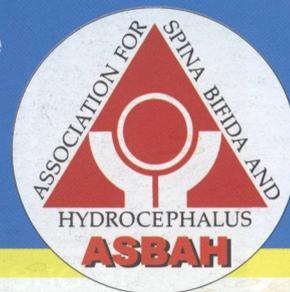


LINK

The magazine for people
with Spina Bifida and
Hydrocephalus



HORSEBACK HAPPINESS

Meet a real
biker bird

NOVEMBER/DECEMBER 2001

ISSUE 196

PRICE
80p

Treloar's

is one of the UK's leading centres for young people with physical disabilities providing education, therapy and care all under one roof.

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A COURSE TO HELP YOU FIND THE REAL YOU

Develop the power to improve your life. The first half of the course concentrates on improving your communication with other people. In the second part, discover ways to improve personal goal setting and achievement.

This event is for adults aged 16 and over with spina bifida and/or hydrocephalus. The facilitator will be Jon Burke, a qualified neuro-linguistic programming practitioner.



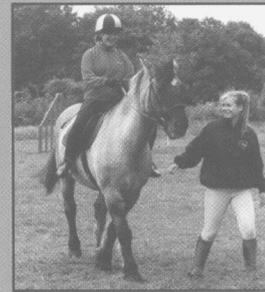
One-day conference call by Your Voice, ASBAH's disabled users working group.

Saturday,
17 November 2001
10am - 4pm

ASBAH National Centre
42 Park Road
Peterborough

Cost: £20 each (inc buffet lunch and refreshments)

Please contact
Lyn Rylance, ASBAH
by 9th November
tel: 01733-555988
lynr@asbah.org



Cover: **HAPPINESS ON HORSEBACK.**
Bethan Williams enjoys an outing at her local riding stables. For story, see page 7.

Editorial

We have said it before. We'll say it again. ASBAH needs friends and supporters at times like these.

Our chairman, Peter Cottingham, reinforced the message at our 35th annual meeting in September.

"Times are tough. ASBAH is under pressure," he admitted.

At a time when we are going through a bit of a financial rollercoaster of a ride, he urged everyone with an interest in securing National's future to consider working in partnership to raise funds.

After spending much of the last 18 months consulting with all of our stakeholders on a five-year development strategy, which is now agreed, it makes sense to make sure we have the means to put it into action.

Plans to generate new income are now well under way, but it will be a little while yet before we get back the money on our investment and substantially more.

In the meantime, hold onto your hats. It's a rough ride. But, if we work together, we'll come out the other side... feeling the better for it!

contents

A real biker bird!	5
Research news	6
Together in film	7
We will overcome	10
Hydrocephalus news	11
People	12-13
Obituaries	14
link.forum launches	15
Fundraising	16-17
New school outlaw	18
Diary dates	19
Dave's Diary	20
Letters	21
Smalls adverts	22
Local Associations	23



Leathered ● Page 5



Cue camera ● Page 7



Own write ● Page 14



Our man M ● Page 17

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ASBAH's vision is a future where everyone with spina bifida or hydrocephalus can get the most out of life.

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.

postmaster@asbah.org
www.asbah.org

Find yourself a winter warmer

WINTER is round the corner and you can prepare for the cold now by applying for Government cash to make your home warmer.

A Warm Front Grant of up to £1,000 will provide a package of insulation and heating tailored to each property, such as loft insulation, draught proofing, cavity-wall insulation and hotwater-tank insulation.

Householders who are receiving one or more of the following benefits are eligible to apply:

- Income Support (that includes a disability premium).
- Housing Benefit (that includes a disability premium).
- Council Tax Benefit (that includes a disability premium).
- Disabled Person's Tax Credit.
- Working Families' Tax Credit.
- Attendance Allowance.
- Disability Living Allowance.

If you are a householder with a child under 16, you can apply if you are receiving one or more of the following: Income Support; Housing Benefit; Council Tax Benefit; Income-based Jobseeker's Allowance.

For details call free on 0800-316 6011; minicom 0800-072 0156. Please have your benefit details with you when you ring.

Look before you leap!

A SINGLE mother on Income Support signed away more than she could afford because she misunderstood the terms of a service contract for the through-floor lift on which she depends.

Now ASBAH advisers have warned other service-users to double check they know what they are putting their name to on agreements for any kind of equipment – even if it means asking someone else they know to read it over with them.

Jeanette Chalmers (37) has double vision due to Arnold Chiari. She is also a wheelchair-user and depends on a through-floor lift to reach the bathroom and her bedroom. The lift was fitted in her house by Social Services before she moved in, and the first year's service arrangements were taken care of.

Jeanette was alone when she opened a renewal form for service and maintenance from Stannah Lifts Ltd. The most attractive option seemed to be the 'fully comprehensive' package – allowing four service visits a year, plus free labour for week-day emergencies before 5pm.

However, she thought the £140 fee was an annual charge and it was only after the form had been returned that a relative saw that it was, in fact, quarterly.

On a low income and with an 11 and 13-year-old to support, Jeanette, of Pontypridd, says she can't afford £140 as a regular outlay.

She said: "I was very angry.

Companies shouldn't be charging these disgusting prices. They know disabled people need these things and take advantage of us. I have no choice but to have the lift maintained as I can't manage without it. The only way I can pay is using Child Benefit money, which I think is wrong.

"If I could crawl upstairs on my backside I would as it would be cheaper, but I can't."

Her ASBAH

adviser, Margaret Stanton, wrote to Stannah Lifts with her concerns but, though the company gave her the option of changing the contract, it accepted no responsibility for what had happened.

Mrs Stanton said: "Although Jeanette decided to stick with the more expensive maintenance cover because the cheaper option gives a lesser level of service, it would have been better had she known the cost beforehand."

Jon Stannah, managing director of Stannah Lift Services, told *Link* that his sales staff would talk a customer through a contract, if help was requested. He advised hard-pressed customers to approach Social Services to see if financial help with maintenance could be extended beyond the first year.





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elini@asbah.org

Jen becomes a real biker bird!

CRUISING at speed in laid-back American style, Harley Davidson fan Jen Howarth fulfilled a dream of a life-time when she rode pillion through the streets of Merseyside.

The 29-year-old was thrilled when one of the big machines, with distinctive high handlebars and descending front wheel, drew up outside her flat in Dingle Lane and a burly, leather-clad biker knocked at her door.

The treat had been organised over the Internet by her friend Walter Hoskisson, the chef at the sheltered accommodation where Jen lives.

"It had originally been intended as a surprise for my birthday but they had to find out about my spina bifida and hydrocephalus so had to fill me in," she said.

So, although the knock on the

door from The Centurians – a Harley Davidson group in Chester – was expected, Jen was nonetheless excited as she settled herself into the comfortably wide, high-backed seat behind the driver.

Her mum, following behind in the car, held her breath as Jen, securely strapped in and enjoying every minute, let go.

Jen told *Link*: "It was my first time on a Harley Davidson and it lived up to my expectations. It was a dream come true."

She has long been attracted to the husky style of the American machines, particularly as their symbol is the eagle and she is interested birds.

Jen is keeping touch with The Centurians and other Harley Davidson groups on the Internet and has been sent various memorabilia from the States.

BE PART OF OUR SUCCESS: Done something interesting? Got a strong opinion? Write to: Liz Cawthorne, ASBAH, 42 Park Road, Peterborough PE1 2UQ; lizc@asbah.org

research

Sue wants to hear from you

NEW ASBAH research fellow, Sue Thompson, wants to talk to service-users and staff about their experiences of health and social services for a report to the Department of Health.

Sue, from Sheffield University Department of Sociological Studies, has been commissioned to compile a well-researched ASBAH submission to the Department's hugely important National Service Framework for people with long-term neurological conditions, expected to be in place in the year 2005.

Sue will also be considering the standards our service-users should expect in health and social services for a separate report for ASBAH.

To achieve worthwhile results, Sue wants to hear from as many people with SB and/or H as possible, and she will be interviewing a wide range of people over the next few months.

She would also like to hear from *Link* readers, who have spina bifida and/or hydrocephalus, or have a family member with the condition(s), whether or

not they use our services. All contact will be confidential.

Sue is particularly interested in the following:

- Your or your family's experiences of health and/or social services: What services have worked well for you? What services have not worked well?

- Have there been any gaps in health or indeed social service provision for you?

- What changes would you like to see in health and social services which would directly help you in the future?

Please pass on your views and ideas to Sue, c/o *Link* at Peterborough; email her at: owlend@hotmail.com Please include your daytime/evening phone number and suggest the best time that she can contact you.

ANOTHER 71 families have signed up to take part in our cheek-swab genetic research project.

Since the last issue of *Link*, this brings the total of families involved to 571 – with 523 coming from England and 48 from Wales. Some 104 Northern Ireland families are also taking part.

New enquiries are still welcome. **Contact the Health Research Board, Dublin, on freephone 0-800-1699050, childheath@hrb.ie**

Please complete this form and send it to:

**GILL WINFIELD, ASBAH INFORMATION,
42 PARK ROAD, PETERBOROUGH PE1 2UQ.**

I give my consent for ASBAH to keep a record of my/ my child's details on the ASBAH database and in ASBAH's paper files.

Signed _____

Date _____

Name (or name of child with spina bifida and/or hydrocephalus)

Address

Date of birth _____

THANKS to everyone who replied to the request in the last *Link* (Sept) asking readers to let us know if they were happy for us to keep their personal data in ASBAH's confidential database and files.

If you haven't returned the permission slip yet, we would still like to hear from you – please fill out and return the form which we have reprinted below.

Alternatively, you can phone or email our Information Manager, Gill Winfield, on 01733-555988, gillw@asbah.org



Putting it on film – together

A COUPLE of film graduates are forming a new life together in more ways than one – by setting up their own film-making company and getting hitched.

Lee Burgess and Tuesday Richards, who worked together on numerous film projects at university, are currently busy making a series of short black comedies on disability, based on real events from real people. They are also preparing for a December wedding at a large manor house in Somerset.

Based in Newport, Gwent, they aim to force the TV channels to give them a prime-time slot instead of the usual low-peak viewing times for films on disability around midnight.

With this in mind, they have formed a company called Maggie Dog Films – named after a family pet.

Lee (22), who has spina bifida, explains: “Maggie is the name of my family dog whom

everybody wants to take home. We want everybody to take our films home.”

With a Film and Video degree from the University of Wales College in Newport, Lee does the camera work and directing. Twenty-one-year-old Tuesday, who graduated in Media and Visual Culture and has cerebral palsy, specialises in screen-writing, researching and script-editing.

They use mini DV and mini disc equipment and have the use of Avid editing equipment.

They own two cameras including a Canon XL1.

Lee says: “In the future, we hope to make films on such taboo subjects as sexuality in disability and other types of personal politics.

“And we hope to start writing a feature film using disabled actors playing all the main roles.”

● Anyone interested in working on different stages of film-making, or who might like to become a sponsor, please contact them on 01633-255719, maggiedogfilms@hotmail.com

Thanks, Bethan, for help!

OUR FRONT cover photo this issue is of 12-year-old Bethan Williams, from Newport, South Wales – who worked with us on an annual review which illustrates the work of ASBAH in Wales.

Bethan, who has hydrocephalus, and her family had lots of support from our advisers as she moved from primary to secondary school. There is now much improved provision of classroom support, though neither the family nor ASBAH are totally happy with the outcome. In her spare time, she enjoys riding lessons.

Foetal surgery 'still not best way to go'

THE LEADER of the foremost research society in our field is maintaining her opposition to the use of foetal surgery to repair spina bifida lesions in the womb.

Carys Bannister, president of the Society for Research into Hydrocephalus and Spina Bifida (*pictured*), which has members from the scientific and medical community around the world, still says that foetal surgery – pioneered in the USA in the last three years – is not the best way forward.

Miss Bannister, who recently retired after 25 years as consultant paediatric neurosurgeon with Manchester Children's Hospital NHS Trust, told *Link*:

"Over 100 cases have been done in the States, the majority in one unit. None of the published data, presentations or discussion at meetings have convinced me that the operation improves the outcome in any way compared to operation after birth."

"There are suggestions that the complication rates of the procedure for both the foetus and the mother are mounting, premature delivery being a major cause of concern for the foetus, accompanied as it is by the risk of brain haemorrhage, lung damage and retinal disease."

She awaits with interest the findings of a new trial at three units in the States which starts

next year and is funded by the National Institutes of Health. It is planned to compare the operated-upon foetuses with controls three years after the procedure.

Miss Bannister, who retired in January, has worked with patients from Barrow to Macclesfield, and from Bolton to the edges of East Yorkshire. She continues with clinics in the foetal management unit at St Mary's Hospital, Manchester, under an honorary contract with her former employers.

In 1999, Miss Bannister received an OBE for services to neurosurgery and this year was awarded an honorary doctorate by the University of Manchester Institute of Science and Technology for her research and teaching.

She says she has contributed



in a major way to furthering understanding of how congenital anomalies affect the growth and development of the brain and spinal cord.

Over the years she has had the opportunity to visit neurosurgical units in many different countries throughout Europe, North America and the Far East.

Recently, through the British Council, she helped set up a campaign to introduce folic acid to the diet of women of child-bearing age at Bombay's Wadia Children's Hospital. The aim was to try to reduce the very high incidence of children conceived with spina bifida in the area.

Cash awards for youth workers

PEOPLE working with children who would like to travel at home or abroad to enlarge their experience in 2002 are invited to apply now for cash help.

Awards, of up to £1,000, are being offered by the Lady Allen of Hurtwood Memorial Trust, a registered charity.

Applications are particularly welcomed from those working with disadvantaged or disabled children. However, awards are not available for academic research.

The closing date for applications is **15 January 2002** with short-listing in February and awards presented in March.

Contact: Mrs Caroline Richards, 89 Thurleigh Road, London SW12 8TY.

Helping your child become more independent

Independence means different things to different people. If your child has bowel or bladder control problems, it could just mean **getting through the day or night** dry. That's why something as simple as a change in clothing may, even in a small way, change his life for the better.

DryNites® absorbent pants can help your child become more independent. DryNites offer discreet protection against accidents, so your child will be able to do more. They **look like real underwear** so they

won't mind wearing them, and because they're easy to pull on and off, they may also make your child feel more **comfortable and self-reliant**.

DryNites can be purchased from all major supermarkets and chemists, found in the nappies and pants section. They are available in sizes for children aged 4-7 years and 7-10+ years old.

For information about how DryNites absorbent pants can help, please call
0800 085 8189.

DryNites for Better Days

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'Tough times' but we will overcome them!

ASBAH is going through lean times financially. But we have systems in place, and a newly-agreed five-year strategy, which will help us through to better times.

That was the general view at our annual meeting in September, after chairman Peter Cottingham warned: "Times are tough. ASBAH is under pressure."

Like other charities of our size and type, we were being squeezed because fewer people were giving money to charity. By contrast, the charities which were making more money spent millions on their marketing.

Mr Cottingham urged members at one of the best attended annual meetings in recent years to come together to boost ASBAH's fundraising capacity.

"The quality of professionalism we are building here is up there with some of the best. Major changes won't happen overnight but I am increasingly confident that, with the professional approach which is being adopted, we will get there."

He urged local ASBAHs to work in partnership with national to grow our fundraising.

"We must make sure that, if there is a real opportunity for fundraising, we grab it. We must make sure that, if there is a local opportunity for fundraising, we grab that too."

The hon treasurer, Mike Allen, said ASBAH ran up a deficit of £161,000 last year, in the year we had to close our computer company because it had no realistic prospect of turning in profits.

The trustees had decided that, as a precaution, reserves should be built up to six months operating costs in the bank. At the moment, they stood at £543,000 – half the required amount. A surplus budget had been set for this year, and some hard decisions were being taken to achieve it.

ASBAH was investing in new fundraising tools, and using external consultants to sharpen our work in this area, said Linda Hams, assistant director (policy and marketing). But new income from the investment was not expected until next year.



STRIDE OUT: the picture on the front cover of our Annual Review

'Huge task' ahead for the commission

WILLIAM BEE set ASBAH's 35-year work for our service-users in the wider context of the struggle for rights and justice for disabled people nationwide.

Mr Bee, whose parents helped set up North Wales ASBAH 31 years ago, is the Wales director of the Disability Rights Commission.

He said the commission started work in April last year – on 'a huge task' to pull down barriers to participation in society, which are found everywhere. It had set out its priorities and was delivering these.

"We have in place just 30 staff and 30 secondees. That means that the first 18 months have been a bungee jump of a ride. We are still recruiting, still sorting out staffing and procedures. Nevertheless, we are getting there," he said.

Mr Bee said the limit placed by the 1995 Disability Discrimination Act on taking up employment cases involving firms with less than 15 employees meant, for instance, that 82% of businesses in Wales were outside the scope of the Act.

The commission does go to court to challenge the worst cases of discrimination, when conciliation had failed. But, this year, it had funds to prosecute only 75 cases.

Software problems 'need to be sorted'

TEENAGERS with hydrocephalus who use laptop computers can struggle with subjects like maths and technical drawing because the school has not considered what software packages are likely to be needed.

Classroom assistants attending a one-day ASBAH course in Belfast identified lack of IT support as a major problem for secondary school pupils with hydrocephalus.

Some said they had to take notes for teenagers in their charge – either because the pupil lacked keyboard skills or



● **LAPTOPS:** Children need better computer support in school

because word processing was the only software package available.

Solutions would be for pupils with spina bifida and/or hydrocephalus to learn keyboard skills while their computers are still on order. At the same time, special educational needs co-ordinators (SENCOs) must recognise, early on, that additional software for maths and other subjects is a necessity.

Veronica Buckland, ASBAH's specialist adviser (education) in Northern Ireland, who helped run the course, told *Link* that a wait for software of up to two terms – the current waiting time – was simply not good enough for 15-year-olds in their first GCSE year.

Veronica said: "It's unfortunate that these software packages aren't thought of when the school decides to order a laptop. I don't think it's a lack of money but a lack of planning.

"Parents aren't going to take issue with the school over this. They are so pleased to have got their child into mainstream that they don't want to upset the apple cart."

Should our kids be learning less?

SECONDARY pupils with hydrocephalus would be



among those to benefit from new moves allowing 12-year-olds to drop subjects such as humanities and languages in favour of ones they like.

ASBAH's education advisers believe the proposal would prevent some pupils with hydrocephalus becoming disillusioned with education due to them having more subjects than they can cope with.

Joanne Grenfell (*above*), who works in ASBAH's Northern Region, said: "For a lot of our youngsters with hydrocephalus, it would be beneficial if they had the choice of reducing the academic workload as it would let them concentrate on subjects that they can succeed in."

Ministers at the Department for Education and Skills have often identified the early years of secondary school as a crucial period in combating disaffection. A DFES spokesman told *The Times Educational Supplement* that it will consider applications from 'good' schools wanting to alter the curriculum in a bid to re-engage children.

In Wales, a review will consider whether pupils should be able to opt out of the curriculum.

New group for Essex women

WOMEN with learning difficulties in NE Essex are being invited to join a new group that aims to give support on a range of issues like independent living, family life, health and expressing feelings.

Gillian Clayton, who has spina bifida and hydrocephalus, masterminded the project. She has won a grant of more than £1,300 from the Millennium Fund to set up and run it.

● Gillian, 41 Kinlett Close, Highwoods, Colchester CO4 4UE.



Liz keeps us in their minds

MAKING more money flow into our work in Wales is the job of Elizabeth Jones, our new fundraiser in the Principality.

Merthyr-born and a graduate of Aberystwyth University, Liz has joined our Wales team – keen that her skills should have an immediate impact.

“I’ve worked in the voluntary sector for over 20 years, and I wanted a job where I could specialise in fundraising.

“I moved back to Wales from London, to



be nearer family but also to enjoy the countryside.”

Liz is married with two daughters. Her last big job was with a housing association in London where she ran new projects and secured their funding.

At ASBAH, she will ensure that major funders in Wales keep us in their sights.

Bowled over by love!

LOVE blossomed after two Welsh carpet bowls squad members met at a sporting event.

Eleri Edwards (31) tied the knot at a chapel in Wrexham with fellow team member, Colin Freeman, after arriving in style in a white Rolls Royce.

Eleri, from Llay, near Wrexham, has been an active fundraiser for North Wales ASBAH for a several years. Her parents, Mari and Trefor Edwards, are both on North Wales ASBAH’s Executive Committee.

Guests included Elin Ifan, manager for

ASBAH in Wales and ASBAH area adviser Peter Bennett.

After a reception at the Wild Pheasant Hotel, Llangollen, the couple honeymooned in the West Country.

We wish Eleri and Colin many years of happiness together.

Before cricket, a family affair!

FOUR generations marked the 70th birthday of a retired ASBAH Adviser who has spina bifida and hydrocephalus.

Margaret Holmes, former Adviser for Bromley, Bexley and Croydon, was joined by her two sons, two granddaughters and four great grandchildren to ride on the London Eye.

Mrs Holmes hails from Bradford, West Yorkshire, then lived in

Bromley for more than 20 years and has been a member of South Thames ASBAH since moving to Dartford.

Next month (December), she and her partner Geoff return to an old love – club cricket. They will be touring in India with the Romany Cricket Club – as scorer and umpire respectively.





Father re-issues a moving biography

SEIZE the chance to read *Angel in White Boots*, a biography inspired by the life of Angela Powell. It has come round again after the book fell out of print a few years ago.

It's a celebration of a young woman with spina bifida, who had it all. There's tragedy in the suicide shortly after her death of her husband, Hartley. The story is compellingly told by Angela's father, Eddie.

The book was first published in 1993, six years after Angela's death in her twenties. It has been reprinted by a small publisher, after BBC Radio Norfolk ran a 'Where's the book now?' item prompted by a listener a few months ago.

Eddie, a retired headteacher, said: "We found that, when Angi was born, there was nobody to turn to. I wrote the book to help parents in similar situations so that they, in turn, could help each other."

Eddie and his wife, Mary (*above*), now run a guest house at West Runton next to the popular resort of Sheringham on the north Norfolk coast. Eddie keeps busy with a Christian ministry in the area.

Their daughter, Angela, is celebrated in a warts 'n' all book, which – though an emotional roller-coaster of a read – is surprisingly unsentimental and not at all self-pitying. There is lots of local, Norfolk colour.

● *Angel in White Boots*, by Eddie Powell, published by The Larks Press, price £5.99. ISBN 0 9522271 0 X.



Green hopes!

HARDLY a night goes by without Ewart Evans playing bowls – a sport that has become an abiding passion.

The 26-year-old, who has spina bifida and arrested hydrocephalus, takes his place alongside senior international players in Irish league games. He wants one day wear the 'green shirt' for Ireland.

Ewart, from Randalstown (*right*), rapidly moved up the ranks of his local club after joining eight years ago and now plays lead or second in a top Irish league, on a rink skippered by a senior international.

His dad, Eddie, a national ASBAH trustee and committee member of Northern Ireland ASBAH, told *Link*: "To be able to play alongside players of such talent is a great achievement for Ewart."

As well as winning club competitions, Ewart has travelled with the club to Scotland and the Irish Cup Games in Dublin.

In winter, Ewart keeps his hand in by playing short mat carpet bowls and indoor stadium bowls at the County Antrim Indoor Bowling Club.

When the world tournament is hosted in the county, Ewart has a great time talking to many of world's top players and collecting their shirts.



She made the grades!

SIXTEEN-year-old Joanna Clyne was celebrating her exam results even before her GCSE grades had been released.

She gained a distinction for a GNVQ in Business Studies – worth four GCSEs – for which she had to give interviews and presentations.

"The main thing about doing well at the course was trying to get myself organised. At one point, I had four assignments on the go so I had to be able to plan and keep to targets."

She is now taking the advanced level of the course in the sixth form at King David High School in Manchester.

She enjoys using her computer and singing with a group in Bury.



Mrs Susan Seager

SUSAN Seager, described as a tower of strength to all who met her, has sadly passed away.

A member of North Yorkshire ASBAH, Mrs Seager was born in 1942, attending the Adela Shaw Orthopaedic Hospital in Kirkbymoorside, near York.

Her school years were spent at Welburn Hall, Kirkbymoorside, where she met her future husband, John, who had had polio at early age.

The couple, both wheelchair-users, had a daughter, Anna, who is now a radiographer.

Mrs Seager, who lived with John in Pickering, had a wide circle of friends including many

from Welburn Hall School and was often involved in 'old student' activities.

Long-standing friend, Faith Seward MBE, secretary of North Yorkshire ASBAH, commented: "Sue had a lovely sense of humour, I remember her once saying to me that she did not know how she would manage without her teeth as she used them for holding so many things.

"She will be sadly missed, but her spirit will live on with all the many friends she had."

A well-attended funeral service took place at Raskelf, near Pickering, where the Seager family came from.

Golden girl in her own write

AN UPLIFTING story of the rise of a child with spina bifida to a world-class athlete and media celebrity, is revealed in a new autobiography by Tanni Grey-Thompson OBE.

Mum-to-be Tanni (32) is Britain's best known Paralympic athlete, having performed at international level for the past 13 years in distances ranging from 100m to the marathon.

Thirteen Paralympic medals, nine medal placings in the London marathon, and her comprehensive set of British and World Records make the Cardiff born athlete's achievements second to none in the disability sports arena.

This year has seen her receive the ultimate accolade – admission to the World's Sports Academy, alongside sporting

legends Pele, Jack Nicklaus, Michael Jordan and Boris Becker. She is the only disabled athlete among the 42 members.

● *Seize The Day, My Autobiography* by Tanni Grey-Thompson is published by Hodder & Stoughton, price £17.99.



Susan Coleman

A COMMITTEE member of Sheffield ASBAH died in August. Susan Coleman, who was also involved in other disability organisations, had been ill for a few months and died two days before her 44th birthday.

Sheffield ASBAH chair, Celia Nicholson, told *Link*: "Susan will be sadly missed for her cheerful spirit and persevering attitude, especially during times of ill health."

Stanley Fitzgerald

STANLEY Fitzgerald, son of Southampton ASBAH secretary Stanley Fitzgerald senior, died on 11 October, aged 41 – two days before Southampton's ChairAbility Challenge wheelchair basketball match with local MPs. Treasurer Cora Bugden took over the event instead.

Young Stanley had spina bifida. The funeral took place on 19 October.

Motoring made easier

MAKE the most of the beautiful Shropshire countryside with a new booklet giving details of accessible amenities.

Scenic Drives in Shropshire, priced £1.75 including p&p, is the latest project of the Mobility Information Service.

The Mobility Information Service has been giving advice to people on a range of mobility issues for 15 years.

It has recently moved to: Unit B1 Greenwood Court, Cartmel Drive, Shrewsbury SY1 3TB, tel: 01743-463072 (10am-4pm).

link.forum

WE ARE starting a new service for *Link* readers.

In each issue, readers will be invited to suggest solutions to a problem such as the one posed below and to offer advice, preferably based on their own experiences.

Contributions must arrive by **14 November 2001** for the next issue. Readers may also

submit their own problems. You can contact link.forum by email:

lizc@asbah.org

or by post to:

**Link.forum, ASBAH,
42 Park Road,
Peterborough
PE1 2UQ.**

Here's one problem to get on with – your comments and other questions to discuss will be welcome

I can't get my daughter up for college in the morning because she's been watching TV all night. She's 20 and has hydrocephalus. What should I do?

Jobs service

PEOPLE on disability benefits who want to work can call a freephone number to find out about the support and advice available in their area.

The New Deal for Disabled People now offers nationwide job-broking services to help people on disability benefits explore their work options.

Just phone the free number and you will be given information about a local 'job broker' offering dedicated advice and support.

Minister for Work, Nick Brown, said: "The organisations delivering the service have great experience of the skills and needs of people with disabilities. They will ensure that this section of the labour force is not overlooked."

**Freephone: 0800-137 177;
the lines are open 7am–
11pm, seven days a week.**

MP shadows are on!

AN ANNUAL event when disabled people spend a day with their local MP is on again – after doubts whether the organisers would repeat it.

The shadowing event is being organised in November and December by the disability umbrella group, RADAR, which has just been restructured. Their director, Kate Nash, cleared away the doubts on 8 October.

She said: "In 1999, 20 MPs agreed to be shadowed and last year we were astounded when the number rose to 100 MPs, including 10 ministers. The feedback from the initiative was positive and constructive and to this end we have decided to continue the service this year."

Kate said she was hoping to encourage younger disabled people to get involved. She was looking out for people not normally involved in campaigning as well as disabled people

whose impairment meant they were often socially excluded.

Instead of focusing effort on one day in December, as in the past, the event this year will last two months to widen the choice of available days.

People can nominate themselves. Contact should be made with RADAR's parliamentary officer, Juliet Tunney, tel: 0207 566 0126, ext 200, or by email: juliet.tunney@radar.org.uk

ASBAH has details of eight members who have already said they would like to take part. We have written to RADAR on behalf of these people.

These members are Hannah Sandford (Lewes), Mike Lanning (Christchurch, Dorset), Lyndon Fishwick (Telford), Neil Lewis (Sheffield), John Richards (Milton Keynes), Sarah Healey (Brighton), Zem Rodaway (Hull) and Maxine Kruk (York).

Inner Wheel

AN ANTIQUES roadshow was among the money-spinning events held by a group of business women that raised £1,505 for ASBAH.

We are grateful to retired magistrate Judith Turner for choosing ASBAH as her charity of the year while she was president of the Inner Wheel Club of Durham.

Mrs Turner, of Fishburn, Co Durham, hopes to raise money for us again as her son has spina bifida. Now 40, Christopher has reached a senior position in his company and is married with a daughter.

ASBAH's fundraising manager, Donna Treanor, is to attend a meeting of the Inner Wheel Club of Durham to personally thank members.

Best feet first in the Lakes

HUNDREDS of insurance company employees put their best foot forward in the Lake District to raise £35,000 for charity.

ASBAH's work supporting 100 service-users in Cumbria benefited from a donation of £444.

ASBAH adviser for Cumbria, Moira Foggo, went to a cheque presentation at Marsh UK's Carlisle office with other charity representatives.



All out of breath – but in a great cause

IT SEEMED to be uphill all the way for eight runners who joined 47,000 others in a major athletics event, officially started by Paralympic gold medalist Tanni Grey-Thompson OBE.

But most succeeded in their intention of completing the 13-mile BUPA Great North Run, from Newcastle-Upon-Tyne to the coast at South Shields, and raising sizable sums of money for ASBAH.

Perfect weather on 16 September combined with a large, enthusiastic crowd helped spur them on their way to a medal and other small prizes at the finish line.

Our runners included:

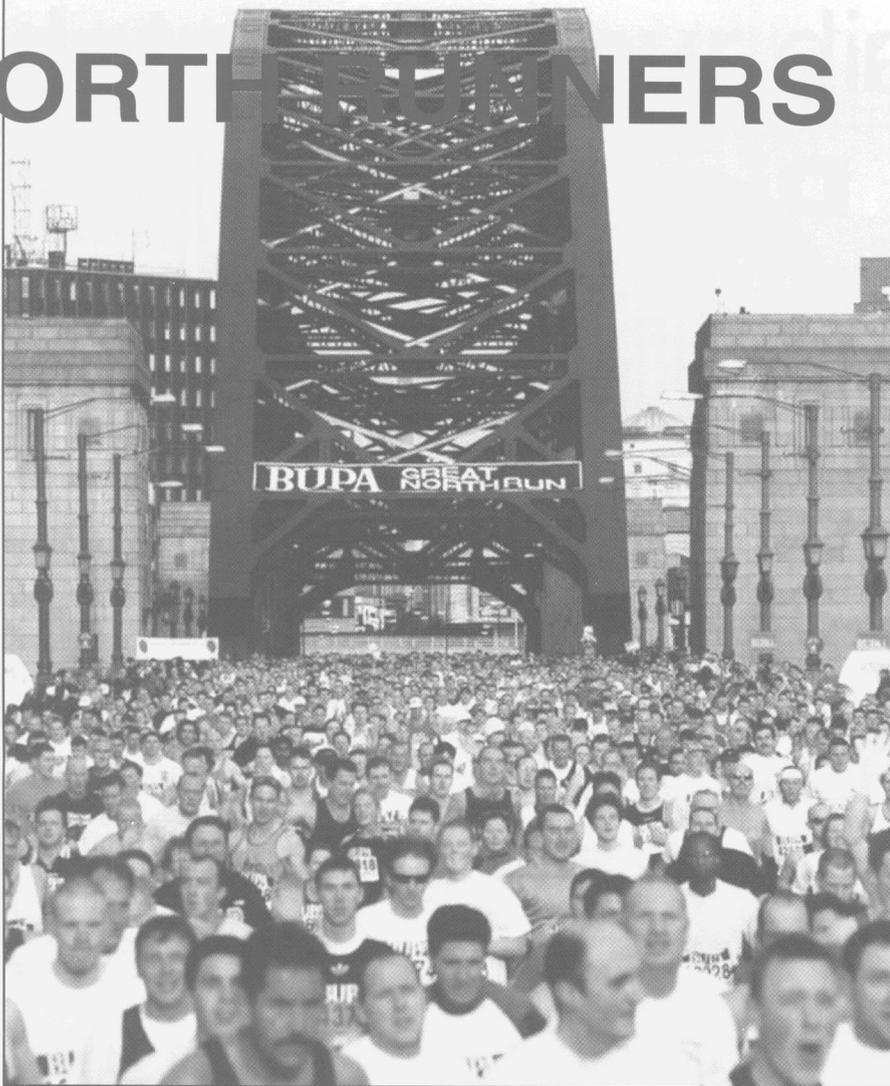
- Brothers Terry and George Sixsmith (*pictured right*), both first-timers, pounded the course side by side, finishing in two hours 32 minutes.

Terry (34), from Cramlington,

Northumberland, has a six-year-old son Blue who has been helped by our adviser Anne Walton. A plan to push Blue round the course was thwarted due to the large number runners taking part. But this didn't hamper Terry's enjoyment of the day



NORTH RUNNERS



● *Runners cross the Tyne bridge during the Great North Run*

nor the £250 he raised for us.

● Lisa Smith (32) completed in two hours 18 minutes and raised £600 for us. She ran alongside Northallerton neighbours Ruth Moffatt and Ruth's mum Christine, also in ASBAH colours.

All three are pictured above left behind Lisa's son, Will (5), who has spina bifida.

"Ruth started running before I did. She made me think that it was about time I got off my backside to do something to help ASBAH," said Lisa, a civilian working in the security department at Northallerton Prison.

● Another first-timer, Lesley Ellison (33) said the initial idea of completing 13.1 miles was

enough to send her looking for the nearest dark room.

But, Lesley, whose nine-year-old son has spina bifida occulta, had an excellent training partner in her husband Derek, and as she crossed the finishing line her smile stretched from ear to ear.

● Manchester University medical student, Laura Wood, and her boyfriend, John Paul Reay, attracted the attention of BBC TV, dressed up in hospital scrubs and shook a bucket for ASBAH as they ran.

John's mother has spina bifida and lent them her support during the race. They have sent us a cheque for £106.

● Finally, Christine Arnold (49), from Ellington, near Morpeth, raised £250.

Our man Money penny

WE HOPE the latest addition to our Northern Ireland team will more than live up to his name.

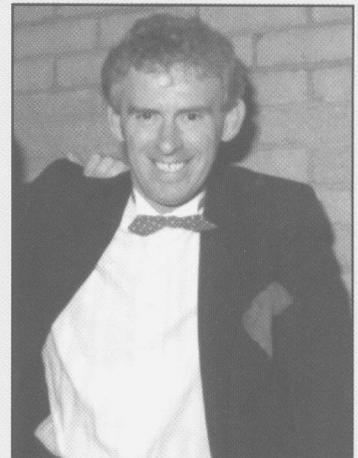
Alan Money penny, a business consultant from Belfast, has a wealth of experience and a thorough knowledge of the province.

Life changed for the senior civil servant after completing a business management course at the University of Virginia, USA, 12 years ago.

Alan (*below*) has since taken the lead in projects in which fundraising has played a big part.

He saw through the Millennium Spectrum Centre in Belfast's Shanklin Road.

He has also worked for



the National Council for the Blind of Ireland and Guide Dogs for the Blind.

He said: "At ASBAH, I'll be trying to identify opportunities, and consolidate those that have already been identified, to provide a sound income base for the Region."

THERE has been a flurry of legislative activity resulting in significant amendments to special educational needs law. For the first time, disabled children and students have the right not to be discriminated against in schools and colleges.

The Special Educational Needs and Disability Act 2001 came into force in September with the amendment of Part 4 of the Education Act 1996, which governs provision for children with special educational needs.

Parents now have more rights to choose a mainstream school for their disabled child. The only grounds upon which a local educational authority (LEA) can refuse to place a disabled child in a mainstream school is where it would be incompatible with the provision of efficient education for other children. LEAs also have new duties to prevent that incompatibility occurring.

Changes this year also see the introduction of new LEA conciliation services; greater information for parents on parent partnership services; new time-limits for LEAs to comply with orders of the SEN Tribunal; simplified arrangements within tribunal proceedings; new rights for parents to require that statements of special educational needs be maintained (when LEAs have determined to cease them) pending appeals to the SEN Tribunal; greater rights of information to parents about provision being made for their children and new rights for schools to request statutory assessments.

The Special Educational

Discrimination dumped in the school sinbin

Needs Tribunal Regulations 2001 make key changes to existing regulations, including giving the child concerned a right to attend a hearing and reducing the number of stages in the tribunal procedure from three to two.

The Disability Discrimination Act 1995 has also been extended to cover discrimination against disabled pupils and students.

From September 2002, disabled children will have a

progressively increase the extent to which disabled pupils can participate in a school's curriculum, improve the physical environment and improve the delivery of education to disabled pupils.

Complaints about discrimination in schools (except for admissions and permanent exclusions) will be brought to the new SEN and Disability Tribunal which replaces the Special Educational Needs Tribunal from September 2002.

By **DAVID RUEBAIN**
Solicitor and Head of the
Education and Disability Law Dept
of Levenes Solicitors



right not to be discriminated against in admissions, exclusions and in the provision of education at school. Moreover, disabled children will have a right to require schools and LEAs to remove barriers, which would otherwise put disabled children at a substantial disadvantage. Barriers might include changing policies, practices and procedures but will not include adjustments to premises (dealt with by the Schools Access Initiative), nor will they deal with provision of auxiliary aids or services (covered by the assessment and statement procedure).

LEAs and schools will also be required to develop accessibility strategies to show how they will

Although the new tribunal will not award compensation, it could order schools or LEAs to provide training and guidance for staff, involve an LEA equal opportunities officer, change policies, practices and procedures, provide a replacement trip or additional tuition for a disabled child who has missed out on a school experience, order the relocation of a school library to make it accessible (short of requiring physical adaptations), or order a written apology.

Admissions and permanent exclusions from schools will primarily be dealt with by the existing Independent Appeals Panels.

dates for your diary

Welcome awaits at Leeds drop-ins

DROP-INS for ASBAH service-users in the North continue until December and beyond.

The regular fixture at our Northern Region Office, Farsley, Leeds, occurs on the first Wednesday of the month – 7 November and 5 December.

ASBAH's new researcher, Sue Thompson – who is gathering service-users' views on the NHS and Social Services – is the guest speaker in November.

Topics discussed depend on who is present. ASBAH local adviser, Bernadette Baldwin, is usually there, and appointments can be made to see her on that day.

ASBAH regional manager, Joan Pheasant, said: "For some people, the drop-ins allow regular contact with ASBAH, which gives them support that we would be unable to give otherwise."

Tell us your plans

AS THE New Year approaches, we would like to hear from all of you who plan to hold regular meetings, or one-off events, for people with SB/H and/or their families in 2002.

Please send the dates, times, venues and titles of these events to: **Diary Dates, Link, ASBAH, 42 Park Road, Peterborough PE1 2UQ, lizc@asbah.org**

To fall in with *Link's* printing schedules, please ensure we receive these details at least six weeks before the first event is due to take place. Cheers!

Upcoming events

Northern Region monthly drop-in

Wed 7 November, Leeds
ASBAH House North
64 Bagley Lane, Farsley,
Leeds. 10–noon. *Tel: 0113-255 6767.*

Dunstable meeting

Monday 12 November,
Monthly meeting for parents/
carers of children/young people
with SB/H, organised by the
South Bedfordshire Support
Group. 1–3pm, Disability
Resource Centre, Poynters
Road, Dunstable. *Valerie
Bottoms, tel: 01582-757745.*

Bromley coffee

Mon 12 November, Bromley
Coffee morning organised by
South Thames ASBAH,
10–noon, United Reform
Church, Bromley. *Peter
Winterton, tel: 0208-462 3011.*

ASBAH Open day

Wed 14 November, Liverpool
Sessions on hydrocephalus,
helping strategies, support into
adulthood and neurosurgery.
Glaxo Neurological Centre,
Liverpool, 10am–3pm.
*Elizabeth Miers tel: 01490-
450360, Angela Lansley,
tel: 0151- 733 8392.*

Reach for the Sky!

17 November, Peterborough
One-day course on improving
communication skills and
personal goal setting for adults
aged 16 and over with SB/H.
*Lyn Rylance, tel: 01733-
555988, lynr@asbah.org*
**Closing date for
applications: 9 November.**

ASBAH Saturday Club

Saturday 1 December, Leeds
Leeds and Bradford, ASBAH
House North, 64 Bagley Lane,
Farsley, 10am-1pm. Christmas
crafts/computer cards. Cost £1.

Northern Region monthly drop-in

Wed 5 December, Leeds
ASBAH House North
64 Bagley Lane, Farsley,
Leeds. 10–noon. *Tel: 0113-255
6767.*

Bromley coffee

Monday 10 December
Organised by South Thames
ASBAH, 10–noon, United
Reform Church, Bromley. *Peter
Winterton, tel: 0208-462 3011.*

Year 2002

Family Weekend

8 – 10 March, Cornwall
ASBAH three-day residential
course for families who have a
child aged 6 and under with
SB/H, their brothers and sis-
ters. £65 per family. *Rosemary
Batchelor tel: 01733-555988,
rosemaryb@asbah.org*

DAVE'S DIARY

David.Fulford-Brown@ntlworld.com
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I'D LIKE to start this Diary with some good news. After a most romantic proposal, my younger brother, Nick, is engaged to the lovely Hannah.

The idea of getting married has clearly melted his brain because he announced that he wants both myself and elder brother Anthony to be joint best men. That same week Anthony quit his job and left on the start of a world tour! I am certain the two events are unconnected, but this rather dumps everything in my lap. Cheers Ant!

I understand that Hannah's family will be doing most of the organising, which is a relief as planning stuff is not my strong point. I think the family was a bit surprised at 'Last Minute Dave' being given such an important job. Especially after my first suggestions which were to either get a quick registry job then down the pub for a pie and pint, or to do what Anthony's friend just did: go to Las Vegas and get married dressed as someone famous. Both suggestions were met unsurprisingly with stony silence.

If I ever get married I'd definitely suggest the Las Vegas trip. As a life-long Trekker I

think the 'Trek Wedding' option is a definite must. Though I've never actually dressed up in Trek uniform. Or been to any conventions. I just like the series, books, films, computer games, plays, etc.

For lots of reasons, life in the Trek universe would be so much better right now than in this one. Yes, you'd have pointy eared aliens trying to blow you out of space. But at least I wouldn't have to work every hour I live just to get pieces of paper to give to other workers.

I was slaving away at work when I heard about the attacks in America. From what I first heard I thought some small plane had collided with a tower. The full scale of the tragedy only hit me when I got home and watched the TV. My heart goes out to anyone reading this who lost friends or relatives in the tragedy.

You could paper over the moon with everything that has been written about the tragedy. I'll not add to that. My thoughts now are on what happens next. As I write, I hear military planes flying through the night. By the time you read this

we will all know what they were for.

Those who did this terrible thing must be punished. But getting at them will be hard work. Sadly we don't live in the Trek universe, so we can't just stun the Afghan people and beam up the Bad Guys. There's going to be a fight and more people are going to get killed or hurt on both sides. 'Surgical' strikes just keep surgeons busy. Perhaps if the warriors understood what it feels like to have a disability for life, they would not be so keen to fight. We can but hope.

One small hope and prayer: *That whatever caused Gulf War Syndrome is not brought to this battle.* After that war there were more babies with spina bifida than usual amongst the armed forces (and presumably amongst the enemy). I pray this doesn't happen again. War is unfair, but to harm those who weren't even born seems most unjust.

Whatever is to come I wish everyone reading this peace and hope. Now please beam me up!

Pen pals

Write to Editor,
ASBAH,
42 Park Road,
Peterborough PE1
2UQ, UK. email:
lizc@asbah.org

Hi, my name is Sharon Laurie and I have spina bifida. I'm 34 and have a 12-year-old daughter.

My husband's name is Bruce and we have been married for 13 years. When we decided to get married, I couldn't find anybody with spina bifida who had a child, so we decided to take the chance.

Janice was born in May 1989. Not only was she born without a disability, but I had a 'normal' delivery.

My main interest is sport. I broke seven South Africa records in 1996 and bettered six of them in 1997.

I did wheelchair racing over distances of 100m – 42km. In 1999, I won the title Disabled Woman of the Year through *Finesse* magazine.

I work at East Rand Christian Academy as a teacher.

Please write to me at: 18 Dawid Street, Witfield, Boksburg 1459, South Africa. Email: sl0202@hotmail.com

Research does not endanger the living

I HAVE a natural sympathy for Chris Page but I do feel he has misled himself. In his letter in *Link* 192 he said: "How on earth are we to promote acceptance of living with (spina bifida and/or hydrocephalus) whilst focusing on primary prevention. The two concepts are diametrically opposed."

The implication is that cancer research, for example, should concentrate solely on the care and treatment of victims, because to look for causes in some way devalues those suffering from it and makes them an 'endangered species' (*Link* 195). Would the same apply to the care of victims in road accidents at a 'black spot?' Don't improve the junction or those injured will be devalued in some way?

Of course, this is reducing the argument to absurdity, but where would Chris draw the line?

I have a fundamental belief that none of us have to bear burdens in life which are too great for us to carry, and that we are to learn from our (often catastrophic) experiences. But I am equally sure we should avoid or overcome disasters wherever we can. But we are not to do this by exterminating victims!

We cannot foresee the future and we need to be alert. But as of now, Chris, such research does not in any way endanger those now living. Nor does it prevent the charity from caring for and improving the lives of those carrying the burden. The two are not at all opposed in terms of the beneficial objects of charity.

I wish you well!

Frank Armour, Horsham, West Sussex

Minority

I AGREE wholeheartedly with the views expressed by Chris Page on the subject of the cheek-swab test (*Link* 195).

Disabled people are not supposed to be like other minorities – instead of regarding our difference as a part of our identity, it seems we are supposed to regard it as something nasty which we can't get rid of, even though we are desperate to do so. Is this really the best way to be?

I'd say that most of my problems come from having to cope in a world built by and for able-bodied people. Also, steps to eradicate disability are likely to harm existing disabled people – why should society accommodate them when disability can be got rid of so easily, by either abortion or genetic manipulation?

Emmeline Burdett, Enfield

Inclusion not alienation

MAY we draw the attention of Chris Page (*So much for democracy, eh? Link* 195 and *Guard the future, Link* 192) to our own letter, *No fears about cheek swab test, Link* 194, in which we gave our views about a project looking into genetic aspects of spina bifida.

We said we were very excited at the prospect of finding out more about spina bifida, so were pleased to take part in the swab tests.

Research which seeks to understand the factors leading to neural tube defects seems to us wholly acceptable and we see no problem in ASBAH supporting such projects.

We also take issue with Mr Page over the conflict he sees between ASBAH promoting independence for people with disabilities on the one hand, and providing accurate information about folic acid, spina bifida and hydrocephalus, on the other, to allow informed choice to parents during pregnancy.

We have relatively mild forms of spina bifida and 'arrested' hydrocephalus, leading a very full and interesting married life. However, we would not wish to have a child with these conditions knowing the restrictions they place on the child and parents. It seems natural for any couple to want a baby free of disabilities.

Mr Page rightly demands inclusion of disabled people in society. However, he needs to be careful not to alienate those we need to help us to achieve our common goals.

Alan & Margaret Twyford, Tolworth, Surrey

● Alan and Margaret are active in their local ASBAH and take an interest in *Your Voice*. Alan is a member of ASBAH's Trustee Board and Services Committee.

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 Julie Parks, tel: 01273-472298.*

BERWICK COTTAGE, EAST HARLING, SOUTH NORFOLK (CATEGORY 1)

Modern, purpose-built, self-catering cottage. Ground floor accommoda-

tion for up to 2 people (single beds) with disabilities. Scan 700 beds: Clos-o-Mat; overhead track hoist bedroom-to-bathroom, wheelchair shower and much more. Up to 4 carers/family/friends upstairs. Awarded Grade 1, Holiday Care. Open all year. Low rates Winter/Spring (£250 to £350 per week) – full centrally heated. Helpful caretakers demonstrate equipment, but otherwise total privacy in pretty village with accessible pub, GP, shops. *Cottage brochure, Lin Berwick, (tel: 01787-882111). Booking forms and full information, George Tickner, The Lin Berwick Trust, (registered charity), 020-8595 7056.*

ISLE OF WIGHT ASBAH

Fully furnished and equipped, two-bedroom bungalow. Beautiful area. Wheelchair accessible. Site clubhouse, shop. Local indoor heated pool. Transport advisable. Excellent rates: Offers early/late season. *Details: Mrs S Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF, tel: 01983-863658, www.iwasbah.co.uk*

ORLANDO, FLORIDA

Purpose-built vacation homes for the disabled of all ages. 3, 4 & 5 bedroom luxury villas. All villas are wheelchair accessible, with roll-in showers and hydraulic lifts for access to the private pool. Situated 20 minutes from Disney and close to all amenities. Wheelchair accessible transport available. *For further information, contact David & Elaine Foley, tel: 0191-488 6845, email: david_foley@lineone.net www.floridadream.sagenet.co.uk*

ORLANDO, FLORIDA

House with a heart for disabled travellers! Spacious, luxury, adapted bungalow situated on golf course. Three double bedrooms, two bathrooms (Mangar bathlift installed), cable TV, free local telephone calls, free Country Club membership. 24-hour 'on-call' management company. 15 minutes Orlando Airport; 20 mins Disney. *Paraplegic owner. Sue Fisher, 5 Park Lane, Broughton Park, Salford M7 4HT, tel/fax: 0161-792 3029.*

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* (January) should be submitted by **Friday, 16 November.**

Please send to:
Editor, ASBAH
42 Park Road
Peterborough PE1 2UQ
Tel: 01733-555988.
lizc@asbah.org
- Display rates on application from Liz Cawthorne, *Link*, ASBAH, tel: 01733-555988.
lizc@asbah.org

WANTED/FOR SALE

WANTED 3-wheeler pedal bike adult size or smaller. *Phone: 0191-3860134 or rach@steveseymour.demon.co.uk*

ELECTRIC wheelchair 20-inch, almost new. Has been serviced plus new batteries. Well-padded upholstery. Kerb climber. Folds to fit into boot of car. Bargain £700. *Tel: 01493-377520 (Norfolk).*

SPECTRA electric wheelchair for child/teenager, VGC, battery & charger, cost £3,500. Offers. *Tel: 0115-952 7698 (Notts).*

SUPER Baltimore home therapy bed, larger than single, for child or adult, excellent condition, cost £2,000. Offers. *Tel: 0115-952 7698 (Notts).*

POWERTECH F45 in teal, as new. Used twice. Battery charger and manual. RH controls. Cost £3,000, sell for £1,100 ono. *Mrs Cross, tel: 01948-666774 (Whitchurch, Shropshire).*

SHOPRIDER Super Deluxe, hardly used, as new. Complete with batteries & charger, front basket. £1,200 ono. *Tel: 01226-384103 (Barnsley, S Yorks)*

SELF-PROPELLED PRO-T Action wheelchair, Avanti cushion, purple/black, seat 16" wide, excellent condition, hardly used. £350 ono. *Tel: 02920-319209 (Cardiff).*

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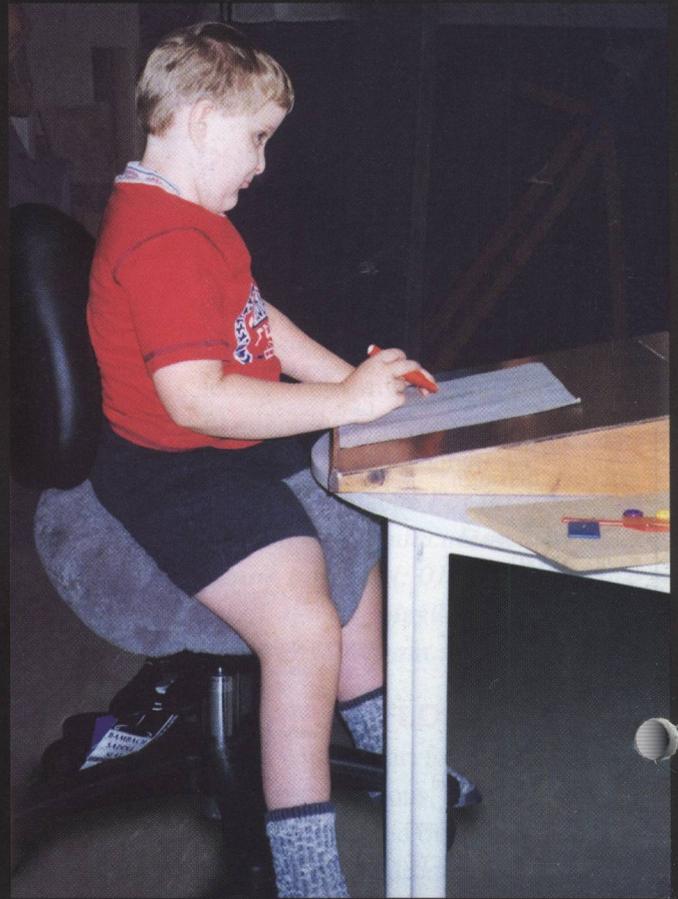
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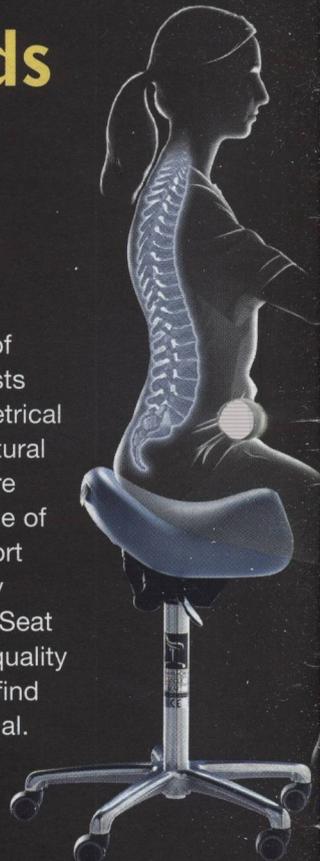
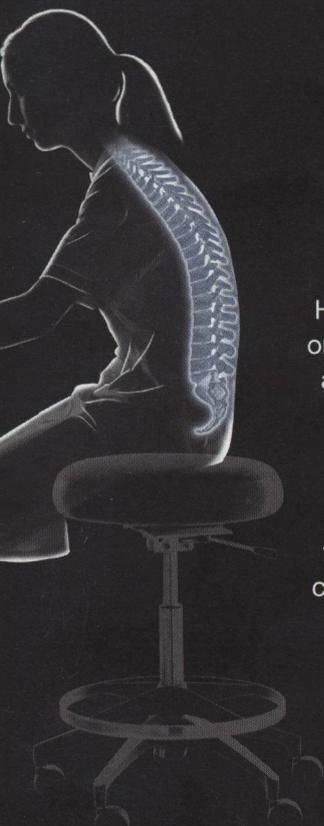


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