

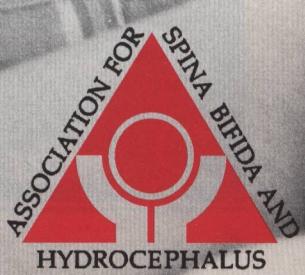
Link

The magazine for people with
Spina Bifida and/or Hydrocephalus



November/December 1999

Issue No 184 Price 80p





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Pre-natal surgery on TV

A MAJOR TV programme about spina bifida births was screened on BBC1 on 19 October.

The programme – in the *Living Proof* series put together by the QED team – looked at controversial work being carried out in the United States to close the spinal lesion before birth.

Cameras filmed an operation on a baby in the womb, carried out by Professor Joseph Bruner and Dr Noel Tulipan at the Vanderbilt Medical University in Nashville, Tennessee. Only 42 other women had tried it before but Kathy and Stephen Gunnells, from South Carolina, decided it should be used to help their child.

Contrast was made with a more familiar operation to close the lesion after birth – carried out in this country in August at Birmingham Children's Hospital. And a British family who have a 10-year-old son with spina bifida were also expected to appear.

Due to the hour, ASBAH's contact details did not appear on screen. They were available, however, on Ceefax, and there was a link to our website from BBC Online.

The prenatal surgery first came to note in the UK last November after a medical journal reported an 'in utero' operation in Philadelphia.

Our double cover stars!



Claire Kidson and two-and-a-half-year-old Cecilia who has spina bifida

GRACING the front of ASBAH's Annual Review 1998-99, and the front cover of this issue of *Link*, are two-and-a-half-year-old Cecilia Kidson and her mother Claire.

Devon-based Claire and husband Mark had been trying to have a baby for 10 years before undergoing successful IVF treatment.

With a history of spina bifida in Mark's family, Claire had been prescribed the daily high-dose of folic acid to help prevent her carry

a baby with the disability, but the preventative effect of the vitamin appears to have been reduced by the anti-convulsant drug she takes to treat her epilepsy.

Mark, a graphic artist, and Claire, an illustrator, are in regular touch with an ASBAH adviser and have attended one of our residential weekends where they have gained strength and support from establishing contact with other families.

Photo: Freemans Press Agency

If you saw the programme and have strong views, we'd like to hear them. Write to *Link* magazine,

ASBAH National Centre, 42 Park Road, Peterborough PE1 2UQ.
Email: lizc@asbah.demon.co.uk

Contents

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| | | | |
|-------------------------|------|--------------------------|-------|
| ▲ Staff news | 4 | ▲ Canal life for Chris | 12-13 |
| ▲ Andrew at his peak! | 5 | ▲ Suzanne Bull column | 15 |
| ▲ SHASBAH trolleys | 7 | ▲ Surrey gets active | 16-17 |
| ▲ Parking row in resort | 8 | ▲ Diary dates, bookshelf | 20 |
| ▲ Our annual meeting | 9&14 | ▲ Letters, small ads | 22-23 |

Cover: Cuddles all round – Claire Kidson and her two-and-a-half-year-old daughter, Cecilia, are also the cover stars of ASBAH's Annual Review 1998-99. Photo: Freemans Press Agency. Story this page.



And do it in style with ASBAH's personalised Christmas cards. 12 designs to choose from, with eight styles of greetings. Prices from £68 for 50. Phone ASBAH fundraising today, tel: 01733-555988, for your free brochure.

STAFF NEWS... STAFF NEWS...

PROJECT worker, Jill Bartlett, has been promoted to adviser.



Continuing as project worker for North Wales until three years of funding from Comic Relief runs out in March, Jill takes over Ynys Mon (Anglesey), Conwy and

Gwynedd from Elin Ifan.

As reported in the last *Link*, Elin has been promoted to manage our new Wales Region.

Jill's background is integrating children with special needs into mainstream schools.

Jill commented: "Wales is now well-covered. Elin will be a hard act to follow but, with her guidance, and the knowledge I already have of service-users in Mid Wales, we will be providing a good service."

Our staff in Wales are: Elin Ifan (manager), advisers Jill Bartlett, Peter Bennett, and Margaret Stanton, project worker Carolyn Jones, education adviser Bruce Graham.

The contact details of ASBAH's Wales Region had not been confirmed as this issue went to press, but inquiries can be sent by email to: elini@asbah.co.uk



ASBAH adviser Lucy Holmes has moved to Birmingham, following her husband Darrell's appointment as a Baptist minister in Balsall Heath.

But she will continue working for ASBAH until mid-January, following up referrals from her patch in London by phone and letter.

EASTERN Region secretary, Rebecca Sewell, has left ASBAH after six years to work at the Environment Agency.

Becky, as she was known to her colleagues, started as a fieldwork secretary and, in October 1994, she became secretary for the Eastern Region.

A highlight for her at ASBAH was the region's first Adventure Weekend at Irthingborough, Northants.

"This event enabled me, for the first time, to meet our client group and I learnt many valuable lessons over those couple of days and met lots of great people. I will never forget it," she said.

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John Naudé ties the knot

JOHN Naudé, who left ASBAH four years ago to become a clergyman, has remarried.

Our former mobility adviser who inspired many service-users to have greater self-esteem, be more assertive and the confidence to try new things, wed maths' Masters Belinda Neil in Kettering, where the Rev John is curate at Christ the King Church.



The couple share the Christian faith and Belinda was attracted by 37-year-old John's strengths.

Their honeymoon was spent touring the USA in a Convertible, starting and finishing in Colorado. A further five days were spent in New York State.

Belinda wants to train to be a teacher and plans for both of them include becoming missionaries in Africa. Belinda, aged 28, has done missionary work already in Zambia and India.

Showbiz farewells

Ex-radio Goon Sir Harry Secombe, who appeared at ASBAH's first-ever fundraising function held in London in 1966, has retired from showbiz. Secombe, who suffered a stroke earlier this year, was best known in recent years for his Sunday night TV programme *Highway*.

And millions watched as Patsy Palmer quit TV soap *EastEnders* in September. The soap put ASBAH on the map in 1997 when her character, Bianca, carried a baby with spina bifida and hydrocephalus. The storyline sparked huge coverage about the disabilities on TV, radio and in the press.

All change for our publications?

ASBAH's publications review is now in full swing, with a view to implementing improvements as soon as possible next year.

Over 200 replies have been received to a readership questionnaire which went out with all four publications between May and August this year.

The returns have been analysed and fed to a focus group, which was expected to have met in October.

The publications are all having their appearance, content, readership, satisfaction ratings and frequency of publication reviewed.

Andrew treks in the Himalayas

ASBAH executive director

Andrew Russell has acquired an entirely different outlook on life – from the rooftop of the world in the Himalayas.

Andrew joined an expedition to the Pindari glacier, 14,000 feet up in the shadow of India's highest mountain Nanda Kot, in October.

Before he went, Andrew said: "I've never done any mountaineering, so the trip will be very challenging."

The six-day expedition from Khali estate, 3,000 feet high in the foothills of Nanda Kot, to the moving ice

wall of the glacier some 60 miles away took place in mid-October.

He joined a party of 10 other people on the expedition, which was being put together by staff employed by Atkins plc, an international engineering and development company which has contracts in India and China.



The group was accompanied by a pack pony and several porters but, because they carried their own kit in rucksacks, didn't find the going that easy as they made their way up 11,000 feet in the rarefied atmosphere.

Andrew said: "A long-standing friend, Ian Mathieson, who works for Atkins, invited me to join them. I've never been to India, so the whole experience will be fascinating."

Andrew, who covered all his own expenses, mountaineered for ASBAH. Colleagues and friends were invited to sponsor him.

"We'll be mountaineering, rather than climbing, and will spend a day acclimatising to the altitude on arrival. Sailing is my usual sport so I shall have to do some hillwalking before I go to get in the best shape possible."

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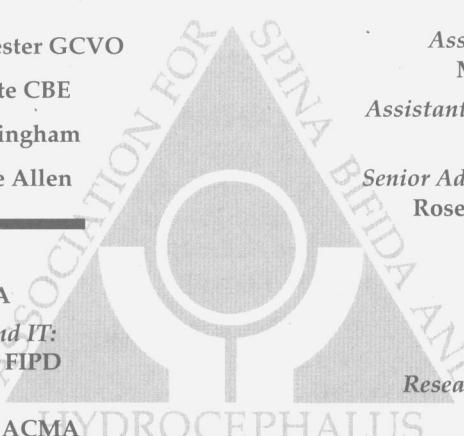
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Red tape delays grants to adapt homes

MANY people are missing out on Disabled Facilities Grants because a third of local housing and social services departments fail to publicise the service and almost half do not work closely enough together on its delivery.

The grants, one means of helping people remain comfortably in their own homes as they get more infirm, are meant to pay for facilities like ground-floor bathrooms, through-floor lifts and improved parking facilities.

But, according to a new survey by Age Concern and RADAR, red-tape tangles clog the system in many areas with too many applications delayed beyond six months, the maximum allowed by law, and

waiting times for non-urgent OT assessments taking up to two years.

Council tenants, who should get equal treatment under the law, were frequently told to move to other properties rather than receiving DFGs.

And even local authorities which operate priority systems for the grants sometimes did not tell applicants what those priorities were. So applicants had no idea how long they should expect to wait. This was a complaint which cropped up in almost one-third of council areas.

The survey report – *Disabled Facilities Grants: is the system working?* – was based on responses from local groups, individuals, councils and

home improvement agencies covering 89 local authority areas.

Age Concern and RADAR called on Government to set clear national performance standards covering provision of information, equitable treatment, target times, joint working between housing and social services departments, after-care, consultation, keeping registers of adapted properties and helping people to move home where appropriate.

Over half of all councils failed to keep registers of adapted properties – so they could not be sure, when reletting the properties, that they went to appropriate disabled people.

2,000 special schools featured in new guide

THE Gabbitas Guide to Schools for Special Needs, a definitive guide to special needs education in the UK, is now fully revised and updated for the fifth edition.

In more than 600 pages, the book explains the system of special education and offers parents comprehensive, independent advice on those areas which concern them most.

With details of more than 2,000 establishments and guidance from experts in all sectors of special education, it is a useful aid to the legal and practical aspects of ensuring suitable provision for children and young people at all stages of education.

Price £14.99, published by Kogan Page, ISBN 0-7494-2998-4, it can be ordered from book shops or it may be available in libraries.

New push on access in London

THE LONDON Access Forum held its first meeting at which 13 access groups and disability organisations from across the capital were represented.

Launched by RADAR, thanks to three years' funding by the Bridge House Estates Trust, the Forum's work will be co-ordinated by Alun Francis, RADAR's regional development officer – access.

The idea is to build on work previously carried out by the Access Committee for England (ACE) which found that London access groups found it difficult to network with each other and the various disability/consumer organisations in the capital.

A major task is to ensure that every London borough has a thriving access group. The Forum also aims to raise the profile of access in the capital by establishing effective working relationships with London-wide bodies such as London Transport, the Association of London Authorities and the forthcoming Greater London Authority and Mayor.

The Forum will also provide support and development to individual London access groups, on request.

For more on the London Access Forum contact: Alun Francis at RADAR on 0171-250 3222 ext 231. Fax: 0171 250 0212. alun.francis@radar.org.uk

SKILL on the 'net

SKILL – National Bureau for Students with Disabilities – has a new e-mail address – admin@skill.org.uk and info@skill.org.uk

You can also catch up with SKILL at its website address – www.skill.org.uk

Lift on tape

Lift, ASBAH's free magazine for people with spina bifida and/or hydrocephalus, is also available on audio tape. Please contact Liz or Tony in Publicity, on 01733-555988, if you would like to receive *Lift* in magazine or audio tape format.

MERRY CHRISTMAS & A HAPPY NEW MILLENNIUM TO ALL LINK READERS

OUR PIECE earlier this year about three-year-old Elizabeth Price racing around on her Shasbah trolley certainly sparked a lot of interest in this 40-year-old way of mobilising toddlers with lower limb problems.

Woman's Own magazine picked up the story and, in September, ran a photo of Elizabeth, asking readers if they had ever spotted one of these 'sporty little trolleys' and if they had wondered what on earth it is?

Re-naming the trolley as 'a Shasbah', the magazine said the Association was now desperate to track down Shasbahs so they can be passed on to provide a degree of independence for kids like Elizabeth.

Readers were told to look out for them at car boot sales or jumble sales, and turn them into us.

Yours truly was even quoted as saying: "Having a Shasbah makes a huge difference to these children. If you're spending your time shuffling about the floor, you're not using your hands to learn and develop hand-eye co-ordination which is such an important part of development."

Not as elegantly phrased as other colleagues might have put it, but I am sure you get the drift!

Shasbahs make a come-back!

By Tony Britton

So there it was. We found ourselves with a recycling mission in life. We must track down every last one and make sure they are put to good use again.

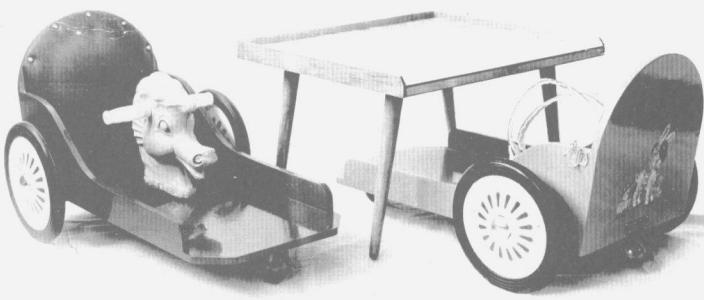
Let's do it! But remember – ASBAH has no storage space. We will, however, pass messages on and keep you up-to-date with the Shasbah trolley mailbag. Keep 'em coming.

'Wants and Founds'

We have taken the following calls from people who want a Shashah trolley, or want to give one away.

◆ Maxine Waterman, Hatfield, Herts, tel: 01707-257070, has a Shasbah in her attic. It was used for a time by her son who has CP.

◆ Joan phoned from the Hamer Primary School in Rochdale. She



Where are they now? Two of thousands of Shasbah trolleys made by South Hampshire ASBAH

said the school still has a Shasbah, which they no longer need. Phone her on 01706-631675 to view.

◆ Mrs Weaire, of Rainow, Cheshire, has a large Shasbah in her loft. Her daughter is now 28 years old, so it's a bit too small. Tel: 01625-572227.

◆ Mrs Sarah Smith, from Kingston-upon-Thames, tel: 0181-546 4503 is in the market for both 'wants and founds'. Mrs Smith is looking for a larger size Shasbah for her son Jonathan, now aged seven and a half. She still has a smaller one in her possession but it has been used so

continued on page 8

Help & Advice

Members seeking help and advice on any matters should make initial contact with ASBAH as follows:

ASBAH South East: 209 Crescent Road, New Barnet, Herts EN4 8SB.

Tel: (0181) 449 0475. **Fax:** (0181) 440 6168. **Regional Manager:** Jo Francis.

ASBAH East: ASBAH House, 42 Park Road, Peterborough PE1 2UQ.

Tel: (01733) 555988. **Regional Manager:** Mary Malcolm.

ASBAH Northern Ireland: Graham House, Knockbracken Healthcare Park, Saintfield Road, Belfast BT8 8BH. **Tel:** (01232) 798878. **Fax:** (01232) 797071. **Regional Manager:** Margaret Young.

ASBAH North: ASBAH House North, 64 Bagley Lane, Farsley LS28 5LY.

Tel: (0113) 255 6767. **Fax:** (0113) 236 3747. **Regional Manager:** Joan Pheasant.

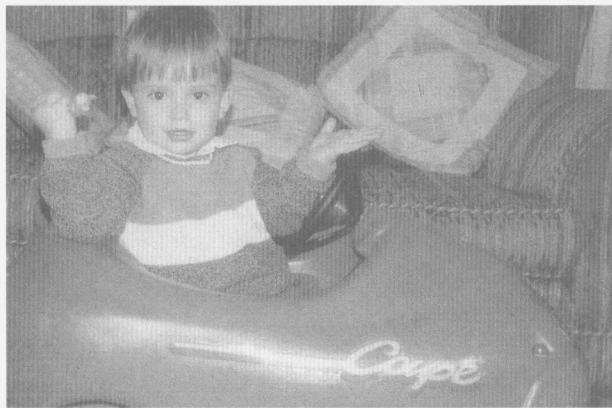
ASBAH Wales: **Regional Manager:** Elin Ifan. **Email:** elini@asbah.demon.co.uk

Rest of England: National Centre, 42 Park Road, Peterborough PE1 2UQ.

Tel: (01733) 555988. **Fax:** (01733) 555985.

Parking row in picturesque resort

A FAMILY on holiday in the Cotswolds caught the rough end of a shopkeeper's tongue when they parked legally in a picturesque village.



Three-year-old Alexander at home in his car!

Ian and April Nicklen were visiting Bourton-on-the-Water with their three-year-old son Alexander, who has spina bifida, when a woman came out, shouting they were ruining her business.

The couple, from Morpeth in Northumberland, had previously spent 20 minutes searching for a space before deciding on what looked a nice, safe spot outside the shop – on double yellow lines. They had their Orange Badge on display.

Mrs Nicklen said: "The woman said she was sick of visitors parking where they liked. She was so rude. I told her that only people with Orange Badges could park there but it did no good."

The couple were so shocked that they did move their car. But Mr Nicklen said: "Surely a place like that depends on visitors."

Roger Perkins, of Bourton Chamber of Commerce, agreed: "We're looking for trade and we actively welcome visitors, including disabled people."

Mr Perkins claimed the incident was a one-off.

Shasbah trolleys, from p 7

robustly, and been repaired so often, that she wonders whether there is still any life in it?

Other calls:

■ The technology teacher from a school in Cornwall rang to see if he could obtain a Shasbah blueprint. His pupils might be able to make a few as a special project. Unfortunately, his details have gone astray, so if this rings a bell with anyone, please do phone me.

■ Martina Dullea, secretary of Cork Spina Bifida and Hydrocephalus Association in the Irish Republic, sent me a copy of the *Cork County Examiner* newspaper, dated 14 September. Page 1 is devoted to a report from Cork Prison, where inmates have just made 14 Shasbahs with 'snazzy velvet brocade upholstery'. Martina's daughter, Sarah, is pictured trying out one.

■ Jed Austin, a carpenter from Liskeard in Cornwall, is interested in recreating a prototype of a Shasbah to judge whether they are worth putting into commercial production. He's seen photos and reckons he could sell them for £70-80 pounds each.

Troy and Elvis – together at last



TROY Sloper, who until his death last year was a huge fan of rock king Elvis Presley, was finally united with his hero when his mum evaded security guards and CCTV cameras to spread Troy's ashes on Elvis' grave.

Despite his physical disabilities, 29-year-old Troy (*pictured above*) had been happy because he had Elvis.

His bedroom wall and ceiling were covered in posters. He read books, watched films and owned nearly every Elvis record.

Troy was cremated in his beloved red Teddy boy jacket to Elvis' *My Way*. He was also wearing a scarf

which an Elvis Presley impersonator gave him after Troy sang on the mike for the first time. Then it occurred to his sister Dawn and mum Patricia that there was only one place to scatter his ashes – Graceland in Memphis, Tennessee.

Despite being told by Elvis' fan club that such a thing was not permitted, Mrs Sloper spent £2,000 on flights for herself, Dawn and Troy's younger brother Nathan. The ashes were hid in four empty camera film canisters.

They went straight to Graceland and saw acres and acres of beautiful gardens and Elvis statues.

But the estate was swarming with security guards and CCTV cameras. It was only when Mrs Sloper got to Elvis' grave that she waited for a security guard to look the other way. She then took her courage in both hands.

"Fear and panic swirled inside me but I managed to open the plastic containers. Troy's ashes settled on the earth," said Mrs Sloper, from Wallington in Surrey.

Although sad there isn't a grave to visit, she feels Troy is finally with Elvis – two heroes together.

But first, our new chairman finishes charity bike ride!

ON THE day he was elected the new chairman of ASBAH, Peter Cottingham was in Scotland finishing off an 800-mile bike ride from the Isle of Wight to John O'Groats.

He hadn't forgotten our annual general meeting in Peterborough but had warned us in advance that he had a long-standing commitment to join four friends on the charity ride. Promises made were promises to be kept.

In his absence, an unusually large attendance of ASBAH Council members welcomed the announcement that the executive committee was recommending Mr Cottingham to succeed Godfrey Bowles as chairman. He was elected unanimously.

The new chairman, who lives in Gloucestershire, is a strategic marketing specialist, who has had a career in the top flight.

With his wife Beverley, he also founded the A-T Medical Research Trust in 1990 after their two-year-old son Thomas was diagnosed with the medical condition, Ataxia Telangiectasia.

"At the time, there was an embryonic group for people with this condition in the UK but nobody was doing any work to raise funds for research," said Mr Cottingham.

"With a small number of friends, we have subsequently raised something like £500,000 to help research work. We have, for example, helped fund a unit in Israel which has detected the A-T

gene and subsequently described its proteins. There are links here to other disorders like Alzheimer's and breast cancer. The whole field of work looks very promising."

Mr Cottingham's bike ride, for his medical research trust, is likely to have raised another £30,000.

Outgoing chairman Godfrey Bowles (*pictured below*) ended a four-year stint with ASBAH in order to fulfil a long-standing plan to retire to live in Sydney, Australia.



His company, Australian Mutual Provident, moved him to Britain almost 10 years ago to run Peterborough-based Pearl Assurance, which they had just taken over. He retired from Pearl at the end of 1994 and then accepted an invitation to be ASBAH's chairman.



Our new chairman, Peter Cottingham

His wife, Elizabeth, flew out to Australia 11 weeks before he did – with Godfrey delaying his move to wind up personal and business affairs in this country and to be at his final ASBAH AGM!

He flew out to join his wife the day after our annual meeting.

Janet Waugh, of Leeds and Bradford ASBAH, presented Godfrey with an inscribed pen and a card as a token of our thanks for the last four years.

■ Our new chairman has been a highly successful strategic marketing specialist and business man. In the 1980s, Mr Cottingham worked as director of sales and marketing services for Boots the Chemists.

In the 1990s, he was chief executive of Clifford Foods plc, then a director of East Midlands Electricity, before becoming chief executive of Leicester Promotions Ltd, the position from which he recently retired. He is also a member of the Council of Leicester University.

Vital lessons to be learned from hydrocephalus tragedy

ALONG with a right to self-determination for all disabled people went responsibilities for society to make young people aware of their own social and health needs, executive director Andrew Russell told AGM. Without self-awareness, tragedies would occur.

Mr Russell was commenting on a sad event which happened in Southampton earlier this year when a young man in his 20s, who was known to his local health and social services departments as well ourselves, died in his flat of acute shunt failure, shortly after he had discharged himself from hospital.

"Equally sadly, he had been living in squalor and was in the process of being evicted from his flat because of repeated neighbour's complaints. He was neglecting not only his health but his personal hygiene, and was refusing to accept much of the help on offer to him," said Mr Russell.

"Possibly his death could have been prevented by immediate neurosurgery, but we know that everything has to go right in the system when these rare emergencies occur."

Mr Russell said ASBAH had

continued on page 14

Have you clothing or footwear problems?

DO you have difficulty finding appropriate clothes or footwear for a child with special needs?

Rosemary Rustin, clothing and footwear adviser at the Disabled Living Foundation, collects information about anything that might be helpful to someone with problems of dressing and undressing, or differences of shape and size, from the latest fashions to mail order catalogues.

She looks out for people who make specific kinds of clothes, such as underwear which buttons down the front, new fastenings, or the use of organic cotton.

It is essential that footwear fits properly but many people prefer shoe-shaped rather than foot-shaped shoes, which does not help. The shoes most difficult to find are for children with very wide or very narrow feet. Girls might just get away with wearing boys' shoes as they are slightly wider, while for narrow feet, lace-up shoes are best, helped by sticking chiropody felt under the tongue.

A booklet, *Footwear for Special Needs*, priced £3, is available from British Footwear Association, 5 Portland Place, London W1N 3AA.

Children or adults who have feet which cannot fit into any high street shoes because of medical reason, should be able to have their footwear prescribed by a consultant via their GP and supplied free on the NHS. Those hoping to get a prescription should ask what their NHS trust policy is regarding footwear; if there is not one, the old NHS standards apply. Odd-sized feet are not considered to be a medical reason alone for prescription.

The Disabled Living Foundation produces a factsheet, *Footwear for Odd-Sized Feet*, which includes details of a number of manufacturers and some good general advice. For a copy contact the Disabled Living Foundation Helpline on 0870-603 9177.

Basketball player Ben benefits from tribute to Rachel Preston



YOUNG wheelchair basketball player Ben Shackleford has reaped the benefits of a series of fund-raising events – organised in memory of eight-year-old Rachel Preston.

Pupils and staff at The Warwick School in Redhill, Surrey, raised a total of £2,393 for ASBAH to be spent on buying a lightweight wheelchair for a child in the South-East.

Rachel, who had hydrocephalus, was the daughter of school year and department head Rod Preston, and the whole school was affected by her death in September 1997.

Various sponsored events took

place during a dedicated charity week and two teachers ran the London Marathon.

Fifteen-year-old Ben, from Crowborough, East Sussex, (pictured left) was chosen to benefit from the school's fund-raising by ASBAH's South-East Region manager Jo Francis.

Mrs Francis said: "Our thanks go to the pupils and staff who worked so hard to raise these funds."

A further £500 has been raised in memory of Rachel this year – £300 was raised by a member of staff of The Warwick School by running the London Marathon, and £200 was collected by Rachel's brothers Paul and Mark after they competed in the London Triathlon in the London Docklands.

Again, the Preston family have asked Mrs Francis to suggest a family, playgroup or school needing a piece of equipment.

Jade's all set for high-tech career

THREE months of ill-health due to shunt malfunction and then infection did not deter Jade Weatherill from continuing with a high-tech degree course.

Designing websites and using the Internet for research were a major part of the year-long course which followed on from an HND in Business Information Technology at Manchester Metropolitan University.

Now with the BSc (hons) in Business Information Technology Management under her belt, the 22-year-old is looking for her first job in the Hertfordshire area.

A former resident of Davis Court, Trafford, Manchester, she said: "I want to work with computers in business and, though I now have a



management qualification, I will consider starting at any level."

Jade, (pictured) who has hydrocephalus by itself, advised three companies when working on her dissertation, *How website design can be used to enhance a small company's competitive advantage*.

Other aspects of the BSc course were databasing, and learning about leadership and different business cultures. jadeb@jadeb.com



LINKS

<http://jadeb.com> Jade's website

Christmas is coming did you see the advert for ASBAH greetings cards on page 4?

Jenny's fine romance!

SHIPS and fire engines have played memorable parts in the life of Jenny Donachie. So much so that, when she and her fiancé Andy decided to tie the knot, they chose a rather unusual venue and some extraordinary wedding transport.

Jenny met her husband-to-be, last year, on a four-day cruise to Spain. She also spent nine happy years as a part-time senior typist/word processor for Avon Fire Service.

For the marriage ceremony, the couple chose the historic steamship SS Great Britain – now a regular venue in Bristol for such occasions.

"We're both interested in ships and boats and as we met on a boat we thought it would be nice to get married on one," Jenny said.

Wearing a cream dress and veil, the 38-year-old used an accessible rear entrance to board the ship.

After the ceremony, witnessed by 70 guests, the bride was carried in

style down the front steps by her new husband.

Waiting to take them to the Filton Folk Centre in Bristol, close to where Jenny used to live, was a fire engine manned by two former colleagues. The happy couple were whisked away, after taking their seats in the back of the engine normally occupied by the rest of the crew.

Jenny said: "I'd only ridden in a fire engine once before, as a special treat, while I was working for the service."

After a reception for more than 70 guests, Jenny and Andy went off to spend their honeymoon in Malta – but this time by plane!



Jenny is settling down to married life in Sydenham, London, and looking for a job. Thirty-two-year-old Andy is an IT manager.

IT HAS been a year of achievement for Cliff Llewellyn who represented Wales as the only disabled team member in an international competition of short mat bowls.

He had played for three years with Swansea club, The Friends of the Young Disabled, and entered some local tournaments independently against non-disabled competitors. At a coaching weekend, he got to meet the Welsh coaches and one of them invited Cliff to attend a trial to play for Wales.

After a couple of trials, he was selected to play for Wales in an international 'A' championships against England, Scotland and Northern Ireland in Eniskillen. Although his team finished third, Cliff (*pictured right*) said: "It was one of the best experiences I've had and hope to be given the opportunity to do it again, maybe this time for the full Welsh team."

Although he did not make the full team this year, he wants to try again.

Cliff takes his place in non-disabled team



In September, the 33-year-old brushed the cobwebs off his racing chair to compete in a 10K race and

raised £300 for Multiple Sclerosis. He and some friends hope to run a longer distance next year.

We've got them taped!

ALL ASBAH's information sheets are now on audio tape. The tapes are available free to those who need this format.

Tape Number 1 has Information Sheets Nos 1-8: *What is Spina Bifida? What is Hydrocephalus? Ante-natal Screening; Genetic Counselling; Vitamin Supplementation; Vaccinations; A Guide to Education Statementing; Spina Bifida Occulta.*

Tape Number 2 has Information Sheets Nos 10 and 13-15: *Just What is ASBAH? Personal Care is Not Sexual Abuse; Benign Intracranial Hypertension (BIH); and Continence Management.*

The price for people who prefer this format is £1.50 per tape (£3.00 per set), plus 50p for postage from our Information Department at National Centre.

ASBAH's *Spina Bifida and Pregnancy* booklet is also on tape – free to service-users who need this format.

Fashion twist for big shop

DISABLED people are being asked to take part in a nationwide survey of clothing stores to find out how 'big' stores are – on physical access, on customer service and attitude and ensuring customers are not excluded from buying the clothes on sale.

The BIG Shop survey has been launched by **awear**, a group of disabled people and fashion industry professionals seeking to ensure disabled people have full and direct access to fashionable clothes of their choice.

The launch coincided with the start of Part III of the Disability Discrimination Act on access to goods and services.

A questionnaire asks five simple questions on service, access, and goods on sale in the clothing shops disabled people visit.

Questionnaires from: **awear**, tel: 0115-953 0439; enquiries@awear.org.uk

Life afloat is the

HOME is where the heart is and for wheelchair-user Chris Patrick that is living on the water.

Never one for being put off by doubters and sceptics, the single mum fell in love with a watery way of life from the first holiday she spent on a boat.

And, she believes, many more disabled people would like to try doing things that are out of the ordinary but are, all too often, put off by those who don't know what they are talking about.

She said: "I live in a house that's neat and compact so it's not as far to get round as a conventional house. It's convenient for holidays, too, because she moves."

Chris has lived on a house boat for the last 14 years. She paid £25,000 for *The Slough*, a 70ft working narrowboat, built in 1936, originally commissioned by the Grand Union Carrying Company to carry grain.

"She needed a lot doing to her.



Chris by The Slough in the NHS chair she keeps 'permanently' on the towpath – one of three chairs she uses to stay mobile. Photo: Derby Evening Telegraph

Canal-dweller CHRIS PATRICK, wheelchair-user, talks to Link Editor Liz Cawthorne about why she chose to spend her life on a narrowboat

I've put in central heating, fuelled by a diesel boiler, and she had to have new steel sides as the wooden ones had rotted."

Chris lives with her 19-year-old daughter, Charlotte, at Sawley Lock on the Trent and Mersey Canal, close to where the three counties of Derbyshire, Nottinghamshire and Leicestershire meet.

The four-cabin boat is snug and well kitted-out with a real homely feel. Teddy bears sit along the top of the sofa and all around the living space.

Chris has also had a specially commissioned Roses and Castles decoration painted on the boat. It is said that this colourful folk art was developed to brighten up the hard lives of the bargees on the old working boats.

Because they could not own

their own homes, represented their the castle their ho

Chris got the boat she hired a boat for many years ago.

Her next step was still just for holidays long, she decided to buy a house and live on the boat permanently.

"You either like boats or you don't," said Chris. "I moved right from the start. I wanted a small compact craft, something different way of life on an estate. I love living in Sawley in the middle of the country."

"I know everyone's path, including the others."

Chris has worked

e life for me, says Chris

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she depends on a
wheelchair for
mobility.

While on board,
she uses a tiny
chair, specially
made for her,
which she pushes
with her feet and
her hands.

Left on the tow-
path is an NHS
chair which she
gets into via a
stool on wheels.
f she wants to get
into her car in the



Time for a brew-up: Chris Patrick in the galley of her narrowboat, The Slough

car park, she leaves the NHS chair by her space til she returns, and drives off with a third chair, a Quickie, which is kept folded up on the passenger seat.

"It sounds a complicated system but it's easy when you know how. It means I'm very good at transferring."

She is a familiar sight along the tow-path as she regularly exercises her three elderly dogs. She also has a cockatoo and a cat.

"There are not many people living along the canal that don't have dogs," she said. "I can get as far as the bridge and the car park myself, but someone needs to push me up the bank if I want to go beyond the bridge as it's too steep."

The boat itself is quite roomy with a kitchen/eating area (galley), including breakfast bar, and four cabins. It is centrally heated so is as warm as a house – it has to be as Chris feels the cold.

There is no electricity but light bulbs are run off batteries which are charged up every day by running the boat's engine. Chris has a small colour TV and a CD player and a main line phone.

Chris lived in Wales for a time, as well as other places, but she was born and bred in Nottingham so has come back to her roots.

"We're about 12 miles from Nottingham. I work, as well, for the Citizen's Advice Bureau in Loughborough, 11 miles away, so it's handy being here, and I have loads of friends in the area. Yet we could be in the middle of the country – at the end of the towpath is Sawley village."

Taking the boat for a holiday requires an extra person to help with the locks, otherwise Chris handles and steers the boat herself. Finding someone to crew for her is not usually a problem.

This year, Chris travelled for

two weeks to Great Haywood, beyond Burton-on-Trent, and, last year, she went to Lincoln by narrowboat.

"I think more disabled people should try it but they lack the confidence. There are too many people out there who say it's dangerous – I don't listen to them."

"It's a great life with no more problems than living in a conventional house but there are attractions that would appeal to many."

Her former ASBAH adviser when living in Wales, Elin Ifan, who now manages our Wales Region, has kept in touch with Chris over the years. Elin said: "Chris is a brilliant person who just gets on with it. She started using narrowboats for family holidays, and liked the freedom so much that she purchased her own to live in permanently."



Obituary: Mrs June Davies

A DEVOTED mother and pillar of a local Association has died after a long illness, aged 66.

June Davies was a founder member of Staffordshire ASBAH and was their secretary for many years.

She spent the last year of her life in hospital which meant that her 32-year-old disabled son, Edward, had to move from their home in Oakhill, Stoke-on-Trent, to respite care.

Before illness forced her to quit her duties as secretary, Mrs Davies highlighted, in *Link* No 177, the dangers of 'superbug' MRSA – bacteria which is resistant to most antibiotics and which caused Edward to have a leg amputated.

What she gave to local Association members went beyond the call of duty. She answered calls at night because she had told parents they could ring when they needed to.

Close friend and treasurer of Staffordshire ASBAH, June Newman, said: "She was a such a kind, caring and supportive person and a

great friend. It was very sad that she had to suffer so much in the end."

The two women first met 25 years ago, soon after Mrs Newman's son was born. "I didn't contact her, she contacted me and introduced herself. I poured my heart out to her. She helped me greatly at that time. She never mentioned Edward until a few weeks later and I then realised my problems were small compared to hers.

"She was so worried how Edward would balance when he lost his leg but he coped wonderfully well."

Elizabeth Woodhouse, chairman of Staffordshire ASBAH, said: "June worked very hard and raised a lot of funds and kept the group together. She was always there for parents to lean on. We were very saddened by her long illness and her death."

Acting secretary Reay Pearman said: "June was the Association in North Staffordshire. She devoted her time and life to it."

Mrs Davies died on 12 September 1999. She leaves three sons and five grandchildren.

Cook with the stars!

STARS like Zoe Ball, Carole Vorderman, Alan Shearer, as well as Prince Charles, have sent recipes for a celebrity cook book to raise funds for a hospital school.

It is hoped that £20,000 will be raised for Nottingham's Queen's Medical Centre (QMC) Education Base by the end of this year.

The money will be used to upgrade IT equipment and buy specialised equipment for youngsters with special needs, with funds left over for maintenance.

The 80-page colour cook book contains more than 200 recipes including those from more than 70 stars, with signed photos.

Cost: £5, plus £1.30 towards p&p. Cheques/POs payable to: QMC Education Base. Please send your order to: QMC Education Base, E Floor, East Block, Queens Medical Centre, Derby Road, Nottingham NG7 2UH. Tel: 0115 9249924 ext 44331. Or you can collect a copy, for £5, from the above address, Mon-Fri, 9am-3pm.

ANNUAL MEETING NEWS ... ANNUAL MEETING NEWS continued from page 9

Vital lessons to be learned from hydrocephalus tragedy, from page 9

discussions with the local authority to ensure that measures to increase independence always included attention to essential healthcare. Preparation for independence often needed to raise self-awareness to levels rarely seen in non-disabled young people.

Mr Russell reported on the

growing success of ASBAH's hydrocephalus shunt alert card initiative, with over 2,160 cards now issued. We were also working closely with the National Shunt Registry to overlay our database on theirs to improve national monitoring of shunt-effectiveness, and give better information to neurosurgeons.

year comprises: Peter Cottingham (chairman), Mike Allen (hon treasurer), Geoff Baxter, Michael Booth, Austin Crowther (vice-chairman), Eddie Evans, Katrina Grounsell, John Hawkshaw, Brian Henley, Bob Ithell, Eileen McCabe, Eric Prentice, Tim Robinson, Beverley Rowe,

Brenda Sharp, Tony Sprague, Kevin Towner, Alan Twyford, Janet Waugh.

▲ A special appeal is to be mounted to cover the costs of ASBAH's new Wales region, where ASBAH Cymru has now been formally recognised as our membership forum in the principality, said executive director Andrew Russell. While ASBAH's agreed five-year strategy ruled out any expansion in service, charities like ours traditionally trod "that narrow line between prudence and profligacy" and he expected a good result from the appeal.

▲ Guest speaker was solicitor Anthony Quinn, on making legal provision for children with learning disabilities. A copy of his firm's leaflet on the subject can be obtained from Anthony Quinn & Co, tel: 0171-242 3332, fax 0171-242 3459.

▲ A FORMER worker at the Royal Naval dockyard in Devonport, near Plymouth, Tony Sprague, was elected to join the executive committee in place of Tracey Proudlock, who stood down because of other commitments.

Executive committee for the coming

Is this YOUR chance to embark on a career in publishing?

A PIONEERING nine-month course, which could set disabled people over the age of 18 on the road to a career in publishing, is now accepting applications.

Pathways to Publishing, based in West London and Southwark, will draw upon the expertise of three organisations: Disability Times Trust, Disability Times Newspaper and the London College of Printing.

The course, which starts in May 2000, will provide any or all of the following: desktop publishing (DTP); journalism; real work experience; personal development; full mentoring support; confidential counselling; interview training and comprehensive jobsearch support; portfolio of published work.

Details/application forms from Ian, 0181-566 1206.

AT the beginning of this year, I decided to form a small independent theatre company called Theatre Provocateur with my friend Liam O'Carroll. You may have seen his name before; he has had small parts in *Desmonds* and *Father Ted* as well as being in several Graeae productions.

Both of us write and we wanted to have the opportunity for others to see our work. As it is virtually impossible for new writers to get their work on stage, we decided that Theatre Provocateur would be the perfect vehicle for our plays.

Liam had been writing a play called *Distress Call*; a one-man show about a blind stand-up comedian. He showed it to me and another friend, Simon Tyler, and we both agreed that it would make a fascinating performance. With Liam as actor, Simon as director and myself as producer, we set about finding a venue and some crew.

We asked around and Graeae Theatre Company suggested that we try the Wimbledon Studio Theatre because it had just become wheelchair-accessible and the artistic director was very supportive. In March, we arranged to meet the artistic director, who spent an hour showing us around. He had read our company biography and the all-important treatment of our play, and he was very keen for us to perform *Distress Call* at his studio theatre. Most importantly, he offered to distribute all our flyers and posters advertising the play for us; the Wimbledon Studio Theatre has a mailing list of 3,000 which they share with the main theatre. Jonathon's enthusiasm for *Distress Call* and his marketing strategy convinced me that this was a good venue. We made the Studio Theatre

Play for today



By Suzanne Bull
Link columnist

an offer one week after our visit, and then we started to panic two days later as we realised what we were letting ourselves in for!

Liam and myself put our own money into the project because we did not want to wait months for funders to accept or reject us. Liam found a local community centre in Kingston which was prepared to let him rehearse for free. Unfortunately, Simon had to stop directing the play, but John Constant, a friend of Liam's from their days at The Green Theatre in Richmond stepped into Simon's shoes. Two more friends Sam and Nick offered to do the sound and lighting – we were off!

I set about doing what I know best; organising all the publicity. We decided upon small postcards as these are ideal to put in cafes and bars, as well as handing out to people at other gatherings. The postcards were from a photograph that Liam had of himself at 14 years old, trying to look cool and leaning against a replica of the Dr Who telephone box. We had the picture enlarged into A3 size posters at the local printers which was also very cheap.

We sent the publicity everywhere;

Liam ended up on GLR (Greater London Radio), *In Touch* on Radio 4; previews and reviews appeared in the local press and some of the disability press. We also got listed in *Time Out* and *The Guardian's Guide* which is unusual as we only had six performances. We also begged and threatened all our friends with excommunication if they did not come and see our play.

Distress Call was a resounding success! Our friends and colleagues did not let us down. We sold out on two nights, with other performances more than 80% full. We broke even – something which hardly any company does on their first production! Mostly, we had a brilliant time and it has spurred us on to write and perform more – perhaps, one day, even leaving our full-time occupations behind us.

At the moment, Liam and myself are waiting to hear from the Royal Court to see if our plays have been entered into its special performances from the Graeae / Royal Court project. By the time you read this, Liam may have performed *Distress Call* in Croatia, in a festival for the theatre of the blind.

Fingers crossed for Theatre Provocateur!

Activity gives members new links



Surrey ASBAH chair Alan Twyford proves he can do it!

FORGET sitting round trying to make small talk over a drink or a meal, get out in the fresh air and give your members something new to think and talk about.

One local ASBAH encouraged 46 people to set themselves physical challenges they were comfortable with on an activity day which focused minds on chosen activities

rather than difficulties of the disabilities.

The real work for the organisers started several months before as ASBAH Surrey members had to be warmed-up to the idea – first by encouraging letters seeking their agreement for such a day, followed

by interest-seeking letters, helped by direct phone and personal contact by ASBAH adviser for East & West Surrey, Jackie Cowl.

Fully funded by Surrey ASBAH, the activity day was taken up enthusiastically by four-fifths of those who originally said they wanted to take part.

The chosen venue was High Ashurst Outdoor Education Centre, between the top of Box Hill, near Dorking, and Headley Down.

Alan Twyford, chair of Surrey ASBAH, said: "It was a most enjoyable day with children and adults alike being thrilled and excited at what they had done. Everyone went home with quite a buzz about the day."

With plans to follow-up the activity day with a camping weekend there in 2000, Surrey ASBAH highly recommends such a centre to others.

Alan said: "Other groups close to the A24 and M25 could find the centre we used a possibility. Other counties and London Boroughs may have their own centres which groups can use."



Right on target are (left to right): Gary Treadwell, Brian Treadwell, Darren Alexander, Stuart Miall, Chris Frith, Ellen Frith, Rob (instructor), Ian Cole, Steve Wallace and Paul Wallace

'ty day members focus

As the photos show, people could choose from rock-wall climbing, abseiling, archery and everyone could try the aerial runway – sitting on a disc and holding on to a rope which was suspended via a series of wheels on a wire from tree height to ground level.

Alan said: "People were encouraged to do as much as they wanted, to go a little further, but to end the session when they felt they wanted to. The centre staff gave support and instruction where needed."

Other suggestions from Alan: "The activity day was very much a team-building day in an informal way. It can also be a way of showing potential funders how you use their donations or an opportunity to motivate members to fundraise."



The three wise women: Trudy Eborn, Margaret Twyford and Mary Bush



Sheer enjoyment: Jonathan Smith and Dan (instructor)

Fact file

High Ashurst Outdoor Education Centre, Mickleham, Dorking, Surrey RH5 6DQ

- Owned by Surrey County Council.
- Situated between the top of Box Hill, near Dorking, and Headley Down. Approached by a rugged track or by a private residential road. Adequate parking.
- It is a large, flatish area, which is divided into segments offering different activities. Surrey ASBAH used the simplest of various rock-wall areas without an overhang. This area was designed for abseiling as well.
- Two kinds of archery targets were used – a round one on an easel and a vertical mattress-style one with a square target area.
- Meals – large area with picnic tables and barbecue.
- The centre is not purpose-built for disabled children and adults, so ASBAH Surrey advises careful consideration of the party's needs and available helpers. The centre staff will work with your group to ensure a very good day.
- Further information from: Tom Baardwyck, Head of Centre, on 01372-377239. Bookings line is 01483-562636.

Business gets its access orders

A NEW code of practice for service-providers gives guidance on the latest requirements of the Disability Discrimination Act.

From 1 October 1999, shops, businesses and other organisations dealing with the public must make reasonable adjustments to make their services accessible to disabled people.

This will include:

- changing practices, policies and procedures which in effect discriminate against disabled people – for example, a no-dogs policy which discriminates against guide dog users;
- providing auxiliary aids and services, for example, information in accessible formats;
- providing services by reasonable alternative means – if a service is based in inaccessible premises, it

may be reasonable to provide a home visit.

This new code costs £12.99. It has been prepared by the National Disability Council.

Another code of practice is available for trade unions and employers associations. From 1 October 1999, they must make reasonable adjustments for disabled members and potential members, including putting information in accessible formats and ensuring that their practices, policies and procedures do not discriminate. This one costs £9.95.

Both codes available in a range of formats from: Publications Centre, PO Box 276, London SW8 5DT. Tel: 0870-600 5522. Fax: 0870-600 5533.



LINKS

www.disability.gov.uk The UK Government's disability website

PETER NOTCHES UP ANOTHER FIRST!

PETER Mynehan, recently named as Kent's young person of the year in a local radio competition, has added to his quiverful of successes by scooping three silver medals at the National Junior Disabled Athletics Championships in Blackpool.

He came second in the javelin, shot putt and discus under-15 competitions, and is now ranked second at this level throughout the British Isles.

Peter, of Rainham, Kent, also reports excellent results in the

classroom. A pupil at Valence School, Sevenoaks, he gained level six in the English test paper of his Standard Assessment Tests, which must be taken by all 14-year-olds.

Peter writes: "Those not familiar with this type of marking system should know this is the equivalent of one O-Level. I have been told by the headteacher that this is the highest ever grade achieved at the school. I was presented with a headteacher's award for what was described as 'a truly magnificent achievement'."

Pen-pals worldwide for children

CILDREN'S Hopes & Dreams, serves more than 9,000 children through a pen-pal programme operating all over the world.

The pen-pal programme is free for children aged five to 17 – with any type of chronic or life-threatening illness or disability. The children are matched by age, sex and category of illness.

Ask for a free enrollment card and poster by writing to: Children's Hopes & Dreams Foundation Inc,

280 US Highway 46, Dover, NJ 07801, USA.

To enrol on behalf of a hospital, local Association or other organisation, write to the same address but ask for a *blue order card* on which multiple copies of enrollment cards and posters can be ordered. You will be joining a network of more than 15,000 hospitals, clinics, Ronald McDonald Houses, camps and support groups for ill children and their families.

Public transport – wait for it!

ALL buses and coaches used on local or scheduled services will be fully accessible to disabled people, including wheelchair-users, by 2017.

The Government is to consult on proposed regulations under the provisions of the Disability Discrimination Act 1995.

This gives the Government power to make accessibility regulations for buses, coaches, trains and licensed taxis.

New Minister of Transport Lord Macdonald said: "Most of us take for granted being able to travel by bus or coach, but for many disabled people such travel opportunities are difficult or impossible.

"These new regulations will be phased in over time for different vehicles, beginning next year with requirements applying to full size single deck buses. By 2017 all buses and coaches used on local or scheduled services will be fully accessible."

Some improvements are already being made and over the last few years, with most new buses being built with low flat floors.

This has resulted in increased bus usage, not only amongst disabled people, but also from people travelling with small children, luggage or shopping.



LINKS

www.det.gov.uk Department of the Environment, Transport and the Regions.

CAB WEBSITE

THE National Association of Citizens Advice Bureaux website has immediate access to reports and briefings on a wide range of issues including employment, discrimination, housing and community care.

*The NACAB website is at:
www.ncab.org.uk*

Ringing the changes at an island ASBAH

MOLLIE Buesnel has retired as secretary of Jersey ASBAH after holding the post for five years.



Mollie (*left*) was presented with a cut glass bowl at the group's annual meeting in appreciation of all her hard work – because her involvement goes back much further than that.

Standing down due to ill health, Mollie helped set up the association in 1968. She's been an active committee member and fundraiser ever since.

Every summer, she organised a team of helpers to run raffles at local hotels and night-spots, raising thousands of pounds. She was also a key person in looking after the welfare of the branch's 26 families.

Jersey ASBAH's new secretary, Ursula Emmanuel, also has long links. She was one of the founder members who linked up with the Lions Club to set up the new association.

Ursula (*right*) was Jersey's first secretary, an office she held for eight years before moving to England. She returned to the island in 1993, rejoining the local branch and being elected to committee in 1994.



Ursula's daughter, Cheryl, is also back on the island and works at the local hospital. They have both enjoyed renewing old friendships, and Ursula looks forward to continuing the success of the branch.

Government test a 'sensitive' approach as they replace BIP

THE SUCCESSOR to the Benefits Integrity Project (BIP) – which was scheduled to start at the beginning of April – actually began on 14 June when the first postal enquiries were sent out. Home visits started on 28 June.

Since then, around 500 enquiries have gone out each week, split evenly between visits and postal enquiries (questionnaire only). The number will stay at this level for at least the first six months.

Compared to the 1,333 postal enquiries and 2,579 visits in January this year under BIP, the periodic enquiries is a 'low volume activity' – roughly a quarter of the amount of cases that went through the BIP. After the much-reviled BIP, this represents an attempt by the Department of Social Security to be more sensitive in its approach to claimants.

Where a change in benefit level may be likely, additional evidence – from either the claimant's GP or a BAMS doctor – must be obtained before a decision is made. This will apply to decisions on both increases and decreases in benefit.

Forms and literature

Information sent to claimants from the Disability Living Allowance

Unit/Benefits Agency does not mention 'periodic enquiry' or review. Instead, it refers to [making] 'sure that you get the right amount' [of benefit]. The information notes on exemptions and letters are identified by a series of letters and numbers: DLA2003-4, and the Questionnaire is DLA300. This should help claimants/advisers identify whether or not they are part of the process.

This approach holds with the Benefits Agency's post-BIP brief to build into the system regular reviews or checks of DLA awards. It follows the Government's commitment to a new system of 'active case management' to ensure that claims are 'right at the outset and remain right.'

The Benefits Agency is also initiating a series of new claims trials – visits by administration staff to new claimants to complete section 2 of the claim pack. Taking part in the trial is voluntary.

Following a request for a claim pack, new claimants will be sent an explanatory leaflet, along with a claim pack. The trials will be held in three Disability Benefit Centre areas – Glasgow, Bootle and Bristol. They were due to start at the end of August 1999.

BETTER DRESSED IN SWINDON & WILTSHIRE

A NEW service for disabled people in Swindon and North West Wiltshire aims to give practical and attractive solutions to clothing problems. **dressability** is the latest addition to a national network of clothing services, known as **awear**.

Like other clothing services in the network, **dressability** provides a specialist service for disabled and/or elderly people. So, if you are unable to bend; have limited dexterity; are larger or smaller than average; have limited mobility, your body shape differs from the 'norm'; you have limited vision, **dressability** help with your clothing needs.

A not-for-profit organisation, the service can also help by altering clothes or making new ones to suit your individual needs.

dressability: open on the first Wednesday in the month, 10am–1pm, at Options Plus, Independent Living Centre, Marshgate, Stratton Road, Swindon SN1 2PN. Tel: 01225-442646. Home visit inquiries on tel: 01225-442646.

To find out if there is a clothing service near you, contact **awear** on 0115-953 0439.

DIARY DATES DIARY DATES

Saturday 20 November

Getting to grips with continence in spina bifida and hydrocephalus, study day facilitated by North Wales ASBAH with support from BBC Children in Need Appeal and Astra Tech Ltd. Venue: Ysgol Gogarth, Nant Y Gamar Road, Craig Y Don, Llandudno.

9.45am-3.30pm. Speakers include: Christine Evans (consultant urologist, Glan Clwyd Hospital), Mary White and Linda Winson (continence advisers). Cost £5 per person (inc buffet lunch, tea and coffee), cheque payable to North Wales ASBAH. Closing date for bookings: Friday 5 November. Details: Peter Bennett, ASBAH Adviser, Cypress Lodge, 18 Wynnstay Lane, Marford LL12 8LG, tel: 01978-852254.

Saturday 20 November

Hydrocephalus - implications for learning and behaviour, ASBAH study day, Botleigh Grange Hotel, Southampton. Speakers include Lisa Blakemore-Brown (psychologist who chairs Promoting Parenting Skills), Bruce Graham,

ASBAH Specialist Adviser (Education), Heather Jury (ASBAH member and parent). 9.30am-4.45pm. Fee £8 per person (inc light lunch). Details from Liz Clayton, ASBAH Adviser, tel/fax 0118-972 4013.

Year 2000

10-12 March

ASBAH Family Weekend, residential weekend specifically designed for families with a child aged six and under with hydrocephalus and/or spina bifida, their brothers and sisters. Venue: Trevelgue Hotel, Watergate Road, Porth, Cornwall. Three parallel programmes - information for parents on medical, educational and social aspects child's disability; fun activities for all the children; special programme for able-bodied brothers and sisters. Cost kept to £60 per family thanks to support from the BBC Children in Need Appeal. Closing date for bookings: 17 January 2000.

Details: Mrs Lynn Thomas, ASBAH National Centre, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988, lynnt@asbah.demon.co.uk

9-11 May

NAIDEX, National Independent Lifestyle Show, Birmingham NEC.

Monday 17 May

Spina Bifida and/or Hydrocephalus - current concepts and treatment, full-day conference organised by ASBAH Eastern Region. Venue: Courtyard Conference Centre, Marriott Hotel, London Road, Newport Pagnell, Bucks. Speakers: Peter Richards, consultant paediatric neurosurgeon, Radcliffe Infirmary, Oxford, and Rowena Hitchcock, consultant paediatric surgeon, The Radcliffe Hospital, Oxford, with additional speakers on education and challenging behaviour.

Professionals £50 each; service-users, parents and carers £15 each*. Price includes refreshments and two-course buffet lunch.

*Assistance with the cost may be available from your Local Association or ASBAH Adviser. Please ask in advance. Details:

Mary Malcolm, Regional Manager, ASBAH, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988, fax 01733-555985, email: marym@asbah.demon.co.uk

BOOKSHELF

- *After 16 - what's new? choices and challenges for young disabled people*, written by Link columnist David Fulford-Brown for the Family Fund Trust. This book has been completely

re-vamped from past editions to reflect the changing attitude towards disability and the demands of young people.

Obtain your free copy by declaring that you are a young disabled person and enclosing an A4 addressed envelope (not stamped) and send to: *After 16, The Family Fund Trust, PO Box 50, York YO1 9ZX.*

● *A Practical Guide for People with Learning Disabilities* - where to find the help you need. It gives information about services from government departments and agencies, the NHS and local government and voluntary organisations. It covers: money, housing, holidays and leisure. Free from Department of Health, PO Box 777, London SE1 6XH. Fax: 01623-724524.

● *SPINAbilities*, reviewed in *Link* No 174, is proving popular as a great introduction to spina bifida. Easy and attractive to dip into, it can help parents think about things they can do now to help their children grow into independent adults, as well as inspiring disabled people themselves. Published by the Spina Bifida Association of America, it can now be ordered through Internet book supplier, Amazon, at a reduced price of £10.39, plus £2.50 for postage and packaging. You can pay by postal orders, cheque or

credit card, with delivery to any address. Amazon can also search for out-of-print books. Find them at Amazon.co.uk

● A new 'power' pack for young carers under 18 has been produced by the Carers National Association and the St John Ambulance with sections on practical advice on caring safely, what to do in an emergency, people you can talk to, help and information. *The Young Carer's Power Pack* from: Carers National Association, 20-25 Glasshouse Yard, London EC1A 4JT. Tel: 0171-490 8818. Fax: 0171-490 8824.

● *Paralysis - the loss of muscle power, a guide to living and coping with paralysis*, a free booklet from British Brain and Spine Foundation, 7 Winchester House, Kennington Park, Cranmer Road, London SW9 6EJ. Tel: 0171-793 5900. Fax: 0171-793 5939, info@bbsf.org.uk

READING through the last issue of *Link*, I thought how true it is that disabled women are under pressure to show that they are 'real women' (whatever the heck that is) by producing sprogs. But I have to say that women are not the only ones under pressure to reproduce.

Now that I've reached an age where most of my female friends are at one end or another of being pregnant, questions are being asked about my single status. When am I going to get married? Will I ever have kids? I firmly explain to these interrogators that while marriage and offspring might be great for other people (and the very best of luck to them!), I will probably never get married and I'll certainly never have kids!

When people hear that I *won't* be having kids (because I choose not to), it is surprising how many, even in my own family, hear that as *can't* have kids. After a tactful pause, mental cogs turn and suggestions are put forward as to how my 'mechanics' can be assisted with the aid of operations, pumps, pills, needles, and assorted contraptions.

Well, I know all about them and yes, as someone with spina bifida, I could go get some free Viagra pills off the Doc. But, I'm dreadfully short-sighted already. I don't need my vision turning blurred *and blue!*

Pills I can cope with, but *needles*? I'm not keen on injections at the best of times. The thought of sticking a needle into my private parts

has got to be the biggest passion killer there is! And again, my lousy sight may put the mockers on this method. When I go out with friends, I usually have a few drinks. What happens if, on a romantic evening, those few drinks mess up my vision or my aim? I don't want to spend the night with a stiff left leg!

Seriously, yes I could and would use the above methods to have kids, if I felt the need and that mechanical breakdown was the *only* reason I would be unable to have them. But it's not. There are loads of other reasons why I'm not planning to have kids any time soon.

The most obvious is: how am I supposed to get married and bring up kids when I don't even have a permanent girlfriend? Bit of a problem, that one! After 30 years I have to admit, I don't understand women. But at least I *like* women. I really don't like babies. Actually I'm *afraid* of them! For one thing, they're too delicate and small for a clumsy oaf like me.

Earlier this year I visited a friend and her new baby. I got involved in a game of 'pass the sprog', where the baby is passed round adoring friends and family like a parcel. Sure enough, when it got passed to me, this previously quiet baby exploded into a howling, sobbing mess! It was just being grumpy but I really thought I'd hurt or broken it!

Apart from being easy to upset or damage, babies are also expensive, emotionally and physically exhausting and time-consuming. Friends with new babies turn from fun-loving party-goers into hollow-eyed people that talk only of their baby, dress in washable clothes and smell of baby sick! Their every waking moment is, it seems, spent thinking about the baby.

I'm afraid of such a commitment. If an ordinary baby requires that much effort, I'm afraid to think what a baby with a disability like SB needs, and if I could ever provide it. This is my biggest reason for not having kids – the great fear they too might have SB!

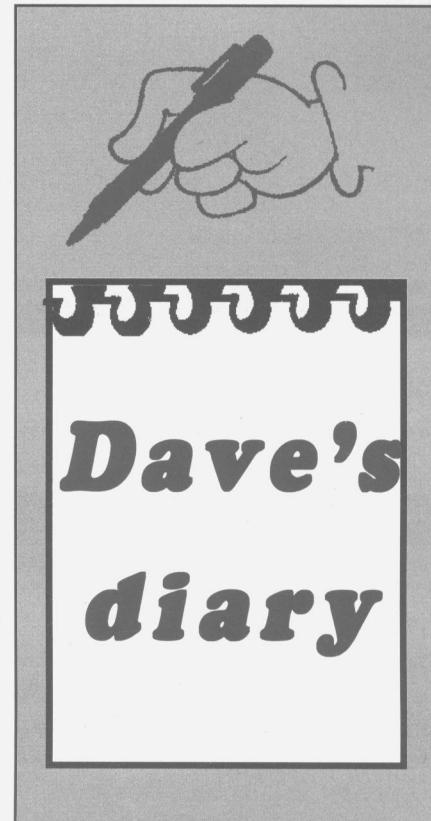
I really don't want to be responsible

Disabled parents group

PARENTABILITY and Parents Too! have merged to become the Disabled Parents Network, offering support and advice to parents with disabilities.

General enquiry line: Mon, 10am–1pm, Janet Bradshaw, 01785-612592; Fri, 10am–4pm, Sarah Evans, 01600-860186.

Practical equipment helpline: Oct & Dec: Mon–Thur, 2.30–4.30pm, Julia Winter, 01245-461281. Nov: Mon, Wed & Fri, 10am–12noon; Tues, 7.30–8.30pm, Louise Moyo, 01582-671822.

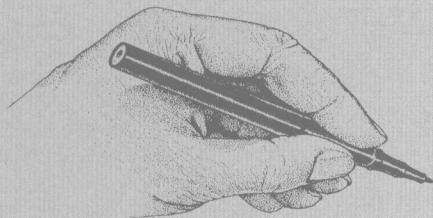


for bringing a baby with SB into this world. Not because the baby has SB (I'd be on pretty thin ice there!) but because society is not yet a fit place to bring a disabled child up in. Yes, things are better than they were when I was born. But not much.

Disabled people still face many of the same problems, the same garbage I had to deal with. Open any newspaper and you're likely to find some loon calling disabled people 'an evil'. Yet another reason I *won't* be having kids! How can I possibly inflict that same garbage and all society's new genetically modified loonies on my child? And worst of all, it might have to face them without the level of love and support which I got from my family, but don't know if I am capable of.

I'd like to end this column, and indeed this millennium, by trying to put into words my gratitude, love and thanks to my family for my life, for their struggle on my behalf, for their great love, guidance and long-suffering support all these years. I'd like to dedicate this article and all other works with love to my mother, my brothers Anthony and Nick, and all my family.

David Fulford-Brown
david.fulford-brown@virgin.net



Letters

 WELL done on your efforts to winkle out all the old SHASBAH trolleys, so they can be recycled and put back into use by families who would appreciate them. We discovered one while on holiday in the ASBAH bungalow on the Isle of Wight and my son, Daniel, loved using it. Not having to be picked up and carried the whole time gave him a real taste of independence while we wait for the arrival of a wheelchair from Whizz-Kidz, which should be with us at the end of November.

When I asked about SHASBAH trolleys at the Child Development

Centre in Portsmouth, they said they had never heard of them. But they are a good idea, particularly for smaller children who do not have their own wheelchairs. There must be somebody out there who could make some more.

In the meantime, does anyone in this area have a SHASBAH trolley they no longer need? We'd give it a very good home. Please phone me on 01705-663226 if you can help.

*Mrs Trudi Cocks
9 Vernon Road
Copnor
Portsmouth, Hants PO3 5DR*

 A FEW months ago we reported on our ASBAH-funded study into the developmental, behavioural and psychological characteristics of six to 12-year-old children with spina bifida and/or hydrocephalus. As stage one is now on its way, I would like to update you on our progress.

In July, a questionnaire was sent out by ASBAH to over 1,200 families. The questionnaire contains questions regarding the child's disability, the child's education and behaviour, as well as the impact of the disability on the family as a whole.

As so many issues come up when trying to cover the experiences of children with spina bifida and/or hydrocephalus and their families, the questionnaire entailed quite a few pages.

Therefore, we are quite pleased to inform you that over 450 parents/guardians have now returned a completed questionnaire! We are now analysing the information and early next year should be able to inform you of our findings.

We like to use this opportunity to thank you for your interest and co-operation in our research, and ... should you find our questionnaire at the bottom of the pile on your kitchen table, please take some time to complete and return it to us.

*Ineke Pit-ten Cate
Research Fellow*

*Centre of Research into Psychological Development
University of Southampton*

 We invite letters for publication. Send them please to: *Editor, ASBAH, 42 Park Road, Peterborough PE1 2UQ*. The Editor reserves the right to edit letters for publication, so please keep them as short as possible.

 DEAN is 23 years old and lives in Wales. He has Arnold Chiari deformity and would love to hear from anybody who has this condition or parents/carers of others who have it.

If you would like to talk to Dean, please contact Paula Thompson at National Centre on 01733-555988.

 I AM a student at Christ Church University, Canterbury, studying for the third year of my BA Joint Honours Business and Tourism degree.

As part of my final year, I am preparing to undertake a dissertation on the level and nature of participation amongst disabled people within tourist activity, especially concerning day visits to tourist attractions anywhere in the UK.

I am particularly interested in this as I use a wheelchair myself and feel that more needs to be done to enhance accessibility in our society.

This study will consist of a survey of disabled and elderly people who need to use a manual or electric-powered wheelchair.

The survey will be strictly confidential, taking the form of a 'tick the box' questionnaire concerned with the level and nature of their individual participation within touristic activity.

Survey time is planned to begin during late October and I will gladly provide confirmation of authority and confidentiality from the university, if required.

If you would like to take part in my survey, please ring me 01303-814050 or send an email to rebeccacullen@onet.co.uk

*Rebecca Cullen
Brabourne
Ashford
Kent*

HOLIDAY ACCOMMODATION

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.*

BERWICK COTTAGE, EAST HARLING, NORFOLK

Purpose-built modern cottage. Ground-floor accommodation for up to 2 people with disabilities. Scan 700 beds. Clos-o-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, 0181-595 7056.*

WEYMOUTH BAY

Fully-equipped, wheelchair-accessible caravan – sleeps five; on Haven Holiday Park, full use of all facilities – heated indoor & outdoor pools, bars, children's club & full entertainment programme. Three miles from Weymouth. *Details from: Margaret Humphreys, tel: 01494-714270 (Bucks & E Berks ASBAH).*

ORLANDO, FLORIDA

House with 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 mins Orlando Airport. 20 mins Disney. Paraplegic owner. *Sue Fisher, 5 Park Lane, Broughton Park, Salford M7 4HT, tel/fax: 0161-792 3029.*

ISLE OF WIGHT ASBAH

Recently refurbished, fully equipped, two-bedroom bungalow, sleeps six. Wheelchair accessible. On site club house, 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.*

ACCOMMODATION

Ilkley, West Yorkshire – vacancy in Flat 3, Denton View, Five Oaks Housing Scheme. Suit ambulant person (there are stairs to the first floor). The self-contained accommodation comprises: spacious bed-sitting room, kitchen, bathroom and hallway. Superb view from the b/s room towards North Yorkshire Moors across the Wharf Valley. A care and support package can be arranged with Bradford Social Services. *Contact: Mark Best, tel/fax: 01943-603013.*

FOR SALE

RENAULT van, M-reg, 17,000 miles, red, three-seater, adapted with ramp so it can take a wheelchair and be fastened in with person on board. Central locking. Cost £13,200, accept £4,500. *Tel: 01332-754 340 after 4pm (Derby).*

TATRA 2 Booster bike, green and grey. Hardly used, excellent condition. Cost £2,500, asking £1,700. *Tel 0171-474 5229 or 0171-474 9675 (Mrs S G Waters, London E6).*

LINK Rates

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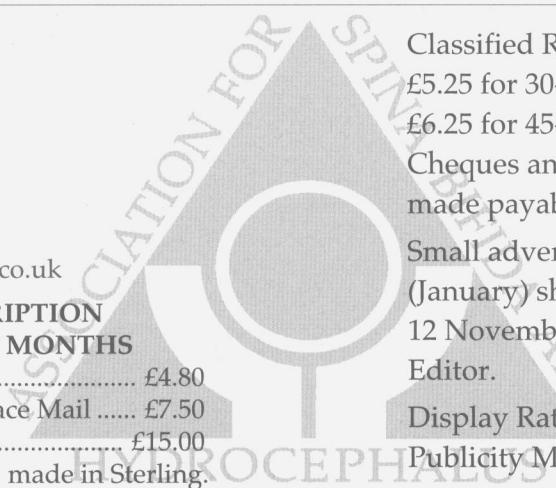
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Classified Rates: £3.75 for 30 words max;
£5.25 for 30-45 words;
£6.25 for 45-60 words.

Cheques and postal orders should be made payable to 'ASBAH'.

Small adverts for the next issue of *LINK* (January) should be submitted by Friday, 12 November. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.



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