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The magazine for people with Spina Bifida and/or Hydrocephalus

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

August/September 1998

Issue No 177 Price 80p

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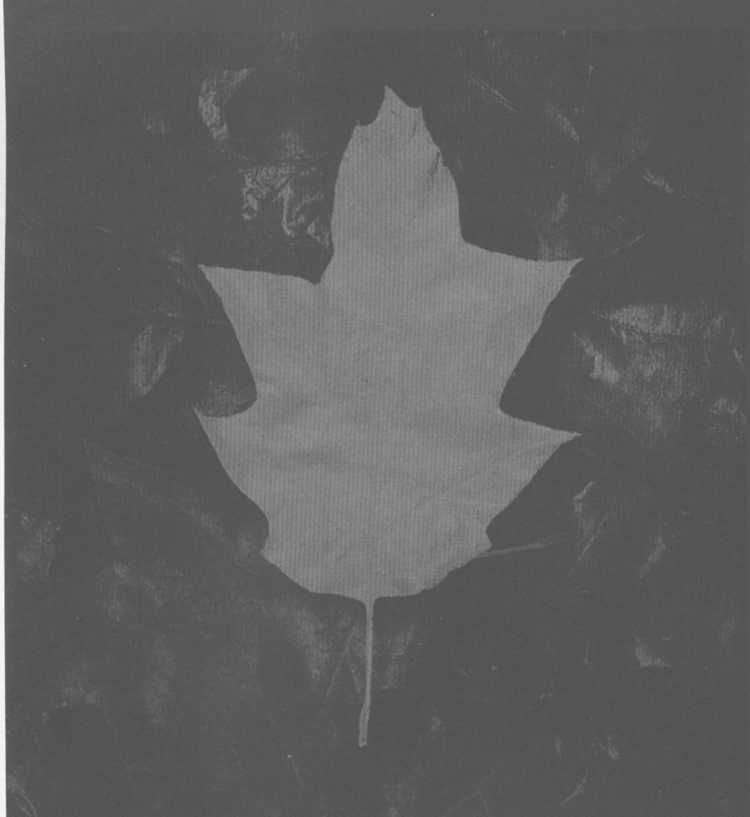

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Inventor of hydrocephalus shunt gains Honorary CBE

JOHN HOLTER, inventor of the Spitz-Holter valve which led to a revolution in the treatment of hydrocephalus in the 1950s, was awarded an Honorary CBE in the Queen's Birthday List.

In 1956, Dr Holter worked around the clock to develop a valve, and then searched for a suitable material to make it with, in order to save the life of his baby son, Casey, and other children like him at the Children's Hospital in Philadelphia, USA.

Dr Holter had been told by doctors there was no successful treatment for his son's hydrocephalus. But, after discussions with a surgeon, he set himself the task of developing a clog-free tube, which could stay in the body indefinitely and which would control the pressure in the brain with mechanical precision.

Dr Eugene Spitz told Dr Holter, an engineer by profession, that the tube would have to be a one-directional valve – allowing fluid to flow only way – which would open and shut automatically as the need arose.

His invention proved a triumph in controlling Casey's hydrocephalus, so Dr Holter gave up his job to devote his time to making the valve full-time.

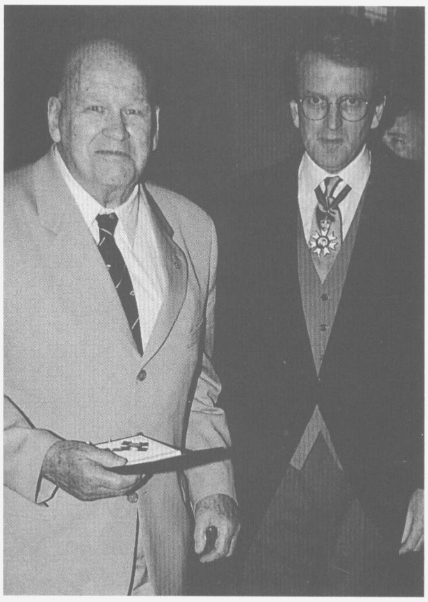
The valve was first used in Britain by Mr George McNab two years later.

By 1967, Dr Holter had made about 75,000 valves which were in use in some 50 countries.

In tribute to Dr Holter, ASBAH's honorary consultant in hydrocephalus, Dr Roger Bayston, said: "The shunt revolutionized the treatment not only of hydrocephalus but also of spina bifida: orthopaedic, urological and other interventions seemed pointless in view of the hydrocephalus, but the availability of shunting stimulated the development of new treatments.

"The shunt has now been in use throughout the world for over 40 years. Dr Holter has now invented over 40 medical devices, mainly concerned with hydrocephalus."

Dr Holter, now aged 81, was invested with his Honorary CBE – a very rare honour – by the British ambassador in Washington on May 1, 1998, in the presence of family and friends.



Dr John Holter (left) with the ambassador at the British Embassy in Washington DC, after receiving his Honorary CBE

In June, he was warmly congratulated on gaining the prestigious award at a meeting in Italy of the Research Society For Hydrocephalus and Spina Bifida, of which he is an honorary member. Dr Holter has continued steadfastly to support this society, both financially through the Casey Holter Memorial Fund, and personally by attending and taking part in almost all the annual scientific meetings.

ASBAH'S NATIONAL SPINA BIFIDA WEEK RUNS FROM 14–21 SEPTEMBER

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: Sir Cliff Richard presents seven-year-old Louise Hunt with a state-of-the-art tennis wheelchair at Wimbledon. Full story on page 16.

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

● A FORMER Royal Mail customer services manager has taken over as our new trusts and legacies officer following the retirement of Elizabeth Glover.

Jane Ayres *(pictured above)* comes to ASBAH after a short gap in full-time employment, during which time she had two children.

Elizabeth, who retired after nearly eight years of service in our appeals department, said: "I have been fortunate in having such good people to work with. I will especially miss Donna Treanor (appeals manager) who started at ASBAH on the same day as me."

● THE LONDON Borough of Sutton is now included in the area covered by our adviser Diane Morgan.

Diane has increased her hours to cover Sutton, as well as her existing patch of Bromley, Bexley and Croydon.

Diane's number is 0181-659 3060.

● FIDELMA Murray, who has been with ASBAH Northern Ireland Region for more than seven years, has left due to ill health.

Replacement cover for Co Londonderry, North Tyrone and North Fermanagh is being worked out.

● JACKIE Cowl has become the adviser for Surrey. She is the first adviser we have had in Surrey for about five years.

A trained nurse for people with learning disabilities, Jackie previously worked in playgroups and did voluntary work for local organisations, including visiting and driv-ing for the elderly.

She has lived in Surrey all her life so knows the county well. She currently lives in Horley and has an 11-year-old son called Christopher.

She said: "The ASBAH position appealed to me because I love work-ing with people and the hours suited because of my son."

The part-time post is being funded by East Surrey Health Authority and ASBAH.

● *Jackie can be reached on 01293-436164.*

● SOMERSET adviser Shirley Hinde has left ASBAH after seven years to write a plan highlighting how the health of people living in Somerset can be improved.

Shirley's new role is to bring together the views of the health authority, social services, education and voluntary groups. She said: "The result will be a health improvement programme which outlines the priorities and major issues of health in Somerset."

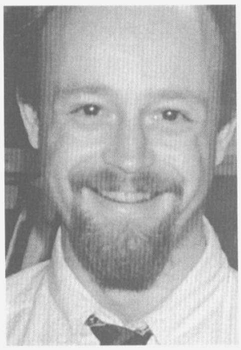
The new job follows a two-year contract to write Somerset's Community Care Plan for Social Services, which she had been doing in addition to her hours for ASBAH.

Although her new role is very different from that of an ASBAH adviser, Shirley is sure that she will carry the experience with her. She said: "I will miss my colleagues although I think we will still keep in touch, and I'll miss the people locally with spina bifida and hydrocephalus. I am not sure how easy it will be to cut off as some have become friends."

● VALERIE Blackman comes to Kent ASBAH with many years' experience as an unqualified social worker and a nursery nurse, which included giving support to adults and children with special needs, and their families.

Valerie, who lives in Maidstone, has been appointed as part-time assistant adviser for Kent. She will be helping Lynda Atkins who covers the county full-time.

Enquiries from Kent should be directed initially to Lynda Atkins on 01474-812070.



● TIM Leech left in June to become membership services director with the Greater London Association of Disabled People (GLAD).

Thirty-year-old Tim joined as part-time specialist adviser (mobility) in November 1996 and built up a reputation for tenacious casework, skill in pulling levers in the outside world to get results, and his knowledge of wheelchairs and the Wheelchair Voucher Scheme.

"At GLAD, I will be heavily involved in disability movement politics and responsible for providing services to 80 disability organisations in the London area. I'll miss the friends I've made at ASBAH but I am looking forward immensely to my new challenge," he said.

Not a lot of people outside support staff at ASBAH House know that Tim's own disability is dyslexia – a condition which made him sensitive to the needs of others struggling to achieve their potential in the education system.

But readers of ASBAH publications will be familiar with his extra-curricular passions: his cultivation of rare varieties of vegetables, enjoyment of fishing and good food and his encyclopaedic knowledge of archaeology.

Obituary: Mrs Sheila Wilkinson

IT is with deep regret that we report the death of Sheila Wilkinson at the beginning of July, after a short illness. A retired adviser for national ASBAH, Mrs Wilkinson was still working for Sussex ASBAH when she died.

Sheila was one of the first two ASBAH fieldworkers in the country. She started working part-time in Sussex in 1971 with just a few families. By the end, she had 140 families with children under the age of 16 on her list, in East and West Sussex.

She worked part-time for Sussex ASBAH after retiring from national ASBAH in 1991.

Margaret White, county organiser for Sussex ASBAH, said: "Sheila gave her total support to Sussex ASBAH. All of us in Sussex will miss her enormously, but we are very grateful for all she has done for us in the past 27 years."

Teresa Cole, national ASBAH's assistant director (services), added: "Sheila's knowledge and expertise was a great support to families and individuals. It was a privilege to know and work with Sheila until her retirement and she will be greatly missed."

Sheila leaves a husband, Charles, three sons, a daughter and seven grandchildren.

A thanksgiving service was held at Wadhurst Parish Church on 17 July.

Triumph born out of tragedy

A SCHOOL pulled out all the stops to raise money for charity after pupils and staff were affected by two personal tragedies within the space of a fortnight.

The Warwick School in Redhill, Surrey, handed over cheques totalling well over £4,000 to ASBAH and the Royal Marsden Hospital children's cancer unit at a presentation in June. Our South East regional co-ordinator, Jo Francis, received the money on behalf of ASBAH.

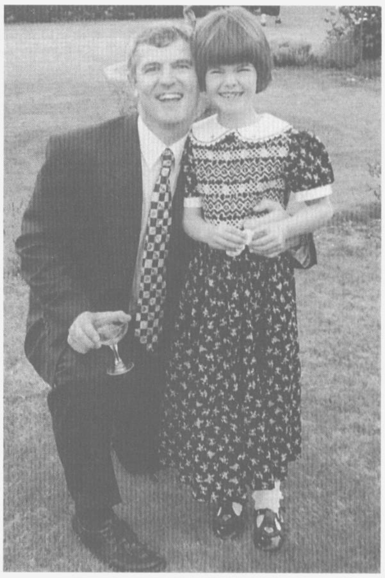
The death of eight-year-old Rachel Preston, of Wolverton Gardens, Horley, Surrey, in September last year was the first event which triggered a busy week of fundraising at the school in the Spring term.

Rachel, the daughter of school year one and department head Rod Preston, had hydrocephalus.

Two weeks later, the 12-year-old daughter of another teacher at the school died of cancer.

"It was an awful time, and not just for the families involved. The whole school was affected by the deaths and, in the run-up to Christmas, we decided to do something for the charities concerned," said Mr Preston.

Various sponsored events took place during a dedicated charity week and two teachers, who ran in the London Marathon this year, presented the money they raised to the school appeal. One marathon runner, John McManus *(pictured above with Rachel)* collected £700 under his own steam.


Rachel Preston, seen here with John McManus

The school has requested that the £2,393 passed to ASBAH should be spent on buying a lightweight wheelchair for a child living in the South East.

A suitable recipient is being identified by Mrs Francis, the regional co-ordinator. A photo of the wheelchair handover will be given to The Warwick School so pupils can see how their money was spent.

Officers & Staff

Free course on special educational needs for parents

A WEEKEND, giving information about the Code of Practice, assessment and statementing, with plenty of time for discussion and and practical work, is being held on 10-11 October.

The Befriender Training Course is being organised at the Forte Posthouse, Gloucester, by Network 81 – a national network of parents of children with special education needs and working towards properly resourced inclusive education. Free residential or day places are available.

Further details from: Val Rosier, on 01279-816108, fax: 01279-816438.

The course is financially supported by The National Lottery Charities Board.

MRSA: cause for concern

by Dr Roger Bayston
MMedSci FRCPath

MOST people have now heard the term 'superbug' used by the media to describe bacteria resistant to most antibiotics. MRSA stands for 'methicillin-resistant *Staphylococcus aureus.'*

S aureus is the most common cause of hospital infections after surgery (though not of shunt infections). Methicillin was developed to cope with the problem of penicillin resistance in the early 1960s, but some strains of *S aureus* have since developed resistance to this and many other drugs, so that MRSA can now be taken to mean 'multi-resistant *S aureus*.

MRSA strains may be carried by health personnel in the nose and spread via the hands to patients. Handwashing is the most important control measure, and special antiseptics can be applied to the nose to eradicate the bacteria. Elderly patients may pick up MRSA in a pressure sore and this can then be spread by district nurses who attend them.

MRSA infections usually have to be treated with intravenous drugs in hospital. These must be used with care if hearing or kidney damage are to be avoided. They are also expensive. These are the reasons why MRSA causes concern; infections with other strains of *S aureus* which are susceptible to antibiotics are just as harmful, but are easier to treat. MRSA now has other implications. Even if a patient is just carrying the bacterium on the skin or in the nose, rather than having an infection, some institutions may refuse admission. This is because MRSA can spread very quickly and there is fear of litigation if a patient 'catches' the infection.

If a serious MRSA infection occurs, treatment should consist of vancomycin, preferably combined with another drug such as rifampicin or fucidin if the strain is susceptible. Unfortunately, strains of MRSA which have developed resistance even to vancomycin are now being reported from Japan and USA.

Resistance is generally thought to be due to over-exposure of the bacteria to antibiotics in health care. However, there are other factors, such as the common use of antibiotics in meat and poultry production, which has been recognised as a very important source of resistant bacteria worldwide. In a recent survey of multi-resistant bacteria in hospital patients, we found that they were already present on patients before reaching hospital.

New drugs are being developed which might help, but history suggests that they will be short lived, and anyway this is probably not the answer. Prevention really is better than cure – or lack of it in this case. Professionals and carers must recognise the underlying risks which lead to infection in the first place, such as careless catheterisation or development of pressure sores. If infection does develop, prompt aggressive treatment avoids the development of chronic situations which may lead to antibiotic resistance.

● *Dr Bayston is Senior Research Fellow, University of Nottingham Medical School, and ASBAH's Honorary Consultant.*

MRSA: cause for concern – see p 30 for a letter from Mrs June Davies.

CSL's year-end profits go to ASBAH

ASBAH chairman, Godfrey Bowles,(left), receives the profits from Computer Sense chairman, Brian Henley, outside the company's offices in Hemel Hempstead

COMPUTER Sense Ltd handed over its end-of-year profits of £34,153 to ASBAH in a special presentation at the company's Hemel Hempstead offices.

The company, which is wholly owned by ASBAH, passes all of its profits to us by way of an annual deed of covenant.

This arrangement has the approval of the Inland Revenue and means that ASBAH can reclaim the tax on the profit – which will swell ASBAH's coffers by another £10,201.

John D'Arcy, managing director of Computer Sense, said: "We're a commercial company, working in a highly competitive environment. But the charity connection works for us. Many customers are impressed not only by the service we give them but by the fact that they are directly helping a very good cause."

Computer Sense has been trading from the Grovelands Business Centre at Boundary Way, Hemel Hempstead, for five years.

It was set up by ASBAH in order to provide income stream diversity as it faces tough competition for every pound from traditional sources.

Computer Sense employs 19 people and trades in all PC and Macintosh computers, offering highly competitive prices for hardware and software, complete system implementation, networking and repairs to all brands of PC equipment.

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

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.*

Regional meetings were a

ATTENDANCES at regional meetings to discuss ASBAH's five-year strategy, *2002 in Prospect*, gave a good opportunity for dialogue between local and national Associations, involving more participants than normally attend our Spring Council meeting.

Instead of members from a handful of local Associations travelling to Peterborough for the first of two Council meetings in the year, 19 local Associations were represented at the five mainland meetings held in May and June.

A total of 57 local Association members met Executive Director Andrew Russell and other staff at venues in Surrey, North Yorkshire, Greater Manchester, Bristol and Peterborough. Members of the national Association's Executive Committee attended all the regional meetings.

In addition, Mr Russell travelled to Northern Ireland and to Cornwall to discuss the strategy with local Association members in those areas.

The meetings achieved their purpose in communicating the strategy. The discussions were cordial, frank and revealed highly different concerns, interests and capabilities between Associations.

Local Associations were reassured that the strategy allowed national ASBAH to look with confidence to a future in which the Association continued to develop and manage relevant services for everyone with spina bifida and/or hydrocephalus.

Wide differences between Associations

LOCAL Associations range from those with just a handful of members, running perhaps a holiday chalet or an annual meeting, to full-service organisations with their own paid Advisers and fundraisers. Most fall somewhere in between.

At local level, the need for points of contact and referral for people with spina bifida and/or hydrocephalus and their families cannot be satisfied by national ASBAH alone. Local Associations will continue to play a vital role in this area, and do a great deal to publicise themselves locally.

Common themes were rising age-profiles on committees and the difficulty of recruiting new members – particularly disabled members – to committees, or even to events laid on for them. Long distances between centres of population accentuated difficulties in rural areas.

Fundraising was a major concern for most Associations, and there was a willingness to share details, both of successes and pitfalls. Lively debate arose, with no easy answers given, about whether or not to involve disabled people in fundraising events, such as street collections.

In the face of tough competition from other charities, some Associations (including national) had achieved successful bids for project funding from the National Lotteries Charities Board, resulting in the employment of additional project staff which we could not have otherwise afforded.

Local-National Communications

The meetings brought the need for regular, structured contacts between local and national Associations into sharp focus. There were clear indications that local Associations would welcome more face-to-face contact, particularly in areas not served by a resident ASBAH Adviser.

Regional co-ordinators undertook to facilitate such meetings, and where necessary to explore the most convenient venues for sub-regional meetings. In non-regionalised areas, national ASBAH should organise and facilitate such meetings.

The absence of a member of staff at national ASBAH with a specific remit to nurture relationships with local Associations was mentioned, and this will also be considered. The development of partnerships with national ASBAH on local lobbying issues could help inform national and add value to local campaigns on shortages in services and benefits provision, and there was a feeling that where possible these should be encouraged. However, many local Associations doubted whether they had the time or resources to run sustained local campaigns.

The work of the resident ASBAH adviser, where s/he existed, was much valued by local Associations. Joint local-national partnerships to secure funding from the NHS and local authorities for existing and new posts will continue to be promoted and, if local Associations have warm contacts in the statutory services, we should make a joint approach.

There was clear evidence that many local Associations would be happy to accept a lead from national on meetings, communications and publicity.

National ASBAH welcomed feedback from members generally on the contents of its *Link* and *Lift* magazines, and will include in its *Bulletin* to local Association secretaries material relevant both to local service-providers and fundraisers. The role of the Hydrocephalus Network within ASBAH needs to be better known.

There was scope to develop ASBAH's Internet web site so it reflected activities in the regions.

External policy matters

There was a broad consensus that national ASBAH services should

chance to talk

continue to be geared towards a perceived growth in numbers of young people with hydrocephalus (although statistics on this trend are not available), as well as towards a more mature population of people with spina bifida, and indeed towards the concerns of more elderly parents.

National ASBAH's services for new and prospective parents were held up as an example of good practice.

National ASBAH should continue to lobby to improve provision of state services and benefits. Identified shortages included adult clinics, consultants in rehabilitation medicine with specific interest in our field, inadequate educational provision, poor continence services and the NHS's failure to provide lightweight wheelchairs to all active wheelchair users.

The meetings again reminded all of us that there are many, many people with spina bifida and hydrocephalus who have grown up, and are living with parents on whom they are highly dependent for transport, a social life and many aspects of daily living. Families may be anxious about the future and may need information and help to access services. Local Associations and ASBAH Advisers do a great deal to help, but more information and publicity may be needed on this so that the individual, the family, the statutory services and ASBAH can work together for the best.

National ASBAH will provide as much independence training as possible, particularly for adults who need to become more independent as they get older. National ASBAH has long recognised the shortage of meaningful alternatives to work for a growing population of adults with the disabilities, an area with which both local Associations and *Your Voice In ASBAH* (national's disabled member forum) were much concerned.

While ASBAH could not afford to duplicate the work of Government agencies and other charities in the provision of employment services and job placements, it will continue to network with these organisations in order to get the best services for members. Whenever possible, National will also lobby for improvements in this area, for example in our recent response to the Government Green Paper on Welfare Reform.

Several local Associations who have had no contact with the forum of disabled members, *Your Voice In ASBAH*, were sceptical about its potential to reverse a decline in membership. Those who had been involved with *YVIA* recognised it did attract disabled members and this was useful to them.

The *EastEnders* TV series, with its spina bifida pregnancy televised in November, was much discussed. The reaction was mixed: congratulations to national ASBAH, for achieving a continuing spina bifida storyline on a TV soap watched by millions, and strong condemnation for failing to achieve a more positive portrayal of disability. We at national ASBAH have determined to learn from the experience and to continue to advocate a strong message about people with disabilities, their great contribution to society, and their right to participate to the full.

Summary

The meetings were generally well-attended and there were very constructive discussions, emphasising the need for regular exchanges between local Associations and national officers. The Spring meeting of ASBAH's Council was suspended by the Executive Committee earlier this year, a decision to which two Associations objected. However, most felt that 'regionalised' discussion is, for the moment anyway, a better alternative and that national ASBAH was right to put effort and resources into this format. The Executive Committee will be considering the outcome of these consultations, including the level of information and support given by national ASBAH to local Associations.

Reprieve for Atkinson Morleys extended

A DELAY in completing the necessary consultations over the future of the children's neurosurgical service at Atkinson Morleys Hospital means that a reprieve is likely to be extended beyond the end of September. But for exactly how long is not clear.

A spokeswoman for South Thames NHS Executive said their review group set up to consider where to base the region's paediatric neuroscience service had not finished its work.

The group is likely to make a recommendation at any time which will then be discussed widely with parents, doctors and other interested parties before being refined to become firm options – which will then be put out to formal consultation if any change is proposed.

The two trusts being considered to provide the service are St George's NHS (which runs Atkinson Morleys Hospital) and Kings Healthcare NHS, both in south London.

A decision to close the service earlier this year was withdrawn after the parent-led group Hospital Action Group threatened a High Court challenge.

Hospital Action group member Mrs Gill Farrington, whose daughter Kirsty has had 11 operations at Atkinson Morleys to revise her shunt, said parents were still hoping for a decision to keep the service based where it is.

● ANDREW Clark, who died when he was 11 years old, has inspired other members of his family to raise thousands of pounds for ASBAH over 30 years.

Since Midland ASBAH sadly folded more than two years ago, the fruits of their fundraising gone to national ASBAH.

Mother, elder brother, sister and father have each, in turn, taken part in the Leamington Spa Mayor's Walk every year since 1968, when Andrew, who had spina bifida, was three.

His father, Ted, a former vice president of Midland ASBAH and a retired lecturer, has been joined by Ian Locke, a colleague at Mid Warwickshire College, in the Mayor's Walk in aid of ASBAH.

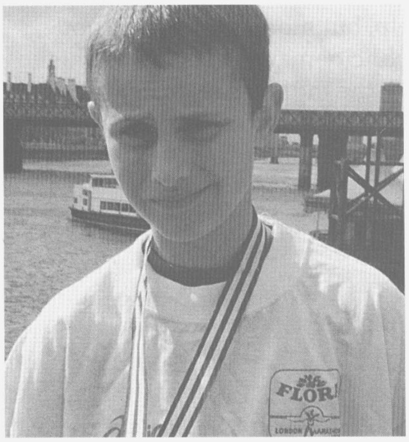
And his mother, Joan, raises about £250 for ASBAH by selling Webb Ivory Christmas cards and goods.

Elder brother, Jon – now married and living in Sheffield – has been continuing the family tradition by running the Sheffield Half Marathon for ASBAH.

Jon *(pictured right)* said: "I raised more than £300 for ASBAH this year, which brings my total to almost £1,000 over the years."

Of the run itself, Jon commented: "I was quite happy with how I did this year – I ran the 13 miles in one hour 39 minutes, which was within my psychological one hour 40 minute time barrier."

OTHER entrants to this year's Flora London Marathon who offered to raise money for ASBAH were: Lucy Stevenson, from London; Phil Robinson from Sleaford, Lincs; Amir Bhati from Ilford, Essex and Mr J W MacLean from Gloucester.



● THIRTEEN-year-old Andrew Hunter ran the London Mini Marathon for his baby sister Katie, who died with a severe form of hydrocephalus 14 years ago.

It was his mum, Sally, who first came up with the idea of Andrew raising money for a charity which was close to the family's heart. Andrew thought it would be a great idea.

A member of the Havering Mayesbrook Athletics Club, who trains twice a week at a track in Barking, Essex, Andrew was selected in trials at Hornchurch to enter the highly competitive Mini Marathon.

Mrs Hunter said: "The day of the run was quite near Katie's anniversary, so I thought it would be a nice thing to do for her but, obviously, it had to be Andrew's choice.

"I don't feel Katie should ever be forgotten and I thought it was lovely that we could do something for her."

At the time, the family were not aware of ASBAH so they tapped into Ceefax and then the Internet to track us down.

Once they had our phone number, they were able to gain the support of our appeals department and could begin to collect pledges of sponsorship money in earnest.

When the big day arrived, Sally and her husband Paul travelled from their home, in Collier Row, near Romford, Essex, to see Andrew compete in the 11-13-year-old boys section of the Mini Marathon, which is held on the same day as the Flora London Marathon.

Mrs Hunter said: "It was a tremendous event – the atmosphere was brilliant – and it was great for him to be a part of it. He got a lovely medal at the end."

His parents were justly proud when Andrew finished 75th out of 339, raising £268 for ASBAH.

● GILL Daly expects to raise £1,000 by running the Flora London Marathon after tapping people at work, friends and family for sponsorship.

It was the first time the 33-year-old BT human resources worker had ever run a marathon. She ran it with both her brothers, her sister and her boyfriend, though each of them finished at different times.

Gill, of Clapham, London, chose ASBAH to support as her cousin, John Wilkie, has spina bifida. She completed the distance in five and a half hours.

"I don't know that I will ever do a marathon again because the training required does take over your life. But it's a good feeling to be able to tell people you've done it."

● TONY McVaddy was spurred on to support ASBAH by running the London Marathon by his young nephew, George, who has spina bifida.

ASBAH has given practical help to George, from Camberley, Guildford, in a number of ways.

This year's 26-miler through the capital was the first marathon Tony had entered and he took four and a half hours to complete it.

"It was a very enjoyable event. I was determined not to make it gruelling so I went at a steady pace," said Tony, aged 33, from Little Baddow, Chelmsford, Essex. "They look after you well with drinks etc along the route."

He raised £370 for ASBAH.

Marathon thanks

APRIL 26, 1998 was a day of achievement for eight men and women, and a teenager. For some, it was the first time in their lives that they had run a marathon – a momentous 26 miles. And they all agreed to do it for ASBAH. [illegible]z Cawthorne reports

Louise Mackeson-Sandbach raises her fists in triumph after completing the Flora London Marathon. She raised £1,300 for ASBAH

● MONTHS of self-motivation and hard work that went into training for the London Marathon certainly paid off for Louise Mackeson-Sandbach, who raised £1,300 for ASBAH.

Louise, who lives and works in London, says she was pushed on by the enthusiasm and support of the crowd, in a day which she describes as 'brilliant.'

But, what with the long period of training required, and the necessity of motivating herself to go out for a run after work, often after dark, she doubts whether she will enter another marathon.

"It was a great day but I am not a runner by nature, so it was the enthusiasm of others that kept me going.

"When I was feeling tired, people in the crowd I didn't even know would call out the nickname on my shirt and shout 'come on' and this would pick me up and start me running again."

Louise, who works for a management consultancy, chose to raise money for ASBAH because she had heard of the good work that we do.

She completed the 26-miler in about four and a half hours.

● REGULAR marathon runner Phil Spicer was inspired to raise money for ASBAH after hearing about the son of a friend at work.

Fourteen-year-old Martin Sandal, who has hydrocephalus, excels at swimming and athletics.

Martin has won trophies and medals for swimming with his local club, the Swansea Otters, and by entering races as an individual. He also enjoys athletics, usually coming in the top three in school races at Olchfa Comprehensive in Swansea.

"Martin is very competitive," says his mum Carmella. "He loves sports, including football, but he knows his limits."

With 14 marathons already under his belt, Phil ran the Big Sur in California in April – which was voted as the top marathon in North America, due to the attractive route and the friendly organisers – all classical music buffs.

Despite the course being re-routed inland due to part of the usual route being washed away by El Nino, it was still very scenic and runners were entertained by classical musicians along the way.

The start and finishing point was Carmel – whose claim to fame is that Clint Eastwood was once its mayor, and where the acting giant still owns a bar and restaurant.

Phil said: "I'd thought about doing the Big Sur for six years but I had to choose the year in which the road had disappeared! But the new route was still very scenic."

Phil's 16-year-old son, Gareth, accompanied him on a six-day trip to the States, which also included visits to San Francisco and Los Angeles.

Phil took four and a quarter hours to complete the run – with time to stop and take photos – and raised £301 for ASBAH.

Elin looks ahead with a Life Plan

YOUNG people's fear of the future and their inability to voice their concerns with parents/carers spurred an ASBAH adviser to find a solution.

Several young people had told North West Wales adviser, Elin Richards, they were worried about what was in store for them. Even worse, they dared not tell the people closest to them for fear of upsetting them. Carers, separately, also voiced similar anxieties.

Elin said: "It seemed very obvious that there had to be a way of breaking down these barriers and it seemed that an outside organisation, such as North Wales ASBAH, could act as a bridge to initiate discussion."

A questionnaire was drawn up by Elin and a trained counsellor and carer, Doris Morris, to find out if these concerns were common to other members of the association. The response was overwhelming, revealing a real need for open discussion on issues that had previously been considered taboo.

So a discussion day was arranged, attended by 30 carers and professionals. The aim was to come up with some ideas for a written plan of each individual's needs and wishes for the future. This became known as a *Life Document*.

Why do we plan for the future?

Peace of mind to both carer and dependent were considered to be the bottom line by participants of the discussion day. Taking the 'burden' of care away from other family members was another important reason for writing a personalised plan.

Concern was expressed about the fate of a young person if their carer became ill or died. Carers at the meeting felt that the dependent should have a say in their future – even if the choice was limited.

What should be covered by a *Life Document?*

The following areas were highlighted during the discussion day:

- What are the choices available in the community for housing.
- How to handle financial affairs to the best advantage of the dependent and siblings.
- Medical procedures.
- Who has a statutory responsibility for care?
- What role does Social Services play in the provision of care? The discussion group felt that the needs and preferences of the dependent should be spelt out, since both their health and welfare could be at risk if their new carers did not know the smallest details of daily routines.

Discussion group facilitator, Catherine Grimshaw – a solicitor specialising in disability rights issues in Lancashire – stressed the importance of a written plan, such as the *Life Document*. Whilst not legally binding, the British Medical Association considered that a written plan "would be considered with consideration and respect."

Difficulties in drawing up and implementing a *Life Document*

- Fear of acknowledging the future should the dependent outlive the carer.
- Not knowing how to start a discussion.
- Lack of time to deal with these issues.
- Lack of financial resources of Social Services departments and not knowing who to approach – this could be solved by lobbying the local authority to allocate more money for community care. If there is lack of choice in housing, you could present the need to your local authority.
- Fear of upsetting the dependent and, in some cases, other family members, even partners.
- Ignorance of how binding/enforceable is a life document. A solution to this would be to try to make your *Life Document* legally binding.

Elin commented: "It was concluded that, however upsetting the process of making a written plan, it is important to tackle the issues in order to achieve the eventual goal – peace of mind."

AT A GLANCE

What is a *LIFE DOCUMENT?*

It's a plan for your future when your carer is unable to look after you.

It tells people about your needs/preferences in:

- housing ● daily routine/diet
- medical treatments/services
- money ● social life ● transport
- any other information you want to include.

You can write each of the above headings at the top of a separate sheet of paper, giving you space to write as much as you like.

Your *Life Document* can be kept in a folder, so you can change the details of eac¡h page as your needs change.

Find out more from ASBAH adviser, Elin Richards, on 01407-840927.

Link cover girl now dancing queen

EIGHTEEN years after being written off by doctors because of her spina bifida and hydrocephalus, Ann-Karin Smith is winning gold medals in national competitions as a wheelchair dancer.

When Ann-Karin was just four years old, she was pictured enjoying the Norwegian snow, with her parents and sister, on the Christmas 1984 *Link* front cover. Inside that issue was reported Ann-Karin's remarkable progress during her first year of life, despite the fact that doctors had felt it kinder to leave untreated her hydrocephalus and spina bifida.

Ann-Karin's family moved to settle in her mother's native country of Norway when she was two months old.

Even in those first few months of life, Ann-Karin showed herself to be very tough and determined, and to have a delightful personality – traits which have continued to show themselves as she has grown up.

In June, she and her able-bodied partner Tor Erik won the Norwegian wheelchair dancing national championships. The pair also clinched a gold medal at the Swedish national championships and got through to the semi-finals of the European championships, which were held in Sweden in September.

Ann-Karin's grandfather, Tony Smith, from Huby, near Leeds, is extremely proud of his granddaughter and hopes her story will inspire other parents and youngsters with spina bifida and hydrocephalus.

He said: "Ann-Karin is progressing well in her schooling, and she hopes eventually to take up a career associated with medicine.

"Encouraged by the Norwegian Spina Bifida Association and fired by her own enthusiasm and ability, she enjoys a wide range of physical activities, winning medals for various sports including slalom, rifle-shooting and archery.

"She has developed a well-rounded personality, becoming increasingly independent and not afraid of tackling any challenges which come her way.

Ann-Karin and her dancing partner Tor Erik

"We hope this article may provide encouragement for parents of other children with spina bifida, particularly in view of the very gloomy prognosis given by the medical folk after her birth 18 years ago."

Problem Behaviour

ASBAH study day to explore practical strategies for real problems.

NSPCC Training Centre, Beaumont Leys, Leicester

Monday 26 October, 9.30–4pm

Speakers include: Jacky Lucas, NSPCC Disability Worker, Northampton; Bob Johnson, Community Psychiatric Nurse, Learning Disability Team; Mike Dodd, ASBAH specialist adviser (education).

Parents: £15; voluntary organisations £25; professionals £35.

Booking forms (returnable by 21 September) from: Rebecca Sewell, ASBAH Eastern Region, 42 Park Road, Peterborough, PE1 2UQ. Tel: 01733-555988.

ASBAH Information Day

The Silverthorne Building, Bishop Road Primary School, Bishopston, Bristol

Saturday 26 September

Speakers include:
Mr Ian Pople, consultant neurosurgeon, Frenchay Hospital, Bristol; Julie Llewelyn, ASBAH specialist adviser (medical/continence); Lizzie Jenkins, Scope.

Attendance fee, including buffet lunch: £3 per family member/disabled person; £6 professionals.

Details from: Julie Knight, ASBAH Adviser, 45 Nevil Road, Bishopston, Bristol BS7 9EG. Please confirm your place(s) by Friday 4 September. Cheques payable to ASBAH.

ASBAH Family Weekend

The Pioneer Centre, Cleobury Mortimer, Kidderminster, Worcestershire

Fri 30 Oct–Sun 1 Nov

Residential for families with a child aged six and under with hydrocephalus and/spina bifida, and their brothers and sisters.

● A chance to learn more about your child's disability. ● What place has therapy in your life? ● Children's programme – ASBAH staff will look after your children; ● Time to relax and meet other parents.

Cost: £50 per family.

Details: Lynn Thomas, ASBAH House, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988. Please let Lynn know by 21 Sept if you wish to attend.

Tina gains the edge with her Whizz-Kidz wheelchair

SIXTEEN-year-old Tina Morgan *(pictured above)* is the envy of her school friends as she has a fluorescent pink Quickie wheelchair, with black and pink wheel trim, given to her by Whizz-Kidz.

Having her friends' approval has meant that Tina's self-esteem has rocketed and, on a more practical level, it has given her the freedom to wheel off around town and to play sports.

whizz-kidz

THE MOVEMENT FOR NON-MOBILE CHILDREN

Tina, from St Austell in Cornwall, has been lucky enough to have two wheelchairs from Whizz-Kidz since she started needing more help with her mobility eight years ago.

Her parents applied to Whizz-Kidz for the latest £1,300 chair, helped by their ASBAH adviser, Lynne Young.

Tina's mum, Lorraine, said: "It was reasonably easy to apply although we had to wait a while for the money to come in to Whizz-Kidz from the London Marathon.

"Tina's first chair was a Marshall Mark 4 and when she outgrew it, five or six years later, we applied to Whizz-Kidz for another one which best suited her needs.

"The chairs she has got from Whizz-Kidz are so much better than she would have received from the NHS. Tina plays basketball and has found having a lighter chair really good for getting around school.

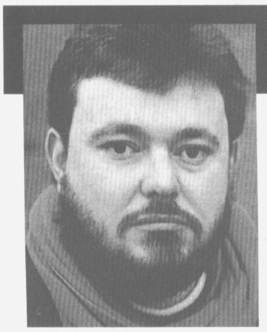
"The best she would have got from the NHS would have been a Remploy Roller. With NHS chairs, you can't modify the wheels to give better manoeuvrability and speed."

Tina's Quickie has been adjusted so that it is a good all-rounder – allowing Tina to play wheelchair basketball, go into town and be a productive member of the team as goal shoot in netball at school.

Other activities Tina has tried in her lighweight chair have been abseiling at a local leisure centre, orienteering and river speed boating.

Mrs Morgan said: "It gives her an edge having a Quickie and has helped her self-esteem. Her friends really love it and are quite envious of her having such a flashy chair. It is something to be proud of rather than ashamed of."

Funds for film-makers *by Paul Darke*



I, as co-ordinator of West Midlands Disability Arts Forum (WMDAF), have been running the National Disability Film and Video Project.

For the first time, since being set up by the Arts Council of England five years ago, this project was run by us at WMDAF. It is all about funding and developing disabled film and video artists who use the medium of film and/or video creatively in synthesis with the subject matter of the experience of disability.

This year, the selection panel awarded three production awards ranging from £2,500 to £19,000, and five research and development awards of £2,000.

A surprising number of applications for R&D awards were from beginners and experienced film-makers.

Projects varied considerably – from original computer animations and creative videos on the history and experience of deafness, to a number of films using water as a metaphor to show how disability can be equalised and to give contrast between calm and destruction (swimming/the sea, etc).

Unfortunately, far too many applications were either outside the criteria or somewhat speculative. Projects must be clear in their creative vision and proposed use of subject and medium. Even the R&D applications must have some idea of what the subject, form and content might be.

More work had to be done before some applicants even considered applying. This was especially true of groups who applied with learning difficulties. The project is very keen to fund the right learning difficulty project and, hopefully, more work, advice and input will create it in the future.

The kind of impairments explored in applications was across the spectrum of disability: deafness; visual impairment; paralysis; mental illness, etc. If the idea was good, the way it was to be explored creative, and if the use of the medium was original, it was funded.

Over the years, there have been hundreds of applications, yet only a single spina bifida specific project. I look forward to receiving one next year from you.

If the project runs again next year, as we hope it will, and you would like to receive an application pack, please write to me c/o Link.

Whizz-Kidz helps our kidz

DUBBED the UK's fastest growing children's charity and the largest supplier of mobility aids for children outside the NHS, Whizz-Kidz is quite a success story.

In eight years, it has grown from two men raising £9,500 to buy a single wheelchair for one child, to a multi-million pound fundraising organisation, employing 25 people.

In 1998, Whizz-Kidz aims to raise £4 million and buy mobility aids for 1,200 children aged from 0–18 years.

Although the charity helps children with a wide range of disabilities, last year 10% (41) of those assisted had spina bifida and/or hydrocephalus.

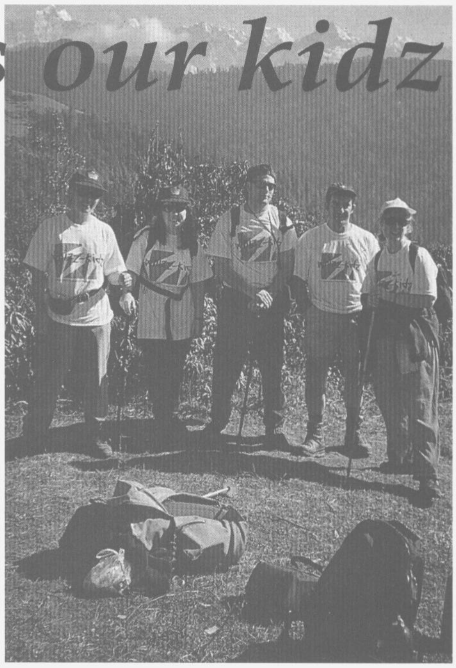
Communications director Sarah Molony said: "Whizz-Kidz receives applications for a variety of mobility aids, including trikes, buggies, walking aids, powered, lightweight and specialised wheelchairs.

"Every child who applies to Whizz-Kidz is assessed by occupational therapists and physiotherapists to ensure they receive the most appropriate equipment and there is emphasis, too, on providing a comprehensive aftercare service."

As the examples on these two pages show, the charity is able to provide the sort of wheelchairs not available from the NHS to ASBAH families who could not afford to buy the same equipment themselves.

All the money spent by Whizz-Kidz comes from voluntary donations – either from individuals or corporate giving from schools, universities, companies, associations and trusts. High profile sponsored events – like the London, New York and Dublin Marathons – are the most usual way that individuals raise money.

There are also special 'challenges' organised by Whizz-Kidz.



In February, the Whizz-Kidz Himalayan Challenge raised £500,000 *(see photo above)*. This summer, 150 adventurous trekkers will be taking part in the Whizz-Kidz Icelandic Challenge – a nine-day 100km trek through spectacular scenery.

- Any parent who would like to register their child for a Whizz-Kidz mobility aid is advised to ring *first thing on the first Monday of the month on 0171-233 6600*. Names are taken on a first come, first served basis. The first 50 children to be registered at this time are put in line for an assessment to find out which type of mobility aid will be most suitable for them, and then go on to receive it.

Shaun's a whizz around the court

TEENAGE basketball player Shaun Newitt's game has much improved since receiving a £1,350 sports chair from Whizz-Kidz.

The 18-year-old struggled to keep up with the rest of the team in his NHS chair until he was told about the charity by his basketball coach.

So he phoned up Whizz-Kidz for an application form and, after having had an assessment, it was only a few weeks until he received his RGK Quatro chair.

Shaun, of Plymstock, Plymouth, Devon, said: "It was really good that Whizz-Kidz was able to help.

"It was harder to play basketball using my existing chair. There's a big difference in handling – the new chair is much lighter and easier to turn so I can keep up with the rest."

Custom-built in his team's colours of purple and yellow, Shaun practices and competes in the chair with the Plymouth Buccaneers – who are currently second in the league, South-West division.

He also uses the chair to take part in a local annual half marathon.

For every-day activities, including work, Shaun uses his NHS chair. He is currently doing a one-year training scheme which involves servicing NHS wheelchairs.

whizz-kidz

THE MOVEMENT FOR NON-MOBILE CHILDREN

LINK COVER STORY

LUCKY Louise Hunt received a smashing new £1,800 sports chair from Sir Cliff Richard at Wimbledon.

The seven-year-old, from Wanborough, near Swindon in Wiltshire, was presented with the special chair by the singing star, on behalf of the charity, Get Kids Going. Sir Cliff is also a regular supporter of ASBAH.

As well as meeting Sir Cliff, Louise relaxed in the Members' Lounge and saw Pete Sampras and Monica Seles in action on Court One.

Louise, who has been playing tennis since she was five, said: "It was really exciting. I thought Cliff Richard was really nice."

Her mother, Linda, added: "Louise loves tennis but is not up to Wimbledon standard. She's very much at the learning stage. If she gets a three-shot rally, we're over the moon!"

Mrs Hunt contacted Get Kids Going after Louise attended a tennis convention where most of the children had sports chairs.

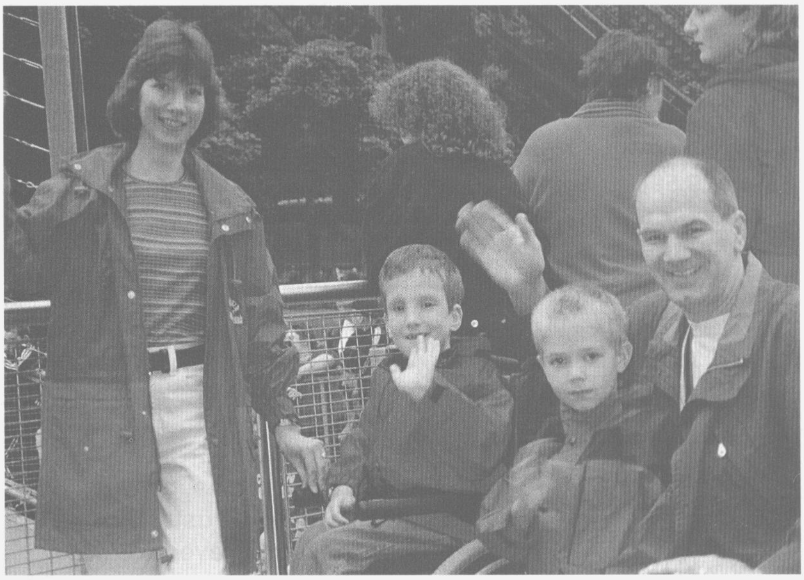
She said: "Many of the children had been loaned their chairs by charities and as soon as we got home I started writing letters."

Director of Get Kids Going, Jane Emmerson, said: "We were thrilled when Louise's mum wrote to us. We only formed the charity nine months ago and this is the first wheelchair we have ever bought."

Louise attends weekly coaching at the Delta Tennis Centre in Swindon and has entered two competitions in Nottingham, organised by the Lawn Tennis Association.

As well as playing tennis, she enjoys playing the piano, horse riding and swimming.

The viewers got up



DOZENS of A
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The organisers a
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Nicholson, who t
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A special menti
Proud, Alexandra
Matthew, Simon
part in the appeal

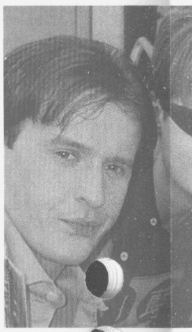
PHOTOS SHOW:

above – Greetings from the Norton family, of Somerset;

top right – The main arena, seen through the Oblivion ride pit;

immediate right – ASBAH appeals manager Donna Treanor, with ASBAH adviser Liz Henshall and her toddler;

below – Mr Motivator takes visitors through their paces.



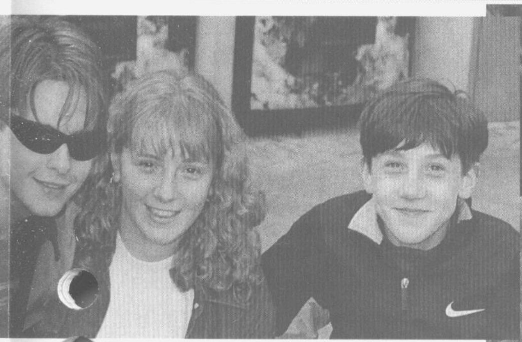
and gave!

ASBAH members and staff lves into a celebrity-studded la on breakfast television. For ly, ASBAH was one of five ies selected to be in the fourth *Get Up and Give* Appeal.

are quietly confident that they l last year's total, when each ed £141,000. The total figure nnounced in September.

yone who helped – from David o travelled to London from his eth, to the telesales team who one morning to BT Tower.

ntion to the families of David dra Howard, Ellemay Pittam, and n and James Bottoms who took eals films.



For 15-year-old David Proud, who starred in one of the appeal films, and his older sister Dawn, the visit to Alton Towers was a day to remember.

They got to meet top boy band '911' (above) and the production team sneaked in an exclusive interview for David with his favourite telly presenter, Fiona Phillips.

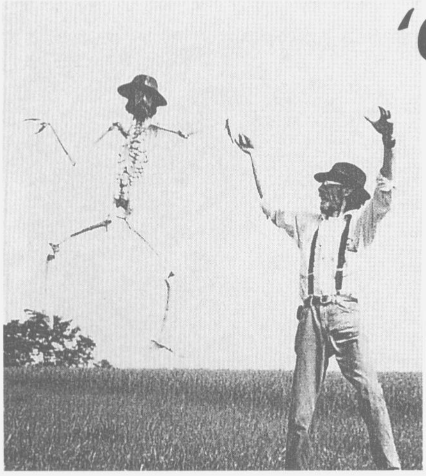
"It was a brilliant day," said David (seen right with mum Wendy, dad Tony and Dawn).

Dawn and David meet boy band

A DAY OF FUN FOR ASBAH AT ALTON TOWERS

GMTV Get Up & Give

'Charlie' exhibition takes off



Peter Kiddle and 'Charlie' – one of the photos of Peter's work currently touring the United States

A DISABILITY arts project, which features photographs of a flying cardboard skeleton called Charlie, attached to a pair of helium balloons, is now on tour in the United States.

Artist Peter Kiddle joined forces with his friend in the United States, Karen Watts, to put on their In/Valid exhibitions on both sides of the Atlantic (*Link* No 172).

Peter received funding from his regional arts board to take the first stages of the project further – enabling him to improve the quality of the work already completed, and to embark on a couple of new pieces.

Peter, who has spina bifida, has now also secured a grant to glaze and frame work already completed, which is due to be exhibited in the next US tour.

Meanwhile, Peter and Karen are looking at the possibility of having two copies of everything, so that they can run two exhibitions at the same time in England and the US, as the project grows.

Peter commented: "The experience of being interviewed about grant applications, and the reactions from people looking at the work that Karen and I have done so far, has been a real eye-opener!

"I was really surprised at the way our work is viewed by some. The project has been seen as an act of 'therapy', and there are so many connotations carried by that word, I've found.

"The kind of therapy our work is about is difficult to define as we are trying to work with words (communication) and visual imagery (expression). Using both words and visual imagery, we find ourselves in fierce debates about what is 'expression' and what is 'communication.'"

Peter wants to talk to other disabled artists about these two concepts and hopes to bring them into the project with a series of photo-interviews in dialogue with him and his ventriloquist's doll – transposing faces between images, himself, the doll and the interviewee.

● ***To contribute to In/Valid, contact Peter Kiddle at Boreston Foot, Halwell, Totnes, Devon TQ9 7LD. Tel: 01548-821381.***

Looking good, feeling great in North Wales

By Jill Bartlett

NINE ASBAH service-users came together to enjoy and experience different activities at the national watersports centre at Plas Menai, North Wales.

The first evening kicked off with some welcome ice-breaker sessions, so everyone learnt a little bit about each other. After the evening meal, we had an excellent talk about aromatherapy and its uses. Two people had a face massage, leaving us all suitably relaxed and looking forward to the next day's activities.

A lot of chatting was done in the bar that evening where we met the duty manager for the following day, who strove to put us at ease regarding the water sports!

After breakfast the next morning, we met the instructors who were to help us with the climbing and abseiling. A few worried faces were to be seen but most people enjoyed the experience and some even managed to look down from the top of the climbing wall!

The Welsh weather smiled on us in the afternoon and we managed to sail and speedboat without getting too wet! Some members had the opportunity to drive the speedboats. Despite wanting to head off for Ireland, they were persuaded not to and made a safe return to shore!

After an exhausting day, a workshop was held on relationships and contraception and a discussion developed on personal relationships.

Afterwards, we met in the bar and a pool tournament, lasting until the early hours, was a great source of entertainment to all!

There were a few bleary eyes on Sunday morning but, after breakfast, Beverley Rowe, a member of *Your Voice In ASBAH (YVIA)*, gave an interesting talk on her involvement in *YVIA* and what it had done for her. The seed has been sown and we'll be asking for more information to see what it can do for us here in North Wales.

This session was followed by a small taster on assertiveness training which opened up some lively debates. This was a successful session with everyone asking for more.

After lunch, we said our reluctant farewells with choruses of 'when can we do this again?' as we departed for our various destinations.

Without exception, we all enjoyed the weekend and were pleased it had been so successful.

We are very grateful to North Wales ASBAH for part-funding this weekend and to the very capable volunteers.

We are looking forward to holding a similar event again in the future.

● ***Jill Bartlett is ASBAH project worker for North Wales. Her three-year post is funded by Comic Relief.***

HYDROCEPHALUS NETWORK NEWS

ASBAH, 42 Park Road, Peterborough PE1 2UQ
Tel: 01733 555988 Fax: 01733 555985
Internet Web Site: http://www.asbah.demon.co.uk/
Reg Charity Number 249338

Autumn '98

Children's behaviour – comparing mums' and teachers' views

By Jane Williams

IT WAS with great reluctance that I resigned from ASBAH in 1993 due to family commitments.

I embarked on a psychology degree and when, in my final year, I was required to do an original piece of research, I had no problem deciding on the content.

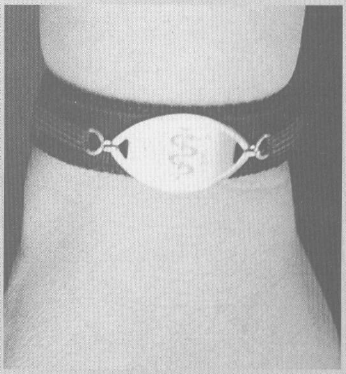
My work at ASBAH gave me the interest, information and support to undertake a study of children with hydrocephalus. I am indebted to the families that agreed to take part and for their enthusiastic participation.

The title of my dissertation was *Mother and Teacher Reports of Behaviour and Perceived Self Competence of Children with Hydrocephalus.* I was interested to see if the teacher's view of the child's behaviour was different from that of the mother. Also, whether the children with hydrocephalus viewed themselves as different from their classmates and, finally, whether the mothers saw themselves as in control of their lives. In addition, I asked the mothers questions about parenting issues related to hydrocephalus.

I interviewed 14 children with hydrocephalus and 14 children without hydrocephalus. This allowed me to do a statistical analysis comparing the two groups of children. This is what I found:

- Children with hydrocephalus did **not** have poorer self esteem than other children although they did rate themselves as less physically able.

continued on page 2



THE NEW MedicAlert bracelet *(pictured above)*, has a fabric strap rather than a metal chain. It offers emergency identification for people with hidden medical conditions.

Having received a grant from the National Lottery Charities Board, MedicAlert is able to provide FREE membership and stainless steel emblems to those people receiving any form of limited income, eg any form of supplemented income, disability allowance or pension. This includes the sports bracelet pictured above. Usual lifetime membership is £30.

For more information, telephone FREEPHONE 0800-581420.

HNN contacts

Network Co-ordinator: Rosemary Batchelor 01733-555988.

Education (National): Petrina Noyes 01733-555988.

Medical (National): Julie Llewelyn 01733-555988.

Medical/Continence, (Eastern Region): Paula Thompson 01733-555988.

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

Education (North): Mike Dodd 01484-510202..

Medical (North): Sue Ingham 0113-255 6767.

Education (Northern Ireland): Lorna Johnston 012477-72191

Medical/Continence, (Northern Ireland): Marie McGonnell 016487-64748.

Hydrocephalus (Northern Ireland): Lorna Johnston 012477-72191.

User-group forum co-ordinator (England & Wales): Jon Burke 0113-255 6767.

User-group forum project worker (Northern Ireland): Helen Clarke 01396-881898.

ASBAH's Hon C onsultant on Hydrocephalus: Dr Roger Bayston MMedSci FRCPath, contact through ASBAH's Services Dept at ASBAH House.

Children's behaviour – comparing mums' and teachers' views, *from page 1*

- Children with hydrocephalus were reported to show more behaviour problems compared to other children. In my study these were both internalising behaviour (eg withdrawn, feels she/he has to be perfect) and externalising behaviour (eg argues a lot, destroys things belonging to others).
- Mother and teacher reports of behaviour did **not** agree.
- Mothers of children with hydrocephalus were more likely to feel that life was out of their own control than the other mothers.

It should be remembered that my study involved only a small number of children and it is, therefore, difficult to draw conclusions.

However, there are a few points from this that it would be interesting to look into further.

Why do mothers and teachers report differently regarding the children's behaviour? This could be that there are differences in the attitude of the adults or that the child behaves differently at school or at home.

What are the nature of behaviour problems? In this study the children were said to have both internalising and externalising behaviours, although in previous studies behaviours have been said to be externalising.

Why do mothers of children with hydrocephalus feel they have less control over their lives? Is this the result of raising a child with a disability?

Whilst doing my study, I was impressed by the feelings expressed by the mothers during the interviews. This is an area that previous research has sadly omitted due to the difficulty in quantifying data. However, there has more recently been an acceptance that such information is equally important as fact and figures.

I hope to develop this part of my study and present the findings at the next meeting of the Research Society for Hydrocephalus and Spina Bifida in Sheffield in 1999.

JANE Williams worked as a disabled living adviser with ASBAH until October 1993 and then took a BSc Hons in Behavioural Sciences, gaining a II (i) in 1997. She is presently working as a nurse with men with learning disabilities and challenging behaviour.

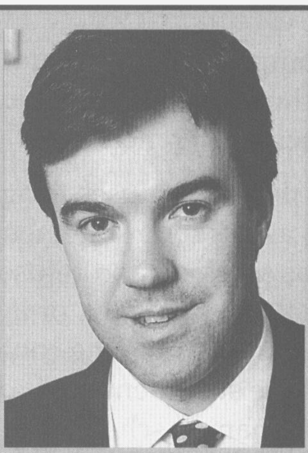
Her study, *Mother and Teacher Reports of Behaviour and Perceived Self Competence of Children with Hydrocephalus*, was extremely well received when she presented it at the June meeting of the Research Society for Hydrocephalus and Spina Bifida in Genoa, Italy.

Why a statement could be important for your child

By Michael Imperato

FOLLOWING his article in *HNN* last year, Michael Imperato *(pictured right)* received several telephone calls from parents who seemed surprised when he informed them that the first step in all educational matters with children with special educational needs is to obtain a statement, which means that they could set the ball rolling themselves.

This time around, Mr Imperato – a solicitor specialising in education in Cardiff – explains how and why you should obtain a statement for your child.



THERE was a time when the term 'statementing' was synonymous with failure. A statemented child, it was widely believed, must be a problem child and unruly and stupid.

In fact, a statement is a passport to resources and help far beyond what a school could provide on its own. Parents should be looking to statements if there is the slightest suspicion that their child is under-performing.

A statement has been compared to a doctor's prescription and diagnosis. It should identify what the child's educational needs are, and what steps and resources are needed to meet them.

The local educational authority (LEA) then provides extra resources to the school to comply with the statement. If the child needs extra teaching support or computer equipment which the school cannot afford, this should be provided by the LEA if recommended in the statement.

There are five stages to go through before getting a statement – from a child being identified as having special educational needs (SEN) through to assessment by the LEA, to provision of a statement. Parents should be closely involved in all stages.

The trigger for invoking stage one is the expression of concern that a child is showing signs of having SEN. The child then usually moves to other stages upon review. However, if it is felt that the need is very great, the child can go straight to the higher stages, such as assessment for a statement (stage four).

If nothing is being done, parents may initiate the process themselves by requesting the LEA to carry out an assessment for a statement. This sets in train a strict timetable, the first part of which is that the LEA has six weeks to decide whether to meet the parents' request and undertake an assessment.

The timetable from start to completion of a statement should take 26 weeks but, in practice, it usually takes much longer.

A child is never too young to have a statement. Parents may request an assessment for a child of less than two years of age. The problem at this age, though, would be that there is less evidence to fully identify the child's SEN, but there will always be exceptions.

Whilst a statement is being prepared, parents can express a preference for a particular school to be named for their child in the statement. If the LEA does not agree with the choice, the onus is on them to prove why it is not appropriate. If the parents' preference

continued on page 4

Why a statement could be important for your child, *from page 3*

is for a private school, then the onus is on them to justify it and they would have to ensure that they have compared it with state schools and can fully justify their preference.

If the LEA refuses to agree to assess for a statement, or has assessed and refused to make a statement, or if there is dispute over the contents of the statement (including any named school), the dispute can be resolved by taking the matter to the SEN Tribunal *(see article by ASBAH's former specialist adviser (education) Peter Walker,* Link *No 169, April 1997).*

Children only have one 'shot' at education. If you believe that your child is not getting the support needed, you can do something about it by invoking the statementing procedure. It can be the key which unlocks the door to the resources that your child needs.

● ***Michael Imperato is a solicitor at Russel Jones & Walker, tel: 0117-927 3098. Although previously based in Bristol, he is due to move to the firm's new office in Cardiff in August.***

Foreign holiday-makers beware

IF you are going on holiday abroad, check your health insurance to ensure that it has a 'fly home' clause in it.

A Medivac flight from the continent will cost you about £5,000, if you are not covered. Note that an E1 11 form only covers you for medical treatment in EC countries – it does **not** cover repatriation.

If your insurance does not include a 'fly home' clause, ASBAH's information officer, Gill Winfield, will find an insurance company that should be able to help you. Tel: 01733-555988.

Changes to the Benefit Integrity Project

A REVIEW to find out if people are receiving the correct amount of Disability Living Allowance (DLA) will no longer include those aged 65 or over.

This change to the Benefits Integrity Project (BIP) was revealed in reply to a Parliamentary Question, planted by the Voluntary Organisations Disability Group (VODG), of which ASBAH is a member.

The answer to a later question revealed that the Government will, in future, discuss BIP – along with other reviews of benefits for long-term sickness or disability – with representatives of disability groups.

People being visited as a result of BIP are adults receiving the High Rate Mobility Component & High Rate Care Component of DLA.

People being sent a detailed questionnaire are adults receiving the High Rate Mobility Component & the Middle Rate Care Component of DLA.

The following groups of DLA recipients are excluded from BIP:

- People who are terminally ill and are receiving payments under special rules;
- People who are both deaf and blind;
- Double amputees;
- People who come within the Department's definition of severe mental impairment;
- People who are quadriplegic/paraplegic;
- People with an underlying entitlement but who are not being paid the benefit, that is, people in hospital or residential care.
- Children under 16.
- People aged 65 or over.

■ ***For more on BIP, see article on page 7-8 of the June/July Link magazine. Send SAE to: Information, ASBAH, 42 Park Road, Peterborough PE1 2UQ.***

True story

by Julia Griffiths
North Anston, Sheffield

MY 12-year-old son has hydrocephalus and is severely visually impaired. ASBAH helped us when we thought everything we wanted for our son was slowly going wrong.

We always fought for Daniel's rights when it came to medical or educational problems because we knew what Daniel could achieve.

One thing we have learnt is that you do have to question and fight for your child; people in authority are not always right.

In the past, Daniel has been in schools which did not meet his educational needs. In our area, which is Rotherham, our schools are poor for visually impaired children with learning difficulties.

If we had listened to the people who thought they knew Daniel – the child psychologist and people in charge of visually impaired services – he would have been in a school which, yet again, did not meet his educational needs, but fell into budget!

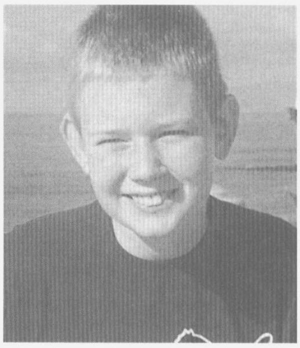
We started six-monthly meetings two years before Daniel was due to start secondary school. At the last meeting, eight months before Daniel was due to leave primary school, we were told there was no school in our area which met all of Daniel's needs. His hydrocephalus causes memory problems and lack of concentration, and his visual disability requires the input of a braille teacher.

We were asked to go and try to find a school ourselves, but the LEA recommended a local special school, with a few hours possibly for braille.

We were left totally alone and had to find someone to help. Luckily, I contacted Mike Dodd, education adviser for ASBAH's Northern Region. We were worried and panicking, not knowing what to do, but Mike talked through with us what we should look for in schools before we set about visiting them.

We worked down a list of 10 schools, including boarding and comprehensives, and were sent information videos and prospectuses.

After visiting the schools over three months, we talked through with Mike what we had found out. We eventually settled on a school which suited Daniel 100% but, as it was a boarding school, we needed reassurance from Mike that leaving home need not be a bad thing for Daniel, although it would be very hard for us, his parents. Indeed, going to Exhall Grange would greatly help him – not only would it give him a good education but also a better chance of independence.



Daniel Griffiths

Exhall Grange is a school for visually impaired children with additional disabilities in Coventry. This was a school that we had been told was unsuitable for Daniel in the last meeting with educational officials.

We knew it would be costly for the LEA to send Daniel to Exhall Grange, and we went into the last meeting ready for a fight. Just knowing we had Mike on our side made us feel able to take on anyone. But the meeting went smoothly and our proposal was partially agreed, and we came away very surprised. Our choice was later approved by a panel.

Daniel has been at Exhall Grange for a year and is doing exceptionally well. It has excellent facilities and qualified staff who fully understand hydrocephalus and can deal with it.

The school has changed Daniel so much. He is more confident, independent and a true 12-year-old with attitude. He loves all the different subjects, which he would not have been able to participate in if at another school.

A big thank-you to Mike Dodd – a very patient and understanding man. He has a way of keeping upset parents calm.

Staff profile

ON standby at the sidelines, armed with a bucket and sponge, watching her son playing football, is where you will regularly find Sue Ingham at weekends.

The new specialist adviser (medical) for the Northern Region likes to support 14-year-old Michael's favourite pastime when she is not at work and he is not at school.

When Michael is playing for the Carverley Junior Team in hotly fought competitions, Sue is recognised by all the teams as the nurse who will sponge down kicked shins and scuffed knees.

And, after the matches, she will join the other mums in serving orange juice and making sure the boys listen to what the manager is telling them in his debrief.

Equal rights to goods and services

THE GOVERNMENT has at last announced the timetable for the full implementation of the third part of the 1995 Disability Discrimination Act (DDA).

This part of the legislation provides a basic right to service and makes it unlawful to refuse to serve a disabled person, offer the service at a lower standard, or offer a disabled customer less favourable terms.

From October 1999, service providers will have to ensure that they are not operating in a manner that could exclude a disabled person.

For example, a restaurant will not be allowed to refuse entry to a guide dog. At the same time, they will have to look at what assistance can be reasonably provided to help a disabled person. This could include providing a sign language interpreter, or installing an induction loop system to help someone with a hearing problem.

In cases where someone cannot physically access a service, the provider will have to consider other options, such as a hairdresser making home visits to a customer. From 2004, service providers will have to remove the physical barriers that prevent access.

As with other aspects of the DDA, people will only have to comply if it is reasonable for them to do so. For example, a businessman may argue that, because of the cost to his business, it is not reasonable to expect him to install a lift in his premises.

Nevertheless, the Government believes that once these new requirements are introduced they will have a widespread impact on the lives of disabled people.

[Source: Disability Scotland].

What's in the Aug/Sept Link

Dr John Holter's CBE . . p3

MRSA: cause for concern p6

Making a life plan . . . p12

Whizz-Kidz helps our kidz p14-15

GMTV's *Get Up & Give* Appeal p16-17

HN News p19-26

Dates for your diary . . p28

Link is ASBAH's main magazine. Subscription details on 01733-555988

ASBAH Family Weekend

A RESIDENTIAL opportunity for families with a young child with hydrocephalus and/or spina bifida is being organised by ASBAH.

The ASBAH Family Day will run from Friday 30 October to Sunday 1 November at the Pioneer Centre, Cleobury Mortimer, Kidderminster, Worcestershire.

There will be three parallel programmes – one for parents; one for all of the children, and a special programme for brothers and sisters.

The cost is £50 per family and is being sponsored by the BBC Children in Need Appeal.

For details, contact Lynn Thomas on 01733-555988. Tell Lynn by 21 September if you wish to attend.

HN NEWS letters

AFTER being poorly and sick for some time, my 14-year-old daughter Sarah, who has hydrocephalus due to a cyst on the brain, was found to have low pressure.

She had been hearing a buzzing noise, on and off, for years and I wonder whether this had something to do with the low pressure.

At the time, the buzzing noise was linked to the times when fluid was building up in Sarah's body just before or during a period.

Due to repeated bouts of vomiting, she was taken into hospital in January and found to have an intermittent blockage.

A new connector at the ventricular end of Sarah's VP shunt was inserted and a Rickham's Reservoir put behind her ear, making it easier for the pressure to be tested, if needed, in future.

We would like to thank Mr Rang Shawis, consultant paediatric surgeon, at the Children's Hospital, Sheffield, for doing the operation. His attitude to patients, and their parents, is lovely.

Sarah is much better and happier after her operation.

Shirley Wassell
Upper Haugh, Rotherham

MY seven and a half-year-old daughter Emily has hydrocephalus and severe learning difficulties.

I would very much like to contact other parents of children with severe learning difficulties who are about the same age as Emily or a bit older to get an idea of what we should expect.

Emily is now at a special school after moving from a mainstream school more than 12 months ago. She is now in a smaller sized class and doing a lot better.

Karen Royle
1 Mithril Close, Widnes
Cheshire WA8 3FH
Tel: 0151-424 1788

MY daughter Ellie is 21 months old. Ellie was born two months premature and on her second day of life, when the nurse tried to pass a naso-gastric tube, we found out Ellie had tracheo oesophageal fistula and oesophageal atresia, which basically means her food pipe went into her lung instead of her stomach.

Due to the trauma of the surgery, she unfortunately had a bleed inside her head. Ellie had a VP shunt fitted and ended up having six operations as there were complications, such as the shunt not draining properly and blockages, which meant Ellie had several revisions. Since her shunt was fitted, Ellie stopped feeding even though she was never a great feeder anyway.

It was not until Ellie was 10 months old and she was admitted to hospital for tests as she was vomiting regularly and failing to put on weight, that we learned she had a gastric reflux.

Ellie has had a feeding tube fitted and is putting weight on but will not eat or drink even when starved and will not put anything near or in her mouth.

Her development is delayed and she is not yet crawling or walking but is compensating in her speech.

I would be very interested to hear from other parents who are, or have been, in this position.

Cara Green
16 Broadhope Avenue
Stanford-le-Hope
Essex SS17 0SJ

Please send your letters to:
Mrs Rosemary Bachelor,
Co-ordinator,
Hydrocephalus Network,
ASBAH,
42 Park Road,
Peterborough PE1 2UQ.

True story

By Sally Harris RGN RSCN from New Malden, Surrey

MY son was diagnosed with congenital aqueductal stenosis in June 1997, aged 18.

During his 'A' Levels, having had a sporty life, Jonathan developed constant headaches. As he was at boarding school, I was not aware of the frequency he was taking Paracetamol, nor how much.

In June, after his exams, he developed double vision and, being an ex-nurse, it was then that alarm bells rang.

Doctors had previously told Jonathan that the headaches were either migraine or stress related. I took him to an ophthalmologist who did not seem too concerned but, as we were going to America a week later, he requested a CT scan.

Within 24 hours, Jonathan was admitted to hospital and his ventricular pressure was measured. He had a diagnosis of congenital aqueductal stenosis. We were amazed. I had nursed at Great Ormond Street and had no idea it could lay dormant for so long. The consultant decided, after much deliberation, that the pressures were borderline and we could go on holiday.

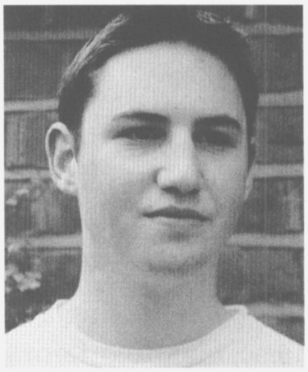
Unfortunately, within 48 hours of arriving in Florida, Jonathan became seriously ill with severe headache, photophobia and was confused. He was admitted to a neurosurgical unit and, after several calls to Britain, a VP shunt was inserted. Within 24 hours, he had got rid of the severe headaches but had acute groin/abdominal pain.

When we returned home, we saw our consultant several times; a general surgeon – who said Jonathan was constipated! – and our GP. None knew what was wrong and, after several weeks, he started getting headaches again.

After three months, I insisted mother's intuition was right – that the abdominal pain was related to the shunt, and we went to see a new neurological/surgical team. They decided, although it was very rare, Jonathan was reacting to the CSF in his peritoneum, so a new shunt was inserted into his atrium (a programmable shunt). During this time, the only person who had believed me was Dr Roger Bayston, ASBAH's honorary consultant on hydrocephalus. I am so grateful for his help.

Jonathan continued to get headaches, first due to low pressure, then high pressure, and the shunt programme was changed to every conceivable level and he had 26 scans. According to the surgeons, Jonathan was 'unique'.

After an anti-syphon device was inserted with no improvement, we began to get very disillusioned with the shunt system. Jonathan was *so* sensitive to any pressure change, even the Medos programmable shunt was not accurate enough to leave him with no headaches.



Jonathan Harris

Thankfully, Jonathan had finished his 'A' Levels and, despite the pain, got into university for this October. But he was on his 'gap year' and had planned to travel overseas. He has been so brave and calm during this time. I am so proud of him.

After trying all sorts of alternative therapies to erase the headaches, the surgeon decided the only option was the Torkeldson's Procedure – an internal shunt system avoiding shunting the CSF outside the brain. Jonathan was very ill afterwards with non-stop vomiting.

In April, the headaches were very slowly easing although the eye pain continued, partly due to him having to stop taking analgesia: the codeine and the Paracetomol were themselves causing headaches and poor liver function, so he had to go 'Cold Turkey.'

In May, the scans looked good but Jonathan is still getting periods of severe eye pain and headaches. Does anyone have any clues as to the cause?

REPORT ON AN EFFECTIVE CONTINENCE SERVICE

A service to be proud of

THE concerns of an ASBAH adviser influenced continence service provision for at least 30 people with spina bifida in North East Wales.

ASBAH adviser Peter Bennett is convinced that his strong reaction against the effects of a continence service re-organisation, three years ago, was enough to sway the chief executive of the Clwydian Community Care Trust (CCCT) into thinking again.

Peter *(pictured above)* said: "Although he told me that I had no cause to worry, I am sure that my letter did have an impact because he knew then that ASBAH was aware of the proposed changes."

At the time, only one of three continence advisers was in post and it was feared that, if the situation were allowed to continue, the service would be significantly affected. However, within a few weeks of his correspondence, a second continence adviser was appointed and the present level of service established.

Continence service manager for CCCT, Linda Winson, said: "It is estimated that 8% of the population suffer from the symptom of incontinence and that of this 70% is curable."

"Consequently, it is the philosophy of the CCCT's continence service to ensure that everyone should have the opportunity to be continent, whatever their age or disability, and to contain incontinence with pads or appliances only if the condition cannot be cured or managed in other ways.

"Despite this, we supply incontinence products to about 4,000 people in North East Wales, at a cost that exceeds our £250,000 budget.

"We believe that it is cost effective to provide high quality products and to manage their usage by policy and set criteria for supply. This

continued on page 28

TWENTY-year-old Lee from Wrexham, and his mum Sue, say help from their local continence service in NE Wales is only a phone call away.

Since Christmas, Sue has often been in weekly telephone contact with continence manager, Linda Winson, to try and solve her son's problems.

Sue said: "I deal directly with Linda Winson. She is really supportive – we ring each other every week. She has been there, if things have got bad.

"Lee's problems have always been severe. He's tried everything, but nothing seems to work 100%.

"If one thing doesn't work, Linda will help Lee try something else. We were so desperate, Linda even offered to give us her home number, but I didn't want to take advantage like that."

Linda ensured that Lee received free supplies of the anal plug before it became available on prescription after he had had some success with it in trials which involved ASBAH. When the trials finished, Lee had problems using the plug but these have become less common.

Linda Winson

Lee says: "I now have a lot of confidence to go out to college or the local PHAB Club."

The supply of pads from Clwydian Community Care Trust has been increased from 45 to 60 per month after Lee's mum asked for more at a recent annual assessment. Their supply of sheets is also to increase.

Sue said: "I feel we are very lucky to have such a good service. If we are worried, Linda will even get in touch with Lee's GP to back up our concerns or wishes for treatment."

Julie Llewelyn, ASBAH specialist adviser (medical), comments:

"Continence services vary considerably throughout the country within various NHS trusts. I am very aware that people often contact ASBAH when 'things go wrong' and when they require someone to fight their cause. This can result in ASBAH having a jaundiced view of continence services generally.

"However, the services provided by Linda Winson and her team have consistently proved to be adaptable and positive for those of our service-users who are lucky enough to fall into her catchment area.

"Faecal incontinence is often not regarded as a priority and consequently not always addressed. Linda has consistently recognised the traumatic effect faecal soiling can have on an individual and she strives to find a manageable treatment to alleviate the problem.

"It is reassuring to know that full support and expert advice are readily available to our service-users in North East Wales."

A service to be proud of, *from page 27*

ensures that treatment and cure is the priority, but that those people who need products get them."

Because of the numbers of people needing continence advice it has been necessary to structure the continence service to maximise the effectiveness of the two continence advisers and address the key functions of clinical services, training, management and research.

The continence advisers hold clinics in 15 locations throughout the area and see more than 100 new patients per month. However, it is not possible for them to see every person who has continence problems, nor is it always necessary, as primary health care teams can provide effective, appropriate treatment.

Traditional attitudes to incontinence are usually negative and seem to be based on the assumption that the condition is not important or life-threatening.

This is a view that is not shared by the thousands of people who have their quality of life, relationships, self-esteem and prospects profoundly affected by the condition.

To ensure that every person presenting with incontinence receives an assessment by trained nurses who are knowledgeable in the treatment and management of their condition, a comprehensive training programme has been established in North East Wales. The programme also provides sessions for untrained staff and carers from the Health Service, Social Services and the private sector. In addition, various information leaflets are available for the public in Welsh and English.

Continence services vary throughout the country but North East Wales is fortunate to have managers who are prepared to invest in clinical services and who have recently appointed two full-time and three part-time continence nurse practitioners to enhance the level of service to the local population.

This will allow the two continence advisers to develop a more comprehensive service to people with disabilities and neurological disease, and to give more attention to health promotion and research.

In cases where the service-user has spina bifida, the continence problems are due to neurological damage, so management is always long-term and a thorough assessment and a knowledge of available options are essential.

Linda Winson and her team are aware of the need and are keen to keep abreast of the latest developments in the treatment and management of chronic bladder and bowel dysfunction.

They were pleased to be able to obtain supplies of the anal plug for individuals with profound bowel problems before they became available on prescription as trust managers agreed to fund their supply from locality budgets.

Co-operation between management and clinical services has made significant changes to the quality and effectiveness of the continence service in North East Wales.

Peter Bennett commented: "People referred to the service now enjoy a standard of service of which the trust can feel proud but we must not become complacent."

As well as writing to the chief executive when he was concerned about potential deteriorations in the service, Peter wrote to him last year commending the current service, which was clearly appreciated by the chief executive.

"Reconfiguration of the trusts in North Wales next year will undoubtedly have an effect on continence services," says Linda Winson, "but hopefully not to the detriment of what has been established by the CCCT."

DATES FOR YOUR DIARY

21-23 August

Parents in Focus, weekend for parents with disabilities and their families, information and social activities, Valence School, Westerham, Kent. Adults £25, children under 14 £10, children under 18 months free. Closing date for applications, 31 July. *ASBAH South East, 209 Crescent Road, New Barnet, Herts EN4 8SB, tel: 0181-449 0475.*

24–27 August

ASBAH's 'Summer Experience', a four-day activities and personal awareness course for 12–16-year-olds with SBAH, Nell Bank Centre, near Ilkley, West Yorkshire. *Joan Pheasant, ASBAH North, 64 Bagley Lane, Farsley, Leeds LS28 5LY, tel: 0113-255 6767, fax 0113-236 3747.*

Monday 14 September

ASBAH South Beds Support Group, Disability Resource Centre, Poynters Road, Dunstable, 1-3pm. *Valerie Bottoms, 01582-605749.*

Saturday 26 September

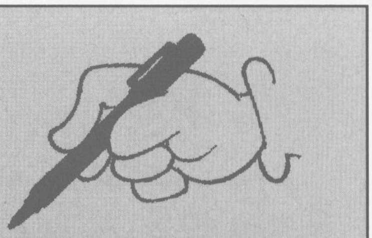
ASBAH Information Day, The Silverthorne Building, Bishop Road Primary School, Clevedon Road, Bishopston, Bristol. Speakers include: Ian Pople (consultant neurosurgeon, Frenchay Hospital); ASBAH specialist adviser Julie Llewelyn; Lizzie Jenkins (Scope). Cost, inc buffet lunch, £3 (family members/disabled people), £6 (professionals). *Julie Knight, ASBAH adviser, 45 Nevil Road, Bishopston, Bristol BS7 9EG.*

Monday 26 October

ASBAH Study Day, 'Problem Behaviour in Children with Spina Bifida and Hydrocephalus,' NSPCC Training Centre, Beaumont Leys, Leicester, 9.30am-4pm. Speakers include: ASBAH education adviser Mike Dodd; Jacky Lucas (NSPCC); Bob Johnson (community psychiatric nurse). Cost, inc buffet lunch, parents £15, voluntary orgs £25, professionals £35. *Rebecca Sewell, ASBAH East, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988.*

30 October – 1 November

ASBAH family weekend, for families with a child aged 6 years and under with SBAH, their brothers and sisters, Pioneer Centre, Kidderminster, Worcs. £50 per family. Closing date for applications, 21 September. *Lynn Thomas, ASBAH, tel: 01733-555988.*



Dave's diary

IT'S been weeks since my 30th birthday and I'm *still* annoyed! Don't get me wrong, I had a great birthday. There were loads of drinking, eating of smoked salmon, Japanese food, cake and dinner with my family in London. I got loads of great presents – the mail order bride I was threatened with, if I reached 30 still single, didn't arrive. So I had a great time.

No, I'm annoyed because I'm 30. An Old Guy! I don't believe it! Actually, I'm surprised to have made it this far, given my lifestyle (zero exercise, maximum drinking and eating). I always thought some time well before 30, they'd find me face down in the wreckage of 'Banquet For Six Persons' at the Chinese. These days I can't eat or drink like I used to do without suffering.

My co-ordination has gone too. When we went for my birthday dinner at a posh London restaurant, they hadn't got a table for us, so kindly offered us a free drink. Typical me, I chose Champagne. I reached for my glass and knocked the whole thing down my front. That's what *really* annoyed me about my birthday: how many times in life do you get given free Champagne? I was sorely tempted to suck my shirt dry!

OK, my co-ordination problem may not have been entirely due to old age, as I did have a glass or three of the wicked brew before dinner. But I am *definitely* losing my marbles. Whether it's Alzheimer's, old age, the hydrocephalus, eating dodgy beef burgers or what, I don't know, but my memory has totally gone.

I went into town to apply for a pass that lets me into the city's pedestrian areas, so I can get closer to the shop and run over a few more tourists. I got one, put it in an envelope, went into two shops, got in the car and arrived home empty handed. In less than 20 minutes, I'd completely lost the envelope and had no memory of it leaving my grasp.

If I'm like this now, what will I be like in another 30 years? What will the world be like? I may go loopy but no matter how things change, some things always stay the same: I was aggravated to find recently that even wonderful privatised trains can be an hour late.

I'm also annoyed to find out the British nuclear test veterans, who have been campaigning for compensation even longer than I've been living, had their recent court case blown out on some kind of technicality. They claim they and their children contracted illnesses after exposure to radiation from the tests. Some of the grandchildren had abnormal levels of SB. If they had got compensation, maybe one day I could have found some cause for SB and claimed compensation too. I could do with the money!

What's happening to our money? It's become unrecognisable since I was born and especially recently. Have you seen the two pound coin yet? It looks foreign and almost like a Euro. I hope (but doubt) the designers checked old or visually impaired people could spot what it's worth. I couldn't, at first. I confess I was afraid to hold it too long in my warm hands for fear the chocolate inside might melt!

Enough grumpiness. It gives me a warm melty feeling in my heart to hear from Diary readers. It reassures me I'm not alone in my frustrations with hammer-headed red tape merchants. Thanks Mr White for writing in recently with his experience of filling in forms.

● *You can write to David c/o ASBAH, or email: david.fulford-brown@virgin.net*

FOR SALE

Swede Elite lightweight manual wheelchair, cost as new £1,400, will accept £300 ono. Tel: 01273-670140 after 5pm.

Lark Triumph 3-wheeled scooter complete with charger. Bought Sept '95 for £1,800. Excellent condition. Sell for £1,000 ono. Contact: 01939-251300 (evenings).

Complete aquatherapy spa system. Includes foot spa, warm air massage, brush and cup. Cost over £950. Little used. £500 ono. Ring 01278-732584 (Somerset).

Concern for Comfort massage bed, 39 inches wide, raises both ends. Bought new six months ago for £1,400, hardly used, asking £900. Mrs Browne, tel: 01268-682340 (Canvey Island).

Second-hand wheelchair hoist in good condition. Will fit any make of car. White in colour, but can be painted. £800. For further information, contact: 01606-883465.

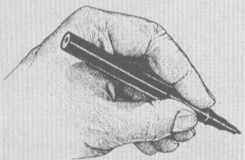
Electric scooter Shoprider Sunrunner 3. Hardly used. £900 ono. Tel: Mrs Nation, 0181-656 9875 (Croydon).

Medicbath with pump, sliding seat for easy access and front-closing door. Hardly used. Cost over £2,000, asking £1,250. Contact Mrs Paterson, Kent, 01732-451135.

Okimat, powered, fully-adjustable, 3ft bed with mattress (cream). Beautiful condition. Hardly used. £800. Tel: 01705-253423 (Portsmouth).

ACCOMMODATION

Sheltered accommodation in self-contained flats for single people with physical disabilities. If interested, contact: Miss Linda Patton, Head of Home, Cheshire House, Kinsale Park, Waterside, Co Derry, N Ireland. Tel: 01504-341861.



Letters

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

MRSA: cause for concern

I feel other parents should be warned of the possible danger of excessive doses of antibiotics to clear the infections experienced by many of our friends with spina bifida and hydrocephalus.

My son Edward, aged 32, has spina bifida and hydrocephalus. He has had many sores and infections on his feet and legs over the last 10 or more years. He has no feeling whatsoever in the lower half of his body and, due to his hydrocephalus, he has no memory retention and a learning age of eight.

Due to these problems, he has never understood the seriousness of knocking his feet or legs. The skin is extremely poor and will rub off after a bath or with pressure.

Just after Christmas, he rubbed the skin off his heel whilst in bed and, in spite of treatment, it became very infectious and required treatment by antibiotics.After three or four weeks, our GP decided we needed daily visits by district nurses.

Then, in February, a sore erupted on the knee and this deteriorated so swiftly that in no time at all we could see the bone.

Swabs showed that he had two different infections so he was treated with two different forms of medication.

Further swabs in March showed one of the infections was MRSA – Methicillin Resistant *Staphylococcus aureus*. This is the 'superbug' bacterial infection we have heard so much about through the media. It usually strikes in intensive care units where patients have had large doses of medication over long periods.

It can be carried by dry skin flakes, is transmitted easily and is resistant to all antibiotics except two, which have to be administered three hourly by drip and are usually only given to hospital patients because the condition can be life-threatening.

The bacterial infection colonised in Edward's knee bones, causing them to dislocate from one another, and there was large amounts of seepage every day.

There was great concern that the infection would spread, especially to his shunts, in which case this condition would be life-threatening to Edward. As a result, he has had to have his leg amputated, which he is finding very difficult to come to terms with.

Mrs June Davies
Secretary, Staffordshire ASBAH

● Turn to page 6 an article on MRSA by Dr Bayston, ASBAH's Honorary Consultant on Hydrocephalus.

Good for Paul Darke!

THREE cheers for Paul Darke *(Link, No 176)*. He is so right about the negative and missing portrayal of disabled people in the media.

The BBC does appear to be trying to redress the balance in widening its database to include a range of disabled people willing to contribute to programmes. It remains to be seen whether this makes any real difference in practice. We shall see.

However, as Paul notes, given the current emphasis on termination, infanticide and euthanasia, one cannot be optimistic.

Perhaps it is possible that if disabled people living very full lives are to be featured on our screens, those who so dogmatically insist on our destruction may find that others begin to submit their views to closer scrutiny.

Mrs Diana Sanderson
BA (Admin), Dip App Soc Studs
Newton Hall
Durham

Fifty years of living with spina bifida and still not out!

HOW pleased I was to see the interesting media article, *Bring me the head of Ironside*, by Paul Darke in the last issue of *Link*.

In it, Mr Darke makes the seemingly obvious, but seldom stated, point that it is unsurprising that the media has a negative or dismissive attitude towards disabled people, given the current enthusiasm for abortion, which ensures that they are never even allowed to be born.

So much is made these days of trying to provide adequate access, and reporting the activities of disabled people in a non-sensational way. It is, however, impossible to do this in any satisfactory way while pre-born babies with the very same disabling conditions are being described by doctors as 'grossly malformed foetuses' and essentially regarded as 'better off dead.'

Congratulations to Paul Darke on pointing out the fact that it is actually impossible to have a satisfactorily positive attitude towards a group of people whose systematic destruction one is simultaneously advocating.

Alison Davis
Milborne St Andrew
Dorset

HOLIDAY ACCOMMODATION

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: 01494-714270 (Bucks & E Berks ASBAH).*

FRANCE – Ile d'Oleron, near La Rochelle – Mobile home for wheelchair users. Fully adapted (shower etc), sleeps six, near beach, disabled owner. *Brochure from M Mardle, Fricourt, Filey Road, Old Heath Road, Southminster, Essex CM0 7BS. Tel. 01621-772447.*

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.*

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, club-house, 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.

MAR Y SOL – TENERIFE– Wheelchair accessible apartments. Heated pool with hoist. Restaurant, pool-side bar, equipment hire. Sunshine guaranteed all year round. Ring today for cheapest prices. *Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx TW19 5NX, tel: 01753-685718.*

ALGARVE – PORTUGAL – Wheelchair friendly luxury villas with swimming pools, or small friendly hotels with adapted rooms. *Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx TW19 5NX, tel: 01753-685718.*

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.*

FRANCE – WESTERN DORDOGNE – Picturesque barn conversion in idyllic rural location. Ground floor fully wheelchair accessible, comprising living areas, large double bedroom and spacious bathroom. Level access to sun terraces, garden and pool. Two further bedrooms and bathroom on first floor. English owners live locally. *Phone for more information from Duncan Clifford on 00335 53 90 99 40.*

LINK Rates

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