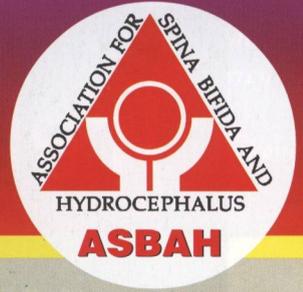


LINK

The magazine for people
with Spina Bifida and / or
Hydrocephalus



Go on - give it a treat!



Summer fun

**PRICE
80p**

NOVEMBER/DECEMBER 2000

ISSUE No 190

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LINK



Cover inset:
Last of the
summer sun!
Jonathan Smith
enjoys a Surrey
ASBAH
Activity Weekend –
see page 15.

Editorial

Dear Readers

WE ARE on the way to mapping out our future once more.

Every so often, ASBAH pauses to take stock of what we are doing and where we're going. It's essential to have a clear view of how to use limited resources and funds to best effect.

That process of renewing the vision has already begun.

There are various consultations taking place on an agenda-setting paper which will lead up, towards the middle of next year, to a new draft strategy plan. The way will then be open to a wide consultation, in which we hope all those who have stakes in ASBAH's future will want to join.

Link will carry occasional reports on the process but, if you want more than that, do ask to be kept in touch with what is going on.

Your views, everybody's views – from whichever direction they are coming – are important.

Tony Britton
Publicity Manager

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

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

postmaster@asbah.org
www.asbah.org

Financial provision when you're gone

HELP is at hand for parents who want to consider how best to make financial provision for a child with severe learning disabilities after they have died.

There are at least two booklets on the subject which explain the options in layman's language.

London solicitors Anthony Quinn & Co will send you theirs, if you phone 0207-242 3322. Mr Quinn was guest speaker at the ASBAH AGM last year.

Mencap also has a leaflet called *Leaving money by will to people with learning disabilities*. Contact the charity on 0207-454 0454.

Paul Muldoon, trusts manager with Greenwoods, a law firm in Peterborough,

told an ASBAH meeting in St Albans last year that the option he prefers is to use a discretionary trust as a way of ensuring that children with learning difficulties have access to the parental estate. There is no legal obligation on non-disabled children to provide for a sibling with learning difficulties, if an estate is divided between them only.

The capital in a discretionary trust cannot be considered when a disabled dependent is being assessed for income support. Mr Muldoon said a side letter to the trustees, whose existence need never be known to the State, makes clear the parents' real wishes.

Folic in flour – jury's out

PUBLIC consultation on adding folic acid to flour closed as *Link* went to press.

The campaign to have the vitamin added to all flour and so reduce the number of pregnancies affected by spina bifida, has our strong support. The evidence is that the low level proposed will not impose unacceptable levels on any group in the population.

The jury's now out – but it could be months before any decisions are made.



Tim takes a tumble during ASBAH day

TORY MP Tim Loughton, who chairs his party's disability group, faked a tumble for the cameras (above) – after playing a mean game of wheelchair basketball during ASBAH's ChairAbility Challenge on 3 October.

MPs round the country broke sweat as they took up the challenge at the Conservative Party conference in Bournemouth, and also in Kent, Birmingham, Manchester, Northamptonshire and north Wales.

It was ASBAH's first ever national awareness day to concentrate solely on the ability and not the disability of disabled people.

Below: spot the MPs! Tim Loughton, Eric Pickles, Tim Boswell and David Amess joined a game in Bournemouth.



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Sainsbury's deliver on special needs

AN ASBAH mum has discovered that a major supermarket chain will adapt its range of shopping trolleys to meet the special needs of its customers.

Jackie Bennett, from Dunstable, Herts, travels to Sainsbury's in Luton each week with her son Kyle, who has spina bifida and hydrocephalus. But the standard trolley was too small for Kyle to sit in comfortably.

When Jackie told the store manager about the problem, he offered to buy in a special trolley with a larger seat and five-point straps. When this proved unsuitable, seat-makers, Recaro, were approached for more designs and finally one was found that gives better support.

Mrs Bennett said: "I really think it's bad that shops don't have these trolleys as standard but at least Sainsbury's was prepared to do something. I wouldn't be able to do my shopping without it. Hopefully, word will get round and other parents of disabled children will use it."

A Sainsbury's spokesman said: "We have a central trolley buyer to whom stores can go if a customer has specific needs. There are 16 different designs to choose from."

The new trolley at Luton will be kept in a storeroom and used on demand.

● ASBAH has sounded a warning to people not to overspend when shopping on the Internet. It may be tempting to order more than you can afford. Tesco commented that on-line customers can change their minds before submitting their credit card details.

Uproar halts train departure

A TRAIN driver halted his express as it was pulling out of a station – after he had left a wheelchair passenger stranded on the platform, while her cat in its basket and her handbag were heading north.

Dozens of passengers on the platform at Huntingdon station, Cambs, shouted at the driver to stop after Pauline Desborough failed to pull the wheelchair containing her daughter, Karen, onto the train before the doors closed.

Mrs Desborough said: "There must have been 30 or 40 people on the platform, screaming and shouting. We were able to put Karen on the train, but she was upset all the way back to Liverpool. We had also booked platform assistance but it wasn't provided."

Karen, who has spina bifida and teaches in Liverpool, had been visiting her mum in Elsworth, near Huntingdon, during a holiday break in August.

Up in the first Rank

OUR independence training work in Northern Ireland has won a welcome vote of confidence from the Rank Foundation, the charity trust built upon a movie-making and distribution empire.

Rank has given ASBAH a £54,000 grant, spread over three years, to keep up the good work. This first-time grant also means that Linda Maxwell, the specialist adviser most involved, will be able to explore widening the courses to include people with personal care needs.

The Rank money, which now funds her job, replaces money from a special European peace and reconciliation fund, which has now run out.

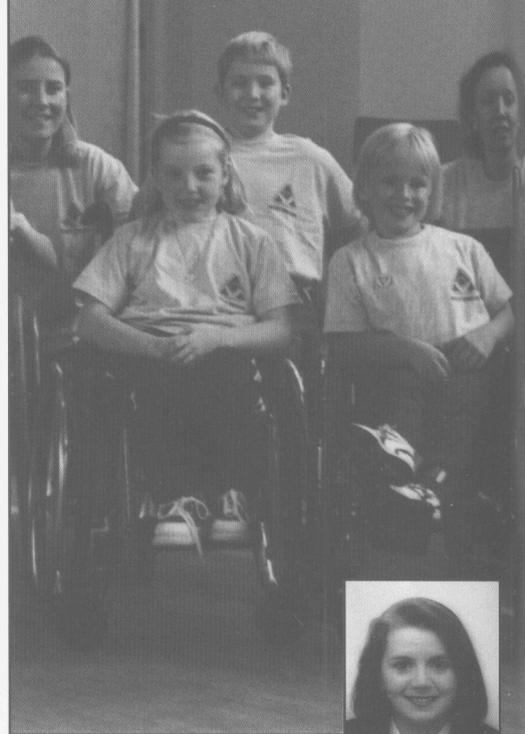
Linda said: "I have been in post for nearly four years, and have managed to lay the

foundation for independence training work with a wide range of users, parents, carers and other professionals.

"Thanks to Rank, we can now build on those achievements. One area where we can now seriously consider extending the work is by offering the service to people with personal care needs – where, until now, we have been unable to afford the extra support services which would be required."

Linda, whose job has been redesignated as development worker, has built up an exciting portfolio of courses.

Training in wheelchair skills remains much in demand, but unusually Linda also runs healthy eating and lifestyle courses. She's done a "Girl Talk" weekend and any number of personal development sessions.



Thanks, Linda (inset)!

She gets young adults to consider their after-school options, and parents to think about letting go of their children so they can be less dependent. And there's case work aplenty in the area of housing support.

Linda added: "The role now needs to be developed, and for a wider group of users to have a stake in it. There will be plenty to do in the next three years."



A long-awaited guide to accessible loos, containing some 4,000 entries, is due for publication later this autumn.

The first edition will cover England only. Later, volunteers will start collecting information in Scotland, Wales and Northern Ireland.

The first edition is available in two A5 formats. One is a single volume, the other is a boxed set of eight regional books in larger print. The guide price for both editions is £10.

While working on the guide, editor Diana Twitchin found herself getting involved in a range of related issues including dialogues with organisations and businesses considering building an accessible loo. As a result, a charitable company, ITAAL (Is There An Accessible Loo?) has been set up to work on future editions and to raise awareness of the difficulties facing disabled people in coping with personal care needs.

● For more details of the guide, or the ITAAL Trust, send your name and address to: ITAAL, 10 Stilecroft Gardens, North Wembley, HA0 3HE. Please do not send money at this stage.

Web ideas for after-school

TEENAGERS with disabilities can now tap into the web for ideas about what to do after leaving school.

www.after16.org.uk has been produced by Family Fund Trust and funded by the DfEE.

medical update

Danes suggest a stress cause

SEVERE emotional stress during pregnancy can cause congenital impairments such as spina bifida and cleft lip in the unborn child, according to research published in *The Lancet*.

Tragedies like a death in the family, a partner having a heart attack or being diagnosed with cancer, can lead to unborn babies developing problems, researchers in Denmark have found.

Women who suffer severe emotional distress in two consecutive pregnancies are twice as likely to give birth to a baby with congenital impairments.

In September, *The Lancet* published the results of a 12-year survey involving more than 20,000 pregnant Danish women – of whom over 8,500 were exposed to “severe life events” while carrying their child or in the previous 16 months.

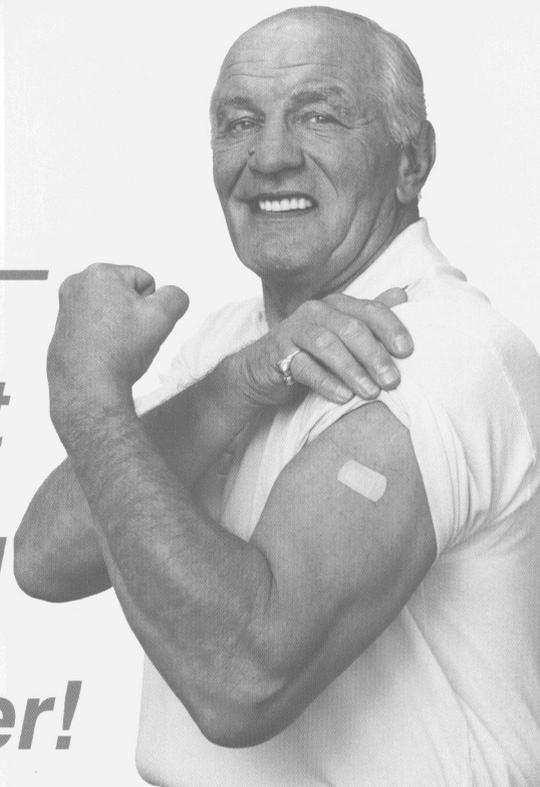
Severe life events included a partner or child dying or being admitted to hospital with a heart attack.

Researchers found that 1.18% of women exposed to severe life events gave birth to a child with cranial neural crest impairments, compared with 0.65% of women who suffered no stress.

Cranial neural crest impairments include cleft lips, congenital heart malformation, and neural tube defects, including spina bifida.

Women who experienced the death of one of their other children while pregnant had an even higher chance of their unborn child developing an impairment.

**'Flu –
jab it
all
over!**



THREE virulent strains of influenza could hit these shores this winter and a new vaccine has been produced to protect against all three strains.

Moscow, New Caledonia and Beijing 'flu have been mapped by the World Health Organisation and, to protect the most vulnerable sections of the population, the Department of Health has ordered 10.4 million doses to be made available.

An advertising campaign has been fronted by Sir Henry Cooper – *Don't let flu knock you out – get your jab in first*. It was launched in September.

If you have spina bifida and/or hydrocephalus, ask your GP if you can have a free jab to protect against complications such as bronchitis and pneumonia.

● Contact NHS Direct on 0845-4647 www.nhsdirect.nhs.uk for more information.

More people than ever carry our shunt card

MORE people than ever are carrying one of our shunt alert cards. Another 260 people have signed up for one since April, bringing the total to over 2,500.

Many are people with spina bifida as well as hydrocephalus. The cards, and accompanying GP leaflet, are designed to inform passers-by and medical professionals in the event of shunt blockage or infection.

Apply for yours by writing to: ASBAH Services, 42 Park Road, Peterborough PE1 2UQ.

● Mrs B has recently been diagnosed with Arnold Chiari type I malformation. She would like contact with other adults with this condition. If you know of somebody, or you have Arnold Chiari Malformation yourself, please contact Paula Thompson, ASBAH National Centre, tel: 01733-555988, paulat@asbah.org

THE CONFERENCE STATED:

1. That people with spina bifida and hydrocephalus live a full life with equal value to that of any other citizen and they should not be seen as a medical condition. Their views should be sought and heard by governments and health professionals, who should acknowledge the right of people with spina bifida and hydrocephalus to speak for themselves.

2. That people with disabilities have the right to aim for lives as rewarding as those of their peers who have what is regarded as a normal life. Supportive systems must be in place when they are needed.

3. That experience over the past 30 years has improved considerably the medical outcome and the quality of life of people with spina bifida and hydrocephalus.

4. Adults with spina bifida underline that their quality of life is not – and should not be given as – a reason for abortion.

5. That prenatal counselling for parents should be carried out by skilled professionals in a multidisciplinary team. It should be supportive focussing on all aspects of life with a child with impairments. This counselling should not be linked with termination or abortion. Parents deserve time to adapt to this new situation before being confronted with a proposal to terminate the pregnancy. Parents must feel free to make a choice.

6. After diagnosis, professionals should work with parent organisations to ensure that information is up-to-date, correct, and understandable by parents.

7. Terminology, such as

Decisions from *The Right to be Different* conference

PIERRE MERTENS, president of the International Federation for Hydrocephalus and Spina Bifida, has sent us the statement agreed at the end of ifHSB's 12th International Conference, held in Toulouse, France, at the beginning of September.

Some 270 people from 22 countries – adults with the impairments, and parents – attended the conference on the theme 'The Right to be Different'.

The text runs:

In recent years, new methods of early diagnosis such as ultrasound have given parents the opportunity to see the condition of their baby before birth. In Western countries, more than 90% of parents opt for abortion or termination of pregnancy when the child has spina bifida. Prenatal diagnosis is not fully able to state exactly the severity of the impairment. Yet, in more and more states, abortion is legally and socially accepted and in many countries there is no time limit on legal abortion when the foetus has severe impairments.

secondary prevention and therapeutic abortion, is misleading.

8. The only way to prevent disability is by primary prevention and the focus should be on this.

9. Further research is needed not only about folic acid but on the real causes of Neural Tube Defects.

10. Primary prevention campaigns must not be seen as carrying hidden messages. All campaigns must safeguard the

The motivation for termination is the prognosis that the outcome for the unborn child could be very poor, which can be taken to mean that life with spina bifida is not worth living. This information is often given by people who have insufficient knowledge about the lives of people with spina bifida and hydrocephalus.

Planned Parenthood and Primary Prevention – taking folic acid before and during the first part of the pregnancy – has been shown to decrease the numbers of births with spina bifida considerably. Primary Prevention requires national educative programmes to ensure that the message reaches the whole population.

All this has an impact on the lives of people with spina bifida and all future parents.

dignity of disabled people.

11. The principle of discrimination, as with insurance, should be outlawed.

12. Prevention and prenatal diagnosis is a complex moral and ethical matter. It needs a great deal of deliberation and it will be an on-going debate. Organisations of and for people with spina bifida and hydrocephalus should be full partners in this debate.

Christmas makeover!

WHILE you prepare for a warm and festive Christmas, don't leave your wheelchair out in the cold.

Our mobility adviser Linda Knight (*pictured*), who sees too many wheelchairs looking one over the eight because they don't get the care and attention they deserve, has some advice to keep your chair in tip-top shape.

She says there are two golden rules to help wheelchair-users get the most, for longer, out of their chairs.

"The first basic is to remember to clean your wheelchair regularly, at least once a week. If you are out and about in it every day in winter, then you'll probably need to clean it twice a week," said Linda.

"And the second golden rule is always keep the screws and bolts tight. Your wheelchair will respond by giving you a cleaner, smoother ride, without wheel-wobble or bits falling off!"

Linda is a trained occupational therapist who works part-time at ASBAH's national centre in Peterborough.

She says NEVER use bleach, abrasive cleaners or pads, or wax or spray polish on

the frame and wheels. They can damage the bodywork. A drop of washing-up liquid on a sponge or scrubbing brush, dipped in a bowl of warm water, will remove the stubbornest dirt.

Use a sponge, or a soft brush on vinyl or fabric seats and back rests, if there is ingrained stains.

If the upholstery becomes grubby, a couple of drops of washing-up liquid or upholstery cleaner should do the trick – wiping in the direction of the texture of the fabric, rinsing with clean warm water and allowing to dry overnight. Mild antiseptic like Dettol can be mixed in with the washing-up liquid.

And a deodorising spray, like Febreze, is a good idea to banish



any lingering smells.

Simple mechanical checks and repairs can be carried out at the same time. Your toolkit should contain a spanner, Allen keys and a screwdriver.

Tip the chair on its back and check the wear on your front castors. If they are pneumatic, check that they are correctly inflated and use the pump provided.

Return the chair to its upright position, and check the pressure and wear on the rear wheels. NEVER use a garage airline, always the pump provided with the chair. Replace any damaged spokes or missing dust caps.

The axles on most modern chairs do NOT

need oiling. Simply clean the axles with a dry, non-fluffy cloth after taking off the wheels.

Similarly, brakes, handrims and footrests need regular checks. The manual supplied with the chair will tell you how to keep these in perfect working order.

Don't do the repairs yourself, if you don't have to. If you have an NHS-issue wheelchair, they'll repair free. Phone your local wheelchair service for information.

If you want to avoid tyres which puncture, there are some good solid tyres on the market. Obtain catalogues from firms like Urathon Tyres, tel: 01249-760 581, or Flatfree Toobz, tel: 01203-351 495.

Link catches up with ASBAH's music man

So you think you have a long commute to work? Check out 57-year-old Jeffrey Tate's itinerary: a look in the Bs reveals Baltimore, Berlin, Bologna, Bonn, Boston, Buenos Aires; or try the Ts: Tanglewood, Tel Aviv, Tokyo, Toronto and Turin. Then add jet lag and hours of daily exercise – not trendy aerobics to canned music, but waving your arms for two, three, or more hours while making music beautiful enough to earn audience ovations, critics' raves and a living.

Tate, an internationally esteemed conductor who was born with spina bifida in Salisbury, England, in 1943, thrives on hectic schedules. Nevertheless, Tate enjoys travelling on holiday, especially in the western United States. "I've become a devotee of the Rockies and the West Coast," he says. "I'm a great lover of

mountains; I love the wide-open spaces." He finds one of the benefits of dividing his summers between Minneapolis' Sommerfest and Santa Barbara's Music Academy of the West, is that "between Santa Barbara and Minneapolis there is a lot of rather wonderful country to be seen."

Tate studied piano from the age of five – at first with a teacher, then on his own after age 10. As a teenager, he accompanied a school production of *Amahl and the Night Visitors* before Gian-Carlo Menotti himself. Also a choirboy, Tate sang alongside Peter

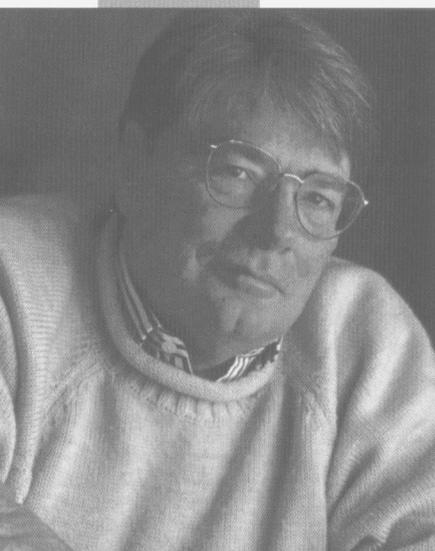
Pears in a community production of Benjamin Britten's *St Nicolas* while the composer listened. But despite his obvious talent for music, Tate took a major detour on his way to becoming a conductor. He studied medicine at Cambridge University and then became a doctor at London's St Thomas's Hospital.

Going back into music in 1970, Tate spent a year studying at the London Opera Centre to become a professional voice coach. He eventually coached not only in England but also throughout Europe and in the United States.

In 1978, Tate entered the freeway on-ramp with his professional conducting debut in Goteborg, Sweden. By 1985, with appointments as principal conductor to the Royal Opera at Covent Garden in London and to the English Chamber Orchestra (ECO), he had moved into the fast lane. Today, Tate continues his ECO post and serves as principal conductor of the Minnesota Orchestra Viennese Sommerfest and as principal guest conductor of the Italian National Radio Orchestra (RAI Turin). A devoted Wagnerian, he has two *Ring* cycles to his credit: the first at Paris' Chatelet and the second, Australia's first complete German-language *Ring*, in Adelaide in 1998.

Tate has more than 50 recordings to his credit on some of the world's major labels. They include all Mozart's symphonies and piano concertos (with Mitsuko Uchida) and the operas *Lulu*, *The Tales of Hoffmann*, *Hansel and Gretel*, and *Arabella*. One of his most recent releases is a 1998 Grammy winner, *The Beautiful Voice*, a collection of songs and arias with Renee Fleming and the ECO.

Tate, who insists he is an amateur



**ASBAH
president
Jeffrey
Tate**

because he did not study conducting in a conservatory, was given the title Commander of the British Empire (CBE) in the 1990 Queen's Birthday Honours, and last autumn was made a full Chevalier of the French Legion of Honour, a distinction usually reserved solely for the French. He has appeared in numerous films and television series, including the starring role in his own made-for-television documentary biography, *Let's Take that Infernal Risk*.

While clearly immersed in music at times, Tate takes pleasure in many disciplines. "Life is also for living," he says. "I think music is a wonderful thing, but it's only part of a huge array of things that make life wonderful. If you're going to do music well, you need to have outside elements in your life. If I had only music, I think I'd become slightly dead Certain parts of me would become numb."

Tate tries to involve himself with charities that pertain to disabilities and/or music and he has become an enthusiastic advocate of Minneapolis' Pacer Center. This Minnesota-wide coalition of disability organisations helps parents become effective representatives for their disabled children in childhood, school-age, and vocational environments. Tate still feels keenly the rejection by his own schoolmates, so he finds the Center's "Count Me In" project especially meaningful. The programme uses child-sized puppets, representing various disabilities, to teach preschool and elementary pupils that children with disabilities are much like children everywhere. In England, Tate is involved with Music Space, a music therapy centre, and with the Association for Spina Bifida and Hydrocephalus, of which he is president.

An avid student of history and culture, Tate is an inveterate reader and a tireless explorer of museums. He loves looking at architecture and is especially drawn to Romanesque churches. "There is an intense concentration in their structure; it's revealing to see the degree to which drama can be obtained by following through with a



single idea," he explains. He also collects early 18th-century Meissen porcelain, a hobby that he calls "a dangerously expensive mania."

Food provides respite to every wayfarer. Fascinated with its preparation since childhood, Tate is an excellent cook. A public relations officer at Covent Garden once said that she was "as likely to get requests for him to be interviewed for his culinary expertise and tastes as for his musical ones," and suspected that the attractions of some conducting venues "might have more to do with the local cuisine than the local concert hall."

"For food I have infinite patience," says Tate. "Only music brings a similar devotion. Gone are the ... tetchy violin section, the bad reviews, and in come a host of new feelings." His dinner parties are legendary and he feels "a great triumph in seeing a table of contented eaters demonstrating approval by asking for more, a triumph as pleasurable as a 'bravo' or a 'bis.'"

But then it's on to Madrid or Minneapolis or Munich.

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Photos
courtesy
of the
Minnesota
Orchestra

They're champion athletes already...

DOZENS of athletes with spina bifida and hydrocephalus were among 4,000 sportsmen and women who fought for medals at the Millennium Paralympics.

October's games were particularly exciting for the half-dozen women powerlifters whose sport was recognised for the first time this year as a Paralympic sport.

Here's a run-down of some of the British athletes with spina bifida who flew out for the 'big one' in Sydney, Australia:

● **Natalie Blake** – powerlifter from Manchester. Her personal best is 80 kilos in the 56-kilo category.

● **Emma Brown** (pictured above) – she is a 21-year-old, from Pontypridd, Wales. Emma competed in the over-82 kilo class and aimed to lift over 130 kilos. She is already world record holder



WESTERN MAIL, CARDIFF

in the under-75 and under-82 categories.

● **Tanni Grey-Thompson** (seen below) – Britain's best known Paralympian, Tanni has won five Paralympic golds, and was hoping for more in Sydney. Primarily a wheelchair track racer, Tanni has also won the London Marathon several times.

● **David Holding** (pictured left) – 32-year-old wheelchair sprinter from Kettering, Northants. He won gold in the 100m last time. This year he entered the 100m and 200m sprints.

● **Jayant Mistry** – a world top 10 wheelchair tennis player and leading medal hope in the men's singles.

● **Anthony Peddle** – powerlifts in the 48-kilo category, benching more than 160 kilos. With one gold from a previous Paralympics, he was hoping for another this year.

● **Lisa Pudner** – another Welsh woman powerlifter, this time competing in the 48-kilo category.

● **Nick Slater** – the present bench press world champion, from Sidcup in Kent. Nick hoped to bench press up to 240 kilos and grab a gold in the 100+/100 kilo categories.

● **Lisa Tuckey** – this Coventry 24-year-old aimed to lift up to 70 kilos in the women's 44-kilo category.



...but they're still on a medals trail

Going strong!

SCHOOL leadership winner, Barbara Berryman, retired this summer but is still putting her talents to good use.

Mrs Berryman, who is on our education advisory committee, won the national 'Plato' award in 1999 for her work at a co-ed special school in Peterborough.

Now Mrs Berryman is a consultant to schools in trouble. She is working two



days a week in Kent at a school for emotionally disturbed children, some with physical difficulties.

"I am there 'til Christmas to get the curriculum right and get OFSTED off their back," she said.

Next, she will work in schools under 'special measures'.

Mrs Berryman was again involved in the 'Plato' awards this year – but as a judge, not a competitor.



Robot wars for James

BOLT From The Blue vanquished the enemy on top TV show *Robot Wars*.

It was second time lucky for the hi-tech horror and its creators – 16-year-old James Procter, dad Lucian and friend Chris.

Last year, they had to pull out of *Robot Wars* after a spate of accidents. But this year the demon machine worked just fine.

A metre long and powered by two wheelchair motors, their 79.4 kilogramme robot can pull a Metro and has a weapon that lifts half a tonne. The air-powered ram works like a flipper, overturning its opponents and it has a hard-to-grab shape.

The competition involved 75 robots.

The Bolt took part in two battles, beating the likes of a Cambridge electronics undergraduate and a Black & Dekker engineer.

James, who has hydrocephalus, said: "We had this robot airborne three times and nearly in the pit. We won the crowd but not the judges who decided in the seeded robot's favour. We were interviewed before and after the battles and, at the end, we were supposed to be disappointed. But the competition isn't too serious and we couldn't stop ourselves from laughing."

James, from Kendal in the Lake District, said: "We do it just to smash up the opposition. We had the least sophisticated robot there, but a lot of it is how well the robot is driven."

The persuader

ASBAH adviser John Richards, has been recruited by the Parents Disabled Network to persuade volunteers to become advocates for disabled parents.

In his new part-time job, which will run alongside his work for ASBAH, Newport Pagnell-based John will talk to all sorts of people about what disabled people can achieve.



September's child

CHILDREN born between 1 September '96 and 31 August '97 can start school next September.

Although you don't have to send your child to school until their fifth birthday, they risk missing part of that school year or all of it if they were born in August.

It is usually best to make up your mind towards the end of the Spring term when you must submit your school choices.

A number of factors will help you decide and many of these can be found out in advance.



Petrina Noyes

For more information, arrange visits to the schools in which you are interested. You'll need to find out:

- Is the school local?
- How many children are there with statements?
- Who is the Special Education Needs Co-ordinator (SENCo)?
- Can you obtain a copy of the special needs policy and discipline policy in advance?
- How many Learning Support Assistants (LSAs) are there?
- Is the building accessible?
- What do other parents of children with SEN feel are the strengths and weaknesses of the school?

This list is a guide only. A few more points to consider as you

walk round include:

- Do you feel welcome?
- Do staff and children greet you?
- Are non-teaching staff helpful and friendly?
- Is there a happy, purposeful atmosphere around the school?
- Is there plenty of display work to look at?
- Are there accessible loos?

Petrina Noyes, one of ASBAH's staff education advisers (*left*), said: "At your appointment, you should have an opportunity to speak to the head teacher when you can find out if they have any previous knowledge of hydrocephalus and/or spina bifida, and whether they are aware of the possible educational implications of both."

"Other areas they should know about are the continence needs of a child with spina bifida/hydrocephalus and the tell-tale signs to look for when a child's shunt is blocked."

The physical environment will have to be considered too, particularly if your child uses a wheelchair, such as accessibility and the availability of suitable changing areas/beds.

Whether the alterations are large or small, find out how long they will take.

There may be other design factors to think about; for example, some children find high windows and highly patterned floors distracting.

Funding support

It is important to find out if the

school will fund any additional support during lessons and break-times and to know what form it will take. Will support staff be undertaking any further training?

If your child needs additional support from OTs, physios or SLT are there suitable facilities?

How often will your child be seen by them and who will be administering the programmes devised?

Medical know-how

Find out if staff are aware of the symptoms of shunt blockages and what to do if one is suspected.

What are the procedures for administering medication and who is responsible for doing this?

For continence management support, will the LSAs have this written into their contracts, and who will train them?

Transport

If your child needs transport to school, you will need to know what form this will take and who will pay. The same goes for school trips and swimming.

As a final test, ask yourselves the following questions:

- What did your child think of the school?
- Would your child be happy to attend?
- Did the school meet your expectations?

There may be more questions you need to ask yourselves and the head teacher. If you would like further help when choosing a school, contact ASBAH.

activity

BUILDING on the success of a previous one-day visit to a local outdoor activity centre, Surrey ASBAH has now fulfilled its plan to hold a similar event there – but this time spread over two days.

ASBAH area adviser for East and West Surrey, Jackie Cowl, enlisted members who could choose whether they attended one or both days. Around 30 people were involved in each of the two days.

High Ashurst Outdoor Activity Centre, Mickleham, Dorking, offered rock wall climbing, abseiling, archery and an aerial runway (in which you sit on a small seat on a rope

pulley and are launched into the air to travel down towards a series of tyres which give you a gentle break so you can dismount safely). The instructors ensured no one did more than they wanted to, yet encouraged as big an effort as possible.

Lunch was a group picnic and a children versus adults football match.

King of the castle

Alan Twyford, chairman of Surrey ASBAH, said the benefits of organising an event like this included confidence-building for all those taking part, as well as bringing together family members and disabled individuals.



Finally, weekends such as these offer people chances to take risks in a controlled, very safe environment.

Photos show:

*Above: Jonathan Smith nearly at the top!
Centre: Rosanna Marsh being prepared for launch on the aerial runway. Below: The group enjoy a picnic in the shade.*

MRI in pregnancy

AT PRESENT the chosen method of imaging the unborn child is ultrasound. This is usually done around 16-20 weeks gestation and can image most of the developed bodily systems. Sometimes an area is seen that does not look completely normal but cannot be characterised fully. This may be the case in babies with spina bifida where the gap in the spine is seen but the severity of the condition is difficult to tell for example whether or not the spinal cord exits through the gap. Also these babies often have associated problems in their developing brains termed hydrocephalus and Chiari malformations.

In Sheffield, we are currently looking into the value of magnetic resonance (MR) imaging to provide more information to guide the doctors and give the parents information ready for the birth of the baby. This work is being promoted by ASBAH and financially supported by other charities.

MR uses magnetic fields and radio frequency waves and has no known harmful effects. The mother needs to lie in a comfortable position on the table for about 30 minutes while images are obtained of the required areas. Each set of images consists of a series of 20 pictures that allow us to look at areas in great detail. We can usually see the spinal cord and the gap clearly. In babies with spina bifida we are able to see if the cord leaves the spinal canal through the gap and whether the tissue in the gap is open or covered by a membrane (myelomeningocele) or by fat and skin (lipomyelomeningocele). All these affect the planning of surgery after the delivery of the baby and allow the paediatric surgeons to discuss these issues with the parents prior to delivery. These factors may

indicate how severely the baby may be affected and MR may provide vital information for parents at an earlier stage in pregnancy than ultrasound is able to.

Surgery for spina bifida during pregnancy has started in some centres in America which means even more detailed information is required as early as possible in the pregnancy. We hope to follow some babies during the pregnancy to establish the natural history of their development so we can fully assess the impact of surgery at this very early stage of development.

MR appears to provide a safe, exciting opportunity to obtain important additional information for both the parents and the doctors and at an earlier stage of pregnancy than ultrasound.

● The authors, Prof Griffiths and Dr Whitby, are currently looking at the changes that occur in the developing child with spina bifida using MRI. They would like to hear from would-be parents, who are expecting a child with spina bifida, who



An MR scanner

would consider taking part in the study. Prospective parents from any part of the country will be considered and assistance given for travel expenses. *Contact Liz Cawthorne at Link, ASBAH, initially.*



ABOVE The ventricles of the brain which contain the fluid in the brain are enlarged – termed hydrocephalus.



ABOVE The spinal cord is seen in the spinal canal (arrow) but then leaves at the level of the gap (arrow) to enter a skin-covered area of tissue (arrow) which will be seen as a lump on the baby's back after delivery. (Lipomyelomeningocele).



ABOVE The spinal cord is seen leaving through the gap in the spine and entering a fluid-filled area covered by a thin membrane. (Myelomeningocele).

by Dr Elspeth Whitby & Professor Paul Griffiths

Professor Paul Griffiths is Professor of Academic Radiology at the University of Sheffield and Honorary Consultant Neuroradiologist for the NHS. His main interest is in paediatric neuroradiology and his current research reflects this. He is currently looking at the normal and abnormal development of the central nervous system in-utero in the hope that this will provide important clinical information for the parents and doctors involved in the care of the fetus and newborn babies.

Dr Elspeth Whitby is a senior lecturer in the academic department of radiology. Her main interest is in the fetus and newborn child and is currently working along with Prof Griffiths looking at fetal development and also neurological development in premature newborn babies.

Nicky's voice – like an angel!



NICKY RICKETT, a hospital school helper with a voice like an angel, has shared a platform with David Dimbleby's daughter Kate and broadcaster Alastair Stewart.



● *Diva for a night: Nicky Rickett with Kate Dimbleby and Alastair Stewart. Top photo: the magnificent Mansion House setting for Nicky's recital.*

Vehicle video does the biz!

MOTABILITY and Banstead Mobility Centre have produced a video to help anyone with a mobility impairment choose the most suitable vehicle.

Right First Time – a guide to choosing a vehicle costs £3.99. From: Motability Vehicle Suitability Service, Goodman House, Station Approach, Harlow, Essex CM20 2ET.

And what a platform! Mezzo soprano Nicky, who has spina bifida, and her fellow performers entertained in the Egyptian Room at the Mansion House in London during a concert to support a £2.5m appeal for new facilities at Lord Mayor Treloar School and College, Hampshire.

Against a backdrop of two enormous classical statues and the mace and sword of the Corporation of the City of London, Nicky sang a cycle of nine folksongs which had the 350-strong audience shouting for more.

Nicky, who discovered she had a beautiful voice during her time as a student at Treloar's, was already back on stage by popular demand – having sung for her old school once before at the Mansion House as a pupil and twice at nearby Glaziers' Hall. The Mansion House was the official residence of Lord Mayor Treloar in 1908, when he founded the institutions which bear his name.

And Nicky plans to give her fans more by creating a takeaway package, just for them. Nicky is working on a CD called *My Favourite Songs*, a songs from the shows

compilation, which will be released early next year.

Nicky said: "I joined the choir at Treloar's in what was then the lower school, and my mother asked if I could also have individual singing lessons, a request duly granted. When I moved to the upper school, my voice was coached by Muriel Binsted, who accompanied me on the piano at the Mansion House."

Nicky, from Winchester, works two and a half days a week as a helper at Southampton General Hospital in the hospital school, and then in the evenings in three different children's wards. After Treloar's, she trained as a Montessori nursery school teacher and then ran her own business teaching singing to nursery school children.

She appeared on stage at the Mansion House in a rousing finale with the other performers. With cabaret singer Kate Dimbleby and the Pipes and Drums of the London Scottish, they lifted the rafters with *Amazing Grace*. Alastair Stewart was MC for the evening.

● Half of the proceeds from the sale of Nicky's planned CD will go to the appeal. Order it through www.treloar.org.uk, or by phoning 01420-526526.

fundraising

Donna Treanor, Fundraising Manager
Tel: 01733-555988 donnat@asbah.org

A walk on the wild side for Jonathan

FAMILIES in the North East will get a little extra help from ASBAH – thanks to a walk on the wild side through Weardale.

Mrs Marie Brown raised £1,100 for ASBAH by taking part in July in her first 10-mile Great North Walk. It will pay the travel costs of needy families from the region attending our family residential courses.

She walked in memory of her grandson Jonathan Brown, who died in hospital in Newcastle-upon-Tyne a year ago last April at the age of seven. Jonathan was severely disabled with spina bifida and cranium bifida.

Marie, from Dawdon Hill Farm, Seaham, County Durham, said: "He was our only grandson, the apple of our eye. He would phone me 10 times a day for a chat. Jonathan died in the hospital which saved him when he was born. But they gave him to us for seven wonderful years.

"Some families in the North East are not well off, and do find it difficult to get to ASBAH family weekends. I want the money to help them."

Marie covered the distance with family friend Kevin Elliott, who last year also raised money in memory of Jonathan on the Great North Walk. They joined 5,000 people who strode out along Wearside for this major social event in the region's calendar.

"We both never stopped talking. In no time at all, two and a half hours actually, we were at the finish. Kevin said he could do it all again, it was such a nice day. And we will – next time getting our sponsors to double the money!"

ASBAH area adviser Anne Walton, who was with the family when Jonathan died, will administer the fund for local families. She said: "Jonathan enjoyed every day, never complaining, and followed Sunderland Football Club on TV".

Dry out time at a seaside shop

IT WAS mop and bucket time for volunteers at our ASBAH shop in Southsea – just two weeks after they opened the place for trading.

A torrential downpour, which devastated homes a little further down the south coast in Southsea at the end of September, also caused havoc in the Leigh Park shopping precinct, Havant, where ASBAH had set up a new shop.

Drains at the back of half a dozen properties couldn't cope and water six inches deep flowed in through the back door and out through the front.

Staff are now working hard to put everything back in order but major work was waiting to be done on the floor as *Link* went to press. New carpets are also needed. It will be some time yet before the shop re-opens.

Christine Cousins, ASBAH's shops co-ordinator, commented: "It was terrible. Everything got wet, the water came in so fast. We lost a lot of stock and electrical equipment like the fridge and a new Hoover."

Just before the rain struck, staff had taken down summer stock and replaced it with winter garments.

"Everyone had worked so hard and it looked so nice," said Christine. "We're really disappointed."

Attempts are now being made to re-stock: women's, men's and children's winter clothing, paperback books and bric a brac are urgently needed.

● If you would like to donate something, please contact Christine on 07880-998433.

Soccer history

ASBAH shared in a slice of football history when we were allowed to auction a piece of grass after the pitch at Wembley Stadium was grubbed up for the last time following England's disastrous game against Germany in October.

The 1ft square turf went to an anonymous bidder after it was put up for auction through an evening paper in Peterborough. The bidder, who lives in a village near Peterborough, decided it was just what was needed for another charity auction! His winning bid was £100.

dates for your diary

Popular weekend moves up North

PARENTS have started to inquire about taking up places on ASBAH's popular, annual Family Weekend – which will be held in Morecambe at the beginning of March.

The event moves to Lancashire after being held in Cornwall last year and in Northampton the year before that.

"Travel costs are sometimes a factor in preventing families from joining us. That's why it is vital to keep moving the weekend around," said co-organiser, Paula Thompson.

Non-disabled brothers and sisters are made to feel welcome, with a special programme tailor-made for them. Thanks to the BBC Children in Need Appeal, the cost of the weekend has been kept down to £60 a family.

If you enjoy trivia, you'll enjoy knowing a bit about the town's rich performance tradition. It was the birthplace of both Thora Hird and the late Eric Morecambe (born a Bartholomew).

Gym will fix it!

A BIG GYM will be at Rehab & Care 2000, being held in the NEC Birmingham at the end of November (see opposite).

And some of Britain's Paralympic athletes have been booked to show how the equipment can help build up levels of fitness.

Couch potatoes, on the other hand, can browse round lots of displays.

Upcoming events

Special Needs Information Day

18 November, Cambridge

For children, parents, carers and anyone with an interest in children with special needs in the Cambridge area.

Workshops and a creche. The Meadows Community Centre, 1 St Catherine's Road, off Arbury Road, Cambridge. 9am – 1pm. *Sharon Cross, Suite B, The Anderson Centre, Olding Road, Bury St Edmunds, Suffolk IP33 3TA.*

Influences Affecting Paediatric Contenance Care

18 November, Southampton

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

London Sports Forum meeting

20 November, London N7

Working Together, a meeting to discuss an inclusive approach to sports, health and leisure for

disabled people, organised by the London Sports Forum for Disabled People. *Details: 0207 354 8666.*

Careers Information Day

Wednesday 22 November, Nottingham

Careers, further education and welfare rights event. For practitioners working with young people with learning difficulties and/or disabilities.

East Midlands Careers Consortium, tel: 0116-287 7033.

Rehab & Care 2000

29 – 30 November, NEC Birmingham

Independent living exhibition, including full range of fitness equipment and demonstrations by Sydney Paralympic athletes.

Tickets and information: 0870-751 1437.

YEAR 2001

ASBAH Family Weekend

2–4 March, Morecambe

Residential event for families who have a young child with spina bifida and/or hydrocephalus, with parallel programmes for parents and for siblings. £60 per family. Sponsored by BBC Children in Need Appeal.

Details: Rita Duell, Services Department, ASBAH National Centre, 42 Park Road, Peterborough PE1 2UQ, tel 01733-555988, ritad@asbah.org

ONE OF THE signs of parents getting older (or going bonkers) is when they start trying to relive their childhood.

I think mum might have gone camping a lot (or been made to go) as a child. This is the only reason I can think of for mum's idea that our next family get-together should be a camping trip!

As I may have mentioned, just once or twice, I have absolutely no love for the Great Outdoors. I went on an outward bound week once when I was young and once is enough thanks very much! I like my creature comforts! It was with a sense of dread that I arrived at the campsite.

To be fair, mum had done her very best to make us comfortable. By the time I got there, she (and friend) had set up all the tents and positioned

DAVE'S DIARY

david.fulford-brown@ntlworld.com

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them near the shower block.

Mum had very kindly brought a 'proper mattress' for me to sleep on. Not that I got much sleep. Having eventually worked out how to get into and undress in something like an overgrown condom, or rucksack, I lay awake listening to the sounds of the Great Outdoors, including something like a cross between a llama and a goose!

Very early next morning the llama-geese turned up the volume and I gave up trying to sleep!

Token in hand I stumbled to the showers. After ages trying to get the water's temperature down to something that wouldn't take my skin off, I got in the shower and stuck shampoo

all over my head, whereupon the time ran out and the water switched off!

Things did improve later on. Mum cooked several excellent meals on a little portable barbecue. The sun finally came out and we spent a very pleasant time working off the food by rowing the family down a river. We raced the boats and my younger brother beat me. People kept getting in my way, and anyway the river didn't flow straight!

So, I have to admit (through clenched teeth) that yes, I did actually enjoy going camping again! Maybe getting older means I enjoy stuff I didn't when I was a kid. Or I'm just going potty!

BENNY FITZ



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

I'M 18. I'm looking for pen-pals my age or older who, like me, have hydrocephalus.

Caroline Hughes
3 Alexandra Road
Parkstone, Poole, Dorset
BH14 9EL

I HAVE achondroplasia, hydrocephalus, and neck problems. I have neck and head pain and extreme tiredness. I also feel quite queasy and my eyes blur periodically although my shunt is not blocked. I would appreciate any suggestions from anyone who has similar problems or, ideally, someone who has found a solution. I'm 21.

Sarah Mitchell
16 Malmaison Drive,
Frenchay, Bristol BS16 1PQ

I HAVE spina bifida and use a walking aid for short distances. I'm looking for a male pen-pal aged 50+ for a sincere friendship or relationship.

I'd like to meet someone who lives near to me, with a car, so we can go out. I am learning to drive at present. I smoke and am a 43-year-old divorcee. I'm ready for a relationship with a lonely kindred soul.

Julia Armer
85 Southwark Close
Stevenage, Herts SG1 4PH

'A captivating personality'

I WAS particularly pleased to see Roger Bayston's appreciation of Prof Emery (*Link*, September), not only because it was a fitting tribute to a great man but also because I had fully intended to write with some comments of my own, but felt I had left it too late.

As an almoner at The Royal Infirmary from 1956–1960, I seem to have been in Sheffield at a formative time in the treatment of spina bifida and hydrocephalus. I remember attending lectures on spina bifida by another great and caring personality, Mr Zachary, but do not think I came across Prof Emery at that time. However, in the 1980s, in my early days with ASBAH, I attended a training course at the Children's Hospital in Sheffield. The second in a list of distinguished speakers was Prof Emery and I still have the notes I took! I even have his first sentence: "We are all Bifid people who have come together more or less."

We were then treated to a brilliant lecture on embryology and what happens in the case of spina bifida. It was clear and fascinating without being over-simplified and I, for one, was spellbound. I was further captivated by his personality and conversation at dinner when I sat opposite him.

I only knew Professor John Emery for one day but I shall always remember him.

Rosemary Seaton, Chipping Campden, Glos.

'Trousers cut to my shape'

HAVING at last found a company which produces excellent clothing for wheelchair-users and disabled people at affordable prices, I felt that others might be interested. I use a wheelchair all the time and it is a relief to have smart, comfortable trousers which look and feel good and do not fall down when I transfer from my wheelchair to my car – not a happy experience.

Wearable Clothing Ltd produces a wide range of clothing for men and ladies and their staff are friendly and helpful. Tel: 0141-774 9000, fax: 0141-774 9064, website www.disabledclothing.com, email enquiries@wearableclothing.com

R J Elliott, Pinner, Middx.

MY NAME is Rachael Seymour and I would love to have pen-pals. I am nine years old and I have spina bifida and hydrocephalus. I have a shunt and I'm mobile. I love my playstation and

computer games, Barbie and Pokémon.

Rachael E Seymour
'Moor House', High Shincliffe
Co Durham DH1 2TQ
Rach@steveseymour.demon.co.uk

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. Clos-o-Mat. Overhead track hoist bedroom-to-bathroom. First floor accommodation for up to 4 carers / family / friends.

Awarded Grade 1 Holiday Care Service. Open all year. Low rates Winter / Spring. Information / bookings: Mr W G H Tickner, The Lin Berwick Trust, 0208-595 7056.

ORLANDO, FLORIDA

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

Advert rates

● Classified Rates:

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

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

● Classified adverts for the next issue of *Link* (January) should be submitted by Friday, 24 November.

Please send to:
Editor, ASBAH
42 Park Road
Peterborough PE1 2UQ.
Tel: 01733-555988.
lizc@asbah.org

● Display rates on application from Publicity Manager, ASBAH.

Tel: 01733-555988.
tonyb@asbah.org

FOR SALE

POWERTEC F45 wheelchair by Sunrise in teal colour. Collapsible. Indoor / outdoor. Charger and manual. Cost £3,000; accept £1,000 ono. Also two Quickie manual wheelchairs, £100 each. Tel: 01948-666774 (Whitchurch).

SUNRISE 4-wheel electric scooter with charger. As new, £1,500 ono. Electric indoor / outdoor wheelchair with charger, £1,500 ono. Tel: 020-8761 8413.

RANGER 4-wheel all terrain scooter. Only six months old. Been used for five miles. Cost £3,595, accept £1,000. Tel: 01729-822441 (North Yorks).

WHEELCHAIR accessible Renault van. Very low mileage, additional front and side

windows. Electrically operated ramp, fitted roof rack. £5,600 ono. Tel: 01275-833436 (Bristol).

PUSHPULL hand controls for Toyota Starlet or any small automatic. £100 ono. Tel: 01484-462426 (could deliver).

ELAP rotating car seat, never used. Lefthand passenger seat for Astra. Cost £600 will accept £400. Tel: 01508-494886.

ADJUSTAMATIC bed, dual action, 5 ft; two 2ft 6in mattresses with separate controls. £3,400 new, used one week only. £1,750 or reasonable offer. Tel: 01491-575726.

HYDROCEPHALUS and You, edited by ASBAH (1999), 81pp, £7.50 (inc p&p) from Information, ASBAH National Centre, Peterborough.

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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
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BURY & BOLTON

Mr David Clyne
51 Cuckoo Lane, Whitefield
Manchester M45 6WD
Tel: 0161-798 7804 (after 4pm)

CAMBRIDGE & DISTRICT

Mr Tony Proud
10 Newlands Road
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Peterborough
PE7 1YX

CHESTER & DISTRICT

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LN6 9EX
Tel: 01522 778781

LINCOLNSHIRE SOUTH

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

LONDON N WEST

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

LONDON SOUTH

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