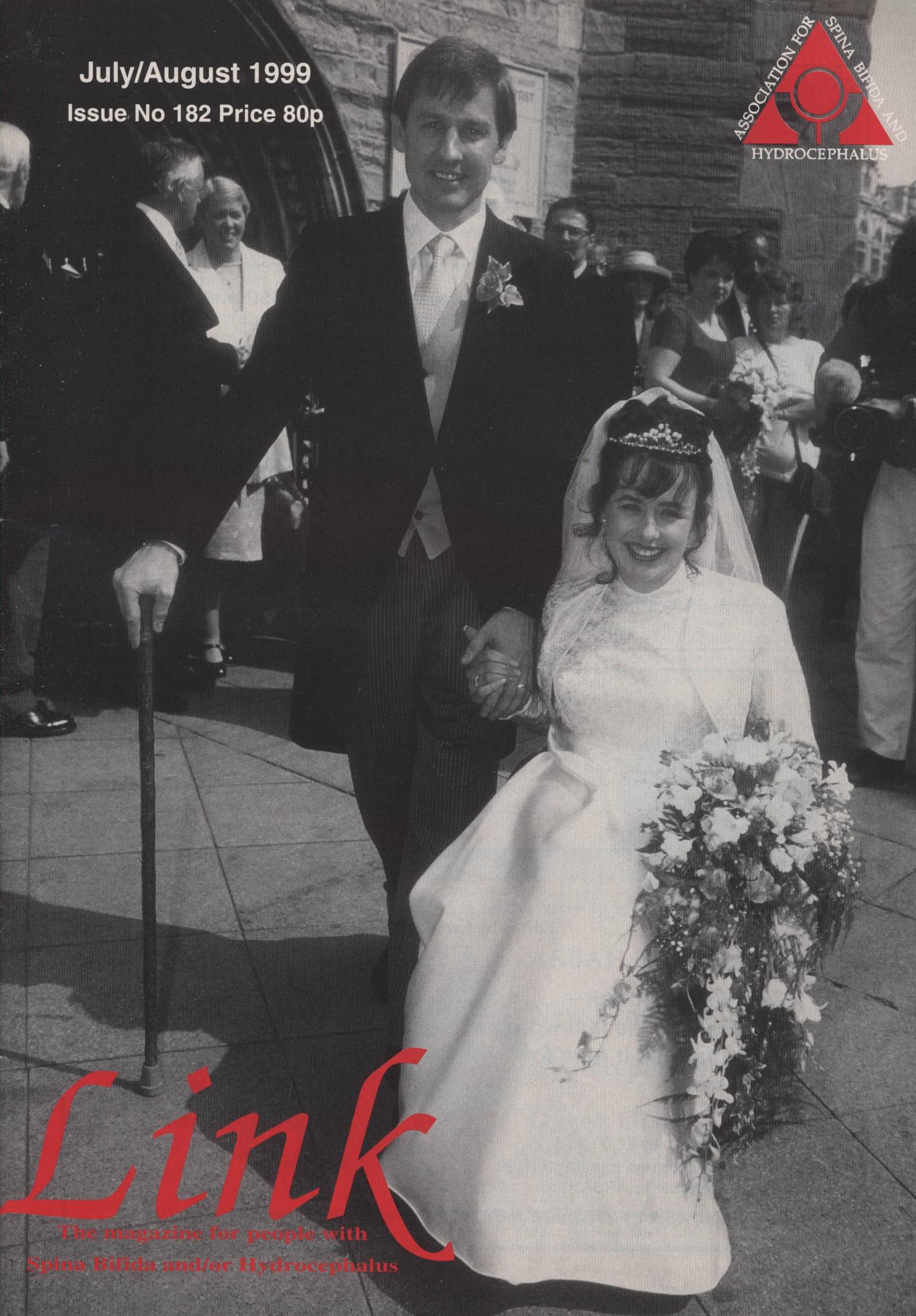


July/August 1999
Issue No 182 Price 80p

ASSOCIATION FOR
SPINA BIFIDA AND
HYDROCEPHALUS



Link

The magazine for people with
Spina Bifida and/or Hydrocephalus



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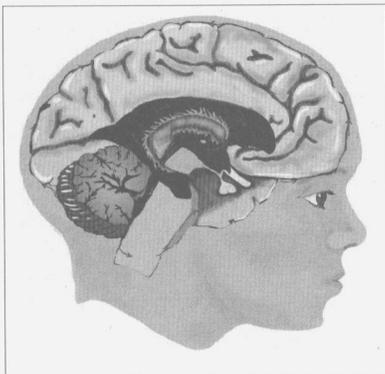
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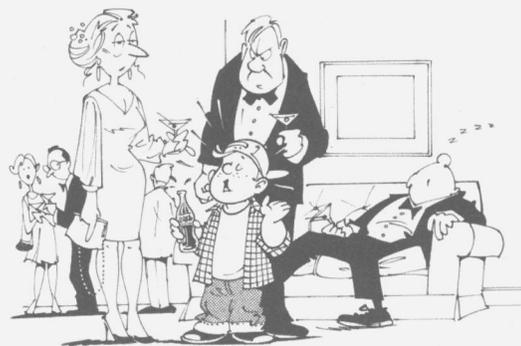
HYDROCEPHALUS AND YOU

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LIFE-LONG Manchester United fan Ray Gainer was among millions of supporters who cheered their hearts out when their heroes clinched their triple cup triumph in Barcelona.

Ray (pictured right) was there, leading a contingent of 52 other disabled club supporters. But Spanish indifference to their access needs left a sour taste in their mouths at the moment of their club's biggest triumph in 31 years.

Ray, aged 39, is a past chairman of Manchester United Disabled Supporters Club (MUDSA), which hired two aircraft to take members and carers to the game.

But, when they reached the stadium, there was no wheelchair access at the turnstiles. Officials, at first, would not open a gate for them.

Once inside, MUDSA found that the only provision made for them had been the removal of a row of seats in part of the stadium where the view was obstructed.

Ray, an active member of Wigan and Leigh ASBAH, has travelled to every ManU game this season. Travelling abroad always takes a bit of pluck as the atmosphere abroad can be intimidating for disabled supporters, he admitted.

"Manchester United security look after you but, at the end of the

Red Army battalion almost didn't get in

Barcelona match, they never came, probably because they had been called elsewhere. I missed the coach back to the plane and someone had to arrange an official car for me. It was a bit worrying as I would have been stuck."

"There was pandemonium. People were going everywhere and there was no control. I didn't arrive home till 5.30 the following morning and I had left at 6am the previous day so it was a very long day but I wouldn't have missed it for the world.

"Seeing so many of us there, mingling in with the rest, it was really special."

When it got to injury time, the supporters were convinced ManU wouldn't win. Then Sheringham and Skolsjaer both found the back of the net and the British supporters erupted with joy.

"We got into extra time and, OK, we got one goal. We were still cheering that goal when we got the corner.

"I couldn't see whether the ball got into the net but the crowd went mad, absolutely mad. Everyone looked at each other in disbelief.



"I felt we were destined to win that game. Ferguson has done such a good job since he's been there."

Ray's proud to be associated with a club that is doing so much for disabled supporters who, through MUDSA, are admitted free to matches in rotation.

"It's not quantity but quality. There are currently 70 wheelchair places and 70 helper seats in a three-tier system, including a section at the front for visually impaired people, plus seats to the front and side for walking disabled people.

"The wheelchair enclosure – which is being extended again – is a fantastic place with six disabled toilets and car parking places opposite the ground like the players.

"The club is 100% behind us."

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Cover: Paralympic athletes Tanni Grey and Ian Thompson on their wedding day. Photo by Barry Gomer, courtesy of Marquesa de Varela International Ltd. Story on page 7.

Hello to money-making Mike!



● MIKE Miller wants to put his business skills and contacts to good use in his new role as ASBAH's fundraiser – corporate development.

Leaving the RAF at 23, after seeing some of the world, Mike has spent

the last 27 years in the computer industry, predominantly in sales, marketing and management.

His last position was business development manager at a computer dealership in Huntingdon. However, he grew disillusioned with making large sums of money for private individuals.

So he has switched to a new position making money for us and we are pleased to welcome him aboard!

Mike, who works full-time in the Fundraising Department at ASBAH House, takes over from Paul Wootton, corporate development manager, now with Victim Support.

Mike will be engaged on special fundraising appeals, particularly corporate relationships and specific trusts.

Born and bred in Peterborough and married to Val with two grown-up sons, Mike's interests include overseas travel, touring in his sports car and motorcycling.

Farewell to ASBAH shops founder

MARGARET Gillmore has stored up more than a few funny stories to look back on in her retirement as the founding national shops co-ordinator of ASBAH's chain of charity shops.

Not quite 60, Margaret decided it was time to quit while she was still enjoying the job and so she could spend more time in the garden and with her grandchildren.

There's the one about the ghost in a long black dress and little black bonnet seen by many helpers and customers at a shop in Havant.

On one occasion, a helper ran downstairs and out into the street after discovering the ghost standing behind her. Another helper used to walk downstairs backwards to ensure that it didn't follow her.

Then there was the shop with the patio doors which a helper slammed shut, locking staff and customers inside. Frantic waves to people outside only triggered waves in response. At last, a passer-by cottoned on to the shut-in and went to the shop's owners for a spare key.

There have been odd items to sell – the silver coffee set which turned out to be stolen property; the ammunition shell in the shop window, discovered to be live, which Margaret had to take by car to the police station; and the hefty

church organ which had to be shifted into a shop in Portchester.

Margaret's interest in DIY came in handy. But drilling through an electric cable and singeing off her eyebrows was one of her unlucky moments. She has put up numerous shelves over the years. Making shelves for 10,000 books when moving the bookshop in Havant, though, took the biscuit, taking three months to complete!

"I have worn many hats," Margaret said, "and it has been a challenge all the way."

Margaret started her career as a photographer, married a sailor, lived overseas for many years, finally settling in the Portsmouth area.

After having a family, Margaret ran shops for the PDSA – the People's Dispensary for Sick Animals – and here she met a woman called Jean Stacey who had a granddaughter with spina bifida.

"It was through Jean that I first heard of ASBAH and I gave ASBAH the idea of having charity shops," said Margaret.

She set up the first one in Southsea and over 16 years has opened and closed 75 shops as temporary lets – mainly in the Solent but also in Wales and East Anglia. Currently, there are nine ASBAH shops: eight in the Solent and one in Wales.



Based at a factory unit, where she shared an office with shops supervisor Christine Cousins, and where the contents of weekly bag drops are stored and sorted, Margaret was involved in every single aspect of the business – from driving the van for bag drops to sorting out saleable items and from designing shop layout to recruiting and managing staff and volunteers.

She has been indebted to the volunteers, some of whom she knew while working at the PDSA. Volunteers have included a JP, an ex-headmistress, a pilot and last year's mayor of Portsmouth. Two helpers met while working at a Southampton shop where romance blossomed into marriage.

She added: "I will miss all of my friends and the team spirit, and if I ever get bored with the three g's – grandchildren, grandfather and garden – I know nine good charity shops that all need helpers!"

THREE-year-old Elizabeth Price adores racing around on her SHASBAH trolley. Not only does it give her mobility around the house, but she is able to join in when the other children go on ride-on toys at playgroup.

The family first saw a SHASBAH trolley – named after South Hampshire ASBAH, the local association which invented them – during a holiday last year on the Isle of Wight.

Elizabeth loved it and her parents tried to find her one when they returned home to Brackley, Northamptonshire.

Then they read about the history of the trolley in *Link* No 176 when we featured Frank Mortimer, who made thousands of the trolleys in the 1960s, being awarded the MBE.

Elizabeth will eventually get a new one made of lightweight plastic from the charity Whizz-Kidz.

Mum Angela said: "Elizabeth loves her SHASBAH trolley and I was in tears when they took it away for repair as it was like they were taking away her legs.

"She is desperate to get out and ends up trying to crawl. At playgroup, she could use the other ride-on toys but needs someone to help her. With the SHASBAH trolley, she is independent."

● If you would like your child to be assessed for a mobility aid like

Whizzkid on a SHASBAH trolley



Three-year-old Elizabeth Price enjoys her SHASBAH trolley.

Photo: Brackley Photographic

the one Elizabeth Price uses, contact your local hospital's Child Development/Treatment Centre to

make an appointment with a therapist who will be able to advise you further.

Does your trolley need a good home?

IN THE mid-60s and early 70s, thousands of low SHASBAH trolleys were made and sold round the world to help children with spina bifida keep mobile.

There may still be some languishing in a forgotten corner of a garage, shed or attic. Well, if all they need is a touch of oil or a lick of paint, please pass them on to someone else who would find them useful.

"People do occasionally ask where they can get hold of one," said ASBAH information manager Gill Winfield. "If anybody has still got a SHASBAH trolley, please let me know and tell me what condition it is in."

Gill can be contacted on 01733-555988 until 4pm weekdays, email: gillw@asbah.demon.co.uk

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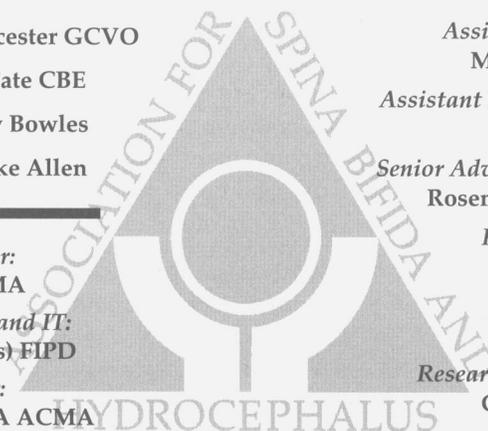
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Benefits Agency – a new business plan

THE GOVERNMENT'S reform of welfare is high on the political agenda, and ASBAH has commented on the Welfare to Work proposals, basing our comments on the views of disabled members. The Benefits Agency, an arms-length executive agency of the Department of Social Security, is beginning to translate the Government's political intentions into an operational plan.

Politicians and bureaucrats have clearly taken note of the severe criticisms levelled at the agency by disabled people and carers, for the inconsistent and sometimes arbitrary and insensitive manner in which the rules are applied. So it is encouraging that of the four objectives of the DSS for 1999, one is aimed solely at benefits for people with disabilities: "To provide people with disabilities, support and financial security to lead a fulfilling life with dignity." The other three objectives relate to helping jobless people back to work, supporting families and children, and promoting financial security for elderly people in retirement.

The ill-conceived Benefits Integrity Project, which was inherited from the previous government and continued, damaged the confidence of disabled people in the Benefits

Agency, and there is a lot of ground to make up.

There is great emphasis in the plan on good communication with customers, an area of service for which the Benefits Agency has had an underwhelming reputation in the past. Specific mention is also made of improving the administration of Disability Living Allowance and Attendance Allowance, and introducing a new system of review for DLA. For disabled people who want to work, the agency is intending to extend its voluntary Personal Adviser Service, in partnership with the Employment Service.

The proposed Single Work Focussed Gateway may in future provide a single point of access to benefits delivery for people of working age. The Gateway aims to integrate the activities of the Benefits Agency (BA), Employment Service (ES) and

local authorities, as well as the private and voluntary sectors.

Several pilot schemes are being run, four by the BA and ES, and four by private and voluntary sector partnerships, to develop and test the system, and encourage innovation.

The scheme revolves around providing people with a personal adviser who will co-ordinate and advise on all aspects of employment and benefits. This scheme is now being extended to disabled people who want to work. The Government has given a full assurance that people who cannot work will receive good benefits and will not be penalised.

We believe that this business plan is now saying the right things, and it is important that we share, within ASBAH, experiences over the next year or two, to judge how well the plan is translated into practice.

By Andrew Russell
ASBAH's Executive Director



Young person of the year in Kent

PETER Mynehan (pictured left) was one of half a dozen people to be rewarded for

their courage and contributions to the community in Kent.

Fourteen-year-old Peter won the Young Person of the Year category of the awards because of the positive way he deals with his disability.

His mum, Lynne, who nominated him for the award, said Peter loves a challenge and proving a point.

She said: "He gets on with life and doesn't think of himself as having a disability. He's always been a bit of a dare devil and has competed with his elder brother Andrew, who is good at sport."

The awards, sponsored by Invicta Radio Group and Sea France, were presented by local radio presenters at a hotel near Maidstone.

Peter competes in javelin and shot put and last year won silver and gold medals at the national championships in Blackpool, coming fourth in the under-15 javelin.

He qualifies for the same competit-

ion this year and a local social club, where he goes on Saturday nights, hopes to raise money for him to have a personal trainer.

Although he faces major spinal surgery later this year, his mum expects he will take it in his stride.

As well as winning other awards, including the McDonalds Children of Achievement Award, presented in 1993 by the Princess of Wales, Peter took part in a TV documentary about transferring to mainstream secondary school and has been asked to do another one on computers.

Happy day for Tanni

PARALYMPIC gold medalist Tanni Grey MBE tied the knot with fellow athlete Ian Thompson on 1 May.

Due to the church bells being sent away for repair, Tanni persuaded some ex-student friends to rig up a sound system with recorded chimes in the church tower.

Family, friends and well-wishers gathered at St John the Baptist Church, Cardiff, to see the cementing of a long-standing relationship between the happy pair.

Twenty-nine-year-old Tanni wore an ivory silk dress, made to her own specifications. It had a plain skirt and gold flower pattern on the bodice, with a high neck and cut away on the shoulders. She wore the dress with a bolero jacket for the ceremony.

The pair exchanged matching gold bands which were made to match Tanni's four-diamond engagement ring.

After a reception for 120 guests at the Cardiff Bay Hotel, Tanni and Ian flew to honeymoon in Switzerland where they trained for five hours a day with Swiss racing colleagues.

Tanni, who has earned five Paralympic and five world championship golds, plus four London Marathon wins and world records at 200 and 800 metres, is now concentrating her efforts on the Sydney Paralympics in 2000.

It was sport that brought Tanni and her husband together. A former time-triallist cycle-racer, Ian turned to disability athletics after an accident left him partially disabled. He holds the British 5,000 metres record for wheelchair racing.

Aged 35, Ian has a PhD in Chemistry and Physics and works as a research technical manager for ICI Chemicals in Redcar.



Paralympic athletes Tanni Grey and Ian Thompson tied the knot in Cardiff on 1 May.

Photo by Barry Gomer, courtesy of Marquesa de Varela International Ltd

Help & Advice

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

Greater London, Berks, Hants, Kent, Surrey, West and East Sussex, Isle of Wight

ASBAH South East, 209 Crescent Road, New Barnet, Herts EN4 8SB.
Tel: (0181) 449 0475. Fax: (0181) 440 6168. Regional Co-ordinator: Jo Francis.

Bedfordshire, Cambridgeshire, Derbyshire, Essex, Hertfordshire, Lincolnshire, Leics, Northants, Nottinghamshire, Norfolk, Suffolk

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

Northern Ireland

ASBAH Northern Ireland, Graham House, Knockbracken Healthcare Park, Saintfield Road, Belfast BT8 8BH. Tel: (01232) 798878.
Fax: (01232) 797071. Regional Co-ordinator: Margaret Young.

Cleveland, Cumbria, Durham, Greater Manchester, Humberside, Lancs, Merseyside, Northumberland, Tyne & Wear, North Yorks, South Yorks, West Yorks

ASBAH North, ASBAH House North, 64 Bagley Lane, Farsley LS28 5LY.
Tel: (0113) 255 6767. Fax: (0113) 236 3747. Regional Co-ordinator: Joan Pheasant NNC.

Rest of England and Wales

ASBAH National Centre, 42 Park Road, Peterborough PE1 2UQ.
Tel: (01733) 555988. Fax: (01733) 555985.

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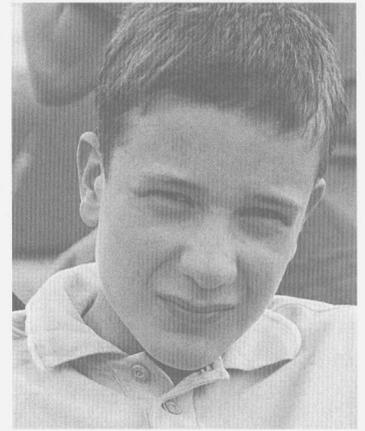
AlphaMed Ltd makes a donation for every prescription order received, as a result of ASBAH's introduction, for continence and medical equipment supplies. Tel services floor, 01733-555988, for introductory Freepost envelope. Prescriptions for drugs or medicines should not be sent to AlphaMed.



● **FOR** the second year, runner **Andrew Hunter** gave his all in the **London Mini Marathon**, raising more than **£160** for us in the process.

Andrew, whose baby sister died with a severe form of hydrocephalus 15 years ago, chose to support ASBAH on both occasions.

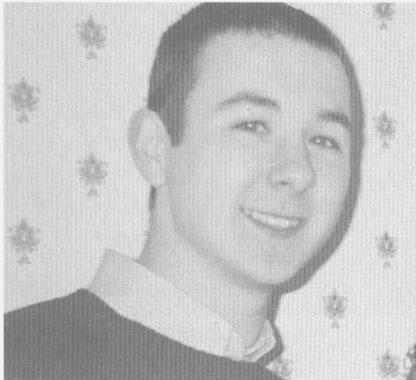
This year he came 57th out of 226 entrants in the 13-14 years age group completing just under two miles in 16 minutes, seven seconds.



● **FOURTEEN**-year-old **Jonathan Desmond** came seventh in the **London Mini Wheelchair Marathon** and raised **£700** for ASBAH.

It was the first time he had covered 2.8 miles in a race, and only the second time he had covered the distance at all. He finished in a time of 14 minutes, 14 seconds.

Jonathan, from Maghull, Merseyside, goes training as often as his school work permits with a wheelchair racing club in Sefton.



● **INJURED** knees failed to stop **Matthew Shapcott** completing the gruelling **26 miles** and raise **£739** for ASBAH.

Family and friends, including mum Kim who has spina bifida, were all proud of and delighted with him.

Matthew, who was featured in the February/March *Link*, finished the run around London in about five and a half hours.



● **THIS** year's London was the 41st marathon for runner **Stuart Wallis**. At the age of 31, that is not bad going!

Stuart (*pictured left*), from Milngavie, Glasgow, chose to raise money for ASBAH this year because he has just got married and his wife's nine-year-old cousin has spina bifida.

He expects to raise around £650 for us.



Photo courtesy of Yorkshire Post Newspapers Ltd

● **A YORKSHIRE** schoolgirl has her eye on the **2004 Paralympics** after enjoying a round of success in wheelchair racing, including the **London Mini Marathon**.

As well as winning her age-group section for girls in the London, with a time of 16 minutes 25 seconds, Danielle won two golds in the 200m and 400m in last year's national athletics championships held in Blackpool. This year she has clinched three golds in the regional athletics championships for her age group.

The 12-year-old, from Rawdon, near Leeds, says that attaining high levels in sport is hard work but she enjoys the challenge.

● **HAVING** spina bifida occulta was no deterrent to running 26 miles for one Kent man.

Twenty-eight-year-old Stephen Horwood raised almost £600 for us after hearing about us through his pharmacist mum.

An active person who likes cycling and swimming, which he finds helps occasional back problems, Stephen thoroughly

enjoyed running the London Marathon.

He said: "I had a wonderful day and suggest everyone do it at least once in their lives. The challenge was that, if I did this one, my wife would do the next, so I may start training all over again with her and enter again next year."

The Bexley electrician only became aware he had SBO when he was 21.

OTHER runners who entered the **London Marathon** and offered to raise money for ASBAH included: nurse **Anne-Marie Currie**, of Northampton, who is aunt of **Gabrielle Gibbons**, ASBAH's face of the year for '98-99; **Ian Gordon**, of London; **Eddie Hatfield**, of Cambridge; and **Mr V R Williams** of Camberley, Surrey.

Our grateful thanks are extended to them and everyone who raised money for us in the 1999 London Marathon.

London Marathon

Sunday 18 April

Link editor, LIZ CAWTHORNE, catches up with the achievers on a day fuelled by perspiration and excitement.

DESPITE eight months in hospital last year, a Northampton man overcame all the odds to take part in the London Marathon.

Thirty-six-year-old Tim Claypole was one of hundreds of wheelchair competitors and more than 30,000 runners competing in the 26-mile event.

For Tim completing the course was a bigger achievement than most. From May to December last year he had three operations at Northampton General Hospital.

His time – at just over four hours 26 minutes – was slower than the five previous times he has taken part, due to the little time he had to train, and because he was still recovering from surgery.

He hopes to have raised £10,000 towards buying a bladder scanner for the ward where he spent much of last year next year.



Photo courtesy of Northampton Chronicle & Echo

● **SUFFOLK** youngsters **Brian Alldis** and **Joe Myers**, who have **spina bifida** and **hydrocephalus**, took **first and third place** in the **London Mini Wheelchair Marathon**, **11-13 age group**.

About 17 boys and girls, in various age groups, were set off their marks on The Embankment by Fatima Whitbread. They were applauded throughout the 2.8 mile route by a fair-sized crowd.

Brian, from Bury St Edmunds, finished first in his age group (fourth overall) in a time of 12 minutes 24 seconds.

Joe, from Newmarket, finished third in his age group (eighth overall) in a time of 14 minutes 35 seconds.

Brian (pictured right) was presented with a trophy by triple jumper Jonathan Edwards.



On 1 May, Joe and Brian joined 180 other athletes to take part in the BT Eastern Region Championship for disabled people in Braintree, Essex.

They competed in the 100, 200, 400,

800, 1500 and 3000 metre races and between them bagged five gold, three silver and two bronze medals and hope they have done well enough to qualify for the national athletics championships in Blackpool in July.

Congratulations to Tanni Grey, who came second, and Dave Holding, who came third, in the women's and men's sections of the London Wheelchair Marathon.

ASBAH research projects

We have always been proud to fund research associated with spina bifida and/or hydrocephalus. Here is a list of current projects that are being funded by ASBAH.

● **Professor Jim Stevenson, University of Southampton, Department of Psychology – *The Developmental, Behavioural and Psychological Characteristics associated with Hydrocephalus and Spina Bifida in Middle Childhood.***

A growing area of concern to ASBAH is the development of children with hydrocephalus, and how to overcome the educational and psychological problems apparent to parents and teachers.

This project is to be a full scientific study over three years, using five groups for comparison purposes, drawing in multi-professional skills. See pages 17 and 19 of this issue of Link for more details of this project.

ASBAH has sponsored the research at a cost of £164,761.

● **Dr Roger Bayston, City Hospital, Nottingham, and University of Nottingham – *Research into Cerebro-Spinal Fluid Shunts.***

Children and adults with hydrocephalus have a valve or 'shunt' inserted to the head to remove excess fluid which causes pressure.

Infection and blockage can occur rapidly and can be fatal if not diagnosed early. Dr Bayston's research will be concentrating on two main areas:

1. Research into Causes, Diagnosis and Treatment of Infection in Cerebro-Spinal Fluid Shunts – It is often difficult for even a

specialist to distinguish between a shunt infection and another problem with similar symptoms, and conventional laboratory tests are not conclusive. Dr Bayston has been studying the antibodies produced in an infection, and a blood test is being developed which promises rapid, reliable diagnosis.

2. Treatment of CSF Shunt Infections – Treatment for shunt infection involves surgical removal of the shunt. Dr Bayston is pioneering techniques and drugs which allow treatment of infection in such a way that shunt removal may not be necessary. This will reduce the need for surgery, reducing risks and costs.

ASBAH is supporting these projects with the help of local Associations at a cost of £10,000, and has awarded a further grant of £13,000 for the purchase of a luminometer / photometer for use in the research.

● **Dr G M Hunt, Addenbrooke's Hospital, Cambridge – *The Survival and Health of 30-year-old Adults born with Open Spina Bifida.***

ASBAH has given extended support for this long-term study of the progress and health of 117 consecutive newborn babies with spina bifida in the Cambridge area.

This study has attracted international interest in its findings on the condition, its effects on individuals, and its social and economic implications. Understanding the long-term results of treatment is essential to the medical management of care of children and adults with spina bifida.

The study records the health of survivors, all main treatments and procedures, achievements in terms of independence, mobility and employment, and major events such as marriage and childbearing. Causes of death are recorded in the cases of non-survivors.

ASBAH is supporting the present stage this research at a cost of £1,000 for administrative expenses.

● **Dr M D Lucock, Division of Paediatrics and Child Health, University of Leeds – *The Character of Intraerythrocyte Folate***

Species: Implications for Prevention of Neural Tube Defects.

Folic acid is known to be an important vitamin in pregnancy, for the prevention of spina bifida but the reasons for this are not fully known.

Lack of folate in the bloodstream is known to be connected with spina bifida conceptions. This research analyses the complex types of folate in the blood cells of women who have experienced neural tube defect pregnancies, compared with those of unaffected women.

The study is examining evidence that a metabolic defect may lead to abnormal folate status. Techniques have been developed to assess differences in the types of folates present. A blood-screening test will be developed to identify women at risk of a neural tube defect pregnancy.

ASBAH is supporting this research at a cost of £32,500 and we are grateful to News International plc and the estate of the late Mr W F Latham towards this cost.

● **Mr David Marshall and Mr Victor Boston, Department of Paediatric Surgery, Royal Belfast Hospital for Sick Children – *Bladder and Bowel Function following Cutaneous Electrical Stimulation in Children with Spina Bifida.***

The majority of children with spina bifida suffer from bladder and/or bowel incontinence, because nerve damage can cause loss of sensation and control to the lower body. The social and psychological effects of incontinence, as the child matures, can be severe. The kidneys may also become permanently damaged.

This study of 50 children is looking at a new technique of applying a weak electric current regularly to the skin, and investigating in detail the effects of this safe, non-invasive treatment on the control and regularity of the child's bodily functions.

It is believed that a time-limited course of electrical field stimulation may produce a long-term improvement in bladder and bowel control.

ASBAH has agreed to underwrite the cost of this study to the extent of £9,400, if required.

continued on page 13

Do you obtain appliances on prescription? If so, please consider trying the **ALPHAMED HOME DELIVERY SERVICE**

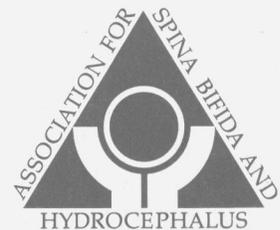
- The service is entirely free of charge.
- Prescription charges paid.
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This service has been created to save you time and worry. It's the most convenient way for you to obtain appliances (eg catheter, leg bag and stoma pouches) that are prescribed for you by your GP. The AlphaMed Home Delivery Service will provide you with the very highest standards of personal, confidential care, and deliver your appliances direct to your home, entirely free of charge.

AlphaMed has been working in partnership with ASBAH for several years, providing a home delivery service for ASBAH members. In recognition of the value that AlphaMed places on this partnership, regular donations are made to ASBAH. The greater the number of ASBAH members who use this service, the greater the benefit to the association.

ALL YOU HAVE TO DO IS:

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3. Send your signed prescription and registration form to us, using the Freepost address below.
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SO what are you doing this summer? Nice villa in the South of France? Island-hopping in Greece? Ibiza (c'mon!)? Summer is here, and that means outdoor music festivals.

There are eight commercial festivals this year in Britain. In addition, there are hundreds of local street or day festivals which are absolutely free, or under £5 to attend. It's not easy to go to the majority of festivals with limited mobility – but which other activities are? – so you might as well take the plunge. Allow me to guide you through some of the pitfalls of big fields filled with ecstatic youngsters!

If you've never been to a festival before, a smaller local festival is a good place to start. You'll know the area well; good parking places and local wheelchair-accessible public toilets. It is also easier to leave a local festival in a hurry, if you need to. In London, I like Kingston Green Fair or Stoke Newington Mid-Summer Festival.

My first major music festival was Reading. I spent the day in seventh heaven, dashing up and down the field so as not to miss any bands, and shopping at the stalls for crazy clothes. Reading Festival has an advantage for me in that it offers day tickets and the site is relatively small, making it easy to negotiate. If I want a break from the dirt, the town centre is 20 minutes away (taxis available).

If you're going to any festival, it is important to remember that Britain is far from blessed with

Survival Special



New *Link* columnist, Suzanne Bull, takes on the world as a young disabled person and explodes a few stereotypes along the way

fine weather! Wheelchair-users will get stuck and thoroughly wet. This is where you can embrace your stylish orthopaedic boots! I don't recommend camping in a tent for anyone in these circumstances, so hire a van or borrow your auntie's caravan.

Alternatively, stay in a hotel (rock and roll!). Holiday Care Service can advise accordingly. It's important that you can keep your clothes, and yourself, warm.

In hot weather, the sites become a dust bowl and there aren't many trees at Reading or Milton Keynes Bowl for shade. Take plenty of sun-tan lotion and a hat. Throwing up in a sweaty tent is unpleasant so bear in mind that alcohol makes you more dehydrated!

Getting around is difficult, especially as it grows darker. Take a group of hefty people to clear a path for you, have a warning sound (scream your lungs out), or just ram!

OK, let's talk disabled facilities. There isn't much on offer. Cambridge Folk Festival is reported to

be the best, and Glastonbury is by far the worst! The maximum you'll get is two (waterlogged) wheelchair-accessible toilets, viewing platforms and an Orange Badge parking area (which can still be quite a distance from the main arena).

Still want to go? I'm going to Reading and V99 this summer. I'm cheating. I hate camping! Reading is within comfortable driving distance and V99 in Hylands Park is 20 minutes from dad's!

If you're interested in making music festivals more accessible, email Jacinda Worrall at jworrall@equality.leeds.gov

Major Festivals (check local or music press for details):

- Sat 10 July – Big Day Out, Milton Keynes Bowl or Fleadh, Finsbury Park.
- 23–25 July – Womad, Reading.
- 30 July – 1 August Cambridge Folk Festival.
- 6–8 August – Big Chill Enchanted Garden '99, near Salisbury.

ROGER Elliott has discovered that, when the Royal Opera House in London reopens for business in December after its £218million refit, it will have no disabled parking spaces of its own.

Mr Elliott, a wheelchair-user who has spina bifida, says that despite good access within the opera house itself the lack of reserved parking will leave disabled patrons in the lurch.

£218m refit but no disabled parking

If it can be done at the Royal Albert Hall, where he and his wife Lucy go to concerts, it can be done at Covent Garden.

Michael Kaiser, chief executive at the opera house, has said that the site has been developed over its entire area with no vacant land available to provide dedicated car parking, which was in accordance with Westminster City Council

policy of discouraging traffic in central London.

In a letter copied to Mr Elliott, Mr Kaiser said there will be a drop-off point for vehicles bring disabled people to the theatre in Bow Street, and seven new parking bays for Orange Badge holders in Bow Street and Floral Street, compared with none at present.

SOME top-notch advice for parents on how to plan ahead for the future of disabled dependents when they are no longer around will be available at the annual meeting of ASBAH's Council later this year.

Lawyer Anthony Quinn, who has his own firm in London, will speak

AGM a time for thinking ahead

on "Wills, Trusts and other financial provisions for disabled people" during the meeting at national centre on 18 September.

If *Link* readers would like him to consider any questions in advance,

please put your question in writing to our executive director, Andrew Russell, and he will pass them on. Advance questions should reach Mr Russell by the end of August.

Planning ahead for dependents with learning disabilities was aired in May at a wide-ranging ASBAH information day held in St Albans.

Paul Muldoon, trusts manager with Peterborough lawyers Greenwoods, promotes the use of discretionary trusts as a way of ensuring that children with learning difficulties have access to the parental estate. There is no legal obligation on able children to provide for a sibling with learning difficulties, if an estate is divided between them only.

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

ASBAH research projects

continued from page 10

● **Professor S C Robson, Department of Obstetrics and Neonatology, Royal Victoria Infirmary, and University of Newcastle – Outcome of Prenatally Detected Mild/Moderate Cerebral Ventriculomegaly.**

In hydrocephalus, the cerebral ventricles of the unborn infant become enlarged by the pressure of cerebro-spinal fluid, a condition which can be detected by ultrasound scans. Parents then need specialised advice, particularly when the abnormality is mild or

moderate, as to the possible outcome of the pregnancy.

This study will follow the progress of a group of 100 children to the age of two years to see whether ante-natal scan results can be a predictor of future developmental progress.

ASBAH, with support from Glaxo Wellcome plc, is supporting Professor Robson's research over two years at a cost of £18,500.

● *Enquiries about ASBAH's research projects to: Executive Director, ASBAH, 42 Park Road, Peterborough PE1 2UQ.*

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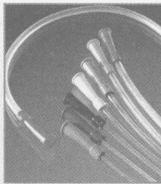
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DDA: the first year

DISABLED people took more employers to court under the Disability Discrimination Act (DDA) 1995 than people did under the race or sex discrimination laws in their first year of operation.

Forty-one percent of cases were settled by arbitration.

Research details cases in the first 19 months of the implementation of the DDA. It draws on studies of 92 cases and potential cases under the Act, as well as interviews with legal and other experts. A database is also being established to record information on cases brought under this legislation.

Key findings show:

- Cases are being brought and won by people with disabilities who use the DDA to combat discrimination.
- Employers sued under the DDA often change policy or practice as a result.
- Disabled people taking action were motivated more by a desire for justice and fair treatment than by financial compensation.
- At least half of the employers knew of the DDA's existence.
- 41% of the 92 cases were settled through ACAS (or the Labour Relations Agency in Northern Ireland).
- The commonest disabilities among applicants were: back or neck problems, depression, bad nerves or anxiety, problems with arms or hands. This pattern was also found among cases taken in the early years of the Americans with Disabilities Act (ADA).

The research was commissioned by the DFEE on behalf of the National Disability Council and conducted by the Institute for Employment Studies.

● *Monitoring the Disability Discrimination Act 1995*, DfEE Publications, PO Box 5050, Sherwood Park, Annesley, Nottingham NG15 0DJ. £4.95, cheques payable to DfEE Priced Publications.



Session of Chinese PE

FIFTEEN young people, some of whom had never been away from home before, took up the gauntlet to try new activities and make new friends in Cornwall.

Eleven boys and five girls, aged 11-16, along with ASBAH staff stayed at Churchtown Farm, Lanlivery.

The week was divided into talks and outings to encourage participants to gel as a group and to make friends.

Every morning started with Chinese PE and there was a second session each evening. The exercises - to music - were

designed so that everyone (including staff!) could manage at least some of the class.

ASBAH staff led classes on personal hygiene, self-image, sex education, healthy eating and wheelchair maintenance. We also had an Agony Aunt's panel game which everyone enjoyed: we had questions on everything from sex to cars and wheelchairs to body odour ... and even a proposal of marriage (refused!)

A member of The Body Shop staff did a session on skincare and make-up, and a local girl with spina bifida came to talk about massage and aromatherapy, and stayed to give individ-



George Cadman, aged 11, at the Owl Sanctuary



ual treatment ses
ingly, all of the o
unteered for this
left the quiz team
ed.

We had a long cl
blazing sunshine
those of us pushi
over the sometim
ground, but wor
stunning views a

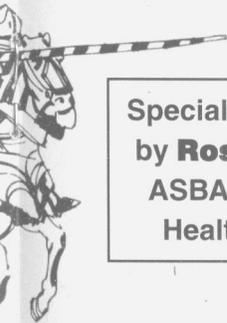
The next morning
that a gentler out
was called for; ac
bottoms wouldn't
strenuous outing

So we went to th
uary at St Austel
owls to pat and c
and we 'adopted
of a donation. Th
appropriately, w
Dr Dolittle.

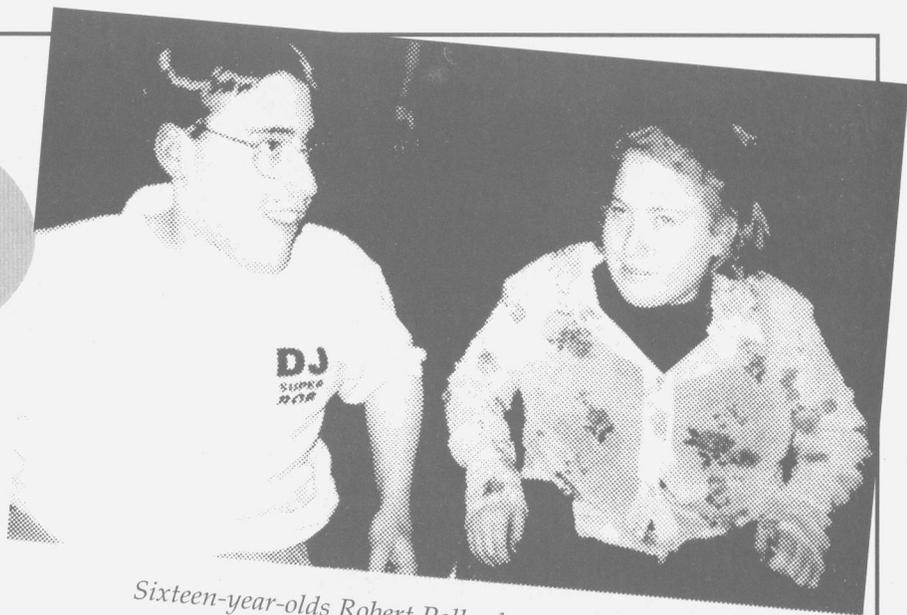
Thursday's ten p
was voted 'cool'.
everyone dressed
disco - the girls s
make-up and the
expertise. It was
the time we chas
bed.

By Friday the sta
ed but the young
unflagging. We
the farm in two
the pigs, the dor

ASBAH's Challenge



**Special activity week report
by Rosemary Batchelor
ASBAH's Senior Adviser
Health & Policy Issues**



Sixteen-year-olds Robert Pollard and Erin Guthrie

sessions. Surprise older boys volunteered for this session which seems sadly depleted.

g cliff-top walk in line: hard work for pushing wheelchairs sometimes rough worth it for the views at Polzeath.

ning, we decided on outdoor activity; aching limbs and didn't cope with a long again.

the Owl Sanctuaries. There were several owls to look at and we had a pair in-lieu that evening, we watched

pin bowling trip. That evening we set up for the girls shared their new-found as a late night by raised them all to

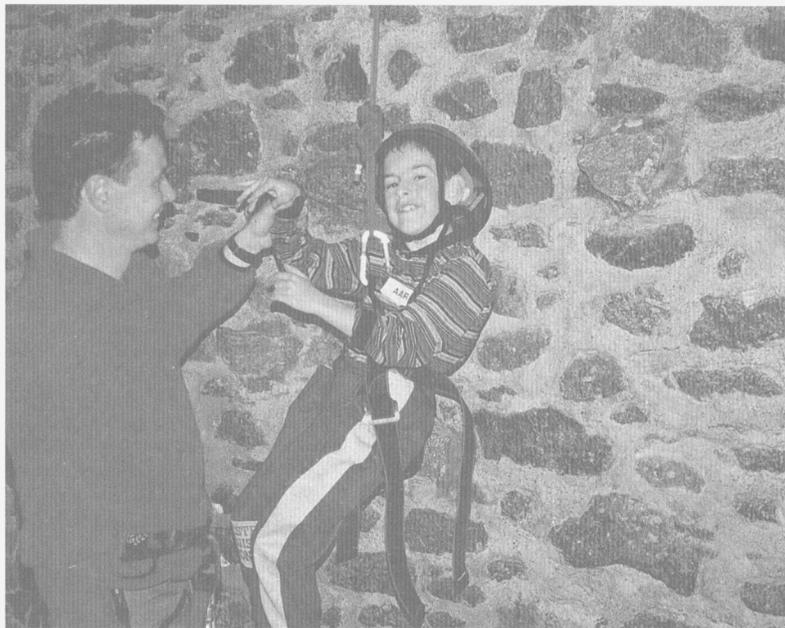
staff were exhausted. People were sent down to groups, patted on the backs and the

rabbits; the braver ones held Otis the snake; the foolhardy went goat racing.

All too soon it was lunchtime, the last session of Chinese PE (with parents who had arrived early) and time to go.

There were sad farewells and exchanges of phone numbers: all the young people took a tape of the Chinese PE music and a folder of information leaflets. Their personal profiles, completed earlier, followed.

As in previous years, ASBAH is indebted to Children in Need: without its generosity, this course would not have been possible.



Eleven-year-old Aaron Gill on the climbing wall



Walk along the cliff-top to Polzeath

New benefit rates from April '99

	OLD RATE	NEW RATE
CHILD BENEFIT		
only, elder or eldest for whom child benefit is payable (couple)	11.45	14.40
only, elder or eldest for whom child benefit is payable (lone parent)	17.10	17.10
each subsequent child	9.30	9.60
DISABILITY LIVING ALLOWANCE		
Care component		
Higher	51.30	52.95
Middle	34.30	35.40
Lower	13.60	14.05
Mobility component		
Higher	35.85	37.00
Lower	13.60	14.05
INVALID CARE ALLOWANCE		
	38.70	39.95
SEVERE DISABLEMENT ALLOWANCE		
Basic rate	39.10	40.35
Age-related addition (from Dec '90)		
Higher rate	13.60	14.05
Middle rate	8.60	8.90
Lower rate	4.30	4.45

	OLD RATE	NEW RATE
INCOME SUPPORT		
Personal allowances		
<i>single</i>		
under 18 – usual rate	30.30	30.95
under 18 – higher rate payable	39.85	40.70
18 to 24	39.85	40.70
25 or over	50.35	51.40
<i>lone parent</i>		
under 18 – usual rate	30.30	30.95
under 18 – higher rate payable	39.85	40.70
18 or over	50.35	51.40
<i>couple</i>		
both under 18	60.10	61.35
one or both 18 or over	79.00	80.65
<i>dependent children</i>		
from birth	17.30	20.20
from Sept following 11th birthday	25.35	25.90
from Sept following 16th birthday	30.30	30.95



Katie Bramall (left) proudly displays her Award, congratulated by her Girls Brigade captain Janet Clarke

KATIE Bramall, who has spina bifida occulta and a tethered spine, has won a rare honour for playing a full part in Girls Brigade.

Despite mobility problems and numerous operations, the 10-year-old joins in as many of the physical activities as she can.

In front of a packed church hall in her home town of Sheffield, Katie was presented with the National Girls Brigade Endurance Award, only seven of which were given last year.

Her mum, Nicola, said: "Katie has been going to Girls Brigade for a few years now. She even went on crutches after an operation because she enjoys it so much. She is a shy, quiet girl and has made a lot of friends there."

A total of £50 was raised for ASBAH at the presentation evening.

Benefits decision-making and appeals update

NEW appeals procedures have been introduced to streamline the process and improve customer service, says the Benefits Agency.

Before April this year, customers lodged their appeals with the Benefits Agency (BA) which then sent on the application to the Independent Tribunal Service (ITS) for registration. ITS then sent BA pre-hearing enquiries and awaited the appeal submission. The appeal submission was then copied to the customer.

Now the BA will, on receipt of the appeal application, prepare the

submission and send the customer a pre-hearing enquiry form on behalf of ITS. This will include a request to the customer to return the form to ITS. At the same time, the appeal submission will be sent to ITS, the customer and the presenting officer.

The pre-hearing enquiry form will be amended to incorporate these changes.

These improvements have been introduced ready for decision-making and appeals changes which will be brought in under the Social Security Act from summer '99.

BA's overall aims with decision-making and appeals are to:

- Improve accuracy and speed of decision-making.
- Improve customers' understanding of decisions and the new dispute process.
- Create a more effective dispute process resulting in the need for fewer appeals and
- Introduce a simpler, faster system for progressing appeals.

More information on appeals improvements on 0171-712 2434.

Hydrocephalus Network News

Ann

Summer'99

New book now on sale

OUR new book, *Hydrocephalus and You*, is now available from the information department at ASBAH National Centre.

In its 81 pages, the book contains a wealth of information on all sorts of topics – from an overview of treatments through to items about precocious puberty, eating problems and upper limb control.

Hydrocephalus and You covers 26 different topics, as well as chapters from Valerie Bottoms, Jo Relfe and Liz Galfskiy who explain how the condition has impacted on their lives and families.

Editors are Leonie Holgate, ASBAH's retired hydrocephalus adviser, and Rosemary Batchelor, co-ordinator of our Hydrocephalus Network and senior adviser (health and policy issues) at national centre.

The book is easy to read and will appeal to people with hydrocephalus as well as

other family members, carers, teachers and other professionals.

Contributors include ASBAH's hon consultant in hydrocephalus Roger Bayston, neurosurgeons Michael Vloeberghs, Paul May and Carys Bannister, physiotherapist Carole Sobkowiak, paediatrician Derek Johnston and Peter Walker, our retired specialist adviser (education).

Illustrations were supplied by hospital neurosurgery unit charge nurse Pete Noons and cartoonist David Swift.

● *Hydrocephalus and You*, published by ASBAH, priced £9.99 (plus £1.00 p&p). Please send cheques (payable to ASBAH) to Information Department, ASBAH, 42 Park Road, Peterborough PE1 2UQ.

Research study seeks parents' views

By Ineke Pit-ten Cate
Research Fellow

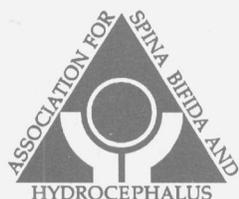
OVER the last 30 years there have been a number of studies identifying specific developmental consequences for the child with spina bifida and or hydrocephalus. However, no recent study has addressed how to integrate these findings and translate them into the educational and home care needs of the children with SB &/or H and their families. Furthermore, with improvements in medical technology and changes in services for children and families with disabilities, things that were true 25 years ago, might not be applicable today.

ASBAH has funded a three-year research project to be undertaken by Professor Jim Stevenson and Ineke Pit-ten Cate at the University of Southampton, Centre for Research into Psychological Development. The study will look at the developmental, behavioural and psychological characteristics of children aged 6-12 years with SB &/or H and will be in two stages.

Firstly, we will ask for the views of a large sample of parents, recruited via ASBAH, regarding the developmental, educational, behavioural and psychological achievements and difficulties of their children with SB &/or H.

Parents all over the country

continued on HNN page 3



Published by the **Association for Spina Bifida and Hydrocephalus**
42 Park Road, Peterborough PE1 2UQ.
Tel: 01733-555988 Fax: 01733-555985.
e-mail: rosemaryb@asbah.demon.co.uk
Registered Charity Number 249338.

Hnn contacts

Network Co-ordinator:

Rosemary Batchelor
01733-555988.

Education (SE and Eastern):

Petrina Noyes 01733-555988.

Education (Wales, SW and

Midlands): Bruce Graham
01865-847332 (phone & fax).

Education (North): Joanne

Grenfell 0113-255 6767.

Education (Northern

Ireland): Lorna Johnston
012477-72191.

Medical/Contenance

(National): Paula Thompson
01733-555988.

Medical/Contenance

(South East): 0181-449 0475
Caroline Berkley (Mon, Tues
& Wed am). Gillian Yaz
(Wed pm, Thur & Fri).

Medical (North): Annette

Whitaker 0113-255 6767.

Medical/Contenance,

(Northern Ireland): Marie
McGonnell 016487-64748.

Occupational Therapist,

(North): Shirley Kearns
0113-255 6767.

Hydrocephalus (Northern

Ireland): Lorna Johnston
012477-72191.

User-forum

(England & Wales):
Jon Burke 0113-255 6767.

User-forum

(Northern Ireland): Helen
Clarke 01396-881898.

LORNA JOHNSTON, who has the dual role in Northern Ireland of specialist adviser (education) and specialist adviser (hydrocephalus), had some of her lines of communication blown after her cockatoo got hold of them.

Ozzie was given the freedom of Lorna's office as she thought she had made it cockatoo-proof.

But Ozzie objected to the door being shut and, when trying to make a break for freedom, chewed through the telephone wires running down the wall by the door.

Lorna's ASBAH phone line and personal phone line were taken out. Fortunately, the ASBAH phone could be hooked up to another outlet in the kitchen.

However, her own phone line, for email and the Internet, were out of operation for three weeks until her husband could fix it.



**Staff
profile**

Ozzie, short for Ozymandias (King of Kings), is let loose in Lorna's office or in the front porch.

Ozzie's favourite activity equipment has been put in the porch – cardboard box with telephone directories in it; a three-tier plant-stand with branches attached to it; and a perch. Ozzie also has two boxes with directories in the office, and one in the kitchen.

Lorna says: "I don't like the name Ozzie – I usually just call him 'my beautiful boy'. I'm willing to consider more creative suggestions!"

New longer driving test should be welcomed, says BSM

DISABLED people should welcome the longer, more difficult driving test which started in May, says the British School of Motoring (BSM).

Keith Cameron, head of road safety policy at BSM, said: "The new test will produce drivers better able to cope with modern driving conditions, and I wouldn't want to make any differentiation in this respect between able-bodied and disabled drivers."

Until 4 May, there had been

no set limit for small faults committed during the test. But the new test regulations stipulate that any candidate committing more than 15 minor errors will fail. As before, one serious or dangerous fault will result in failure.

Other changes include: seven extra minutes on the road, more driving on higher-speed roads, only one in three candidates being told to make an emergency stop and a printed explanation of the test results.

Research study seeks parents' views, from HNN p 1

will receive questionnaires by mail. A wide range of views should enhance our understanding of the experiences of children with SB &/or H and their families.

The second stage involves an assessment of children with SB &/or H living in the Southampton area. We will also assess a group of children born prematurely and a group of children without any health problems to allow comparisons to be made.

We will then try to answer the following questions:

- What is the impact of H &/or SB on intelligence, language, specific cognitive abilities, gross and fine motor control, and on emotional and behavioural development. And is there a relationship between these developmental aspects?
- To what extent can variation in these developmental outcomes be accounted for by differences between the children in the severity of their condition and by differences in family and social circumstances?
- What are the educational needs arising from the developmental and psychological difficulties identified above?
- Are parents and teachers aware of the psychological difficulties experienced by these children in general and in relation to individual children? What solutions have been found? And what is their success rate?

Mum fights on to assert parents' rights in hospital

CAROL Glass, who took an NHS trust to the High Court because hospital staff went against her wishes by refusing her profoundly disabled son life-saving treatment, has vowed to continue her fight for parents to be heard.

Twelve-year-old David is now home. He has hydrocephalus and is currently blind, has spastic quadriplegia and severe learning difficulties.

Last July, he was admitted to St Mary's Hospital, Portsmouth with a chest infection. He spent 23 days on artificial ventilation before going home. In October, when he was readmitted, the hospital trust chief executive – contrary to his mother's wishes – told medical staff to administer pain-killing diamorphine which his mother feared would hasten his death.

It led to a violent incident, with doctors and police being injured, as about 15 family members entered the ward and vigorously resuscitated David, despite requests not to from hospital staff.

Mrs Glass said: "David was in a drug-induced state and needed to be revived. The hospital had decided to write him off and claimed he was in a persistent vegetative state, but he was not. I also knew that he was in neither stress or pain."

Mr Justice Scott Baker in the High Court rejected a move for judicial review over the family's rights. He said if difficulties arose in future, it would be desirable that the matter be referred to the High Court's Family Division before the situation became acute.

Mrs Glass is appealing against the High Court's decision to give her no right of appeal.

She told HNN: "Parents should question doctors if you are in doubt about treatment. Or, if you feel you are being railroaded, ask the hospital for the number of the Official Solicitor.

"Parents know their children best; medical staff only see them when they're ill. Some of them don't believe disabled children have a quality of life."

- To what extent are children aware of their own psychological difficulties?

The success of this research depends largely on the cooperation of the families we contact. As we have said, it will be initially families contacted via ASBAH that will

take part and, in anticipation, we would like to express our appreciation for the time and interest you may show in helping us with this work.

● *All families on the ASBAH database with a child aged 6-12 will be sent a copy of the questionnaire.*

Paper on Benign Intracranial Hypertension (BIH)

by Sussman, Sarkies and Pickard

WHAT an excellent paper on BIH, pulling together references dating from 1897. However, it has not been written for those who lack medical knowledge, or those with little or no understanding of the problems and complications which are commonly associated with this condition.

The paper gives details of all aspects of BIH, its definition, incidence, clinical symptoms and signs, investigations, the causes and effects of raised intracranial pressure and its management. The paper commences with a poem on *Life with BIH* which demonstrates that patients should be looked at as 'real' people with lives, emotions and feelings, not just a 'medical condition.'

BIH is illustrated as a controversial condition, with a variety of opinions on its causes, effects (especially in respect of brain swelling) and methods of management. This latter section, on management, is very enlightening. It specifies various methods of treatment including weight reduction, serial lumbar punctures, drug therapy and surgery. There are many references to the viability, complications and possible outcomes of all these treatments. The various types of optic nerve surgery are well documented. My attention was drawn to the statement 'too many patients have not been adequately investigated.'

Most of the references are

Review by Liz Galfskiy
founder member of the
BIH Support Group



dated from between 1966 and 1993, with very little noted over the past five years. It is surprising that the evidence for incidence is based only on statistics from Iowa, Louisiana and Libya, which were published 11 years ago (1988). The last series for evaluation of untreated patients, who appeared to undergo spontaneous resolution, was in 1968 and 1981. The most recent references noted seem to have an emphasis towards the eyes.

Although it was stated that 'BIH is self-limiting', there was no source reference for this statement. I feel that this article highlights that more research is urgently needed. Perhaps there is a need to go back to basics. To collate

numbers of people with this condition in Great Britain, their statistical details (age, sex, weight, etc), treatment with drugs (including outcomes) and surgical procedures. Once we have more recent, accurate, up-to-date information, then, perhaps, the most desirable treatment and (more importantly) a predisposing cause may emerge.

Postscript: I heard from a Japanese neuro-ophthalmic surgeon that in his country no one has BIH. Perhaps sufferers should start eating sushi or move to Japan?

● *For more about the BIH support group, contact Lyn Rylance at ASBAH House, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988.*

NEWS IN BRIEF ... NEWS IN BRIEF ... NEWS IN BRIEF

● THE Disability Foundation (TDF), at Edgware Community Hospital, Middlesex, offers complementary therapies like reflexology and massage at reduced prices, support groups and a large disability database. In time it hopes to offer counselling, benefits advice and many more services.

TDF, Edgware Community Hospital, Middx HA8 0AD. Tel: 0181-952 5410. Email: info@the-disability-foundation.org.uk

● THE Court Service has a free telephone helpline for disabled court users on 0800-3583506 (open office hours). It gives information on access to courts and take comments and complaints.

True story

MY SON Ben was born by Caesarean Section but he got stuck so they used forceps.

When Ben was three months old, I noticed his head was a funny shape. When I mentioned this to my health visitor she said it was due to putting him to sleep on his back and it would change again once he was sitting up.

When he was nine months old, I asked my GP if she thought Ben's head was large and an odd shape. She measured it and said it was very large and well off the centile chart. She arranged for the hospital doctors to see him the following day.

The hospital ran tests. A CT scan didn't show a lot of fluid but I was told to come back each week so that his head could be measured.

The following week his head had not grown but I told the doctor that Ben was getting more irritable and was always stroking his head. They put a pressure monitor in his head. This proved he did have high pressure and they put in a VP shunt when he was 10 months old. This made a huge improvement and he became a happy contented little boy again.

About six weeks later, Ben became irritable and tired-looking, so I took him to my GP. He put it down to a virus

**By Anita Clinton,
Newcastle-Upon-Tyne**

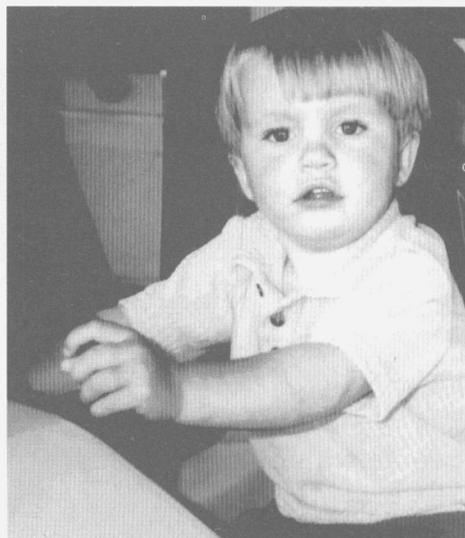
and told me not to worry. A few weeks later, Ben was still not well, so I took him to a female GP at the practice, which proved to be my best move. She phoned the hospital straight away and spoke to his neurosurgeon. Ben had another pressure monitor put in which again showed he had high pressure.

When revising the shunt, the old one was found to be blocked. Ben had a lot of fluid this time. He improved again and was happy.

Ten weeks later, Ben started showing familiar symptoms so I took him to my GP and again she phoned the neurosurgeon straight away. The hospital did a scan which showed more fluid. Measurements showed his head had grown half a centimetre in three weeks so he had another shunt revision.

Thirty-six hours after being discharged he had a stroke. The doctors say it was caused by the operation as his shunt was stuck and, when they pulled it out, it had caused a bleed. He was paralysed down his left side.

Ben has regained most of his strength down his left side but he still shakes, mostly in the morning.

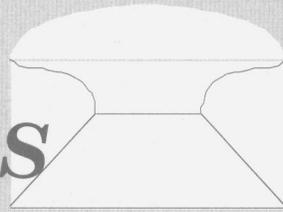


Ben Clinton

In April '98, he started to feel unwell again. A pressure monitor showed there was low pressure but the doctors decided low pressure wasn't a problem so they left him to see if he improved. He didn't improve, so they reluctantly changed the valve to a Delta 2. The result was great – he returned to the happy, contented little boy of old. He had a good few months but, at the end of July '98, he became very irritable and cried constantly for two weeks, but then became happy and playful.

Ben was great until last October – one minute he was happily eating his lunch, the next he became listless and sleepy and, about 30 minutes later, he vomitted (projectile). We took him to Casualty, bearing in mind he could hardly move his head. We waited three hours to see a doctor and all this time he was asleep and vomiting. But the doctor did not think it was his shunt and we were sent home. Ben improved over the next couple of days.

continued at foot of page 6
Ann 5



 I JUST wanted to tell you about our conference held in Sydney. It was successful with about 60 people with hydrocephalus and parents attending. Among our speakers were four neurosurgeons.

*Penny Wilkinson
Hydrocephalus Support
Association
Australia*

**Please send your letters, True Stories and feedback to:
Rosemary Batchelor
HNN Co-ordinator
ASBAH,
42 Park Road
Peterborough
PE1 2UQ**

 I HAVE hydrocephalus and used to write to a lad in Canada called Sean Sudol from Barrie, Ontario. I have not been in touch with him for some years – does anyone have his address.

If anyone else would like to get in touch, please feel free to write to or e-mail me.

*Peter Davis
84 Valley Road
Sheffield S8 9FY
email:*

Peter.Davis@student.shu.ac.uk

What's in the July/Aug Link

Red Army Progress	p3
Tanni's wedding	p7
London Marathon	p8-9
ASBAH research	p10
Enjoying ASBAH'S Challenge in Cornwall	p14-15
New benefit rates	p16
HNN	p17-24
Link letters	p26

Link is ASBAH's main magazine. Subscription: £4.80 a year (six issues). Details: National Centre.

Hnn – Annual subscription rates (four issues a year) are: £2.00 (UK); £5.00 European and overseas surface mail and £10.00 by airmail.

If you are not sure when your subscription is due, please phone Lynn Thomas in ASBAH's Services Department on 01733-555988.

True story

Ben Clinton, from page 5

Since then, Ben is up and down and keeps vomiting every so often, and he feels sick a lot also. His development has also stopped, his behaviour is bad, sometimes so bad, he seems disturbed. I cannot do anything for him, he screams for no reason. Ben's pre-school teacher, who comes to see him, agrees with me and says a lot of the time

he seems 'spaced'. He just cannot be bothered to do anything other than play with the video player, fast forward it and rewind it all day.

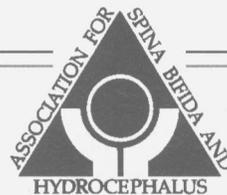
Doctors think I am over-protective. They don't think it is Ben's shunt but the 'terrible twos.' But Ben is my third child and I know the difference between tantrums and what Ben does. It's frightening and bound to be having an effect on him. As each doctor dismisses my worries, Ben is suffering. I feel the neurosurgeons only take any

notice if you are unconscious. Ben has had a scan but this proved okay. I asked if it could be intermittent shunt blockage and was told it could be, and that was that.

When Ben is well, he is a real pleasure – happy, funny and very loving. I wish Ben could always feel that way but, unfortunately, he doesn't which is the most heartbreaking thing a mother can watch her beautiful son go through.

If anybody feels they can help, I would love to hear from them.

ASBAH publications review



We are undertaking a review of all of ASBAH's publications, and would like your views. Please fill in this questionnaire today and return it straight away to:

**Information Dept (GW), ASBAH
42 Park Road, Peterborough PE1 2UQ**

Tick boxes where appropriate

1. Which publications do you receive?

- Link Bulletin
 Lift Hydrocephalus Network News

2. What do you like in the magazines / newsletters?

(please state which one you are referring to if you have ticked more than one box above)

3. What don't you like in the magazines / newsletters?

(please state which one you are referring to if you have ticked more than one box above)

4. Is there anything that you would like to see in the magazines / newsletters that is not in them at the moment?

5. Are you

- a parent of someone with SB/H?** *Please specify which* _____
 someone with SB/H? *Please specify which* _____
 other? *Please specify* _____

6. Age. Are you

- under 18?** **31-50?**
 18-30? **over 50?**

Thank you for taking the trouble to fill in this form. Please now photocopy or cut out this page and send it to the address above.

True story



Daniel Berney

DANIEL was my first born. He was my little miracle.

I had been told I would need help to conceive so I was almost in a state of shock when, one day, a consultant told me I was 23 weeks' pregnant.

Born 20 days late and weighing nearly 10 pounds, Danny was resuscitated at birth after a difficult labour.

We took our bundle of joy home and all was going well. At the weekly check-ups at the nearby clinic, they were only mildly concerned about his 'floppy' head. Even when his head circumference had gone off the scale (100%+) at seven weeks, they seemed indifferent. However, they did arrange an appointment for Danny to see an appropriate specialist. This took 13 weeks and, then, we were sent to a plastic surgeon. No other arrangements were made.

Over the next fortnight, Danny started having what

**By Rachel Berney,
Leamington Spa**

we now know to be seizures. Being beginners at parenting, I asked the health visitor for some advice. She sent me to the GP who actually saw a seizure whilst we were at the surgery but he only gave Danny antibiotics and sent us away!

One night Danny had about 25 of his fits in one and a half hours. We were now very concerned and frightened. We took him to Casualty early the next morning. After excellent attention and thorough examinations, we were told that Danny had blood on the brain and they didn't know why.

Every parent who has never been through such experiences with their child wonders how they would cope ... I can honestly say that you go on to automatic pilot. You hold it all in for the sake of your little one. After four days of further assessment, we were told he had hydrocephalus. We were told that a shunt would help and went home after two weeks to start daily physiotherapy to help him get movement back to his left side which he lost through brain damage.

Danny is a bright, affectionate, endearing little boy who is always keen to please. He loves playing football and playing on his computer.

I thought that the mild hemiparesis (restricted movement) on Danny's left side would be the only scars. But last November, I finally rang ASBAH to ask about some of Danny's behaviour that my gut instinct told me had a root cause in his hydrocephalus.

The lady on the phone was of medical background and was fantastically helpful. All the things that had bothered me or that I'd struggled to manage in my own son, suddenly made sense. I wasn't looking for an excuse for his behaviour, I just wanted to help him by using the correct strategies.

Danny is now in his second year of mainstream schooling and, up to now, has had no extra support.

By coincidence, ASBAH ran a day course in Birmingham, *Education and the Hydrocephalus Child*. Three members of staff from Danny's school attended, one of whom was his class teacher. She now feels that we should apply for extra classroom support for Danny. This we can now do *together* on a more informed basis. There were a lot of parents and teachers on the course simply looking for ideas on how to cope. The course certainly gave us many ideas. More of the same please!

Thank-you ASBAH. I feel like I've found a pot of gold!

IN a previous Diary, I mentioned that I was going to buy a new computer. I had finally got enough money to replace my useless old computer. A new computer would greatly speed up my writing and work. Or so I thought.

What should have been a joy turned into confusion and nightmare. I read through a few magazines to see what computer I wanted and what I could get (what I needed never really entered my thoughts). I wandered into a few shops and was confused by the variety of computers on sale and trying to spot a bargain.

The problem is that, although different computers can be for sale at roughly the same price, no two are alike. One will have a bigger screen than the other, but the other might have more memory. Some have software; others don't. It was impossible to compare them and see if I was getting a bargain or not.

How much you'll end up paying is not always obvious. Computer adverts often show the price with VAT (small numbers) and without VAT (large numbers). Sometimes they show the price without VAT, leaving you to work out the total (after you've added on an extra amount for using a credit card or having your computer delivered). Most confusing!

Even when you use a famous company and the price is shown including VAT, you have to watch out. After months of looking around, I spotted what I thought was a bargain. The shop was half an hour's

drive away but mum gave me a lift (you can't carry a computer on to the bus). I got to the shop, tried out the computer and had my credit card on the table, when the assistant checked the price. Apparently, the price I'd seen advertised was a special offer which had ended. The new price was another sixty quid, thanks very much.

I was a tad miffed and explained that, before we set off, I'd phoned up to confirm they still had that computer and no-one had said by the way, it's just got loads more expensive! I said I didn't just have another sixty quid hanging around. No problem, said the salesman. If I bought an extra £250 worth of insurance he could knock off the £60. Really? I may have problems with my maths but that still didn't sound like 'bargain of the month'! I walked out, never to return.

Eventually, I got a computer from a local company that gave me a straight price. I brought it home and, surrounded by wrecked packaging, spent hours setting it all up. I accessed the Internet to check my email, then went to sleep. Next day I found I had a killer virus which would stop me from doing any writing for weeks.

The virus had nothing to do with my own lousy health, but was a computer programme, created by some teenaged spawn of Satan, which had come down the phone line and was now doing horrible things to my precious files.

After weeks of pressing buttons, reinstalling all my files and long calls to technical support trying to

work out what's wrong, I took the computer back. They promptly gave me a new computer and some free software as an apology. I was happy but surprised they'd not included some software with the computer that would kill these viruses before I had to bring it back. I bought some there and then!

So, if anyone's looking to buy a computer, tread carefully, check the price, and for goodness sake check you have your programmes on disk and anti-virus software before you go anywhere near the Internet. And check your old software will work on the new computer. Surprise: after all that, mine didn't! Aaargh!

After all this aggro, was it worth buying a new computer? Absolutely! Because now I'm back writing again and it is much quicker. But also because I can get on the Internet. Getting onto the Internet made my old computer cough and wheeze and die. The new computer handles the job with amazing ease. Being on the Internet means I can find information on, and places discussing, every issue under the sun – including spina bifida. I can also meet people around the world who have SB!

David Fulford-Brown
david.fulford-brown@virgin.net

Diary dates ... Diary dates ... Diary dates

Sunday 18 July

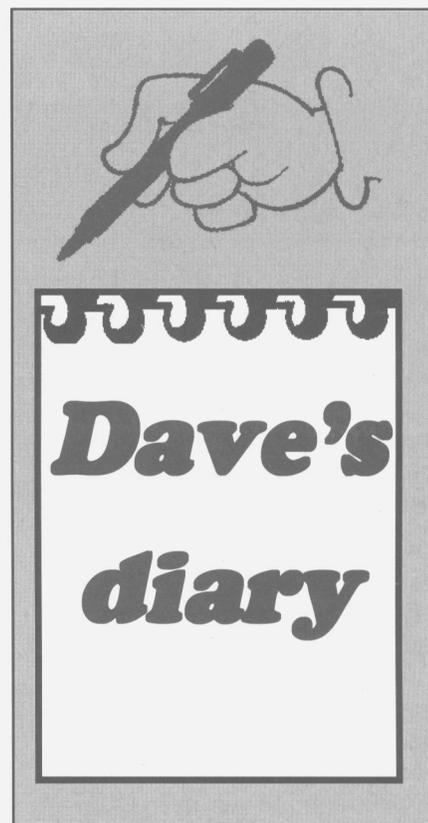
Disability Awareness Day, Walton Hall Gardens (off A56), Warrington, Cheshire. *Dave Thompson*, tel: 01925-664064.

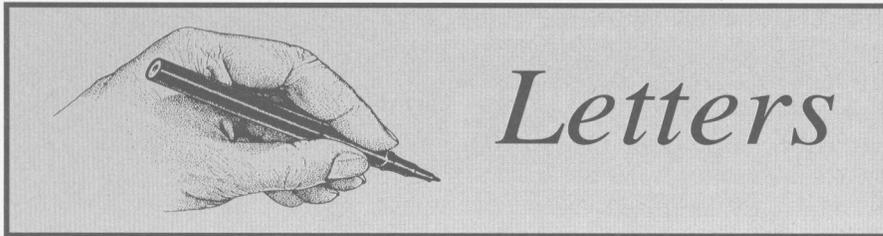
8 – 15 August

Activity holiday for physically disabled/able-bodied 15-17 year olds, organised by the Scripture Union, Valence School, Westerham, Kent. Cost: £141, grants to help in cases of special hardship. *Miss Paula Smith*, tel: 0181-393 1376.

24–26 September

North Wales ASBAH presents 'Breakaway!', a weekend of activities and workshops for severely disabled people with SB and/or H and carers, Plas Menai, Portdinorwic, North Wales. Cost: £90 per couple (inc B&B, and all meals from Friday evening to Sunday lunch), £30 payable on booking as deposit. *Details: Mrs Jill Bartlett, ASBAH, 4 Tai'r Felin, Felinheli, Gwynedd, North Wales LL56 4JF.*





 I READ in the local paper about Professor Zachary's death and the well deserved Memorial Service for him on 23 June. Unfortunately, I cannot be there, much as I would love to be. However, I wanted to give you some personal memories of a great man.

I had the great privilege to work with Mr Zachary or 'Zac' as we called him privately many years ago, first as a student nurse then later as Acting Sister. Throughout that time he always treated myself (and my colleagues) as equal partners in the care of the children. I saw him on the wards, in Outpatients, in Casualty and finally 'scrubbed' for him many times in theatre. He was always a true gentleman; any reprimand had an edge of humour; he was also very patient with inexperience!

The most memorable facet of his character was his constant love and concern for all his patients. Many times I saw him rapidly gain the total confidence of a frightened child, even when everyone else had failed. We all knew of his strong religious faith and we were well aware he would visit the wards on a Sunday morning very early before Mass and realised that the children were probably remembered in his prayers there.

No child was ever regarded by him as a 'hopeless case'. He always did everything he could for them no matter how disabled they were. I well remember when he introduced the Spitz-Holter valve which he brought from America. Not everyone agreed on its value, but his determination has been well vindicated. Now there must be hun-

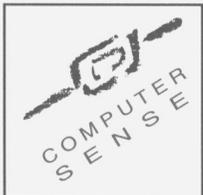
 We invite letters for publication. Send them please to: **Editor, ASBAH, 42 Park Road, Peterborough PE1 2UQ.** The Editor reserves the right to edit letters for publication, so please keep them as short as possible.

dreds of people living happy, normal lives with children and grandchildren who would never have had that opportunity but for him.

I hope his retirement was as happy and fulfilled as he deserved. May he rest in peace and light perpetual shine upon him.

Though I will be in Malta on 23 June, I intend to remember him there and light a candle to celebrate his life. Do tell his family (though I'm sure they will know already) that there are many more nurses with good memories, who feel proud and privileged to have known and worked with him.

Mrs E R Pownall RSCN RGN RHV (retired), Balby, Doncaster



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 OUR 16-month-old son Samuel has spina bifida and hydrocephalus. He also suffers from respiratory problems relating to his Arnold Chiari Malformation Mk II. When Samuel cries, he fails to inspire which leads to a breath-holding spell or apnoea, and he rapidly turns blue and faints.

We would be very interested in any help or advice from parents of children who have suffered the same complications. In particular, we would like to find out if the respiratory problems reduce as Samuel matures.

*Mr and Mrs Guy
Chapel Down Cottage
1 Fore Street
Exbourne, Near Okehampton
Devon EX20 3RU*

 ON 7 and 8 August myself and five of my 'gym friends' will be doing a sponsored cycle ride following the coast to coast route from Whitehaven to Sunderland (140 miles).

We aim to raise approximately £1,000 for ASBAH. I have a 13-year-old son with hydrocephalus and I would like ASBAH to use the money to help in new research.

I would appreciate any donations from readers of *Link*. Donations can be sent to me at the address below.

*Keith Weavin
The Chalet, Laurel Lane
Halesowen, West Midlands B63 3DA*

HOLIDAY ACCOMMODATION

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

ISLE OF WIGHT ASBAH –

Fully-equipped, wheelchair-accessible, two-bedroom bungalow. Sleeps six. Clubhouse, indoor heated pool, shops etc. Lovely views, many interesting places to visit. Own transport advisable. *Details: Mrs S Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF, tel: 01983-863658.*

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.*

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: 01494-741270 (Bucks & E Berks ASBAH).*

KILN PARK HOLIDAY CENTRE, TENBY, WEST WALES –

Fully equipped five-berth wheelchair accessible caravan situated in holiday park with excellent facilities including pools, shops, entertainment. Close to beaches and town. *Details: Mrs Brenda Sharp, 01446-735714, 4 Lakeside, Barry, CF62 6SS.*

ORLANDO, FLORIDA –

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

LOIRE VALLEY, FRANCE –

Self-catering farmhouse, south of River Loire. Ground floor bedroom has double & single beds with en suite bathroom/toilet equipped for wheelchair-users. English-speaking owners live next door, one of whom is wheelchair-user. *Cheryle & Rinus Baker-Noordhuizen, Guinefolle, 49560 Clere-sur-Layon, France.*

FOR SALE

MEDICBATH with shower attachment, sliding seat for easy access, front-closing door. Pump included. Hardly used. New over £2,000, asking £1,250. *Contact: Mrs Paterson, tel: 01732-451135 (Kent).*

RED tricycle with chopper-style seat, suit age 6-10 years, free to good home. Much loved outgrown tricycle of a child with hydrocephalus. *Tel: 01472-691221 (Mrs Pratten, Cleethorpes, N E Lincs).*

SEAT TERRA van. G-reg, fully adapted to carry wheelchair passenger. Pull down ramp, electric winch, MOT'd until Feb 2000. Only 32,000 miles. £1,900 ono. *Telephone (01204) 795276 (Bolton).*

FORD ESCORT 1.6LX 16-valve automatic, 3-door, 1997 P-reg, 4,000 miles, air conditioning, ABS, pepper-red metallic. Passenger-side electric lift with electric wheelchair. £22,000 when new, asking £9,500. *Parkland Motors, Midhurst, West Sussex, tel: 01730-813225.*

SUNRISE Sterling Midi Senior almost new scooter. £1,200 (new £1,850). *Tel: 01923-856474 (Herts).*

ACCOMMODATION

ILKLEY, West Yorks – Sanctuary Housing Association wheelchair-accessible flat, sharing with two females. Emergency warden cover and support services available, if required. Semi-rural location with panoramic views across Wharfe Valley. Half-hour by train from Leeds and Bradford. *Contact: Mark Best, tel/fax: 01943-603013.*

LINK Rates

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£6.25 for 45-60 words.

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

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

Display Rates on application, from the Publicity Manager.

AFFILIATED ASSOCIATIONS

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

BEDFORD

Mrs M Simmonds
16 Parkstone Close
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Cheshire WA1 4PD
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Llandudno
Tel: 01492 878225

South Wales

Mrs Brenda Sharp
4 Lakeside, Barry
S Glamorgan CF62 6SS
Tel: 01446 735714

NORTHERN IRELAND

Mr J Rippey
Long Eaves
24 Tullywiggan Road
Cookstown
Co Tyrone BT80 8SD
Tel: 0164 87 62290

NON AFFILIATED ASSOCIATIONS

Blackpool & Fylde

Mrs Diane O'Hagan
83 Boothley Road
Blackpool
Lancs FY1 3RR

Calderdale

Mr A L Crowther
12 Elm View
Huddersfield Road
Halifax HX3 OAE
Tel: 01422 341497

Cannock & Walsall

Mr Ken Hall
17 Wallhouse Street
Cannock, Staffs
Tel: 01543 504847

Chesterfield

Mrs K Tomlinson
23 Hathern Close,
Brimington Common
Chesterfield, Derbys
Tel: 01246 272724

Cornwall

Helen Youngman
13 St Petry, Gears Lane
Goldsithney, Penzance
Cornwall TR20 9LA
Tel: 01736 710261

East Anglia

Mrs L Turner
7 Stow Gardens, Wisbech
Cambs PE13 2HS
Tel: 01945 466205

Essex

Mrs R McCarthy
26 Brixham Gardens
Ilford, Essex IG3 9AX
Tel: 0181 594 1852

Isle of Wight

Mr D J S Sprake
Springfield, Town Lane
Chale Green, Ventnor
I W PO38 2JS
Tel: 01983 551234

Lancaster, Morecambe & District

Mrs Dyson
25 Royds Avenue
Heysham, Morecambe LA3 1PA

Nottinghamshire

Mr Allan Barratt
127 Linnetree Road
Hucknall
Notts NG15 6AW
Tel: 0115-953 7291
Fax: 0115-953 2081 (8am - 6pm)

Rochdale

Mrs Anne Lawton
20 Spencer Street, Chadderton
Oldham, Lancs
Tel: 0161 6524487

Whitchurch (Salop)

Mrs E Calder
Southfork
Sedgeford, Whitchurch
Salop SY13 1EX
Tel: 01948 663627

OTHER ASSOCIATIONS

SCOTTISH SBA

Executive Officer:
Mr Andrew Wynd
190 Queensferry Road
Edinburgh EH4 2BW
Tel: 0131 332 0743

IRISH ASBAH

Ms Claire Gill
Hon Secretary, Irish ASBAH
Old Nangor Road
Clondalkin, Dublin 22
Tel: 003531 4572326

JERSEY, Channel Islands

Mrs Mollie Buesnel
Villa Acacia
Sunshine Avenue
Five Oaks, St Saviours
Jersey JE2 7TS

Association secretaries requiring changes to this list should contact: LINK EDITOR, ASBAH, 42 PARK ROAD, PETERBOROUGH PE1 2UQ Tel: 01733 555988 Fax: 01733 555985.