

- Fantastic Family Weekend
- News round-up

- Father's Day gift ideas
- Hydrocephalus Action update

- Meet the expert - Richard Edwards
- Danny Mills's golf challenge

LINK

*The magazine for
people with
hydrocephalus
and spina
bifida*



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Peter Farrall writes

Fundraising underscores all of ASBAH's activities. Without money coming in we simply wouldn't be able to help our service users, including those whom you read about in every issue of *Link*.

We are so grateful to people like footballer Danny Mills (p11), whose helpline appeal has already raised £6,000 and has now won the backing of his own club, Middlesbrough. Danny is hosting a pro-celebrity golf classic on 16 May and this will boost the appeal further.

The Royal Pigeon Racing Association has again come up trumps this year, with their annual show raising £15,000 for us. And not forgetting all those individuals on pp12 & 13 whose resourcefulness and hard work make such a difference to us.

Little bits of magic have been worked closer to home, too. The combined resources of our Central and East region and our Northamptonshire local association have succeeded in securing £16,000 from Northamptonshire County Council (p4), which will fund a family support worker for a full 12 months.

The second Benny Bear book was launched at the Family Weekend in March (an event made possible by BBC Children in Need). *Benny Bear Goes to School* (pp20-21) is an exciting second instalment in the series, to be followed this summer by *Benny Bear Goes on Holiday*.

With spring here, there's a spring in our step too!

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

Best wishes,
Peter

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HRH The Duchess of Gloucester GCVO
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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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**£15,000 donation at the
Homing World Show of the Year**
(see p 9)



**Danny and David on
the GMTV sofa**
(see p 11)



**New Association - Thames
Valley is open for business**
(see p 8)



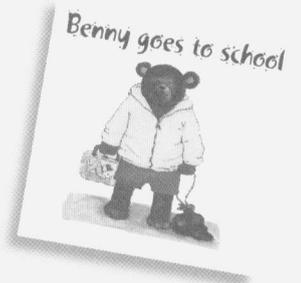
contents

Richards Edwards
expert insight - an interview
(see p 19)



**Benny Goes to School,
Fiona experiences the family
weekend and the BACTISEAL™
shunt is explained**
(see p 20 & 21)

**hydrocephalus
action**



**Family weekend -
a 'funtastic' time had by all**
(see p 16 & 17)



**Father's Day - gift ideas and
Ainsley does the Charchar**
(see p 14 & 15)





Congratulations to Karl Goddard (in the middle of picture) and his classmates from Sheffield's Notre Dame High School who have won the Kielder Challenge. This is a national competition between schools testing team work, communication and co-operation in different situations.

They made it through from an original entry field of 210 schools to the finals of 12. Each team consisted of eight students, four of whom were disabled – Karl, 15, has SB/H. Kielder is one of several Calvert Trust centres specially built to enable people with disabilities to safely experience adventurous outdoor activities. The most challenging heat in the finals was working out how to pass a piece of wood along a series of hooks using only ropes, which they won by the highest margin despite feeling they hadn't done at all well.

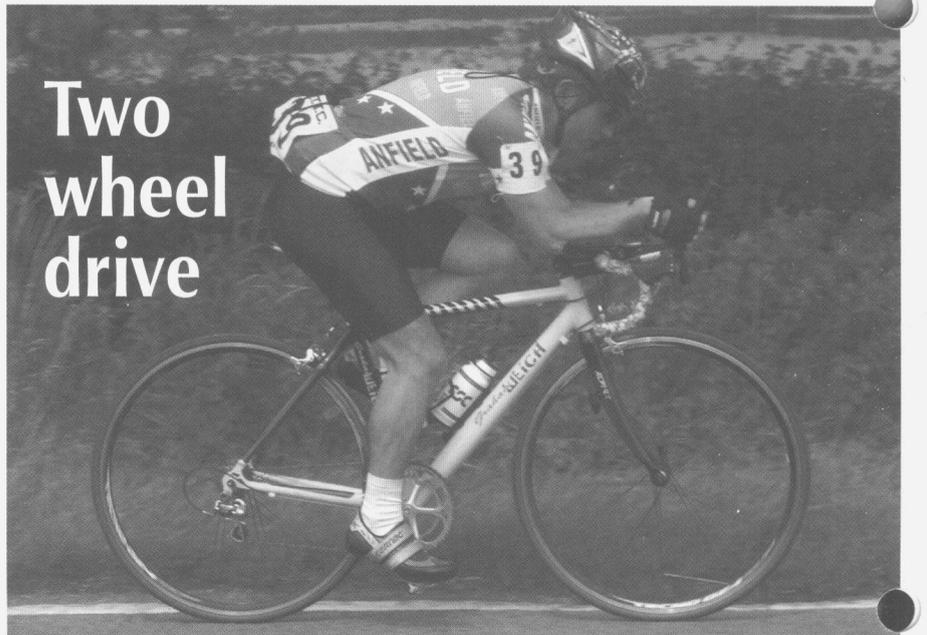


**Northamptonshire
County Council**

Council funds support service for SB/H

Lobbying by the Northamptonshire Local Association, in partnership with ASBAH national, has paid off handsomely with the award of £16,000 from Northamptonshire County Council to fund an area adviser to help and support families affected by SB/H.

Lyn Jones, Commissioning Manager for the Physical Disabilities Team at the council's Social Care and Health Department, said that she was delighted that their service is being extended to cater for the specific needs of those individuals with SB/H and their families.



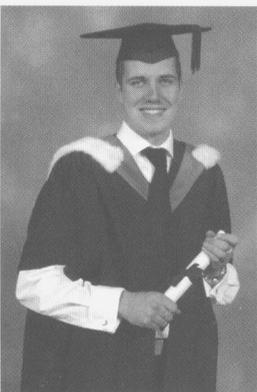
Two wheel drive

Keen cyclist Geraint Catherall has set himself the toughest of challenges for this year: to beat his personal best times of 2003.

Geraint, 30, who has hydrocephalus, claims that a new cycle and lots of

determination helped him to achieve new records in most of the long distance races he has competed in. Among his triumphs were a 25-mile time trial which he completed in 59 minutes 33 seconds and 100-mile trial which took him 4 hours 49 minutes.

He also entered the national 24 hour championship, notching up a staggering 308.5 miles. A dental technician from Anstey, near Leicester, Geraint said: "I've been cycling competitively since the age of 15, but last year was definitely my best ever. With my rides in the 24 hour, 12 hour and 100 mile trials, I finished 21st in the nationwide 24 hour Fellowship Best All Rounder competition. Now I'm aiming to better my times again this year."



Graduation success

Congratulations to Gary Graham, who recently graduated from Chester University College.

Gary, 22, who has spina bifida, was awarded a Bachelor of Education (Hons) degree in geography and is now teaching at Upton Heath Church of England Primary School in Chester. He is a member of ASBAH Mid-Ulster branch, based in Cookstown. Gary's mother, Elizabeth, has been honorary secretary of the branch for the past 15 years and is currently also honorary secretary of ASBAH Northern Ireland.



Prize snapper

Super snapper Rob Pollard has clinched a prize in a prestigious national photography competition.

Rob, 21, from Mount Hawke in Cornwall, was one of 12 winners in *The Sunday Telegraph* Racing Spirit Photography Challenge. The winning shots were published in the newspaper and are featured in its 2004 racing calendar.

Rob's award winning picture was taken at Stratford-upon-Avon racecourse on a wet and windy day. He recalls: "My initial shots were of the bookmakers painstakingly setting up their pitches. But I heard a bang and spotted this stand had overturned. It was a bad day for the bookie but a golden opportunity for me."

Rob, who has SB/H and is in the second year of a photography course at the National Star College in Cheltenham, said he was surprised and thrilled to have won the award. He told *Link*: "My tutor encouraged me to send in a couple of pictures, but I certainly didn't expect to win. I'm hoping to become a freelance photographer, so this is a good start to my career."



Top of the class

Sara Hibbits is celebrating after scooping a top accolade for her enthusiasm and determination in life by winning West Yorkshire's Shipley College Student of the Year Award.

Sara, 19, who has spina bifida and is studying for a BTEC First Award in childcare, has been in a wheelchair all her life and has undergone 19 operations. She continued her college course despite having to have two operations to remove a cyst from the top of her spine.

She told *Link*: "The latest operations were vital, because if I didn't have the cyst removed I could have been paralysed from the neck down within two years. The bubbly student, who hopes to go to Bradford University to study teaching, said she was thrilled to be given the award. "I was so surprised and pleased that people think so highly of me," she said.

SASBAH cash boost

SASBAH (Sussex ASBAH) is celebrating a £5,000 award from pharmaceutical company GlaxoSmithKline.

It was among 300 charities which entered the company's IMPACT Awards. The work and dedication of staff earned the association a place in the final 20 – and a much needed cash boost. SASBAH Vice-Chairperson Kevin White and Assistant General Manager Ram Sanglaji attended the award ceremony at London's National Gallery in February to pick up the cheque.

SASBAH's Liz Owen said: "We were thrilled to have made it to the final shortlist as it recognises the great work and efforts of our team here. The financial award is obviously very welcome and as there are no restrictions on how we spend the cash, we plan to use it to help cover day-to-day running costs."



STOP PRESS

● **Ryanair fined over wheelchair**
Ryanair (see *Link* 207 p23) has been found guilty of discrimination for charging a disabled passenger £18 to use a wheelchair at Stansted. The airline is appealing against the ruling and in the meantime is levying a 50p charge against all its passengers at Stansted and Gatwick to cover the cost of providing the assistance service.

USA

Florida support group

The parents of a child with hydrocephalus helped to launch a family support group at a leading medical centre in the United States.

Tony and Alison Barber were living in the States when their son Jordan, now 6, was born with the condition.

Jordan, who has undergone 20 shunt revision operations, was treated at the Wade Centre in Orlando, Florida, one of the largest hydrocephalus centres in the country.

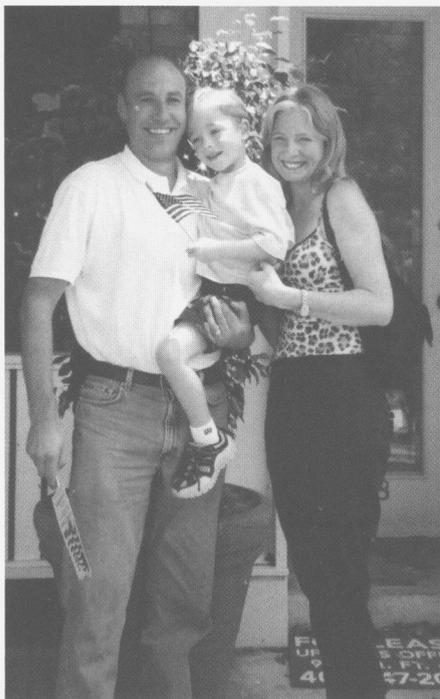
His neurosurgeon, Dr Jogi Pattisapu, was keen to set up a family support group and approached the parents of various patients for their help.

Tony explained: "Alison and I were invited to be on the initial committee and were involved in launching the group. There wasn't a hydrocephalus support group in the whole of Florida, so there were several hundred families we could help."

Much of their work involved going into the hospital and talking to parents whose children were recently diagnosed, giving them information as well as emotional support.

Meetings were arranged to enable people to get to know each other and different specialists would hold question and answer sessions.

Tony told *Link*: "After a while there was a real community feeling within the group. It is so good to be in touch with other parents who know exactly what



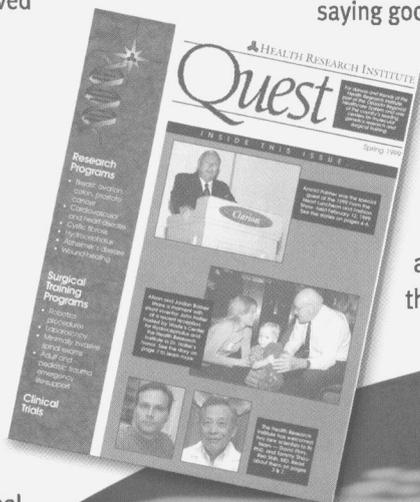
you are going through."

The family's return to England was completed last year and once they'd settled in to their new home in Whitchurch, Hampshire, they contacted ASBAH.

"Our local adviser Caroline Cashman has been fantastic," Tony said. "Jordan needs to attend a school for the hearing impaired so Caroline came to the school to talk to the teachers about his needs. She was very helpful."

Tony added: "It was quite a wrench saying goodbye to the Florida

support group, but we are getting to know people at ASBAH and are enjoying the first class help and information they offer."



World

Seasoned traveller Warren Tofts is planning his most thrilling trip yet – to journey through the Ugandan jungle looking for gorillas. Set to depart in July, it follows a seven month backpacking tour of Australia, Papua New Guinea and Fiji.

After leaving school in Welwyn Garden City Warren, 20 (who has SB/H), worked at Tesco's to save up for a dream trip. He says: "I was bored and always wanted to travel. I had such a great time that I really got a taste for more."

Paradise islands and making new friends have been part of the unforgettable experience. "I've always been fairly content, but now I'm more aware of the world."

One of the most thrilling experiences of his tour was in Papua New Guinea when he stood just feet away from a smouldering volcano. "The volcano's on a small island off the mainland, so I got there by boat with a guide and a friend. It had erupted in 1994 and has been smoking ever since so it was very exciting to get so close. I had to use my crutches, but I managed OK."

Papua New Guinea is a third world country, so wheelchair access everywhere wasn't very good. But people were very keen to help if I needed it", he says.

Mother Pauline adds: "Like all mothers I worry, but because Warren is in a wheelchair and needs medication he appears especially vulnerable. But I've just had to stand back and let him get on with it. I think he's amazing and an absolute inspiration."

beater

Zambia


 hydrocephalus
action

International rescue

The impact that the Codman BACTISEAL shunt plays on people's lives all over the world was recently graphically illustrated by their intervention in the case of little Aqueela Essopjee, a baby girl who was born in Lusaka, Zambia, in May last year.

Born to Sadick and Nazarene Essopjee, Aqueela was diagnosed with hydrocephalus when she was six weeks old.

Nevertheless, Aqueela had her first shunt inserted just two days later. When this failed, a second one was fitted at the beginning of August. But this also blocked and her condition began to deteriorate.

Naturally her family, including extended family in England, were now very concerned about her. Her great aunt Kay Butt lives near Watford with her husband Dean and they got right on the case in the search for a solution – to locate a shunt that would work. After trying everything from Yellow Pages and directory enquiries right through to Great Ormond Street Hospital they were still getting nowhere until Kay brought home a brochure about ASBAH from the nursery where she works as a support worker. Straightaway they were on the phone to Rosemary Batchelor.

Says Dean: "When we contacted

Rosemary we were quite frustrated and helpless. Speaking to her was like a breath of fresh air. It was a relief to find someone who spoke the same language as us, because at that point no one seemed to understand us. She put us in touch with Mark Attenborough at Codman, who was quick to tell us that his colleague Graeme Loughlin, UK Country Manager, would get back to us; true to his word Graeme got in touch with us."

Graeme told us that he could possibly supply a suitable shunt valve with an antibacterial impregnated catheter system, known as the BACTISEAL shunt, to try to combat the high risk of infection.

"Because of his kindness and professionalism he arranged for two shunts (one back-up) to be flown to Lusaka from the UK at his own personal expense. At the same time Aqueela had had two seizures but the shunt arrived, after some hair raising

moments, two days after these on 25th September. She was operated on that night and was already better the next day. She was out of hospital within a week. We will never ever forget Graeme's kindness."

Aqueela's grandmother in Lusaka, Mariam Bhana, has written to Kay and Dean with the latest news following a check-up in mid-March: "All's well: no vomiting, no stiffness, she moves well, has gained weight and can sit without a support behind her head. Head size is as normal as it should be in her case. Her doctor says that it's only five months since she had three ops, so by 18 months she will show a big improvement."



New drive to help affiliated associations starts

A new drive has started to help the local associations affiliated to ASBAH to develop and to integrate them more closely within ASBAH, benefiting both local and national standing and effectiveness.

February saw the setting up of a new consultation and development programme to see how their focus and performance could be improved, and give them national and regional support. It may lead to the introduction of agreed ways of working within a reasonable timeframe.

This first phase of the process will run until August. During this time ASBAH is holding regional meetings to outline its agenda and listen to the views of the associations; this will then be

followed by some further meetings with non-attendees, after which new standards will be set out.

The second phase will see those standards put up for agreement by local association representatives at September's AGM, after which they

The whole process leading to this is about consultation and mutual agreement. I'm confident that we'll get there together.

will be widely circulated; more detailed work would then start with selected associations, supported by regional and national managers.

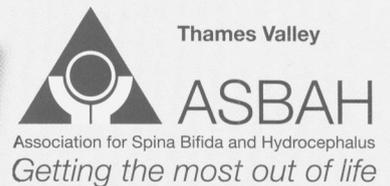
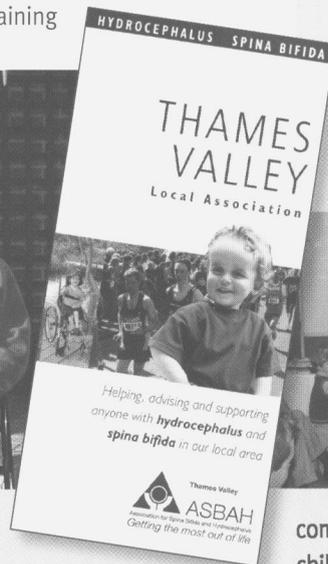
At the same time a programme to recruit national and regional development potholders will start. Their job will be to give improved support to the associations, such as guidance on their responsibilities and liabilities, and training

on important topics.

Andrew Russell, Executive Director, told *Link*: "This is an ambitious and exciting initiative designed to raise the level of professionalism across our association to a higher level. While there are 39 affiliated associations, all with different histories and identities, we need to adopt one set of standards to which they can all aspire. But it isn't something that's going to be landed on them from on high. The whole process leading to this is about consultation and mutual agreement. I'm confident that we'll get there together, because at the end of the day what counts is that our members and service users should benefit from ASBAH's combined knowledge and commitment."



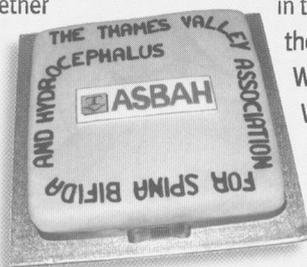
Andrew Russell



New association is born

ASBAH's comprehensive network of local associations was further widened in February with the launch of Thames Valley ASBAH.

Some parents of young children with hydrocephalus and spina bifida are behind the new association, together with some members of the old Berkshire local association, which has come about following the loss of area adviser Liz Clayton to Spain. The new committee are



determined to raise enough money to part fund Liz's successor.

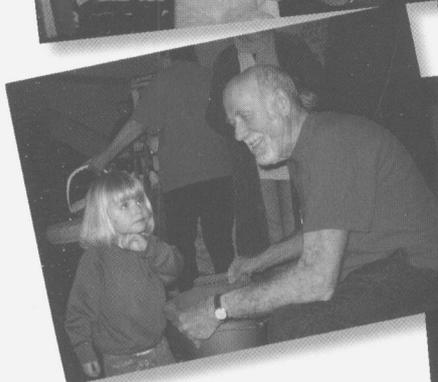
Not forgetting the underlying purpose of any association of course; that is, to provide support and information to individuals with SB/H, their families and carers – in this case in the Thames Valley area which covers the west Berkshire towns of Reading, Wokingham, Bracknell, Maidenhead, Windsor and Slough.

The chairperson is Sarah New, the secretary is Marina Sawyer and Karen Mclean, Francis Gaham and Tony Campbell sit on the

committee. The first three of these have children with hydrocephalus and the latter two have SB/H.

The association is full of hope for the future. Already they hope to raise £1,000 following a sponsored spinathon, and they are applying to the Lottery Community Fund for a grant. When their fundraising targets have been met they will pay 50% of the salary of a new adviser, which will be matched by ASBAH national.

Says Marina Sawyer: "We'll be helping all members with issues such as education and independent living." We welcome them aboard and wish them every success for the future.



Birds of a feather

A significant weekend for ASBAH took place in January at Blackpool. It wasn't actually an ASBAH event, but thanks to the number of people who went to it ASBAH is now £15,000 better off.

The Royal Pigeon Racing Association's (RPRA) British Homing World Show of the Year 2004 was held at the Blackpool Winter Gardens over the weekend of 17th and 18th January. With nearly 30,000 visitors it was one of the best attended shows of recent years and, with over 2,000 birds on display and 200 trade stands, there was plenty to see and do. This year the show also hosted an international youth exchange with delegates from Belgium, Germany and the Netherlands joining RPRA's young fanciers in Blackpool for a weekend of competitions and events.

Each year the show raises around

£100,000 for charity, mainly through charity pigeon auctions, raffles and attendance fees. For the 31st year running ASBAH was one of the main beneficiaries.

ASBAH is very grateful to the RPRA committee, its General Manager Peter Bryant and to Mrs Mac and her team for all their hard work behind the scenes.



RAF Wittering

Servicemen and women from RAF Wittering near Peterborough have made a special cake to help raise money for ASBAH.

Adorned with the RAF Crest and RPRA logo, it was the star prize of ASBAH's tombola at the RPRA's annual show, which made £750.

And the icing on the cake? RAF Wittering, 37 RAF Regiment Squadron, has adopted ASBAH as one of their two charities of the year.



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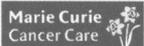
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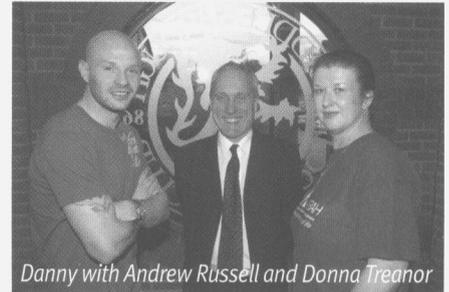
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Danny Mills
**DANNY MILLS
 ASBAH HELPLINE
 APPEAL**



Danny with Andrew Russell and Donna Treanor

Mills launches ASBAH appeal

Danny Mills's £300,000 ASBAH helpline appeal has won the backing of his own club, Middlesbrough, when in March it hosted a joint press conference by Danny and our own Andrew Russell for the official launch.

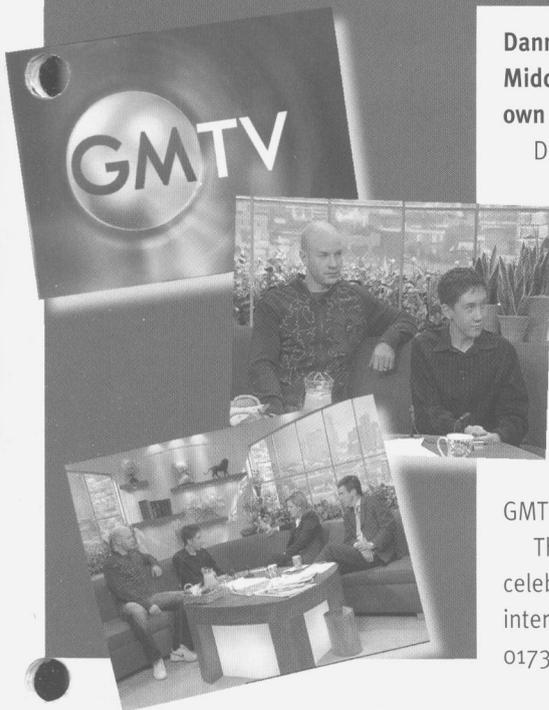
Danny told the media present at the club's training ground in Hurworth-on-Tees:

"Every spina bifida or hydrocephalus case is different and we want to raise awareness of these conditions and raise vital cash for ASBAH. A helpline that worried parents and families can turn to for information help and support would make such a difference for so many people. If we can ease anyone's pain by any percentage then all the work will be worthwhile."

Nationwide publicity for the appeal (left) was boosted in January by Danny's appearance on the GMTV sofa. Interviewed by John Stapleton and Penny Smith, he was joined by David Proud (whom *Link* readers will remember from last summer's issue when he was the first subject of the new 'Days in the life of' video diary).

GMTV attracts six million viewers every day.

The appeal has raised over £6,000 so far. On 16 May Danny will be hosting a pro-celebrity golf classic at The Warwickshire Golf Club at Leek Wootton in Warwickshire. Any interested teams of three who would like to take part should contact Donna Treanor on 01733 421327, email donnat@asbah.org or visit www.asbah.org



Northern Ireland Golf Day

Former Manchester United and Northern Ireland record breaker Norman Whiteside is throwing his weight behind ASBAH.

The footballer, still the youngest player ever to appear in World Cup finals at the age of 17, has agreed to spearhead a major sporting fundraiser for the charity.

Norman, also the youngest to score in an

FA Cup final, has put his name to a golf day.

Whiteside, now 39, worked alongside old friend Alan Money Penny when Alan was working with Guide Dogs for the Blind. Now Alan is the ASBAH fundraiser for Northern Ireland, Norman has nominated ASBAH to be this year's beneficiary.

Northern Ireland, has already attracted 25 teams from the business community

Alan said: "Norman backed a golf event promoted in Northern Ireland and brought a lot of football and showbusiness friends over to play local businessmen."

So when Whiteside decide to repeat that successful event he remembered Alan

and suggested ASBAH as the nominated charity.

The event, scheduled for 29 July at the Hilton Templepatrick course in County Antrim, Northern Ireland, has already attracted 25 teams from the business community.

Main sponsors linked to the ASBAH benefit include Bombay Gin and luxury car maker Aston Martin.





**METROPOLITAN
POLICE**

Working for a safer London

You bet!

ASBAH has struck lucky with Mohammed Dalil and London's Metropolitan Police.

Mohammed has a son, Kareem, 5, with hydrocephalus, and when Mohammed started his five week training last year at the Met's Hendon Police College he

jumped at a fundraising opportunity. For with each intake the Met supports a charity recommended by one of the recruits; not only did Mohammed nominate ASBAH but we were chosen. As a result in December adviser Rachel Nicholls was presented with a cheque for the fantastic amount of £9,330. That was great, Met - you bet!

L to R: Michele Savage, Ian Morley, Fiona Reeve and Lucia Grimer.



Picture perfect!

ASBAH recently received a state-of-the-art digital camera from the Charity Committee of John Lewis's Peterborough store.

Fiona Reeve and Lucia Grimer of the committee are seen here presenting the camera to Ian Morley and Michele Savage from ASBAH's fundraising team.



Ken Hanks donation

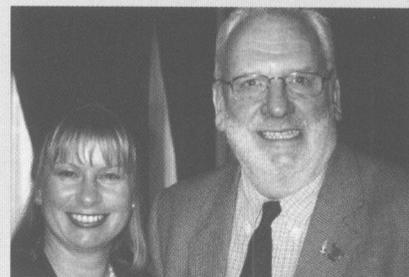
Yeee-ha! A big-hearted Country and Western fan has handed over a £209 cheque to ASBAH.

Ken Hanks, or 'Dancing Ken Hanks' as he is popularly known, runs Country and Western evenings each week at various venues in Cheltenham and Gloucester. Halfway through performances he often holds small charity auctions to help various good causes. One of the regulars at Ken's Monday night shows at the Cavern Club in Cheltenham nominated ASBAH, and Ken was happy to oblige. Ken, 69, said: "I've been in the business for more than 30 years and I still enjoy every minute. The audiences are mostly made up of regulars, so we're like one big family. The auctions are always well supported and we're always pleased to be able to help various charities."

Especially for us

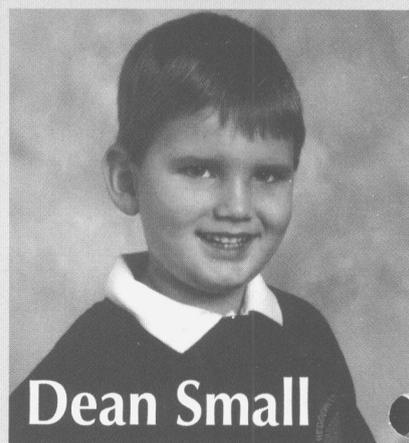
Cleethorpes teenager Kylie Pratten may have her own health problems to deal with, but she still finds the energy to fundraise.

Kylie, 15, has hydrocephalus and underwent her nineteenth operation last November. But instead of get well cards, she asked family and friends to make a donation to ASBAH to support others with her condition. Over the years she's raised an impressive £2,121 and recently presented a cheque to ASBAH area adviser Julie Turnbull. Hand on our hearts, thanks Kylie.



ASBAH's Fundraising Project Co-ordinator Michele Savage receiving a £2,000 donation from Derek Barnard, 2003-2004 President of the High 12 Square & Compass No 1186 Masonic Club at RAF Mildenhall in Suffolk. Over the years Derek Barnard has been a regular supporter of ASBAH and he has made ASBAH his Presidential charity.

Tribute



Dean Small

Dean Small, aged seven, died on 18 November 2003 from a complete shunt blockage. His mother Tracy Slade, from Hillingdon, writes: "Throughout Dean's short life I called on ASBAH for different bits of advice about hydrocephalus and Lucy Hughes was very helpful in meetings relating to his educational statements. Dean was a wonderful, unique little boy and I know he will be greatly missed by all who knew him, especially his sister Amy and brother Shane."

Donations to Tracy's chosen charities were requested instead of flowers for the funeral. As a result £310 was donated to ASBAH, for which we are very grateful.



ASBAH's Fundraising Manager Donna Treanor receiving a cheque for £3,000 from Jack Knights, Honorary Treasurer of the British Society of Flavourists (BSF). The society represents creative flavourists, flavour application chemists and food technologists from the food and beverage industry and it raised the money at its annual gala night dinner and dance, which was held in London last November. BSF President Paul Firby is a supporter of ASBAH.



Boxing Day dippers

ASBAH benefited from last Christmas's Boxing Day Dip in Co. Durham when five brave souls - Ian and James Wood and Alan, Sarah and Andrew Smith - plunged into the North Sea at Seaton Carew in an annual fundraising event organised by the Hartlepool Lions. James Wood, 8, won the prize for raising the most money (£240) in the under 12 age group.



James Wood with the Mayor of Hartlepool



Taking a closer look

The three-year-old face of a 1980s' £100,000 ASBAH fundraising appeal is now hoping to forge a career in forensic science.

Susan Gray's image was used to head a money spinning drive by Birmingham's BRMB radio station back in 1981. Susan, who has SB/H, inspired thousands throughout the city to collect cash to boost the cause. Many more turned out to see the little girl in person at the final presentation in the city's Chamberlain Square.

Now, 22 years on, Susan has achieved a 2:2 in Forensic Science at Anglia University and is looking for her first job in the field. From her home near Royston in Hertfordshire she says she first became interested in forensic science through her mother's work as a police surgeon: "It always seemed a fascinating area and as I learned more about it through TV programmes and books, I decided that was what I wanted to do."



Woollies wonder

Staff at a popular high street store showed the wonder of fundraising by collecting £200 for ASBAH and a children's charity.

Woolworths in Newquay, Cornwall, held a raffle, balloon race and cash collection to clock up £400, which was divided between ASBAH and a local children's hospice. But a giant five kilo chocolate bar up for auction failed to attract a single bid.

A big "well done" to nine-year-old Carly Williams from Portsmouth, who raised £150 for ASBAH in the BUPA Mini South Run at Southsea in October. It was the second time Carly, who has hydrocephalus, had taken part. All the more amazing, too, in that this time she had to run with a broken arm



ASBAH's Lynne Young, whose 21-year-old son Alex works at the store, said: "We had no bids for the bar, so perhaps there are no chocoholics in Cornwall, and we're still wondering what to do with it! But we were delighted with the donation from Woolworths. It's a very small store and the staff worked hard to raise it and raised our profile at the same time."



Father dear father!

20 June is Father's Day, the perfect time for us to say thank you to dad. Whether he gets up early to take you to weekend activities, is a star chef in the kitchen or is simply always there when you need him, you're hopefully sure to want to make a fuss of him on his special day.

We've searched high and low for a selection of fantastic gifts to suit dads across the nation. Whether he's an ace golfer, crazy about his car or a green fingered gardener, there's sure to be a gift to make him smile!

1 Why not award your dad the coveted title 'Dad of the Year'? This smart trophy is a bit of fun and he can wear the socks regularly to remind the family that he's a superstar!

Available from Big W and selected Woolworths stores at £5.99. For stockist enquiries, call 01706 862 789.

2 Make dad a cuppa on Father's Day and then present him with this handy car accessory. This clever drinks holder securely holds cups, cans, water bottles and juice cartons in the car. So no more spillages! Available from Halfords at around £4.99. Buy online at www.halfords.com or visit a stockist near you.

3 Most dads are constantly on the move, so this nifty Tiny FM Radio is the ideal gift to ensure that he never misses the footie or Gardener's Question Time. Measuring just 6cm in length, it comes complete with earphones and a built-in clip, as well as button cell batteries and costs just £5.00 from Gadgetshop. Buy online

at www.gadgetshop.com or check the site for a stockist near you.

4 Every keen gardener knows that a good pair of gardening gloves is essential. These Master Gardener Gloves from Lakeland might look ordinary, but are in fact pretty special. Specifically designed to protect the wearer from the perils of prickly thorns, the 100% cotton gloves have a latex coating to provide a non-slip grip, protection from damp and exceptional comfort. Available from Lakeland by mail order on 01539 488 100, at their branches, or online at www.lakelandlimited.com, the gents size retail at £4.95.

5 Dads like to pamper themselves too! We normally shower nicely scented goodies on mum on special occasions, but dads like to look and smell good too. The Body Shop has a great range of products suitable and this zingy Grape Seed Bath & Shower Gel is sure to be a big hit in the bathroom. Costing £4.50 for a 250ml bottle, visit a branch of the Body Shop to make dad's day.

6 It's probably safe to say that dads who don't like chocolates are few and far between! Yummy chocolate makers Thorntons always have a wide selection to suit all tastes and budgets. This 180g Continental Selection comes in a smart box and costs £5.00. Take a trip to your local stockist. You can call 0870 160 1911 to find your nearest store or see www.thorntons.co.uk





Ainsley Harriott's

CHAR CHAR CHICKEN AND LEEK PASTA

Serves 4

Ingredients

- 350g/12oz spaghetti
- 1 pack of baby leeks, cooked (normal leeks if not available)
- 6 tbsp olive oil
- 2 boneless, skinless chicken breasts, cut into 6 strips
- 1 lemon
- 75g/3oz Parmesan, grated, plus extra to serve
- 1 garlic clove crushed
- 1 tbsp tarragon, roughly chopped

Method

Heat a griddle pan.

Cook the spaghetti in another pan, according to the packet instructions.

Brush the leeks with 1 tbsp of oil, cook in griddle pan for 2-3 minutes on each side until slightly charred, cover and set aside.

Place the chicken in a medium bowl, grate over the zest of the lemon and stir in 1 tbsp of olive oil, mix well, season with salt and pepper. Char-grill for 2-3 minutes on each side until golden brown.

Meanwhile make the dressing. Mix together the remaining oil, the juice of the lemon, Parmesan, garlic and tarragon; season with salt and pepper.

Drain the pasta and return to the pan. Pour over the dressing and gently fold through the chicken and leeks. Divide between four pasta bowls and garnish with shavings of Parmesan.

7 Budding chefs can create a super aroma in the kitchen with this Chef's Candle by Price's Candles. Feast your senses with the aroma of natural basil, patchouli and geranium. The candle has an approximate burning time of 30 hours and costs £4.99. Available from Lakeland by mail order on 01539 488 100, at their branches or see at www.lakelandlimited.com

READER OFFER



8 It's so annoying when you can't find your keys and dads are often in a hurry, so why not treat him to this ingenious Auto-find Keychain with Light. Clap and it reveals the keys' location; it also features a useful light and comes complete with two lithium batteries. Available from Argos, it costs £7.99. See www.argos.co.uk or pop into your nearest outlet.

Spring READER OFFER

We have three Auto-find keychains from Argos Extra, worth £7.99 each, to give away.

For a chance to win simply write your name, address and telephone number on a postcard and send it to: Link Reader Offer, ASBAH, 42 Park Road, Peterborough PE1 2UQ.

The closing date for all entries is 18 June 2004.

WINTER READER OFFER WINNERS

Winners of the Boots White Collection Handcare Kits are:

- C Mizzi - Southampton*
- E Thomas - Anglesey*
- K Jones - Pill, Bristol*
- R Smith - Saughall, Chester*
- M Woolman - Sheringham, Norfolk*
- S Elliot - Acocks Green, Birmingham,*
- A Mills - Eye, Suffolk*
- D Toon - Farnborough, Banbury*
- M Taylor - Stalybridge, Greater Manchester*

Congratulations to them !!





Supported by



All brightness light on the

by Rosemary Batchelor

The generosity of BBC's Children In Need means that ASBAH's long tradition of Family Weekends continues.

This year we had two local families by day and 16 resident families from all over England (one cancelled at the last minute when their child needed emergency surgery) to the Old Park Hotel at St Lawrence on the Isle of Wight. Once again we were over subscribed and had to turn down 13 families.

The group was made up of 17 children aged 6 or under with spina bifida and or hydrocephalus, and all their brothers and sisters - whose ages ranged from seven weeks to 12 years.

Two of the disabled children were twin brothers with hydrocephalus; five had visual impairment, two had no speech, others had associated epilepsy or behavioural problems. Four were very disabled and needed one-to-one care. They were all accompanied by their parents: one family brought their 19 year old daughter to help and we had one American family who are living in the UK on a military exchange.

To care for the children (and to

supervise the parents!) we took 18 staff supported, as always, by willing volunteers. These included a representative from our Hydrocephalus Action campaign partner Codman (who was meeting children with hydrocephalus for the first time) and a nurse from Great Ormond Street Hospital.

They were joined by three experienced hands: a complementary therapist, a member of ASBAH's board of trustees and our (invaluable!) dedicated driver.

The children were divided into four specially named age-related groups. The babies' group was called Bats, the 2-4s' Badgers, the 5-7s' Squirrels and the siblings' group was Owls.

Each group had their own group leader and individual programme. And while ASBAH staff looked after and entertained the children, the parents had their own programme of talks.

Saturday started with the Squirrels loaded into two minibuses and taken to the island's Amazon World, where a good time was had by all.

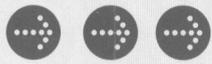
The Owls, after some hectic ice-breaking games in the grounds, relaxed

with Ashley the guide dog and his blind owner John Richards, who is an ASBAH adviser. The Badgers had fun in the ball pools and the Bats divided their time between sleeping and wailing.

Later, half the group (now known as Otters!) either went swimming or for some therapy; the Squirrels got back from Amazon World and - while the sun shone - the Bats were taken out for walk others attempted the woodland trails by wheelchair or (often wobbly) foot.

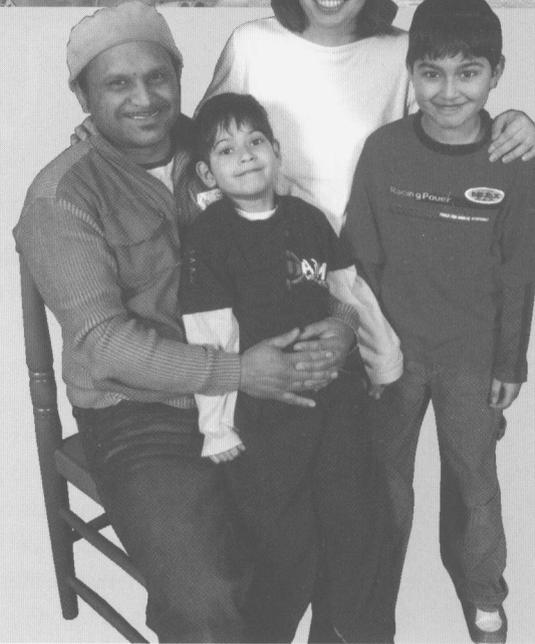
Our neurosurgeon Dr Richard Edwards (see *Meet the Expert on page 19*) arrived from





Our thanks go to the Old Park Hotel for their hospitality, to Wightlink Ferries for the generous discount, to Amazon World and especially to BBC Children in Need, whose grant made another successful weekend possible.

ES & e Isle of Wight!



Bristol to speak to the parents and to – bravely! – stay for the rest of the weekend. At last: a chance for parents and children to ask all those questions they had never asked their own neurosurgeon, and an opportunity for our doctor to live with families of children with spina bifida and hydrocephalus for the weekend and see how they coped on a daily basis.

After lunch our driver happily chivvied the Owls into the minibus and returned for his second trip to Amazon World.

The others painted, had their faces painted and tested Ashley's patience as they measured him, patted him, fell on him, climbed over him and – finally! – took him out to play frisbee.

We try to give the parents a treat on Saturday evening; so, after settling the children with the Great Randini and his magic, they all went for a candle-lit dinner with wine, courtesy of Codman.

Randini was a real success, as were the badgers who later came to eat supper

outside the bar window. The children relaxed by playing 'Finding Nemo' in one room and reading stories and playing games in another.

The parents reappeared, claimed their children (most of them!) and, after putting them to bed, made the most of our offer to baby-sit and returned to the bar. Time to sit with staff, ask questions, share experiences and generally relax.

Sunday morning was bright and sunny. Out went the Owls by minibus to a local beach; the Bats were put into their pushchairs and taken for a walk; the Squirrels and Ashley the dog went to the woods and the Badgers created havoc in the soft play

area followed by story time.

The second half of the group – known as the Water Rats – went swimming, so staff took advantage to start packing the toys and paints onto the mini bus.

The Owls returned and settled down to 'sibling work', looking at their experiences and feelings as siblings of disabled children.

Soon, it was lunchtime and farewell. But not quite! We met up with several families on the ferry to Portsmouth and the chatting continued.

As always, we bring back memories:

- the eagle owl at Amazon World calmly sitting to be patted by Nathan (aged six)
- Fiona from Codman emerging from the ball pool followed by an adoring little boy
- Qasim (six) convinced that the badgers were part of the magician's act
- Ashley sighing as yet another child got down for a cuddle
- twins Nial and Reece (five), laughing and joking with Garry, our nurse volunteer
- parents, seeing the wheelchairs on display and acknowledging that their children will not walk and will need wheelchairs
- their children in the wheelchairs and enjoying the freedom it gives
- Executive Director Andrew Russell being once more just a humble volunteer!



Culture Vulture

Fancy a cultural day out? Not sure where to go? North, south, east or west – which way is best?

Well, the good news is that, with so many venues boasting excellent level access and disabled friendly facilities, planning a visit to the theatre, an art gallery or museum needn't be a chore anymore. Here's a whistle-stop guide to just a few arts attractions around Britain to whet your appetite and offer you a little inspiration to find out what's going on near to where you live.

North of England

- **NEWCASTLE** is home to the Baltic Centre for Contemporary Art, on the south bank of the river Tyne. Disabled access is well thought out, with level access and suitable toilets. Admission is free. More info: www.balticmill.com or tel: 0191 478 1810
- **LIVERPOOL** has quite a few museums, but the largest is Liverpool Museum which houses fascinating and varied collections covering archaeology, ethnology and the natural and physical sciences. Level access is available (currently via Central Library) and wheelchairs can be borrowed on request. More info: www.liverpoolmuseums.org.uk or tel: 0151 478 4399

The Midlands

- **NOTTINGHAM** is the home of Robin Hood and a visit wouldn't be complete without a visit to the Nottingham Castle Museum and Art Gallery which is situated on the site of the medieval

castle. Exhibits are clearly positioned for the benefit of wheelchair users.

More info: www.24hourmuseum.org.uk or tel: 0115 915 3700

- **BIRMINGHAM'S** Thinktank complex at Millennium Point is well worth a visit. Ten themed art galleries spread over four floors provide a diverse range of exhibits and the venue is fully accessible for people with mobility difficulties with disabled toilets on all levels and designated parking spaces nearby. More info: www.millenniumpoint.org.uk or tel: 0121 202 2222

The South

- **BRISTOL** is home to The City Museum and Art Gallery. Whilst there, you'll be able to dip into wheelchair accessible displays on topics including Egyptology, natural history, Oriental arts, porcelain and geology. Afterwards, pick up some mementoes in the museum shop and then enjoy refreshments in the on-site café. Open 10am-5pm each day, admission is free. More info: www.bristol-city.gov.uk/museums or tel: 0117 922 3571
- **BOURNEMOUTH** is well known for its famous pier and a visit to the seaside could also include a trip to The Pier Theatre. Disabled access is possible by arrangement through the box office and a unisex disabled toilet is available. More info: www.thepiertheatre.co.uk or tel: 01202 456400

Wales

- **CARDIFF'S** New Theatre, which has level access to the box office, stalls bar and disabled person's toilet, as well as discounts available for the theatre's selection of wheelchair-compatible seats. More info: www.newtheatrecardiff.co.uk or tel: 029 2087 8889
- **SWANSEA'S** Grand Theatre presents over 500 performances throughout the year. The Arts Wing hosts a monthly Comedy Club as well as weekly Jazz Nights. A lift provides access to all floors and wheelchair users can find level access to the stalls as well as the Footlights Bar. More info: www.swansea.gov.uk or tel: 01792 475715

Northern Ireland

- **BELFAST'S** Grand Opera House, which always has a programme of the very best of live theatrical performances and entertainment to satisfy the widest possible range of tastes and interests. More info: www.artsworld.ie or tel: 01232 241919

Useful information

There are many organisations which can help make travel and days out for disabled people easier. Good starting points include: www.disabledgo.info provides free detailed access information for disabled people throughout the UK. www.transportforall.com provides useful information to assist disabled people travelling in London.

Meet the expert

Richard Edwards, BSc MB BS FRCS Specialist Registrar in Neurosurgery



Parents and children who went on this year's Family Weekend on the Isle of Wight were fortunate to have the opportunity to talk to one of the country's leading hydrocephalus experts, Mr Richard Edwards of Bristol's Frenchay Hospital.

Richard Edwards, 35, is the hospital's Hydrocephalus Research Fellow as well as Specialist Registrar in Neurosurgery at Frenchay Hospital, Bristol. He is also a clinical lecturer at Bristol University.

He trained at St Mary's Hospital Medical School in London, graduating in 1994, before moving to Frenchay Hospital in 1999 to complete his neurosurgical training.

He's known to countless families in the west of England through both his weekly NPH clinic and his monthly hydrocephalus clinic. He operates on about 25 NPH patients a year, 50 cases of other types of hydrocephalus, as well as carrying out a further 150 neurosurgery operations.

In January 2004, he completed a two year research programme into hydrocephalus, studying a large group of patients treated over 30 years at Frenchay Hospital by comparing endoscopic technique to shunt treatment. He explains: "My research is looking at ways of reducing proximal catheter obstruction in hydrocephalus and the long-term effects of an endoscopic technique called 'choroid

plexus coagulation'.

"I looked at what long term effects choroid plexus coagulation had on the course of hydrocephalus in subsequent years and assessed whether there were any advantages to using this technique when treating children with hydrocephalus."

The research programme also looked at decompensation of arrested hydrocephalus in children and adults no longer believed to be shunt dependent.

Richard, who is also involved in studies looking at the long-term outcome of post meningitis hydrocephalus, is working in collaboration with the Institute of Child Health and Veterinary College to look at microscopic changes in the choroid plexus following post haemorrhagic hydrocephalus.

He has written several academic papers on hydrocephalus and has also contributed to a review article in the journal *Neurosurgery Clinics of North America* on the techniques of endoscopic neurosurgery in treating hydrocephalus.

In addition to his heavy workload at Frenchay, he has spoken at an American Association of Neurological

Surgeons conference and the Congress of Neurological Surgeons, the Society for Research into Hydrocephalus and Spina Bifida and the Society of British Neurosurgical Surgeons, where he won a prize for best paper at the 2003 meeting. In April 2003 he also picked up the Vesalius Award from the American Association of Neurological Surgeons for a paper on the history of choroid plexus surgery for

The current treatments of hydrocephalus need to be subjected to clinical trials to establish which treatments are best for which specific types of hydrocephalus.

hydrocephalus. His paper *Efficacy of an in situ Treatment Protocol for CSF Shunt Infections* will be presented at the European Society of Paediatric Neurosurgeons' Rome conference in May 2004.

Telling *Link*

about his hopes for

future medical developments, he says: "Hopefully shunts will be developed that function in a physiological way and are more biocompatible. There may also be new treatment options that control hydrocephalus in relation to water channel expression in the choroid plexus. It may be possible in the future to develop drugs specific enough to control hydrocephalus by reducing production of cerebrospinal fluid.

"The current treatments of hydrocephalus need to be subjected to clinical trials to establish which treatments are best for which specific types of hydrocephalus. That requires collaboration across many neurosurgical centres in many countries and it'll be the best way to push forward treatment options in the next decade."



Codman - Working in partnership with ASBAH



Fiona Anderson
European Product Manager

ASBAH's popular family weekend, this year on the Isle of Wight, proved an eye-opener for one guest speaker.

Fiona Anderson from Codman got a chance to meet some of the many children helped by ASBAH who have spina bifida and hydrocephalus at the Children In Need get-together in March.

In her role as European Product Manager Fiona jets around the continent dealing mainly with medical professionals. But she relished the rare chance to speak face-to-face to parents and children and learn more about their problems and experiences.

Fiona told *Link*: "The whole experience was a great leveller. I often have to fly around Europe, being in Hamburg one day, London the next. To have the opportunity to spend time with the families was fantastic. I rarely get the chance to see the results of the impact of our products."

She admitted to feeling apprehensive before the weekend, where she gave a presentation called 'You and Your

Shunt'. "I haven't been exposed to an environment with so many children like this since my medical training," she revealed.

Fiona's presentation covered issues including the anatomy of the brain and the processes relating to cerebral spinal fluid. Other topics covered ranged from the manufacture of shunts, the input of research and development from Codman, what can go wrong with a shunt and how it can be resolved.

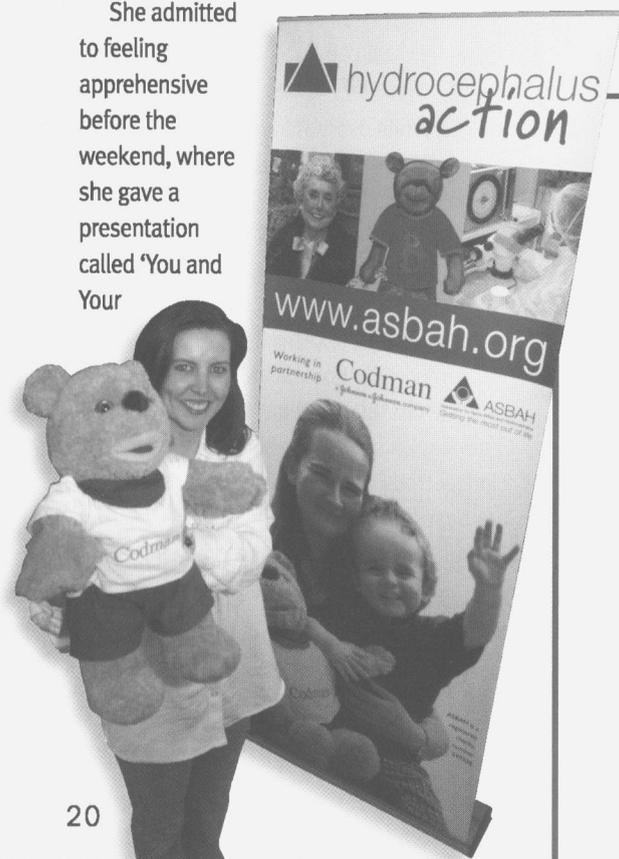
While she wasn't talking to parents, Fiona was able to relax and join in the general fun. She said: "I had a wonderful time playing with the children. The ball pool was great because it was interesting to see how some of the children were hesitant at first but after a while gained confidence and had loads of fun. One little girl, Joanna, didn't speak at all while she was in the ball pool, but it was fantastic just hearing her laugh and giggle. It made my day."

Benny goes to school



2nd Benny Bear book launched

Hot on the heels of the success of his first book, *Benny Gets Better* (Link 205), Benny Bear has embarked on a new adventure by starting school.

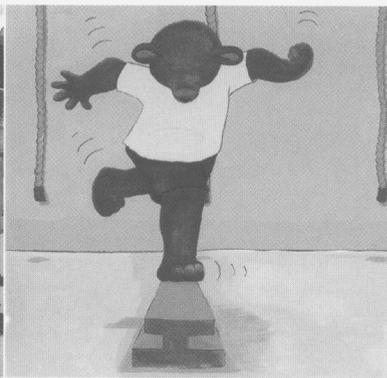


Codman
a Johnson & Johnson company



In 2004 Codman and ASBAH will work in partnership to promote 'Hydrocephalus Action', a campaign aimed at heightening hydrocephalus awareness through many channels and events.

Codman - Working in partnership with ASBAH



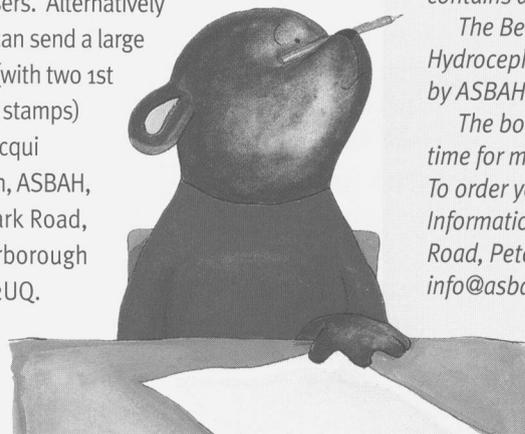
This is the subject of the next book in the series, *Benny Bear Goes to School*, where he settles into school life and becomes more independent. Topics such as sports activities and lessons are simply and sensitively explained, sending the clear message that school is somewhere to learn and have fun, even if you have hydrocephalus, which may mean you need extra help sometimes.

Benny Bear is a teddy bear which has been produced by Codman to help neurosurgeons explain to parents and children what a shunt operation involves.

The book was written by Rosemary Batchelor and Val Meyer-Hall, with beautiful illustrations by Charlotte Meyer. Published by Codman, it was launched at the Family Weekend in March.

Peter Farrall told *Link*: "Benny Bear helps explain in simple language how children with shunts can get the most out of life. Benny is a friendly face who's doing a fantastic job to help dispel concerns and provide reassurance about shunts."

Copies of the small book can be obtained free of charge from ASBAH advisers. Alternatively you can send a large SAE (with two 1st class stamps) to: Jacqui Smith, ASBAH, 42 Park Road, Peterborough PE1 2UQ.



Coming soon... to a beach near you!

The next in the series of Codman sponsored Benny books, "Benny goes on Holiday" is currently being produced.

"Benny goes on Holiday" demonstrates, in a child-friendly way, the considerations for parents taking their child on holiday. Benny goes to France by aeroplane and understandably has many worries. His holiday, however, as you can see, is quite wonderful! With words by Senior Medical adviser, Rosemary Batchelor and illustrations by Charlotte Meyer, the book contains a check list for parents to consider.

The Benny series is part of the Hydrocephalus Awareness campaign run jointly by ASBAH and Codman

The book will be available in June, in time for most family summer holidays. To order your copy, please contact the Information Department, ASBAH, 42 Park Road, Peterborough, PE1 2UQ or email info@asbah.org

The books are available free of charge - but a contribution towards postal costs would be appreciated.



Codman's revolutionary BACTISEAL™ shunt

Since the international introduction of shunts to control hydrocephalus in the late 1950s, infection has been recognised as one of their major problems. The consequences can be serious and can lead to permanent deterioration in quality of life.

Since I was appointed the first ASBAH Research Fellow in 1974 I have been working to understand how shunt infections happen, and particularly how to prevent them. One of our early discoveries was that shunt infections begin at the operation to

insert or revise the shunt, even though they might appear much later; staphylococci from the patient's skin are the commonest cause.

Most patients receive antibiotics at the time of their shunt operation to reduce the risk of infection, but our studies in the mid-1990s showed that this was not helpful. We have invented a process which makes shunt material kill bacteria on contact, and this has undergone extensive investigation to ensure its safety and efficacy. The idea was adopted by Codman, who named the new shunt 'Bactiseal', and it was launched three years ago.

Since then about 15,000 have been used throughout the world. The rate of infection in shunts varies but in babies (where most

new shunts are used) it can be as high as 10-15%. While over 1,000 infections could be expected in the three years of Bactiseal use, only 20 have been reported. Obviously some must have been missed but there has clearly been a dramatic reduction in infection. This has recently been underlined by a clinical trial in high risk patients in South Africa, where the infection rate due to staphylococci was reduced from 16.7% to zero.

The next step is to apply this idea to external ventricular drainage (EVD), where the infection rate is even higher, and Bactiseal EVDs are now available.

Dr Roger Bayston MMedSci FRCPath
Senior Lecturer,
University of Nottingham Medical School



ASBAH trustee Austin Crowther

Austin Crowther is ASBAH's longest serving trustee, having been in post since 1974. As a trustee he's involved in much of ASBAH's work: as Chair of the Services and Marketing Committee, Vice-Chair of the Policy and Resources Committee and a member of the Education Advisory Committee. To cap it all, he's ASBAH's Vice-Chairman.

A qualified youth worker, his involvement in the voluntary sector dates back to the 1960s when he became involved in an aunt and uncle scheme through a children's home in his home county of Worcestershire and, with his wife Florrie, had a child from the home to stay at weekends and holidays. After moving to his adopted Yorkshire he got more involved, this time at the Ian Tetley Home in Harrogate where he and Florrie would have three children with spina bifida and hydrocephalus to stay, each in turn.

In 1970 their daughter Caroline was born with spina bifida. His involvement with the disability world grew and as a result Austin became involved with ASBAH's Calderdale Association, which is not now meeting but still works with its past membership.

His involvement with the association had started with a request from a local church attended by Austin and his wife who wished to donate the proceeds of a practical harvest festival to a local charity group. ASBAH was identified as a result of the contact the church had had with the children Austin and Florrie were involved with from the Ian Tetley Home.

From this initial contact with the local

ASBAH group grew a closer involvement and Austin became the association's honorary secretary in 1971 at the invitation of chairman Fred Brown. He was secretary right up to its voluntary disaffiliation in 1997.

As is the case with Austin, who is 65, one thing led to another and he was soon attending ASBAH's council meetings on Calderdale's behalf. In time he became a prime mover behind two important initiatives: the formation, with Lady Jean Mackenzie, of the service users' group Your Voice in the 1980s and the expansion of the field workers network.

Your Voice was inspired by what had been happening within PHAB (Physically Handicapped and Able Bodied). In comparison, ASBAH members were still being "talked at and not talked to". Meeting with ASBAH staff mostly in and around London at first, the scheme soon expanded to South and West Yorkshire as well as Manchester. As an advisory working group within ASBAH, Your Voice's contribution has been to make ASBAH realise that service users have a contribution to make in the running of ASBAH and their contribution over the years has been of benefit to its growth.

Mr. MacFarlane, affectionately known as 'Mac' had been the first field worker, on secondment from National Westminster Bank. The impact he soon made alerted ASBAH to the need for a nationwide field worker network and under Austin

Crowther's and the whole board of trustees' aegis the number now stands at around 40.

In his time ASBAH has become a much more professional organisation having had the input of the three chief executives who brought with them different backgrounds and experiences – ASBAH today is more forward looking and business like. It responds far more so than in the early days to service users' needs and has become more involved

ASBAH today is more forward looking and business like. It responds far more so than in the early days to service users' needs.

with statutory bodies and other organisations in order to give service users as comprehensive and detailed assistance as possible.

Austin values the extremely good relations between the staff and the board of trustees. He's often to be seen in both

national office and the Leeds office and staff know that they can talk to him about anything. This relationship is two way, because he knows just as much as anyone that without the staff to support all the service users in many ways and means it does, then ASBAH simply wouldn't be doing the job it's destined to do.

Austin feels that the future of the association still has uncertainties, with all the changes being introduced by government; but that, with the determination of the trustees, staff and management, every effort will be made to continue to serve those for whom the association was first formed.



By Marshall Thomas

Aiming for the top

In five months' time the world's best will battle it out for the most coveted of all accolades in disability sport - a Paralympic gold medal - when the twelfth Paralympic Games takes place in Athens, Greece, from 17 to 28 September.

Athletes from over 140 countries are expected to participate in 19 sports. Great Britain is expecting to take about 220 athletes and around 100 support staff to the games.

Great Britain finished second in the overall medal table at the Sydney 2000 Paralympic Games, with an impressive haul of 131 medals - 41 golds, 43 silvers and 47 bronzes. They finished just behind host nation Australia, but the undoubted aim in Athens is to finish top of the medal table.

With the Paralympics starting a little over two weeks after the Olympic Games finish, using the same venues and facilities as for the Olympics, much of the focus until now has been on whether the Athens facilities will be actually ready in time for the start of the Olympics.

However, for the athletes, qualification and selection criteria have long been the main aim and the British Paralympic Association recently announced the first sets of athletes to be selected to represent Great Britain in Athens.

Among those selected for the GB Powerlifting Squad are a trio of athletes with spina bifida: Emma Brown, Anthony Peddle and Natalie Blake. Brown became the first British woman to win a Paralympic powerlifting medal when she struck gold with a world record lift of 135kg the

under 82.5kg division in Sydney in 2000. The prolific Welsh athlete will be among Britain's main hopes for gold once again, while Peddle also aims to defend the 48kg title he won in Sydney. Blake finished just outside the medals in the women's 56kg category in Sydney, but won a silver in the 2002 World Championships in Malaysia and a gold at last year's European Championships in Slovakia.

Meanwhile, dressage rider Liz Stone has been named on the shortlist of 10 riders for the GB Paralympic Equestrian Squad. Liz, 31, who also has spina bifida, was a World Championships gold medallist back in 1994 and a Paralympic team and individual

If I don't make it this time, so be it, but I'll just keep looking forward to Beijing in 2008

gold medallist at the Atlanta Paralympics in 1996. Having missed the Sydney Games she is now one of three riders on the British Equestrian Federation's World Class Potential Programme to be among the shortlist of 10. The final selection of seven riders to represent Britain at Athens will be made following an international competition at Moorselle, Belgium in May.

"If I don't make it this time, so be it, but I'll just keep looking forward to Beijing in 2008", says Liz, who recently moved from east London to Warwickshire to be closer to her regular mount, the 10-year-old-gelding Pogues Mahone (pictured here with Liz).

Wheelchair tennis player Jayant Mistry is also on course for selection. The international rankings race to achieve qualification for Athens ends in mid-April

after two final major tournaments in Florida, USA. The Great Britain team will be announced sometime thereafter and Jayant, currently ranked No 9 in singles and No 6 in doubles, looks set to contest his fifth Paralympic Games. He made his Paralympic debut when wheelchair

tennis was just a demonstration sport at the 1988 Games in Seoul, Korea, and then just missed out on a Men's Doubles Bronze medal with fellow Briton Simon Hatt in Sydney four years ago.

A broken finger sustained while playing in Australia in February disrupted Jayant's start to the year, but he hopes to hit back with a vengeance in Florida before bidding for an eleventh Men's Single title at the National Wheelchair Tennis Championships in Gloucester, from 30 April - 3 May. Then, long after the GB wheelchair tennis team has been announced, Jayant will continue battling on the NEC Wheelchair Tennis Tour, hoping to improve his ranking and therefore his chances of a good seeding for the Athens Paralympic tennis event.

For further information and news updates on GB team selections for the Athens Paralympics, see www.paralympics.org.uk or www.bbc.co.uk/disabilitysport



Liz Stone being presented with an earlier award



Linda's line

Well the Oscars are over, the Golden Globes have gone and the BAFTAs have been dished out to the great and the good. Yes, the film awards season is now behind us, and film fans and critics alike can look forward to the summer blockbusters at the cinema.

Top of my list, of course, is the long awaited Harry Potter film *The Prisoner of Azkaban*, which is scheduled for general release in early June. If it's anything like its predecessors it will not disappoint, and should hopefully win its share of the gongs and trophies next year.

But can anyone tell me why we need so many award ceremonies? Surely there's only so many times you can have 'best film', 'best director' etc – wouldn't it be more interesting to have some new categories? For instance, why not have nominations for 'most boring film'? I bet you can all think of examples where the high-octane roller coaster action promised by the advertisers had all the speed of an elderly ride-on lawnmower. And how often have you sat down to watch a film on TV, only to find it had less buzz than a dead bluebottle?

In fact, the more I think about it, the more I'm convinced that it would be a public service to shortlist those films which are so boring they should carry a government health warning. So, what would you nominate as the most boring film you have ever seen? For me there is no competition – it has to be *Fitzcarraldo*.

If you haven't seen it (and believe me, you haven't missed much!) it's about an Irishman who wants to build an opera house in the middle of the South American jungle. However, the majority of this overlong film is taken up with the characters dragging a large boat over the top of a mountain, and no, I don't know why either – long before the end I had totally lost the plot. I wouldn't mind, but that's three hours of my life I'll never get back. Scotty can definitely beam that one up!

Thankfully, I'm sure no such magic will be needed on the *Prisoner of Azkaban*, and if it's as good as the book, it will have a Harry Potter magic all of its own.

Anne Walton

ASBAH said farewell to Anne Walton and her husband Reg in January.

Anne joined ASBAH in May 1991 as the adviser for the North East of England. She made her mark working with families and adults in that area; she was also well known to many of the professionals and worked in partnership with other voluntary organisations. She was well liked by her service users and is missed by them.

Anne was ASBAH in the North East. She was a great support at the many events and residential organised in the region. She would turn her hand to almost anything, from abseiling down the Cow and Calf

Rocks in Ilkley during the Summer Experience, to spending Boxing Day morning with Reg supporting the Wood family when they did their dash and dip in the North Sea to raise funds for ASBAH. Anne marvelled at the generosity of those living in the North East, as she was often called upon to go and receive cheques on ASBAH behalf.

Anne and Reg's help with fundraising didn't stop there; they responded to an appeal by ASBAH for help at the RPRA's British Homing World Show in Blackpool, where they have been regular helpers for the past eight or nine years. Only last year they stood at the finish line of the Great North Run and welcomed home all those running for ASBAH, handing out medals and drinks.

Anne was a respected and valued team member who offered a great deal to the team through her support and friendship.

Joan Pheasant - Manager, Northern Region

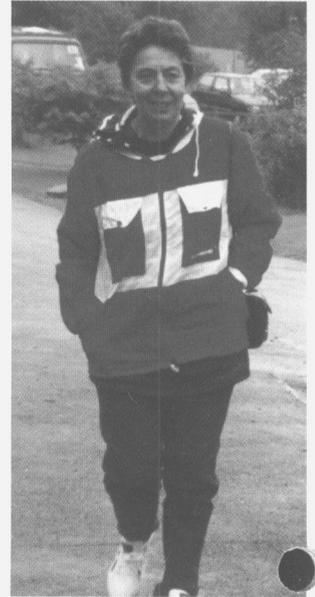
Janet Stewart

Janet Stewart, our adviser for Nottinghamshire and Derbyshire for fourteen years, retired at Christmas.

During all her time at ASBAH she showed true commitment and clearly enjoyed her work. Janet established excellent relationships with the service users in her area, which I was privileged to see at first hand when I joined ASBAH last summer. She also worked tirelessly at developing strong professional working relationships with the Queen's Medical Centre in Nottingham.

Janet was a very popular member of the Eastern Region team and was always prepared to share her knowledge, skills and expertise. She is much missed by her colleagues, service users and many medical professionals.

David Isom - Manager, Central and East Region

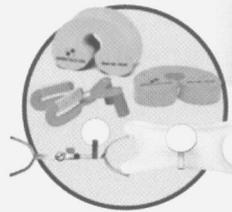




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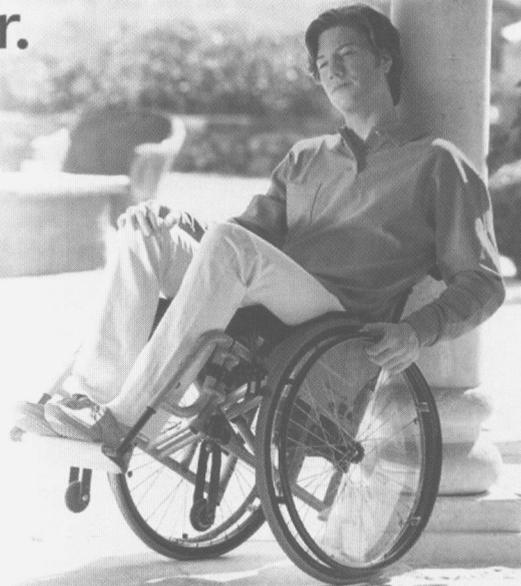
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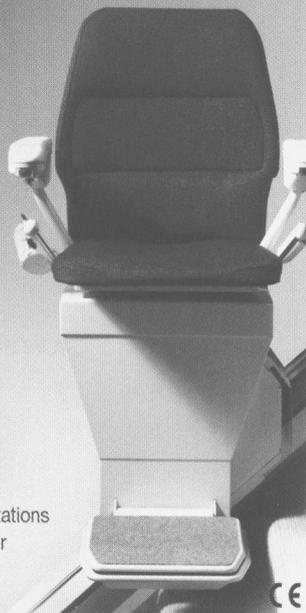
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John Grooms
Working with Disabled People

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Pass time

by Gill Yaz

Passing your driving test is often a giant leap towards independence for people with disabilities. Talking to adult service users at a spina bifida clinic it seems that the new hazard perception part of the theory test could present particular challenges to people with hydrocephalus.

The hazard perception test contains 14 different moving scenes containing driving hazards; the candidate watches the clip and, as soon as the hazard is spotted, clicks the mouse. Points are awarded for a speedy response.

Many people with hydrocephalus find that exam nerves seriously affect their performance in these tests; the stress

of time limited tests interferes with the concentration needed to perform accurately. Also, the candidate is being asked to respond to a driving hazard in a very unfamiliar way, not by using driving skills learned on the streets. A person with hydrocephalus may find it hard to change their response so quickly, and service users have reported difficulties in understanding exactly what was required of them.

CD ROMs are available to help practice the theory test and hazard perception exams; I looked at Lifestyle's *Driving Test Success* (£9.99), which contains many clips similar to the official test. I

New information sheets

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

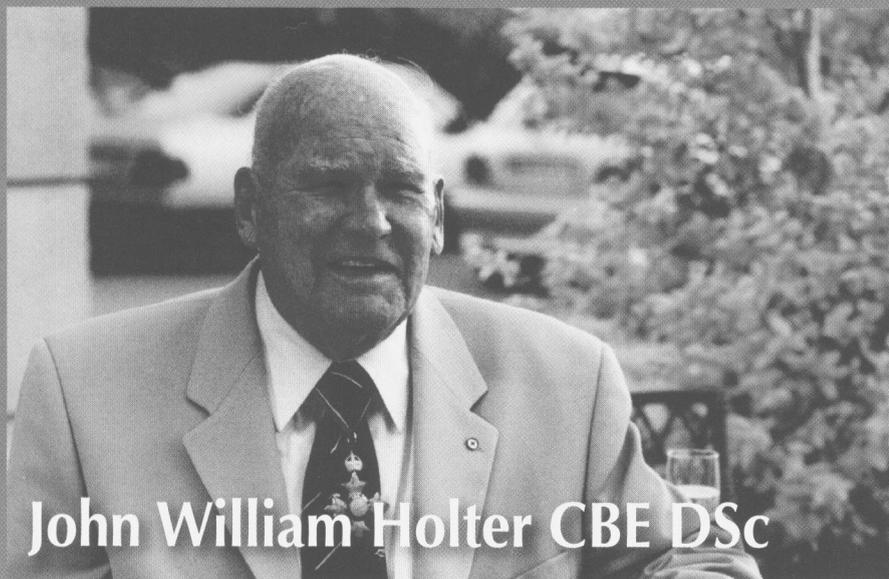
• Driving

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.

was struck by how watching the clips differed from real driving, and even as an experienced driver, I improved drastically with practice. People with hydrocephalus may find it helpful to practice the tests at home, when they are relaxed.

The Driving Standards Agency (DSA) have audio sets to help with reading and language issues and BSA-signed tests; the agency will allow extra time for the theory tests; call the DSA on 0870 0101 372 to discuss your needs.

Tribute



John William Holter CBE DSc

John William Holter was an engineer and successful businessman. In 1955 his son Casey was born with severe myelomeningocole and developed hydrocephalus at the age of three months.

From that moment Dr Holter devoted all his professional skills to the development of shunting systems for the treatment of hydrocephalus, and incidentally became a pioneer of collaboration between engineers and surgeons. Working with a surgeon, Dr Spitz, a one way valve was designed and the first Spitz Holter system was inserted at the Children's Hospital of Philadelphia in March 1956. The British Surgeon

George Macnab visited Dr Holter, brought back the device to England and started to use it at Great Ormond Street Hospital in 1958; this led to its use worldwide. The Spitz Holter system has survived the test of time, is still universally used and has revolutionised the lives of thousands of people with hydrocephalus enabling them to live near normal lives.

Although an American and an honorary member of the American Association of Neurological Surgeons, he revelled most in his reception by the United Kingdom. In 1963 he was made an honorary member of the Society for Research into Hydrocephalus and Spina Bifida, becoming the first non-medical

member. In 1965 he established for the society the Casey Holter Lecture and the Casey Holter Essay Prize in memory of his son. He was a vigorous participant at the society's annual scientific meetings which he attended regularly, latterly accompanied by his longtime friend Rina Dardozi. In 1976 Sheffield University conferred an Honorary DSc on him. In 1998 he was invested as an Honorary CBE, an honour of which he was intensely proud. The event was celebrated at the Genova meeting of the Research Society that year. Dr Holter made other innovative and notable contributions to medicine, including designing heart valves and artificial hearts used in research and development, artificial hand tendons and many speciality instruments.

He served with the American Army from 1941 to 1945 seeing action in North Africa, Italy and France. A keen sailor, he indulged his hobby after his retirement until failing health prevented the activity in 1997.

John Holter is survived by three nephews and a niece, by Rina and by thousands of friends from all corners of the world who remember him with affection, gratitude and admiration.

John William Holter b. 1916 d.2003



Driving

Driving is the key to independence for many people with hydrocephalus or spina bifida and the following information is to help you get started.

Driving Licences

You may find that there is some delay in obtaining a provisional licence as the DVLA will often make a medical check with your own doctor before issuing the licence.

If you have a history of seizures you will normally have had to be seizure free for a year before getting a licence (if you only have seizures in your sleep, this may be different). You can also not drive for six months after a shunt revision. Details of all the medical rules for obtaining a driving licence can be found on the DVLA website at www.dvla.gov.uk

Driving Assessments

Anyone with hydrocephalus or spina bifida should have a driving assessment before spending a lot of money on lessons and a car. Hydrocephalus can affect driving ability (for example how to judge speed and distances, co-ordination, concentration etc) and it is important to see if this is likely to be a problem. Driving instructors may say that they can do this assessment for you but it is difficult for them to be truly independent.

An independent driving assessment is also very useful if you need to apply to Motability for a grant for a specially adapted vehicle – most people with spina bifida need power assisted steering and may well need an automatic car with hand controls and possibly special seating, hoist etc.

An assessment could cost anything from £60 to over £100 but is it money well spent (it may be cheaper if you just want information on aids and adaptations). It consists of a medical assessment, usually a drive on a private roadway (for which you do not need a provisional licence) and an assessment by a professional

such as a physiotherapist or occupational therapist: you will have your vision tested and sometimes be asked to do a few perceptual tests. For details of where your nearest independent mobility centre is contact: Motability's customer services on 01279 635666, or phone MAVIS (Mobility Advice and Vehicle Information Centre) on 01344 661000

Driving Lessons

If you have a Motability car, you can apply to Motability for help with the cost of driving lessons; under their Charitable Driving Lessons scheme.

Motability also administer the Young Drivers Scholarship scheme for 16-24 year-olds who receive the higher rate of DLA Mobility Component and have a provisional licence. For this scheme you do not have to have a Motability car.

To apply for either of these schemes write to Motability at Goodman House, Station Approach, Harlow, Essex CM20 2ET, giving your name, national insurance number, age and date of birth and outlining your needs.

Motability will send you an application form to fill in and return. It takes some weeks for the application to be processed and for a decision to be made as to whether you have been successful. Funds are limited. Details of instructors who have done a special training course for teaching disabled drivers are available from Queen Elizabeth Foundation Mobility Centre, telephone 020 8770 1151, or MAVIS on 01344 661000, along with details of whether their learner vehicles are adapted. Also, BSM has 200 instructors who have undertaken specialised mobility training to teach disabled people to drive - for more details contact them on 08457 276276.

The Association of Wheelchair Children will fund a course of 10 lessons for a wheelchair user of 16 or 17. The client must be sponsored by a professional and AWC must be in receipt of a pro forma invoice

from a registered driving school using qualified driving instructors for 10 hours worth of lesson (e.g. 10 one hour lessons or 5 two hour lessons). Association of Wheelchair Children, 6 Woodman Parade, Woodman Street, North Woolwich, London E16 2ll
Tel. 0870 121 0050

Financial Help with adaptations

Motability have long waiting lists for applications to both the funds they administer for help with adaptations, so apply in writing well before you think that you will need the vehicle. Motability's Charitable Grant can provide help towards adaptations such as hand controls, swivel seats or wheelchair hoists. The Specialised Vehicles Fund is for more costly and complex adaptations such as wheelchair accessible vehicles and special controls eg joystick steering.

After the initial contact, they will send you a detailed application form and also advise that you approach voluntary organisations such as ASBAH, for some additional help towards the cost of adaptations. ASBAH can sometimes give limited help towards adaptations such as hand controls but cannot help with car deposits.

Motability will expect you to contribute a certain amount if this is your first application. If you are living at home with your parents, their financial details will be taken into account by Motability. If, after Motability has given you a decision, there is still a shortfall, it is sometimes possible to approach other trusts for help. Let ASBAH know as early as you can if you are likely to need help with this - it often takes a long time and probably will not be successful for deposits but might be possible for items such as hoists.

Theory Exam

This may be difficult for some people, especially those with hydrocephalus, so do ask about any extra help or time which may be available to you. BSM has facilities on its web site for people to practice theory tests, as often as they wish for one month, for a fee of £5.99. Visit BSM's web site at: www.bsm.co.uk

Wheelchairs

If you are a wheelchair user, it is important for you to be able to get your wheelchair in and out of your car without help. This may mean that you need to look at hoists or special chairs, or might just mean buying a really lightweight chair if you can't manage those available from the wheelchair service. You might use the wheelchair service voucher system for this. Again, it is sometimes possible to raise some (but not all) financial help towards this, so contact ASBAH if you think you will need help.

Further Information

The following organisations can be contacted for information:

MAVIS

(Mobility Advice and Vehicle Information Centre):
Telephone 01344 661000 email: mavis@dft.gsi.gov.uk
Web site: www.dft.gov.uk (then go to Access and click on MAVIS)

Queen Elizabeth Foundation Mobility Centre:
Telephone 020 770 1151

Disabled Drivers Association:
Helpline 0870 770 3333 email: ddahq@aol.com
Web site: www.dda.org.uk

Disabled Drivers Motor Club:
Helpline 01832 734724 email: info@ddmc.org.uk
Web site: www.ddmc.org.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

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

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£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 2nd July 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.

Just to say how much I like the new look Link. I received it yesterday and enjoyed once again reading articles and help and advice you give for those with hydrocephalus and spina bifida.

I was surprised to see that you mention that Dr John Holter, the inventor of the shunt valve, had died. I was one of the first to have a Holter shunt fitted, but it failed. Judging by what I have been told I went on quite a lot longer with it than what was first thought, as they couldn't really say what the life of one of

these devices would be back in the 1960s. My neurosurgeon Mr Pople shows a great interest in me; he also knew my original surgeon at Queen Mary's in Carshalton, Mr Herbert Eckstein.

Not working at the moment I'm busy writing a book about me, doing arts and crafts and getting used to my new computer. I'm also learning to handbell ring and also hoping to join a choir again soon.

Emma Bosworth - Street, Somerset

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

'Getting the Most out of Life'

Fri 7 - Sun 9 May

Greenbank Sports Academy,
Liverpool
For 12-17 year olds; cost: £50
Details: Angela Lansley,
tel: 0151 733 8392
nro@asbah.org

Wheelie Club, Belfast

Sat 15 May

Musgrave Park
Details: tel: ASBAH Northern
Ireland
028 9079 8878
niro@asbah.org

Wheelchair Mobility Course

Sat 22-Sun 23 May

Wirral, Cheshire
Details: Elizabeth Miers,
tel: 01490 450 360
nro@asbah.org

Greater Manchester area drop-in

Wednesday 2 June 10.30-1pm

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

Motability Roadshow

Thurs 17- Sat 19 June

Donington Park, Derby
- ASBAH's stand is no. D39
Details: Jacqui Smith,
tel: 01733 555 988
jackies@asbah.org

Sheffield Association

Sat 17 July

40th birthday celebrations
Details: Barbara Clark,
tel: 0114 269 9299

Summer Experience

Activity Course

Mon 6 - Thurs 9 September

Keppleway 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

Please e-mail the editor (link@asbah.org) dates for the next issue of Link by Friday 18 June 2004, giving the name of event, purpose, location, date, cost (if applicable), contact name, phone no. and email address.

ASBAH offices

ASBAH

42 Park Road
Peterborough PE1 2UQ
Tel: 01733 555988
Fax: 01733 555985
Email: postmaster@asbah.org

ASBAH EAST

42 Park Road
Peterborough PE1 2UQ
Tel: 01733 555988
Fax: 01733 555985
Email: ero@asbah.org

ASBAH NORTH

64 Bagley Lane,
Farsley, Leeds LS28 5LY
Tel: 0113 2556767
Fax: 0113 2363747
Email: nro@asbah.org

ASBAH SOUTH EAST

209 Crescent Road
New Barnet, Herts EN4 8SB
Tel: 020 84490475
Fax: 020 84406168
Email: sero@asbah.org

ASBAH IN WALES

4 Llys y Fedwen,
Parc Menai, Bangor,
Gwynedd LL57 4BL
Tel: 01248 671 345
Fax: 01248 679 141
Email: wro@asbah.org

ASBAH N. IRELAND

Graham House
Knockbracken Healthcare
Park, Saintfield Road,
Belfast BT8 8BH
Tel: 028 90798878
Fax: 028 90797071
Email: niro@asbah.org

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Link went to visit Rachel Nicholls, an ASBAH adviser based in the South East of England. Rachel spoke to us about her routine and her daily challenges.

...Rachel Nicholls

“I’ve been working as an adviser for ASBAH for over 15 years now and I still love the direct contact with the many people I visit.

I’m responsible for 148 service users, including around 100 families, and I’m based at my home in south east London, working two-and-a-half-days a week, which fits in well with my family life. On a working day the first thing I do is check

my answerphone. I usually plan my visits a week ahead, so I’ll know that I’ll have three or four visits to make and why I need to see the families concerned.

I always make sure I allow enough time to see everyone, because unexpected things can happen while I’m there. Parents may be upset about something they have received through the post or have had a telephone call about an issue that I have to deal with right there and then. On several occasions I’ve visited a child and they have been taken ill while I’m there, so I’ve actually driven the child and their parents to the nearest hospital.

It’s a very rewarding job and very satisfying when I feel I have made a difference to families’ lives. Getting benefits sorted out or finding the right school, for example, helps take some of the stress away from the families so they have one less thing to worry about.

I enjoy the direct contact I have with service users and families during visits. It’s great to go into a household where the family is as comfortable with me as I am with them. There may be three or four issues to discuss and I often need the family’s help and support to help them achieve their goals.

Like any job it has its downside and there are issues I do find difficult to deal



with, such as family grief, distress and injustices. As an adviser it is very easy to get knocked back when you’ve just overcome one issue, only to be confronted by another. Sometimes I just have to

stand back, take a deep breath and ask myself ‘How are we going to approach this problem?’, and then decide how to tackle it.

Working from home does suit me but I’m fortunate in that I always have ASBAH’s south east office in Barnet to go to. I speak to other ASBAH staff at least once a week and see them every six weeks, so I do have a close network of colleagues even though I generally work alone.

When I’m not working I do try and find some time for a little relaxation. My favourite ways of unwinding are reading, gardening, cooking and swimming. I’m quite a practical person really.”

It’s a very rewarding job and very satisfying when I feel I have made a difference to families’ lives.



Directory of independent local associations

AFFILIATED ASSOCIATIONS

BEDFORD

Mr R C Simmonds
16 Parkstone Close
Bedford MK41 8BD
Tel: 01234-400068

BRISTOL & DISTRICT

Mr G Egan
64 Rookery Road
Knowle, Bristol BS4 2DT
Tel: 0117-9777942

BUCKS & EAST BERKS

Mrs Karen McClean
5 Candelmas Mead,
Beaconsfield
Bucks HP9 1AP

BOLTON & BURY

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

CAMBRIDGE & DISTRICT

Julie Desborough
Summerlin Farm
Boxworth Road, Elsworth,
Cambs, CB3 8LJ

CHESTER & DISTRICT

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

COVENTRY

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

DUDLEY & WOLVERHAMPTON

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

GRANTHAM

Mrs J Hickling
3 Goodliffe Road
Grantham, Lincs
NG31 7QB
Tel: 01476-401643

GREENWICH & DISTRICT

Mrs M Mears
29 Wellmeadow Road
London SE13 6SY
Tel: 0208-244 3526

HERTS AND SOUTH BEDS

Mrs Jennifer Hammond
28 Gladeside
St Albans, Herts AL4 9JA
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The Hollister Advance to Independent Living ROADSHOW



The Hollister Advance to Independent Living Roadshow is a unique opportunity for people to see a wide range of companies specialising in varying lifestyle needs for people who perform ISC (intermittent self catheterisation) and sheath users. The Roadshow is being held at Blenheim Palace, Woodstock, Oxon on Saturday 15th May 2004. Attendance is free.

If you would like the chance to attend the roadshow, please complete and return the slip below to Hollister Limited.

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I would like to attend **The Hollister Advance to Independent Living Roadshow**.

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Post code:

Do you require wheelchair access?

Will anyone be accompanying you?



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