

- Siobhan shares her personal diary
- Meet the expert - Rosie Kelly
- Festive festivals
- Northern Ireland golf day report
- Hollister travel certificate
- Hydrocephalus Action update

LINK

*The magazine for
people with
hydrocephalus
and spina bifida*

**Carl
takes to
the road**

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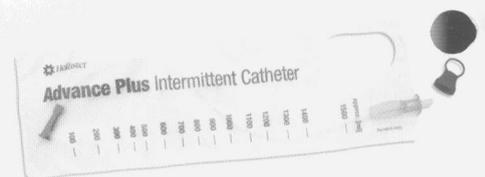
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Peter Farrall writes

Link readers are an active bunch of people, and this issue we take a look at some of the more unusual sports they are involved in. From Caroline Walsh who works as a marine conservation scuba diver to biker Carl Hodgetts, they are people who refuse to let their wheelchair get in the way of exciting experiences.

This issue sees the start of a new series, Siobhan's Diary, in which Siobhan Corr, who has spina bifida and hydrocephalus, shares the highs and lows of her first pregnancy. It's an emotional time for any woman, without the additional concerns surrounding Siobhan's own health, so it will be an interesting read.

We also report on a new DNA research study that shows that half the Irish population at increased risk of neural tube defects.

Amongst all these articles we have still found room to include all the popular regulars such as Happy Days, which looks at several of the international festivals celebrated around the world during the winter months.

This, of course, prompts me to wish all our readers a very Merry Christmas and a Happy New Year. And if you have problems making and sticking to your New Year resolutions, take a look at Linda's Line. You'll find that you're not alone!

Peter Farrall
Assistant Director
(Marketing and Communications)
peterf@asbah.org

*Best wishes,
Peter*

Tatron:
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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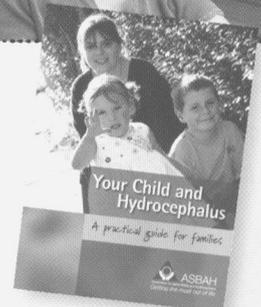
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Blue in the face over blue badges!

Wirral Association members have recently been experiencing problems with parking. Their local council introduced changes to parking enforcement late last year and as a result more parking attendants are now patrolling the borough's roads.

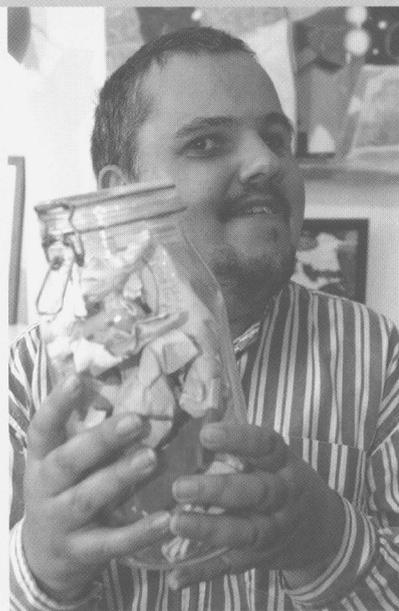
Anyone parked on yellow lines or in council car parks without a relevant badge or parking ticket risks getting a penalty charge notice (PCN) and a fine of up to £60.

The new enforcement regime also targets motorists who abuse use of disabled parking bays. So it is essential that valid blue badge holders in the Wirral display their permits properly – and the same should go for anywhere else for that matter. So here's a quick reminder for ALL blue badge holders of how the scheme works:

- do not leave your vehicle in any location where doing so would create a hazard or obstruction to other road users or pedestrians
- ensure that your blue badge is correctly displayed, with the expiry date and serial number clearly visible for parking attendants to see
- do not display the badge photograph-side up
- ensure details on the front of the badge remain legible. If they become unreadable, the badge must be returned to the authority for re-issue
- do not park on yellow lines without also clearly displaying your disabled person's disk clock on the vehicle dashboard. The clock must be set to the time of your arrival – and remember, you can only park in this area for three hours
- people who have free car tax because of a disability do not automatically have dispensation for parking in disabled bays or on yellow lines. They must still apply for a blue badge
- blue badge holders cannot park in any area where loading restrictions are in place.

If you have encountered problems over disabled parking in your area then write to [Link](#) and let us know.

Happiness is pure poetry



Gerard Dupé, 37, from Newport has won a special prize from a local art gallery following a competition inspired by Ian Drury and the Blockheads' hit Reasons to be Cheerful. Ian Drury had polio as a youngster and in later life did a lot of work for disabled people.

Gerard, who has hydrocephalus, entered the competition run by Janet Martin of Gwent Picture Framing. His piece was called Prescription for Laughter, which contained a poem and a glass jar filled with tablets, all with cheerful messages on them. "The combination of his words and the encapsulated sentiments in his glass jar was totally moving and thoroughly worthy of the special award," Janet said.

Prescription for Laughter

*Why can't you bottle laughter
Or take it as a pill?
You could have it from the doctor
Whenever you are ill.*

*You can have it on prescription
And you could pass it around
And you could call it 'wondercure'
This great new drug you've found.*

*Laughter is infectious
And it could be a cure
The great thing about laughter is
It leaves you wanting more.*

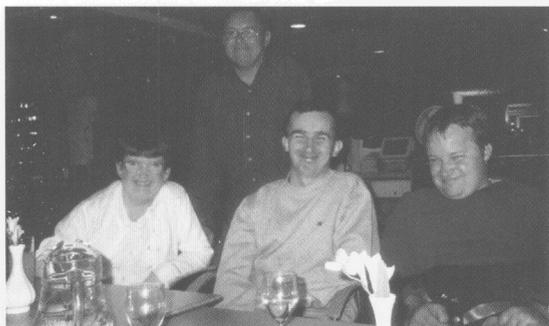
*So take a dose of laughter
And have it once a day
And it would free you of all ills
And chase your cares away.*

Gerard has written hundreds of poems since he was eight years old. In keeping with the theme of the competition he says: "It's personal things which make me cheerful, like my family, friends and my nephews and nieces." He has also studied painting and drawing at his local community centre and since January has been having lessons from family friend Fay Prevot.

Whizzkid Aiden

While Team GB have been doing their bit for glory in Athens, closer to home Aiden Clarke, 14, from Harlow has been doing pretty well too. A member of the Eastern Region Team, he came home from June's British Disabled Athletic Championships in Blackpool with no less than two silver medals and one gold in wheelchair racing. This bettered even his 2003 tally in the same championships of one gold and one silver. Clearly someone to watch!





My Your Voice weekend by Bonnie Harris

Although diagnosed at birth, I have to say that up to a few months ago my use of ASBAH's information and support networks has been somewhat limited, particularly in terms of meeting other people in the same situation.

I attended mainstream school, where I was the only one with spina bifida and hydrocephalus throughout the entire time I was there; also, I never had many opportunities to meet other people locally of my own age with spina bifida and hydrocephalus.

Not being at all outgoing when I was little, I would not have been overly keen to go on social activities. However, having rather come out of myself I really enjoy this sort of thing now.

And so I eagerly attended Your Voice's late August weekend in Birmingham which focussed on beauty, skincare and health (and yoga!).

When I first arrived at the hotel I was pleasantly surprised by the number of delegates; speaking of the hotel, I thought that (apart from the most minor hiccup concerning an oversight over the preparation of my room) it was absolutely flawless.

The staff could not have been more helpful, accommodating and friendly. I felt nothing would have been too much trouble. Apart from there being just steps and no ramp to the check-in desk there was not a place in the whole hotel where we could not all have gone unaided.

After a lovely dinner on the first night we found an attractive and relaxing bar to go and sit in. There I made all the acquaintances I was to keep all weekend.

The two workshops I attended were yoga in the morning and then skincare and beauty in the afternoon. The skincare one was fascinating: I found out what skin type I am (I always complain of dry skin, but now it's official!) and which skincare products from the Body Shop's range are the most suitable. I got the most relaxing makeover; which also proved useful, as we had arranged to go out straight after dinner and I was half ready by four o'clock!

On a more serious note, I also learnt about the important work the Body



Shop does to improve conditions in third world countries and to minimise exploitation of farmers and labourers. At the same time they ensure that these people's crops are used in making the cosmetics, and as a result the Body Shop's products all have something of a selling point in that they are very natural and plant based.

Finally, we had a very interesting presentation on the work of ASBAH and the Your Voice committee on Sunday morning; this was followed by a feedback session, which I think was very valuable.

"If you haven't been before you may not be sure that you will get anything out of it, but believe me you will!"

It was then that I was asked to write this article, as a reminder to those whom I hope enjoyed the weekend as much as I did, and to attract new people to come on future ones. If you haven't been before you may not be sure that you will get anything out of it, but believe me you will!

Apology - Link 209

Apologies to Sister Ellie Shepherd and care assistant Sue Murden from the The Chelsea and Westminster Hospital Medical Day Unit, whose names were missing from the article in *Link 209*.

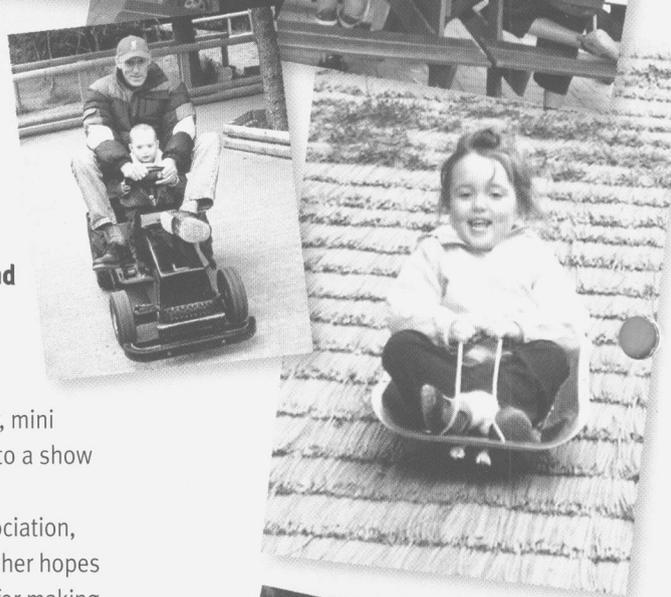


North Wales Fun Day

Eight families from all around the North Wales area gathered together to enjoy a day of activities and entertainment at Greenwood Forest Park in Felinheli, Gwynedd. This was the second North Wales Fun Day after an extremely popular event last year. The day was organised by the North Wales ASBAH team.

The park is entirely eco-friendly, and features a rollercoaster, inclined railway and a self-propelled Jungle Boat, as well as archery, mini tractor driving and a 70m sledge run. The group were also treated to a show with magicians and clowns.

The day was entirely funded by the North Wales ASBAH local association, and area adviser Jill Bartlett commended their efforts and expressed her hopes for more such events in the future: "I'd like to thank the whole team for making this day possible. It was a great success, and everyone had a great time. Our aim now is to build on this and make the Fun Day an annual event."



A good time had by all!

Sunshine and glorious weather heralded the start of this year's Summer Experience and continued throughout at the Keppleway Centre in the Lake District. This was the third four-day course organised by Northern Region's Manager Joan Pheasant and a team of staff and volunteers for 14 adults with spina bifida and/or hydrocephalus.

Morning sessions included abseiling and tree climbing, archery and canoeing on Coniston Water. Said Joan: "The instructors were excellent. Their knowledge in how to make the activities inclusive was amazing, as was their ability to promote confidence and a feeling of self-worth in all the participants."

Afternoon activities included bowling, shopping, a boat ride on Lake Windermere, a look around an aquarium or just chilling out and resting.

A good time was definitely had by all!



Caroline in action

Down under

Caroline Walsh has spina bifida and has used a wheelchair since she was 15... but that hasn't stopped her from taking on an exhilarating day job as a diver. Caroline is the founder of Access to Marine Conservation for All International (AMCAI), which trains the growing number of disabled scuba divers wishing to become active in the protection of the marine environment.

She says: "For someone who is physically challenged diving may not necessarily be a first choice of recreation, but it can be a truly equalling sport. The feeling you get when you're

just floating mid-water looking over the corals - especially over a sheer drop off - is truly exhilarating and amazing!"

For further information about AMCAI contact Caroline at c.a.walsh@btinternet.com or see www.amca-international.org



Photographs copyright AMCAI 2003/2004

More training for youngsters

A new training manual has been published by the Association of Wheelchair Children to help youngsters improve their road safety.

Research has revealed that the 100,000-plus children in the UK who use wheelchairs do not receive the training they need to help them become independent and safe travellers.

ASBAH, a keen supporter of the Association of Wheelchair Children (AWC), has welcomed the launch of the new manual, which explains all aspects of road safety, from how to find a safe place to cross to negotiating different types of road junctions.

The AWC and ASBAH have enjoyed strong links for several years, with many service users benefiting from AWC's one-day training courses.

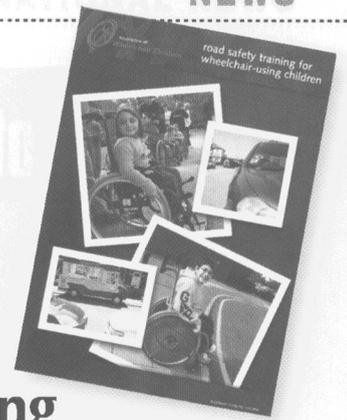
Each year more than 240 children nationwide are taught, free of charge, how to use their wheelchairs more effectively.

Mary Malcolm, ASBAH's Assistant Director (Services), said: "The AWC provides a fantastic service. The courses are run throughout the year all over the country, and we are always keen to encourage children and young people to attend.

"Being taught how to use their wheelchair properly makes such a difference to their agility, and gives the child so much more confidence."

Anyone wishing to book a place on an AWC training course should contact their local adviser or ASBAH regional office.

Both the road safety manual and course details can be found on the AWC website at www.wheelchairchildren.org.uk. The manual can also be obtained, free of charge, by calling AWC on 0870 121 0050.



Degrees of success

Luke Rich is celebrating after graduating from Newcastle University with a BA (Hons) in Economics and Business Finance.

Luke, 21, is now working as a data inputter before beginning his chartered accountant training next year.

For delighted parents Pat and Dave, Luke, who has hydrocephalus, has come

a long way since his first shunt operation when he was just six weeks old.

"They were a lot of very difficult days during Luke's early weeks," Pat remembered. "We felt that our world was crashing down. So when he phoned after getting his exam results, it was a wonderful end to 21 years of anxiety."

The couple, who live in Bishop



Auckland, County Durham, said they wanted to reassure new parents whose child has been diagnosed with hydrocephalus that there is a positive future for their child.

"Now our biggest worry is that, like most of his friends, he drinks too much on a night out at the Bigg Market," Pat laughed.

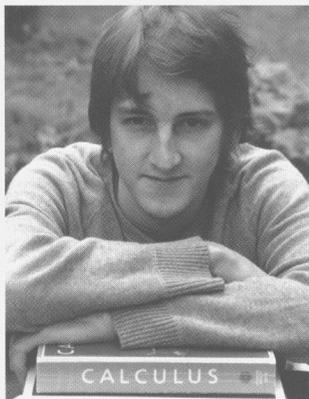
Harry Wayne's

hard work and a determination to excel has helped him to win a coveted place at Cambridge to read maths and physics.

Harry, 18, has spina bifida, and although he enjoys good mobility, he's

endured many major back operations over the years, missing months of schooling.

After gaining first class grades in his A Levels, with As in maths and further maths, physics and chemistry, he's now



starting a new life at Emanuel College.

"We are especially proud of Harry's achievements, because he has worked so hard," mother Fran said from the family home in Forest Row, Sussex. "He faced many operations over the

years and missed a lot of time at school, but he's never made a fuss and was always determined to succeed.

"Harry attended mainstream schools which were very supportive of his needs,

although he never asked for special treatment. I remember the PE teacher wincing when Harry was at the bottom of a rugby scrum. It wasn't long after that he broke one of the rods in his back!"

Fran admitted that in the early days she worried relentlessly about Harry's future, and although it was tough saying goodbye, she is excited that he is beginning a new, independent life.

She laughed: "I've got a feeling that Harry is keen to get away and be in control of his life. I don't suppose it will be easy for him at times, but he is very determined and I know he'll be fine."

Sheridan Nurse is combining work with studying for a second degree in her drive to become a probation officer. She graduated with a 2:2 in psychology and sociology from Anglia Polytechnic in 2000 and is now studying for a second degree in community justice as part of her probation officer training.

She was inspired to begin the two year training programme after working with the Youth Offenders team in King's Lynn, Norfolk.

Sheridan, 25, who has spina bifida, explains: "I knew I wanted a job helping people in some capacity. I saw the job with the Youth Offenders team and thought it would be the perfect opportunity to get some experience and training.

"It also helped to build my confidence and become more used to dealing with all types of people and help them to get back into normal society. Being in a wheelchair

means that I know what it is like to feel 'different', so it gave me some common ground with the youngsters and my experiences made it easier for me to relate to them.

"After junior school I started at a high school in town, where I was made to feel like an outsider. Most of our classrooms were upstairs, and as the school had no lifts, I had to work away from the other children downstairs. I was bullied and no one really talked to me. It was a very difficult time. I was very depressed and my confidence hit rock bottom. My sister ended up fighting my battles for me, which of course made things even worse."

After 18 unhappy months Sheridan changed schools, starting back at a high school in a village seven miles away. From



there she didn't look back.

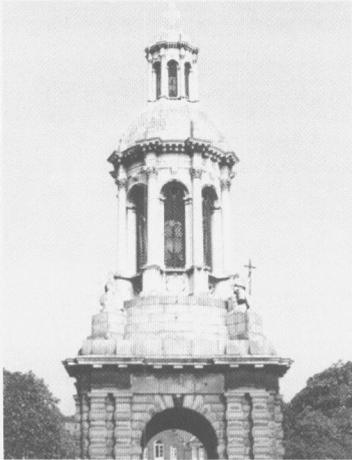
These days life is fairly hectic as she combines three days with the Probation Service with two days

distance learning with the de Montfort University. Her work is stressful but can be tremendously fulfilling, supporting people as they strive to improve their lives.

"It's very stressful at the moment, but if I qualify it will be well worth it. I haven't decided on which area to specialise in yet... I'll concentrate on graduating first," she adds.

The future's certainly looking bright for the bubbly young lady, with another qualification and marriage in the offing. Sheridan, who lives independently, is looking forward to tying the knot with fiancé Jamie Hall in 2006.

Dublin



SRHSB meets in Dublin

Leading neurosurgeons and neurologists from all over the world descended on Dublin in late June for the 48th meeting of the Society for Research into Hydrocephalus and Spina Bifida (SRHSB).

Taking Benny Bear with them, ASBAH's team of medical advisers also attended. Rosemary Batchelor, ASBAH senior medical adviser, was elected to the executive committee. A memorial service for John Holter, co-pioneer of the Spitz Holter shunting system (see tribute in last *Link* magazine) was held at St Ann's Church on the opening day and attended by most of delegates. Former director of ASBAH, Moyna Gilbertson, gave the address.

Over 60 scientific papers and posters were presented concerning all aspects of spina bifida and hydrocephalus. Papers of particular interest included *Neuropsychological Profile of Patients with Normal Pressure Hydrocephalus and Alzheimer's Disease* by Professor JD Pickard. This year's Casey Holter Essay Memorial Prize winner was Behroze Vachha with her paper, *A Temperament for Learning: The Limbic System and Myelomeningocele*.

We hope to reprint some of the conference papers in forthcoming editions of *Link*.

Oslo

Crossing borders

Four members of Your Voice, including new IF board member Jon Burke, along with Andrew Russell, attended IF's (International Federation for Spina Bifida and Hydrocephalus) 25th anniversary annual conference, 'Crossing Borders', in Oslo at the beginning of September. There was a broad programme of topics to reflect interests of the delegates from all around the world.

One of the highlights was the showing of two films contrasting the experiences of living with spina bifida and hydrocephalus in Norway and Tanzania.

Jon Burke joins IF board

Your Voice Chairman, Jon Burke, has been elected to the board of IF (International Federation for Spina Bifida and Hydrocephalus) for a two year term, after which he will be eligible for re-nomination. He replaces former ASBAH Assistant Director (Services), Teresa Cole, who has given 15 years distinguished service.

Jon said about his appointment: "I support the goals of the organisation and I would like to contribute to their development. I have a lot to offer through my involvement in issues affecting disabled people and I am enthusiastic to share this with other board members. I am also keen to learn from other people's experience and to integrate any lessons

The problems in Tanzania are particularly acute, where the shortage of shunts can lead to enlarged heads for people with hydrocephalus. As a result family break-ups occur with mothers often deserted by their husbands.

For the first time there was a special closed session for disabled adults, with a master class on how to become more involved with their national associations.

The AGM was also held during the conference and a special resolution, initiated by ASBAH, was passed calling on the UN and all nations to implement a programme of dietary fortification with folic acid for the primary prevention of spina bifida.

www.ifglobal.org

learned into other activities I am involved in."

Teresa was presented with a bouquet of flowers at ASBAH's recent AGM in recognition and thanks for all of her sterling work on the IF Committee.



If you have an issue, travel experience or interesting story with an international aspect, then please let us know by contacting *Link*. You can write to us at *Link*, 42 Park Road, Peterborough PE1 2UQ or email us at info@link.org.uk

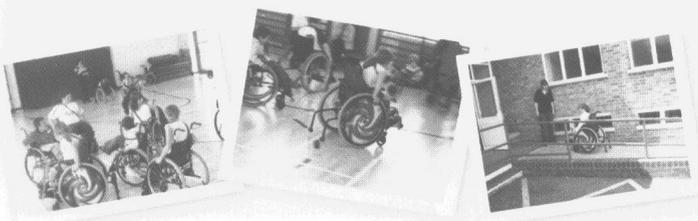


ASBAH is richer to the tune of £2,000 thanks to a generous donation from the Women's India Association of the United Kingdom.

The group raised more than £44,000 during the last 12 months and divided it between a number of charities based both in India and the UK.

Neena Dugal, Honorary Chairman of the Association, presented the cheque to Peter Farrall, Assistant Director (Marketing & Communications) at the Association's AGM in London's West End.

Photograph courtesy of XP1.com



Rosie learns her wheelchair skills on the course run by the Association of Wheelchair Children.



Wheels within wheels

Youngster Rosie Booth can keep up with the fastest of her friends on the playground, thanks to a new lightweight wheelchair provided by ASBAH and BBC Children in Need.

Rosie, 6, from Chester, now enjoys showing off her new skills: balancing on the back wheels, pirouetting and even going up slopes backwards.

Rosie always refused to use her heavy NHS wheelchair on the playground because it was so heavy and difficult to use. Instead she spent playtimes sitting on a bench watching her classmates having fun.

ASBAH donated £800 towards the cost of the new £2,700 titanium chair, with Children in Need making up the balance.

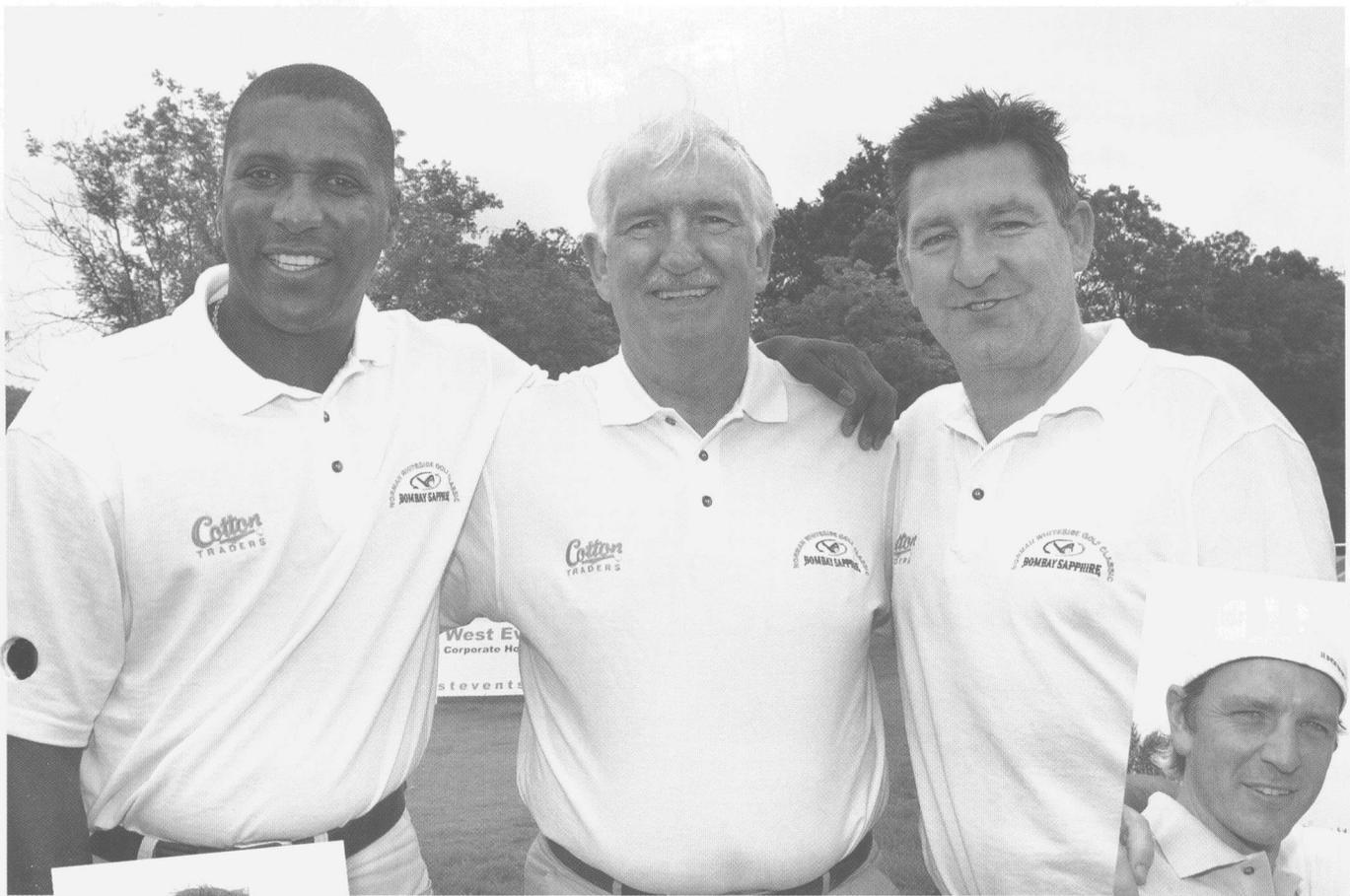
Mother Helen says: "We wanted a lightweight chair with expandable width so that it would last Rosie for years. They are so expensive, so we are very grateful to ASBAH for their generous contribution.

"The new chair arrived just in time for a two day wheelchair skills course run by the Association of Wheelchair Children. Rosie has been using it at school ever since. She often has quite an entourage skipping around her on her circuits of the playground."

Rosie, who has spina bifida and borderline hydrocephalus, is also able to push herself to school, another huge bonus for Helen. She previously had to push Rosie in the old wheelchair, with younger sister Katie sitting on her knee. Baby brother Peter, now 18 months, was carried in a back carrier.

"Walking to school was quite a drama," Helen laughs. "Life is so much easier and more relaxed now."

Rosie, who has spina bifida and borderline hydrocephalus, is now able to push herself to school



Golf day raises £15,000

The most successful fundraising event in Northern Ireland took place at the end of July in the form of the Northern Ireland Golf Day. A whole bevy of one time football greats descended on the Hilton Golf Resort at Templepatrick in Belfast ready to swing their clubs for ASBAH.

These included ex-Manchester United players Norman Whiteside, Viv Anderson, John Beresford, Lee Sharpe, Gary Pallister, Wilf McGuinness, Frank Stapleton and Alex Stepney (who also played for England). They were joined by ex-Arsenal player Sammy Nelson, ex-Everton players Mike Milligan and David Hirst, ex-Middlesbrough player Keith O'Neill (who also played for the Republic of Ireland) and Ally McCoist, who used to play for Glasgow Rangers and Scotland. From the world of rugby there was Tyrone Howe and the TV comedian Bill Bean also played.

“It was a lot of hard work, but very enjoyable for everyone. £15,000 is a large amount of money by anybody’s standards.”

The day was broadcast live on BBC Radio Ulster and covered in all the Ulster dailies. Said ASBAH’s fundraiser in Northern Ireland, Alan Moneyppy:

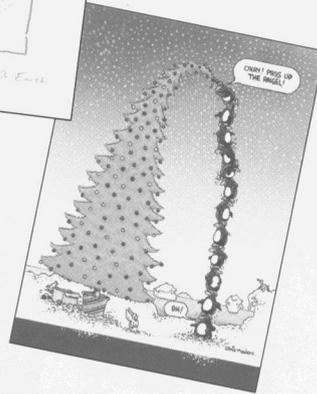
“It was a lot of hard work, but very enjoyable for everyone. £15,000 is a large amount of money by anybody’s standards.”

With special thanks to Norman Whiteside for his help and support.



Each pack of 10 cards and envelopes comes with a greeting inside each card that reads: *With all Good Wishes for Christmas and the New Year.* In addition the ASBAH logo and registered charity number appear on the back of the cards.

The back of the Benny Bear cards also have an explanation about the Hydrocephalus Action campaign.

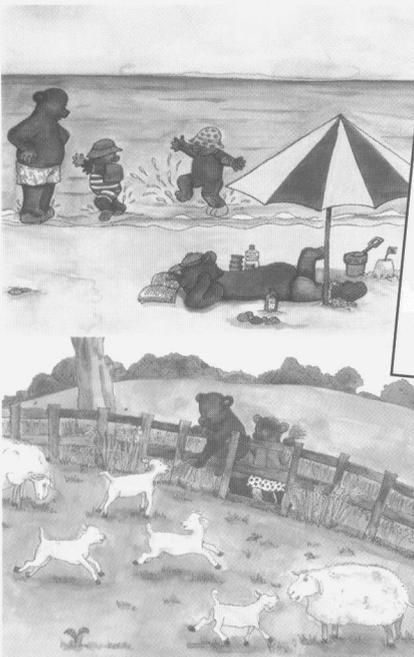


Christmas Cards

If you would like to order some ASBAH Christmas Cards or Benny Bear Christmas selection packs, please complete the attached form.

Calendar 2005

Each month has a different colourful illustration showing Benny Bear. If you would like to order a Benny Bear calendar for 2005, please complete the attached form.



Benny Bear selection of 10 cards and envelopes comprising all three designs



ASBAH Order Form

Christmas Cards

Please send me:	Qty	Price	Total (£)
Penguins		£3.95 plus p&p	
Dove		£3.95 plus p&p	
Robin		£3.95 plus p&p	
Snowman		£3.95 plus p&p	
Wintry Scene		£3.95 plus p&p	
Benny Bear		£3.95 plus p&p	

Christmas card p&p (postage and packing) - £0.75p per pack

Calendar 2005

Benny Bear	£3.99 plus p&p
Calendar p&p - £1.15p each	Total order (inc p&p) £

Payment

(please tick/fill in your preferred method of payment and complete your name & address details)

Cheque (made payable to 'ASBAH')/PO order enclosed

Or

VISA Mastercard/Access Amex

Card no.

Start date Expiry date

Signature _____

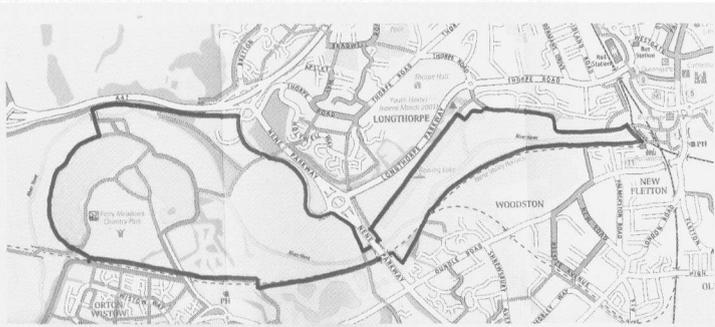
Mr/Mrs/Miss _____

Address _____

Postcode _____

Telephone _____

Please send the completed order form together with your payment to:
ASBAH, 42 Park Road, Peterborough PE1 2UQ
Registered charity no. 249338



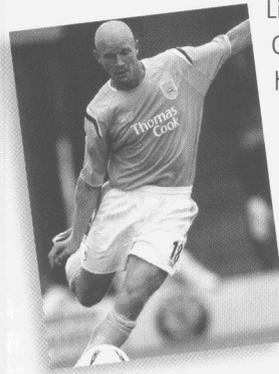
Danny Mills
**DANNY MILLS
 APPEAL**
 Helpline & Information Service

Update

It's been a busy few months for soccer star Danny Mills.

The England and Middlesbrough player was recently signed by Manchester City manager Kevin Keegan, and is now settling into life at the City of Manchester Stadium.

Danny's now searching for a home so his family, wife Lisa and their three children, George, Mya and Stanley, can join him in the northwest.



But somehow, in between the demands of his professional and personal life, Danny, one of the country's most formidable right backs, is still finding time to support ASBAH.

The Danny Mills Helpline Appeal, which kicked off last

December, was boosted by the £33,000 raised at his charity golf classic in May. Danny is now planning a second tournament for next spring, this time in the northwest, and he hopes to involve many of his Man City colleagues.

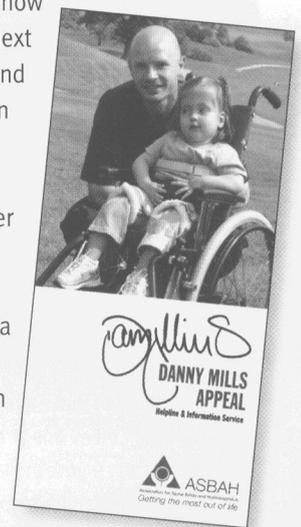
More support for Danny's £300,000 appeal came in September from several runners in the Great North Run.

Danny is also the figurehead for a new campaign leaflet, which will be mailed to ASBAH supporters later in the year.

Meeting any fundraising target is difficult, but Danny is a persistent man, both on and off the pitch. In a recent interview he said: "If you are hungry and determined enough to make things happen, they will."

And there's no doubt about it, he's resolved to get the helpline up and running to provide the information and support that families so desperately need.

Danny explained: "People can call ASBAH for support and guidance, but there is a need for a helpline and information service that worried parents and families can turn to. It would make such a difference for so many people."



Mega bucks

£2,000 has gone towards paying for the services ASBAH provides thanks to Ian Morley's annual Megacycle 24 hour marathon, which took place in Peterborough on the first weekend of July. Starting the event was North West Cambridgeshire MP, Sir Brian Mawhinney with ASBAH Chairman Richard Astle. ASBAH's valiant team comprised of Monica Cox and her husband Geoff, Shelly Bullard, her husband Michael and their daughter Georgia, Gill Winfield and Margaret Black and her daughter Angela. Also special thanks to Keith and James Weavin for their involvement and kind support. Other teams came from insurance companies AMP and Churchill. The distance covered by all the riders in the marathon came to a total of 1,852 miles.





Linda's line

Hands up everybody who is going to make a New Year's resolution this year...

Just as I thought, lots of you, and yes, my hand is in the air as well. I love the idea that at the end of each year you can wipe the slate clean and start afresh on 1st January with a new list of aspirations, but I have long harboured a suspicion that making new year's resolutions is about as pointless as rearranging deckchairs on the Titanic.

I always write my new year's resolutions in my diary on the 1st January page, but I've noticed over the last few years that there is a familiar re-occurring theme to this wish list. For example, I always write "Eat less chocolate" - fat chance of that one lasting past 5 pm on New Year's Day! Then there is usually something about being less stressed (that one fizzles out after a couple of days back at work). And then there's the perennial favourite - "Do more exercise" (ha ha!).

The trouble is that deep down, I think I prefer my takeaway pizza and DVD lifestyle and I would need someone like Tanni Grey-Thompson to motivate and inspire me. OK Tanni, what's your fee for becoming a personal trainer? Hmm...on second thoughts, don't book your train ticket just yet, coz I've spent all my savings on the new bathroom.

You see what I mean? It's either too difficult or completely pointless.

It doesn't stop people trying though - go into WH Smith in January and look at how many diet and exercise themed artefacts clog up the book, magazine and video shelves. I mean, has anyone ever tried one of those exercise videos? I have a Rosemary Conley one at home and it should definitely carry a government health warning! One minute she's side-stepping along the carpet, arms gently swinging; then suddenly, without any warning, she's lying on the floor with feet and legs all over the place! In fact, I'm sure some of those configurations of hips and legs cannot be anatomically correct - the woman must have hinges somewhere.

Honestly, it's enough to put anyone off their resolutions altogether... and while I remember, I am going to photocopy the front page of my diary - saves me re-inventing the wheel next time around...

UK Businesses 'cannot run and cannot hide' from equal access laws says DRC

The new equal access laws which came into force on 1st October 2004 will have as dramatic an effect on opening up business and services to disabled people in the UK as similar laws have had in the United States, the Disability Rights Commission (DRC) has said.

Catherine Casserley, Senior Legislative Adviser for the DRC has also predicted a future in Britain of increased assertiveness amongst disabled people no longer willing to tolerate a second class service.

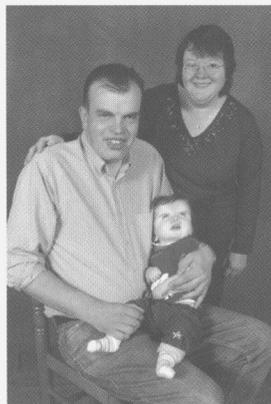
"In the run up to the 1st October deadline, the DRC invested heavily in projects aimed at making sure that disabled people know about and assert their new rights post October," she said. Increasing the capacity of disabled people and organisations to monitor progress and complain is also a key aim.

Part 3 of the Disability Discrimination Act (DDA) requires every business, large or small - from the local shop to restaurants, health clubs, dentists and supermarkets - to become more user-friendly to Britain's 10 million disabled people. The law means that businesses will need to make reasonable changes - such as adapting premises, removing physical barriers or providing the service another way - so that disabled people can use the service. The change will affect over 2 million British businesses. Failure to act could result in legal action.

Commenting on the business case for making improvements to disabled

access, Catherine Casserley said: "The DRC's year long Open4All campaign has put at centre stage for business the real benefits of making services open for all. UK businesses will lose out on the £50 billion combined spending power of disabled people if they fail to make the improvements needed to ensure disabled access. But it's not just disabled people whose custom they will lose - a national poll by NOP commissioned by the DRC revealed that when confronted with poor access seven in every 10 people would advise family or friends to use another service. The facts are clear that bad access really is bad for business."

But Catherine Casserley provided a stark warning to businesses and service providers that had made little or no efforts to implement improvements to remove barriers to access in time for the October deadline: "Increased awareness and activism amongst disabled people after October 1st is a given that business and service providers should not be in denial about. In this new setting there will be nowhere to run and nowhere to hide for businesses that have not made or planned improvements. Over the last year the DRC has been monitoring the progress of well-known service providers and we will be looking to test the law at the earliest opportunity to achieve the maximum effect."



Tribute

David Jackson

David Jackson, aged two, the son of Karen and Martin Jackson, from Wakefield, died on 20 August.

David and his family were regular attendees at ASBAH events, including drop-ins, family days and most recently the Family Weekend on the Isle of Wight. Everyone from ASBAH extends their deepest sympathies to the family.

Meet the expert

Rosie Kelly Paediatric Neuro-urology Outreach Sister



One of the most renowned spina bifida clinics in the UK is operated by the Spina Bifida Service at Guy's Hospital in London. Originally founded by the late Dr Margaret Borzyskowski and Professor Neville, one person from the clinic familiar to hundreds of people over the years is Rosie Kelly, the paediatric outreach sister.

Rosie Kelly's career began when she qualified as a registered sick children's nurse at the Royal Belfast Hospital for Sick Children, after which she joined Guy's Paediatric Intensive Care Unit in 1983. From 1985-88 she was a paediatric night sister. She then became a school nurse in Tower Hamlets, providing valuable experience for her later role as an outreach sister. She recalls: "I was responsible for five schools and working with healthy children was quite a learning curve, giving me a great insight into their needs when they're in their own environment."

Rosie returned to Guy's in 1991. Back then she was the only outreach nurse in the department – now there are 15, covering many specialities. Her role encompasses a wide range of duties: she teaches on clean intermittent catheterisations; she advises on medications and incontinence products; she runs a separate clinic for bladder function assessments, pre-operative assessments and post operative follow up for cystoplasty patients; and she prepares children for videourodynamic studies, then catheterisation for those who need it.

Guy's & St Thomas' HOSPITAL TRUST

A major part of this work is actually done in children's own homes. "I spend a lot of time on the road, visiting children at home. My patch extends from Northampton to Chichester, so you can imagine how much time this takes. But it's time very well spent, as it's at home where the child feels most relaxed and this gives them and their parents the chance to ask all those questions they could otherwise keep wrapped up. It's the most satisfying part of my job, because it makes the advice and care I provide more relevant to the families."

Back at Guy's, the team sees seven children at each clinic. At least seventy cases are ongoing, requiring repeat visits and in total Rosie has probably seen over 500 patients over the years. "In fact, despite the perception that spina bifida is on the decline, the referral rate is increasing. Many of the children sent to Guy's are referred at birth by the Neurosurgical Service at King's

College Hospital. Most of the time we see them when they've reached a few months old for an overall assessment, looking at bladder, bowel and mobility. We can then produce a care plan for the baby, when we'll see it every three months in the first year and then just once a year if there are no ongoing issues," she says.

"In fact, despite the perception that spina bifida is on the decline, the referral rate is increasing. Many of the children sent to Guy's are referred at birth by the Neurosurgical Service at King's College Hospital."

Rosie is a member of the Association of Continence Advisors (ACA) and of the Royal College of Nursing's Paediatric/Urology Continence Special Interest Group. For the past two years she has been studying for her master's degree in nursing at City University, and was awarded an

MSc this year. Already a co-author of a published paper, as well as a speaker at this year ACA's national conference, she's clearly a name that many more people will become familiar with over the years to come.

Siobhan Corr's diary

My first 12 weeks of pregnancy

In the first of a new series, Siobhan Corr opens the pages of her personal diary to share the ups and downs of her first pregnancy.



Siobhan Corr – 36 years old (spina bifida and hydrocephalus), full-time teacher, member of the committee of the Bolton and Bury ASBAH local association.

Husband – Martin, 41 years old, trainee Probation Officer.

Married for 11 years, both originally from Northern Ireland and now living in Bolton.

Wednesday, 14 April 2004 It's the

Easter holidays and my parents have been visiting from Northern Ireland for the Easter week. We've been busy entertaining – visiting some local sites of interest. My mum and dad leave today and I act immediately on a suspicion that I might be pregnant. I rush to the pharmacy as soon as they leave and nervously carry out the pregnancy test – it is positive.

During the week that follows, I start feeling increasingly nauseous in the afternoons from lunchtime onwards. Unfortunately, I cannot face any truly healthy foods at present – broccoli and all those other folic acid rich foods simply make me feel ill, both in terms of taste and smell. I am trying to keep up my fluid intake too but this is difficult since I cannot face tea, coffee and many other beverages.

My biggest problem seems to be constipation. I am afraid that constipation is making my sickness much worse. The GP assures me that I can rely on Senokot for relief of these symptoms, dried fruits and prunes are also good remedies.

When Carl Hodgetts fell in love with the high speed thrill of the wind in his hair, a minor inconvenience like spina bifida certainly wasn't going to stop him. The 26-year-old action man had always been in love with the open road and the power of motorbikes - just like his dad.

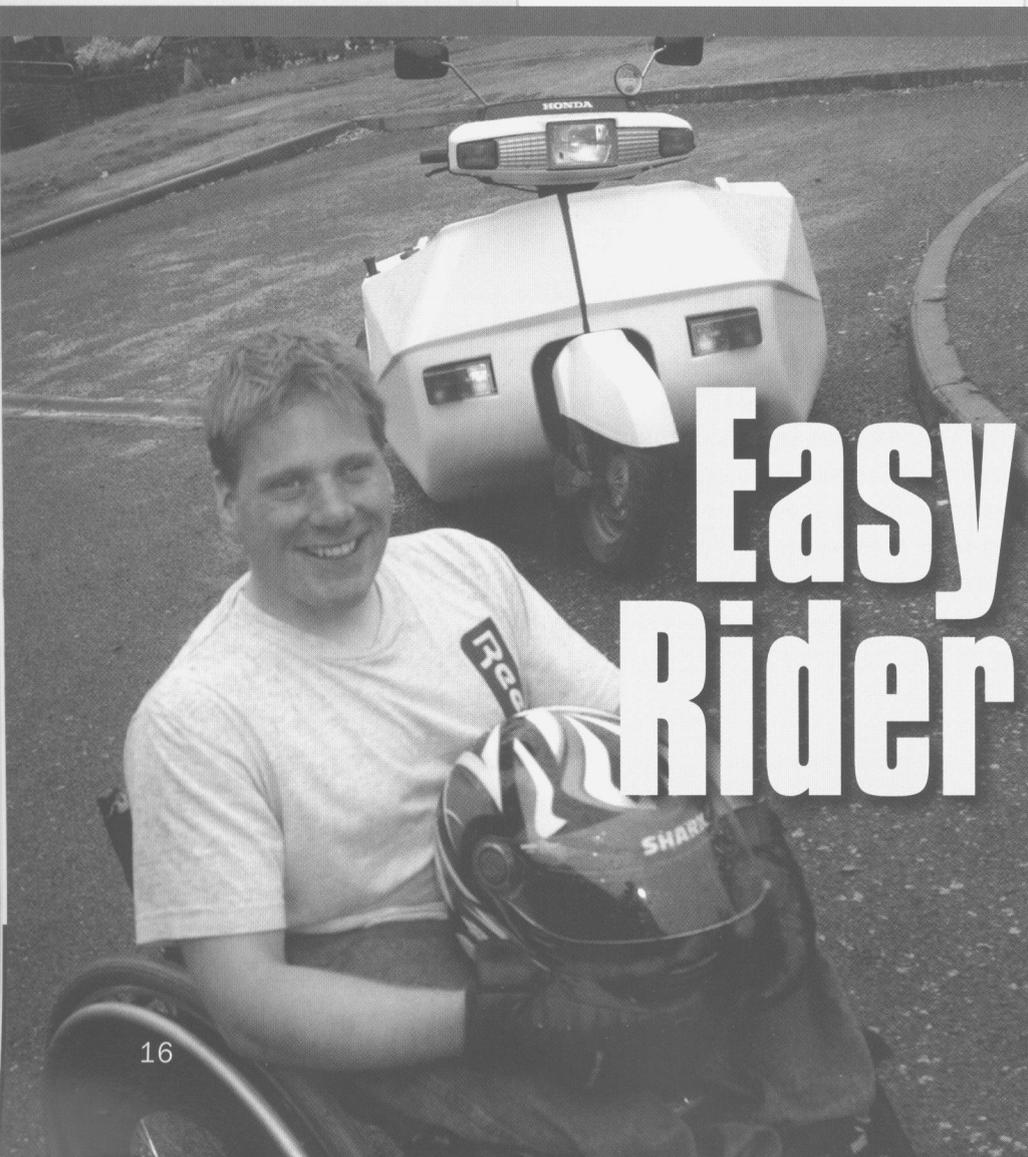
It wasn't until he visited a disability show and saw specially adapted bikes for sale that he realised he didn't have to miss out on the exhilarating biker lifestyle.

Thrill seeker Carl, who is also no slouch on the karate mat, is a popular face as he burns rubber near his home in Monks Kirby near Rugby.

Maybe burning rubber is an exaggeration, but wheelchair user Carl is certainly impressive when he hits the road in his 80cc Honda with its top speed of 45mph.

Carl bought his first bike two years ago after seeing a stand at a fair in Derby promoting motorbikes designed to take wheelchairs.

He says: "I had a trial go and was hooked. I went back the next day with my



Easy Rider

Friday, 30 April 2004 I see my GP who is happy to refer me to St Mary's Hospital in Manchester which is the local specialist hospital for the North West. I should expect an appointment in the next 2 weeks. In the meantime, I am receiving my ante-natal care thanks to aol.com. Worryingly, not one person has recommended me to take folic acid. Of course I am dosing myself with it – the higher dose.

Wednesday, 5 May 2004 I spoke to Marcia Conroy (ASBAH adviser) about ante-natal care today. She has confirmed my decision to seek treatment at St Mary's in Manchester and suggests that I speak to Carys Bannister (retired neurosurgeon) about foetal monitoring. Marcia suggests also that I should have a general MOT at the Spina Bifida clinic. Marcia proposed that I could contact some women who already are mothers. I search the ASBAH website for contacts and advice and find that much of the information is child-focussed rather than adult-focussed.

Sunday, 16 May 2004 Carys Bannister rings us at home. She thinks that I should have my kidney function checked at the Spina Bifida Clinic. She assures me that she will arrange an appointment at the Spina Bifida Clinic in Manchester. A referral to St Mary's would be the best choice for ante-natal care.

Wednesday, 19 May 2004 I have my first ante-natal appointment at my local GP practice. My blood pressure and protein levels in my urine are all normal. This is the first time that I have been advised about the use of folic acid. I am about 10 weeks pregnant and if all women are only advised about the use of folic acid at their first ante-natal appointment then surely the advice comes rather too late for most!

Thursday, 20 May 2004 I have an appointment at the Spina Bifida Clinic at Hope Hospital in Manchester. Dr Lewis carries out an ultrasound of my kidneys and reports that they appear fine. My

medical notes relating to any surgery and test results prior to this appointment appear to have gone missing. Dr Lewis is keen to ensure that I maintain contact with the Spina Bifida clinic in order to monitor any changes in my kidney function.

Friday, 28 May 2004 I go back to the GP, as I am now increasingly anxious about the lack of specialist treatment/care I am receiving. We have not heard anything from St Mary's and it appears that the GP has forgotten to refer me to the hospital.

Tuesday, 1 June 2004 At last an appointment at St Mary's – but not until Thursday 17th June. I will be more than 14 weeks pregnant by then. It has been a real struggle up to this point to access proper specialist ante-natal care, but at last I feel that I am being listened to.

Link will continue to follow Siobhan's progress through her pregnancy and we send our best wishes to her and husband, Martin.

dad, to see what he thought and bought one. My dad, Rob, has always been a keen biker so I'd always had an interest, but biking wasn't something I'd really considered myself. I really fancied the idea of being able to go out with him on our bikes."

But Carl's need for speed isn't going to stop there now he's caught the bug.

"You can buy 125cc models which obviously go faster so maybe one day I'll start saving up for the next model up," he says. His current three wheel model, a Nippie, is an M reg, which set the speed demon back a cool £3,000.

Carl, who admits he loves a challenge, adds: "It's great to go out in and during the summer I use it all of the time. Obviously it isn't so good in bad weather.

You can buy a roof to fit on, but that's not in keeping with the spirit of biking. I like to feel the wind on my face."

But it wasn't always fun on the open

road – there are times when disability catches up even for Carl. "There was one embarrassing incident when I ran out of petrol on the way to work. I had to stop the Brinklow postwoman and ask her to phone my dad," he admits.

Carl's wife Tracey was shocked when he rolled up on the bike, but accepts there is no point trying to tame her 'wild

"I had a trial go and was hooked. I went back the next day with my Dad, to see what he thought and bought one."

child' husband. He works four days a week on a farm near Rugby teaching woodwork and horticulture to adults with learning difficulties: "I love the job. It's interesting and fulfilling,

but can be mentally tiring. It isn't always easy getting around in a wheelchair, but I've always loved a challenge."

Carl, who was a keen archer, cricketer and basketball player at school, has recently joined a karate club in Kenilworth which teaches able bodied and disabled people. "We work in mixed groups and in my group there are two of us in



wheelchairs and one able-bodied person, and it works really well."

"I do find it tricky to learn new moves, but I'm always willing to push myself and enjoy new challenges. Obviously the wheelchair is a bit of a hindrance, but I know how to combat someone and have learned a lot of ways to defend myself," he says.

*The National Association for Bikers with a Disability (NABD)
Tel 0161 233 0122 www.nabd.org.uk*

demonstrating more understanding *

While the news is full of stories about mix-ups in fertility clinics, the Courts have become preoccupied with the costs of bringing up disabled children.

It is now established that a hospital ultrasound scanning department should be able to pick up an open spina bifida lesion on a routine anomaly scan. If the scan is not conclusive, it should lead to a prompt referral to a better equipped unit. The Royal College of Obstetricians and Gynaecologists has laid down guidelines to make sure that any such problems are not missed but these are sometimes ignored or not followed.

Both the emotional and financial costs to families can be considerable. It is often hard to obtain vital equipment and care. We have often been asked to investigate whether the hospital should compensate families in such a position. It can lead to a wealth of other issues relating to the provision of services by Local Authorities, educational requirements and the need for re-housing.

The medical and legal issues in relation to care during pregnancy along with the complex and sometimes daunting problems that follow often require specialist advice.

If you require advice you should contact Anthony Fairweather on

0117 916 9352

or via email at
afairweather@clarkewillmott.com

* clarke
willmott

festive festivals

The traditional Christmas season is getting closer, but the next few months also bring special times for many other cultures. Here are some other festivities that will be lighting up the winter months.

Ramadan

15 October - 12 November

Ramadan, the ninth month of the Islamic calendar, is when the prophet Mohammed is thought to have received the Qu'ran from Allah (God). Throughout Ramadan nothing can be eaten or drunk during daylight hours. In the evening the fast is broken with prayer and a meal called the 'iftar'.

The end of Ramadan is marked by the three-day celebration of Eid-ul-Fitr. Gifts are exchanged, and friends and family gather together to pray and to enjoy large meals.

Diwali

Beginning on 12 November

The Hindu festival gets its name from the Sanskrit word 'deepavali', meaning rows of lights.

Hindus light clay diva lamps or other decorative lights in celebration of the return from exile of the Lord Rama and his wife Sita, and this brings Lakshmi, goddess of wealth, into their homes.

Festivities last for five days, beginning with worship followed by a celebration breakfast. Gifts and sweets are exchanged and quarrels are ended.

Bandi-Chhor Divas

12 November

Bandi-Chhor Divas ('the day of release of detainees') commemorates the release of the sixth Sikh Guru, Guru Hargobind, by the Indian emperor Jehangir.

Sikhs also celebrate Diwali although it has no religious significance for them. It's an important festival throughout India, with the theme of freedom having great significance.

Hanukkah

7 -15 December

Hanukkah means dedication in Hebrew, and commemorates the rededication of the Temple in Jerusalem after it was recovered from the Syrians. Each night, Jews light candles in the menorah. There are eight candles, and a middle one, the Shamash, is used to light the others. Each night one more candle is lit. Gifts are exchanged, foods fried in oil are eaten, and parties are held.

Bodhi Day

8 December

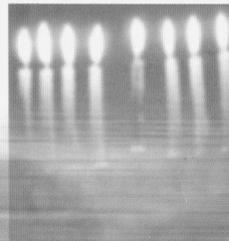
Bodhi Day celebrates Buddha achieving enlightenment. Buddha left a life of luxury to search for the meaning of life. Celebrations vary around the world, but Bodhi Day is generally observed with meditation and visits to temples or monasteries. The day is used to reflect on Buddhist teachings.

Chinese New Year

Beginning on 9 February 2005

Chinese New Year celebrations last for 15 days and involve visiting friends and relatives, exchanging gifts and communal meals. It's a time to encourage good luck and prosperity.

On New Year's Eve a dinner is held to honour the family's ancestors and at midnight there are firework displays. Celebrations end with the Festival of Lanterns, with singing, dancing and lantern shows. 2005 will be the year of the Rooster.



North Wales

Vice-chairman Michael Mason speaks to *Link*

In the 1960s parents of children with spina bifida and/or hydrocephalus were meeting at clinics up and down the country and saw that if there was no one outside the medical world who could also help them, then they'd better do it themselves.

The North Wales Association for Spina Bifida and Hydrocephalus was started in 1967 as a result of the concerns of parents for children with spina bifida and/or hydrocephalus to have the right information about spina bifida and/or hydrocephalus and for there to be adequate health, social care, education

and employment provision as well as better disability access. These parents also wanted to provide emotional support and financial assistance where hardship arose as the result of disability but where the particular need fell outside of the responsibility of the statutory agencies.

I first became involved with the association in 1977 after moving to the area from Birmingham. I'm just one of five committee members who have spina bifida and/or hydrocephalus, the others being Huw Griffith, David Hallows, Barbara Leach and Diane Salisbury. Parents are represented on the committee by Val Conwy, Marie and Trevor Edwards, Pam Hall and Jennifer Hayes. The remaining committee members are Arthur Todd, who is our Chair, and Adrian Jones.

We have 240 members. Last year £15,000 was raised through store collections, sponsored walks,

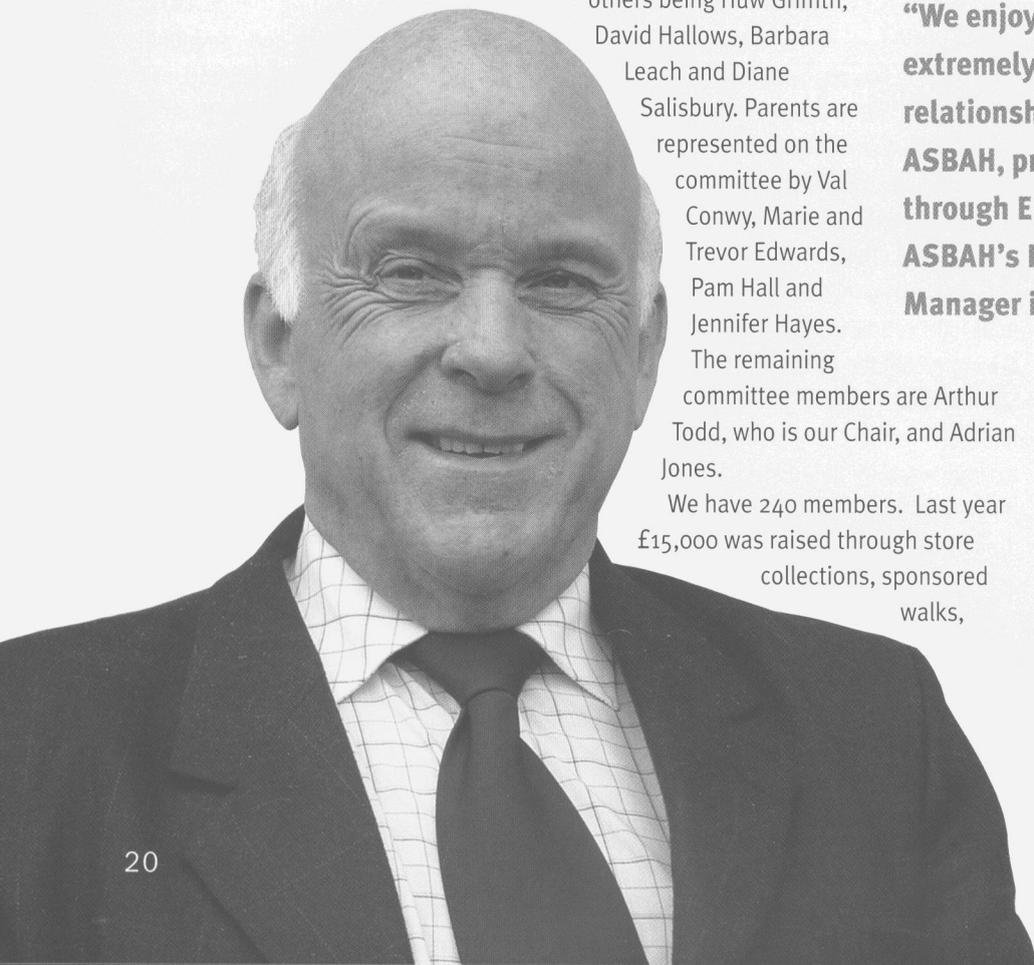
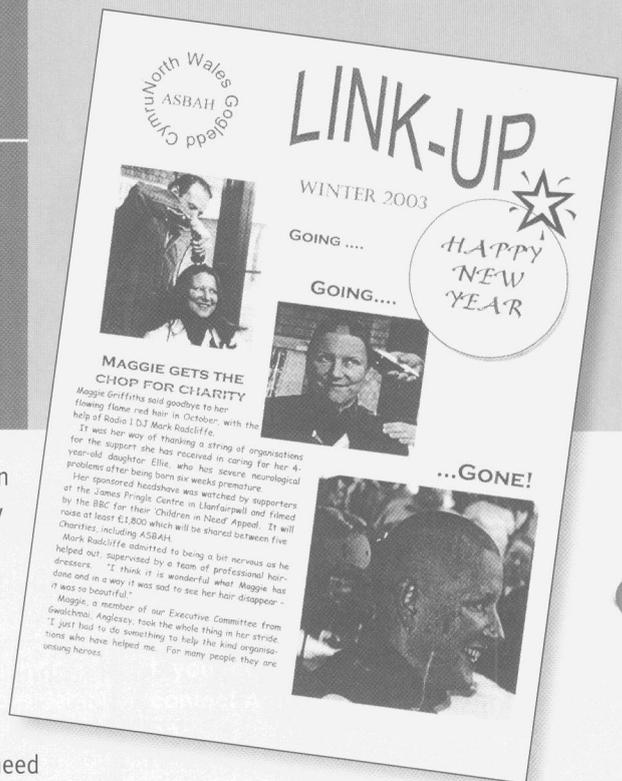
the One Hundred Club, individual donations and grants from local councils. In turn the association distributed £5,500 in grants in 2003.

To help with all this we have a partnership arrangement with ASBAH's regional office in Bangor which includes providing administrative support, as the association stopped employing staff last May. We enjoy extremely positive relationships with ASBAH, primarily through Elin Ifan, ASBAH's Regional Manager in Wales. Elin attends the executive

meetings as often as she can, as do the area advisers Jill Bartlett and Peter Bennett.

Proof of this positive relationship is that I'm currently Chair of ASBAH yn CYMRU – ASBAH in Wales. This provides regular opportunities to meet with Andrew Russell and his senior team and I believe that we do make a difference in being able to reflect the grass roots view of our experience of disability and the ways in which ASBAH's services and influence impact upon them.

Michael Mason



SWIMMING STAR

Sam Bradley



One person whose sporting year has been going swimmingly is ten year old Sam Bradley from Luton. A member of Luton Swimming Club, training for five hours a week, Sam returned home in triumph from the Junior Nationals back in March with no fewer than four medals – three silver and one gold.

Sam swam for the Eastern Region Team, playing a big part in helping them become overall winners of the competition. The four heats that he got the medals for were the 50m backstroke and 50m freestyle (both silver) and in two 25m relay events (silver and gold).

Sam, who has spina bifida, only started learning how to swim three years ago, which makes his rapid advance all the

more remarkable. These classes were with able bodied children.

His favourite stroke is freestyle but, as the medals prove, he is also a good backstroke swimmer. He can do breaststroke and is improving all the time but at present he has to swim without using his legs as his stroke is not legal according to ASA swimming regulations; he therefore crosses his legs at the ankles and does not kick with them.

He can also do butterfly as he has tremendous upper body strength and his coach, Sue Gilbertson, feels that in time he will make a good butterfly swimmer.

The Junior Nationals were in fact his first major competition ever. Since then he

he was due to swim in the Junior League Finals at Wardown Swimming Pool. Before the end of the year he will be competing in Colchester to hopefully qualify again for the Nationals in Sheffield next March.

In fact, the year has just kept on getting better. In the summer Sam was awarded the Boys' 2004 Achiever's Award by the club. He also featured in a profile of the team published in the *Luton News* after March's success.

Asked how he does it, Sam says: "It's fun. I've made lots of friends and even though I can't do a lot of sports, swimming is one that I'm good at."

His mother Sharon and dad Rob add proudly: "We have never treated Sam any differently from his brother or sister and have encouraged him to try things, whether it be riding his bike with no stabilisers or learning to swim. His determination at times is remarkable, and we hope that this will encourage others to achieve. Sam is our little star."

Golden haul for the Luton four

LUTON Swimming Club is celebrating after four of its members won a host of medals at the Disability Sport England National Championships.

Clare Emma, Chris Fish and Sam Warren, Chris Fish and Sam Warren, Claire Warren and Sam Bradley came away with six medals, two silver and four bronze medals from the weekend at Sheffield's Ponds Forge pool.

And if that wasn't enough, the group also collected 16 personal bests and two national junior records home with 19 gold, a bronze and a national record in the 200 metres individual medley, all earned in the 13 year age group.



WELL DONE: Chris Fish, Claire Warren, Emma Cattle and Sam Bradley with their medal haul.

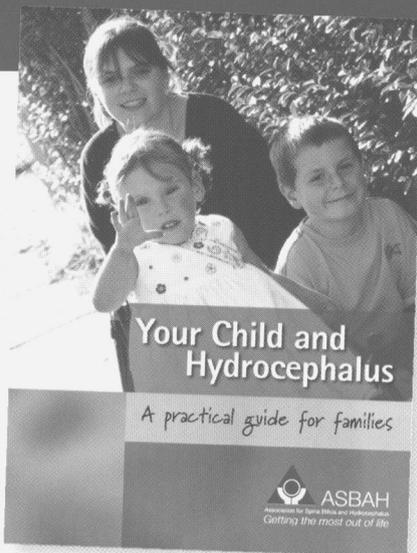
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Codman - Working in partnership with ASBAH

NEW PUBLICATION

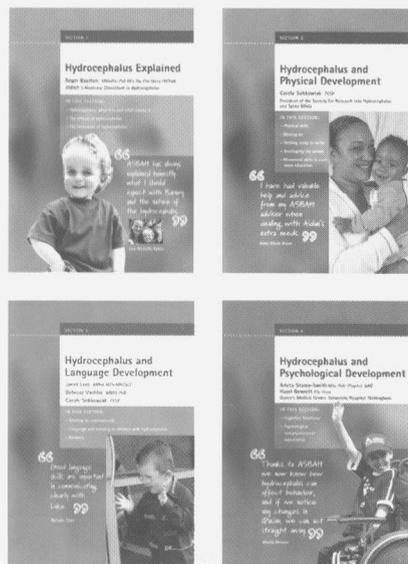
Your Child and Hydrocephalus

This new book is an invaluable practical illustrated guide for families of children with hydrocephalus.



Look out for more details on www.asbah.org

Published in November, this book will be available from: *The Information Department at ASBAH, tel 01733 555988 or write to 42 Park Road, Peterborough PE1 2UQ.*



World beater

Benny Bear is becoming an international jet setter as he travels the globe explaining to children the issues surrounding shunt operations.

The Benny Bear books are now available in many English speaking countries throughout the world and have also been translated into French and German.

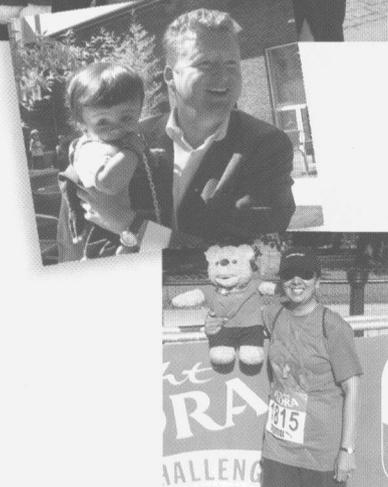
Already he has a huge following, as children with hydrocephalus embrace the loveable bear who has the same worries and problems as them.

It is an incredible success story for the young bear created by Codman in 2001. The idea for Benny came about when Sydney May, a nurse from Liverpool's Walton Hospital, wanted an aid to teach patients about shunts. She approached Mark Attenborough, Codman's International Training and Education Manager, and he found a company which made a bear with other 'diseases' and who had also been contacted by Jackie Campbell of the Radcliffe Infirmary in Oxford (see Link 209). Together Mark and Jackie hit upon the idea of a teddy bear with a hydrocephalus shunt.

Mark explains: "Hydrocephalus can strike at all ages, but it can be particularly



Here's Aqueela Essopjee outside Great Ormond Street Hospital in July (picture left) with her mother, Nazarene; aunt, Kay Butt; cousins, Shabeena and Hamza; Codman's Graeme Loughlin and ASBAH's Rosemary Batchelor. Following on from the article in Link 208, Aqueela went to GOSH to have squint surgery on her left eye. The operation was a complete success and Aqueela went back home to Zambia one very happy little girl.



And Benny makes three... Shabeena and Kay thanked GOSH the hard way by running in September's Flora Women's 5km Challenge in London's Hyde Park in aid of GOSH. Not forgetting Benny Bear though. "Benny was a big hit with everyone. They all asked his name and I said he was a very special bear with hydrocephalus," Kay said.



In 2004 Codman and ASBAH are working in partnership to promote 'Hydrocephalus Action', a campaign aimed at heightening hydrocephalus awareness.



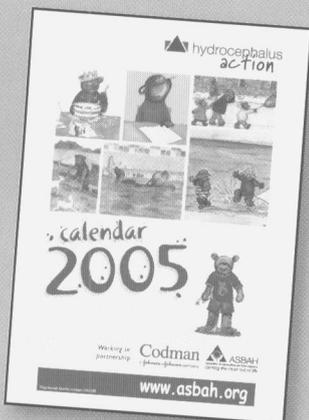
Codman - Working in partnership with ASBAH

worrying when the patient is very young - not only for the child, but also their parents who may be quite young themselves. Everyone benefits from having things explained in a physical way rather than just in words. It can be frightening to hear terms such as 'tunnelling', and Benny can help in these situations."

He adds: "Benny is so well received here and abroad, and everyone thinks the concept is a fascinating one. Benny is usually in my hand luggage when I travel abroad and I get some very odd looks if I get stopped at security. They are surprised to see a large bear being carried by a grey haired gentleman."

"Of course Benny is far more popular than I am. He works really hard and is a most unusual travelling companion."

There are now three books in the series: *Benny gets better* (which deals with having a shunt fitted), *Benny goes to school* (how Benny copes with school) and *Benny goes on holiday* (Benny flying to France by plane for his summer holiday). To receive a set of the three Benny bear books send a cheque made payable to ASBAH for £5.50 (inc postage and packing) to the Information Section, ASBAH, 42 Park Road, Peterborough PE1 2UQ.



The Benny Bear Calendar 2005 is now available. If you would like to order some copies, please complete the order form on page 12 of this issue of Link

Alessandro Bocci

Europe, Middle East and Africa Product Director, Codman



Alessandro Bocci answers our questions from his Rome office about hydrocephalus in mainland Europe.

How many countries are you responsible for?

Our Europe, Middle East and Africa (EMEA) region has 23 local legal entities. Some of them cover more than one country; for instance Codman Scandinavia covers Sweden, Finland, Denmark, Norway and the three Baltic countries. In total there are 47 countries.

What are some European translations for hydrocephalus?

Well, it's "idrocefalo" in Italian, "idrocefalia" in Spanish and "hydrozephalus" in German, for example. All European language translations of the word are based on the Greek etymology of 'hydro' (water) and 'cephalus' (head).

How prevalent is hydrocephalus in Codman's European market

Congenital hydrocephalus strikes two newborn babies in every 1,000; normal pressure hydrocephalus is estimated to occur in 5% to 10% of all dementia patients. We can't be so precise about secondary hydrocephalus. Overall, around 30,000 shunt implants take place each year in all of Europe.

Are there any particular countries where hydrocephalus is very common?

The incidence of paediatric hydrocephalus is about the same in all countries. Adult hydrocephalus is often misdiagnosed and not treated.

What public awareness is there of hydrocephalus in Europe?

Awareness is generally higher in Scandinavia and Germany. Our efforts in these past years have gone into raising awareness throughout the EMEA region. We still have a lot to do, but we have made progress undoubtedly.

Are there similar organisations to ASBAH in Europe?

Yes, there are some national organisations. What I would like to see is more co-ordination among the European associations.

How many hospitals and neurosurgeons are there in Europe for operating on hydrocephalus?

Hydrocephalus treatments can be performed in any neurosurgical unit. There are more than 500 centres in Europe, and each has 10 neurosurgeons on average.

What's the post-operative success rate for hydrocephalus cases in Europe?

Complications can arise in 20% to 40% of cases, mostly due to infections and proximal catheter occlusions.

Which country has the best record for diagnosing and treating hydrocephalus?

Paediatric hydrocephalus is easier to diagnose than adult hydrocephalus, as well as being easier to treat. There are centres of excellence for NPH all over Europe, but most of the research for this is carried out in Scandinavia and Germany.

How does Europe compare to the UK in the treatment of hydrocephalus?

Adjustable valves are used more than fixed pressure valves, whereas in the UK there is still a prevalence of fixed pressure valves.

For how long have Codman's shunts been made in Switzerland and where is the factory?

We started making them in Europe in the late 80s at a factory in Le Locle, near Neuchatel.

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

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

You can help us make that difference!

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

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



ASBAH

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

Registered charity No 249338



LINK

The **ESSENTIAL** magazine for people with hydrocephalus and spina bifida

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

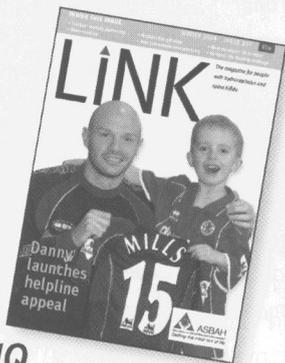
Nici Picken
Gloucestershire



SUBSCRIPTION FORM

Link is published quarterly (Winter, Spring, Summer and Autumn). The cost of an annual subscription is £4.80, Airmail £15, Surface Mail £7.50. To subscribe please complete the form and return it with your cheque/PO (made payable to ASBAH) to:

**Link Subscriptions
ASBAH
42 Park Road
Peterborough PE1 2UQ
Tel: 01733 555988
email: link@asbah.org**



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CONTINENCE CASE STUDY

Karl Hassell

Eight-and-a-half year old Karl Hassell has spina bifida and hydrocephalus, and he's a typical little boy. He's happy, outgoing and independent. He loves playing basketball and he goes to cubs; he enjoys playing with his brother Liam, and he's always getting into scrapes

At the same time he also has to cope with being completely incontinent, with all that this entails. So, how does he manage? Well, he is independently self-catheterising and, at his own request, he has an antegrade continence enema (ACE) to help with bowel control (see continence information sheet on page 27). As a result his continence greatly increased in terms of reliability and cleanliness, but he still sometimes has accidents.

Karl's day inevitably has to be tailored to cope with all this. Each catheterisation takes ten minutes and a daily bowel washout lasts

for one hour, helped by his mum or dad.

Anal plugs minimize the risk of soiling. These are very effective but can't guarantee to keep him completely clean. Fortunately at home the family has a specially built large bathroom with a roll-in, roll-out shower with special chair, so that he can shower himself. At school he is able to use a separate toilet to the other children. This has the great advantage of meaning that his friends do not need to know that he uses catheters and gives him the same privacy that the others have.

Karl does not want any surgery at the moment. His mother Helen says: "If he



ever needs a urostomy or another procedure, we want it to be his decision when he's older. Further intervention will be discussed after puberty, when the urinary sphincter muscle may naturally tighten. Otherwise, as he gets older his bladder capacity will grow from 40mls to 250 mls thanks to taking Oxybutinin. But his urinary deterioration is really due to the neurological problems caused by the

tethering of his spinal cord – his last operation for this was only in May."

Karl has been helping ASBAH to write the text for new continence information books for children. The books will be published at the end of the year in partnership with continence product manufacturer, Hollister.

"Beg, borrow or buy this book if you can!"

Living with Spina Bifida by Adrian Sandler MD

University of North Carolina Press
www.uncpress.unc.edu ISBN 0-8078-5547-2

viewed by Rosemary Batchelor

This book is written primarily for parents - and potential parents - of children with spina bifida; but paediatricians, therapists and other professionals involved in the care of children and babies with spina bifida should find room for it on their bookshelves too.

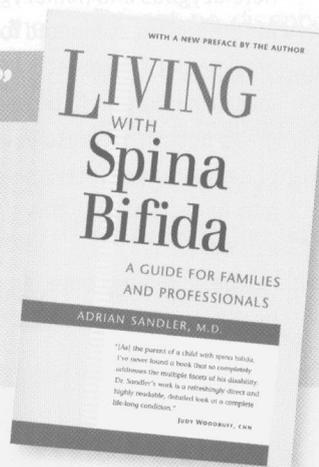
Adrian Sandler, who is Medical Director of the Olson Huff Centre at Mission Children's Hospital in Ashville, North Carolina, draws on his extensive experience of treating children with spina bifida to provide accurate and up-to-date information on the disability in a format that families will find easy to access and to read.

It is very much a book to dip into and not to try to read from cover to cover - an 'all you need to know' guide following the child

from pre-birth to adolescence, written in an upbeat and approachable style which reflects Dr Sandler's way with his patients and their families.

Families outside the USA will find that they have to be selective when using the chapters on schooling and health insurance, as some of the information is only pertinent to North America, but everyone who has an interest in spina bifida will benefit from Dr Sandler's expertise in viewing the child holistically.

There are few comprehensive books for parents on the market today and none, I think, of this calibre - beg, borrow or buy it if you can!



Leeds hospital launches VP shunt care pathway

The Neurosciences Department at Leeds General Infirmary has launched a VP shunt care pathway for adults.

In future patients will be discharged with their own patient-held records, a copy of a CT scan taken when their shunt was working correctly, a copy of the VP shunt care pathway, an advice sheet (*What to do if you think your shunt is blocked*) and a letter to explain to anybody who needs to know that the patient is included in the VP care shunt pathway, giving the contact number for the hospital ward.

The hospital plans to extend the VP shunt care pathway at a later date to include children.

DNA research study shows that half of the Irish population are at increased risk of birth defects

New DNA research carried out by the Health Research Board, Trinity College Dublin, the National Institute of Child Health and Human Development and the National Human Genome Research Institute in the United States reported in June that a variation in a gene (known as a gene variant), which occurs in 50 per cent of the Irish population, increases the risk of developing a severe group of birth defects known as neural tube defects. Spina bifida is, of course, the commonest type of neural tube defect.

An enzyme (known as MTHFR) plays a vital role in how bodies use folic acid. A variant in the gene (known as C677T) which provides the code for this enzyme means that the enzyme does not work normally and so does not process folic acid properly. This genetic variant is common: 40 per cent of the population are heterozygous for the variant (that is, they have one copy of the gene variant and one copy of the normal gene) and 10 per cent are homozygous (that is, they have two copies of the variant gene). The researchers found that during early pregnancy, Irish babies who were homozygous for the variant were more

likely to develop spina bifida or another neural tube defect. This confirms earlier results by the team and other researchers.

The new finding in this study was that heterozygous babies were also at higher risk of neural tube defects. The risk for heterozygous babies, although raised, was less than that for homozygous babies. They were able to show that the heterozygous genotype was linked to more neural tube defects in the population than the homozygous genotype. This happens because a much greater proportion of the population are heterozygous for the variant (that is, 40 per cent of the population are heterozygous compared with 10 per cent who are homozygous). The study estimated that the combined heterozygous and homozygous genotypes for the variant accounted for 26 per cent of all neural tube defects in Ireland. As folic acid is known to be involved in about 50-70 per cent of these defects, up to half of neural tube defects related to folic acid may be explained by this single genetic variant.

These findings have important public health implications. Since half of all

New information sheets

The fifth in our series of a new and revised range of information sheets follows on pages 27 and 28:

• Get clued up on continence

You are now able to download from www.asbah.org.uk the current series of information sheets, they can also be obtained from the Information Department at ASBAH House, 42 Park Road, Peterborough, PE1 2UQ.

babies will have either one or both copies of this gene in its less functionally active form, they are at increased risk of developing neural tube defects in early pregnancy. Thanks in part to research supported by ASBAH in the past, the increased risk caused by having the gene variant can be greatly reduced if the mother takes folic acid before and during early pregnancy. These new findings underscore the importance of public health intervention programmes of folic acid supplementation and food fortification targeted at all women of childbearing age to prevent these defects.

As last reported in Link 206, 400 ASBAH families have participated in some separate research by providing DNA samples and completing questionnaires. The HRB was delighted with the quality of the DNA and it is currently carrying out laboratory analysis of the samples; it will be testing whether the same gene variant is a factor in these British samples.

Further information can be found at: www.hrb.ie and www.bmj.com

New Hollister travel certificate

Hollister has produced a handy little travel certificate card for people affected by incontinence to show that they have special travel needs. Written in eight languages, including English, it states that:

This is to certify that the person named on this certificate has a condition which requires him/her to carry out a procedure called intermittent catheterisation to remove urine from the bladder. This person may be carrying catheters which are vital to this procedure and should not be separated from this person.

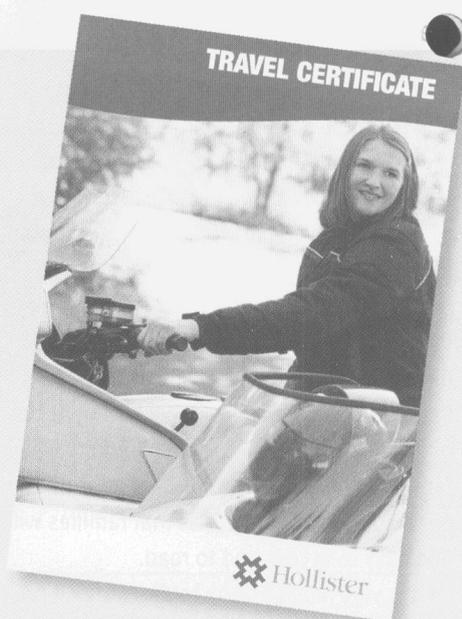
The owner of this certificate may also

be carrying an emergency pack consisting of catheters, dressings, wipes etc, in his/her main luggage.

It is essential that these emergency supplies remain intact and are not mislaid.

Users of the card must complete their name, address and passport details and obtain their doctor's signed details.

The cards are available from Paula Thompson at ASBAH, tel 01733 555 988, e-mail paulat@asbah.org or from Hollister Limited, Rectory Court, 42 Broad Street, Wokingham, Berkshire RG10 1AB, tel 0118 989 5000.





Get clued up on continence

Antegrade Continence Enema

Many people who have spina bifida will suffer with problems of constipation. The antegrade continence enema or ACE is usually used when all other efforts to train the bowel have been tried and have been unsuccessful.

Who is it for?

Before choosing this method of continence management you must be completely sure it is the right method for you, as there is a lot of hard work involved and you must be committed to it. Before the operation the bowel needs to be completely empty, as problems may occur if any hard stools remain. At least a week of strong laxatives and/or enemas may be needed to clear the bowel. This can be a difficult period as there is a chance that faecal soiling may happen.

Having an ACE requires an operation. The appendix is used to make a channel from the outside of the abdomen to the bowel. If the appendix has been removed, part of the bowel itself can be used. A stoma (which is a small opening) is made on the abdominal wall. This will then be used to introduce fluid into the bowel whilst sitting on the toilet. The fluid will push the faeces out through the anus. This is called the "washout".

After a few days the first washout is given, although this may vary from one hospital to another. The washout is given through a soft catheter that is inserted into the stoma at the time of the operation. Saline solution (salt water) or a phosphate enema is usually used. This is put in under pressure ^ the bag is hung just over a metre from the floor ^ whilst the person is sitting on the toilet. The solution and the contents of the bowel will empty into the toilet.

Do not be disappointed if there is not a good result after the first washout. The catheter is generally left in place until the stoma heals, and you can usually go home two days after the operation. You may have to go back to the hospital to have the first washout. You may still need to take some bowel medicine, that helps to keep the stools soft, for a little while after the operation.

Once the catheter has been removed there is no leakage from the stoma as it is designed to be leakproof. However, a catheter should be inserted into the stoma daily. The whole process takes between half an hour and three hours, (on average, about one hour) every other day. Some people have to do it less often and some more often. Constipation may occur if there is too long a gap between washouts.

It may take a little while for the system to settle down, and the amount and/or type of fluid may need to be

changed. For some people things seem to work out quite quickly and they soon become accustomed to doing the washouts. For others it may take a lot of time and patience to get things right.

There can be times when things do not go well, for instance if you have to take antibiotics, or you get a tummy upset. There are ways of overcoming these problems and with experience you will learn how to cope with them.

For a few people, complications do occur. Sometimes the stoma becomes narrow and it is increasingly difficult to pass a catheter. This can be overcome by passing a catheter every day even if the washouts are not done daily. Occasionally infections occur. Once again, these are often resolved with a course of antibiotics.

Sometimes it is necessary to have further surgery to solve these difficulties. The complication rate is quite low. Sometimes people choose not to continue to do the washouts, but most people who have the antegrade continence enema have gained immensely from it. They can now do things that they thought of as impossible before, eg swimming.

Talk to your doctor or continence adviser and decide together if this is the way forward for you. There are hospitals which offer a variation of this procedure.

Caecostomy Button

This is a device which is used for regular irrigation of the bowel, without the need for an ACE Procedure. This is a "pull through" method, whereby a piece of bowel is pulled to the surface of the skin and a catheter is inserted. The Caecostomy button is attached to the catheter, and closed when not in use. The procedure can be performed under local anaesthetic and sedative.

Additional information sheets

- Adaptions for Toileting
- Artificial Sphincter
- Toilet Training
- Intermittent Self-Catheterisation: Bladder Augmentation
- The Mitrofanoff Procedure
- Test & Procedures

Help us to help you

This information is provided free but ASBAH needs your help to enable us to go on providing a wide range of specialised information on all aspects of hydrocephalus and spina bifida, for families, professionals and students.

If you would like to help us continue with our information provision, we welcome your donation (cheques made payable to ASBAH). Please send to ASBAH, 42 Park Road, Peterborough, PE1 2BR

Thank you

Holiday let

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

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Six Berth all electric wheelchair accessible caravan situated within a mile of the beach. Site facilities include indoor and outdoor pools, sauna, steam room, children's play area, hire shop, amusements, licensed club and seasonal entertainment. All electricity & club passes are included at no extra cost. Tel: **Devon ASBAH on 01803 522556**, www.dasbah.com)

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Tel. 01274 591850, e-mail jo@baxterjo.freeserve.co.uk

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Classified rates

£3.75 for 30 words max.
£5.50 for 30-45 words
£6.75 for 45-60 words

Cheques and postal orders should be made payable to 'ASBAH'. Classified adverts for the next issue of Link should be submitted by Friday 17th December 2004

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

BERWICK COTTAGE, EAST HARLING, NORFOLK

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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.

Hi my name is Daniel, I am 14 years old, could anyone write to me with their flying experiences. I am a little worried about flying with a shunt.

Thank you
D. Proctor

Write to D.Proctor c/o Link magazine, 42 Park Road, Peterborough PE1 2UQ.

ASBAH offices

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

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

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

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

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

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

Diary dates

Northern Region Drop Ins

First Weds of each month: 10am - 12 noon
Northern Office, Bagley Lane, Farsley, Leeds
Details; Joan Pheasant
tel: 0113 255 6767 nro@asbah.org

Greater Manchester Drop In

Wednesday, 8 December: 10am - 12 noon
BASIC, 554 Eccles New Rd, Salford
Details: Marcia Conroy
tel: 0161 864 1394 nro@asbah.org

Middlesbrough Drop In

Tuesday 7th December: 10.30 am - 12 noon
For Venue details contact
Geraldine Binstead
tel: 0113 255 6767 nro@asbah.org

York Drop Ins

Wednesday 10 November 2004: 10.15 am - 12 noon
Tuesday 14 December: 12 noon - 2pm
Low Moor Community Centre, Bray Road, Fulford, York
Details; Geraldine Binstead
tel: 0113 255 6767 nro@asbah.org

Northern Ireland Wheelie Club

Saturday 20 November: 10.30am - 2pm
McKinney Hall, Musgrave Hospital, Belfast.
To register for a place please contact: Brendan Heaney,
tel 028 90798878 niro@asbah.org

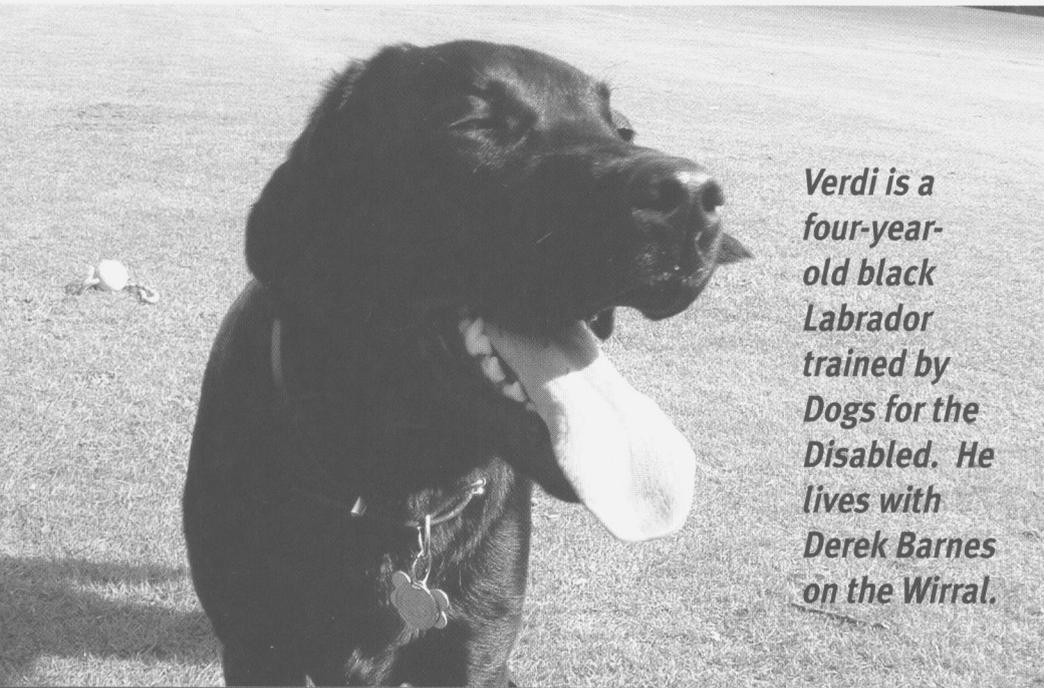
Hollister Roadshow

A unique opportunity for people to see a wide range of companies specialising in varying lifestyle needs for people who perform intermittent self-catheterisation (ISC) and sheath users:

9 November, Bristol Zoo

For more information contact Ellie Green
on 07834 093597 or e-mail
ellie.green@hollister.com

Please e-mail the editor (link@asbah.org) dates for the next issue of Link by Friday 10 December 2004, giving the name of event, purpose, location, date, cost (if applicable), contact name, phone no. and email address.



Verdi is a four-year-old black Labrador trained by Dogs for the Disabled. He lives with Derek Barnes on the Wirral.



...Verdi

It took two years for me to be fully trained at a special centre in Banbury. I then went to live with Derek, who has spina bifida, at his house on the Wirral. He's my dad - I give him all the trust, loyalty and love that I can.

What's a typical day? Well, I wake up at about 6.30 am and go into the bedroom to see if mum and dad are awake. After mum has helped dad into his hoist I push his footrest down and bop him on the leg with my nose just to let him know it's me! He says "paws on" and that's my instruction to put my two front paws on dad's legs so he can give me a good morning stroke. Then it's through to open the lift; when he's in I bop the button and the door closes. I then run down the stairs to wait for the lift and bop the

button and the door opens. Mum has unlocked the back door by this time, so dad goes over to it and gives me the signal to open the door and tells me "busy busy".

When the post arrives I automatically go and fetch it for dad. He doesn't need to tell me to do this, as I do it every day. I bring the letters one at a time, because every time I give him a letter he gives me a treat. If mum has put the

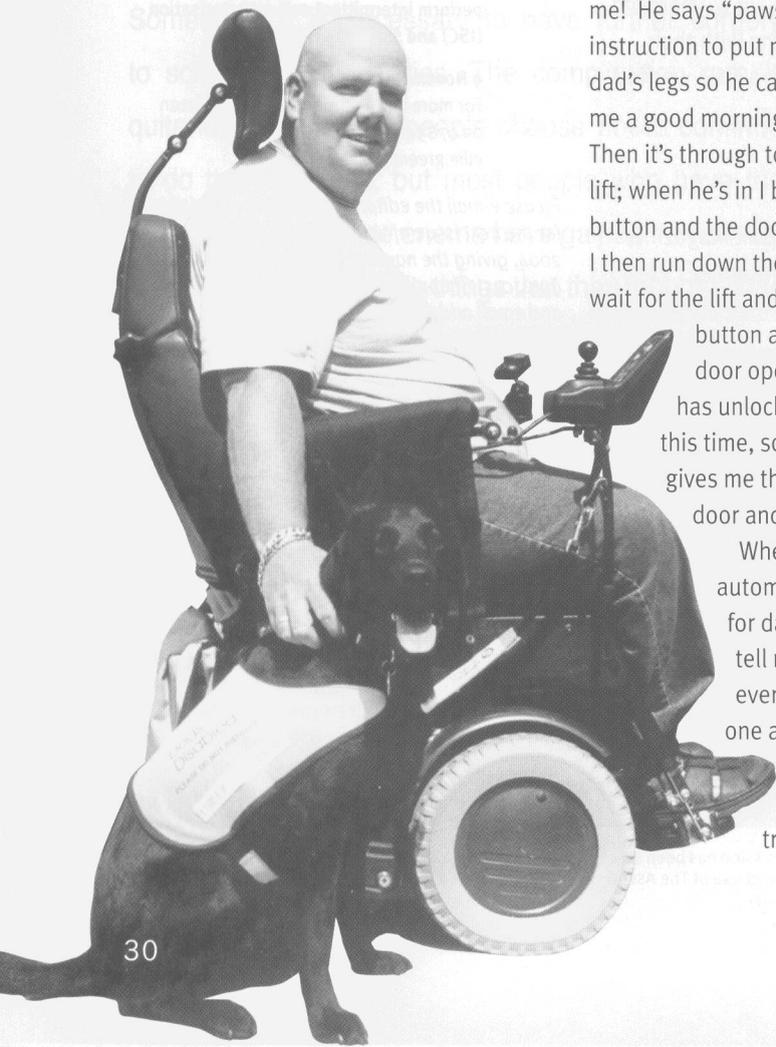
"If mum has put the washing machine on I get out the washing when I'm asked by dad."

washing machine on I get out the washing when I'm asked by dad.

Around lunchtime dad asks me to fetch my yellow coat: he holds the loop of it and says "head in"; I put my head into the coat the dad and I go for a walk - my lead is attached to his wheelchair. When we get back home I have a bowl

of water and we go into the living room. If there are any books or magazines hanging over the table I bop them back on so they don't get under dad's wheels. At teatime I open my food cupboard when asked and have my tea. When dad is settled in his recliner I jump up and get lots of cuddles; then we play fetch the toys.

When it's time for bed I sleep on the landing, where I can see him. You see, I like to keep an eye on him - my work's never done.



Directory of independent local associations

AFFILIATED ASSOCIATIONS

BEDFORD

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

BRISTOL & DISTRICT

Mr G Egan
64 Rookery Road
Knowle, Bristol BS4 2DT
Tel: 0117-9777942

BUCKS & EAST BERKS

Mrs Karen McClean
5 Candelmas Mead,
Beaconsfield
Bucks HP9 1AP

BOLTON & BURY

Mr David Clyne
51 Cuckoo Lane,
Whitefield
Manchester M45 6WD
Tel: 0161-798 7804
(after 4pm)

CAMBRIDGE & DISTRICT

Audine Desborough
Summerlin Farm
Boxworth Road, Elsworth,
Cambs, CB3 8LJ

CHESTER & DISTRICT

Mrs P Ithell
34 King Edward Street
Shotton, Deeside
Clwyd CH5 1DW
Tel: 01244-811074

COVENTRY

Mrs N Newman
11 The Earls Court
Cheylesmere
Coventry CV3 5ES

DUDLEY & WOLVERHAMPTON

Mrs Lorna J Wootton
14 Leveson Road
Wednesfield,
Wolverhampton
West Midlands
WV11 2HF
Tel: 01902-738724

GRANTHAM

Mrs J Hickling
8 Goodliffe Road
Grantham, Lincs
NG31 7QB
Tel: 01476-401643

GREENWICH & DISTRICT

Mrs M Mears
29 Wellmeadow Road
London SE13 6SY
Tel: 0208-244 3526

HERTS AND SOUTH BEDS

Mrs Jennifer Hammond
28 Gladeside
St Albans, Herts AL4 9JA
hamrock@supanet.com

KENT

Office address:
7 The Hive, Northfleet
Kent DA11 9DE
Tel: 01474-536202

LEEDS & BRADFORD

Fiona Bryett
c/o ASBAH North
64 Bagley Lane
Farsley
Leeds LS28 5LY
Tel: 0113-255 6767

LEICESTERSHIRE & RUTLAND

Mrs A Twomlow
29 The Crescent
Market Harborough
Leicestershire LE16 7JJ
Tel: 01858-432967

LINCOLN & MID LINC'S

Mrs P Malson
"Pinfold", Chapel Lane
North Scarle
Lincoln LN6 9EX
Tel: 01522 778781

LINCOLNSHIRE SOUTH

Mrs P Mason
67 Boston Road
Heckington
Sleaford, Lincs
Tel: 01529-460322
(after 6pm)

LONDON NORTH WEST

Mrs H Prentice
37 Milton Road, Hanwell
London W7 1LQ
Tel: 0208-579 4685

NORTHAMPTONSHIRE

Mrs Maggie Nichols
11A West Street,
Weedon
Northants NN7 4QU
Tel: 01327-340732

PRESTON & DISTRICT

Mrs Vera Dodd
"Roslea"
Nixon Lane
Leyland
Nr Preston
PR26 8LY

SHEFFIELD

Mrs Barbara Clark
35 Woodhouse Lane
Beighton,
Sheffield S20 1AA
Tel: 0114-269 9299

SOMERSET

Mr Peter Harding
94 Winchester Road
Burnham-on-Sea, Somerset
TA8 1JD
Tel: 01278 780946

SOUTH THAMES

Mr Peter Winterton
35 Paynesfield Road
Tatsfield, near Westerham
Kent TN16 2AT

SOUTHAMPTON & DISTRICT

Mr S J Fitzgerald
32 Ellis Road, Thornhill
Southampton SO19 6GR
Tel: 023 8040 2644

STAFFORDSHIRE

Mr Reay Pearman
2 Spode Grove
Westbury Park, Clayton
Newcastle-under-Lyme
ST5 4HF

STAINES, HOUNSLOW & DISTRICT

Mrs Pamela Page
237 Upper Halliford Road
Shepperton,
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