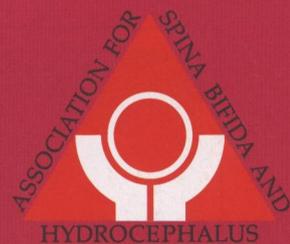


# LINK

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coco in  
the  
park!**

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JULY/ AUGUST 2000

ISSUE No 188

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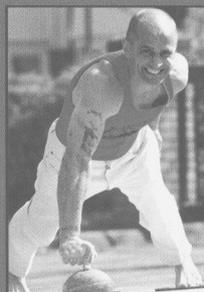
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# LINK



Cover:  
Mickey Gooch  
smashed his world  
record for a local  
ASBAH – story on  
page 17. Photo: The  
Medway Standard

## Editorial

Dear Readers

Thank you for all your messages of support and compliments on our new *Link* magazine.

The closest we came to criticism was the chap who said that he hoped the new, snappy style would not mean an end to medical articles contributed by experts. Well, it mustn't. There must still be a place in *Link* for readers to receive reliable medical and surgical information supplied by the medical professionals themselves. All we ask the medics, busy even now crafting their contributions, is that they should share their thoughts in a language which we can all understand.

In a future issue, we plan a simple guide to understanding the wheelchair voucher scheme – reprieved by the Government but refused a new lease of life, because hardly anybody understands it. We would love to talk to people who have had good experiences of it ... and bad. Please phone.

Tony Britton  
Publicity Manager

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Editor in Chief: Tony Britton Editor: Liz Cawthorne Designer: Tony Nero  
LINK is published by ASBAH, National Centre, 42 Park Road, Peterborough PE1 2UQ

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Subscription Rates (six issues per year):

UK £4.80  
Europe & Overseas Surface Mail £7.50  
Air Mail £15.00

Patron: HRH The Duchess of Gloucester GCMG  
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ASBAH exists to provide advice, support and advocacy to people with spina bifida and/or hydrocephalus, their families, and their carers.

ASBAH aims to empower its service-users by providing up-to-date information, extending their choices, and maximising their opportunities for independence.

[postmaster@asbah.demon.co.uk](mailto:postmaster@asbah.demon.co.uk)  
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NEWLY wed Rachel Stanworth, a former manager in our services department, pictured in step with her landscape designer husband Charles Andrzejewski on their wedding day in April.

Rachel was manager of ASBAH's Disabled Living Services, now Specialist Advisers, for more than four years. She left in 1994 to begin a PhD.

The couple will live in London.  
We wish them the best of luck.



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## ASBAH welcomes new brainwash

A TREATMENT in early development which flushes blood clots from the brains of premature babies has been welcomed by ASBAH.

The technique involves pumping fluid through the brain to remove clots that can trigger hydrocephalus and has been developed by Professor Andrew Whitelaw at Southmead Hospital in Bristol. The first patients he has treated in such a way are reported to be in good health.

About 150 premature babies a year have severe brain haemorrhages and, if the treatment was applied widely, it is thought it could save the lives of 30 children a year and prevent brain damage in 120 others. The traditional treatment for hydrocephalus in

premature babies has been the insertion of special CSF shunts.

ASBAH said the new treatment needed further evaluation, but the research was important because good neonatal treatment meant more babies survived premature birth – often associated with bleeding in the brain which leads to hydrocephalus.

ASBAH executive director Andrew Russell commented: “We need to be careful not to claim too much for this treatment as it is early days. CSF shunts also remain an important and essential treatment for hydrocephalus and, for most children, they do not repeatedly fail throughout childhood, as the researchers claim. Parents should be reassured about this.”

## Display yourselves!

OPPORTUNITIES for all types of artists around the country are flagged up by mailings from The Art House, which works for disabled and non-disabled artists. Link was told about The Art House by Shirley Kearns, ASBAH's OT in the North of England, after she read our article about cartoonist David Swift.

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## Minister reprieves voucher scheme

WHEELCHAIR services in England and Wales have been instructed to continue with the powered wheelchair initiative and the voucher scheme – despite researchers calling for an end to vouchers in districts where vouchers are not popular.

Health minister John Hutton has decided to continue pumping £14m a year into both the NHS EPIOC (electrically-powered indoor and outdoor wheelchairs) scheme and the voucher scheme, but he left it to service specifiers and providers in consultation with users to decide exactly where they should spend the money.

The voucher scheme – heavily underspent in some districts and subject to widespread criticism by many professionals – should continue to be operated by all wheelchair services to improve the choice available.

Linda Hams, assistant director (policy and marketing) with ASBAH, said: "One of the reasons why vouchers failed to attract support has been that they were so little understood. Their benefits now need publicising much more clearly to users."

Researchers from the University of York last September criticised the operation and take-up of the voucher scheme, with only 5,800 vouchers being issued in its first three years.

In many areas, vouchers had been introduced against complaints from staff, who said they had been caught on the hop. The scheme was also millions of pounds underspent – money which could have been directed instead towards improving core wheelchair services.

There was a greater all-round welcome for the EPIOC scheme, which was more successful. But even its take-up of 8,700 powered wheelchairs fell well short of the 40,000 demand estimated in the 1993 Muscular Dystrophy Group report *Batteries not Included*.

## Foundation bangs the table

GOVERNMENT guidelines for the development of NHS continence services have been welcomed by the Continence Foundation – despite an earlier battle of wills when the Foundation accused health minister John Hutton of watering down the recommended policy.

The 'minimum cost / maximum gain' guidelines issued after a year's delay include an insistence on service-integration between all parts of the NHS. They also urge an end to restrictions on the supply of continence aids, issuing of incontinence aids only after assessment and completion of a treatment plan, and no exclusion of children from school on incontinence grounds alone. A director of continence services will be appointed.

Prof Paul Abrams, of the Continence Foundation, banged the minister's table when it appeared an action plan was being reduced to advice on best practice. The minister then issued a set of stronger guidelines.

## Big London service boost for ASBAH

A BIG win for ASBAH in grant support will help ASBAH's service-users in London.

Two new Specialist Advisers were appointed in June, with Bridge House Estates Trust funding. Sharon Edwards will advise on housing issues, while Judy Hunt will work on independent living issues. They are expected to start work in July.

The Bridge House Estates Trust has generously provided £120,000 of project funding for the two part-time posts, spread over three years. The Trust is an historic one run by the Corporation of London, which has accrued capital over many centuries from revenues coming in from bridges over the River Thames.

Jo Francis, ASBAH regional manager, said the new posts will provide much needed specialist support to the London Advisers.

---

## Freedom photos

*FREEDOM in Focus* is a new photo competition from *Disability Now* newspaper and charity Leonard Cheshire to highlight the every-day challenges faced and overcome by disabled people.

There are two sections and two age-groups – 'Sporting Challenges' and 'Challenges'; under-16s and 16 and over.

There are great prizes. The adult winner of the sporting challenge will pick up £500 and two tickets to see England v Germany at Wembley (a camera and two tickets to the same game for the under-16s).

There is another £500 for the adult winner of the every-day challenge section, plus a week for two at the Park House Hotel, Sandringham. Top under-16s prize in this section is a camera and an afternoon at the London Eye, with a professional photographer in tow.

The competition is open to disabled people, who can be either professional or amateur photographers. Closing date is 30 August 2000.

● Application forms from *Disability Now*, FREEPOST WD 4323, London N7 9BR.

## No tears for demise of TV programme

BBC2's decision to axe its weekly disability programme *From The Edge* has been welcomed by media commentator Paul Darke – who has long campaigned against it.

"As you know, I despised *From The Edge*. People there who had any talent usually left to work elsewhere," said Paul, former film and media columnist for this magazine.

Jane Root, new controller of BBC2, is known to be looking at reformatting the disability strand this autumn but no announcements have yet been made about what will replace *FTE*, first screened in 1992.

It has been the leading national disability TV programme since the

end of ITV's *Link* last year.

Paul said: "Part of the problem with *FTE* lay in the disability programmes' unit itself. I understand that whatever emerges will still be based on the dpu – essentially the same people.

"*FTE* could also never make up its mind about its market. Did they want to make programmes for disabled people, or for mainstream? I still believe in disability equality programming – the BBC2 output will be better if it goes further down that road."

After Paul joined the monthly *Disability Now* newspaper two years ago as a columnist, he often criticised *FTE*'s output in his column.

---

## Education topic sheets

A RANGE of highly detailed topic sheets on hydrocephalus and education are available from ASBAH.

The 10 sheets are based on leaflets written by one of our education advisers, Lorna Johnston, and were first circulated

last year in Northern Ireland.

They have now been adapted for England and Wales, and can be obtained from the Information Department in Peterborough or from your nearest regional office.

## Tragic death of Sheffield pioneer

ONE of the leaders of the Sheffield-based renaissance in spina bifida surgery on newborn infants has died while trying to rescue his dog from his blazing home.

Professor John Emery died in the house where he was born in Aylburton, Gloucestershire, on 1 May. His Airedale terrier, Sophie, died with him.

Professor Emery (84) and his wife Marjorie had fled the house in the Forest of

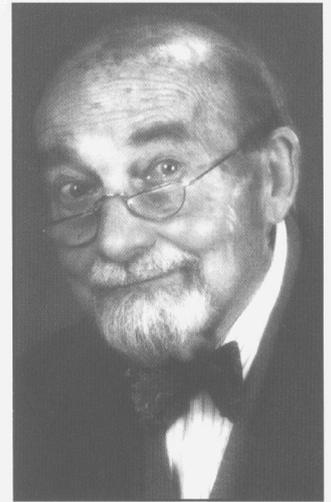
Dean at 5am after being woken by smoke and flames. Once safe outside, he ignored his wife's pleas and went back for the trapped dog.

The professor read a lesson at the ASBAH memorial service last summer for paediatric surgeon Professor Bob Zachary, who for 11 years was ASBAH's first chairman.

He was paediatric pathologist at Sheffield Children's Hospital from 1947 until he retired in 1980. While there, the

training he offered colleagues in the pathology of spina bifida helped transform clinical practice round the world – with Sheffield establishing its eminence in the field around surgeons like Bob Zachary and John Lorber.

John Emery was probably best known, however, for his pioneering research into the causes of cot death, being heavily involved in setting up the Foundation for the Study of Infant Deaths.



Sheffield University appointed him emeritus professor of paediatric pathology after his retirement, when he and his wife spent their time between their Gloucestershire and Sheffield homes.

Prof Emery is survived by six children and 15 grandchildren.

## Race day diary

FAVOURITES Tanni Grey-Thompson and David Holding failed to show their form in the London Marathon this year – just months before the Sydney Paralympics, in which both will take part.

Tanni (31) finished second in the marathon, let down by a puncture five miles from the start which took 15 minutes to fix. She came in 11 minutes after surprise winner, 19-year-old newcomer Sarah Piercy.

David Holding (*pictured right*) trailed six minutes behind the winner in the men's race, finishing third.

Tanni will compete in the 100m, 200m, 400m and 800m at the Paralympics. David (also 31) will focus on defending his 100m title.

Brian Alldis, Danielle Morrison and Stuart Bloor grabbed honours in the 11-13 sections of London Mini Marathon.

Brian, from Bury St Edmunds, knocked two minutes off his previous time, finishing the 2.2 mile course in 10.22. He also raised hundreds of pounds for charities including ASBAH.



Danielle, from Leeds, beat her previous time of 16.25. Danielle has the same coach as Brian and now has her sights on the national athletics championships in Blackpool, even though her training has been interrupted by a spell in hospital.

Both Danielle and Brian won their sections of the Mini Marathon for the second year running.

Twelve-year-old Stuart, from Crewe, achieved second spot despite being forced to switch from a racing to a sports chair, due to a knee problem.

## A great start for ASBAH in Wales

**E**VERYTHING is now in place to convert words into action so that a real, working partnership can be forged for the benefit of service-users between a revitalised ASBAH and government in Wales.

The winds were set fair when our new national structure, ASBAH in Wales, was launched at the National Assembly building in Cardiff by Jane Hutt, the Assembly's health and social services secretary.

But the gathering of over 100 guests on 11 April was told that the time had arrived for government to put its money where its mouth was.

Mike Mason, chairman of ASBAH Cymru, said: "Local associations for spina bifida and hydrocephalus in Wales have seen little action so far in bringing about formal partnerships for the provision of support to our 900 service users in Wales.

"Our estimate is that something in the region of £3,000 per year is the sum total of local authority financial support to these associations.

"We sincerely hope that this performance can be built upon and that, now you have been able to announce

increased financial support for social services, perhaps there is after all some real cause for optimism but only if people with disabilities, who are under 65, benefit too!"

Mr Mason, whose committee comprises a majority of disabled service-users together with representatives from the four local associations in the principality, said the voluntary sector had been exhorted to get involved in the 'joined-up thinking' of planning and providing services.

But financial restrictions in the statutory services, organisational change and initiative overload had all too often resulted in needy people being cast adrift.

"Many – following the introduction of charges and eligibility criteria – have found themselves excluded from services, as seemingly not being people with great need. In fact, their need is to be enabled to live independently in communities and engage in activities and lifestyles that other people take for granted."

Jane Hutt responded positively – pledging her support for a continuing dialogue with ASBAH in Wales, which had clearly established its credentials to





participate in the emerging partnership between government and the voluntary sector in Wales.

Former ASBAH chairman Patrick Daunt, who ran the European Union's disability bureau in Brussels, thanked Mrs Hutt.

Among the guests were Assembly leader Rhodri Morgan, Plaid Cymru leader Dafydd Wigley, newly appointed Wales director of the Disability Rights Commission Will Bee, singer Margaret Williams, actors Mici Plwm and John Henry Hughes and TV director Pennant Roberts, who directed the first of the *Tenko* series.

*ABOVE: Health and social services secretary Jane Hutt receiving flowers from Angelina Humphries. Mike Mason stands behind with, from the left, ASBAH executive director Andrew Russell, former chairman Patrick Daunt and Wales manager Elin Ifan.*

*Photos below, from left: (1) Plaid Cymru leader Dafydd Wigley gesticulates in conversation with Elin Ifan, MP and assembly member Ieuan Wyn Jones and Mike Mason (2) ASBAH member John Henry-Hughes (second left) with actor John Pierce-Jones, singer Margaret Williams and actor Robin Griffith (3) ASBAH adviser Jill Bartlett (left) with TV director Pennant Roberts and his wife Betsan (4) Actor Mici Plwm (left) with assembly member Gareth Jones.*

**Photos: ROB STRATTON**



## Graham Webb – hair care magnate

# How to succeed in business when you're really trying!

**T**HE sky's the limit if your heart is in it, says millionaire businessman Graham Webb who has soared to the top in hairdressing while battling through life with spina bifida.

As well as disability, he grew up surrounded by low expectations and low income, where you readily accepted what the great and the good decided for you.

His family and various doctors never looked deeply into the cause of his problems and it was not until he was 33,

after a 'ghastly' air myelogram and his spinal cord untethered, that he learnt he had spina bifida occulta.

"At school, I became an expert at walking round the school pretending my trousers were dry," he said.

Graham left school at 15 in 1962 with poor self-esteem and no qualifications. After unsuccessfully applying to 62 companies for jobs in sales or marketing, he was offered the choice of becoming a plumber, carpenter or hairdresser.

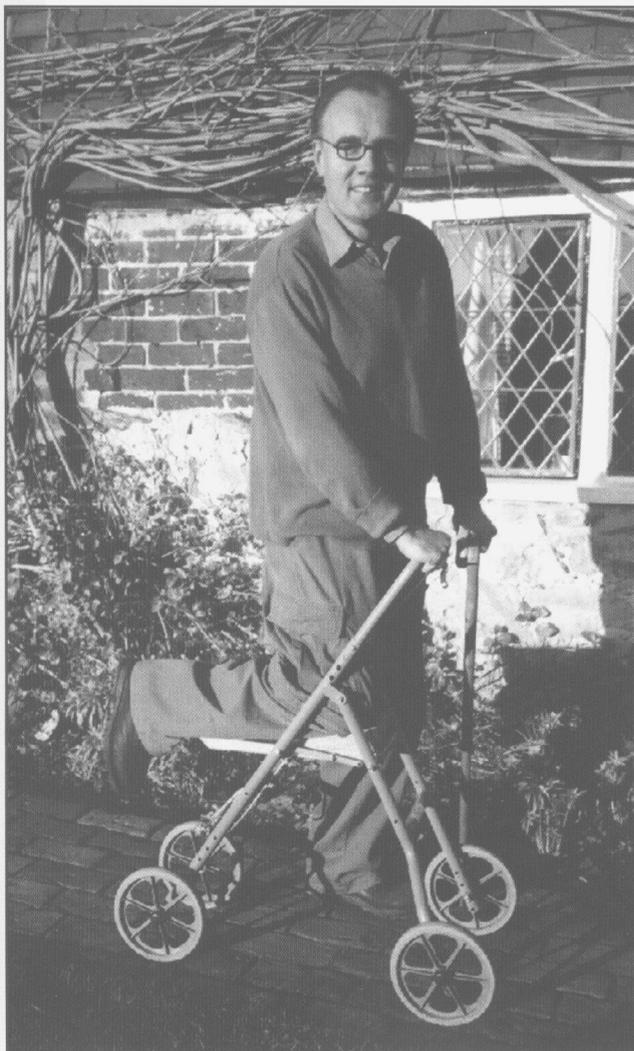
"I was teased about going into hairdressing but, within a couple of years, I was going out with a Wella top model, so that shut people up a bit."

Now that he enjoys his name leading a multi-million pound company, with 11 salons, 230 staff, an accredited international hairdressing school, a large international hair academy in Washington, USA, and haircare products selling in 26 countries, Graham is in a strong position to lobby the government and others for irrationally rating academic success so much higher than skilled trades. After all, he says, this is where most of the entrepreneurs are!

Like many teenagers in the 60s, he formed a rock 'n' roll band. He played drums but recalls the bass drum, operated by his right foot, was occasionally a bit off beat. Only much later was he able to deduce that this difficulty was caused by spina bifida.

"It was disgraceful that I saw many orthopaedic surgeons from the age of 10 to 33 about my feet – specialists at three top London hospitals – but nobody thought my problem was neurological.

KENT MESSENGER GROUP





*Graham with some of his staff at the Sevenoaks salon*

“I was even sent to a psychiatrist as some GPs thought my incontinence was psychological! I feel angry about this now.

“With hindsight, I would encourage people to take the initiative when dealing with medical practitioners. You have to be politely aggressive. You can’t lay back and let them make decisions for you.”

One of his first hairdressing jobs was on a cruise liner, heading for Hawaii. “Seeing the world like that, my self-esteem began to rise and I realised that my problems weren’t so large.”

Even though he was promoted to a first class ship, his dad wasn’t happy about him being a hairdresser. So, while on-shore, he got a job with Bovril Group Marketing. A year later, in 1966, he had the unusual title of Britain’s top rice pudding salesman.

Then, on a lonely trip to Walsall, his life changed yet again. He met a Wella representative who told him he should work for them.

“I rejoined hairdressing at the time of Sassoon and the mini-skirt – when hairdressing became today’s vibrant industry.”

Three years later, with the help of a friend, he rented his first shop in Lee Green, Lewisham – his home territory

where many of his friends still lived.

As his business grew, new challenges had to be overcome.

Graham – a trustee of Kent ASBAH – says one secret of his success has been picking the right staff, then training them thoroughly. Others are having a positive attitude and networking.

When, in 1997, his continence became unmanageable, Graham was put in touch with a specialist who said he refused to allow someone like him to be incontinent. “It seems that, for 50 years, my bladder had been only half-emptying. My kidneys were dilated through severe reflux. After complicated surgery on the neck of my bladder, I now intermittently catheterise five times a day.”

Then Graham found someone who really does specialise in feet – Dr Lowell Scott Weil in Chicago.

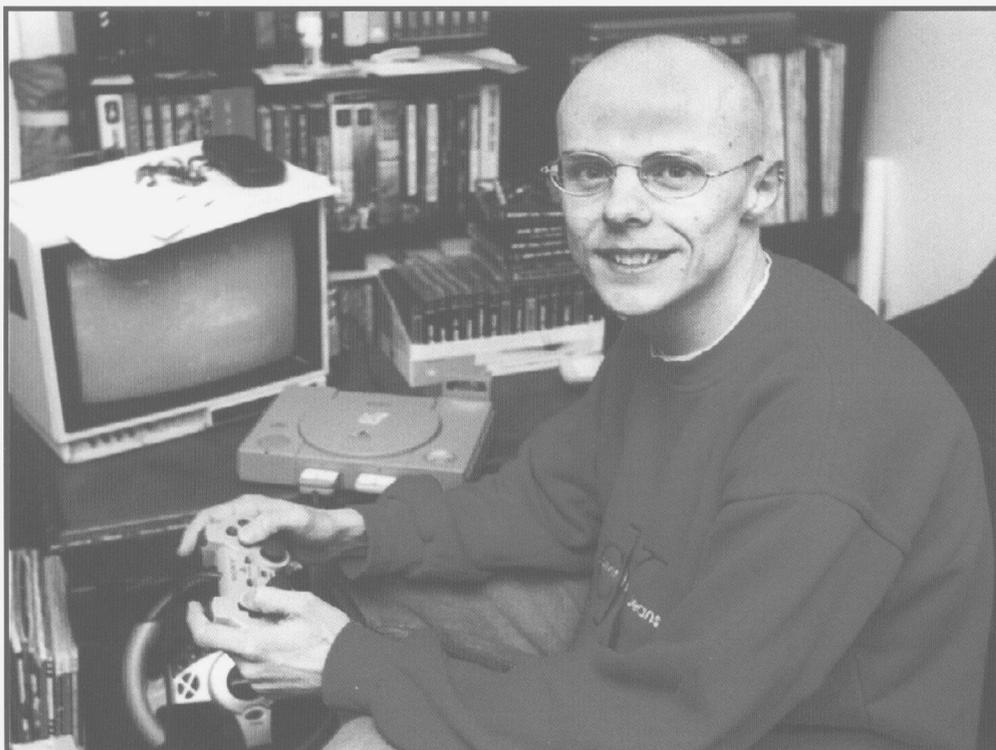
“I thought I’ve only got one chance and, as I often work in the States, I decided to visit him when next there. I got a wonderful Roll-a-bout (*pictured left*) to help with my mobility during recovery. I could move faster than my friends and relatives!”

Graham was so impressed by the Roll-a-bout, he now plans to import them to this country.

● Words by Liz Cawthorne

**“I was teased about going into hairdressing but, within a couple of years, I was going out with a Wella top model, so that shut people up a bit.”**

LINCS FREE PRESS



## Game boy has fun

COMPUTER games buff Daniel Linger has landed what he describes as 'a bit of a dream job.'

The South Lincolnshire fightmaster of the small screen has been signed up by the official UK *Playstation Magazine* as a freelance writer for their tips section.

Daniel (33), who lives in Spalding, showed he had the gift of the gab – talking his way into becoming a contributor when he phoned up to check out stuff that their tips editor had just printed on their new *Star Wars* game.

"I sent off a 500-word piece – a review of *Dino Crisis* – and a couple of tips. They found them good enough to use and now, basically, I get rewarded to do something I enjoy," said Daniel, who has spina bifida occulta.

He will write general tips as well as comprehensive walk-through guides for new games and has worked on *Resident Evil: 3*.

Daniel, who cut his gaming teeth in his teens on the old Sinclair ZX81 computer, has agreed terms whereby he gets paid in games. He can pick any game he wants as payment. A free subscription to the magazines, plus assorted freebies, are also part of the deal.

Like most men, he enjoys the cyber-enhanced charms of Lara Croft but his all-time favourite is *Silent Hill*. With its spine-chilling spooks and air of menace, it has the edge. Images from the game crowd his brain hours after switching off his screen.

"I am currently completing work on *Colin McRae Rally 2*, which is due for release next week," he said at the end of May. "I have also been entrusted to work on the hottest game (or at least the one shrouded in the most secrecy) to be released later this year – *In Cold Blood*."

And, no, he's not giving away any tips about it, until its release.

## Paul on the pilgrimage

FORMER *Link* columnist Paul Darke has won a Churchill Fellowship which will allow him to spend six weeks this summer following in the footsteps of the faithful on the Santiago di Compestella pilgrimage.

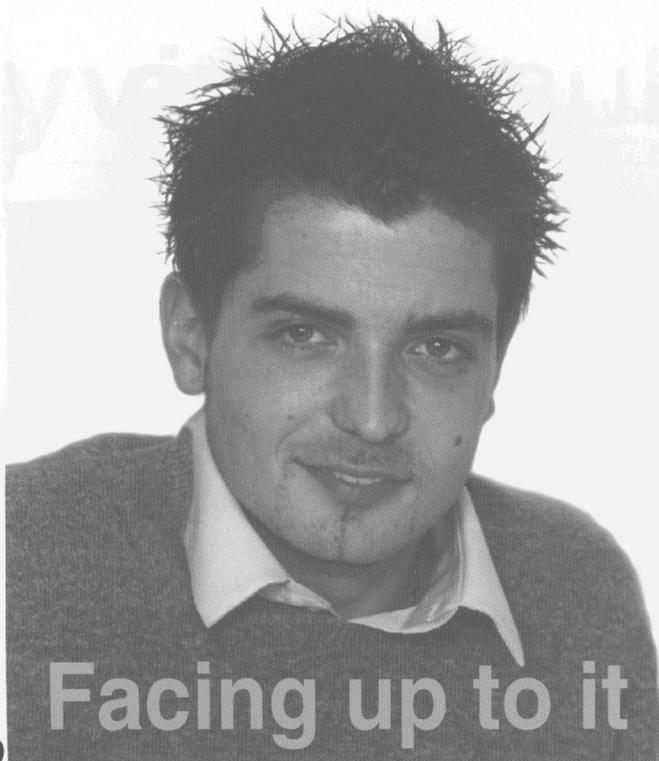
Paul will use his £6,000 award to see how access to the 1,500-km pilgrimage can be improved for people with disabilities.

"I'm doing a major Catholic pilgrimage as an atheist. But I have nothing but admiration



for the people who undertake it, most of them doing it on foot," said Paul, who in April gained a PhD in film and disability studies.

Compestella is the third most important pilgrimage route in Christianity. Pilgrims start from one of two sites in France, winding their way along historic routes to the shrine in north west Spain.



## Facing up to it

IT'S been a busy six months for modelling sensation Ben Ashwell – now getting used to seeing his face spread over the media.

The Essex 24-year-old has been on TV and in the papers several times since coming joint first in a nationwide modelling contest for disabled people last year.

He's modelled for Marks and Spencer and worn Red or Dead on the catwalk. And his television appearances include the *From The Edge* programme and the *Nine O'Clock News*. In July, he will be on *Rapido* on Channel 4.

After coming joint first out of 500 contestants in the first ever contest of its type run by the Leonard Cheshire charity and VisABLE, an agency for disabled models, he has also been in London's *Evening Standard*.

The aim of the contest was to get more disabled people used as role models on TV and in advertising campaigns, and the campaign continues this year.

"I've had some brilliant experiences so far," said Ben, who works for Cazenove in the City as a shareholder analyst. "I've had a slight amount of training, mainly on the job, but I don't really mind being on camera – I just go for it."

His slot on the *Nine O'Clock News* was part of coverage of a fashion shoot in the crypt of St Paul's Cathedral, used to launch the VisABLE contest for this year.

Ben has been so busy that he's been forced to put his pet interest on the back burner. Last year, he told ASBAH that he wanted to set up a new wheelchair basketball team based in his home town of Chelmsford. But he hopes to rekindle this in the near future.

## On the rights track

ONE of the top jobs at the new Disability Rights Commission has been landed by Will Bee, who became director with responsibility for Wales on 5 June. Will (42) has known ASBAH for many years. His mother Joan, who celebrated her 80th birthday a few weeks ago, and late father Ron helped set up North Wales ASBAH in the mid-60s.

Will, who will commute from Bristol to Cardiff, returns to disability politics after 13 years. He moves to the DRC from the Bristol Regeneration Partnership, where he was a senior manager running six schemes.

He said: "In terms of the visibility of disabled people and basic access, things have undoubtedly improved in the last 13 years. But there's still a lot to do in the physical environment, at work and on people's attitudes."

## In among the gold!

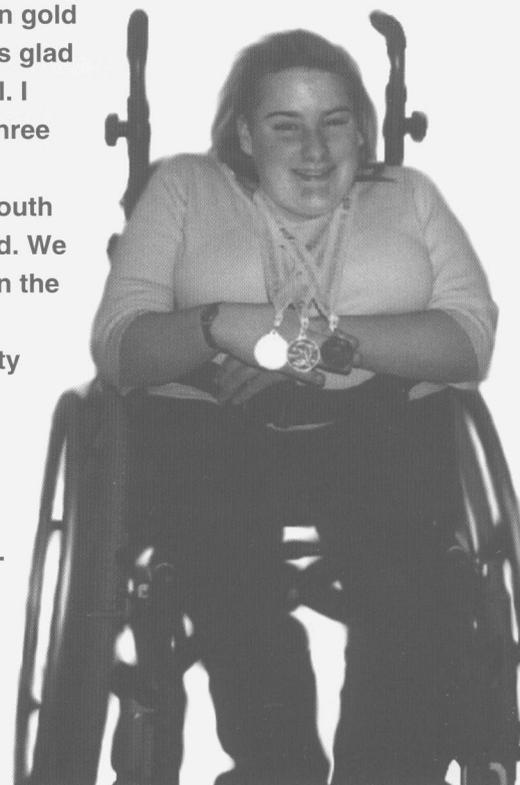
**CONGRATULATIONS to 13-year-old Kristy Baldock who for the second year running won gold medals in the National Junior Swimming Championships.**

**Kristy, from Uckfield, East Sussex, this year won gold in the 100 and 50 metre breast stroke race, and silver in the 25 metres.**

"I wanted to win gold in all three but was glad to have swum well. I also took part in three relays with other members of the South East Region squad. We came 9th overall in the competition."

Next year, Kristy will move up to compete in the senior section so she will have to swim much faster.

"I'm training hard and I will try and qualify in every stroke and the individual medley as well."



**I HAVE always struggled to accept my disability. I seem so normal, yet not quite altogether.**

I am 24 years old. I was born with hydrocephalus and I have had a shunt since I was six months old.

I love sport, although because of my poor co-ordination, I'm not brilliant.

My academic success is much the same although through hard work and determination, I gained a 2:2 in Biblical Theology.

My parents looked to God



## True Story

# Determination and the love of a good woman!

when they discovered my disability. I came to believe in God as a child. During my degree studies I came to reconcile God's love and my disability in that I am unique even amongst people with hydrocephalus, rather than just suffering a cruel twist of fate.

Last year, I married a wonderful woman, Karen, who simply loves me for who I am. We met on holiday at a Christian camp in Burgess Hill, West Sussex, her home town, during 1991.

Employment has always been a problem due to my lack of co-ordination as much as employers' ignorance.

After a spell in telesales, I trained as a BT operator for the directory inquiry service -192-through Blue Arrow recruitment agency.

It was difficult finding the

right job, given the economic climate and job situation.

Having hydrocephalus only compounded the problem. My parents steered me into computers which demands more accuracy than speed.

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**By Richard Wilkinson  
Mansfield, Notts**

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Most employers look for fast workers but, by training, there are jobs where accuracy is more important than speed, like accountancy and clerical work. Slowness, caused by poor co-ordination associated with hydrocephalus, does not show through as much because your colleagues are working at a similar pace.

Other tips are to be punctual, have a good attendance, be polite etc. These allow such things as being slightly slow to be overlooked.

Try to avoid jobs with multiple tasks. I remember one such job, counting off 10 plastic coat hangers, binding them with an elastic band, and packing them in a box – all the time the machine produced more coat hangers than I could deal with.

I have struggled to fill in application forms because I never wanted to be registered as disabled, but I am disabled under the Disability Discrimination Act. So I answer 'yes' when the forms ask: do you have a disability but answer 'no' if it asks if I am registered disabled. I say that I am disabled and that it affects my co-ordination slightly.

In interviews, when asked about my disability, I describe it as 'water on the brain'. I know this term is crass but employers then understand the basics without being blinded with medical jargon.

## Wigan weekend – just the ticket!

A WEEKEND in Wigan on various forms of mobility boosted confidence and increased awareness.

More of the same is being demanded, particularly with more emphasis on knowing your new legal rights on all types of goods and services.

Organised by our disabled user group YVIA, the event drew 25 people from all over England.

Jon Burke, YVIA co-ordinator, said: "From the feedback we have received it is clear that participants felt that the content was very useful.

"Every opportunity was taken to swap information and experiences. Linked to enquiries about the next activity, we came away feeling that it had been a resounding success."

The event was designed for everyone – not just car drivers and wheelchair-users.

Two 'know your rights' type sessions were the most popular topic in discussion. A workshop on general rights looked at the Orange Badge

scheme and care component of DLA. Another session focused on your rights under the Disability Discrimination Act when seeking car insurance independently for a non-Motability vehicle.

Mary King, from Greater Manchester, said: "The weekend was very enjoyable although I think there should have been a little less free time to cover more issues. We could do with more on the DDA – perhaps a weekend conference on this could be considered."

Announcing YVIA's event of the year  
**CIC 2000**

## Choice, Independence and Control

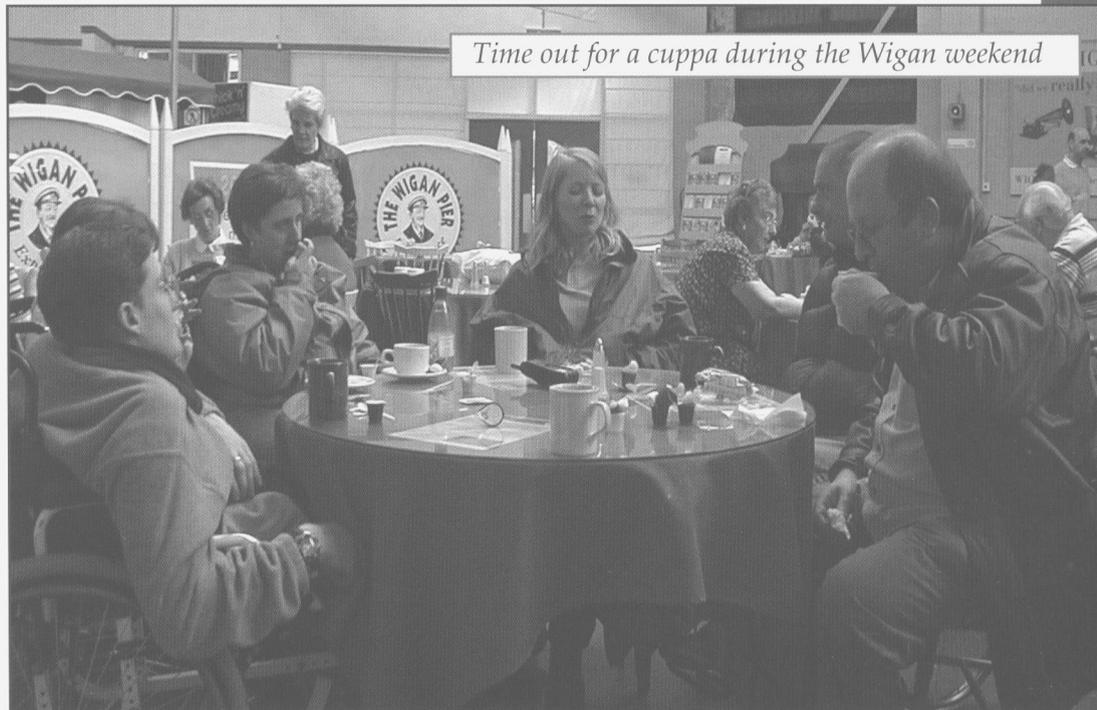
1– 3 December 2000,  
Leicester Hilton,

£30 (provisional price for the weekend)

- Any activities that you would like to see included in the programme?
- Want to make an early booking?

Contact Jon Burke, 0113-255 6767,  
jonb@asbah.demon.co.uk

*Full details and a provisional programme will appear in the next issue of Link.*



Time out for a cuppa during the Wigan weekend

## Fencing and the first class of its type in the country

**B**LACK cab driver David Varey has been a fencing coach for 10 years and it had long been his ambition to open up the sport to people with physical disabilities.

It turned out that his local secondary school was a favourite choice of young wheelchair-users and, after doing a trial coaching session there, the headteacher decided that this was a sporting opportunity that should be continued.

Funding was found when art teacher Geraldine Walkington told David that a new charity was being set up to raise money for certain sports at the school.

David now teaches six wheelchair-users – including two with spina bifida – once a week at Mount St Joseph High School, Farnworth, Greater Manchester. They are allowed to leave timetabled classes and join him in the sports hall.

One student in the class, 13-year-old Ruth Madeley, from Daisy Hill, Westhoughton, said a couple of her colleagues had real natural ability and would go far.

The aim of the game is to 'hit before being hit' with a concentration on

learning hand skills rather than footwork.

The wheelchairs are positioned at an angle to each other and stay put rather than having a two x 14 metre 'strip' to move around in like other fencers.

After putting on lightweight helmets, the fencers measure the distance so their swords can touch the opponent's torso when reaching forward; salute by holding up the sword and then begin.

The game improves hand-eye co-ordination, confidence and general fitness – and it provides a lot of fun for the players.

"Teaching these children is very satisfying. They want you to be there and it is not just a fill-in," said David.

"I am all for integration but I believe that disabled kids will get off to a better start if they are not going to be stared at or made to feel different. But we're the only non-mixed fencing group in the country."

David said agility and a free range of movement were demanded rather than upper body strength. Both can be improved by doing exercises. And to encourage the youngsters to do the best they can, there are British Academy of Fencing awards to work towards, and the Athens Paralympics in 2004 are not being ruled out.

"Two out of six of my pupils have the right physical and mental attributes to achieve high levels in the sport," David said.

"It is so exciting. I thought it was going to be like non-disabled fencing and take years and years to get off the ground. But the group has only been going four months and we've got this far."

Coupled to this, David has organised two in a series of national coaching days, attracting 15–30 fencing coaches, in a bid to get more of them teaching the game to wheelchair-users.

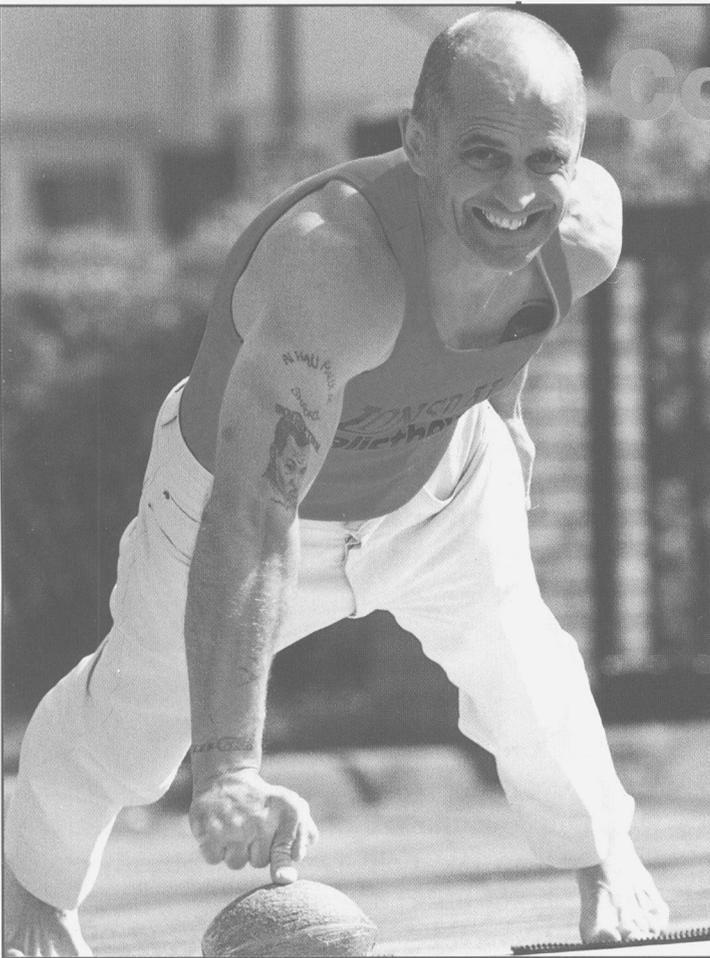
● David Varey, tel: 0973-878841, [fencing@coach2000.freeseve.co.uk](mailto:fencing@coach2000.freeseve.co.uk)



# down your way

A look at what's happening locally

MEDWAY NEWS / MEDWAY STANDARD



## Coconut shiner

MICKEY Gooch smashed through the pain barrier to almost double his world record of the greatest number of press-ups on one finger on a coconut.

He pulled off the stunt for Kent ASBAH and another charity as he is close friends with KASBAH member, Jody Duff, together with Billy Ripley, who started using a wheelchair after a football injury 10 years ago.

Mickey's existing world record was 16 and his first public attempt to break it in was on *The Big Breakfast* TV show in April. On that occasion, he managed 23 press-ups but the attempt didn't count as it was not done under world record conditions.

Then, in May with a large crowd of well-wishers behind him, Mickey, from Chatham in Kent, achieved an amazing 31. The officials overseeing the extraordinary feat were the mayor of Medway, Councillor Dai Liyanage and local boxing champion Johnny Armour.

**A SUPPORT group for the parents of children with spina bifida and / or hydrocephalus has been set up in Gloucestershire.**

**Five members attended the inaugural meeting at a church hall in Longlevens, Gloucester, on 8 April.**

**For information, phone Mrs Christine Alexander, whose nine-year-old son James has hydrocephalus, tel: 01452-309946.**

## Have a go at a new activity in Sussex

NEWCOMERS are invited to join a group of disabled people in Sussex who get together every week to take part in a range of sporting activities.

Darts, pistol shooting, table tennis, short mat bowls and Boccia are played on Sundays, with outdoor bowls and archery added to the list in the summer. The Sunday sessions are held at The Arena, Bognor Regis

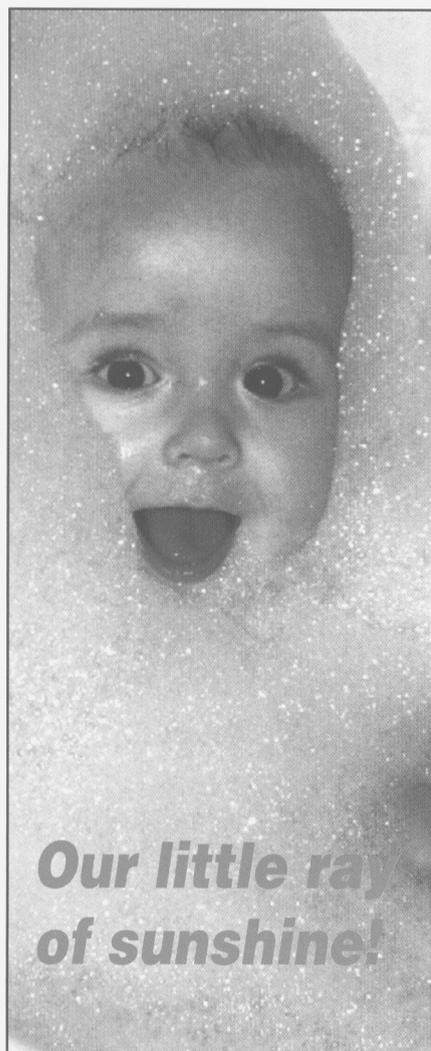
Community College, Westloats Lane, Bognor Regis.

Other activities held regularly are: indoor bowling on Fridays at Nyewood Lane and swimming on Thursdays at Arun Leisure Centre.

● For further information, or if you would like to join, please ring Kate Allen, secretary of Arun Sports for the Disabled, on 01243-583868.

We welcome contributions from Local Associations. Please contact Liz Cawthorne, 01733-555988, [lizc@asbah.demon.co.uk](mailto:lizc@asbah.demon.co.uk) with your ideas.

**WINGATE House, Cheshire, is the home of the Special Gymnastics Association, a registered charity working with people with disabilities of all ages. Short activity breaks are available. Information packs, tel: 01270-780456.**



**Our little ray  
of sunshine!**

## 'Bubbles' – a legend in his own bathtime

THIS photo of 'Bubbles', baby Gareth Picken, sent in by his parents, is on the front of our new fundraising leaflet.

Nici and Mark Picken have ordered 100 copies for family and friends where it is having maximum effect!

The first copy arrived on the day that baby Gareth's nursery – Stepping Stones in Cirencester – was holding a ball to celebrate its fifth anniversary, with £300 gained from the raffle going to ASBAH.

Gareth attended the ball with his parents. Nici, a primary school deputy head, gave an impromptu speech about her son to a hushed audience. Interest was sparked from other ball-goers so there is the promise of ASBAH becoming charity of the year for other organisations.

Northleach Primary School in Gloucestershire, where Nici teaches, sent in £25 from a Christmas card sale. A similar sale was held at Burford, near Oxford, by Mark's parents.

Nici and Mark were helped in the early stages by our adviser Julie Knight. A little more than a year old, Gareth has already faced a blocked shunt and surgery to correct dislocated hips.

Nici said: "ASBAH has been fantastic from the word go. We recently attended the Family Weekend which was superb and provided a lot of information. It's amazing – sending in a photo starts an awful lot."

## A perfect marathon day

THE ADIDAS billboard at 23 miles kept Sharon Hine on route to personal victory in her first London Marathon.

'One step in front of the other. One step in front of the other,' it said. "I looked up, read the sign and thought you're so right!" said Sharon (28), who wiped everything from her mind but the thought of crossing the finishing line.

Sharon, from Dorking, Surrey, finished in five and a half hours, raising £520 for us.

Her family has given money to us since her brother Anthony,

who had spina bifida, died many years ago, aged six weeks.

Sharon was supported all the way by boyfriend and colleague Peter Bentley. The couple are pictured at the litter-strewn end of the marathon course near Admiralty Arch, central London.

● Congratulations and thanks to other runners who gave ASBAH their support including: London IT project manager Michael Green who raised £500 with a better time than expected; Alison Bone, of Sandhurst, Berks, who ran the London for the first time, aged 43; and Jim Bird, of London.





## They're the very best of British!

**KEY figures in the pigeon racing world gathered near Peterborough to mark a massive fundraising milestone.**

Over the last 28 years, the pigeon racing community have raised £350,000 for ASBAH – making them our largest-ever donor. Their latest annual donation was £15,000.

The donations come from the annual British Homing World 'Show of the Year' at Blackpool, whose main organiser Peter Bryant popped in to present ASBAH fundraising manager Donna Treanor with a commemorative cheque at the end of April.

Mr Bryant, general manager of the Royal Pigeon Racing Association, visited the pigeon loft of champion racer Geoff Jakings in the village of Yaxley for the cheque hand-over.

Geoff, who owns dozens of championship birds, said: "Pigeon racing's a tight-knit

community. Hardly anybody outside knows that we have become the biggest-ever supporter of a national charity which is based in Peterborough."

Geoff and his wife Geraldine were joined by fellow pigeon racers Peter Clarke and Roger Howland.

Donna Treanor commented: "The Show of the Year took ASBAH under its wing because one of the original organisers had a son with spina bifida, and he got terrific support from us.

"We've grown since then, and so has the Show of the Year. But it's no secret that their regular donations over the years made it easier for us to develop our unique services to people with spina bifida and hydrocephalus. We owe them a big debt of gratitude."

*ABOVE: Peter Bryant, general manager of the Royal Pigeon Racing Association, presents the £350,000 milestone cheque to ASBAH's Donna Treanor. In the rear, from the left, are top Peterborough pigeon racers Peter Clarke, Roger Howland, Geraldine and Geoff Jakings.*

*BELOW: Cool! Peter Bryant and Donna Treanor inspect the pigeons.*

*Photos: GRAHAM LOWNDES*



# dates for your diary

## Stimulating mix after the holiday fun

HERE'S something to get your teeth into after the summer holidays – our South East region conference 'The Way Forward', being held in Greenwich during the first weekend of September.

It'll be a mixture of fun, which could include a visit to The Dome or a river trip, with serious stuff aimed at bringing out the best in those taking part. There will be sessions on education, independence, employment, housing, assertiveness, and young parents' issues.

ASBAH regional manager Mrs Jo Francis is also booking in time to update those who are interested on the legal side of running your own associations.

The conference costs £80 each for those who want to stay for the whole weekend, but there are day places available which cost £20 each. And the venue, Avery Hill College, is wheelchair-friendly.

## ChairAbility Challenge

NATIONAL ASBAH, Kent ASBAH and other local associations team up on 3 October for our ChairAbility Challenge (*see opposite*).

The event will pair off Members of Parliament with disabled members in games of wheelchair basketball – to show off the fantastic ability of Britain's wheelchair users.

Wheelchair players who can volunteer some time that day should contact Tony Britton, on the number given opposite.

## Upcoming events

### 'Share Music' course

**15 – 22 July and 22 – 29 July, Stackpole Centre, Pembrokeshire.**

Enabling young people with physical disabilities or sensory impairments to take part in creative music-making.

*Dr Michael Swallow, 15 Deramore Drive, Belfast BT9 5JQ, tel/fax: 01232-669042.*

### Disability Awareness Day, DAD 2000

**23 July, Walton Hall Gardens, Warrington, Cheshire**

Large, voluntary-led disability and family fun day  
*Tel: 01925-240852*

### Pressure sore prevention from a multi-disciplinary perspective

**25 July, Derbyshire Royal Infirmary**

Whole day conference.  
*Mrs P D Jones, tel: 01332-254679*

### Surrey ASBAH activity days / weekend

**29 – 30 July, High Ashurst Outdoor Activity Centre, Mickleham**

*Jackie Cowl, tel: 01293-436164*

### 'Share Music' course

**29 July – 5 August, Calvert Trust, Cumbria.**

*Dr Michael Swallow, as above.*

### Northern Mobility Roadshow

**17 – 18 August, Sheffield Arena**  
Open daily 10am-4pm.  
*Tel: 0114-243 5355.*

### International Federation for Hydrocephalus and Spina Bifida

**31 August – 3 September, Toulouse, France.**

12th Congress. 'The Right to be Different' Centre des Congrès Pierre Baudis, Toulouse, France.  
*ifHSB Office, Cellbroersstraat 16, BE 1000 Brussels, Belgium. Fax +32 2 502 11 29. Tel +32 2 502 04 13.*

### ASBAH South-East Region L A Conference

**1 – 3 September, Greenwich.**  
'The Way Forward', Avery Hill College.

*Jo Francis, tel: 020-8449 0475. jof@asbah.demon.co.uk*

### AGM, national ASBAH

**16 September, Peterborough.**  
11 for 11.30am. Help us to plan the next few years. Discussion to focus on how local Associations can help shape the future strategy of national ASBAH, with case studies of local campaigns (how to get your viewpoint across and win some arguments with the authorities).

### ASBAH's ChairAbility Challenge

**3 October, nationwide**

MPs v wheelchair athletes head-to-head in demonstration basketball games.

*Tony Britton, tel: 01733-555988, tonyb@asbah.demon.co.uk*

WRITING in the last Diary, I said that working for a living was making me tired. Since then I've realised that getting up early and travelling to work are, like the work at the office, just part of the hassle of working and something I will just have to learn to accept. What I really don't need is being stuck with something which is absolutely nothing to do with me, isn't my fault, but which people hassle me about anyway.

So far this month I've had two major hassles at work which are absolutely nothing to do with me or my work. The first was courtesy of the phone people who have decided that the people of London need their numbers changing yet again! As a result, I (who have other work to do) have just spent a happy few days trawling through the database changing hundreds of phone numbers. When you have entries for faxes, home numbers, secretary's numbers, and direct lines, this stops being a 10-minute job. Once the database is sorted, we will spend a fortune changing all our printed stationery, telling confused customers our new number and checking theirs. And then, after a few years when everything has settled

down, we'll no doubt be doing this all over again! Aaargh!

The other hassle of the month is courtesy of the European Union. The office I work in is right next to a huge car park and although we are absolutely nothing to do with it, the public often complains to us when the ticket machine jams, there's a spilt milkshake, or a thousand and one other things which are absolutely nothing to do with us.

Recently we've started having a new problem. Some genius decided that all Orange Badges should now be Blue Badges, to match the rest of Europe. Orange Badges are, apparently, still valid until they expire, then you get a Blue Badge when you go to replace them. The problem (and complaints) started when signs went up saying spaces were for Blue Badge holders only.

Confused and worried people trundled in saying they only had an Orange Badge but could they park there anyway – they'd only be five minutes! Eventually the signs were changed to Blue or Orange Badge holders only. Presumably, when there are enough Blue Badge users, the 'Blue Badges Only' sign will go

up and I will finally be rid of this Euro-muddle!

I imagine this furious changing of signs, leaflets and cards from Orange to Blue is going on all round the country. No doubt it is costing councils and businesses a small fortune (and making sign writers very happy). So what good has this expensive and confusing change done? Well, it's given me an ear full of confused Orange Badge users!

The biggest problem is that the badge may be a different colour and accepted in some parts of Europe but, throughout Europe, there are still different rules about where you can and cannot park (and for how long). What's the point of having 'one badge for Europe' if everyone is doing their own thing and I still can't park in most of London without getting fined?

I dearly wish the genius who decided on this change was here now, so he could explain to these irate and confused card-waving people why we had to change and that it's not my fault!

# DAVE'S DIARY

david.fulford-brown@virgin.net

## Do it **SOON** – if you want to claim **SDA**

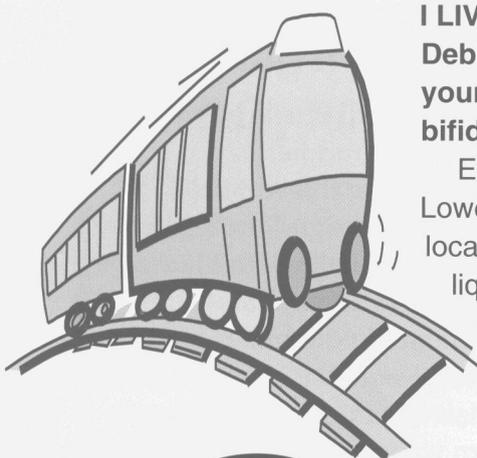
ANYONE who might be entitled to Severe Disablement Allowance should apply quickly as no new claimants will be accepted after April 2001.

A special take-up leaflet for people aged 20–64 has been produced by the Disability Benefits Alliance, plus an easy to follow factsheet explaining in straightforward language who the benefit is for and how to claim.

Claimants need to show that they have been incapable of work for 28 weeks prior to making a claim. Existing claimants will continue to get Severe Disablement Allowance if they continue to meet the qualifying conditions.

● For a factsheet, please send an A4 size SAE to: SDA factsheet, Disability Alliance, Universal House, 88-94 Wentworth Street, London E1 7SA.

Seasoned UK traveller MARTIN THORN paints a bright picture of rail travel for the disabled.



## Ride smooth guide

EVERYTHING you need to know about wheelchair travel round the UK, and probably a great deal more besides, can be found in the *Smooth Ride Guide to the United Kingdom*, which came out in June.

No access guide has ever before included between one set of covers the multitude of accommodation, attractions, leisure, sporting and transport facilities which are available to people with mobility difficulties or the wheelchair-traveller. Full access details are given for all entries.

It is the third in a series which so far has covered Australia and the eastern seaboard of the United States. The UK book has been funded by the National Lottery Charities Board.

It has a pocket-size 430 pages, costs £9.95 (inc p & p) and is available from leading booksellers.

**I LIVE in Peterborough with my wife Debby and our three children – the youngest of whom, Gilly, has spina bifida and hydrocephalus.**

Every year we go to Kessingland near Lowestoft to stay in a chalet owned by our local ASBAH. We need to take Jevity liquid feed, bags, giving sets, a feed pump, suction pump, nebuliser and a large array of medicines, as well as normal holiday luggage.

The simplest way is for me to take one child and the luggage in the car, while Debby uses a Family Rail Railcard, taking Gilly in her wheelchair and our other child on the train. The journey is from Peterborough to Norwich on Central Trains and then with Anglia Railways from Norwich to Lowestoft, where I collect them having first dropped off the luggage.

Preparation is important. There is a national advice and help line – 0345 484950 – or you can visit a staffed station and book there. If assistance is required, the railway companies ask for at least a week's notice. On the day, staff will be on hand to escort you to the right platform and see you on to your train, using the mobile wheelchair ramp kept at most stations. Most railway companies reserve seats free of charge.

Things occasionally go wrong but, with each company operating to a customer charter, the situation is better than 10 years ago. One year we arrived at Norwich to find the track damaged, with trains unable to get to Lowestoft. Buses were laid on, with taxis provided free to deliver elderly people and wheelchair-users with their carers to whichever station along the line they had tickets for.

GNER, which operates the

East Coast Main Line, one day came up trumps when given no notice at all. I took a blind man to the station and helped him on to the London train. A member of the platform staff asked which carriage he was in. She then phoned through to King's Cross and another member of staff boarded the train on arrival to help him off the train and out of the station to the taxi rank.

At most London terminus stations, an electric buggy with a driver and room for up to four passengers and their luggage is available without charge at only 24 hours notice. This comes up to your carriage and takes you to the taxi rank or main concourse. If you are travelling across London and cannot use a taxi or the Underground, a wheelchair-accessible bus travels in a big circle to all of London's termini.

We use a Family Railcard, costing £20 a year and allowing up to four over-16s and four under-16s to travel at a discount. Adults receive a 25% discount (sometimes more), while children travel for just £2.

A Disabled Railcard is also available at £14 a year, which allows the holder and a companion to travel with up to 50% discount each.

As for the actual trains, all mainline trains now have dedicated wheelchair space in both classes. Cross country and local services tend to be operated by two-coach diesels.

Most companies took delivery in the late 80s of coaches which had a dedicated wheelchair space. These are now being replaced by a new class with space for three wheelchairs, a wide, sliding door to the toilet alongside and a baby-changing shelf in the loo.

# holiday lets

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

## SELSEY, WEST SUSSEX (SASBAH)

Fully equipped, purpose-designed for wheelchair access, mobile home. Sleeps six, ramp and large veranda, payphone, colour TV, midi stereo etc. Clubhouse entertainment, heated swimming pool, free site bus service. Nature reserves and places of interest nearby. Details from Mrs B Nunn, tel: 01903-763473.

## ISLE OF WIGHT ASBAH –

Recently refurbished, fully equipped, two-bedroom bungalow. Sleeps six. Wheelchair accessible. On site clubhouse, shop, local indoor heated pool suitable. Interesting places to visit, lovely views. Own transport advisable. Details: Mrs S Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF, tel: 01983 863658.

## BERWICK COTTAGE, EAST HARLING, NORFOLK –

Purpose-built modern cottage. Ground-floor accommodation for up to 2 people with disabilities. Scan 700 beds. Close-Mat. Overhead track hoist bedroom-to-bathroom. First floor accommodation for up to 4 carers / family / friends. Awarded Grade 1 Holiday Care Service. Open all year. Low rates Winter / Spring. Information / bookings: Mr W G H Tickner, The Lin Berwick Trust, 020-8595 7056.

## ACCOMMODATION

**ILKLEY, WEST YORKSHIRE –** vacancy at Flat 1 Wharfedale, Five Oaks Housing Scheme. Suit couple with or without a child, alternatively two to three adults willing to share the tenancy. The accommodation comprises three bedrooms, living room, kitchen, bathroom, toilet / shower room and hallway with storage. Wheelchair accessible throughout and on the ground floor; benefitting from patio and access to shared gardens and laundry facilities. Superb views from kitchen and bedrooms across the Wharf valley. At least one of the intending occupants must have a disability. A care and support package can be arranged with Bradford Social Services. Contact: Mark Best, tel / fax: 01943-603013, address: Five Oaks Housing Scheme, Ben Rhydding Drive, Ilkley, West Yorkshire, LS29 8BD.

## 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 (Sept) should be submitted by Friday, 4 August.

Please send to:  
Editor, ASBAH,  
42 Park Road,  
Peterborough PE1 2UQ.  
Tel: 01733-555988.  
lizc@asbah.demon.co.uk

### ● Display Rates on application from Publicity Manager, ASBAH. Tel: 01733-555988. tonyb@asbah.demon.co.uk

## FOR SALE

**LEADER 3** Scooter, 4 years old, bought for £2,000, selling for £500. Has battery, basket, lights etc. One careful owner. Tel: 01275-833541 (Miss Jowa Hall).

**CONVERTED** Mercedes Vito Versa 113, R-reg, 15,000 miles, wheelchair-access through rear tailgate, electric winch fitted, power steering, air conditioning, tinted windows, two seats at rear, two-litre petrol engine, excellent condition. £10,950. Tel: 01923-449 514 (Watford).

**ADAPTA** powerchair, 3-speed, for inside and outside use. VGC. New £7,000. Complete with

tilting Recaro seat, joystick control, footrest, battery charger. Only six months use. £2,500. Tel: 01929-471097 (Dorset).

**HYDROCEPHALUS** and You, ed by ASBAH (1999), 81pp, £10.99 (inc p&p) from Information Department.

## PERSONAL

**FEMALE**, 33, recently moved to London, wishes to meet other people with spina bifida / hydrocephalus in the area. Please write to: Claire Meaney, 15 Rose Way, Stoneyfields Lane, Edgware, Middx HA8 9SD.

## AFFILIATED ASSOCIATIONS

### BARNSELY

Mr Geoff Jenkinson  
12 St Leonard's Way  
Ardley, Barnsley  
S Yorks S71 5BS  
Tel: 01226-292546

### BEDFORD

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

### BOURNEMOUTH, CHRISTCHURCH & DISTRICT

Mrs G Lanning  
2 Riverway, Christchurch  
Dorset BH28 2QW  
Tel: 01202-567649

### BRISTOL & DISTRICT

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

### BUCKS & EAST BERKS

Mrs Abigail Biscoe  
15 Elm Road  
High Wycombe  
Bucks HP12 4TA  
Tel: 01494-639773

### BURY & BOLTON

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

### CAMBRIDGE & DISTRICT

Mr Tony Proud  
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