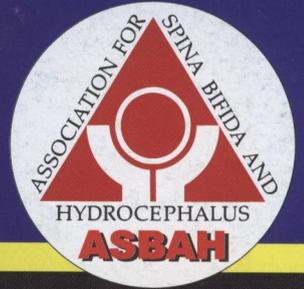


LINK

The magazine for people
with Spina Bifida and
Hydrocephalus



**Thank you,
Matthew!**

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SEPTEMBER/OCTOBER 2001

ISSUE 195

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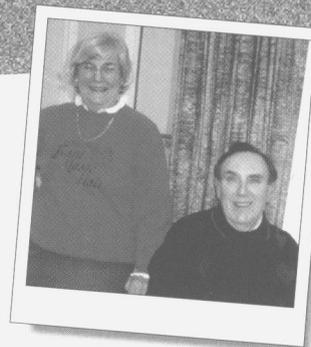
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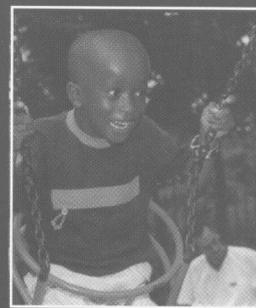
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LINK



Cover: Matthew Kposowa has helped us create our Annual Review this year. Story on page 10. Photo: CAROLINE KERSLAKE.

Editorial

OUR STAR find in this issue is the special airline seat for children who cannot sit upright unsupported – which charter carrier Monarch provides to its passengers on request.

Paula Thompson, one of ASBAH's specialist advisers, spotted a story about the seat as she was flicking through *Connections*, the Microcephaly Support Group newsletter.

An MSG member and frequent air traveller was praising the seat, the likes of which she had never seen before, for helping her to travel comfortably and in safety with her disabled daughter.

It seemed just the sort of news which we should pass on – not to extol Monarch over any other airline, but to give readers information and possibly more power. If you are flying with a young child who cannot sit up without support, you now know what to ask for when booking.

Link asked a couple of other airlines about whether they also used the seat. BA didn't bother to respond to our inquiry, while Air 2000 said it was conducting safety checks on a similar chair.

Don't expect to find them widely used. But do ask about them. Create a demand.

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

ASBAH's mission is to work with people with spina bifida and/or hydrocephalus, their families and carers to promote individual choice, control and quality of life.

postmaster@asbah.org
www.asbah.org

Government revises the education code of practice

GUIDELINES governing the level of provision in school for children with special educational needs have been withdrawn for reconsideration.

A chorus of complaints from ASBAH and other organisations led schools minister Baroness Ashton to pulling the draft code of practice which accompanies the new Special Educational Needs and Disability Act on 12 July, shortly after it was tabled for debate in Parliament

The minister said: "We recognise the need to make changes to the guidance on quantifying provision in statements."

Conservative peer Baroness Blatch told the House of Lords that the draft code "left the door open for vague statements to be written about children" in respect of their special educational need.

Critics of the code – including the Action on Entitlement alliance – said provision must be made to beef up the requirements on specifying and quantifying the amount of support a child receives at school.

The new Act outlaws disability discrimination in schools and colleges. Leading education and disability lawyer David Ruebain will describe it in more detail in the next issue of *Link*.

Monarch – is it the king of the airlines?

CHILDREN who cannot sit upright unsupported can now fly safely in a special harnessed seat that is provided by at least one airline.

Sian Cook was delighted to discover that Monarch Airlines could offer the travel chair to her severely disabled daughter when the family flew to Tenerife last October. Previously, Mrs Cook had resorted to using the four-year-old's car seat but this did not fit properly into the aircraft seat.

Mrs Cook, from Newbury, Berkshire, said: "Our way of coping is to carry on as normal and go abroad for a holiday, so it was wonderful that we could do this and know Amy was safe and comfortable. It made a huge difference."

Monarch Airlines is believed to be the first airline to offer the £600 padded chair which is suitable for 1–9-year-olds. It comes on their charter flights from Luton, Gatwick, Manchester and Birmingham.

Families with children with special needs, and individuals with special needs, are advised to contact Monarch Airline's customer services department at least two full working days before their departure date with their requirements.

● As we went to press, *Link* checked whether BA and Air 2000 offered the special chair. BA failed to respond, while Air 2000 said they are conducting safety checks on a similar chair.



ASBAH's new Research Fellow



NEW ASBAH research will give service-users and staff the chance to shape future NHS healthcare policies.

Sue Thompson (*pictured*) has been appointed ASBAH Research Fellow to collect information which will form the basis of a report for the Department of Health.

The timing of the report has been planned to influence the hugely-important new 'National Service Framework' for people with long-term neurological

conditions. The aim of the framework will be to stop service provision being a lottery, depending on where you live.

ASBAH executive director Andrew Russell said: "This Framework will be introduced in 2005 but progress will be made in the next year or so, so we will ensure that the needs of our service-users are included."

Sue, an experienced researcher, will be working on the project for 10 months and will be supervised by Sheffield University's Department of Sociological Studies.

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Our Executive Director ANDREW RUSSELL warns the government against pandering to prejudice.

A bad day's work

WHEN the government recently announced its intention to bring in new checks on Incapacity Benefit recipients, many of us were surprised at what seems to be a government attack on disabled people, for no apparent reason.

The evidence on disability benefits is that there is an extremely low level of fraud and that, far from overclaiming, many people are wrongly denied benefits by Department of Work and Pensions Decision Makers which are subsequently won at appeal.

Whilst the government is right to insist that benefits expenditure is properly controlled, it needs to be very careful how it presents its arguments. The disability lobby is strong in both Houses of Parliament, and a great deal of ill feeling could be stirred up not only in political circles, but in the voluntary sector whose partnership the government needs. We are playing a big part in refining and implementing many of the policy initiatives in health and education that are being developed.

The Prime Minister spoke of claimants being paid £4,000 a year for up to 20 years, with no one ever checking on whether their benefit is justified by a disability. His implication is that disabled people are cheating the system. Actual evidence of this has been searched for, but not found.

Memories are long enough to recall the ill-fated Benefits Integrity Project, under the previous

government, which miserably failed to meet its money-saving targets, cost a great deal to implement, and caused a lot of suffering and inconvenience in its implementation.

ASBAH's concerns about the system of medical examinations conducted through the DSS were so great that we arranged a private meeting with the Social Security Minister earlier this year, to secure improvements to the training and administration of these services. Our concerns about the competence of the medical and administrative system handling these decisions are shared by other disability organisations, so it concerns us that the government is targeting a large group of disabled people for further checks before it has addressed the effectiveness of its own system.

Incapacity Benefit has grown in importance, for ASBAH members, since Severe Disablement Allowance was closed to new claimants. Existing Severe Disablement Allowance recipients will continue to receive it, but new, long-term disabled claimants are directed towards Incapacity Benefit.

A recent report from the new Department of Work and Pensions shows that the government's official error in administering Incapacity Benefit leads to overpayments of £13 million per year, whilst customer error only leads to £1 million overpayment. Incidence of fraud was found to be insignificant.

Turn to foot of page 7

PowerTrike pulls prize

A BOLT-on wheelchair motor, featured in the last *Link*, has scooped a top award on the BBC TV's *Tomorrow's World* programme.

The detachable PowerTrike gives stability and power to manual wheelchairs, enabling users to go off-road over rough ground, grass and gravel.

Winning inventor Vincent Ross (49), himself a wheelchair-user, was selected from more than 500 entries to *Tomorrow's World*.

Vincent (*pictured*) was presented with the Inventive Individual award by Trevor Bayliss, the inventor of the clockwork radio, at a ceremony

in Earls Court, London.

Vincent said: "It's a tremendous honour to win such a prestigious award and it will help PowerTrike go from strength to strength.

"I had an inkling I was in with a good chance at the awards ceremony when I was seated on the top table next to Richard Branson."

The awards, run in association with NESTA (the National Endowment for Science, Technology and the Arts), are a celebration of the best scientific innovation in Britain.

Vincent developed an early prototype of the PowerTrike 10 years ago for hanggliding.



The success of this prototype made him realise it had many more possibilities. He formed **pdq mobility** with two businessmen, and the PowerTrike was put into production.

● www.pdqmobility.com

Obituary: Roger Tadd

ROGER TADD, an active local Association member in Surrey, has died of cancer at the age of 53.

As well as being father to Andrew, James, Paul and Helen, he was hon treasurer of Surrey

ASBAH for five years. He is pictured abseiling at a recent family activities weekend.

He had a busy and demanding business life at Boots and was a keen squash and bridge player.

He and his wife Liz always made the committee welcome for its meetings and the children often popped in to say 'good night' or to see how many cups were needed.

Roger arranged street collections in Sutton and helped at an annual fete, putting up a tent and delighting children with a marble-into-flowerpot game.

Surrey ASBAH colleague Alan Twyford said: "Roger dealt with his illness with great courage and with the same quiet resolve which he demonstrated in his general life."



Church go-ahead

TO THE joy of ASBAH member Christine Helliwell, the final legal hurdles have been cleared to a plan to make worship fully-inclusive at St Martin's Church, Brighouse, West Yorkshire.

Three objections to the scheme to turn this parish church built in a bygone age into a place with easy access for all disabled people have been dealt with by the diocesan legal authority.

Christine is a leading parishioner who has long spoken in favour of the plan, which includes accessible toilets and a lift to an upstairs meeting room and kitchen. She also organises the church's transport scheme for disabled people.

medical update

The value of keeping a full set of records

KEEPING your own copies of medical records and scans could prove very useful.

Melissa Peacock has been meticulous in keeping her daughter's records in diary-form since she was born.

What started out as simply an exercise to help her come to terms with having a baby with disabilities quickly became a way of recording Ashleigh's treatment for spina bifida and obtaining best care for her four-year-old.

Mrs Peacock, who takes Ashleigh (*pictured right*) to Liverpool for treatment, said: "To be forewarned is to be forearmed. I don't like to go into a room with no knowledge at all."

The diary also proved useful when applying for Disability Living Allowance. "I listed every appointment Ashleigh had ever been to and we got it straight away," she said.

Some hospitals pass on

copies of patients' records.

If your hospital doesn't, you'll have to ask.

You will probably be able to find relevant past history and the most recent scans.

Mrs Peacock's medical diary holds records from past hospitals and copies of recent scans, some of which she has paid for.

"Two out of three hospitals went along with my request, which I made to them in writing," she said.

Now Mrs Peacock has found a neurosurgeon she trusts, she no longer keeps her own day-to-day records.

"When Ashleigh had an MRI scan of a cyst on her spinal cord, her neurosurgeon underlined the positive bits in the report and told me I could keep it for my records.

"He understands that I need to know and he will explain it."



New continence topic sheets

ASBAH has published a new set of continence topic sheets. Eight different topics are covered. They are:

- Toilet Training and Spina Bifida
- Toilet Training and Hydrocephalus
- Adaptations for Toileting
- Clean Intermittent Self-Catheterisation
- Bladder Augmentation
- Antegrade Continence Enema
- Colostomy, Ileostomy and Urostomy
- Artificial Sphincter.

Individual sheets are available free from ASBAH Information, 42 Park Road, Peterborough PE1 2UQ, or from our regional centres – but enclose a large SAE.

If the whole series is required, it is available as a pack, priced at £3. Cheques payable to ASBAH.

Remembrance

PARENTS, carers or relations who have lost someone may find it comforting to record their passing in ASBAH's Book of Remembrance.

The hard-bound book is kept at ASBAH's national centre in Peterborough.

● Details are available from: Rosemary Batchelor, ASBAH Services, 42 Park Road, Peterborough PE1 2UQ; tel: 01733-555988, or email rosemaryb@asbah.org

A bad day's work *from page 5*

Some of us are also a little anxious at the government's emphasis on the key role of work and employment, to provide both self-esteem and an income for disabled people.

ASBAH strongly supports policies which enable those disabled people who can and wish to work, to do so. But we should acknowledge that many barriers remain, both physically and in attitudes, to this aspiration. The government is rightly trumpeting the importance of social inclusion in all spheres of life, and Ministers should wake up to the fact that it is deeply unfair for the government itself, through hints, to pander to that minority, ill-informed public attitude that classes disabled people as a lazy and dishonest group of the population who need to be put to work.

Massive response to help crack riddle of spina bifida

A MASSIVE response from ASBAH families is helping researchers put together a jigsaw which when completed could help solve the riddle of spina bifida.

So far, 550 families from England and Wales have volunteered to give DNA samples to a genetic study being run from Dublin – with \$3-million worth of support from the USA.

The latest phase of DNA collection was launched in this magazine four months ago. Researchers in Dublin have already collected over 500 samples from people living in Northern Ireland and Eire.

There is still time to take part in the survey which involves people with spina bifida and, if possible, their parents. They contribute DNA by

Folic replies

OVER half of the replies to the consultation on fortifying flour with folic acid favoured the measure. But the consultation is taking longer than expected because of the need for further research into potential risks of fortification and possible restriction of consumer choice.

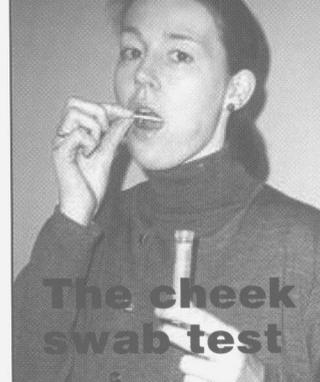
taking cheek swab samples, using a home-testing kit which will be supplied.

Researchers at Trinity College, Dublin, want to build up as big a genetic database as possible.

A beneficial side-effect of the study is that it might point the way to improving folic acid usage in the prevention

of spina bifida pregnancies in the future.

Dr Mary-Patricia McKeever, project manager at the Health Research Board, Dublin (*pictured*), told *Link*: “If we can identify the genes that are functioning less efficiently in the transport or metabolism of folic acid and related nutrients, this will improve our understand-



ing of how spina bifida arises and allow us to give better guidance and nutrition information to families at risk and mothers-to-be.”

● For information about taking part, please phone freephone 0800-1699050.

Application forms from ASBAH Information, tel: 01733-555988, email: gillw@asbah.org

More volunteers wanted to boost ASBAH's psychological survey

VOLUNTEERS are being urged to join an ASBAH study to find out the impact of spina bifida and hydrocephalus on behaviour and general development.

A team of psychologists at Southampton University has received a further £49,000 from ASBAH to broaden their study to include teenagers – comparing the perceptions of parents and the adolescents themselves.

They want to hear from families with six–12-year-olds (for the first study) or 13–18-year-olds (for this later study) who have spina bifida, or spina bifida

and hydrocephalus. People should live in Hampshire, Bristol, East and West Sussex, Wiltshire, Berkshire or Kent.

For the first study, 560 families have so far returned lengthy questionnaires and many have been interviewed to establish the developmental, educational, behavioural and psychological achievements and difficulties of their children.

Research fellow Ineke Pit-ten Cate, in a team led by Professor Jim Stevenson, said: “Families have been very willing to share their experiences with

us, which has provided us with a lot of very useful information, but we'd like to hear from more parents with children with spina bifida in both the 6–12 and 13–18 year groups.

“Once developmental consequences for the child with spina bifida and / or hydrocephalus can be identified we will attempt to translate these findings into the educational and home care needs of these children and their families.”

● To volunteer your family, please call the research team on 023-80595452 or email I.Pit-ten-Cate@soton.ac.uk

Treloar's

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

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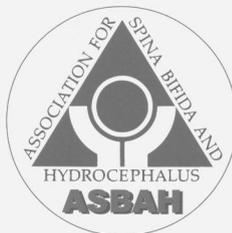
Treloar School and College are supported by the Treloar Trust, registered charity number 307103

Reach for the sky!

A COURSE TO HELP YOU FIND THE REAL YOU

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

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



One-day conference call
by Your Voice,
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or book a place now,
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Lyn Rylance, ASBAH
tel: 01733-555988
lynr@asbah.org

Not a Motability word about being barred!

MOTABILITY upset two Dorset customers – by not telling them that they had been ‘barred’ from reapplying for leased cars.

Michael Lanning and Richard Antell, who both have spina bifida, depend on their cars for getting about. Both had leased from Motability for years.

But, when the leases came up for renewal this year, neither of them heard a word that, for different reasons, they’d been put on hold.

Michael (32 and pictured above) heard later that he made ‘too many’ insurance claims during the three-year lease.

His mother, Gill, secretary of Bournemouth, Christchurch and District ASBAH, said: “Had we known about this we would not have claimed for them, as one was to get his old car up together prior to returning it, and one, we think, was a no fault claim.

“No-one had thought to tell us about this, which left us six weeks to find and get adapted a new car. This was achieved with only days to spare.”

Michael travels 25 miles a day to work at the Benefits Agency. He’s active socially.

“Our main complaint was that no-one bothered to tell us. We were not able to speak to anyone as they batted us back and forth from Motability to Motability Finance to the insurers.”

Mrs Lanning added: “Michael was lucky in that he had us to sort him out, but not everyone has parents who can do that. It makes me fume. And to think that this is a Government scheme!”

A Motability spokesman pointed out that if a customer’s ‘at fault’ accident record was high, Motability had to determine whether that person was an insurance risk to the scheme. If this is determined, the customer will be refused insurance, which happened to Mr Lanning.

The spokesman added: “Customers are notified of this action, by a letter sent automatically by Motability Finance Limited. Unfortunately it seems that Mr Lanning never received this letter, for which we apologise.”



Twenty-five-year-old Richard Antell, from Poole, Dorset, has leased two cars from Motability since 1995. Customers are normally informed in advance of a renewal but this time no word was sent.

In May, Richard’s father, Gordon, phoned Motability and was told a bar had been applied but they couldn’t immediately say why.

After a few days, with still no explanation, Mr Antell spoke to the agents and they promised to sort it out. Within 24 hours they found that ‘the bar’ was due to Richard’s first car being internally damaged. The block hadn’t affected his second car as the application had gone through before he returned his first car.

Mr Antell said: “As it turned out, they have reinstated him and he is now getting his third Motability car. But, two and a half years down the road, no-one had chosen to write and say this was about to happen. In these days of computerisation, they could have got out a standard letter about the bar. We heard nothing and were waiting notification for a new car.”

The Motability spokesman commented: “We are currently reviewing our processes to ensure that customers are aware of any actions required of them before they can reapply for a new scheme vehicle. We are pleased that this situation is now resolved and Mr Antell’s application is going through for his third car on the Scheme.”

Happy time on the swings

Our thanks to Matthew Kposowa, who is almost six, mother Satta and their family for allowing ASBAH to feature them in this year’s Annual Review, which will be published after the Review and Accounts are approved by members at our AGM on 29 September.

Photographer Caroline Kerslake caught up with the family at their home in Hackney, East London, and in the nearby park where Matthew enjoyed the swings. ASBAH has been working with the family since soon after Matthew was born.

Avoid magnets near programmable shunts

PEOPLE with shunts which are programmable should avoid close contact with heavy-duty magnets in their everyday lives, researchers have warned.

Staff at Addenbrookes' Hospital, Cambridge, now issue warning cards to patients because they are worried that the settings on some shunts can be affected by some magnets in the home and at school.

Researchers, led by Marek Czosnyka, tell us that their concern was highlighted by one case where the setting on a shunt was altered by a child who leaned against the magnetic catch on a kitchen cupboard door.

Other risk avoidance advice in their warning card includes fridge magnets, toys with magnets in them, household tools which have strong solid magnets and appliances designed to attach to metal surfaces, like wall knife-holders.

The advice covers situations where people come in close

contact with magnets, or where children might play with them. Simply walking past these magnets will do no harm.

The researchers have no undue concern about shunt settings being altered by mobile phones, telephone handsets, telephone headsets, or metal detector gates at airports.

But ASBAH advises people with programmable shunts to err on the side of caution at airports by following advice given to people with heart pacemakers. This is not to go through the gate but to tell security staff that you have a hydrocephalus shunt which could be affected by magnets.

"Patientline" headsets used in many hospitals will affect shunts as they attach by magnets.

We have a commonsense approach to the use of mobile phones by people with hydrocephalus shunts. Don't talk too long, and hold the phone on the other side of your head!

Review of new shunt test

NEW research could pave the way for a non-invasive shunt test that could be used in outpatients' clinics.

Using a tool to assess pressure in the head via the ear canal, the painless test takes about an hour with the results being made available immediately.

It contrasts to current methods of assessing shunts in which a pressure monitoring device is inserted into the head – a procedure which carries the risk of infection and is poorly tolerated.

After seeing a good response in a small group of patients, scientists in Newcastle are to try it on a large group of healthy volunteers to ensure they are obtaining similar results on repeated tests. The team, which has received £50,000 for the study from the Action Research charity, will then assess its effectiveness in detecting shunt malfunction in a large group of 'real' patients.

Dr Kathryn Bannister, from the Regional Medical Physics Department at Newcastle's General Hospital, said: "If this test is shown to be of value, it will not only vastly improve the care of patients with hydrocephalus, but will open up exciting areas of research for other conditions, including hearing and balance disorders and brain tumours."

Contact with people with late diagnosis

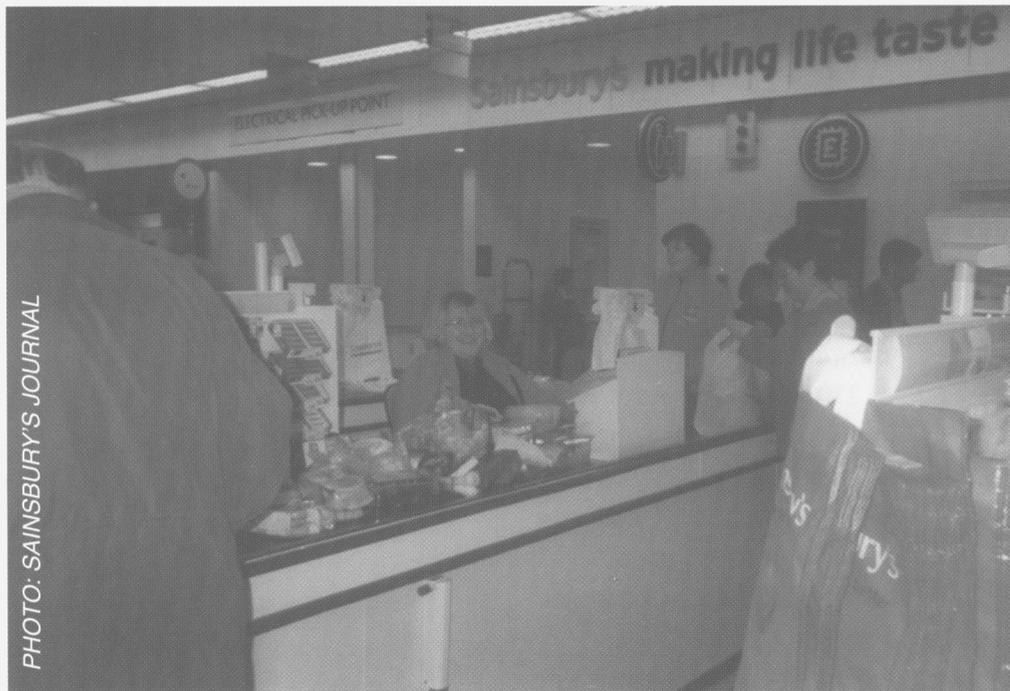
I AM 39 years old and noticed the first symptoms of hydrocephalus last autumn (wobbly gait, tremor in my right hand, photophobia and headaches).

I had a VP shunt inserted in February 2001. I am going to hospital again this summer for further tests as some of my symptoms have begun to recur.

I would like to make contact with people who have contracted hydrocephalus as late as their 30s or beyond.

Frank Stapleton, The Old Rectory, Hollymount, Claremorris, Co Mayo, Eire. stapletonfrank@hotmail.com

people they make us tick!



Ciara at the checkout

AN ELECTRIC wheelchair has transformed work for Sainsbury's checkout lady, Ciara O'Connell, who has spina bifida.

When she first joined St Clare's store in Hampton, Middlesex, Ciara faced a daily challenge – the transfer from her own wheelchair to the checkout chair and the discomfort of prolonged sitting.

This was made worse by her dependence on colleagues in emergencies and the

fact that she could operate from only the few checkouts where wheelchair access was relatively easy.

Fortunately, a risk assessment by a disability employment adviser resulted in a recommendation for a powered wheelchair.

Through Rainbow Rehab, Sainsbury's found the Flexmobile – a chair which recharges overnight, adjusts to Ciara's specific needs and reduces her dependence on others.

Today Ciara is able to use every checkout and make her own way around the store.

Ciara said: "I don't need to use the checkout chairs at all anymore as the new chair adjusts to the right height at the touch of a button.

"It also solves the problem of having to get someone to hold the checkout chair to stop it swivelling when I want to leave the till. Now I can do it all on my own."

Baby on way for Tanni

GOLD medallist Tanni Grey-Thompson is expecting her first child in February. The 31-year-old, who won four gold medals at last year's Sydney Paralympics and won this year's London Marathon, is very excited.

She is quoted in *The Mirror*: "I have had many special days, but this news is very exciting. Having a baby is going to be a very different experience."

She is married to fellow champion athlete Ian, who is 36.

Good enough to be bottled!

IF YOU COULD bottle enthusiasm and sell it, Dutch student Olga de Wit would make a fortune.

Olga (23), who has spina bifida, hopes to qualify as a neuropsychologist.

A member of BOSK, our sister association in The Netherlands, she has spent part of the last six months finding out about the ASBAH childhood psychology project at Southampton University to see if it can be copied in Holland.

Olga has completed a four-year degree at



Maastricht University, but there's still six years of medical studies ahead of her.

If the excitement she showed throughout a recent visit to ASBAH national centre is anything to go by, she'll sail through them.



Bury's champion receives an MBE

CONGRATULATIONS to Eileen Taplin on being awarded an MBE for a life-time's work with local ASBAHs and other disability groups.

Eileen attended the first meeting of parents of children with spina bifida and/or hydrocephalus in 1963, after reading about it in the local paper, which led to the formation of North-West ASBAH.

As secretary, she helped form four groups in Greater Manchester and was in charge of the bookings and maintenance of two caravans at Prestatyn.

Aged 70, Eileen still devotes two days a week to voluntary work. Her disabled son Chris (43) lives with her and she keeps an eye on her mother.

The MBE mainly honours her works with Bury and District Disabled Advisory Council (BADDAC), of which she is chairperson.

Based at the Seedfield Resource Centre at Bury Metro, BADDAC has grown from a few volunteers to 17 (soon 19) paid employees – providing a range of services like access audits, disability awareness training and befriending schemes.

Eileen is also involved with Bury Carers Partnership, her local Shopmobility, and was local secretary for Crossroads, the carers' service.

THE STORY of the SHASBAH toddler trolley, which were sold round the world, looks like making it into a book. Author Brian Woods, who is writing a history of the wheelchair, has promised to talk to Southampton pioneer Frank Mortimer (85) about his part in a production line which mobilised thousands of children with spina bifida.

Toddler trolleys to go in book?

Classic bloodline

CLASSIC cars have been in Chris Jones's blood since as a boy he listened to his mechanic grand-dad talk about the 1950s and 60s.

The first car he did up was a 1100 Austin Estate. Chris, from Wrexham, next fell for the Wolseley Hornet (a mini with a boot). He bought one while rebuilding the Austin over six years – new floors, wings, sills, doors and an engine.

"I did the mechanics myself with help from others. I asked one of my mates to do the electrics," he said. "If you can't find the exact part you look for the equivalent. It's like a puzzle and you wonder where can I go for that?"

Now he's renovating a 1967 Sunbeam Stiletto – the sports version of the Hillman Imp – bought last year for £250. The engine's at the back and the petrol goes in at the front.

Chris (25), who has hydrocephalus, said: "It's not just a matter of owning a classic car that's enjoyable. It's the way complete strangers will come up to you to tell you their particular memory of that type of car. It's intriguing and sometimes you find out something."



yacht racing

Advisers sail wight round the island!



A RACE on the high seas, riding high waves and drenched by torrential rain, exhilarated two ASBAH advisers – who took to it like ducks to water.

Lucy Hughes and Liz Clayton were among 15,000 sailors who raced against each other in the Isle of Wight's Round Island Race – the biggest yacht race in the world.

Lucy (41), who has spina bifida and enjoys a challenge, took a 'competent crew' course with Sail UK earlier this year and joined them again for the race.

Liz got hooked on the excitement of sailing on her 50th

birthday two years ago after many years of sedate river cruising. It was the second time she and husband Steve (pictured above) completed the 50 or so miles around the island but this year they were really moving – in their own 34-foot boat and taken in hand by a professional skipper.

Berkshire-based Liz commented: "It's the most exciting thing I've ever done. The seas were bigger than any we've been on. We were fighting strong seas, strong winds and then it poured!

"We lost sight of the boats in front as they disappeared beneath the waves. The most hair-

raising moments were going round the Needles with big seas, lots of boats and a narrow channel, and the finish with 100 boats crossing the line in half an hour."

Lucy, one of our London advisers, said: "There were long stretches of doing nothing but then there was a rush to do something. We had to stay very alert and change course quickly if we needed to. There were hundreds of boats in close quarters and several near-misses; we saw a big boat hit a smaller one. Several crews retired just past the Needles.

"Each crew member took turns at the helm; changing the sails to maximise speed; looking after each other with food and drinks; watching out for other boats and finding the best course."

Liz's yacht, *Moondance*, came 378th out of 1,743 in a second less than nine hours. Lucy's boat was only six minutes behind but was positioned 22 places afterwards.

The day was a record-breaker. Lucy's boat beat its previous record by 50 minutes and the overall race records for mono and multihulls were shattered. Strong winds favoured the larger boats this year.

● Liz and Steve Clayton, with their crew



Setting your records straight

EARLIER this year we told readers about the new Data Protection Act.

As recommended by the Act, we published our Data Protection Statement which is printed again in the panel on the right.

At every opportunity during the last year, we have been asking our service users to give us their permission to hold their personal data in ASBAH's confidential database and files. But there are still lots of you we haven't reached yet.

If, after reading our Statement, you are happy for us to continue holding this information, please complete the tear-off slip below and return it to:

● Gill Winfield,
ASBAH Information,
42 Park Road,
Peterborough.

● Or you can email or Gill at gillw@asbah.org or phone her on 01733-555988.

Thanks for helping us to keep our records up to date.

ASBAH's Data Protection Statement

The new Data Protection Act governs what information can be held on an individual and how that information can be used.

Like many voluntary organisations ASBAH holds information about our service users, including names and addresses, disability details and records of our contact with you.

Our main reason for holding this information is to enable us to provide a service to you.

All the information given to ASBAH by you, and held in paper or computer files, is strictly confidential. We will NOT disclose any information to any other organisation or individual outside ASBAH, without you prior consent.

Statistics gathered from our records may be used anonymously to monitor trends in the use of ASBAH's services. Statistics can also help ASBAH in its aim of lobbying for improvements in statutory services for people with spina bifida and/or hydrocephalus.

Holding the information also enables ASBAH to ask relevant service users if they would like to take part in particular research projects.

Please complete this form and send it to:
GILL WINFIELD, ASBAH INFORMATION,
42 PARK ROAD, PETERBOROUGH PE1 2UQ.

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

Signed _____

Date _____

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

Address _____

Date of birth _____

Alcohol-free in Salisbury

FOUR people went on a Lent temperance drive for charity in Salisbury in the run-up to Easter this year – raising £1,500 from friends, colleagues and customers.

Kathrine Connery, from The House of Steps in the High Street, kept her partner Michael Byrne and two barmaids from the Old Ale House on track as they forsook the demon drink for what she described as “a moment of madness” challenge.

As she presented £500 from the total to ASBAH, Kathrine who has spina bifida said: “Giving up alcohol for six weeks wasn’t the hardest bit – it was collecting the money afterwards. But we set ourselves a time limit and people were very generous.”

Dressing down at NIG insurers

STAFF at NIG motor insurers round the country took part in a ‘dress down’ day for ASBAH – expecting to raise several hundred pounds for us.

Jane Rodger, who works in the company’s call centre in Peterborough, put ASBAH’s name into a hat for selection because she knows our fundraising manager, Donna Treanor. And we drew lucky, thanks very much!

“In the call centre alone, we have about 56 people. Across the company, there are probably 300 who took part,” said Jane.

Staff paid for the privilege of taking part in the event.





A quiet day? You must be joking!

BUSY AT BROOKLANDS

DEEP in the Surrey countryside, the Brooklands motor racing circuit made history again at the end of July – when the Sporting Bears Motor Club held its first ever Dream Rides day for charity.

Well over 100 owners of the classiest cars in Britain turned out to support ASBAH and two local organisations. They allowed the club to sell rides in their motors.

Children supported by the charities rode for free, in a massive convoy round the test track. The remains of the historic banked oval, where John Cobb's Napier Railton broke the circuit speed record in 1935, were left undisturbed in the sunshine. But it was very busy in

the Paddock with convoys moving out about every 20 minutes.

Photos, clockwise from above:

The remains of the historic banked oval; the Sporting Bears mascot; the clubhouse at Brooklands; a convoy gets ready.

Young passengers getting ready for their 'Dream Rides'; two beautiful Bentleys; a Lamborghini with gullwing doors, next to the new Mini; Kylie Pratten waves before going out on her ride, next to ASBAH parents David and Sheree Bridge (with camera) and event organiser and chief marshal Joe Rayner (top).

Photos: TONY BRITTON and DAVID BRIDGE.





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E: info@rgk-wheelchairs.co.uk

W: www.rgk-wheelchairs.co.uk

Customer satisfaction that exceeds expectations

dates for your diary

Guest speaker at our AGM

WILL BEE, Wales director of the Disability Rights Commission, will be the guest speaker at our AGM in Peterborough on Saturday, 29 September.

Will, who has spina bifida and whose family has a long connection with North Wales ASBAH, will speak in the after-lunch session on the UK-wide disability rights agenda.

The morning session will comprise AGM business and presentations on *The Way Ahead*, ASBAH's strategic plan covering the next five years.

The meeting starts at 10.30 for 11am.

Fair challenge

THE CHAIRABILITY Challenge is set fair for this year.

ASBAH's National Awareness Day, involving local games of wheelchair basketball against MPs and other celebrities, will be held on Saturday 13 October.

Some local ASBAHs already have a full programme planned.

For details of how to get involved, please contact ASBAH Publicity, tel: 01733-421316, tonyb@asbah.org

Family weekend

IT'S BACK to Cornwall for our popular Family Weekend from 8 to 10 March next year. Families must have a child aged six and under with SB/H, to be included. Details: ASBAH Services, tel: 01733-555988.

Upcoming events

Hydrocephalus two-day conference

8 – 9 September, Heathrow

ASBAH two-day conference on the effects on education, daily living and employment. Le Meridien Hotel, Heathrow. Liz Clayton, ASBAH Adviser, tel: 0118-972 4013, email: liz@nickel-free.freeseerve.co.uk

Dunstable meeting

Monday 10 September

Monthly meeting for parents/carers of children/young people with spina bifida and/or hydrocephalus, organised by the South Bedfordshire Support Group. 1–3pm, Disability Resource Centre, Poynters Road, Dunstable. Valerie Bottoms, tel: 01582-757745.

ASBAH AGM

29 September, Peterborough

(see panel alongside)

ASBAH National Awareness Day

Saturday 13 October, national

ASBAH's 2nd annual ChairAbility Challenge, games of wheelchair basketball against MPs and local celebrities. Get involved, contact ASBAH publicity, tel: 01733-421316, tonyb@asbah.org

ASBAH Study Day

Saturday 13 October, Suffolk

Hydrocephalus – implications for learning and behaviour, Needham Market, Ipswich, Suffolk. Valerie Meyer-Hall, ASBAH Adviser for Suffolk, tel: 01379-871071 or ASBAH East Region, 01733-555988.

ASBAH Study Day

Thursday 1 November, Luton

Living with Hydrocephalus, The Chiltern Hotel, Luton. Sponsored by the Rotary Club of Luton and the Chiltern Hotel. ASBAH East Region, tel: 01733-555988; shirley@asbah.org

ASBAH Activity Day

Saturday 3 November, Dorset

For 12-16 year olds, The Gryphon School, Sherborne, Dorset, 10am-4pm. Free day inc wheelchair basketball, ball skills & target practice, wheelchair safety exercises, Body Shop skin care and facial sessions, discussions on assertiveness, self-esteem and nutrition. Bring own lunch. Rachel Clark, ASBAH Adviser Somerset, tel: 01460-240462, rachelclark@asbah.greatxscape.net

Reach for the Sky!

17 November, Peterborough

Day course run by Your Voice, ASBAH's disabled users group, on improving communication skills and personal goal-setting. Details: Lynn Rylance, tel: 01733-555988, lynr@asbah.org

DAVE'S DIARY

david.fulford-brown@ntlworld.com
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I WAS delighted to read in *The Independent* that scientists have discovered a new and potentially huge source of stem cells. With a bit more work, stem cells could be turned into other things like bones, skin and nerve tissue. If that can be done, then the cells can be used to repair nerves, burns, broken bones and a load more medical problems.

The big drawback with stem cells is that, up to now, they have been taken from unborn foetuses, which is often seen as morally 'iffy.' Fortunately, cells could now be got from a source which is unlikely to trouble anyone's conscience: fat cells. Yes, fat cells, of all things! Strange to think that, rather than just being something that hides my feet, my beer gut could actually have an important medical use.

I've always wanted to be a donor. I've always been impressed by those who give parts of themselves away to others. But I've always been a bit squeamish about blood (and parting with it could do strange things to my blood pressure), and I didn't think the rest of me was

worth donating. Now it looks like I've got something to give after all.

Of course, having so much, I would be willing, *delighted* even, to have some lard siphoned off and donate it to others without fat reserves of their own. I'm not just talking about some supermodel who falls off the catwalk and busts her leg. Stem-cell based repairs could be used by everyone.

But, with increasing demand for these cells could we see a situation where desperate mobs pursue some chubby for their lard, as they shuffle for their life? Well, no. Blood donors have been around for years and, apart from the odd vampire, you don't see people chasing them do you?

So I think fat donors will be safe. And who knows they may even become respected members of the community, which will be a change for us chubbies. Fat donating might even become as publicly admired as giving blood.

And I am more than willing to

play my part as a donor. It will mean some unavoidable lifestyle changes, but that is a sacrifice I'm willing to make. I will abandon all dieting immediately and ensure that from now on I eat only junk foods, cakes and things with a high fat content. That way I shall always have plenty of reserves to donate should a medical emergency arise. With my proven ability to pile on the pounds I could even become the regional stem cell store! (I wonder if they'll give me a medal for large donations?)

I hope you will all respect my new training plan and think on the reasons for it before criticising what looks suspiciously like greed. Then, next time you see me steaming through plates full of cheeseburgers, you'll see me not as someone stuffing their face like a pig in a trough, but as someone who is developing a vital medical resource and trying to do their bit for the community. *Cheers!*

Whizz-Kidz charity has big money for big ideas

A CHARITY has got big money to hand out for big ideas from people aged 12–18, who use wheelchairs or other mobility equipment to get about. The Whizz-Kidz charity is calling for ideas which are able to be worked up into projects to benefit the proposers and their communities.

Whizz-Kidz can make up to 90 'No Limits' Awards over the next three years – each worth between £2,000 to a maximum of £8,500 for an individual, or a maximum of £10,000 for a group.

"If you really want to do something, but can't find the money for it, Whizz-Kidz is encouraging you to bring your ideas forward," said Kidz Board

member 14-year-old Ruth Madeley who has spina bifida, from Daisy Hill, Westhoughton, near Bolton.

The award could be related to sport, design, fashion, music, web, journalism, campaigning, dance, theatre, writing, broadcasting, the visual arts, or whatever takes your fancy.

The 'No Limits' Awards Scheme has been funded by The Millennium Commission with funds from the National Lottery. Up to 30 awards will be made each year.

But move fast! Applications for 2001 must be in by **Tuesday 11 September. Phone 0207-233 6600 for your 'No Limits' application pack.**

letters

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.

e-mail contacts

CALLING all e-mailers. We continue our regular listing of contacts in the UK and around the world, who would like to exchange e-mails. If you wish to go on this list in a future *Link*, please write to lizc@asbah.org

Elizabeth Bullen (44) Lincoln,
ep.bullen@tesco.net

Chris Jones (25), H
geraint51@hotmail.com

Danielle Margan (17)
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dani2235@bolt.com

Mark Riley (45), SB
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Robert Paton (18), SB
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Balbinder Sandhu, SB
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Harmesh Singh (24), SB, law student, Malaysia
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Mandy Smith (36)
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Frank Stapleton (39), H
stapletonfrank@hotmail.com

Brian Ward (46)
B-Ward@ic24.net
Alexandra Wood (33), H
alexandra.wood@cwctv.net

So much for democracy, eh?

IT seems that no one read my letter published in *Link* recently (*Guard The Future*) if the last two issues are any indication.

I refer, of course, to the major study being carried out into the genetic nature of SB/H, which ASBAH is co-operating in. I believe that it could be used as a tool by the eugenics lobby to eradicate SB/H altogether. Also, in the insert detailing the project, too little weight was given to the viewpoint of those of us who oppose such research. One sentence was put in as an after-thought. So much for democracy, eh?

I worry that young people with SB/H will be coerced into taking part by their parents, who may have been given the misguided belief that to have a child with our condition meant that there was automatically 'something wrong with it', when they are too young to be able to understand the possible misuse of the findings of this research, and what it may mean to future generations.

I urge parents to think seriously about the implications of volunteering their families' services to this project. I appreciate that there are many views on the subject, and I am more forthright than most, but to me, at least, this is like volunteering to become an endangered species. Still, on the bright side, ASBAH could apply to become a subsidiary of the World Wildlife Fund!

Chris Page, Letchworth, Herts

French holiday exchange offered

WE are a French family with four children. Rodolphe the eldest (16) has spina bifida. We would like to correspond with an English speaking family in order to organise holiday exchanges in the future.

We would like to get to know a dynamic family with a dynamic boy who is working hard to become an independent adult.

Rodolphe likes sports (tennis, football, basketball) and video games. He has learnt English for five years. In September, he goes to college and will be learning the accountancy.

I work at home, my husband works in human resources. Rodolphe's brothers are 13 and 11 and his sister is 12.

If you would like to get in touch, please write to: **Mr & Mme Sabardeil, 63 rue de Bretagne, 44880 SAUTRON, France. Phone/fax: 02-40-94-87-91. jsabarde@aol.com**

What's in a word? Well, 1,022 actually!

CONGRATULATIONS to Laura Gear who took up the challenge to make as many words as possible in 'hydrocephalus.' She beat Carolin Hughes, of Poole, who told us she had found 236 words. Laura, from Brislington, Bristol, came up with 1,022!

We will be sending Laura a t-shirt in recognition of her hard work.

Pen pals

I AM 10 years old and I have hydrocephalus and I have a shunt. My hobbies are swimming, playing on my PC and going to Guides. I would like to have pen-friends who also have hydrocephalus.

Rebecca Purseglove, 122 Chesterfield Road, Huthwaite, Sutton-in-Ashfield, Notts NG17 2QF.

I AM aged 38 with spina bifida, and live on my own in a council bungalow. I have a small dog, but no children. I don't get out a great deal. I'd like to hear from anyone in the country, male or female.

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

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* (November) should be received by **Friday, 5 October.**

holiday lets

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

ISLE OF WIGHT ASBAH

Recently refurbished, fully equipped, 2-bedroom bungalow. Sleeps 6. 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, www.iowasbah.i12.com*

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

Modern, purpose-built, self-catering cottage. Ground floor accommodation for up to 2 people (single beds) with disabilities. Scan 700 beds: Clos-o-Mat; overhead track hoist bedroom-to-bathroom, wheelchair shower and much more. Up to 4 carers/family/friends upstairs. Awarded Grade 1, Holiday Care. Open all year. Low rates Winter/Spring (£250 to £350 per week) – full centrally heated. Helpful caretakers demonstrate equipment, but otherwise total privacy in pretty village with accessible pub, GP, shops. *Cottage brochure, Lin Berwick, (tel: 01787-882111).*

Booking forms and full information, George Tickner, The Lin Berwick Trust, (registered charity), tel: 020-8595 7056.

ORLANDO, FLORIDA

Purpose-built vacation homes for the disabled of all ages, 3, 4 & 5 bedroom luxury villas. All villas are wheelchair-accessible, with roll-in showers and hydraulic lifts for access to the private pool. Situated 20 minutes from Disney and close to all amenities. Wheelchair accessible transport available.

For further information, contact: David and Elaine Foley, tel: 0191-488 6845, email: david_foley@lineone.net www.floridadream.sagenet.co.uk

SELSEY, WEST SUSSEX (SASBAH)

Fully equipped, purpose-designed for wheelchair access, mobile home. Sleeps six, ramp and large veranda, payphone, colour TV, midi stereo etc. Clubhouse entertainment, heated swimming pool, free site bus service. Nature reserves and places of interest nearby. *Details from Julie Parks, tel: 01273-472298.*

ITEMS FOR SALE

BOOSTER Roadmaster 128 Town & Country, 3-wheeler, never used, as new. £1,200 ono, includes battery and charger. Original invoice available for proof of cost. **Tel: 01226-205247 (Barnsley).**

MONARCH Malden 306, electric go-kart suitable for children up to 12, kept in dry garage for some years. Free to a good home. **Mrs Slater, tel: 01244-348236 (Chester).**

QUICKIE F55 Powerchair, 18in, RH controls, vcg. New £4,000, sell for £1,000. **Tel: 01372-466451 (Surrey).**

MANGAR Freestyle powered wheelchair, cub seat 14 x 12 inches, suit child or small adult. 7 years old, comes with charger and armrest mounted tray. £100 ono. **Tel: 01296-425400 eve, or 01296-392711 day (Aylesbury).**

AFFILIATED ASSOCIATIONS

BARNESLEY

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

BEDFORD

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

BOURNEMOUTH, CHRISTCHURCH & DISTRICT

Mrs Gill Lanning
43 Rothesay Drive, Highcliffe
Christchurch, Dorset, BH23 4LD
Tel: 01425-276820

BRISTOL & DISTRICT

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

BUCKS & EAST BERKS

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

BURY & BOLTON

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

CAMBRIDGE & DISTRICT

Mrs G D Greville
38 Thongsley
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CHESTER & DISTRICT

Mrs P Ithell
34 King Edward Street
Shotton, Deeside
Ciwyd CH5 1DW
Tel: 01244-811074

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Mrs N Newman
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DUDLEY & WOLVERHAMPTON

Mrs Lorna J Wootton
14 Leveson Road
Wednesfield, Wolverhampton
West Midlands WV11 2HF
Tel: 01902-738724

GRANTHAM

Mrs J Asken
88 Goodliffe Road
Grantham, Lincs NG31 7QB
Tel: 01476-401643

GREENWICH & DISTRICT

Mrs M Mears
29 Wellmeadow Road
London SE13 6SY
Tel: 0208-244 3526

HERTS AND SOUTH BEDS

Mrs Jennifer Hammond
28 Gladeside
St Albans, Herts AL4 9JA
hamrock@supanet.com

HUDDERSFIELD

Mr Stephen Bolton
361 Bradley Road
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HD2 1PR
Tel: 01484-424479

KENT

Mrs S Stevens
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DA11 9DE
Tel: 01474-536202

LEEDS & BRADFORD

Fiona Bryett
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64 Bagley Lane
Farsley
Leeds LS28 5LY
Tel: 0113-255 6767

LEICESTERSHIRE

Mrs A Twomlow
29 The Crescent
Market Harborough
Leicestershire
LE16 7JJ
Tel: 01858-432967

LINCOLN & MID LINCS

Mrs P Malson
"Pinfold"
Chapel Lane
North Scarle
Lincoln
LN6 9EX
Tel: 01522 778781

LINCOLNSHIRE SOUTH

Mrs P Mason
67 Boston Road
Heckington
Sleaford
Lincs
Tel: 01529-460322 (after 6pm)

LONDON NORTH WEST

Mrs H Prentice
37 Milton Road
Hanwell
London W7 1LQ
Tel: 0208-579 4685

LONDON SOUTH

Mrs S Cudd
15 Woodvale Walk
Elder Road
W Norwood
London SE27
Tel: 0208-761 2400

NORTHAMPTONSHIRE

Mrs Maggie Nichols
11A West Street
Weedon
Northants NN7 4QU
Tel: 01327-340732

OXFORDSHIRE

Mrs Shirley Dale
14 South Row
Chilton
Didcot
Oxon OX11 0RT
Tel: 01235 -834785

PRESTON

Mrs S Thompson
Flat 3
62 Alexandra Road
Southport
Merseyside PR9 9HH

St HELENS & DISTRICT

Joanne Barrett
10 Halefield Street
St Helen's WA10 2DE
Tel: 01744-612860

SHEFFIELD

Mrs Barbara Clark
35 Woodhouse Lane
Beighton, Sheffield S20 1AA
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SOMERSET

Mrs Iris Coton
3 Court Gardens, Yeovil
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SOUTH THAMES

Mr Peter Winterton
35 Paynesfield Road
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SOUTHAMPTON & DISTRICT

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STOCKPORT & TAMESIDE

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will my sheath
blow off?

will my bag
slip?

will I get into
the toilet?

can I risk it?

**LEAKS
STOP
PLAY**

**NO CONFIDENCE TO GO OUT?
FEEL CHAINED TO THE TOILET?**

If this sounds familiar, you need to talk to us.

TOTAL CONTINENCE CONTROL

- UNIQUE PRESCRIPTION LEG-BAGS**
- The Bendi Bag - for wheelchair-users (1300ml)
 - Discreet Thigh Bag - for use with short clothing
 - Comfort Bag - standard bag with velvet soft backing and flexible adjustable inlets. Reduces skin and catheter trauma
- SHEATHS**
- Urinary Sheaths - in 11 sizes solving penile retraction
- URINALS**
- Uribag - unique range of pocket-sized urinals

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from our helpline - all our advisers use and rely on our product*



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