LINK

The magazine for people
with Spina Bifida and
Hydrocephalus

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS
ASBAH

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MARCH/APRIL 2002 ISSUE 198

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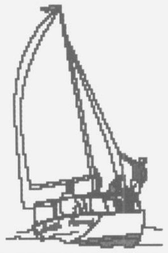

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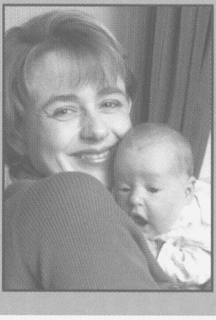

Cover: Paralympic gold medallist Tanni Grey-Thompson and baby Carys. Photo: Graham Bool

Editorial

THIS issue of *Link* brings mixed news for ASBAH: sadly we report on the death of a long standing member of our Trustees and on proposals for the redundancy of four ASBAH adviser posts forced by a shortage of income. On a much happier note we congratulate Tanni Grey-Thompson on the birth of her daughter Carys and readers can see how once again we benefit from the generosity of The Royal Pigeon Racing Association at their annual show.

Two stories, on completely different topics, show how ASBAH continues to battle to ensure that individuals and families do not miss out on their entitlements: be it to zero VAT rating on an adapted car, or adequate provision for children at school.

Also in this issue are features on fashion and research as *Link* aims to deliver a varied package of information and views to appeal to all its readers – but don't forget it's a two way process and we're always keen to hear from you, email or write to us and let us know what you want from your magazine.

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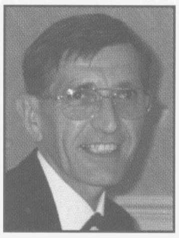

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ASBAH's vision is a future where everyone with spina bifida or hydrocephalus can get the most out of life.

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.

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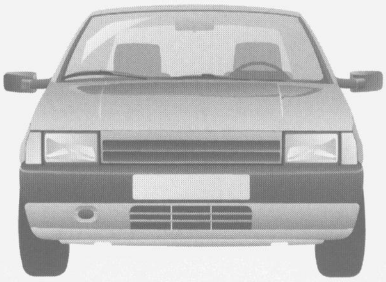
Buying a car? Yours could be zero-rated



AFTER publishing the good news that ASBAH Adviser Marcia Conroy paid no VAT on a new adapted car, we received several inquiries on the new rules.

HM Customs and Excise has been giving out wrong information on its website and advice line. So, ASBAH wrote to the Minister responsible, Mr Paul Boateng MP, urging him to put things right. He has now replied: "I am sorry that disabled people using the National Advice Service have been given misleading and out of date advice about the changes to the VAT relief." Mr Boateng goes on to say that steps are being taken to ensure the latest information is readily available from the Advice Service and the web site.

This article aims to clarify the new rules.

LAST April, all permanent wheelchair-users and their families became eligible to pay no VAT when buying a motor vehicle adapted for the disabled person's use.

A disabled person no longer has to travel in a wheelchair or lie on a stretcher, but can sit on any seat. He or she can be a passenger or the driver.

However, occasional wheelchair-users and people who normally use a mobility scooter are NOT entitled to VAT-relief on cars.

Zero-rating now applies to **adapted** vehicles carrying up to 12 persons (driver + 11 passengers). So larger families also benefit.

Buyers must fill out an 'eligibility declaration form' for the vehicle and/or adaptations and servicing. These forms are available from vehicle suppliers or HM Custom & Excise, or this web page: www.customs.gov/forms/notices/info0701.htm

To qualify for zero VAT, the adapted vehicle must be for domestic or personal use and not be used for commercial or business purposes. Disabled people who have bought adapted vehicles at the zero rate may use them for work where this is incidental to their main use as a private vehicle.

It is important that the adaptation should meet the needs of the wheelchair-user and the relevant eligibility declaration should be completed.

What is a permanent and substantial adaptation?

The following are examples of adaptations which **may** be made to enable a wheelchair-user to enter, drive or travel in a qualifying vehicle:

- A swivel seat;
- A hoist to lift the wheelchair into or onto the vehicle;
- A box for the wheelchair which is fitted to the top or the back of the vehicle;
- Adaptations which enable a wheelchair-user to drive the vehicle.

Such adaptations should generally be welded or bolted on to the vehicle.

The following are **examples** of adaptations which do NOT make the vehicle eligible for VAT relief:

- The fitting of a roof rack;
- The attachment of a trailer to the back of a vehicle;
- Automatic transmission.

The repair and maintenance of an adapted vehicle, which qualified for VAT relief when purchased, are also zero-rated.

The repair and maintenance of a vehicle adapted *before* 1 April 2001 is only eligible for VAT relief if the vehicle was purchased VAT zero-rated under the old legislation.

Where the vehicle was adapted *after* it was supplied to a disabled person, repair and maintenance of the adaptations are eligible for VAT relief. All other repairs and maintenance are liable to VAT.

If a wheelchair-user buys a vehicle and then has it adapted, there is no VAT relief on the purchase of the vehicle. However, no VAT will be due on the supply of the adaptation.

Charities also benefit from the new VAT relief when purchasing eligible adapted vehicles.

Up-to-date information is available on this web-page: www.customs.gov/forms/notices/info0701.htm

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ASBAH's Executive Director ANDREW RUSSELL says we will continue to be here when you need us.

Income shortage forces Adviser redundancies

ASBAH faces hard times financially because our fundraising is closely related to the national economy and business confidence, which are uncertain and cautious at present. We are determined to go on providing services, information and research, and to make sure that the Association is there in the future for all those who need us.

We have therefore announced, with great regret, that several Adviser staff posts will have to be made redundant for financial reasons. This is a harsh setback for the Association and for the particular staff members affected. We are very unhappy to have to make these proposals, but they are necessary to keep national ASBAH viable.

During the last year and more, as income has not reached the expected level, we have cut back on staff hours here at our national office, both through redundancies and non-replacement of leavers.

To service-users who are worried that ASBAH will not respond to their requests for support, I would say whilst our ability to respond to requests for help and support will be affected, ASBAH will still offer information and advice where it is needed. We will continue to offer a team of professional Advisers, and the Regional and National offices for you to contact.

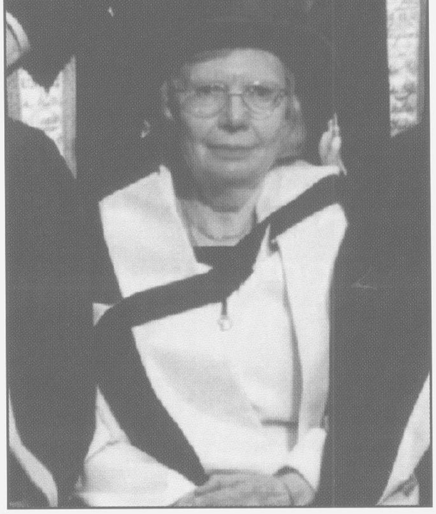
To Local Associations who support us I would like to say how much it is appreciated and to stress how essential this support is in maintaining the services in local areas. If any Local Association can dig deeper to help, this could make a big difference, and I would be very happy to discuss this with you. All income from donations is important to us, and I would like to thank all our supporters for their commitment and generosity. If anyone is willing to consider doing a sponsored event, or has a fundraising idea, we would love to hear from you.

To increase income we have reviewed all our fundraising and we are gearing up a number of appeals. Donna Treanor, our Fundraising Manager, will say more about this in the next *Link*. Charity fundraising is intensely competitive, with individuals, organisations, foundations and companies having to choose from amongst many appeals. We are confident our fundraising plans will in time deliver more income on a regular basis. In the meantime we have to ensure that expenditure does not exceed income as ASBAH has never held large reserves.

This is an unsettling time for staff, particularly those directly affected. It is almost two years since any ASBAH staff received a cost-of-living pay rise, and not a single complaint has been voiced by them.

I believe we can solve this financial challenge by working together for the important aims that we all share.

Discovery of a gene which may cause spina bifida



By Carys M Bannister OBE, FRCS(E), BSc(Oxon), DSc(UMIST)
President of the Society for Research into Hydrocephalus and Spina Bifida (SRHSB)

THE INHERITANCE pattern for spina bifida and hydrocephalus has long been accepted as having both genetic and environmental components. The involvement of folic acid in the environmental aspect of its inheritance has been extensively discussed and researched over many years.

In spite of much work, until now, there has been no success in identifying a gene or genes responsible for the abnormalities that occur in the central nervous system in the condition. It is, therefore, extremely exciting that Dr Philip Stanier at Imperial College in London and Professor Andrew Copp of University College, London, have recently reported that they have found a gene that appears to be responsible for spina bifida in mice. All mammals share many genes and, whilst it's too early to be able to say whether humans have this same gene in their DNA, it's possible that they do and I'm sure it won't be long before many researchers are looking to see if this is the case.

How may the identification of a gene change our approach to a condition such as spina bifida? These days there is a lot of talk about genetic engineering and gene modification but we are a long way from being able to easily and successfully remove "bad" genes from cells and replace them with "good" ones or to change "bad" genes into "good" ones. Because the evidence points to the defects in spina bifida occurring very early in the developmental period, probably within the first four weeks of pregnancy, it follows that realistically if gene modification or engineering were possible they would have to be carried out before that time. Ideally sperm and ova would be treated in order to insure that none of them would carry problem genes. As far as I'm aware this has not yet been done for any condition.

It's more likely that intervention would be carried out on embryos thought to have spina bifida after they had been produced by in vitro fertilisation. In vitro fertilisation would make available embryos at two, four or eight cells stage for treatment, when perhaps the "bad" genes in their cells could be swapped for "good" ones. This too is something that is not currently being undertaken. Therefore, the most likely use that would be made of the ability to identify an abnormal spina bifida gene is what is being done in other conditions where abnormal genes are known to occur: that is, a number of embryos could be produced by in vitro fertilisation and tested for the spina bifida gene: only embryos shown not to have the abnormal gene would be implanted and go on to produce a baby.

Being able to identify an abnormal gene might also allow affected fetuses to be identified earlier in pregnancy than is currently possible. If fetal cells are collected either by amniocentesis or by removing a small part of the afterbirth (placenta), it might be possible to identify the spina bifida gene in the laboratory. Being informed that the fetus was carrying the abnormal gene would allow the parents the option of a termination within the first few weeks of the pregnancy rather than at the 18th or 20th week as happens now.

All these possibilities are pure speculation and whether any of them will ever be carried out will depend on whether the genes responsible for spina bifida are identified in humans. I hope that they will and that the discovery will be made in the near future.

School provision should relate to child's needs, says new Code

CRUCIAL changes have been made by the Government in a Code of Practice which local education authorities (LEAs) must follow when issuing Statements for children with special educational needs.

ASBAH was part of a coalition of charities that fought last year for a new version of the Code to be revised as we believed parents would find it harder to obtain a specified and quantified Statement.

The revised new Code was approved in November and has significant impact on the ways in which schools and professionals work in meeting the needs of children with special educational needs (SEN). Examples include:

1. SEN policies

All early years education providers, including childminders, day nurseries and schools, must now have regard to the code and produce a written SEN policy.

2. School-based support

'School Action' replaces the old stages 1 and 2, and 'School Action Plus' replaces stage 3. School Action is where the school provides intervention that is additional to what it normally offers in its curriculum or strategies. An important element is collecting information about the pupil, particularly from parents. SENCOs co-ordinate the work.

School Action Plus is where the pupil's needs are such that the school has to consult outside agencies – usually an educational psychologist or an external support service such as a behaviour support team. Again, parents should be consulted.

3. Statutory assessments

The criteria for statutory assessment is no longer focused on the specific type of learning difficulty. Instead, the LEA must look at the needs and requirements of the child in terms of: Communication and interaction; Cognition and learning; Behaviour, emotion and social development; and Sensory/physical.

By Joanne Grenfell and Bruce Graham
ASBAH Specialist Advisers (Education)

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4. Statements

The provision described in Statements should be specific and should relate to the needs of the child. The Code says provision should normally be quantified but mentions flexibility may be required on occasion. We will have to see how LEAs respond to this wording.

5. Speech therapy

Speech therapy should now normally appear in Part 3. This is good news for many children with hydrocephalus as, although speech therapy previously appeared in Parts 5 or 6, it was not enforceable and resulted in some parents being forced to go to tribunal.

6. IEPs

Individual Education Plans, where the teacher lists a number of specific learning targets for the term, take place three times a year in early years education with the involvement of parents.

For primary and secondary school children, IEPs will be reviewed at least twice a year. At secondary level, pupils as well as parents will be involved.

7. Statement reviews

Annual review discussions for secondary school transfer begin in Year 5. These continue in Year 6, with placements completed by the beginning of March.

Transitional reviews occur in Year 9 and must involve Connexions – a Government agency. These must review the Statement and provide a coherent plan for the young person's move to adult life.

8. Conciliation

When parents disagree with an LEA on Statementing, they can use a conciliation service to help resolve the dispute. Using this service does not remove their right to lodge an appeal with the tribunal. The two services run in parallel.

Parent Partnership Services will be available to all children with SEN, not just those who are Statemented. The child will be encouraged to be involved.

obituary

Geoff Baxter 1941–2001

DESCRIBED as one of the solid rocks upon which one of the country's most successful local ASBAHs rested, Geoff Baxter passed away in December, aged 60.

Geoff's unassuming and quiet ways belied his strong commitment and hard work, helping Leeds & Bradford ASBAH go from strength to strength. He was also a trustee of national ASBAH.

He and his wife Jo (pictured above) joined the local Association in the early 70s. Their son Martin had spina bifida and hydrocephalus. Martin's death in 1993 was a harsh blow to the whole family, but Geoff continued his commitment to ASBAH.

By 1975 he was Honorary Secretary of Leeds and Bradford and for the next 25 years he held the positions of secretary, deputy chairman and treasurer, fulfilling those roles, efficiently and most effectively.

Over the years, Geoff was responsible for the local Association's caravan bookings; involved in interviewing and selecting staff; and co-ordinator of Activity Group Leaders. He was a major contributor to a successful Lottery grant application and as treasurer revolutionised the group's book-keeping and financial management by computerising its accounts, producing annual budgets and monthly financial reports.

He travelled thousands of miles over 20 years to meetings all over the country.

Michael Booth, chairman of Leeds and Bradford and national ASBAH trustee, spoke of Geoff's immense commitment and described him as someone who insisted on doing things properly.

He added: "Geoff was the powerhouse, the engine room of the local Association and we are going to miss him terribly. He was also one of life's nice guys."

Joan Pheasant, manager of ASBAH's Northern Region, also knew Geoff for many years.

She said: "He was a wonderful, kind and generous man who will be missed greatly. The many committee members, employed staff and members that celebrated his life at the Memorial Service show how highly he was thought of."

Geoff's huge commitment to others was also shown through the Oddfellows Friendly Society, the Scouting Association, St Peter's Church, Shipley, and as junior vice-president of Shipley Rotary.

He leaves a wife Jo and a son Andrew.

A 'CHARITY Bash' held by a branch of the Royal British Legion raised hundreds of pounds for a local ASBAH.

Wallace Elliott, grandfather of Derbyshire ASBAH member, Chris Elliott *(pictured below, bottom left)*, organised the event for the Legion's Allestree branch. £500 was raised for Derbyshire ASBAH, boosted by another £70 raised in an auction.

The other charity receiving a cheque for the same amount was the Nottingham Brain Tumour Research project.

On the left of the photo is Mr Jonathan Punt, consultant neurosurgeon, who recently left Nottingham's Queen's Medical Centre. *Photo courtesy of the Derby Evening Telegraph.*

Ordering a large hat

An older person with hydrocephalus describes how he dealt with a problem. Younger members take note!

HAVING lost my fourth hat in 40 years on a return rail journey, I rung numerous shops to find someone who could make a size eight and one eighth hat.

Although this had been possible 10 years ago, this time I received no positive responses.

By David Nicholson

I decided to phone a bespoke gentlemen's tailor in Alnwick, Northumberland.

Definition of **bespoke**: made-to-order; usually said of clothing; dealing in custom made articles.

In response to my question: "Could you advise me of someone who could make a size eight and one-eighth hat?" I received a somewhat surprising response – which I took to be from a young assistant: "What you need is a dustbin!"

I responded "I beg your pardon?"

"What you need is a dustbin, Sir. The largest hat size is seven and a half . Are you sure you do not mean seven and one eighth?" (Actually seven and seven eighths is the largest hat size; the largest cap size is seven and a half).

I wrote to the shop manager noting that:

1. I was astounded at the opening comment of the shop assistant. I previously had **four** hats of size eight and one eighth.

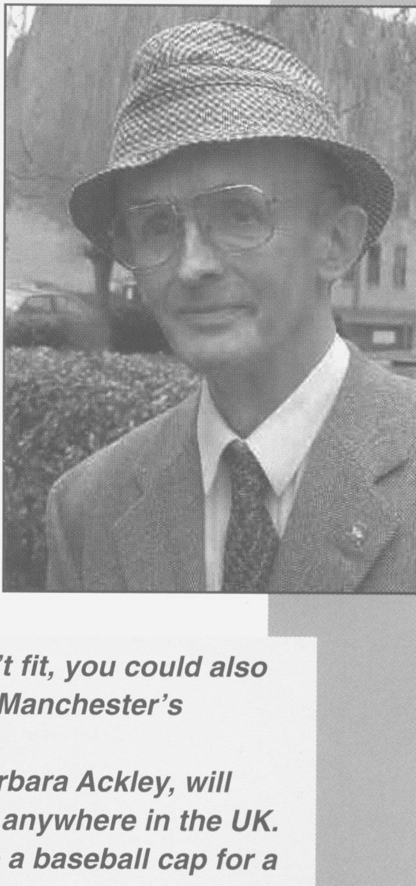
2. I understood that bespoke tailors got much of their profit from providing the unusual requirements of their customers.

3. I assured him of a continuing demand from ASBAH service-users for large hats.

4. I concluded that during the 25 years which I had lived next to the manager's grandmother in Newcastle she had never shown any adverse discrimination against me; quite the reverse.

However, after consideration, I decided to give the manager the opportunity to measure my head and confirm my size. Accordingly I drove the 12 miles to his shop. On arrival, I was somewhat disappointed to discover that it was the manager who had answered the phone! On measuring my head he had to concede that it was at least size eight.

Meanwhile I tried a medium-sized department store in Morpeth where a senior staff member suggested several suppliers whom I had already approached. She suggested that I needed a milliner. Definition of **milliner**: a person who makes, trims or designs or sells women's hats.



In *Yellow Pages*, under the heading *Hat Shops And Milliners*, I noted Jane Corbette who agreed to make me a hat for £80.

Anybody requiring further information about Jane can contact me via ASBAH. The minimum measurements she needs are: circumference of head and height from above circumference to top of head.

IF off-the-peg hats don't fit, you could also try The Style Centre at Manchester's Disabled Living Centre.

Clothing adviser, Barbara Ackley, will make a hat for anyone, anywhere in the UK. For example, she made a baseball cap for a man in Sheffield.

She will need your dimensions: (a) circumference of head and (b) height of the crown (from centre of ear, over the top of the head, to the centre of the other ear).

- ***Contact Barbara on 0161-214 5959 or email: fashion@disabledliving.co.uk***

Fashion

CLOTHES designers of tomorrow were challenged to make a collection of menswear for both disabled and non-disabled people.

The 2002 Design Challenge involved second years from Nottingham Trent University Fashion Department and disabled students from Portland College, Mansfield. The competition was masterminded by **awear**– the organisation aiming to give disabled people full and direct access to fashionable clothes – and supported by leading textiles manufacturer Penn Nyla.

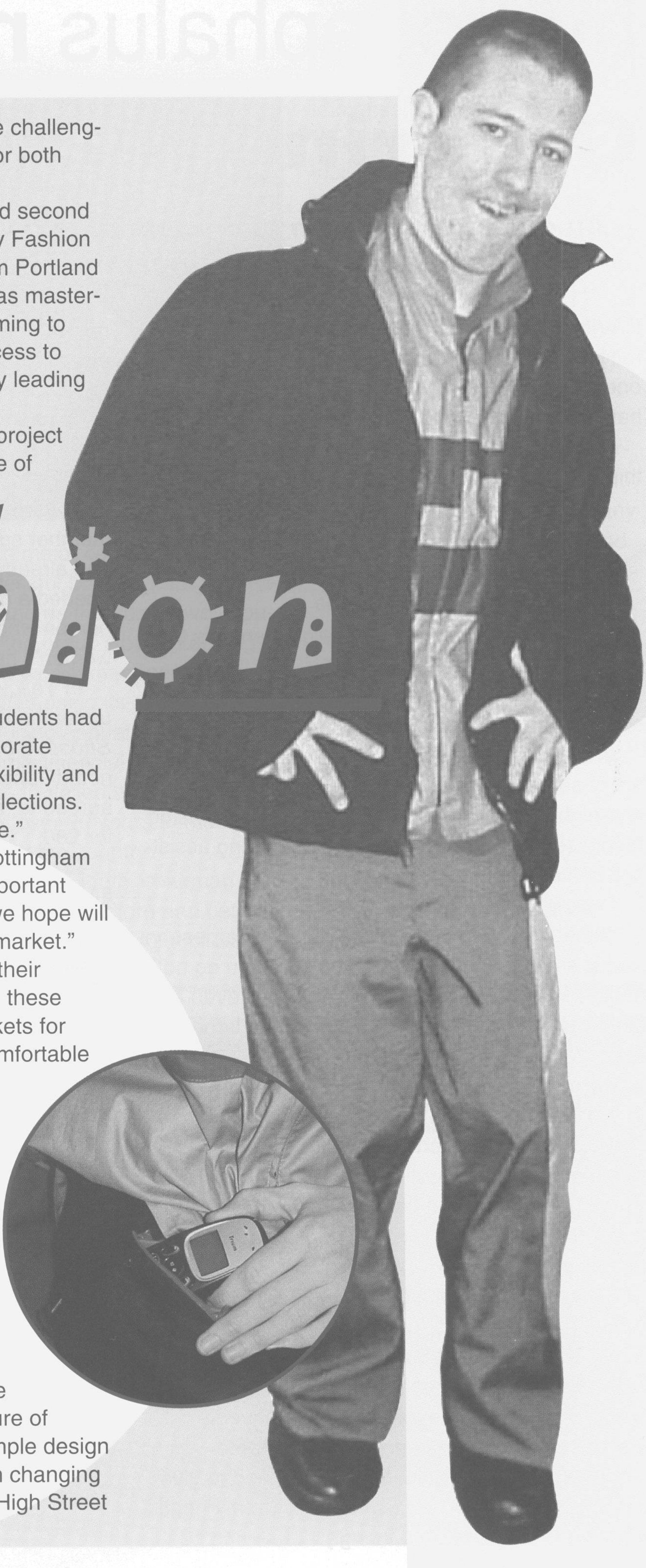
Sarah Collis, of **awear**, said: “This project created an opportunity for an exchange of ideas and experiences. The design students had to rethink some of their ideas to incorporate issues such as ease of movement, flexibility and wear and tear in the design of their collections. All agreed it was a valuable experience.”

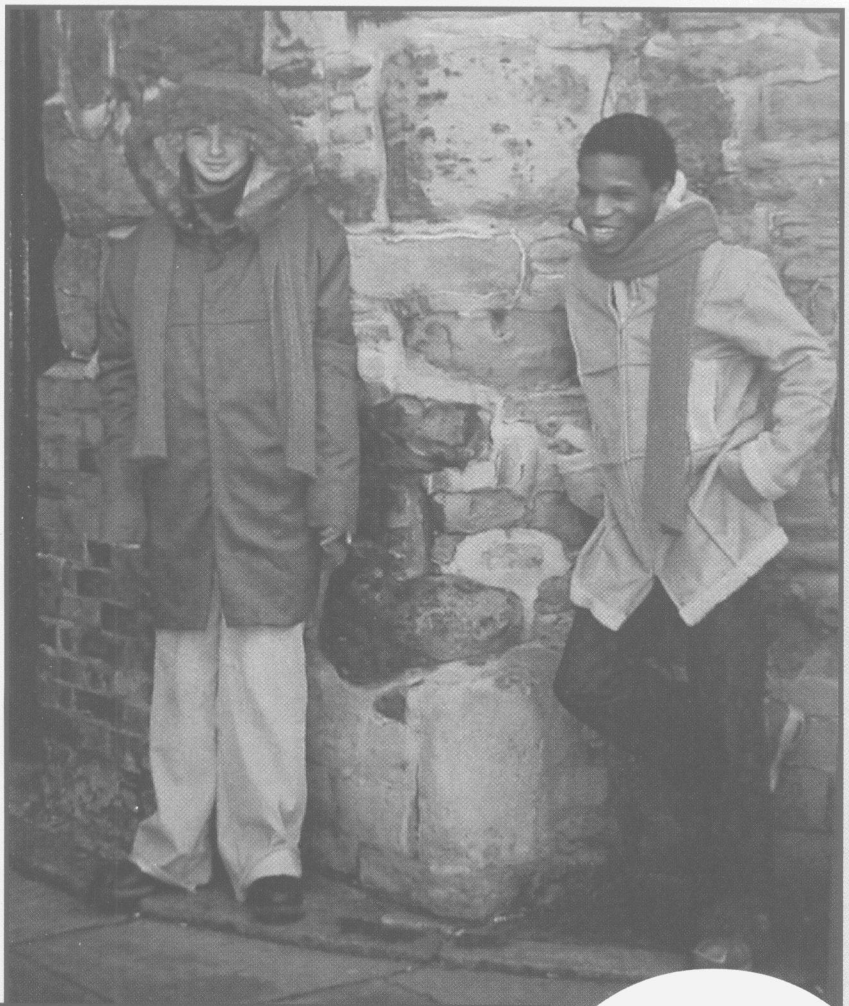
Maria Stafford, senior lecturer at Nottingham Trent University, added: “This is an important project for the students and one that we hope will raise their awareness of the disabled market.”

The top design team won £250 for their inclusive range of clothing – shown on these pages – featuring well-positioned pockets for easy access, good fastenings and comfortable design.

Tops, jackets and coats could be worn sitting or standing, and trousers were designed to fit both figures, or were altered using **awear’s** ‘Softawear’ technology which can cut patterns to any shape. Developed with help from the Community Fund, ‘Softawear’ could be taken up by the industry to make individual garments for High Street retailers.

Sarah, from **awear**, concluded: “We hope this project will influence the future of design to include disabled people. Simple design features can make all the difference in changing the way disabled people shop on the High Street for comfortable, fashionable clothing.”





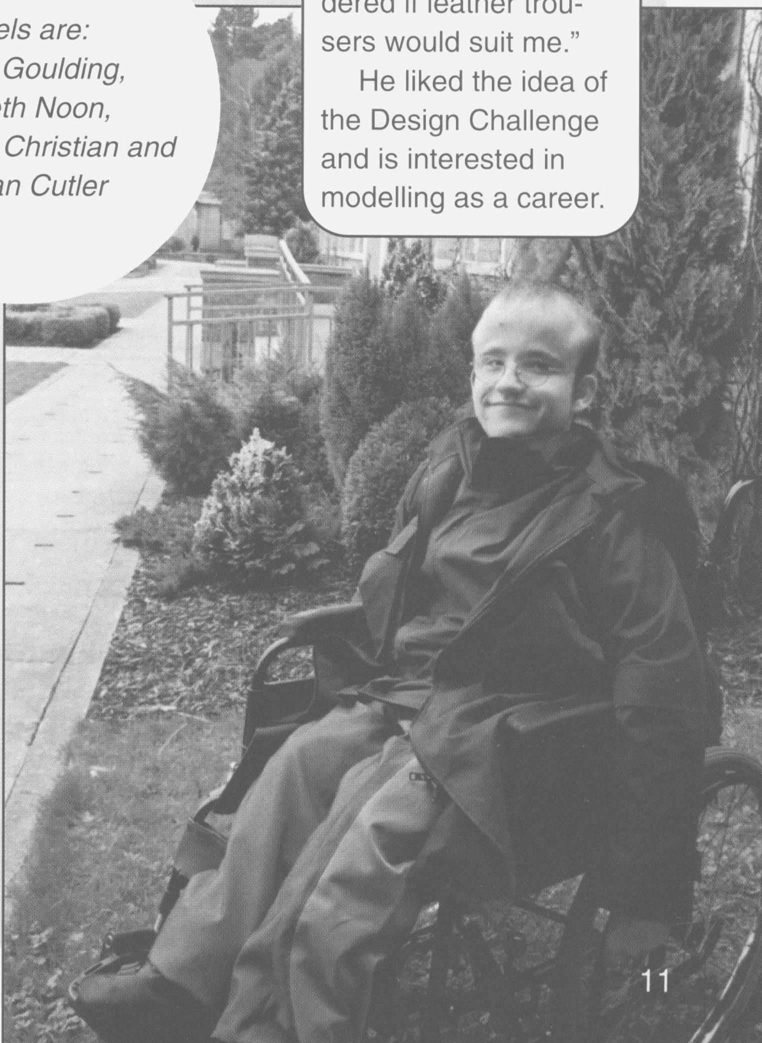
Models are:
Matt Goulding,
Gareth Noon,
Paul Christian and
Adrian Cutler

PHILIP Stonehouse *(below)* was only too pleased to pose for us when we said we were looking for someone with spina bifida/ hydrocephalus to try out togs created by fashion students for a Design Challenge.

Hailing from Cleveland, 20-year-old Philip is doing a year of practical skills at Portland College in Mansfield, Notts.

"It was my girlfriend who got me interested in clothes and fashion," he said. "She got herself some leather trousers and I wondered if leather trousers would suit me."

He liked the idea of the Design Challenge and is interested in modelling as a career.



For more about ***awear*** *log on to* ***www.awear.org.uk***
email: ***clothingservices@awear.org.uk***
or phone 0115-953 0439.

Portrait of motherhood

FEBRUARY saw the safe arrival of Carys Olivia, daughter of Paralympic gold medallist Tanni Grey-Thompson OBE and her fellow wheelchair athlete husband, Ian.

This picture shows Tanni looking happy and relaxed in her new role.

She returned to her family home of Cardiff for her ante-natal care at the University College Hospital.

Tanni went to 'term' and Carys was delivered on 4 February by Caesarean Section, weighing 7lb 12oz.

Tanni and Ian said: "This has been the most exciting experience of our lives and we are both very proud."

DRUSILLA Henley, an active former Your Voice steering group member, sadly died in January at the age of 33.

Drusilla, of Great Witley, Worcester, was involved in many groups. She worked at a music shop in Malvern for several years where she ran a points scheme for ASBAH.

Drusilla's warm personality and good humour will be much missed.

History: teaching us a thing or two

CONGRATULATIONS to Emmeline Burdett who, having achieved a law degree, has embarked on an MA in Modern History.

One of the highlights of her law degree at Westminster University was the 10 months she spent at the University of Maastricht as part of the Erasmus Exchange Programme. She enjoyed meeting people of all nationalities there.

The 23-year-old then made the switch to History at University College, London, because she decided she didn't want to be a lawyer.

"There are close links between History and Law, particularly the Nuremburg Trials," explained Emmeline, who has spina bifida.

"The old saying that we can learn from history not to repeat past mistakes doesn't often ring true and there have been so many exterminations of innocent people since then, that I don't expect to change the future, but at least help to give these issues a public airing."

Her first MA dissertation is *A Comparison Between Utilitarianism and Genocide*.

She said: "The Holocaust started with the murder of disabled people, but such crimes shouldn't be committed against anyone or any group."

When she's finished studying – and she would like to do a PhD next – Emmeline, of Enfield, Middlesex, wants to become a historian or academic working at a university or institute of historical research.

STOCKPORT EXPRESS

Spill the beans to this school access wizard

WHEELCHAIR-users at secondary schools have a real opportunity to shape the future by passing on their views to a go-ahead teenager with spina bifida.

Eleni Burgess's idea to show how difficult it can be for chair-users in mainstream school was a winner in the Whizz-Kidz 'No Limits' Millennium Awards.

She won £5,500 to produce and mail a questionnaire to disabled pupils all over the UK. *Link* readers and their friends who are wheelchair-users are invited to take part.

Eleni (15), of Stockport, said: "I want to show there is still a long way to go to achieve integration and aim to produce a checklist for schools and local authorities."

She wants to find out about: getting to school; access at school; school trips; games lessons; after-school activities; relevance of curriculum; work experience/careers advice; parents/pupils networks and bullying.

As well as publishing a report of the statistics from returned questionnaires, she wants to highlight the 10 most interesting stories to persuade education authorities that action needs to be taken to improve school life for pupils who use chairs.

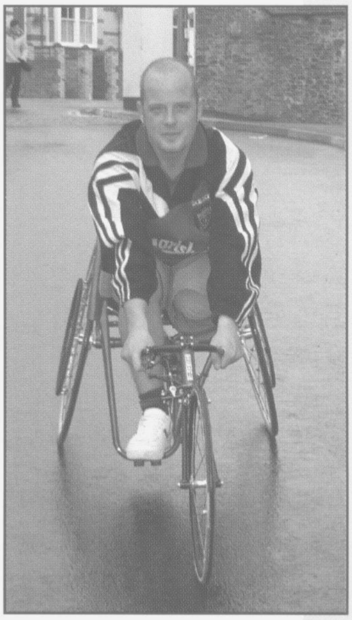
She said: "If I can say, for example, that 70% of pupils can't get through the school front door or can't attend school trips or after-school activities, my survey will be a powerful tool for change."

● Email Eleni on Chris.Burgess7@btinternet.com

Back in the race after five years

THE HAPPIEST years for Ryan Henry were his teens when he was competing in track events like shotput, discus and javelin.

He has seven national gold medals to prove his success and, now that some major leg surgery is out of the way, he's determined to get ahead in sport again.



His local paper raised more than £2,000 for a racing chair, with Ryan choosing ASBAH to benefit from the £313 left over.

The 25-year-old is delighted but now faces new challenges. Living in Bideford, North Devon, he cannot find a club or trainer to spur him on. Neither can he find a sponsor to help fund travel expenses.

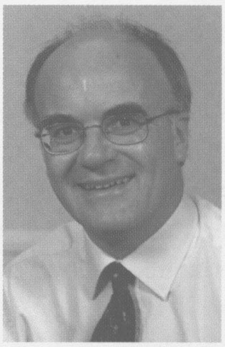
"I want to do something with my life and, now that I've got the chair, I'm serious about getting back into disability sports," he said.

"I am working on my fitness at the gym, swimming pool and with equipment at home and I am going to try and get to some events if I can find out where they are."

● ASBAH's Cornwall adviser, Lynne Young, suggested Ryan speak to Tony Fortune, the wheelchair basketball development officer for Portsmouth & Exeter, about his requirements.

ALL CHANGE for Tony Britton who left ASBAH in December when the post of ASBAH publicity manager was made redundant.

He joined the ME Association as PR and communications manager at its new head office in Buckingham.



Feeding problems in children with spina bifida and hydrocephalus

AN OBSERVATION that a proportion of children attending a spina bifida clinic in Belfast had had or were currently experiencing feeding problems prompted two researchers to find out more. NAN HILL and MARION WILLIAMS, at the Royal Belfast Hospital for Sick Children, who undertook this study, write about it below. Nan Hill has been Consultant Paediatrician at the Regional Clinic for Spina Bifida and Hydrocephalus in Belfast for the last 16 years. Marion Williams is a senior house officer in paediatrics.

WE STARTED our study by circulating a questionnaire to parents to find out past and current feeding problems in 70 children (42 male; 28 female). Some of the children had experienced problems from birth which had improved with time, some a plateauing of feeding ability and some a deterioration in feeding skills.

Details on current neurological functioning, health and medication were also noted. The youngest child was two months and the eldest 16 years. Sixty-seven were one year or above and so at an age when feeding should have been mature.

Twelve were in pre-school provision, 27 mainstream, 21 special education for physical needs, nine special education for severe learning difficulties, one special education for visual impairment.

The following health problems were recorded: shunt dependent hydrocephalus (62), visual problems (36) of which 23 had a squint, epilepsy (10), hearing problems (8), upper limb problems (25). Other health problems were reported in 17. Two children had problems with apnoea, both of whom had deterioration in feeding.

Thirty parents said their child had current feeding problems and 15 reported feeding problems that had not resolved *(see Tables 1 and 2).*

Twenty-one children were reported to be notably slower eating a meal (greater than 15-20 minutes) than their peers. Fifty-five children fed themselves at mealtimes, 11 required some assistance, and four required to be fed.

Modification of food or feeding method was needed in 11 and included liquidised (6), added calories (2), finely cut (1), thickeners (1), intermittent nasogastric feeds (2) and gastrostomy feeds (1).

Forty-six parents considered their child's weight to be average, 15 overweight and nine underweight. Weight was not consistently documented in the clinic notes, especially in the older children.

Of the five children with a definite deterioration of feeding skills, three have had posterior fossa decompression surgery with some improvement in a range of symptoms including feeding; one surgery for spinal syrinx and psychological support, and one a tracheostomy and gastrostomy.

Brain imaging data (CT or MRI) was available in 36 of the 70 children *(see Table 3).* Chiari malformation was the most common finding. Scan information was available in too small a proportion of children to draw many conclusions. Where there had been a deterioration in feeding and there were other neurological symptoms, the difficulty was most

Table 1
Current feeding problems (n=30)

Vomiting	3
Fussiness	7
Choking/gagging on lumps	15
Difficulty chewing	3
GO reflux	3
Absorption problems	1

commonly associated with Chiari malformation with pressure on the hind brain structures. Those who had experienced a significant deterioration in feeding skills all had both upper limb problems and a Chiari malformation and two of the five had a history of apnoea.

Table 2
Resolved feeding problems (n=15)

GO reflux	4
Poor suck	1
Problems with lumps	6
Slow to wean	5
Vomiting	1
Difficulty drinking	1

A history of feeding difficulties, or current feeding difficulties are common in children with spina bifida, occurring in 45 out of 70 in this study.

Help with feeding needs to be available for parents and carers especially in the early years. Health visitors, speech therapists, dieticians and clinical psychologists all have an important part to play. Feeding continues to be much slower for the children, irrespective of whether there are more specific feeding concerns.

Table 3
Neuroimaging (n=36)

Chiari malformation	20
Syrinx/hydromyelia of cord	6
Brain tumour	2
Diastematomyelia	1
Agenesis of corpus callosum	1
Tethered cord	1
No significant abnormality	9

It is also important to recognise that some children experience a deterioration in feeding. Further assessment of shunt function and neurological status, with special investigations such as neuroimaging and swallowing videofluoroscopy may be needed. In some, neurosurgical intervention has stabilised the clinical situation.

The reasons why children with spina bifida have feeding problems has been little studied. Developmental, behavioural and neurological factors all play a part. For parents/carers and the young people themselves feeding is so central to the enjoyment of life and living that problems in this area warrant further support and research.

● **Paula Thompson, ASBAH's Specialist Adviser (Medical), writes:** ***Dr Hill's research findings are very similar to what we at ASBAH have been discovering for the past few years. Dr Hill and I hope to share information in the future. If you have any concerns regarding your child's eating habits, please do not hesitate to contact me here at National Office.***

Family benefits to rise

ABOVE-inflation rises in benefits and tax credits are to go to parents of disabled children.

The Disabled Child Premium rises by £5 above the rate of inflation to £35.50 a week, from April. From April '03, the premium will rise by another £5 above inflation.

Also from this April, Working Families' Tax Credit (WFTC) and Disabled Person's Tax Credit (DPTC) rates and thresholds will be increased by the Government's inflation index of 1.7 per cent.

But credits for disabled children under 16 in DPTC and WFTC will go up by an extra £5 a week. Further increases of £5 are planned for 2003.

Households with a child under 16 at the beginning of the tax year and where the income of the highest paid parent is less than £42,000 can apply for Children's Tax Credit.

For incomes less than £33,395, the maximum of £520 will be available; over this limit the credit decreases by £1 for every £15 of income.

● ***Details from your local tax office.***

link.forum

Last issue's problem:

I can't get my daughter up for college in the morning because she's been watching TV all night. She's 20 and has hydrocephalus. What should I do?

Gay Foley, parent: I AM not surprised that you received no answers to your first problem! It's a problem that cannot be answered, but can I suggest one or two things? The mother should say: *I will call you in time to get up for college - if you don't get up you will miss college* and she must mean it! Or, try: *While you live in my house, you will switch off the TV at a reasonable time – if you want to watch TV all night, it must be in your own home.'*

We live with a 21-year-old with hydrocephalus and CP, and have had an equal lack of success over the years with an number of other similar problems. Luckily, our daughter goes to bed early!

I do not think, however, that you can negotiate with a young adult with hydrocephalus. They are told all the time by numerous people that they have equal rights to anybody else, and the right to exercise them, whether or not they are in their best interests.

Val Hartley, parent: HOW do you make any 20-year-old do what you think is best let alone one with hydrocephalus.

My 15-year-old knows the difference between wrong and right but appears to be bloody minded about a lot of things, argues and then as long as she hasn't been too upset, does conform eventually.

She has missed out on many things because of her attitude and like everything else in her life has had to be trained to get this far.

Social issues are by far the hardest things to cope with having a teenager with hydrocephalus.

Debbi Fields, National Hydrocephalus Foundation: I AM located in the US and run a non-profit hydrocephalus organisation, and I received such a question not long ago.

My suggestion was and is: the daughter must be given and taught self discipline. No TV in the bedroom (if there is one), until it can be proven that she has earned it. If there is no TV in her room, then, like a child, she must go to bed at a certain time, get up at a certain time.

If this does not work, I would highly suggest that a psychologist be seen. There possibly could be something underlying in this situation.

Gill Yaz, ASBAH specialist adviser (medical), SE Region: TALK to your daughter about whether college is interesting, relevant, and whether she wants to continue the course or do something else.

If she still wants to complete her course, talk about which programmes she really wants to watch, and help her decide a 'switch-off time.'

It may be that your daughter finds it harder to make the decision to turn off the TV because she is tired.

Consider getting a time switch for the TV plug and set it to go off at the pre-arranged time. This way your daughter is in control of the decisions earlier in the day when she is not tired. The timer will make it easier for her to put it into practice.

Here's another problem:

WE are finding it hard dealing with our five-year-old's VP shunt. We know the signs of shunt failure, but the signs can mean so many other illnesses and he is a child who always has a cold, a UTI or something. How do we know when to use his open access to his neurological centre and bypass our local hospital?

● To suggest a solution – or submit your own problem – please email link@asbah.org or write to: ***Link.forum, ASBAH, 42 Park Road, Peterborough PE1 2UQ.***

tribute

DAVID Thomas, consultant urologist at the Princess Royal Spinal Injuries Unit, Northern General Hospital, Sheffield, has now retired but, over 30 years, he helped many people with spina bifida solve their continence problems. Here *Link* columnist DAVID FULFORD-BROWN and ASBAH member CHRISTINE HELLIWELL give their own separate accounts of how Mr Thomas changed their lives.

SO, farewell Mr Thomas. He's the surgeon who looked after my waterworks. Now he's gone and retired on me. I'm shocked. I suppose I shouldn't be surprised as he looked after me for 20 years. I can hardly complain. In fact, I have a great deal to thank Mr Thomas for. The surgery he did has improved my life more than I can describe.

But the brilliant surgery is only one reason why I will not forget Mr T. In a life full of nameless doctors who treated me like another block on the conveyor belt, Mr T always managed to make me feel noticed, though he must have seen thousands of patients. He also helped me through some tough operations by explaining what was going to happen. When he knew the procedure was going to be horrible, like the infernal bowel prep, he seemed genuinely apologetic even managing to cheer me up a bit by joking that the world was about to fall out of my bottom!

Long may he live to enjoy the fruits of his labours. As I do.

David Fulford-Brown

DOCTORS are very busy people. Mr Thomas always took the time to ask me how I was. In the context of a medical consultation this had extra meaning. I feel he cared about the whole family and the impact on all of us of David having another operation or a reprise. His concern made life easier to bear.

Thank you, Mr Thomas, from all our family and friends, for the wonderful effect your operations have had on David. His independence is due to his freedom from worry about embarrassing personal accidents. This gift was due to your skill. We will all miss you.

Jenny Fulford-Brown (mother of David)

I HAD reached the age of 39 never having had a kidney check-up. I was still wetting the bed at night which often prevented me from holidaying in the places I wished to.

After an unsuccessful consultation in London, I was put in touch with Mr D G Thomas in Sheffield. He suggested I try intermittent catheterisation. Silver catheters kept me drier, but still not perfectly so.

My bowel cannot empty properly without help and was putting pressure on my bladder when full and was contributing to urinary tract infections.

Though a Cardiomed catheter had helped, it was not perfect. I was in my early 50s when Mr Thomas suggested the ACE – Antegrade Continence Enema – and he assisted a US-trained surgeon in this procedure.

The ACE has been the best thing for me. I am now dry so can sleep anywhere in the world without worrying. It has got rid of the terrible backache I had before, partly due to having a blocked bowel. My attendance at work is better; I am walking better and feel brighter. I can now go six months or more without a urinary tract infection. I try to stick to a high fibre diet and drink plenty.

The 45-minutes that has to be spent every other day to clear my bowel out is worth it.

I lead as near normal life as is possible and this is thanks to a wonderful consultant.

Christine Helliwell

Homing in on the sh

ONCE again, ASBAH's Fundraising Department headed for Blackpool for our major event of the year – *The Homing World Show of the Year* – to receive yet another magnificent cheque for £15,000.

The Royal Pigeon Racing Association remains ASBAH's biggest and most longstanding donor. At the last count, we had received almost £400,000 since 1973 when the first show took place in aid of ASBAH.

Year after year, punters revisit our tombola stall to spend their fortunes.

Even at a Homing Pigeon Show it proved lucky that our Adviser Anne Walton was on hand as some people wanted information and advice because of personal experience of spina bifida or hydrocephalus.

One generous supporter, Julie Todd, won our first prize, a DVD player, and then introduced us to her father, Brian, who has kindly volunteered to fundraise for ASBAH in the coming year.

● ***Photos (clockwise from top left):*** *two of the thousands of birds on display;* ***super volunteer Reg Walton, husband of ASBAH Adviser Anne Walton, busy in the background;*** *double prize winner Clive Taylor, of Derby, congratulated by ASBAH trusts and legacies officer Jane Ayres;* ***this cuddly prize was won by Angela Dix of Leeds;*** *money-grabbers Ian Morley, ASBAH fundraising assistant, and his partner Val;* ***big spender Julie Todd takes away our first prize, a DVD player;*** *the face of this young supporter says it all: 'It's mine!'*

ow of the year

Donna Treanor, ASBAH's fundraising manager, said: "We are indebted to Peter Bryant, the show manager, and all his team who organise the event each year. Long may its success continue."

Nicky's feel good factor

WITH a 10K under her belt, first-time wheelchair racer Nicky Quant has a lot to be proud of.

We, at ASBAH, are grateful to the native New Zealander for raising £285 for us when she completed the road race in Taunton last autumn.

Full of enthusiasm for life now, after years of depression, and recalling the 'high' she felt after her first road race, Nicky (30) has set her sights on another 10K in April.

Last time, her motivation soared by having a training partner, who she advertised for at her local gym in Taunton. She particularly liked working out on the rowing machine.

"The training made me stronger mentally. I'm much more confident and out-going," she said.

"Now I've done it once, I know I can do it again. I'd recommend training to anyone."

dates for your diary

Anything you can do!

YOUR Voice, ASBAH's Disabled Users' Working Group, is trying something completely different in its *Anything You Can Do!* weekend.

By the popular demand of members, the event will allow participants to try out a range of sports and activities.

Motorcycling, wheelchair tennis, T'ai Chi, aromatherapy, archery and sailing are just some of the activities expected to be on offer.

Mary King, Your Voice Steering Group chair, said: "We want to get people doing something they wouldn't normally do. This may involve getting them out of their wheelchair, or they may prefer to try something more relaxing.

"Just because you are in a wheelchair doesn't necessarily mean you can't do something. Above all, the aim is to have fun."

- ***For details of the event, on 19–21 April at The Marriot Hotel, Peterborough, contact Lyn Rylance on 01733-555988 or lynr@asbah.org***

Sharing and learning

SHARING experiences of school, work and leisure was a highlight of two separate days for parents with disabled children under five organised by ASBAH in Northern Ireland.

A Good Start also included advice from professionals.

A subsequent course, *Taking A Back Seat* – for parents of children aged five to 12 years – took place in February. The theme of the day was encouraging independence.

Upcoming events

Dunstable meeting

Monday 11 March

Meeting for parents/carers of children/young people with SB/H. South Bedfordshire Support Group. 1–3pm, Disability Resource Centre, Poynters Road, Dunstable. *Valerie Bottoms, tel: 01582-757745.*

ASBAH Weekend, N Ireland

23 – 24 March

Well Away! – challenge weekend for young people with SB/H. Ballinran, County Down. Funded by Right Fit – a Barnardo's/Glaxo Wellcome initiative. *N Ireland Regional Office, 028-9079 8878.*

Prejudice reduction, Lancs

16 March & 26 April

Award-winning workshops helping to eliminate prejudice and inter-group conflict. Organised by National Coalition Building Institute (NCBI). *Details: 0116-222-9977; info@ncbileic.org.uk*

Anything You Can Do!

19 – 21 April

Your Voice, ASBAH's Disabled Users' Working Group organise a weekend of challenging activities to try for people 18 and over who have SB/H. Wheelchair tennis, sailing, archery, T'ai Chi and others. Marriot Hotel, Peterborough. £50. Closing date for applications: **15 March 2002.** *Details: Lyn Rylance 01733-555988; lynr@asbah.org*

Dunstable meeting

Tuesday 16 April

Meeting for parents/carers of children/young people with SB/H. South Bedfordshire Support Group. 1–3pm, Disability Resource Centre, Poynters Road, Dunstable. *Valerie Bottoms, tel: 01582-757745.*

Prejudice reduction, Leics

Wednesday 17 April

For details see entry in March. *National Coalition Building Institute (NCBI), 0116-222-9977; info@ncbileic.org.uk*

Prejudice reduction, Lincs

Saturday 20 April

For details see entry in March. National Coalition Building Institute (NCBI), 0116-222-9977; info@ncbileic.org.uk

ASBAH Summer Experience, Cumbria

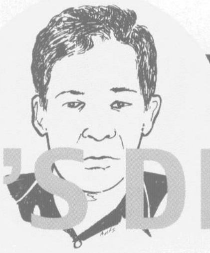
4 – 7 June

Four-day activity holiday for teenagers with spina bifida and/or hydrocephalus at the Kepplewray Centre, Cumbria. *Details: Joan Pheasant 0113-255 6767, joanp@asbah.org*

Children's Fun Day, Belfast

Saturday 8 June

M'Kinney Hall, Musgrave Park Hospital. *N Ireland Regional Office, 028-9079 8878.*



DAVE'S DIARY

david.fulford-brown@ntlworld.com

LATE last year my grand parents finally bit the bullet and moved out of their great big house and gardens into a flat. They've lived in that house for 15 or 20 years – most of my life. So I couldn't imagine them moving out. Neither could they. But eventually it was agreed that maintaining the big house was just too much work and they needed to bail out to somewhere more suitable while they could.

Mum has just bailed out too. She caught the family bug for going abroad and legged it to the US. I should have gone with her but work and other commitments put the boot into my holiday. That's the second holiday I've missed this year. My good friends Tanya and Stuart offered me a free holiday with them earlier this year, only for it to go pear-shaped at the last minute.

So I'm here, holiday-less and stuck looking after a foreign student, cat and assorted plants. So far all are still alive, but it has been a close thing. The cat is certainly living on borrowed time!

If looking after a cat is anything like a small child I will *never* have kids. I loath the cat and it hates me. Why else would it wait until just *after* every kitchen surface is polished and the carpet freshly hovered, to race in and leave filthy paw prints everywhere?

The cat's latest trick is to chuck up in the middle of the lounge just before my friends come round for dinner. So instead of looking relaxed, cool and trendy I'm down on all floors sponging up sick. Usually when they arrive Tan and Stu just have to cope with seeing me stumbling half-dressed out the shower because I've lost track of time. Sights like that can really put you off your take away!

I nearly choked on my Chinese when Tan casually announced she and Stu had finally got engaged. I thought they'd never do it. With Nick and Hannah about to go down the aisle as well it's like there's a bug going round. Hopefully I'm immune.

Still I hope married life works for Tan and Stu. They are two of the nicest people and best friends I've ever known and I wish them great joy and all the best. Now I'm ducking for cover.

Charges dropped

BLUE Badge holders everywhere will be entitled to a full discount on central London charges when a new scheme to cut congestion gets underway.

Now it's proposed that visitors as well as residents should benefit, but a yearly registration fee of £10 is still being planned.

It is likely that disabled people will have to phone or email the registration number of the vehicle they are using each time they enter the charging zone. This will mean that badge holders who don't drive but who use others' cars will still be eligible for charge exemption.

Access to leisure survey

LEISURE facilities and clubs are often inaccessible to disabled children and young people.

Contact-a-Family is conducting a leisure survey to help identify good and bad practices.

Pauline Shelley, national development manager, said: "We need as many parents as possible clamouring for better and more inclusive services."

Detailts from:* www.cafamily.org.uk/leisure.html *or email* pauline@cafamily.org.uk *or phone Pauline on 0207-608 8771.

Snap and win

FREEDOM in Focus 2002 is a competition for amateur disabled photographers, run by *Disability Now* and Leonard Cheshire.

Entrants who are 18 and over could win a digital camera and a week's holiday for two. Under-18s could win a digital camera and an afternoon on the London Eye with a professional photographer.

***Closing date: 29 April. Details: 020-7619 7319, email:* judith.reid@scope.org.uk, *or go to* www.disabilitynow.org.uk**

Got a strong opinion on any of the stories in *Link?* Email link@asbah.org now

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 Julie Parks, tel: 01273-472298.*

ISLE OF WIGHT ASBAH

Fully furnished and equipped, two-bedroom bungalow. Beautiful area. Wheelchair accessible. Site clubhouse, shop. Local indoor heated pool. Transport advisable. Excellent rates: offers early/late season. *Details: Mrs S Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF, tel: 01983-863658, www.iwasbah.co.uk*

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* (May) should be submitted by **Wedesday, 3 April.**

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

TORREVIEJA, SPAIN

Fully furnished wheelchair accessible 3-bed 2-bathroom apartment. Will sleep up to 8 people. Shops, town centre, medical unit, beach etc all within 10-minute walk. Quiet family location. Ideal for group holidays. Available all year. Rates are £250–£400 per week. *For further details/bookings, contact Julie on 0775-3684708 or Pete on 0780-3614770.*

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 & Elaine Foley, tel: 0191-488 6845, david_foley@lineone.net www.floridadream.sagenet.co.uk*

ORLANDO, FLORIDA

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

NAISH HOLIDAY VILLAGE-NEW MILTON

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

GRANGE COURT HOLIDAY VILLAGE

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

MILLENDREATH HOLIDAY VILLAGE

Excellent seaside site with good facilities, just outside Looe in Cornwall. Restaurant, clubhouse, indoor pool. Fully-equipped, and fully wheelchair accessible, two bedroom chalet accommodation. Sleeps six – well-furnished and comfortable. *Details: Mr P Cash, tel: 01425-672055, petercash1@compuserve.com Bournemouth Spina Bifida Association, registered charity number 261914.*

FOR SALE

ELECTRIC pavement vehicle, four-wheel, Star 4 Sunrise Medical, with battery charger and basket. 18 months old. Cost; £2,000: will consider offers. ***Tel: 0208-9851031 (Hackney, East London).***

CONTROLLER armchair, designed to support and improve upright sitting position. Reclining back, footrest. Seat width 12". Suit young disabled child up to 8 years. Free. ***01244-535402 (Deeside, North Wales).***

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Leicestershire
LE16 7JJ
Tel: 01858-432967

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LN6 9EX
Tel: 01522 778781

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Heckington
Sleaford
Lincs
Tel: 01529-460322 (after 6pm)

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37 Milton Road
Hanwell
London W7 1LQ
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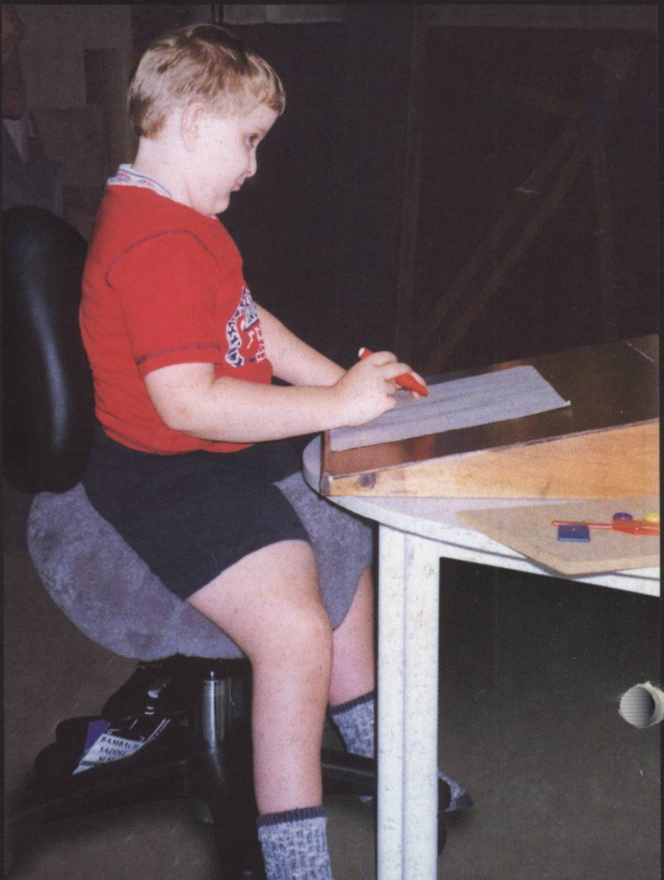
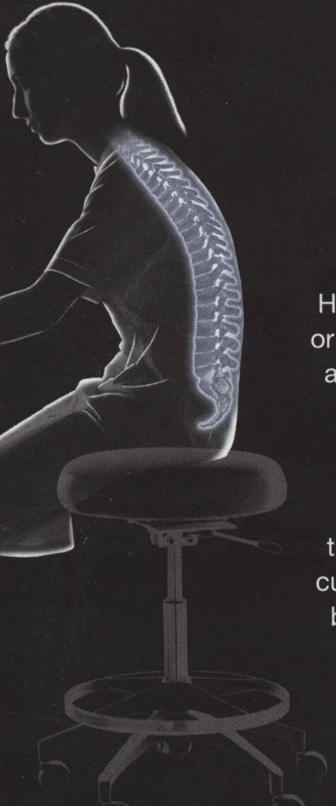
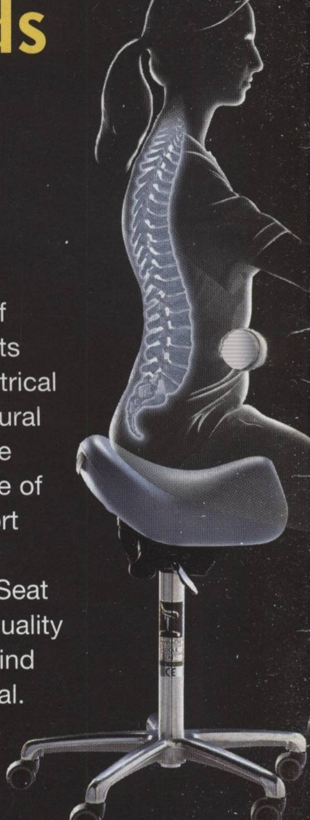




Posture Problems?

Special needs need a special seat



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