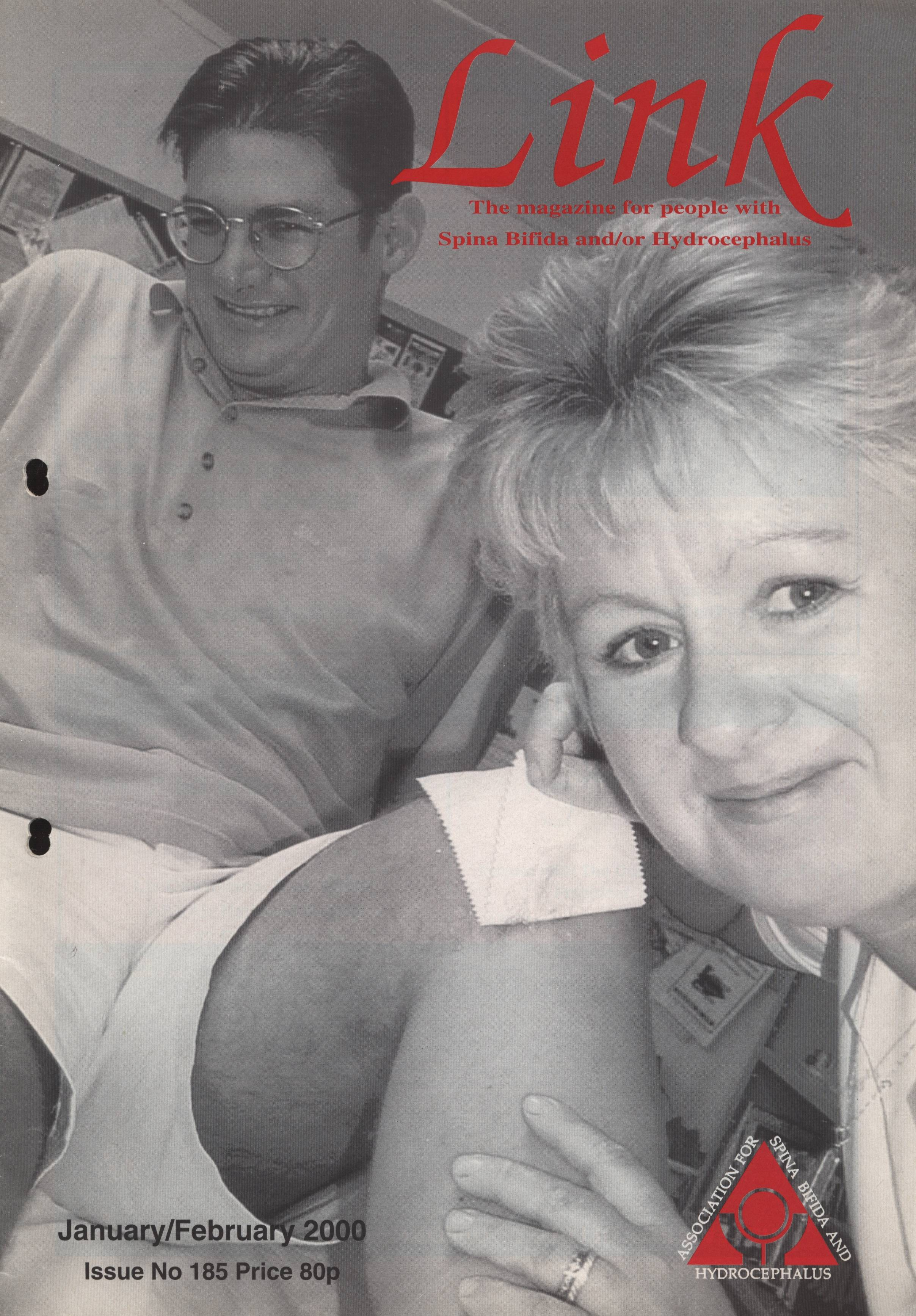
Link

The magazine for people with
Spina Bifida and/or Hydrocephalus



January/February 2000
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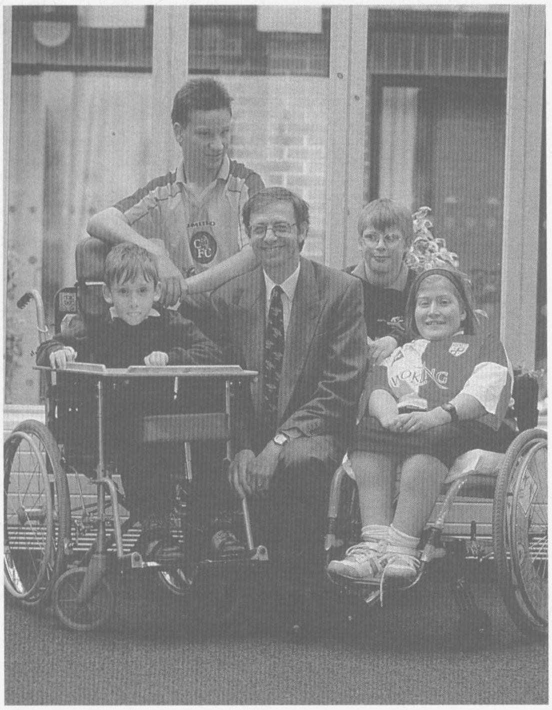
ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS



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Cover: Sgt Jim Duff grimaces as beautician Nicki Visagie is in mid rip! More than £500 was raised for ASBAH when soldiers in Cyprus agreed to have their legs waxed. Full story page 9.

Editorial

Dear Readers

Thank you to those who wrote to let us know what you thought of the television programme about intrauterine surgery for spina bifida. The letters we had – all from people with spina bifida – were positive. You wanted to know when the surgery would be introduced into Britain.

But the procedures are highly controversial. While they have potential benefits, these do need to be further explored and they do carry risks for babies and mothers.

On the centre pages, we give prominence to Dr Joseph Bruner's address on the subject at a recent conference in Perth, Western Australia. I would like to thank the conference organisers, the Spina Bifida Association of Western Australia, for allowing us to quote extensively from the conference tapes. On page 5 – our new main news page – we cover late-breaking news from the Society for Research into Hydrocephalus and Spina Bifida, which entered the debate when president-elect Carys Bannister was interviewed by *The Lancet* in November.

We'll keep you in touch with this and other controversies in the future, and attempt to provide balance and explanation on the way. There will also be more reporting on non-clinical subjects. One other thing we intend to carry out in the first year of this new millennium is a long-overdue revamp of this magazine's appearance. That should be entirely non-controversial. Watch this space!

Tony Britton

Tony Britton
Publicity Manager

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

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

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

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Motability scheme comes under fire

MOTABILITY needs a complete overhaul, say two *Link* readers.

Neil Lewis, a newly-elected borough councillor in Oswestry, Shropshire, has slammed the scheme for penalising drivers who clock-up high mileage.

And Katrina Grounsell, ASBAH Executive Committee member from Essex, has spoken out against Motability for not having a hire company to turn to which can supply hand-controlled cars when members' cars go in for repair.

Neil, aged 23, returned a car to Motability after the usual three-year term – paying a total of £320 because his mileage went over 12,000 a year because he made regular 200-mile round trips to hospital and had council duties.

Neil said: "Motability's philosophy is to keep disabled people mobile. That's great but they are only doing it to a certain level; above this and you have to pay."

Katrina was left stranded after her Motability car was involved in an accident. She could not get another car through Motability as she was told that the car hire firm they dealt with did not supply hand-controlled cars.

She said: "Motability has got a lot of work to do. I would think that 90 per cent of their drivers have hand controls."

Another thing that annoys Neil about the scheme is that he feels it discriminates against non-ambulant people.

"If you need hand controls, you have to pay £240. I find that very hard to swallow.

"The whole scheme needs an over-haul. Although Motability pay for servicing, tax and insurance, there are lots of hidden little extras which add up and which disabled people can't afford."

Motability declined to comment.

Disability awareness hits the mainstream

A TRAIL-BLAZING partnership between schools and a local ASBAH has resulted in hundreds of children discussing disability seriously for the first time in their lives.

Disability awareness training has taken root in a number of secondary schools in Leicestershire – due to an initiative built upon by members of Leicestershire ASBAH.

"It began in Market Harborough, where Gary Farnsworth has had terrific contacts with the Robert Smyth School for years," said scheme organiser Carole Armour. "He spends a fortnight at a time at one school, leading dozens of sessions.

"We picked up Gary's idea and asked other secondary schools in the county if we could go in to raise awareness and discuss disability issues with their pupils. Lots say they can't fit us into their curriculum but some – like Shepshed and Rushey Mead, Leicester – have been very supportive."

The eight-person Leicestershire ASBAH group works with small groups of pupils, using talks, videos and question-and-answer sessions to involve everyone. Topics discussed include everything under the sun, from inaccessible buildings and SEN units to maintaining active lifestyles and personal care.

At one school, the discussion raced ahead when pupils seized on Bianca and Ricky's spina bifida pregnancy in *EastEnders* to pose a huge number of questions.

Carole, a member of ASBAH's own education advisory committee, added that each course needed thorough preparation. But group members were committed and did not take on more than they could chew.

Warning on pre-natal surgery

WORK in the United States on intrauterine repair of spina bifida lesions should pause for a period of reflection, suggests the Society for Research into Hydrocephalus and Spina Bifida.

In a report in *The Lancet*, society president-elect Carys Bannister warned that "modest short-term benefits were achieved only at great risk to both fetus and mother."

The only two teams in the world to have declared they are working on intrauterine repair of spina bifida have now published results of deliveries after surgery on the babies in the womb. The results – involving only relatively small groups of patients – show reductions in both post-natal hindbrain herniation (the Chiari malformation) and the need to insert hydrocephalus shunts.

"We were suggesting in *The Lancet* that they probably now had enough patients in the two series to answer the questions that could be asked about checking on the outcomes," said Miss Bannister, consultant paediatric neurosurgeon at St Mary's Hospital, Manchester.

The work is being carried out by teams at Vanderbilt University Medical Centre, Tennessee, and Philadelphia Children's Hospital. They are led, respectively, by Joseph Bruner and Scott Adzick.

The SRHSB acknowledge that reduction in hindbrain herniation and in the need for shunts would bring benefits but point out that neither of the groups in the States had yet assessed walking ability, bladder and bowel function and cognitive ability in more than a handful of patients treated.

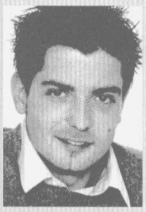
Neither team had yet investigated the long-term effects of intrauterine surgery on mother's future ability to conceive and carry another child. SRHSB also alleged that Vanderbilt's use of the Bayley Scale for infant development testing was crude and out-dated.

Miss Bannister told *Link* about two other areas of concern – lack of pictorially convincing evidence of reduction in hindbrain herniation on the basis of the MRI scans published so far. Instead of single, rather poor photos, she would prefer to see whole sequences of scans. Noel Tulipan, the neurosurgeon attached to Dr Bruner's team, should also publish more.

When told that ASBAH had received letters from people with spina bifida advocating the introduction of intrauterine surgery into the UK, Miss Bannister commented: "That's not our experience. In St Mary's, for instance, husbands have said they would not want that treatment for their babies or their wives."

- Turn to centre pages, to find out more – in Dr Joseph Bruner's own words.

Modelling top spot for Ben



AN ESSEX foreign exchange dealer has been named as one of Britain's most promising new faces by coming first in a national modelling contest – aimed at getting more disabled people used as role models on TV and in advertising campaigns.

Ben Ashwell, aged 23, who has spina bifida, was chosen from 500 others in the competition organised by the Leonard Cheshire Foundation and VisABLE, an agency for disabled models.

Ben, who works for a bank in Chelmsford, said: "I didn't set out to make a political point but the more I think about it the more I agree with the aims of the competition. It's a good idea."

● ***More on the contest in the next issue of ASBAH's* Lift *magazine.***

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Contacts

People

they make us tick!

- CAROLINE Berkley, specialist adviser (medical), South-East Region – *pictured right* – has left ASBAH after more than six years to become a Hospice At Home co-ordinator, based in Welwyn Garden City.
- EDUCATION adviser for our East and South-East Regions, Petrina Noyes, gave birth to Lucy Rebecca towards the end of October. The baby weighed in at 6lbs 14oz, the second child for Petrina and husband Sean.

Down to earth after Himalayan adventure

BACK from the roof-top of the world – Andrew Russell has a heap of ripping yarns about his holiday trek in the Himalayas.

Our executive director survived an expedition to the Pindari glacier, 14,000 feet up in the shadow of Nanda Kot, India's highest mountain, in October.

Andrew *(fourth from left in this group photo)* came back with his usual zest for recalling the highs and lows of an eventful trip. With an account of hundreds of thousands of people crowding the road to Nanda Kot, and rickety buses dodging out of disaster's path in the final nano-second, it sounded more fun than *Raiders of the Lost Ark*!

But, if you want to keep your lunch down, don't ask him the one about the shoeshine man with an unerring aim and a guaranteed way to catch out his clients. That story was just too disgusting!

- OUR new adviser for W/SW London, who replaces Lucy Holmes, brings wide experience to the job.

Robyn Verney has been a social worker, occupational therapist, nutritionist, assessor of funding applications for the National Lotteries' Board and conciliator. Most recently, Robyn was co-ordinator for the Duchenne Family Support Group, which is part of the Muscular Dystrophy Group.

Relaxed Ray drives in to see The Queen

RAY GAINER grins broadly from his car – having actually driven in to Buckingham Palace – after receiving his MBE from The Queen in October.

Ray, honoured for his services to charity in the borough of Wigan and his voluntary work for disability sport in the North West, said: "The Queen was very laid back, not at all like the person you see on TV, and made you feel very much at ease. She knew about my work with disability sport, and took a little bit of a fancy to my sports wheelchair."

Aged 39, from Crosby, Liverpool, Ray is a qualified wheelchair tennis coach and champion, a former chairman of Manchester United Disabled Supporters' Club, and he travels thousands of miles each year, encouraging disabled children to take up sport.

Ray parked before the investiture inside Buckingham Palace with wife Gillian, brother Jimmy, sister Christine and Mary Roberts, of Wigan, Leigh and District ASBAH.

'Oscar' winning teacher joins forces with ASBAH

ASBAH has pulled off a major coup – persuading one of the first winners of teaching's equivalent of the Oscars to join our Education Advisory Committee.

Barbara Berryman *(right)* won the 'Plato' for secondary school leadership and a £23,500 prize for her school last summer – receiving the award from Prime Minister Tony Blair. Earlier in the year, she had also received an MBE for services to special education.

For 11 years, Mrs Berryman has been headteacher at Marshfields School in Peterborough, an LEA maintained co-ed special school with pupils aged from five to 18 years. At the moment, the school has one pupil who has hydrocephalus.

"In the government's desire for inclusion as an equal opportunities issue, some children with special needs will not find in the mainstream the specialisms they need. We don't need a special child to be included in mainstream classrooms as a form of tokenism," said 59-year-old Mrs Berryman.

A member of the national Association for Head-teachers special needs committee, she is working with the DfEE on a website about special education.

The Brains Trust

BBC asks: Are they really the cleverest of them all?

FOUR neurosurgeons spilled the beans on some of what makes them tick when they took part in a discussion broadcast on BBC Radio 4.

It was the last in the series of *The Healers* – looked at the personalities behind the consultants who care for us when we are unwell.

Connor Mallucci, paediatric neurosurgeon at the Walton Centre in Liverpool; Peter Hamlyn from the London Hospital and founder of the British Brain and Spine Foundation; Dorothy Lang from Southampton General; and Kevin O'Neill from Charing Cross in London, spoke about the advent of new technology; how they broached the subject of a risky surgical procedure with patients and / or parents; and the increasing level of knowledge patients have about their conditions due to the input of organisations such as ASBAH and access to the Internet.

As the brain is the body's most complex and perplexing organ, the neurosurgeon has an unenviable task.

Traditionally regarded as the most clever in the profession, programme presenter Niall Dixon wanted to know: "Are you the brightest stars in the medical firmament?"

Although they admitted to this not being necessarily the case, neurosurgeons were pronounced to be extremely dedicated and totally committed to patients who are critically ill.

Advances in scanning technology were recognised. Neurosurgeons are now able to plan and predict operations in advance to an extent to which they were never able to do in the past.

Mr Hamlyn commented: "The days of the exploratory craniotomy, where surgeons who trained me opened the head to see what was there, are over. We know what's there, it's just whether we can deal with it."

To understand more about the stress which neurosurgeons face, a pre-recorded interview with consultant neurosurgeon, Miss Anne Moore, in theatre at the Atkinson Morley Hospital in South London, was played on the programme.

Miss Moore was asked if she ever thought that her work might change the very nature of a person's being.

She said: "Yes, I do think about that. To a large extent many neurosurgical operations run the risk of altering people's whole life by leaving them with a disability either in terms of their cognitive functions, their personality, their abilities, but also, obviously, in terms of their physical status. And that is something that is very hard to live with sometimes."

Miss Moore balanced the stresses she faced with the joys of the job – the times when she saved somebody's life, against all the odds.

Connor Mallucci was then asked how he reacted when something went wrong, particularly when working with children.

Mr Mallucci said: "Children often can't consent for themselves so you are really asking a mum and dad to hand over their precious child for you to operate on. I think the key is to build a relationship of trust and to be honest, and I think that if there is going to be a post-operative problem, the most important place to start is to have gained the trust of the parents beforehand."

There was some discussion on how knowledgeable patients were of their own conditions.

Mr Mallucci commented: "One of the things that I've noted over the past three or four years particularly is that .... people now get a lot of information before they come and see you. Particularly, the Internet has changed things significantly and I would say that almost one in 10 of the patients I see now, parents of, particularly, children with hydrocephalus and spina bifida, for which there is a world set-up information base both with societies and Internet, usually know what you do, who you are and what can be expected, and they usually also are able to see what's happening across the Channel or across the Atlantic."

The low level of service provision in neurosurgery in the UK were then picked up by Mr Hamlyn who revealed that there were seven times the number of neurosurgeons per head of population in the United States as over here.

Mr Mallucci then pointed out the areas where he looked forward to further advances – in the treatment of brain tumours, hydrocephalus and spina bifida.

Meningitis C vaccinations

YOUNG people and children with spina bifida and hydrocephalus are advised by ASBAH to have the meningitis C vaccination currently being offered by the NHS.

This does not mean that people with hydrocephalus are more prone to meningitis but the symptoms of shunt malfunction and those of meningitis can be very similar and, therefore, easily confused.

Although the target groups are college/university students and 15 to 17-year-olds, anyone with hydrocephalus working with these groups, that is teachers, should also consider having the vaccination.

Immunisation against meningitis C is not a live vaccine.

Rugby-mad brothers meet the Samoans

AS RUGBY fever swept Wales during the World Cup, two fans collected a host of happy memories to look back on.

Main photo: Rhys and Geraint James with their signed Samoan rugby team memorabilia.

Inset: Geraint and Rhys at the special lunch at the Swansea Marriott Hotel with the Samoan team. Photos courtesy of South Wales Echo

Avid Wales supporters, Rhys and Geraint James, aged 12 and 14, set themselves the challenge of collecting memorabilia from every international rugby team to play at Cardiff's brand-new Millennium Stadium.

Their requests reaped a huge bounty of goodies, and some great meetings with some of the teams.

Mum Elayne said: "It was really special for them because they've had lunch with Samoa, trained with the Wallabies and had signed balls from Japan and Argentina but they actually got to see New Zealand playing against each other in training."

The boys, from Llanederyn, Cardiff, who both have disabilities, lunched with Samoa before being presented with a signed ball, limited edition rugby book and exclusive baseball caps only worn by the players.

Elayne said: "Pat Lam, the captain, made a very touching speech saying that the Samoans were known for being very brave and strong but that Geraint and Rhys were stronger in their day-to-day life than any of the team."

The entire squad then stood and gave an impromptu performance of Samoan chants and songs that will stay with the James family forever.

"It was like a professional choir," dad Bryn told the *South Wales Echo*. "The music was haunting."

Rhys, who has spina bifida, said: "It was really nice – I felt happy inside. I loved the dancing and the singing."

Wales region

OUR new regional centre in Wales opened just before Christmas. The offices are in Bangor, north Wales – just 20 minutes across the bridge from the Isle of Anglesey home of Elin Ifan, our regional manager.

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No pain, no gain!

SEVEN courageous men from JS Equipment Support Branch, at British Forces Headquarters in Cyprus, went through the pain of having their legs waxed to raise more than £500 for ASBAH.

We were chosen as the charity to benefit by Sergeant Jim Duff. ASBAH is very close to Jim's heart after tragically losing his first child to the condition in 1993.

The 'girls' from the office, Karen, Vicki and Tracey organised the event and collected the sponsors.

Nicki Visagie, of *Top to Toe* beauty salon gave her time to help with the dastardly deed, and staff from Episkopi Hive provided the wax.

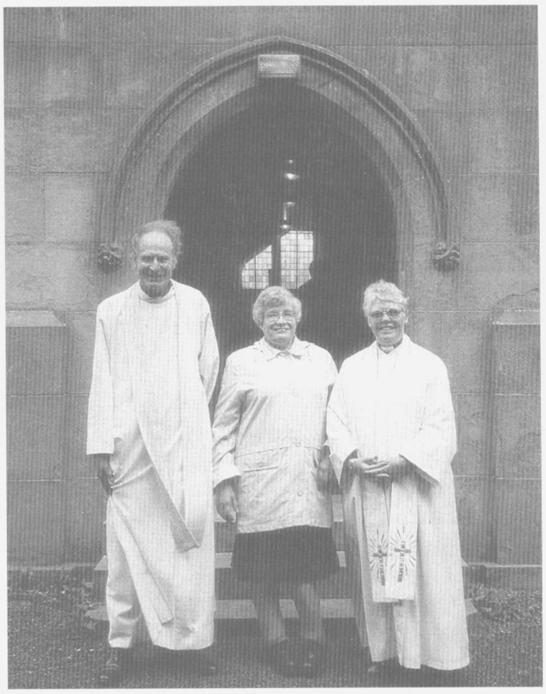
With all the minor details arranged, there was only the major task of waxing those legs!

As the front cover of this issue of *Link* shows, Sergeant Duff led the way and his statement 'no pain, no gain' was very apparent from the grimace every time the waxed strip was ripped off.

Following on were: Lieutenant Colonel Terry Perks, Flight Sergeant Steve Sullivan, Warrant Officer Class One Roy Rogers, Major Phil McMahon, Staff Sergeant Graham Mundy and Private Robert Miller.

ASBAH sent a huge thank-you to all those contributing.

Orders for access



Christine Helliwell is pictured at the door to St Martin's Church, Brighouse, with the vicar, the Rev Giles Harris-Evans, and the curate, the Rev Marie Teare

A HALF MILLION pound plan to make the act of going to church in Brighouse, West Yorkshire, into a pleasure for disabled people has been given the blessing of Christine Helliwell.

Christine, a member of our YVIA members forum, has helped draw up plans to revolutionise church-going at St Martin's Church, Brighouse, where she is a leading member of the congregation.

The plans, recently approved by Church of England authorities, call for the introduction of accessible toilets at the back of the church and a lift upstairs, where kitchen facilities and a meeting room will be built. Specially sound-proofed children's facilities will also be placed in the main body of the church.

"The fact that we want to make an old, beautiful building fully accessible to people in wheelchairs makes it quite expensive, but we are determined to do it and raise the necessary money," said Christine.

"This is an immensely exciting project for the parish. The church is already ramped and we have held a number of services where there have been special arrangements for disabled and elderly people to come in to join in our worship", said Christine, who works as an analytical chemist.

In a country where church attendances have been in free fall for years, St Martin's is bucking the trend, and it is taking steps to see it stays that way.

Recent special events, where Christine has organised the transport, included a Songs of Praise service in October where dozens of extra members of the congregation were brought in from residential and private homes in the area.

BOOKSHELF

● RAW CRICKET as it is played out anonymously on village greens and club playing fields is the background to *Playing Away,* a comic novel now on sale in aid of Kent ASBAH.

For £6 (inc post), readers can follow the misfortunes of down-at-heel Brickfield Wanderers Cricket Club in 1982 as Noggin Bracegirdle stakes a £300 bet – a month's pay as a teacher – that the team will survive another year. Noggin, alarmingly for his blood pressure, has just taken on the task of the organisation of the team, promising to field 11 players more or less sober for each game.

***The book, written by Rob Zanders, can be obtained from* Playing Away, *c/o London Plant Hire, Belmont Parade, Chislehurst, Kent BR7 6AN. Cheques should be made out to* Playing Away.**

Money raised from sales for Kent ASBAH will be put towards its new independent living project, due to open later this year. The scheme will offer a safe and caring environment and specialised training for up to eight youngsters with spina bifida and/or hydrocephalus.

● FORMER ASBAH continence adviser Mary White, and Penny Dobson, have written *Bowel & Bladder Management in Children with Special Physical Needs,* a new 36-page booklet published by the Enuresis Resource & Information Centre (ERIC) at £3.50.

Packed full of information, practical tips and pictures, this has been produced for parents of children and with physical disabilities who take longer than other children to gain bowel and bladder control, and for health professionals.

For some children, the disability causes a permanent problem. The book shows how they can be helped to achieve control or, if this is impossible, how they can manage the condition effectively so their problems are minimised.

Orders to ERIC, 34 Old School House, Britannia Road, Kingswood, Bristol BS15 8DB. Cheque payable to ERIC.

● A GUIDE to opportunities for students wanting to get into higher education has been published by Skill, the national bureau for students with disabilities. In 92 pages, *Higher Education 2000* explores the market, and gives examples of how disabled students overcame discrimination. ***£2 to disabled students, trainees and job seekers; £6.50 to others. Tel: 0207-450 0620.***

APPEALS PAGE

With a little help from our friends!

Coast-to-coast

FOUR-strong group of cyclists – Keith Weavin, Mark Stevens, John Marsh and Gary Smith – handed over a cheque for £1,079 to ASBAH's fund-raiser Ian Morley *(front, left)*. The riders raised the money by cycling 140 miles, from Whitehaven to Tynemouth, in two days. Also pictured *(front right)* is Mr Weavin's son, James, aged 14, who has hydrocephalus.

Rally champ races in to support ASBAH

RALLY CAR driver Allen Griffith races back into competition this year – with a £44,000 car, a 12-man back-up team and a promise to donate track takings and half his prize money to ASBAH.

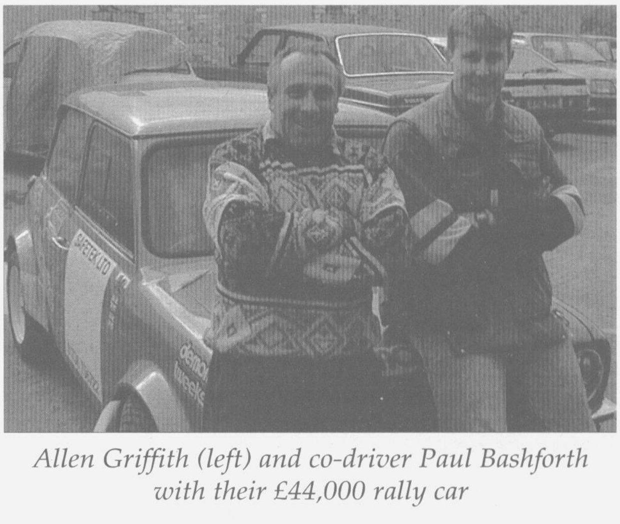
The former Welsh champion and American Indy driver and his team Griffton Racing have signed up to a 10-month racing season, starting at Cadwell Park and finishing with the Network Q Rally of Britain.

The garage owner from Truro, Cornwall, has been entering motor rallies since first allowed a set of wheels at the age of 13. He has spent the last three years creating his dream machine out of the shell of a Mini Clubman 1300 turbo.

He used to support another charity, donating many thousands of pounds to them over the years. He offered to switch his allegiance to ASBAH after a chance encounter over the phone with an ASBAH National fundraiser. Corporate fundraiser Mike Miller then travelled to Cornwall to discuss details.

"Racing's in the blood. My great grandfather, who used to do the wall of death, hung about with Donald Campbell," said 44-year-old Allen.

"And I've passed it on. My son David, who is 13, is Griffton Racing's chief mechanic and, when we're not out on the road, he is doing his own mini-stock car racing."



Allen Griffith (left) and co-driver Paul Bashforth with their £44,000 rally car

ASBAH depends on the generosity of its supporters. One area where you can help is by doing a sponsored event.

You choose the activity – running, cycling, walking, parachuting or whatever. We'll come up with the t-shirt, sponsor forms and a certificate when it's all over... to prove how much you raised.

ON YER BIKE!

or whatever else takes your fancy

If you or your friends can take rise to a challenge while raising money for ASBAH's unique range of services, please let me know.

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ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

‘Short rations’ from the NHS?

TWO of ASBAH’s staff – Marcia Conroy and Jon Burke – told MPs how they thought the NHS could be improved for people with life-long conditions such as spina bifida and hydrocephalus. Each addressed a fringe meeting at the Conservatives’ and Lib Dems’ annual conferences.

The meetings were organised by the Long-Term Medical Conditions Alliance and groups like the Haemophilia Society to show how knowledge and awareness, as well as resources and expertise, were rationed within the NHS.

The medical care of people with spina bifida and hydrocephalus had in some ways developed enormously in the past 30 years, Marcia Conroy said at the Conservative Party conference in Blackpool.

Marcia mentioned advances in treatment and operations, now routine, which had dramatically increased the quality of life and lifespan of people with hydrocephalus and/or spina bifida.

Praise was also due where effective support was given to people with spina bifida and/or hydrocephalus – and their families – who were often experts in their own conditions and who were aware of signs of developing problems. Early intervention, Marcia said, was crucial as it often avoided problems becoming chronic.

The positive attitude of GPs and other professionals towards disabled women wishing to become mothers, as well as the appropriate medical care, were also big steps forward for the NHS.

However, Marcia noted many gaps in the provision of medical care for people with spina bifida and/or hydrocephalus:

- When a child with SB/H is born, input from medical professionals can be negative.

Marcia said: “Parents need to be given holistic information around the life opportunities of their child and not just the medical problems that their child may have.

“Many people with spina bifida and/or hydrocephalus are now attending mainstream education, doing college courses, working, having relationships, owning their own homes, raising their own children and taking part in society as we all do. These aspects are not discussed enough and doctors need to develop the appreciation that the lives of people with spina bifida and/or hydrocephalus is not the same as it was many years ago.”

- Lack of knowledge by many GPs has big implications around people with SB/H getting the right medical care. Often GPs do not understand the need to refer to consultants and this can become a struggle between patient and doctor.

Marcia told Tory MPs: “More than this, GPs need to have an understanding of these conditions and also an understanding that people with spina bifida and/or hydrocephalus need to be listened to and their experiences taken seriously.”

- Inappropriate wheelchair provision. Marcia said: “Disabled people need to use wheelchairs that do not further stigmatise their disability and, at the present time, wheelchairs that are provided by the NHS can be very stigmatising.”
- The financial strain of prescription charges for catheters and dental care for employed disabled people.
- After the age of 16, therapeutic services such as hydrotherapy and physiotherapy become very limited.

Marcia said: “Medical intervention under the NHS should not just be about providing the best consultants and the most up-to-date operations but other services, such as physiotherapy, wheelchair provision, continence provision and GP care, should be recognised as valuable forms of service.”

Lib Dem MPs, including Commons and Lords’ party spokesmen, heard Jon Burke’s presentation on the NHS in Harrogate.

Jon looked at the more obvious kinds of rationing which people can come into contact with in the NHS, such as waiting lists for consultants and the availability of drugs.

He then described the rationing of GPs’ knowledge of specific medical conditions and lifestyle issues, which Jon put down to lack of information and training.

Another form of rationing was input from the patient in being allowed to decide the way forward in terms of their treatment.

“For example, you may have a consultant saying this is what we are going to do to you when perhaps he should be involving the patient and making the decision on the basis of an individual’s lifestyle, mobility, amount of time and degree of independence at home,” Jon said.

Silver is the new black

by Suzanne Bull

RECENTLY I took part in a photo shoot for Artsline's Fundraising Fashion Show (to be held on 12 April 2000) at Selfridges. I had always dreamed of doing something like this, and I had a fantastic time! Myself and two friends, Liz and Mike, turned up early in the morning. It was Mike's birthday the day before so, by the time he had sobered up, Liz and myself had already chosen our outfits and were heading towards make-up!

There were three categories of clothes: urban wear, evening wear and casual. Knowing that I rarely get a good fit on a dress and my kind of casual is combats, I picked urban wear. Whilst Liz draped herself in diamanté and Mike got into his corduroys, I sped off towards the synthetics.

Selfridges press officer was our personal assistant. Apparently, when she was helping me, I was whizzing past the rails, grabbing randomly and she was running behind me, her knees buckling under the weight of the clothes!

The designer urban wear at Selfridges is fab! I picked out lots of silver, black and red. I tried on a couple of Gaultier outfits but he does not really cater for the larger chested (except Madonna!) and his choice of colours can be gaudy. In the end, I opted for a long-sleeve top by a new haute couture company, who have a strong Red Or Dead meets Vivienne Westwood influence, called 'Jesus, Elvis and Haute Couture.' It was black with white crosses and the words 'Elvis Forever'. Now I've described it, it sounds absolutely hideous, but it isn't! (I bought it!). I also picked out a pair of black trousers and a red jacket by Girbaud that I cannot describe except to say that some people may not think that I possess an iron! I also bought the jacket for £195 – in place of a summer holiday. A girl needs something to compliment her new RGK wheelchair, you know! My hair was turned into a delicate sculpture as it was spiked up on high and my make-up was fairly dramatic (and hard to scrape off at the end of the day). Finally, I was photographed in the Modern Furnishings section and at last I could get to sit on a chair a la Christine Kieller (clothes on, thank you!). My, was I happy!

I found Selfridges to be helpful and accessible although I was there in a different context. The staff were very supportive with our fashion shoot and were more than happy to be involved. After all, it was good PR for them as well as us. I could manoeuvre fairly easily in the changing rooms and when the press officer had to rush off and I looked like another shopper, if I asked for assistance, staff were obliging.

My biggest bug-bear with shops is that they do not stock enough in 14+ or under size 10 which I, bizarrely, fit into both of those categories. Apart from the difficulty of steps to enter the shop, they often do not leave enough room between aisles to move around. The counters are always above one metre and it is literally a pain in the neck to reach up. Most of all, I hate the moody assistants who act like they are doing you a big favour if you ask for help especially when the shop is busy. Anyway, enough moaning and more turning up at places that are inaccessible to get in, then venues will have to do something about their access and attitude. There are only so many times you can be turned away!

A bit of help with Council Tax!

FROM this April, some people with disabilities in Band A properties can now qualify for a Council Tax reduction.

The amount of Council Tax can be reduced where a resident (adult or child) is substantially disabled and at least one of the following is provided in the home:

- a room which is mainly used and needed by the disabled person;
- a second bathroom or kitchen is needed by the disabled person;
- a wheelchair is used indoors by the disabled person.

The reduction is awarded by charging on the band immediately below the normal banding.

For a property in Band A (the lowest band) no reduction is awarded at the moment.

However, the Government has changed the law and, from April 2000, a council taxpayer with a property in Band A will be eligible for the reduction. If granted, the reduction would amount to over £85 a year – the exact amount varying from area to area.

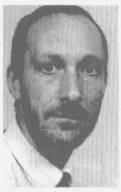
Typically, B and A properties will be small houses and flats so the facility most likely to qualify would be a wheelchair used indoors.

Claimants do not need to receive any benefits in order to obtain this reduction.

More visits to www.asbah than ever

OVER 1,460 visits were made to ASBAH's website during one week in November – a new record high.

Since the website started three years ago, there has been a steady rise in the number of 'hits' to our webpages, but not without the occasional, inexplicable dive.



Dobson: 'nothing flash'

Designed for ease of access, with no megabite-hungry photographs or flashy add-ons to slow surfers down, 1,000 hits per week were first recorded in February 1999.

Paul Dobson, ASBAH's director of personnel and IT, designed and maintains the site. He said: "Our 78-page website loads quickly on to the average home computer. I have kept pictures small and down to a minimum so people can get in to the site and move around it quickly."

ASBAH's website contains extracts from our annual Guide to Services, Information Sheets, articles from *Link* magazine, diary dates, and contacts for local ASBAHs and other associated groups – like the International Federation for Hydrocephalus and Spina Bifida, continence groups and other disability groups.

Paul said: "As the links on our website to other groups grow, the number of people who we're exposed to increases.

"I also check around the 'search engines' [Internet directories] and make sure we're listed."

LINKS

www.asbah.demon.co.uk
ASBAH on the web

PRE-NATAL SURG
the most active

ABOUT 60 babies with spina bifida have had their spinal lesions closed while still in their mothers' wombs at a hospital in the USA.

The technique of lifting the womb out of the pregnant mother, draining off the amniotic fluid and opening the womb to expose the lesion is being pioneered at the Vanderbilt University Medical Centre in Tennessee, USA, by obstetrician Joseph Bruner. He spoke about his work at a conference in Western Australia in September,

Women carrying babies with myelomeningocele have travelled to Vanderbilt from 26 US states and from Canada in the hope that surgery during pregnancy will lessen the disabling effects of spina bifida. They have chosen intrauterine surgery even though the lives of both mother and baby are put at risk, he said.

Most of the operations had been performed at 21-30 weeks of pregnancy. 54 of the babies have been born alive, but prematurely – age at delivery averaging 34 weeks.

The oldest child was born in June 97, so only a small number of children operated upon in the womb are more than a year old. So far, no significant change in leg function has been noted.

Future plans to operate earlier – at 21 or 22 weeks – should result in better leg function, he claimed. But the risks will increase. If labour starts then, few of the babies will survive.

Dr Bruner recognised the ethical dilemma: "When our parents come to us, we ask everyone what's the worst that could happen? Interestingly enough, they all say the same thing: the worst that could happen is that my baby could die. But, if you think about it, this can't be true. If the worst that could happen is that their baby could die, they should do nothing at all. If they do nothing, their baby will be live-born, go to the nursery. The only risk of death this child has is if they come and see me!

"And this is a serious, ethical issue. What would this child decide to do if it had a vote? Obviously, there is a lot of work to be done in this area."

Fewer of the babies on whom he and neurosurgical colleague Noel Tulipan had operated required shunts after birth, compared to babies who did not have this type of surgery. Those that did, he said, needed shunts at a slightly older age than usual.

In a second talk, Dr Bruner described his first intrauterine operation for hydrocephalus by itself, on a baby at 23 weeks with enlarged ventricles. A special, prenatal shunt had been put in place and, when the baby was born a little prematurely, he had near normal-size ventricles.

A legal loophole threatened the effectiveness of the US government's strategy to compel the addition of folic acid to all flour-based products, said another speaker.

Neurosurgeon Jerry Oakes, also from the US, said spina bifida was a huge issue in the States where 2,300 babies with myelo-
meningocele were
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bout confidentiality and, of course, we don't use any of the confidential data. I think it is very important to reassure people about that."

Dr Joseph Bruner

LINKS

http://webriver.com/bruner/index.htm Jo Bruner's website

To operate on the spina bifida lesion before birth or just after birth – that was the question posed in October by *Born Twice*, a major BBC1 film.

The surgeon in the documentary, Joseph Bruner, had the previous month spoken about his work at length at a three-day conference called by the Spina Bifida Association of Western Australia. On the left, we give extracts from his talks there.

On the next page, we print extracts from letters about the TV programme and neurosurgeon Vic Boston explains why in Northern Ireland they choose a third way – neither closing the lesion immediately after birth, as happens in most of mainland Britain, nor doing intrauterine surgery (because, of course, the facilities for this operation do not exist anywhere in the UK).

Over several months, ASBAH co-operated with the TV programme. We pointed the film crew to a few of the many people who had made a go of their lives since having neonatal surgery in the UK. The comparisons they made with the limited results so far from intrauterine surgery were balanced, accurate and fair.

For the present, ASBAH says there is no overwhelming evidence that intrauterine surgery is better at improving limb function than neonatal surgery, and there is only limited evidence that the operation defers the onset of hydrocephalus. The surgery is still somewhat experimental and the full results have not been published. The work does, however, hold promise for the future.

What conference delegates from the UK had to say ...

● **KATRINA GROUNSELL**, from Essex, was disappointed that much of the conference was aimed at professionals and not enough emphasis was placed on what disabled people can do with their lives. "Some speakers spoke above the lay person. But the one I was expecting to talk above us, Dr Bruner, didn't. He made it so people could understand and I was very impressed."

● **ANDREW RUSSELL,** ASBAH executive director, said: "We enjoyed a well attended international conference. The audience included a good mix of disabled people, parents and professionals, with a very high level of presentation and discussion. There was a rather traditional strong emphasis on health and medical subjects, rather than on rights and choices, but the conference programme appeared to be warmly welcomed by the disabled participants as well as parents and professionals. I hope the next international conference will have a stronger emphasis on enabling people with spina bifida and hydrocephalus to take their proper place in society.

However, I attended a very good workshop on employment, which indicated that Western Australia has essentially the same problems as we, in the UK. A lot of work is still needed to improve the attitudes of employers and public."

continued on page 16

Bruner: points from the post

✉ THE programme stressed that the operation did not cure spina bifida and mentioned early surgery which had been unsuccessful. Although doubts about the surgery and the risks associated with prematurity were expressed, as one of the parents said there are no easy choices associated with treating such conditions.

I was saddened to hear that Dr Bruner still performed abortions, while thinking how the child could be treated and enabled to enjoy life with only mild disability. This does not bode well for this potentially life-changing surgery becoming the norm. Although surgeons in the UK argue that the number of successful operations is too small to justify performing this operation here, its potential benefits are too great to be ignored.

ASBAH should actively support further research and clinical trials in this revolutionary new treatment which could transform the lives of future generations.

Miss Helen M Butler
Hatfield, Doncaster, S Yorkshire

✉ I AGREE with Dr Bruner's work agree whole heartedly. I only hope that in England we have the optimism to do the same operation. That way the children who have been diagnosed with spina bifida won't have do go through what I had to endure as a child 36 years ago.

I was 10 hours old and had to have a five-hour operation, which left my back in an awful mess. It was such a rush job to close my back that, if they had not done what they did, then either I wouldn't be here or my parents were told I would have been a cabbage. Thank God that didn't happen.

Miss Lynda M Jones
Clevedon, North Somerset

UK delegates *(from page 15)*

● **TERESA COLE**, vice-president of the International Federation for Hydrocephalus and Spina Bifida, enjoyed the event and networked: "The river cruise with buffet and dancing immediately after registration was an excellent idea. People got to know each other right from the outset and it helped 'set' the friendly atmosphere of the entire conference."

Is early closure of the back lesion in spina bifida usually necessary?

By Mr Victor Boston
MD, FRCS (Ed), FRCS (Eng), FRCSI
Consultant Paediatric Surgeon
Belfast, Northern Ireland

IT IS known that most babies suffering from spina bifida suffer progressive damage to the exposed nervous tissue at the back lesion and that, by the time of birth, the majority will have completely destroyed all functioning nerves in that region. This damage is permanent and early surgical closure of the back lesion does not result in any restoration of function. Some years back, the consequence of not closing the back lesion at birth was not clearly understood. In those days there was a popular belief that surgery shortly after birth was essential in order to avoid infection and potential life threatening complications.

In Belfast, we were able to demonstrate that, by not closing the back lesion immediately after birth, these babies with spina bifida were not exposed to increased risk, providing they received all other measures to treat complications of their disease. In addition, we were able to show that avoiding early surgical closure defers the onset of hydrocephalus that would otherwise usually have required treatment shortly after birth. This may be of benefit because it is known that complications from CSF shunt surgery are more frequent in younger children during the first year of life.

Most children who are treated without initial closure of the back lesion will avoid major surgery because this will heal spontaneously after about one month. In our experience, most of these babies will have a soundly healed scar which is painless and which will not require surgical closure. However, once the back has healed, closure can be undertaken at any time thereafter without increased risk. It is important to understand that those children who have not had the back lesion closed will have been offered this treatment in order to improve the outcome. This should not be seen as inferior treatment that will expose the baby to increased risk of complications.

This being the case, which children will benefit from early closure?

Protection of the exposed nervous tissue at the back lesion can be achieved by surgical closure of the back lesion shortly after birth. This is clearly of no benefit to babies who have completely damaged the exposed spinal cord. On the other hand, if there is evidence of preservation of nervous function, surgical closure should be undertaken to prevent neurological deterioration that would otherwise occur if an operation were not undertaken.

Lastly, there are a small number of babies with open back lesions which are situated near the anus and these should be closed early in order to avoid infection which might result in meningitis.

The answer to the opening question is therefore, yes, early surgical closure of the back lesion in spina bifida is indicated in some cases but not always.

● *As a consultant in Belfast for nearly 25 years, Mr Boston has been involved in the treatment of babies with spina bifida. In the mid to late 1970s, his department saw about 150 new cases per year. Since then, there has been a decline. They now see about 10-15 new cases per year out of a present population in Northern Ireland of about 1.75 million.*

Hnn
Hydrocephalus Network News
Winter '99/00

A Happy New Millennium to all Hnn readers

Marian meets The Corrs

ICING on the cake for Marian McIlroy was meeting pop sensations The Corrs during a weekend brimming over with treats.

Marian, who appeared on the front of the Autumn *HNN* as fund-raiser for baby Charlotte Linton, was one of 10 winners of an all-Ireland children's award, presented by the Irish president, Mary McAleese.

The 11-year-old – the only winner from North of the border – joined TV and sporting celebrities at a gala ceremony at Dublin Castle.

As well as a certificate, she took home a party bag with goodies worth more than £200 including a radio and personal stereo.

She was nominated by her mum, Ann, who spoke of her determination. Mrs McIlroy said: "We are so proud of Marian. She has tremendous strengths and let's nothing stand in her way. For example, she has had a fear of water since she was a child yet since starting secondary school she has begun swimming lessons. Once she takes something on board, she won't put it down."

As reported in the last issue, Marian raised £3,000 to help buy sensory equipment for Charlotte.

Marian and Charlotte – who were both nominated for the awards – had another treat in store as they were due to join a Christmas party in Dublin for all winners and nominees.

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User-forum (Northern Ireland): Helen Clarke 028-4488 1898.

DIARY DATES .. DIARY DATES ..

Saturday 22 January

ASBAH Looking Good/ Feeling Good Day to include aerobics for all, make-overs, colour consultants, aromatherapy, plus lots of opportunities to have a chat and meet old friends. Venue: Gloucestershire County Cricket Ground, Nevil Road, Bristol. 9.30am–4pm. ***Please book in advance. Details: ASBAH Adviser Julie Knight, tel: 0117-924 5077.***

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***

7–8 April

Spina Bifida, Sex and Relationships, a course for adults with spina bifida run by people with spina bifida, West Shore Hotel, Llandudno (fully wheelchair accessible). Cost £30, including dinner, bed and breakfast, plus sandwich lunches, coffee and tea. Llandudno is accessible by rail and participants can be met at the station. ***Details: ASBAH Advisers Angela Lansley (tel: 0151-733 8392) or Elizabeth Miers (01490-450360).***

9–11 May

ASBAH at Naidex 2000, the independent lifestyle show, Hall 1, NEC Birmingham. Supported by *The Guardian* newspaper.

Monday 17 May

Spina Bifida and/or Hydrocephalus – current concepts and treatment; a whole-day conference organised by ASBAH Eastern Region. Venue: Courtyard Conference Centre, Marriott Hotel, London Road, Newport Pagnell, Bucks. Speakers include: Peter Richards, (consultant paediatric neurosurgeon, Radcliffe Infirmary, Oxford), and Rowena Hitchcock, (consultant paediatric surgeon, The Radcliffe Hospital, Oxford), with additional expert input 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 East, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988, fax 01733-555985, marym@asbah.demon.co.uk***

554 families respond to questionnaire

ASBAH is funding a three-year research project at Southampton University into the developmental, behavioural and psychological characteristics of children with spina bifida (SB) and/or hydrocephalus (H).

In July, a questionnaire was sent to all families known to ASBAH with a child with SB/H aged 6-12 years (about 1200 in total). The questionnaire included questions concerning spina bifida and hydrocephalus, its treatment and related medical problems, the child's level of independence and functioning, education, behaviour and well-being, as well as family background, impact of the disability on the family, family needs and care-giving.

A total of 554 completed questionnaires have been returned to researchers based in the university's Department of Psychology. Research Fellow Ineke Pit-ten Cate, who is assisting Prof-essor Jim Stevenson in the project, said: "We are very happy with this large number as we realise the length of time involved in completing the questionnaire. We are also very pleased with the amount of parents/guardians indicating that we could contact their child's teacher."

In October, teachers received a questionnaire on how particular children were faring in school. There were 200 completed teacher questionnaires (a response rate of 45%).

Most parents indicated they would like to take part in another stage of the research.

Ineke said: "We would like to thank parents for their interest in our study and their time completing the questionnaire."

Hope for three-year-old Ben

ANITA Clinton wrote a *True Story* about the continuing ill-health of her son Ben and received numerous offers of help from readers. Mrs Clinton, of Newcastle-Upon-Tyne, now has some good news.

AFTER Ben's story was published, he continued to vomit every few weeks. After another trip to casualty and being told his shunt was working, I decided to ask our GP for a second opinion.

We saw a neurologist who suggested that next time Ben vomited, I bring him in and he would be seen by his neurosurgeon quickly.

I did what we agreed but, as there were no neurosurgeons about at the time, Ben didn't see his consultant for 24 hours, by which time he was OK again. They did some scans and tapped his shunt – all normal, which I knew they would be as it was too late.

Ben saw his consultant neurosurgeon Christopher Gerber in June. He compared his scans and said his ventricles looked small. I had read about slit ventricle syndrome in *HNN* and the article seemed to describe Ben. Perhaps this is what Ben had? Mr Gerber said it could be and thought that subtemporal decompression was the appropriate measure but wanted a second opinion.

In November, Ben saw Jonathan Punt, senior lecturer in paediatric neurosurgery at the University of Nottingham and honorary consultant paediatric neurosurgeon at University Hospital, Nottingham, for a full assessment, including an MRI. Mr Punt asked us lots of questions and listened. He said Ben had intermittent shunt blockage due to slit ventricle syndrome. At last, we had found out what was causing Ben's vomiting.

Mr Gerber performed a subtemporal decompression operation in Newcastle – removing a piece of skull, about the size of a 50p, just above the ear, and Ben is recovering well. I am so relieved.

Thanks to everyone who wrote giving me support and to ASBAH for all your help and support. Knowing you are there is a great comfort.

View from

NEARLY all parents of a disabled born child know this feeling of deep fear and total helplessness in the moment when the doctor tells you that there is something wrong with your baby. This drastic experience for us is now more than three years ago when the doctor told me during a routine check that there was too much liquid in the baby's head. Within the next few days, we were sent to several specialists but all were not sure about the cause and the consequences. In the hospital UKE in Hamburg we heard the diagnosis 'hydrocephalus' for the first time. And indeed, our son Max was born with hydrocephalus.

Seven weeks after his birth by Caesarean Section, he was given a medium pressure shunt system from his brain to his stomach in order to reduce the pressure in his brain – with success! Since that time Max has been doing very well. His general development is a bit delayed but, apart from this, he is a very happy and bright boy. He has a lot of friends – disabled (what is disabled?) and non-disabled. He very much likes going to kindergarten and enjoys his first steps towards independence. By the way, it is a mainstream kindergarten.

I think it is a very important experience for children, disabled or not, to get the chance to live their own lives. Perhaps they will have certain limits but they should not always be reduced to their disability. Children don't see any differences between disabled or non-disabled people. Adults have more problems with it.

At first, our whole family was shocked but, today, we regard our wanted child as a big challenge to make the best of. Within the last three years we met a lot of very nice and helpful people and had a lot of very worthy experiences.

I cannot speak for all parents in Germany but it is possible to receive State benefits like tax reductions on your income, no car tax, cheaper fares on public transport, subsidies for the kindergarten and for several therapies.

Apart from financial benefits, can recommend the membership in ASbH Germany, Arbeitsgemeinschaft Spina bifida und Hydrocephalus. We have received a wide range of psychological help and well-founded information. Every month, we meet other parents of small children with hydro-

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DESPITE the considerable achievement of informing hundreds of thousands of women and thousands of health professionals about the risks of women catching a blood infection while pregnant, 10 years have gone by and pregnancy screening for this condition is still not routinely available .

The Toxoplasmosis Trust, which does this work, had mixed feelings when it marked its tenth anniversary.

Toxoplasmosis is a common parasitic infection which can be caught from various sources including eating meat which is raw, raw cured or undercooked. It can also be caught from infected cat faeces. If caught during pregnancy, it can cause layers of calcification to form in the foetus's brain which may, in turn, cause brain damage and, in the most severe cases, block the ventricles, and so causes hydrocephalus.

Trust founder Bea Teuten, whose daughter Natasha has hydrocephalus due to congenital toxoplasmosis spoke of her hopes for the Trust when i all began – that screening for toxoplasmosis would become routine in the UK as it is in other countries within 10 years, and that the Trust would work to inform women and their carers about toxoplasmosis, and support those with an affected child.

The Trust began with Natasha *(pictured left with her mum)*. When she was a baby, her parents had been so shocked to learn that she would have suffered less had she been born across the Channel, they wanted to give other women access to information that they had not had in England.

Germany

By Tanja Mettenbrink
Buchholz, Germany

cephalus and learn a lot about new therapies, operation methods, problems in daily life and how other parents solve them. Besides these, we regulary receive the journal *ASbH-letter* which is similar to the *Link* magazine but with more medical information, future activities and reports about meetings, new books are presented and a lot more.

In Germany, the medical infrastructure concerning hydrocephalus is quite good. We live in Buchholz, a town 40 km away from Hamburg with approximately 30,000 citizens and we can choose between several very good neurological hospitals that have expertise in hydrocephalus and shunts. Furthermore, the Werner-Otto-Institute is also situated in Hamburg. It specialises in the development of children and we were informed about several possible therapies in order to improve Max's development. The doctors answered all our questions concerning this topic and this helped a lot.

Our family doctor in Buchholz is very good within certain limits. Concerning Max's hydrocephalus, we prefer to ask our doctor in the above mentioned hospital in Hamburg. For psychological help, we address ASbH and so on. I think it is important and helpful to have several people to ask for support. No-one knows everything or can feel the hell you went through. For the best result, you need to talk to a variety of people and, certainly, you need support from your partner and rest of your family. Thank you to all people who have helped us the whole time!


Max Mettenbrink

10th birthday of TTT celebrated with mixed feelings

Bea writes: "Natasha was born [illegible] beautiful, apparently robust baby at full term. However, when she was only six weeks old, we were told at her routine check-up that she had hydrocephalus.

"Tests at Great Ormond Street the following week also showed that she had severe damage to the sight in both eyes and that she had extensive brain damage which, the doctors thought, would prevent her from attaining her normal developmental milestones.

"Natasha then had to spend the following year taking courses of strong drugs to try and prevent any further effects of the infection.

"At three, Tash was diagnosed as having epilepsy and, at five, she had to have three shunt revisions in three days.

"No sooner had she recovered from that episode, when she was diagnosed as having precocious puberty. This means that due to damaged glands in the brain, the child goes into full blown puberty early – in Natasha's case at six. To halt this, Tash has had to have injections every month.

"With a medical history like this, you might have thought that Natasha would be some sort of shrinking violet. Not so! Natasha is now 11, goes to mainstream school with minimal support, has three very rowdy younger brothers and sisters and has just won a gold medal in the school swimming gala and the school cup for endeavour! She does find life tough at times, often bumping into things and, as a result, hurting herself quite severely. She has also a dread of returning to hospital for another shunt revision or eye operation."

LINKS

www.toxo.org.uk
Toxoplasmosis Trust website

Pressured

By Liz Galfskiy

This article was written in response to a problem Liz had in persuading medical professionals to recognise 'low pressure' (or shunt over-drainage).

I'M fed up, cheesed off, had enough. Too many thoughts about how I feel. Do I have high pressure, low pressure, a headache, sickness or are my shunts working today? I really just want to get on with my life and not have to think about how I feel. In four and half years, I have had little more than a few months when my shunts have been working and not giving me trouble.

My VP shunt, after four revisions, has worked well for over three years but my LP shunt has given me numerous problems.The hardest think to cope with has been the periods of over-drainage when I have suffered from the symptoms of low intracranial pressure. Perhaps behind my difficulty in facing this problem has been the continuing memory of a consultant neurosurgeon (<u>not</u> the one treating me now!) who told me that the condition does not exist and my referral to a psychiatrist.

Shunt over-drainage is awful. It makes me feel permanently drugged, as if I have a constant hang-over, without the pleasant memories of a good night out. Life goes on but I'm living it in my own little world just waiting to be woken up. The headaches are really terrible, I get nausea, a continuously stiff neck, visual problems and pins and needles in my limbs. Another symptom is the extreme tiredness but I almost see this as an advantage – sleeping for hours both day and night is a wonderful escape from what seems like an unreal life.

The mental difficulties are very hard to describe but include a loss of concentration, a sense of disorientation and panic. The panic I feel is very bad; it's very, very difficult to control. I battle by telling myself it's just my head giving me wrong messages and try to be philosophical in thinking through the feelings but, at times, it is almost impossible to behave in a rational way. I am aware that perhaps not all doctors would agree with my list of problems associated with low pressure but how many of them have suffered from it?

As you can imagine, I hate having over-drainage but am pleased to say that I now have a high pressure valve fitted to my LP shunt and am feeling much better. For me, it seems to take much longer to recover from a period of low pressure than a period of high pressure.

Sometimes I wonder how children or people unable to communicate easily, manage with intracranial pressure problems. If people have had hydrocephalus since birth or childhood, they can't know how it feels to be well – to have an automatically perfectly regulated intracranial pressure – where is their understanding of 'normal'?

If intracranial pressure was easier and less risky to measure perhaps the management of conditions by shunting would become more controlled. I have a dream that one day doctors will be able to hold a small pen-like instrument to the head and measure intracranial pressure. If scientists can move a robot vehicle on Mars, why can't they measure the pressure under a bit of bone here on Earth?

● ***Liz, from Hampshire, is a founder member of the BIH (Benign Intracranial Hypertension) Group.***

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.

Hydrocephalus Network News
HNN LETTERS

I am planning to travel to Australia this Spring. This will be my first 'long' trip since being treated for adult onset hydrocephalus in 1997 (third ventriculostomy). I am interested in other people's experiences and any advice that can be offered, particularly relating to insurance cover, what to take, likely problems etc.

Liz James
"Harpfield"
St. Briavels, Lydney
Glos GL15 6UQ
liz@ibullen.freeserve.co.uk

I AM 23 years old and I have hydrocephalus.

I would like to contact anyone in or around Nottingham with hydrocephalus and/or spina bifida who is interested in rock music or gothic music. I am also interested in art.

Please write to me, Cordell Hindley, c/o HNN, ASBAH, 42 Park Road, Peterborough PE1 2UQ.

What's in the Jan/Feb Link

***Link** is ASBAH's main magazine. Subscription details from National Centre.*

MY four-year-old daughter, Justine, was diagnosed at the age of three with congenital hydrocephalus. She had a VP shunt fitted in October 1999 at Birmingham Children's Hospital.

Most cases of hydrocephalus that I have read about have been diagnosed fairly close to birth. However, I would love to hear from other parents if they have a child where diagnosis was made so late!

Donna Cole
18 Michael Crescent
Malvern
Worcs
WR14 1UD
donna.cole@lineone.net

Please send your letters, *True Stories* and feedback to: Rosemary Batchelor
***HNN* Co-ordinator**
ASBAH, 42 Park Road
Peterborough PE1 2UQ

I'm 21 years old and would love to correspond with others around my age with hydrocephalus. I found out I had it when I was 13 and had a shunt fitted.

I'd just like to find someone to share my experiences with and who knows how it feels.

Katie Roberts
1 Shapwick Road
Hamworthy
Poole
Dorset BH15 4AP

Our publications' review in full swing

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

More than 200 replies were received to a readership questionnaire which went out with our four publications in the summer.

The returns were analysed and fed to a focus group.

The publications – *Link, Hydrocephalus Network News, Lift* and *Bulletin* – are having their appearance, content, readership, satisfaction ratings and frequency of publication reviewed.

Linda Hams, assistant director (policy and marketing), who is heading the review, said: "Our publications are vital to the task of communicating ASBAH's core values, to the image of ASBAH as a modern, vibrant service-provider, and making sure our stakeholders are kept well-informed and up-to-date."

"The publications review is helping us achieve this. I would like to thank everyone who has contributed so far."

True story

AFTER almost nine months of regular spells of ill health, my young daughter Amy's shunt was finally revised in July.

By Sharon Randall
Woodbridge, Suffolk

Amy Randall, aged four

Her first shunt was put in in February 1997 when she was 10 months old as fluid seemed to have built-up rapidly over a couple of weeks. Scans were done and doctors said there may have been a gradual build-up which had gone unnoticed.

Early November 1998, Amy's condition seemed to slowly get worse with fortnightly episodes of vomiting. She lay around and was very irritable, complaining a lot. For months she was in and out of hospital, with doctors trying to find out why she was continually having spells of being really ill.

Gradually, she was feeling ill on more days that she was feeling well and I did not know what to do to help her.

In the last two months of being ill, I felt my daughter was almost floating along, vomiting badly, on one occasion being taken to hospital by ambulance and still nothing was done. One doctor tried to tell me perhaps the cause was migraines.

Finally, a CT scan showed she had narrow ventricles. Monitoring was done in June which showed unusual pressure readings – high to very high pressures.

When her shunt was taken out, unfortunately, she had a bleed and was in intensive care and on an external drain. It took a week for the blood to clear and then the new shunt was fitted. It was a Medos plus reservoir and valve put towards the front of the head.

Once she had recovered from the trauma, she changed completely. She was very happy and cheerful and full of energy – a big contrast to what she was like before.

She is now developing mentally and physically like any other four-year-old, enjoying life again.

After all that happened, I still feel a big debt of gratitude to the doctors and hospital for making her better.

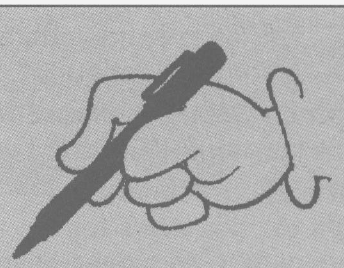
I kept a diary of Amy's condition while she was ill and found it a big help to note things down.

I would say to any parent who is going through what I went through, there is light at the end of the tunnel and you learn as you go along.

Thank you ASBAH for your support.

Hnn – Annual subscription rates (four issues a year) are: £2.00 (UK); £5.00 European and overseas surface mail and £10.00 by airmail.

If you are not sure when your subscription is due, please phone Lynn Thomas in ASBAH's Services Department on 01733-555988.



Dave's diary

IN the last *Diary*, I said I wasn't having kids because I can't afford them. The truth is, I can't afford most things right now. I'm skint and lack two pence to rub together! This is not a recent thing though. I've always been a bit short of cash.

To be short of cash is one thing, but to be poor and disabled is double pain – especially as the cost of living seems that bit higher if you are disabled. A fact not easily grasped by assorted politicians!

I realised some years ago that State benefits weren't going to cover me for life's little luxuries (food, warmth, a place to live, etc), and I needed to think of other ways to get money. Thoughts of crime and robbery were swiftly dismissed, for practical reasons as well as the usual moral ones. Although the thought of doing over a bank seemed attractive (especially when I saw how much mine is charging me for my loans and overdraft!), loud bangs (like from a gun) make my eyes flicker uncontrollably. As for a quick get-away, I don't want the last thing I hear to be: "Quick, stop him! He's shuffling slowly towards the door!"

So I turned my mind to more realistic (and honest) ways of getting cash, such as a job. Getting a full-time job has proved harder than I thought. Much of my employment history has been about bouncing from one temping or part-time assignment to another. Another day another contract.

In a past *Dave's Diary* I mentioned Shopmobility and how much fun it is to use their scooters when shopping. Well, I've gone and got a job with my local Shopmobility office. Like a poacher turned gamekeeper, where I used to trash the scooters to death, now it's me who has to make sure the equipment is looked after properly, and speeds are kept down. I've also had to learn how to escort visually impaired people around shops. Believe me, it's nowhere near as easy as it sounds!

First, I had to be the one being escorted – walking around our lovely new shopping centre with my eyes closed. In a flash, the place changed from a comfortable building full of happy shoppers, to a mad house full of noises and zombies crashing into me! Not being able to see and having to trust someone to guide me was an amazing experience. I was even more amazed when my trainer closed her eyes and asked me to lead her to Debenhams. I was doing fine – til I walked her straight into a display full of stainless steel pans! After that, I think I'm lucky to have kept the job!

Luck plays a major part in another way I've tried to get some money: gambling on the National Lottery. People say the odds are against me but I look at it like this: if the odds are against being born with SB, then maybe it works the other way and, against the odds, I could win the lottery. Though if life worked that way, I suppose everyone with SB would have won the lottery by now.

Something that's always struck me as a bit of a lottery is suing someone in court. Some people get hundreds of grand straight away for things like burning themselves on hot coffee or injuring their back while having sex on their office desk(!), while people with disabilities have to fight for years for a few quid. Some have been successful, however.

I first got interested in the idea of suing when I read that some kids with cerebral palsy had sued hospitals for several million quid. Although I'm not nearly as disabled as them, I thought if they could sue someone for being disabled, why can't I? A fat cheque would come in handy right now. I may not get millions but, at this point, a few thousand would do me!

Aside from the cheque, there would also be the pleasure of having someone specific to blame for SB. But finding a guilty party and proving the case is not easy. A group of Nuclear Test veterans were convinced that the MoD exposing them to radiation was responsible for a large number of their grandchildren having SB. I was gutted when the court rejected their case! I've always believed my SB was the result of some kind of pollution near my home. But I've not been able to prove it (yet!) or find who was responsible.

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

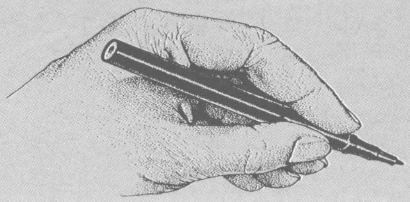
Return of sheepskin in pressure care management

NATURAL sheepskin is returning to the armoury of products available in the management of pressure care – with new green-coloured skins from Australia, which have been preshrunk and heat-treated to destroy infective organisms.

Other characteristics claimed for HITEMP UR sheepskins include their ability to absorb up to a third of their weight in perspiration, air insulation and retaining their resistance to the damaging effects of the chemicals in urine.

Products include mattress overlays, pressure care boots, slippers, heel and elbow protectors, and wheelchair cushion and backrest covers.

The products have been evaluated at the Dept of Medical Engineering in Salisbury. *Details from: BES Rehab Ltd, 9 Cow Lane, Fulbourn, Cambridge CB1 5HB, tel/fax 01223-882105, besrehab@thefree.net*



Letters

Please send letters for publication to:

Editor, ASBAH, 42 Park Rd, Peterborough PE1 2UQ.

The Editor reserves the right to edit letters for publication, so please keep them as short as possible.

'Weronika gives us so much joy'

I AM so pleased to receive *Link* as it is not only a good source of information but a source of optimism for me.

For those of you who remember my letter to *Link* two years ago, regarding the birth of Weronika in Poland, I would like to tell you about her progress.

Weronika was delivered by Caesarean Section on 15 May 1997 and her spine was operated on the same day. It took six hours to close. She then had another operation to put a valve in for her hydrocephalus.

She spent 100 days out of her first 120 days of life at the Mother and Child Institute in Warsaw where she was born.

In summer '98, she spent another 72 days in hospital. She was given a long antibiotic treatment and then underwent two operations. An infected valve was removed and a new one was put in instead.

After such a long stay in hospital, she was emotionally 'blocked' and reserved. But four months later she was making strides in her physical and emotional development.

In November '98, her head was tonographically tested. The results were good and promising, considering the problems she had been going through.

Weronika is a lovely, amazing and cheerful child and gives us so much joy.

In May '99, during a week in the country, we noticed a considerable turning point in Weronika's progress. She started using sentences and normal words instead of baby talk. She opened herself to the people around and became more self-confident.

After a 400 km long car journey, we noticed a small sore on Weronika's back. The first treatment recommended by a doctor was a complete failure since the wound became larger and deeper. The treatment adopted subsequently is effective but takes time.

Weronika is a chatterer. She has a good ear for music, so she can easily perform songs she hears on TV or those sung by her parents.

She is cheerful and smiling most of the time. Tears seldom come and, if they do, it is sometimes when her bedsore dressing is being replaced.

From June until September, the weather was good and Weronika stayed a lot in the countryside. She benefited from being out in the open as we do not have many green areas near our home in Warsaw and walking the streets with her is neither pleasant nor healthy.

Rosita Turowicz-Wlazniak
Warsaw, Poland

Melinda's tribute to Bob Zachary

I WAS very sad to hear of Professor Robert Zachary's death earlier this year – he was a most wonderful man.

I was a patient of his in the early 1950s and will always be eternally grateful to him and his team for all they were able to do for me – increasing my quality of life. I know for a fact that, had it not been for him, I should not be where I am today living a very independent life.

Professor Zachary was such a kind, considerate man with a wonderful disposition. I'm sure all his patients have spoken highly of him. Nothing was ever too much trouble for him.

I will always remember my last visit to him when I was 14 years old. He wondered why I was so nervous of him. It was certainly not him I was nervous of but, perhaps, the treatment he might have had to give me. I'm still a coward to this day. He was one of the nicest people anyone could wish to meet and I shall always be grateful to him.

Melinda Exley
Farnham, Surrey

HOLIDAY ACCOMMODATION

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

NAISH HOLIDAY VILLAGE, NEW MILTON – Clifftop park with "excellent" status at New Milton, Hampshire. Excellent site facilities within 100 yards, with indoor/outdoor pools, restaurant, bar, take-away. Fully-equipped, two-bedroom, fully wheelchair accessible log cabin accommodation. Sleeps six, well-furnished. Free club membership.

GRANGE COURT HOLIDAY VILLAGE – Park with "good" status at Goodrington Sands, Devon. Excellent site facilities within short walk, with indoor/outdoor pools, restaurant, bar, take-away. Fully-equipped, two-bedroom, fully wheelchair accessible, mobile home. Sleeps 4-6, well appointed. Free club membership. (Purchased with funds from the National Lottery).

MILLENDREATH HOLIDAY VILLAGE – Excellent seaside site with good facilities, just outside Looe in Cornwall. Restaurant, club-house, indoor pool. Fully-equipped, and fully wheelchair accessible, two-bedroom chalet accommodation. Sleeps six – well-furnished and comfortable. Free club membership.

Details: Mr P Cash, tel: 01425-672055 – Bournemouth Spina Bifida Association, registered charity number 261914.

BERWICK COTTAGE, EAST HARLING, NORFOLK - Purpose-built modern cottage. Ground-floor acccommodation 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.*

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.*

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.*

ACCOMMODATION

Ilkley, West Yorkshire – Ilkley, West Yorkshire – vacancy in Flat 3, Denton View, Five Oaks Housing Scheme. Suit ambulent 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 Wharfe Valley. A care and support package can be arranged with Bradford Social Services. *Contact: Mark Best, tel/fax: 01943-603013.*

FOR SALE

Four-wheeled Sterling Midi scooter, with front basket; batteries new last year and battery charger. Four years old. Cost £1,700. Accept £700 ono. *Mrs Fitzgerald, tel: 0115-960 9790 (Nottingham).*

Baronmead battery operated manual stair-climber. Suitable for child aged 6-11 years. Cost almost £2,000. Free to good home. *Contact 01444-484350 (West Sussex).*

Link ad rates

- **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'.**

- **Classified adverts for the next issue of *LINK (March)* should be submitted by Friday, 28 January.**

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

- **Display Rates on application from the Publicity Manager, ASBAH,**
  42 Park Rd, Peterborough PE1 2UQ.
  Tel: 01733-555988.
  tonyb@asbah.demon.co.uk

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

DIRECTORY OF INDEPENDENT LOCAL ASSOCIATIONS

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12 St Leonard's Way
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S Yorks S71 5BS
Tel: 01226 292546

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16 Parkstone Close
Bedford MK41 8BD
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15 Brackley Road
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51 Cuckoo Lane, Whitefield
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10 Newlands Road
Whittlesey
Peterborough
PE7 1YX

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34 King Edward Street
Shotton, Deeside
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Tel: 01244 811074

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11 The Earls Court
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Coventry CV3 5ES

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St Merryn, 20 Burley Hill
Allestree, Derby DE3 2ET
Tel: 01332 841893

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88 Goodliffe Road
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Tel: 01476 401643

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29 Wellmeadow Road
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Tel: 01252-845765

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Herts
AL4 9JA

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Huddersfield HD2 1PR
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LN6 9EX
Tel: 01522 778781

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Tel: 01529 460322 (after 6pm)

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Hanwell
London W7 1LQ
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15 Woodvale Walk
Elder Road
W Norwood
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12 Adam Avenue
Northampton
NN1 4LQ
Tel: 01604 634419

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14 South Row
Chilton
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Tel: 01235 834785

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Mrs S Thompson
34 Beatty Road
Southport
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Tel: 01704 542589

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St Helen's WA10 2DE
Tel: 01744-612860

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237 Upper Halliford Road
Shepperton
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Tel: 01932 783991

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265 Adswood Road, Adswood
Stockport SK3 8PA
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42 Gowanburn
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Tel: 0191 415 1725

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Averys, Rusper
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W Sussex RH12 4PR
Tel: 01293 871217

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Manchester M32 8AX
Tel: 0161 865 0222 (am only)

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Miss Nancy Gleave
16 Hilltop Road
Woolston
Warrington
Cheshire WA1 4PD
Tel: 01925 819329

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123 Gerrards Green
Beaminster, Dorset DT8 3EA
Tel: 01308 862614

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Leigh WN7 2LQ
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28 Stavordale Road
Moreton
Wirral, Cheshire L46 9PR
Tel: 01516 784409

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49 Brueton Avenue
Fringe Green
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Worcs B60 2AW

YORKSHIRE NORTH
Miss Faith Seward MBE BA
45 The Paddock
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Tel: 01904 798653

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Mrs Anthea James
61 Westland Close
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Tel: 01792 428004

Mid Wales
Liz Vaughan
Myrtle Cottage
Four Crosses, Llanymynech
Powys

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