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WINTER 2004 ISSUE 211 80p

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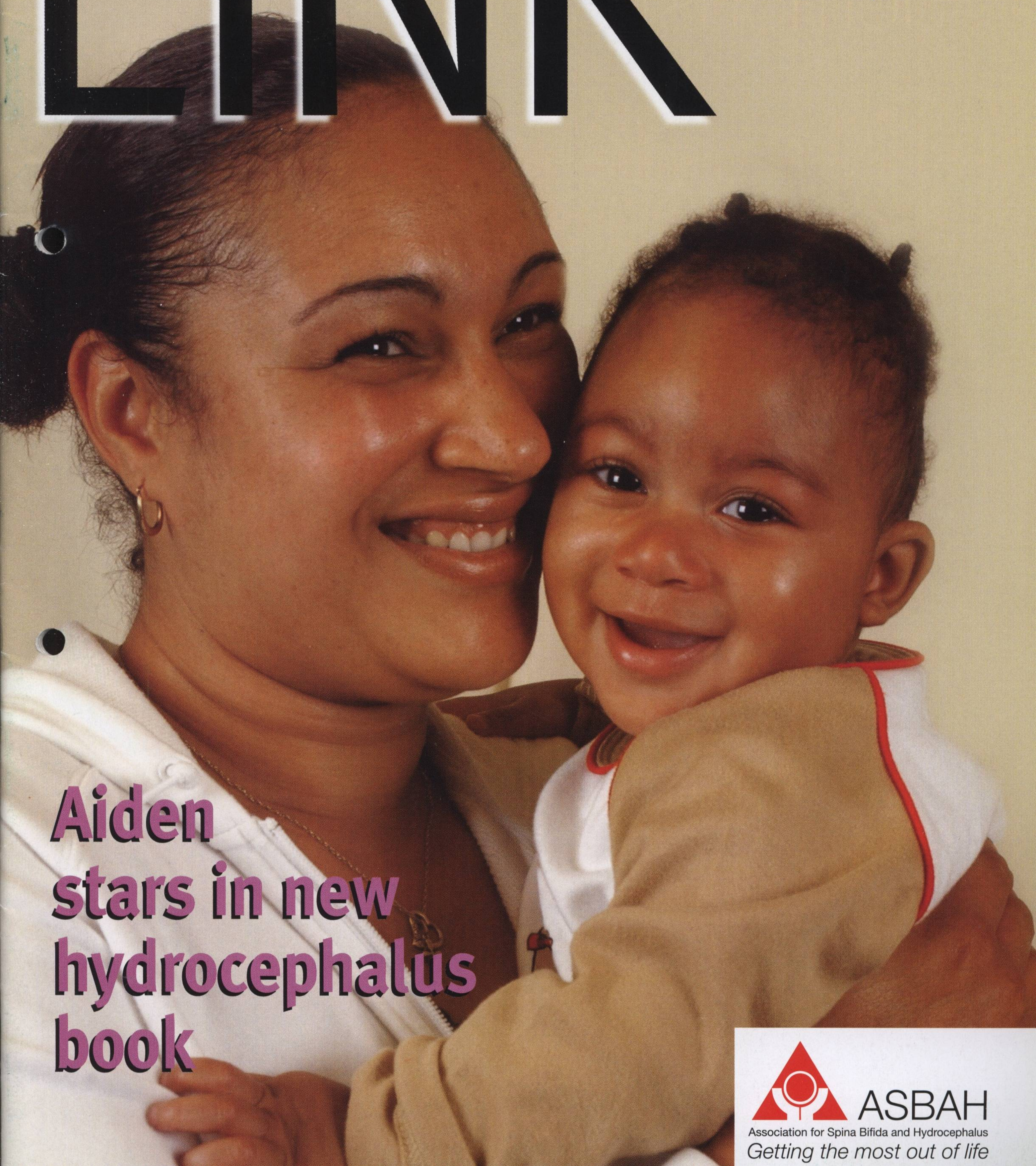
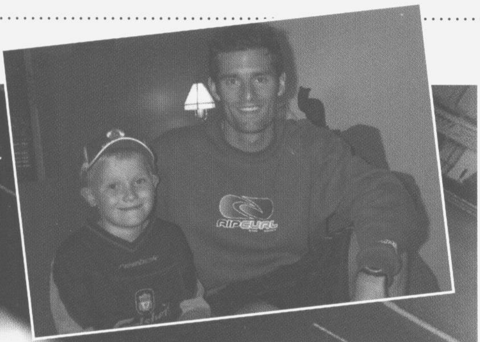
LINK

The magazine for people with hydrocephalus and spina bifida

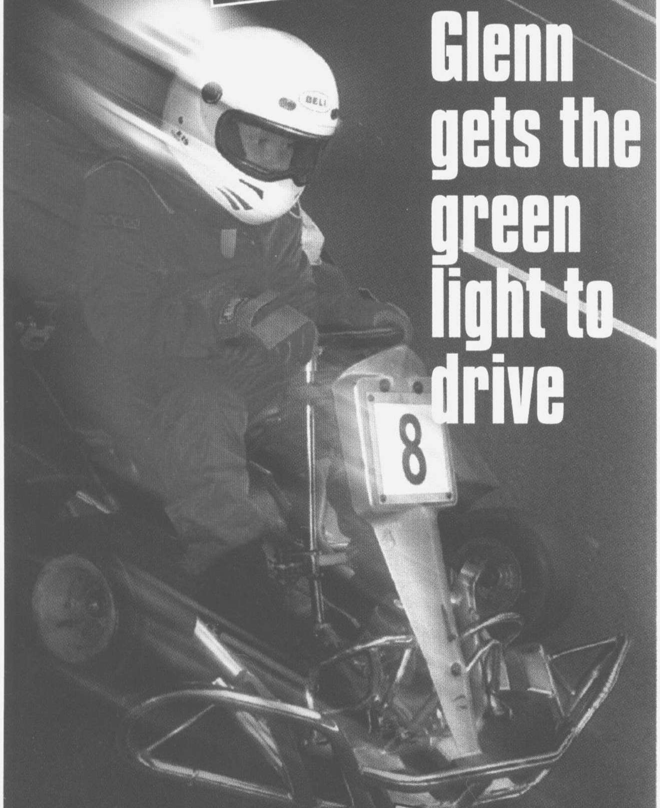


Aiden stars in new hydrocephalus book

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



Glenn meets Formula 1 driver Mark Webber



Glenn gets the green light to drive

Youngster Glenn Alcock is enjoying life in the fast lane after taking up an exciting new hobby.

Glenn, who has spina bifida and hydrocephalus, is now a leading light at the Silverstone Karting Race Training Club after gaining his competition licence.

The thrilling sport has brought a new lease of life to the nine-year old, who admitted, "I used to feel down a lot of the time because children said horrible things to me at school and I didn't think that I was good at anything.

"I got upset a lot and cried for no reason except that I was sad. I thought life was so unfair and I never wanted to take part in anything."

Glenn's interest in the sport was sparked in 2000 when he became friends with a neighbour, John Feakin, who had his own kart.

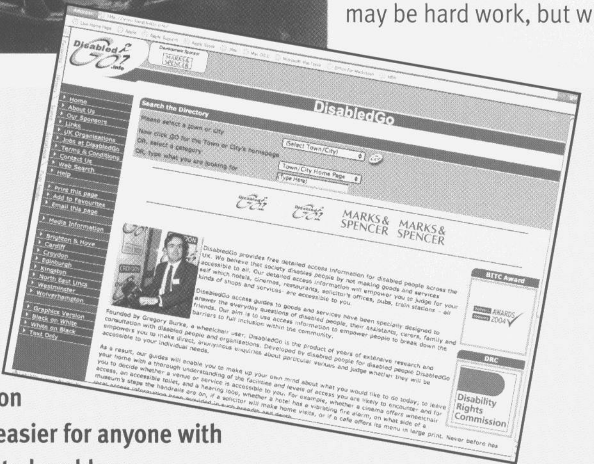
"That was what really made me want to learn to drive," said Glenn. "But I was still too young."

He finally got his chance to get behind the wheel at Silverstone last year. After thorough health and safety checks he joined the karting club and learnt to drive.

He passed both the practical and written tests with flying colours and now drives regularly with the club.

Glenn added: "Passing the test proved to me that I may be a disabled child but I am just as good as any so called normal child, and if someone wants something so much, they should have a go. It may be hard work, but with help and a little luck, you can succeed."

Access information available online



DisabledGo provides free detailed access information for disabled people across the UK. We believe that society disables people by not making goods and services accessible to all. Our detailed access information will empower you to judge for your self which hotels, cinemas, restaurants, solicitor's offices, pubs, train stations - all kinds of shops and services- are accessible to you.

DisabledGo access guides to goods and services have been specially designed to answer the everyday questions of disabled people, their assistants, carers, family and friends. Our aim is to use access information to empower people to break down the barriers to full inclusion within the community.

Founded by Gregory Burke, a wheelchair user. DisabledGo is the product of years of extensive research and consultation with disabled people and organisations. Developed by disabled people for disabled people DisabledGo empowers you to make direct, anonymous enquiries about particular venues and judge whether they will be accessible to your individual needs.

As a result, our guides will enable you to make up your own mind about what you would like to do today; to leave your home with a thorough understanding of the facilities and levels of access you are likely to encounter and for you to decide whether a venue or service is accessible to you. For example, whether a cinema offers wheelchair access, an accessible toilet, and a hearing loop, whether a hotel has a vibrating fire alarm, on what side of a museum's steps the handrails are on, if a solicitor will make home visits, or if a cafe offers its menu in large print. Never before has local access information been provided in such breadth and depth.

DisabledGo is a new information service designed to make life easier for anyone with mobility, vision or hearing related problems.

The website, founded by Gregory Burke, a 30-year-old wheelchair user, is the product of extensive research and consultation with disabled people and organisations.

It includes details of access to places throughout 12 towns, cities and areas featured on the easy-to-use website.

Leisure venues including pubs, restaurants, hotels, theatres and cinemas are featured in detail. You can find out where the nearest accessible parking is, whether there are steps into the building or doors to be opened and what kind of toilet facilities are available. Shops and services are also profiled.

DisabledGo.info is a free service and currently features guides to Westminster, Croydon, Brighton, Edinburgh, Cardiff, Kingston, North East Lincolnshire, Richmond, Kirklees, Wandsworth, Wolverhampton and Wakefield.

Service user Emma Bosworth was moved to verse when she had difficulty falling asleep one night.

Emma, from Street in Somerset, came up with a poem about ASBAH, which she says "does such good work".

A is for Achievers of which there
are many
S is for Support you would never
be without
B is for the Brave, you know who
you are
A is for Advisers and you are
always there
H is for Hydrocephalus for those of
you out there who care

Many thanks for sending your poem in Emma, it's always good to hear that ASBAH's work is appreciated.

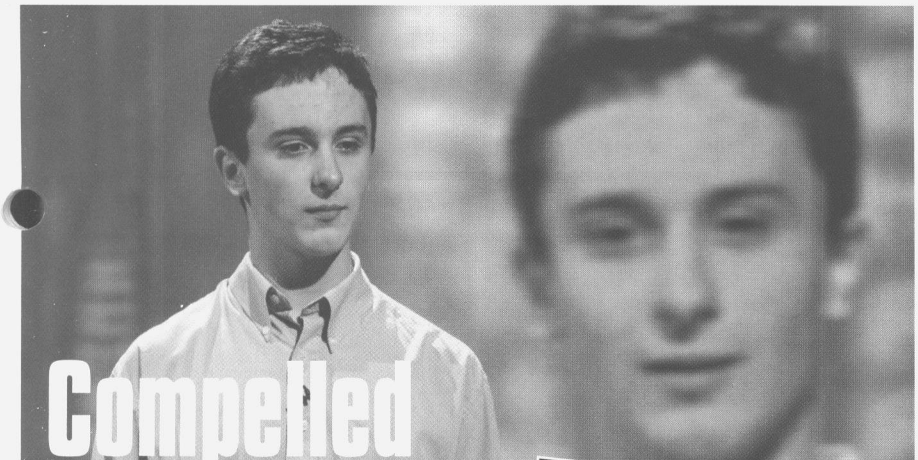
Graduation success

Congratulations to Alison Crawford, who recently graduated from the University of Ulster.

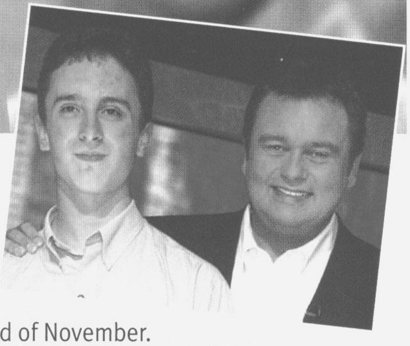
Alison, 22, gained a First Class BA (Hons) in English Literature and American Studies, gaining the highest mark in her year.

Alison, who has spina bifida and is a member of the Belfast & District branch, is now studying for a PhD in American Animation.

Alison's mother Veronica is Honorary Secretary of the Belfast and District Branch. She said: "I am very proud of Alison and what she has achieved. We've obviously had a lot of concerns since her birth, but she has always had a wonderful attitude and just gets on with things."



Compelled to spell



Teenager Tas Cooper hit the small screen after beating thousands of young hopefuls to a place on the BBC show Hard Spell.

Tas, 14, who has hydrocephalus, made it through to the top 50 young spellers after a nationwide hunt for Britain's best.

During the summer producers of the new children's TV show saw 100,000 youngsters take part in the regional heats.

Tas, from Reigate in Surrey, entered the Southern regional heat after coming top in a spelling competition at Reigate Grammar School where he is a pupil.

Proud father Brian explained: "The regional heats were held at the Connaught Rooms in London, with 120 children competing in each region. Only the top five made it to the national final, and we were thrilled when Tas got through."

The Hard Spell national finals, which were filmed for TV, saw five children from ten regions compete for the prestigious title of Britain's Best Speller. The programme was shown on screen at the end of November.

Brian added: "The studio setting was quite intimidating but Tas was very laid back and took it all in his stride.

"Unfortunately he didn't get through to the final round, which I have to admit was probably my fault.

"I'd told him not to rush, to take his time and think clearly. But although he didn't make any mistakes, he was spelling against the clock and ran out of time."

But the family, which includes Mum Rosemary, brother Kyle and sister Beth, are naturally thrilled with Tas's achievement.

"When Tas was younger we naturally worried how his hydrocephalus would affect his development, so it is great to see what he has achieved."

Chat room safety

Internet chat rooms are a popular way of meeting people, particularly for disabled people who may feel isolated and see them as a good way to meet people of the opposite sex.

But while some ASBAH service users have found love over the Internet, the press has recorded many incidents where children and other vulnerable people have been lured to meetings by unscrupulous imposters.

Mary Malcolm, Assistant Director, Services, told *Link*: "I know that many of our service users visit chat rooms as a way of talking to new people. They have met up and several couples have married as a result.

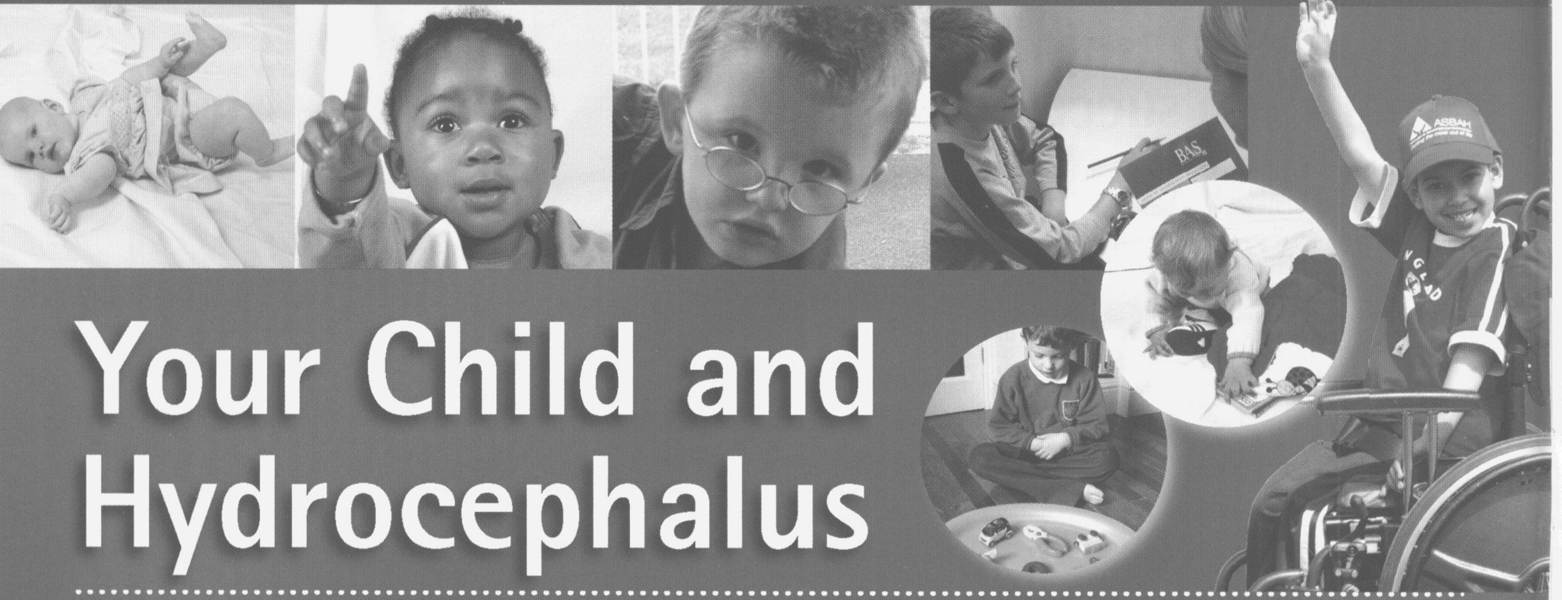
"But the chat rooms are a way for paedophiles and other dubious characters to get to know someone under false pretences and that is a concern for ASBAH. Many of our service users do live independent lives, but they may still be very vulnerable."

If you use Internet chat rooms there are some guidelines to help you stay safe.

1. **Be aware that people online may not be who they say they are.**
2. **Do not give out any personal information such as your email or home address, phone number or any other personal details.**
3. **Arranging to meet someone you have spoken to online is dangerous.**
4. **If you do agree to meet someone, choose a public place and if possible, take a friend or parent with you.**
5. **If you have planned a meeting, always tell someone where you are going and when you'll be back.**

Have you found love through the Internet or did you have a bad experience after contacting another chat room user? We'd like to hear about your experiences, so drop us a line at the usual *Link* address or email: ***link@asbah.org***

A major NEW book from the Association for Spina Bifida and Hydrocephalus (ASBAH)



Your Child and Hydrocephalus

This practical guide for parents and family members tackles the major areas of child development with advice and suggestions for parents of children with hydrocephalus *(see over for more details).*

Written by guest authors from the UK and America, this 100 page, full colour illustrated work is the definitive hydrocephalus text for parents.

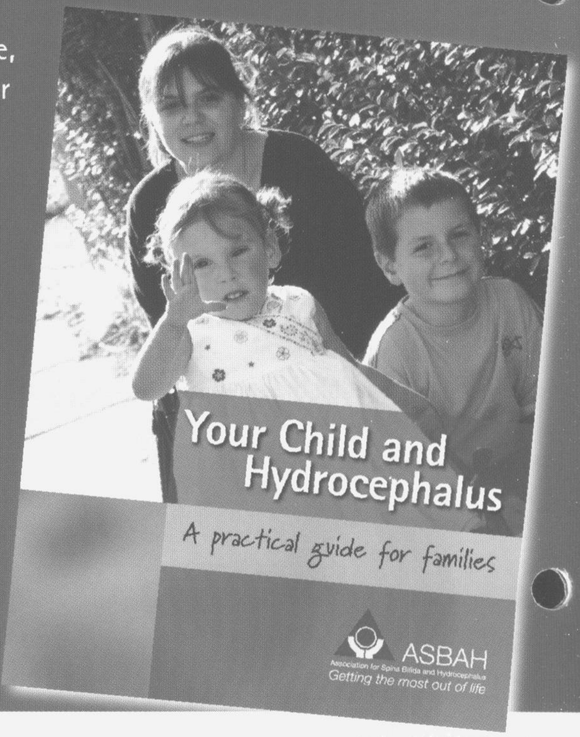
Order your copy now at £16.99 (plus p&p £2.00)

Special offer

Families affected by hydrocephalus in England Wales and Northern Ireland; existing ASBAH service users; or UK subscribers to ASBAH's 'Link' magazine can get their copy of the book at the special price of £9.99 (plus £2.00 p&p) – hurry, order now– whilst stocks last!!

Complete the coupon below or

order on-line at www.asbah.org



Your Child and Hydrocephalus

A practical guide for families

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

Order form

Please send me ☐ copies of *Your child and Hydrocephalus.*

£9.99 per copy - (for families in England, Wales and Northern Ireland) and for 'Link' magazine UK subscribers

or

£16.99 - healthcare and education professionals, european & worldwide rate

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ASBAH is committed to safeguarding the privacy of our service users whilst providing the highest possible quality of service to them. We will only use the data that we collect about you, in accordance with the UK Data Protection Act 1998, for statistical /research purposes or to inform you of new publications / information on hydrocephalus All information will be kept secure and not disclosed/sold to any third party or external agency. If you would not like ASBAH to hold your information and inform you of new publications, please tick the box ☐

Send the completed coupon, together with your payment to:

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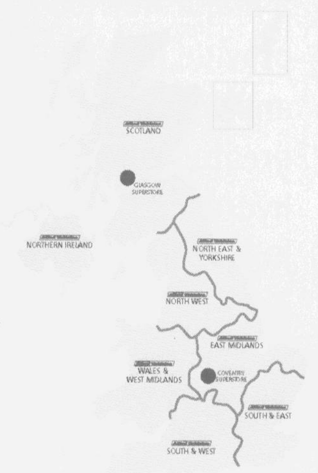
ASBAH is a registered charity Number 249338

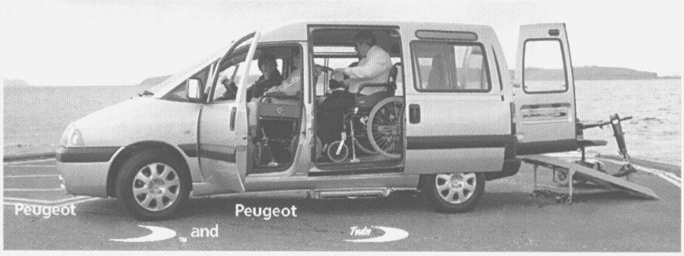
ASBAH
Association for Spina Bifida and Hydrocephalus
Getting the most out of life

Meet the family...



Who are we...?

- Allied Vehicles has been a leader in the vehicle industry for nearly 40 years and is the UK's leading specialist in vehicle adaptation.
- Our specially adapted manual cars, automatic cars, people carriers and minibuses are designed to make you more mobile and help enrich your quality of life.
- Every vehicle adaptation has been engineered and tested to the highest standards with total commitment to quality, safety and value for money.



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- **5 year unlimited mileage warranty***
- **Free no-obligation home demonstration**
- **Nationwide delivery**
- **Dedicated customer care team and excellent service and back-up**

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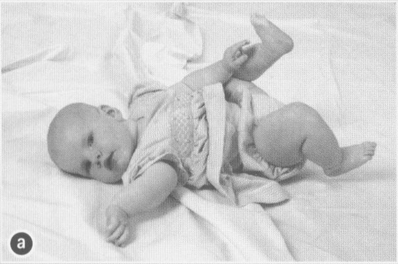
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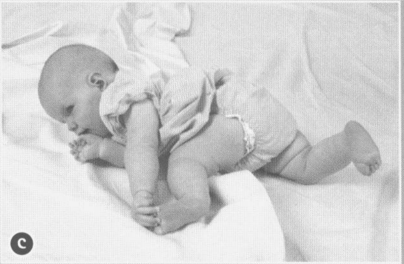
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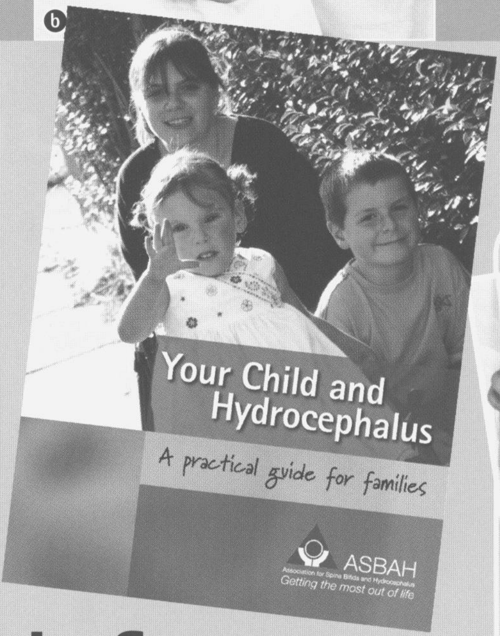
ASBAH has published a major new book to provide parents, carers and teachers with a greater knowledge of hydrocephalus and how it affects a child's development.



House of Lords launch for new hydrocephalus guide

The 100-page guide – *Your Child and Hydrocephalus* – is the first information book of its kind, and has been written by specialists from both the UK and United States specifically to help families with children who have hydrocephalus.

The new guide was launched at a special reception at the House of Lords by Lord Filkin, the Minister for Education with responsibility for special needs on Thursday 4 November.

The official host for the evening was Baroness Masham, an ASBAH Vice-President, who welcomed the guests, which included many of the writers and service users featured in the book.

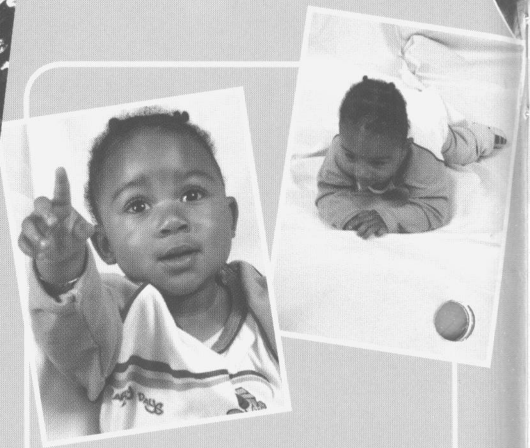
Andrew Russell, ASBAH Executive Director, explained: "The authors were fantastic and put in such a wealth of expertise and effort that we wanted to thank everybody – writers and sponsors – at a really high quality launch. Where better, when ASBAH has so many friends in the House of Lords?"

He added: "It also gave us the opportunity to invite the new Education Minister, Lord Filkin, and fix up a private meeting with him in January about special education policy."

At the launch, which was sponsored by Codman, Lord Filkin praised the new information guide.

He said: "For thousands of parents, it is a frightening and challenging experience to learn that their child has hydrocephalus. This new work demonstrates that the most important factor for disabled children is a positive and informed approach by confident parents."

"Your Child and Hydrocephalus" is published by ASBAH and is available at £16.99 for professionals. For families in England, Wales and Northern Ireland at £9.99. Telephone 01733 555988 or visit the website at ***www.asbah.org*** *to order your copy*



"I like to know as much as I can about hydrocephalus and how I can continue to help and support my son's development. The book is a fantastic guide packed full of helpful tips and advice. I don't think you can ever have enough information so the more advice and help the better for me.

"I am always picking up leaflets and packs that can help me learn more about hydrocephalus so this guide is fantastic. Aiden is only 18 months old and with this book I am able to plan for his future. I can anticipate key development stages and learn about what to do to encourage his development.

"On the day Aiden took part in the book photoshoot, he seemed a little daunted at first but he soon found his feet. He has a big personality and bags of character and thoroughly enjoyed all the attention everyone gave him, posing to the camera and smiling and laughing at everyone. I was very proud of him and to be part of such a great book is even better – I hope other parents find it as good and useful as I have."

Anne Marie Bryan

Your Child and Hydrocephalus

Review

Reviewed by Conor Mallucci, MBBS, FRCS(SN) Consultant Paediatric Neurosurgeon, Royal Liverpool Children's Hospital and The Walton Centre for Neurology and Neurosurgery; with a special interest in hydrocephalus.

This book really fills a void; written by a team of specialists it gives parents greater insight into hydrocephalus and its effect on their child's development. However it's spot on for health professionals too; it provides a necessary reference point for all physicians and carers involved so that everybody's 'singing the same tune' and parents aren't getting conflicting advice.

Written in an upbeat, family friendly style, the facts and practical advice fall into colour coded sections - naturally following a child's development from 'Hydrocephalus Explained' through, 'Physical Development', 'Language Development', 'Psychological Development, to 'Growing up'. This book really comes into its own when the acute phase is over.

Parents are given a chance to start considering some of the questions about their child's future. Because 'Your Child and Hydrocephalus' is in such complete sections it's easy to dip into the section applicable to your child's development. Easy however to keep reading! This is where we as health professionals should be at hand to guide you. Readers should remember that this is a reference book not a list of what their child is going to have.

The pictures and imagery are an integral part of the book. Not only do they reinforce the text but they help to demystify hydrocephalus. Many medical terms are "spouted" at parents by differing health professionals and these pictures cut through the terminology offering tremendous reassurance to parents and professionals alike.

The pictures and imagery are an integral part of the book. Not only do they reinforce the text but they help to demystify hydrocephalus.

The strategies on offer, for now and the future, are where this book simply shines. Parents often need practical advice from somebody. *Your Child and Hydrocephalus* is packed with sane, pragmatic ideas for coping, along with role play activities for families to master at home.

Conor Mallucci, MBBS, FRCS(SN)

Parent Study Days

A series of Parent Study Days is being set up to help parents get the most from the new 'Your Child and Hydrocephalus' book.

ASBAH is organising a series of days across England, Wales and Northern Ireland to allow parents to learn, participate and have a better understanding of their child's hydrocephalus.

The one-day seminars, with practical workshops and talks, follow the areas of child development featured in the *Your Child and Hydrocephalus* book, and are designed to offer parents practical help and advice about various aspects of helping their child with hydrocephalus.

Speakers at the seminars will be drawn from speech and language therapists, physiotherapists and educational/clinical psychologists – to cover the widest aspect of child development.

Shunt manufacturer Codman have offered to attend each venue, and where possible will bring along sample shunts for parents to talk about and handle.

Anyone interested in attending the ASBAH parent study days should contact their local advisor, regional office or see the ASBAH website ***www.asbah.org*** for updated information.

In order that children don't distract parents during the day, it is proposed that the day is open to adults only.

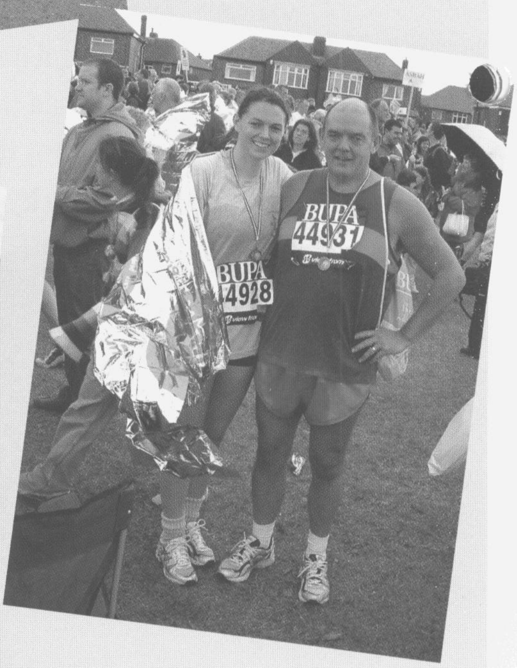
Dash for cash

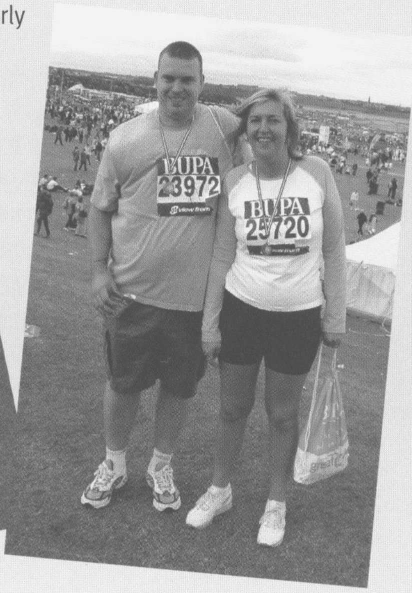
A team of 32 enthusiastic runners have run up another fundraising success for ASBAH by taking part in the BUPA Great North Run in Newcastle, the biggest half marathon in the world.

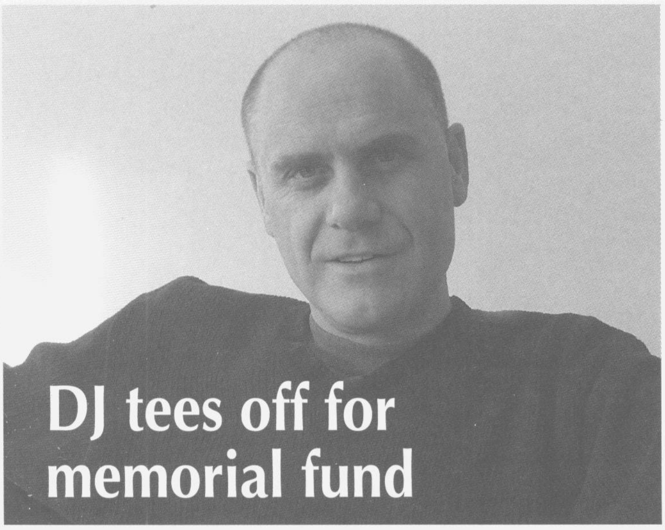
Around 49,000 people lined up for the 24th Great North Run on Sunday 26 September 2004, which was started by double Olympic gold medal winner, Kelly Holmes.

The sporty squad running for ASBAH included two plucky ladies who donned Baywatch inspired bright orange swimming costumes. The team ran the 13-mile course taking them from Newcastle town centre, past the Tyne Bridge and ending in South Shields.

ASBAH would like to thank all the runners for their gallant efforts in raising nearly £4,000 so far.







DJ tees off for memorial fund

Radio 2 DJ Tim Smith took to the fairways to boost an ASBAH fund set up in memory of his sister.

Every two years Tim meets up with friends for a small golf competition.

The event, which was held this year at Telford Golf and Country Club, raised £475 for the Carolyn Smith Memorial Fund.

His late sister Carolyn worked for ASBAH between 1986 – 89 as an accommodation officer. After taking a year out to study at the London School of Economics, she returned to ASBAH, this time as the field worker (local adviser) for North London. Sadly Carolyn died from a brain turmour in September 1991, aged 28.

Carolyn's family set up a memorial fund in her memory and decided that all donations to the fund should be used to help people with S B / H who are planning to live independently - a cause very close to Carolyn's heart.

Tim explained: "Carolyn was so young when she died and had spent most of her working life with ASBAH. Raising money for the fund helps us to keep Carolyn's memory alive and reminds us how dedicated she was to her job.

"A group of my friends have met up every couple of years to have a round of golf and raise money at the same time. It is a small, personal thing rather than a big showbiz event."

Lyn Rylance from ASBAH added: "The fund has benefited many people over the years, helping them to buy the equipment they need when they move into their own home.

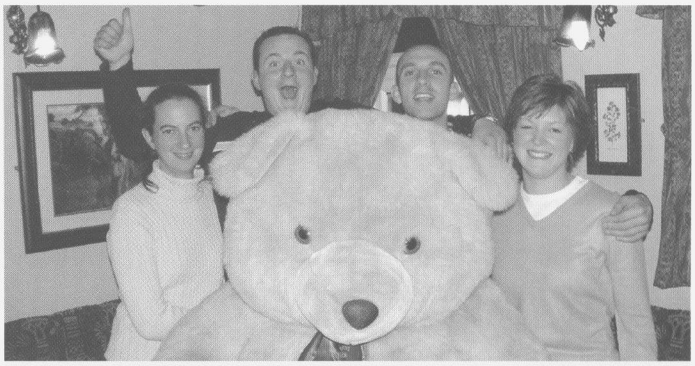
"It is also a lovely tribute to Carolyn. Many people at ASBAH , including myself, worked with Carolyn and have very fond memories of her. She was a lovely, bubbly woman."

Ski marathon

Completing a marathon circuit in snow, cross country and on skis is no mean feat but that's exactly what intrepid adventurer Jonathan Calascione did for ASBAH, raising over £3,250 in the process.

Jonathan, whose niece has spina bifida, joined 12,000 other competitors in Switzerland to take part in the 42km ski race. The route took them across snow-covered lakes, around a mediaeval castle, through St. Moritz and a forest before ending in 'Golan Heights'.

This is the second time Jonathan has completed the marathon ski race on behalf of ASBAH and we would like to thank him for his continued support and efforts.

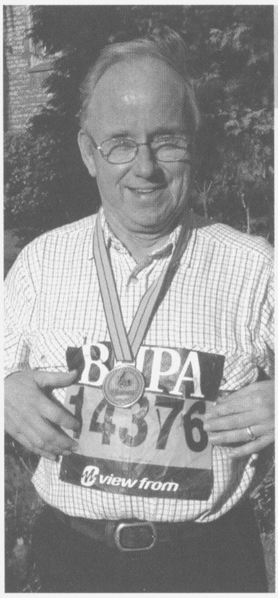


The bear necessities

Thanks go to 'The Lord Nelson' public house in Bourne, Lincolnshire, which hosted a memorable bonfire bash on Friday 5 November in aid of ASBAH.

Revellers enjoyed a fantastic fireworks display followed by traditional hot-dogs and burgers. The climax of the evening was the chance to win a giant teddy bear, which was kindly donated by Lesley Tibble, a close friend of Jane Ayres in the Fundraising Department.

The teddy bear raffle was won by a member of the charities committee at RAF Cottesmore. The evening's activities and raffle raised in excess of £115 for ASBAH.



Duo run up £850 for ASBAH

Two ASBAH runners put their best feet forward to tackle the gruelling Great South Run.

Jo Francis, ASBAH South East Region Manager and Alan Twyford *(pictured left)*, member of the Surrey local association and ASBAH trustee, raised £850 for ASBAH from their efforts.

The fleet-footed duo joined 15,000 runners on the 10-mile circuit around Portsmouth and Southsea – now in its 13th year.

Jo said: "The route was lined with people clapping and cheering. Runners were dressed in fancy costumes, including Batman, and nearly all the people were raising money for charity. It was great that so many people, young and old, fit and unfit, were willing to put themselves out for charity."

Alan added: "It was a fantastic day and I wore my medal day and night for a week after I was presented with it."

New face in fundraising

Helen Dow has joined the ASBAH fundraising team as Project Co-ordinator.

Helen, who spent ten years as Trust Officer at The Leprosy Mission, also based in Peterborough, took up her new position in September.

She told Link: "My responsibilities include large funding applications to the Lottery and specific Trusts for particular areas of ASBAH's work.

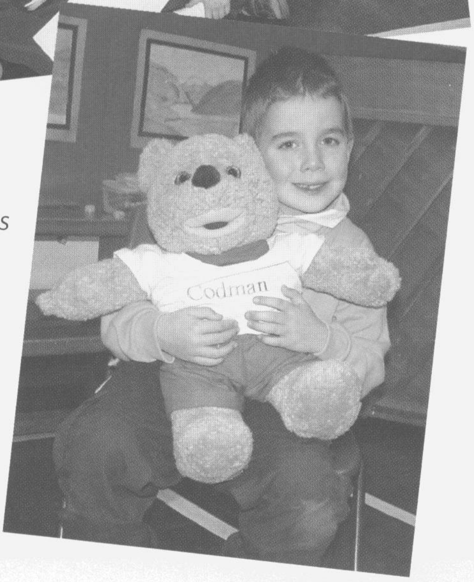
"I am really pleased to have joined ASBAH. I am finding the work ASBAH does to support its service users very interesting and having worked for an international organisation I am looking forward to the challenge of working for a national charity."

Norman sinks a hole lot of money

Thanks to the success of the Northern Ireland Golf Day, hosted by ex-Manchester United player Norman Whiteside in July, ASBAH has been presented with a cheque worth over £12,000.

ASBAH's Assistant Director of Fundraising, Donna Treanor, travelled to Northern Ireland to receive the cheque, which was presented live on BBC Radio Ulster by radio host George Jones and Norman Whiteside.

ASBAH is also delighted to announce that it will be the beneficiary of the next golf day in 2005 and would like to thank Norman and North West Events for their continued support.



Matthew Coates cuddles Benny Bear

Eager beavers get smartie

Our thanks to the 1st Marston Moor Beaver group whose 'sweet' fundraising idea of filling up Smartie tubes with loose change raised over £80 for ASBAH.

The task was set after the Beavers, based in Tockwith, Yorkshire met Joanne Grenfell, ASBAH's education advisor. Joanne was invited to talk to the group about hydrocephalus by group leader, Ruth Lee, who was looking for a worthwhile charity for the Beavers to support.

ASBAH had been suggested to Ruth by a mother whose child has hydrocephalus and also attends the group. Ruth said; "I wanted a charity that the children could raise money for in the run up to Christmas and one that meant something to them. ASBAH seemed ideal.

"It's important that the children learn why fundraising is important and also that at Christmas time to give is just as important as to receive.

"Joanne's talk was absolutely fantastic and the children responded extremely positively. In fact, they were so inspired by what they heard, that every child returned the next week with their Smartie tube brimming over with pennies."

According to Ruth, the children's fundraising and charity work is an important module towards one of three badges a Beaver can be awarded.

ASBAH thanks all the Beavers for their donation and wishes them every success in achieving their next badge.

ASBAH benefits from disco night

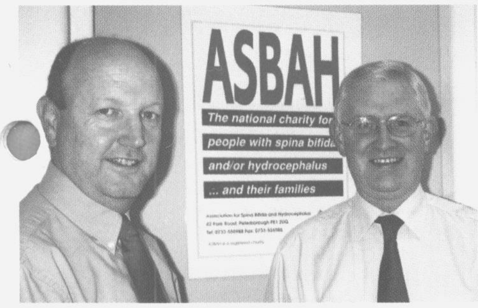
Ray Pobgee (left) presents the donation to ASBAH events co-ordinator Ian Morley.

A 60's reunion disco at a Peterborough youth club boosted ASBAH's funds by more than £400.

Former members of the Dogsthorpe Methodist Sunday Club got together for the first time in 30 years at the charity disco. Ged Belson, who organised the party night, was delighted with the £415 raised for ASBAH. Ray Pobgee presented the cheque.

Ian Morley, events co-ordinator at head office, said: "We were thrilled at being chosen. It is always nice to receive donations that we haven't had to ask people for.

"We are relatively unknown in Peterborough but this kind of event helps us to develop public awareness."



Dance donation

ASBAH are very grateful to the Northern Ireland branch of the British Computer Society (BCS) which raised £1,300 from its annual dinner dance.

BCS committee member, Stewart Henderson, whose niece has spina bifida and hydrocephalus, presented the cheque to ASBAH's Northern Ireland Regional Manager Brendan Heaney.

BCS is a professional body in the computing and information system field and has members in over 100 countries.

DANNY MILLS APPEAL

Helpline & Information Service

Update

Danny Mills pictured with award winners and fellow presenters at the Nationwide Junior Sports Awards, organised by Disability Sport England.

Danny meets junior sports stars

Danny Mills presented an award at a special ceremony to mark the sporting achievements of disabled youngsters.

Danny, now playing for Manchester City FC, was delighted to take time out from his hectic training schedule to attend the Nationwide Junior Sports Awards. The Awards, organised by Disability Sport England, were held this year at Manchester's Victoria and Albert Hotel.

The ceremony, on 30 November, marked the end of a successful year in disability sport, when Britain finished second in the medal table at the Athens Paralympics.

This year's winners, who came from the world of swimming, athletics and the Mini Games, were thrilled to meet famous faces including Everton's Lee Carsley.

Danny, who was joined by ASBAH Assistant Director of Fundraising, Donna Treanor, and local adviser Marcia Conroy, told *Link*: "It was an honour and a pleasure to attend the Awards.

"I am very lucky in football that the media follows my sport actively. Disability Sport England and disabled sportspeople are not given the amount of recognition they deserve. They work just as hard, if not harder, than all other sportsmen and women and often have to overcome adversity.

"Many have to face difficult challenges on a daily basis and to go on and excel in sport deserves special recognition. It is really important to encourage talented youngsters and show them that their achievements are noticed. It was a great pleasure to meet and congratulate our future disability sports champions."

Danny has also been busy planning a second golf day for ASBAH after the success of his first venture in May 2004.

The next Danny Mills Charity Golf Day takes place on 12 April 2005 and will be held at the Worsley Park Marriott Hotel and Country Club, Worsley Park, Manchester.

Danny hopes the event will raise more funds for the Danny Mills Helpline & Information Appeal. Last year's charity golf classic raised £33,000.

Linda's line

I have just ruined the second pair of tights this week and it's absolutely maddening.

They really are a triumph of design over common sense and you chaps who don't even have to think about such things can count yourselves dead lucky. It's not as if I could go bare legged either for two reasons: firstly it's the middle of winter and therefore rather chilly. Secondly, and far more importantly, I can't expose my legs for fashion reasons unless, of course, it has suddenly become the in-thing to have white pasty legs that couldn't get a sun tan if their life depended on it? No, I thought not.

However from a sales point of view, someone somewhere must be laughing, as the damage potential is huge. First time you trip over – wham, big hole. Snag on a microscopic shard of fingernail and you get a ladder. Yank them out of the washing machine and one leg is instantly longer than the other. OK, critics may point out here that one of my legs probably is a teeny bit longer than the other – but not by several inches!

Unfortunately, the trouble I have with tights pales into insignificance when you get on to the topic of shoes. When I was younger, shoes were always a tricky subject and the combination of Clarks odd sized shoe scheme and a little help from Remploy could, at best, be described as a compromise arrangement. As I looked enviously at my friend's fashionable footwear, the built-up shoe option became less and less acceptable, to the point at which a minor domestic rebellion occurred.

Once I started looking around for myself though, I discovered a whole new set of choices opening up before me under the heading of hand made shoes. I took the plunge and, for the first time in my life, I became the proud owner of a fantastic pair of shoes. The choices (and the cost) depend upon what your shoe requirements are and it is definitely not a cheap option, but with a bit of care and regular polishing, they will certainly last you for many years (unlike tights).

Tribute by Moyna Gilbertson OBE FCSP

Duncan Forrest with Moyna Gilbertson

Duncan Mouat Forrest MB ChB FRCS
1922-2004

Duncan Forrest was a New Zealander and took his first medical degree at the University of Otago. He immigrated to the UK working his passage as a ship's doctor and becoming a Fellow of the Royal College of Surgeons in 1951. He started his career in paediatrics as part of a pioneering team at the Hospital for Sick Children, Great Ormond Street, and in the early 60's he became consultant at Westminster Children's, Queen Mary's and Carshalton and Sydenham Children's Hospital.

Always interested in research and development, he was at the forefront of surgical developments in spina bifida and hydrocephalus and worked with George MacNab who was responsible for the introduction in this country of the Spitz-Holter shunting system contributing important refinements in the fitting and maintenance of shunts.

Duncan was an early member of the Society for Research into Hydrocephalus and Spina Bifida and a distinguished President from 1982 to 1985. Always acutely conscious of the need to support families he was a founder member of the Association for Spina Bifida and Hydrocephalus and served faithfully for many years on the executive committee as member and then chairman of the medical advisory committee and wise counsellor to staff.

During his time as chairman of the medical committee he played a vital role in the setting up of the international study of folic acid supplementation in the prevention of spina bifida.

His concern for families was international and he was a keen supporter of ASBAH's involvement in the founding of the International Federation of Hydrocephalus and Spina Bifida. He attended the inaugural meeting and subsequently he and his wife entertained the Federation's executive committee when it was England's turn to host the meeting.

He was trustee and chairman of the Wade Trust, founded in the early 90's to support research into spina bifida and hydrocephalus.

After his retirement from clinical practice in 1987 he became increasingly involved with the work of Amnesty International and the Medical Foundation for the care of victims of torture, working in the field of human rights, specifically the examination of survivors of torture.

He always retained his interest in the Society for Research into Hydrocephalus and Spina Bifida and attended the Dublin meeting in June 2004 where he was his usual lively self, thoroughly enjoying being with old friends and colleagues. It was a privilege to know Duncan and he will be long remembered with gratitude and affection.

His wife June died in 2001. He is survived by four children, Allison, Ian, William and Paul, and six grandchildren.

New support pledged for local associations

Local associations will be working more closely with ASBAH to benefit service users across England, Wales and Northern Ireland.

Members voted unanimously to adopt a Local Association Compact at the national AGM in September - an agreement which was put together after a year-long consultation with the associations.

The network of 39 local associations throughout England, Wales and Northern Ireland is a vital resource for thousands of individuals and families affected by spina bifida and/or hydrocephalus and ASBAH is keen to provide support in a variety of forms.

ASBAH will offer help guides in the management of local associations as well as providing good quality publicity materials so all branches of the organisation become more widely known.

The local associations have agreed to have a regular contact point that people can use to get in touch. They will build a resource of local contacts and produce a newsletter on a regular basis.

ASBAH's Executive Director Andrew Russell said: "The need for local contact and support is as strong now for newly diagnosed individuals and families as it was for founder members of the local associations back in the 1960s.

"New families should be able to expect certain key standards from their local association. These basic essentials will form the basis of a new compact between ASBAH and the local associations."

Many affiliated local associations are thriving and have no problems attracting new committee members who bring in fresh ideas and activities. Others, however, have declining membership and struggle to survive.

Andrew added: "I've learned a lot from local associations. There is a huge scope to work together for the benefit of all and the improved standards will help everyone involved with ASBAH, especially those with spina bifida and/or hydrocephalus, their families and carers.

STOP PRESS

To date 10 local associations have signed up to the Compact.

Guide to meeting Compact standards

After consultations with local associations, ASBAH has identified seven basic essentials for local associations to strive to achieve and maintain, to meet the key standards of the Compact which is expected to be implemented during the next 12 – 18 months.

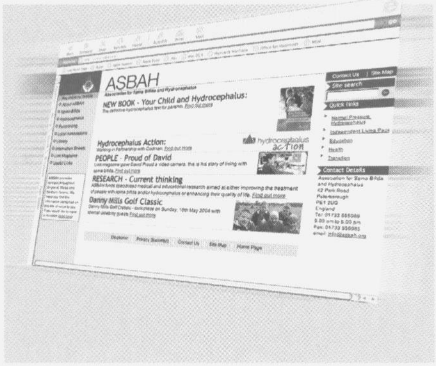
Local associations are expected to...

1. **Be easy to contact by telephone**
2. **Be available for new members – people with SB and/or H and their families**
3. **Make ASBAH's publications and leaflets available**
4. **Send out a regular newsletter**
5. **Provide support for people with SB and/or H**
6. **Keep an up-to-date list of contacts**
7. **Keep ASBAH informed**

The Compact also outlines key areas where ASBAH is expected to provide help and support to the local associations.

1. **Provide technical support and guidance on legal and organisational matters**
2. **Keep affiliated Local Associations informed by a quarterly newsletter**
3. **Give marketing and publicity support where feasible**
4. **Offer expertise in areas such as fundraising and provide signposting**
5. **Work in close partnership to improve local services**
6. **Provide information via a standard information pack**
7. **Provide training on agreed topics**

A full copy of the agreement has been sent to all local associations and it is hoped that all 39 will agree to sign up to the Compact. Anyone who has any queries should contact either Andrew Russell or Peter Farrall on 01733 555988.



It's your website

Every affiliated ASBAH local association will be given their own page on the main ASBAH website as part of the new web development plan.

The page will include information on the work of each association, contact details, forthcoming events and pictures.

Peter Farrall said: "Each website page will be designed to show each local association as a welcoming and approachable group that people will want to get involved with and support. We hope that affiliated local associations will send details of forthcoming events to us. ASBAH's website is visited by over 3,500 people per week and this is an ideal way to put them in touch with their local association."

Codman - Working in partnership with ASBAH

Happy Days for Benny Bear

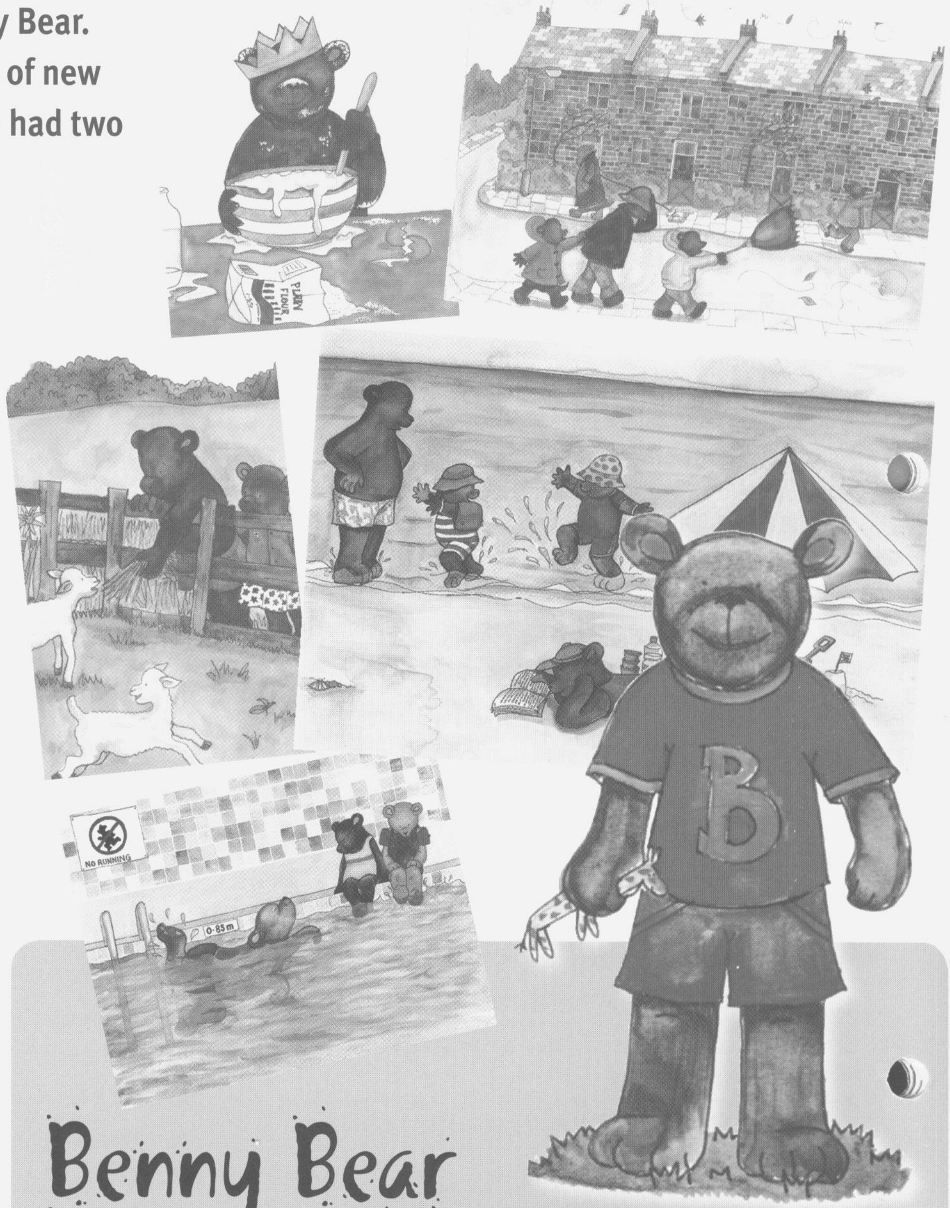
2004 was a busy time for Benny Bear. The loveable teddy packed lots of new experiences into the year... and had two new books written about him.

To help Benny and his many friends remember some of the exciting things he got up to, ASBAH and Codman produced a colourful new calendar for 2005.

For anyone who didn't get their hands on a calendar this time, another will be produced in the autumn for 2006, so look out for the adverts in Link and on the ASBAH website.

A set of three Benny Bear books - Benny Gets Better, Benny Goes to School and Benny Goes on Holiday - are available for £1.75 inc p&p. Please make cheques payable to ASBAH and send to the Information Section, ASBAH, 42 Park Road, Peterborough PE1 2UQ.

And if you've forgotten some of the activities Benny enjoyed last year, here are a few reminders...



hydrocephalus
action

Continuing through 2005 Codman and ASBAH are working in partnership to promote 'Hydrocephalus Action', a campaign aimed at heightening hydrocephalus awareness.

Codman
a Johnson & Johnson company

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

Benny Bear Drawing Competition

We would love to find out what adventures YOU would like to see Benny Bear enjoying this year.

So we're running a drawing competition for up to 10 year olds to give our younger readers the chance to have their say.

We'd like you to send in your pictures of Benny having fun in 2005 and we'll publish the winning entries in the next issue of *Link*.

The best three pictures will be chosen by Rosemary Batchelor, author of the Benny Bear books, and the lucky winners will each receive a Benny goodie bag.

Send your pictures , along with your name, address, age and a contact telephone number, to: Benny Bear Picture Competition, The Editor, *Link*, ASBAH, 42 Park Road, Peterborough PE1 2UQ. Closing date for entries is friday 17th March.

Best of luck

ETV an alternative treatment for hydrocephalus

Endoscopic third ventriculostomy (ETV) is a procedure used to treat hydrocephalus, as an alternative to a shunt.

Although the procedure, which is a natural way of draining the CSF fluid from the brain, is only suitable for a small percentage of hydrocephalus patients, it has many advantages over shunting.

***Link* talked to Conor Mallucci, Consultant Paediatric Neurosurgeon at the Royal Liverpool Children's Hospital and The Walton Centre for Neurology and Neurosurgery, to learn more about ETV.**

"Endoscopic third ventriculostomy was attempted years ago, before shunts were invented. A man called Dandy performed it as an open operation in the early twentieth century. But basic endoscopic attempts with primitive endoscopes even preceded this. It was always a logical way to try and treat hydrocephalus.

Modern equipment to carry out ETV didn't exist until about twenty years ago, so it is only now that we are able to review the procedure, and look at success rates and possible complications.

Third ventriculostomy does the opposite to a shunt. Instead of draining the CSF away, it keeps it within the brain and spinal cord.

Hydrocephalus is a group of conditions with different causes, and the treatment should naturally select itself depending on the cause.

Traditionally we have used shunts to drain the cerebral spinal fluid (CSF) from the ventricles in the brain to another part of the body, and this is still the main method of treatment.

Third ventriculostomy, on the other hand, does the opposite to a shunt. Instead of draining the CSF away, it keeps it within the brain and spinal cord.

We make a hole in the thin membrane at the base of the third ventricle, which allows the fluid into the area that lines the brain and the spinal cord called the sub arachnoid space. Once the fluid has drained into this space it can be absorbed.

The ETV technique is performed via a hole similar to that of a shunt, usually at the front of the head, just behind the hairline, using an endoscope of between 2 and 5mm in diameter.

This is a beautiful technique, which drains the CSF more naturally, but unfortunately this is only a solution for less than a quarter of all patients.

The patients for whom ETV is going to work well are people who have pure obstructions within the brain such as aqueduct stenosis, or patients who have tumours.

A second set of people who respond well are those who have had shunts for many years and have developed an obstructive form of hydrocephalus. An MRI scan will show if the patient has a blockage of the CSF pathway in their brain.

The success of ETV procedures depends on the experience of the surgeon and most importantly, the patient who is selected.

If patients are carefully chosen, the success rate for pure obstructive hydrocephalus in new patients is around 70 per cent. The failure rate is highest in the first 2 to 3 months, and if it doesn't work then, we can go to shunt.

If the ETV has worked beyond those initial few months, then it is more likely

continued over page

ETV case study

Liz Potts

When Liz Potts, 42, was diagnosed with hydrocephalus in July, her neurosurgeon at Manchester's Hope Hospital said an endoscopic third ventriculostomy would be the best treatment for her.

Here Liz, who has spina bifida, talks to *Link* about the reasons for the operation and her health since then.

"Health wise, my spina bifida had never caused me any horrendous problems, until the 1990s when the discovery of dermoid cysts meant three spinal operations since 1998, leaving me wheelchair dependant.

But about 18 months ago I started to feel quite ill, vomiting quite frequently and always feeling very tired. My health had really deteriorated by June of this year, when I was admitted to my local hospital for two weeks.

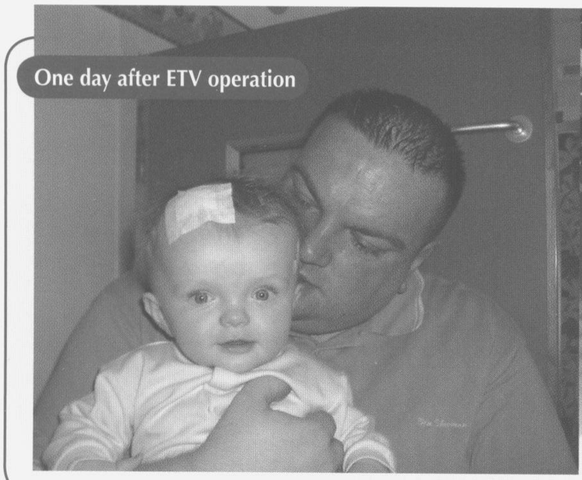
It was initially thought that I had bowel problems because I had lost so much weight. I was finally given a CT scan when I was diagnosed as having hydrocephalus.

I was transferred to my local neurosurgical unit had an endoscopic third ventriculostomy. The neurosurgeon talked to me the day before the operation, and told me about the success and failure rates, but I was so ill that I didn't take much in.

Following the ETV I was in hospital for another eight weeks in rehabilitation. The usual recovery rate is much shorter, but because I was so run down it took me longer to recover and build my general strength up.

My health has improved dramatically since the ETV, which is a huge relief. When I was ill it was a terrible strain on my family. I still don't feel 100 per cent though, and have an appointment booked with my neurosurgeon this month to make sure all is well."

Codman - Working in partnership with ASBAH



One day after ETV operation

Two months after ETV operation

continued from page 17

to stay working. But it is important that patients are aware that the procedure isn't a cure for hydrocephalus, it is an alternative treatment.

There is currently an international study looking at the success rates of third ventriculostomy in the under ones, because it is felt that in these children, despite the anatomy being suitable, the success rate isn't as high as later on.

This is possibly because the child's brain and skull is not fully formed, and the pressures generated within the brain aren't high enough to keep the third ventriculostomy open.

I tend to offer third ventriculostomy in any child who has purely obstructive hydrocephalus, but I make the parents aware that success rates are probably lower in newborn children than they are later on in life.

If patients are suitable for a third ventriculostomy, then there are several advantages to the procedure over shunts. Firstly the infection rate, at two per cent, is very low. The other main advantage is that we do not see the over-drainage problems, which can lead to headaches, because it is a natural way of draining the CSF.

So while shunts still remain the mainstay of hydrocephalus treatment, third ventriculostomy is a complementary procedure suitable for a group of patients, and remains a useful adjunct for patients who have shunt problems or blockages later in life."

ETV case study

Emma Tucker

Emma Tucker underwent an endoscopic third ventriculostomy (ETV) when she was six months old.

Now, 12 months on, her mother Sue talks openly to *Link* about the experience.

"Emma's hydrocephalus was diagnosed after her routine six week check when the circumference of her head was measured and it was found that her head was growing too quickly.

We were referred to our local hospital where Emma had an ultra sound scan and it was discovered that she had hydrocephalus.

It was at this stage that I contacted ASBAH and learned about the possible causes of the hydrocephalus, and the treatments which were available.

Emma then had an MRI scan at the neurosurgical hospital, where we learned that ETV would be the best procedure for her. Because I had some knowledge of this, I felt much happier about the operation.

Emma still has regular health checks, with her head being measured once a month.

We took Emma into hospital on the morning of the ETV, and although I had felt calm until then, it was horrendous, so frightening to see my tiny, smiling baby taken to theatre.

The actual operation thankfully only took about an hour, and, looking back, it seems like a blur. We were allowed up to see her in the recovery room immediately afterwards, and it was wonderful to hear her cry and know that she had come round from the anaesthetic.

I think the biggest shock for me after the operation was the fact that so much of her hair had been shaved away at the front of her head. There was also a small bump, about the size of a 2p, where a reservoir had been implanted. That was something I wasn't expecting.*

Emma was sick initially, but she recovered very quickly from the operation. Her head was measured before she was discharged from hospital.

We took Emma home on the fourth day, and after that we saw our health visitor every week to have her head measured.

Emma still has regular health checks, with her head being measured once a month. At the moment her head is growing at the normal rate, but if it suddenly begins to grow too fast, our neurosurgeon can insert a needle into the reservoir at the front of Emma's head to measure the pressure.

We know that it is possible that tissue could grow and block the hole created by the ETV, but the procedure can be repeated two more times.

I think what helped me to cope was having knowledge of the procedures. If I have information I can prepare myself mentally and deal with things more rationally.

Now, of course, Emma's hair has grown back and at a glance you would never know she'd had the operation."

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* *Not all surgeons insert a reservoir when performing an ETV. See the Conor Mallucci article on page 17.*

Cost of living shortfall

Disabled people on benefits are £800 a month short of an acceptable quality of life, according to a new study.

The study, produced for the Joseph Rowntree Foundation was compiled by researchers from Loughborough University who worked with disabled people from Birmingham, Derby and Nottingham.

They calculated standardised budgets of what the volunteers would need for a standard of living on a level with able-bodied people. The study took into account the costs of essentials such as personal assistance costs as well as normal expenses such as food, clothing, leisure and transport.

Noel Smith, of the Centre for Research in Social Policy at Loughborough University, and co-author of the report, said: "Even maximum benefit levels fall well short of meeting the true costs of disability. It is equally clear that many disabled people in paid work cannot achieve the income required to meet their needs either."

Specific disability benefits help towards the extra costs resulting from a disability and the Independent Living Fund enables thousands of severely disabled people to pay for their own personal acre and live independently

In most areas of day-to-day living, costs were substantially higher for disabled people, researchers discovered. For example, someone needing a lot of personal assistance needed at least £533 a week to achieve an acceptable quality of life.

The study also compared living costs to the amount of state support available to disabled people in a range of different circumstances.

Researchers discovered that those relying on benefits were between £200 and £230 a week short of the money they need to live a comparable quality of life to able-bodied people. Where a disabled person worked 20 hours a week on the minimum wage, they were still between £118 and £189 a week short.

Author Noel Smith added: "Official statistics show that 30 per cent of disabled people are in poverty. But these figures are based on income and do not take into account the additional costs of disability. Our research highlights just how substantial these extra costs are and it clearly shows that the extent of poverty among disabled people is seriously under-estimated."

A spokesman for the Department for Works and Pensions, responsible for disability issues, said it welcomed the report.

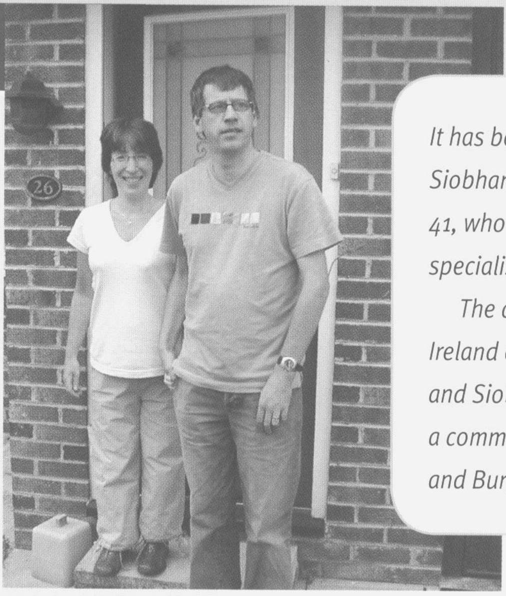
"Specific disability benefits help towards the extra costs resulting from a disability and the Independent Living Fund enables thousands of severely disabled people to pay for their own personal care and live independently," she said.

Siobhan Corr's pregnancy diary

Weeks 14-18

In the last issue of *Link* we met Siobhan Corr who opened the pages of her diary to share the ups and downs of her first pregnancy.

This time Siobhan, who has spina bifida and hydrocephalus, shows us her entries for weeks 14 – 18 of her pregnancy.



It has been anxious time for Siobhan, 36, and husband Martin, 41, who had to fight to receive specialist ante-natal care.

The couple, from Northern Ireland originally, now live in Bolton and Siobhan, a full-time teacher, is a committee member of the Bolton and Bury ASBAH local association.

Thursday 17th June I am 14 weeks pregnant now and have my first antenatal appointment with a specialist at the Hypertension clinic. I had a scan, too early to see any minor anomalies but sufficient detail for them to spot any major problems.

However, they are delighted with the scan results and put our minds at rest that everything appears absolutely normal. I have been prescribed a low dose of antibiotics to avoid any Urinary Tract Infections (UTI) as these can bring on labour. Two litres of water a day seems to be the advice to reduce the onset of UTI. My consultant says there is no need to take folic acid now - hurray.

The Midwife talked to us at length about the "double test" – a blood test which gives an indication of risk of chromosome abnormalities. It does not predict structural abnormalities such as spina bifida etc – the 20-week scan is the most reliable indicator of spina bifida. We decide that we wish to have the test, they schedule it for Monday 21st when I will be 15 weeks pregnant.

Friday 25th June I ring to get my results of the "double test". The results are not as we had hoped - they advise me that the results indicate a high risk of Downs Syndrome. We are both devastated.

The Midwife advises me to consider my options – either to continue the pregnancy, knowing the risks are high or to have an amniocentesis which would accurately tell us one way or another. We decide to have an amniocentesis.

Wednesday 30th June My amniocentesis is booked for 9am. The Consultant explains the procedure - a needle would be inserted into my tummy and some amniotic fluid drawn off, the Consultant tracks the progress of the needle using a scanner.

We were offered the quick test (which you have to pay for) where results regarding the risk of Downs Syndrome could be gained after 3 working days - we declined this. The procedure was not unpleasant. The Consultant was very positive and felt that in his experience the baby appeared normal as the scanning equipment could create a very accurate image and he was able to measure all the key limbs and organs which might indicate any anomaly.

The risk of miscarriage was quoted as 1/300 with this procedure. I was told to rest for a few days. I have a 2-3 week wait for the results. I have only told a few of my closest friends about the test since some people have very strong views about testing and might make unfair judgements about my motives.

Tuesday 13th July The Midwife rang to confirm that the amniocentesis results were normal. We are so relieved, as I am starting to feel some fluttering in my tummy now and some friends are starting to comment on my thickening waistline.

It would have been such a difficult decision at this stage if the amniocentesis result had shown up any abnormality. I have always been pro-choice, but to some extent, this has made me much more aware of the issue of choice as regards termination and how complex an issue it is.

STOP PRESS

As we were completing this issue of Link, Martin phoned to let us know that Siobhan gave birth to Daniel James on Tuesday 7 December. Daniel weighed in at 7lb 4oz. Both mother and baby are doing well.

ASBAH sends its congratulations and best wishes to the family.

ATHLETE TOM DREAMING OF BEIJING

Tom Docherty

Talented athlete Tom Docherty picked up an incredible eight medals in the National Wheelchair Games and is now dreaming of taking part in the 2008 Paralympics.

Tom, 16, from Shrewsbury, had never competed at the javelin, discus, shot putt or the 60-metre sprint before the Games... but came away with a gold medal in each category.

He also picked up coveted silver medals in the Slalom, Power Lifting and Zone Hockey events, plus Bronze in Table Tennis at the competition at Stoke Mandeville.

Now Tom, who has spina bifida and hydrocephalus, is hoping to train for a place on the British team for the Beijing Paralympics.

After meeting four weeks of challenges you feel you can cope with anything. It really helped my confidence

Leading coaches at the championships were so impressed with Tom's natural abilities that they have invited him to training sessions at a Stoke Mandeville centre, which has first class disabled facilities.

But the family will struggle with the travelling and accommodation expenses and their local newspaper, the Shrewsbury Chronicle, has backed their appeal for financial help.

Tom's sporting successes have proved the perfect end to a great year for him.

He explained: "2004 has been a busy and exciting year for me.

"In January I heard that I'd been chosen as one of 22 disabled and disadvantaged young people to go on a Journey of a Lifetime by the charity JoLt.

"It is run by eight female volunteers who take 20 or so young people on an expedition every two years. My trip was to New Zealand for four weeks."

For Tom, who had never been away from his family or abroad before, the first challenge was to raise £600 towards the cost of the trip. He collected in excess of that amount through a gruelling 20-mile sponsored wheelchair push.

He told Link: "The expedition was fantastic. I spent three days crewing a square-rigger out of Auckland Harbour, sand boarded down giant sand dunes and even met the New Zealand Wheel Blacks, who are the wheelchair paralympic rugby team.

"Those with a disability were treated no differently to the able-bodied people. We all worked hard and played hard together. After meeting four weeks of challenges you feel you can cope with anything. It really helped my confidence."

In between his travels and the National Junior Wheelchair Games Tom kept busy with the Wolverhampton Rhinos, the wheelchair basketball team he plays for.

And Tom, the youngest of six children, is full of encouragement for anyone thinking about getting involved in a sport.

"Having a disability and being in a wheelchair doesn't mean life has to be boring. Sport keeps me very busy and I've made hundreds of friends," he said.

Sport for all

Fancy taking up a new sport but don't know where to turn for help and advice?

Log on to ***www.wherecanido.com***, a health, sports and fitness website for people with physical disabilities.

It has details about new sports, suitable local facilities and clubs in your community. There is also a monthly newsletter called WCID you can subscribe to.

Or if you've always fancied messing about on the river, check out ***www.wheelyboats.co.uk***, the website of the Wheelyboat Trust.

The Trust was originally set up in 1985 to help anglers with disabilities to get on the water. It now helps many other disabled people, young and old, enjoy a wide range of other activities as well, including photography, painting, bird watching and family picnics, or simply the fun of being on a boat.

Phillip is pounds lighter after healthy eating regime

Phillip Rogers is enjoying a new lease of life after shedding an amazing 5 stone in weight on a healthy eating and fitness programme.

Phillip, 33, was forced to tackle his weight problem 18 months ago when his weight soared to 17 stone 6 pounds. His breathing problems increased and staff at Shinewater Court where Philip lives feared for his life.

"I found it very difficult to breathe, especially when eating, and I'd go blue around the mouth," Phillip, who has spina bifida and hydrocephalus, explained. "I was reluctant to lose weight, but I didn't have any choice. I'd been going to a gym for a while but I really needed to watch what I ate."

Staff at the Eastbourne residential home where Phillip lives introduced a Friday morning weigh-in and put him on a healthy eating plan to help shift the pounds.

He boosted his weight loss with regular workouts at Freedom Leisure in Hailsham, which boasts specially adapted fitness equipment for wheelchair users. Three sessions each week on the rowing machine and a variety of weight machines also improved his general fitness.

Phillip told *Link*: "It hasn't been easy to lose so much weight, but I feel so much healthier. My breathing has improved and I now have a new wheelchair, which is 4 inches narrower than my old one, which means I can get into taxis and get through normal-sized doorways. I'm much more confident than I was before too, because I feel so much better and can move around more freely."

Keeping Phillip on the straight and narrow where his diet was concerned was the job of Georgina Abbott, Unit Administrator at Shinewater Court, which caters for 30 disabled adults.

Georgina said: "I think Phillip reached a point where he knew he had to tackle his weight problem. It was really a case of re-educating him about the sort of foods he should be eating – healthy meals with plenty of fruit and vegetables and definitely no snacking between meals.

"I have a regular weekly weigh-in for several people here – myself included – so we all help and support each other. Of course Phillip's success has inspired us all. It is a marvellous achievement."

In October Phillip tipped the scales at a slim line 12 stone 4 pounds, and he is determined to lose a few more pounds.

But one problem his amazing weight loss has created is the need for a whole new wardrobe of clothes. Phillip added: "My Mum comes and takes me shopping quite often – she's thrilled with my new look."

Sensible eating for long term weight loss

Healthy eating is the key to weight loss success, according to nutritional experts.

Crash dieting, or following the latest celebrity fad, may result in a fast weight loss initially, but the pounds are likely to pile back on again once regular eating habits are established.

Catherine Wickens, Community Dietician for South Warwickshire Dietics Service, said: "These quick fix diets may work in the short term, but they are impossible to keep up, day in, day out, and don't give your body the nutrition it needs to stay healthy.

"Anyone wanting to lose weight should eat sensibly and develop a pattern of healthy eating that they can stick with for life. You have to find foods that you enjoy eating or you will get bored and are more likely to fail in the long-term."

She added: "Most people are aware that to lose weight the body must burn up more fuel than it consumes, which is obviously more difficult for people who have mobility problems.

"Everyone has days when they feel bored and turn to food for comfort. In my role as Community Dietician I see a lot of people who are sometimes housebound because they have problems with mobility. If you are in the house a lot it is easy to eat perhaps more than you should."

Catherine says the key to long-term weight loss success starts with making small changes to your normal diet.

"Reducing your calorie intake can be quite simple and relatively painless," she said.

- *Eating smaller portions is a good way to start. If you have too much food on your plate to begin with, it is easy to eat it all, even though half the helping would have been enough to fill you up.*
- *Think about giving up that spoonful*

of sugar in your tea or coffee. One teaspoon of sugar has around 20 calories. That isn't a lot, but if you have five cups of tea a day, that means 100 calories. In a week that adds up to 700 calories. "The drink might taste foul for the first couple of weeks," Catherine said, "But after a couple of weeks your taste buds adjust and the chances are you won't want to take sugar again."

- *Do you really need high-fat spreads on your sandwiches or beans on toast? All fats are high in calories.*
- *A good guide for main courses is to fill half the plate with vegetables, which are full of vitamins and, providing they aren't cooked in fat, are low in calories.*

A quarter of the plate should have protein foods, which the body needs for growth and repair. Choose lean meat, fish, eggs, quorn or tofu.

The remaining quarter of the plate should have a carbohydrate food, such as potato or pasta, again, not prepared with calorie-laden fats. Carbohydrates provide a slow release of energy which will help stop between-meals snacking.

Do things gradually and you'll develop good eating habits that will last a lifetime and eating will continue to be a pleasurable experience

Catherine added: "Set yourself small targets and you're more likely to be successful. For example, cut out sugar for the first couple of weeks. Then try eating smaller portions.

"Everyone who needs to lose weight wants to lose it by the end of the week, which is unrealistic and impossible.

"Do things gradually and you'll develop good eating habits that will last a lifetime and eating will continue to be a pleasurable experience."

Quick Question

Q. Which is higher in fat, butter or olive oil?

A. *Olive oil may be a healthy food, but its fat content is 99 per cent, while butter has a fat content of 80 per cent.*

For healthy eating - look online

If you need more advice to help you improve your diet, there are many websites offering sensible and practical ideas.

Log on to Weight Wise, the site of the British Dietetic Association, which helps you find the right approach for you if you're planning to lose weight. It makes interesting reading for anyone keen to improve their eating habits.

www.bda.uk.com

Other recommended sites include...

NHS Direct
www.nhsdirect.nhs.uk

Health Promotion Agency for Northern Ireland
www.healthpromotionagency.org.uk

Health Promotion Wales
www.hpw.org.uk

Health Development Agency
www.hda-online.org.uk

British Heart Foundation
www.bhf.org.uk

Heart UK
www.heartuk.org.uk

Food and Drink Federation
www.foodfitness.org.uk

Diabetes UK
www.diabetes.org.uk

Shop around for cheap travel insurance

A *Link* reader complained to the Disability Rights Commission after his usual travel insurance provider suddenly refused to offer cover for his son who has hydrocephalus.

When the father, who wishes to remain anonymous, queried the decision, the company then agreed to provide travel cover, but it proved to be at an unfavourable rate.

Mr X's 19-year-old son was eventually offered the same £26 premium as each of his parents to cover a week's holiday in France next summer... but with an excess of £5,000 and with cover only to a maximum of £100,000.

Mr X told Link: "We have used the same holiday company for the past ten years and have always arranged travel insurance through them.

"Our son has been lucky in that he has only had two partial shunt revisions in his life, so there is no great medical risk which could push the premium up."

Mr X contacted the Disability Rights Commission to see if the underwriters used by the tour firm were breaking the Disability Rights Act.

He said: "Our suspicions that our son was being discriminated against were confirmed. Firstly because the underwriters had not obtained detailed medical information about our son's hydrocephalus, and secondly because the cover they did eventually offer him was clearly inferior to that offered to myself and my wife."

Mr X then complained to the holiday company, outlining his grievances and is considering whether or not to make a formal complaint.

ASBAH Information Officer Gill Winfield said: "Unfortunately this isn't a one-off complaint. I have received many phone calls during the past few years about insurers increasing premiums for people with hydrocephalus for no apparent reason. We advise people to keep shopping around.

"We do try to find companies which will offer reasonably-priced deals, and are sometimes able to make recommendations to our service users."

A spokesman for the Disability Rights Commission was unable to comment on the case, but suggested that for advice on the law, Link readers should contact the DRC Helpline on 08457 622 633 or email: ***enquiry@drc-gb.org***

Are you *willing* to make a difference to his life?

Barney has hydrocephalus but, with ASBAH's support, he and his parents are looking confidently to the future. ASBAH supports and provides specialist advice throughout England, Wales and Northern Ireland for thousands of children and adults with hydrocephalus and spina bifida, making a positive difference to their lives.

You can help us make that difference!

We rely upon donations and legacies to enable us to continue our work with children like Barney. For further information please write to Jane Ayres at the address below or ring 01733 555988.

Association for Spina Bifida
and Hydrocephalus
42 Park Road,
Peterborough PE1 2UQ
email: janea@asbah.org
www.asbah.org

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

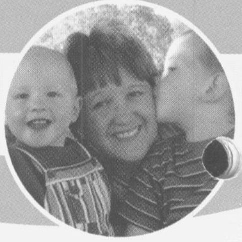
Registered charity No 249338

LiNK

The ESSENTIAL magazine for people with hydrocephalus and spina bifida

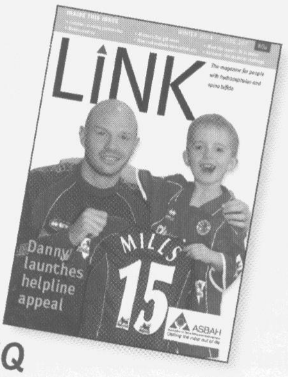
ASBAH's magazine, Link, is an absolute lifeline!

Nici Picken
Gloucestershire



SUBSCRIPTION FORM

Link is published quarterly (Winter, Spring, Summer and Autumn). The cost of an annual subscription is £4.80, Airmail £15, Surface Mail £7.50. To subscribe please complete the form and return it with your cheque/PO (made payable to ASBAH) to:



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UK registry monitoring the use of shunts

A small and dedicated team based at Cambridge's Addenbrooke's Hospital is carrying out vital work monitoring the use of shunts throughout the UK and Ireland.

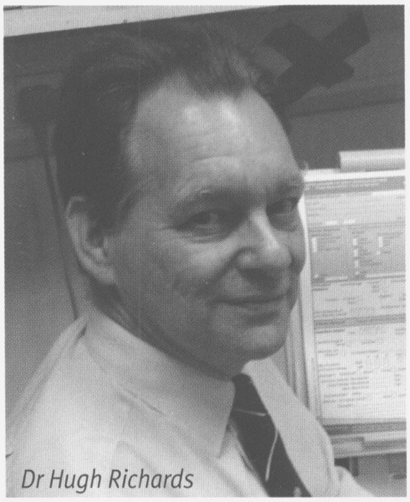
The UK Shunt Registry has a detailed database of the number of shunts fitted, different shunts used and any problems associated with them.

The Registry was set up in 1994 by Professor John Pickard and was funded for the first five years by the Medical Devices Agency (now known as the Medicine and Healthcare Products Regulatory Agency, MHRA), which was keen to measure the performance of all hardware.

Dr Hugh Richards, Data Manager, said: "Our main objectives are to define the current state-of-the-art shunt management and to provide an accurate picture of the use of different types of shunt.

"The registry also enables us to identify substandard shunt systems, measure infection rates and also the reasons why shunt revisions are needed."

Since its launch ten years ago, the Registry has details of 32,000 shunt procedures on its database. Currently about 3,000 shunt procedures are performed every year in the British Isles, including 1,850 new patients being shunted for the first time.



Dr Hugh Richards

Dr Richards added: "Having this information is extremely valuable and we have discovered that only one third of shunting is carried out because of congenital or Normal Pressure Hydrocephalus.

"Shunts are more commonly used as a result of acquired hydrocephalus which is a result of brain tumours, blood clots, trauma and cerebral infections. Because patients with shunts are heterogeneous in terms of age and pathology, large datasets are needed for meaningful analysis"

The registry also enables us to identify substandard shunt systems, measure infection rates and also the reasons why shunt revisions are needed.

Another vital role of the Registry is to monitor new products on the market.

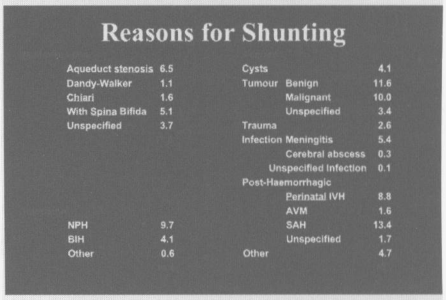
Dr Richards explained: "New shunts do not have to undergo clinical trials, although they do need approval from the MHRA. Through the registry we can keep watch on new shunts and make sure they are performing to the manufacturers' specifications."

The team is currently funded by annual contributions from neurosurgical units around the UK and several shunt manufacturers keen to see how their product performs.

ASBAH has developed a close relationship with the UK Shunt Registry and Dr Richards has made presentations at ASBAH conferences, with the next booked for Belfast in February.

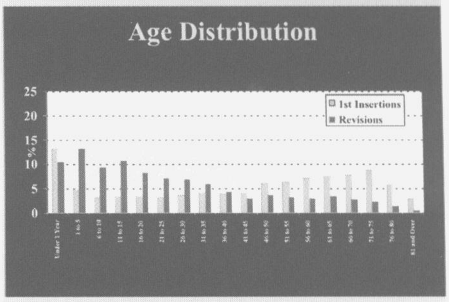
The UK Shunt Registry

Prof. John Pickard Registry Supervisor
Helen Seeley Auditor
Dr. Hugh Richards Data Manager
Meryl Madakbas Secretary

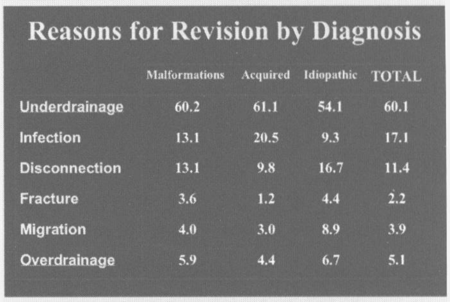


Reasons for Shunting

Aqueduct stenosis	6.5	Cysts		4.1
Dandy-Walker	1.1	Tumour	Benign	11.6
Chiari	1.6		Malignant	10.0
With Spina Bifida	5.1		Unspecified	3.4
Unspecified	3.7	Trauma		2.6
		Infection	Meningitis	5.4
			Cerebral abscess	0.3
			Unspecified Infection	0.1
		Post-Haemorrhagic		
			Perinatal IVH	8.8
			AVM	1.6
NPH	9.7		SAH	13.4
BIH	4.1		Unspecified	1.7
Other	0.6	Other		4.7

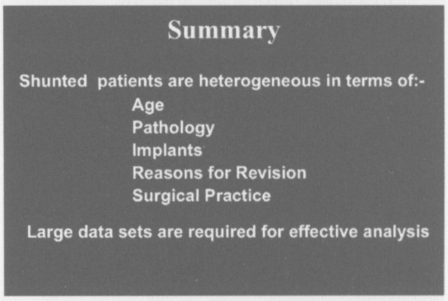


Age Distribution



Reasons for Revision by Diagnosis

	Malformations	Acquired	Idiopathic	TOTAL
Underdrainage	60.2	61.1	54.1	60.1
Infection	13.1	20.5	9.3	17.1
Disconnection	13.1	9.8	16.7	11.4
Fracture	3.6	1.2	4.4	2.2
Migration	4.0	3.0	8.9	3.9
Overdrainage	5.9	4.4	6.7	5.1



Summary

Shunted patients are heterogeneous in terms of:-
- Age
- Pathology
- Implants
- Reasons for Revision
- Surgical Practice

Large data sets are required for effective analysis

ASBAH questions folic acid link to breast cancer

New research suggests that taking folic acid late into pregnancy may increase a mother's risk of breast cancer.

But the findings - by the Universities of Aberdeen and Bristol - are highly questionable because they are based on such a small number who developed breast cancer.

Scientists, who published their report in the British Medical Journal in December, do not question the great benefits of taking folic acid before and during the first months of pregnancy, and say the link may be a chance finding. They also stress that their findings need to be tested with thorough follow-up studies.

The research team followed up 2,928 women who took part in a trial of folic acid supplementation in the 1960's.

The women were either given a 0.2mg or 5mg dose of folic acid or a dummy pill.

By the end of September 2002, 210 women had died, with 40 deaths attributed to cardiovascular disease, 109 to cancer and 31 to breast cancer.

Andrew Russell, Executive Director of ASBAH said: " Common sense suggests that it is unsurprising that after almost four decades, out of almost 3,000 women, some have died from breast cancer. In fact only 14 women have died from those who took folic acid supplements.

"It is wrong to attribute those deaths to the fact that they took a vitamin supplement for a few months 38 years ago."

Andrew added: "The benefits of folic acid are proven whilst this new research is weak. Indeed, the researchers themselves say it is inconclusive and the results may be caused by chance.

"Further work should of course be carried out, but unless there is convincing evidence of increased cancer risk being related to enhanced folate status, the disadvantages of neural tube defects and risks to the mother associated with abortion outweigh this opinion."

ASBAH and medical experts, including the scientists at the Universities of Aberdeen and Bristol, continue to recommend that all women considering pregnancy should take a folic acid supplement of the existing recommended dose.

ASBAH and medical experts are continuing to recommend folic acid supplements at the time of conception and during pregnancy.

Antenatal testing info online

A new website has been launched to give more information to pregnant women and their partners about antenatal tests.

AnSWeR, funded by the Wellcome Trust, hopes to clear up some of the mysteries surrounding the screening and diagnostic tests available during pregnancy.

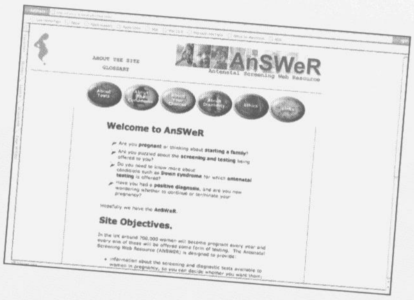
In the UK, 700,000 women become pregnant every year, and every one of these will be offered some form of testing.

AnSWeR has been designed to explain clearly the tests and the conditions, such as neural spinal defects, that they might detect. Also featured on the website are personal testimonies from women and families directly affected by these conditions and the decisions they have been forced to make.

A spokesman for AnSWeR said: "Our aim is to provide information so that women and their partners can make the best decision for themselves and their family, whether you decide to test, or not to test.

"AnSWeR cannot tell anyone what to do, but our site will offer information to enable people to make the decision."

AnSWeR can be found at: ***www.antenataltesting.info*** or through the link on the ASBAH website.



Welcome to AnSWeR

- Are you **pregnant** or thinking about **starting a family**?
- Are you puzzled about the **screening and testing** being offered to you?
- Do you need to know more about conditions such as **Down syndrome** for which **antenatal testing** is offered?
- Have you had a **positive diagnosis**, and are you now wondering whether to continue or terminate your pregnancy?

Hopefully we have the **AnSWeR**.

Site Objectives.

In the UK around 700,000 women will become pregnant every year and every one of these will be offered some form of testing. The Antenatal Screening Web Resource (AnSWeR) is designed to provide:

- information about the screening and diagnostic tests available to women in pregnancy, so you can decide whether you want them;

Sam

When mother-to-be Sam Copeland had a routine blood test 16 weeks into her pregnancy, the possibility that her baby could have spina bifida had not occurred to her.

When a follow-up scan revealed that her baby – due in early February – did have spina bifida, Sam, from Cheshire, was naturally devastated.

But the immense love she felt for her unborn baby girl helped her to come to terms with the news, and look forward to the birth.

Here Sam talks to Link about her experiences, and how the support of her family, friends and ASBAH have helped prepare her and husband Mark for the new addition to the family.

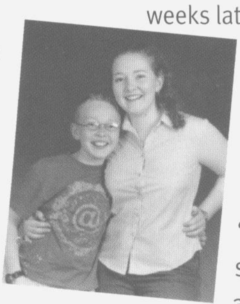
Copeland

Sam Copeland and husband Mark had longed for a baby since they married in 1999.

Sam, 35, already has two children – Laura, 15, and David, 12 - from her first marriage, who were adopted by Mark in 2003, and the couple wanted a third to complete the family.

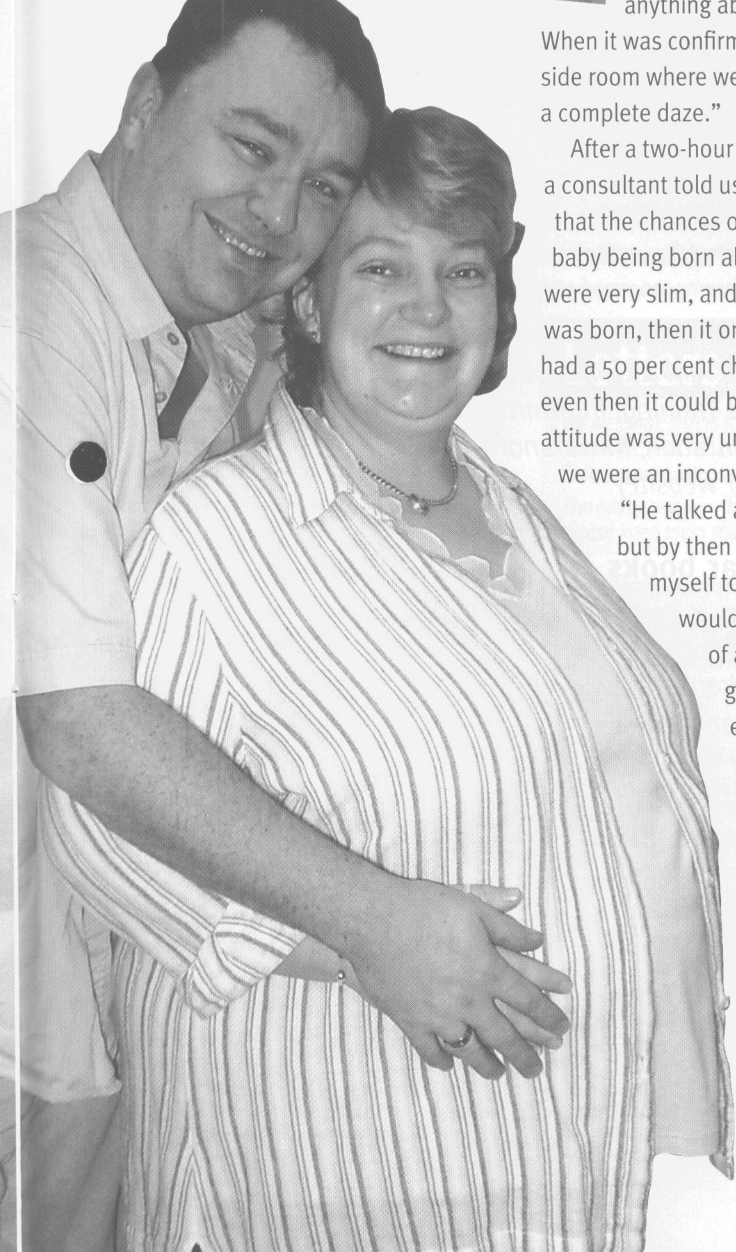
After suffering a miscarriage in February, she was thrilled to discover she was pregnant [illegible]ain.

Sam decided to have the routine AFP blood test that is offered to all pregnant women at 16 weeks. "My main concern was that the baby could have Downs Syndrome," Sam explained. "If that was the case, I thought it would be better to know, so we could prepare ourselves."



It came as a great shock when, two weeks later, Sam was called for an ultra sound scan at her local hospital, which revealed that the baby had spina bifida.

"I was so shocked that I just burst into tears," Sam recalled. "I'd considered Downs, but never spina bifida. I didn't really know anything about the condition. When it was confirmed we were taken to a side room where we sat in a complete daze."



After a two-hour wait, a consultant told us that the chances of our baby being born alive were very slim, and if it was born, then it only had a 50 per cent chance of survival, and even then it could be brain-damaged. His attitude was very unfriendly, almost as if we were an inconvenience.

"He talked about our options, but by then I'd started to pull myself together. I knew that I wouldn't entertain the idea of a termination and I was going to give my baby every possible chance."

I knew that I wouldn't entertain the idea of a termination and I was going to give my baby every possible chance

Sam was referred to a professor of neonatal medicine at a university hospital and she said: "He was wonderful, his attitude could not have been more different. Straight away he held my hand and said, "Let's see what we can do for you." During the scan he told me "Your baby does have spina bifida, but has as good a chance of survival as any other."

The scan also revealed that the baby is a girl – and Sam and Mark have already named her Elisabeth.

Baby Elisabeth will be delivered by Caesarean section at the university hospital in early February, at least two weeks before her due date.

She will then be transferred to the city's children's hospital where the lesion on her back will be closed by a paediatric neurosurgeon. If Elisabeth has hydrocephalus, the shunt will be inserted around seven days later.

When Link spoke to Sam, she was 27 weeks into the pregnancy, and thoroughly excited about the birth.

"The shock has worn off now and Mark and I feel more prepared. I contacted ASBAH as soon as we found out and they have helped to allay many of my fears.

"I felt much calmer as soon as I had spoken to Rosemary Batchelor. She was able to deal with all my questions, from the larger medical issues to the little details that had been worrying me, such as would an ordinary car seat be suitable." Local adviser Elizabeth Miers has also given the family much-needed support.

"We've explained all the issues surrounding spina bifida to Laura and David, "Sam explained. "We felt it was important that they know what to expect. It was obviously a shock to them but they have taken everything in their stride.

"David was more horrified that the baby is a girl than by anything else," Sam laughed. "But they too can't wait for Elisabeth to be born. This baby is so longed for, we can't wait to meet her."

Look out for more news on Sam Copeland and Elisabeth in the next issue of Link.

Leaflets and publications available from ASBAH

Information sheets

☐ What is hydrocephalus?

☐ What is spina bifida?

☐ Spina Bifida Occulta

☐ Ante-natal screening

☐ Genetic counselling

☐ Vitamin supplementation (in reducing risk of SB)

☐ Vaccinations

☐ Continence management

☐ Supporting children with SEN

☐ Pre-school information for professionals

☐ Feeding problems associated with hydrocephalus and spina bifida

☐ Personal views on hydrocephalus

☐ Shunt malfunction - a guide for employers

☐ Shunt malfunction - a guide for schools

☐ BIH (Benign Intracranial Hypertension)

☐ BIH and the child at school

☐ Going to college/university with BIH

☐ Behaviour problems

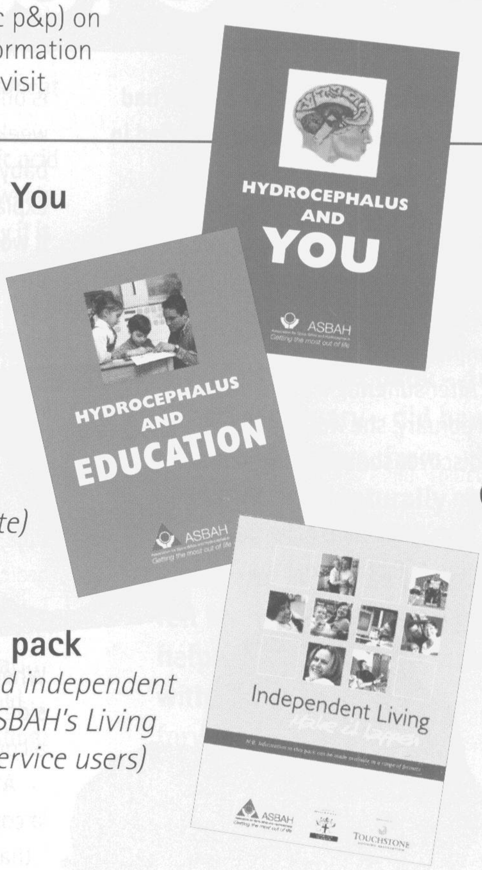
☐ Developing skills through toys

☐ Driving (for people with hydrocephalus and spina bifida)

Single copies of information sheets are free, send a large self addressed envelope and loose 2nd class stamp (if more than one title is required please ensure you enclose sufficient stamps to cover postage) to ASBAH Information Section, 42 Park Road, Peterborough PE1 2UQ. Or visit our website - all these leaflets are available at: www.asbah.org

Other publications

Prices for all publicatiions (inc p&p) on application to the ASBAH Information Section. Tel 01733 555988 or visit www.asbah.org



1. Hydrocephalus and You

(81 page book)

2. Hydrocephalus and Education Information pack

(10 detailed topic sheets, also available on our website)

3. Independent Living pack

(a self –help assessment and independent living guide produced by ASBAH's Living in London forum of adult service users)

4. Pregnancy booklet

(for women with spina bifida and/or hydrocephalus)

5. Continence pack

(including sheets on: ACE, Adaptions for Toileting, Artificial Sphincter, Toilet Training, Intermittent Self-Catheterisation: Bladder Augmentation, Mitrofanoff, Test & Procedures. Also available on our website)

6. Benny Bear books and posters

(colourful and informative stories for children with hydrocephalus and their families dealing with having a shunt fitted, starting school and going on holiday. Produced as part of the Hydrocephalus Action awareness campaign)

Holiday let

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

ISLE OF WIGHT ASBAH - HOLIDAY BUNGALOW

Fully-furnished and equipped two-bedroomed bungalow. Beautiful area. Wheelchair-accessible. Site clubhouse, shop. Local indoor heated pool. Transport advisable. Excellent rates. Offers early/ late season. **Details: Mrs S Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF Tel: 01983 863658,** *www.iwasbah.co.uk*

PAIGNTON, DEVON

Six Berth all electric wheelchair accessible caravan situated within a mile of the beach. Site facilities include indoor and outdoor pools, sauna, steam room, children's play area, hire shop, amusements, licensed club and seasonal entertainment. All electricity & club passes are included at no extra cost. **Tel: Devon ASBAH on 01803 522256,** *(www.dasbah.com)*

PRESTATYN, NORTH WALES

Choice of two adapted caravans for disabled holiday makers. Each sleeps 6 people (2 wheelchair accessible bedrooms), wheel-in shower with seat, open plan lounge, dining, kitchen area. Caravans have ramp access and are overlooking a children's play area in a site adjacent to the beach at Prestatyn – a small market town on the North Wales coast within easy travelling distance of Rhyl, Llandudno, and Snowdonia National Park. Costs are between £95-£275 per week; **for further information contact Leeds & Bradford ASBAH, c/o Jo Baxter, 8 Staveley Court, Shipley, BD18 4HF. Tel. 01274 591850,** *e-mail jo@baxterjo.freeserve.co.uk*

BERWICK COTTAGE, EAST HARLING, NORFOLK

Purpose-built, self-catering accommodation for people with disabilities, their families or carers. Sleeps 6 (2 with disabilities). Facilities include Scan 700 beds, Clos-o-Mat toilet, bedroom-to-bathroom hoist, wheelchair shower and much more. Awarded highest National Accessible Scheme ratings. Weekly rates £295 - £645. Open all year. In pretty village with pub, shops and GP. **For bookings tel/fax: 01787 372343 (office hours) or email:** *info@thelinberwicktrust.org.uk* **Website:** *www.thelinberwicktrust.org.uk*

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Letters

We welcome letters for publication, which should be sent to: Editor, Link, 42 Park Road, Peterborough, PE1 2UQ.

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

Diary dates

Contact your regional office for more details on the following dates:

Northern Region Drop Ins

York Drop In
Tuesday, 8th February: 12noon - 2.00pm
Wednesday, 9th March: 10.15am-12noon
Tuesday, 12th April 2005: 12noon - 2.00pm
Low Moor Community Centre
Bray Road, off Hollands Road
Fulford, York

Leeds and Bradford Drop In
First Wednesday of each month:
2nd February: 10am - 12noon
2nd March: 10am - 12noon
6th April: 10am - 12noon
Northern Regional Office
64 Bagley Lane, Leeds LS28 5LY

Northern Ireland
Saturday, 19th February
Hydrocephalus Awareness Parents day
(based on the *Your child and hydrocephalus* book)

South Eastern Region
Saturday, 7th May - Banstead, Surrey
Saturday, 18th June - Maidstone, Kent
Hydrocephalus Awareness Parents day
(based on the *Your child and hydrocephalus* book)

Eastern Region
Saturday, 5th March
Eastern Region - Local Associations forum

ASBAH AGM, Peterborough
Saturday, 24th September

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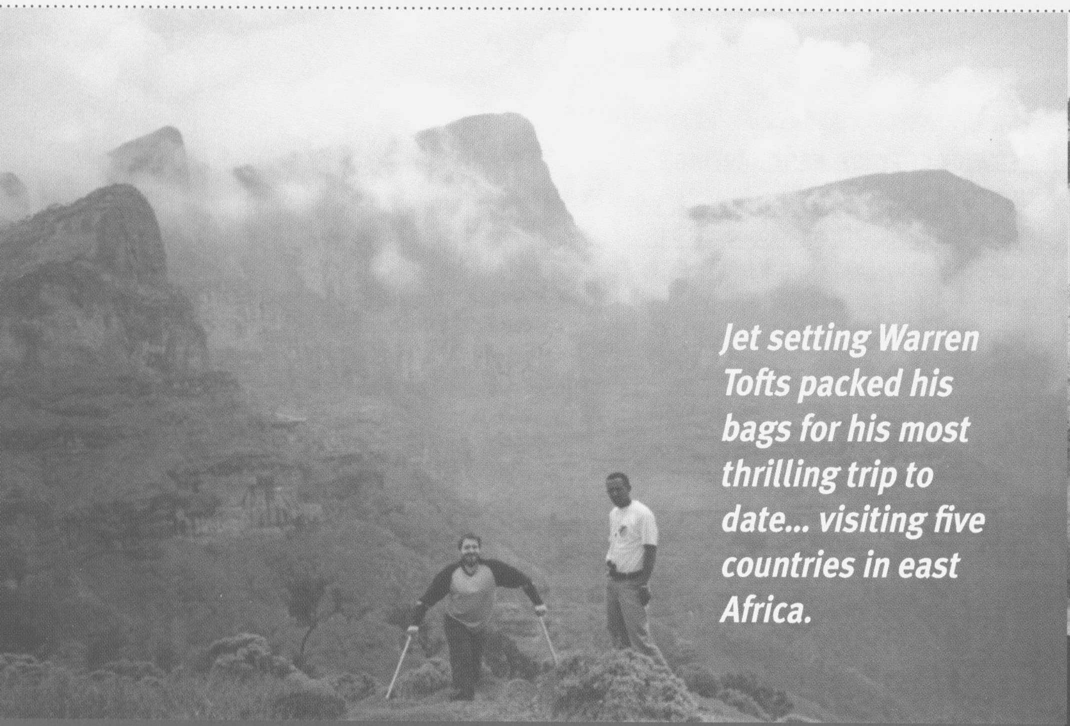

Jet setting Warren Tofts packed his bags for his most thrilling trip to date... visiting five countries in east Africa.

...Warren Tofts

Warren's latest adventure came hot on the heels of a seven-month backpacking tour of Australia, Fiji and Papua New Guinea.

The 21-year-old from Welwyn Garden City saved a large portion of his wages from his job on the checkout in Tesco to fund the latest trip.

On 8 July he headed for Africa, where he visited five countries in 10 weeks. The seasoned traveller was determined to see as many of the sights of Kenya, Tanzania, Uganda, Sudan and Ethiopia as possible... even if it did cause mother Pauline many sleepless nights.

Warren, who has spina bifida, told *Link*: "It was an incredible trip. As a traveller I wanted to visit countries which are completely different to anything I had experienced before, and I certainly achieved my aim.

He planned the journey carefully booking hotels, guides and trips before he left the UK, but Warren hadn't planned on two punctures to his wheelchair tyres – one of which happened in a Sudanese marketplace.

Warren laughed: "Punctures were something I hadn't really given much thought to, and when it happened in the middle of a busy market, I wondered what I would do. But everywhere I went people were so friendly and keen to help. My wheelchair was whisked away and returned within ten minutes, puncture fixed."

His experiences from the 10-week trip could fill all 32 pages of *Link*, so we asked Warren to briefly describe the highlights of his time in each of the five countries.

The mammoth tour may be a distant memory now, but Warren is busy working to amass enough cash to fund another adventure. Next stop, South America.

Kenya

"My first point of call. From Nairobi I spent several days in the Masi Mara, visiting villages. I also went on several boat trips and got to within ten metres of a group of hippos bathing in the water. What an amazing sight!"

Tanzania

"I spent seven days in Tanzania and visited, among other places, the Ngorongora crater, which is a collapsed volcano and has been called the 8th Natural Wonder of the World. From there I travelled north to Serengeti and went on safari at the Serengeti National Park, which has stunning landscapes and wildlife."

Uganda

"In Uganda I fulfilled one of my ambitions – to trek into the jungle to see gorillas. It was a five-hour round trip and ten guides took it in turns to carry me. They had rigged up a special chair, made up of an old deck chair with a couple of poles tied on with string. I thought they were joking at first! But it worked well and I managed to see gorillas close-up."

Sudan

"I had never seen a desert before so travel from Khartoum to the Nubian Desert was incredible. I travelled north to visit the ancient Pyramids of Meroe. My guide was fantastic, encouraging me to go under the pyramid and volunteered to carry me down."

Ethiopia

"I travelled through some beautiful green countryside in Ethiopia, which I hadn't expected to see. The history of Ethiopia is of great interest to me and there are some awe-inspiring sights. Lalibella, for example, was fascinating, with churches made purely from rock."

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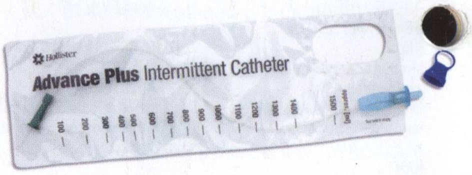
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