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LINK

The magazine for people with hydrocephalus and spina bifida



Benny Bear takes to the skies



ASBAH

Association for Spina Bifida and Hydrocephalus
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Motability

Allied Vehicles
Driving For Perfection

Peter Farrall writes

This issue delves deeper inside the medical world than we have for some time, providing an important reminder of fundamental issues that affect you and your family.

In December the government is expected to announce a new national service framework for long-term medical conditions of people of working age; Andrew Russell outlines ASBAH's hopes and expectations following our behind the scenes lobbying.

Staying with the NHS, we get an insight into the important work of clinical nurse specialists by meeting Jackie Campbell of Oxford's Radcliffe Infirmary; across in Nottingham at the Queen's Medical Centre we learn more about the daily work of Roger Bayston, the pioneer of the Bactiseal shunt; and you can read about the popularity of London's Chelsea & Westminster Hospital's clinic.

We also confront the issue of shunt blockages and learn about positive developments in the diagnosis of NPH. Much further afield we take a couple of looks at what's going on in Africa.

Sandwiched among these items are all the regular features you've come to enjoy from the invigorated *Link*. With summer here (supposedly!) we take a look at some good accessible beaches and report on the publication of the latest Benny Bear book, *Benny Goes on Holiday*.

So, plenty of food for thought – whether it's to do with the everyday concerns of living with SB/H or escaping from it all with ways to take your mind off things.

Peter Farrall
Assistant Director
(Marketing and Communications)
peterf@asbah.org

Best wishes,
Peter

Patron:
HRH The Duchess of Gloucester GCVO
President: Jeffrey Tate CBE

ASBAH's mission is to work with people with spina bifida and/or hydrocephalus, their families and carers to promote individual choice, control and quality of life

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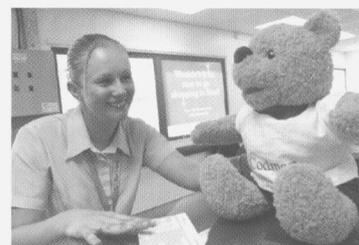
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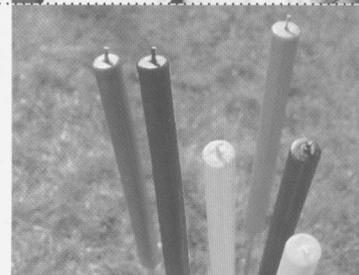
hydrocephalus
action



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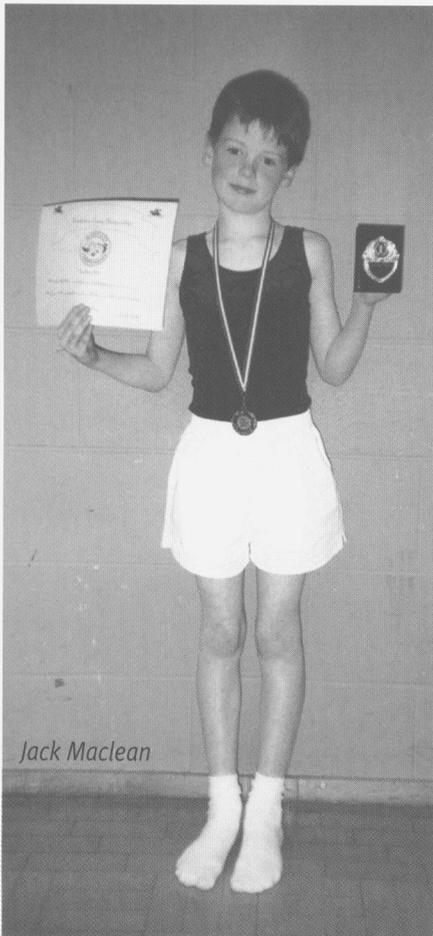
Bouncing back

Young Jack Maclean, 9, has bounced his way to trampoline success in his county championships. Jack, who has hydrocephalus, picked up the prestigious Under 10's County Champion title after impressing judges of the competition at Grantham in Lincolnshire.

Jack, a keen member of the Grantham Trampoline Club, took up the hobby as a three-year-old, trying out the trampoline in the garden used by his brother Tom, now 16, and sister Ella, now 14.

Mum Vicky says: "Jack was always very keen on the sport from an early age, but he didn't take it up seriously until about 18 months ago. His hydrocephalus was caused by a cyst which he had from birth. It grew quite large and surgeons operated to deflate it. There was some concern about his balance and co-ordination when he was younger, but he seems to have overgrown those problems now."

That's something we would very much agree with!



Jack Maclean

Hollister holds its first roadshow



Hollister Roadshow



Chloe Kidde

ASBAH service users were among the many visitors to the 'Hollister Advance to Independent Living Roadshow' at Blenheim Palace in May.

Hollister, which specialises in products for ostomy and continence care, invited several charities, including ASBAH, to attend. Exhibitors included companies specialising in lifestyle needs for people who perform intermittent self-catheterisation (ISC).

Jackie McPhail, Hollister's Marketing Manager, said: "The roadshow was the first we have organised, and we were very pleased with the response. It was a fantastic day and we received some good feedback from visitors.

"As it was our first roadshow it was very much a learning exercise and we hope the second will be bigger and better," she said.

(See diary dates p29)



Blenheim Palace

Sheila Thompson retires

Preston & District's Sheila Thompson (*right in picture*) was presented with an Olympus camera by association chairman Adele Scott to mark her retirement in April after more than 21 years as honorary secretary. Sheila, who lives in Southport, first became involved with the association when she worked at a local Barnardo's Home.

Adele Scott thanked Sheila for her valued contribution as secretary, saying: "Without her continued dedicated and efforts the association would not have run smoothly as it has."



ASBAH cautious over proposed new framework

The government is expected to announce later this year a national service

framework (NSF) for long-term medical conditions of people of working age.

The NSF will have a particular focus on the needs of people with neurological conditions and brain and spine injury.

The Department of Health (DoH) describes NSFs as "blueprints for care, aimed at raising standards, reducing variations in services and improving healthcare. They set national standards and define service models for a defined service or care group; put in place strategies to support implementation; and establish performance milestones against which progress within an agreed timescale will be measures".

ASBAH has been playing its full part giving the DoH its views about the proposals for the new NSF. Andrew Russell represents ASBAH on the Neurological Alliance, which has pressed for the following:

- that each individual patient or user has access locally to dedicated neurological services, integrated across health and social care agencies and backed up by appropriate specialist services
- that services are planned and provided in such a way as to enable people with long-term conditions, and their carers, to live as they choose, in the setting of their choice
- all health and social care services are focussed on the needs of users and carers, providing choice whenever possible, and will at times respect

issues of quality and diversity

- patients should be provided with readily understandable information about living with their long-term condition/impairment, and their entitlement to health, social care and other support services, including information about relevant charges. Information needs should also be addressed at regular reviews
- that there should be clarity and transparency about any charges for health and social care, and at which stage in an individual's deteriorating health they should receive all aspects of their care from the NHS (i.e. free of charge)
- that services be planned, provided and co-ordinated to ensure carers can support the cared for person as they both would wish and, recognising the specific needs of carers, can maximise their own quality of life
- care and support for people should be co-ordinated using key workers i.e. a principal point of professional contact for the service user
- the changing health and social care needs of people with rapidly progressing neurological conditions are anticipated and met in a timely and appropriate manner, in recognition of the link between speed of progression of disease and speed of response required.

The next phase in the consultation process sees the DoH consulting people with neurological conditions. After that the proposed framework will be submitted to the Cabinet Office for approval, with a decision expected in December.



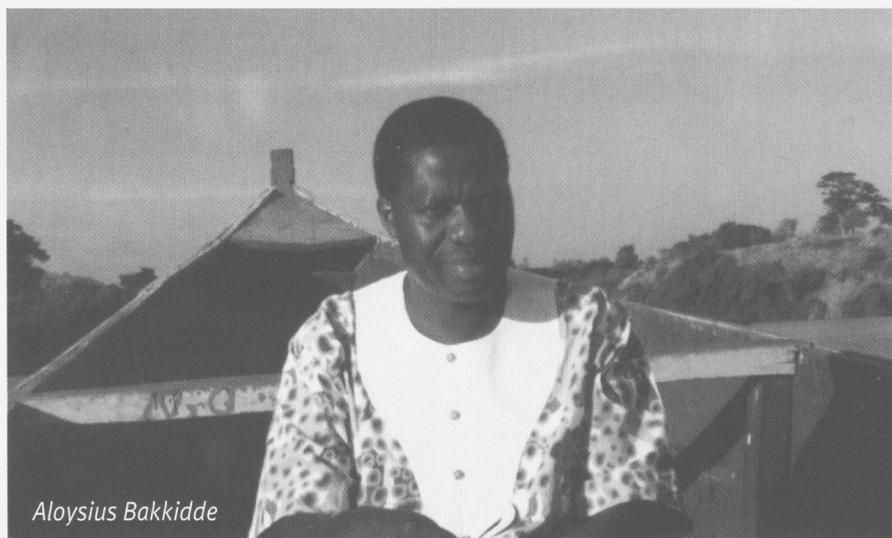
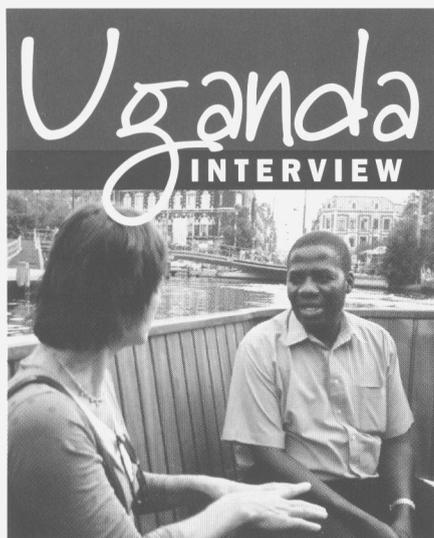
Andrew Russell

Andrew Russell told *Link*: "The process has been long, but should be worthwhile, and ASBAH is playing its full part. We're very much in support of NSFs in principle, but we have to be cautious

how this particular one will work and it's certainly too early to say how far reaching the benefits will be. For instance, we had hoped that it would also cater for children, but a separate NSF is being drawn up for all children, including disabled children, in which ASBAH has had a say.

"Issues like the acute shortages of neurologists will need addressing, as huge investment is needed for the training of new ones if numbers are to double over ten years, as the government has promised. The overall hope is that society, and government, will recognise neurological conditions and give political and financial backing for better services," he said.

ASBAH has consistently pressed for both NSFs (children and adults) to emphasise the need for good information, empowerment for service users and carers, and the improvement of social care as well as healthcare.



Aloysius Bakkidde

'If' member Aloysius Bakkidde answers our questions

IFSBH member Aloysius Bakkidde is a partner in a firm of consulting engineers in Uganda. We asked him about spina bifida and hydrocephalus in Africa.

How prevalent is spina bifida in sub-Saharan Africa?

AB: Spina bifida is more common in very poor families or parents whose incomes are generally low, and the majority of them live in rural areas where health services are limited and not easily accessible. It's therefore difficult to talk of reliable records, as it's possible that the majority of children born under such difficult conditions die before they get medical attention and therefore will not be recorded.

How prevalent is hydrocephalus?

AB: The experiences the parents of spina bifida children go through are similar to those for hydrocephalus, except that from records of those that reach the health services, hydrocephalus cases are more prevalent than spina bifida.

Are there any particular countries where SB/H is very common?

AB: More awareness raising is going on such that it may be difficult to compare countries or even provinces within one

country. A country that has embraced inclusion in all its programmes starting from grassroot level is bound to have sufficient information to be able to compare with other countries. Uganda is moving fast in that direction- courtesy of NGOs (non-governmental organisations).

What awareness is there of SB/H?

AB: Awareness of SB/H is still low. The situation is better in the cities than in the rural areas. As I mentioned, most of these children are born to poor families. Poverty and lack of knowledge about these disabilities are the main causes for negative attitudes and practices. Poor families are more occupied with the struggle to survive than anything else. This means that raising awareness is a very slow process.

In short, the majority of people in sub-Saharan Africa do not know about SB/H. They easily blame their wives or witchcraft for the misfortune. There is hope, however, as more support comes to Africa through training of experts, direct interventions through service provision in rural areas by organisations like IF, and more concern and involvement by governments.

Poverty, HIV/AIDS and conflicts remain the big challenges for Africa.

How many neurosurgeons – in how many hospitals – are there in Uganda who can operate for hydrocephalus?

AB: There are five in the whole of Uganda, but not all of them work in the country because of poor remuneration packages and poor working environment

due to a lack of adequate equipment and other necessary materials.

What's the post-operative success rate hydrocephalus cases in Uganda?

AB: This is a difficult question, because for the National Referral Hospital at Mulago, and indeed most government hospitals, there is no follow up, as no social workers are employed to do that. The hospitals are therefore limited in getting to know the success rate. However, in the private CURE Children's Hospital, which works in partnership with other private projects like the Cheshire Homes, the success rate is known to be more than 80%.

What is your response to Aqueela Essopjee's case, as told in the last issue of Link?

AB: It is a story which tells it all. It is that sad in most countries. I know, for example, that the National Referral Hospital here in Uganda has no shunts in stock at the moment. The shunts are usually donated by well wishers and it is clearly known that, because of limited resources, shunts are not included on the priority lists. This is because the government has not got enough to cover the whole budget. Even with the budget support by donors, some of these items are left off the lists.

Your Voice to attend international conference

Representatives from Your Voice will be joining experts from around the world at the annual conference of the International Federation for Spina Bifida and Hydrocephalus (IFSBH or 'If') in September.

Now in its 15th year, the conference is being organised by the Norwegian Association for Spina Bifida and Hydrocephalus and will take place in Oslo on 2-4 September. Called 'Crossing Borders', it will start with statements from people from all over the world, including those with SB/H and parents of children with SB/H.

ASBAH Executive Director Andrew

Russell will attend the event along with four members of ASBAH's Your Voice committee. He told *Link*: "If' and ASBAH believe that it is very important for young disabled adults to be involved in events such as this. The trip will give several committee members the opportunity to hear what is said and to be included in the discussion sessions.

"ASBAH has always been very keen for young disabled adults to take a greater role in their association, and this message is now spreading across other nations. It should be an interesting conference and I believe we will all benefit from what is discussed," he said.



The event will include lectures by leading neurosurgeons from Norway, Tanzania and Uganda, plus a presentation on the treatment of children with SB/H in developing countries. A workshop will be held for adults with SB/H, with a second looking at growing up with SB/H. Discussion topics will include having a child with a disability, educational challenges and concerns about leaving home.

'If' was launched in 1981, with members from 20 countries taking part. Today more than more than 40 countries are involved.

For more information: www.ifglobal.org



Helping Sudan

by **Carole Sobkowiak**

President of the Society for Research into Hydrocephalus and Spina Bifida

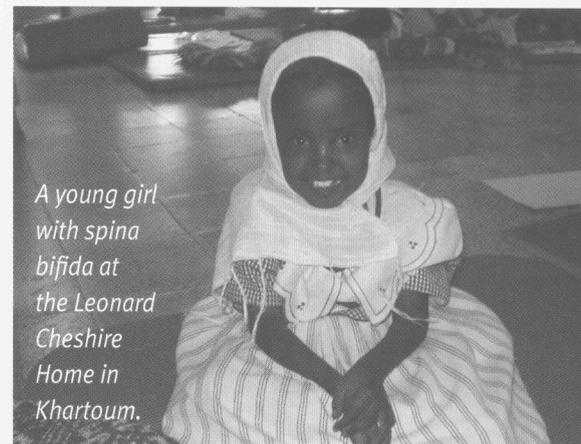
Co-operation between the UK and Sudan has grown considerably since the award in 2001 by the British Council of a two year grant for establishing a higher education link between Manchester Children's Hospital, St Mary's Hospital, Manchester, and Soba University Hospital in Khartoum.

As a result teams from the UK visited Khartoum in 2003 and 2004 and the enthusiastic Sudanese medical, nursing and physiotherapy staff have visited Manchester.

Shunts are very expensive in the Sudan with the ongoing problem of infection – imagine living in the desert with the worry that your valve may need attention. Training has now been given in the use of 3rd ventriculostomy for those children who are suitable.

Help has also been given in the management for bladder and kidney problems, as there is no routine scanning. The Leonard Cheshire Foundation shipped out a donation of catheters to their Khartoum Home; one father walked for three days to Khartoum to get a catheter for his son.

There are very few physiotherapists in the Sudan and so lectures and demonstrations were given in the Cheshire Home, which is an excellent centre providing outreach work. The new hydrotherapy pool is heated from solar energy by fixing rubber tubing, bought in the market, to the roof connected to a pump. When I was there at the end of January, with temperatures in the 30s, I asked why nobody was using the pool. Apparently it was the coldest month



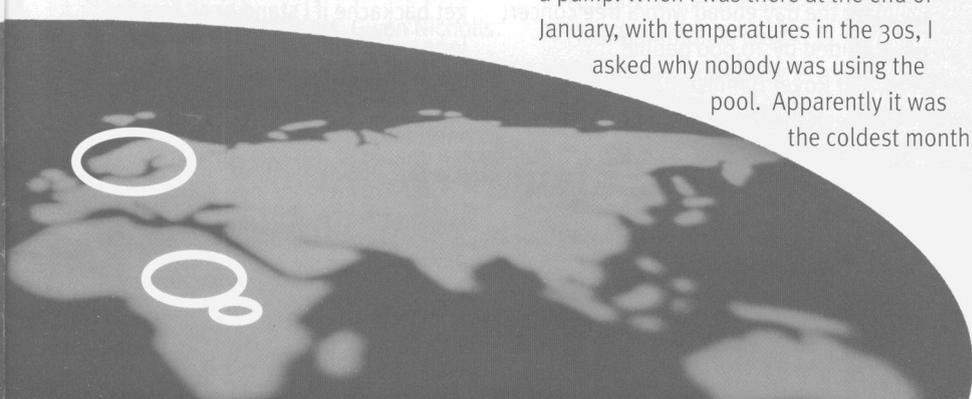
A young girl with spina bifida at the Leonard Cheshire Home in Khartoum.

and the mothers would not undress their children. Some of the children were wearing hand knitted cardigans, woolly trousers and hats!

Emphasis is being given to developing antenatal screening and also encouragement to develop a folic acid campaign, as the incidence of spina bifida is probably one of the highest in the world.

We were made to feel very welcome in Khartoum and the hospitality was so generous. Imagine being invited to a stranger's home for a ladies only wedding night of dancing and singing!

Other team members from the UK were neurosurgeons Carys Bannister and John Thorne, nephrologist Malcolm Lewis, obstetrician Dr Sarah Vause and Nurse Anita Baxter.





Linda's line

The Corbett countdown has commenced. Not for Cheam's first interplanetary space flight, but for our summer holiday – hooray!

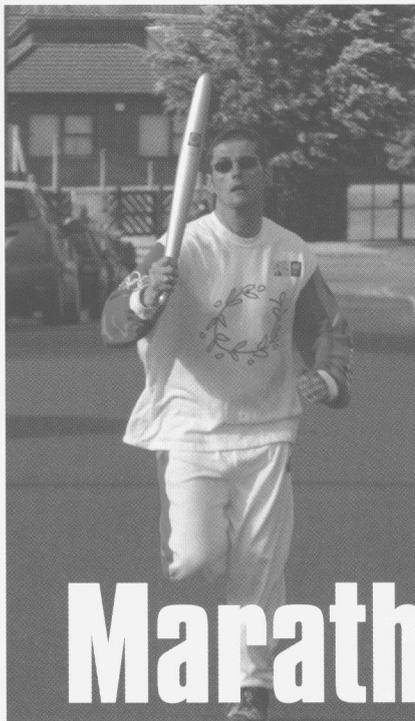
This year half the Corbett household is off to soak up the sun in Tuscany for a week, and those of you who read the winter edition of *Link* will know that the other half of the household comprises of Albert & Woodstock, the guinea pigs. The passport-less pigs go to a more local destination which seems to me like the guinea pig equivalent of the Savoy hotel, rather than animal boarding (however this does not prevent Albert from doing his condemned guinea pig routine whenever he goes in the car – he hates travelling).

I, on the other hand, love holidays and spend weeks planning what to take. My husband Andrew has come to the conclusion that my principles for packing are take everything and then see if you can close the suitcase (usually not on the first attempt!). It's then a matter of deciding what can be left out.

Definitely not the clothes, or the chocolate rations, nor the emergency toe repair kit – my Italian phrase book does not extend to “a packet of gauze and a roll of one inch micropore, please”. As we will be self-catering this year, I will also want to take my box of breakfast cereal, despite the fact that it invariably reappears looking like it has been hammered into the suitcase and squashed flat (although I think I know the reason for that...).

Of course, the weight restriction is a bit of a nuisance and we always end up swapping bits around to make sure that both cases are under the limit. It's at this point that I normally discover Andrew's shirts, which were oh-so carefully folded up by yours truly, are now wedged under a pile of books and shoes. Thanks matey!

Anyway, if you happen to be at Gatwick airport in mid-September you'll spot us a mile off – just look for someone around 4'6" who looks like they are trying to carry their own body weight in luggage, and a bloke in a crumpled shirt.



Marathon man

ASBAH service user Robert Pedley (above) was one of 140 torchbearers who carried the Olympic Torch when it came to London in late June for the UK leg of its relay around the world.

The flame left host city Athens on 2 June and visited 34 cities across five continents in 36 days. It arrived in London from Paris on the 23rd stage of the journey – the first time it has been in London since the 1948 Olympics.

Robert, 30, was runner number 138 in the relay team of 140 runners, each carrying the torch for 400 metres along its 48km journey. His route took him along the Embankment, where he passed the flame to Ade Adepitan of the British Paralympic basketball team. It was then passed on to Sir Steve Redgrave, who lit the Olympic cauldron in The Mall; the day ended with a free concert attended by 70,000 people.

Sir Roger Bannister, the first man to break the four minute mile in 1954, had started the relay at the Wimbledon Tennis Championships. After leaving London, the flame continued its journey by heading to Madrid. It finally

arrived back in Athens on 9 July.

Robert's proud father, Stephen, was among the thousands who turned out to cheer the runners on and get a glimpse of the famous flame which hadn't been in the capital since the 1948 Olympic Games.

Robert, from Chadsmoor in Staffordshire, said: “It was a wonderful experience. There was a fantastic atmosphere and, as most of the runners stayed overnight at the Thistle Hotel in Westminster, there was a great feeling of comradeship. I wasn't nervous at all before my run - it wasn't until I got home the following day that that enormity of the event really sunk in.”

Robert, 30, who has SB/H and is also blind in one eye, is now in training for the Wolverhampton Marathon, which takes place in September. He says: “I get backache if I stand or sit for too long, so running feels great and helps to strengthen the tendons in my legs, one of which is shorter than the other. I'm unable to work because I have short term memory loss, which can be quite severe if I'm having a bad day. Running gives me a great focus.”

It wasn't until I got home the following day that that enormity of the event really sunk in.



Star performer

Luke Paton, 13, from Iver in Bucks, was so inspired by reading about the Danny Mills Helpline Appeal in the last edition of *Link* that he is donating some of the funds he raised from taking part in April's London Mini Wheelchair Marathon to the appeal.

The marathon, which took place on the same day as the main London Marathon, saw Luke - who has hydrocephalus - attract over £700 in sponsorship; some of this even included matching funding from Sky Television, where his father, Mark, works. In fact, Luke was interviewed afterwards on Sky News. Luke, you're a star!



Forest Quilters

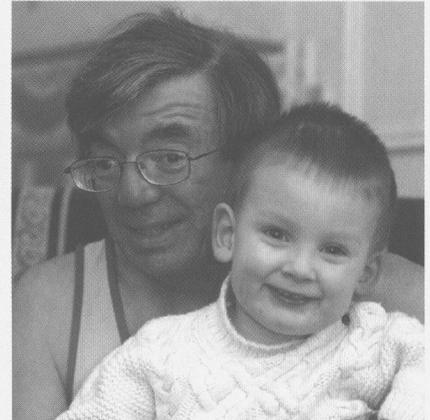
ASBAH is very grateful to Jan Moir and the Forest Quilters of Kidderminster who have kindly donated this magnificent quilt which they made in memory of one of their late members, Gwen Nicholls. As a beautiful piece of craftsmanship it took a considerable time to make, using Gwen's favourite colours. Donna Treanor, Assistant Director (Fundraising), seen here (left) with the quilt, hopes that it will be raffled in aid of ASBAH at the Quilters' Show later this year.

KEEP ON RUNNIN'

Run, run, run!

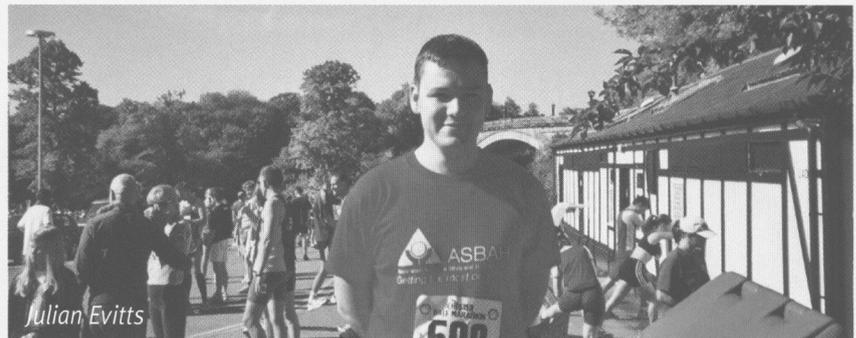
Thanks to intrepid Michael Hall, ASBAH is better off to the tune of over £900. How? Well Michael, who's 58 and from Coventry, ran in this year's Paris Marathon. He was inspired to do this by his grandson William Masterson, aged three, who has hydrocephalus.

Michael ran two London marathons in the 1980s and always planned to do another. "I always thought I would do another marathon, but as the years went by I got distracted. I enjoyed being able to smoke and drink and stay in of an evening rather than go out running. About two years ago I tried to run and found I couldn't even get round the block. I realised I had to do something," he told the *Coventry Evening Telegraph*, who reported on his training. So he started training and got fit again.



Michael Hall

"ASBAH has been brilliant for William. They are always there to give general support and advice. Now he has his shunt he is coming on in leaps and bounds. He is walking better and putting together his own sentences. William was the motivation I needed and I wanted to do something to support ASBAH," he said.



Julian Evitts

Marathon fundraiser

Our thanks to Julian Evitts of Chester, who raised £1,100 for ASBAH by running in the Chester Half-Marathon in May. Completing the run in 2 hours 13 minutes, he was raising money because his son Rhys, aged 16 months, has SB/H.

COUNTDOWN TIME

The year is flying by and, while for some of us relaxing in the sun beckons, for others there's only a relatively short training time left before that annual event on 26th September, the Great North Run. Here's wishing good luck to all the runners registered to date as running for ASBAH:

Malcolm Anderson, Kerry Anderson, Neil Barnes, Michael Brown,

David Burns, Julie Burns, Dianna Capstick, Tracey Elkington, Brian Gregory, Marie Griffiths, Nichola Hall, Katherine Hempel, Malcolm Henderson, Ian Histon, Donna Hudson, Phil King, Lynn Mawdsley, Joe Patten-Brown, Richard Parker, Sara Richards, Jon Tibke, Gillian Tough, Andrew Warbrick, Katherine Winrow and Ken Wood.

Keep up the good work!



Golf Classic scores £33,000 for h

The sun shone in more ways than one on the Danny Mills Golf Classic, which was held in May in support of the Danny Mills Appeal for a helpline & information service. Thanks to Danny and his sporting mates, a staggering £33,000 was raised on the day.

As flagged up in the last *Link*, the match took place at the Warwickshire Golf Club, which is at Leek Wootton near Kenilworth. It was a gloriously hot day.

And, of course, you can't have celebrity sports events without celebrity sports people. Among those friends of Danny who joined him that day were Alan Smith of Manchester United; Maik Taylor of Birmingham City; Leicester's Ian Walker and Trevor Benjamin; Middlesbrough's Gareth Southgate and Frank Quedrue; boxers Jonny Nelson and Ryan Rhodes; ex-Norwich and Scotland Goalkeeper Bryan Gunn and SkySports presenter Alan McInally.

In addition to sponsorship of the day's programme by



Danny Mills
**DANNY MILLS
 APPEAL**

Helpline & Information Service



helpline appeal

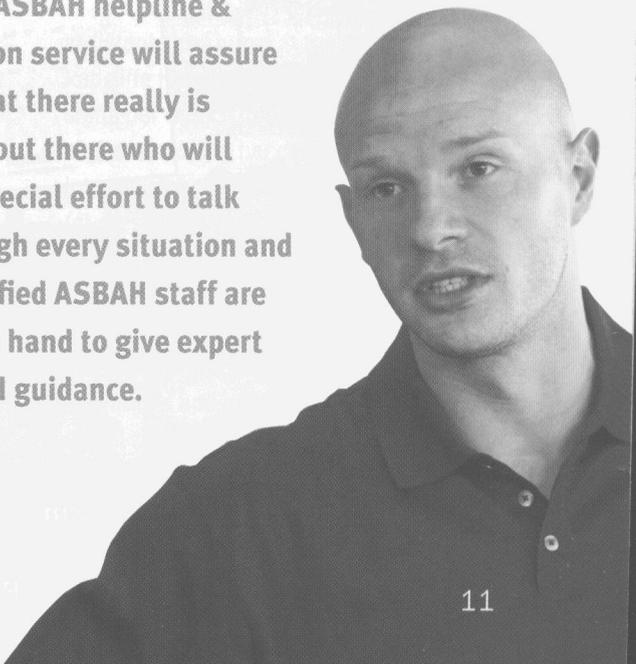
Strutt & Parker, Gross & Cole, Barclays, MJP Solicitors and Sport Link, real money was made when the guests, celebrities and other players delved deep into their pockets at the auction that night, bidding for some incredible items: a US Open Pebble Beach pin flag, signed by Tiger Woods, was bought by Alan Smith for £1,500; a Jack Nicklaus Masters Celebration framed piece fetched £5,000; a Nick Faldo-signed scorecard from the Irish Open raised £700; a Martin Johnson-signed World Cup rugby ball went for £900; a signed Muhammad Ali boxing glove was bought for £1,500; and an Arsenal shirt worn by Ashley Cole and signed by the squad attracted £1,100 – to name but a few items.

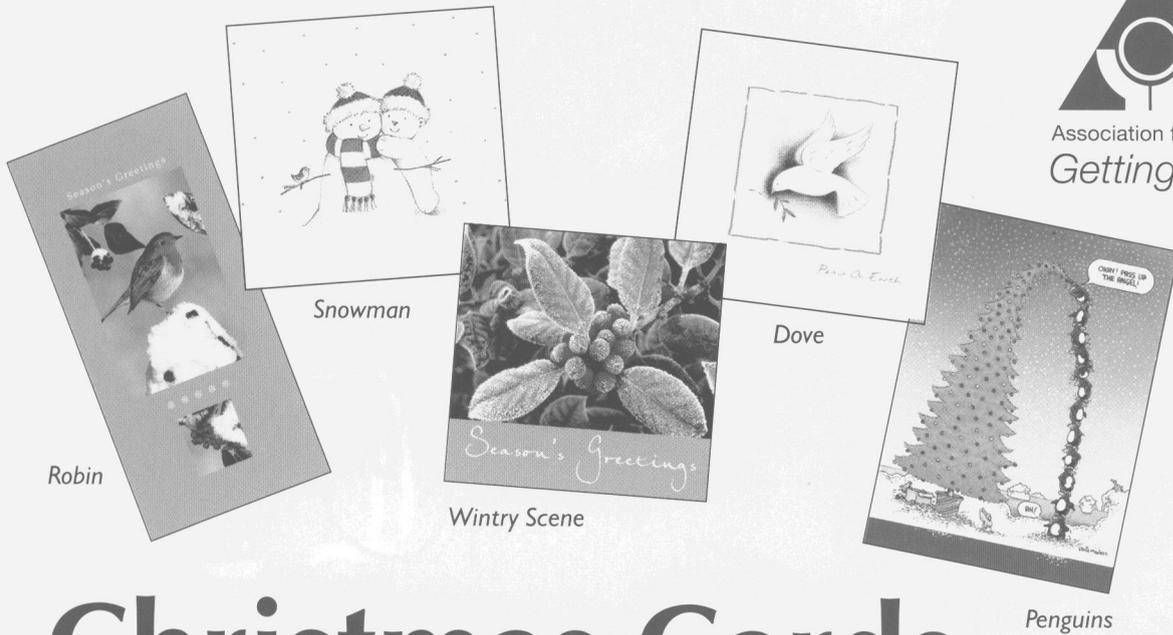
All in all, it was an outstanding success, breaking all records for an ASBAH fundraising event. Here's to next year's event, which will be even bigger and better – if that's possible!

Sincere thanks to Danny for all the hard work he put into the event.

A special ASBAH helpline & information service will assure people that there really is someone out there who will make a special effort to talk you through every situation and that qualified ASBAH staff are always on hand to give expert advice and guidance.

Danny Mills





Each pack of 10 cards and envelopes comes with a greeting inside each card that reads: With all Good Wishes for Christmas and the New Year. In addition the ASBAH logo and registered charity number appear on the back of the cards.

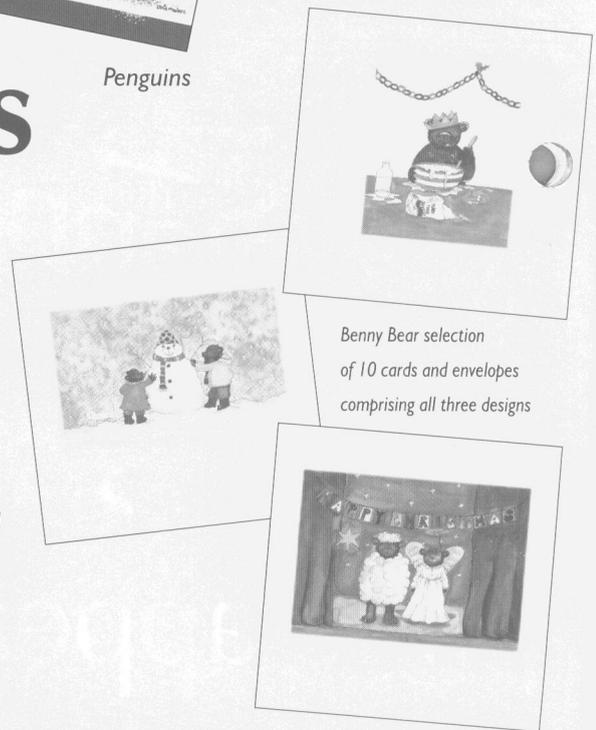
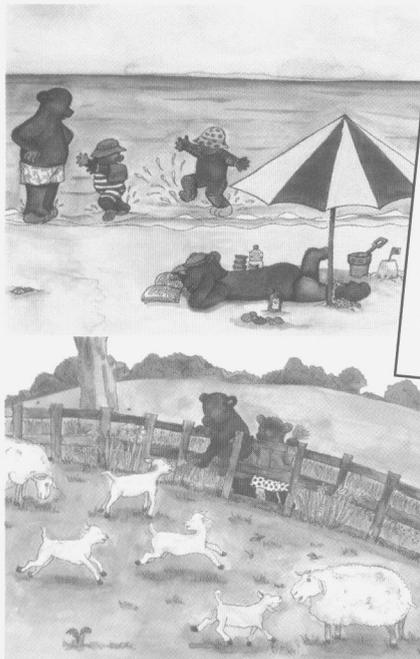
The back of the Benny Bear cards also have an explanation about the Hydrocephalus Action campaign.

Christmas Cards

If you would like to order some ASBAH Christmas Cards or Benny Bear Christmas selection packs, please complete the attached form.

Calendar 2005

Each month has a different colourful illustration showing Benny Bear. If you would like to order a Benny Bear calendar for 2005, please complete the attached form.



Benny Bear selection of 10 cards and envelopes comprising all three designs

ASBAH Order Form

Christmas Cards

Please send me:	Qty	Price	Total (£)
Penguins		£3.95 plus p&p	
Dove		£3.95 plus p&p	
Robin		£3.95 plus p&p	
Snowman		£3.95 plus p&p	
Wintry Scene		£3.95 plus p&p	
Benny Bear		£3.95 plus p&p	

Christmas card p&p (postage and packing) - £0.75p per pack

Calendar 2005

Benny Bear	£3.99 plus p&p	
Calendar p&p - £1.15p each	Total order (inc p&p)	£

Payment

(please tick/fill in your preferred method of payment and complete your name & address details)

Cheque (made payable to 'ASBAH')/PO order enclosed

Or

VISA Mastercard/Access Amex

Card no.

Start date Expiry date

Signature

Mr/Mrs/Miss

Address

Postcode

Telephone

Please send the completed order form together with your payment to:
ASBAH, 42 Park Road, Peterborough PE1 2UQ
Registered charity no. 249338

Meet the expert

Jackie Campbell *Clinical Nurse Specialist*



Enter deep into the heart of Oxford's Radcliffe Infirmary and you will find

Jackie Campbell on Leopold Ward. Jackie is a clinical nurse specialist and therefore is one of the ward's central figures.

Clinical nurse specialists (CNS) feature strongly in the lives of many people who are affected by SB/H. They usually first meet a CNS at a clinic and, because of the very nature of a neurosurgeon's work, it's the CNS who'll become the primary contact. Leopold Ward's clinic is held once a week; supervised by Jackie, 16-20 children are seen in a morning – the majority of cases are for hydrocephalus. Leopold Ward has an open-door policy, meaning that very few patients are ever discharged, with an ongoing watch kept over the years.

Jackie, 37, always wanted to be a nurse, but she had no idea until she completed her basic training that she wanted to be a children's nurse. She started her training to become a registered general nurse at London's King's College Hospital in the mid-1980s; she then spent one year training as a registered sick children's nurse (RSCN) at Guy's Hospital. She came to Oxford in 1991, specialising in children's surgery at the John Radcliffe Hospital (JRH). The next year she joined the Radcliffe Infirmary's children's neurosurgery department as a senior staff nurse, going on to study for a diploma in neuroscience nursing.

The infirmary is Oxford's original general hospital specialising in head and neck surgery and serves every bordering county: Berkshire, Buckinghamshire, Wiltshire and Northamptonshire. It's

therefore the only paediatric neurosurgery centre between Birmingham and London and as a result Jackie is an important contact with wards and community nurses in hospitals throughout the region.

This wider role means that she's a volunteer helper with the Oxford-based Children's Brain Injury Trust, who organise support groups for parents and arrange week-ends for brain injured children and their siblings. Jackie also sits on the Paediatric Neuroscience Benchmarking Group, which represents 26 hospitals from around the country, working together to identify and implement best nursing practice for neuroscience children.

CNSs came onto the hospital scene in the UK in the early 1990s in response to the need for better liaison between hospitals, the community and families, facilitating better continuity of care after discharge. However, Jackie's patients are mostly in-patients, so when they return home most of the contact is made over the phone.

The infirmary's consultant paediatric neurosurgeons are Peter Richards and David McAuley. Other members of the team include two registrars, a senior house officer, three paediatric anaesthetists, a clinical psychologist, physiotherapist, dietician and 24 nurses for two wards, plus play specialists, teaching staff and support staff.

Jackie is clearly very enthusiastic

about her work, saying: "I love children's nursing for a variety of reasons: caring for families, whom I get to know so well; the two-way relationship and the child-friendly environment. Over the years the profession has definitely learned how to care for children and families better, and nursing has changed for the better as a result. The ward has beds for 13 children, and we can arrange accommodation for 13

I love children's nursing for a variety of reasons: caring for families, whom I get to know so well; the two-way relationship and the child-friendly environment.

or so parents, some of them in a dedicated parents' suite within the hospital. We have cooking and washing facilities both on the ward and in the suite, and the parents' suite offers both an escape for parents, and acts as a halfway house so that parents can care for their recovered child before

finally leaving the ward."

Jackie, whose husband John is the assistant chief nurse at the Oxford Radcliffe Hospitals NHS Trust, works three shifts per week. Outside these hours she's developing her career with some interesting projects: writing guidelines (at present, on the prevention of pressure ulcers), and developing information leaflets for parents and children (for example, about naso-gastric feeding, in addition to information on neurosurgical operations and aftercare, such as tethered spinal cord).

So, CNSs seem to be the way of the future. This can only go to make a hospital stay a more reassuring experience.

Voice power

ASBAH benefits immensely from a group of adult members who play a keen behind-the-scenes role in its decision making processes.

The Your Voice Steering Group was set up more than ten years ago to give disabled service users the chance to have an active input in the development of ASBAH's policies and the information it publishes.

Although committee members come and go, the original enthusiasm continues and its role is as important as ever.

Jon Burke is the current chair and leads the 15-strong team. He is also one of the committee's founder members. Jon is naturally a firm believer in the Your Voice ethos, which is to give ASBAH's adult disabled service users the chance to speak up on



Jon Burke

significant issues which affect them.

Jon, from Huddersfield in West Yorkshire, says: "The group was set up to have two important functions. Firstly, to give more influence to adult members over services provided by ASBAH; and secondly to bring adults with spina bifida and hydrocephalus together, increasing their confidence and their awareness of significant issues that affect them."

The Your Voice group is made up of people from across the country with a wide variety of experiences. The current committee was elected last October and will serve a three year term.

Jon explains: "We meet up every two months for a weekend meeting and discuss a wide range of issues during that time. For example, the group is currently arranging its next national event, which takes place from 20 – 22 August in Birmingham and which will have a healthy living theme."

As the group has members from all over England, it likes to meet in different parts of the country. However this is not always easy because it is difficult to find venues that offer the accessibility they require, for a reasonable cost.

The group was set up to have two important functions. Firstly, to give more influence to adult members over services provided by ASBAH; and secondly to bring adults with spina bifida and hydrocephalus together.

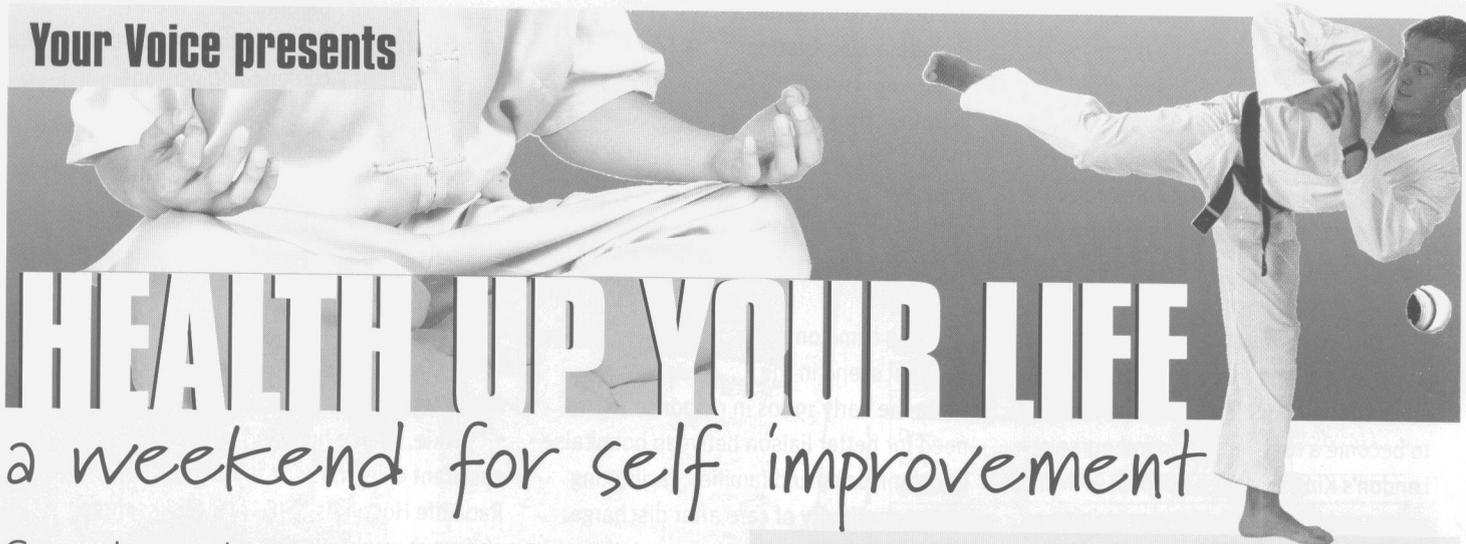
Twice a year it reports to ASBAH's trustees, enjoying a formal link with the decision making part of the organisation.

"Working on the Your Voice Steering Group is very enjoyable and rewarding," Jon adds. "It's vital that we get together and share ideas about issues that are important to

us and report back to ASBAH.

"We are taken very seriously by ASBAH because Your Voice keeps the organisation grounded. It is its direct line to disabled service users and one of the ways ASBAH keeps in touch with our needs."

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 **ASBAH**
Association for Spina Bifida and Hydrocephalus
Getting the most out of life

Jamie's independent hopes

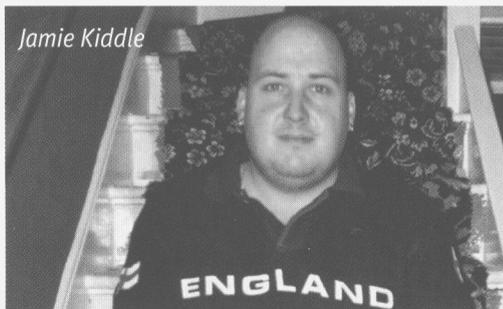
Jamie Kiddle has lived at home with his family all his life, so naturally the thought of living independently is a daunting one for the 26-year old.

But Rachel Nicholls, his ASBAH adviser, passed on a copy of the *Make It Happen* information pack when she recently paid him a visit.

Jamie, who has arrested hydrocephalus, is hoping to leave the family home in Abbey Wood, north London, later in the year and has found the Independent Living Pack a huge help. He told *Link*: "I feel that I'm at the age where I should think about moving out. It's lovely being at home but I can't live with my family forever. I need to become more independent.

"I have found the pack really useful in prompting me to think about several issues that I hadn't even considered. I didn't realise that there were so many things to think about, such as the many different housing options. Having read the information and filling in the questionnaires makes me feel better equipped when I begin house hunting."

It's lovely being at home but I can't live with my family forever. I need to become more independent.

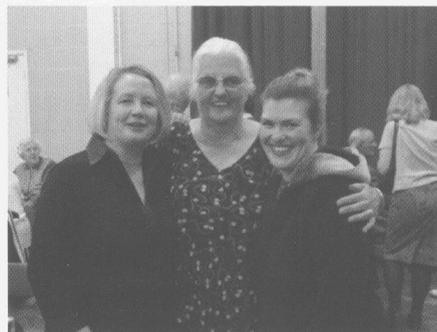


Jamie Kiddle

Jamie added that he found the pack very easy to read and well laid out, with the information presented in a clear and concise way.

Rachel, who is helping Jamie to complete a council housing application form, said that there has been a very good response to the Independent Living Pack from service users in her area. "It's a very comprehensive pack and will help people to really consider all the different aspects of independent living," she said.

More information about *Make It Happen* can be seen at www.asbah.org. It can be obtained from local advisers or by contacting: Information Section, ASBAH, 42 Park Road, Peterborough PE1 2UQ. Tel: 01733 555988; info@asbah.org



Pat Edwards (centre) with colleagues Liz Morris (left) and Eleri Joneson (right)

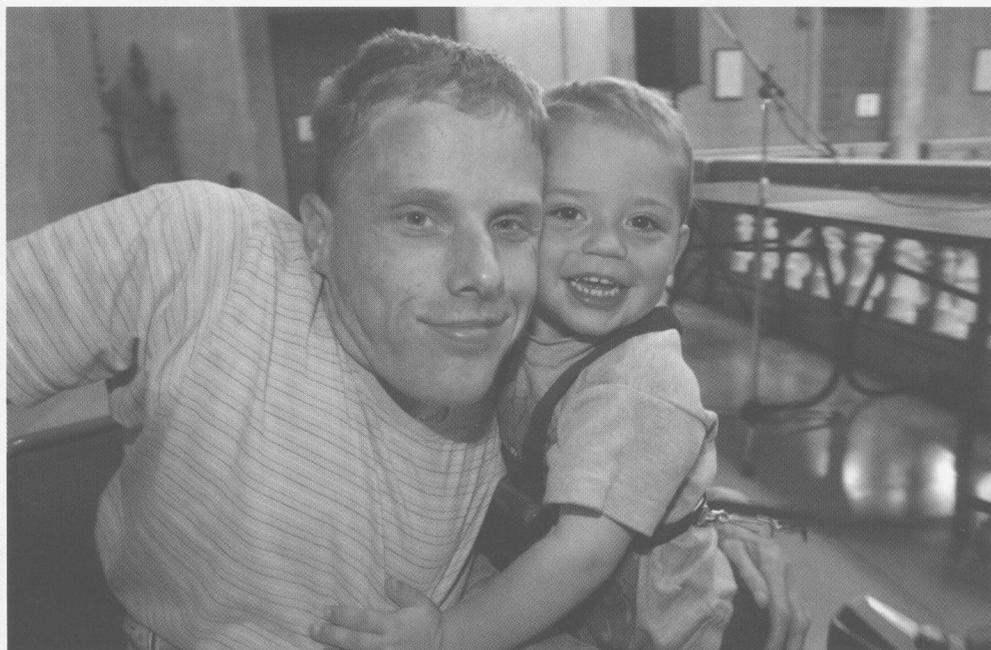
Palace honour for Pat

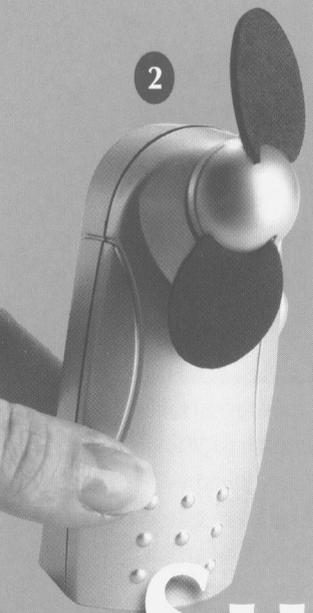
Mid-Wales ASBAH founding member Pat Edwards has been awarded an MBE in the Queen's Birthday Honours for services to the community as a district nurse for 40 years in the Dwyf Valley, North Powys.

On receiving her letter from the Palace, Pat, who lives at Llandrynmair, said: "I couldn't believe it and I was very pleased. Coming so soon after my retirement this year, when I was given a farewell concert, it's the icing on the cake." In June Pat was elected association chairman and we wish her well in her new post.

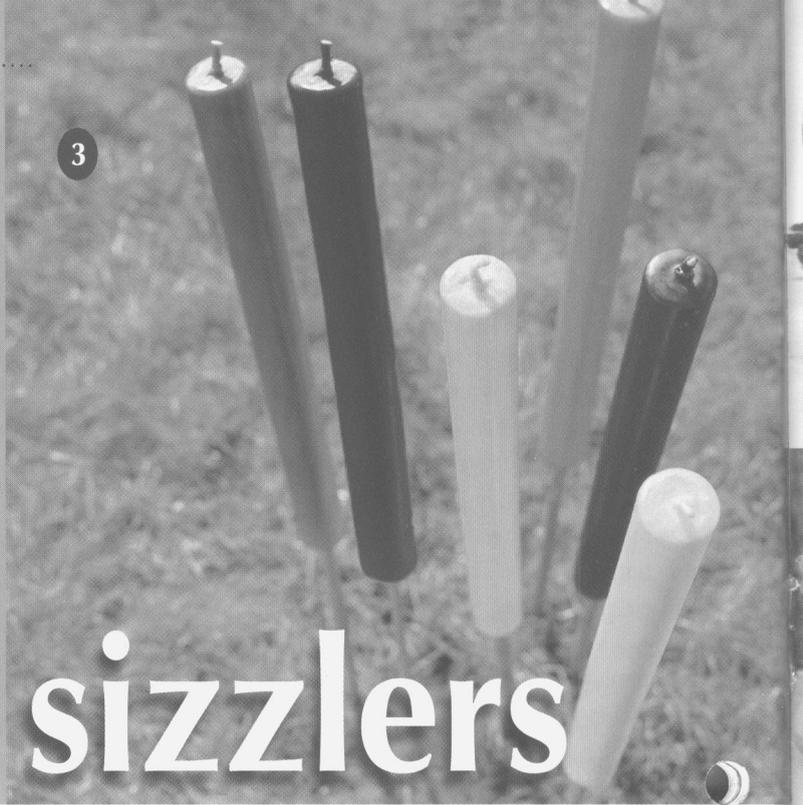
Pat is also a member of the ASBAH Cymru group of Welsh local associations, which represents the local associations in Wales and advises on service needs, policy issues and ASBAH services affecting people in Wales.

Thanks to funding from the Lloyds TSB Foundation, Jason Merrill (pictured right, with his son Joseph) has been appointed the Your Voice co-ordinator at national office. Jason, 32, who will be working two days a week, was also elected to Bretton Parish Council in the May elections. We wish him well in his work for Your Voice.





2 Summer is here at last and we can start planning outdoor fun. Whether it's a lazy day in the garden, a leisurely trip to the park or an exciting outing to the beach, we've got summer well and truly covered.



Summer sizzlers

1 Blow away your cares with some bubble magic. See who can blow the biggest bubble, or compete to send it the highest...how long can a bubble last before it bursts? This classic, gentle game never fails to captivate children and adults alike. *Bubble Shower, £1.99, available from Chad Valley, exclusive to Woolworths.*

2 Stay chilled out as the temperature rises, with this dinky little hand-held fan. Providing a welcome blast of cool air with its foam propeller, it's compact and lightweight, fitting easily into a handbag or pocket. Battery included. *'Cool' Handy Fan, £5.95, available from Lakeland Limited at their stores (telephone 015394 88100 for your nearest outlet) or via www.lakelandlimited.com*

3 Citronella has long been considered the best insect deterrent and it's natural too! These citronella garden candle sticks are pretty as well as practical, lighting up your summer outdoor evenings and keeping those annoying bugs at bay. *Citronella garden candle sticks, £2.99 each, available from Woolworths. Always enjoy candles safely and never leave them unattended.*

4 Enjoy summer dining without fear of breakages with this funky plastic tableware. Brightly coloured candy coloured dots adorn the matching bowls, glasses, plates and even the cutlery, so you can eat al fresco in fully co-ordinated style! *Plate bowl and glass, £1.99 each. Fork and knives set £2.49 and salad bowl £2.99. Available from Woolworths.*

5 Perfect for picnics, these sturdy glasses and water jug look sophisticated, yet according to the dedicated product testers at Lakeland, no amount of crashing, bashing or crushing will damage them. Put them to the test – cheers! *Unbreakable water jug £9.95, wine glass £3.95, hi-ball glass £2.95, all available from Lakeland Limited at their stores (telephone 015394 88100 for your nearest outlet) or via www.lakelandlimited.com*

Imagine delicious home-made ice lollies all summer, at a fraction of shop bought prices and in whatever flavour you choose? Yummy fruit flavours, milkshake or yogurt, the choice is yours and as soon as you finish, you can pop another load into the freezer for a refill! *Lickety Sips Ice Lolly Maker, £4.55, available from Lakeland Limited at their stores (telephone 015394 88100 for your nearest outlet) or via www.lakelandlimited.com*

The extra space of the great outdoors and soft, grassy surfaces are an enticing opportunity to get active with summer games. Take your pick from six fun activities, including Velcro spinning catchers, an amazing flying disc, catching cups and ball – and at the end of the day, just pack them up into the lightweight backpack, ready for another sunny day. *Mothercare 6-in-1 Sports Set, £9.99, available from Mothercare stores nationwide. www.mothercare.co.uk*

Picnics on the go aren't complete without a state-of-the-art cooler bag these days, but it needn't blow the budget. Enough food and drink to feed the whole family can be stored in this cheerful 40 litre cooler bag. With a heat sealed, wipe clean liner, front zip pocket, side pockets and adjustable shoulder straps, it's the bee's



Teriyaki Beef Skewers



Photograph courtesy of British Meat

Feeds: 4
Time to cook: See chart below
Key Ingredients: Beef rump steaks (or use sirloin steaks), Garlic, honey, soy sauce, chilli

Drizzle Mix together 2 cloves garlic, crushed, 2cm (¾") root ginger, peeled and grated, 30ml (2tbsp) honey, 30ml (2tbsp) soy sauce, 1 red chilli, seeded and chopped, and 5ml (1tsp) sesame seeds

Brush or drizzle over 2 lean beef steaks or kebabs during the last 2-3 minutes of cooking time. Alternatively serve as a dipping sauce for steaks or kebabs.

Dollop Mix together 2 spring onions, sliced, 3" (7.5cm) cucumber, cut into strips, 1 red chilli, sliced, 15ml (1tbsp) soy sauce, 15ml (1tbsp) sesame oil and 5ml (1tsp) sesame seeds to make an oriental salsa. Serve onto or alongside the barbecued steaks or kebabs.

Serve with a noodle and vegetable salad.

Remember this recipe contains nuts.

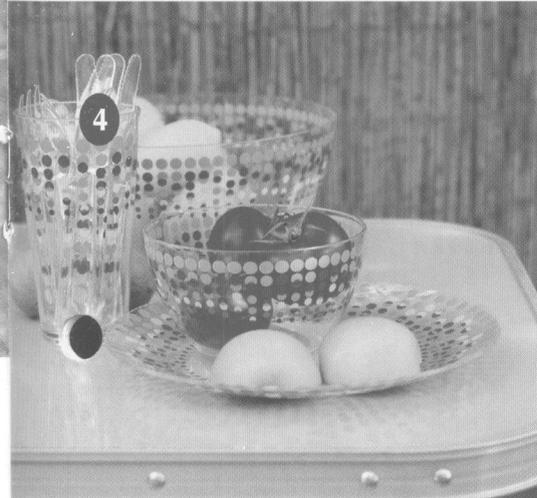
Cooking Information

1. Timings below are for each side
2. Remember, the timing relates to the thickness of the meat

Beef steaks	Thickness	Timings per side
- Sirloin or rump	2cm (¾")	2 minutes (rare)
- Fillet steaks are approximately 1cm thicker so will need an extra 1-2 minutes cooking time each side		4 minutes (medium) 6 minutes (well done)
Kebabs	Timings	
Simply make your own kebabs by cutting the above steaks into (approximately 2.5cm (1") size cubes	15 minutes in total	



5



4

knees for foodies!

Pro Action 40 litre cool bag, £12.99, available from Argos via stores nationwide or visit www.argos.co.uk

Keep your burgers under control on the barbeque with a wire burger holder. Simply place the burger between the mesh sides, lock securely into place and watch the food cook. The wooden handles ensure fingers don't get too hot when turning the burgers.

Wooden handle BBQ Burger Holder, £3.47, available from ASDA stores nationwide. www.asda.co.uk

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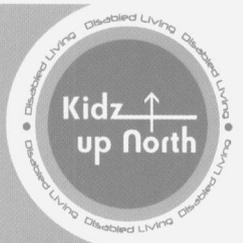
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- Practical Solutions to Toilet Training & Continence Promotion *and lots more ...*



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On the beach

Pack the picnic, grab your beach gear and hat and start the car – summer's here and it's time for a day out at the beach! But hold on, what's the access like, are there disabled toilet facilities and disabled car parking spaces?

Check out our guide to see where some of the country's better served beaches are located and then all you have to do is take your pick and decide which one you'd like to visit.

England

NORTH TYNESIDE: Seaburn Beach is a wide sandy beach with a promenade. Lifeguards and a first aid post are available, as are deckchairs and a café. Toilets have disabled facilities and the free car park has spaces for disabled visitors. *Sunderland Tourist Information Centre:* 0191 553 2000

www.visitsunderland.co.uk

ESSEX: Brightlingsea is a classic small British resort ideal for families, with a pleasant sandy beach and colourful beach huts. The café/shop is very close to the beach and toilets with disabled facilities are available. There is ample free parking. *Clacton Tourist Information Centre:* 01255 423400

www.essex-sunshine-coast.org.uk

NORFOLK: Mundesley sandy beach is backed by a raised promenade and beautiful cliff top gardens. Toilets for the disabled are conveniently adjacent. A grassed area can be used for picnics and the large car park at cliff top level has disabled parking bays.

Mundesley Visitor Centre: 01263 721070

WEST SUSSEX: West Wittering is a mile-long stretch of dune-fringed sandy beach. Disabled toilets are available, deckchairs and windbreaks can be hired and the pay car park has disabled space provision. *West Wittering Tourist Information Centre:* 01243 775888 www.chichester.gov.uk

KENT: Ramsgate and Ramsgate Main Sands are popular with families and are near to a picturesque harbour. Toilets for the disabled are available and there is a 200 space pay car park, including spaces for disabled visitors.

Thanet Visitor Information Centre: 01843 583333

www.tourism.thanet.gov.uk

DORSET: Lyme Regis looks out over a sandy beach. The area also has an international reputation for its Jurassic cliffs and is known as the Jurassic Coast, which contains a vast array of fossils, and is a UNESCO World Heritage Site. Toilets include disabled facilities and the pay car park has 500 spaces including some allocated for disabled visitors.

Lyme Regis Tourist Information Centre: 01297 442138 www.westdorset.com

CORNWALL: Praa Sands East and West is a mile long beach with some rocky sections. Amenities are at the western end; there is a café and disabled toilet facilities and pay parking for up to 500 cars.

Helston Tourist Information Centre: 01326 565431 www.go-cornwall.com

Wales

CEREDIGION: Aberforth has two sandy beaches at the picturesque resort and there are disabled toilet facilities and showers. Pay car parking is available for 50 cars, including disabled spaces. *Cardigan Tourist Information Centre:* 01239 613230 www.ceredigion.gov.uk

Northern Ireland

LONDONDERRY: Benone Strand is part of a seven-mile stretch of golden sands and this safe beach has lifeguard patrols from July to August. The beach has disabled toilet facilities and free car parking is available with provision for disabled visitors.

Limavady Tourist Information Centre: 028 777 60307 www.limavady.gov.uk

It's always worth telephoning the local tourist board to find out about facilities in detail before you travel. For a more detailed guide to the best beaches in the country, the *Good Beach Guide*, produced by the Marine Conservation Society, is available free of charge, with just a nominal charge for postage. Visit www.goodbeachguide.co.uk and complete the form or call 01989 566017 to order your copy.



Bolton & Bury

Link talks to chair Geoff Madeley



Bolton and Bury ASBAH must be one of the few local associations to stretch across two counties - Bolton being in Lancashire and Bury being a part of Greater Manchester.

Not that minor details like that worry Geoff Madeley, who stepped into the chair last May having been treasurer since 1995. Geoff – along with the rest of his dedicated committee – is more concerned with spreading the ASBAH word across the area.

“Our biggest problem is simply getting our name and telephone number known,” he explains. “There are a lot of hospitals out there and if they don’t even have our telephone number how will people contact us?”

Earlier this year the association team sent out around 120 laminated flyers to doctors’ surgeries to generate more publicity, and future plans include a website to provide another point of contact.

Geoff and his wife Jackie became involved in the Bolton & Bury (B&B) Association 18 years ago following the birth of their daughter Ruth, who has spina bifida and scoliosis. “We received a lot of information and support from ASBAH,” Geoff recalls, “so we became involved with the association to put something back, as well as to get to know other families in the area.”

B&B was set up more than 30 years ago and operates mainly as a self-help group for the 46 families who are members. “We

found out some time ago that it’s almost impossible to arrange get togethers for everyone. It’s difficult enough to find times that suit all members of the management committee, never mind everyone else,” Geoff says.

So instead of regular meetings the association provides information and telephone support, as well as arranging the occasional social gathering. The most recent was an alternative therapies day at Bolton’s Jarvis Hotel, where guests could learn more about homeopathy, aromatherapy, reflexology and other treatments, as well as enjoying a buffet lunch.

Thanks to a legacy B&B also has sufficient finances to award grants for hospital stays, driving lessons and to pay for cars to be adapted. The money was bequeathed in the will of a William Rogers.

“It was obviously a wonderful surprise,” Geoff says. “We don’t know anything about our benefactor, apart from his name and that his estate was divided between three charities. We use some of the money to award grants and keep the remaining sum in a trust fund. Thankfully it has taken the pressure off us financially and we won’t have to worry about fundraising for some time.”

Many of ASBAH’s local associations are still run by the original founders because new volunteers don’t often come forward. But the B&B committee mainly represents a new generation of support. It is made

up of deputy chair Siobhan Corr; secretary David Clyne, who also sits on ASBAH’s services & marketing committee; David’s daughter Joanna, who has spina bifida, and fellow committee member Martyn Gardiner; and Cath Greenlough, Geoff’s predecessor.

The committee benefits from the help and support of Joan Pheasant and her team at the ASBAH North office in Leeds. “We’ve got a close working relationship with the office, especially with Marcia Conroy, the area adviser. But one of our main problems is a shortage of committee members and people to help with general duties. Everyone is obviously very busy with work and family commitments, but being involved with the local association is very rewarding and there’s a great deal of job satisfaction. I can and do recommend it,” Geoff says.

Indeed the latest issue of B&B’s newsletter, *ASBAH Arrow*, features an appeal for help with general admin and press officer duties, plus someone willing to edit *ASBAH Arrow* itself.

The committee has also sent out a questionnaire to the 46 participating families, to make sure that they are continuing to provide the services that members need. “We last surveyed our members three years ago and have based our work on what they suggested. After all, there’s no point in putting time and effort in if we aren’t listening to the people we serve,” he points out.

With Geoff and his committee’s dedication and concern it seems that the Bolton and Bury Association is right on track for another successful year.

We became involved with the association to put something back, as well as to get to know other families in the area.



ParalympicsGB

Paralympic Preview

Karen goes for gold

Top athlete Karen Lewis-Archer is preparing for an assault on track gold at the Athens Paralympics, thanks to a career that began after a quirk of fate.

The 29-year-old, who has spina bifida, was obsessed by swimming in her early teens and made it into the British squad. But a crisis in the athletics team meant they were one short for the relay and Karen took up the challenge that was to prove the springboard for a successful track career.

The determined sportswoman from Carluke, South Lanarkshire, recalls the moment she realised wheelchair athletics were

for her. "I'd been part of the swimming squad, but when the track team was a person short they asked me to take part. I did and it really grabbed me. It's like any job though - you have your ups and downs and some weeks you can't be bothered to train, but you do anyway."

But husband Wayne, who hopes to be in the Athens crowd to cheer Karen on, provides wonderful support when she needs an extra boost.

Now, after coming fourth in the 100 and 200 metres at the 2000 Olympics in Sydney, she is moving up to the longer sprint of 400 metres in Greece this summer.

One of three Scots in the squad, Karen is a shining example for any disabled youngster who thinks their condition can beat them. She trains up to six days a week on road and track, covering between three to 10 miles a day as well as doing weights and her old favourite, swimming.

Karen, who has spent the last four years preparing to win a place in the squad, will spend ten days in a training camp in Cyprus to acclimatise before the Games start on 17 September. "It's great to be at the Paralympics and experience the atmosphere, but

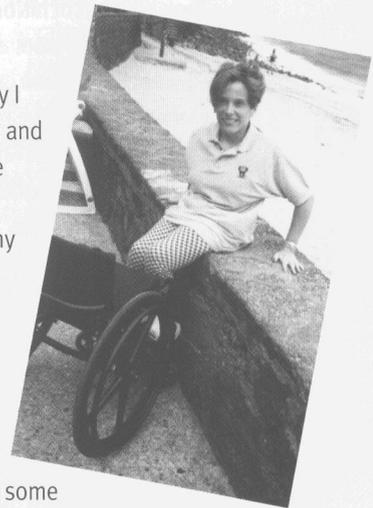
most importantly I want to go there and win medals. The 2000 Games in Australia were my first and I don't think there will ever be another games like it - Athens will be good but Sydney will take some beating."

Karen has been pacing her preparations for the Games well with a 400 metre European Championship win in Holland

this year, as well as silvers in the two shorter distances. The Red Star Athletics Club member, who uses a custom-built wheelchair in races, is also the Scottish and British champion for 100, 200 and 400 metres.

After Athens Karen plans to take some time out to take a long look at her life,

and to decide whether to continue her hectic athletics schedule. "I'm undecided whether to retire or push to get to the Beijing Paralympics in 2008," she admits. "But at the moment I'm concentrating on going to Athens to get the medals. I want to do as well as possible - it's what I've spent the last four years training for."



It's great to be at the Paralympics and experience the atmosphere, but most importantly I want to go there and win medals.

Codman - Working in partnership with ASBAH

Mark Attenborough

International Training & Education Manager



Mark Attenborough's role as Codman's International Training and Education Manager takes him all over Europe, the Middle East and Africa.

He took time out of his hectic schedule to talk to *Link* about his work and his hopes for the Hydrocephalus Action campaign.

"I joined Codman 21 years ago as a product manager, and certainly didn't expect to stay as long as I have, although my job has evolved over the years.

My work today is basically running training courses explaining how our products work, so our sales people can answer any questions from doctors and nurses.

"If I'm not running courses I'm usually in the office planning them or sorting out problems and queries. After 21 years within a company you become the guru of knowledge, and get the 'Did we used to...?', 'Can you remember...?' type questions. I suppose I'm the unofficial company historian!

"There's a great deal of travelling in my job. I run a basic two week training course twice a year, then travel around for a week at a time, visiting several countries.

"I was recently in Dubai and then Jordan at the same time as Colin Powell, so security was very fierce. I was teaching a group of Iraqi neurosurgeons about shunts, which they really appreciated. Many of the surgeons had been trained in this country, so they have connections from long ago.

"It's very rewarding when I talk to surgeons and hear how well Codman products work. Rosemary Batchelor at ASBAH gives me feedback about the popularity of Benny Bear, which also gives me a boost.

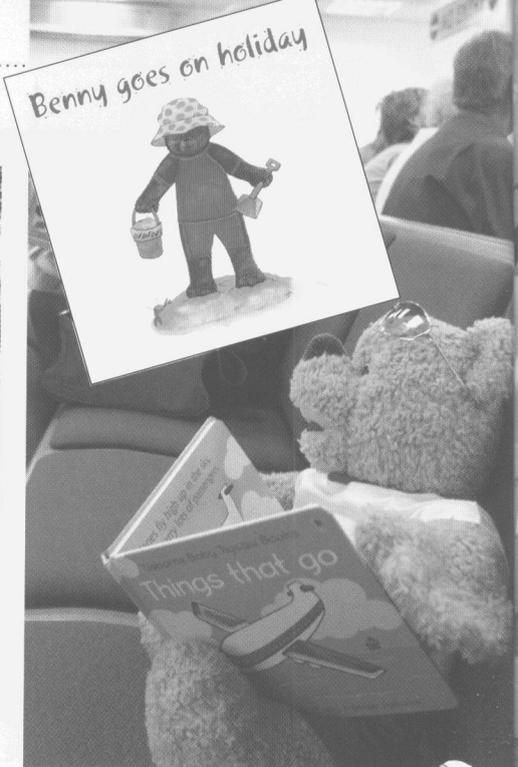
"I do occasionally get the chance to meet

people with hydrocephalus, through ASBAH in the main, and sometimes in hospitals. It's always very interesting and rewarding to meet people whose lives have benefited from our work.

"Awareness of hydrocephalus is very important and I hope the Hydrocephalus Action campaign will take some of the mystery away, so people have a better understanding of it and don't find it so scary. That's got to be good for families and teachers who come into contact with people with hydrocephalus to enable them to manage things better.

"I have a fascinating job. The whole area of neurosurgery is very exciting because lots of new and important discoveries are being made all the time. I've noticed big changes over the last 21 years in the way patients are treated and how much better they are becoming.

"Codman has contributed a lot to these developments and it gives me a good feeling to be part of it."



Benny Goes French

Young fans of the Benny Bear books will be pleased to hear that a third story was published in early July

In perfect time for the summer holidays, the latest offering, *Benny Goes on Holiday*, will help to allay any concerns parents of children with hydrocephalus may have about travelling abroad.

Benny Bear was created by Codman to help neurosurgeons explain to parents and children what a shunt operation is. The new book sees Benny and his family planning a holiday at a French campsite and looks at the problems and concerns of children and parents when travelling abroad.

It kicks off with a visit to Benny's neurosurgeon, who gives them a CD-ROM with Benny's scans to take with them in case Benny is ill in France. Other preparations for the trip include trying out French food (and reassuring Benny that he doesn't have to eat snails!), learning a few words of French and packing their bags for the flight.

Of course the holiday is a huge success and Benny, like many children, throws a



In 2004 Codman and ASBAH are working in partnership to promote 'Hydrocephalus Action', a campaign aimed at heightening hydrocephalus awareness.

Codman
a Johnson & Johnson company



Codman - Working in partnership with ASBAH

NPH research hope

Simple tests help select patients

A small research team is making big strides in the diagnosis of normal pressure hydrocephalus. The team, based at the Royal Preston Hospital in Lancashire, is 18 months into a study of NPH which normally occurs in people aged 60 and over.

Many of its symptoms are the same as those of dementia, Alzheimer's and Parkinson's Disease – imbalance, forgetfulness and memory loss - making it difficult to diagnose. As a result the condition often goes untreated.

The team is designing a series of simple, cost-effective and reliable tests to help select patients who could benefit from a shunt operation. The rigorous tests include an MRI brain scan, walking motion checks, neuropsychological tests to determine any loss of brain function and a diagnostic check of the spinal fluid.

After a successful pilot study, the project won funding from the Sydney Discroll Foundation (a charitable organisation in Preston) and was launched in April 2003.

Mr Gopalakrishnan Balanurali, a registrar in the Neurosurgery Department, is the main researcher leading the study. He told *Link*: "Patients diagnosed with NPH can be treated with a shunt. If the cause of NPH is known, success rates can be as high as 60-80 per cent.

"In cases where the cause is not known, the success rate varies from 25 per cent to 75 per cent. The higher success rates have been reported from centres using the more demanding diagnostic tests which we are trying to improve on."

The team currently has 34 research patients who have undergone an initial series of tests as part of a programme running until 2005. So far 16 have had shunts and two are awaiting the operation. But analysis of the results so far shows that the patients selected for the shunt have shown a significant improvement in their test results and a boost to their quality of life after the operation.

The team, which is recruiting its patients

by referral from GPs and physicians within the hospital, aims to review progress of patients after two years and again after a further five.

Specialists from the Royal Preston Hospital and the University of Central Lancashire make up the pioneering team, with back-up from consultant to secretarial level. Key figures are consultant supervisor of the research Mr Aprajay Golash and psychologist Dr Nicola Starkey, who is studying memory problems related to NPH patients.

The research team has published its initial results and has presented at peer review groups around the country. It's thought to be one of the few centres in the country who have a dedicated research programme looking at the various dilemmas about managing patients with NPH.

Mr Balamurali added: "We recently teamed up with the Neurosurgical Department at Manchester's Hope Hospital, which has a larger population of patients and more referrals, with a hope to further our research with their help. Our team also hopes to look at some of the causes of the disease and ways of preventing it in the future.

"I feel that our research has taken a big leap from the conventional way of identifying patients for a shunt operation, at least in the north west region.

"Although it may be too early to speculate the results of the research, we have seen significant improvement in patients wellbeing. The families of patients have been overwhelmed with the results of their loved one who, for the first time in months to years, have shown signs of progress and character.

"Needless to say, we need support and confidence from the community to be able to carry out a major research in a world with increasing population to help the future generation."



tantrum when it is time to leave.

Peter Farrall, ASBAH's Director of Marketing and Communications, told *Link*: "We're very pleased with the contents and illustrations of the new book. *Benny Goes on Holiday* demonstrates in a child-friendly way what parents must think about when taking their child on holiday."

With words by Senior Medical Adviser Rosemary Batchelor and illustrations by Charlotte Meyer, the book also contains a checklist for parents.

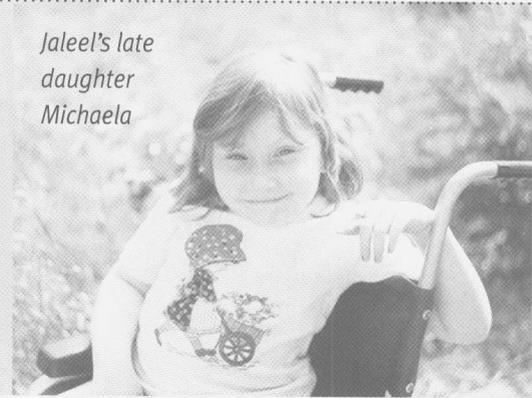
Benny Goes on Holiday is available free of charge from your ASBAH adviser. Alternatively, send a large SAE with two first class stamps to: Information Section, ASBAH, 42 Park Road, Peterborough PE1 2UQ.

All three Benny books, *Benny Gets Better*, *Benny Goes to School* and *Benny Goes on Holiday* are available for £1.75 inc p&p. Please make cheques payable to ASBAH and send to the Information Section at the address above.

Link would like to thank Coventry Airport and Thomsonfly for their help with the pictures for this article.



Jaleel's late daughter Michaela



Research project stalled by funding withdrawal

A leading research scientist working to prevent the neurological deficits in some types of congenital hydrocephalus cases is struggling to find funding for the project.

Dr Jaleel Miyan, Senior Lecturer in Biomolecular Sciences at Manchester University's renowned Institute of Science and Technology (UMIST), is leading a research team doing ground breaking work on the underlying biology of the condition. ASBAH has agreed in principle to support the research and is seeking funds for the purpose.

After eight years of intensive research the team is convinced they can prevent and even potentially reverse the arrested development of the brain that occurs when the fluid in the brain is

obstructed. Moreover, they believe that in the future many cases of congenital hydrocephalus could potentially be diagnosed by a blood test early in pregnancy.

The lack of funding is now hampering the work and the scientists need £30,000 a year to maintain the vital research.

The lack of funding is now hampering the work and the scientists need £30,000 a year to maintain the vital research. The project was backed by the Wellcome Trust for six years, but the organisation has recently been forced to reduce its funding of all research programmes. The team has now applied for funding to the Medical Research

Council and Cerebra, the Welsh foundation for the brain injured infant, and is keeping its fingers crossed for a successful outcome.

The current treatment for hydrocephalus - shunting - relieves the pressure of fluid around the brain, but does not rectify the abnormal development of the cerebral cortex; children continue to suffer a range of neurological deficits even after shunting. Dr Miyan's research project has been working to identify molecules within the CSF which are responsible for the abnormal development of the cerebral cortex, to see how they work. "We now know that there is something in the fluid

London clinic leads the way

People with SB/H from all over England are benefiting from the work of a pioneering clinic which takes a holistic approach to healthcare.

The Chelsea and Westminster Hospital clinic in London's Chelsea is proving so popular that people are travelling from as far afield as Lancashire to be seen by the small team of experts.

It opens once a fortnight, acting as a one-stop-shop for people with spina bifida and hydrocephalus who need monitoring to stay healthy.

From an initial medical assessment, which may include shunt x-rays and bladder scans, patients can be helped in a number of areas, including continence advice, physiotherapy, psychology and occupational therapy.

While children's clinics organised along similar lines operate across the country, it is thought that there are only two in England which are open to adults - Chelsea and Westminster Hospital and one at Chailey Heritage in Sussex.

Gill Yaz, ASBAH's adviser for north east London and specialist adviser for medical and continence matters for the South East region, is a keen advocate of the clinic.

She tells *Link*: "The clinic takes a holistic view to healthcare, looking at the person and their lifestyle as a whole. People are

prepared to travel great distances to get to the clinic, which is perhaps one of the best advertisements it could have. Around 13 people can be seen during one session and consequently there are very long waiting lists."

She adds: "Children are reasonably well catered for, but when they become adults the healthcare usually becomes fragmented, and they see a variety of people to treat their different needs. This is both unsatisfactory as well as being inconvenient to busy lifestyles."

Gill is encouraging service users and local advisers to lobby locally for clinics like this one:

"People are entitled to the best possible care, and those with spina bifida and/or hydrocephalus can have complex needs. It makes sense to treat all their issues under one roof."

The Chelsea and Westminster Hospital clinic team are: consultant Richard Morgan, occupational therapist Andra Hare, continence adviser Ann Wing and neuropsychologist Jo Iddon. The clinic also receives much needed help from Sister Ellie Shepherd and care assistant Sue Murden from the hospital's

People are entitled to the best possible care, and those with spina bifida and/or hydrocephalus can have complex needs.

that stops cells dividing in the brain. We know that the cells are normal and we now need to identify this molecule so that we can stop it and allow the brain to fully develop. It would be a dream come true to unlock the potential brain in these children," he says.

When asked about possible prevention, he added: "There is data that led me to believe that around 60 per cent of all cases of foetal hydrocephalus could be prevented by blocking specific interactions between mother and foetus at critical stages of development. Susceptible pregnancies could be identified by simple blood tests in the early stages of pregnancy and mothers treated to protect the developing foetus.

"Hydrocephalus is not directly caused by a genetic defect (except x-linked hydrocephalus), but by interactions with some environmental factor which we think it should be possible to detect through a blood test."

It is a very frustrating time for the research team, and in particular Dr Miyan,

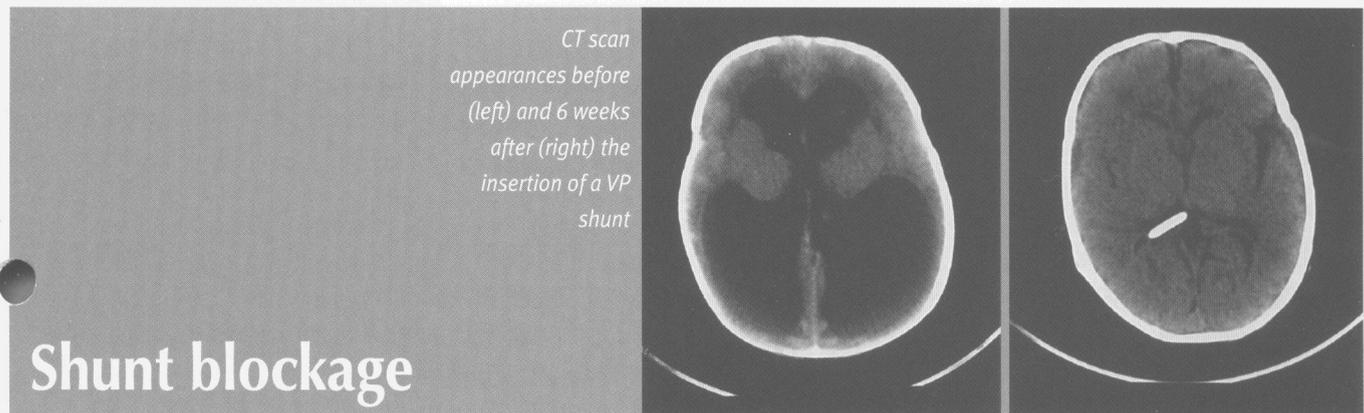
who has first hand knowledge of living with a child with a neurological condition: his stepdaughter Michaela was born with SB/H. Sadly, she died of a shunt blockage in 1986 at the age of ten.

Dr Miyan says: "I feel we can now see light at the end of the tunnel, so it's very frustrating to have run out of money. Funding would allow us to prove the principle that CSF is a causative factor and then we can examine potential treatments.

"It's so difficult to get funding these days because money is mostly made available to research diseases, not conditions such as hydrocephalus, because it's believed that conditions don't have one specific cause. However, our interest is in the outcome of fluid obstruction which is the same whatever the cause," he says.



The UMIST team: Dr Miyan (front centre), and (L to R) Mohammad Nabiyouni and Mahjiub Zendah of UMIST, Dr Reza Kaje-Daluae, visiting professor from Iran, Carys Bannister of St Mary's Hospital Foetal Management Unit, Preston and Dr Fran Morgan of the Wade Centre for Hydrocephalus Research in Orlando, USA.



CT scan appearances before (left) and 6 weeks after (right) the insertion of a VP shunt

Shunt blockage

Shunts remain the mainstay of treatment for hydrocephalus and, in the majority of cases, this remains an effective treatment.

However, they can never perfectly mimic normal physiology and, like any mechanical device, they are prone to malfunctions of various sorts.

Shunt blockage, along with shunt infection, remains the commonest cause of shunt malfunction. In the vast majority of cases of shunt blockage prompt investigation and revision of the shunt is associated with full recovery and discharge from hospital within a few days. In rare

situations shunt blockage can be fatal, particularly when the diagnosis is delayed.

There hasn't been a significant improvement in the level of blockages in recent years. The rate of shunt blockages is highest in the first year after insertion, when it can be in the order of 20-30% - decreasing to approximately 5% per year thereafter. Over half of patients who have a shunt fitted will need at least one shunt revision in the following 10 year period.

Shunt blockage, along with shunt infection, remains the commonest cause of shunt malfunction.

Obstruction can occur in any part of the shunt. If the shunt is not working properly, either all or part of it will need to be replaced. It is the ventricular catheter (the part of the shunt that passes into the ventricles of the brain) where the shunt most commonly blocks. The holes in the shunt tubing may become obstructed by the choroid plexus (this is the membrane which manufactures the CSF) or by a build up of cellular debris.

The clinical presentation is usually dominated by signs of raised pressure

as the brain fluid (CSF) builds up. This increase in pressure results in symptoms of, most typically, headache, vomiting and drowsiness. Sometimes the symptoms come on quickly over hour or days, but occasionally they may develop over many weeks with intermittent headache, and tiredness, change in behaviour or deterioration in schoolwork. In babies an enlarging head circumference, bulging fontanelle (the soft part at the top of the head), CSF tracking along the course of the shunt and, rarely, seizures, are additional indicators of underlying shunt malfunction.

Less common symptoms include seizures, abdominal swelling (due to malabsorption of CSF by the peritoneum or encysting of CSF in the peritoneal cavity), cranial nerve palsies (particularly in the spina bifida child).

If a shunted child becomes unwell, it's important that the possibility of a shunt blockage be considered (and hopefully excluded) as soon as possible.

Two prospective studies of 104 admissions to the paediatric neurosurgical unit at Great Ormond Street Hospital NHS Trust showed that drowsiness was by far the best, but not definite, clinical predictor of shunt blockage. Headache, vomiting and irritability were less predictive as to whether the child's shunt was actually blocked, and nor was the duration of the symptoms. The presence of a raised temperature suggests an alternative diagnosis for the symptoms or may indicate that the shunt is malfunctioning because it is infected.

It is important that children who have had treatment for hydrocephalus (this includes those who have had endoscopic third ventriculostomy) and their families are aware of the symptoms and signs of shunt blockage and who to contact if they are concerned. Most paediatric neurosurgical units provide 24hr telephone advice and many offer an open access policy for children who have shunts.

Diagnosing shunt blockage is not always

straightforward. Commonly there will be an alternative explanation for the symptoms for example ear infection, common colds etc. In fact, parents can be as successful at diagnosing shunt blockage as GPs and paediatricians.

Whilst additional investigations such as CT scan, plain X-rays and a shunt tap may be decisive, a definitive diagnosis is sometimes only possible through surgery.

Families should always be advised about shunt blockages, why and how they happen, at the time a shunt is first fitted. All children who have a shunt in situ should be registered with a designated neurosurgical unit to which they can be referred when the shunt goes wrong. If a child moves to another part of the country with their parents they must be reassigned to a new neurosurgical facility as

soon as possible.

Families should have open access to their neurosurgical unit for emergency advice. Deteriorating conscious level visual failure/obscurations, neck pain/stiffness or slow pulse rate all imply dangerously elevated intracranial pressure and constitute a neurosurgical emergency. Urgent medical advice must be sought in this situation; this may mean that the child will be seen at their local hospital initially where doctors can stabilise the child's condition and liaise with the neurosurgical team regarding emergency transfer.

It is important to repeat that most children who develop a shunt blockage will make a full recovery once the problem is treated. Children with shunts are as prone to all the usual childhood ailments as children without and new symptoms or signs will commonly have an alternative explanation. It is always better to seek advice sooner rather than later – when in doubt shout!

The editor wishes to thank Dominic Thompson, Consultant Paediatric Neurosurgeon at Great Ormond Street Hospital, for his assistance with the preparation of this article.

It is important that children who have had treatment for hydrocephalus and their families are aware of the symptoms and signs of shunt blockage and who to contact if they are concerned.

New information sheets

The fourth in our series of a new and revised range of information sheets follows on pages 27 and 28:

• Developing Skills Through Toys

You are now able to download from www.asbah.org.uk the current series of information sheets, they can also be obtained from the Information Department at ASBAH House, 42 Park Road, Peterborough, PE1 2UQ.

Behroze Vachha awarded Casey Holter Prize



The Casey Holter Essay Memorial Prize has been awarded to Behroze Vachha for *A Temperament for Learning: The Limbic System and Myelomeningocele*.

Behroze Vachha is Assistant Professor of Paediatrics at UT Southwestern Medical Center and research scientist in the Paediatric Developmental Disabilities Department at Texas Scottish Rite Hospital, Dallas, Texas. Her main research has focused recently on cognitive/learning differences and their impact on wellness issues (medical and academic) in children with SB/H.

The prize, which is awarded every three years, was presented by Carole Sobkowiak at the 48th Annual Scientific Meeting of the Society for Research into Hydrocephalus & Spina Bifida (SRHSB), which took place in Dublin in June. It was endowed by the late Dr John Holter (tribute, *Link* 208) in memory of his son Casey, who died as a result of hydrocephalus.

Developing Skills Through Toys



When choosing toys and games for children with hydrocephalus or spina bifida, it is important to consider not only what will provide enjoyment, but whether the toy will also help all round development.

There are aspects of play with toys or games which can be used positively for specific learning: to develop concentration; to emphasise sequencing (putting events or thought processes in step-by-step logical order); memory training; perception (size and shape); manipulation (the use of hand and fingers) and co-ordination (especially hand/eye co-ordination). Some of these are the specific learning difficulties that have now been highlighted as problems associated with hydrocephalus.

There are many good pre-school toys and games on the market which cover the development of such skills and could help in the early years.

It must be stressed, that to gain the maximum play and learning value from these toys and games, adult

supervision and guidance, reinforced by talking to the child about what he/she is doing while playing, will help the child with concentration and meaningful play.

All areas of play and development overlap, especially with a young child, where movement, hearing, seeing and thinking are all closely linked and vitally dependent on each other. Bearing this in mind, although the following toys and games have been grouped for specific learning skills, there will be other benefits:

Mobiles: encourage eye focus and movement, leading to reaching out. Baby gym: encourages eye focus and reaching out and hand/eye co-ordination, as well as being a reward toy.

Pop-up pets: (progressing to hammer balls) encourage hand/eye co-ordination.

Posting boxes: involve recognition and matching of shapes. Hand and finger control are required to post shapes.

Picture dominoes and lottos: require matching of shapes, hand/finger and direction activity. Help in learning to take 'turns'.

Finger paints and puppets: encourage hand and finger play.

Play Doh, modelling materials: materials to develop the feeling of different textures.

Building and construction kits: excellent for hand and finger training as well as for learning the position of objects in space and turning 2D pictures into 3D objects. These will include: Lego, stickle bricks, Duplo, Popoids, K,nex, Meccano.

The next stage may be mosaics, peg boards, picture templates, stencil sets, Etcha sketch, Magna doodle, paint by numbers and board games. These help thought processes, sequencing, logic, memory, pre-reading, writing and number work.

Computerised games: eg Game Boy, Play Station, will help with dexterity and hand/eye co-ordination. It is very easy to leave a child to play with these games but a computer cannot take the place of a parents, involvement and time with Game Boys etc should be limited.

To help the child's gross motor skills encourage hopping, skipping, balancing, bouncing (eg Space Hopper, trampoline), running and jumping.

Children will also enjoy using scooters, ride-on toys and bicycles. The child with hydrocephalus may need stabilisers on his/her bike well after his/her peer group have dispensed with theirs.

Imaginative play should be encouraged, although it does not always come easily to children with hydrocephalus. However, most will enjoy using prams, toy kitchens, toy cars and garages, dolls, etc. It is amazing how easy it is to construct a 'house' or 'tent' using two chairs and a sheet!

Toys do not need to be expensive - explore the charity shops and look in your cupboards - pots and pans, plastic colanders, empty plastic bottles (fill with rice or lentils to make 'music'), wooden spoons, sheets and towels will give hours of play.

Imagination costs nothing!

Further information:

Action for Leisure is a charity which promotes inclusive access to play and leisure for disabled children and their information service offers play leaflets, as well as information and advice on equipment. You can contact them by phone or email or visit their website: Action for Leisure, c/o Warwickshire College, Moreton Morrell Centre, Moreton Morrell, Warks CV35 9BL Tel 01926 650104 www.actionforleisure.org.uk

Early Learning Centres sell many of the types of toys mentioned in this leaflet. You can order a catalogue from them on 08705 352 352 or visit their website at www.elc.co.uk

Help us to help you

This information is provided free but ASBAH needs your help to enable us to go on providing a wide range of specialised information on all aspects of hydrocephalus and spina bifida, for families, professionals and students.

If you would like to help us continue with our information provision, we welcome your donation (cheques made payable to ASBAH). Please send to ASBAH, 42 Park Road, Peterborough, PE1 2BR

Thank you

Holiday let

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Tel: 01983 863658, www.iwasbah.co.uk

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Tel. 01274 591850,
e-mail jo@baxterjo.freeserve.co.uk

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Classified rates

£3.75 for 30 words max.
£5.50 for 30-45 words
£6.75 for 45-60 words

Cheques and postal orders should be made payable to 'ASBAH'. Classified adverts for the next issue of Link should be submitted by Friday 30th September 2004

Please send to: Editor, ASBAH
42 Park Road, Peterborough PE1 2UQ.
Tel: 01733 555988. Email: link@asbah.org

Letters

We welcome letters for publication, which should be sent to:

Editor, Link, 42 Park Road, Peterborough, PE1 2UQ.

The editor reserves the right to edit letters, so please keep them short.

Diary dates

Northern Region Drop Ins First Weds of each month, 10am-12noon

Northern office, Farsley, Leeds
Details: Joan Pheasant
tel: 0113 255 6767
nro@asbah.org

Northern Region Drop Ins Weds 11 August & Weds 13 October

554 Eccles New Road, Salford
Details: Marcia Conroy
tel: 0161 303 1143
nro@asbah.org

Drop in Coffee mornings

Wed 11 August,
10.15am-12.00 noon;
Wed 8 September,
10.15am-12.00 noon;

Tues 12 October,
12 noon-2pm
Low Moor community centre,
Bray Road, Fulford, York
Details: Geraldine Binstead
tel: 0113 255 6767
nro@asbah.org

Summer Experience Activity Course

Mon 6 – Thurs 9 September
Keplewary Centre, Lake District
Cost £110. Details: Joan
Pheasant, tel: 0113 255 6767
nro@asbah.org

ASBAH AGM

Sat 18 September
42 Park Road, Peterborough
Details: Lyn Rylance
tel, 01733 555 988
lynr@asbah.org

Mid-Wales & Border Counties Association

Sat 18 September
Discovery Centre, Craven Arms,
Shropshire
40th birthday celebrations
Details: Joan Carter
tel 01588 673 775

Independent Living London Weds 22 – Thurs 23 September

Wembley Conference &
Exhibition Centre
For free tickets
tel. 0870 429 4372
To pre-register: see www.independentlivingevents.co.uk

South East Region Local Association Day

Sat 30 October 11am-3pm
Banstead Day Centre, near
Epsom
Details: Jo Francis
tel 020 8449 0475
sero@asbah.org

Eastern Region Local Association Forum Meeting

Saturday 16 October
10.30am-3.00pm
ASBAH House, Peterborough
Details: David Isom
tel 01733 555988
ero@asbah.org

South of England Martial Arts Festival for Disabled People December (two days)

Details: terry.taylor@tw.twt.org.uk



A unique opportunity for people to see a wide range of companies specialising in varying lifestyle needs for people who perform intermittent self-catheterisation (ISC) and sheath users:

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For more information contact
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07808 906779 or e-mail
jacquie.mcgarry@hollister.com

18 September

Midland Air Museum, Coventry

For more information contact
Beverley Everton
on 07753 579949 or e-mail
beverley.everton@hollister.com

7 October

Stoke Mandeville Hospital

For more information contact
Chris Trimmings on
07712 008401 or e-mail christine.trimmings@hollister.com

9 November

Bristol Zoo

For more information contact
Ellie Green on
07834 0935970r e-mail
ellie.green@hollister.com

Please e-mail the editor (link@asbah.org) dates for the next issue of Link by Friday 17 September 2004, giving the name of event, purpose, location, date, cost (if applicable), contact name, phone no. and email address.

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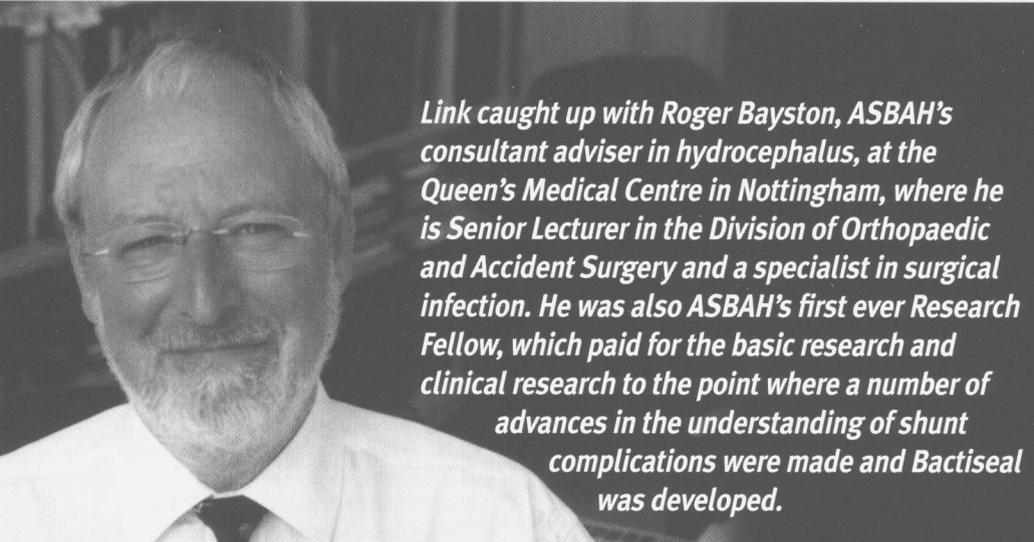
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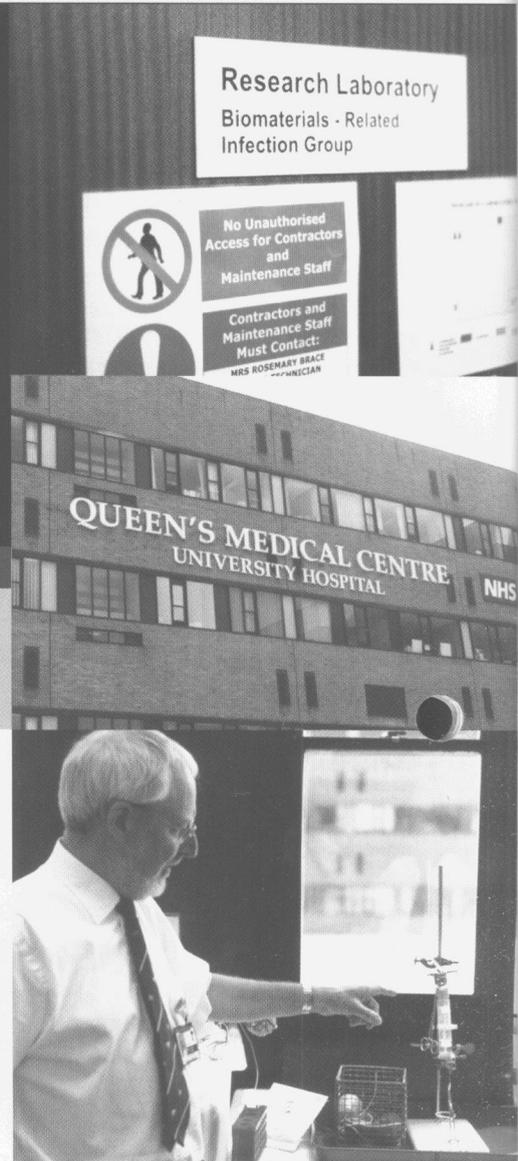
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Link caught up with Roger Bayston, ASBAH's consultant adviser in hydrocephalus, at the Queen's Medical Centre in Nottingham, where he is Senior Lecturer in the Division of Orthopaedic and Accident Surgery and a specialist in surgical infection. He was also ASBAH's first ever Research Fellow, which paid for the basic research and clinical research to the point where a number of advances in the understanding of shunt complications were made and Bactiseal was developed.



...Roger Bayston

My job can be divided into several sections: a large part of it is carrying out research and assessing other people's research for research councils and reviewing publications for around 25 international journals; I also teach, both within the division and other schools within this university hospital and in other universities. My students are drawn from science and engineering courses as well as from medicine. I run a special course for third year medical students on surgical infection and I also teach postgraduate doctors.

I deal with clinical problems here at the Queen's Medical Centre, and for other hospitals I give clinical advice on the diagnosis and treatment of infections. I do this by email, telephone - only today I had two queries from the States.

When I'm in the department a typical day begins at around 8am, when I check emails from previous day and act on urgent requests. I then see my research group one by one, depending on who wants to see me first, reviewing and guiding their progress in informal sessions.

I review articles from various journals as an expert for the editors - it's an essential part of the system. We also write our own papers.

I try to do at least one hour a day in the research laboratory and I do my personal research whenever I can. My main interest is in shunts and shunt complications and has been since the mid-1960s. This brings me into contact with hydrocephalus patients, their GPs and surgeons etc. I also run a biomaterials infection research group. One of our key interests is the prevention of infection and this is where the research we do is so important in our understanding of the causes.

Our previous research has also provided advances in the treatment and diagnosis of shunt infections. We're currently looking at the potential for vaccination to cut the

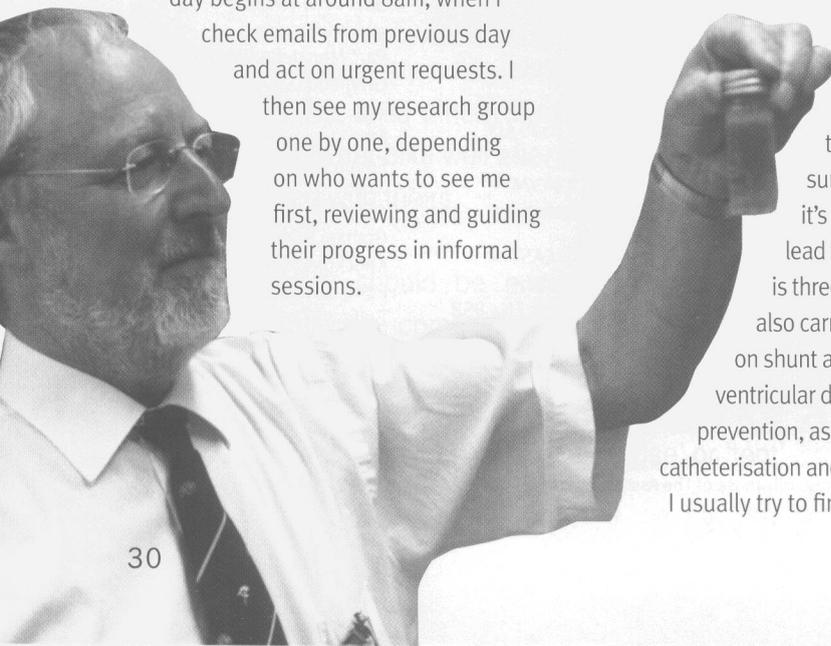
infection rate for hip and knee implant surgery, which will also apply to vascular graft surgery. We now know it's feasible, but the lead time for the science is three to four years. We also carry out clinical trials on shunt and EVD (external ventricular drain) infection prevention, as well as in urinary catheterisation and other areas.

I usually try to finish work at about

6.00pm, but I also usually work at least part of most Sundays. It's the only way to pack it all in!

I teach abroad a lot due to the demand on the expertise in this area, which is not very well catered for. I am constantly asked to address various professional bodies, which are often collections of neurosurgeons, orthopaedic surgeons or infection control doctors. A few weeks ago I was lecturing in Troms in the Arctic Circle one day and in Oslo the next, with Switzerland the following week.

The home I share with my partner is four miles from the hospital; we have two grown up sons, who now live away from home. The house has an enormous organic garden, which I see as a management of biodiversity. It's like hospitals, where you have to control infections; but if you try to sterilise a hospital that's when you run into trouble and multi-resistant bugs start to develop.



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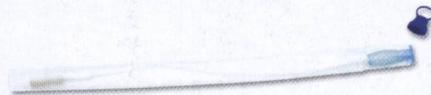
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