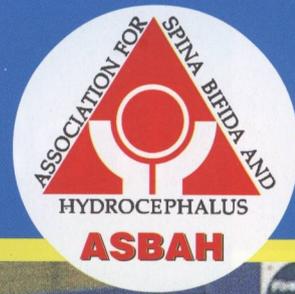
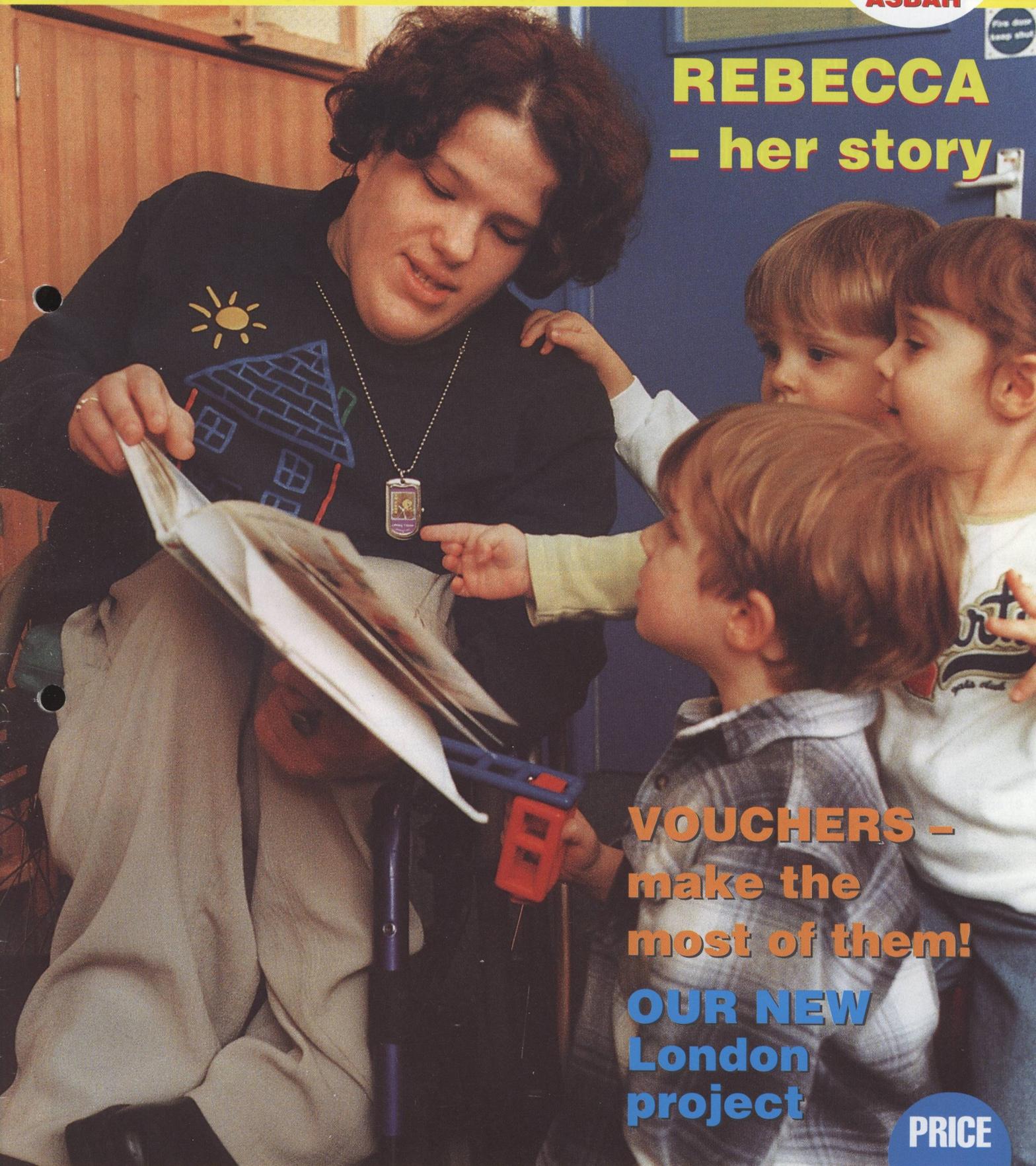


LINK

The magazine for people
with Spina Bifida and / or
Hydrocephalus



REBECCA - her story



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SEPTEMBER/ OCTOBER 2000

ISSUE No 189

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LINK



Cover:
Rebecca Castle
doing rather well
as a nursery nurse.
See page 16.
Photo:
Jacky Chapman

Editorial

Dear Readers

WE ARE arranging two major landmark events in the near future.

Our AGM on 16 September will be important not just for talking about what we did last year, but in its looking forward – as we open up the review of ASBAH's strategy for the next five years.

Local Association representatives will have real choices to make about effective joint working, while we continue to respect each other's differences and strengths.

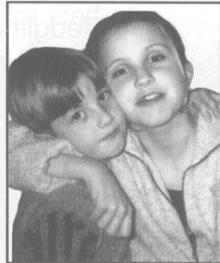
And, on 3 October, we are having a national ASBAH awareness day which will celebrate ability not dis-ability. We are inviting MPs to take part in our ChairAbility Challenge – games of wheelchair basketball round the country.

We have already invited local ASBAHs to organise challenges in their area. Please be part of it, and show that working together can be effective and enjoyable.

Tony Britton
Publicity Manager

contents

News	5-6
Medical Update	7
Obituaries	8
Wheelchair guide	10-11
People	12-13
Survival guide	14
True Story	15
Rebecca's story	16
HPE explained	17-18
Fundraising	19
Diary Dates	20
Dave's Diary	21
Letters/small ads	22-23



Medical ● Page 7



Vouchers ● Page 10



Clinical ● Page 17



Straw Bears ● Page 19

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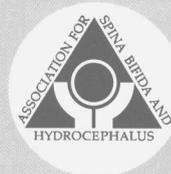
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President: Jeffrey Tate CBE



ASBAH exists to provide advice, support and advocacy to people with spina bifida and/or hydrocephalus, their families, and their carers.

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

postmaster@asbah.demon.co.uk
www.asbah.demon.co.uk

Even better buys?

A NEW business can track down and supply products suitable for children with special needs that are not easily available.

Fledglings is run by Ruth Lingard, who says the most popular item is the 'Snoozy bedpad', a quilted waterproof square in bright designs, that is put on top of the sheet when toilet training.

Ruth also has a wide range of bibs, including stylish neckerchiefs for children who dribble, but who don't want to wear bibs. The neckerchiefs cost £3.50 (small) and £4.50 (large) plus postage and packing at cost.

There are also mirror balls – from £1.99 – which you hang up in your child's bedroom for sensory experience.

Many other toys and sensory aids are available, including ones for children with sight impairments.

● *Fledglings, 6 Southfield, Ickleton, Saffron Walden CB10 1TE, tel: 01799-530412.*

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Low-key opening for Wales office

ASBAH's new office in Wales has been opened by ASBAH Cymru chairman Mike Mason.

The low-key ceremony was attended by ASBAH staff in Wales, representatives from local associations in Wales and other senior staff – on the same day as a regular meeting of our ASBAH Cymru committee.

A bi-lingual information and advice service is available to the whole of Wales from the office and visitors are welcome by appointment.

Wales manager Elin Ifan said: “There have been lots of new referrals following the opening. Lots of professionals from health, social services and education departments have also been phoning in

to fix up meetings.”

An additional remit is to liaise with the Wales Assembly on issues that affect ASBAH's service users.

Unfortunately, the office cannot always be open as secretary Lester Bath works part-time and Elin has to travel throughout Wales.

The office is in Bangor's recently developed Parc Menai business park. It is wheelchair-friendly and is easily reached from the A55.



ABOVE: executive director Andrew Russell invited ASBAH Cymru chairman Mike Mason to cut the tape at the official opening.

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Mother attacks jail sentences

A MOTHER has defended relatives who battled with hospital staff as they administered diamorphine to her 12-year-old severely disabled son, after doctors claimed he had only a few hours left to live.

"My relatives are in jail for 12 months for defending David when he couldn't defend himself. It's disgusting. His life was worth defending – he has as much right to life as anybody", Carol Glass told *Link*.

Two of David's aunts and an uncle were each jailed for up to a year after being convicted in July of violent disorder and assault after David – now aged 14 – was admitted to St Mary's Hospital, Portsmouth, in October 1998 with a chest infection.

The attack happened after doctors claimed he had only a few hours to live, stopped feeding him and administered diamorphine. The judge commented, when sentencing the relatives: "Most people would regard what you did as quite outrageous".

David, who has hydrocephalus and was born brain-injured, recovered after the drug was withdrawn. St Mary's Hospital now refuse to treat him further. David is referred instead, whenever necessary, to Southampton General.

Carol Glass added: "They said we were cruel to try and save David's life but it wasn't our job to save him. It was the hospital's."

Consultation starts

A MOVE to consult the public on fortifying all flour with folic acid has been welcomed by ASBAH – on the grounds that the 50% of women who do not plan their pregnancies will gain extra protection for their babies against spina bifida.

The four UK governments and the Food Standards Agency are seeking the views of doctors, scientists, and the public in a 12-week consultation due to finish on 31 October.

The consultation follows advice by a committee of experts. They argued that, by putting 240 mcg of folic acid into every 100g of flour, the number of pregnancies affected by spina bifida and other neural tube defects would be reduced by 41%. The experts added that this level of fortification would not impose unacceptably high levels on the population at large.

The consultation is UK-wide, but each country's government can take its own decisions on public health issues. EEC approval is also required.

Fortification of flour has been carried out for years, except in wholemeal flour. Iron, calcium, niacin and thiamin are already added to flour compulsorily in order to replace vitamins and trace elements lost in the milling process.



We catch up with 900 years of history!

NINE hundred years of history finally caught up with ASBAH when we obtained major project funding from the Bridge House Estates Trust Fund.

The trust, which has controlled four Thames river crossings since the days of the Norman kings, will give us £120,000 over three years to improve our services in London.

The money will be spent employing two new specialist advisers to help young adults become independent.

ASBAH fundraising manager Donna Treanor said: "We have an urgent need for a range of housing support services to help young adults live independently. This generous funding from Bridge House will help us meet this need in the capital.

"Many young people we work with need help to secure accessible housing, and training in practical skills such as cooking, cleaning, budgeting

as well as confidence building – all of which are necessary to live independently in the community."

Bridge House, part of the Corporation of London, has built huge reserves in the last 900 years. They could, if London Bridge collapsed, use them to rebuild the bridge entirely. Since 1995, it has had powers to use surplus reserves for wider charitable purposes.

Our two new specialist advisers – Judy Hunt and Sharon Edwards – joined us in July.

Judy Hunt managed a team of occupational therapists for a London borough and has done research on the subject for an MA thesis at East London University.

Sharon has just finished a BA (hons) degree in housing studies at Sheffield Hallam University.



Judy Hunt



Sharon Edwards



World travel, and paid for it!

IF you have a project you would like to undertake overseas next year – and it fits in one of the categories listed below – you can apply now for a Winston Churchill Travelling Fellowship.

Like former *Link*

columnist, Paul Darke, who this year obtained a fellowship to look at access on a pilgrimage route in France and Spain, the chance of a life-time could be yours.

British citizens from all walks of life can apply and

there is no age limit.

In 2000, the Trust awarded grants in excess of £600,000 to cover return air fare, daily living, travel within the countries being visited and, in exceptional case, some assistance with home expenses.

● For an application, send a large, self-addressed stamped envelope to: The Winston Churchill Memorial Trust, 15 Queen's Gate Terrace, London SW7 5PR. Closing date is 24 October 2000. People who get on the short list will be interviewed in January next year.

WINSTON CHURCHILL Travelling Fellowship categories for next year include:

- Any project in Australia
- Farmers, farm workers, horticulturists, foresters and others involved in the rural economy
- Artists and craftsmen working in the field of British heritage
- Teachers of the Arts (dance, drama, music and visual arts)
- Young people under 25 on 31 December 2001 – the Trust will support projects that encourage personal development as well as benefit your community
- Workers in ecological management (including ecotourism) and marine conservation
- Mental health workers
- Librarians and archivists
- Adventure, exploration and leaders of expeditions.



Special bugs to eat bacteria?

WORK on finding yet more ways to treat shunt infections are being led by our honorary consultant in hydrocephalus, Dr Roger Bayston.

Following his success in inventing and marketing an anti-bacterial shunt, Bactiseal, his team at the University of Nottingham Biomaterials-Related Infection Group are trying two other approaches to knock out shunt infections.

The first is to find drugs which, while not necessarily killing the bacteria, prevent them from making a protective layer around themselves.

If this layer can be removed, antibiotics might then work efficiently – avoiding the need to remove the shunt.

The second approach is to subject the bacteria to virus infections, known as bacteriophage (eaters of bacteria).

Three bacteriophages have been found which are capable of digesting the protective layer so they can reach the bacteria and kill them.

Both approaches are being tested by Dr Bayston's team using special equipment which simulates shunt infections.

If either of these approaches are successful in the laboratory, they will then need to be carefully tested further before human use can be considered.

Alert card 'ignored'

A TEENAGER has told how doctors risked her life by ignoring her Shunt Alert card.

Three years ago, Kelly Bridge (*pictured with a nephew*) was vomiting heavily. She was taken to her local hospital.

Her mother showed her shunt Alert card but this was ignored.

"I received a very poor standard of care – I was left all day with no drink, the doctor coming in at intervals, adamant that it was a virus and nothing to worry about," writes Kelly.

During the night, Kelly slipped in and out of consciousness and could not see.

A scan next morning prompted Kelly to be rushed to a larger hospital. She was in a coma on arrival and operated on straight away. Afterwards the neurosurgeon told her parents: 'I've just saved your daughter's life.'

Now 14, Kelly treasures her life dearly.

● Since Shunt Alert Cards were featured in our May issue, another 100 people have applied for one. The card stresses the need for urgent assessment of the shunt in a specialist centre if there are symptoms of shunt failure or blockage.

Put your mobile to the other ear!

ASBAH has received no adverse reports of people with hydrocephalus shunts using mobile phones.

However, if you have any concerns, we advise people to use their mobile on the opposite side to their working shunt.

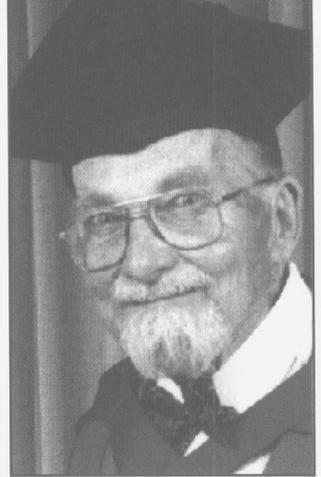
In addition, the Department of Health advises that no-one uses a mobile for long periods at a time (ie half an hour or more).

● Settings on Codman Hakim programmable valves can be changed if an audio headset, found on a hospital bed, slips off a patient's head. The interference is caused by a magnet accidentally moving next to the valve.

It has been recommended that these Patientline headsets are removed from all beds in which patients with these particular shunts may be nursed.

Professor John Lewis Emery

An appreciation by DR ROGER BAYSTON MMedSci FRCPath, ASBAH's honorary consultant in hydrocephalus and head of the Biomaterials-Related Infection Group, Division of Microbiology, University of Nottingham Medical School.



● Professor Emery

SOME of you may have read of the death, on May Day this year in a house fire, of Professor John Emery at the age of 84.

John Lewis Emery MD DCH FRCPath began work as a consultant pathologist at Sheffield Children's Hospital in 1947. John was an ideal person for such a post, his interests in medicine and pathology and indeed in other subjects including the arts being very wide.

He was responsible for an enormous amount of basic research into hydrocephalus and spina bifida which went far towards explaining the complex problems faced by those with these conditions.

He and his staff presented their original research findings

at meetings of the Society for Research into Hydrocephalus and Spina Bifida which he helped to found and whose President he became in 1967.

These presentations attracted an international reputation, which he generously shared with his colleagues. Indeed, the 'Emery stable', of which I was fortunate to be a member for 13 years, became known for the quality of their research presentations, a product of Emery's late night drilling for days beforehand.

All junior surgeons and many junior paediatricians in Sheffield Children's Hospital spent six months in Emery's department learning anatomy and carrying out fundamental research into the causes of childhood illness.

After the Holter valve became available in this country in 1957,

Robert Zachary (paediatric surgeon), John Lorber (paediatrician) and John Sharrard (orthopaedic surgeon) saw an opportunity to improve the quality of life for those with spina bifida, now that their hydrocephalus could be treated.

Many of their improvements rested on Emery's research findings and Sheffield became known throughout the world for its pioneering work in both hydrocephalus and spina bifida.

His staff and students will remember him as a formative influence in their lives. Those with hydrocephalus or spina bifida, their carers and professionals involved owe a great debt to John Emery, not only for his major contribution to knowledge but also to the creation of a band of 'Emery-trained' individuals worldwide.

During his immensely full professional life, he also found time to set up the first bereavement counselling service (he would be horrified by the term) run by a pathologist for parents who had lost a child, and to help found ASBAH.

Later he developed another of his interests, sudden infant death syndrome, and became almost as well-known for his research in that area.

● A memorial service for Prof Emery will be held in St Mark's Church, Broomhill, Sheffield, at 2 pm on Friday 8 September.

Miss Alice Burgess, aged 91

AN ACTIVE supporter of ASBAH when she lived in South London, Miss Alice Burgess, who was not expected to live long when she was born with spina bifida, has died at the age of 91.

The only girl in a family of five children, she always wore calipers but was determined to live life to the full. In 1940, the family were living in Bromley when they were bombed out in an air-raid which killed one of her brothers.

Alice lived with her mother until

1951, when mother died. With the help of a trust created by her brothers she bought a maisonette in Bromley and looked after herself. She was also secretary of the local ASBAH.

Miss Burgess worked in accounts for Harris babycarriages but was eventually made redundant after the company was taken over by Mothercare. She then became an insurance company clerk until her retirement.

In 1972, she moved to Ipswich where she died on 20 July, one day after having her hair permed. The funeral was in Ipswich on 28 July.



© G C Burgess, Bicester

Day about ability – not DIS-ability

ASBAH has challenged MPs round the country to games of wheelchair basketball – in a national ASBAH awareness day with a difference on Tuesday 3 October.

MPs are already queuing up to accept our **ChairAbility Challenge**, as we are calling this special event.

The Challenge breaks away from the traditional discussion of the disabilities as medical problems. Instead, ASBAH and Kent ASBAH have teamed up to pair MPs with people with spina bifida and/or hydrocephalus in their constituencies to play 'one-on-one' games of basketball.

And we have invited other local ASBAH associations to join in the fun – to achieve maximum impact.

The Conservatives

will be in Bournemouth that day for their annual conference. Disability frontbencher Tim Boswell MP already plans to field a whole team against disabled players. The Great Britain Wheelchair Basketball Association is working with ASBAH on the arrangements at Bournemouth.

Elsewhere, involvement of other MPs virtually guarantees a local media splash.

"MPs are great self-publicists. If you can persuade your local MP to play on a basketball court in his or her constituency, you'll find the local evening paper and perhaps TV and

radio will turn up," said Linda Hams, ASBAH's assistant director (policy and marketing).

"All you've got to do is invite your MP, find a venue – a basketball court prepared to give you free use for an hour – a couple of wheelchair basketball players (one to play the MP, one to keep in reserve) and a spare wheelchair.

"Keep our publicity people at National in touch all the way, so they can spin the correct message while making sure your association collects all the credit!

"For the event to work, there must be wide picture coverage in the media and a consistent theme. The only way to get that is if we all keep it simple and work together."

MPs who have indicated their willingness to take part in ASBAH's ChairAbility Challenge so far include:

- Chris Pond** (Gravesham),
- Howard Stoate** (Dartford),
- Candy Atherton** (Falmouth),
- Helen Brinton** (Peterborough),
- Jim Dobbin** (Heywood),
- Win Griffiths** (Bridgend),
- Derek Wyatt** (Sittingbourne),
- Betty Williams** (Conwy),
- Roger Berry** (Kingswood),
- David Lepper** (Brighton Pavilion).

Contact Linda Hams or publicity manager Tony Britton if you want to come on board – either as a wheelchair basketball player or local ASBAH, willing to arrange an event.
Tel: 01733-555988,
tonyb@asbah.demon.co.uk

Call out the basketball demonstration squad!

A FULLY-EQUIPPED mobile coaching, teaching and demonstration unit has been launched by the Great Britain Wheelchair Basketball Association – ready to travel to any school, club or group in the country which shows an interest in the sport.

The Wheelchair Basketball Roadshow contains 16 sports wheelchairs of various makes and also carries balls, badges, certificates, coaching information and leaflets.

Events it will attend are coaching clinics, seminars, awareness and taster days, tournaments, competitions, demonstrations and exhibitions.



Information: Gordon Perry, national development officer, GBWBA, The Woodlands, Brookend, Keysoe, Beds MK44 2HR. Tel/fax: 01234-708741, mobile 0850 373858, gordon@gbwba22.freeserve.co.uk



Wheelchairs get the one

IF you've had an assessment for a new wheelchair in the last year or so, you will have heard of the Wheelchair Voucher Scheme.

If you haven't been assessed recently and don't know much about the scheme, it may be time to make an appointment with your local wheelchair service.

If you don't know where your wheelchair service is, ask ASBAH's mobility adviser, Linda Knight (*pictured left*), or your ASBAH area adviser.

The Wheelchair Voucher Scheme was set up to give more choice and an alternative to accepting a wheelchair prescribed from NHS stock. Yet relatively few users have taken up the two options available under the Wheelchair Voucher Scheme (*see below*). This may be because, in some parts of

the country, it has only been advertised to new users, not existing ones.

Take-up is beginning to accelerate and the Government is recommending that the scheme continues although individual wheelchair services, in consultation with their user-groups, may decide otherwise.

Most people like the choice offered to them with a voucher – providing they have some cash to add to the voucher to buy a 'better' chair.

Unfortunately, the choice of chairs varies depending on where you live. Worse still, users with the same needs have received vouchers worth different amounts, simply because their needs have been viewed as being adequately met

The choices

IF YOU don't want the wheelchair prescribed for you from NHS stock, there are two options you can go for under the wheelchair voucher scheme:

1 Contribute to the cost of a more expensive wheelchair of your choice though still prescribed for your needs, with the user owning the wheelchair and being responsible

for maintenance and repair (the independent option).

2 Contribute to the cost of a more expensive wheelchair of your choice from a range selected by the local wheelchair service, with the NHS owning the wheelchair and being responsible for its maintenance and repair (the partnership option).

- a simple guide to you REALLY want

by different wheelchair services.

"It's the inequality of service throughout the country that is really upsetting people," said Linda, who is based at ASBAH's National Centre. "The people I deal with are getting about £200 when they know people in other areas are getting £1,000.

"If you are not satisfied with the service you have received, you must tell them, or tell me. If you accept what is given to you, when it is clearly not adequate, then the service will assume that it's fine."

Sometimes it is a matter of those who shout loudest getting the best deal. A 34-year-old service-user from the North-East was offered a £570 voucher but this was not enough for the lightweight chair he needed and he couldn't afford to make up the difference.

Yet, after he got Linda's support, he was immediately offered a lightweight chair from NHS stock. Unlike his assessor, Linda recognised that this user was not a standard case as he has arthritis and can stand with support, so is able to lift a lightweight chair into the boot rather than drag a heavier one across the front seat. He is now highly satisfied but would not have been had the wheelchair service not changed its mind.

Round the regions

HERE IS some feedback from ASBAH's Area Advisers on the Wheelchair Voucher Scheme:

KENT People can spend hours waiting to see a therapist – there is an appointment system in place but therapists work with no sense of urgency therefore are always running late.

DEVON AND CORNWALL

Provision under scheme is variable. Although service-users now obtain decent lightweight wheelchairs from the NHS, the value of the voucher varies. Some service-users have

obtained lightweight wheelchairs under the independent option without having to make any contribution; other service-users have had to contribute up to £650 towards the wheelchair.

LIVERPOOL

Little knowledge of the voucher system among potential users and little advertising. Useful for people who could have bought their own chairs anyway but hasn't made any significant improvement for those in the 'old dinosaurs'. Shop around – don't be pressured by one supplier.

- LINDA KNIGHT can be phoned on 01733-555988. But she works part-time so, if her advice is required, it may be easier to send an email to lindak@asbah.demon.co.uk
- If you are a wheelchair service user-forum member, please let *Link* know whether you think the voucher scheme will be replaced in your area. lizc@asbah.demon.co.uk



Royal day for Kirsty

A DAY of splendour and excitement as Bangor's 'royal' went on and on as Kirsty Rowlands took up her regal role as visiting queen at other festivals in the area.

It all started when Round Table members in Bangor decided that, after a lapse of seven years, Bangor should once again have a carnival queen.

As Kirsty had major surgery twice last year, the eight-year-old was chosen to grace a float decked with flowers, ribbons and balloons that was the centrepiece of a parade through the city.

Wearing a gown made for her, Kirsty enjoyed being centre stage – along with younger brother Gino, her page boy (*also pictured*), and four girl attendants, all friends from Ysgol Hirael school.

She was crowned queen of the carnival by Bangor's mayor, then settled down to enjoy the other attractions – fancy dress and bonny baby competitions, sideshows, music and a funfair.

Asked afterwards if she had enjoyed the experience, Kirsty replied: "I wish I could rewind today – especially the part when I was riding on the lorry."

BABY Charlotte Doyle was famous for a day when her story appeared on Teletext, Channel 3.

Like most toddlers, it was said that Charlotte, who is 18 months old, enjoyed singing along to the Tweenies and crawling into places she shouldn't.

But the real reason mum, Carolyn, from Cheshire, was interviewed by *24 Hours* was to highlight the condition of hydrocephalus, with a sprinkling of information about Charlotte's shunt and her ASBAH Alert card should things go wrong.

At the end of the story, we explained that there was a shortage of hydrocephalus specialists and our phone number was published.

Fame
for 24
hours!

Life after Ozzy!

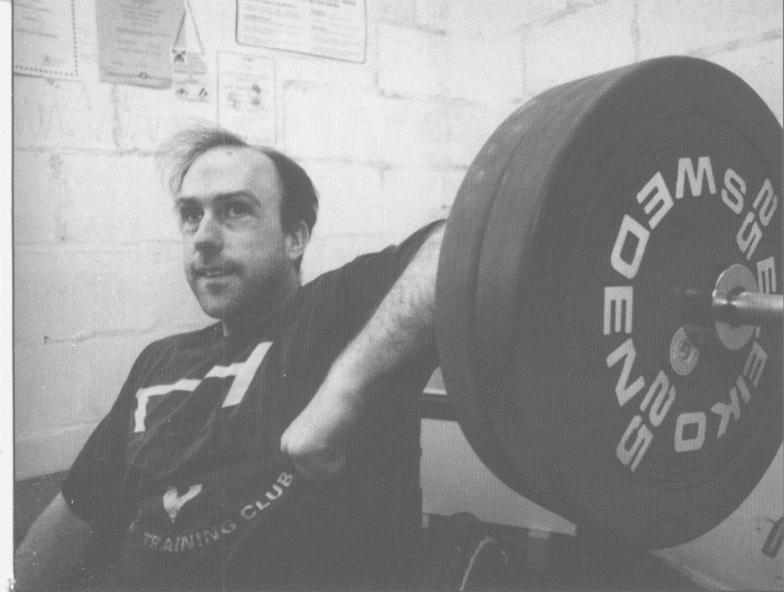
LORNA JOHNSTON has reclaimed her home after ousting her cockatoo, Ozymandias, to a dedicated aviarist. Our Northern Ireland education adviser had allowed Ozzie freedom to roam in her office – while she had to sit in the kitchen to catch up with her ASBAH paperwork.

Lorna confided that Ozzie is now in a much better place where the owner and his family love even Ozzie's infantile behaviour. Apparently,



the bird still holds up his bottom to be wiped and at least once a day begs the lady of the house for his evening cuddle.

"I miss him, but I know I'm being hypocritical," said Lorna. "I keep having this urge to go and visit and make sure everything's okay but, if it wasn't, what could I do?... I've got my own life back again, and there is so much more time in the day for everything else."



Powerlifting ambition

POWERLIFTING champ Andrew Caldwell has watched the World's Strongest man on TV and now wants to make one of those stunts his own.

The 30-year-old Scotsman has set himself a new challenge – to be the first disabled powerlifter on the show to accomplish a lorry-pull.

Despite being a third of the body-weight of the world's strongest men, he thinks he could be successful by sitting on the ground holding a number of ropes from the lorry and hauling the vehicle towards him.

He plans to use the stunt to raise money for a trainer in England who has helped him by sending him training programmes to follow.

At a mere 8.5 stone, the British recordholder has been undefeated in his category for seven years. He is ranked number four in Europe

and was 14th at the last world championships (1988). His current British record is 127.5 kilos (or 20 stone, 1 lb).

Andrew, from North Lanarkshire, said: "I'm trying to find out if a disabled powerlifter has done a lorry-pull before but I've contacted the TV programme to find out the rules and regulations."

Andrew has been competing for 21 years. He started as a swimmer and then moved into athletics (shotput and discus).

Around the time of the Barcelona Paralympics, he noticed that at least one powerlifting competitor was lifting less than he could – he thought he could do better. And he did.

● *If you know of a powerlifting wheelchair-user who has attempted a lorry-pull in the past, email lizc@asbah.demon.co.uk*

Back on the ice

DAVID PROUD, who practically invented wheelchair ice-skating at his local rink in Peterborough, was ordered off when a new member of staff spotted him doing his unique skids and slides.

David, aged 17, complained that he had been allowed to take his chair on the ice many times before. For good effect, he dropped in the word 'discrimination.'

In the time it takes turn 180° without falling off, management let him back on the ice – but insisted that his sister took responsibility for him.

Chile out there!

YOU don't get the chance to camp in the world's hottest desert, go white water rafting and trek across Chile every day.

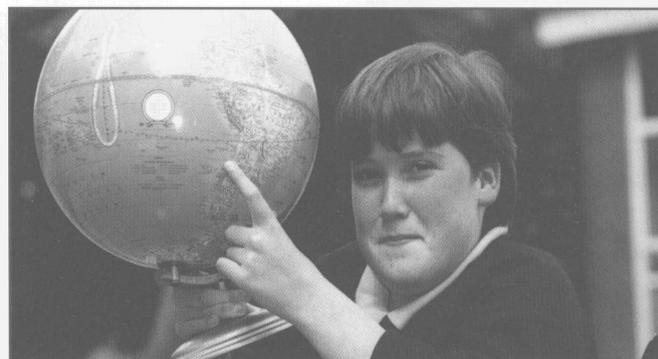
But that's exactly what 17-year-old Jody Rothwell, from Liverpool (*below*), did during four weeks this summer.

She was chosen with 23 other children from all over the UK to be part of the 'Journey of a Lifetime' expedition which gives disabled and under-privileged youngsters aged 16-18 the chance to fulfil their potential.

Before leaving, Jody, who has spina bifida, told Merseyside's *I Can Do That!* disability newspaper: "I'm really excited about the trip – especially the thought of spending two nights under canvas in the Atacama Desert.

"This is the biggest thing I've ever done. I've been on a pilgrimage to France, but nothing like this!"

Jody's four-week journey took her right across Chile using coaches, boats, muscle power and ingenuity!



THE LIVERPOOL ECHO

LEAVING home for college or university is exciting, what you've worked for – but worrying. And, if you are worried, think how your parents feel!

A bit of thought and a lot of commonsense will make it easier for all of you.

At first, it will be strange having to work out the time it will take for everyday tasks – and, of course you are in a new environment with unfamiliar bathrooms and loos.

You need to time how long it takes you at home to get up, shower, catheterise or go to the loo, get dressed, have breakfast etc. **Then double it!**

And yes, it will mean setting your alarm for earlier than usual but it's better than rushing and missing lectures etc because you haven't left enough time. And far better than having to leave showering or washing until later and being smelly all day. Yes, students traditionally are smelly, but that's usually a combination of fags and feet.

GETTING ABOUT

Familiarise yourself with your college, hall of residence and don't be afraid to ask for help (eg in opening doors) if you need it.

Make sure that you can look after your wheelchair yourself – change tyres, blow up cushions **PRACTISE!**

Look after your pressure areas especially feet and bottom. **A sore is preventable but a long time healing.**

Rosie's survival guide for students going to college



by ROSEMARY BATCHELOR from ASBAH's Hydrocephalus Network

REMEMBER YOUR SHUNT!

Tell people that you've got one. Show them your Alert Card (if you haven't got one, phone now. If you want more than one, that's okay), make sure your friends / tutor / college nurse know what to do if you should have shunt problems.

Partying is part of student life and that means you too. Drink a glass of water for **each** drink of alcohol you have. If you wake up next day with a headache which does not improve, do **not** assume you have a hangover.

Find out where the nearest neurosurgical unit is (ask ASBAH) and let them know you're a student in the area.

Drink a glass of cranberry juice a day if you have continence problems. If you were in America, you'd know just how trendy cranberry juice is.

THINK ABOUT SEX

Sexual relationships often start at college. If you are having sex, (or thinking of it), go to the GP or Family Planning Clinic and discuss contraception. Girls, you are also likely to get pregnant as anyone else.

At the same time remember folic acid. Those of you with spina bifida need a prescription dose of 5mg a day, everyone else needs the 400 mcg dose from the chemist or supermarket. **Think folic before you frolic!!**

Have you applied for Disabled Student Allowances?

Phone: 01752 232278 for more information.

ASK FOR HELP

Your tutor is there to help. If you are struggling with anything from assignments to where you live, **ask. Nothing can be done if no-one knows anything is wrong.**

Mobile phones – don't run up huge bills by using your phone for long calls. If you are worried about the mobile affecting your shunt (and we have no evidence it will) use it on the opposite ear.

Remember to phone home regularly. Your parents will want to know you are okay, but won't want to fuss. Put them out of their misery!

Finally, enjoy it! And remember, there is usually an ASBAH adviser not far away if you need one.

True story

HERE WE GO again! James is having headaches.

OK, so the neurosurgeon said he'd have headaches and good and bad days, but headaches every day. I don't think so!

It's the changes in behaviour that give it away. The almost hyper behaviour creeps in; he becomes very excitable, and takes an emotional step backwards. As the evening goes on you see the gradual lead up to stropy and aggressive behaviour. You know he's not really feeling very well – a headache! – but does he have to keep antagonising Rebecca and maybe even throw things at her?

You steel yourself to get firm with him; show him this sort of behaviour isn't acceptable. After all he is nine years old now and should be able to control it now.

After being sent to bed with much verbal abuse from him, slamming of doors and the stairs visibly cringing as he stamps up them, you tell yourself not to make excuses for him. He must be subject to the same house rules as our other two children.

Upon going into his bedroom a little later you find him sat on his bed, clothes still on, and on the verge of tears. He apologises saying he tries to control it, but sometimes he finds it too much and, by the way, he doesn't really wish we were dead.

His headache has now reached epic proportions and he's obviously in a lot of pain. He is pale and dark around the eyes. As he stands so I can help him get his pyjamas on he looks like he has had 'one over the

by **CHRIS and MIKE ALEXANDER**

Earlier this year, Mrs Alexander (pictured with her family) founded an ASBAH support for Gloucestershire parents. For info, tel Julie Knight, ASBAH adviser, on 0117-924 5077.

eight' as he wobbles around the bedroom. Once he is safely in bed, I hug a sobbing child, who is obviously frustrated and anxious at this onslaught of headaches again. I feel unable to say the right things. Painkillers are useless against his headaches. Just hugging is enough for this very tired, emotionally unstable and traumatised child. We don't feel much better as we try to comfort him, but hugging helps us too.

Morning dawns, it's the usual school day rush of getting breakfast down everybody, checking they have their dinner money, swimming kit, etc. James seems okay – sigh of relief. Suddenly you are aware of a commotion. Rebecca's shouts say it all. James has become stropy and is swearing, lying on the settee, refusing to get up, and kicking out at anyone who approaches. Simon remains calm and is gently telling James to get his shoes on or they will all be late for school. I lose my temper and smack him. This is not something that works with a highly charged, emotional James.

He goes out of the front door



swinging his coat around. Simon holds him back as he just may go straight across a busy road without looking. The strops continue until we nearly arrive at school. James stops, head hung low, in tears. 'Sorry mum,' he says, 'headache again!' I walk him into the school, telling his teacher, who sits him on a chair until he feels better.

I walk home, mulling over these events in my mind. Am I being too lenient with him? Are the headaches just an excuse to use bad language and behaviour?

There's no doubt in our minds that his behaviour has definitely deteriorated. James is fed up with hydrocephalus and headaches. No, I am not making excuses for him!

James has congenital hydrocephalus that was not diagnosed until he was two years old. He has a shunt and has had numerous revisions because of infections and malfunctions. He has been well – virtually headache-free – for about a year since the last revision.

We now have appointments with his neurologist and neurosurgeon and wait to see what they have to say.

Having a disability need not rule out a career in the early years sector, as ANNETTE RAWSTRONE finds out. This story first appeared in *Nursery World*.

Trusting Rebecca



Photo: Jacky Chapman

IT IS easy to focus on Rebecca Castle's wheelchair, but her talent for working with children, gaining their trust and caring for their needs is equally obvious.

Despite her capabilities and qualifications, including an NNEB and GNVQ in health and social care, Rebecca became a pro at handling job rejections until the Old School Day Nursery in Ascot overlooked her disability and offered her a position based on the merits of her CV.

"It was unbelievable when I got the job," says Rebecca, who has spina bifida. "I was so excited and pleased that someone had given me the chance to prove myself. To keep getting rejection letters was devastating. It was a real knock to my self-esteem, because I started to feel that I wasn't good enough, when it was probably just because I was in a wheelchair."

Nursery manager Arlene Cadow agrees. "I think some people are worried about employing staff with disabilities because they don't know how to treat them. We know that Rebecca, like other nursery nurses, will just ask if she needs help. She has the attitude that nothing will stop her."

Wooden ramps needed to be fitted in the nursery, based in an old Victorian building, but Rebecca's wheelchair has proved an unexpected plus when it comes to working with the small children.

"While most nursery nurses are rushing about and towering above their children, Rebecca, because of her wheelchair, is at eye level," Arlene explains.

"It is common for children to tug on an adult's clothing to get their attention, but they don't have to do that with Rebecca. An upset child will often go straight to her and climb on her knee for a cuddle."

The two- and three-year-olds Rebecca cares for are fascinated by her

wheelchair. "They always want to push me and they keep touching the wheels and the brakes, but I have to keep an eye on them just to make sure they don't get their fingers trapped," she says.

"They are used to me, and see me as Rebecca and not the women in the wheelchair."

The young children may have been unfazed by Rebecca's disability when she started working at the nursery last September, but the older children at the after-school club were in for a big surprise.

Arlene says: "We were intrigued about how the children in the after-school club would react. At first, they were disappointed when they found out we had employed a woman, because they are used to men.

"One of the boys, seeing she was in a wheelchair, said, 'Oh no, she's got wheels, she'll never be able to play football.' But, within half an hour, she was talking to them about basketball – and later on she thrashed them in a game. Now they think she's cool."

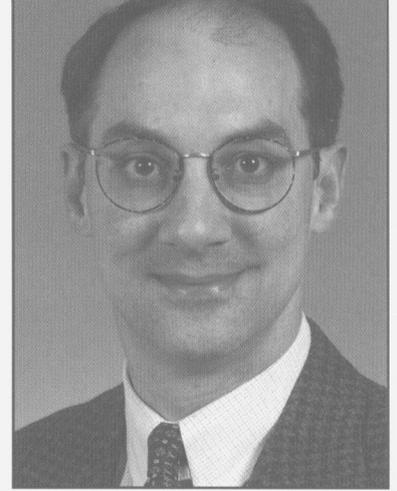
Although the toddlers don't regard Rebecca as any different to themselves, they do show consideration towards her. If she drops something on the floor, they'll automatically pick it up. The older children have also adapted and are now careful not to cause blockages by cluttering the corridor with their school bags.

"I think my working in the nursery has given the children an opportunity to learn that not everyone is the same and some people use wheelchairs," Rebecca says. "The children are starting to be aware of other people who are different. Recently, a two-year-old pointed out a girl in a wheelchair to his mum when they were out shopping."

Arlene believes Rebecca is an asset to the nursery team. She says: "Rebecca is a nursery nurse, and they are either good or bad. Rebecca is very competent and does her job well."

clinical practice

by *STEPHEN L KINSMAN, MD, child neurologist at Kennedy Krieger Institute in Baltimore, Maryland, USA. Besides directing the Carter Center for HPE at Kennedy Krieger, he manages the medical and rehabilitational needs of children and young adults with spina bifida and hydrocephalus.*



HYDROCEPHALUS acquired in infancy or childhood has many causes. One of the more common causes is a malformation of the brain. One such brain malformation is holoprosencephaly or HPE.

HPE affects about one in 10,000 live births. HPE is a term that describes a disorder of brain development where there is a failure of the embryonic brain to form into two separate hemispheres (ie during pregnancy, the infant's brain does not grow into two halves as normally expected).

This failure of separation can be complete, leaving a brain that has one rather than two hemispheres, or partial where at least part of the brain is separated into two hemispheres.

Any of these forms of HPE can be associated with hydrocephalus because of maldevelopment of the channels through which cerebrospinal fluid flows.

Holoprosencephaly has many suspected causes including genetic, environmental, and diabetes during pregnancy, but it is often hard to find the cause in isolated cases.

Holoprosencephaly is often classified into three different types: alobar, semilobar, and lobar.

In alobar HPE, the most

HPE explained

severe form, there is a single or monoventricle which can be quite large. Also, there is frequently a collection of fluid in the rear or dorsal region of the skull cavity called a dorsal cyst. It is believed that the ventricle and the cyst communicate with each other.

In semilobar, or moderate HPE, there is partial separation of the brain in the posterior (back) region, but a lack of separation in the front parts (frontal lobes). Separate occipital horns of the ventricular system are usually present. There may or may not be a dorsal cyst.

Lobar forms of HPE have even more separation of the brain into hemispheres. In all forms of this condition, craniofacial abnormalities such as cleft lip and/or palate are common, although not always present.

The primary problem in HPE is the failure of the brain to form properly. Not only does the brain fail to split into two separate hemispheres, but it is usually underdeveloped. This is

particularly true in the more severe forms.

It is the underdevelopment/maldevelopment of the brain that causes the majority of the neurologic problems for a child with HPE.

These problems may include: developmental delay/mental retardation, problems with vision and/or hearing, motor difficulties, oral motor dysfunction, gastrointestinal problems, sleep difficulties, irritability, seizures, hormonal problems and poor regulation of temperature, heart rate and respirations.

Hydrocephalus needs to be considered a secondary problem in HPE. As in other childhood conditions where hydrocephalus can be a problem, children with HPE need to be monitored for the presence or emergence of hydrocephalus.

In general, the best definition of hydrocephalus is the abnormal accumulation of cerebrospinal fluid in the ventricular system under a situation of increased pressure within the skull. The increased

Continued page 18

From page 17

pressure appears to be most important.

Many brain malformations, including many HPE cases, have enlarged ventricular systems because of a lack of developed brain tissue. This is not considered hydrocephalus.

In the newborn and infant brain, when the ventricles are growing large under pressure, hydrocephalus causes abnormal growth in the size and shape of the head. Measuring a child's head circumference at each clinic visit and examining the growth rate can usually detect problems suggestive of hydrocephalus.

Consideration of the need for a cerebrospinal fluid shunt, usually a ventriculoperitoneal shunt (which allows excess fluid to drain from the ventricles through a tube into the abdomen), under circumstances of rapid head growth (especially when accompanied by loss of developing skills) is important. However, the decision of whether or not hydrocephalus is present and whether or not to shunt is not always easy.

Expert clinical evaluation is indicated and each case requires careful consideration. Not all children with HPE that have hydrocephalus will benefit from a shunt, however some children show remarkable results.

Conditions such as HPE are roughly 10 times less common than childhood hydrocephalus in general. One can imagine it is hard to find expert help for a

condition such as HPE. This has been the experience of parents and professionals alike.

To meet the demand for a center of excellence for HPE, the Carter Centers for Brain Research in HPE and Related Malformations were created. Funded by the Don and Linda Carter Foundation, the Carter Centers consist of teams of physicians, nurses and other health care professionals at the Kennedy Krieger Institute (Baltimore, Maryland), Lucile Packard Children's Hospital at Stanford (Palo Alto, California) and Texas Scottish Rite Hospital for Children (Dallas, Texas).

The major goals of the Centers are to identify parent and family needs and to promote research into HPE. To accomplish these goals we are reaching out to families and physicians across the globe through the worldwide web <http://www.stanford.edu/group/hpe>. The Carter Centers' web page contains up to date information on HPE and provides the opportunity to communicate with the Centers' staff.

We also run an international HPE registry to provide a means for families to contact other families (after consent is given), to allow families to receive information regarding potential new developments and research projects, and to collect clinical information for research purposes.

We also conduct specialised clinics for children diagnosed with HPE to meet child and family needs, evaluate outcomes

and gather data so we can better understand HPE.

The efforts of the Carter Centers has taught us that, although there is a lot we do not know about HPE, there is a lot we do know about how to manage children with HPE and similar problems. We have also learned that textbooks often have incomplete and sometimes misleading information.

Unfortunately, this information is often passed onto families creating confusion and despair. Clear communication, extensive education, and a collective effort such as the Carter Centers brings much needed support to children with HPE and their families.

For those interested in learning more about the Carter Centers, please contact: Nancy J Clegg RN, PhD, Project Director, email: nclegg@tsrh.org, tel: 00 1 214 559 8411, fax: 00 1 214 559 7835, Texas Scottish Rite Hospital for Children, Department of Neurology, 2222 Welborn Street, Dallas, TX 75219-3993.

● In the UK, the Holoprosencephaly Support Group has been in contact with 60 families over the last nine years. Membership is free though donations are welcome.

Contact: Julie and Bob Kingshott, 70 Liphook Road, Lindford, Bordon, Hants, GU35 0PG. Tel: 01420-473065; email: HPEjulie@breathemail.net

The Scottish contact is: Shirley & George Stewart, 34 Waughton Place, Johns Haven, Aberdeenshire, DD10 0HH. Tel: 01561-362097.

fundraising

Elite motor club turn in a classic

LEADERS of an elite classic and sports car club – The Sporting Bears – have visited Peterborough to seal the bear essentials of a link up with ASBAH.

Founding couple Roger and Jan England parked their Chevrolet Camaro outside our national centre, while they presented us with a £1,500 cheque.

The presentation followed a classic and sports car run – dubbed the Lazy Bears Sunday Run – through the rolling countryside of Northamptonshire, Leicestershire and Rutland on 18 June.

On that day, 36 cars travelled from Barnwell Mill near Oundle to Stanford Hall motor cycle museum near Leicester.

ASBAH fundraising manager Donna Treanor said: “Roger and Jan organised the day for us, for the first time. I went along, was spoiled rotten by the participants, and was then thrilled to be told that the Sporting Bears will definitely raise more money for ASBAH in the future.”

The first contact with the Sporting Bears came when ASBAH fundraiser Debbie Smith made a chance phone call to Bedfordshire-based Roger England, while he was at work.

Since they formed in 1989, the Sporting Bears have raised over £235,000 for children's charities.

BELOW: from the left, are Jan England, Donna Treanor, Debbie Smith and Roger England.



THE LEICESTER MERCURY

Geoff triumphs in his long haul

GEOFF WRIGHT from Leicester was honoured by his home city after completing a 25-day trek the length of the UK in a Shopmobility scooter.

Forty-eight-year-old Geoff, who has a muscle disease, set himself the John O'Groats to Land's End challenge to raise money for several charities including ASBAH.

The marathon journey was also a tribute to his girlfriend of 23 years, the late Sharon Sterland, who had spina bifida.

The Lord Mayor of Leicester, Councillor Barbara Chambers, and the Lady Mayoress, Heather Chambers, congratulated Geoff and his friend, Jeff Wilkinson, who accompanied him on the trip. At a town hall reception, Geoff was presented with a framed certificate, a tankard and several bunches of flowers.

Geoff donated £100 to ASBAH out of the money raised in the sponsored event.

Readers who can organise a fundraising event for ASBAH should contact our fundraising manager, Donna Treanor. Tel: 01733-555988, donnat@asbah.demon.co.uk

dates for your diary

The best of ASBAH

A SERIES of short, sharp presentations about local and national ASBAH activities has been lined up for our Annual Meeting this year.

Taking place on Saturday 16 September, in Peterborough, there should be lots of ideas and encouragement for everyone.

The start time of the meeting is 11am for 11.30am and the venue is national centre at 42 Park Road, Peterborough.

If you would like to attend, please contact Lyn Rylance as soon as possible on 01733-555988 or email lynr@asbah.demon.co.uk.

Wheelchair users might get costs paid

WANT to know what needs to be done to jack up standards in the wheelchair service? Then ask a wheelchair user.

That's the thinking, well almost, behind a two-day conference on raising standards at the Hilton National, Coventry, in November (*see opposite*).

Disquieting, though, that none of the organisers can guarantee places for those who matter most. The cost, if you want to attend, is £295 – way beyond most people's budgets.

The best these brains come up with is to say ask your local wheelchair service for sponsorship, and get on to them as soon as possible. Go on, give it a try... the subject's too vital to be left to the professionals!

Upcoming events

ASBAH AGM

16 September, Peterborough

21st Century Rights

19 September, London

Challenging benefit decisions in light of the Human Rights Act, a Child Poverty Action Group conference. Keynote speaker: Richard Drabble QC. 10am–4.30pm. *Training Dept, CPAG, tel: 020 7837 7979.*

Scotland's Millennium Mobility Roadshow

14 – 16 September, Glasgow

Free admission to indoor and outdoor exhibitions, test drive the latest converted cars.

Tel: 01844 267105, rachael@mdmltd.com

ASBAH's ChairAbility Challenge

3 October, various venues

MPs versus wheelchair athletes head-to-head in demonstration basketball matches.

ASBAH Awareness Day

11 October, Liverpool

Access to ASBAH local and specialist staff. Programme covers

continence management, emotional difficulties, behaviour and hydrocephalus issues. Free. *Angela Lansley (ASBAH Adviser) tel 0151-733 8392 or Elizabeth Miers (ASBAH Adviser) 01490-450 360.*

Influences Affecting Paediatric Continence Care

18 November, Southampton

Paediatric Urology and Continence Special Interest Group conference. *Amelia Denny /Jacquie Trevett, Wessex Paediatric Nephro-urology Unit, Ward 4, Southampton General Hospital, Tremona Road, Southampton SO16 6YD.*

Information Day

22 November, Nottingham

For practitioners working with young people with learning difficulties and/or disabilities Careers, further education and welfare rights event. *East Midlands Careers Consortium, tel: 0116-287 7033.*

National Wheelchair Conference

27 – 28 November, Coventry

'Quality Services for a Quality Lifestyle', organised by emPOWER, National Wheelchair Managers Forum, Department of Health, and British Healthcare Trades Association. Residential places £295. *Sarah Lepak, BHTA, tel 01732-458868, sarah.lepak@bhta.com*

NOW I know I'm getting old: I've just been to the wedding of Emma, a friend whose christening I (*vaguely*) remember! It was a great day. The service was short and sweet, the lousy weather held off, and everything was well organised. Being organised is, I think, what makes a good wedding day. Guests need to get organised too.

I needed to organise a new suit. For years I've had but one suit, and that has done me for job interviews, christenings, weddings and funerals. It had seen her two sisters' weddings, but would it do for Emma's? After much squeezing and puffing, I decided it would take surgery to get me into that suit. Reluctantly, I set off shopping for a new one.

In the middle of a heat-wave, I was puffing, panting and (yuck) sweating my way around every suit shop in town. I staggered into every tiny chair-less cubicle and tried on every rag that called itself a suit. *Nothing* fitted! If the trousers were perfect the jacket would fit a gorilla. Or the jacket fitted perfectly and the

trousers ended about a foot after my legs!

Who designs this junk? Who decides that if you have a 30-something inch waist you must have legs like a giraffe? They should be stretched on a rack, the same as I would have to be to fit their lousy gear.

Despairing of my egg-shaped physique, I gave up and went home. I tried the suit on once more. Slap me with a kipper, the wretched thing fitted me! All that exercise must have melted enough pounds for me to wear the suit again.

Suitably prepared, we set off. The B&B we stayed in on the way served wonderful sausages for breakfast – straight from the farm's piggery. To say the farm ponded would be chronic understatement!

At church we were soon bobbing up and down, kneeling to pray or standing to sing. I 'sing' with all the harmony of a wounded rhino. It doesn't help that the tunes have all changed

since I sung them in school, going up or down when you least expect them to. Or ending suddenly. If you go into a church and hear some guy still singing a beat after everyone else has finished, that's me!

Singing isn't the only embarrassing noise I make in church. As well as killing my knees, all this up and down routine bothers my innards. I get a terrible urge to 'break wind', usually right in a quiet bit of the service. Breaking wind in church is bad enough, but dreadful when everyone hears. While others are praying about love and such, I'm gritting my teeth and praying for my guts to quiet down!

So if it's such a trauma, why go to weddings? Because I'm not entirely the hard case I make myself out to be. Seeing Emma walking down the aisle brought a football-sized lump to my throat and made it all worthwhile. And there was a smashing party afterwards!

DAVE'S DIARY

david.fulford-brown@ntlworld.com

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Changes might work to your benefit

TWO small changes have been notified to the rules on Disability Living Allowance (DLA) and Attendance Allowance (AA) which could affect some members.

Disabled people who pay the full cost of their care in local authority-run residential care homes will now be eligible to claim DLA and AA. The Social Security department said it had long been its policy that DLA and AA cannot be paid to a disabled person in local authority owned or managed residential care, if they paid the full cost of that care from their own resources. The change

will now put these residents on a par with disabled people living in private or independent care homes where the benefit can be paid.

And another rule change will benefit disabled people who spend short but frequent spells in hospital, particularly on care breaks. The change here means that DLA or AA will continue to be paid to cover the day of discharge – at present, the benefit is only paid only paid on the day of admission. DLA and AA are adjusted when care is provided in hospital for someone is receiving free in-patient treatment.

We welcome letters for publication, which should be sent to: Editor, ASBAH, 42 Park Road, Peterborough PE1 2UQ, The Editor reserves the right to edit letters, so please keep them short.

Pen pals

MY NAME is Deborah. I'm 19 and I have hydrocephalus. I've got three shunts and have had 32 neuro-operations at Walton and Alder Hey hospitals in Liverpool.

I love most pop bands and am a Darren Day fan. I'm looking for female and male pen pals from the Wrexham area, aged 19-24, who like having fun. So get writing!

Deborah Davies
37 Ffordd Elfed
Rhosnesni
Wrexham LU2 7LU

I'M 52, and have spina bifida and arrested hydrocephalus. I divorced recently after nearly 30 years of marriage and want to build up my

life again. I do part-time clerical work in a hospital and I am a walker. I don't think I'm ready for another relationship just yet, but I'd love a pen pal.

Theresa Sweeney
Rainbows End Cottage
3 Miers Court Road, Rainham
Kent ME8 8JB

I AM 37 years old with spina bifida. I am a divorcee, have no children but do have a small dog. I don't go out much as I don't drive, taxis are costly and there is nowhere in my home town to go to.

Write, if you are interested in becoming my pen-friend.

Liz Weelands
17 Kipling Close, Stanley
Co Durham DH9 6UA

Trouble with the trains!

I GOT very cross reading Martin Thorn's description of rail travel with a wheelchair (*Link*, July). He is clearly living on another planet and should try getting about on South West Trains. My experiences have been simply horrific because:

1. I need to use a footbridge to get my son and his wheelchair off the station platform (impossible without the aid of at least two strong men). The only option is for me to carry my son (17 kgs of long, unco-operative deadweight) and for someone else to carry the wheelchair. The station nearest to us is not manned so this involves either going there and asking some other passenger for help or going to a station further away and asking rail staff for help. Usually they want to know when you will be getting to the station and usually I don't know the answer to that until I get on the train in London, hospital appointments being notoriously unreliable.

2. His wheelchair will not fit through the doors of the trains (old slam-door type). The only option is to carry my son in, lay him on the seat (assuming one is free), ask someone to stop him from falling off while I struggle to fold the wheelchair and get it through the door. I then have to sit holding my son with the wheelchair folded on the floor taking up legroom for myself and other passengers.

South West Trains suggests I use the guard's van for the wheelchair. It is noisy and cold and I cannot stay in there with him (no seats) and he is only three years old and has epilepsy and is blind. Nobody in their right mind would leave such a child in there unattended. I have tried complaining to the head of customer service but the number I am given is never answered. Funny that.

I think Martin Thorn is very much in the minority in finding rail travel straightforward.

Isobel Backhouse, Bracknell, Berkshire.

Misery of the mobile phone bill

MY FRIEND and I went to a mobile phone shop to enquire about buying one. We were served by a young man who seemed to have no idea that we had a learning difficulty, and he showed us some. We explained that we didn't need a mobile to use all the time but just for emergencies.

My friend and I thought we understood the contract that we had to sign but, after a year, my friend rang me to tell me that she had received a big bill to pay because the contract was written in her name. This caused an argument between me and my friend and now we are not talking to each other.

In my eyes, people with learning difficulties need to be careful that they are not exploited and they understand what is being said to them when buying something.

Gillian Clayton, Colchester, Essex.

holiday lets

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

SELSEY, WEST SUSSEX (SASBAH)

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

ISLE OF WIGHT ASBAH

Recently refurbished, fully equipped, two-bedroom bungalow. Sleeps six. Wheelchair accessible. Clubhouse, shop, local indoor heated pool. Beautiful area. Own transport advisable. Excellent rates: Details: *Mrs Griffiths*, 3 Western Road, Shanklin, Isle of Wight PO37 7NF, tel 01983 863658.

BERWICK COTTAGE, EAST HARLING, NORFOLK

Purpose-built modern cottage. Ground-floor accommodation for up to two people with disabilities. Scan 700 beds. Closso-Mat. Overhead track hoist bedroom-to-bathroom. First floor accommodation for up to four 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.

COMMON RIGHT BARN, WISBECH ST MARY, CAMBS

Self-catering, wheelchair friendly units (Category 2 & 3) in newly refurbished barn buildings. EETB approved. Rural fenland setting with enclosed gardens / parking. Pub / restaurant 800 yds. Village two miles. On-site meals if required. From £200 per week. OPEN ALL YEAR. Local places of interest and many more within easy distance. *Teresa Fowler*, tel: 01945 410424.

Advert rates

● Classified Rates:

£3.75 for 30 words max.
£5.50 for 30-45 words.
£6.75 for 45-60 words.

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

● Classified adverts for the next issue of *LINK* (Nov) should be submitted by Monday, 2 October.

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

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

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

FOR SALE

SUNGIFT Legend electric wheelchair, charger and pair of metal folding ramps. £900 ono. Tel: 0115-974 8335 (Nottingham).

PEGASUS Air Wave Mattress suitable for a single bed. Excellent condition. Cost more than £3,000 - accept £800 ono. Phone *Linda Burton* on 01978-290920 (N Wales).

ORTHO-KINETICS Reha buggy, 15" wide. Cost £1,100, asking £250 ono. Very good condition. Tel: 01268-415314 (Basildon, Essex).

'HUNTLEIGH' Home and Away 3 electric wheelchair. Hand-built chrome frame, joystick control, kerb climber. As new condition. Three years old. Cost £2,600 new; accept £500 ono. Tel: 01234-350241 (Bedford).

BATH lift seat. Neptune, very good condition, fits inside bath. £524 new, £150 ono. Tel: 0208-502 2829 (London).

PREMIER walk-in bath with shower. Cost £4,000, excellent condition, will accept £500. Tel: 01792-774329.

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