LINK

The magazine for people with Spina Bifida and / or Hydrocephalus

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

Royal visitor to ASBAH

First Link in full colour – enjoy!

HIDDEN TALENT BEHIND OUR CARTOONS

PRICE 80p

MAY / JUNE 2000

ISSUE No 187

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LINK

Cover: HRH The Duchess of Gloucester visited our National Centre – pictures and story on page 5

Editorial

Dear Readers

AFTER almost 34 years of ASBAH's magazine and after introducing colour only fleetingly 87 issues ago – and then just on the front cover to celebrate *Link's* 100th edition – we've finally done it. Full colour throughout!

We hope you like the results. We also hope that readers who have come over from our *Hydrocephalus Network News* and the *Lift* magazine, both now closed, will discover that they are catered for inside. We have used some pretty lurid colour coding to signpost you towards special interest pages in the magazine but, as we hinted in this space last time, the good news is there's a decent spread of material throughout.

We've cut much of the verbiage. We think *Link* now gets to the point more quickly, and does not shy away from controversial material.

I hope you agree.

Tony Britton

Tony Britton
Publicity Manager

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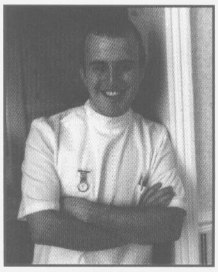

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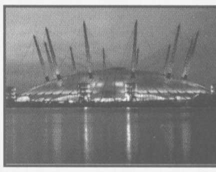

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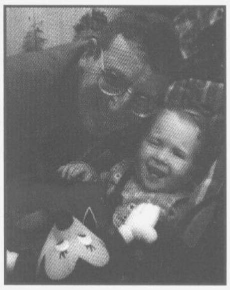

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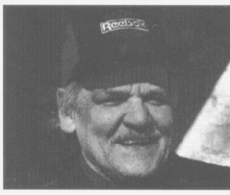

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President: Jeffrey Tate CBE

ASBAH exists to provide advice, support and advocacy to people with spina bifida and/or hydrocephalus, their families, and their carers.
ASBAH aims to empower its service-users by providing up-to-date information, extending their choices, and maximising their opportunities for independence.

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news

Chancellor gives £400m Budget boost to charities

MEASURES to benefit charities by an estimated £400 million a year in tax relief were confirmed in the Budget in March.

Building on his pre-Budget 'Getting Britain Giving' statement, Chancellor Gordon Brown confirmed the following:

- Abolition of the £250 lower limit for Gift Aid donations, which qualify for tax relief.
- Allowing donors to join the 'Gift Aid' scheme by phone or Internet.
- Allowing UK non-residents to make Gift Aid donations.
- A new tax relief for gifts of listed shares and securities.
- Greater VAT relief for the sale by charities of donated goods to disabled people and those on means-tested benefits.
- Extension of VAT relief for bathrooms built for disabled people in day centres, sheltered accommodation and houses owned by charities.
- Broadening the VAT zero rate for charity advertising
- Extension of VAT exemption to more fundraising events.

The measures have been introduced following consultation with the sector. All came into effect in April this year.

■ Inquiries – *Tel: 020-7438 6420. www.inlandrevenue.gov.uk*

New legal rights for carers?

A NEW Bill which will enable carers to receive services in their own right is still working its way through the House of Commons.

The Parliament website showed at the end of March that the Bill is still in committee. It is due to go to the Report stage on 5 May.

Under the Bill, carers for the first time will be able to seek support, even if the person cared for has refused an assessment.

The Carers and Disabled Children Bill was introduced by Labour MP Tom Pendry, with government support.

Paid to go shopping!

A MARKET research company is recruiting disabled people as mystery shoppers. This involves pretending to be an ordinary customer of whichever company is being researched.

Companies want to know how their premises and staff attitudes measure up to the standards of new disability legislation, and have a basis on which to take action if they are not up to scratch.

The job could range from buying a loaf of bread from your local supermarket to having a meal for two in a restaurant.

You are always given clear instructions, in your chosen format, as to what is required on the visit or telephone call: whether you show interest or wait to be served, whether you should buy anything or what questions you should ask.

There is a questionnaire to complete after every visit. Mystery shoppers are paid between £10–£12 a visit plus expenses. For telephone contacts, the fee is between £4–£6.

● *Grass Roots, tel: 0870-870 4483; textphone: 0870-870 4485. Quote reference Dept 01. Info packs are available in a variety of formats.*

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We give a right royal welcome to our Patron

WE'D HAVE rolled out the red carpet if we had one when The Duchess of Gloucester revisited the national centre in Peterborough which she opened 10 years ago.

Her Royal Highness, who has been our patron for 27 years, has always kept in close touch.

During her 30-minute visit at the beginning of March, the Duchess met key members of our fundraising and services teams and chatted to many of the 40 people who work at Peterborough.

Flourishing the latest copy of *Link* magazine, she said: “It is so nice to meet so many of you again. I congratulate you and look forward to receiving your news.”

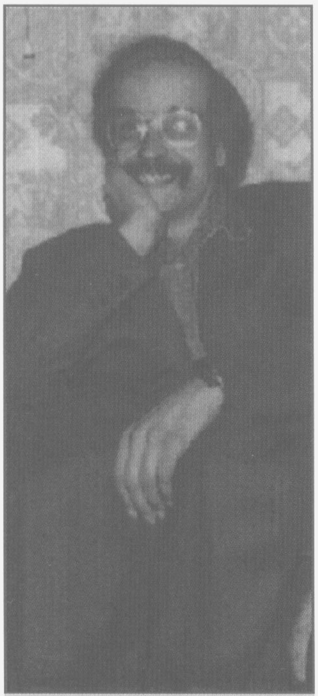
One of the people she chatted to was Eastern Region manager Mary Malcolm, who said: “She's lovely and was really interested in how many service users we have and how many counties we cover.”

Colleague Milly Rollinson, assistant director (services), added: “The Duchess showed she had a real understanding of the disabilities.”

Executive director Andrew Russell commented: “Her Royal Highess has had a special affection for ASBAH since the early days of her marriage, when she was known as the Princess Richard. We were the first charity to invite her to become their patron, and it was a delight to meet her again.”

Top photo: Telesales clerk Kokila Patel presents flowers to The Duchess. Bottom left: The Duchess with, left, telesales operator Asif Shaheed and Andrew Russell. Bottom right: Telesales manager Tom Logan makes a point. Photos courtesy of the Peterborough Evening Telegraph.

Fashion makeover for Balbir



Balbir in his new Wayne Hemingway suit.

FASHION conscious Balbir Singh enjoyed being made to feel like a superstar when he took part in a make-over for TV.

Those who saw *From The Edge* on BBC 2 in March will remember following the fortunes of Balbir from the first time he met top fashion designer Wayne Hemingway through fittings with a tailor to the final pose at Claridges.

Balbir chose the type of garment he wanted – a suit – and the finer details of cloth, colour and cut.

He said: "I gave Wayne the idea of what I wanted and we discussed what would be good for me, for example, I usually use a buckle but, as I have a hump, we talked about elasticated trousers."

Then Balbir met a top London tailor and was shown different types of suits, materials and colours. He chose a light, comfortable material in grey with pink and other colours running through it. This pattern was chosen as it disguised drink spillages. The best length to fit his posture was also discussed.

Some time later, Balbir returned to try the suit and have alterations made.

Finally, the whole process and the stunning result were reviewed by Balbir and Wayne at top London hotel Claridges.

"I had a field day. Everyone was brilliant, even the people behind the scenes like the drivers," said Balbir, who lives in Penge, SE London. "They bought me lunches and I was treated like a celebrity."

Balbir was given the suit, plus a spare pair of trousers, which he kept under wraps until the show went out, despite being pressed by friends to show them off.

"Having something made to measure never occurred to me before. It's fantastic."

Action needed on equipment services

PEOPLE are being stripped of their dignity and independence because NHS disability equipment services fail them in many parts England and Wales, says the Audit Commission.

In its report 'Fully Equipped', the commission says: "Equipment services provide the gateway to independence, dignity and self-esteem for many older or disabled people. Effective service will improve quality of life and promote independence but in many places the quality of services is unacceptable.

"The current organisation of equipment services is a recipe for inequality and inefficiency so urgent action is needed to improve standards and provide a fairer service."

According to the disability charity consortium, emPower, recent research showed that 76 per cent of users experienced problems with equipment, and half had problems with the assessment service.

Users frequently complain of equipment which does not meet their individual needs, is not cosmetically acceptable and in uncomfortable.

These concerns have been raised in Parliament through an all-party Early Day Motion in support of emPOWER's campaign for a National Service Framework on Disablement Services. The motion had been signed by almost 150 MPs by 28 March.

emPOWER chairman Sam Gallop welcomed the publication of the critical Audit Commission report. "We know that Health Minister John Hutton is a keen advocate of improving the provision of prosthetics, orthotics, wheelchairs and assistive technology. This report gives him further evidence to support this cause."

Positive pictures

YOU could win a Pentax camera and be part of a book and exhibition showing positive images of disability.

If you have an eye for what makes a striking photograph and you are aged 30 or less, then think about entering.

You should send at least one photo for the following five categories: sports and leisure; culture; training/education; working activities and family life.

The photos should be accompanied by a journalistic-style text in which you answer the following questions: what? who? why? where? and when?

The closing date for entries for the Positive Images of Youth and Disability Photo Competition is 15 June 2000. Don't forget to include your name, address and contact details as well as your date of birth.

● *Susan O'Flaherty,*
Mobility International,
18 Boulevard
Baudouin, 1000
Brussels, Belgium.
Tel: 32 201 56 08; fax: 322 201 57 63, email: mobint@arcadis.be

Winners of the final Lift competition

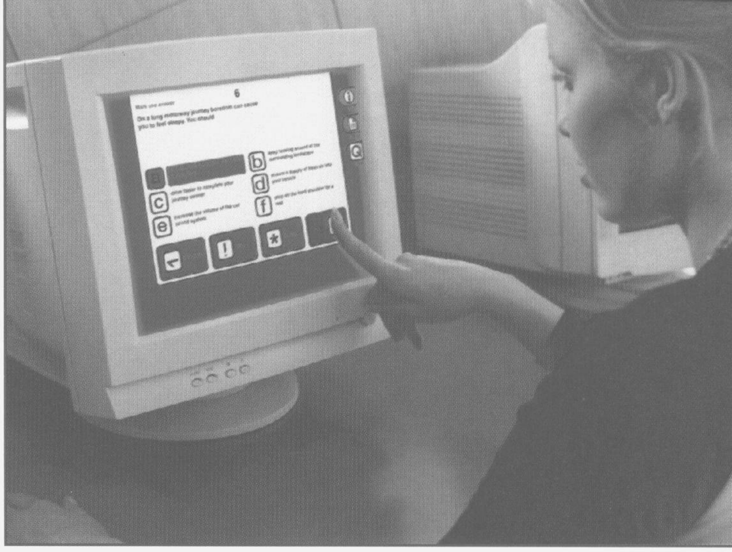
CONGRATULATIONS to the winners of the New Year *Lift* competition which appeared in our last ever *Lift* magazine.

Gordon Carter from Papworth Everard, Cambs, and Louise Roberts, from Wrexham, spotted all of the hidden names of male singers in the Wordsearch contest.

Each won a £10 gift voucher to treat themselves at Boots.

Regular *Lift* readers will remember Gordon in a previous issue as part of a feature on employment. He had landed a voluntary job taking phone calls from listeners to a show on BBC Radio Cambridgeshire. He still enjoys doing this.

He has many other interests including astronomy, creative writing, art and producing a newsletter for the 30 or so tenants who live in care supported flats run by the Papworth Trust.



L-test support

A NEW CD-ROM will help learner drivers with disabilities on the road to driving success by enabling them to practise for the theory test from their home computer.

New Driving Standards Agency rules mean that, other than in exceptional circumstances, candidates for the driving theory test are no longer able to use pen and paper. Instead, they must demonstrate their knowledge using computer technology.

BSM has developed a CD-ROM version of its best-selling book Driving Theory Test Questions 1999-2000. The CD-ROM contains all the possible theory questions and mirrors the way in which the actual test is presented.

Students can brush up their skills by choosing to work through questions topic by topic or they can select a random test option. Either way, the interactive CD-ROM will help them to assess their performance, telling them whether they would have passed or failed. And, where they selected wrong answers to the multiple-choice questions, the right answers are explained.

Suitable for both PC and Apple Mac, BSM's CD-ROM is available from WH Smith, PC World, Dixons and Currys and is priced £19.99. It is also available from BSM centres for just £12.99, a saving of £7.00 on the recommended retail price.

Also look on BSM's website www.bsm.co.uk for more support with Theory Online.

ASBAH benefits leaflet

ASBAH has published a new eight-page leaflet on benefits information, written for parents and carers of children with the disabilities. *To obtain a copy, please ask your ASBAH Adviser or contact ASBAH Information, tel: 01733-555988.*

medical update

Latex warning in multi-dose vaccination

PEOPLE with latex allergy should not be vaccinated against meningitis from a multi-dose vial. This is because the "bung" is usually made from latex.

This also applies to all multi-dose injections or those preparations which are made up by the nurse or doctor giving the injection, eg penicillin.

There are latex-free preparations. These may be single dose or a pre-loaded syringe.

To obtain the correct vaccine, your GP should contact the vaccine co-ordinator (often the local CCDC) for their area and request a preparation which is latex-free.

Fears about chlorine in water supplies

DOUBTS are being raised about the safety of chlorine in drinking water due to fears that it may cause spina bifida and other birth impairments.

British scientists at London University will carry out research after scientists in Norway and Canada reported high levels of birth impairments in areas with chlorinated drinking water.

A Norwegian study of 141,000 births over three years found a 14 per cent increased risk of birth defects in areas where chlorine was added to drinking water.

Dr Per Magus, who carried out the Norwegian research, told the *Sunday Telegraph:* "We are in a unique position in Norway to make these observations because in some areas our water comes from the mountains and doesn't require cleaning with chlorine."

The Norwegian government has ordered more research. Concerned families there have been filtering tap water. A popular method has been to place sachets of coral sand, dredged from fjords, into water before it is drunk – removing all traces of chlorine in tap water in 15 minutes.

Researchers at Dalhousie University, Nova Scotia, found that high levels of trihalomethanes, a by-product of chlorine in drinking water, significantly increased the risk of stillbirth.

An independent specialist on water quality, John Fawell, told the *Sunday Telegraph* that at present the World Health Organisation and other concerned bodies thought that the risk from contaminated water supplies outweighs the risk to health from chlorine. "Levels of chlorine and its by-products have been falling in water. The amount coming out of the average tap is half a millilitre per litre."

Shunt alert card is a must for everyone!

IF YOU'VE got a hydrocephalus shunt, even if you also have spina bifida, you should be carrying one of our Shunt Alert cards.

At present, 2,234 people carry Shunt Alert cards which provide important information to the emergency services in the event of shunt failure caused by blockage or infection.

Most card carriers have hydrocephalus as their main disability. But, says our Hydrocephalus Network co-ordinator Rosemary Batchelor, many people with spina bifida as well as hydrocephalus are NOT carrying cards.

They are missing out on an opportunity to pass on vital information if they, too, experience shunt failure.

"These cards really do work – whether you've got hydrocephalus as the main disability or whether you also have spina bifida", said Rosemary.

"We heard only the other day of one service user with shunt failure who was taken to the local hospital where they had no experience of working with shunts. As a direct result of reading the alert card, the patient's consultant was called in to advise on the best treatment.

"Demand for the Shunt Alert card should be much, much higher than it is."

● *To obtain a Shunt Alert card, contact: ASBAH Services Dept, 42 Park Road, Peterborough PE1 2UQ; tel: 01733-555988; fax: 01733-555985.*

Scope fights clichés

NEWSPAPERS undermine disabled people by using stereotypical images and offensive language on a daily basis, a report by Scope has revealed.

Scope identified 80 disparaging terms which were used in national and local newspapers.

Negative language like handicap, the disabled, cripple, invalid, spastic, brave, plucky, wheelchair-bound, victim, sufferer and disease influences the way society thinks about disabled people, said the report.

Sensational words such as freak, maniac, psycho and retarded were shown to be still commonly used.

Conversely, positive language such as disabled people, wheelchair user and non-disabled respects disabled people as active individuals with control over their lives.

The report acknowledged there were many examples of good practice in newspaper reporting.

Stop Press! showed there was a large increase in the total number of stories relating to disabled people since the last survey in 1991. This was most marked in the tabloids, where there was an increase of over 400% in the number of stories. This, might be attributed to disabled people asserting their rights.

● *Stop Press!, priced £3, from: Scope, 6 Market Road, London N7 9PW. Tel: 020 7619 7245. campaigns@scope.org.uk*

QA Photos/NM

Dome from home for Millennium worker

GREENWICH ASBAH member Chloe Mears, who is 21, is working at the British landmark for the 21st Century, The Millennium Dome.

The excitement of being part of a major new, and frequently controversial, attraction that is high in people's minds combines with the challenge of working a physically demanding eight-hour shift each day.

Wheeling herself backwards and forwards in a chair that she soon hopes to replace, to greet scores of sight-seers as they come off coaches, boats or trains, can be very tiring.

The New Millennium Experience Company has sorted out one or two problems of where Chloe is positioned.

She said: "They are pretty good in my section as they still ask me if they are doing things right. I say I'll tell them if there is anything wrong.

"I think there are 15 or 16 disabled people out of 2,300 employees. I don't think that's a bad proportion. They have done pretty well to get and keep us."

Chloe got a job at The Dome through Sabre, an employment agency for disabled people funded by Lewisham Borough Council and the Government. She started on a rigorous training programme last November and works either in the ticket booths or, what she likes best, going out to meet new bunches of visitors to check tickets and answer questions.

"There are so many different types of tickets, it gets very confusing. Sometimes you have to read a ticket a hundred times to check it's valid and not just a receipt," Chloe said.

Her usual shifts are 8am to 4.45pm or 8.30am to 5.15pm and she travels by a black cab, part-funded by Access To Work.

"I enjoy it because The Dome is new for everybody. The job I like best is meeting and greeting visitors on the pier because the boats arrive at certain times and you can gauge the number of people by the size of the boat. I don't like sitting in the booths because I like talking to people face to face and not having a barrier between us."

Sands Family Resort, Porth, Cornwall: 10 – 12 March 2000

Seaside fun and games – with learning curve!

ASBAH has a long tradition of running study days for families. Since the concept of Family Weekends was introduced in 1994, these have become very popular.

We try to move our venue to cover all areas of the country. This year, we went to Porth in north Cornwall.

We used Sands Family Resort, a hotel with special facilities for children and which opened specially for us.

There were 17 children with spina bifida and/or hydrocephalus and aged six and under – several were profoundly disabled; others had associated epilepsy or behavioural problems.

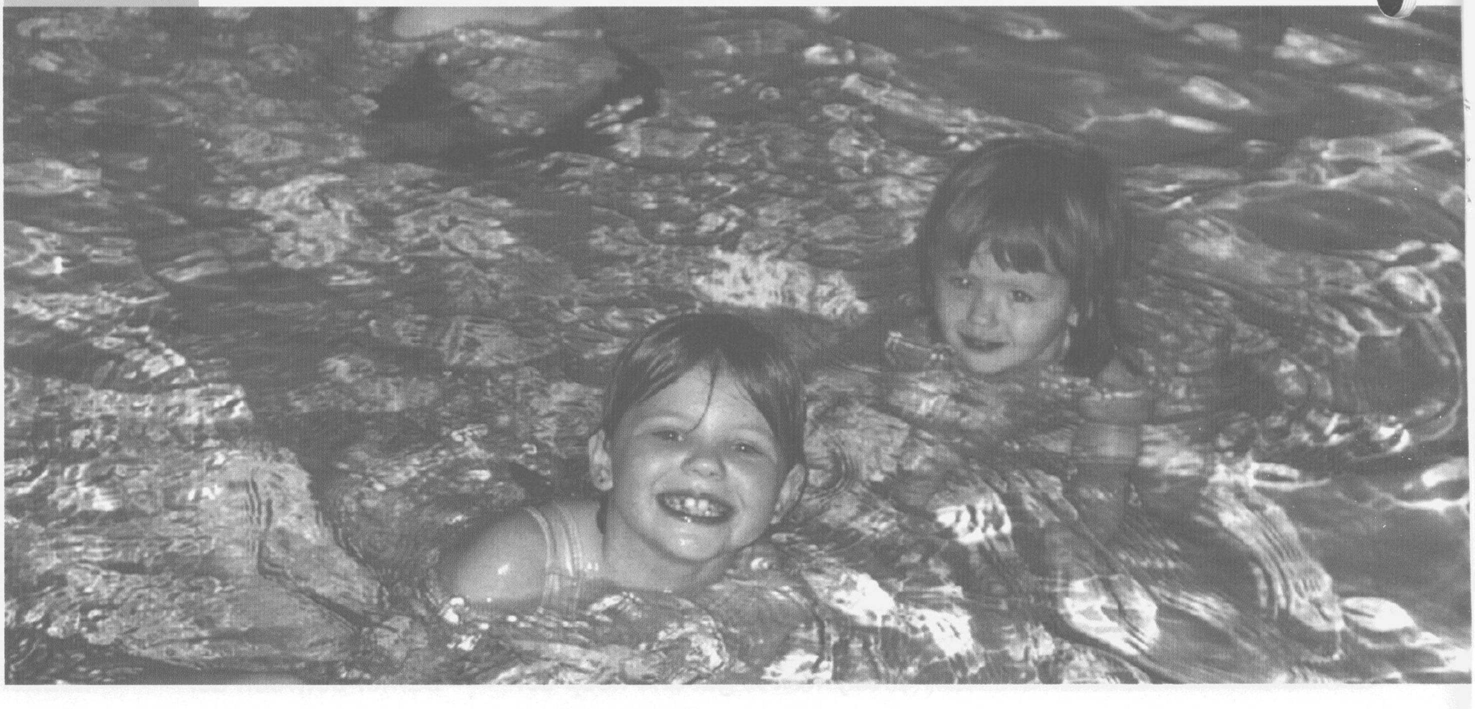
The youngest child was 11 months old and the oldest six and a quarter. They were all joined by their parents and by brothers and sisters, making 30 children – the oldest being 15 years – and 34 adults.

We were swamped with applicants and had to turn down 10 families. Two children were hospitalised and unable to attend, but we filled their places with two days to go. They will both be offered places on future courses.

We took 16 ASBAH staff, including three from our telesales team ("old hands" at Family Weekends now) and our fundraising manager. A clinical psychologist working in the field of problems associated with hydrocephalus came as a volunteer, as did a PhD student from Nottingham University (her third time with us).

A local girl with spina bifida and hydrocephalus came as a volunteer to help with the babies, and another came as a visitor to see our mobility adviser.

The children were divided into four groups according to age. Each group had its designated group leader, and its own seaside themed name.



BBC CHILDREN IN NEED

The babies were Sandcastles, 2–4s Buckets and Spades, 5–7s were Fishes and the oldest group were Boats. One very disabled boy had his own nurse-trained member of staff allocated to him.

While the children had their own programmes, the parents had lectures and chances to share experiences.

In the evenings, we babysat. One family with a very disabled toddler had rarely had a babysitter; others had only ever been left with family members.

On the Friday night, while the parents went to a quiz organised by the hotel, most of the children were up and eager to be entertained.

A lively group went to the squash court for parachute games – the staff tired before the children! Others played board games or table tennis or snooker.

There was a sea mist the next day, but nothing seemed to quell the children's high spirits.

One group went to the beach to look in rock pools and fly kites. A little boy of five, who is very disabled and who has no sight, obviously enjoyed putting his hands in the sand and sea.

For all the others, there was the visit of the animals from Newquay Zoo to look forward to. No tigers or llamas, but we all patted the ferrets and held the snake and stick insect.

Other activities included face-painting and collage, fun in the ball pool, story time, beachcombing, swimming, wheelchair skills and group work when the older children were encouraged to talk about their disabled siblings.

One group went to the Zoo. They came back happily wearing animal masks and full of stories about the "dragon" they'd stroked, the ducks and geese they had fed.

We treated the parents on Saturday evening. ASBAH staff and children ate high tea at 5.30pm,while the parents got ready for their candle-lit dinner. After the chaos of feeding 31 children, it was almost a relief to sit down with them to be entertained by Bodgit the Clown!

The hour passed all too quickly. Then it was back to games for the older children and a video for the others.

Parents started to appear after 9pm to put the little ones to bed and by 10.30pm all was quiet.

On Sunday, the children were all lively and settled (except for one baby) and raring to go.

It was a sunny day, so the older children went off to nearby Newquay with three members of staff. The babies were walked outside, then slept in the sun. The Fishes went to the fort and the Buckets and Spades went into the pirate ship (both adventure playgrounds).

All too soon , it was lunchtime and the end of the weekend.

And what did we learn?

That children with profound disabilities can be part of a group, with a little thought and care.

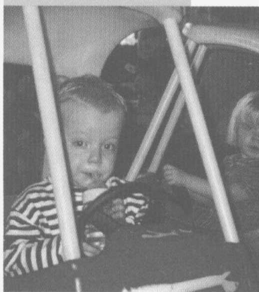
That our storyteller ex-headmaster hadn't lost his touch!

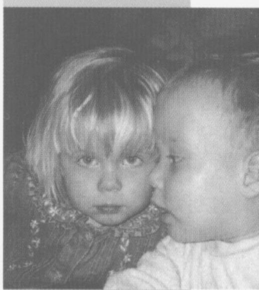
That face-painting is a great ice-breaker, especially when an adult is happy to spend the day painted as a tiger.

That, although exhausted, we know the children had a super weekend and their parents obtained information and support they do not get anywhere else.

That the parents and children want more of the same!

● **Words by Rosemary Batchelor**





people they make us tick!

Royal date for Rachel

A COMMITTED volunteer in Wales was invited to Buckingham Palace to meet the royal family as a way of recognising her hard work. Rachel Roberts was among 700 volunteers to be welcomed at the event.

The Wrexham 24-year-old chatted to Princess Alexandra, Terry Wogan, Gaby Roslin and newsreader Martyn Lewis.

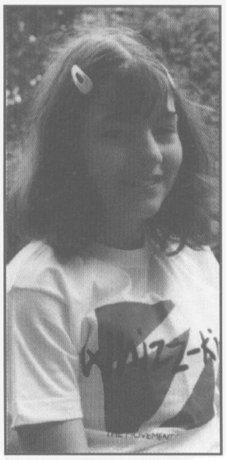
A member of many local organisations including ASBAH's service-user group in Wrexham and North Wales ASBAH, Rachel enjoyed meeting the royal family and celebrities and being able to wander all over the first floor of the palace.

"It was just really nice. Not at all daunting. Just like going to see friends."

Rachel was put forward to attend by the Red Cross for the work she does as part of a national group of young people which promotes disabled people within the organisation.

As well as promoting an interest in and understanding of disabled people among non-disabled Red Cross members, the group publishes literature to encourage more disabled people to join the organisation.

Rachel is also a committee member of Wrexham's Phab Club, Disabled Sports Club and Disability Forum. She plans to continue as a volunteer for all of these despite now having a full-time job at the Benefits Agency.



BOLTON EVENING NEWS

Diana honour for Ruth

TEENAGER Ruth Madeley will receive a new honour created in memory of Princess Diana. The 13-year-old, who has spina bifida, was chosen because her outstanding contribution to the community makes her an inspiration to others.

Staff at Mount St Joseph School in Farnworth, Lancashire, nominated Ruth for the determined way she has overcome her physical difficulties to help others and enhance the lives of those around her. Ruth, of Daisy Hill, Westhoughton, tirelessly raises money for Whizz-Kidz to help children like herself and is on the junior board of the charity.

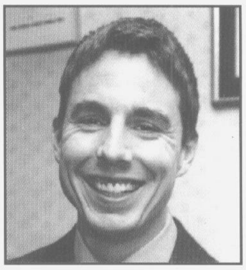
Top HND student

HARVEY JONES was runner-up in the national HND Student of the Year competition.

Harvey (29), from Meopham, Kent, who has hydrocephalus, hopes to graduate with a BA in business studies from East London University next year. He joined the HND award winners in the City of London in February – after winning a regional heat.

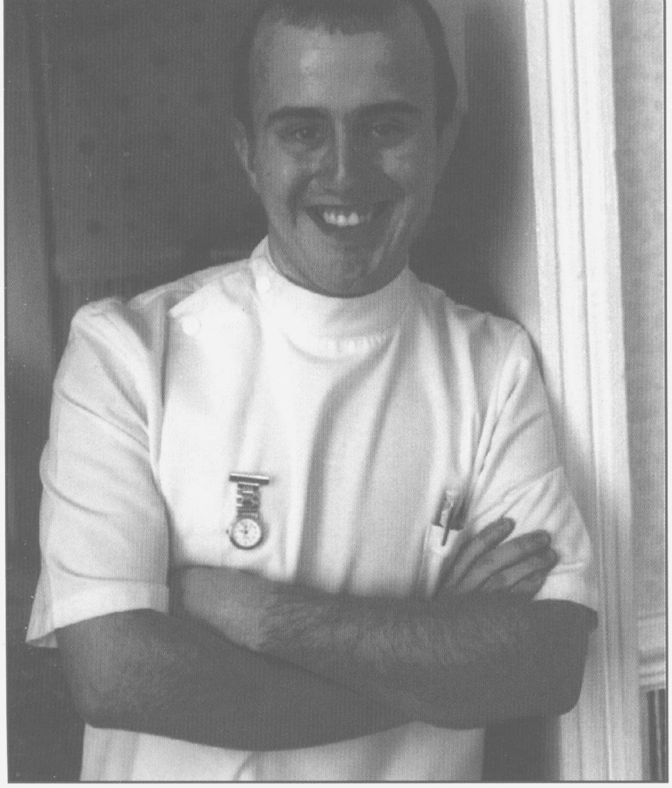
Although having four weeks off for an operation, he gained his HND in Business Studies last year. He gained 12 distinctions in a 14-module course.

Harvey played down his illness. "I was fortunate to be in such a good group as much of the course relies on group work."



ILFORD RECORDER

A clean cut image and lively personality have helped Harvey to pay his way through university. He temps for Office Angels and as a VIP steward at the London Arena – work which puts him in contact with showbiz stars like Mick Hucknall, Liam Gallagher and Patsy Kensit.



THE LIVERPOOL ECHO

Now caring for others

REACHING 21 years of age and being well on his way to becoming a qualified nurse was a double triumph for Colin Hincks. There were moments when his family thought he would not survive as he battled against cancer as a teenager.

Now Colin hopes to be an inspiration to others as living proof that cancer can be beaten. He is also lending his support to a local newspaper appeal which aims to raise £250,000 for a new cancer unit at Alder Hey Hospital.

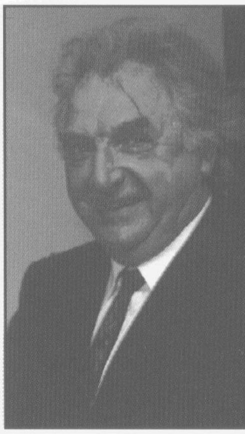
Colin, from Walton, Liverpool, told *The Liverpool Echo:* "It started when I had a tiny pea-sized lump on my head. We all thought it was just a cyst or something like that. I was absolutely shattered when I was told it was a tumour.

"At the time, I was 12. I had only recently been discharged from Alder Hey because of my spina bifida and then was plunged straight back into it all for an intensive course of chemotherapy. The treatment lasted for two years... I was lucky – the treatment was successful."

Colin had a home tutor and was able to catch up with his education at West Derby Comprehensive. But it was a long, hard road.

He said: "I was exhausted all the time. I would come home from school and just sit in a chair with my coat on.

"But I got through, did my A Levels and decided to go into nursing. I do want to help, to put something back, and also I've seen everything there is to see in a hospital – nothing will shock me."



Still bubbling with ideas

LARGER-than-life personality Brian Henley has resigned from ASBAH's executive committee – anno domini having sprung upon him, almost unnoticed.

"I'm 72, but feel 45. I've still got so much enthusiasm but there comes a time when you must stand back and let younger people take over," said Brian, a retired industrial sales manager with Colgate-Palmolive.

He's been involved with ASBAH for 30 years, and got a local association off the ground in his home county of Worcestershire.

"One of the best things ASBAH ever did was move from London to Peterborough and, even though numbers of people with spina bifida seem to be diminishing, we are still able to pull in people of quality. We have had a succession of first-rate chairmen and treasurers, and some wonderful people to run us."

In June, Brian will be selling the Malvern record shop he bought for son Tim and daughter Drusilla, following Tim's decision to go into computers.

"Now, there's the future. Tim finds stuff on the computer that I never knew existed." *Then the enthusiasm kicks in, once again.* "We've got this web site where we sell styluses and needles for old gramophones, that sort of thing. The joy is you can run it from home, anywhere.

"Mind you, we've got to keep on our toes. I've just had someone from Poland chasing up the first contact he made with the website only last Friday..."

Ozzy's on top!

LIFE has never been the same since a sick cockatoo came to one of our specialist advisers, Lorna Johnston. Now Ozzy is feeling better, he's quite a handful.

His feathers have regenerated and he can now fly. He works hard at ripping up directories, or whistles in conversation with Lorna while she does the housework. He's so demanding that Lorna, our education specialist in Northern Ireland, gave him the freedom of her office while she banished herself to the kitchen.

Lorna's slowly reclaiming her house. "I now bring him into the kitchen and he will sometimes amuse himself for nearly 30 minutes while I type."

Holiday shock for the Ibuno family

True Story

My son, Ivan, at 22 months old was diagnosed with a Dandy Walker Cyst, which caused hydrocephalus.

While on holiday in America last June, I noticed him a bit dazed and staggering about one evening. We rushed him to hospital and they asked me what had happened.

Ivan had been playing outside with my brother's children and their friends. My sister-in-law was outside with the kids and said Ivan did not fall down and no other kid hit him. She noticed him falling asleep on the swing and brought him in the house where I noticed him a bit dazed.

The doctor at the emergency room said he would like to do a CT scan of Ivan's head to see if there was any bleeding etc. I said to my sister-in-law 'what's he talking about?' The doctor asked if our doctor in London had ever mentioned that Ivan had a big head for his age. I said 'No', though friends and family had teased him about this.

The CT scan revealed a congenital abnormality. The doctor said there was a fluid build-up which made Ivan's head larger than normal and shaped the way it is. He called this condition a Dandy Walker Cyst as Ivan also had an enlarged fourth ventricle. I stood there stunned and wondered if I was dreaming.

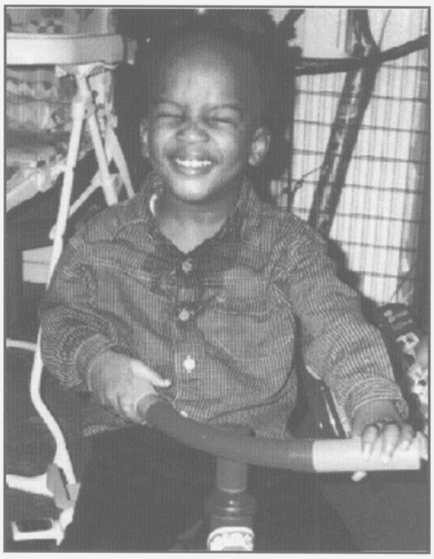
Ivan stayed overnight at the hospital for observation.

I met a neurosurgeon the next day who explained the condition in more detail. He said Ivan being dazed the day before may not have had anything to do with his Dandy Walker condition. He examined Ivan and said he looked fine. I was worried if he would be OK for the three weeks we had before going home. The neurosurgeon said it would be best to fit a shunt in London for follow-up reasons.

We got back to London in July and saw our GP who referred Ivan to Kings College Hospital. According to the GP's notes, Ivan's head had been bigger than average at his six-week and eight-month check-ups, but the GP had never bothered to check the chart or mention it. The GP let me down and my confidence in doctors has been shattered.

We showed the neurosurgeon at Kings College Hospital the CT scans from America. An MRI scan revealed pressure was building up and part of his brain had not formed. I could not believe that for 22 months Ivan had had this condition. He had cried a lot sometimes – maybe it was headaches or pressure building up. His balance has not been affected much, only his development mentally.

He had always been lively and active and we had never suspected a congenital abnormality. Friends and family members used to tease us that he had a big head, but we took no notice as I felt natural big heads run in my family and I had never heard about hydrocephalus before.



Two months later, he had a VP shunt inserted – just after his second birthday. This has, so far, caused no problems. Sometimes he gets irritable and cries. It is very hard to understand what is going on when he cannot communicate. We just pray he is OK and look forward to each day with him. His younger sister likes playing with him but he is not too interested in her.

By Itohan Ibuno
London

In December, Ivan was also diagnosed as having Autistic Spectrum Disorder.

We know with the right help and support, Ivan will lead a normal life though he may be slower than kids his own age. My husband and I work together as a team and support each other. Our main concern is his development. Thanks to everyone who has been supportive.

London calling! YVIA takes off

THE biggest demand ever for a local presence of Your Voice In ASBAH has sprung from service-users in London.

Close to 50 people in the capital had shown an interest in joining a local YVIA group as this issue of *Link* went to press and the closing date for reply had not passed.

It is expected that several YVIA groups will soon begin to develop across London due to the overwhelming response of people with spina bifida and/or hydrocephalus who were approached directly to find out if they would like to be involved in a group in their area.

The London groups will be set up in a similar way to others across the country.

Jon Burke, ASBAH's user-forum co-ordinator, explained: "The idea will be that the groups are developed by the members themselves, with me helping the group members to identify useful training or giving them some ideas in how to find local accessible meeting places."

In addition to the groups, a number of more locally based group 'supporters' will be identified to give more locally based support.

If you would like to know more about YVIA, please contact *Jon Burke tel: 0113 255 6767.*

Wales survey

DISABLED service-users in Wales have told ASBAH they feel hemmed in by restricted choices when they want to move out of their parents' home. The more rural the community in which they live, the harder it is to break free.

In a major survey covering a whole range of perceptions about themselves, 57 out of 82 adults who replied said they lived with their parents – the vast majority of them in their 20s and 30s, when one would normally want to leave home.

Only six had their names on housing waiting lists. Very few lived in housing association properties and all these lived in urban areas.

The survey – carried out by Wales Project workers Jill Bartlett and Carolyn Jones – also revealed a worryingly high proportion of young adults without school qualifications who had not gone on to further education.

And half had received no advice whatsoever aimed at improving their chances of finding work.

ASBAH Wales manager Elin Ifan said the survey underscored what ASBAH knew already.

Opportunities for good quality, accessible further education courses were few, it was difficult for young adults to get good adapted housing of their choice, real jobs were few, health and social service provision was patchy and sometimes non-existent, and public transport was inaccessible.

Every day's a challenge, says new YVIA co-chair

JANET WAUGH has succeeded Alan Twyford as co-chair of our Your Voice in ASBAH disabled users' forum. She will run the group looking after policy and development.

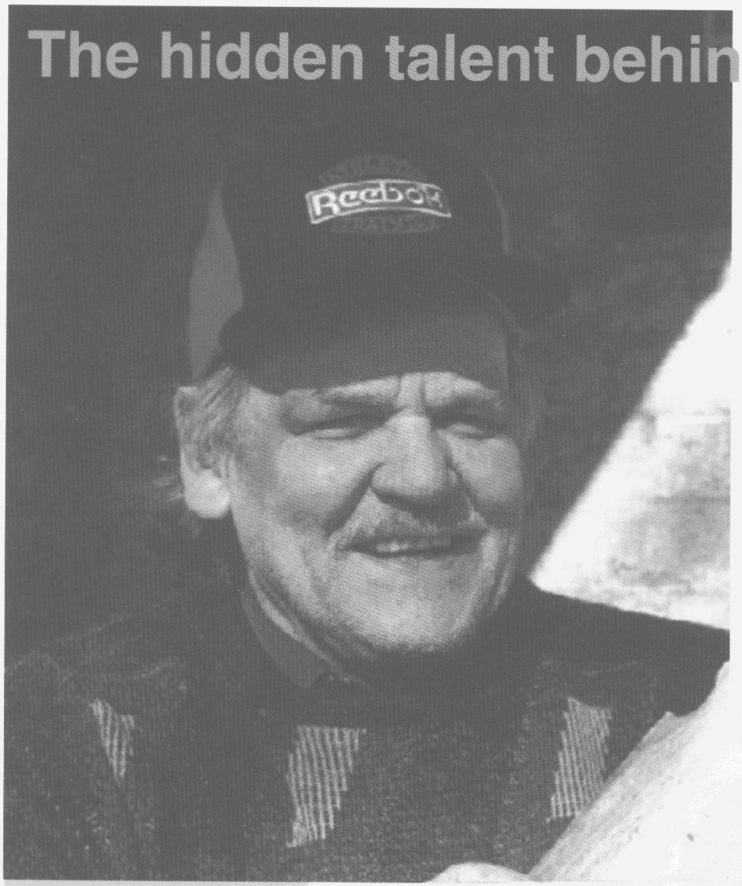
"I can't see me chaining myself to the railings outside ASBAH House but, like every disabled person, I find there are things to be challenged in other people's prejudices and assumptions about disability, whether at work, in housing or whatever," said Janet.

"YVIA's really is an extension of that, and we have been very important to ASBAH because – as the people most affected – we have helped the association develop policy in areas like the DDA and disability rights."

Janet, a civil servant, has been involved with YVIA for almost five years. She turned up once to see if it had anything to offer to her personally, liked what she saw and stayed to develop a niche of her own.

On the way, she became a member of ASBAH's executive committee and deputy chair of Leeds and Bradford ASBAH.

The hidden talent behind our cartoon strips



David Swift – artist with no thumbs

DAVID Swift, whose cartoons regularly grace ASBAH publications, is skilled in many areas. But he has been reluctant to seek wide acclaim for any of his talents.

Author, poet, song-writer, cartoonist and woodworker, some of his work has been broadcast and published but success has been 'one-off' rather than sustained.

His musical play, *Johnny Samson*, including 11 songs was staged at the Nottingham Playhouse in 1984. Like all his work, its theme was disability – in this instance, demonstrating that strength can come from weakness, taken from the idea of Samson and Delilah.

Penning another musical play is what he would love to do most of all, but he has been put off by a TV producer telling him long ago that there are no happy endings in disability. David loves happy endings.

"People let you down in show business and I am easily disheartened," he says. Like the time when a producer of The Young Ones wanted to meet David after reading one of his scripts.

"First he wanted to see me in London, then he wanted to come to my home, then he turned me down altogether. I'd gone all out to get the script done; I can't afford to waste my time."

Currently, a Carlton TV producer wants him to finish a children's story about a group of disabled animals – a pigeon with no sense of direction; a rabbit with no teeth; an owl that's not wise because it's dyslexic and a magpie that is a kleptomaniac. But he is in no hurry to do that final scene.

" I don't have the strong desire to do anything unless someone, say from ASBAH, rings me up with a project to think about and complete. I like deadlines.

"When you write you need an audience. I'm at home all the time so I don't have enough of an audience. I really need to be in a group."

In 1996, he joined a local writing group and was amazed at the burst of applause after he read out a story.

> "I don't have the strong desire to do anything unless someone, say from ASBAH, rings me up with a project to think about and complete."

This encouraged him to write a few stories for local radio but he was paid so little it didn’t seem worthwhile to continue.

Severe depression set in after a road traffic accident which left him with a fractured spine in 1994. He was forced to abandon a Masters degree with Trent University.

But David has been disabled from birth, although it was not until fairly late in life that he discovered the cause was genetic. He now has no use of his thumbs and is quadriplegic.

“I think my strength lies in overcoming my disability. When I was a teenager, I used make up stories about my disability. I had been told by my parents that I ’d been made disabled by falling down a tree. I didn’t know I’d got a disease (an extremely rare type of spinal atrophy) till I’d got all my five children. They’ve all got deformed feet except one and he played football for Arsenal as a lad.

“If my parents had been honest with me, I could have taken steps not to have had so many children.”

David used to be a self-employed joiner. At the age of 56, he still makes things on his workbench and he has become a master craftsman at cartoons despite having to strap his thumbs to his hands to use a pencil.

“I like to be creative,” he says. “I want to do a book of cartoons – I’ve got stacks of them – but I can’t find a publisher.

Situations for cartoons come to him easily but drawing takes a lot of energy and concentration.

“Creating a cartoon takes a lot out of you. Loads of people can draw but not many people can see the humorous side of disability; it’s in-built.

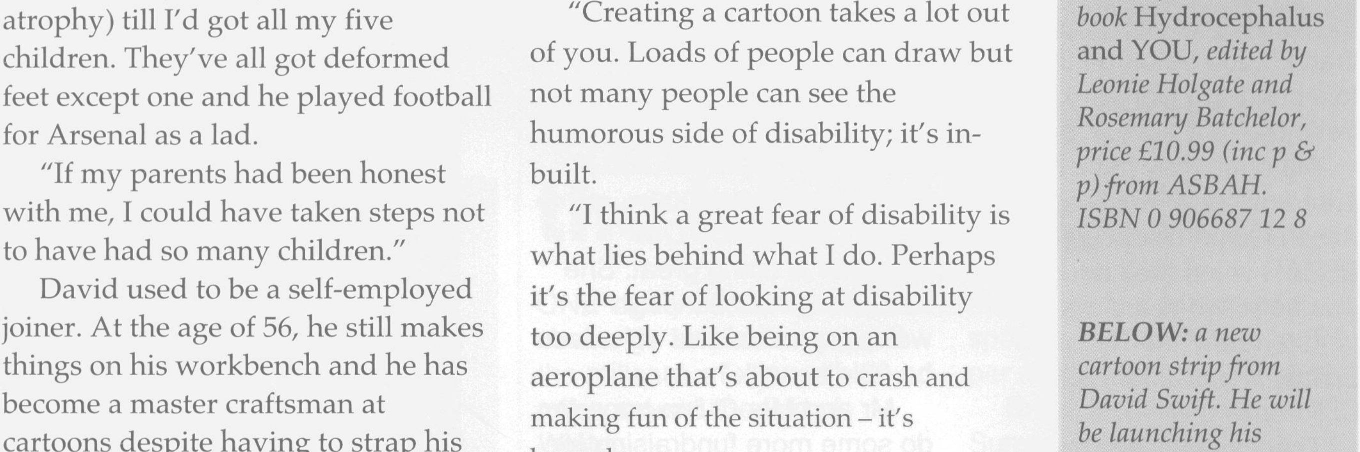
“I think a great fear of disability is what lies behind what I do. Perhaps it’s the fear of looking at disability too deeply. Like being on an aeroplane that’s about to crash and making fun of the situation – it’s bravado.

“You can learn to draw but can you learn about fear, pain or the experience of going into an operating theatre?”

● **Words by LIZ CAWTHORNE**

ABOVE: *David Swift’s cartoon about dislike of loud crashing sounds for our 1999 book* Hydrocephalus and YOU*, edited by Leonie Holgate and Rosemary Batchelor, price £10.99 (inc p & p) from ASBAH. ISBN 0 906687 12 8*

BELOW: *a new cartoon strip from David Swift. He will be launching his "Benny and Fitz" strip in* Link *later this year –outlining the trials and tribulations of one disabled man and his dog.*



fundraising

Darling daughter

SPINA bifida research is more than £5,000 better off thanks to a couple in Northern Ireland.

Although they have no area adviser, Frank and Aileen Quinn discovered ASBAH when their daughter was born two years ago and transferred to the Royal Belfast Hospital for Sick Children.

Then, when Naoishe was having her back closed last year, they decided to do something to help ASBAH.

So they organised a dance with a couple of live local bands at the Saval Club, close to where they live in Newry, County Down, selling 100 tickets at £5 a time. Drinks and snacks were donated.

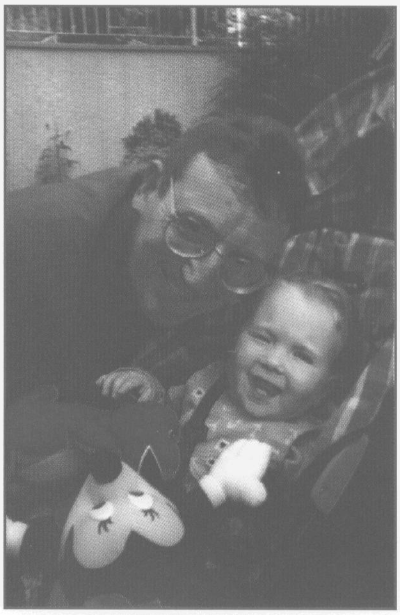
"The place was full and we had some good craic and raised a good amount for ASBAH which does a good job," said Mr Quinn, *pictured right with Naoishe.*

More money was raised by a raffle on the night and a golf day at Dundalk to which people were taken by bus.

Our Coleraine adviser Sharon Galway received a cheque at the Saval Club on the night of the dance.

Mr Quinn said: "Our daughter is doing great. She is crawling now although we've been told she will never be able to walk."

Mr and Mrs Quinn hope to do some more fundraising for ASBAH this year.



Small change, great heart

LOOK after the pennies and the pounds will look after themselves... about £100, in pennies and other small change, has been collected for the second year running by market trader Jean Hadden.

Our most successful collecting box holder, Jean keeps a box prominently displayed on her stall and persuades other market traders to do the same.

She was moved by the *EastEnders*' story of Bianca and Ricky's heart-rending decision to terminate a pregnancy affected by spina bifida and hydrocephalus.

And one of her regular customers has hydrocephalus.

Now in her late 70s, Jean sells birthday cards and wrapping paper at the Spanish City Indoor Market in Whitley Bay, Tyne & Wear. But for 50 years, she worked on markets across the region – in Darlington, Durham and Chester-Le-Street.

ASBAH fundraising manager, Donna Treanor, said: "We are extremely grateful to Jean and her customers for helping us to continue our work."

Fairer sex

OUR thanks to the fairer sex at Brent Valley Golf Club in Hanwell, west London, who sent us a cheque for £550 from the proceeds of a raffle.

Ciara O'Connell, daughter of lady's captain Lily O'Connell, of Wick Road, Teddington, wrote to say that her mum, Kathleen Maloney, Marge Griffin, and all the club's lady members took part in the fundraiser.

"I have got spina bifida myself and, when my mother became captain, someone suggested they do something for ASBAH and mum followed through," said Ciara.

"Thank you for all the support that you give to me and my family." And thank you, you lovely people!

They walked round the Isle of Wight!

ONE family set themselves a challenge for the last year of the millennium – to walk 60 miles around the Isle of Wight.

Walking such a distance over 12 months may not seem such a feat, but when three of you are children, not very keen on walking, it is a worthy achievement.

Relatives and friends were sufficiently impressed that they agreed to sponsor the children, one of whom has hydrocephalus, and a total of £300 was raised for ASBAH.

Tasman (8), Kyle (6) and Beth (4) were spurred on to complete the legs of two, three and six miles, by their parents Brian and Rosie Cooper. As well as incentives like numerous ice creams, mum and dad generously sponsored the children for £1 per mile each for ASBAH.

Brian, from Reigate, Surrey, writes: "We thoroughly enjoyed the walk, and were often joined by friends and relations for different parts. It features very varied scenery, from muddy paths through woodland, to open cliff tops, to Victorian seaside resort promenades.

"By the end of the walk the attitude of the children remained unchanged – not desperately keen on walking. So this year we are planning to sail round."

Photo shows (from the left) Tasman, Beth and Kyle Cooper who hot-footed it around the Isle of Wight.

dates for your diary

A wide range of subjects at ifHSB conference

THE TITLE of this year's ifHSB conference is provocatively *The Right To Be Different*. It will be held in Toulouse, France, in the first weekend of September *(see panel alongside)*.

Speakers at this event will include people with disabilities. The conference is being run by the International Federation for Hydrocephalus and Spina Bifida.

Topics to be discussed include primary prevention campaigns; termination when the baby has the disabilities; inclusive education; levels of practical support in employment; love and spina bifida; and living independently. The conference language will be English, with simultaneous translation this year into Spanish.

High-powered on continence

SOCIO-LEGAL and child protection expert Maddie Blackburn will be speaking at the Mac Keith Meeting on continence management in children in disabilities *(see panel alongside)*.

Mary White, a continence adviser well-known to ASBAH, will also be on the podium.

Issues to be discussed include 'Someone else owns my body', the value of urodynamics, surgical options, the young adult with incontinence and the impact on the family, and the provision of statutory services.

Upcoming events

Spina Bifida and/or Hydrocephalus – current concepts and treatments

Wednesday 17 May, Newport Pagnell, Bucks.
Conference organised by ASBAH Eastern Region at the Marriott Hotel. A few places left. *Mary Malcolm Tel: 01733-555988, fax: 01733-555985, marym@asbah.demon.co.uk*

Disability Action Show

2 – 3 June 2000, Belfast
Mobility 2000. Tel: 028- 90 491011.

Management of Continence in Children with Disabilities

14 June 2000, Royal Society of Medicine, London
Open meeting in the Mac Keith Press Meetings series. *Emma Chaffin Tel: 020-7290 3934.*

Spina Bifida and Hydrocephalus Study Day

16 June 2000, Middlesborough
Organised by ASBAH Northern Region, 9.45am-4pm. £7 parents and service users, £15 for professionals. *Joan Pheasant Tel: 0113-255 6767.*

Special Children's Day London Zoo

17 June 2000
Special reductions and activities, if pre-paid by 7 June. *Education Department. Tel: 020-7449 6551.*

Mobility Roadshow

23 – 25 June 2000, Donington Park, Derbyshire.

Society for Research into Hydrocephalus and Spina Bifida

21 – 14 June 2000, Atlanta

Hydrocephalus Study Day

1 July, North Wales
£5 per adult. Book by 10 June. *Peter Bennett*
Tel: 01978 852 254

Therapy in Schools: problems, policies and good practice

4 July 2000, Royal Society of Medicine, London
Of special interest to teachers working with children with learning difficulties in mainstream as well as special schools. *Emma Chaffin*
Tel: 020 7290 3934.

International Federation for Hydrocephalus and Spina Bifida

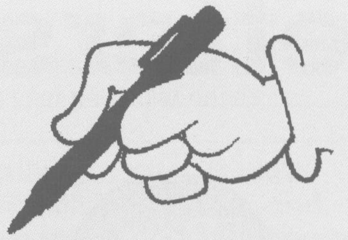
31 August – 3 September 2000, Toulouse, France
12th Congress, 'The Right to be Different'. *ifHSB Office*
Fax: +32 2 502 11 29
Tel:+32 2 502 04 13.

ASBAH South East Region LA Conference

1 – 3 September, Greenwich
'The Way Forward.' ASBAH South-East Region Local Associations' Conference. £80 per delegate (day & residential places). *Jo Francis*
Tel: 020-8449 0475.

AGM, national ASBAH

16 September, Peterborough.



Dave's diary

david.fulford-brown@virgin.net

OOver the last few years I've either worked for myself or not at all. It's been a long time since I did a nine to five stretch for someone else. Now I remember why I avoided it: I'm exhausted! No sooner have I gone to bed than it feels like I have to wake up again, as tired as when I went to sleep.

It isn't that I'm not sleeping enough hours. I make sure I sleep the required eight or nine every night before I go to work. I realised long ago that if I am to work a full day, I do need my beauty sleep. Without it I become grumpy, unco-ordinated and forgetful. Now I think about it, the mental problems that led to me messing up my first full-time job (and losing it), may not have been entirely to do with having spina bifida or hydrocephalus, (although they sure didn't help). It might have been something as depressingly simple as not getting enough sleep!

As well as sleeping long enough, I have no problem dropping off to sleep. In fact, this is one occasion when being disabled has given me a useful skill.

Having spent my childhood in hospitals full of noise, smells and lights on 24 hours a day, I have learned to sleep and stay asleep whatever is going on around me – as my poor brother learned one long fortnight in America.

My family went to the US for a long promised tour of California. Unfortunately, to keep the budget my brother and I had to share a room. I don't remember this at all, but one night my brother claims I snored so loudly that he was driven to whacking me over the head with a pillow, screaming 'For God's sake Dave SHUT UP!' I slept on regardless. Oh, and it is unfair for Anthony to claim I snore. I don't. I simply breath loudly at night!

I think my sleep problem is not that I lack the quantity of sleep I need, but the quality. Although I'm sound asleep, something is nagging me and keeping that part of my brain that absorbs sleep awake. It could be lumps in the mattress or lumps and bumps in me.

The real reason why I'm desperate to buy a new mattress now is my lumps and bumps, especially the shape of my back. I've always been concerned about my back and keeping it healthy and straight. Recently, I read a little about a condition called scoliosis which has quite worried me. Apparently, with some cases of spina bifida, something happens to the spine which causes it to start curling up like a leaf in winter. I've been checking the mirror and I'm sure my back isn't as straight as it was.

So, before I end up having to iron my shirts on an upturned wok, or have someone take a rolling pin to my back to straighten me out, I'm going to buy a new mattress. One with more support than the one I use already. Even more! I already sleep on an orthopaedic bed. 'Orthopaedic' is a posh word for 'hard as steel'. If I need an even harder bed to keep my back straight, what am I looking for? A concrete bed? Pass the sleeping tablets!

Sussex ASBAH test run Knowles Tooth centre

LONE parents and couples are being linked in new initiatives run by Sussex ASBAH at a centre which gives short breaks to families under stress. Knowles Tooth, at Hurstpierpoint is a house tucked away in the countryside near most of Sussex's towns.

With ample parking and new facilities for disabled people, it caters for a variety of gatherings such as team building, training days for staff, time for reflection, activity pursuits for youngsters, workshops for new skills.

Trevor Hutton, weekend activity co-ordinator for Sussex ASBAH, said: "We have organised weekends for lone parents and couples to encourage less isolation and more participation."

● *For a Sussex ASBAH view of the centre, contact Trevor Hutton (01273-462979). Visits to Knowles Tooth can be arranged on 01273-832363.*

letters

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

Pen pals

Dandy Walker

MY two-year-old son, Ivan, was diagnosed at 22 months with Dandy Walker Syndrome, which caused him to have hydrocephalus. He had a VP shunt inserted in August 1999 at Kings College Hospital, London.

I would like to find someone who has a child with Dandy Walker Syndrome and hydrocephalus and to find out when the diagnosis was made. I would also like to find out if the child's development has been affected much. Ivan does not say any words at all and does not understand when he is being spoken to.

I hope to hear from any parent!

Ito Ibuno, 58 Delverton
House, Delverton Road
London SE17 3QQ
iibuno@candi.ac.uk

Indian massage

RACHEL is mum to Danny, who has hydrocephalus. She would like to hear from anybody who has had experience of Indian head massage, or cranial osteopathy.

If anyone can talk to Rachel about it, she would love to hear from you.

Rachel Burney
18 Lamintowne Drive,
Leamington Spa,
Warwickshire CV32 6SJ.
Tel: 01926-334011

Courtesy and hand controls

ELSIE WILSON may have a point (Barking up the wrong Motabilatree?, *Letters, Link,* March 2000). Perhaps *Link's* call for a 'complete overhaul' of Motability based on the experiences of two individuals was over the top.

But, in suggesting that I could take a taxi while my hand-controlled vehicle is in for repair, she misses the fact that for many of us taxis are not an option, and that most buses still remain an inaccessible alternative.

I live in a single-income family. That income just does not stretch to taxi fares.

A hand-controlled car makes me mobile. It gives me the ability to follow my interests outside the home. Motability should consider how they can keep their many customers who rely on hand-controls on the road when their contract car is out of action. A small stock of courtesy cars, regionally-based, could be the answer.

Katrina Grounsell, 75 Glebe Crescent, Witham, Essex CM8 2HX

Cancel excess mileage charge

IN *LINK* No 185 (January/February 2000), there was an article criticising Motability. I totally agree that excess mileages should be withdrawn. We use our full allowance to pay to lease Motability cars, yet we get a limited mileage. It's discriminatory.

I did put an article in my local evening newspaper last year on this subject to try and get a petition together. Although I collected only five names, I sent the petition to my MP, Brian Idon. He forwarded it to Motability and I got a letter back saying there is supposed to be a high mileage rule being brought into force, but when I don't know.

There should be no limited mileage at all.

You can give my name and address to Neil Lewis who was quoted in the *Link* article and maybe between us we can try and do something to get this excess mileage abolished.

Marie Reilly, Bolton, Lancs

FOR SALE

POWERED wheelchair, model E45, one year old, very clean condition, under warranty. Cost: £3,840, will accept £1,500. Good reason for sale. Will bargain. *Tel: 0161-226 7675; 07879-652 746.*

ELECTRIC 'Carony' wheelchair system, Recaro designer touring seat with belt and power rise/fall seat; 12" puncture-proof rear tyres; manual foot rests; attendant-control fitted to left backrest (but can be placed anywhere); 24v gel-type battery charger; revolving manual base plate for fitting in car to receive wheelchair in place of front passenger seat; electric/hydraulic hoist for fitting into boot of car to transport wheelchair base/wheels/motor. Purchased Feb '99 – chair price: £7,685; hoist: £850. Used occasionally over six months. Any reasonable offer considered. *Mrs Hawkins, tel: 01483-760084 (Woking, Surrey).*

ELECTRIC wheelchair Quickie F55, eight months old, never been on road. Cost: £3,750. Asking £1,500 ono. *Tel: 0115-9733136 (Long Eaton, Notts).*

WHEELCHAIR motor, never used. Free. *Tel: 01304-832426 (Dover).*

SUNTEC 18" manual wheelchair and cushion. Excellent condition. £150 ono. *Miss Bell, tel: 01652-634939.*

holiday lets

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

SELSEY, WEST SUSSEX (SASBAH)
Fully equipped, purpose-designed for wheelchair access, mobile home. Sleeps six, ramp and large veranda, payphone, colour TV, midi stereo etc. Clubhouse entertainment, heated swimming pool, free site bus service. Nature reserves and places of interest nearby. Details from *Mrs B Nunn, tel: 01903-763473.*

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- Classified Rates:
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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 accomodation. Sleeps six, well-furnished. Free club membership.

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

ACCOMMODATION

ILKLEY, WEST YORKSHIRE – vacancy at Flat 1 Wharfedale, Five Oaks Housing Scheme. Suit couple with or without a child, alternatively two to three adults willing to share the tenancy. The accommodation comprises three bedrooms, living room, kitchen, bathroom, toilet/shower room and hallway with storage. Wheelchair accessible throughout and on the ground floor; benefitting from patio and access to shared gardens and laundry facilities. Superb views from kitchen and bedrooms across the Wharf valley. At least one of the intending occupants must have a disability. A care and support package can be arranged with Bradford Social Services. Contact: *Mark Best, tel/fax: 01943-603013, Five Oaks Housing Scheme, Ben Rhydding Drive, Ilkley, West Yorkshire, LS29 8BD.*

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