ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

May/June 1999
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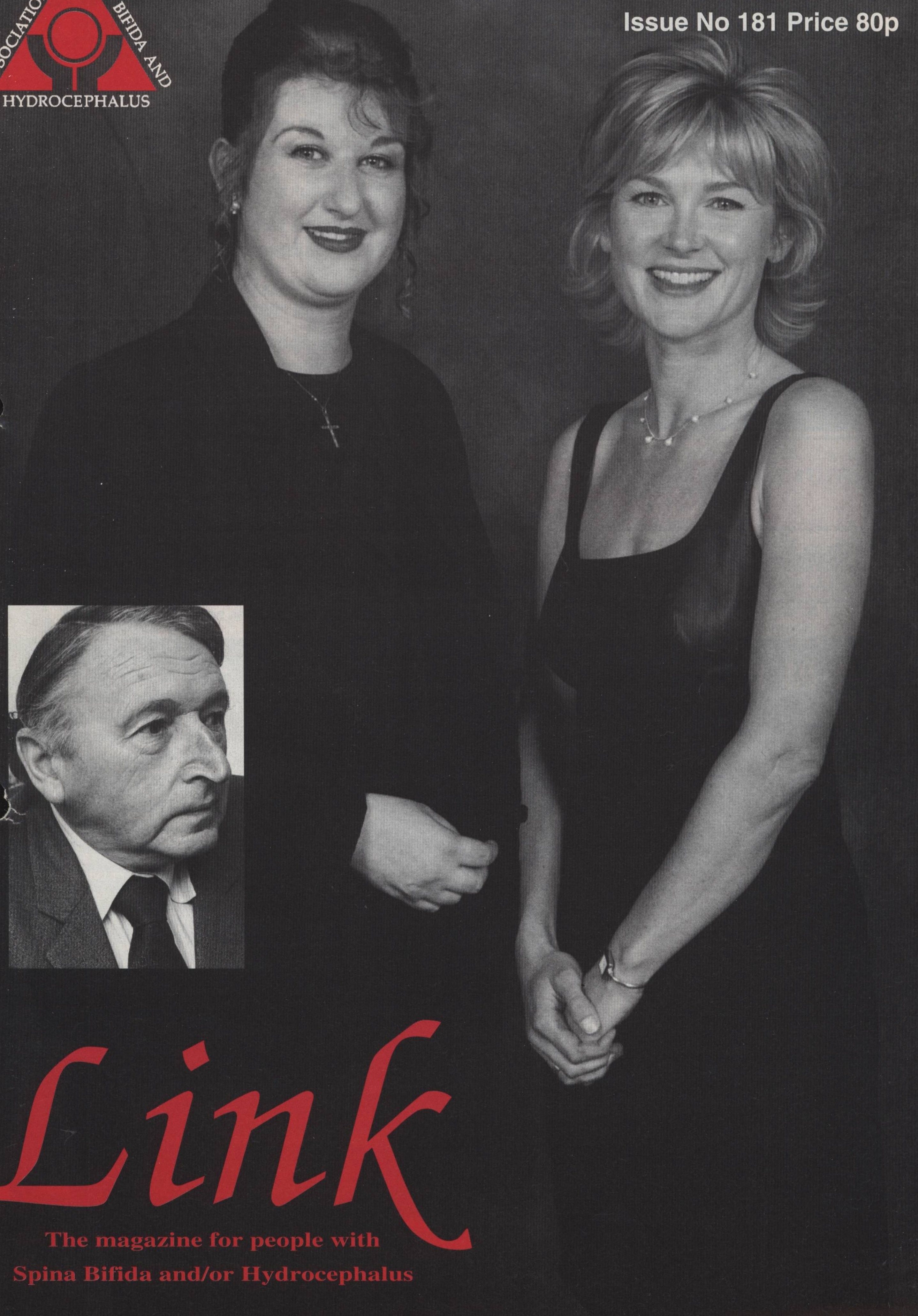

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The magazine for people with
Spina Bifida and/or Hydrocephalus

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Railtrack on line for ASBAH

WITH the clatter of trains in their ears, service-users from Peterborough picked up a £6,000 cheque for ASBAH from Railtrack at the city's railway station.

Debbie Thorn and her 11-year-old daughter Gillian use the train when travelling to Kessingland in Suffolk for their summer holiday because the family and Gilly's helper can't all squeeze into the car, and have been impressed by Railtrack's service.

Railtrack's Community Panel gave us £6,000 to develop our network of education advisory services.

Pictured left to right are: ASBAH executive director Andrew Russell, Mrs Thorn, Gillian Thorn and Vicki Smith, Railtrack's communications manager for the Eastern Region.

Memorial service for Professor Robert Zachary

A MEMORIAL service for the late Professor Robert Zachary, who died in February, will be held on 23 June at the Roman Catholic Cathedral in Sheffield, at 10.30am. The arrangements are being made jointly by National and Sheffield ASBAHs.

The service will coincide with the opening day of this year's scientific meeting of the Society for Research into Hydrocephalus and Spina Bifida, which is also being held in Sheffield. Prof Zachary was the founding chairman of ASBAH, a position he held for 11 years.

Turn to pages 14-16 to read our tribute to this 'towering' figure.

Taped publications

LIFT, ASBAH's free magazine for people with sb/h aged 14 years and upwards, is available on audio tape. If you prefer to receive *Lift* in this format, please contact Liz or Tony in the Publicity Department on 01733-555988.

ASBAH's Information Sheets 1 and 2 – *What is Spina Bifida?* and *What is Hydrocephalus?* – are also available on audio tape. Other ASBAH Information Sheets are taped, on request.

Contents

ASBAH is a registered charity

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

Cover: Our fundraising manager Donna Treanor joined TV presenter Anthea Turner at the Off Balance Ball in London which raised £50,000 for ASBAH. Story on page 10. Photo by: Photo Grosvenor. Inset photo: former ASBAH chairman Prof Robert Zachary, who died in February.

STAFF NEWS .... STAFF NEWS .... STAFF NEWS....

Change in Greater Manchester

● A YEAR of travel is planned by one of our advisers who retired in March after giving more than 11 years of service.

But the involvement of Jean Black in the local association she helped found 38 years ago will continue.

Our Greater Manchester adviser has personal experience of hydrocephalus as her son, Michael – now a father himself – has the condition.

"We felt we were lucky and wanted to help others and that is why we set up the local association."

Brian was founder chairman and Jean secretary of Trafford and Salford ASBAH. Jean's father devoted a lot of time to fundraising, and an independent living scheme – Davis Court – is named after him.

Her husband is now president and Jean plans to return to the committee after a six-month break.

The job of ASBAH adviser has been varied and rewarding. Some of the biggest challenges have been combating bullying in schools and helping parents receive Disabled Living Allowance for children with hydrocephalus alone by ensuring they do not omit essential information when filling out the application form.

Jean has worked with five local associations – Stockport, Wigan & Leigh, Bury & Bolton, Manchester (now folded) and Trafford & Salford.

Jean is also a fundraiser and community worker as vice-president of her local Lions Club which raised £30,000 last year for charity.

Involvement in the Lions last year took Jean and Brian by narrow boat to Birmingham for an international convention.

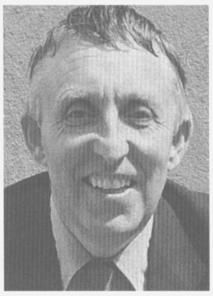
Unfortunately, their enthusiasm for narrow boating, which took them on relaxing holidays, has taken a dive since Brian hurt his shoulder in an accident.

So their holiday plans for this year are rather different – the Greek island of Kos in May, a pilgrimage to Assisi in September and a trip to Michigan, USA to spend Christmas and New Year with Jean's brother.

Jean also looks forward to spending more time with her six grandchildren and at her local church where she is a lay minister.

● SHARON Galway is the new adviser for Co Londonderry, North Fermanagh and North Tyrone.

The former care worker looks forward to working again with disabled people after two years in teaching. ***Based at her home in Dungannon, her usual ASBAH days are Mon–Wed, tel: 01868 722145.***



● A WALK across the desert is a test for most people, but when you are blind and have spina bifida and hydrocephalus, it is even more of a challenge.

John Richards, adviser for Beds/ Herts & Milton Keynes, walked 60 miles in five days, across sandy valleys and sandstone hills from Sharm el Sheikh to Mount Sinai.

He did the walk in a group and hoped to raise £2,000 for the Guide Dogs for the Blind Association.

● CONGRATULATIONS to North Wales adviser Elin Richards who has remarried. Her name is now Elin Ifans (pronounced Evans). ***Tel: 01407-840 927, fax 01407-840 917.***

WITH two years' experience of *Your Voice In ASBAH (YVIA)* under her belt, Marcia Conroy steps into the role of adviser for Greater Manchester.

Taking over from Jean Black, whom she has known all her life, Marcia describes her appointment as a 'dream come true.'

Becoming an ASBAH employee means that Marcia must resign as *YVIA* co-vice-chair for the Northern Region and from our Services Committee.

"I was brought up in Manchester so I know a lot of people there and enjoy networking and finding the best sort of help for people.

"I have a lot of empathy with the service-users because I have got spina bifida and can see life through a younger person's eyes," she said.

Marcia, aged 27, has the Diploma in Social Work and is taking a BA in Professional Studies (Social Work).

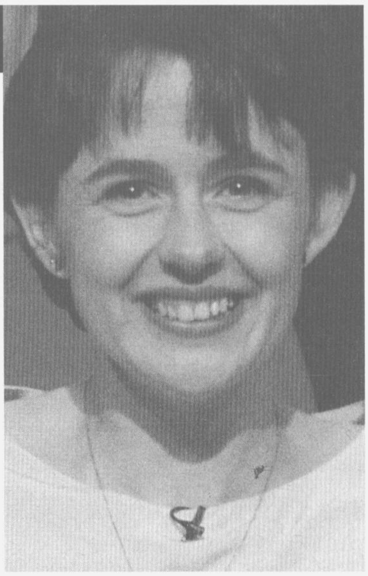
"I am very keen to find out what people want me to do as an adviser and am interested in training and giving talks to agencies."

She wants particularly to find black people with spina bifida and/or hydrocephalus in her patch to identify their needs.

● ***Marcia works Mon-Thurs, based at her home in Runcorn, Cheshire, tel: 01928-779 784.***

Countdown to Paralympics 2000

Tanni quits job at BT Athletics and marries in May



Tanni Grey

WHEELCHAIR racing gold medallist Tanni Grey MBE has quit her job at BT Athletics and announced a wedding date.

She left her job as co-ordinator of the BT Athletics Scheme to concentrate on training for what, at the age of 29, may be her last Paralympic Games in the year 2000.

And, in May, she will be marrying fellow athlete and long-standing boyfriend, Ian Thompson, in Cardiff. The happy day fits in a gap in the pair's training programmes in the 18 months leading up to the Sydney Paralympics.

During her two years at the BT Athletics Scheme, based in Birmingham, Tanni administered more than £500,000 to benefit disabled athletes throughout England, Scotland, Northern Ireland and Wales.

Tanni said: "It's been a stimulating two years but, increasingly, I have found myself caught between two stools. There have been times when I have felt neither fit nor strong enough to compete successfully at the highest level – and I'm determined to give Sydney my best shot."

Although she won gold and two silver medals at the world championships last year, the strain of holding down a full-time job and managing a rigorous training programme has taken its toll.

"I found myself having to train as late as 11.30 at night, going to bed at 1am – sometimes 1.30am – and then often having to get up at six," she explained.

Tanni said it came down to a simple choice.

"I think I've got something to offer on the track but, if I am to give my-self a chance of winning events in Sydney, I will need to be 100% focused."

Her goal in Sydney is to emulate her performance of Barcelona in 1992 when she won three track golds.

Tanni's coach, Jenny Banks, is based in Australia so Tanni will do some of her winter training over there.

Also scheduled are a number of trips to the USA and some top flight competition. Her main challenger in the 400m and 800m at the world championships – Leanne Shannon – is from the States and they are sure to meet in the months ahead.

Tanni is looking forward to moving to Middlesbrough to live with Ian, who she has known since she was 16.

"It's good that he's an athlete as he understands the way I am. May is a quiet time for us between now and the Paralympics so it seemed a good time to get married," said Tanni.

Ian, a former club level cyclist before being left disabled by an accident, is also hoping to qualify for the 2000 Paralympics.

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ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

BIP ends, but new check system planned

THE BENEFIT Integrity Project (BIP) ended on 31 March 1999, although cases already in the system will continue through the process.

From April this year, a new system of 'periodic review' will bring all levels of Disability Living Allowance (DLA) into line with other benefits already subject to regular review.

The data collected from BIP has provided the Department of Social Security with information on just one section of the DLA caseload. It believes the new system will provide similar knowledge on the remainder.

The future goal of the Department is that "awards will be checked at intervals appropriate to the likelihood of a person's care and mobility needs changing, for example in certain cases the normal progression of a disabling condition would indicate that needs would increase over specific periods; in other cases where the claimant's condition could be expected to improve as a result of, perhaps, an operation."

The Royal Association for Disability and Rehabilitation (RADAR) has argued that more use must be made of applicants' suggested contacts for further evidence about their condition. Similarly, there have been calls for adjudication officers and others involved in the information gathering and decision-making process to specialise in various conditions and build-up a better knowledge of both how particular conditions progress and the effects of ageing on other disabilities.

It is thought that the new system will 'initially' exclude DLA recipients whose cases were examined under BIP as well as people with a fixed period award due to end within the next three years. The exemption categories identified under BIP will continue and it is understood that these may be added to as information emerges.

Visits and questionnaires as a means of gathering information will continue, although applied across the board with a view to finding the most suitable approach. RADAR does not yet know who will receive a questionnaire and who a visit.

The overall aim of the review is to make sure awards are made at the correct rate and level and, while supporting the aim, RADAR believes the approach to achieving this is misdirected: greater effort and resources must be put into getting awards right to start with.

Water meter imposed on family

MID KENT Water showed 'staggering insensitivity' by imposing a water meter on a family who have a child with exceptionally high laundry and bathing needs.

Twelve-year-old Adam Jones has severe disabilities. Some nights, he needs to use an iron lung kept on standby in the garage to make sure he keeps breathing.

His family – who moved from a semi-detached to a detached home in Hawkhurst, near Tenterton – discovered out of the blue their new property was earmarked for a water meter when they found workmen digging a hole on their drive.

Mid Kent Water then sent a letter saying the Jones family would go over to a compulsory meter in 28 days.

"My husband Colin took early retirement as a paramedic to help me provide 24-hour care for Adam, and we've put everything we've got into this house," said Adam's mother, Francesca, who has two older children. "We have to be so careful with our money, and we would not have bought the house if we had known it was to be water-metered.

"Adam's laundry means that I have to use my washing machine at least three times a day. He also showers at least twice a day and he finds it very beneficial if he also has a bubble bath with his toys to calm him down.

"I'm frightened that, totally unexpectedly, we are going to get massively high bills for water which we just can't afford."

Adam has numerous disabilities, including severe epilepsy, hydrocephalus, cerebral palsy, gastro-oesophageal reflux, which causes vomiting, and apnoea, which stops him breathing at night.

Tony Britton, ASBAH publicity manager: "This is a staggering example of insensitivity by a water company which is ignoring the special needs of someone with disabilities. Companies should check on exceptional household require-ments before installing meters.

"Mr and Mrs Jones are now anxious whether they can afford to live in Horns Road, and continue to care for Adam in the way they feel necessary."

The company put the family's water account on hold pending inquiry.

Missing Links

RETIRING ASBAH area adviser, Jean Black, presented a near-complete set of *Link* magazines to her regional office. However, some back numbers were missing – 1, 10, 14, 78, 81, 112-118, 126, 131 and 149.

Anyone who has any of the above issue numbers and wants to dispose of them, please send them to: ***Joan Pheasant, ASBAH North, 64 Bagley Lane, Farsley, Leeds LS28 5LY.***

Young and upbeat, Suzanne Bull is Link's new columnist on page 11

Education conference for parents

A NATIONAL network of parents of children with special educational needs, working towards properly resourced inclusive education, has announced details of its annual conference and a new helpline number.

Network 81 will be holding a conference for everyone wanting to know about inclusive education in mainstream schools on 12 June at Sunderland University.

Inclusion in Action, supported by the National Lottery Charities Board, includes a variety of speakers and workshops. The cost is £5 per person, including lunch and a free creche.

Programmes and booking forms are available from Network 81 on 01279-816108 – early booking is advisable.

Closing date for conference: 28 May 1999; closing date for creche: 30 April 1999.

Network 81, an umbrella organisation of parent support groups, was established to advance the education of children with special needs and to educate their parents about all matters relating to the education of their children.

- ***Free advice and information line, Mon–Fri, 10am–2pm, 01279-647415.***

New treasurer

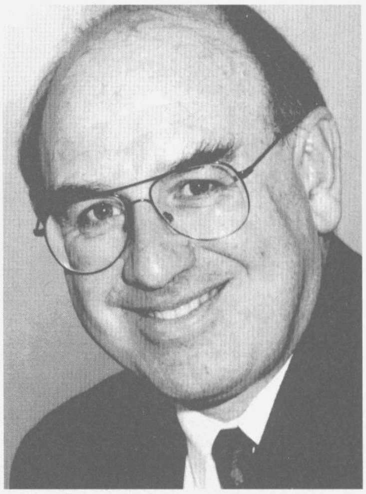
ACCOUNTANT Mike Allen, who had worked for Anglian Water for 22 years, has succeeded Charles Ortner as honorary treasurer of the Association.

Mr Allen, finance manager with Anglian Water Engineering and Business Systems Ltd until his retirement in 1996, was recruited to ASBAH after feelers were put out through REACH, the Retired Executives Action Clearing House.

"I'd been looking to put something back into the community when I received an approach from ASBAH, of which I was only fleetingly aware because I have a relative with spina bifida," said Mike.

He lives in Buckden, near Huntingdon.

ASBAH executive director Andrew Russell said: "We recently employed a new finance director. Now, with Mike Allen also on board acting in a voluntary capacity, we have a superb blend of strategic financial planning skills and experience."



Mike Allen

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.

ASBAH welcomes and appreciates the support of its commercial partners.

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

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

Glass designer Maralyn O'Keefe has donated some of her artwork to ASBAH

A glass act for ASBAH

A North East glass artist and designer is backing ASBAH by letting us put two handcrafted artworks up for sale to raise funds.

Maralyn O'Keefe, who runs Glass Design UK from her home at Consett, County Durham, has handed over a large panel made up of 105 pieces of glass. She was filmed making the panel for a recent Tyne Tees television programme.

Based on Charles Rennie Mackintosh's white lady carving outside Glasgow School of Art, it comes with a £400 price tag, and was first put on show at a new art gallery in Peterborough. It was accompanied by a smaller panel, for which offers were invited.

She said: "Some people, including myself, assume that the white lady is the Virgin Mary, and that the roses represent the embryos of Christ and other children. I'm not religious but this theme does touch my heart. I think the theme is appropriate for ASBAH, and that's why I want them to have it."

Maralyn, aged 47, who has a nephew with hydrocephalus, has seen orders flooding in for her work since she graduated with a fine arts degree from Sunderland less than a year ago.

A six foot rotating kaleidoscope of the Giant's Causeway in Northern Ireland, using 18 panels of stained glass and the central feature of her degree show, is now displayed at the National Trust visitor centre there. A chess board and chess set, first crafted for the same show and based on the causeway's hexagonal rock formations, is being produced at The National Glass Centre which opened this month.

Another design from the same show – *A Piece For Good Friday and Forever* – was presented to survivors of last year's Omagh bombing in County Durham to mark the first anniversary of the Good Friday peace agreement.

Maralyn changed career midstream when struck down by illness while working as a personal assistant to the managing director of one of the North East's biggest companies.

She and her husband Ron, a former RAF officer, now plan to open a new studio in a Consett factory unit because the converted front room of her terraced house in Medomsley Road is no longer big enough to double as a design area and glass workshop.

Barnstormer Paula leaves lift as legacy

A NEWLY patented stairlift, which retracts steps or stairs to let people in wheelchairs glide gracefully up as high as 1.3 metres, was the brainchild of a remarkable Southend businesswoman, who was never daunted by her spina bifida.

The Sesame Access system – now overcoming access problems at Petworth House, Surrey, and in a Swiss bank in St James's Square – was dreamed up by Paula Smith, before her death early last year at the age of 48.

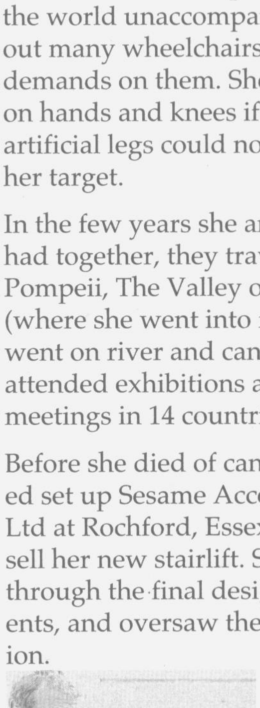
Paula, comercial director at BMAS Ltd, a firm supplying vehicles to the airport industry from its base at Southend Airport and a former Lib Dem member of Essex County Council, had a barnstorming approach that nothing should block access for anyone.

"She never thought of her disability getting in the way. Her attitude was 'My money is as good as anyone else's. If you take my money, you treat me the same as anyone else'," said fellow BMAS director Richard Boyd, who married Paula in 1995.

Paula, a double-amputee, travelled the world unaccompanied, wearing out many wheelchairs with her high demands on them. She would crawl on hands and knees if wheels or artificial legs could not take her to her target.

In the few years she and Richard had together, they travelled to Pompeii, The Valley of the Kings (where she went into four tombs), went on river and canel cruises and attended exhibitions and business meetings in 14 countries.

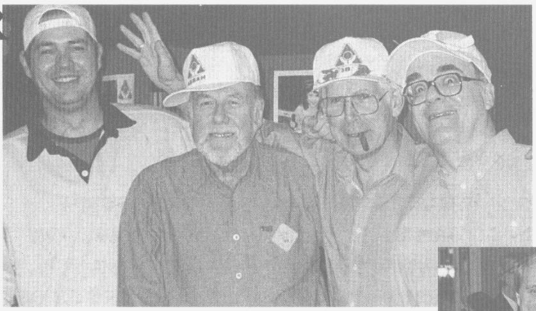
Before she died of cancer, she helped set up Sesame Access Systems Ltd at Rochford, Essex, to make and sell her new stairlift. She worked through the final designs and patents, and oversaw the first installation.



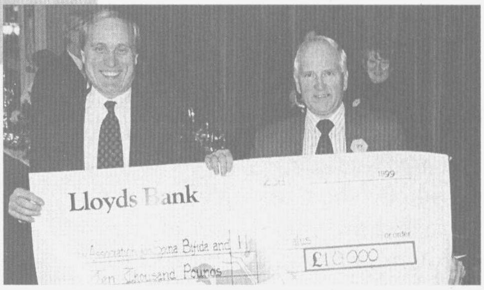
Paula Smith with party leader Paddy Ashdown while she was a county councillor.

PIGEON POWER

By Tony Britton



Backing up fundraising manager Donna Treanor and volunteer Anne Walton (an ASBAH Adviser) was this bunch of cheerful reprobrates. From the left: Ian Morley, Reg Walton, Paul Wootton and Tony Britton.



ASBAH executive director Andrew Russell (left) received £10,000 from the event. Little did he know that another £10,000 would soon be on its way…

PIGEON power, which has beamed teams of ASBAH fundraisers to Britain's premier racing pigeon event every year since 1973, once again fuelled a series of pleasant surprises earlier this year.

Our share from 26 years' proceeds at the British Homing World's annual 'Show of the Year' in Blackpool Winter Gardens – mecca for racing pigeon enthusiasts and ASBAH's most generous supporter – topped a massive £300,000.

A £10,000 cheque was presented in public at the show in January, based on the results of last year's event. This doubled in value when Peter Bryant, incoming general secretary of organising body, the Royal Pigeon Racing Association, signed off another £10,000 as one of his first duties of his new office.

We said a sad farewell to his predecessor, Major Edward Camilleri, who was responsible for modernising the show when he moved it to its permanent base in Blackpool from Doncaster race course, allying it for the first time to an international Olympiad – homed into by pigeon racers from around the world. But we welcomed Peter Bryant, a former RAF squadron leader, in his place.

This year, the Olympiad returned to Blackpool to run alongside the Show of the Year. The combination produced an event of such magnitude that it had to be spread over three days, not two. Thirty-two thousand visitors packed the venue.

The event turned in a profit of over £100,000. Out of 33 charities being recommended for support, 31 got lucky. The show's goodwill bucket kept spilling over, with well over £1 million donated to charity so far.

Peter Bryant, describing himself as "an administrator by trade", said he was thrilled by the complexity and diversity of his new posting. "If you were unkind enough, you might quote me as saying that I am now a wing commander instead of a squadron leader," he told *Link*.

Parents fight closure threat at Barbara Priestman School

PARENTS and a whole community in the North East have rallied to save from closure a school which has made their children blossom.

A group of parents went to London to deliver 14,000 letters of objection to the Secretary of State for Education and Employment, David Blunkett. Their colourful posters attracted the attention of the department and one of Mr Blunkett's assistants drew up in a car to find out what was going on.

Each letter to the DfEE received a reply, and Charles Clarke, Parliamentary Under Secretary of State (School Standards), has met a group of parents to hear their views.

Sunderland City Council wants to close the Barbara Priestman School and reopen it for children with severe learning difficulties.

Bill Michie, father of nine-year-old Kirsten, who has spina bifida, said: "Thousands of people have been knocked for six by these plans. Every parent is against it and the local council is in uproar."

The school's 130 pupils, aged from four to 18 years, have personal programmes worked out for them, and there are nurses, physiotherapists and hydrotherapy on site. Mr Michie said the school had a fantastic report after an Ofsted inspection and is recognised in Europe as a progressive school.

"The council wants to take out all the physically disabled children and chuck them into mainstream, but mainstream has failed 30 per cent of the children at Barbara Priestman.

"Kirsten goes to Brownies and mainstream swimming but needs a settled environment in order to learn: the security of being with pupils who have the same problems, without the pressures and hassles from children with better mobility. She has blossomed at the Barbara Priestman School."

He added: "We are not against integration into mainstream but it shouldn't be rushed and it should not be compulsory. Under these plans, we will be forced to send Kirsten to a mainstream school."

The school's future is now in the hands of Mr Blunkett and a decision is due to be announced in May.

Link cover story

ANTHEA Turner brought glamour and fun to an annual extravaganza which pulled in £100,000 to be shared by two charities including ASBAH.

She was representing ASBAH at a party for 1,200 City dealers who sat down to dinner and danced through the night for £100-a-head.

With *EastEnders* star Ross Kemp (Grant Mitchell), Anthea helped the money roll in for ASBAH at a £10-a-ticket raffle and then an auction of luxurious treats such a weekend for two in New York, a champagne tasting day for two in France, a diamond necklace and a trip to the Sydney Test Match.

The Swap Ball committee, which organises the Off Balance Ball at The Grosvenor House, London, has sent ASBAH half of the expected £50,000 – to be put towards a new hydrocephalus research project.

Donna Treanor, ASBAH's fund-raising manager who attended the event along with colleague Paul Wootton, commented: "We would like to say big thank you to the Swap Ball committee for choosing ASBAH and for organising such a fantastic fundraising event."

DIARY DATES ... DIARY DATES ... DIARY DATES

Saturday 24 April

Hydrocephalus Study Day, Post Graduate Centre, Frenchay Hospital, Bristol. 9.30am-4pm. £4 to service-users and family members, £8 professionals (buffet lunch included). Speakers include consultant neurosurgeon Ian Pople; ASBAH specialist adviser (education) Bruce Graham; and ASBAH senior adviser (health and policy issues) Rosemary Batchelor. ***Details: Julie Knight, c/o ASBAH National Centre, tel: 01733-555988, lynnt@asbah.demon.co.uk***

Saturday 8 May

Hydrocephalus Network coffee morning, Wood Cottage, Ollerton, Knutsford, Cheshire, by kind permission of the Adshead family, 10.30am-12noon. ***Elizabeth Miers, tel: 01490-450 360.***

Tuesday 11 May

Isle of Wight ASBAH study half day, Understanding Spina Bifida and Hydrocephalus, The Riverside Centre, The Quay, Newport, IoW, 1.30pm–4.00pm. Main speakers: Liz Clayton, ASBAH Adviser; Gillian Yaz, ASBAH Specialist Adviser (Medical). ***Details: Derek Sprake, tel: 01983-551234.***

Saturday 19 June

Special Children's Day, London Zoo, Regent's Park, London NW1 – for children and adults with special needs. Over 680 different species of animal. Animals in Action, and Meet and Touch encounters. British Sign Language interpretation at all events. Children under four years free; children 4-18 £3.90; adults £6.50, carer (essential only) free (one per family). Rates apply to tickets pre-booked and prepaid before **9 June**. ***Contact: education dept, 0171-449 6551.***

26 June – 4 July

Youth in Action, a leadership training course in Integrated Youth Work, module 2, Ballinran, Northern Ireland (with financial support from the Youth for Europe Programme, European Commission), for people aged between 16 and 25. ***Susan O'Flaherty, projects officer, Mobility International, 18 Boulevard Baudouin, 1000 Brussels, Belgium, tel +32 2 201 56 08, fax +32 2 201 57 63, email: mobint@arcadis.be***

Slippers for your wheelchair!

AT ONE time it was the height of good manners to remove one's shoes when arriving home and to put on slippers – that meant anything you'd trod into on the street remained on the sole of the shoe and was not tramped over carpets.

Eileen Daily has now taken that a step further and introduced a tyre slipper for wheelchair-users which she is calling 'Cosey Wheels', and sell at £14.99 a pair.

"I got fed up with muddy and wet tyre-marks on the carpet, the thought of what my daughter may have run over made me cringe but, most of all, she sometimes had red and swollen eyes which I'm sure happened because she was propelling herself around and accidentally transferring stuff the wheelchair had picked up off the ground to her face," said Eileen, whose 14-year-old daughter Joanne has spina bifida and hydrocephalus.

"Since she started putting the slippers on her tyres when she comes home, there've been – touch wood – no more blotchy eyes."

Cosey Wheels can be made to fit any wheelchair size and can be put on using a pair of wheel clips, which are supplied, while moving the wheelchair forward. At the moment, they only come in red tartan but that could change as soon as orders pick up.

For details, contact: Eileen Daily at 11 Tower Road, Little Downham, Ely, Cambs CB6 2TD.

Flatfree Toobz

A MIDLANDS firm is hoping to give peace of mind to wheelchair-users after making an inner tube which cannot be punctured – a lightweight, bouncy development of the solid rubber tyre of old. South African inventor Jens Sunde has teamed up with Nuneaton engineer Tony Street to produce Flatfree Toobz. ***More information on 01203-351495.***

Big night out!

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

Hi my name is Suzanne Bull and I'm a former Essex girl (originally from Brentwood) turned Chelsea girl (I am currently living in Earl's Court).

I came to the capital because I wanted to party all night. I feel exactly the same about going out in London now as I did when I started at Goldsmiths' College in 1989. I spent four and a half glorious years in New Cross and Deptford, going from one squat party to another. The pungency of sweat, perfume and watered-down beer, the ringing in my ears from the sound speakers, the bass beating in my chest and rattling in my ribs got me hooked.

In February 1994, I was living near Portobello Road and I thought the world was my oyster. Then I had an operation which changed my mobility drastically. I caught a serious infection from a small operation to straighten three toes. It took two years to subside. I have become a part-time wheelchair-user to relieve the strain.

My lust for life never changes. Now I must have the right access information and money to pay for cabs. I have a slight advantage because I am Artsline's publications and promotions officer. My main role is to edit access publications. This comes in handy when I want to check out a new venue!

So can a young disabled femme-fatale chill out in the capital? Both yes and no. Some venues clearly have **not** got their finger on the pulse. Unfortunately, the majority of these are clubs and music venues! Whilst Artsline was researching where young disabled Londoners go, typical responses from venues were: "We get very few disabled visitors." Some thought it was a lack of access (only 40% of London's music venues are wheelchair-accessible), but many also stated a "lack of interest." It seems that young disabled people are not part of youth culture.

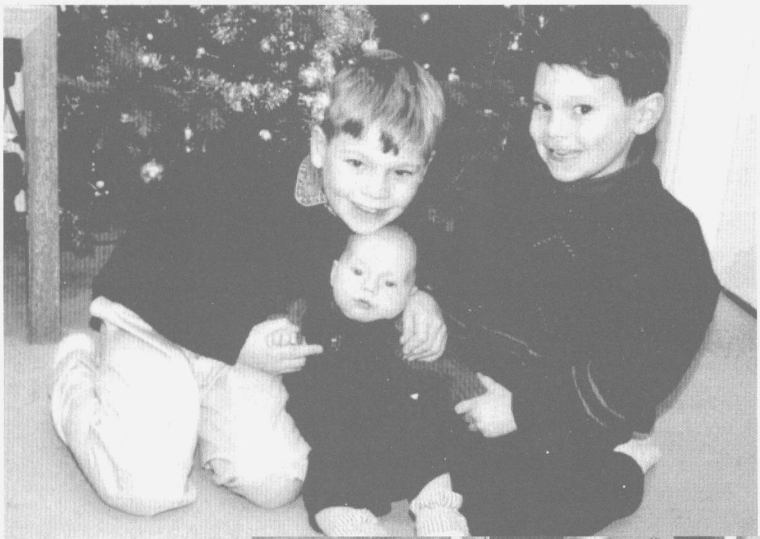
The lack of disabled "celebs" is filtering down to young disabled people. If you do not see yourself represented on the telly, how do you know what you can do? My predecessor, Paul Darke, discussed the misrepresentation of disabled people in the media. I believe this is one of the reasons why some young disabled people have low esteem and a lack of confidence.

Attitude makes all the difference, and I have one! It has got me in trouble and out of it! Bouncers at clubs have attitude. If you want to gain entry, the bouncers are often the main obstacles. If my access is barred, I will always say: *What's wrong with my money*, and force them to say: *Well, it's the wheelchair.*

Is it worth the hassle? I love the hassle. If I had the money and the energy, I would go out every night. I thoroughly enjoy gate-crashing private parties and winding up the "beautiful people." I get recognised all the time (and not only in London).

Most importantly, I have made some genuine friends. Without them, I am nothing!

Children cherish their friend's memory by raising money for us



Top: Nick Graney (left) with his brothers Stephen (right) and Patrick.

Right: Nick's classmates with the cheque for ASBAH

KIND-HEARTED primary school pupils raised £822 for ASBAH in memory of their 10-year-old friend.

Twenty-six pupils of Shrewton CE Primary School, near Salisbury, raised the money by cycling six miles around their village and by taking part in a non-uniform day at school.

At the time of Nick Graney's sudden and tragic death last September, donations to ASBAH were brought by villagers to the school instead of flowers, at the request of Nick's family.

Nick's best friend, 10-year-old George Kinsey, organised the bike ride and, as well as the youngsters, some parents and school governors took part. More than £700 was raised at this event.

Then the school organised a non-uniform day and this raised more than £60. More fundraising events will be organised as Shrewton CE Primary School has chosen ASBAH as its charity of the year – nominated by Nick's father, David, who is vice-chairman of the school's governing body.

Despite being born with hydrocephalus, Nick enjoyed a full and active life. He loved reading history books, particularly those about Ancient China, and was a James Bond fanatic. He played rugby, tennis, and was an excellent swimmer and a qualified life-saver. He had just earned a yellow belt in judo. He was also an accomplished guitar and recorder player, and a member of the local cubs. Just 24 hours before he was rushed to hospital, he had performed a solo rendition of 'Any Old Iron' in a school musical.

His mother Sue said: "Having hydrocephalus didn't limit Nick's life in any way."

The magnificent sum raised by the school, parents and other residents of Shrewton village was presented to ASBAH adviser for the Bristol area, Julie Knight.

New trains must be accessible

ALL new types of rolling stock used for trains and trams must be accessible to disabled people according to regulations introduced under the Disability Discrimination Act.

Minimum standards laid down by the new regulations include:

- Provision of travel information which can be seen as well as heard.
- A minimum number of designated spaces for wheelchair-users, depending on the train length.
- Boarding devices to enable wheelchair-users to get onto trains more easily.
- Larger and easier priority seats for disabled passengers.
- Where toilets are fitted, a number of larger and significantly more accessible ones will be required.
- Proper colour-contrasting features such as handrails and doors to help people with poor vision.

The Rail Vehicle Accessibility Regulations 1998 (SI 1998 No 2456) are available from: The Stationery Office, 123 Kingsway, London WC2B 6PQ. Tel: 0171-430 1671. Fax: 0171-489 8366.

Women's writing

A COLLECTION of writing on the issue of parenting has been published by The Women's Press.

Bigger than the Sky takes its title from one of the stories in the book when a mum asks her five-year-old son: *Know how much I love you?* He giggles and asks how much, how much? *Bigger than the sky!* the mum shouts and then dive bombs him an embrace.

Whether it be as a birth mother, an adoptive parent, a godparent, a friend, or a woman who has made a positive choice not to become a parent, the writers in this collection show the possibilities are limitless.

- *Bigger than the Sky*, edited by Michele Wates and Rowen Jade, price £8.99 (0 7043 4545 5).

Homes Fit for Children

PARENTS Paul and Margaret Gale have a reasonable income – he is a policeman and she works part time as an occupational therapist's assistant – but, incredibly, they have been told by their district council that they must pay the first £52,000 on adaptions to their home.

They say that they are being penalised for striving to pay for a home and for saving for the future when their eight-year-old daughter will need an electric wheelchair.

Mr and Mrs Gale applied to the Forest of Dean District Council for a Disabled Facilities Grant to pay for a lift to carry Rachel up three steps to her bedroom.

Under the present rules of the grant system, local authorities are obliged to take into account the family's income and savings but do not have to consider outgoings, even on essential items such as rent or mortgage payments.

Other adaptions to their house, in Cinderford, Gloucestershire, including ramps to front and back doors, will be needed to allow Rachel to be independent as she gets older.

Now a campaign is underway to make the system fairer and help all disabled children, irrespective of their parents' income.

Homes Fit for Children, supported by ASBAH, says it is vital from the points of view of disabled children, their parents and society as a whole that disabled children live in homes which are convenient and in which they can achieve independence.

Mr and Mrs Gale, who also have a younger daughter Rebecca, spent two years looking for a home they could afford which was large enough for Rachel, who uses a wheelchair all the time, to move around easily.

Rachel Gale, aged eight, needs a lift up three steps to her bedroom

Mrs Gale said: "We are very angry at the outcome of our application for a grant. We do have a reasonable income but we have a lot of outgoings – on our mortgage and daily travelling.

"Rachel's occupational therapist and physiotherapist were amazed to hear the judgement of the district council.

"They had heard of the council demanding that the family pays the first £5,000 or £10,000 for adaptions, but nothing like this."

Now they have become aware of Homes Fit for Children, Mr and Mrs Gale have alerted their MP to their own particular problem and placed it in the context of the campaign.

Until the lift is installed, Mr and Mrs Gale will have to continue lifting Rachel, weighing almost six stone, up and down the steps to her bedroom. This strenuous activity has prompted them to make private appointments with an osteopath to keep back problems at bay.

If their MP is unable to help the Gales, and no other charitable help is available, Mrs Gale said they would be forced to take out a loan.

"We have a choice: either we spend all our finance now and go begging for something else in the future or we take out a bank loan which will probably mean no annual holiday for 10 years.

"The system is unfair to those who have struggled and strived to keep a home. It is not me that needs the money, it's my daughter and it is she who is being penalised."

Reasons for the campaign

MANY thousands of severely disabled children in England need to have their homes adapted so they can continue to live with their families.

Adaptions, like lifts and special bathrooms, can be very expensive and many families with disabled children are already experiencing financial hardship.

The means test of the Disabled Facilities Grant can result in families on an average income having to contribute as much as £10,000.

Most families don't have such sums of money, and so struggle on without the adaption, or try to raise the money as best they can. This can cause delays of as long as three and four years, and stress and exhaustion for the family.

Homes Fit for Children is working for a fairer means test so families can afford the adaptions that their disabled children badly need. It is supported by 30 organisations, including ASBAH, and individuals concerned with childhood disability.

The campaign's aim is to get the test of resources abolished for all adaptions for children and the full cost met by central and local government. The short-term aim is to press for the test of resources to take into account families' expenditure on essential items, like housing. Campaigners also want fixed allowances replaced.

You can support the campaign by writing to:

- The Secretary of State, Rt Hon John Prescott MP, Department of the Environment, Transport & the Regions, Eland House, Bressenden Place, London SW1E 5DU.
- National newspapers, TV, radio.
- Local newspapers and radio.
- Your MP. Reading about your story could be the first time s/he will have realised the seriousness of the situation. Send it to your MP at the House of Commons, London SW1A 0AA.

Professo
Robert Zach
1913–199

WORDS BY LIZ CAWTHORNE AND TONY BR

BOB ZACHARY, who pioneered early operations on newborn babies with spina bifida and towered over the early development of ASBAH, died at home in Newfoundland on 1 February – one month before his 86th birthday.

Zachary, made professor of paediatric surgery by Sheffield University in 1976 and chairman of ASBAH for 11 years since its inception in 1966, was leader of a group of exceptional clinicians who created a renaissance in spina bifida surgery at the Sheffield Children's Hospital in the mid-50s and 60s.

While many other hospitals had negative attitudes towards the treatment of spina bifida, often discouraging the treatment of babies, particularly those with the secondary complication of hydrocephalus, he built Sheffield into an internationally acclaimed unit which worked to a radically different agenda.

After a successful, earlier career in orthopaedics, Zachary set his cap at paediatric surgery and, with the help of a grant from the Nuffield Foundation, went to Boston in the United States to be trained by some of the world's leading practitioners.

Six months before finishing training, he was tipped off that if he wanted the new post of consultant paediatric surgeon at Sheffield he had better hurry to apply as the closing date was fast approaching.

He arrived back in England in a nick of time on Good Friday 1948. The other candidates had already been seen but special arrangements were made to reassemble the panel to interview Zachary on Easter bank holiday Monday.

He was offered and accepted the post at £2,000 a year, to be taken up after completing his training in Boston that September.

Zachary promoted early surgical closure of the myelomeningocele, active treatment of associated hydrocephalus and continued follow-up and aggressive management of orthopaedic, renal and bowel problems.

"I was aware of my considerable responsibilities for the surgical care of children and especially of the newborn for which my training had prepared me. Yet I was concerned about the mothers of babies with spina bifida," he recalled in his memoirs.

"In the plan of management in Boston, no operation was done in the newborn period, but many of the babies were sent home after two or three weeks with a simple dressing on the back wound, which would allow the wound to heal in a few weeks or months.

"I became more and more convinced that these mothers faced a double burden. They had to care for an infant with paralysed legs and probably poor control of the bladder, yet in addition there was a large swelling on the back, the covering of which might rupture, spill fluid and allow infection to pass inside the spinal canal and cause meningitis.

"It was for this reason that, when I started neonatal surgery in Sheffield, I decided to remove such swellings as soon as possible after birth, instead of leaving them for 18 months or two years."

It was Sheffield's successful blend of talent, dedication, personalities, local fundraising, and a network of available specialities on the hospital campus, including spinal injuries and plastic surgery, which resulted in increasing workloads and clinics which overran well into the evening.

Referring physicians knew quality when they saw it, and Zachary was busy.

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He was in great demand internationally as a guest speaker, frequently delivering lectures in the language of his audience, whether in Russia, Poland or Czechoslovakia.

He was not called up during the Second World War, having been rejected for service because of his own severe spinal curvature. But he tended war wounded at Nuffield Orthopaedic Hospital, Oxford, pioneering new surgical techniques and building a national reputation even then. He performed some of the first tendon transplants on hands and wrists, procedures now commonplace. He was elected Hunterian professor at the Royal College of Surgeons in 1944 for research in orthopaedics and worked for the Medical Research Council on peripheral nerve injuries.

After the death of his first wife Faith in 1981, Zachary went out on a lecture tour of Australia, where he had a whirlwind romance with an old family friend, Winifred Cawley.

Undeterred by age or traditional encumbrances, he emigrated to Australia in his early 70s, married and lived there happily for six years. He travelled and wrote memoirs and fiction extensively until he had a stroke.

When his second wife passed on, he emigrated again – this time to his final home in St Albans, Newfoundland, where his daughter Anne lives and where he met his third wife, Janetta Hoskins.

His son, Christopher, writes: "His friends and family will forever have an image of Robert with his third wife, Janetta. They sat together for seven years, holding hands. They could not have been happier."

Professor Zachary is survived by Janetta, his children of his first marriage – Anne, John and Christopher, all doctors – and seven grandchildren.

more on page 16

Prof Zachary meeting HRH Princess Anne during a royal visit to an ASBAH function during his long inaugural chairmanship

Flashback to the 1970s. A large money wheel, which included a Mickey Mouse cartoon of Professor Zachary, was erected at the front of the Children's Hospital, Sheffield. Money was being raised for a roof house.

Never far from children whether operating or teacher. Here he is doing a demonstration for school children (1975).

Talks with Zachary over tea and biscuits led to formation of ASBAH

PROFESSOR Zachary's concern that parents of children with spina bifida should get every assistance away from outpatient clinics and hospitals led directly to the formation of ASBAH in 1966.

On Saturday afternoons, he and a paediatric medical colleague would talk to parents as a group, offering tea and biscuits and then continue the discussion afterwards.

He learned that similar approaches had been made to parents in London, Manchester and Birmingham and decided to invite representatives, doctors and parents to his home for a Sunday buffet lunch.

"On that day was born the Association for Spina Bifida and Hydrocephalus. Our first general meeting was to be in Birmingham the following spring. It is from these beginnings that ASBAH has grown to be a great organisation with the aim of helping these infants, young children and adolescents as they grow up and also to help their parents in their extra responsibilities.

"I was elected the first chairman and was privileged to lead the association through its most difficult early years – at one time giving my personal guarantee to cover the heavy cost of launching the project. If called upon, I would have had to sell my house."

Colleagues and friends pay tribute

TRIBUTES to Professor Zachary have been pouring into ASBAH. Here are a few:

Mary Oughtred, who joined ASBAH as our first general secretary in 1969:

"He was a man of infectious optimism. He had great skill as a surgeon, coupled with a firmly held conviction that life was a sacred trust.

"He had a natural gift of reconciling opposing ideas by being almost unwilling to see conflict. He gave much time and energy, especially at weekends, to the work of the Association – chairing meetings and conferences – often in a surgeon-like way, finding on-the-spot solutions for problems as they arose.

"By what he was and what he believed, he gave much to this field of modern medicine and to those touched by it and their families. They hold him in thankful and warm esteem."

Moyna Gilbertson OBE, physiotherapist and former ASBAH executive director:

"Professor Zachary believed in pretty heroic surgery to keep babies alive. His faith was enormously important to him – that really was Bob Zachary. He was a marvellous person, and absolutely convinced that what he was doing was right."

Sheffield parent Les Clark, whose son was treated by Bob Zachary and who went on to set up Sheffield ASBAH with his wife Barbara:

"Mr Zachary was very caring, nothing was too much trouble. He was the kind of person who was always there if you needed him. He wanted to improve the quality of life of the babies that lived."

Carole Sobkowiak, physiotherapist and honorary secretary of the Society for Research into Hydrocephalus and Spina Bifida (SRHSB), of which Professor Zachary was 1964-67 president:

"Professor Zachary was an outstanding surgeon who cared deeply for the children and their families. It was an inspiration to work with him and other exceptional colleagues in Sheffield during the 1960s and 1970s.

"As a founder member [of the SRHSB], Professor Zachary has left a legacy for future generations worldwide to debate their innovative ideas."

Professor John Sharrard, orthopaedic surgeon who worked closely with Prof Zachary at Sheffield:

"He was a remarkable man and remarkable in his abilities. His work in spina bifida was quite new. Operating on a newborn child with spina bifida had never been done before. He started a completely new field of work."

Duncan Forrest, surgeon, a fellow founder member of ASBAH, and chairman of our Medical Advisory Committee:

"His overriding qualities were his warmth and his humanity. His attitude and approach to his patients was so human that everybody loved him. He felt always that something could be done for his patients. In his talks and papers, you could see this love and warmth. His techniques were highly successful. He was a brilliant surgeon and his efforts did bear fruit."

Professor Christopher Zachary, dermatologist in San Francisco and son of Bob Zachary:

"Until the day he retired, my father pioneered new techniques for all types of childhood diseases. He became internationally known for his work. He trained a core of British paediatric surgeons who are now leaders themselves."

Professor Lewis Spitz, paediatric surgeon at Great Ormond Street Hospital, London, who worked with Zachary in Sheffield, writing in *The Times*:

"Zachary campaigned for paediatric surgeons to be given a monopoly of neonatal surgery, so that they might accumulate sufficient expertise in a variety of work.

"As chairman of the Specialist Advisory Committee of the Royal College of Surgeons of England, he emphasised the need for specialist centres to provide training for future generations of paediatric surgeons and to carry out essential research and development to promote the speciality.

"Above all, Zachary was a hands-on surgeon and a superb teacher."

HNN
Hydrocephalus Network News
Spring 1999

A new shunt to resist infection

RESEARCH funded by ASBAH could improve the quality of life of thousands of people around the world who are being treated for hydrocephalus.

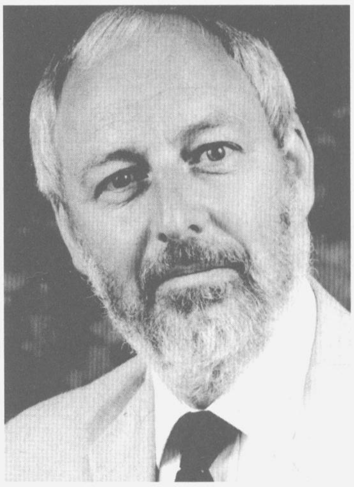
For over 20 years, ASBAH has been supporting the search for a breakthrough in the control of a major complication in the use of the hydrocephalus shunt.

Post-operative infection has led to the failure of many shunt implants because bacteria originally found on the skin have colonised the shunt tubing, causing it to be blocked. Up to 4,000 shunt operations are carried out each year in the UK – many of them involving replacing infected shunts.

Although the shunt is still the best available treatment for hydrocephalus, problems of infection and blockage have bedevilled the shunt implant since its invention in the 1950s.

Now, ASBAH-funded research at the University of Nottingham looks like reducing the risk of this complication by up to 80 per cent. A new infection-resistant shunt, developed by our consultant in hydrocephalus, Dr Roger Bayston, has started to be used in operating theatres around the world.

Dr Bayston, head of the university's Biomaterials-Related Infection Group, said: "As with all implantable devices, infection is a serious complication requiring surgical removal and further spells in hospital. In shunts, the infection rate varies from about five per cent in adults to between 10 and 15 per cent in babies."


Dr Roger Bayston

The new shunt, which goes by the trade name of Bactiseal, costs about three times as much as a conventional

continued on HNN page 2

NEW ASBAH BOOK

Hydrocephalus and YOU

The basics. The treatments. The implications for learning and life. Working with children and with adults.

Hydrocephalus and YOU **is a compilation of some of the best writing on the subject, by people who know what they are writing about.**

Edited by Leonie Holgate and Rosemary Batchelor, ASBAH.

Available: Spring '99.

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

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/Continence (National): Paula Thompson 01733-555988.

Medical/Continence (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/Continence, (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.

ASBAH's Hon Consultant on Hydrocephalus: Dr Roger Bayston MMedSci FRCPath, contact through ASBAH's Services Dept 01773-555988

New shunt resists infection *from HNN p1*

shunt. But, since its launch last October by Codman Ltd – part of the global healthcare products group Johnson & Johnson – money appears to be no object to its purchase.

"I'm told that hospitals are buying it readily," said Dr Bayston.

Only two nations have put the product on hold in its first six months: the USA, where the federal Food and Drug Administration is still withholding final approval, and Japan, where the authorities have had problems with an unconnected implant.

Dr Bayston said: "As the idea was a new concept, regulatory authorities around the world have taken a great interest in it and demanded extremely rigorous testing, probably more than for any other implant."

Bactiseal has been rigorously lab tested but its first major clinical trial started in essence when it was launched on the market. Dr Bayston is hoping that clinicians who use it will measure both successes and failures, and report these results.

ASBAH executive director Andrew Russell commented: "This is an exciting development, which could improve the quality of life for many thousands of people who rely on hydrocephalus shunts to stay healthy.

"If properly taken up, it could also save millions in healthcare budgets round the world as surgeons carry out many fewer shunt replacement operations."

Holistic holiday in Scotland

DREAMWEAVERS is a holistic holiday where disabled people can go with their families to enjoy independence in a beautiful area of Scotland.

Spacious accommodation allows easy access and aids are available to give as much independence as possible.

On-site activities, both indoor and outdoor, are provided for children and adults, and in the surrounding area there is a range of holiday activities and centres of interest.

Traditional entertainment in the evenings includes music, dance, craft and storytelling. Childminding is provided to give parents/carers a break.

Activity packages can be designed to ensure that every day spent at Dreamweavers is full of new experiences.

Holistic therapies such Reiki, aromatherapy, crystal therapy and deep relaxation are also available.

Prices are stable throughout the year. Bed and breakfast is £20 per person per night; children go half price if they share their parents' room.

Dreamweavers Highland Holiday Experience,
Earendil, Mucomuir, By Spean Bridge PH34 4EQ.
Tel: 01397-712548. Email: helen@dreamweavers.co.uk

Which shunts perform well?

PLEASE help us!

ASBAH is working with the National Shunt Registry to find out how all the different types of shunt perform. It is important to know which shunts perform best, which may suit particular types of hydrocephalus, and whether particular shunts have any special problems.

The National Shunt Registry was established in May 1995, funded by the Department of Health, to gather information about the performance of shunts systematically. The aim is for everybody with a shunt to be monitored, for the benefit of everybody.

If you (or your child) have a shunt fitted, please help in the following ways:

- If you carry our shunt Alert card, you will soon receive a short questionnaire. Please take the time to complete and return this in the envelope provided.
- If you have a shunt but do not carry the shunt Alert card, please consider contacting us immediately. We advise all people with a shunt to carry the card in case of sudden medical complications.

We would like consent from individuals to give brief details of them and their shunt to the National Shunt Registry. This information will be treated in strict confidence. Over 2,000 of our members now carry the shunt Alert card, and this would be a significant addition to the information held by the Registry, for the benefit of the consumer – the person with the shunt.

What's in the May/June **Link**

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

Local self-help group for parents of children with hydrocephalus and feeding problems

PAULA Thompson, our national specialist adviser (medical), has built up some expertise and a database of children with hydrocephalus and feeding problems over the last two years. Now, one of the mums she has advised is forming a self-help group.

Little Squirts has been set up for the Thurrock area by Cara Slowman to allow parents to share experiences.

If you need medical advice, or don't live in Thurrock, please contact Paula at our national centre on 01733-555988.

Cara's two-and-a-half-year-old daughter, Ellie Green, is tube-fed and developmentally delayed but the support group is for parents of children of all ages and with any kind of feeding problem.

Cara said: "I'd also like to hear from parents whose children had feeding problems but who feed OK now."

As well as a newsletter, Cara wants to compile a list of parents' names and addresses – with the parents' consent – to circulate among the group.

Cara also hopes to hold regular meetings for parents at Basildon Hospital's Child Development Centre.

You can contact Cara at:
16 Broadhope Avenue,
Stanford-le-Hope, Essex
SS17 0SJ. Tel: 01375-674659.

- ***Dr A E Hill, consultant community paediatrician for South & East Belfast Health and Social Services Trust, has kindly agreed to undertake a survey of children with hydrocephalus comparing those with feeding problems with those without. We hope to be able to announce the results in due course.***

True story

By Sue Mander
Chorleywood,
near Watford

I DEVELOPED hydrocephalus at the age of 41 after a lifetime of good health. I suddenly had uncharacteristic headaches which the doctors all thought were migraine. I must have seen various doctors at least six or seven times and was sure that I had meningitis as the pain was so bad and no tablets seemed to help.

Eventually, my husband insisted that I go to hospital as I was being violently sick and in a very bad state. There I had a brain scan and was rushed by ambulance to Charing Cross Hospital. Next day, I had an exterior drain attached which made me feel a bit like a Teletubby and I had to remain very still in bed so that the drain was at the same level as my ear. I could then watch my cerebral fluid fill a test tube next to my bed. Not a very pleasant experience!

A few days later, I had a decompression operation done on the back of my head. After this, I had to decide whether to have ventriculostomy or a shunt. I went for the former as I didn't want a foreign body in my head and was discharged from hospital after about three weeks.

Unfortunately, I was only home for 10 days before I started being very sick again and was readmitted for more operations. It was decided to put a shunt in as the ventriculostomy had not worked.

The first shunt to be put in was not successful and also got infected. It was at too high a level and the infection made me incontinent. After what seemed an eternity, when blood tests were taken every day to see whether the infection had gone, I was fitted with another shunt. This one was at a much lower level and seemed to suit me much better.

I went home after nearly eight weeks in hospital and seven operations.

My husband had come to hospital every day and somehow managed to juggle work, visiting me and looking after out five-year-old daughter, Rebecca. I had fallen ill a week before the school summer holiday and was discharged finally a week after it finished. Friends rallied around and someone looked after Rebecca every day so that my husband could visit me but the strain was enormous on my family and I will always be grateful for the love that they showed me during such a difficult time.

When I got home, I was extremely weak and tackling stairs made my legs feel like jelly. I had lost two stone in weight and as I was not overweight to begin with, I looked awful. My hair had been chopped and shaven and the first wash did not remove the matted clumps which I had to cut out. What a mess I felt! I had various symptoms such as weird ear noises and stomach pains which I didn't know whether were normal or not. At least I had an appetite so I could put the weight back on!

Four months later (January), the only thing that reminded me I was ill was a slightly stiff neck and I could feel the bump where the shunt was inserted. I feel stronger every day and look forward to having my driving licence again. Then I hope to get back to playing tennis, swimming and yoga.

I had always thought that only babies had hydrocephalus and still cannot believe that I lived for 41 years with the malformation called Arnold Chiari at the back of my head with no symptoms at all.

I tend to forget I have a shunt and, at my final check, my consultant said there was nothing I cannot do!

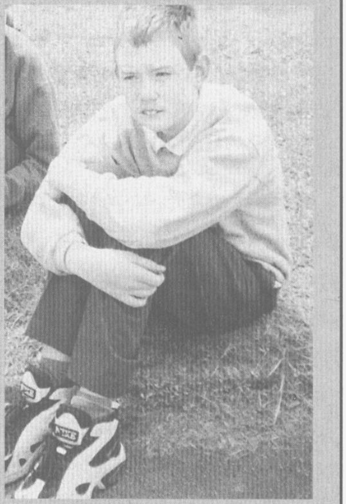
I would be pleased to know of anyone else who has had a similar experience.

Special school merger scare

AFTER writing about her son's progress since joining a school for visually impaired and physically disabled children (*HNN* Autumn '98), Julia Griffiths received the shock news that the school was to be merged with others.

Quite a battle followed but, with the help of Mike Dodd, who was our specialist adviser (education), and the RNIB, it looks like Exhall Grange in Warwickshire has been saved.

Now Mrs Griffiths is keen to promote the school to help increase its intake of pupils. The government has awarded the school Beacon Status for excellence.



Daniel Griffiths

WE sat back thinking how lucky we were to finally find such an excellent school – one which Daniel had settled into really well and was giving 110% in all his subjects.

Then we were sent a letter from Warwickshire Education about a meeting to discuss the merger of two local schools into Exhall Grange School. To us, and the other parents of visually impaired children who attend Exhall, this would have meant the upheaval and rebuilding of all the children concerned.

When we attended the meeting with other concerned parents, education officers and councillors, we realised that we really did have a problem. It seemed that decisions and plans had already been made by Warwickshire Education.

We realised we needed help, so I contacted my 'right arm', your now retired specialist adviser (education), Mike Dodd. We sent him the proposal and he agreed we needed as many parents to appeal against it as we could get. Parents also had to write to Warwickshire Education, Warwickshire County Council and their own LEA and make their feelings known.

Mike wrote to them on Daniel's behalf and explained how important schools like Exhall Grange are to visually impaired children and that a merger would be unsuitable for them.

Unfortunately, many authorities want to merge smaller special schools into a large regional school so the schools double in size but the pupils suffer because of the variety of special needs in one class and larger class sizes.

Mr Blunkett, the Secretary of State for Education, wants integration but has not allocated enough money. We tried integrating Daniel into mainstream school, but it did not work due to the lack of qualified staff and scant resources.

Warwickshire Education's proposals frightened a lot of parents who had moved to be in Exhall Grange's catchment area. *We* were worried because, if the proposals went ahead and the school ended up with a wide variety of disabled children and lost visually impaired status, then our education authority could have refused to continue paying Warwickshire Education, and moved Daniel to a special school locally.

Parents and organisations like the RNIB and ASBAH made an impact because a merger is, hopefully, now not going to happen. But the question of limited numbers of pupils at the school which operates on a vast, expensive-to-run site is being addressed.

I want to make it known that we do have excellent schools all over but sometimes we have to hunt to find them because LEAs do not promote them.

To me, Exhall Grange has been a ray of light and we can now see a future for our son who is happy and confident and enjoys school. This is due to the experienced, dedicated staff who have the best interests of the children at heart.

● *Information videos and a prospectus on Exhall Grange are available from the school on 01203-364200.*

IT IS eight years since I wrote to ask readers for help, information and experiences of bringing up a child with hydrocephalus.

I was completely ignorant of the condition. I was, however, determined to find out as much as I could and so I read anything I could get hold of. I was conscious that my boy's future and well being were squarely in my hands, so there was no problem about motivation. In my search for any kind of help, I found *HNN* and thought why not?

My letter to you brought lots of replies from mothers who were eager to pass on what they knew on a practical level and to offer support and to confirm there was light at the end of the tunnel. I am still in contact with a couple of these mums and have learned so much over the years.

My very handsome son, Francis, is now 10. I find it incredible as I look back and remember vividly whole nights of sitting awake while he vomited non-stop – in and out of hospital – the dreadful headaches and the economy-size bottles of Calpol.

I can remember lying awake alone and crying about the future of this tiny person who would need support all his life, part of which I likely wasn't going to be there for him. It's difficult to be positive at 4am. I remember the mind-numbing terror that is always at its worst in the wee small hours and is non-transferable to anyone else.

The adage to 'take one day at a time' is truly the most unhelpful thing you can hear, however well meant. As a mum involved completely in appointments, reviews, etc that are the inevitable lot of the child, you need to hear something that you can hold on to and signs that give hope for the future, not a platitude thank you very much.


Francis Lees

Francis has a weakness of his left side which results in a limp and an all-but-useless left arm ... what the heck, he's right-handed anyway ... no problem.

His writing is a bit 'untidy' ... hey, we have a computer and he types faster than he can write ... no problem.

His balance is suspect and he can't ride a bike or roller blade ... but he will be the first of his peers to get his own automatic Metro (he's actually looking forward to it being a Ferrari).

I used to fret about his academic future – I have a very strong belief in education being one of the most important things in life: it opens up so much magic and so many doors. We took decisions which seemed to go against all advice and common sense and removed him from his special school when he was six. With help and great understanding from his new school, staff and pupils, he is progressing so far above my hopes that I am constantly humbled and ashamed of expecting so little of him.

Each term, the children do a three-minute presentation on a subject of their own choice. Francis chose to 'educate' his class about hydrocephalus with the aid of a borrowed valve and some very bright and simplistic homemade diagrams. He came second in the class and was the talk of the school for the next week. Classmates were impressed with his knowledge and being able to handle the valve.

I can't begin to tell you how proud I was, and grateful, that his classmates had reacted so enthusiastically to him. As Francis has been with the same set of children for nearly four years now, he is treated as 'one of the boys' and sometimes comes home with the bruises to prove it.

When I look back at the true despair I felt at times, my heart goes out to new parents just starting out on the same apparently bleak-looking trail into the unknown future.

I can only commend them to *HNN* and contact with as many other families as they can, by post or email. Nothing concentrates your mind so much as sitting down to write exactly how you feel about your situation – guilt feelings, anger, and the other unspeakable things we all have to experience as parents of extraordinary children.

Linda Lees
5 St Winifred Road
Rainhill, Prescot
Merseyside L35 8PY
email: llees@breathe.co.uk

Hydrocephalus Network News
HNN LETTERS

I would like to correspond with women with hydrocephalus who have had children.

I am 31 years old and have congenital hydrocephalus. I have had 14 shunt revisions, the last being in 1996. Previous to that I had no shunt revisions after 1980.

I lead a normal life and work as a telephonist for government department in Australia. I have done a Bachelor of Commerce at university so have not let the condition set me back from my goals.

The issue of having a child, though, was more daunting due to my tubing: I was concerned about the effect having a child would have on my well-being.

I am considering pregnancy but have not had any positive feedback, so far, from my specialist. His concern mainly is that there is so little known about hydrocephalus and its causes, especially, as in my case, there was no previous family history of the condition.

I have written to Nancy Bradley – the mum in the US who is doing a data collection for mums with hydrocephalus.

Tanya Slater
36 Clarence Street
Tenambit NSW 2323
AUSTRALIA
email:
tanya.tl.slater@centrelink.gov.au

I WOULD like to correspond with adults with hydrocephalus about this condition and how they deal with day to day life.

I am frustrated because, although I was born with hydrocephalus, I didn't find out about it until I was 24 years old. I am now 28.

I would find it very helpful if someone could write back. Thank you.

Juliet Moreland
PO Box 524
Soquel 95073
USA
Email: SCTrudger@AOL.COM

ARE you a parent in Somerset? Has your child been recently diagnosed with hydrocephalus? Would you like to contact another family in a similar situation to share experiences and give support to each other?

Please contact Rachel Clark, Somerset adviser, 01460-240462.

WHEN my son was almost 47 years old, in January 1996, he had a third ventricle colloid cyst removed. In the following October, a ventricular shunt was inserted and from then on, he has had intractable neck pain.

This has been diagnosed as a degenerative disorder, although there was no sign of it before the shunt was inserted. There are several prolapsed discs in the cervical area which could have been caused during the twisting of his neck while the shunt was put in position.

Nerve root injection, analgesia, use of a Tens machine, collar and acupuncture have been tried to no avail.

My son is only free of pain when he lies down. Can anyone suggest a way in which he can have a life free of pain?

Please write c/o HNN Co-ordinator, Mrs Rosemary Batchelor.

MY HUSBAND Doug, aged 64, has diabetes and has been diagnosed as having hydrocephalus after a series of strokes. He doesn't have a shunt.

I would like to hear from other people in a similar position to share experiences.

Rita Evans
24 Iveagh Crescent
Newhaven
East Sussex BN9 0QP

ANYONE who previously corresponded with Penny Wilkinson in Australia and would like to do so again, should please contact her c/o ASBAH.

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

Kelly Upson

True story

By Kelly Upson from Emswoth, Hampshire

I AM 17 and, last June, I was diagnosed with congenital hydrocephalus. A week after my GCSEs, I was lying flat on my back after an emergency operation to save my life.

I had been suffering from bad headaches since the previous November and these were put down to exam stress. In the four days after my last exam my headaches became so severe that my chin was forced on to my chest. I was rolling about on the floor, holding my head and screaming: "Somebody take these headaches away!"

My mother took me to an out-of-hours clinic that evening, yet the doctor could give us no explanation for the headaches. He checked me over and told me to see my GP as soon as possible. My GP could offer no explanation either.

In three and a half days I saw five doctors, including my GP. One left me some very strong painkillers and another told me it was migraine. During the Wednesday afternoon, my parents were told by our GP's surgery to phone an ambulance because my symptoms were so severe. The paramedics told my parents I was suffering from hypoglycaemia. They treated me for this and then left.

On the Wednesday evening my symptoms had not improved so my mother called the duty doctor out. He referred me to hospital because I was dehydrated and it was affecting my diabetes. My parents breathed a sigh of relief as they now knew that we would eventually find out the cause of the headaches.

The next morning, after a night of tests, I was taken to another hospital for a CT scan. When my mother arrived, the nurse in charge told her that the scan had shown fluid on the brain and that I was being transferred to a neurological unit. That was the moment when my mother felt her heart hit her boots.

That evening, I had an emergency operation to insert a ventricular drain. Five days later, I had surgery for Third Ventriculostomy. Everything seemed fine and I was sent home five days later.

I started college in September and, after three days, I went back to see my GP because a lot of the symptoms I had had in June returned. I was admitted and, after a few tests, it became obvious that the ventriculostomy had not worked and I needed a shunt.

Two days after going home, I was readmitted due to having an infected shunt. A new shunt was inserted in October and everything is fine.

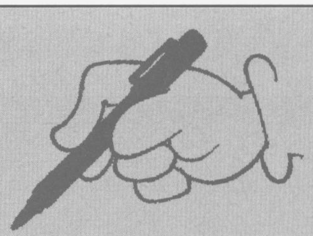
I tried to go back to college but, missing nine weeks, I had got too far behind. I have decided to work for a year and start my 'A' levels this coming September.

I am still suffering from a headache, although the hospital has checked the pressure in my head, and the function of my shunt. My consultant says he can see no reason for the headache. My GP told me that it is a tension headache.

Can anyone offer any other explanation?

***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.



Dave's diary

IN THE past, I've said that I'm a bit on the large side. My family has some excellent cooks in it (my gran and my mum being two that come to mind). Sadly, for all my love of food, the art of cooking seems beyond me. My cooking is dreadful!

When I, eventually, left the nest and went to university, there was great concern (not least by me) over how I would eat. I managed it through the traditional male student ways of either going down the chip shop every night. Or (and feminists will probably burn this magazine after reading this), I persuaded the only girl in the house to cook dinner for us both, promising that I'd do the 'mighty warrior' routine and hunt round Sainsbury's for the food.

I became a bit more independent (and liberated) when my brother kindly gave me a microwave. Stuffing ready meals into the microwave made life much easier. But it did nothing for my taste buds and didn't solve the problem I had with cooking – I just didn't know what I was doing. The bread and butter pudding from hell proved that.

I spotted a family pack of bread and butter pudding and my greed overcame my sense. I bought it, microwaved it and stuffed as much as I could down my throat. Unfortunately, my appetite was not as developed as it is now. I barely got through a third of it. So I put it back in the fridge. Next day I reheated it and ate some more. Still, I wasn't finished. So, for a third day, I took it out the fridge, reheated it and finally finished it off. Little did I know it would try and do the same to me! That night I woke with dreadful gut ache, which swiftly descended into a fever, sickness, and swelled-up glands. The doctor told me I had the worst case of food poisoning she'd ever seen and I should stop re-reheating eggy microwave meals! We live (just) and learn.

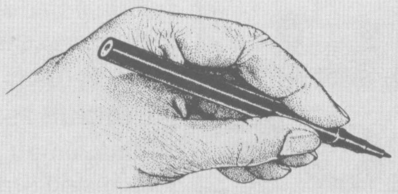
Why should cooking be so painful, confusing and downright dangerous? Is it because I have spina bifida? Certainly, I can't stand straight for long, and seeing me stagger about with pans of boiling water does tend to make people a tad nervous. It could be that my hydrocephalus puts the boot in and makes me forget things like cooking instructions, time and ingredients. Certainly, I was the only kid in the Home Economics class who made 'vegetarian' meat and potato pie after managing to leave the beef at home. (I chucked in a load of Oxo cubes, hoping no one would notice!)

Being disabled doesn't help, but I'm sure there are loads of people more disabled than me who make an excellent job of cooking. Nor is it, because I'm a bloke (despite what female friends suggest).

Cooking just seems too fussy and complicated for me. And I'm not alone in this. When Delia Smith brought out her series on making simple food, people mocked but loads of people watched and bought the book. I ended up buying the cheaper and better *Cooking for Blokes*. I used *CFB* when I recently did a meal for two female friends.

Of course, it all went horribly wrong. I came down with raging 'flu and couldn't get dinner together at all. Fortunately (but most embarrassingly) for me, mum was around to save the day. So I want to end this Diary with humble thanks to her for doing dinner (and all the other meals over the years).

David Fulford-Brown



Letters

I AM 36 years old and have spina bifida myelomeningocele and live in Colombia, South America. I have studied special education and am now studying psychology.

For my thesis, I want to look at the psychological effects in a family when having a child with spina bifida and, for this purpose, I would like to get in touch with parents of children with spina bifida to share experiences. I would like to focus on fear and guilty feelings.

For my practice, I am going to work in a hospital in my city to help children with spina bifida from birth through to 16 years old. With my own experience and my knowledge in psychology, I think I can help a lot. This is another reason why I have chosen my thesis subject – I want to be well prepared so I can help as many people as I can.

I would like to focus my job as a therapist in helping people with health problems which cause them psychological disorders.

If you would like to help, please write by post or email to:

Monica Uribe
Edificio torre del Laurel
Carrera 77 # 33 A 73 Apt 402
Medellin
Colombia
South America
email: monuribe@supernet.com.co

More letters on page 26

We invite letters for publication. Send them please to: *The 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.

OUR six-year-old daughter has spina bifida and hydrocephalus. She also has epilepsy and we would be interested in any help or advice from parents of children, with spina bifida and epilepsy, who are slightly older than Mary.

Mary has grand mal seizures and is on medication. In particular, we would like to find out what Mary may be feeling and experiencing during her attacks.

Mrs A Bate
30 Oak Green
Old Park Farm Estate
Dudley
West Midlands
DY1 3QX

A YOUNG lady with hydrocephalus by itself is about to undergo bladder surgery. She has been given the choice between having a urostomy or a Mitrofanoff.

She would like to contact somebody who has had similar surgery to try to understand more what is going to happen to her.

Please contact Paula Thompson, specialist adviser (medical/continence) at national centre on 01733-555988 in the first instance.

I AM 29 years old. I like horse riding, activity holidays, doing things like abseiling, microlighting. I also love TV and chart music from the 60s, 70s and 80s. I work for a local water company and live with a five-year-old cat. I have SB&H but walk unaided.

I am looking for a pen-pal who is of similar age and interests.

Sarah Gompertz
54 Barnet Road
Potters Bar
Herts EN6 2RB

FOR SALE

NISSAN SERENA 2.0 ltr diesel LX, red, M reg, 4-door, 10,100 miles. Brotherwood conversion (rear wheelchair ramp) – 4 point anchorage. Seating for 5 people including wheelchair-user and driver. Six months MOT. Excellent condition. £11,500 ono. ***Contact: Mr Cannon on 01246-278952 (Chesterfield).***

THERMOPOSTURE electrically adjustable bed, massage facility, 6' x 6'6" (including divan), wine-coloured quilted headboards. 18 months old. Possum interface. Cost £3,680. Accept £2,000 ono. ***Tel: 01246-278952 (Chesterfield).***

TWO CUMBRIA stairlifts, unused with full manufacturer's warranty. Both right-handed, one 10ft, the other 7ft long. Accept £1,300 each or £2,400 the pair (less than half price) ono. ***01245-222150 (Essex).***

CRUISER 4E electric wheelchair, with charger, accessories and tools. Seat width 26"–28". Range 13 miles, gradient 20%. Kerb lifter. Cost £3,200. Accept £2,000 ono. ***Tel: 01332-754340 after 4pm (Derby).***

RENAULT VAN, M-reg, 15,000 miles, red, three-seater, adapted with ramp so the Cruiser 4E electric wheelchair (advertised above) can be wheeled in and fastened with person on board. Central locking. Cost £13,200. Accept £6,000. ***Tel: 01332-754340 after 4pm (Derby).***

SUNRISE POWERTEC electric wheelchair, with battery charger, speedo and kerb-climbing facility. Cost £2,700 when new (1998), asking £1,900 (no offers). VGC. ***Danny or Peter, tel: 0181-581 9931 (Hayes, Middlesex).***

SUNRISE MEDICAL F4 electric wheelchair, hardly used because owner is learning to drive. Lightweight, easily dismantled and put together again. £2,300. Battery charger included. ***Mrs Cantrell, tel: 01623-406506 (Mansfield).***

QUICKIE F55, powered wheelchair, eight months old, black, 6mph, with kerb climber, comfort seat, light indicators and separate battery charger, plus other extras. Seat width 44cm, seat depth 56cm. Total wheelchair height 110cm, 63cm wide. Cost £5,000, accept £2,995 ono. ***Tel: 01222-625273 (Cardiff).***

POWERTEC F40 purple, r/hand drive, seat-width 16", three years old, hardly used. Battery and charger included. Kerb climbing and dismounting facility. Offers around £1,000. ***Mrs Tutty, tel: 01268-571618 (Essex).***

SUNRISE POWERTEC folding wheelchair, less than one year old, battery charger included. Seat width 450mm, height from floor to handles 950mm. Paid £2,700. Accept £1,900 no offers. ***Tel: 0181-581 1388 (Middx).***

HOLIDAY ACCOMMODATION

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

ISLE OF WIGHT ASBAH – Recently refurbished, fully-equipped, two-bedroom bungalow, sleeps six. Wheelchair accessible. On site clubhouse, shop. Local indoor heated pool suitable. Interesting places to visit. Lovely views. 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.***

ORLANDO, FLORIDA – House with a 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.***

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. (Hon Sec South Wales ASBAH).***

GALWAY BAY, IRELAND – Brandy Harbour Cottage Apartments – Two luxury, two-bedroomed, self-catering apartments on sea front in scenic area. 20 minutes from Galway City. Ideal for touring The Burren, Connemara etc. Wheelchair-accessible. ***Tel: 00353-91 796 491.***

ACCOMMODATION

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

FOR SALE

FORD ESCORT 1.6 Automatic. Registered 1988, 48,000 miles with full service history, MOT, two owners from new; last owner since February 1989. Immaculate condition. Factor 2 power steering, offside hand accelerator/brake (+ normal controls), electric powered boot lift for electric scooter. 3-wheel electric scooter and accessories included. £2,300. ***Tel: 01702-232811 (Essex).***

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

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

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

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

LINK Rates

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Small adverts for the next issue of *LINK* (July) should be submitted by Friday 14 May. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

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

BEDFORD
Mrs M Simmonds
16 Parkstone Close
Bedford MK41 8BD
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Tel: 01494 714270

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

CAMBRIDGE & DISTRICT
Mr Tony Proud
10 Newlands Road
Whittlesey
Peterborough PE7 1YX
Tel: 01733-755686

CHESTER & DISTRICT
Mrs P Ithell
34 King Edward Street
Shotton, Deeside
Clwyd CH5 1DW
Tel: 01244 811074

COVENTRY
Mrs N Newman
11 The Earls Court
Cheylesmere
Coventry CV3 5ES

DERBYSHIRE
Mrs A Hewitt
St Merryn, 20 Burley Hill
Allestree, Derby DE3 2ET
Tel: 01332 841893

DUDLEY & WOLVERHAMPTON
Mrs Lorna J Wootton
14 Leveson Road
Wednesfield, Wolverhampton
West Midlands WV11 2HF
Tel: 01902 738724

GRANTHAM
Mrs J Asken
88 Goodliffe Road
Grantham, Lincs NG31 7QB
Tel: 01476 401643

GREENWICH & DISTRICT
Mrs M Mears
29 Wellmeadow Road
London SE13 65Y
Tel: 0181 244 3526

HAMPSHIRE NORTH, W SURREY & S BERKS
Miss Vicky Beken
41 Lynchford Road
Farnborough
Hants GU14 6AN
Tel: 01252-845765

HERTS AND SOUTH BEDS
Mrs Jennifer Hammond
28 Gladeside
St Albans
Herts
AL4 9JA

HUDDERSFIELD
Mr Stephen Bolton
361 Bradley Road
Huddersfield HD2 1PR
Tel: 01484-424479

KENT
Mrs S Stevens
6 Croftside
Vigo Village
Meopham
Kent DA13 0SH
Tel: 01732 822985

LEEDS & BRADFORD
Anna Waddington
Mullion Cottage
Main Street
Hawksworth
Guiseley
West Yorks LF20 8NX

LEICESTERSHIRE
Mrs A Twomlow
29 The Crescent
Market Harborough
Leicestershire
LE16 7JJ
Tel: 01858 432967

LINCOLN & MID LINCS
Mrs P Malson
"Pinfold"
Chapel Lane
North Scarle
Lincoln
LN6 9EX
Tel: 01522 778781

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

LONDON N WEST
Mrs H Prentice
37 Milton Road
Hanwell
London W7 1LQ
Tel: 0181 579 4685

LONDON SOUTH
Mrs S Cudd
15 Woodvale Walk
Elder Road
W Norwood
London SE27
Tel: 0181 761 2400

NORTHAMPTONSHIRE
Mrs Alison Walter
12 Adam Avenue
Northampton
NN1 4LQ
Tel: 01604 634419

OXFORDSHIRE
Mrs Shirley Dale
14 South Row
Chilton
Didcot
Oxon OX11 0RT
Tel: 01235 834785

PRESTON
Mrs S Thompson
34 Beatty Road
Southport
Merseyside PR8 6LB
Tel: 01704 542589

St HELENS & DISTRICT
Joanne Barrett
10 Halefield Street
St Helen's WA10 2DE
Tel: 01744-612860

SHEFFIELD
Mrs Barbara Clark
35 Woodhouse Lane
Beighton
Sheffield S20 1AA
Tel: 0114-269 9299

SOMERSET
Mrs J Eastley
46 Hamilton Road
Taunton
Somerset TA1 2ER

SOUTH THAMES
Mrs Margaret Holmes
24 Hawthorn Road
Dartford
Kent DA1 2SB
Tel: 01322 408876

SOUTHAMPTON & DISTRICT
Mr S J Fitzgerald
32 Ellis Road
Thornhill
Southampton SO2 6ER
Tel: 01703 402644

STAFFORDSHIRE
Mrs J Davies
8 Oakhill Avenue
Oakhill
Stoke on Trent ST4 5NJ
Tel: 01782 845365

STAINES, HOUNSLOW & DISTRICT
Mrs Pamela Page
237 Upper Halliford Road
Shepperton
Middx TW17 8SP
Tel: 01932 783991

STOCKPORT & TAMESIDE
Mrs Tracy Ryan
265 Adswood Road, Adswood
Stockport SK3 8PA
Tel: 0161 474 1299

SUNDERLAND
Mr J Pounder
42 Gowanburn
Fatfield, Washington
Tyne & Wear NE38 8SG
Tel: 0191 415 1725

SURREY
Alan Twyford
86 Tolworth Park Road
Tolworth, Surbiton
Surrey KT6 7RH

SUSSEX
Mrs M White
Averys, Rusper
Horsham
W Sussex RH12 4PR
Tel: 01293 871217

TRAFFORD & SALFORD
Mrs T Gaynor
Davis Court, Cyprus Street,
Stretford
Manchester M32 8AX
Tel: 0161 865 0222 (am only)

WARRINGTON & DISTRICT
Miss Nancy Gleave
16 Hilltop Road
Woolston
Warrington
Cheshire WA1 4PD
Tel: 01925 819329

WESSEX
Mr T Poole
123 Gerrards Green
Beaminster, Dorset DT8 3EA
Tel: 01308 862614

WIGAN, LEIGH & DISTRICT
Mrs Pat Stridgeon
24 Greendale Crescent
Leigh WN7 2LQ
Tel: 01942 676091

WIRRAL
Mrs M Appleyard
28 Stavordale Road
Moreton
Wirral, Cheshire L46 9PR
Tel: 01516 784409

WORCESTERSHIRE
Mrs Ann Cotter
49 Brueton Avenue
Fringe Green
Bromsgrove
Worcs B60 2AW

YORKSHIRE NORTH
Miss Faith Seward MBE BA
45 The Paddock
York YO2 6AW
Tel: 01904 798653

WALES

Llanelli
Mrs Anthea James
61 Westland Close
Loughor, Swansea SA4 2JT
Tel: 01792 428004

Mid Wales
Mrs J Carter
12 Lambeth Close, Craven Arms
Shropshire SY7 9QY

North Wales
Mrs V Conway
4 Ewloe Drive
Bodnany Road
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 Limetree 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.*