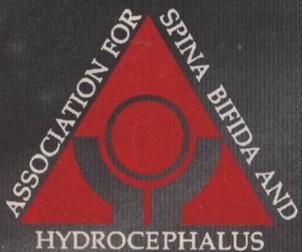


Link

The magazine for people with
Spina Bifida and/or Hydrocephalus



September/October 1999

Issue No 183 Price 80p



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MBE FOR RAY

A MAN dedicated to helping others in sport and paving the way for disabled people to be accepted in all walks of life has been awarded the MBE.

Ray Gainer, featured in the last *Link* about his trip to see Manchester United's triple triumph in Barcelona, will receive his honour from The Queen on 26 October.

Ray paid tribute those who have encouraged and helped him. He said: "I'd like to share this honour with those who have worked with me - my parents, family and friends got me to where I am."

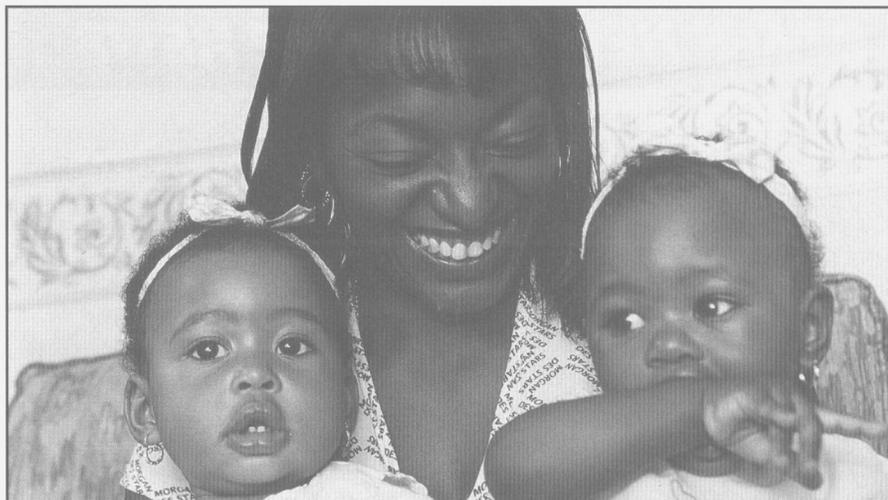
The 39-year-old, from Crosby, Liverpool, is a qualified wheelchair tennis coach in the North West.



Seeded tenth in England and a doubles world competitor, Ray's next big plan is to organise a Millennium world tennis event in Warrington.

Despite losing a leg and a chronic kidney problem, Ray is a qualified captain of 737s and has passed the theory of an exam to fly 757s.

He is also in *The Guinness Book of Records* for a wheelchair push from Blackpool to Paris.



Happiness comes in twos

TWO YEARS ago, Earlin Alexander told readers of our *Hydrocephalus Network News* how she had been diagnosed with hydrocephalus shortly after her 30th birthday and had a shunt inserted.

That had happened in 1994. A couple of years later, she became ill again but doctors refused to listen to her when she insisted that her shunt should be checked. She persisted and, eventually, after every other imaginable test had been carried out, the shunt was replaced.

Since then, as you can gather from the happy photos, life has been on the up. She gave birth to gorgeous twin girls, Kanice and Kayla, last September and has already flown

them away for a month to Granada to show them off to her family.

"Touch wood, I have had no problems with the shunt since then and I feel very well indeed. There were also no pressure problems with flying," said Earlin, who lives in Catford, south east London.

Earlin said doctors were never able to give her a totally convincing explanation of the cause of her hydrocephalus, particularly as no tumours were evident.

The most likely candidate was the toxoplasmosis brain infection she had at 19. She was very ill and had a severe reaction to her antibiotics. Meningitis, contracted at that time, may also have been a suspect.

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Cover: Earlin Alexander looks stunning with her baby daughters, Kanice and Kayla - just a few years after she had been taken ill with hydrocephalus. Photos: Caroline Kerslake.



● CAROL COE (left) is the new specialist adviser (medical) for ASBAH's Eastern Region.

The Eastern

Region covers Bedfordshire, Cambridgeshire, Derbyshire, Essex, Hertfordshire, Lincolnshire, Leicestershire, Northamptonshire, Nottinghamshire, Norfolk and Suffolk.

She works at the East Region office in Peterborough, telephone 01733-555988, on Tuesdays, Wednesday mornings and Thursdays.

Carol had wanted to be a nurse since the age of 12. She qualified in

her mid-30s after having had a family and a varied career in sales, administration, the civil service and as an adviser for SSAFA.

Carol explains: "My husband was in the army and, with moving around a lot, we were never in one place long enough for me to do my nursing training."

Now living in the Peterborough area, Carol has experience in Hospital At Home, community nursing and health promotion.

Of her job at ASBAH, she said: "I look forward to doing something that is challenging, constructive and varied, and that is making a useful contribution."

She continues to work as a part-time health promotion worker for smoking cessation and, when time permits, a bank nurse with Hospital At Home.

Her interests include complementary medicine – she is a qualified Reiki therapist (hands-on healing to relieve stress and promote relaxation) – and, whenever possible and appropriate, applies an holistic approach to her work – treating the whole person, rather than just the presenting problem.

● CHRISTINE COUSINS has succeeded Margaret Gillmore, who, in June, retired as ASBAH's national shops co-ordinator.

With 10 years' experience working with Margaret in the capacity of shops supervisor, Christine knows how to keep the tills ringing.

She came to ASBAH as Margaret's assistant to help run three shops which, at that time, were staffed entirely by volunteers.

When the chain grew to six, the management task became too much for the two of them, so paid managers were brought in.

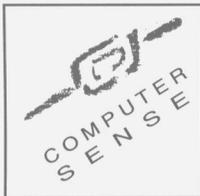
Christine said: "I am looking forward to the challenge. I worked very closely with Margaret so I know how important it is to make sure stock is coming in all the time to every shop, know who needs what, and that unsold goods are rotated round the shops.

"It's also my job to ensure that managers and volunteers are happy – without the volunteers we would not be able to open the shops."

She would like to see ASBAH rent more shops permanently rather than as temporary lets.

Currently, there are nine ASBAH shops, eight in the Solent and one in Wales, with eight paid managers and, of course, the volunteers.

● SUFFOLK adviser, Val Meyer-Hall, has moved house. Her new ASBAH telephone number is 01379-871071.



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● Northern and Eastern Regions co-ordinators, Joan Pheasant and Mary Malcolm, have both gained the Diploma in Management Studies.

● Margaret Stanton, adviser for South Wales, gained a BA honours in Social Science after six years of study with the Open University.

● Greater Manchester adviser, Marcia Conroy, gained a 2:1 degree in Professional Studies (Social Work).

ASBAH is to inject resources and energy into our services to people in Wales, following a decision of the Executive Committee.

ASBAH will be opening a regional office as soon as possible. Its staff will knock on the doors of health and social service providers, and create new links with Assembly members to explain the needs of our service-users.

The full-time position of regional co-ordinator has been advertised and has been filled by ASBAH adviser Elin Ifan (*see below*). A requirement of the post was the ability to communicate in Welsh and a knowledge of Welsh issues, as well as relevant qualifications and experience.

The setting up of self-government in Wales through a new Assembly has created a new political reality which now needs to be reflected by ASBAH, decided the Executive Committee.

Executive director Andrew Russell says that ASBAH will work with

ASBAH region for Wales

other disability groups in Wales, as well as promote our own particular agenda on behalf of those with spina bifida and/or hydrocephalus.

The news of a new ASBAH region – underlined when chairman Godfrey Bowles and a small delegation met a cross-party group of Wales MPs before Christmas – has been endorsed by ASBAH Cymru, our Wales member forum.

Mr Russell said: "We have all been encouraged by the great response of our affiliated local Associations in Wales, who have been enthusiastic about meeting to formulate plans and hear the reports of staff.

"Our three advisers and two project officers are doing tremendous work and we need to build on this. Political devolution has come at the right time for us."

Mr Russell said the new Welsh Assembly was focusing the minds of politicians and making them more

receptive to the kind of message we are sending.

"We want service providers to open up far more opportunities to disabled people, targetting the correct training and help to young people, and recognising the huge contribution that parents and families make."

A special appeal is to be launched later in the year to raise some of the extra cash needed to fund the new region.

"We will have to work within tight finances, but the Executive Committee's decision was unanimous and enthusiastic. The experience and knowledge of our staff will be invaluable in bringing ASBAH's name to the fore.

"We are very much needed because of a loss of focus by health and social services, following local government reorganisation a couple of years ago. There's a lot of ground to make up, working with and for our disabled members."

Elin takes the hot seat

AFTER 16 years as adviser for people with spina bifida and/or hydrocephalus in North West Wales, Elin Ifan (formerly Richards) has been chosen to lead our new Wales Region.

Elin believes the regional office will be a focus for people in Wales to identify what ASBAH does and will help ASBAH gain an overview of the needs of its service-users in the region so we can present them more effectively to the statutory sector.

She said: "We'll be starting quite small with an office in North Wales and I see my new job as a developing role."

Although Welsh is Elin's first language and she has been with ASBAH for a long time, she has lived in other parts of Britain and has had a varied career. She graduated from Leeds University with a geography degree and is a qualified teacher but her work has mainly been community-based.

She has worked with volunteers with disabilities in an information project and, in another role, enabled residents on a council estate to take control of their lives through self-help and empowerment.



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Doctors must decide

A MOTHER, who refused to let her profoundly disabled son die in hospital, has lost her battle to change medical procedures.

Carol Glass, who wanted a declaration that doctors acted beyond their powers, was told she could not take her campaign to appeal. But the wording of the ruling by three senior judges in the Court of Appeal offered her the chance to claim a partial victory. They said, if parents and doctors could not agree on such 'grave' matters, the dispute should be brought before a court.

Quoted in the *Daily Mail*, Mrs Glass said: "I knew it wasn't going to be clear cut. I am pleased with parts of what the judges said. I got what I wanted."

Members of Mrs Glass's family managed to resuscitate her son David as he lay close to death at St Mary's Hospital, Portsmouth, last October. This incident is the subject of a separate court proceeding.

David was born with hydrocephalus and is blind, has spastic quadri-

plegia and severe learning difficulties.

His mother, who was interviewed in the last issue of our *Hydrocephalus Network News (HNN)*, claimed doctors acted illegally in deciding against her wishes and without going to court that David should be given painkillers and allowed to die 'with dignity.'

David, who has recovered from the life-threatening illness which hospitalised him, is now back at home in Portsmouth and, his mother said, 'enjoying the sunshine.'

The High Court had already rejected Mrs Glass's request for a declaration against the doctors. In the Court of Appeal, Lord Woolf, Master of the Rolls, sitting with Lady Justice Butler-Sloss and Lord Justice Robert Walker, said it would be 'inappropriate' to overrule that judgment.

Lord Woolf described David as 'dearly loved and cared for most effectively by his mother and her family', who wished him to live out his natural lifespan.

He said there had been a breakdown in trust between family and doctors.

The family's actions in pulling David from his bed to stimulate his breathing was said to have prevented him from dying. But doctors condemned it as 'cruel.'

David would, in future, be treated at a Southampton hospital, the judge said.

Mrs Glass was seeking reassurance that, if he was to be treated in hospital, her wish that he be kept alive would not be overridden by the doctors. Lord Woolf said: "I understand why she might feel comforted by a court taking that action, but I have no doubt it would be inappropriate for the court to do so.

"Considerations which can arise in relation to David and other children who have disabilities of that sort are almost infinite.

"The best course is for the parent of a child to agree on the course which the doctors are proposing to take, having fully consulted the parent, and for the parent to be fully understanding of what is involved."

If that was not possible and the conflict was of a grave nature, then it must go to court.



Continence news

THE bladder with the megaphone has been chosen by the Continence Foundation as the logo for this year's Continence Awareness Campaign, which takes place from 20-24 September.

Although little of this year's campaign is of immediate value to people with spina bifida and/or hydrocephalus, the new logo appears at a time of great significance for everyone who hopes to see improvements to nationwide continence services.

The Continence Foundation has been a major contributor to the NHS policy review on continence,

whose report was originally promised for the spring of this year but is now not expected to be published until September.

"Expect detailed guidance on organisation, standards and accountabilities from top to bottom of the service," said director, David Pollock, in the foundation's newsletter.

● *Link* carried a report last autumn, about ASBAH's own contribution to the NHS policy review on continence services. This followed our own snapshot survey of continence services which showed a worrying trend among several NHS trusts of cutting services to pre-school age children.

Have you lost a ring?

SORTING through the safe at National Centre, we have found two rings that were either left or lost by visitors / members/ ex-employees – we think over two or three years ago. If you lost a ring about that time, we may have it. **Please contact Brian Deffee (Finance Director) tel: 01733 555988.**

If we are unable to return the rings to their rightful owners by the end of September, we will sell the item(s) and pass the proceeds to ASBAH.

ASBAH AT YOUR SERVICE



◀ Paul Dobson, Personnel and IT Director



Brian Deffee, Finance Director ▶



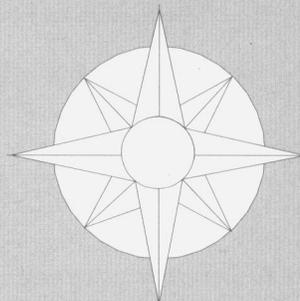
Andrew Russell
Executive Director



◀ Milly Rollinson,
Assistant Director (Services)



Linda Hams, Assistant Director ▶
(Policy and Marketing)



ASBAH in the regions



Margaret Young, Northern Ireland Co-ordinator ▶



Jo Francis, South East Region Co-ordinator ▶



Mary Malcolm, East Region Co-ordinator ▶



Joan Pheasant, North Region Co-ordinator ▶



Elin Ifan, Wales Co-ordinator (from 1 September) ▶

Key contacts at National Centre



◀ Donna Treanor, Fundraising Manager



◀ Tony Britton, Publicity Manager



◀ Tom Logan, Telesales Manager



◀ Gill Winfield, Information Manager



◀ Rosemary Batchelor
Senior Adviser, Health and Policy

Telephones National 01733 555988 Northern Ireland 01232 798878

North 0113 2556767 East 01733 555988 South East 0181 4490475

New commission – 'an historic milestone'

THE Disability Rights Commission Act, which is intended to sharpen the teeth of the existing Disability Discrimination Act, became law on 28 July.

Minister for Disabled People Margaret Hodge hailed the new law as an historic milestone for the eight million disabled people who live and work in the UK.

"The Disability Rights Commission will be open for business in April and will work towards securing comprehensive and enforceable civil rights for disabled people," she said.

The new Act sets out that most of the Commissioners must be disabled, but does not require the appointment of a disabled person to the chair.

However, Mrs Hodge has given an assurance that it would be inconceivable for the first chair to be a non-disabled person. The Commission itself will have about 150 staff.

The Commission will have the power to investigate complaints of discrimination and prosecute complaints in the courts, if conciliation fails.

On a clear day, you can see forever

A HARD surface footpath has been created in Hastings Country Park – thanks to ASBAH member Linda Mooncie, who is vice-chair of Hastings and Rother Disability Forum.

The one kilometre trail gives wheelchair-users, parents with pushchairs and anyone with mobility difficulties access to the heart of the park.

They can also enjoy views across the hills towards

Dover and Beachy Head and, on a clear day, to France.

The forum worked in partnership with Hastings Borough Council which owns the park. The council donated £20,000 towards the project and the forum had to match this amount by approaching local charities, companies and organisations.

Linda said: "The project has taken three years of hard work but I guess I knew it would be a great success."



YVIA group shows how 'assertive' can be good

THREE one-day courses on assertive communication and empowerment for disabled people, organised by Your Voice In ASBAH (YVIA), have been well received.

The courses were held in London, Birmingham and Peterborough, and led by professional disability equality trainer Judy Erwin.

Those attending found the programme very useful and many said that they would have liked more time to discuss the areas which came under the spotlight.

Judy began by setting a framework for the day. This was about the group agreeing important issues in terms of respect, equality, participation and confidentiality. The group went on to look at issues related to disability and oppression, for example, how disabled people were disadvantaged by the way society perceived them. Firstly, she gave her interpretation of discrimination and oppression and then briefly showed how history, the media, language and the different ways disability is viewed, have created disabling 'barriers' which affect disabled people's lives.

The groups looked at how these negative ways of viewing disability may be absorbed and 'internalised' by disabled people themselves and can contribute to low self-esteem.

The way we feel about ourselves, in turn, affects the way we behave and communicate and what we expect from our lives.

Different situations in which we find ourselves, trigger various responses from us which are linked to our beliefs and values. So, for example, if we think we are 'no good' at something this is could be linked to how we have been treated in the past and how other people view us. The course aimed to increase the range of strategies people have for feeling good about themselves and for communicating effectively.

Judy said: "In any situation, we can react by behaving aggressively, passively or assertively, and I encouraged the groups to examine what each of these types of behaviour were. We also looked at the effects on ourselves and others when we behave in different ways.

"When you're aware of how you behave in a situation, you are in a better position to change if you want to. There are things we can do to make changes to our thoughts and beliefs, and the way we interact with others if these are damaging to our relationships.

"For example, some group members said they had difficulty saying 'no', others had difficulty asserting their independence in family situations or with carers and others wished to handle situations better with friends or at work.

Judy said: "Most people would agree that they have the right to be treated as an equal, intelligent, capable human being but do we always apply that right to ourselves and to everyone else? It is not always easy or straightforward."

The way people communicate their views and feelings was a crucial strand running through the sessions – how do you express your needs and wants to others. You may communicate them in a round about way or aggressively – in either case, not getting a satisfactory outcome for either party.

Judy said: "The course focused on empowerment from within – how do I take control of my life, feel good about myself and know my rights while respecting the rights and feelings of others."

... in the right circumstances

● *Interested in future courses on a similar theme?*
Contact Jon Burke, YVIA co-ordinator, 64 Bagley Lane, Farsley, Leeds, LS28 5LY, tel: 0113-255 6767;
fax: 0113-236 3747. Email yvia@asbah.demon.co.uk

Government warning on powered wheelchairs

A WARNING against disengaging the freewheel device on electrically powered wheelchairs and scooters has been issued by the Government as, in most cases, this will cancel out the only effective braking system available to the user.

The Medical Devices Agency says: "If a unit were left at the top of or adjacent to a slight incline with the drive disengaged, then the effect of the user boarding it might be sufficient to start it to roll. The user would have no means of slowing or stopping the wheelchair."

Sometimes, manufacturers fail to provide this warning in instruction manuals or to include it in on-board labelling.

After receiving a copy of the warning notice, ASBAH mobility adviser Linda Knight commented: "Most release mechanisms for the free-wheel device are found at the bottom of the wheelchair. To turn it off, you have to lie on the ground and be pretty fit.

"Mostly, it's done by relatives who want to move the wheelchair into a confined storage space or over a sill. Electrically powered wheelchair-users should always check that the freewheel device is re-engaged before using the wheelchair".

● *The Medical Devices Agency has also issued a warning in respect of the Phoenix powered wheelchair from Invacare. It says that the optional 'pram-type' handle can come off if not correctly fixed. Always check that it is fully engaged and the thumb-wheel clamps fully tightened.*

Lift on tape

Lift, ASBAH's free magazine for people with SB/H, is also available on audio tape. Please contact Liz or Tony in Publicity, on 01733-555988, if you would like to receive *Lift* in magazine or audio tape format.

Affectionately yours

WE REMEMBER BOB ZACHARY

ONE of the seminal influences in the modern surgical treatment of spina bifida and the founder chairman of ASBAH, Professor Bob Zachary (pictured right), was remembered with affection at a service of thanksgiving held in Sheffield on 23 June.



Around 300 colleagues, friends, patients and their parents joined members of the family in St Marie's Cathedral for a service organised jointly by national and Sheffield ASBAHs.

Bob died in Newfoundland in February at the age of 85. The city where he practised for 30 years as a consultant paediatric surgeon and the voluntary organisation he guided for its first 11 years were reminded of his gifts and enthusiasms.

Christopher Zachary, one of three children and who is now a professor of clinical dermatology in San Francisco, said in a eulogy that his dad was a proud Yorkshireman but had won respect, recognition and friendship in many countries.

He was a devout Catholic, but not preachy about it. Few people knew that he would get down on his knees each night to pray, even after suffering a stroke, until the day he died.

He was a man of enormous energy, with mental and physical stamina, despite his own spinal deformity, which he never let affect him. Like many others, he kept Codeine or Distalgesic as constant companions.

Christopher said: "But I knew him as a man of great energy. He had both mental and physical stamina. Few were the nights that he wasn't called in to revise a shunt or close an acute myelomeningocele.

"At the age of 85, he would still chuckle about the occasion when he applied as a young lad for a position as a clerk to a shipping firm in Harwich. He was rejected. They told him that, in his physical condition, he would not survive the rigors of

life in a shipping office. Some rigors, some life."

Other touching tributes came from Miss Mary Oughtred, ASBAH's first general secretary, and from Jonathan Burke, co-ordinator of our user-group forum Your Voice in ASBAH, who is a former patient of Bob Zachary.

Miss Oughtred recalled life on the front line with Bob Zachary in the early days of ASBAH and said the team of which he was part at Sheffield Children's Hospital had revolutionised the way spina bifida was treated.

Mr Burke had the profoundest of messages – that he and many other people simply owed their lives to the great man. This was a view shared by many former patients in the congregation.

ASBAH patron HRH The Duchess of Gloucester was represented by the Lord Lieutenant of South Yorkshire, the Earl of Scarborough. The event coincided with the annual meeting at Sheffield University of the Research Society for Hydrocephalus and Spina Bifida, whose hon secretary Carole Sobkowiak gave one of the readings.

Other readers were John Emery, emeritus professor of paediatric pathology at Sheffield University, and Fr Terry Tolan, priest of Bob Zachary's former Sheffield parish.

Intercessional prayers were read by Mrs Celia Nicholson, chairman of Sheffield ASBAH, and ASBAH publicity manager Tony Britton. The service was led by Fr Charles Neal, the Cathedral's parochial administrator. Organist was Philip Jakob, and cantor was Victoria Helliwell.

Making a splash with dolphins



Left: Michael is introduced to the dolphins. Below: Swimming with Squirt and Fonzie

MICHAEL Byrne has had an extra glint in his eye ever since he was lucky enough to swim and play with dolphins.

An out-going and bright boy before flying to Florida, Michael now has an added confidence and feeling of well-being.

Michael was introduced to Squirt and Fonzy, sitting at the water's edge, wearing a life jacket.

When he first entered the water with a physiotherapist, the three-metre long dolphins came near him, nosed his back and legs, and retreated as if they were 'sussing' him out. They swam under and around him and Michael held out his hands. They waved and squirted water at him, gently pushed at his feet and he threw a ball for them. One of them let him hold on to a dorsal fin as it towed him along.

Michael's father, Andy, said: "It was very emotional – the joy and laughter on Michael's face, the clicking and squeaking of the dolphins – there were the tears in everyone's eyes. It was as if these mammals were taking care of him in the water."

The charity, Dreams Come True,

paid for Michael to have two 45-minute sessions. Mr Byrne paid for a third session in which he joined Michael, four dolphins, other children and carers in the water.

He said: "After the sessions we watched the dolphins being fed and talked with staff. We stayed around from five to seven hours a day for six days. The people were so nice."

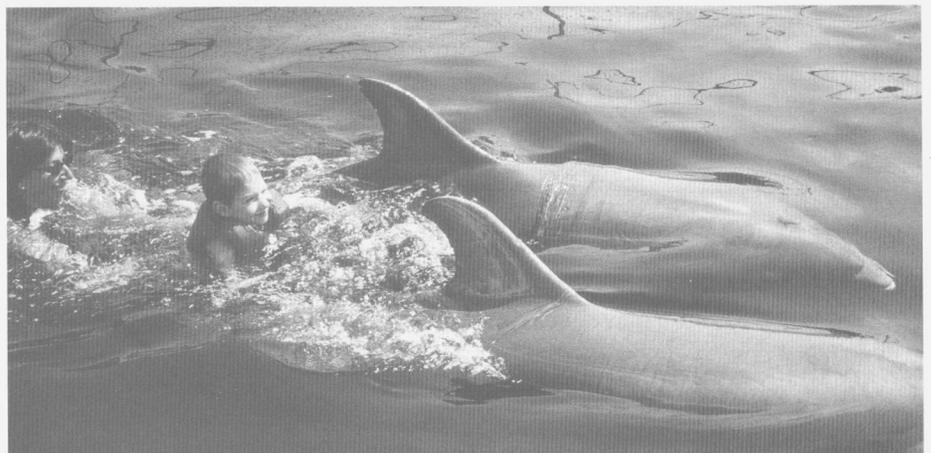
One of Michael's most treasured memories is when one of the dolphins retrieved a pencil from the bottom of the water and gave it to him.

Now two psychology students from Denmark, who were present during the Byrne's visit, are using Michael as a case study in a project they are doing on Island Dolphin Care.

Andy and Barbara Byrne, from Wallasey, in the Wirral, contacted Dreams Come True as Michael had said he really wanted to swim with dolphins.

The charity paid for Michael and a carer (his mum) to meet the dolphins and, not to miss out, Michael's father paid his own way there. Then they decided to extend their trip to Florida by a week so Michael could visit Disney as an added treat!

● **Island Dolphin Care Inc, Dolphins Plus, PO Box 2728, Key Largo, Florida 33037, USA. Tel: (305) 451-5884. Fax (305) 451-3710. Email: fonzie@islanddolphinscare.org**



Pre-Millennium Tension

THE collective rush to make big life changes before 31 December is getting me down. I am 29 at the turn of the century; being 30 did not bother me until I read the novel *Bridget Jones's Diary*.

Mid to late twenties is a very strange time. Your life changes very rapidly as you leave college and start work; your parents are approaching retirement; suddenly your female friends are panicking. The biological clock is ticking and it is time to find 'a man.'

Am I a dying breed of women who want to remain staunchly independent? I did not understand Bridget Jones. I could not relate to the calorie counting, I do not have a match-making mother and I am not desperately clinging to a man. In fact, once I had finished reading, I threw the book up in the air in hope that Bridget's kind of life never touches me!

I am disabled; that is why I cannot relate to Bridget Jones. I do not suffer fools gladly. Hence the chances of me getting wed are pretty slim!

A past boyfriend said: "I feel uncomfortable with our relationship." That roughly translates into "I can't cope with your disability." Anyone who cannot accept me for who I am gets the push.

Sexual healthcare for young disabled women is a joke. It was not until I was 16 that I was able to attend the hospital on my own to ask my questions: "Can I go on the

Pill? Can I have babies?" The sniggering reply was "Don't worry, they're not likely to have spina bifida" and "Isn't it too early to be worrying about it?"

I got my answer about having babies in my mid-20s. The consultant gave me lots of supporting literature as well as predicting what sort of effect childbirth would have on my body. Most importantly he made me really think about why I wanted children. All my concerns were around how a baby could harm my body whereas the consultant was trying to ensure that the baby would not get harmed by the shape of my body. It was obvious. I wanted a baby to keep up with the 'Joneses.' A baby is the ultimate symbol of womanhood. Disabled women are not often seen as 'sexual beings' so I thought my baby was my status symbol and its production would shut my critics up.

It has taken me five years to get a smear test because my GP did not believe in my sex life. Getting contraception was literally a near-death experience. I read in a newspaper that the drugs for my circulatory problems would react with the Pill to cause thrombosis.

Who is in control of my life as I approach the Millennium? Early this year I discovered that the pains



By Suzanne Bull
Link columnist

in my stomach were due to my spine bending.

After a short investigation involving no MRI scans, I was told to stop walking. At the moment, there is no evidence that my spine will crush my major organs, but then again, if it does "something has to be done before it is too late!"

Naturally, I am seeking better information but it looks like I will have more than sorting out my wedding dress for a complete answer to life in the Millennium!

Editor's note: When discussing pregnancy with Suzanne, I hope the consultant stressed the importance of her taking the higher daily dose of folic acid at least one month before conception and in the first 12 weeks of pregnancy. The dose is a 5mg tablet each day which has to be obtained on prescription from your doctor.

DLA advice guide

ANYONE who wants to make a claim for Disability Living Allowance (DLA), or who wants to know more about how the benefit works, may find a new guide useful.

The booklet clearly explains the qualifying conditions for benefit, how to make a claim, and how decisions are made.

A checklist, also included in the

booklet, will be useful to anyone who ever has to fill in the complicated benefit form. It provides help and suggestions on how to complete the form and present your case effectively.

Disability Living Allowance – A Guide and Checklist – is suitable for claims for both adults and children, and has been updated to take account of the new system of decision-making from October 1999.

● Price £3.50 post free. Bulk order prices: five copies for £14; 20 for £45; 50 for £85, all post free.

When ordering, print the name and quantity of the booklet you require, and your name, address, postcode and phone number. Send your order with a cheque/PO, payable to Disability Alliance, to: **Disability Alliance, Universal House, 88-94 Wentworth Street, London E1 7SA.** Please allow 28 days for delivery.

Wheelchair sport makes Sam blossom



trums, wouldn't go to school and was back under the psychologist.

"Elizabeth Miers phoned back and said she had a leaflet about a primary sports camp at Stoke Mandeville, organised by the British Wheelchair Sports Foundation."

Luckily there was a space, though the event was only two weeks away, and Sam went.

Having never tried wheelchair sports before, due to going to a mainstream school, Sam found that he was rather good. A further boost to his confidence was being told by a Paralympic javelin coach to come back when he was 11 to train for England!

Going to the Primary Sports Camp led to Sam receiving an invitation to the Disability Sport England Mini Games in May, at which he won four golds in the 8-12 years section – two in swimming and one each in wheelchair sprint and table tennis.

All this led to Sam finding out about other training, clubs and competitions for people with disabilities.

He now plays cricket locally in St George's, Shropshire, and his team has won a trophy. He has come second in a fishing competition. He is having a go at the triple jump and long jump.

Mrs Scott said: "He is trying every-

thing. Someone spotted him at Stoke Mandeville and told him, when he's a big boy, he's going to be in the Paralympics. He is very skinny but his upper body is strong, and he is determined he will get there.

"He also met another boy with spina bifida at Stoke Mandeville – Myles Skelton – and they became firm friends. They spurred each other on in the events but, at the finish, they were cuddling.

"These activities have turned him around. He has stopped seeing the psychologist and is a completely different boy.

"He had changed from someone who came home from school, saying he couldn't do PE and was no good, to someone who takes his medals to school for the headmaster to show to the others."

Sam's contact with the British Wheelchair Sport Foundation has also helped to set him on an equal footing with non-disabled boys, when working for the Athlete's Badge, in Cub Scouts. New badge targets for wheelchair-users were worked out by the British Wheelchair Sports Foundation and, as a result, Sam was able to show he could immediately achieve the highest, third stage of the badge.

● **For more on the Primary Sports Camp or Junior Games, telephone Charlie Bethel at the British Wheelchair Sports Foundation on 01296-395995.**

LIFE has a whole new meaning for an eight-year-old wheelchair-user after his ASBAH adviser suggested he go to a sports camp at Stoke Mandeville.

Young Sam Scott's new positive outlook comes from doing well at a host of wheelchair sports, meeting other disabled youngsters and regarding his chair as an asset rather than an encumbrance.

His ASBAH adviser, Elizabeth Miers, suggested he attend the come-and-try session after hearing from his mother that Sam had become miserable on learning that he would have to use his wheelchair more often.

Mum Sandra explained: "He was unbearable. He was having tan-

New Disability Rights Handbook

A GUIDE to benefits and services for all disabled people, their families, carers and advisers is available from Disability Alliance.

The 1999-2000 Disability Rights Handbook, 24th edition, includes:

- A new section on help for carers.
- The latest on Incapacity Benefit including changes arising from case law and the new linking rule for people trying out work.

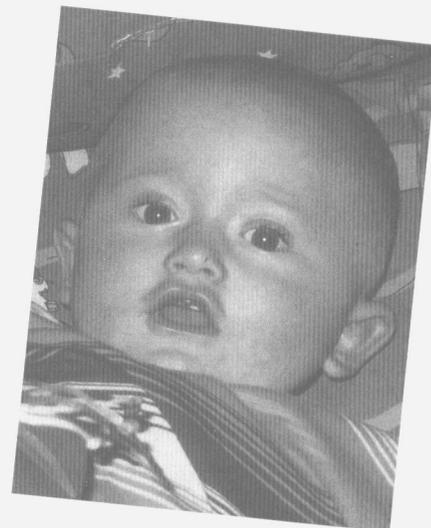
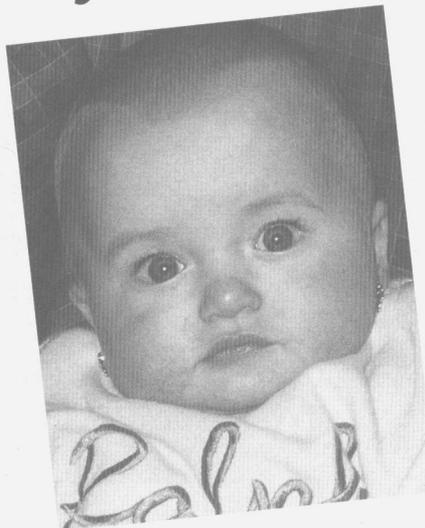
- Details of the new Disabled Person's Tax Credit.
- Updates on Disability Living Allowance and what to do if you are not happy with the decision made about your benefit.
- Details of the new system for decisions and appeals.
- A section detailing the new benefits available to people in hospital or residential care homes.

- A section explaining Community Care law.

The price is £11.50 post free (£7.50 if you're on benefit). Please make cheque/PO payable to Disability Alliance. Stating the title and quantity of the book you want, send your order and payment to: *Publications, Disability Alliance, Universal House, 88-94 Wentworth Street, London E1 7SA. Tel: 0171-247 8776.* Please allow 28 days for delivery.

Happy birthday to Chloe and Robert

LAST year, *The Twins' Tale* pregnancy diary was published in *Link*. October 7 is Robert and Chloe's first birthday and mum, **Ann Wright, who has spina bifida and hydrocephalus, wants to mark the occasion by telling readers what has happened since the birth.**



Chloe and Robert, aged about six months

Attitudes, equipment and access

Initially, friends questioned us about the twins and didn't believe us when we said they were ours! They thought we were babysitting or had gone into business in child-care – partly, I suppose, because I was so small during pregnancy.

I now feel great and the stomach problems I'd had in pregnancy have disappeared. I can now eat fruit again and am eating buckets of it! I'm feeling better and healthier.

Both Stuart and I are feeling happier because, now we have the twins, we feel useful again.

People said it would be difficult for us coping with twins as they only see our disabilities. But it's been a doddle. We've got more patience than most as we're used to waiting in hospitals which can be trying.

I am still using my scooter as I've still got an ulcer on my foot, so I only walk in the flat and take the twins into the large garden behind our block.

The pram we bought from Mother-care is rubbish – after only six weeks, a wheel came off. As I can't walk distances, Stuart is the one who pushes it.

When I left hospital, I was gutted to find that the form recording the birth said I'd had two boys! Then we had trouble registering the birth. I couldn't get up the stairs of the

Register Office, in Brixton Road, Lambeth, as it was a Victorian house with no lift, so I had to wait while Stuart went up to register. Stuart is dyslexic so when they asked him to check the spelling of *Chole*, he said it was OK.

Then we were under pressure to catch transport home, so I didn't have time to look at the certificate, which cost £7. I didn't notice it was wrong until got home and was livid.

When we went back to point out the mistake they told us it could take months to change the name. This was an added worry as we had to present the birth certificates in order to claim benefit and this had to be done within a set time.

In the end, we had to admit it was our mistake, when I feel it was their fault for having inaccessible premises. No one chooses to be disabled. It was also annoying as they stuck Chloe's correctly spelt name at the bottom of the certificate instead of issuing a new certificate, and we had to pay a further £14.

Feeding

I started breast feeding the twins but changed to the bottle for Chloe after a couple of weeks as she was so small and I was concerned about how much she was getting. I was really disappointed not to be able to continue breast feeding for longer.

At first, I wasn't aware of growing sprees but I now realise that Robert

was having one during the first few weeks. He was attacking me like a vulture and wouldn't let go of the breast. I breast fed Robert for the first few weeks.

In the first six weeks, Chloe was sick every time she had a feed. My GP said she was fine and that maybe her stomach muscles weren't working properly, but she was so unhappy that I made repeat visits to the surgery and eventually was referred to hospital. There we were told that we were over-feeding her, so we tried reducing the feeds. Something still appeared to be wrong with Chloe and, at the twins' six-week check, we pleaded with the health visitor and GP to find out why Chloe was being sick. The health visitor fed her and told us she was starving (she had lost weight in a week). We were told that her digestion would improve once she started solid food.

Things started to look up after their six-week check.

Sure enough, when I weaned Chloe at five months, she stopped being sick but she is still more finnickier about food than Robert. Robert was weaned three weeks before he was four months old as he is the larger of the two. The first food for both was yogurt.

Sleeping and teething

Both twins were good sleepers to start with. At four or five

continued at foot of page 14

A SURPRISE return visit by TV presenters and film crew to the home of a 16-year-old model car fanatic led to one local ASBAH association being £500 better off.

Charlie Dimmock and Tommy Walsh, who host the BBC TV *Ground Force* programme with Alan Titchmarsh, turned up to film the garden they had transformed two years ago for Gary Axford.

After interviewing the family and filming Gary in the garden, Charlie and Tommy presented Gary with a cheque for £500, to be passed on to Isle of Wight ASBAH.

The money had been given to the *Ground Force* team by a national group of businesses in the garden industry as it is estimated that turnover in this sector has increased 30% since the programme was first shown two years ago.

Charlie Dimmock said: "We all had such a great time on the Isle of Wight, and we are thrilled to know

Ground Force returns with cash boost



ISLE OF WIGHT COUNTY PRESS

the money will benefit people like Gary."

Gary, a wheelchair-user, has been enjoying the fruits of the *Ground Force* team's work ever since they made his garden accessible and built a circuit for his model cars.

Gary said his appearance on TV for

the original make-over had made him feel like a local celebrity, particularly with his school friends.

The *Ground Force* garden, in Ryde, was open to the public in August to raise money for Isle of Wight ASBAH, in its 30th anniversary year, and BBC Children In Need.

Happy Birthday Chloe and Robert, from page 13

months, Robert jumped in his sleep, waking every couple of hours, as if he was scared of something.

At eight months, the first of four teeth appeared at about weekly intervals, while Chloe only had her first tooth showing.

At five months old, the two of them became very interested in TV. They also like music – they sway backwards and forwards to it.

First words

When she was two months old, I was changing Chloe's nappy in the bedroom and I coughed and she copied me. I did it again and she repeated it too.

At five months, Robert said 'Dad' and at eight and a half months he started to roll over. Chloe rolled over at six months and said 'hello' at about seven months.

When she gets in a mood she'll say 'mummy'. She is very determined and frustrated not being able to do more. She doesn't give herself time.

Getting mobile

Chloe was the first to crawl – first backwards and, by the end of July, forwards. She wants to be continually on the move and goes very fast. At nine months old she was holding on to the furniture. She's very determined and doesn't want to sit. She is into everything, particularly the video player.

At nine months, Robert would lie on the floor and roll on to his belly.

Personalities

When we first got them home, Robert would look right through Chloe, but she would stare at him. Now they communicate and smile at each other. Sometimes they burst out laughing. At nine months old, Robert had learnt how to wave and say 'goodbye'.

They are twins but are very different personalities and are developing in different areas at different rates. I used to get annoyed when people referred to them as 'the

twins' because I think they should be regarded as individuals.

They have lovely round faces like Stuart and Samantha. I don't come into it as far as appearances go. Chloe has big blue eyes which attract everyone's attention. She is always smiling. Robert is more reserved and calmer but, at nine months, he was getting more boyish. Chloe is the rogue of the two.

Weight

At nine months, Chloe had almost caught up with Robert in weight. At nine and a half months, Robert weighed 21 lb 6 oz and Chloe 18 lb 10 oz. She is very active and does so much more than Robert, so is petite, whereas Robert is broad. But they are not chubby babies.

I try to give them balanced and varied meals. They don't eat out of jars unless we're out. They like chicken and Chloe loves fish and fruit.

At five months, I started solid foods and I bought them some tangerines. Robert liked them particularly and now when we bring some home, they are screaming for one!

Hydrocephalus Network News Ann

Autumn 1999



FIND out how Jim stayed cool in Florida on page 3.

Hand of friendship

THE COLERAINE TIMES



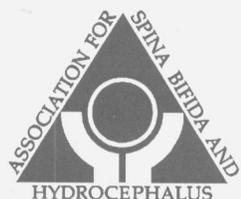
FRIENDSHIP between two families has led to an 11-year-old girl with hydrocephalus raising thousands of pounds to give a baby with a similar condition the best chance to overcome her difficulties.

Marian McIlroy cycled five miles, raising £3,000 to buy equipment that will stimulate the senses of 16-month-old Charlotte Linton, who was born almost blind and deaf.

She decided to do the cycle ride as part of a series of fund raising activities for Charlotte organised by Mrs McIlroy and Mrs Linton – who have become firm friends since being introduced by their ASBAH adviser.

Marian Doherty, adviser for Coleraine in Northern Ireland, explained: "Marian's mum was keen to have contact with others and, when Charlotte was born, I remembered the photos shown to me of Marian as a baby, and there seemed to be a lot of similarities between

continued on HNN page 2



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User-forum

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Hand of friendship

from HNN p1

the two of them, although the causes of their hydrocephalus were different.

"The two mums first met at a local association meeting."

Charlotte's mum, Dympna Linton, said: "Charlotte has very little sight and hearing and so we are trying to renovate a ground-floor room in the house which will include specialist sensory equipment to stimulate her.

"We don't know if Charlotte will ever walk and she could suffer from epileptic fits as her brain is severely damaged. However, Marian was given the same prognosis as a baby and she is now a source of inspiration as she can walk and run and is now even cycling to raise money for Charlotte."

Marian Doherty added: "The two families live 15 miles apart and the two mums support each other. When Charlotte recently had three shunts removed and replaced, the support her mum received from Marian's mum was important. They have become very close.

"Marian loves little Charlotte and was so aware that she was doing the cycle ride for Charlotte."

The sensory room will include fibre optic lights, a bubble tube, overhead projector to make patterns on the ceiling, special beanbags, music equipment and an aromatherapy pack.

Coleraine & District ASBAH contributed £1,000 towards the special room.

EDUCATION ADVISER FOR WALES, SOUTH-WEST & THE MIDLANDS, BRUCE GRAHAM ...

enjoys walking along footpaths in the countryside. But he doesn't relish meeting animals lurking in the undergrowth.

He said: "I seem to bring out the worst in them – the most docile of animals turns into a slavering, teeth-baring creature."

Sheep have gradually surrounded him, blocking his way, when he was once walking in a field.

Dogs have bitten him on several occasions while he was walking in London. He

has been chased by dogs when cycling and a Pekingese has dug its teeth into his ankle, refusing to let go.

He is sure that even rabbits would curl their lips, and snails would become menacing, if he confronted them.

Bruce used to be head teacher of Oxfordshire Hospitals Education Service.



*Staff
profile*

Hats on!

SOME like it hot. But for Jim Hallworth keeping his head covered in the sun was a major concern when he travelled to Florida.

The 34-year-old nearly didn't take his place on the once-in-a-life-time trip because he couldn't find a hat to fit.

Then he phoned ASBAH's Information Department and found out about a clothing service.

The Style Centre in Manchester agreed to specially make two large-brimmed sun hats for Jim.

He is delighted with them and was able to enjoy the holiday, along with other members of Stockport and Tameside ASBAH.

He said: "We had a fabulous eight days yet I wouldn't have gone if it hadn't been for The Style Centre.

"I am losing my hair and the skin underneath is sensitive so, in temperatures of 90 degrees, my head would have burnt without covering.

"The Style Centre was a God-send. I couldn't find a hat that would fit in any shop or market stall. Now I say to people that I have my own personal hat maker!"

It was the first time Jim had travelled abroad and he was impressed by Disney, the huge airport at Orlando and massive shopping malls.

"It was the first time I'd flown and I was fine. I came back tired and skint but some of us are already planning another visit next year."



HYDROCEPHALUS research is £800 better off after a generous family asked that money raised for them at a day of live '60s music go to ASBAH instead.

The '60s show featured the music of Scarborough band, The Shadowcasters, and a local guitar club.

The event was organised by the Alexandra Bowls Centre in Scarborough for 10-year-old Matthew Briggs, from Filey, who is a member of the centre's Bowls 'n' Buggies

club. The idea was to raise money for Matthew, who has hydrocephalus, as a thank-you for taking part in a charity bowl-a-thon.

His parents, however, asked for the money raised at the '60s night to be used to aid Dr Roger Bayston's research into shunts.

ASBAH would like to thank the Briggs family and everyone taking part in the '60s night for the generous donation.

THE STYLE CENTRE FACT BOX

● **The Style Centre, Disabled Living Centre, Redbank House, 4 St Chad's Street, Cheetham, Manchester M8 8QA. Tel: 0161-832 3678; fax: 0161-835 3591.**

Open Mon-Fri, 9am-4.30pm.

● Alters and makes clothes for people with disabilities; staff will go with you into a shop to see if a garment can be altered. It also runs design-and-make courses for teenagers with moderate learning difficulties – to

increase self-confidence and encourage them to make choices.

● Prices for alteration of clothes are comparable to in the high street.

● If you can't find clothes that can be altered, The Style Centre will make to measure and not charge the full cost.

● To find your nearest clothing service, contact the national network, **awear**, on 0115-953 0439.

ICP monitoring

What is 'ICP' and why is it measured?

ICP (intracranial pressure) means simply the pressure inside the skull, which is normally about 10-15 cm of water in adults, but lower in children. In newborn babies it is normally only 2-5 cm of water, whereas in older children it is about 5-10 cm of water. When ICP rises suddenly, for example after a severe head injury or when someone has a stroke due to a bleed into the brain, the end result is often fatal. If the pressure rises more slowly, as for example when a CSF shunt blocks or during the onset of the condition called benign intracranial hypertension, characteristic symptoms such as headaches, drowsiness and vomiting will arise.

ICP can be raised in many different medical conditions, but the commonest reasons for monitoring ICP are for the control of pressure after head injury and in the investigation of patients with hydrocephalus, or benign intracranial hypertension (BIH). In hydrocephalus, ICP monitoring is perhaps most useful when trying to sort out whether someone with a shunt, who is having headaches, is experiencing

By Ian Pople MD FRCS
Consultant Neurosurgeon

high intracranial pressure due to a shunt blockage, or low pressure due to the shunt draining too much fluid ('low pressure syndrome'). Patients with a functioning CSF shunt usually have a *lower than normal* ICP and in many patients it will be found to be between 0 and -15 cm for most of the day. Fortunately, only a few people with CSF shunts and such low pressures suffer troublesome headaches as a result and for these it is usually possible to improve things by adjustments or additions to the valve. In assessing some patients with large cerebral ventricles found on their brain scan, who may not have many typical symptoms or clinical signs of hydrocephalus, ICP monitoring is sometimes useful when deciding whether or not to operate.

How is ICP monitoring done?

The most accurate way of measuring the pressure within the head is to place a catheter into the lateral ventricle and connect it to a device called a

pressure transducer. Some people who have been treated for hydrocephalus will already have such *ventricular catheters* attached to a reservoir under the skin of their scalp (usually on the front part of the head). By placing a very thin needle ('butterfly needle') through the scalp and into the reservoir it is possible to measure ICP very accurately. One problem with this technique is the very small risk of introducing infection into the ventricles, that can very occasionally lead to serious side-effects.

The next best way of measuring ICP is probably by inserting a very narrow-gauged monitoring cable into the outer part of the brain substance, rather than deeper within the ventricle of the brain. This is called a *parenchymal monitor* and can be put in through a very small wound in the scalp, usually in the front of the head. It is particularly useful in people with benign intracranial hypertension, who often have very small ventricles, making a ventricular catheter much more difficult to place. The

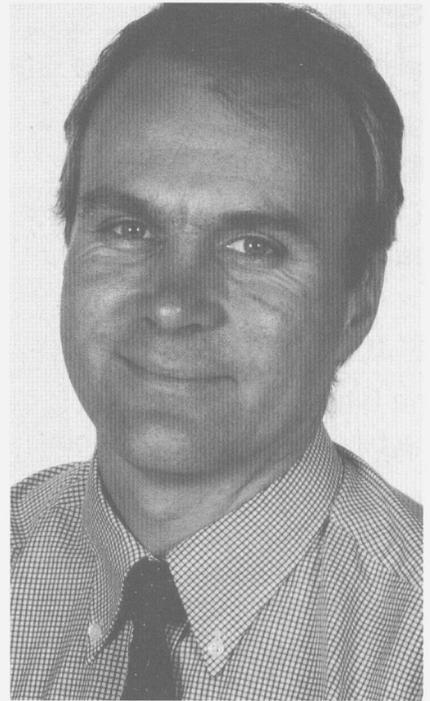
operation can be done under local anaesthesia, but most patients prefer to be 'put out' under a general anaesthetic! The infection and bleeding risk of this technique is very low and the device can be safely left in for more than the usual 12-24 hour period of ICP monitoring.

Other techniques are used less commonly as they do not give such direct and accurate measurements of ICP. These include lumbar punctures, which can give a misleading idea of intracranial pressure (especially in patients with BIH, or non-communicating hydrocephalus) and shunt valve taps, where blockages of the upper part of the shunt system can obscure true pressure measurement. Indirect assessments of ICP can be obtained by non-invasive techniques such as tympanic membrane displacement and trans-cranial Doppler, both of which are particularly useful for detecting high pressure, when previous readings on the same patient are available.

Some problems with ICP monitoring

As mentioned above, there is a very small (2-3%) risk of infection and bleeding when using these techniques, but much useful information can be

Ian Pople (pictured right) is a consultant neurosurgeon at Frenchay Hospital, Bristol, with a special interest in children's neurosurgery, hydrocephalus, benign intracranial hypertension and spina bifida. Some of his training was spent in Memphis, USA, where he did a project on ICP monitoring.



gained by a 12-24 hour period of monitoring and the potential benefits usually outweigh the risk of complications.

However, in some circumstances the ICP reading can appear to be 'normal' in a patient with a blocked shunt. For such an individual the ICP may actually be higher than their usually negative pressure when their CSF shunt is working. Readings taken during ICP monitoring can therefore occasionally be difficult to interpret and may not give a clear explanation for particular symptoms.

Some patients with hydrocephalus have such a slow progression of their condition that their ICP may be normal during the period of monitoring and other investigations such as CSF infusion tests may be needed to find out whether

an operation might be needed.

Summary

ICP monitoring is just one of several different possible investigations for patients with hydrocephalus and is not needed in the majority of patients who are admitted to hospital with a blocked CSF shunt. It is most useful in differentiating patients who have shunt over-drainage from those who have shunt under-drainage, or blockage and this is very important when treating hydrocephalus patients who have headaches of uncertain cause. ICP monitoring with a parenchymal device is becoming an essential part of the investigation and treatment of patients with benign intracranial hypertension.



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| Hydrocephalus and YOU, 81-page book, edited by Leonie Holgate and Rosemary Batchelor | 10.99 | | |
| Children with Spina Bifida and/or Hydrocephalus at School – Edited by ASBAH | 2.75 | | |
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- What is Spina Bifida?
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- Ante-Natal Screening
- Genetic Counselling
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- Vaccinations and Spina Bifida and/or Hydrocephalus
- A Guide to Educational Statementing
- Just what is ASBAH?
- Continence Management
- Spina Bifida Occulta

YOUNG PEOPLE'S LEAFLETS

(for adolescents with spina bifida and/or hydrocephalus). Single copies free with self-addressed envelope and two stamps

- ★ Bullying
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DIARY DATES

24 – 26 September

North Wales ASBAH presents 'Breakaway!', a weekend of activities and workshops for severely disabled people with spina bifida and/or hydrocephalus and their carers, Plas Menai, Portdinorwic, North Wales. Cost £90 per couple (inc B & B, and all meals from Friday evening to Sunday lunch), £30 payable on booking as deposit. **Details:**

Mrs Jill Bartlett, ASBAH, 4 Ta'ir Felin, Felinheli, Gwynedd, North Wales LL56 4JF.

Saturday 9 October

Hydrocephalus Support Group for Parents, at St Andrew's Church Hall, Preston Grove, Yeovil, Somerset. The group starts at noon with a shared lunch and talks start at 1.30pm. Finish time aims to be 4pm. *If any parents with children with hydrocephalus want to attend, please contact ASBAH Somerset adviser Rachel Clark on (01460) 240462.*

Wednesday 13 October

'Spina Bifida and Hydrocephalus Study Day', at Elsham Hall, Elsham, Nr Brigg, North Lincolnshire. *For details, contact ASBAH North, tel: 0113-255 6767.*

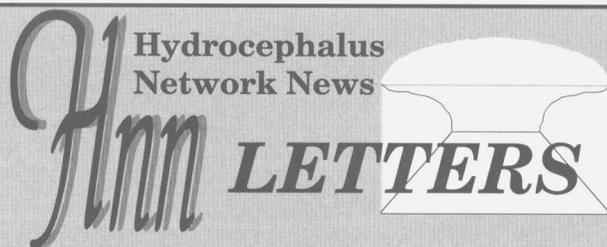
24 – 25 November

Neuropathic bladder course, multidisciplinary two-day course, covering day-time wetting, neurological concerns, video-urodynamics, surgical management, renal problems and infections, nursing support, sexuality and disability, psychological care, associated bowel problems. Newcomen Centre, Guy's Hospital, London. Cost: £150.

Details: Debbie Hudson, course administrator, tel: 0171-771 5282.

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.



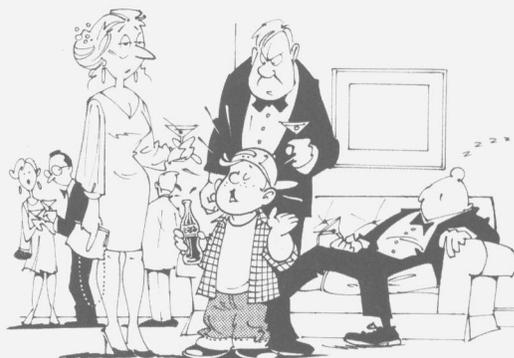
Please send your letters, True Stories and feedback to:
Rosemary Batchelor
HNN Co-ordinator
ASBAH, 42 Park Road
Peterborough PE1 2UQ



I HAVE a son Andrew who is nearly four years old who has hydrocephalus. I would like to hear from other parents who have a child with hydrocephalus. There is no support group in Aberdeen for children who have hydrocephalus only.

Denise McIntosh
6 Lintmill Place
Aberdeen
AB16 7ST

HYDROCEPHALUS AND YOU



ASBAH's new book – definitely NOT the last word on the subject, but as good as it gets for the moment!

£10.99 inc p&p from ASBAH

True story

I AM 27 years old, married with two children, Thomas, aged four, and Nathan, who is two and a half years and has congenital hydrocephalus and cerebral palsy.

Nathan's condition was diagnosed the day after his birth; his head circumference then was 37 cms, which increased to 46.5 cms at four weeks of age, when his first VP shunt was fitted.

At the age of eight months, my mum, Thomas, Nathan and I were shopping in the local supermarket when Nathan began screaming, the most blood-curdling scream I'd ever heard in my life, which stopped as suddenly as it began.

This continued over all of Saturday and through Sunday. I fed him Calpol and only on the Monday, after talking on the phone to a friend, who asked what was wrong with Nathan, who she could hear in the background, did I begin to wonder if his shunt could be the cause?

I rang our GP and got an instant appointment. I was there in under 15 minutes but our GP was on holiday. We were ushered in to see a locum, who mumbled: 'Give him Calpol and plenty to drink.'

I asked if he'd read Nathan's note; he shook his head. I then said my son had con-

**By Jenni Jarvis
from Shawbury,
Shropshire**

genital hydrocephalus, controlled by a VP shunt, at which he picked up the phone and had Nathan admitted to our local children's ward.

Here he was observed for 24 hours and, only after pressure from his dad and myself, agreed to tests. I wanted him to have a CT scan but they decided on x-rays which showed a large kink in the shunt tubing: their answer to Nathan's problem. I wasn't convinced and pushed for him to be transferred to the care of Nathan's neurosurgeon.

Two days and many episodes of 'just screaming' later, we were taken to another hospital, still under the care of the same surgeon, who was not convinced of a shunt problem. A CT scan showed there was no problem but, eventually, under duress, he agreed to take Nathan into surgery for an exploratory operation.

The plan was to open the stomach and check whether CSF was draining through the shunt. On opening, no CSF fluid was found to be draining so a shunt revision was done. The problem was an intermittent shunt blockage.



Nathan Jarvis at last year's ASBAH Family Weekend

The shunt was blocking and the pressure was building up, causing the screaming fits, and, eventually, for whatever reason, the shunt unblocked and the pain stopped.

It was seven days before the cause was found. It was fortunate that we pushed as hard as we did and found people willing to listen to two 'over-protective parents', but it was hard work.

I just knew my baby wasn't right. I kept that in my mind and kept pushing for what I thought we needed. Luckily, it was the right thing to do. Nathan had no other symptoms of shunt blockage or infection, except the blood-curdling, recurrent screaming.

All the doctors in the world can tell us we are over-protective but we will fight every time if we believe it to be in the interests of our son.

York praised on access and welcome

A FAMILY has heaped praise on the city of York, after returning from a holiday there, for its facilities for disabled people.

There seemed to be no attraction that was not accessible to 32-year-old Tracey Theis, who is a wheelchair-user.

If a place was not clearly accessible, the people of York did their best to make it so.

- The Jorvik Centre – Tracey, her mother, Barbara, and grandfather, Joseph Turford, were taken, straight away, to the front of a long queue and made very welcome. One of the carts taking people round the exhibition had a side flap to enable wheelchair-users to get on board. A small lift down to the exhibition took up no room at all and was quite unobtrusive.

- The Yorkshire Museum – Tracey was able to spend a good hour looking at everything with the help of a small lift.

- The Art Gallery – a stair lift did not detract from the elegance of the building but allowed Tracey to do something she had not done in years – go up a flight of stairs.

- The Railway Museum – everyone was extremely helpful and a small lift and ramps allowed access to most of the building.

Then they discovered that Tracey could board a little road train that ran back to the Minster.

Mrs Dunn said: "The man running it was very helpful and told us there was no problem: a simple tail lift in the end carriage enabled Tracey to do something others took for granted."

- The North Yorkshire Railway – Tracey got on through the guard's van and enjoyed her first train ride. She could have travelled in the carriage if the wheels on her chair had been less wide.

DISABLED PERSONS TAX

CREDIT – from 5 Oct '99 replaces Disability Working Allowance (DWA).

Basic tax credit

| | |
|--------------------|--------|
| Single person | £51.80 |
| Couple | £81.05 |
| 30-hour tax credit | £11.05 |

Credit for dependent children

| | |
|-----------------------------------|--------|
| from birth | £15.15 |
| From Sept following 11th birthday | £20.90 |
| From Sept following 16th birthday | £25.95 |

Disabled child's credit (paid in addition to dependent credit) £21.90

Childcare tax credit up to 70% of eligible childcare costs, up to a maximum of £100 pw for one child or £150 pw for two or more children.

Threshold

| | |
|------------------------------|--------|
| Single person | £70.00 |
| Couple or lone parent | £90.00 |
| Taper rate (above threshold) | 55% |

New benefits

WORKING FAMILIES TAX

CREDIT – from 5 Oct '99 replaces Family Credit (FC).

Basic tax credit

| | |
|-----------------------|--------|
| Couple or lone parent | £49.80 |
| 30-hour tax credit | £11.05 |

Credit for dependent children

| | |
|-----------------------------------|--------|
| From birth | £15.15 |
| From Sept following 11th birthday | £20.90 |
| From Sept following 16th birthday | £25.95 |

Childcare tax credit up to 70% of eligible childcare costs, up to a maximum of £100 pw for one child or £150 pw for two or more children.

| | |
|------------------------|--------|
| Threshold | £90.00 |
| Taper rate (above £90) | 55% |

Capital limits, and earnings and capital disregards are the same as for the former Disability Working Allowance.

- At every café, pub and hotel the family went to, people were helpful.

- The Ghost Boat Trip from Kings Staith – staff carried Tracey down a flight of steep steps onto the boat.

Mrs Dunn concluded: "I think a committee from every major tourist town in the country should be sent to York and shown just what can be done if they put their minds to it.

"Whenever we go to a new place, my daughter always says at the end of the holiday: 'I want to come back, mum.' I usually say OK but do not

always return if it has been very difficult getting around with her. This time I am in complete agreement and we are already planning to return next year."

The only small criticism the family had of York was that few hotels and apartments inside the city could accommodate a wheelchair-user. But Mrs Dunn says this will cause no problem as they can travel around York on wheelchair-friendly buses – something they are definitely not used to in their home town of St Albans!

NEWS IN BRIEF NEWS IN BRIEF NEWS IN BRIEF

- WALES Disabled Drivers' Assessment Centres have moved to Rockwood Hospital, Fairwater Road, Llandaff, Cardiff CF5 2YN. Tel/fax: 029-20 555130.

- NEW guidance, published by the British Bankers' Association, will help to ensure bank custom-

ers get a fair deal when Part III of the Disability Discrimination Act comes into force on 1 October this year.

- A CHAT website for the over 50s has been set up by the younger arm of Age Concern at <http://www.babyboomerbistro.org.uk>

Benefits: changes in appeals process

MAJOR changes in the way you can appeal benefits decisions are now coming into effect, under the Social Security Act 1998.

You now have only one month from the date of a decision – instead of three – to apply for a revision of an unfavourable decision.

Some benefits have already been affected by the change – Child Benefit and Child Support. The one-month time limit for Disabled Living Allowance and Jobseeker's Allowance comes in on 18 October; and for Income Support and the Social Fund, it takes effect from 29 November.

A further 14 days can be obtained if you request a 'statement of reasons' why the benefit has not been awarded or not at the rate you expected – the Benefits Agency has to supply that statement within 14 days of the request.

The agency which made the decision under appeal – the Benefits Agency, Child Support Agency or Employment Service – now handles the appeal up to and including the preparation and issuing of the submission. It is only at this point that the appeal will be passed to the Independent Tribunal Service (ITS) which will arrange a hearing and deal with any further evidence.

The administration of an appeal should run as follows:

1. Appeal form or letter sent to agency

Agency acknowledges appeal and begins preparing submission. It will not usually send a copy of the appeal to the ITS at this stage; therefore any queries or further evidence should be sent to the agency concerned. However, if it appears that an appeal may have been made late, is outside the tribunal's jurisdiction or is not duly made, it will be forwarded to the tribunal for a decision on whether it can be admitted. If there is any doubt about what has happened to an appeal in these circumstances, the agency should be contacted as soon as possible.

Where an appeal is delayed because the agency is taking a long time to prepare a submission, the administration of the appeal will be under the control of the agency. Therefore, complaints should be made to the supervisor at the agency involved, then the customer service manager and/or district manager.

One of the aims of the changes is to reduce the number of formal appeals. Emphasis is placed on altering decisions within the agency. Under the new system, any revision which is more advantag-

eous to the appellant will result in their appeal lapsing and they will need to make a fresh appeal against the new decision.

2. Submission prepared and sent by the agency

Once prepared, a copy of the submission and original appeal letter will be sent to the ITS which will arrange a hearing. At the same time a copy of the submission, information about tribunal procedures, enquiry form and prepaid envelope for return to the ITS will be sent to the appellant (and respondent in child support cases). Representatives will not be sent copies of the submission. Although appellants should get a copy of the appeal papers at an earlier stage than they did before April, representatives will not get a copy at all. Good communication between client and representative is therefore even more important than before. Between issuing of the submission and the hearing any further evidence should be sent to the ITS which will distribute it to all relevant parties, including representatives.

Appellants **must** complete and return the enquiry form requesting a paper or oral hearing within 14 days of its issue. The Social Security Act gives powers to clerks to strike out appeals where an enquiry form is not returned.

3. Notice of hearing

The ITS will send notification of the hearing to appellants, respondents and their representatives.

Where the Social Security Act 1998 applies, 14 days' notice should be given of a hearing.

Interim arrangements

In appeals where submissions had already been sent to the ITS prior to 5 April 1999, the ITS will send copies of the submission to appellants, respondents and representatives when the case is listed for hearing.

[Source: *Welfare Rights Bulletin* 150/June 1999]

10th birthday of ASBAH supporter

A COMPANY which delivers prescription products to your door and which supports ASBAH is celebrating its 10th anniversary.

Novacare was started in 1989 by Robert and Christine Tromans, delivering colostomy, ileostomy, urostomy and continence appliances.

With more than a thousand variations available on prescription, the company prides itself on having a wide knowledge of products and a sympathetic understanding of customers' needs.

Novacare employs a stoma care nurse Wendy Sharland CNS, RGN, who visits customers on request throughout Shropshire and Mid-Wales. Wendy can be contacted on freephone 0800 21 22 58.

Since 1996, Novacare has extended its service nationally and, this year, the company moved to new premises at Hortonwood, Telford.

Also included in the service is a freephone helpline – 0800 21 22 58 – and the free supply of useful extras, not available on prescription, such as disposal bags and wipes.

A READER'S letter reminded me that, although I've written in my *Diary* about almost every subject under the sun, I've never really mentioned hydrocephalus or my shunt. I apologise for that, to my readers, and to myself. After all, I have spina bifida and hydrocephalus. My disability has two sides.

So why have I rabbitied on about one side and not the other? I think it is because I am embarrassed at having a 'mental disability'. Why it should be any more embarrassing to talk about that than my being incontinent for 20 years, I don't know. It just is. Well, that changes with this issue! So there!

I was born with hydrocephalus and spina bifida 31 years ago. Shortly afterwards, I had a shunt installed and stuck into my heart. Why it was put there and not in my guts, I don't know. Perhaps the surgeon just got bored one day? Anyway, while the heart, though surrounded by a thick layer of lard, is still going, the shunt, apparently, gave up the ghost a few years later.

Whether the shunt helped prevent problems or not, I still have all the usual stuff that people with hydrocephalus have to put up with. I get the headaches, the depression, the lousy co-ordination, zero stress tolerance and poor concentration. I'm bog-eyed, my hearing is going (although this, as my Grandpa said, is probably down to listening to loud pop music on my headphones), and I have no sense of direction. Frankly, I couldn't find my way out of a cupboard without a map. This is especially annoying as the rest of my family have the instincts of homing pigeons.

My memory is useless! Thanks to the Big H, when I go searching my brain cells for a word, it seems to disappear down a black hole. As I am trying to make my living by writing, this can be a bit of a pain! Then again, it may be the hydrocephalus that scrambled by brain cells enough to (allegedly) bring out the ability to write in the first place.

People always talk about the bad side of any disability. But everything has a good side. The good side of my hydrocephalus is that it

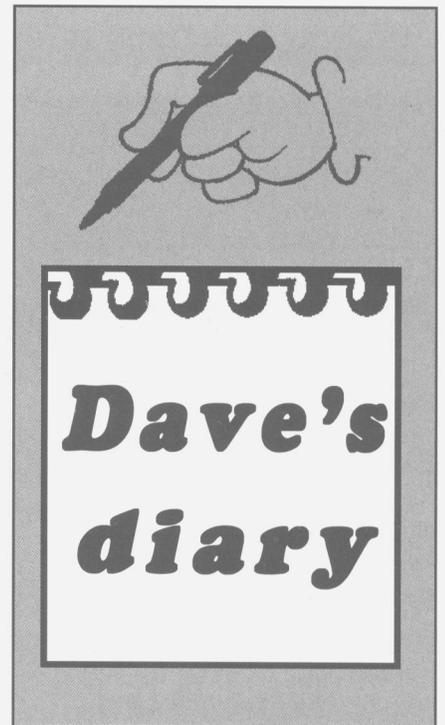
has given me a couple of unusual abilities. I'm not talking about receiving messages from Martians, or anything like that. But I do pick up some signals others miss.

Some people have corns that pick up changes in weather, but I have a weather vane brain. Thanks to the hydrocephalus, I can tell if it is going to rain, or a storm is on the way, well before anyone else notices.

I feel 'heavy weather' as increasing pressure on my head, an ache behind the eyes, or like a blow to the neck. In hot weather, I sweat buckets off my forehead and get light-headed, but feel great. My mind clears and my abilities improve dramatically! As hot weather improves my health, I wonder if my doctor would write up a prescription for two weeks in Spain? If she did, would the NHS or DSS foot the bill. I doubt it!

My other ability is to be able to tell when something electrical is plugged in, without looking at it. I pick up a sort of electrical hum that no one else can hear! Unfortunately, it only works sometimes so I can't hire myself out as a walking circuit finder!

My kind of shunt was a miracle 30 years ago and I'm grateful for having it. But I look around at the latest generation of shunts with their 'remote controlled variable flow adjusters' and all that, then I think of my fixed capacity, blocked-up drain pipe. I feel like I'm carrying a Model T Ford, while all the youngsters are zooming about with their turbo-charged Ferraris. I mean, *remote control*? What next, satellite TV?



I think I've got shunt envy!

New or old-fashioned, if you think your shunt, or your hydrocephalus, gives you strange abilities or affects you in strange ways, write to me c/o Link.

David Fulford-Brown

novacare

PRESCRIPTIONS TO YOUR DOOR

“Thank you for the speedy, efficient, courteous and friendly service - such a refreshing change. I am particularly pleased with the magnificent holdall”

TPN, AVON

This compliment from one of our many letters of appreciation is a typical response to Novacare's prescription delivery service throughout over ten years in this specialised healthcare field.

As a totally independent supplier we are not tied to any manufacturer and we cater for all stoma and continence appliance needs including catheters, sheaths, leg and night drainage bags.

Our completely free service also includes free extras to aid application, disposal and cleansing. Ask for details.

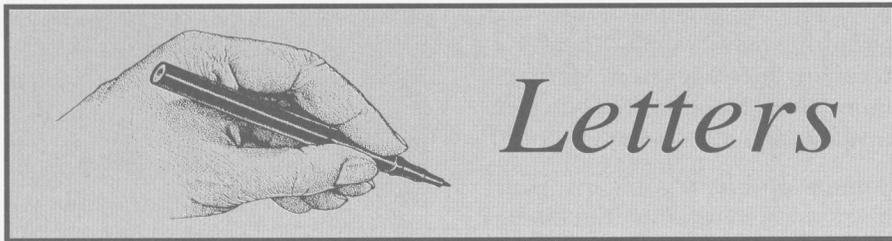
We invite you to evaluate the acclaimed Novacare service for yourself and as a thank-you we will be pleased to send you a voucher for the FREE OFFER featured below

For advice or ordering call us free on 0800 21 22 58

or write to Novacare, FREEPOST SY480 Telford, Shropshire, TF1 4ZZ

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INTRODUCTORY OFFER!
a discreet Home
and Travel Holdall
Phone free or
send for
details



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

Memories of Mr Zachary



I WAS deeply moved to hear of the death of Robert Zachary. All kinds of memories came flooding back. Perhaps most of all there were memories of his kindness and the hope that was around him.

I remembered the first time we took our son Andrew to the Tuesday Spina Bifida Clinic at Sheffield Children's Hospital. We were worried and frightened: worried about our child and frightened of what we saw in the conditions of the other children. But Mr Zachary, as we always knew him, was so positive as well as realistic.

He was kind to Andrew and he was kind to us as parents, always warm and comforting. And he always wanted to know our views on anything to do with Andrew's condition; he believed that the observat-

ions of the parents and carers were part of the essential diagnostic information.

I remembered emergencies, times when Andrew had valve problems and how he sidestepped the formalities in order to deal with us as patients and parents; how he operated on Andrew one evening and suggested that we ring at 10pm in order to check how it had gone. Our enquiry was put straight through to the operating theatre where he had just finished inserting a new valve. He was able to confirm "that the operation had been successful, the fluid was flowing well and Andrew was comfortable again and will be pleased to see you when you visit tomorrow."

I also knew him through ASBAH where, with John Lorber and Duncan Forrest, he put in valuable

time which, I suspect, few other surgeons of his standing would have been willing to spare.

As the first chairman of ASBAH, he was patient in what seemed like interminable meetings, sorting out mundane issues like the name, the constitution, the price of Christmas cards, fund raising appeals etc and always with a good humour.

I consider it an honour to have known Robert Zachary. The world is a poorer place for his passing, but an infinitely better place for what he contributed in his life.

Stephen Hinchliffe
Founder trustee of ASBAH
and first editor of *Link*
Middleshaw Hall
Old Hutton
Kendal
Cumbria LA8 0LZ



I WOULD like to contact other people who have had setbacks and are now fighting back.

I am just one person (with hydrocephalus) who would like to see more recognition given for those who, just like myself, have experienced trouble from birth.

In my own life, a childhood accident left me temporarily blind and partially paralysed down my right side. I returned to school, after seven and a half weeks in hospital, with a very awkward right arm and

leg which meant I had to learn to write with my left hand.

Because I was so slow, it caused a lot of torment in the shape of remarks from the teachers but more from the pupils. I now look back on the experience with anger: after all, it was a school for physically disabled children.

One of the good things was I learnt to type and, although it was frowned upon by most of the teachers, one or two remained on my side.

Since then, I had another blow.

Coming out of care in 1988 to live with a friend, I had a stroke, losing my speech and memory. It was only through my perseverance that my speech returned.

Behind a disability lies the person, and I would like to offer my support to others who are fighting adversity, and who need as much encouragement as they can get.

Mary Stredwick
39 Walerand Road
Lewisham
London SE13 7PQ



OUR two and a half-year-old has spina bifida and is learning to walk in a hip guidance orthosis. We understand that he is very young to be learning to walk in this way and we would be very grateful to hear from parents of children who use this method of

walking, or indeed from anyone with experience of a hip guidance orthosis.

Sue Wakely
135 Bradford Road
Combe Down
Bath BA2 5BS

WANTED

Baby clothes. Ann Wright, featured in this issue of *Link*, needs baby clothes for rapidly growing Chloe and Robert. If anyone has any 18-24 months and upwards clothes to donate, please contact SE Region 0181-449 0475.

HOLIDAY ACCOMMODATION

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

SELSEY, WEST SUSSEX

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

ISLE OF WIGHT ASBAH –

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

WEYMOUTH BAY – Fully-equipped, wheelchair-accessible caravan – sleeps five; on Haven Holiday Park, full use of all facilities – heated indoor & outdoor pools, bars, children's club & full entertainment programme. Three miles from Weymouth. *Details from: Margaret Humphreys, tel: 01494-741270 (Bucks & E Berks ASBAH).*

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

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

ELECTRIC powered wheelchair, Wayfarer-Sunrise. Remote controlled, bought new 19/4/99 for £3,750, requiring £700. Battery and accessories included. Frame size 18". *Telephone 01985-215578 anytime. 45 St George's Close, Woodcock Road, Warminster, Wiltshire BA12 9ET.*

ELECTRIC pavement wheelchair, Powertec. Hardly used. Also air mattress. Price: £1,500. *Tel: 0181-480 9369 or mobile 0956-869548.*

ORTHOKINETICS Pony II child's battery-operated trike. Pneumatic tyres, battery and charger. VGC, one careful owner. £1,400 new, will sell £400. *Tel: 01942-811184 (Bolton).*

STERLING FOUR Elite Scoota. Excellent condition, only two hours total running time from new. Cost £3,140, accept £2,500. Phone 01480-860834 or email andrew.pooley@btinternet.com

NISSAN Vanette cruiser, N-reg. 2.3 diesel, 22,000 miles. Side windows, sun roof. Fitted with Ricon hydraulic lift. Six-seater, two removable for wheelchair. Colour red. Workshop conversion. Immaculate condition. Bargain £8,500. *Tel: 0115-972 7621 (Notts).*

LINK Rates

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£6.25 for 45-60 words.

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Small adverts for the next issue of *LINK* (November) should be submitted by Friday, 24 September. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

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