Link

The magazine for people with hydrocephalus and spina bifida

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SUMMER 2003 ISSUE 205

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

InCare

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Link

Cover: Lisa Nicholls-Sykes introduces Benny Bear to son, Barney.

Peter Farrall writes

Well, summer's here and holidays are in the air. Whether you get this edition of *Link* before you're lucky enough to go on holiday or it's waiting for you when you get back, treat it as a good summer read – there's something for everyone.

It continues the new features, which we started in the spring edition. Continuing the holiday theme, there are features on cameras and Harry Potter-inspired days out.

In fact, we've had good feedback on the new feature pages in general. It's good to know that people value *Link* and appreciate the improvements we're making.

On a more serious note there's a heartfelt article in this edition from Linda Dixon on what it's like to have benign intercranial hypertension and a letter from Sahedur Rahman about ear problems. Both of them are hoping readers will get in touch with them to share experiences. I think this demonstrates one of the wonderful things about *Link* – it brings people together.

But read on – and enjoy!

Best wishes,
Peter

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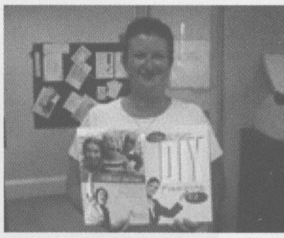

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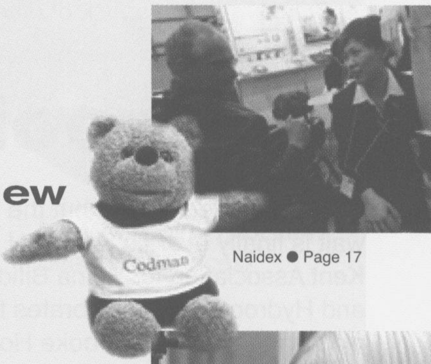

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ASBAH's mission is to work with people with spina bifida and/or hydrocephalus, their families and carers to promote individual choice, control and quality of life.

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

New primetime TV series on disability

Emily Spiers with her baby brother

This summer a new Channel 4 series on living with disability hit our TV screens. Described by the makers as a 'frank and unsentimental portrait of the pressures and joys of life with a disabled child', the Born to be Different series consisted of three films following the families of six babies born with physical and mental disabilities; they include three-year old Emily Spiers, who has spina bifida and hydrocephalus, is one of ASBAH North's service users.

From the initial shock of diagnosis, the series charted the day-to-day practicalities of coping with disability within the family. Looking at how parents deal with medical issues and prejudices, it also revealed how hopes and fears changed over the three years. The final film saw the children approaching their third birthdays when differences between them and their peers were becoming more pronounced.

With the programme makers aiming to re-visit the children every three years, Born to be Different looks set to play a useful part in improving the public's understanding of disability.

Let *Link* know what you think about this series – good or bad – by writing to ***The Editor, Link, ASBAH, 42 Park Road, Peterborough, PE1 2UQ.* Email** link@asbah.org

Seabrooke House opens its doors

It's taken sixteen years but the wait is finally over as KASBAH (the Kent Association for Spina Bifida and Hydrocephlus) celebrates the official launch of Seabrooke House, its new independent living training centre. President of KASBAH, Kypros Nicolaides, officiated at the project's opening in Swanscombe in May.

Seabrooke House is a residential centre for teaching independent living skills to disabled people. There are six self-contained rooms, a kitchen, a large open plan room, a training room, a conservatory and a private garden. Next door are two flats called Janus Court, after the Roman God of new beginnings. They act as a half-way house for those who are almost ready to live independently in the community.

Each trainee will learn practical skills like cooking, cleaning, shopping and budgeting. They will also be encouraged to use the leisure, educational and training facilities available in the local community. As the trainee's confidence, ability and independence grows support is reduced.

KASBAH service manager Lynda Atkins explains: "This is a moment in KASBAH history, which, thanks to the generosity of those providing the funding, represents years of planning coming to fruition. It's our hope that this training will enable our trainees to sustain fuller and more active lives, both within their immediate community and society as a whole."

Left to right: Pam Gaskin (KASBAH Chairperson), Jodie Charnock (trainee), Professor Kypros Nicolaides and Lynton Fairman (trainee).

Huw unravels the clues to make TV history

Huw Griffith, a member of North Wales ASBAH, made a little bit of TV history when he was the first wheelchair user to take part in an episode of BBC Wales' physically demanding History Hunters series. Shown in May on BBC 2, Huw and friend Hywel Williams had spent two days visiting different landmarks in south Wales, racing against the clock to unravel cryptic clues to discover the theme linking them together.

Series producer Ali Kedge adapted filming schedules accordingly, saying afterwards: "It's made me more aware of the potential of working with people with disabilities in the future."

ASBAH has said farewell to **Milly Rollinson**, who retired as Assistant Director (Services) at the end of June. Milly joined ASBAH nine years ago as Services Manager, taking over the post of Assistant Director four years ago in 1999.


Milly Rollinson

Comings and goings

Milly successfully led a department that was constantly stretched at local, regional and national level. She also played a full part in the senior management of ASBAH, contributing to all aspects of the association's work.

During her time with ASBAH Milly saw many changes, from new national legislation and funding, to changes in funding streams and government priorities. Through turbulent times Milly ensured that ASBAH always responded appropriately. Milly was widely respected and regarded with trust and affection by her colleagues.

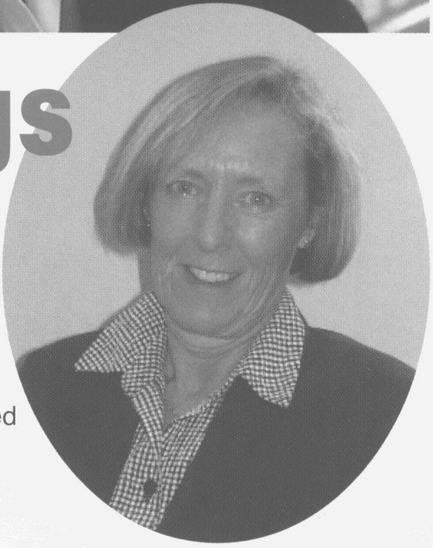
Rita Duell, Services secretary, has also retired after 13 years. *Link* would like to wish her and Milly long and happy retirements.

Milly has been succeeded as Assistant Director (Services) by former Eastern Region Manager, **Mary Malcolm**. Mary joined ASBAH in 1989 as Assistant Field Manager and then, in 1994, she took up the post of Eastern Region Manager. Prior to working for ASBAH Mary worked for social services and has extensive experience of working with young people.

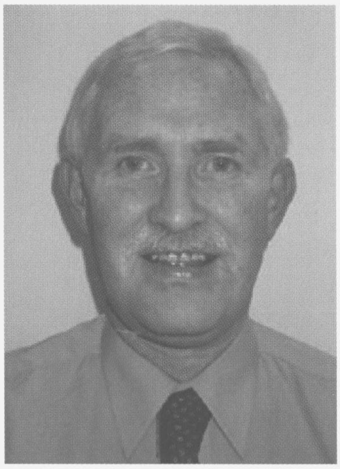
David Isom, who has joined ASBAH from MENCAP as Eastern Region Manager. David trained as a psychiatric nurse and has extensive knowledge of the voluntary sector and experience of working with people with disabilities.

Link would also like to extend a warm welcome to **Brendan Heaney,** who has joined ASBAH as Regional Manager, Northern Ireland, from RNID. Brendan was involved with the highly successful campaign to have digital hearing aids provided free through the National Health Service.

Another newcomer is **Michele Savage**, who has taken up the post of Project Co-ordinator, Fundraising. She previously worked in Peterborough MP, Helen Clark's, constituency office.

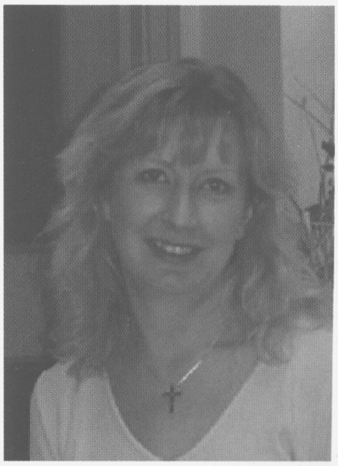

Mary Malcolm, Assistant Director (Services)

Finally, **Jacqui Smith** has joined the Services Department from our Telesales Department as secretary.

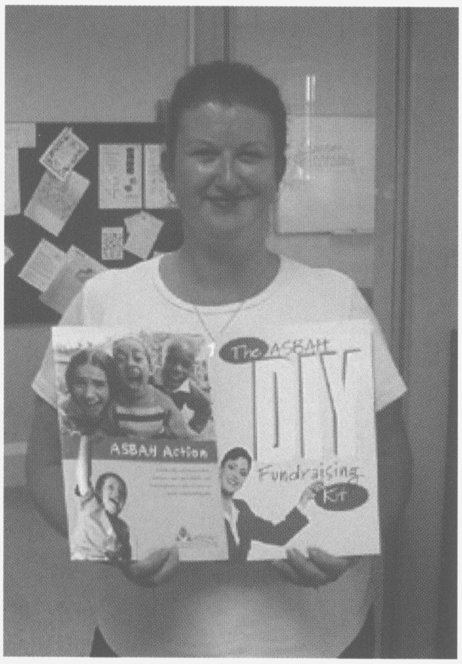

Brendan Heaney, Regional Manager, Northern Ireland


Michele Savage, Project Co-ordinator, Fundraising


David Isom, Manager, Eastern Region

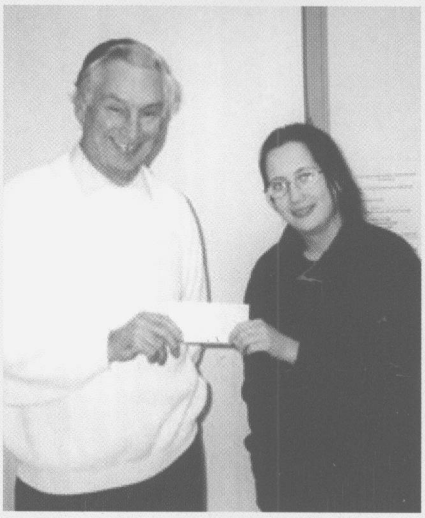

Jacqui Smith, Services Secretary

New fundraising toolkits



Here is ASBAH's fundraising manager, Donna Treanor, with our new fundraising toolkits. She is proudly holding the packs, *Action Pack for Schools*, aimed at the younger fundraiser, and *DIY Fundraising Kit*, aimed at general fundraisers. With their practical advice, helpful tips on how to make your event extra special and useful posters and sponsorship forms, both packs are set to become invaluable tools for would-be fundraisers.

To get your hands on either of the packs contact ***Ian Morley at ASBAH, Tel: 01733 555988, Email:*** *ianm@asbah.org*



Going swimmingly

Thanks and well done to Hayley Witt who raised £50.40 for ASBAH when she did a sponsored swim of 70 lengths in December. Here she is handing over the cheque to Stan Fitzgerald, Chairman of Southampton & District. Hayley's twin sister, Kerry, is an ASBAH member who has just completed a course in childcare at Southampton College.

From there to **eternity**

Just 64 years young, Bryan Crick is tackling a challenge that would make many a person blanch - walking the hundreds of miles from Land's End to John O'Groats.

And despite having to break his journey because of a foot infection, he's full of determination and stories about the trip so far.

For instance, a phantom lake that had him and fellow walker Ron Johnson mystified because it just wasn't on the map. It then dawned on them that it was a sea of plastic sheeting!

Or the many kindnesses of people who took them into their homes, let them stay overnight, fed them and gave them cash for ASBAH.

Bryan, whose daughter Eleanor died at the age of two-and-a-half when her shunt failed, had teamed up with fellow British Backpackers Club member Ron, a remarkable 71, and set off in March this year.

He recalls: "Previously, my longest walk had been 294 miles on the Pennine Way, while the toughest was the 200 miles from Fort William to Cape Wrath in Scotland.

"Although I live in Gateshead, we set off from Land's End because we wanted to follow the improving weather as it moved progressively northwards. We wanted to arrive in Scotland after the winter snow but before the summer midges."

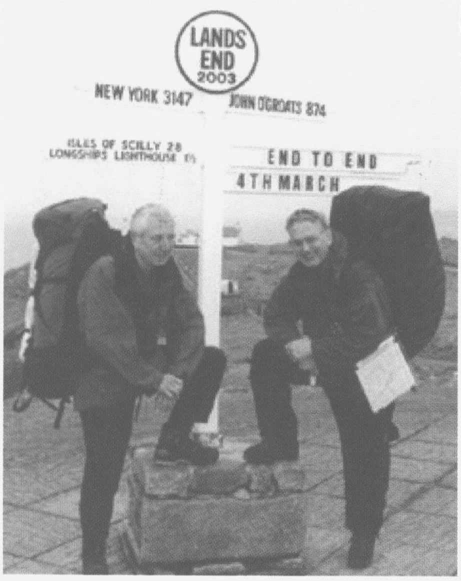
Carrying tents, clothing, bedding and food in packs weighing around 40lbs, they trekked anything up to 18 miles a day.

"For the first 250 miles, to around Bath, you're actually walking eastwards because of the country's geography. Equally, although the distance by road to John O'Groats is 874 miles, on foot it's more like 1,200 miles because of the meandering footpaths and the ups and downs of hills and valleys," Bryan explains.

But just short of the Scottish border, after they'd completed around 700 miles, they had to call a halt because blisters on Bryan's foot had become infected. "I was almost on my hands and knees," he says.

They mean to complete the trek as soon as Bryan's fit enough.

Bryan adds: "At the moment I have no idea how much we've raised through our sponsors, but we were given £200 by people we met along the way and another £150 was sent in Euros by relatives of mine in Italy. It's certainly been a challenge, but I'll remember it most for the many lovely people we met along the way."



Stop press: **Bryan and Ron have now completed their trek. More in next issue.**

Alan's magnificent seven

Left to right: Graham Dean, Dave Davison, Dave Nutman, Jeff Stone and Dave Bernard

Seven bikers tackled a 150-mile coast-to-coast cycle ride to raise money for ASBAH in memory of Alan Rance.

The seven - five of them school friends of Alan's and the other two golfing acquaintances of his - expect to have netted more than £3,000 in sponsorship after their four day trip from Whitehaven, in Cumbria, to Tynemouth on the east coast.

Since Alan and his friends from Chesham High School in Buckinghamshire left school they have had an annual golfing reunion every year.

But following Alan's sudden death at the age of 39 last December they agreed it would be a great idea to do the ride - not just to raise money, but in memory of the man himself.

Old family friend Dave Nutman explains: "Alan was a guy with lots of time for other people, a talented sportsman and successful in his career, as well as adoring his wife Kathy and their twin sons Matthew and William."

Other members of Alan's magnificent seven were Andrew Donaldson, Jeff Stone, Dave Bernard, Andy Ferris, Graham Dean and Dave Davison.

Andrew said: "None of us is a regular cyclist, so that although one [illegible] two managed to do a bit of training beforehand, it was a tough challenge but very enjoyable at the same time! We cheated a bit though, in that each night we had our bags sent on ahead of us by taxi. We were teased for this by a couple of Dutchwomen cyclists we met en route, who were absolutely loaded down with belongings. They reckoned we were real cissies!"

The intention is to continue to raise even more money in Alan's memory; a cricket match and golf event are already planned this summer.

"As with our bike ride, the principal theme will be about enjoyment for those involved - very much in Alan's spirit. We were constantly amused by the thought that Alan himself would never have tackled the ride – he'd have asked us what we thought cars were for!" Dave says.

Thorpe Hall School presentation

Here is Catherine Crook (right) proudly handing over the money raised to ASBAH's marketing trustee, Katrina Grounsell

Thanks to Thorpe Hall School in Thorpe Bay, Southend-on-Sea, who raised £568.52 for ASBAH. Over the years Thorpe Hall School has had a number of pupils with hydrocephalus, so when the staff and children were picking their annual charity ASBAH was chosen, a relevant as well as worthwhile cause.

Not so 'lite' a cheque

One of new project co-ordinator Michele Savage's first duties was certainly a pleasant one, when she received a cheque in April for £750 from North West Cambridgeshire MP Sir Brian Mawhinney. This was raised by local radio station Lite FM in its Christmas on-air auction, which made more than £17,000 for 18 local charities and organisations. We'll be using our share of the money to support our services for children and young people in Cambridgeshire.

Lite fm
106·8
PETERBOROUGH

Getting a grip – getting camera happy!

From barbeques and weddings, to day-trips and holidays, the summer months can whizz by. Autumn always comes too soon - so why not capture your memories of the long sunny days on film and savour them then?

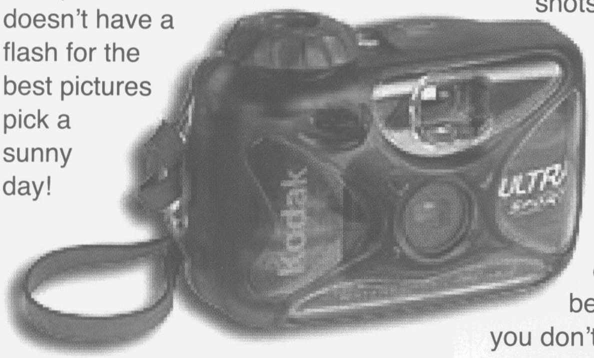
Disposable cameras are the perfect choice because they are light, easy to use and incredibly robust. They're also great value for money and are the perfect alternative when you don't want to risk using, or can't run to, expensive cameras.

A picture says a thousand words and *Link* is always interested in what its readers get up to, so why not keep a disposable camera handy and capture your summer fun on film for us?

With so many different types to choose from it can be a bit bewildering picking the camera that'll help you get great pictures, so here's a run down of some of the best.

The great outdoors

For those of you who like to get back to nature in the great outdoors you'll need a robust, or even waterproof, disposable camera. Kodak's Ultra Sport camera is sealed in rubber casing, making it waterproof and sandproof. However, as the camera doesn't have a flash for the best pictures pick a sunny day!



If you want to capture the beauty of majestic hills, sweeping beaches or the rolling ocean Fujifilm's Quick Snap Panorama is the perfect camera for you. This is an unusual disposable camera, because it can take panoramic (extra wide) pictures of the great outdoors.

Party animal fashion accessory

A disposable camera is a must have accessory for all those summer parties. Boots has silver and purple cameras, which will not only jazz up your gear but also capture the antics of friends and family for an (un)welcome reminder the next day!

Kodak has also launched a new generation of disposable cameras. Its Ultra Compact cameras are set in a sleek, silver body with a signature touch of striking colour – choose from red, orange and blue. Thanks to the built in flash this camera is perfect for indoor pictures or evening shots. It was recently voted 'best buy' by *Which?* magazine.

Camera crazy kids

Single use cameras are perfect for giving to children. They're not only easy to use, but because they're inexpensive you don't have to worry about the camera getting damaged or lost. Fuji has a fun looking single use camera called Flash Cat, which offers maximum quality and picture taking flexibility and is also suitable for use indoors. It is the perfect entry into photography for any budding snapper.

Family fun

For families who all want to get in on the fun why not buy multi-packs, like the Kodak Party Pack, which contains four flash single use cameras, and then the whole family can see who has the makings of a professional snapper.

Five top tips for perfect pictures

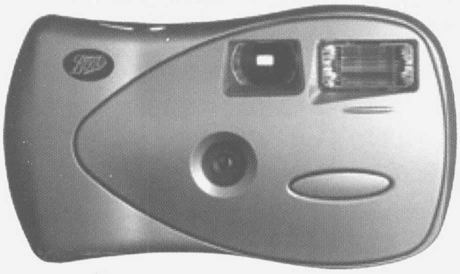
So now you've bought your disposable camera and you're carrying it around with you, ever ready to capture friends and family on film. But what can you do to avoid disappointing pictures? *Link* asked the photographic experts at Boots for their top five tips.

1. Hold your camera correctly

Good photo opportunities come

and go quickly and it's easy to get your fingers in a tangle when you're rushing to get a picture. Take time to familiarise yourself with the camera so you instinctively feel for the correct position.

2. Shoot with your back to the sun
Taking photos of people with the sun behind them makes them appear as featureless, dark silhouettes. Try and have the sun behind you instead. If your position makes this impossible, if you are standing on a balcony or bridge for example, turn on the flash to force extra light onto your subject.

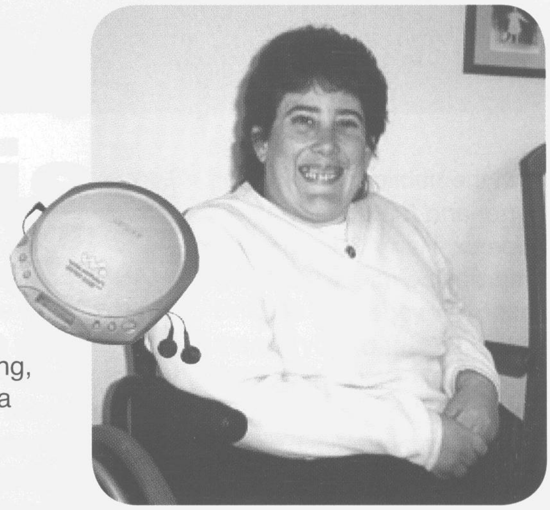


3. Avoid distracting backgrounds
Distracting background shapes, like a lamp post behind a person's head, can ruin an otherwise great photograph. For staged shots why not experiment with foliage - an excellent alternative for those who want something more interesting than a neutral backdrop.

4. Try different viewpoints
Experiment with different angles to achieve an unusual perspective. A picture taken from below will have a completely different mood to the same shot taken from above. If you're unable to move into different positions easily ask your subject to kneel down or stand on some steps.

5. Take more than one picture
Professional photographers always take a couple of shots of the same thing to ensure perfect results. This is a particularly good tip when taking pictures of people, as there is always the risk they may move slightly or blink at the wrong moment!

Last issue's winner



Congratulations to Siobhan Harding, of Rushden, Northants, who won a Sony CD player in the last issue's competition. Her favourite artist is Jamiroquai.

Reader offer

Link has 10 disposable cameras to give away

- Five Kodak Ultra Compact single use cameras worth £8.99 each and five Fujifilm QuickSnap Panorama cameras worth £8.99 each.

For a chance to have one of these cameras simply print your name, address and telephone number on a postcard and send it to:

***Link* Reader Offer,**
ASBAH, 42 Park Road,
Peterborough, PE1 2UQ

The closing date for all entries is 12 September. The first ten entries drawn after the closing date will each win one of the 10 disposable cameras.

Powertrike competition

Thank you to everyone who entered the PDQ mobility "Powertrike" competition. Unfortunately due to contractual difficulties with PDQ mobility, the competition has had to be abandoned.

We apologise for this development and would advise readers that their entries will be automatically entered into the next *Link* competition.

Happy days

Pottering about

With the publication of *Harry Potter and the Order of the Phoenix,* Harry Potter fever is spreading across the country yet again.

Alnwick Castle
Alnwick, Northumberland
(Hogwarts School in *Harry Potter and the Philosopher's Stone* and *Harry Potter and the Chamber of Secrets,*

The gardens are fully accessible for wheelchairs. The castle's state rooms are on the first floor, and there is a lift; unfortunately it's too small for a wheelchair but the staff will assist visitors and then provide them with one of their own wheelchairs on the first floor.

Open every day until 31 October, 11am - 5pm (last admission 4.15pm). See *www.alnwickcastle.com* or call 01665 511100.

London Zoo
Regent's Park, London
NW1

(Harry Potter and the Philosopher's Stone). Most of the zoo is accessible for wheelchair users and those with walking difficulties, There is no access to the Moonlight World or direct access to the aquarium.

There are six manual wheelchairs and two electric buggies available at the zoo entrance. There is no hire charge, but a deposit of £25 is required. It's strongly recommended that you book a wheelchair in advance of your visit to ensure that you get one - telephone 020 7449 6576 to reserve one.

See *www.londonzoo.co.uk* or call 020 7722 3333
Open every day throughout the summer, 10am-5.30pm.

The Jacobite Steam Train
Fort William Railway Station,
(Harry Potter and the Philosopher's Stone and *Harry Potter and the Chamber of Secrets).*

You can experience your own magical train journey by taking a trip on the Jacobite Steam Train which follows the famous Road to the Isles, between Fort William and Mallaig.

The guard will help disabled people on and off the train, but for best views you will need to take a seat in the main section of the train; assistance is available.

See **www.steamtrain.info** or call 01524 732100.
Open Monday-Friday until 3 October; Sundays from 27 July to 31August.

Departs 10.20am from Fort William, arrives back at 4pm.

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

Bristol & District

Rookery Road, Knowle, Bristol: welcome to the nerve centre of Bristol & District Association.

This is the home of Gordon and Sheila Egan and their daughter Kim. Kim was born with spina bifida and hydrocephalus in 1963 and in those days, of course, ASBAH wasn't around to help. But Kim attended a local hospital clinic where soon Gordon and Sheila and all the other parents saw the need to get together on a permanent basis so that they could share their experiences and support each other.

Sheila recalls: "Back then hospitals were unable to offer the level of support which they do now. There was little information even about how shunts worked - one couple even thought the tube would be on the outside. The association soon got moving and made a point of ensuring other parents knew where we were and what we could do to help them. A lot of our work was done by visiting their homes."

Without a doubt if it wasn't for the continued and unstinting hard work of Sheila and Gordon - Gordon is the association secretary - the association wouldn't be around today. Steve James has been Chairman since 1991 (his son Trevor was born with spina bifida in 1969) and Richard Hall is the Treasurer; other committee members are Max Buckley, Ted Pritchard, Lyn Griffiths, Val Collins, Julia Hall and Sue Mileston. Sheila's also in charge of the Welfare Sub-committee and Kim and Julia run the Social Committee.

"We like each other and we support each other. 80% of the members who support our events are the original ones. That's not a bad loyalty base, is it?", Steve James says.

Three trustees support the committee: neurosurgeon Ian Pople, Dr Richard Kinsman and Ray Mabbutt. That completes an impressive array of people. This is just as well as they don't have the extra resource of a regional office to work alongside. Indeed this is a moot point, as Steve explains: "We feel we may be missing out on the benefits that an ASBAH regional office would give us, especially in being a more vibrant and vigorous association. Some time ago ASBAH started to open regional offices, but I believe the funds ran out and the south west didn't get one."

But thanks to Bristol & District Association the region has the next best thing: in conjunction with ASBAH it pays part of the costs of service adviser Julie Knight, who's been in the post since 1995.

Because of Julie's work ASBAH makes quite an impact regionally. This, along with the work of Bristol Social Services and the world class expertise of Bristol's Frenchay Hospital, means you could say that things are pretty well ship shape and Bristol fashion.

That's not forgetting the Children's Centre at Frenchay Hospital, which opened by children's TV presenter Johnny Morris in 1972 following a major fundraising campaign by the association and in collaboration with the local health authority.

And where would an association be without a newsletter - or even the *Newsletter*, as in Bristol's case?

It has to be said that there isn't the demand for help that there once was; the decreasing occurrences of spina bifida are an obvious case in point. So the association is looking at its fundraising strategy to see how it can best adapt. In 2002 the association raised nearly £1,500 and thanks to fundraising from previous years it was able to give out £3,500 in welfare grants last year alone. Individuals and families affected by hydrocephalus are a definite cause for concern. Says Sheila: "We need to tell any of those brought to our notice who are affected by hydrocephalus what we can do to help. They need us just as much as we need them."

And what of the future? Gordon says: "The association hopes to be around for a long time to come and will do all in its power to ensure the region retains a field adviser."

Picture shows: Sheila and Gordon Egan and Kim Egan with their dogs Tahly and Heidi.

Ageing and SB/H

Getting old is a prospect that faces people in even the very best of health. But because intensive treatment of spina bifida and hydrocephalus did not really begin until the early 1960s, it is only recently that relatively large numbers of people with these conditions have been assessed. Thus, there are precious few case studies that can accurately be reviewed as a guide to others. So what does the future hold?

One thing is clear: once young people reach the end of their education, and leave the paediatric services for those of the adult hospital, they may lack continuation of health care and lose contact with various medical specialties. That places a great deal of responsibility on the individual themselves to carefully monitor the effects of their health care, lifestyle and attitude.

Above: Alan and Margaret Twyford (see next page)

Dr Jill Hunt, who has studied spina bifida and hydrocephalus for more than 35 years, says: "People do live a quite extraordinarily long time, and generally speaking the milder the case the longer the life expectancy - into the seventies and even eighties. But no one really knows or can accurately predict how long an individual will live."

However, the effects of ageing may be expected to include more pressure sores, weight gain, blood pressure problems and reduced mobility. Dr Hunt says: "One of the first priorities is to keep appointments with your GP or hospital consultants.

By the age of 35, only 25 per cent of people still attend hospital regularly. Even if you are quite well, it is important to check blood pressure, urine and eyesight every year. If you ever go to see a doctor - and everyone gets a cough or some other ailment from time to time - then get them to check your blood pressure, which is also an indicator for kidney problems."

One of the best ways to detect shunt problems is to have your eyesight checked by an optician. A squint is often symptomatic of intracranial pressure. The optician will also check the back of the eyes as well.

Says Dr Hunt: "Don't ignore headaches or neck aches, which could indicate a blocked shunt. People often get misdiagnosed, in that a stiff neck will be referred to a rheumatologist when, in fact, it may be caused by intracranial pressure. Similarly, headaches and sickness should be viewed in this light."

She goes on: "Everyone is aware of pressure sores, which can cause enormous damage, but there are many specialist cushions currently available. Avoid hard surfaces."

And she advises: "Always wear a 'medic alert' type bracelet and carry an ASBAH shunt alert card so that, in the event of unconsciousness, medics are aware that you have a shunt."

Finally, she stresses that one of the most debilitating problems is weight gain. Obesity is a common problem and one that poses a major threat to health. Inactivity may lead to osteoporosis, or brittle bones, which can be tackled by eating a diet with plenty of vitamin D and calcium (skimmed milk and low-fat yoghurt are good sources, while exposure to sunlight provides us with the active form of Vitamin D). Taking HRT with some anti-epileptic drugs may also cause osteoporosis

Says Dr Hunt: "You have to eat far, far less than the average person, simply because you are not running about and getting the exercise. You need to stick to a diet - it's no use convincing yourself that a few biscuits does not constitute a meal, because they are loaded with calories.

"Weight gain affects not just the patients - it wears out the carers too, with the stress and strain of having to lift the extra weight, creating back problems that may mean the patient themselves having to go into a care home.

"And if you can stay slim, you will be more active and independent and have more fun!"

John Henry Hughes, 63, is a former metallurgist turned TV and radio actor who has appeared with John Thaw in Kavanagh QC, as well as with other such notables as Jeff Goldblum, Ian McShane and Sian Phillips. Married to university lecturer Elizabeth for 38 years - she is president of the Association of Occupational Health Nurse Practitioners and a Fellow of the Royal Society of Health, as well as a Cambridge City councillor - they have a son and daughter and four grandchildren.

Born with spina bifida, John Henry has no feeling in his legs and feet. He says: "When I was younger, comments that I would not be able to do specific things made me all the more determined to do them - for instance, I played cricket and am a second dan black belt in judo.

"Getting older is not making a huge amount of difference to me, except that I am unable to walk anywhere near as far as I used to. However, although I have a wheelchair, I flatly

Continued on next page

New independent living guide on the way

Left to right: Lucy Hughes, Stephen Smidmore, Keith Marshall, Kathy Smidmore, Judy Hunt and Lisa Cain

The transition to independent living can be daunting, with the difficulty of getting information, support and advice all adding to the stress. Having experienced this struggle first hand, the Living in London Forum decided to produce a guide called *Independent Living – Make It Happen*. As the project nears completion *Link* caught up with the forum, led by project workers Lucy Hughes and Judy Hunt, to find out how they tackled this important topic.

"It was frightening but reassuring to discover that other people had encountered similar problems to me. Everyone spoke of their frustrations with red tape and the difficulty in knowing what help was available," explained forum member, Lisa Cain.

The forum worked in two groups and during regular meetings they wrote and designed the guide's individual sections. Lucy Hughes explains: "Judy and I acted as facilitators for the group. We encouraged them to use their personal experiences and our specialist knowledge to produce a guide that they would have found useful when first making the move to live independently."

Judy Hunt adds: "The whole process was experimental and we all learnt as we went along. A core group wrote and designed the leaflets but a wider circle contributed ideas and feedback."

Independent Living - Make It Happen will include the leaflets *Prepare For Independent Living, Housing Options* and *Direct Payments*, two self-help questionnaires – *What Housing, What Support?* and *Daily Living* - as well as a personal information sheet, *About You*. Further topics are planned over the coming months.

Independent Living – Make It Happen will be out in October; we'll tell you how to get it in the next *Link*.

Contacts for Living in London Forum: Lucy Hughes, tel 0118 9346783; email lucyh@asbah.org Judy Hunt, tel: 020 8363 4110; email judyh@asbah.org

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Continued from previous page

refuse to use it.

"My weight is pretty constant - I have been just over 9st for years now, but then I am careful about what I eat.

"I think you have to be sensible and responsible for your own approach to life; I firmly believe some people give in far too readily to problems. But having said that, I also believe that I have been very lucky in life and have enjoyed myself enormously."

Being aware of potential health problems, and taking steps to prevent them so far as possible, is the positive approach adopted by Alan and Margaret Twyford. They are both 58 and both have spina bifida.

Says Margaret: "I am very conscious of the danger of thinning of the bones and take calcium supplements. I also have bone scans at the Chelsea and Westminster Hospital's spina bifida and hydrocephalus clinic, which we both attend for regular check-ups on our general state of health, including renal (kidney) health.

"We've found that many people with spina bifida and/or hydrocephalus fail to go to clinics after leaving school. There is a health education need in later life to encourage their using such clinics."

Says Alan: "Because my weight has tended to see-saw quite significantly - by half a stone or so - I recently joined a weight-watchers' club, which is brilliant. Although not seriously overweight, I lost about 1st and have managed to maintain it pretty well."

Married for 32 years, the couple have no children or immediate relatives to offer help and support if their health deteriorates significantly. Says Alan: "We have to face the prospect of ultimately losing our current level of mobility. This might mean our becoming wheelchair users and requiring more in the way of housing adaptations, support in daily living tasks, difficulty using transport, etc.

"There's a very real need to plan ahead not just in such things as housing, finance, health, etc., but also in general interests - what you are going to fill your time with? In this respect, it is worth considering pre-retirement courses or finding out what other options are available from such organisations as the local council."

Useful tips

- Don't let your health deteriorate. Get help when you notice any problems developing.
- As soon as you lose a faculty, you're going to be more dependent on people. Remain as independent as possible for as long as you can.
- Make sure you exercise your mind as well as your body
- Exercise, including wheelchair exercises are very useful, and are not just for the young. It's a good idea to take along a friend to take note, so that you can repeat the exercises at home.
- Seek advice as soon as you can on any health concerns. Therapy, including physiotherapy can be very useful. There are a whole range of complimentary therapists.

Are you ready for higher education?

Your exams are over and, fingers crossed, the results will mean you're off to start an exciting new life at college or university this September. But now's the time to rest on your laurels. You will need to prepare carefully if you want to spend your time studying and having fun, instead of worrying about the practicalities of everyday life.

Disability co-ordinator

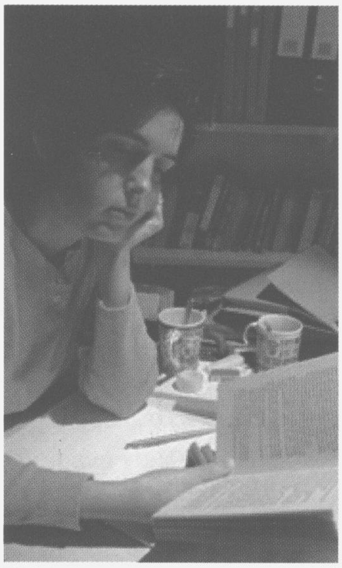
The first step is to get in touch with your institution's disability co-ordinator, whose job it is to advise students with disabilities. They will help ensure all your support needs are met, put you in touch with other disabled students, advise on Disabled Students' Allowances (DSAs) and act as an advocate during discussions with your academic department.

Stephanie Barbaresi, disability co-ordinator for the University of Wales, Bangor, explains her role: "We like to set up a dialogue with our disabled students as early as possible because this relieves a lot of the pressure they are under, minimising the stress of starting university."

Your disability co-ordinator will also provide you with the institution's disability statement, which outlines current access, provisions for disabled students as well as future plans for improvement.

Physical environment

One of your concerns about starting college or university life may be the practicality of getting around the campus. Under the current Disability Discrimination Act educational establishments have to renovate their buildings and improve access to facilities such as lecture halls, classrooms and libraries. Although this legislation came into force in September 2002, adjustments are not required until September 2005.



Hopefully you will have already made a visit to your chosen institution, but if not you should arrange an appointment now.

Personal assistance

If you're going to be living away from home for the first time you will already have arranged the necessary personal assistant for your domestic life. However, you also need to consider the personal assistant requirements of your academic life. The way study-related assistance is provided will vary from institution to institution. In some colleges and universities the support workers will be employees, others will use volunteers or staff from private agencies. Some institutions do not have a system in place and you'll need to recruit your own assistants. The disability co-ordinator will be able to steer you through this process.

Health matters

This stage of your life could also be the first time you have to take responsibility for your own health. With this in mind ASBAH is in the process of producing a guide called *Leaving Home for College or University*, which will be available in September.

ASBAH's senior health and policy adviser, Rosemary Batchelor, recommends you find out where the nearest neurosurgical hospital is and let them know you are coming to the area. Don't forget to sign on with a local GP and bear in mind that if you're currently receiving complimentary therapy your new GP may not continue to fund it. Find out where you can get your continence appliances from and set up a delivery service. It is also a good idea to find out where the nearest wheelchair service centre is.

Rosemary adds: "Be aware of how your new lifestyle may affect your health. For example, learn how to recognize a shunt headache and don't confuse it with a hangover headache - help yourself by drinking a glass of water for every glass of alcohol. Most importantly, you must ask for help when you need it - not just for any physical issues but also for any aspects of college or university life that you find difficult including meeting deadlines."

Funding

As a disabled student you may be able to get extra funding DSAs. These cover

extra expenses you incur whilst studying and as long as they arise because of your disability.

DSAs are needs-based and you will receive a grant to cover the cost of specific items of equipment or human support costs etc. The DSAs are not means-tested, so you get them regardless of the income of you or your family.

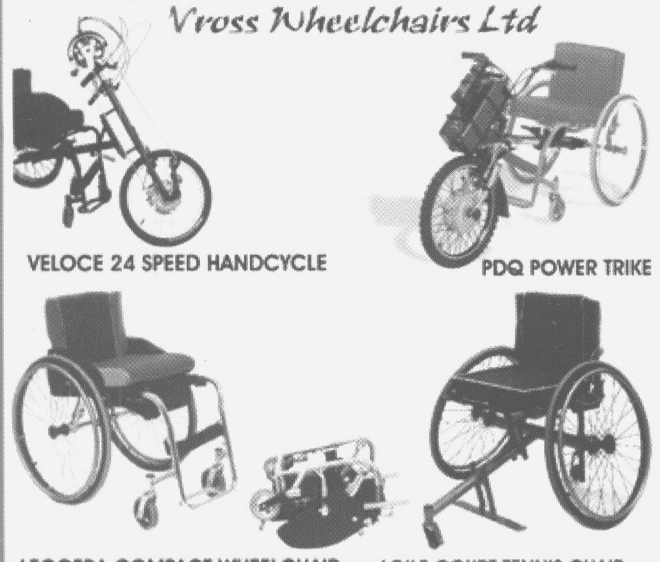
Go for it!

ASBAH's education adviser, Joanne Grenfell, adds: "Many students with disabilities have successfully completed courses in further or higher education. But remember that these institutions accept students on the basis of their academic achievements and potential. Be realistic, but go for it - going to college or university is a great way to empower yourself!

For more information or to order a copy of* Into Higher Education 2004 *go to* www.skill.org.uk *or call 0800 328 5050.

For further advice contact Joanne Grenfell, ASBAH's education adviser, Tel: 0113 255 6767, Email: *joanneg@asbah.org*

To obtain a copy of* Leaving Home for College or University *contact Jacqui Smith, Tel: 01733 555988, Email: *jackies@asbah.org*



DAVE'S DIARY

david.fulford-brown@ntlworld.com
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I've lost the sweater I bought at the Star Trek Experience. I'm so annoyed. It was really cool (I think), really comfortable and totally irreplaceable. It was also one of the few pieces of clothing I've ever just bought for myself.

My family usually gets my clothes. Well, they do know more than me about fashion. Then again, knowing I loathe our cat, Anthony did buy me a t-shirt with a cute picture of a cat - on a plate with the words "I like cats, they taste like chicken"! I might do my own shopping in future.

Shopping is exhausting and deciding on what to wear is extremely stressful. That's if I can get to the clothes. Clothes shop floors are obstacle courses of small tables, raised bits and steps. Why? Is it not possible to sell clothes on a flat surface? Add to that hundreds of shoving people, loud music and extremely snotty assistants that obviously think I should be five stone lighter or in a different store and you can see why I don't cheer if someone suggests a clothes shopping trip.

How we buy clothes needs kicking into the 21st century. Instead of having to go to shops and take the clothes they offer in the size they offer, why can't we have low cost clothes made to measure? Laser scan yourself, email your measurements in, then just tell the shop what you want and (importantly for me) what the material needs to be. I sweat easily so I need light clothes. I've noticed Rohan make shirts with a material which allows sweat and heat out and keeps me dry.

Imagine a world where all clothes react to weather and wearer, where shirts can absorb that tomato sauce I've just dropped down my front or trousers absorb wee if I have an accident. Imagine a world like in Star Trek where clothes are ordered and produced at the touch of a button with no shopping, loud noise or unpleasant shop assistants. Until that happens, beam me up Scotty!

The next annual general meeting of ASBAH will be held in Peterborough on Saturday 20 September.

The trustees of ASBAH are keen to broaden the skills and expertise base of the Board. If you think you can offer your skills - maybe in marketing, public relations, legal, education, websites, management - or indeed bring your experience as a parent or as a disabled service user, then we'd like to hear from you.

Please contact Brian Defee, Company Secretary, for informal discussion on 01733 555988. Nominations close on Friday 5 September.

Naidex – a consumer's view

The biggest range of healthcare products ever seen in the UK was on show at this year's Naidex and KideQuip exhibition at the NEC in Birmingham. Naidex offers advice and information to older people, those with a disability, and healthcare professionals. It featured 275 exhibitors taking in everything from the latest revolutionary wheelchairs to hot and cold compress packs to soothe aches and pains.

At the end of the show an innovative portable alternative to chairlifts and permanent ramps was picked by show visitors as the best new product.

Roll-a-Ramp, which can be easily moved around to provide smooth and safe access in and out of buildings, was one of 10 new inventions which qualified for a place in the final voting.

Roll-a-Ramp director Andrew Cohen said: "Disability access is a major problem because it affects so many individuals. Roll-a-Ramp, which also won the 2002 Best New Product award at the USA's MEDTRADE exhibition, is so simple that it can be set up in a matter of minutes. Made of lightweight aluminium, it can also be neatly rolled or folded up for convenient storage. Occupational therapists and access consultants seem to agree that it is extremely useful as a shared ramp in institutions like nursing homes and daycare centres, and in private homes where access needs to be improved.

"Wheelchair and scooter users, who previously might have struggled in day-to-day situations, have come back to us saying that the ramp has opened a whole new world of independence for them".

The last time Keith Collins went along to the NEC, he was with a colleague who was in a wheelchair. At this year's Naidex he saw life from the other side of the fence, still shocked by the loss of his own mobility more than 40 years after being born with spina bifida.

Until then, Keith had been a qualified social worker, spending his free time as chairman of a residents' group, as a school governor, organising a chess club and watching Birmingham City football club from the terraces.

He says: "I had been told that it was unusual for someone with such severe SB to be as mobile as I was. When I was born, my parents were told I would probably never walk, but they were determined that I should literally stand on my own two feet. Dad even made me a little red truck to encourage me to push it around. Despite the fact that my left leg was virtually paralysed, my right leg proved strong enough to support me and in my youth I was always active in sports, particularly in football.

"But then suddenly, last year, my good leg failed and I found myself relying on a wheelchair to get around - something I'm still learning to adapt to. As well as a lightweight wheelchair, I bought myself an electric scooter so that I could exercise my border collie, Macca. However, I managed to turn it over - it was supposed to cope with kerbs, but I reckon you had to be Evel Knievel to do it."

Admits Keith, aged 43: "Without the support of Selly Oak Limb Centre and one or two close friends and family, my quality of life would have deteriorated greatly."

At Naidex Keith was hoping to find solutions to some of his newly-encountered problems, including wheelchair access to his ground-floor maisonette, a visitors' intercom and opening his garage door.

After visiting the show on two days, he was able to report a very positive appreciation of what was on offer.

He says: "If there was a fault, it was that there seemed to be a heavy emphasis on mobility features - not surprising, really - but less on other features, such as sight or hearing limitations.

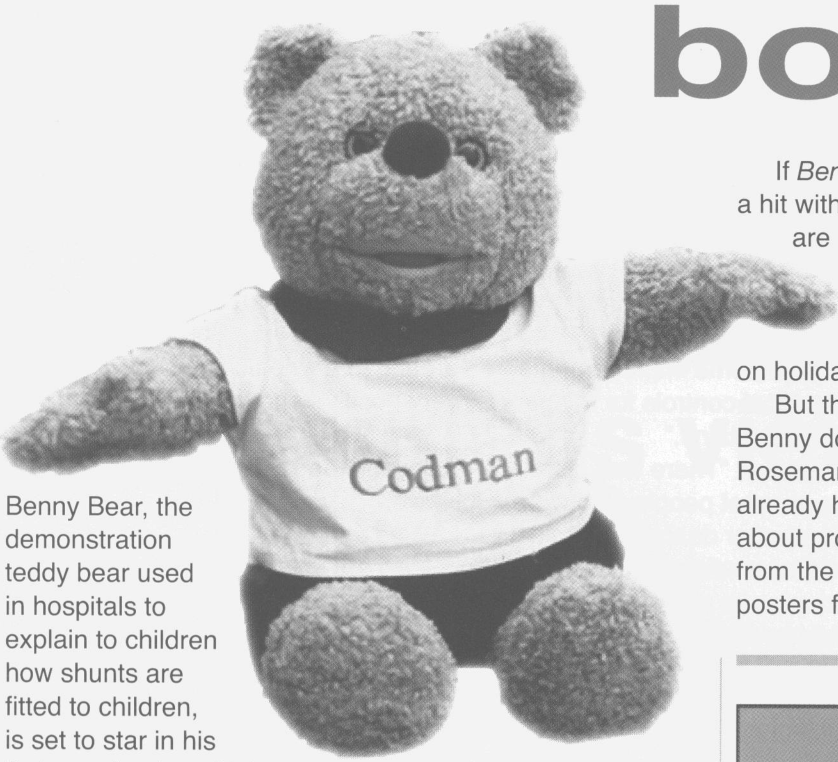
"Another weakness was that signs meant to explain the locations of different companies were not particularly helpful, in that they just gave names and little, if any, indication of the products on offer. But I did have very useful conversations with an engineer and a designer from Penny Aids Ltd., which manufactures air-assisted door opening systems, and with several occupational therapists who suggested home improvements such as electrical controls for things like doors and curtains."

And he added: "There was also the chance to meet people who were, for want of a better description, role models - for instance, a man disabled in an accident, who explained how he had adapted to disability and actually enjoyed life more now than before his injury. There was also a lady bombing around in a wheelchair, who was also very positive and helpful.

"All in all, the two days were very enjoyable and encouraging."

Pictures show Keith Collins visiting Naidex. Next year's Naidex is 11-13 May

Benny Bear to star in his first ever book



Benny Bear, the demonstration teddy bear used in hospitals to explain to children how shunts are fitted to children, is set to star in his first ever book, called *Benny Gets Better,* which is being published by leading shunt manufacturer, Codman UK, this autumn.

The brainwave of ASBAH's senior health adviser, Rosemary Batchelor, *Benny Gets Better* is a lively tale about Benny being diagnosed with hydrocephalus, explaining to children what it means to have a scan and be fitted with a shunt.

Rosemary felt that although the existing Benny Bear teddy bear was a wonderful demonstration model for doctors to explain about shunts to children and their families, it would be nice if children could also take something home with them. A children's book seemed the perfect solution and Codman, the shunt manufacturers whose international trainer, Mark Attenborough, designed the Benny Bear teddy bear, agreed to support the project.

Rosemary joined forces with Val Meyer-Hall, ASBAH's adviser in Suffolk, to co-write Benny's tale. The beautiful illustrations, which give the book its distinctive character, are the work of Charlotte Meyer, whose sister Jessica has hydrocephalus.

Peter Farrall, Assistant Director (Marketing and Communications), explains: "This book has been produced by people who have extensive experience of working with children with hydrocephalus, which has given us an insight into the best way to present information so that the children don't get bored with the story. There isn't another book like it."

If *Benny Gets Better* is a hit with the children there are plans to produce further books on subjects like going to school or on holiday with a shunt.

But the plans for Benny don't stop there, as Rosemary explains: "We've already had discussions about producing spin-offs from the book, such as posters for hospitals or bravery stickers. The book has also been well received by Codman in America, Italy and Switzerland, so you never know - Benny may even be translated into different languages!"

Benny Gets Better will be available free of charge this September. Many hospitals will have the book available to give to children who are undergoing treatment for hydrocephalus and you can also obtain a copy from your ASBAH adviser. Alternatively you can send a large SAE (with two 1st class stamps) to ***Jacqui Smith, ASBAH, 42 Park Road, Peterborough, PE1 2UQ***

Sporting life

by Marshall Thomas

Shortly after the last issue of *Link* came out, the Prince of Wales relit the Paralympic flame at the new Stoke Mandeville Stadium and declared the redeveloped National Sports Centre for the Disabled officially open.

The Stoke Mandeville Stadium, owned by the British Wheelchair Sports Foundation, invited some 700 guests to celebrate the re-opening after a £10 million refurbishment. The project has been funded by a Sport England Lottery Fund award, together with donations to the BWSF Sporting Chance Appeal.

Prince Charles and guests had the opportunity to see demonstrations of several wheelchair sports, including wheelchair racing on the specialised track, fencing, rugby, and table tennis in the Cazenove Sports Hall; swimming in the Wolfson Pool, and weightlifting in the 80-station fitness centre, with wheelchair accessible equipment supplied by PowerSport.

The reopening ceremony also saw the induction of the first four Paralympians into the Stoke Mandeville Hall of Fame including, Tanni Grey Thompson and the late Sir Ludwig Guttmann, the founding father of the Paralympic Games.

Back in the heat of competitions, Great Britain recently finished fourth in the medal table at the first ever European Paralympic Athletics Championships in Assen, Holland. The event brought a return to winning ways for Tanni, who won gold medals in the women's T53 100m, 200m and 400m. However, her quest to equal her Sydney Paralympic clean sweep of four golds was thwarted in the 800m when she was pipped by less than half a second by Sweden's Madeleine Nordlund.

There were also impressive performances from former Paralympic 100m champion David Holding, who took another gold in the men's T54 100m and collected bronze in the 200m. Holding, a former London Marathon winner, was followed home in the 100m by another former London champion, David Weir. Weir, from Surrey, who was second in this year's London Marathon in April, claimed bronze behind Holding in the 100m, but finished one place in front of his countryman in the 200m and also claimed a second silver in the 400m.

As the European Athletics Championships ended in Assen, the European Men's Wheelchair Basketball Championships got underway in Sardinia, with Great Britain reaching the semi-finals with four wins from five matches in their group stage. This was enough to secure their qualification for the 2004 Athens Paralympics, but they then had a disappointing 56-47 loss to host nation Italy in the semi-finals. However, the Brits pulled themselves back together for the third/fourth place play-off, coming from behind to beat France 74-64, with Liverpool's John Pollock, recently featured in this column, finishing as Britain's second highest scorer on 23 points.

Looking ahead, another exciting summer of sport includes the British Open Wheelchair Tennis Championships, a part of the NEC Wheelchair Tennis Tour, which take place at Nottingham Tennis Centre, from 22 - 27 July. One of just three tournaments in the world to have Super Series status (the equivalent of Grand Slam), the British Open will see Loughborough's Jayant Mistry once again lead the domestic challenge in the men's main draw singles. Mistry, who won his tenth men's national title in May, will team up with Dutchman Robin Ammerlaan for the men's main draw doubles, in which the partnership will be bidding for their third consecutive title.

For all you sports buffs who like to follow disability sports events, BBC Sport has recently launched its own disability sport web pages. The site is at www.bbc.co.uk/sport - click on 'other sport' in the left-hand menu to find the 'disability sport' pages.

Motability introduces new deals

Twenty five years after its launch, Motability has just celebrated the anniversary with a garden at the Chelsea Flower Show and some blooming good news for its 400,000 customers.

Since those early days, Motability has provided more than 1.5 million cars and powered wheelchairs.

Through more than 3,500 approved dealers this year alone it will supply around 150,000 cars - about six per cent of all new cars in Britain.

In February it introduced changes that will bring benefits to users, including improvements to its hire purchase deals and fair wear and tear policy.

One of the key improvements is in its contract hire scheme policy, dealing with unavoidable scratches and scuffs caused by wheelchairs and other mobility aids.

Until now customers were obliged to repair such damage.

Now, when a car is inspected at its annual service and at the end-of-agreement stage, all such damage is classed as fair wear and tear.

A spokesperson for Motability explains: “We feel that the new policy is fairer and reflects the needs of many of our customers. However, they should continue to repair any other type of damage that falls outside normal wear and tear and ensure that the car is returned in good condition. This enables us to obtain the most favourable price on sale, thus keeping scheme costs as low as possible for all customers.”

Meanwhile, the Motability car hire purchase scheme has been completely restructured to provide a more cost-effective and attractive option to buying a new or used car.

Buying a vehicle through the hire purchase scheme provides models and options perhaps not available under the contract hire scheme.

- a four- or five-year agreement to buy a new car.
- two-, three-, four- or five-year agreements to buy a used car (less than five years old and with under 60,000 miles on the clock).

The new competitive repayment rates are applicable to all customers, irrespective of their personal circumstances:

- two-year used car scheme from 10.8%
- three-year used car scheme from 8.5%
- four-year new or used car scheme from 8.5%
- five-year new or used car scheme from 7.9%

More miles on contract hire

All new contract hire agreements include a 25% increased allowance, from 36,000 to 45,000 miles; all miles above this cost 10p a mile. For agreements which started before 1 February customers can drive up to 38,000 miles without extra charges.

Applications will now also be approved even when a customer’s allowances fall up to six months short of the three year agreement period, without the need for an extra deposit.

The Motability scheme for powered wheelchairs and electric scooters has received a lot of criticism in the past from customers, dealers and disability groups alike. Says Motability: “It has been decided to transfer the scheme to a new service provider, route2mobility Ltd, which allows Motability to concentrate on the car scheme that represent 98% of the Motability scheme.

The new scheme is planned to give, among other things, better value for money, greater customer choice, special assessments to ensure the most appropriate product is supplied, and improved hire purchase lengths and flexibility.

For full details on powered wheelchairs and electric scooters please call route2mobility on 01264 384480 or see ***www.motability.co.uk***

Extended rights to hit the statute books?

Draft regulations laid before Parliament in May will make significant changes to the employment provisions of the Disability Discrimination Act (DDA). The regulations, which implement a European directive, bring within scope of the DDA a further one million small employers, around seven million additional jobs and 600,000 disabled people who already work in them.

They will also include final duties on service providers to make reasonable adjustments for disabled customers.

If they are approved by Parliament, the regulations will come into force in October 2004.

DRC celebrates third anniversary

After decades of campaigning by disabled people and disability organisations, the Disability Rights Commission (DRC) opened its doors for business three years ago.

Since then it's provided advice and support to nearly a quarter of a million people who have called their helpline. And it's proving a popular source of information as last year we received a twenty five per cent increase in enquiries about disability rights and experiences of discrimination.

Since the DRC was established, it's provided a variety of advice to its callers. This has ranged from intensive legal support to a disabled person calling about their rights at work, to a national service provider wanting to ensure their services are fully accessible to disabled people.

As well as advice from its helpline, nearly six thousand disabled people have received one-to-one support from one of the DRC's legal advisors. In the last year, it supported 1,781 people with experiences of discrimination at work, socially or in the education system.

For example, the DRC heard from the mother of a five year old boy with mobility impairment. She wanted to take him swimming, but the local pool wouldn't provide the equipment her son needed to get in and out of the pool. The DRC made contact with the leisure centre and persuaded them to provide the equipment needed along with some extra aids and games for use in the pool.

A trend which became apparent over the past year concerned the large numbers of disabled people continuing to face discrimination at work. Over half of the people supported in the past twelve months had faced workplace discrimination. This is a disturbing finding and many of these situations would have been unlawful.

Often all that is needed for a disabled person to operate effectively is a small adjustment such as a change of duties or working hours. This may cost nothing or very little.

Last year the DRC consulted with a large number of disabled people, disability organisations and businesses about ways in which the current legislation - the Disability Discrimination Act - could be tightened to protect more disabled people from discrimination. The result is the first major review of British disability discrimination legislation, which the DRC is presenting to the Government on its third anniversary. Among a wide range of proposals is the need to see more disabled people protected by anti-discrimination legislation, such as those with a genetic predisposition to an impairment and people newly diagnosed with a progressive condition such as cancer or multiple sclerosis.

The DRC was set up to champion the rights of disabled people and to work towards a society where all disabled people can participate fully as equal citizens. After three years, the DRC has made good progress in achieving their vision, but much needs to be done before they can see the vision realised completely.

You can contact the DRC's helpline on 08457 622 633,
Textphone 08457 622 644,
Email: enquiry@drc-gb.org
Or see www.drc.org.uk

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FLOCATH
» More than just a new intermittent catheter.

connexions

"Let's talk about you"

It's been two years since the Government began replacing the old Careers Service with Connexions. In April the rollout of the scheme across the country was completed and in May the Government announced that the new service has a 90% approval rate amongst the 16,000 young people surveyed. But what is Connexions all about? And how does it cater for the needs of disabled young people?

The Connexions service has been designed so that it is just as useful for disabled people as it is for anybody else. It aims to provide integrated advice, guidance and access to personal development opportunities for all young people, helping them make a smooth transition to adulthood and working life. It offers all abilities practical help with choosing the right courses and careers, including access to broader personal development through activities like sport, performing arts and volunteering activities. Connexions also provides help and advice to disabled people on issues like independent living or making arrangements for interview appointments to ensure any special needs are met.

Connexions provides young people with access to a personal adviser, who offers confidential advice and support. Link spoke to Jackie Wooldridge, a personal adviser from Worcestershire who specialises in helping young people with special needs. She explained that although Connexions is for 13-19 year olds, young people with disabilities can continue to use the service until they are 25.

"Disabled students have additional things to consider as they go through the transitional stage of life so they need extra support for longer. I can help them address any barriers they face to fulfilling their ambitions, be it housing, funding or support. It's important they feel they have someone to turn to," she says.

Jackie went on to explain the role of a personal adviser in more detail: "Young people are usually first put into contact with a Connexions personal adviser when they're 14 years old because this is when they start to think about their future after compulsory education.

"I'm a single point of contact to provide advice and support on any issue they choose, from potential education and career options through to personal problems such as bullying, depression, drug abuse or sexual health. Many young people don't know where they can go to get information and advice and my job is to offer the relevant support or put the young person in touch with another agency who is better equipped to assist."

The support provided by a personal adviser is also offered as Connexions Direct, a telephone helpline, mobile SMS text messaging service and an online web chat advice service, which ensure that young people can receive the support they need at a time and place of their choosing.

Minister for Young People and Adult Skills, Ivan Lewis, said: "The Government is committed to providing all young people with the support and help that they need to succeed, overcome barriers and become active citizens. I'm delighted with the success that Connexions has achieved to date and that young people throughout the country will now be able to take advantage of the service. Connexions not only fulfils a real need amongst young people, but also encourages them to make the most of all the opportunities available to them."

For more information see **www.connexions.gov.uk.**

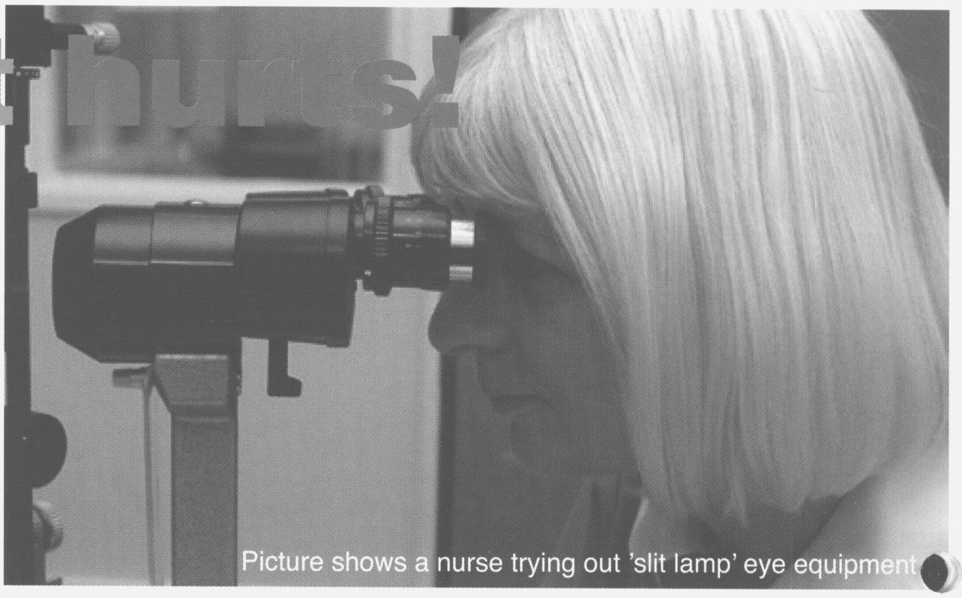
DLA made easy

A handy new guide to applying for the Disability Living Allowance has been published by Cerebra, the Foundation for the Brain Injured Child.

For a free copy (incl. free p+p)
tel. 0800 32 81 159
email info@cerebra.org.uk
www.cerebra.org.uk

Blast it hurts!

by Linda Dixon


Picture shows a nurse trying out 'slit lamp' eye equipment

I was diagnosed with benign intracranial hyptertension (BIH) in 1984 and have been told by various specialists that this is a very rare disease that only affects three out of every 100,000 women; I've also been told by some people that I am a hypochondriac and am not suffering the types of pain I describe. I do understand it is rare and not researched properly; in fact, I probably understand more than the doctors but I am fed up of being treated badly because people don't understand.

Symptoms include headaches like migraines multiplied by 10, visual loss and disturbances, tinnitus, nausea, balance loss, memory loss, neck and back pain, bad sleep patterns, depression, suicidal tendencies, papillodeama, blind spots, joint pain and various other things. There is no cure and only extreme measures to relieve it; it ruins relationships and the drugs used and operations involved are fraught with so many side effects.

I was asked to contribute this article because of my experiences and because we need to raise awareness of this disease, which is also called idiopathic intracranial hypertension or pseudotumour cerebri. It's not benign in the kind sense of the word, nor am I an idiot and, although it shows all the symptoms of being a tumour but isn't, neither am I faking it!

Currently I am suffering and out of remission again. Yes it can go into remission, but I am trying homeopathic treatments this time and it seems to be working for me.

I am asking for one thing from those of you who read this and those who have the condition or care for someone who has it. Let's get together and raise awareness of this awful thing that affects us. I am involved in various groups including ASBAH and PTC groups all over the world through the Internet. You can email me at lindix@btinternet.com about an article I wrote for an ASBAH seminar which played on the letters 'BIH', or about raising awareness and also homeopathic treatments.

I would like to thank you all for taking the time to read this; and also my homeopaths for listening and believing in me; and finally my friend and carer Mark, without whom I would not have had the strength to work through this again.

If you don't have access to a computer then feel free to write to me at Allcare Nurses Agency, Unit 1, Station Yard, Ramsgreave Road, Wilpshire, Blackburn, BB1 9BH, as I am moving house shortly. Just address it to Linda. With grateful thanks to Rachel my boss who understands.

Carole becomes SRHSB President

Folic acid campaigner Carole Sobkowiak (right) has been elected President of the Society for Research into Hydrocephalus and Spina Bifida (SRHSB).

Carole's particular interest is in neuronal migration and the development of the cerebral cortex. She hopes to continue to link the exciting research in this field to the practical implications for people with spina bifida and/or hydrocephalus, especially in relationship to motor and language development. This research is likely to have educational implications for children.

Her involvement with the folic acid campaign has been ongoing since she was first elected to ASBAH's Medical Advisory Committee in 1982, which she still sits on. Encouragement is being given to international projects concerned with food supplementation and fortification with folic acid.

Carole is also a member of ASBAH's Marketing and Services Committee.

ASBAH ACE survey

ASBAH advisers in the North West recently surveyed a number of people who are using ACE (antegrade continence enema), a form of bowel management involving a bowel washout with fluid inserted through a stoma on the abdominal wall. Having hoped that ACE might be both effective as well as a technique that people could do independently, we were concerned at reports from service users of their difficulty in doing it unaided, how long the procedure could take and thus its impact on individual and family life.

21 ACE users answered a questionnaire and 19 of these continued to use the system. Some of the main findings were:

- about half the sample reported potentially serious post operative difficulties.
- most reported some leakage from the stoma at various times.
- 11 said that ACE kept them clean; eight said that it sometimes did.
- the majority do it daily or every other day.
- five people could do it in less than an hour. For two people it took over two hours.
- nearly half the sample, including a number of young adults, needed help with the technique. Difficulties with co-ordination, measuring and pouring the fluid into the catheter, loomed large.
- despite a lot of negative comments, 16 out of 19 thought that ACE had made their lives better.

The most enthusiastic were those who had had ACE done as adults and all stressed the commitment and attention to detail that needed to be taken to make it work.

For further details contact
Angela Lansley Tel: 0151 733 8392
***Email:** lansley@freeola.com*

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.

I am 23 years old and have had hydrocephalus since I was three weeks old. I also have some deafness in my left ear.

Last year I visited my local ENT clinic and was told there was nothing wrong with the ear itself. They explained that the nerves for hearing are cross wired – left ear nerves are on the right side of your brain, right ear nerves are on the left side of your brain. The doctor believed that my hearing loss in my left ear is due to damaged hearing nerves on the right side of my brain, caused by my VP shunt. Although this doctor was not a hydrocephalus or a neuro expert another consultant at the spina bifida and hydrocephalus clinic at the Chelsea and Westminister Hospital also believed this may be the case.

I wanted to find out if there are any other readers with hydrocephalus and a VP shunt who are hard of hearing or deaf on the opposite side to where their shunt is.

Sahedur Rahman, Tel: 07985 199227

Tribute to Alan Rance

Editor's note: unfortunately an incorrect picture of Alan Rance appeared in the initial print run of Link issue 204. This was rectified in subsequent copies and we are happy to re-run the same tribute with a correct picture of Alan, with his wife Kathy, to whom we have extended our sincere apologies.

Alan Rance, husband of Kathy and father to twins Matthew and William, was a well loved and highly thought of family man. His connection with ASBAH began when his son Matthew was born with hydrocephalus in 1997.

Above: Kathy and Alan Rance

Tragically, Alan died suddenly aged 39 on 15 December following an unexpected viral infection. Donations to ASBAH of over £5,000 in his memory have been received to date and fundraising events are now being organised by his family, friends and colleagues.

Alan was athletic and a very good sportsman. His main love was cricket and he played for the Chenies and Latimer Cricket Club, near his home in Amersham. In honour of Alan the club is organising a benefit game against Alan's family and friends.

Alan worked at Xerox in Buckinghamshire as the sales operations manager for the Middle East, Russia and Asia, and many of his colleagues are planning to run in this year's London marathon. Another colleague is also planning a coast-to-coast sponsored cycle.

The twins' school, Chenies School, is building a play area with a special quiet spot and a weeping willow pear tree has already been planted in memory of Alan, with a dedicated bench.

All the money raised in Alan's memory has been extremely welcome for ASBAH. The fundraising team is working with Kathy to decide how the money should be spent.

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the issue

Trains give the strain

Vicky Beken from Northcamp, near Farnborough in Hampshire, would dearly love to travel on trains on the spur of the moment but unfortunately she doesn't have that luxury.

Having lived in the area for over 10 years, with relatively few problems taking the train to Reading for an evening out during most of that time, Vicky has been bitterly disappointed with the changes to the local Thames Trains service.

Previously the guards on the trains would help her get on and off the train whenever there weren't any platform staff.

Now Northcamp station only has platform staff until 8pm during the week and until 2pm on Saturdays and other members of staff aren't insured to help.

Vicky told *Link*: "I was told by Thames Trains that if Northcamp wasn't manned then I can't get off the train until Guildford. This means that I'm unable to have an evening out in Reading unless I pay for a taxi home."

Vicky experiences the same problems if she happens to travel on a morning when a member of staff is off sick or on holiday. There also used to be two ramps at the station and now there's only one, so even if someone did offer to help there isn't a ramp on the other platform.

Ron Strutt, Business Manager at Thames Trains, has said in a letter to local MP Gerald Howarth: "It has been the practice of many of our conductors to assist disabled passengers on and off trains at Northcamp whenever possible, but for reasons of health and safety we cannot insist that they should do so."

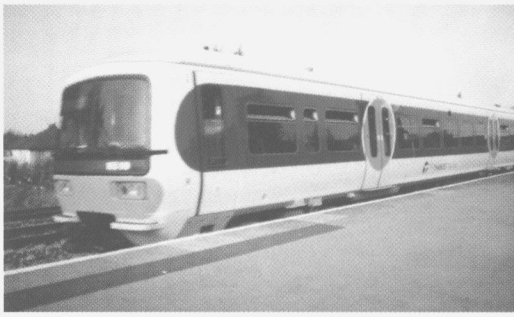
This isn't much help to Vicky, though, who still has to soldier on with the same transport problems.

But Thames Trains has also said that due to the Strategic Rail Authority's recently published code of practice for disabled travel, rail companies are examining trains to see how they could make them more user friendly.

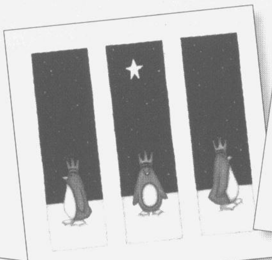
The downside? They've also stated that extra funding would be required in order to fulfill such requirements.

In the meantime Vicky's struggle continues.

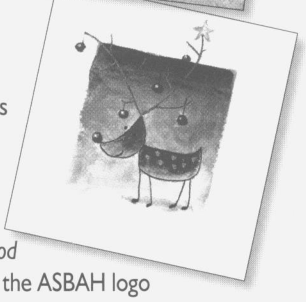
If you have anything to add or have a similar tale to tell, please write to *Link's* editor.



Christmas Cards



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



If you would like to order some ASBAH Christmas Cards from the above selection of festive designs, please complete the attached form.

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.

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Advert rates

- 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 19 September 2003.

  Please send to:
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Fully adapted well equipped holiday chalet, 2 bedrooms, sleeps 4/6. Overlooking sea. Ideal base for touring Norfolk. Transport essential. ***For further details contact LASBAH on 0116 2517462***

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Home with a heart for disabled travellers! Spacious, luxury, adapted bungalow situated on 18 hole golf course. 3 double bedrooms-sleeps 6, 2 bathrooms (Mangar bathlift installed). Custom furniture, patio & conservatory, cable TV. Telephone. Free Country Club membership. 24 hour 'on-call' management company. 15 minutes from Orlando Airport; 20 mins Disney. For current availability contact paraplegic owner. ***Sue Fisher, 5 Park Lane, Broughton Park, Salford M7 4HT. Tel/Fax: 0161-792 3029 or email:*** *rita.sue.fisher@ntlworld.com* ***website:*** *http://homepage.ntlworld.com/susan.fisher33*

GASCOGNY, France. B & B for disabled travellers. One twin-bedded ground floor room, fully accessible ensuite bathroom (shower). 1st floor: one double ensuite. (Further double and twin-bedded sharing bathroom if renting house). Children only if W/C bound. Care assistance available. Swimming pool with ramp. Rural location, magnificent views. Bilbao/Santandar, Pau, Biarritz, Toulouse within 3 hours drive. ***Contact Dido 0033 562 70 81 88 or email:*** *deedoenfrance@aol.com*

Accommodation to let

ILKLEY, WEST YORKSHIRE

3 bedroom groundfloor wheelchair accessible flat now available. Part of Five Oaks Housing Scheme which provides general counselling and support from two ASBAH housing support staff. Also benefits from: community alarm system with mobile warden service; fire monitoring; communal laundry; communal lighting; gardening and window cleaning. There is also a communal activity room on site. ***Further Details: Mark Best, Five Oaks Housing Scheme, Ben Rhydding Drive, Ilkley, West Yorks LS29 8BD. Tel/Fax: 01943 603013***

For sale

Pride Mobility four wheel scooter, as new, used only half a dozen times. Black with grey seat trim, alloy wheels with solid tyres. £2,499 new. Any reasonable offer considered. ***Contact Barbara 01246 417371.***

dates for your diary

Upcoming events

Friday 8 - Sunday 10 August
Your Voice Activity Week
Worsley, Manchester
A weekend for self-development. Come along and enjoy a weekend [illegible] Fashion, Yoga, T'ai Chi, Communication Skills just a few of the things we're offering to help you improve your life. ***Details: Lyn Rylance. Tel: 01733 555988 Email: lynr@asbah.org***

Monday 11 – Thursday 14 August
Summer Experience
Kepplewray, Cumbria
A residential activity week for 11-16 year olds. Course full. ***Details: Joan Pheasant, tel 0113 255 6767 or e-mail: noro@asbah.org***

Saturday 30 August
Wheelie Club, Belfast.
Opportunity for young people to improve their wheelchair skills at McKinney Hall, Musgrave Park Hospital, Belfast. Three groups: Wheelie Kids (10-11.30am), Speedy Wheelers (11.30-1pm) and Wheelie Power (2-3.30pm). NB free maintenance no longer available. ***Contact: ASBAH Northern Ireland, tel: 028 9079 8878 or e-mail: niro@asbah.org***

Saturday 30 August - Saturday 4 October
Wheelchair skills, West Midlands.
Dates/venue in Sandwell to be confirmed. Free Whizz-Kidz course over six Saturdays for manual/ powered wheelchair-users aged up to 18. Each Saturday is split into three sessions so children/ young people can learn skills in their own peer group. Emphasis on developing independence, making new friends and having fun! Places allocated on a first come first serve basis. ***Contact: Sarah Jefkins, tel: 020 7233 6600 or e-mail: s.jefkins@whizz-kidz.org.uk for a registration pack.***

Monday 8 September
Support group, Dunstable
Regular meeting for parents/carers of children/young people with SB/H organised by the South Bedfordshire Support Group. 1-3.30pm, Disability Resource Centre, Poynters Road, Dunstable. ***Details: Valerie Bottoms, tel: 01582 757745 or e-mail: valerie.bottoms@ntlworld.com***

Monday 13 October
Support group, Dunstable
Regular meeting for parents/carers of children/young people with SB/H organised by the South Bedfordshire Support Group. 1-3.30pm, Disability Resource Centre, Poynters Road, Dunstable. ***Details: Valerie Bottoms, tel: 01582 757745 or e-mail: valerie.bottoms@ntlworld.com***

Saturday 15 - Sunday 16 November
Children's Wheelchair Training course
The course will be run by the Association of Wheelchair Children and will be free to all participants. 9.00am-4.00pm, Bishop Road Primary School. ***Details: Julie Knight, tel: 0117 9245077***

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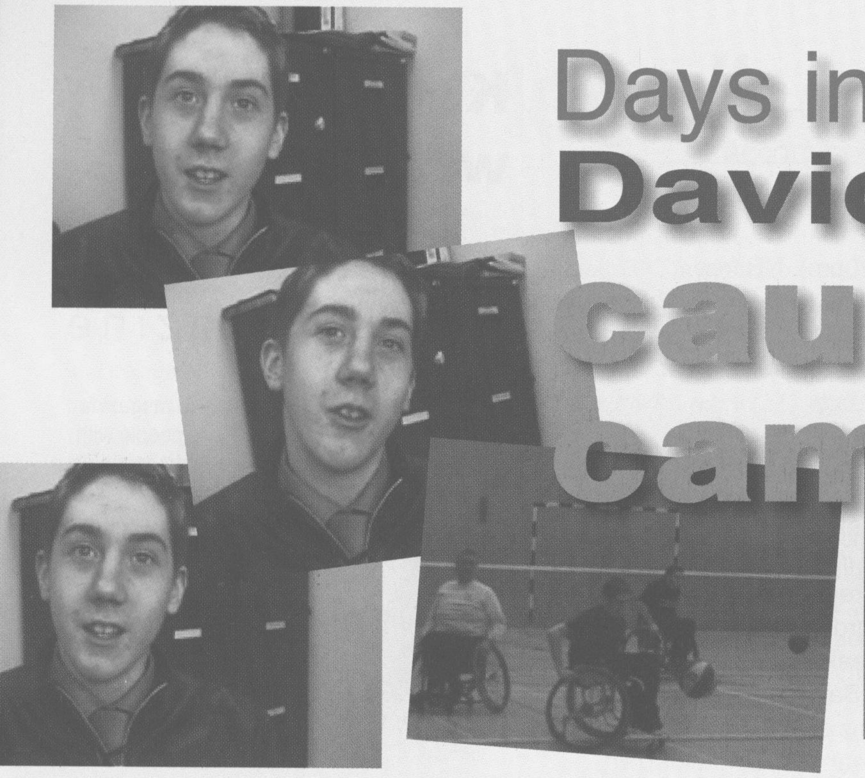
Days in the life of David Proud- caught on camera



With Big Brother fever spreading across the country Link has decided to introduce a regular new video diary column. The first ASBAH member to take up the camcorder challenge is 20-year old David Proud from Peterborough. Through a series of roving reports and diary room revelations, David gave us a peek into ten days of his life.

As soon as the camera started rolling one thing seemed to dominate David's existence. Basketball. He explained that this passion is all thanks to former ASBAH mobility specialist, John Naude: "He came round to the house and whilst still sat in his chair he tipped it up on one wheel and took the other wheel off – I was lost for words! He then showed me a video and took me to a game. If it wasn't for him I would never have got into basketball, which would have been a great shame as it is a huge part of who I am – my confidence and my mobility."

During filming David received some fantastic news – he was invited to go to Canada to compete in the Spitfire Wheelchair Basketball Tournament. David explains: "If I can go and represent my country that would be fantastic – I'd love to go and show the Americans how to play basketball!" Unfortunately, since completing his video diary David has decided to postpone his trip until next summer due to the SARS threat.

When he's not on the basketball court David works for the DSS: "A lot of people depend on me at work. It's a high-pressure job, but I like the responsibility," he explained. With a promotion in the pipeline and a new member of staff to train up, things at work are looking good.

David used to be on the CASBAH committee, but his hectic job led to him dropping out. However, he's still full of praise for everything it does: "It's hard to sum up in words what ASBAH means to me. When you're young and disabled you have so many questions – you have a fear of the future. Having someone to explain things helps you develop. It would be good if ASBAH could get more money so they could have more advisers."

David's full life often leaves him tired at the end of the day but this is a side he doesn't like people to see. "It's one of my weaknesses", he explains. But he's never down for long thanks to his 'fantastic' family and particularly his sister Dawn: "She spots when I'm having an off moment and picks me up again - Dawn is my rock."

As David films his final diary entry he is about to go on a road trip to Portsmouth and Exeter. Why? To play basketball of course!

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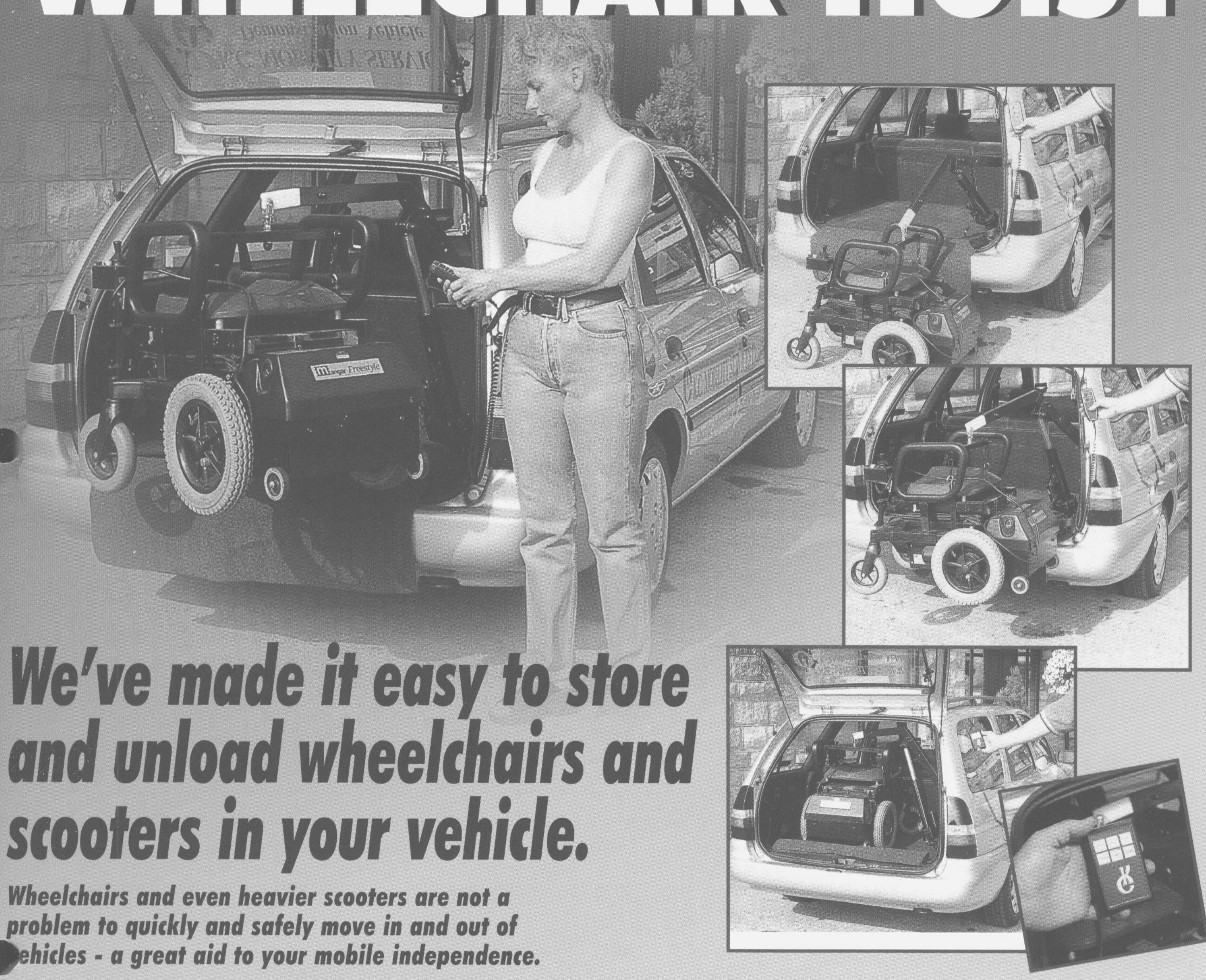

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