Danny then fixed it for the team shop to supply Michael with a red home strip shirt with a zip so that it would fit him; the shop also gave him a blue away strip.

Danny met Michael in November and it made the front page of the local paper. Christmas had definitely come early!

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



Barney has hydrocephalus but, with ASBAH's support, he and his parents are looking confidentally to the future. ASBAH cares for and provides specialised services throughout the community for over 15,000 babies, children and adults with hydrocephalus and spina bifida, making a positive difference to their lives.

You can help us make that difference!

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

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

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

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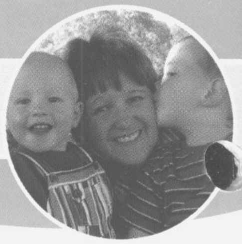
LINK

The ESSENTIAL magazine for people with hydrocephalus and spina bifida

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

Nici Picken
Gloucestershire



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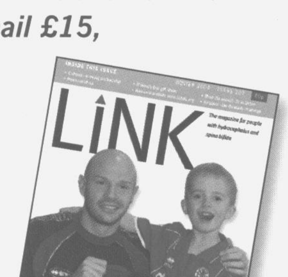

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Keeping ahead with fundraising

John Wills recently braved the razor again and had his locks shaved off for the fourth time in order to raise £335 for ASBAH. The deed took place at Idle Baptist Church, Bradford, where the minister's wife, Rachel Dodds, played hairdresser and was let loose with the razor!

John has been raising money for ASBAH in memory of his fiancée, Andrea Winterburne, who had spina bifida and died several years ago. He said: "I feel as though I want to keep the memory of Andrea alive with raising money for ASBAH."

Thanks to the folk at Quinn

By Alan Moneypenney

Early last year a group of employees from the Quinn group in County Fermanagh decided to run a fundraising event to support a number of worthy causes. Their idea was simple: to create a mass participation event for which people could obtain sponsorship, the setting of a financial target and the sourcing of the associated sponsorship required to make things work.

Simple and straightforward – except, as anyone who has worked in fundraising knows, finding that magic blend and identifying the organisers to take the idea forward is easier said than done.

The idea was straightforward: to hold a sponsored abseil in 2003. This has been done lots of times before and is becoming a little bit passé, except the good folk of Quinns had their own idea.

Anyone familiar with the Fermanagh Border and in particular the road from Lisnaskea to Ballyconnell will have seen the cement silos that tower several hundred feet above the landscape. They are tall, very tall and therefore the idea to abseil down them was absolutely unique. Sponsor cards were prepared and distributed through the fleet drivers who set sail to collect towards the set target of £5,000. The organising was left in capable hands and the date set for the big event.

What happened next is a great credit to all concerned. The original target figure was blown out of the water with a total of £30,000-plus eventually being reached. The big day cost not a cent; the silos were made available by Sean Quinn himself and he insured the event through one of his associated companies. The crane to raise the participants to the silo roof was provided by another generous neighbour. The entertainers came free and the stage was set.

The big day came complete with driving rain and gusting wind. This affected nothing at all. Dozens of folk descended the silos under the careful eyes of specialist instructors from a nearby outdoor pursuit centre. The bands played, the dancers danced and everyone had one powerful day all in the name of a good cause.

To some extent the rest is history. Brave people - including one in a wheelchair and others in kilts - raised a huge amount of money for the organisations they had decided to adopt. The Children's Spina Bifida and Hydrocephalus Unit at the Royal Victoria Hospital received a cheque for the purchase of crucially needed equipment to the value of £10,000 plus; the children of Chernobyl received £15,000 and ASBAH nearly £5,000.

Alan Moneypenney (left) receives the cheque from Louise McDermott

The event created a huge amount of local publicity but most significantly it was featured on local television when Ulster Television showed the event and interviewed some of the participants.

The modest people who made this work so well have our grateful thanks for the contribution not only to ASBAH but also to the Children's Unit. Basically they prefer anonymity but it is important to name Alice and Barney McDermott who seemed to have a hand in absolutely everything.

Thank you everyone!

Giving as you're paid

Yet another publication has been brought out by the ASBAH fundraising team, as it seeks to explore every opportunity for people to help ASBAH financially

The new leaflet is about payroll giving. 'Give as you Earn' is a popular and fast growing way of giving money to charity. It's tax free, so this way people are able to donate more as their regular gift has the tax benefit added to it by the government.

For example, agreeing to give £5.00 each month to ASBAH means that the cost to you is £3.90 (@22% tax, net) and ASBAH actually receives £5.50 with the benefit of the tax and government subsidy. This is money which is really needed to help provide all of ASBAH's services.

If you think that you can help ASBAH by giving a regular monthly contribution from your income, then email Shelly Bullard in the fundraising department at shellyb@asbah.org or call her on 01733 555988. Shelly will send you the leaflet, together with details of how to complete it.

'Sibly' great!

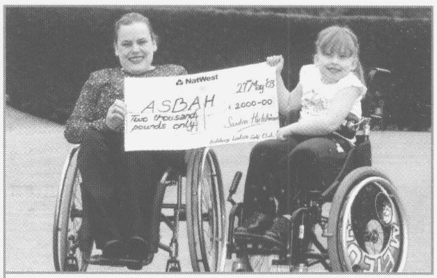
Got a brother or sister? Well, do they know about Sibs? This organisation is for people – siblings - who grow up with a brother or sister with special needs, disability, chronic illness. There are at least two million of these siblings in the UK and many need support, information and advice at different stages of their lives.

Growing up with someone with special needs can be very rewarding and very difficult at the same time. When someone in the family needs a huge amount of help and support, this can have a negative impact on the other family members.

The single biggest issue for child siblings is not getting enough attention from their parents. For adult siblings the biggest issue is worrying about who will care for their brother or sister when their parents are no longer able to.

Sibs's purpose is to make a positive difference to the lives of siblings – to make growing up with someone with special needs a bit easier. It's a registered charity and the majority of trustees are adult siblings.

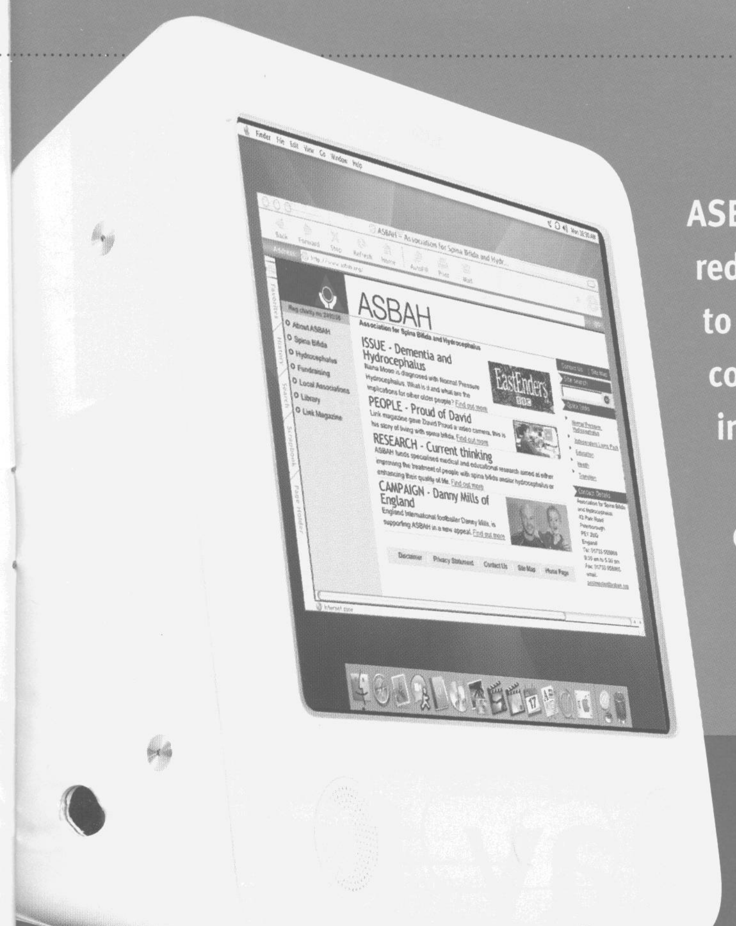
Email them at info@sibs.org.uk, call the Sibs helpline on 01535 645453 or write to them at Sibs, Meadowfield, Oxenhope,West Yorkshire BD22 9JD.



A grandmother remembered - Didsbury Ladies' Golf Club has given ASBAH £2,000. The money was raised under the captaincy of Sandra Hutchinson, whose granddaughter Amy, six and a half, has spina bifida. Sadly, Sandra died in January 2003 before she could present the cheque herself; so Amy *(pictured right)*, presented the cheque in memory of her grandmother to Greater Manchester adviser Marcia Conroy.

Sandstone Trail walk

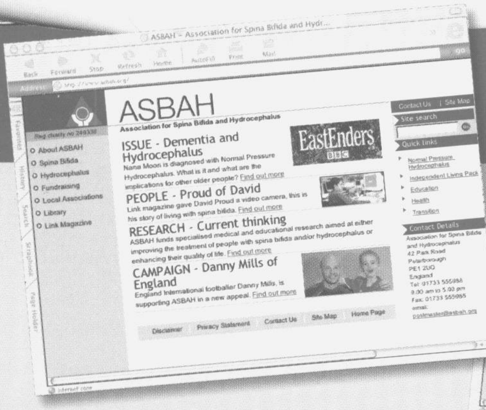
David Murray, David Pollard, Phil Barlow, John Pickering and Lawrence Chalk (pictured left to right) raised £674 for NWASBAH when they walked the 35-mile Sandstone Trail from Frodsham to Whitchurch. David Pollard's son Ben has spina bifida.



ASBAH's website, www.asbah.org, has been redesigned to make it more interactive and easier to navigate. It's now brighter looking, with colour pictures, and carries a greater range of information.

The site has been divided into four areas: current issues, people, research and campaigns. These are flagged up on the homepage, where 'find out more' links take you straight to the full information.

NEW LOOK WEBSITE



ASBAH
Association for Spina Bifida and Hydrocephalus

ISSUE - Dementia and Hydrocephalus
Nana Moon is diagnosed with Normal Pressure Hydrocephalus. What is it and what are the implications for other older people? Find out more

PEOPLE - Proud of David
Link magazine gave David Proud a video camera, this is his story of living with spina bifida. Find out more

RESEARCH - Current thinking
ASBAH funds specialised medical and educational research aimed at either improving the treatment of people with spina bifida and/or hydrocephalus or enhancing their quality of life. Find out more

CAMPAIGN - Danny Mills of England
England International footballer Danny Mills, is supporting ASBAH in a new appeal. Find out more

Association for Spina Bifida and Hydrocephalus
42 Park Road
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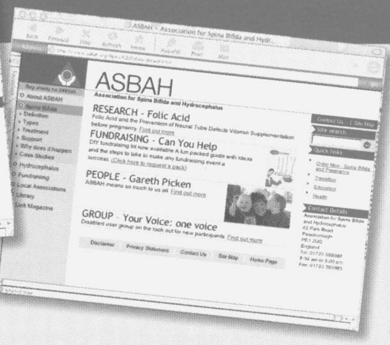
England
Tel: 01733 555988
9.00 am to 5.00 pm
Fax: 01733 555985
email:
postmaster@asbah.org



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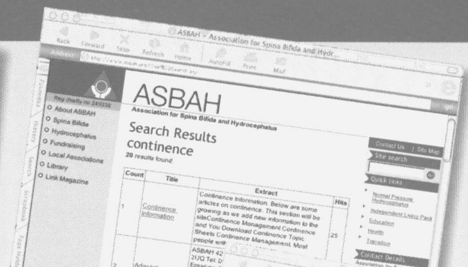
RESEARCH - Folic Acid
Folic Acid and the Prevention of Neural Tube Defects Vitamin Supplementation before pregnancy. Find out more

FUNDRAISING - Can You Help
DIY fundraising kit now available A fun packed guide with ideas and the steps to take to make any fundraising event a success. (Click here to request a pack)

PEOPLE - Gareth Picken
ASBAH means so much to us all. Find out more

GROUP - Your Voice: one voice
Disabled user group on the look out for new participants. Find out more



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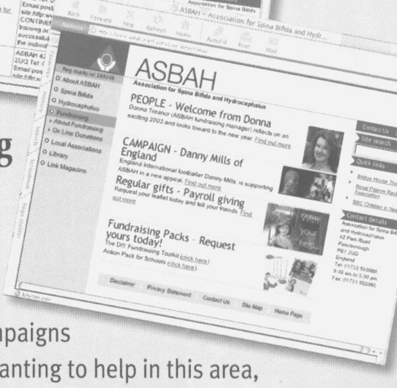
Search Results
continence
20 results found

Count	Title	Extract	Hits
1	Continence Information	Continence Information. Below are some articles on continence. This section will be growing as we add new information to the siteContinence Management Continence and You Download Continence Topic Sheets Continence Management. Most people with	25
2	Adaptations for Toileting	ASBAH 42 … 2UQ Tel: … Email:post… site:http:… CONTINE… training or … successful… the individ…	
	Bladder…	ASBAH 42 … 2UQ Tel: … Email:pos… site:http:…	



ASBAH
Association for Spina Bifida and Hydrocephalus

PEOPLE - Welcome from Donna
Donna Treanor (ASBAH fundraising manager) reflects on an exciting 2003 and looks toward to the new year. Find out more

CAMPAIGN - Danny Mills of England
England international footballer Danny Mills, is supporting ASBAH in a new appeal. Find out more

Regular gifts - Payroll giving
Request your leaflet today and tell your friends. Find out more

Fundraising Packs - Request yours today!
The DIY Fundraising Toolkit (click here)
Action Pack for Schools (click here).

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Fax: 01733 555985

Homepage

On the left hand side of every page is now a drop down menu, with quick links to other areas of the site, so that you can navigate your way through the site with ease.

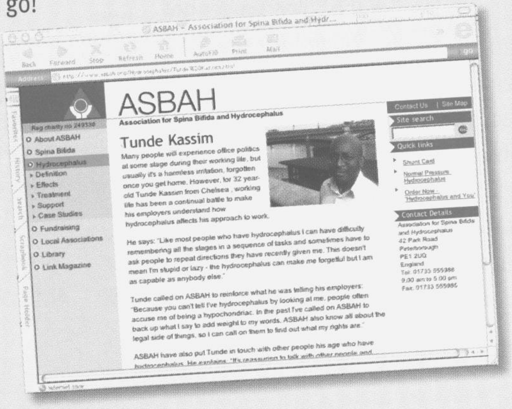
Information on spina bifida and hydrocephalus can also be found using the drop down menu. There are a number of sub-categories under the spina bifida and hydrocephalus option: click on the title that interests you and away you go! Information includes a definition of each condition, medical advice, treatment and support. Also within this section, you can now read about case studies.

Site search facility

A really useful new feature is the new site search option, making it much quicker to find what you're looking for as well as making the whole site more accessible.

Case studies

Case studies are another new feature, giving a useful insight into the lives of ASBAH members and the issues they face.



ASBAH
Association for Spina Bifida and Hydrocephalus

Tunde Kassim

Many people will experience office politics at some stage during their working life, but usually it's a harmless irritation, forgotten once you get home. However, for 32 year-old Tunde Kassim from Chelsea , working life has been a continual battle to make his employers understand how hydrocephalus affects his approach to work.

He says: "Like most people who have hydrocephalus I can have difficulty remembering all the stages in a sequence of tasks and sometimes have to ask people to repeat directions they have recently given me. This doesn't mean I'm stupid or lazy - the hydrocephalus can make me forgetful but I am as capable as anybody else."

Tunde called on ASBAH to reinforce what he was telling his employers: "Because you can't tell I've hydrocephalus by looking at me, people often accuse me of being a hypochondriac. In the past I've called on ASBAH to back up what I say to add weight to my words. ASBAH also know all about the legal side of things, so I can call on them to find out what my rights are."

ASBAH have also put Tunde in touch with other people his age who have hydrocephalus. He explains: "It's reassuring to talk with other people and

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Fundraising pages

You can now keep up-to-date with fundraising campaigns and for those wanting to help in this area, fundraising packs can be ordered online and delivered in no time!

In fact it's now quicker and easier to make online donations using the donation form and completing credit or debit card details.

If you have any ideas or comments on the ASBAH website please email peterf@asbah.org

Mother's Day treats

Mother's Day on 23 March will be a chance to really show mum how much you love and appreciate her by giving her a special treat. Whether you're eight or 38, here are some top treats that won't cost the earth but will bring a smile to her face.

1. A fab facial

A great treat for mum is to book her in to have a facial. However facials can be costly! Why not give your mum a facial in the comfort of her own home, with the Basil Purifying Mask. Suitable for all skin types, this herbal mask is the perfect tonic for troubled tired skin. Enriched with basil and antioxidant fennel extracts, it leaves skin feeling hydrated, clean and fresh. It also contains Community Traded sesame oil from Nicaragua to help leave skin smooth and conditioned. Plus there should be some left over for her to use for another day! Available from the Body Shop, at £6.50 for 100ml.

2. Bathtime bliss

As we all know, mums do a lot of running about and have little time to stop and relax. For her special day run her hot bath, with some scented candles and her favourite music softly playing in the background and let her fully relax with a leisurely soak in the tub!

Try Relaxing Lavender Milk Bath Powder: with a sensational herbal/floral fragrance, the Lavender range offers superb relaxing benefits and is reputed to help reduce anxiety and promote restful sleep. This beautiful bath powder is a relaxing additive to your bath, containing soya milk powder and pure lavender essential oil to give you a luxurious, and pampering bath experience. Available from the Body Shop, at £7.50 for 200g.

3. Lavender candle gift set

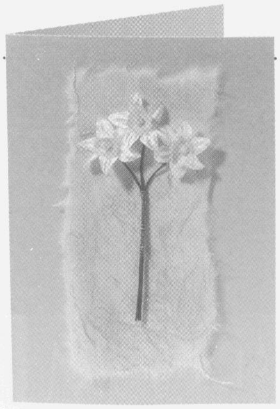
Five piece mini candles in box. Available from Boots, £8.00.

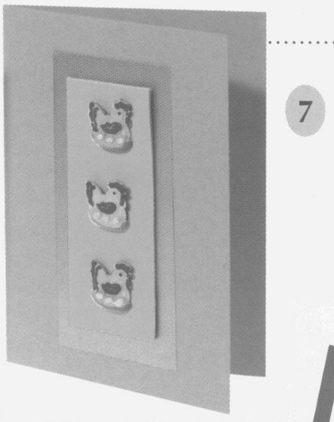
4. Pot Pourri

These dried leaves and petals come in organza bags and are available in sandalwood, vanilla and peach. The vanilla and peach pot pourri are available in dried leaves and petals. The sandalwood pot pourri is available in dried berries. £4 from Boots.

5. Novelty Fabric Bag with Flowers

Flowers make the perfect present and are guaranteed to make your mum smile, so pick up the Novelty Fabric Bag with Flowers, available from Marks & Spencer, at £3.99 each.





6. Beauty Journal & Address Book Set

Pretty and compact, the Beauty Journal & Address book is perfect for keeping mum organised. £8, from Marks & Spencer.

7. DIY card

Make her a special card, adding your own personalised message. Try making the Fresh Flowers Greeting card following these simple instructions.

What you need: miniature fabric daffodils; green card; yellow mulberry paper or card; copper jewellery wire; glue gun & glue sticks. All these can be bought at a HobbyCraft centre. To find your nearest centre see www.hobbycraft.co.uk or call freephone 0800 027 2387.

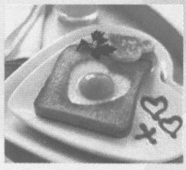
To make:

1. Arrange three daffodil flowers and bind their stems together by winding copper wire around the stems.
2. Tear a rectangular piece of yellow mulberry slightly larger than the three daffodils. Stick this to the centre of a blank green card using double sided tape.
3. Finally apply small dabs of glue to the daffodils and onto the mulberry, holding in place until they've adhered to the paper.

8. A Hearty Breakfast!

'A Hearty Breakfast' is from celebrity chef's Annabel Karmel's *Complete Party Planner* (see www.annabelkarmel.com). It's particularly good for kids to make (supervised by an adult who isn't their mum!), takes 30 minutes to prepare and less than 10 minutes to make.

Ingredients:



1 thick slice white bread
15g butter plus an
extra knob
1 egg
salt and freshly ground black pepper.

Method

1. Cut a hole in the centre of the bread using a heart-shaped cookie cutter approx 8cm wide at its widest point.
2. Melt the butter in a small frying pan and sauté the bread on one side until golden. Turn the bread over, melt an extra knob of butter in the heart-shaped cut-out, break the egg into it and season lightly.
3. Cook covered for about two minutes or until the egg is cooked to your liking. You can also dip the cut-out heart in a little egg and sauté that too.

9. Thorntons Chocolates

Thorntons Continental will be available in a heart shaped box for Mother's Day, price £6.00. Thorntons also has a gift delivery service. See www.thorntons.co.uk or call 0870 160 1911.

READER OFFER

We have 10 Boots White Collection Handcare Kits, worth £12 each, to give away. These stylish kits contain handwash and hand lotion with a delicate fragrance.

Courtesy of HobbyCraft we've also have got six copies of Peel-Off Greetings Cards *by Judy Balchin (Search Press, £6.99).*

The first 10 entries drawn will each receive a Handcare Kit; the next six drawn will each receive the book. A draw will then be made of all 16 lucky entries, and the winner will also receive a copy of Annabel Karmel's Complete Party Planner *(Ebury Press, £12.99).*

For a chance to win simply write your name, address and telephone number on a postcard or sealed envelope and send it to: Link Reader Offer, ASBAH, 42 Park Road, Peterborough, PE1 2UQ.

The closing date for all entries is 19th March 2004

AUTUMN READER OFFER WINNERS

Toni&Guy winners are:

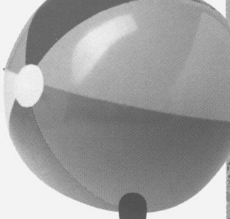
Miss Kirsty Copping
Ipswich

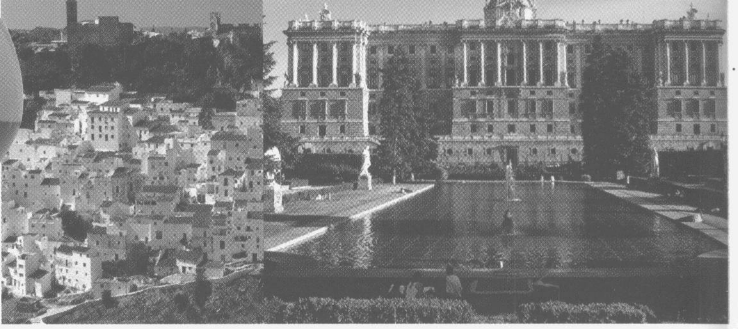
Mrs M Bowmar
Thurcroft, Nr Rotherham, S.Yorkshire

Mrs R Smith
Saughall, Chester

Ms Joy Jones
Bristol

Congratulations to them !!





Si señor!

Tired of dull and drizzly winter? Well, summer's slowly getting nearer and now's the time to start thinking about where to go.

Spain is an ever popular tourist destination, with its golden beaches and cities steeped in history and culture.

If you have hydrocephalus and are hesitant for medical reasons, both Palma de Mallorca and Madrid have hospitals that are equipped to deal with shunt emergencies. And ASBAH can even help with providing cards in Spanish to explain what's needed in such an emergency.

Specialists in holidays specifically for the disabled:

- **Holiday Care:** *www.holidaycare.org.uk*
  email: *info@holidaycare.org*
  or call 0845 124 9971
- **Accessible Sun:**
  www.accessiblesummersun.co.uk
  email: *info@ccessiblesummersun.co.uk*
  or call 01452 729 739

Andalucia

This region has golden beaches, beautiful mountain ranges, 3,000 hours of sun per year - and not forgetting the beautiful whitewashed villas. Here you can see the magic of flamenco and bullfighting in its most authentic style, and trace the steps of legends Don Juan and Carmen.

Flying to Malaga:

- *bmibaby* flies from Cardiff, East Midlands, Glasgow, Manchester *(www.bmibaby.com)*
- British Airways flies from Heathrow, Gatwick, Stansted, Manchester *(www.ba.com)*
- *easyjet* flies from Heathrow, Gatwick, Stansted, Bristol, Belfast, East Midlands, Newcastle and Aberdeen *(www.easyjet.com)*
- *Monarch* flies from Gatwick, Luton, Manchester *(www.monarch-airlines.com)*

The Balearics

There are five Balearic islands: Mallorca, Menorca, Ibiza, Formentera and Carbrera. Thanks to their climate, beaches and all-purpose tourist attractions, they're one of the most prestigious and attractive places to get away from it all in the entire Mediterranean.

Palma de Mallorca

Palma has numerous architectural treasures, among them the 14th century Bellver Castle, the Gothic cathedral, the ancient Lonja or market area, the Archbishop's Palace and the Monastery of St. Francis.

Flying to Palma:

- *bmibaby* flies from Cardiff, East Midlands, Glasgow, Manchester
- *easyjet* flies from Gatwick, Stansted, Luton and Liverpool
- *British Airways* flies from Heathrow, Gatwick, Stansted, Birmingham and Manchester
- *Opodo* flies from Gatwick, Birmingham, Glasgow and Manchester *(www.opodo.co.uk)*
- *Flyglobespan* flies from Belfast *(www.flyglobespan.com)*

Barcelona

Barcelona is the historical capital of Catalonia and is Spain's second city. It's become very popular since hosting the Olympics in 1992. Famous for Las Ramblas, this exceptionally beautiful city has an impressive architectural heritage that includes the Gothic Quarter, the old City Hall, the Episcopal Palace and the Palace of the Generalitat. It also boasts the work of the modernist architect Antonio Gaudi. Two museums are the Picasso Museum and the Museum of Catalan Art.

Flying to Barcelona

- *bmibaby* flies from East Midlands, Glasgow, Manchester
- *British Airways* flies from Heathrow, Gatwick, Stansted, Birmingham, Edinburgh, Manchester
- *easyjet* flies from Heathrow, Gatwick, Stansted, Belfast, Bristol, East Midlands, Newcastle and Aberdeen
- *Ryanair* flies from Birmingham, Bournemouth, Dublin, Liverpool and Stansted *(www.ryanair.com)*

Madrid

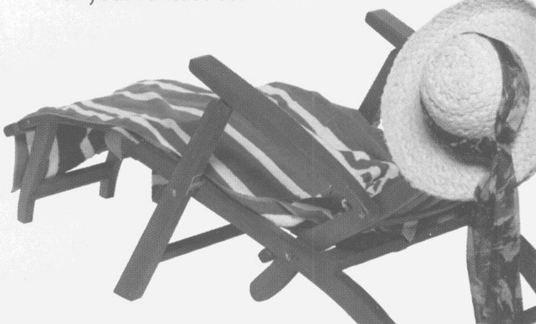
Madrid is the bustling cosmopolitan at the heart of Spain, with its wide avenues and elegant plazas dominated by Renaissance, Neoclassical and Romantic architecture. It enjoys more cloudless days than almost any other city in Europe. Attractions include the Royal Palace, the Prado Museum – and Posh and Becks of course!

Flying to Madrid airport:

- *bmibaby* flies from Gatwick, Glasgow and Manchester
- *British Airways* flies from Heathrow, Gatwick, Stansted, Birmingham, Edinburgh, Manchester
- *easyjet* flies from Gatwick, Luton and Liverpool
- *Opodo* flies from Birmingham, Gatwick and Manchester

Other information:

- the Spanish Tourist Board has useful addresses, accommodation details (including details of disabled access) and detailed information about all areas of Spain, *www.spaininfo.com* email: *londres@tourspain.es* or call 020 7486 8077
- if your Spanish is poor or non-existent and you want to write to somebody in Spain, *www.freetranslation.com* will translate text from English to Spanish for you. Fantastico!



Meet the expert

Dr Jo Iddon, neuropsychologist

In the last issue of *Link* David Isom reviewed a book by Dr Jo Iddon called *Memory Booster Workout* (Hamlyn, £12.99). London-based Jo's main fields of interest are memory and dementia, age-related cognitive decline, hydrocephalus and spina bifida.

As a senior research associate and neuropsychologist she's a specialist in the profiling of cognitive function following brain damage or disease. Jo works at both the Department of Neurosurgery at Addenbrooke's Hospital, Cambridge and at the Chelsea and Westminster Hospital in London.

She also freelances, carrying out private neuropsychological assessments and she's currently developing a number of her own clinical projects, applying the research concepts of neuropsychology to the real world; this includes the development of the Memory Assessment Centres for the early detection of dementia.

Jo's the author of a growing number of academic papers and book chapters and regularly reviews for several leading journals. She's had a number of pieces published in the mainstream press, including *The Times, The Irish Sunday Times, Daily Mail, The Lady* and *Reader's Digest.*

On this page we reproduce the summary of her joint paper *Neuropsychological Profile of Young Adults with Spina Bifida, with or without Hydrocephalus.*

SUMMARY

NEUROPSYCHOLOGICAL PROFILE OF YOUNG ADULTS WITH SPINA BIFIDA, WITH OR WITHOUT HYDROCEPHALUS

JL Iddon, DJR Morgan, C Loveday, BJ Sahakian, JD Pickard

Objectives: to determine the relative impact of hydrocephalus and spinal dysraphism in young adults on intellectual and cognitive functioning. Sub-groups of patients with congenital hydrocephalus and/or spina bifida were selected from a large clinical pool from two centres (London and Cambridge), assessed between 1995-2003. The entry criterion into the study were that individuals should have (i) intact global function, (ii) average verbal intelligence (or above) and (iii) should not have clinical depression. There were three sub-groups: patients with hydrocephalus and spina bifida, patients with hydrocephalus without spina bifida, and patients with spina bifida without hydrocephalus.

Methods: patients were neuropsychologically assessed as part of their normal clinical assessment during their annual medical review. Each individual completed a screening battery assessing global functioning, verbal intelligence and mood. In addition they completed additional tests as time allowed including measures of emotional intelligence, memory, attention and executive function.

Results were analysed to compare the performance of the patient sub-groups and were also compared to a healthy control group.

Results: patients with hydrocephalus (with or without spina bifida) were significantly impaired on the vast majority of all test scores as compared to patients with spina bifida and healthy controls. They were particularly poor on measures assessing delayed memory, learning, and tests requiring a high level of attention, that is, tests of executive function. By contrast for patients with spina bifida with no associated hydrocephalus, the significant majority of all test scores fell within the average range or above.

Conclusions: the neuropsychological profile of patients with hydrocephalus is one of relative impairment and this is similar whether or not spina bifida is present. In spina bifida alone, in the absence of hydrocephalus, cognitive function is relatively spared.

Codman - Working in partnership with ASBAH

hydrocephalus action

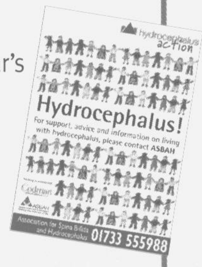
In 2004 Codman and ASBAH will work in partnership to promote 'Hydrocephalus Action', a campaign aimed at heightening hydrocephalus awareness through many channels and events.

hydrocephalus action

2004 ACTIVITY

Spring

- Launch of Benny Bear's new book - *Benny Goes to School* - and poster campaign for neurological clinics and GP surgeries



- New website section - keep watching *www.asbah.org*

Summer

- Launch awareness days - local seminars for GPs

Autumn

- National conference for medics and local authority professionals

Plus much, much, more!
Keep a look out in Link for news throughout the year.

Think of Johnson and Johnson and you think of baby bath time, warm fluffy towels and talcum powder, an image we know and have become accustomed to seeing in supermarkets, chemists and on television all over the world.

One does not automatically think of hydrocephalus, shunts and the manufacture of a range of neurosurgical equipment for the treatment and management of hydrocephalus and other neurological disorders. Codman, a division of Johnson & Johnson, provides exactly that.

In 1838 Thomas Codman established a manufacturing business in medical and surgical devices in Boston, Massachusetts. More than one hundred and sixty years later Codman continues to pursue the same principles upon which it was founded: quality, innovation and excellence.

Today Codman focuses on neurosurgery and disorders related to the central nervous system.

Through the years the company has exhibited solid growth in its sales, employee base, reputation, and most importantly, in the number of its satisfied and loyal customers around the world. Their strong leadership position within neurosurgery has been built upon a commitment to the fundamentals of customer service, and this commitment continues today as their primary operating principle: understanding, anticipating and meeting the needs of both patients and medical staff.

In 1964, Codman & Shurtleff, Inc. joined the Johnson & Johnson family of companies. During its quarter century of Johnson & Johnson affiliation the company has displayed steady growth and its history of significant innovations has continued. Codman was one of the first companies to introduce a hip prosthesis for total hip replacement surgery. These products later became part of the nucleus of a new company founded within Johnson & Johnson to focus upon the orthopaedic joint replacement markets. This was the beginning of the Johnson & Johnson Orthopaedics division, today named DePuy. Many instrument kits were also designed in co-operation with surgeons to better enable them to perform new and more effective procedures.

Today Codman focuses on neurosurgery and disorders related to the central nervous system - pain and spasticity management in particular - whilst continuing to expand its operations and its horizons. Through quality products, a tradition of unmatched customer service and high standards of integrity, Codman looks to the future with a high degree of optimism for continued growth and service to meet the ever-expanding needs of patients and medical staff.

Codman's effectiveness in the marketplace depends upon close contact with the neurosurgical community they serve: neurosurgeons, operating room nurses, hospital administrators and other healthcare professionals are routinely called on by sales specialists. In many ways, the Codman sales specialist is 'Codman' to their customers. Recruited with prior sales experience and a strong

Codman - Working in partnership with ASBAH

Codman
a Johnson & Johnson company

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

academic background, these individuals receive extensive in-house and field training. Unlike many healthcare companies which utilise distributors, Codman sells its products on a direct basis to hospitals and surgeons, allowing them to set and manage high expectations. Face-to-face selling is today, and has been through the years, the single most important means of providing ultimate customer service.

In addition to the responsibility they feel in providing the highest level of customer service, Codman has a significant responsibility to partner with organisations who provide patient support in the community. ASBAH is one such organisation that is pivotal in providing patient support on all aspects of daily living for hydrocephalus patients, carers and families.

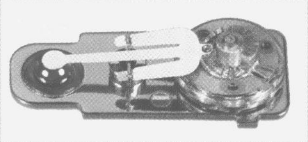
In 2004 Codman and ASBAH will work in partnership to promote 'Hydrocephalus Action', a campaign aimed at heightening hydrocephalus awareness through many channels and events. Hydrocephalus can mean very little to those not directly involved either as a patient or carer. With this campaign we hope to increase the level of understanding amongst the general public, healthcare professionals and public policy decision makers throughout the UK.

Throughout 2004 we will be bringing you information on events.

Codman shunts

Hydrocephalus comes from the Greek words meaning 'water' and 'head'.

Irrespective of its cause, hydrocephalus is due to an accumulation of cerebrospinal fluid (CSF) within the ventricles of the brain resulting in raised pressure inside the head. The solution in principle appeared simple: insertion of a tube into the swollen ventricles to drain off the excess fluid and return the pressure inside the head to normal again. Simple as it may seem, historical attempts at this method were disappointing due to infection or blockage of the tubing.



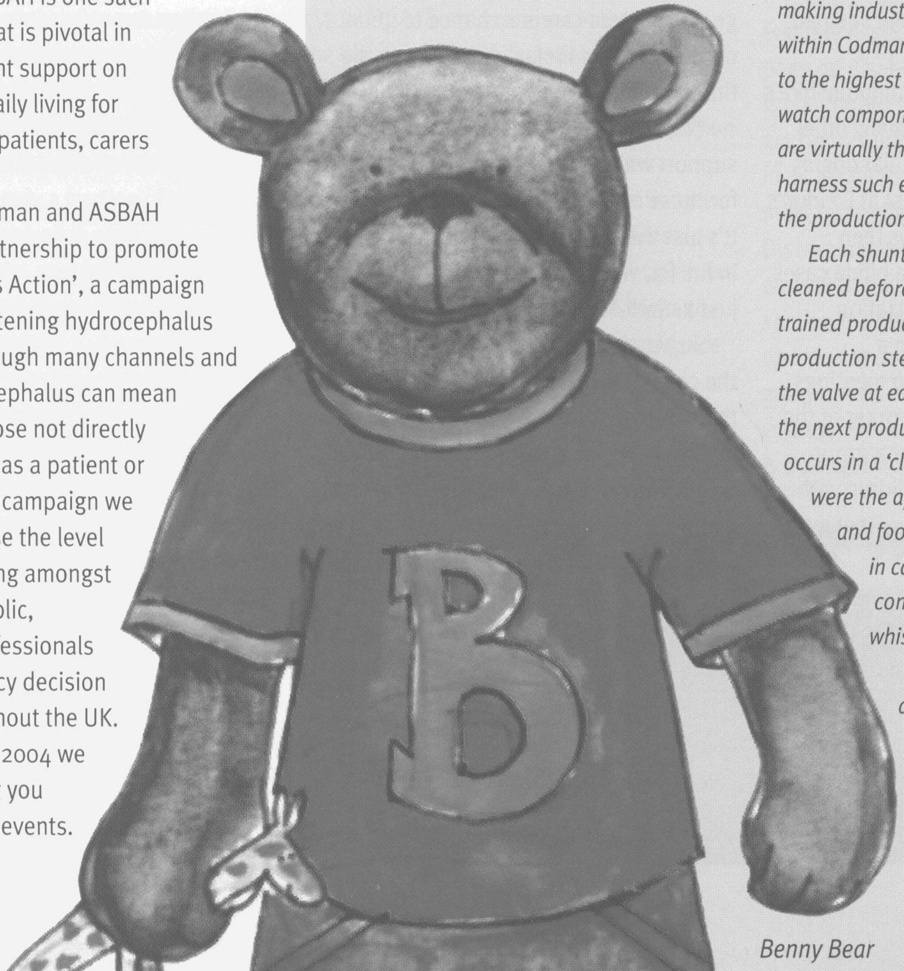
In the 1950s an American engineer whose son had hydrocephalus invented a shunt system from silicone rubber. Successful in his son's treatment, the Holter valve then became the treatment of choice. Following its success other similar shunt devices developed all made from the same material and having similar valve mechanisms.

Today there are different types of shunts available. Codman manufactures both fixed pressure and programmable or adjustable shunts. The choice of the shunt used is the decision of the surgeon and is based on the patient's condition.

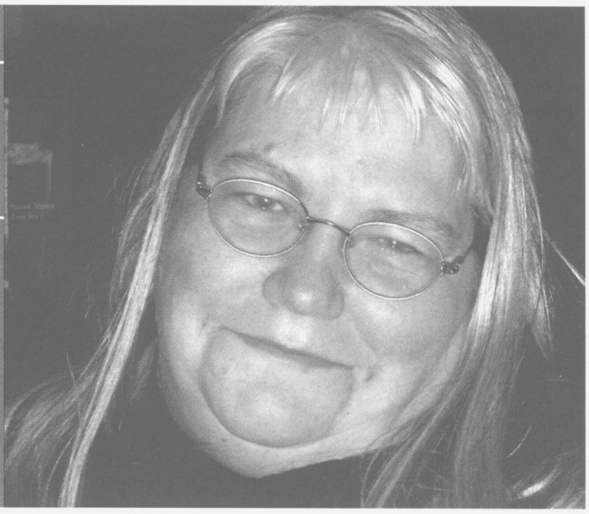
The manufacture of shunts requires high levels of precision technology and expertise and even in today's high tech world, shunt manufacturing remains a manual process. The Codman shunt factory is based in Le Locle, Switzerland, nestled between the Rolex and Tissot watch making facilities. The skills attributed to the watch making industry are the same skills required within Codman in order that shunts are made to the highest precision and quality. Since watch components and shunt components are virtually the same size it makes sense to harness such expertise and craftsmanship in the production teams.

Each shunt component is vigorously cleaned before being delivered to the highly trained production teams who complete each production step individually, rigorously test the valve at each stage before passing on to the next production phase. All production occurs in a 'clean room,' where staff must were the appropriate clothing, headwear and footwear (no make-up is allowed, in case particles could come into contact with any part of the shunt whist it's being made!).

Final rigorous quality testing and sterilisation complete the process and only when each individual shunt has passed all validation processes can it be released for sale.



Benny Bear



Northamptonshire

Pete Griffiths talks to chairman Alison Walter

Northamptonshire – who hasn't been through it? With the M1 going right up the middle, it's difficult to avoid. Locked in by so many different counties as well, there are plenty of people who live next to it even if they don't live in it.

Northampton's certainly a long way from Southampton – as well as Liverpool, which is where chairman Alison Walter came from before she moved with her husband Steve in the 1980s. They've been happily settled in the town ever since, and have three children: Alissa, 20, Stephanie, 16 and James, 15. Alissa was born with semantic pragmatic disorder – autism – so when Stephanie was born with spina bifida and hydrocephalus it must have seemed like a double whammy.

As you might expect, Northamptonshire's beginnings in the 1960s echo many other ASBAH associations. Its particular origins lie in the efforts of a neurologist at London's Westminster Hospital (as it was then known), which had many spina bifida cases.

Alison found that the association couldn't offer much more than a sympathetic ear. "They had no meetings on a regular basis. The field worker at the time, Pat Waller, wanted to get a group going for parents of young children with SB/H. So we joined that and we met every week in a school."

Fast forward to 1993. What was effectively a mothers' and toddlers' group had become dynamic enough to challenge the status quo and mount a bid to take on the whole association. They pulled it off and Tony Sharpe became the first chairman. The successes of their original group were now writ large: regular meetings - held once a month - for all ages. Families with young children were especially welcome.

In fact NASBAH's success lies in its fresh approach to meetings. This is because they don't have any in the traditional sense. What they do have are socials. Alison explains: "It's up to the members what we do. We do what they want and what that means is getting together socially, in restaurants. This makes for a far more relaxing atmosphere. No one's intimated or feels they have to speak or ask questions. Instead they can just chat and swap notes. Dads like this especially - they just wouldn't come if it was called a 'support group'. It gives carers a chance to get out of the house and relax - but still use the time constructively.

"We're lucky in that, thanks to financial support we've attracted locally, the meals for these evenings are free. It's just the drink that we pay in full for, which is probably just as well," she assures me.

It gives carers a chance to get out of the house and relax - but still use the time constructively.

So, who's there from the committee? All of them: Maggie Nichols, the secretary - who's currently on sick leave - and Gill McCormack, the treasurer. The other two committee members are Rachel Robertson and Michelle Walden.

The core membership totals about 25 families, who come from all the main parts of the county - places like Corby, Rushton, Daventry and Brackley - and it's increasing. "We'd love to hear from anyone in the area, especially anyone interested in taking an active role in the running of the group," Alison says.

The county no longer has an adviser. Pat Waller - having left and come back again, when the gap was filled - left for good in 2001. So how do they help people, I asked. "Well, if it's about continence, we either provide special information, refer them to a medical adviser at Peterborough or to one of the council's advisers – there are three of them now; if it's housing, we say who they should contact at the council. But above all we listen."

"We do put our money where our mouths are, of course. We give grants for hospital visits - expenses can mount up and hospitals don't provide free meals for families! We can do this thanks to a small bequest we were left. We also have the occasional flag day and, of course, we have permanent collection tins at some shops - even the police station. We're lucky in that other organisations also give us money. Local companies have also awarded us grants. This all keeps us going and means we can get on with the job," Alison tells me.

NASBAHs's relationship with Peterborough developed strongly it was consulted over the five year strategic plan. They miss area manager Mary Malcolm now that's she's been promoted but Mary's successor, David Isom, is "making all the right noises" and has already visited them.

After our lunchtime meeting in a popular Northampton watering hole, Alison then rushed back to nurse a sick James. A mother's work is never done.

By Marshall Thomas

9 months and counting

Three days after the Athens Paralympic Games finish on 28th September 2004, legislation comes into force in the UK that will have implications for Britain's own bid to stage the Olympic and Paralympic Games in London in 2012.

From 1st October 2004 the final stage of the Disability Discrimination Act (DDA), relating to physical access for disabled people, comes into force. This will affect anyone who provides a service to the public, including gyms, swimming pools, leisure centres and sports stadia - all will have to make "reasonable adjustments" to ensure they are not difficult for disabled people to use.

The Disability Rights Commission (DRC) estimates that there are a total of 8.5 million people in the UK with some nature of disability. While only a fraction of those 8.5 million will be involved in competitive sport, in keeping with the population as a whole a much higher proportion are potential fans and paying spectators. If you are paying spectator, surely you then should have the same rights as your fellow spectators.

Part M of the Building Regulations (1999 Edition), which looks at access for disabled people, states that the minimum requirement is for 6 or 1/100th of public seating (whichever is greater) should be spaces for wheelchair users. But Part M sets only a minimum target and more comprehensive guidance and alternative options are provided within the British Standard BS 8300.

Nevertheless, spectator viewing is only one aspect of a trip to watch you favourite team. Everything from access to the car parks, the stadia, ticket desks, toilets and refreshments all play an important part in your visit, and, from 1st October, legislation will go beyond the provision of ramps and wider doorways to, for instance, the provision of adequate signage.

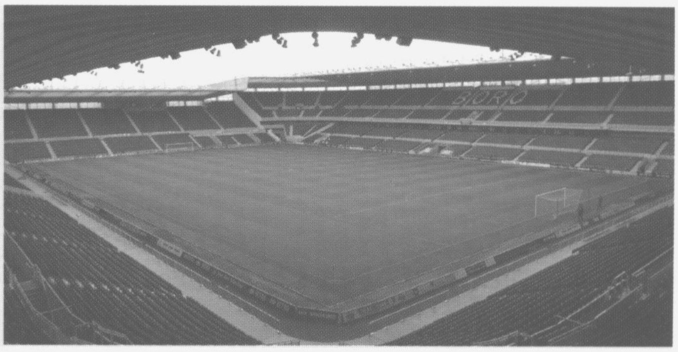
Football has possibly the largest fan base of disabled people in the UK and many top clubs have active disabled supporters clubs, which undoubtedly should be of help when bringing existing or new facilities up to the standards required by the DDA. But up until recently even the likes of Liverpool's Anfield stadium was found not to be fully accessible. For disabled football fans, the 2003 publication Access to Football Grounds - a book researched by Pauline Hephaistos Survey Projects - focuses mainly on Premiership and First Division clubs. The information for the book was gathered by actual visits to the clubs featured, providing a good guide to what can be expected – and perhaps what should be expected come 1st October.

It's been suggested that England's recent World Cup triumph will bring an influx of supporters to Rugby Union. Since coming into being in 2000, the Disability Rights Commission has acted on behalf of a wheelchair using rugby supporter who felt discriminated against at an international ground, while leisure holiday company Centreparcs has also been the subject of another case followed up by the DRC.

Already honoured last year for its provision for disabled supporters, this year the Rugby Football Union has appointed a three man team - two of whom are disabled - to do a survey of facilities at its 12 Premiership grounds. Questionnaires will be distributed to disabled supporters and, in spring 2004, a report will be published on the findings with suggestions on future action that is needed.

The example set by the RFU was used successfully in the lead up to the 2002 Commonwealth Games in Manchester, when disabled people were involved as partners and volunteers in the preparations to make the games fully accessible. The games expected to help contribute to the continued regeneration of Manchester and many of the accessibility features introduced were expected to be permanent.

Finally, back to football. As I write, the Football Association's website carries a page on disability stating that "the FA is committed to making sure that there are opportunities for disabled people in all activities and at all levels and to meet our obligations under the Disability Discrimination Act." Thereafter the page ends with the following statement: *"This section is under development and will be updated in due course"*. I guess there are many sports clubs and venues around the country who could say the same. The clock is ticking. Nine months and counting.



Middlesbrough Football Club, home to Danny Mills. There is an elevated view of the pitch via a purpose built lift system. In case of an emergency, the stadium is well equipped with evac-chairs and many lifts can be used in case of an emergency.

Linda's line

On Christmas Day half the Corbett household tucked into a selection of carrots, broccoli, spring greens and apples.

Lest you think that I've suddenly turned vegan, that healthy stuff was scoffed by Woodstock and Albert the guinea pigs. Meanwhile, the humans hoovered up the usual turkey dinner with all the trimmings, followed by Christmas pudding, sherry trifle and chocolate tree decorations - in short, we over-indulged!

Small wonder then, that when I finally plucked up courage after the festive season to get on the scales, they shouted back something very alarming indeed! I have tried the Linda Corbett instant weight loss technique of holding onto the washbasin whilst getting on the scales and then letting go very slowly. It didn't work. Then I did best of three - alas no better.

So now I'm having a diet crisis. The problem is that none of the diets I have seen in the post-Christmas magazines mention anything at all about being allowed to have chocolate...or cheese...or a nice glass of chilled Chardonnay with my dinner. It's all wrong really - the things I like are supposed to be bad for you, and the stuff I regard as guinea pig food is supposed to be healthy. OK, if that's true, why is Woodstock a strong contender for fattest guinea pig in the Northern Hemisphere?

No, I believe we are all made to feel guilty about eating things that taste nice, and that they are not essential elements of one's daily intake. But what if these things were useful as well as tasting nice? That would surely tip the playing field a bit. For example, how many people will be buying chocolate teddies and other chocolate gifts for Valentine's Day just because it is a nice thing to do? Instead of having "I love you" or some other cute message iced on them, why not make it say something practical? It opens up a whole new market for chocolate merchandising and means that all those difficult messages can be said far more diplomatically.

Who knows, I might even see if they can fit "please put your socks in the laundry basket" on a chocolate heart.

hydrocephalus
action

Uncertainty surrounding the declining health of EastEnders' character Nana Moon began to clear when her consultant told her that she had normal pressure hydrocephalus (NPH).

Her loss of memory was one of the symptoms recognised in NPH; the other classic symptoms, not shown by Nana, are deterioration in walking, balance and incontinence. Up to 5% of patients in the UK aged 60 and over thought to have dementia in combination with these symptoms may in fact have NPH. This 5% could represent up to 24,000 people who may be suitable for assessment for treatment.

Says neurosurgeon Conor Mallucci of Liverpool's Walton Centre, who sits on ASBAH's Medical Advisory Committee: "Many people think that when older people have the combined problems of walking, forgetfulness and incontinence that they are simply suffering from dementia, Alzheimer's or Parkinson's Disease. But it's increasingly recognised that there may be a significant number of sufferers in whom such symptoms may not be initially associated with the diagnosis of NPH."

The treatment involves an operation whereby a fine tube ('shunt') is inserted inside one of the spaces of the brain ('ventricle') so as to drain the excess CSF and divert it to another part of the body where it can be reabsorbed.

Quick facts:

1. What is NPH? Normal pressure hydrocephalus (NPH) is an excessive build-up of fluid in the cavities or ventricles of the brain. Under normal conditions cerebrospinal fluid (CSF) circulates through the brain, its ventricles and the spinal cord acting as a protective cushion and provider of nutrients. NPH results when the flow of CSF is blocked in some way and it occurs most often in people aged over 60. The word 'hydrocephalus' is derived from the Greek words for water ('hydro') and head ('cephalus').

2. What causes NPH? For most patients the cause of NPH cannot be determined. In some cases history of previous brain injury or surgery can result in hydrocephalus. Examples are brain haemorrhage, aneurysm, trauma, tumours or cysts, infections or subdural haematomas. In other cases the imbalance in the production or absorption of CSF causes the hydrocephalus.

3. What are the symptoms? The three main symptoms are gait (walking) disturbance, dementia and urinary incontinence – commonly known as 'Adam's triad'. Diagnosis of NPH is often difficult due to the symptoms being similar to other disorders. In many cases the NPH is thought to be mil[illegible] dementia, Alzheimer's, Parkinson's disease or simply old age factors. Many cases go completely unrecognised and are never treated.

4. How is NPH diagnosed? GPs should consider referring patients with these three symptoms to a neurologist or a neurosurgeon. The most common diagnostic tools are neuro-imaging devices, such as computerised tomography (CT) or magnetic resonance imaging (MRI), and a careful clinical assessment. More invasive tests involve assessment of CSF dynamics.

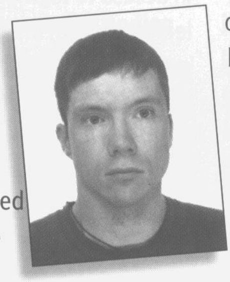
5. Hydrocephalus is most commonly found in young people.

...the Disability Rights Commission is preparing a court action to stop disabled people being charged £18 for access to the Stansted Airport's wheelchairs.

Air travel

Despite the fact that there are as many as nine million people in Britain with some form of disability, the travel industry has never has never seemed fully geared up to cater for their needs.

As a result this can be very trying, and adds to the hassle we all experience when trying to get from A to B. This is none more so then when travelling by plane.



Graham Nugent (right) from Cheshunt in Hertfordshire, 33, who has SB/H and skis for Britain, was recently preparing for the Disabled World Cup Race and the World Championships at Innsbruck in Austria. On top of all the training beforehand he was asked by his airline, Austrian Airways, to provide a form signed by his doctor confirming that he was well enough to travel. This was entirely unexpected and naturally was an extra worry that he had to deal with. Fortunately everything was okay and, at the time of going to press, Graham was all set for take-off and ready to encounter all the practical difficulties of flying, which he has done several times in his sporting career.

In fact it appears that Austrian Airlines tries to be as informative as possible in advance to disabled passengers. Its website has a special section on disabled access to flights, with several points of advice for it to prepare the assistance disabled passengers require.

Elsewhere the Disability Rights Commission is preparing a court action to stop disabled people being charged £18 for access to the Stansted Airport's wheelchairs. The DRC believes that Ryanair or Stansted's owners, BAA, is discriminating against disabled people by making them pay for a wheelchair at the airport they depart from. Under the Disability Discrimination Act a disabled person cannot receive 'less favourable' treatment than a non-disabled person, such as having to pay an additional charge for a service. All other airlines including budget and charter flights provide this service free.

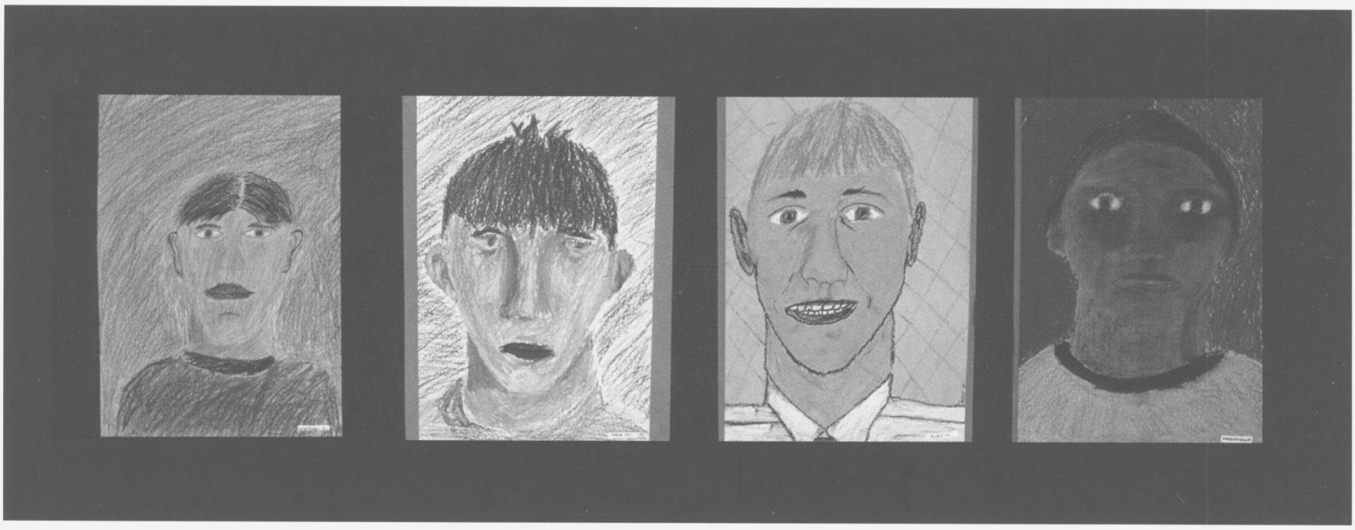
Flying is a particularly notorious area, since it largely falls outside the remit of UK law. So the government has said the UK aviation industry must focus on the needs of disabled people and work to achieve access for all. To help bring this about, it has introduced a voluntary code of conduct, Access to Air Travel for Disabled People. This targets the needs of individuals with a disability from the moment they book their flight to their return journey home by setting out minimum standards of service and access in terminals and on planes.

Recommendations in the code concentrate on meeting the needs of disabled people when booking their flight, travelling to the airport, using facilities within the terminal building and aircraft and provide a comprehensive resource for the travel industry to follow.

The code was introduced at the same time as a guide for disabled passengers, issued by government advisers the Disabled Persons Transport Advisory Committee (DPTAC). The guide follows a step by step journey, from planning the flight to getting to the destination. It explains why airports and airlines need information about disabled and less mobile passengers and also what they can be expected to provide to make journeys easier.

Editor's note:

1. *A copy of the Access to Air Travel for Disabled People can be found at the DfT website at www.dft.gov.uk or by contacting the Department for Transport at Disability Policy Branch, DfT Mobility and Inclusion Unit, Zone 1/18, Great Minster House, 76 Marsham Street, London, SW1P 4DR. Tel: 020 7944 2914. Fax: 020 7944 6102 or miu@dft.gov.uk*
2. *The guidance for disabled travellers can be obtained at www.dptac.gov.uk or by writing to the Disabled Persons Transport Advisory Committee, c/o Secretariat, Great Minster House, 76 Marsham Street, London, SW1P 4DR. Tel 020 7944 8011. Fax 020 7944 6102. Minicom 020 7944 6100.*



New Green Paper for children

Plans to reform children's services to protect children from neglect and harm and ensure that each child is able to fulfil their potential have been set out by the government.

The Green Paper *Every Child Matters* proposes:

- integrated teams of health and education professionals, social workers and Connexions advisers based in and around schools and Children's Centres;
- sweeping away legal, technical and cultural barriers to information sharing so that, for the first time, there can be effective communication between everyone with a responsibility for children;
- establishing a clear framework of accountability at a national and local level with the appointment of a children's director in every local authority responsible for bringing all children's services together as children's trusts;
- new duties on police, health and others to safeguard children and require them to come together into local safeguarding children boards;
- children's services to be judged on joint working through integrated inspection framework overseen by Ofsted;
- a national campaign to recruit more foster parents and a workforce reform package to make working with children an attractive career, and improve the skills and effectiveness of the children's workforce;
- the appointment of an independent children's commissioner to champion children's views.

Responding to the Green Paper, the Disability Rights Commission said that the government should set explicit targets to bridge the attainment gap between disabled and non-disabled children. It also warned that a failure to establish flexible support services for disabled children could result in increased levels of family breakdown.

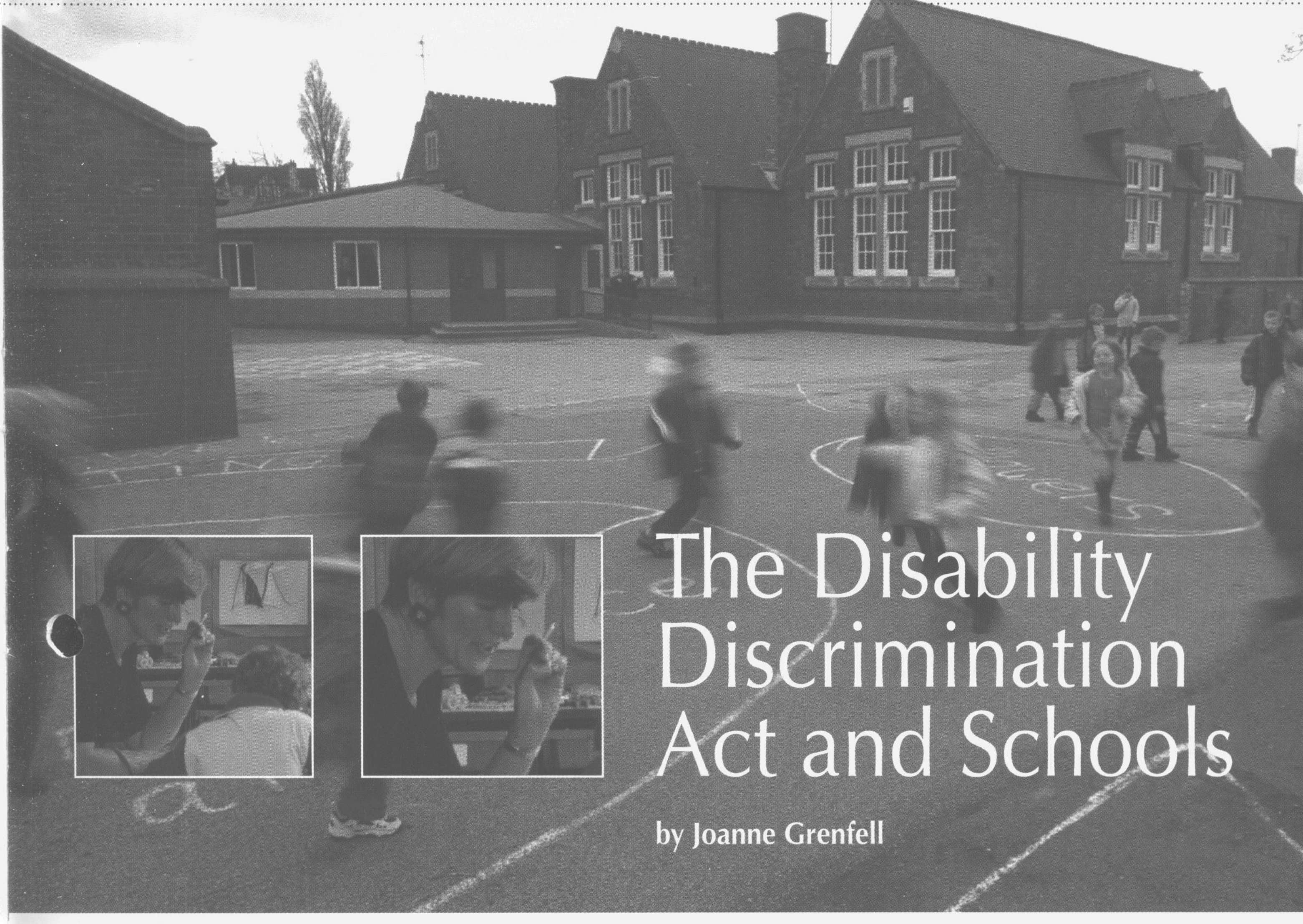
It said that disabled children and their families have a high risk of social exclusion and experience marked inequalities if they do not receive appropriate multi-agency support, in many cases throughout their lives. Despite this the green paper fails to acknowledge disability as a key factor in predicting inequality and sets no clear targets to redress the disadvantage faced by disabled children, young people and their families.

It went on to say: "Families of disabled children incur considerable additional costs on heating, housing, clothing, equipment and other items. Although their needs may be greater, families with disabled children are less likely to own a car or a telephone than families with non-disabled children.

"Young disabled children are more likely than their non-disabled peers to leave school without qualifications. 70% of disabled adults currently rely wholly on benefits for income and many young people have low expectations of employment, relationships and quality of life as adults. Recent developments in access to high quality education, leisure, health and social care have greatly improved the life chances of some disabled children. But the majority and their families continue to experience multiple difficulties, social exclusion, and fragmentation of support services.

"Difficulties in accessing appropriate services can have significant impact on the quality of life of disabled children, siblings and families and can in turn increase the risk of subsequent exclusion from school, poor educational attainment and limited chance of gaining higher education qualifications, vocational training and employment. The increasing lack of appropriate and flexible support services can lead to family breakdown," the DRC said.

Consultation ended in December 2003 and the government says that legislation will be introduced at the earliest opportunity.



The Disability Discrimination Act and Schools

by Joanne Grenfell

It's now law that local education authorities (LEAs) and governing bodies have a legal duty not to discriminate against disabled pupils in any aspect of school life.

Previously the Disability Discrimination Act (DDA) had limited application to pupils and was mainly aimed at employment and non-educational discrimination. The Special Educational Needs and Disabilities Act, which amends the DDA, ensures provision must be made for disabled pupils. LEAs and schools must treat all pupils equally and never unfavourably, unless it can be justified. What this means in reality is that all schools must have effective strategies for delivering education to disabled pupils.

Even where schools have no disabled pupils they must draw up appropriate plans. They must ensure all disabled pupils have full access to the curriculum; and they must consider how to improve the physical environment of their school, such as making it accessible.

Schools need to consider how to improve the delivery of their written information, such as in textbooks, handouts, worksheets and school letters. Improvements are expected to cover not only teaching and learning but also access to the wider curriculum, such as before and after school clubs and club visits. Should any parent of a disabled child have cause to complain about discrimination in provision then they have the right to go to a tribunal. Any less favourable treatment is unlawful if it cannot be justified. Justification is only possible where "reasonable adjustments" cannot be made to accommodate the pupil's needs.

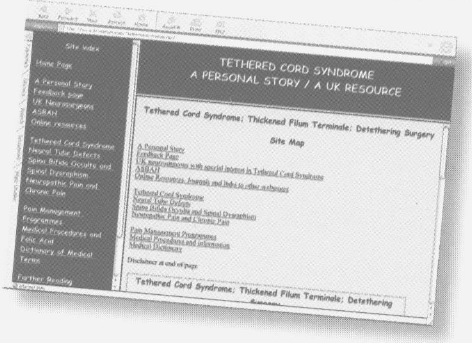
Under the new duty, schools don't have to make immediate adjustments to the physical facilities of the school or provide auxiliary aids for individual pupils. Such needs are specifically excluded under this Act. Instead, schools are responsible for ensuring teachers and staff are trained and equipped to teach and support disabled pupils.

LEAs should ensure sufficient training and advice are provided and that schools have enough information about the disabled children attending the school.

Even where schools have no disabled pupils they must draw up appropriate plans. They must ensure all disabled pupils have full access to the curriculum

My new tethered spinal cords website

by Nina Bunton



TETHERED CORD SYNDROME
A PERSONAL STORY / A UK RESOURCE

Tethered Cord Syndrome: Thickened Filum Terminale: Detethering Surgery

Site Map

A Personal Story
Feedback Page
UK neurosurgeons with special interest in Tethered Cord Syndrome
ASBAH
Online Resources, Journals and links to other webpages

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Neural Tube Defects
Spina Bifida Occulta and Spinal Dysraphism
Neuropathic Pain and Chronic Pain

Pain Management Programmes
Medical Procedures and information
Medical Dictionary

Disclaimer at end of page

Tethered Cord Syndrome: Thickened Filum Terminale: Detethering Surgery

Tethered cord syndrome, thickened filum terminale and detethering surgery: all these terms were just words to me in 2000. I didn't understand fully what was wrong with my deformed feet, and I had no idea about, or understanding of, tethered spinal cords. Of necessity I have become very familiar with many aspects of tethered cord syndrome since then!

The condition of my tethered spinal cord began to deteriorate in early 2000. After recovering from the shock of diagnosis and my huge fears of disability, I tried to find information on the internet to learn more about the problem but very few UK sites with relevant information existed. Any details I could find were from US sites (universities and medical centres), which were wholly aimed at the fully informed medical professionals and were very technical indeed.

It seemed there was a gaping hole in the information available in the UK on tetheredspinal cords and the associated conditions, so I produced *www.btinternet.com~tetheredcordresources/* This is a website based on my own experiences of this condition and successful detethering surgery:

The site also consolidates information and resources I found in my Internet search, and includes information pages with clickable links and journal sources. I make no apologies for it being a wordy site with no fancy gizmos, but it is always under review.

I hope it will become a useful resource for people with tethered spinal cords subsequent to spina bifida occulta. I welcome feedback, advice, and personal stories that you feel happy about publishing, so that this site can grow and continue to provide support. Please contact me on *nina.bunton@talk21.com*

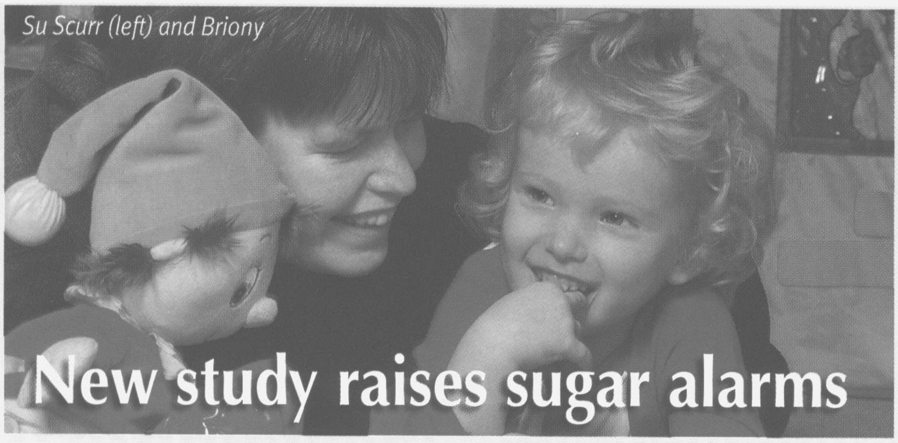
New information sheets

The second in our series of a new and revised range of information sheetsis follows on pages 29 and 30:

- ***Behaviour problems associated with hydrocephalus***

You will soon be able to download from www.asbah.org.uk the current series of information sheets, but in the meantime these can obtained from the Information Department at ASBAH House, 42 Park Road, Peterborough, PE1 2UQ.

Su Scurr (left) and Briony



New study raises sugar alarms

An American study of 1,000 women has found that the risk of neural tube defects such as spina bifida in babies was much greater amongst mothers who consumed higher levels of sugar when pregnant. Other foods with highly refined carbohydrates, such as potatoes, rice and corn flakes, also increased the risk.

Dangerous foods also cited include popcorn, chocolate bars, cooked carrots, honey and some soft drinks. These fall into the category of foods with a high 'glycemic index' (GI). This means they release large amounts of glucose quickly, giving a sugar rush, followed by a low.

This surge may overwhelm the baby in the womb, the study says, interfering with key stages of development, such as formation of the tube of bone around the spinal column.

The new findings were reported in the American Journal of Clinical Nutrition. ASBAH chief executive Andrew Russell says this is the first research to find such a link and it should therefore be regarded with great caution. "To tell a mother who ate cream cakes early in pregnancy that she is responsible for her child's birth defects is simply not justifiable at this stage," he warns.

"Neural tube defect research is very complicated. The idea that a sugar surge in the maternal blood could cause spina bifida, while not impossible, would need a lot of corroboration from follow-up studies. What we do know for certain is that a shortage of certain vitamins – most notably folic acid – in the early days of pregnancy cause neural tube defects. But the link to the GI of your diet, though worthy of research, is by no means proven.

Dr Ross Welch, a specialist in foetal medicine at Arrow Park Hospital in Cheshire, said in *The Sunday Telegraph*: "Assuming these results have a sound statistical basis, then this is important. The question we have to ask is what we do about it? Most mothers did not realise the crucial importance of diet in the first days of pregnancy, he said.

"High blood sugar levels have already been linked with foetal abnormality in diabetes, and this new research seems to be in line with that. He added: "Preconceptual folic acid is, however, still likely to be more important."

Su Scurr, from Tiverton, Devon, whose three year old daughter Briony has spina bifida, welcomed the research. She told *The Sunday Telegraph*: "If these foods are a significant factor, then women need to be made aware of this research. I wouldn't wish what happened to me on anyone. It was awful. We found out that I was carrying a child with spina bifida at about 22 weeks.

"I took folic acid in the two months before I got pregnant and made sure I ate lots of fruit and salads, but in the past I had eaten quite a lot of sugar. Who doesn't eat cereals? We need more research into spina bifida."

With thanks to The Sunday Telegraph for permission to reproduce the quotes

Information

ASBAH

February 2004

Behaviour problems associated with hydrocephalus

Children with hydrocephalus often exhibit behaviour problems that are mistakenly attributed to naughtiness (or disruptive tendencies). Of course children with hydrocephalus can be naughty as much as any other child and the difficulty often lies with sorting which cause the perceived bad behaviour has.

If the child's behaviour deteriorates rapidly, think shunt; if the onset is insidious, it is likely to be due to the damage caused by the hydrocephalus.

Examples of problematical behaviour may include:

Hyperactive/inattentive

The hyperactive child is disruptive in the classroom setting: he won't get on with his set work and his behaviour will make sure that his peers' work suffers too.

The inattentive child may get up from his seat and wander around: he may hum, tap his fingers etc. Both problems are often associated with poor short term memory and may improve if strategies to overcome this are employed. These strategies can include reminders (verbal and written), setting work to be done in short bursts, trying to increase the child's memory span by "memory games".

Verbal aggression and swearing

The swear words seem to "come from nowhere" and where the child hears them is often a mystery. However, once the child finds the attention he gets and the effect that swearing has on others, he will use it as a powerful tool to get his own way.

Verbal aggression - threats, demands etc. - is also distressing and often shocking, again is a way of controlling adults.

Bizarre behaviour

A good example is the boy that laughs loudly for long periods (sometimes several hours) with no trigger and often in the middle of the night. He has no explanation, why should he? To him this is quite usual. The parents are powerless to stop it.

Role play

Where the child really believes that he is the person whose persona has taken on e.g. the boy who is an airline pilot and talks jargon obviously learnt from old films - "Chocks away", "Roger and out" etc.

Threatened suicide

This is, fortunately, uncommon in children and usually involves long, convoluted accounts of how he is going to commit suicide - mostly unrealistic. For example "I shall jump out of the window and run across the road under a car and then I,ll go to the railway line and chuck myself under a train and then I'll drown in the river and you'll be really really sorry".

Parents, quite rightly, become very worried: the threat of suicide (in children) is rarely carried out but your doctor needs to be aware.

Obsessions

Children with hydrocephalus are often obsessive with objects and shapes (often circles), colours (particularly primary colours) and people.

Children may be overprotective towards their chosen obsession and unable to share: they may become aggressive to people they are obsessed with and this can increase if this person is seen to prefer another child or even if they just talk to another child.

As you can imagine, life can be difficult if the child is obsessed with a family member (particularly mother) or a teacher as the situation will, of course, arise when this person has to be shared. The concept of sharing people's attention needs to be talked through with the child (and often repeated)

Robotic behaviour

The child may exhibit complicated rituals at home, at school, at play. Everything has to be done in the same order by the same person: it can start insidiously with more components gradually included. It has been known for a child to stretch bedtime out to include 17 separate actions!

No sense of danger

The child will walk off the top of climbing frames, step off roundabouts when he has finished playing etc. Just as important, "stranger danger" needs frequent reinforcement - "frequent" may mean daily for some children.

Temper tantrums

These can affect children of all ages. There is often a trigger, which starts this mode of behaviour but this can be so subtle that it is difficult to identify - often a change of routine, a perceived insult, a change in weather. Commonly, the child will have to continue the tantrum until it reaches a natural end: they seem incapable of stopping the behaviour despite the parents/cares applying usual, distractions or discipline.

Mood swings

"From angel to devil" in a matter of minutes. This can be a daily (or many times daily) occurrence and can appear to be cyclical in both boys and girls: keeping a diary will help note the regularity.

Social isolation

Many children have no friends of their own age and this can be due to many factors; but remember, some children like being on their own.

Inappropriate sexual behaviour

Even young children may make sexual remarks, may touch other people sexually and may even make sexual approaches . If nothing is done (and parents do find it embarrassing and shocking and difficult to address), this can carry on into adulthood. The problem must be addressed well before puberty. If you are uncomfortable with broaching the subject, do ask for professional help from your GP or ASBAH adviser.

The need to follow a pattern of behaviour to its conclusion

Unless you can identify the trigger which provokes the behaviour, you will not stop the child until he is ready to stop.

It is as though, once started, the child has to progress through certain stages and is powerless to interrupt the process or allow it to be interrupted.

Lying

All children lie. Children with hydrocephalus believe that what they say is the truth however improbable or outrageous the lie is. Unlike most children, they will, however, often change their story when challenged.

Manipulating - people and situations

Children soon learn the best method to get their own way and how to maintain their position of dominance in the family. Using their condition (hydrocephalus) is so easy and so effective!

Once a behavioural problem has been identified, look for possible reasons

First, is this a shunt related problem? Did it start post shunting? Do you know that the child's shunt is working efficiently? When did your child last see a neurosurgeon? (If no check in the last year or if the behaviour has started since his last check, make an appointment now).

- does the behaviour fluctuate? Is it cyclical? If yes, keep a diary and show it to the surgeon.

Then:

- is there associated epilepsy? If yes, check medication for side effects.
- has any medication been started or stopped?
- is your child taking unprescribed (even herbal) or "social" drugs?
- has puberty arrived? Remember some children with hydrocephalus have precocious (early) puberty.
- and is the behaviour related to short term memory problems? Spatial awareness? Concentration?

Now, look at the time of day:

- is the child feeling harassed? Are you hurrying him? (Try to allow more time if this is the case).
- has the daily routine changed?
- do you think your child,s blood sugar is low. (Lucozade or glucose tablets may help).
- is the child tired?

Has there been a change in circumstances?

- New school?
- New sibling?
- New step parent?
- Even new furniture can affect some children.

Stress may be a factor:

- SATS.
- exams or test of any kind.
- arguments with friends.
- appointment with doctor/dentist/ optician etc.

Regular behavioural changes first thing in the morning or at the end of the day may signify pressure changes.

What do we do?

There are no simple solutions - if only there were! However, a few simple suggestions may help:

- parents and school need to work together and appear united.
- do not discuss your anxieties in front of the child or his siblings.
- make eye contact with the child when you are speaking to him.
- give one instruction at a time; ask one question at a time. Keep it all in simple steps.
- acknowledge good behaviour.
- be positive.......when you can.
- avoid difficult situations which may trigger poor behaviour. This could involve a different route to school to avoid road works etc. Or you could try diversionary tactics i.e."look at the aeroplane".

Try to discuss what has happened after the event

- What triggered the behaviour?
- Why?
- What could have you, the parent done to help?

Avoid:

- threats e.g. "if you do that you will get no dinner". The child will only retain the last part of the sentence and will therefore assume that he will not be eating tonight.
- using sarcasm e.g. "oh well done" - it will be taken literally.
- ridiculing the child.
- verbal overload: a long lecture is a waste of your time and energy. The child will soon lose interest or will forget what he is being lectured about.

Hydrocephalus is a complex condition, no two children are alike. Many will have few or no behaviour problems; others will, unfortunately, demonstrate far more difficulties although not necessarily all at once.

Further information:

1) Hydrocephalus and You -published by ASBAH

2) Your neurosurgical unit may have a neuro psychologist with an interest in hydrocephalus.

Holiday let

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

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Tel/Fax: 0161-792 3029 or
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website: *http:homepage.ntlworld.com/susan.fisher33*

Independent Living

Stretford/Manchester
(convenient all amenities)

1 Bedroom groundfloor wheelchair accessible flat/bungalow available soon. Davis Court Scheme of Trafford & Salford ASBAH. Limited support for independence scheme, pullcord alarm, communal laundry, gardening and window cleaning. Details: **Tammi Gaynor tel: 0161 865 0222.**

Classified rates

£3.75 for 30 words max.
£5.50 for 30-45 words
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Cheques and postal orders should be made payable to 'ASBAH' Classified adverts for the next issue of Link should be submitted by Friday 19 March 2004

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

Letters

We welcome letters for publication, which should be sent to: Editor, *Link*, 42 Park Road, Peterborough, PE1 2UQ. The editor reserves the right to edit letters, so please keep them short.

Living with ACE

Life as a spina bifida person is never easy, as there many problems to overcome. But an antegrade continence enema operation has probably changed my life.

My main problem now is how or where to hang half a litre of saline solution when going to the toilet. Many cubicles don't have hooks or places to hold the fluid at the necessary height, and there's nothing available on the market. But you can try using collapsible tent poles that have hooks, or even collapsible camera stands. Ladies' vanity bags are also useful for travelling.

Anyone wanting further ideas can contact me.

David Stott, Nelson, Lancs Tel: 01282 691 518

Diary dates

ASBAH Northern Ireland AGM
Sat 6 March
Details: ASBAH Northern Ireland,
tel: 028 9079 8878; niro@asbah.org

Support Group, Dunstable
Mon 8 March
Details: Valerie Bottoms, tel: 01582 757745;
valerie.bottoms@ntlworld.com

Wheelie Club, Belfast
Sat 13 March
Details: ASBAH Northern Ireland,
tel: 028 9079 8878; niro@asbah.org

Leisure and Lifestyle Group
Sat 15 March
Visit to Knebworth House, Herts. £8.50
Details: John Richards, tel: 01908 610 611

Workshop on hydrocephalus and children, Northern Ireland
Sat 27 March
Details: ASBAH Northern Ireland,
tel: 028 9079 8878; niro@asbah.org

Northern Region, Liverpool
Fri 7 May – Sun 9 May
'Getting the Most Out of Life' for 12-17 yr olds with sb/h; £50.
Details: Angela Lansley,
tel: 0151 733 8392; angelal@asbah.org

Support Group, Dunstable
Wed 21 April
Details: Valerie Bottoms, tel: 01582 757745;
valerie.bottoms@ntlworld.com

Hertfordshire Support
Mon 10 May, 7.30
'Australasia on Wheels' by Warren Tofts
Details: John Richards, tel: 01908 610 611

Naidex, NEC
Tues 11 May – Thurs 13 May
The UK's largest exhibition for disability and rehabilitation products; free admission. Details: tel: 0870 429 4428; wwwnaidex.co.uk

ASBAH AGM
Sat 18 September
42, Park Road, Peterborough
Details: Lyn Rylance, tel: 01733 555 988,
lynr@asbah.org

Please e-mail the editor (link@asbah.org) dates for the next issue of Link *by Friday 12 March, giving the name of event, purpose, location, date, cost (if applicable), contact name, phone no. and email address.*

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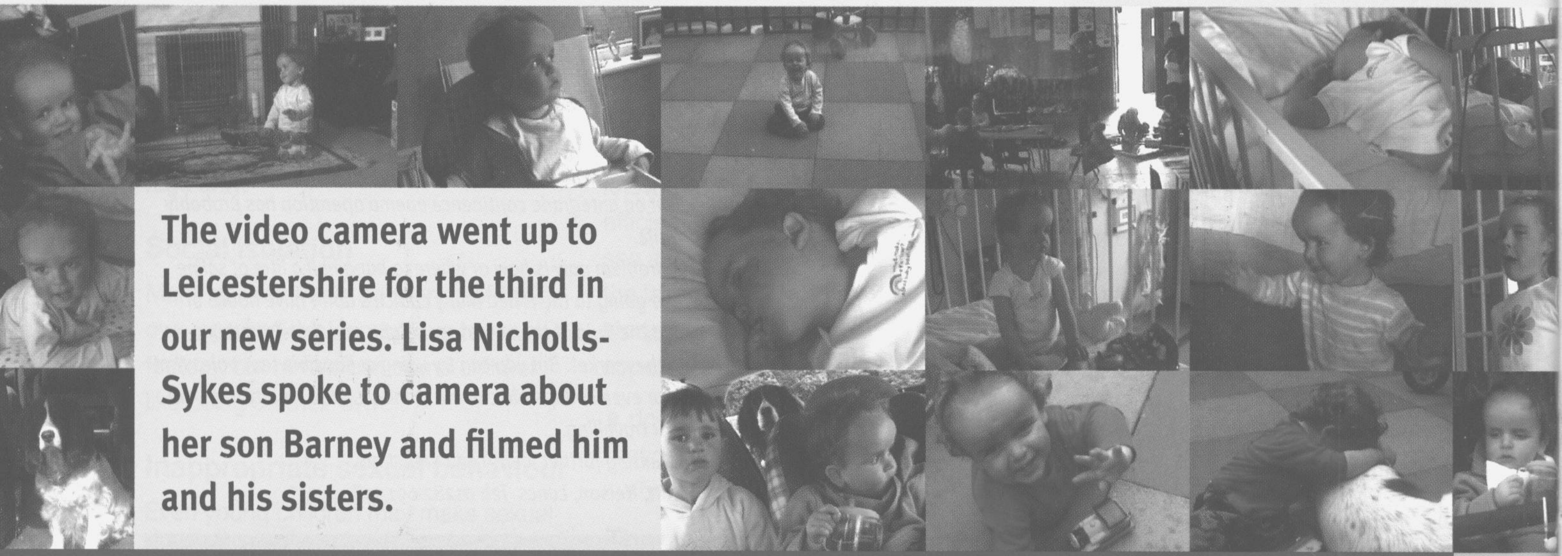


The video camera went up to Leicestershire for the third in our new series. Lisa Nicholls-Sykes spoke to camera about her son Barney and filmed him and his sisters.

...Lisa and Barney Nicholls-Sykes

"Barney has hydrocephalus, which is fluid on the brain. We all have fluid on the brain, which drains away naturally. But, with Barney it doesn't and this causes problems.

It's a hidden disability and to passers by Barney looks normal so people can't understand why he is slow for his age. Hydrocephalus is hidden - hard to quantify. It's hard to pinpoint the symptoms. It's difficult to decide whether his behaviour is due to the hydrocephalus or if he is just being difficult. We have explained to his sisters that he is different and he'll learn less quickly.

His development delay is quite significant - he's about a year behind his milestones. He can sit and crawl but he can't walk or talk like other two-and-a-half-year-olds. Every case of hydrocephalus is different, so we don't know if he will be going to main school or not.

It's not knowing what the future holds that's the hardest part. I took a career break to have Barney and his two sisters but although I planned to go back to work last year I wasn't able to. His delay in development could reduce as he gets older, but we just don't know.

Neurosurgeons don't have time to explain things thoroughly or answer all our questions. When Barney was diagnosed we were given ASBAH's *Hydrocephalus and You* leaflet, which was brilliant. It's reassuring to know that other people are experiencing the same things.

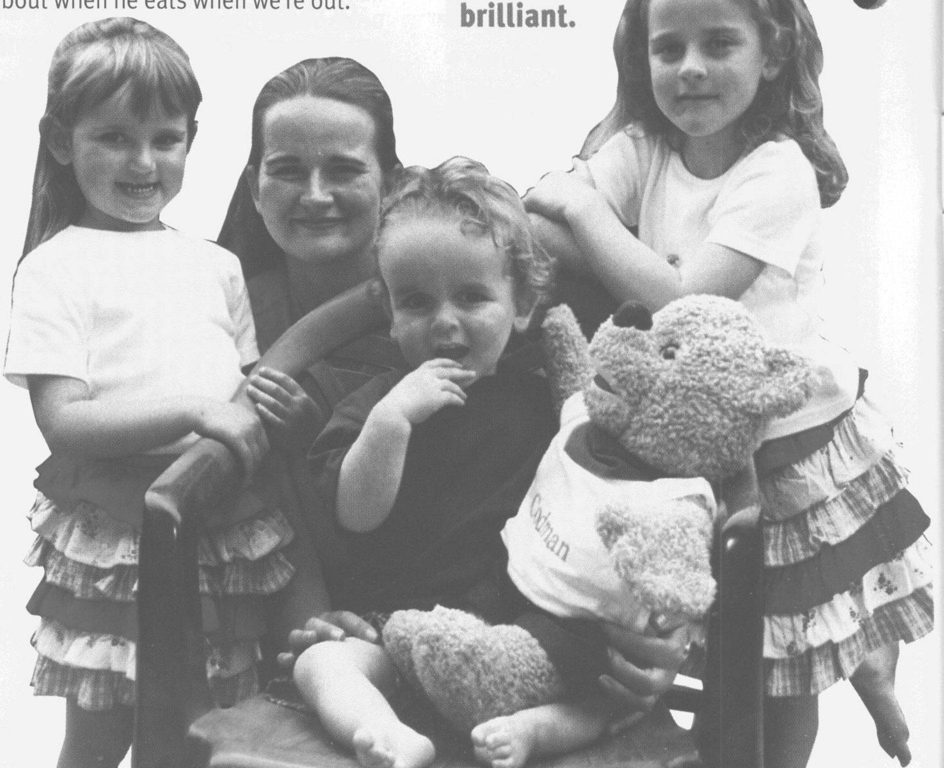
It's hard to find suitable clothing for Barney. I like to get soft t-shirts, which will go over his head easily, as it's still quite pronounced. It's also difficult finding sun hats - hats designed for his age are too small and adult hats just look plain ridiculous.

Barney had a shunt revision last year. When he is in hospital it can be expensive eating and travelling.

One of the hardest things about living with Barney's hydrocephalus is that it makes life very rigid and inflexible. He has eating problems and he's still not feeding himself. We have to stick to a routine of mealtimes and we have to be punctual about when he eats when we're out."

hydrocephalus action

When Barney was diagnosed we were given ASBAH's *Hydrocephalus and You* leaflet, which was brilliant.



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