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The magazine for people with
Spina Bifida and/or Hydrocephalus

April/May 1997

Issue No 169 Price 80p

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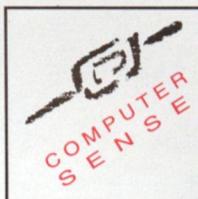
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THE NUMBER of women taking legal action against various health authorities after giving birth to children with abnormalities linked to an anti-convulsant drug has risen to more than 80.

A legal researcher involved in the cases described the action in *The Sunday Telegraph* as 'bigger than Thalidomide.'

The first case – involving 29-year-old Diane Walker of Wallasey in Merseyside – was due to start in April. Her solicitor, Nina Roland, was due to issue a writ against Wirral Health Authority for failing to warn Diane that by taking Epilim during pregnancy she was risking the health of her unborn child.

Miss Roland recently set up a new law partnership, Lindsay & Roland, in Poulton-le-Fylde, Lancashire, after moving from Liverpool-based lawyers Goldsmith and Williams. She told me: "Diane went with her fiance to a consultant prior to becoming pregnant to see if she could have children. The consultant's attitude was 'don't waste my time, there's nothing wrong with the drug' and told them to go away and have 26 children. They went away elated."

Sodium Valproate actions – 'bigger than Thalidomide'

by Liz Cawthorne

Diane, aged 29, continued to take anti-convulsant drugs tegretol and sodium valproate, sold as Epilim, before conceiving and during pregnancy. She did not learn that her unborn child had spina bifida until she was eight and a half months pregnant. John is now six years old.

Diane will be suing Wirral Health Authority for more than £500,000 – a figure which takes into account the costs of a carer when John's parents are no longer around.

Some of the claims against health authorities will top £1 million.

In Diane's case, Miss Roland is to serve a writ, along with medical evidence, in April, and in due course will get a defence. She

expects the health authority to deny liability, in which case she will then take the necessary procedural steps to go towards trial.

"We will proceed to trial unless there is a settlement," Miss Roland commented

Epilim is alleged to be the only anti-convulsant drug which can cause a foetus to have spina bifida and hydrocephalus if it is taken by the mother during pregnancy.

Another severe form of disablement claimed to be caused by the same drug is foetal valproate

continued on page 8

● Women with epilepsy should **never** stop taking anti-convulsant drugs if they are pregnant or are planning a pregnancy unless they have been advised to do so by a neurologist. Their GP can refer them to a neurologist, who is best qualified to assess whether the woman should stay on or come off the drugs.

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E-mail: postmaster@asbah.demon.co.uk Find us on the Web – <http://www.asbah.demon.co.uk/>

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Cover: Parents Therese and Tim Lawton are over the moon after winning more hours help in school for their five-year-old daughter Samantha. Full story on pages 7 & 8.

STAFF NEWS STAFF NEWS STAFF NEWS

● NORTHERN Region staff have moved temporarily into offices in the centre of Ilkley, West Yorkshire – pulling out of an overcrowded office in the Five Oaks activity centre.

The new address is:

**1 The Wells Walk, Ilkley,
West Yorkshire LS29 9LH.
Tel: 01943-609468;
fax: 01943-603013, (tel & fax
the same as before).**

This move will be temporary until permanent, wheelchair-friendly offices can be found in the area.

Northern Region co-ordinator and START manager, Joan Pheasant (pictured below), said: "As far as working conditions go, it's the light at the end of the tunnel."



Joan Pheasant

Joan's team, housing support workers, as well as Leeds and Bradford ASBAH – have been confined to a small office in an outbuilding at Five Oaks, since the main house and garden were sold to a private buyer last year.

The outbuilding now becomes the community centre for two blocks of flats for physically disabled people in the grounds of Five Oaks, which are owned by Sanctuary Housing Association but managed by ASBAH. Bradford Social Services is also a partner in the housing scheme.

ASBAH still keeps three housing scheme support staff at Five Oaks.

TWO project officers have been appointed in Wales to improve and develop ASBAH's links with local authorities, local associations and services users. The 15-hour-a-week posts will be funded over two years by Comic Relief. Both post-holders started on 17 March.



● JILL BARTLETT will be project worker for North and Mid Wales, based at her home in Felinheli, Gwynedd.

The mother-of two previously worked for an education authority integrating wheelchair users into mainstream schools in the area. The youngsters had a range of disabilities such as spina bifida, muscular dystrophy and cerebral palsy, and were aged up to 16 years. She had been working with some of the youngsters since they were three years old, when she was based at an assessment centre.

Jill started out as a qualified nursery nurse and for some years worked as a physio aid at a child development centre.

● CAROLYN JONES, of Penylan, Cardiff, will be project worker for South and West Wales.

For six years, Carolyn taught English, Welsh and education at further education colleges. She has also taught children with special educational needs.

Carolyn, who has a 17-year-old daughter, said: "The job with ASBAH appealed to me as I liked the independence, the travelling around and meeting people, and making contacts."

While working in community education, Carolyn was very aware of the lack of input from disabled people, so she is very interested in this aspect of the post.



● LIZ HENSHALL has taken up a newly created part-time post with ASBAH – area adviser for Staffordshire and Wolverhampton.

The job was created after area adviser Elizabeth Lawlor lost Staffordshire as part of her patch due to moving house. The new

post will be funded from savings made on the salary of Mary White, who left last year.

Before joining ASBAH, Liz was a senior paediatric nurse at Burton-on-Trent. She trained in Birmingham, at the same time studying for a teaching and assessing certificate.

"I am looking forward to the challenge of this new job. I was ready to do something different and have always been interested in community work – the environment is so different from hospitals," said Liz, who has a little boy, Joseph, aged one, and lives in Cheadle.



Emotional and sexual needs discussed

YOUNG disabled adults in Leeds and Bradford were given the freedom to discuss their emotional and sexual needs at a study day.

They listened to talks on social attitudes and their rights, and took part in workshops on forming and nurturing relationships, parenting, contraception and sexual infections and continence.

Relationships, Sex and You was held at the William Merritt Disabled Living Centre, St Mary's Hospital in Leeds.

Joan Pheasant, ASBAH Northern Region co-ordinator, said: "Disabled people have as much right to form relationships and have sex as every other adult.

"Contrary to a considerable body of able-bodied prejudice, use of crutches and wheelchairs does not disqualify people from having sexual relationships nor turn them into asexual beings. They have as much to offer to a relationship, and in many cases the same needs, as any other person."

The day was organised by ASBAH with the Young Adult Team at St Mary's Hospital and Project 16-30, run by Bradford Social Services physical disabilities team.

A FIRST-TIME lucky strike on the lottery has enabled Bournemouth and District ASBAH to boost the level of wheelchair-friendly holiday accommodation available in the South-West.

An award of £18,800 from the National Lottery Charity Board will be spent on installing a purpose-built mobile home, capable of sleeping up to six people, at Goodrington Sands, Devon.

The new holiday let – at Grange Court Holiday Village – should be ready by the end of May.

"There is a great demand from people in wheelchairs for

Bournemouth strikes it lucky

problem-free places to stay. We are having this mobile home specially built to meet it," said association secretary Mrs Gill Lanning.

Bournemouth ASBAH already has a 20-year-old chalet for holiday hire at a holiday village near Looe in Cornwall and a log cabin at New Milton, Hampshire.

● See page 27 for details of all three holiday homes.

Take off with *Lift* this spring

LIFT, ASBAH's free magazine for 13-30-year-olds, takes off with a new look and new contents next month (May).

Things to look forward to include:

- the pros and cons of getting a place of your own;
- staying healthy as you get older;
- a 'get real' consumer column;
- an 'overseas view' of what it is like having spina bifida and/or hydrocephalus abroad;

○ an honest look at the success (or otherwise) of readers' holidays.

All this plus old favourites like pen pals, letters and news of people like you with interesting stories to tell.

Order your copy of *Lift* (four issues a year) by sending your name, age, address and phone number to: *Lyn Thomas, Services Dept, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.*

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Music shop gives points for ASBAH



An enterprising brother and sister, who run their own music shop, are donating money from a customer points scheme to ASBAH.

more obscure catalogues, right round the world. This is real customer service."

Tim and Drusilla set up the business with dad Brian, a member of the ASBAH executive committee, when they were looking for work they could get their teeth into. Tim had a job he hated in a supermarket while

Drusilla, who uses a wheelchair, was out of work – having just been let go by West Mercia Police.

The family snapped up the Malvern shop and started selling all types of music. With just three other generalist stores in the small town selling CDs and tapes, and a ready market for a more enterprising music culture from well-heeled pupils at three top-of-the-range independent schools in the locality, the Henleys have been kept busy since.

IME Counterpoint now has five staff on the payroll and opens seven days a week, including noon to 5pm on Sundays. Its accreditation points to a range of eclectic marketing abilities. It has become a blue riband classical dealer for Gramophone magazine; it is a Network Dealership shop, good at finding lesser-known pop and indie music.

"Just today, we had to find an Ella Fitzgerald track *Please Help Me*, a Beatles cover-version only on one album. We found the album. It was in stock," said Tim.

IME Counterpoint's Counter Action Points (CAP) scheme to benefit ASBAH works like this. In addition, the firm is offering some special deals for ASBAH customers. When ordering, just tell them you want CAP points to be credited to ASBAH.

Details of the scheme

Place your order for any type of order, in any format, with IME Counterpoint, and say you're with ASBAH. When IME fulfil the order, they will allocate five Counter Action Points worth a penny each for every £ spent.

At intervals during the years, the total points allocated will be added up and a cheque sent to ASBAH. Customers will receive a quarterly newsletter about new releases. IME will even gift wrap the music and enclose a message on payment of an extra £1. Gift vouchers are available.

There will be a 10% discount and free delivery on orders over £29.99.

**IME Counterpoint, Unit 1,
32 Church Street, Malvern,
Worcestershire WR14 2AZ.
Tel: 01684-561860
Fax: 01684-577563. e-mail:
musicshop@enterprise.net.**

"An unusual request recently was from a blind girl who lives in Malvern, and is a *Queen* fanatic. She had brought a boxed set, £350-worth of CDs, every album they ever did, but could not identify the box because the embossed emblem on it had bubbled up. We found her a new emblem.

"And another customer wanted to check whether a Bon Jovi CD on sale in this country was identical to the same title on sale in America. We went into the Internet and found an American CD store listing. The contents were just the same."

A SPECIALIST music shop, which has a 'we find it, so long as it is in print' motto, has launched a special donations scheme for ASBAH.

For every pound spent by an ASBAH customer, IME Counterpoint in Malvern, Worcestershire, will donate five Counter Action Points worth five pence. On a full-price CD, they will tot up to around 65 points.

At intervals during the year, partners Tim and Drusilla Henley will scoop up all the points, convert them into cash and write out a cheque to ASBAH.

Taking orders by mail, phone, fax and Internet, IME Counterpoint believes the world is their – and ASBAH's – oyster.

"Unlike the Virgin and HMV stores, we can find 99.9% of anything in any format, so long as it is still available," said Tim, who started the business with his sister over three years ago.

"We use lots of information sources and, since the advent of the Internet, we can access the

Parents win extra hours school help for Samantha

by Liz Cawthorne

PARENTS Therese and Tim Lawton have won a battle for their five-year-old daughter to receive more hours help at school.

A Special Educational Needs Tribunal ruled that Samantha, who has severe mobility problems, should be given an additional five hours a week help from a personal welfare assistant.

Samantha started at St Elizabeth's RC School in Coton Green, Tamworth, Staffordshire, last September.

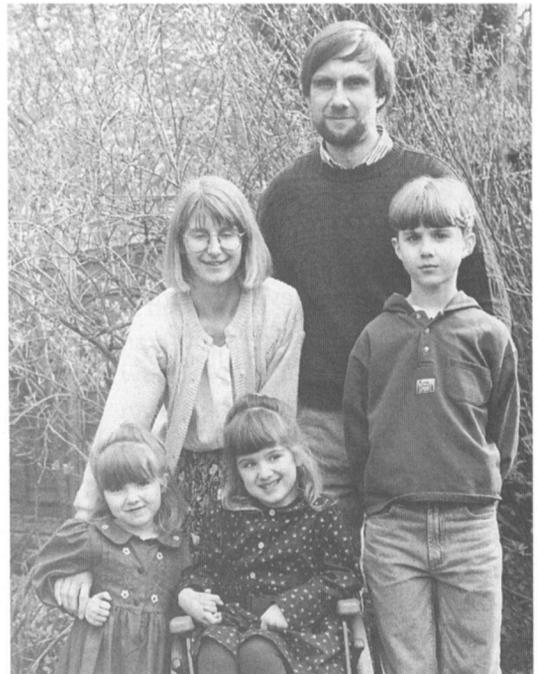
After a lot of meetings and pushing, her parents secured 20 hours a week help from a personal welfare assistant, but they believed this really needed to be full-time.

The local education authority (LEA) argued that if Samantha needed full-time help she should go to a special school.

Mrs Lawton said: "We didn't agree as we knew a lot of children like Samantha who are coping very well in mainstream school.

"Samantha already knew the school because she used to go there with me to pick up her brothers. All her friends were there. It was her community."

In addition to this, St Elizabeth's had put in ramps and changing facilities for Samantha ready for her arrival, and the pupils



Therese and Tim Lawton with Samantha (centre), sister Kathryn (3) and brother Christopher (10)

accepted her because they had been given a talk on what it is like to have spina bifida by ASBAH area adviser Jenny Green.

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Help & Advice

Members seeking help and advice on any matters should make initial contact with ASBAH as follows:

London, Surrey, Kent, West and East Sussex

ASBAH South East, 123 East Barnet Road, New Barnet, Herts EN4 8RF.
Tel: (0181) 449 0475. Regional Co-ordinator: Jo Francis.

Lincolnshire, Cambridgeshire, Leicestershire, Nottinghamshire, Northamptonshire, Norfolk, Suffolk, Essex, Hertfordshire, Bedfordshire

ASBAH East, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.
Tel (01733) 555988. Regional Co-ordinator: Mary Malcolm.

Northern Ireland

ASBAH Northern Ireland, 73 New Row, Coleraine, Northern Ireland BT52 1EJ. Tel: (01265) 51522 Regional Co-ordinator: Margaret Young.

Northumberland, Durham, Cleveland, North Yorkshire, South Yorkshire, West Yorkshire, Tyne & Wear, Humberside

ASBAH North, 1 The Wells Walk, Ilkley, West Yorkshire LS29 9LH.
Tel: (01943) 609468. Regional Co-ordinator: Joan Pheasant NNC.

Rest of England and Wales

ASBAH National Centre, 42 Park Road, Peterborough PE1 2UQ.
Tel: (01733) 555988

ASBAH welcomes and appreciates the support of its commercial partners.

Larkhall Natural Health gives us 10p from the sale of each container of Cantassium Folic Acid tablets. These can be obtained in chemists and health food shops.

AlphaMed Ltd makes a donation for every prescription order received, as a result of ASBAH's introduction, for continence and medical equipment supplies. Tel services floor, 01733-555988, for introductory Freepost envelope. Prescriptions for drugs or medicines should not be sent to AlphaMed.

Parents win extra hours school help for Samantha

from page 7

When Samantha's Statement was issued, the LEA said 20 hours a week was enough to cater for Samantha's needs – even though she had received full-time help from her assistant Jane Tulley at nursery school.

Samantha cannot use her full-length callipers and needs help standing up and sitting down. She is still learning to use a walker which she uses with her callipers in the classroom. She needs help getting into her wheelchair at play-time, lunch-time and hall assembly. She needs help changing for PE and getting items in and out of her bag. She needs help with catheterisation twice a day. She still wears a nappy which, if it becomes soiled, has to be changed.

Her parents applied to the LEA for full-time help (32 and a half hours a week, including lunch-times). When this was refused, they appealed to the Special Educational Needs Tribunal.

At the time of the tribunal (February) Samantha was very ill in hospital with a serious infection – contracted following a minor operation – so neither parent was feeling on top form.

"It was hard work," commented Mrs Lawton. "A few weeks before the tribunal, with Samantha being

Sodium Valproate actions – 'bigger than Thalidomide'

from page 3

syndrome – typified by a wide-bridged nose, wide forehead, mental retardation and difficulties with movement. Congenital heart defects are also linked to the drug.

About one quarter of the 80-plus cases Miss Roland is dealing with affect children with spina bifida and hydrocephalus. In one or two of these cases, the babies were so severely disabled, they died shortly after birth.

Some of the children have been harmed by the drug in more minor ways, for example, cleft palate and hare lip.

Cases which have come to light occur in all parts of the country – for example, Devon, Newcastle, London, Lancashire and the Cotswolds. The oldest child in a case is 15; the youngest is just a few months old.

Miss Roland said: "We will be issuing writs individually at first but at a later stage in proceedings we may bring them all together."

ill, I was very panicky and wanted to call the whole thing off, but like every parent you do what you have to do for what's best for your child."

So they were pleasantly surprised when they later heard that the personal welfare assistant's weekly hours would go up from 20 to 25.

Mrs Lawton, who has also appeared on BBC TV's *Trust Me, I'm a Doctor!* in support of a campaign for folic acid to be put into flour, said: "We were happy with the extra five hours. Although it doesn't seem much, when you are juggling hours and where best to use them, an extra hour a day makes all the difference."

She added: "It was only going to a

hospital outside the community that I learnt from other parents what is available in other areas. We believe Samantha is receiving the most hours for personal welfare assistant's help in the whole of Staffordshire.

"Perhaps the LEA will re-think its policy and not just say children with severe problems should go to special schools, if the parents don't want to take that pathway. I think parents should know what's available and have a choice."

For the hour and a half a day when Samantha receives no help from Mrs Tulley, she spends half an hour having lunch, and the remaining hour is covered by a general classroom assistant.

Food fortification with folic acid – more benefits than risks, say USA researchers

THE BENEFITS of fortifying food with folic acid greatly outweigh the expected risks, researchers in the USA have found. But they say more research is needed, including studies into the clinical effects of vitamin B12 deficiency.

In the USA, flour is to be fortified with 140mcg folic acid

per 100g of cereal grain product over the next few years in an attempt to prevent neural tube defects.

Concerns about fortification include the possibility that high intakes may mask the haematologic effects of vitamin B12 deficiency, resulting in neuropsychiatric damage, or that high intakes may

trigger neurological symptoms in older people.

Increased folate intake is associated with reduced homocysteine, which is linked to reduced incidence of heart disease events and strokes.

● *The above is taken from an article which appeared in Nursing Times, January 8, 1997*

▲ Contenance supplies campaign ▲

A CO-ORDINATED campaign which seeks to improve on the delivery of NHS continence management treatment and supplies to people with spina bifida and hydrocephalus is being developed by staff at ASBAH.

Readers are invited to take part in it by filling in and returning the form on this page. Just let us know if you want to discuss a problem; we can find out the details when our nearest specialist adviser contacts you.

"Design of services is confused and delivery is patchy. And many of our service-users have no clear idea of the standards of service which they can expect," said ASBAH executive director Andrew Russell.

"The situation is further aggravated because central government seems not be giving a lead on minimum standards – leaving questions on the design, delivery and control of services to be settled locally.

"In 1997, national ASBAH will be carrying out research to find out how difficult things can be for many of our service-users, and following this up with ideas for improvement. We shall pursue individual complaints and also be prepared to publicise examples of good practice, as we find them.

"We shall certainly want to raise the profile of continence issues among MPs, both before and after the General Election. And – if we get no satisfaction from the NHS Trusts which provide the continence services – we shall take up individual issues with the district health authorities, who buy them."

ASBAH's continence campaign will have a number of aims:

- ▲ To find out what clients can expect as a 'right' or at least an accepted quality standard of

service, equipment and supplies;

- ▲ To find out more about what's happening to our service-users;
- ▲ To provide an action guide for users/members, informing people of their reasonable rights and expectations and how to press to have their needs met;
- ▲ To increase advocacy for clients in cases of poor service;
- ▲ To issue ASBAH guidance/information to professionals, in order to emphasise good practice;

- ▲ To lobby government and the NHS to improve consistency and demands.

A number of similar initiatives have started in this area with which we shall be involved. These most notably involve The Continence Foundation and the Association for Continence Advice.

But ASBAH intends to pursue its campaign separately so that as high a profile as possible is given to the requirements of people with spina bifida and/or hydrocephalus, and their carers.

Turn over the page to find out who is your nearest ASBAH specialist adviser (medical/continence)



Continence Supplies

Yes, I want to tell you about my problems in this area.

Name _____

Address _____

Postcode _____

Phone number (day-time) _____

Best day of the week to contact me _____

When completed, please cut out or photocopy this form and send it to:

**Mrs Julie Llewelyn,
 Services Dept, ASBAH House,
 42 Park Road,
 Peterborough PE1 2UQ.**



▲ **ASBAH'S
SPECIALIST
ADVISERS
(MEDICAL/
CONTINENCE)**



CAROLINE Berkley works full-time for ASBAH South East Region, including London.

She attends the Adult Spina Bifida and Hydrocephalus Clinic at the Chelsea and Westminster Hospital once or twice a month.

Caroline answers questions over the phone and does home visits.

Queries often relate to continence or hydrocephalus (what it is and how it might affect someone), and post termination of pregnancies.



JULIE Llewelyn works full-time for Eastern Region and national ASBAH.

She has a lot of involvement with teaching children to catheterise and has a special interest in bowel management and faecal incontinence.

As well as telephone work and home visits, she attends a clinic at Addenbrooke's Hospital in Cambridge and a neurosurgical clinic at Lincoln, covering all aspects of medical care concerned with spina bifida and/or hydrocephalus.

She is also a member of the national Special Interest Group in Paediatric Urology, which meets four times a year.



GERALDINE Potuszynskij covers Northern Region.

Her patch includes Liverpool,

Lancashire, Manchester, South Yorkshire, North Yorkshire, Cumbria, Northumberland and Tyne & Wear.

Most of Geraldine's work is done through hospital and home visits and joint visits with other area advisers. She also answers enquiries over the phone.

She attends the Joint Spina Bifida Clinic at Leeds, Clarendon Wing, once every three months, with a paediatrician and a urologist. From April, she will also be attending a Paediatric Neurology Clinic in the Clarendon Wing.

At these clinics, Geraldine says, she is often raising awareness among parents about ASBAH.

She is also happy to attend clinics on an individual basis for those who are nervous or in need of some support.



MARIE McGonnell covers Northern Ireland part-time.

Most of her workload is continence-related. She does a lot of home/school visits, some phone work and attends clinics.

She says: "The most common questions I get asked are about other types of pads/washable products, catheters, bed protection, cause of incontinence and spina bifida."

Marie attends the Adult Spina Bifida Clinic at Musgrave Park Hospital on the third Tuesday of every month with Dr McCann and Mr Louchridge. The area adviser, an occupational therapist and wheelchair technician also attend.



PAULA Thompson works part-time at ASBAH national centre, answering telephone enquiries from the whole of England and Wales.

Paula is currently collecting information on eating disorders in children with hydrocephalus as young as three years old.

ASBAH has signed up to support this year's **National Continence Day** on 3 June – with the help of £40,000-worth of funding for publicity material from the Department of Health.

The event will draw attention to the problem of incontinence which, according to The Continence Foundation, affects over three million adults in the UK but which few people are prepared to talk about, admit to or seek help for.

Foundation director David Pollock says that about 80% of problems can be cured and much help offered to other people.

Continence Day will contain a media event in London involving a sports or television personality at a well-known fitness club or gymnasium. Mrs Yvonne Moores, chief nursing officer at the Department of Health, will also lend her support.

Other events will be organised round the country with the assistance of local exercise instructors and continence services, so as to provide 'pegs' for press coverage.

In the longer-term, the Continence Foundation is hoping to increase its impact by employing a publicity officer. An application for funding to cover the costs of the post has been made to the Department of Health.

Publicity materials from: The Continence Foundation, tel: 0171-404 6875.



In the driving seat

Glenys Jones has realised her ambition to learn to drive and is now taking lessons with BSM instructor Alan Garland

THANKS to her sheer determination and a little help from ASBAH, Glenys Jones has helped to get a specialist driving programme for people with disabilities into gear.

Glenys, aged 37 and from Llanfairfechan, near Bangor, was keen to learn to drive to become more independent, but was unable to find someone to teach her.

So she wrote to her MP and the letter was passed to the North Wales Assessment Centre in Llandudno which, in turn, asked BSM for help. BSM had been planning to expand its mobility training scheme into north and mid Wales due to an increase in demand for the programme.

BSM Mobility caters for the special needs of people with disabilities. It helps many people who are unaware they can learn to drive and who don't have access to specialist training or adapted cars.

"Glenys really set the ball rolling because we began to receive enquiries from disabled people from all over north Wales who were really keen to learn to drive and needed our help," said Steve Blackburn, manager of BSM's Chester branch.

"In view of this demand, we were

able to bring in another tuition vehicle and instructor Alan Garland was immediately faced with quite a lengthy waiting list. BSM Mobility is proving extremely popular."

Glenys, who received an ASBAH grant towards her driving tuition, was disappointed when she could not find anyone locally who could cater for her particular needs. "There is such a large community of elderly and disabled people who live on the coast, I decided I had to try and do something, and I was delighted when BSM responded so quickly to the challenge," said Glenys.

Elin Richards, ASBAH area adviser, explained that ASBAH aims to help young people to be as independent as possible and that driving is often the key to this, especially for those with very little mobility. She said: "We always ensure that people who apply to us for help are assessed and we receive confirmation that they are capable of driving before we offer a grant."

BSM instructor Alan Garland now operates in an area including Llandudno, Caernarfon, Bangor, Holyhead, Porthmadog and Bala and is currently teaching around 15 people with disabilities.

The BSM tuition car is a dual-controlled Vauxhall Corsa with an automatic gearbox, power steering and seat height adjuster, and is equipped with a range of adaptations to cater for all kinds of disability, from spina bifida to cerebral palsy and the requirements of arthritis and stroke victims. These specialist controls include a steering ball, an accelerator pedal which can be moved for left foot operation, and hand levers which activate the brake/accelerator.

"It is essential that we work with each student to gain their confidence and by understanding their particular needs, we can structure lessons accordingly," explained Alan.

"The only adaption Glenys needs is an accelerator for left foot operation, but we always advise students on equipment which will make life easier for them. A panoramic rear view mirror for example provides increased vision for students with limited upper body movement who experience difficulty carrying out reversing manoeuvres," he added.

Further information on the BSM Mobility programme from Steve Blackburn on 01244-321170 or BSM's national Mobility helpline on 0181-545 1390.

Could this vitamin close the gap left by folic acid?

by Liz Cawthorne

RESEARCHERS have discovered another B complex vitamin which shows signs of preventing the 30% of neural tube defects not affected by folic acid.

A three-year study at the Institute of Child Health in London has shown that spina bifida in a strain of mice, not affected by supplements of folic acid, is prevented by large doses of inositol.

Andrew Copp, professor of developmental neurobiology, is cautiously optimistic about the implications for humans. He told *Link*: "Until we test it on humans, we won't know whether inositol is as effective in preventing certain types of spina bifida as it is in mice but we hope it will be.

"Our trials on mice have shown that we can divide spina bifida cases into those which respond to folic acid and those which do not. We have found that some of the mice which don't respond to folic acid, do respond to inositol."

However, said Professor Copp, who is carrying out the work with Dr Nicholas Greene, more trials are needed with mice and then humans before inositol can be considered suitable for humans.

Further detailed information is needed, for example, on the size of dose and the best way to give it – for instance, by mouth or by injection.

Other questions still to be answered include the best time in pregnancy to give the vitamin and whether other abnormalities are caused by large doses. A trial of inositol used on psychiatric

patients in Israel produced no side effects.

The experiments by Professor Copp and Dr Greene have also shown that spina bifida is not caused by a vitamin deficiency.

"Spina bifida can affect any part of the spine and we think each type of defect is caused by a different gene.

"When large amounts of folic acid or inositol are given, a bio-chemical pathway is opened which bypasses the genes usually causing the defect, so allowing the embryo to develop normally.

"We need to know how the vitamin is acting by working out its biochemical pathway. Currently, we do not even have this information for folic acid."

Once all these questions are answered, a human trial will be needed to evaluate the effectiveness of inositol. Such a trial would

have to involve a number of centres up and down the country with the participation of a large number of women who are at high risk of having a child with spina bifida and who are planning a pregnancy.

Professor Copp explained: "We would need to conduct a randomised trial in which some of the women take folic acid and some take both folic acid and inositol. This would have to be approved by ethics committees in the participating hospitals."

If a trial gets off the ground, it will be several years before it is known whether taking inositol is a way of preventing spina bifida in humans.

Inositol is a water-soluble vitamin found in most foods. However, the amounts in the average diet are substantially lower than the doses that prevented spina bifida in mice.

Professor Copp said: "In mice we have found that 10 times the amount of inositol is needed than is taken in the normal diet. This would mean humans would need a daily intake of 10-20g, so it would have to be taken as a supplement."

Editor's note: Please remember that the study involving mice described above is very much at the experimental stage and that inositol has not been approved for administration to humans to help prevent spina bifida. The use of folic acid supplements before conception and for the first three months of pregnancy remains the most effective strategy in the prevention of spina bifida and related neural tube defects.

Disabled drivers' group offers new membership

DRIVERS can now enjoy the benefits of being a member of the Disabled Motorists Federation wherever they live.

Until now membership was available only through local groups which meant that, in many areas, drivers with disabilities were 'missing out' since there was no club in their area.

As a member you have access to

what is claimed to be the largest database on mobility products in Europe. There is advice on 'best buys' and free, unlimited use of the award-winning route planning system, RAMP – taking the worry out of longer journeys.

The Disabled Motorists Federation, National Mobility Centre, Unit 2a Atcham Estate, Shrewsbury SY4 4UG. Tel: 01734-761889; fax: 01743-761149.

Darke looks at the media



In my new style column I will comment upon disability in a variety of cultural forms and media; thus, in this column, I ask: soap operas: where are the disabled?

With impairment being so prevalent in society – 1 in 8 people have one – you would think the most obvious place where disabled people would be represented is in the 'realistic' soaps on all four, now five, terrestrial television stations. It is not! There are a few exceptions: *Emmerdale*, *Coronation Street* and in past and present *Brookside*. Some of the Australian soaps have had some of their central characters become disabled and then overcome it, but they have not had any long-term and significant characters who are impaired.

The reasons for such an omission are varied (ratings worries; impairments seen as 'too' depressing; no disabled writers of soaps; ignorance; etc) and somewhat inexplicable as disabled people are real and easy to include either realistically or as dramatic devices in the soap opera format.

The legacy of Sandy in *Crossroads* may be of significance. The 'naffness' of his character in that classic soap has meant that those which followed have been frightened off due to the potential linking of a new wheelchair-using character in a soap opera with Sandy's char-

acter. Thus the old lady in an electric wheelchair in *Coronation Street* is as far from Sandy in representation as one can get. This character I do find troubling as she must be the only wheelchair-user in the world to be problem-free – there seem to be no access, attitudinal or community barriers in her life (unlike ours). *Coronation Street* must be a disability utopia. This is a dangerous representation as it ignores the reality of wheelchair-using whilst appearing to be realistic.

A similar characterisation occurs with Chris Tate's character in *Emmerdale*, but here at least his bitter, frustrated and evil nature is in no way placed upon his impairment as he was a 'little shit' even before he became a wheelchair-user. The only problem here is that people who have switched on to the soap more recently – after his disablement – may presume it is his impairment that is the reason for his character. Even so, I do like this character as it is at least consistent with his previous characterisation. Equally, in *Emmerdale*, the learning-disabled Dingle brother, Zac, is problematic in that his 'stupidity' is a caricature of a learning disability in the worst manner possible. By the way, has the actor playing this part changed, or has a new character been introduced who is less of a caricature? Please write in and tell me.

When the Farnhams had a child with Down's Syndrome in *Brookside*,

I had hoped for a more fruitful and realistic, long-term exploration of having a child with such an impairment. But it was not to be. Stereotypically, the family broke down and the child with Down's Syndrome disappeared from the soap – though, I am told, the real baby is in an integrated nursery and extremely happy and well. I had hoped for more from *Brookside*. Hopefully, the arthritic future mother-in-law of Mick will be a longer term character and used more effectively and realistically – dealing with both her social disablement and her physical impairment.

Whatever the case, what I would hope, and argue, for is a wider variety of disabled characters on all soaps. Our exclusion from 'realistic' soaps damages disabled people by making them seem to be unique when, in fact, we are an everyday part of society. Equally, soaps should play a key role in dispelling the myth that not all disabled people use wheelchairs and that not all those with specific impairments are the same; they should start with people with spina bifida and/or hydrocephalus.

NEWS IN BRIEF NEWS IN BRIEF NEWS IN BRIEF NEWS IN BRIEF

● FAMILIES who have been affected by Lipomyelomeningocele or Tethered Cord Syndrome may be interested to know about a network working to unite them.

For further information contact:
Lipomyelomeningocele Family Support Network, c/o Chris McAfee, 321 Hopewell St, Birdsboro, PA 19508, USA.

● A SEVEN-month-old baby, not a million miles from St Helens, was prescribed corrective footwear. A boot duly arrived. On enquiring as to where its pair was, the baby's mother was informed that, because of cutbacks, non-walkers were given only one shoe! On trips out, she is now fending off legions of concerned passers-by pointing out that her baby has lost a shoe

● DO you have an artificial hip or knee or other joint? Are you using CAPD (continuous ambulatory peritoneal dialysis)?

If you can answer 'yes' to either question, please contact Rosemary Batchelor at ASBAH House, giving details. Please add information on whether you have spina bifida and/or hydrocephalus, and what type of shunt (if any) you have.



PHOTO COURTESY OF BRISTOL OBSERVER

MEET Bristol couple Paul and Kathleen Bennett (*pictured above*), who raised £1,934.36 for ASBAH in a collecting box campaign in their home city of Bristol at Christmas.

Noted local charity fundraiser Paul gave up hours of his

precious time to shake a tin in North Street and then outside Sainsbury's in Winterstoke Road – while wearing the Santa outfit presented to him by Noel Edmonds on his Christmas Day television show a couple of years ago.

"Every year, we raise money for a different children's charity because, 11 years ago, I had a stillborn baby and we have never been successful since. This is our way of celebrating Christmas," said 48-year-old Kathleen from the couple's home in Agate Street, Bedminster, Bristol.

Paul, who has received a medal from the city's Lord Mayor for his charity fundraising, works as a van driver for a local electrical supplies firm and first heard about ASBAH from one of his customers.

So far, they have collected over £10,000 for various charities, with the ASBAH total representing their personal best collection.

The money was presented to ASBAH adviser Julie Knight in February at the Sainsbury store where Kathleen works.



Left to right: M... corporate affairs

Fabulous fun

HIGH winds buffeted six students from Ilkley College, West Yorkshire, as they paddled 180 miles along the canals to Birmingham in mid-February to raise money for ASBAH and a Marie Curie centre.

They were heading for the International Canoe Exhibition at the NEC after setting off from

the Leeds-Liverpool Canal at Silsden.

Team member, 21-year-old Darren Edmondson, said the weather had been far worse than expected. "The wind was going in the opposite direction for much of the time, and we even had to get out at one point and walk along the towpath because

we couldn't paddle against the wind."

In three teams of two, they took it in turns to travel 13 miles along canal routes which took them through Manchester, Chorley, Macclesfield and finally to Birmingham.

Part proceeds from the college

students' Rag W... will go towards... Bradford ASBAH canoe trip moved territory, the intr... decided national... should benefit fr

Blanche notches up 28 years

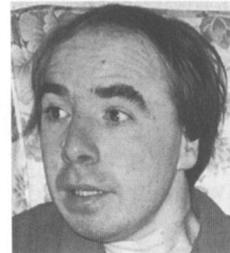
BLANCHE Little, whose 30-year-old son's hydrocephalus has left him with severe learning difficulties and unable to talk, has been fundraising for ASBAH for 28 years, selling hand-knitted goods.

Last September she sent us £370, then £150 in February and another £41 in March. She sells baby clothes, tea cosies and dolls clothes on a stall every week at a church hall. A monthly raffle makes £30 or £40.

Every August Bank Holiday, the family have a stall at a Donkey Derby organised in their home town of Bexley in Kent.

Mrs Little said: "It's hard work selling as people will only pay a few pounds for hand-knitted things even though they're much better than what you buy in the shops. I do it because I just like knitting."

Keith, a keen Charlton supporter, goes out three mornings a week with home support and



Keith Little

attends a local day centre three afternoons. "He understands what you say and enjoys TV, but can only say a few words. We've got used to it – he's always been like that," said Mrs Little.



£27,800 in a year!



Marion Daly and Lesley Welsh (News International advertising), News International director of Jane Reed, ASBAH appeals manager Donna Treanor, presshall supervisor Steve Baker with son Thomas and wife Sarah, and Kathleen Herron from The Sunday Times

AN INCREDIBLE £27,800 was raised by News International in one year – topping even our most optimistic expectations.

Half the amount was raised by staff in various fundraising events and a Give As You Earn scheme. This figure was then doubled by a pound-for-pound donation by the company which publishes *The Sun*, *The Times*, *Sunday Times* and *News of the World*.

The marvellous result came about thanks to Steve and Sarah Baker who nominated ASBAH as the News International Staff Charity of the Year for 1996. They gave a moving account of how ASBAH had helped them to the News International Employee Consultative Council sub-committee, which selects the Staff Charity of the Year.

Sarah and Steve had been forced to make the painful decision of terminating a pregnancy affected by a neural tube defect. Before speaking to ASBAH, they had been given conflicting information on the chances of them having another child with spina bifida.

The couple, from Eastleigh in Hampshire, say nominating and fundraising for ASBAH has been good experience for both of them. "We felt we were doing something positive after what seemed like a very negative experience," said Steve.

Sarah added: "The money will be going towards research which will lessen the chances of what happened to us happening to other families."

ASBAH appeals manager Donna Treanor said: "When I heard the amount I nearly fell off my chair. It is a tremendous figure and we are incredibly grateful to News International and all the staff who contributed."

ndraisers!

Week this year
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from this.

AS a charity, ASBAH relies almost entirely on voluntary contributions from the public. So the fundraising initiatives of individuals are very important to us. Here are a few recent examples of people who have helped us by raising funds.

Little boy is the spur

THE determination of a little boy with spina bifida was the spur to make Craig Bickles realise an ambition and jump out of a plane for ASBAH.

Craig raised £1,519 when he completed a 15,000 feet free fall and he's now persuaded work colleagues at money brokers Martins UK Ltd to dedicate all their sponsorship money to ASBAH when they tackle a 14-mile assault course next year.

"ASBAH is a charity very close to my heart as my 18-month old nephew Harry has spina bifida.

He is a very determined little chap. Although he has no feeling in his legs, he is now attempting to walk," said Craig, from Hornchurch in Essex.

ASBAH was a great help to parents Graham and Natalie Blyth when Harry was born. He had an operation last year to close the lesion in his back at Great Ormond Street Hospital, and has splints to correct his feet which turn outwards. Natalie, of Rush Green, Essex, said: "Harry's fine. We're trying to get him to stand and then walk."



OUR article on latex allergy and spina bifida (December/January '97 *Link*) was well received by parents and service users.

Many of those affected by latex allergy did not know the condition is often associated with spina bifida and were relieved to learn they are not alone in having the problem.

We received more than 20 replies from service users and parents in Britain, the United States and Australia. Many had startling stories to tell of their reactions to latex in different situations – at home, school and in hospital. Some were also allergic to certain foods like bananas or peanuts. One service user with hydrocephalus alone is allergic to latex.

Many of the letters we have received contradict a theory prevalent in the United States that individuals with latex allergy only experience one type of reaction. For example, one of our service users experienced a skin rash, tight chest and breathing problems.

One girl was allergic to her swimming cap so her parents informed the local hospital of her problem with latex. But paramedics on board an ambulance had to be told separately. Even though they proceeded to take off their gloves, latex dust particles were released, causing anaphylactic shock. Luckily, the girl – like many individuals who are allergic to latex – carries an epi-pen which offsets this life-threatening reaction by injecting adrenalin.

Another individual had surgery carried out on his back and was placed face downwards on a latex sheet. His skin reaction was so severe that his face became unrecognisable. Other sufferers reported hand prints all over their bodies when touched by latex gloves.

Rosemary Batchelor, ASBAH's coordinator, specialist advisers, commented: "If you know you are allergic to latex you must tell your

Good response to our survey on latex allergy

GP, dentist as well as all hospital staff you come into contact with."

Johnson & Johnson Medical has brought out a booklet entitled *Hospital Care of the Latex-Allergic Individual*. It makes the following recommendations to patients:

1. Wear a Medic Alert bracelet or carry a Latex Allergy Warning Card produced by Johnson & Johnson Medical. **The cards are available free from Johnson & Johnson Medical by telephoning 01344-871000 and speaking with the gloves product manager.**
2. Carry a pair of non-latex gloves at all times for use by medical attendants during examinations and emergency procedures. These are available through retail pharmacies.
3. Tell friends and relations about the allergy.
4. Make an appointment for immunological evaluation with a dermatologist.

More news on latex allergy

- A Latex Allergy Support Group has been formed, made up of people who have the condition, a parent, a dentist, a medical journalist, nurses, health service workers and managers from latex-free glove manufacturer Regent Medical. ASBAH will keep in touch with this group's progress.
- A list of every-day products containing latex and available alternatives will hopefully be produced in the not-too-distant future. Watch this space for details.
- A Durex latex-free condom, made of polyurethane, known as Avanti, is currently being tested in the western states of America. If these tests go well, it could soon be available in Britain.

If you think you are allergic to latex, here is another opportunity to fill out our survey form, if you have not done so already.

ASBAH SURVEY ON LATEX ALLERGY

Child's name _____ Date of birth _____

Address _____

_____ Disability _____

Telephone _____ Parent's name _____

When and how was latex allergy diagnosed? _____

How does it affect the child / symptoms? _____

Does the child have any other allergies? _____

Does anyone else in the family have a latex allergy? _____

Please cut out or photocopy completed forms and send to Rosemary Batchelor, ASBAH, 42 Park Road, Peterborough PE1 2UQ.

SALISBURY confidence-building course instructor Kathrine Connery has been doing ASBAH proud.

Kathrine, who has a mild form of spina bifida, had the benefit of years of training which helped her overcome her nerves when she made her first-ever parachute jump for us last autumn.

Since then, she has been spreading the word about our work and getting other people involved in raising money for us.

Despite her disability, 37-year-old Kathrine was accepted for a tandem skydive – strapped to an experienced instructor.

"It was a wonderful experience which I'll never forget," said Kathrine, a trained therapist, who persuaded her 20-year-old daughter Miranda to do a tandem jump at the same time.

"Miranda is very conscious that, when she becomes pregnant, her children will have a higher chance than normal of having spina bifida. She wanted to do something for ASBAH, which campaigns for the wider use of folic acid before and during pregnancy."

She was talked into doing the parachute jump by her brother

A giant leap for ASBAH



Above: Kathrine (left) and Miranda Connery. Right: Kathrine doing her tandem parachute jump in aid of ASBAH.

Peter, a veteran of the Falklands War, who now skydives as a hobby.

Peter, who lives in Rotherhithe in London's Docklands, has persuaded staff and customers at his local pub *The Clipper* to pull out all the stops for ASBAH.

A couple will be doing sponsored parachute jumps, while the landlord is hoping to organise a fund-raising event.

"We thought as a family that we would spend a year or so helping make some money for ASBAH," said Peter.

Break for carers for a 'donation'

AN ATTRACTIVE house in West London which gives welcome breaks for carers is offering its services for the price of a donation.

The Kiloran Trust, which runs 157 Blythe Road, London W14, aims to give carers a much-needed break during which nothing is expected of them and where there are no hidden pressures.

It is a place where the normal routine of managing a home is taken care of, enabling visitors to be free to concentrate on letting go and relaxing. You can choose whether to be alone or with others.

Each visitor is offered the exclus-

ive use of a large comfortable bedroom (three single and one double) with en suite bathroom. All meals are provided. Visitors can manage the time as they like.

Kate Gibbs, director, said: "If carers need a break but can't afford the full cost, we would still like them to stay by making a donation towards costs. If there's any chance we can get their stay paid for by another organisation, we will discuss that with them."

For more details telephone Kate Gibbs on 0171-602 7404 or write to her at: The Kiloran Trust, 157 Blythe Road, London W14 0HL.

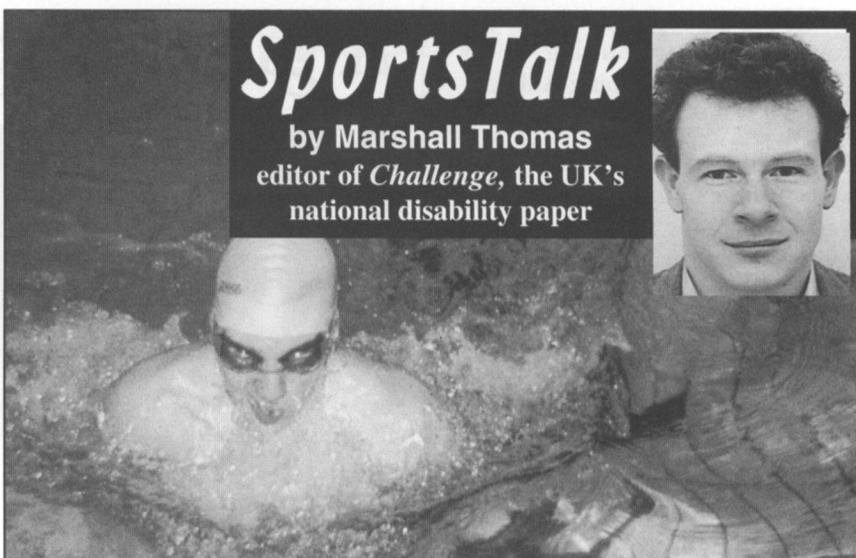
Lady Coggan resigns

LADY COGGAN, a regular supporter of ASBAH at important functions, has resigned as a vice-president of ASBAH for personal reasons. She has been a vice-president since the days when her husband Donald was Archbishop of York. Lord and Lady Coggan now live in Winchester.

Faith Seward, secretary of North Yorkshire ASBAH, who originally recommended Lady Coggan as a vice-president, said: "I am still in contact with her and she writes every Christmas. She was always very good to us in York."

SportsTalk

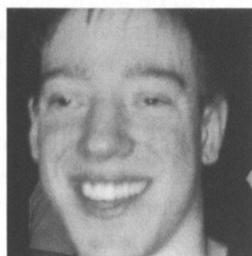
by Marshall Thomas
editor of *Challenge*, the UK's
national disability paper



SWIMMING is one of the best forms of all-round exercise you can do, but for Geoffrey Gayton, Hannah Bickerdike and Gregg Brassett, swimming has become much more than just a great form of exercise. All three have their sights on the Paralympic Games.

At the BT National Junior Swimming Championships, organised by the British Sports Association for the Disabled, in Darlington on 1-2 March, Geoffrey, Hannah and Gregg were just three talented youngsters with Paralympic ambitions out of a field of 200 swimmers.

Geoffrey, 16, from Christchurch in Dorset, started swimming competitively five years ago after watching one of Britain's most successful Paralympians, Sarah Bailey, on television competing at the 1992 Barcelona Paralympics. "That inspired me to start training and competing myself and now I'm looking towards Sydney in 2000,"



Geoffrey Gayton

he said, after setting a national record in the SM6 class 100m individual medley at the BT Junior Championships. Geoffrey gained his national record and two other gold medals – in the 50m butterfly and 50m freestyle – after two months off with a foot infection, so he is in good form. However, he has yet to swim fast enough to train with the Paralympic squad.

The event in which he is most confident of achieving the qualifying time for the Paralympic squad is the 200m freestyle. He has seen his personal best improve dramatically since joining mainstream swimming club Christchurch Seagulls just over a year

ago. He now does six training sessions per week, swimming 4000m in each session.

Geoffrey aims to achieve the qualifying time for the Paralympic squad at the BT Long Course Championships, so called because all events are in a 50m Olympic-sized swimming pool as opposed to the 25m pool used at the Junior Championships. The event, on 17-18 May at Ponds Forge, Sheffield, is also the target for both Hannah and Gregg, who are also closing on Paralympic squad times.

Hannah swam four personal best times out of the eight events she contested at the Junior Championships. Among them were two national records in the S5 class 25m butterfly and 100m freestyle, while a third personal best came when winning a gold medal in the 50m freestyle.



Hannah Bickerdike

"I'm thrilled to have got two national records, but my main aim this year is the Long Course," said the 17-year-old York student. "My ambition is to swim in Sydney."

Gregg, who has hydrocephalus,

has similar ambitions. A current personal best in the SB10 class 100m breaststroke of one minute 32 seconds puts him three seconds off the qualifying time for the British squad. At the BT Junior Championships there was no 100m breaststroke for the Essex 15-year-old to contest, but in the shorter



Gregg Brassett

50m breaststroke he, too, set a new national record when winning one of nine individual gold medals. He also captained the BSAD Eastern region to third place in the team competition.

"I'm really pleased with the national record. It's the first personal best I've broken in ages," he said. "Now I hope I can do the same in the 100m breaststroke in Sheffield in May."

If you would like to know more about swimming for disabled people, or any other sporting opportunities, call Disability Sport – England (formerly the British Sports Association for the Disabled) on 0171-490 4919 and ask to be put in touch with your regional contact.

ALL PARENTS want what is best for their children and this applies to education as well as other aspects in life.

Parents with children with special educational needs often want them to be treated as normally as possible and ask for provisions which they consider to be necessary for the fulfilment of these ideals.

The 1993 Education Act declares that a child should be educated in a mainstream school—providing that it is compatible with the pupil receiving the special educational provision which the learning/medical problems calls for, the provision of efficient education for the rest of the children and the efficient use of resources. But there may be certain instances where a pupil's education could be more suitably addressed in a special school. One must always remember that a local education authority is not obliged to provide the 'best' education but an education which can adequately meet a child's needs.

In order to provide a suitable education for pupils with learning/physical difficulties, it is very important that each pupil's problems are accurately identified and the necessary provision to meet their needs is secured. Many parents unfortunately are not aware of the 'system' and they should seek expert advice from the specialist advisers who are employed by ASBAH.

If a child has special educational needs, there are various formalities which must be undertaken by the parents, the school and local education authorities (LEAs). Before recourse to the Special Educational Needs Tribunal, these procedures must have taken place. A child's special needs must have been identified at stages 1, 2 and 3 within the school and appropriate action to meet those needs, including the drawing up and monitoring of an Individual Education Plan.

Tribunal as a last resort

by Peter Walker
ASBAH specialist adviser
(education)



If it is blatantly obvious either before a child enters school or during the early years at school that a child will have particular difficulties, then a referral for a statutory assessment can be requested either from a health professional, the school or the parent. The Code of Practice declares that: "The LEA must comply with such a request, unless they have made a statutory assessment within six months of the date of the request or unless they conclude, upon examining all the available evidence, that a statutory assessment is not necessary."

In order to avoid any possible difficulty should an LEA refuse, a parent must personally request an assessment in writing. Unless this happens, a parent has no right of appeal to the Special Educational Needs Tribunal. Children with special educational needs are legally entitled to have their needs identified and met with appropriate provision but unfortunately whether they are able to access that entitlement depends very often on the determination and persistence of their parents.

The Special Educational Needs Tribunal is a body to which an appeal can be made when parents cannot reach an agreement with an LEA regarding certain educational issues. It is a totally independent body which is composed of a chairperson (a qualified lawyer) and two lay members who have an expertise in either special educational needs or local government, or both. Hearings are informal and normally held in private. Both parents can attend

together with a representative and witnesses. It must be noted however that there are only certain things you **CAN** appeal about, namely:

- The refusal of an LEA to make a statutory assessment.
- The refusal to issue a statement after an assessment.
- The description in a statement of a child's special educational needs.
- The description of how the LEA intends to meet the needs.
- The school named in the Statement.
- The LEA not naming a school in the Statement.
- An LEA's refusal to change the school named in a Statement and a refusal to re-assess a child's special educational needs.

There are certain things about which an appeal **CANNOT** be made, namely:

- The way the LEA carried out the assessment or length of time it took.
- The arrangements being made to provide the help set out in the Statement.
- The way a school is meeting a child's needs or the description of a child's non-educational needs and how the LEA plans to meet those needs.

Generally parents who are lodging an appeal can contact the Tribunal Office in London (tel: 0171-925-6902) to obtain the help they need

continued on page 20

Tribunal as a last resort

from page 19

and some very practical advice. ASBAH's advisers and specialist advisers are prepared to assist parents when searching for an appropriate education for their child.

It is important for parents to be aware that they have certain rights:

- When an LEA decides not to issue a Statement after an assessment, parents have the right to receive copies of all the professional advice that was gathered.
- When an amendment to a child's Statement or the cessation of a Statement is proposed, a parent has the right to receive copies of any professional evidence that has influenced the LEA's decision.
- When Statements are reviewed or re-assessments have been made, any professional advice or opinion should be given to the parent.

Often LEAs are not 'having regard' to the Code of Practice on the identification and assessment of Special Educational Needs and this is taken into account along with written evidence submitted prior to the hearing and the oral evidence given at the hearing. Parents must be aware however, that unlike cases in law, the decision of any tribunal hearing cannot be quoted as a precedent. Each case is individual and relates to one particular child and one particular set of circumstances. The Special Educational Tribunal has been operating since 1994 and certain problems have been highlighted since then:

- There is no legal duty on LEAs to quantify special educational provision in Statements.
- There is no legal deadline for LEAs to implement tribunal decisions.
- There is no legislation in the

area of provision for children who have a need for speech therapy.

- Many LEAs seek to prevent their employees (SENCOs, teachers, educational psychologists etc) from testifying or acting as witnesses on behalf of the parents.

The latter, however, can be overcome by seeking permission for the President of the Tribunal to issue a subpoena. It is asserted, however, that even summoning a witness and putting him/her on oath, does not offer professionals adequate protection.

Obviously, if at all possible, every effort should be made to enter into negotiation with an LEA concerning your child's special

educational needs. Sometimes a tribunal hearing can be avoided by discussing differences even though an appeal has been lodged. In a significant number of cases, the issues between the various parties have been narrowed and even resolved either before or during a hearing. Co-operation is preferable to confrontation.

A very useful booklet on the Special Educational Needs Tribunal can be obtained either from ASBAH or The Department for Education and Employment Publications Centre, PO Box 6927, London E3 3NZ (tel: 0171-510 0150).

Don't forget that ASBAH's advisers/specialist advisers are always willing to give you assistance.

Appeals made by parents to tribunals have fallen into the following categories:

	94-95 %	95-96 %
Against refusal to assess	21	24
Against refusal to make a statement	21	16
Against refusal to re-assess	2	2
Against refusal to change name of school	2	3
Against decision to cease to maintain statement	7	5
Against contents of statement	28	37
Against school named in statement	18	12.5
Against failure to name a school in statement	1	0.5
	100	100

Free holidays on Dartmoor this summer!

FUN and adventure around the theme of King Arthur can be had for free this summer at camps for disabled young people on Dartmoor.

Run by experienced and qualified staff, the week-long holidays are organised by youth charity *Go For It*. There will be a number of static camps around the edge of Dartmoor and the children will move from a camp to camp each day. They will be on a quest, overcoming challenges to

gain access to information or meet characters that will assist them in their quest for King Arthur. Activities will range from abseiling or canoeing, to music making or environmental issues.

The holidays are for 11-14-year-olds. The dates are: 19-26 July and 26 July-2 August.

Contact: *Go For It, Windward House, Coronation Road, Salcombe, Devon TQ8 8EA. Telfax: 01548-844074.*

Can parents combine caring for a disabled child and work?

Reader's viewpoint

I READ with interest the article by David Wainwright of *Parents at Work* in *Link* (Dec/Jan '97).

I have two children, Claire who is nine years old and Dominic who is six years old. Claire has spina bifida and hydrocephalus.

During their pre-school years, I chose to be at home during the day and I worked in a restaurant some evenings to earn extra money, and also as I enjoyed being at work. However, when both children started full-time education, I began to work during the day part time as an administration officer in a mobility centre. My manager was very understanding – she allowed me to be flexible with my hours and I could change work days to suit myself. I now work part time as a carer's support worker, which is also a job which allows flexibility.

I feel that as a mother, a flexible job is vital, particularly as any child can be off school sick. My daughter has many hospital appointments, which I am able to manage as I can swap work around. My daughter's teacher is also very helpful in arranging meetings either before or after work.

During the school holidays there is a play scheme operating in our area for children with learning disabilities, which my daughter attends. This is particularly helpful as I can continue working throughout the holidays.

The few problems I have encountered are with family support and child care after school. Child care for my daughter would be a lot more difficult to arrange and a lot more expensive than for my son. I recently asked for Family Support for my daughter, just for an hour after school on the days that I work. I was told that Family Support was only provided for

by Helen Youngman
a working mother from
Penzance, Cornwall

respite for the parents, not so that a parent could work. I took this up with the district operational manager at Social Services and he agreed to provide Family Support so that I could work. After all, to me personally, I argued that work is my respite!

I also lost my Invalid Care Allowance when I took on my current job as I earned over £50 a week. I do feel that this is unfair as, even though I work, I still look after Claire for more than 35 hours a week.

Overall, however, I find it easy to combine caring for my daughter and working, and I am sure this is because I have a flexible job with understanding employers, good facilities during the holidays, and my own parents living nearby who help me enormously.

Parents at Work seems to be campaigning in exactly the right areas:

- Having understanding employers who are prepared to be flexible.
- Adequate daycare facilities for after-school and in school holidays for children with disabilities.
- Service providers prepared to be flexible with appointment times.

My own experience has proved that these three factors are vital to be able to care for a child with disabilities and work.

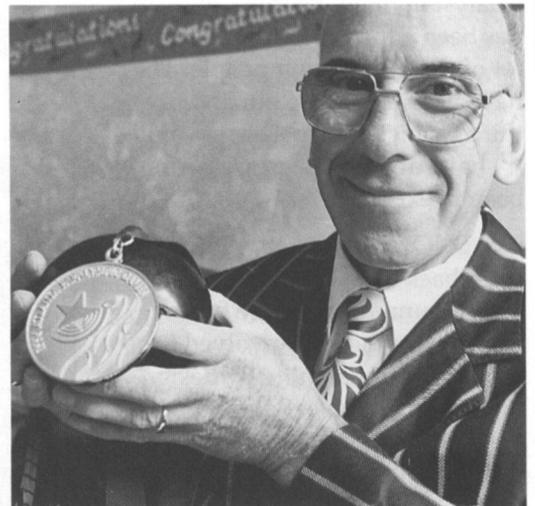
David bowls them over!

AFTER winning a silver medal in indoor bowling at last year's Paralympics, David Heddle (pictured right) is gearing up to defend his British title and to fly down under for the world championships.

The 54-year-old describes his 20-day trip to Atlanta last year as 'super' and 'unforgettable' and is looking forward to Australia in October.

"It will be a long trip over, but I fancy going," he said.

David, who has spina bifida and walks with sticks, was picked for the 16-strong British Paralympics bowling team after winning a gold in the World Championships in the previous year. He is five times



indoor and four times outdoor Scottish champion, and four times British bowling champion. He defends his British title in Scarborough in May.

When he's not competing, David works as a salmon splitter at Mac Fish in his home town of Fraserburgh, north-east Scotland, where he has worked for 36 years. He started bowling more than 30 years ago in a church hall.

"I just love a game of bowls," he said. "It keeps me active and keeps me going. It's a great game, anyone can play."

Nothing about me without me

Clubability
Challenge

THE IGNORANCE of many non-disabled young people about the lives of their disabled peers was the impetus which got an awareness-raising group in Lancashire off the ground.

SHOUT! was formed four years ago to give disabled young people a voice in all aspects of every day life.

The group – aimed at 16 to 26-year-olds – has made inroads in society, some big, some small, but all have had an impact on the members' lives, the people they know and the places they go to.

Group worker Brenda Escreet explained: "SHOUT! has been a catalyst in many people's lives and has been a focus point for quite a lot of disabled young people. They have been able to go out and do things which they perhaps wouldn't have done if the group hadn't been in existence."

One SHOUT! member volunteered to go back and work at his day centre, running a picture framing course. Another got involved in publicity campaigning by designing eye-catching leaflets and posters. Others have started music groups to express themselves and inform others. And some have become volunteers at local youth centres and gone on to become youth work trainees.

Brenda said: "The youth work trainee package is part of Lancashire County Council's *Pace Into Pulse* course, which challenges the image of disabled people by training them to be service providers rather than service users."

All ideas for SHOUT! activities have come from the members themselves. They are particularly concerned about leisure provision in their localities – access to pubs, clubs, shops and cinemas.

One notable example is the British Film Museum in Bradford. Brenda takes up the story: "We went round the whole museum, and when we later pointed out in a letter that their Video Box was non-accessible, they promptly re-designed it so that it was accessible to wheelchair users."

Over the years, SHOUT! has seen members come and go – some have stopped attending meetings due to transport problems, ill health or have decided to go to college or university.

But Brenda does not see ailing membership as a problem. "All groups have a natural life-span and will go on as long as they are needed by the members."

Early this summer, SHOUT! will be holding a conference, delivered by its members, to pass on their experience to a wider audience, and to highlight other projects which give opportunities to disabled people and allow them to take their full place in society.

● *If you would like to know more about SHOUT! or attend the conference, contact Gabby Beattie at Talking Heads Youth and Community Centre, Ribbleton Hall Drive, Preston, tel: 01772-798324.*

Clubs Round-up

Clubs welcoming ASBAH young people

● **Harrow PHAB Club, Bentley**

Day Centre, Uxbridge Road, Harrow Weald, Middx. All activities integrate disabled and able-bodied on equal terms!
Contact: Shirley Bennett 0181-429 2920.

● **Inner City Club, Longsight Youth Centre, 422 Stockport Road, Longsight, Manchester M12 4EX.** Open to disabled and non-disabled young people aged 13-25 and operates on a Tuesday evening from 7-10pm. **Contact: Colin Floyd on 0161-274 4843.**

● **Lancashire County Council Youth & Community Service** operates an equal opportunities policy and warmly welcomes young people and people from the community with disabilities. **Contact Liz Neat or Brenda Escreet on 01254-694643** who will put you in touch with the nearest accessible centre to you.

● **Manchester Youth Service Disability Project** offers support to any disabled young person in Manchester who wishes to attend a local youth club. This support may take the form of home visits or pre-visits to the youth clubs with a member of staff. The aim is to bring together disabled and non-disabled young people in an environment of mutual trust and understanding. **Contact: Colin Floyd on 0161-274 4843.**

● **Newport Pagnell Youth Club, Wolverton Road, Newport Pagnell, Bucks MK16 8HX.** Ramps to front entrance and sports hall, and a unisex toilet for disabled users. Wide range of sport, arts/craft activities, computer and Internet. Three-day summer holiday project for disabled young people, at the club, is also planned. Suggestions for other clubs or events are welcomed. **Contact: Yvonne McLaughlin on 01908-211701.**

Doorstep deliveries from a wheelchair!

TWENTY-eight-year-old Stewart Aird has earned £2,500 in less than three months as a part-time Kleeneze agent.

Now he wants other wheelchair users to know there is a very good living to be had with Kleeneze.

Next year he expects to turn over £165,000 by building a team of agents. This will elevate him to executive distributor level, entitling him to all sorts of perks including a 10-day stay at the Shangri-la Hotel in Thailand, which ranks among the top five hotels in the world.

Stewart, who lives in Peterhead, Aberdeenshire, said: "It's hard work but very exciting. I'd never done selling before but I'm doing well."

Kleeneze depends on its agents to expand its business, so it treats them very well, rewarding those who are doing well with foreign conferences and bonus payments.

Stewart spends just 12 hours a week in his Kleeneze business which he does in addition to his full-time job as a machine operator at a local factory.

"It was my cousin who introduced me to Kleeneze and I decided to take it up after the company I work for was taken over and I was concerned about my job security.

"My cousin is earning serious money. In 29 months with his team he's turned over £3.5 million. He has 140-180 agents in his team throughout the UK and Ireland, and expects to be turning over £1 million a month by Christmas 1998."

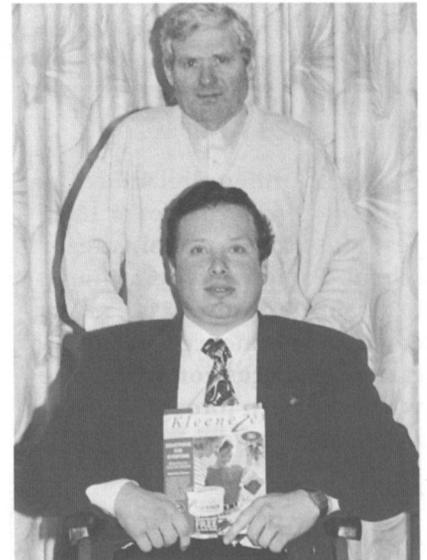
You can only become successful in this business if you are willing to work hard and work consistently, and are willing to help other people become agents and find success with their Kleeneze business.

Stewart said: "I want to go as high as I can with Kleeneze. I want to be comfortably off while I'm still young."

He added: "It would be great to see more people with disabilities become Kleeneze agents because you can earn a very good monthly income."

Stewart distributes brochures on Monday, Tuesday and Wednesday evenings; collects brochures on Thursday and Friday evenings and delivers on Saturday mornings, but you can work hours to suit yourself.

"You get a mixed reaction," he said. "Some people like the products, some don't. A lot of older people who can't get out are glad of it. I got a £70 order after



Stewart with his father at home

leaving a brochure at a sheltered housing scheme."

Stewart is accompanied by his father when out with his brochures – to reach high door bells and to assist with any steps.

"You get full help and training in all aspects of this business. There are evening meetings arranged near your home. Other agents come along to the meeting and share all their tips."

Senior executive Hazel Stephen commented: "Stewart has a fantastic attitude. He doesn't see himself as others see him. He wants to make a success out of his life like everyone else."

○ *If you would like to work with Stewart as a Kleeneze agent in your local area, give him a call on 01779-475422.*

Holiday service

DO you need help finding suitable holiday accommodation in the area of your choice?

If you do, then *Holidays for You and Me* could help.

The proprietor, Sian Hughes, has had muscular dystrophy since childhood. She has had many years experience in the tourism industry and has travelled to some of the most beautiful areas in the

UK to find suitable cottages, chalets, apartments and caravans.

She will be happy to assist anybody in choosing the most suitable accommodation for their individual holiday requirements, offering a friendly and personal service.

Phone or fax on 01348-837833 or write to: Sian Hughes, Holidays for You and Me, Caerau Bach, Croesgoch, Haverfordwest, Pembrokeshire SA62 5JU.

THE SCOLIOSIS Association (UK) – a national self-help group giving information and contacts for people with twisting and curving of the spine – has a new helpline number – 0181-964 1166. It is open Mon-Thurs 10am-1pm.

Or you can send a large stamped addressed envelope for further information to: *The Scoliosis Association (UK), 2 Iwebury Court, 323-327 Latimer Road, London W10 6RA.*

DATES FOR YOUR DIARY

Saturday 26 April

ASBAH Northern Ireland region, *Looking Ahead* course for 13-16 year olds attending mainstream school. Topics include: attitudes to disability, growing up, management of continence and skin care, with discussion with those who have been through it all. Regional centre, tel: 01265-51522.

April-June

ASBAH Northern Ireland Region, *Lifeskills - A Survivor's Guide*, series of Tuesday morning courses for young adults with spina bifida and/or hydrocephalus at NICOD Training Centre, Balmoral, Belfast. Regional centre, tel: 01265-51522.

Thursday 8 May

Disability Alliance course, *Introduction to Job Seekers Allowance*, 356 Holloway Road, London N7 6PA. Dominic tel: 0171-247 8776.

Saturday 10 May

Waving, Not Drowning: Can Parents of Disabled Children Work? conference organised by *Parents at Work*, 10am-4pm. Admission £10 plus £5 for buffet lunch. London Voluntary Sector Centre, Holloway Road, London N7. Tel: 0171-628 3565.

Monday 12 May

Spina bifida/hydrocephalus support group meeting, Disability Resource Centre, Poynters Road, Dunstable, 1-3pm. Valerie Bottoms, tel: 01582-605749.

Monday 12 May

ASBAH conference for medical and health professionals, *Current Approaches to Spina Bifida and Hydrocephalus*, National Motorcycle Museum, Birmingham, 9.30 for 10am-4.30pm. Speakers include Mr A E MacKinnon, Mr M Vloeberghs, Mr J H Patrick, Miss J Iddon, Mr K Parashar. Geraldine Long, ASBAH, 12 Priory Road, Alcester, Warwicks B49 5DY.

Tues-Thurs 13-15 May

Naidex Care Management exhibition, Hall 1, NEC, Birmingham. Lynn McBain, tel: 0181-910 7837.

Saturday 17 May

Spina Bifida & Hydrocephalus - An Holistic Approach, study day organised by ASBAH Eastern Region, The Lincoln Suite, The Lawn, Union Road, Lincoln, 9.30am-4.05pm. Speakers: Professor Kypros Nicolaides, consultant paediatric neurosurgeon Jonathon Punt, consultant paediatric surgeon and urologist Christopher Rance, ASBAH specialist adviser (medical) Julie Llewelyn. £15 service-users and family members, £30 professionals. Details: Rebecca Sewell, ASBAH East, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988.

Sunday 18 May

Jewish baby memorial service at 4pm at The West London (Reform) Synagogue. For people who have lost a baby either pre-term or within the first 30 days of birth and those who have been unable to conceive.

Monday 19 May

Disability Equality Training

Course, introductory course led by Barbara Lisicki, Greater London Association of Disabled People (GLAD), 9.30am-5pm, at 336 Brixton Road, London SW9 7AA. Brenda Ellis, tel: 0171 346 5805.

Thursday 22 May

On the Move, ASBAH Northern Ireland Region, half-day course for parents on lifting, handling and skin care. Disabled Living Centre, Musgrave Park Hospital, Belfast. Regional office, tel: 01265-51522.

Tuesday 3 June

National Continence Day. Publicity materials from *The Continence Foundation*, tel: 0171-404 6875.

Saturday 7 June

Hydrocephalus Study Day, organised by ASBAH South East Region. Speakers include: Dr Richard Morgan, consultant physician, Chelsea and Westminster Hospital, and Leonie Holgate MCSP. Post Graduate Medical Centre, Barnet General Hospital, Well House Lane, Barnet, Herts. 9.15am for 9.45am-4pm. £5 per family, £15 for professionals (certificate of attendance supplied). ASBAH South East, 123 East Barnet Road, New Barnet, Herts EN4 8RF, tel: 0181-449 0475.

We've got it taped!

AUDIO tapes of information sheets No 1 (*What is Spina Bifida?*), No 2 (*What is Hydrocephalus?*) and No 10 (*What is ASBAH?*) will be available from ASBAH's Information Department from 30 May.

Audio taping of the remaining information sheets will be completed over the course of financial year 1997/98.

Master tapes of all recordings will be kept by the Information Department and copies made for people to borrow as required.

It is not expected that any charge will be made, but it does depend on the circumstances. Certainly, if there are requests for audio tapes from blind or visually-impaired service users, then no charge will be made.

At the urging of *Your Voice in ASBAH*, recordings will also be made of the revamped *Lift* magazine, which goes out free on request to young disabled service users - the first issue of which is due to appear in May.

SOMEONE famous (can't recall who) said that on meeting an architect at a party, one should simply hit them. I feel much the same about insurers and their agents. I view them with the same warmth I reserve for lungworms and Dutch Elm disease.

I feel strongly that the present insurance system (in this country at least) is a form of legalised discrimination that I, for one, could do without. In the wake of all that fuss about the 'cloned sheep,' a big article appears in the newspaper on genetic testing. Apparently, insurance companies will make it compulsory to obtain a gene test for certain conditions before insurance is granted.

Like the Aids test, people who choose to go for a test may be financially penalised by the insurance companies. This means that people may not go for fear of having to pay higher premiums, all for the sake of a *possibility* of future illness. That illness may be passed unwittingly from the parents to their offspring because the parents didn't go for a test. I look forward to children, disabled by some detectable and preventable condition, suing the pants off the insurance companies 20 years from now.

A good night's sleep

DISTURBED nights caused by a sleepless child can be a real headache for parents and other family members.

A new book offering step by step help in tackling such problems has been published for parents and health professionals.

Solving Children's Sleep Problems is by Dr Lyn Quine, who has helped more than 600 families to resolve their children's sleep problems.

The book, price £12.99, is published by Beckett Karlson. ISBN 1 901292 01 0.

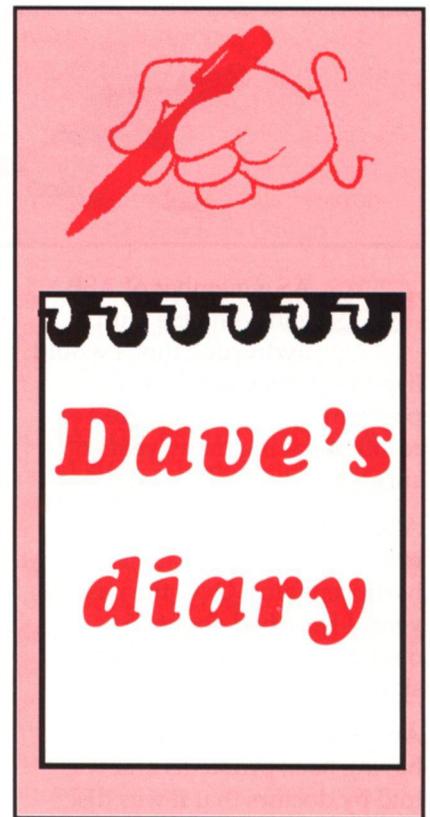
Why this deep dislike of insurance companies? Simple: I'm disabled and bought car insurance. After I got through those companies which wanted my entire medical history and a brain scan before they'd give me third party, I found an insurer which was prepared to treat me as a human being. A human that, for reasons which seem entirely illogical, should be relieved of a great deal of cash.

The moment the word 'disability' was out of my mouth I swear I heard cash registers ringing and my premium go up by 30%! Well, you'd expect me to be a hot-rodding maniac in my 1.4 litre Volvo, wouldn't you! The strange thing is, someone must have found it acceptable to insure all non-disabled people who appear doing motorway u-turns and such like in the Police Stop videos. Perhaps we should seek a gene for stupidity?

The insurers must be a bit dim if they see gene testing as the complete answer to their prayers. Testing is not going to cut down all the risks of accident or illness. There are plenty of conditions whose gene markers haven't been found yet.

In defence of genetic screening, the article quotes an insurance bod as saying that it will help people to moderate their lifestyle. If, say, they find they are susceptible to cancer they can cut down on the ciggies. But what about me? I may contain a gene for spina bifida. Just how will insurers detecting that help me to change my lifestyle? What can I do? Get a body transplant? There will be thousands of people whom insurers will tell 'You have the risk of contracting x. Insurance denied. Good luck.' A great help, I'm sure.

If there's one thing worse than being denied insurance, it is to be offered it and then refused. I am heartily sick of having some chirpy voice on the phone offer me medical insurance with one of the big schemes. Yes, I would like to be pampered, offered good food, brought champagne and have my

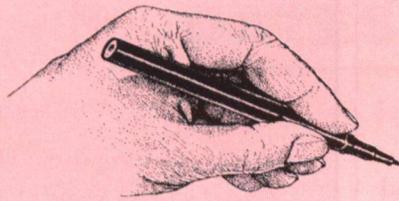


pillows fluffed by model nurses. So I go for it. The sales bods are all smiles (well, chirpy voices) until the words 'pre-existing condition' come up. Then, it seems, you have to pay them 10 years' cash in advance and sign over your house, car and first-born before they let you have a sniff of the wine list! Life is hell.

If life is bad now, consider what it will be like for the next generation. Will advances in genetic engineering, coupled with pressure from insurers and society, permit all socially non-desirable (and hence uninsurable) conditions to be deleted? Who knows? Like the consequences of the cloned sheep, it's all hype, hope or horror stories right now.

As for what people might deem an undesirable trait, I have a suggestion: test for a brain's bias towards the arts or mathematics. Look for all those whose possible interests may include statistics, percentages and probabilities, (ideal insurance calculators' fodder, in other words), and screen the bleeders out!

David Fulford-Brown



Letters



We invite letters for publication. Send them please to: **Editor, ASBAH, 42 Park Road, Peterborough PE1 2UQ.** The Editor reserves the right to edit letters for publication, so keep them as short as possible.



AS a member of ASBAH and someone with hydrocephalus, I would like to inform you of a new problem which has occurred as a result of having many years of surgery.

After having two brain tumours removed as a child, I then had hydrocephalus. Over the past 26 years I have had about 25 operations to renew blocked shunts.

About six years ago I started having back problems and was told by doctors that it was disc

problems and was given tablets and several courses of physiotherapy. Early last year, I had to go into hospital to have a cyst drained which had formed at the top of my spine. After the operation I was told that I had a condition called 'arachnoiditis.'

Arachnoiditis is an inflammation of the arachnoid layer of the spine and causes a sort of furring-up effect of scar tissue along the spinal cord. The scar tissue can press on the spinal nerve roots and even the spinal cord.

I was told by doctors that, after so

many operations, the scar tissue had built up along the spine. I have now been left with severe spasms in my legs and terrible back pains.

I thought it would be worth telling you what can happen as a result of lots of brain or spinal surgery and wonder if there are any other members of ASBAH who have this condition.

Name and address supplied



MY 15-year-old son Jean-Baptist would like to stay in England for about three weeks this summer, probably on an exchange basis. His summer holiday runs from 3 July to 16 August.

I am looking for a kind guest family which is able to handle a person with spina bifida and hydrocephalus.

Jean-Baptist is a pupil in the 9th class of a Rudolf Steiner School,

speaks a little English, is a nice fellow and, in principle, is very independent (not only confined to his wheelchair).

I would be glad to hear from anyone interested in having my son to stay.

Thank you very much.

*Hildegard Kammerzell
Papestr. 59
D-45147 Essen
Phone: 0201-773136*



PAUL Darke's film column is readable and informative. It is on par with any of the weekend reviews. He keeps his focus of presenting disability in the context of cinema to the fore. I am surprised the column isn't more widely read. His piece on *Crash* was especially interesting.

*Dr J C Dearlove
Consultant Paediatrician
Yeovil District Hospital
Yeovil, Somerset*



MY NAME is Jill Burn. I am 28 years old and have spina bifida. I am currently unemployed but hopefully will be getting a new job soon.

I enjoy reading, going out to the cinema and out for a drink or a meal. I like animals and spending time with my family.

I would like anyone, male or female, with any kind of disability, between the ages of 20-36, to write to me.

*Jill Burn
21 Ingram Road
High Green, Sheffield
South Yorkshire S30 4GB*

RENAULT Extra, three-years-old, 14-15,000 miles on the clock. £9,000 ono. Tel: 0121-308 1062.

SLEEPEZE fully-automatic bed, remote control, separate head, foot-raise, three-speed built-in massage unit, beautiful condition. Used four times. Cost £1,800. First £500, will demonstrate. Also Balsan 3 hydrotherapy bath/Jacuzzi with separate foot spa. Cost £1,200. First £500. Tel: 0161-281 1643.

ELECTRIC 'Bec' Sterling scooter, Sunrise Medical. Used holidays only. Excellent condition. Basket,

waterproof cover, stick 'clips', charger. Comfortable seat. Easy controls. Dismantles for car transportation. £900. Tel: 01327-260181 (Northamptonshire).

FOR SALE a Disability Trust one bedroom ground floor flat at Eastbourne (East Sussex) with 24-hour care staff. Designed for the disabled with lounge, equipped kitchen and bathroom. The flat is large enough for a carer to share with the handicapped person. There are gardens, lounge and bar and meals are available. Price is £44,500. Phone: 01323-811297. Roger Tidy.

MISCELLANEOUS

HOLIDAY ACCOMMODATION

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

WEYMOUTH BAY – Fully-equipped, wheelchair accessible caravan - sleeps five; on Haven Holiday Park, full use of all facilities - heated indoor & outdoor pools, bars, children's club & full entertainment programme. Three miles from Weymouth. *Details from Margaret Humphreys, tel: 01494-714270 (Bucks & E Berks ASBAH).*

ROMNEY SANDS, KENT – Two-bedroom holiday chalet, sleeps six, fully equipped, wheelchair accessible. Full club facilities, heated pool etc. Across road from sandy beach. *For details, contact Fran Chapman, tel: 01797 367342.*

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.*

FRANCE – Ile d'Oleron, near La Rochelle. Mobile home for wheelchair users. Fully adapted (shower etc), sleeps six, near beach, disabled owner. *Brochure from M Mardle, Fricourt, Filey Road, Old Heath Road, Southminster, Essex CM0 7BS. Tel: 01621-785899.*

ISLE OF WIGHT ASBAH – Fully-equipped two-bedroom holiday bungalow, sleeps six plus cot. Clubhouse, indoor heated pool, shop etc. Site overlooks sea. Own transport advisable. *Details: Mrs P Burden, 36 Sherbourne Avenue, Binstead, Ryde, IOW, PO33 3PX, tel: 01983-564604.*

COLERAINE, BALLYMONEY AND DISTRICT BRANCH. FOR SALE/TO LET – Fully equipped caravan designed for wheelchair access throughout. Sleeps eight. Sited at Dhu Varren Caravan Park between Portstewart and Portrush, Co Antrim, N Ireland. *Details from Dorothy Hill, 25 Townhead Street, Ballymoney, Co Antrim, N Ireland, BT53 6BE. Tel: 012656-63954 (after 6pm).*

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

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

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

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

LINK Rates

Link ISSN 1360-323X
 Editor: Liz Cawthorne
 Published by ASBAH,
 ASBAH House,
 42 Park Road,
 Peterborough PE1 2UQ
 Telephone: 01733 555988.
 E-mail: lcawthorne@asbah.demon.co.uk.

LINK SUBSCRIPTION 6 EDITIONS – 12 MONTHS

UK £4.80
 Europe and Overseas Surface Mail £7.50
 Air Mail £15.00
 All payments should be made in Sterling.

Classified Rates: £3 for 30 words max;
 £4.25 for 30-45 words;
 £5.50 for 45-60 words.

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

Small adverts for the next issue of *LINK* (June) should be submitted by Friday, 9 May. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

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