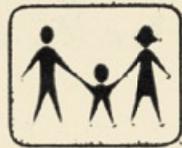


JOINK



The Journal of **The Association for Spina Bifida and Hydrocephalus Limited (A.S.B.A.H.)**

Spring 1966

One Shilling



Looking back at



Link has certainly progressed from its humble beginnings.

We took a look back at the first issue which was published in Spring 1966, priced one shilling.

Run on a very limited budget, the 16-page magazine was printed in black and white with few pictures.

The editorial team, led by editor Stephen Hinchliffe, may have been short on cash, but they were big on ideas, and put together a lively mix of news.

Medical and self-help articles were interspersed with lively interviews, news from local association groups and advice columns.

Here are some excerpts from *Link* Issue 1...



From the Editor: Stephen Hinchliffe

"We decided on the name of *Link* because we hope it will link member to member, member to doctor, doctor to member and doctor to doctor."

"While at all times we will try not to offend, we will not be afraid to be controversial."



National Secretary Mr. Tudor Williams at Central North London Group's children's party

"The National Health funds and the local authorities should not be expected to provide anything other than a fairly limited range of standard items."

"There are problems of treatment, which is unobtainable for some, years delayed for many and performed by a few overworked doctors who have the faith and the vision to know that their positive treatments are the right ones."

"... the local authority are permitted to help, but are not compelled to do so. The result is that there are wide differences in the amount of help obtained from different local authorities."



"Courageous Anne is as brave as she is bonny..... and successfully holds down a secretarial job in the highly competitive business world." An interview with 21 year old Anne Ross who has spina bifida.

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- ASBAH 40th year anniversary
- Disabled flying

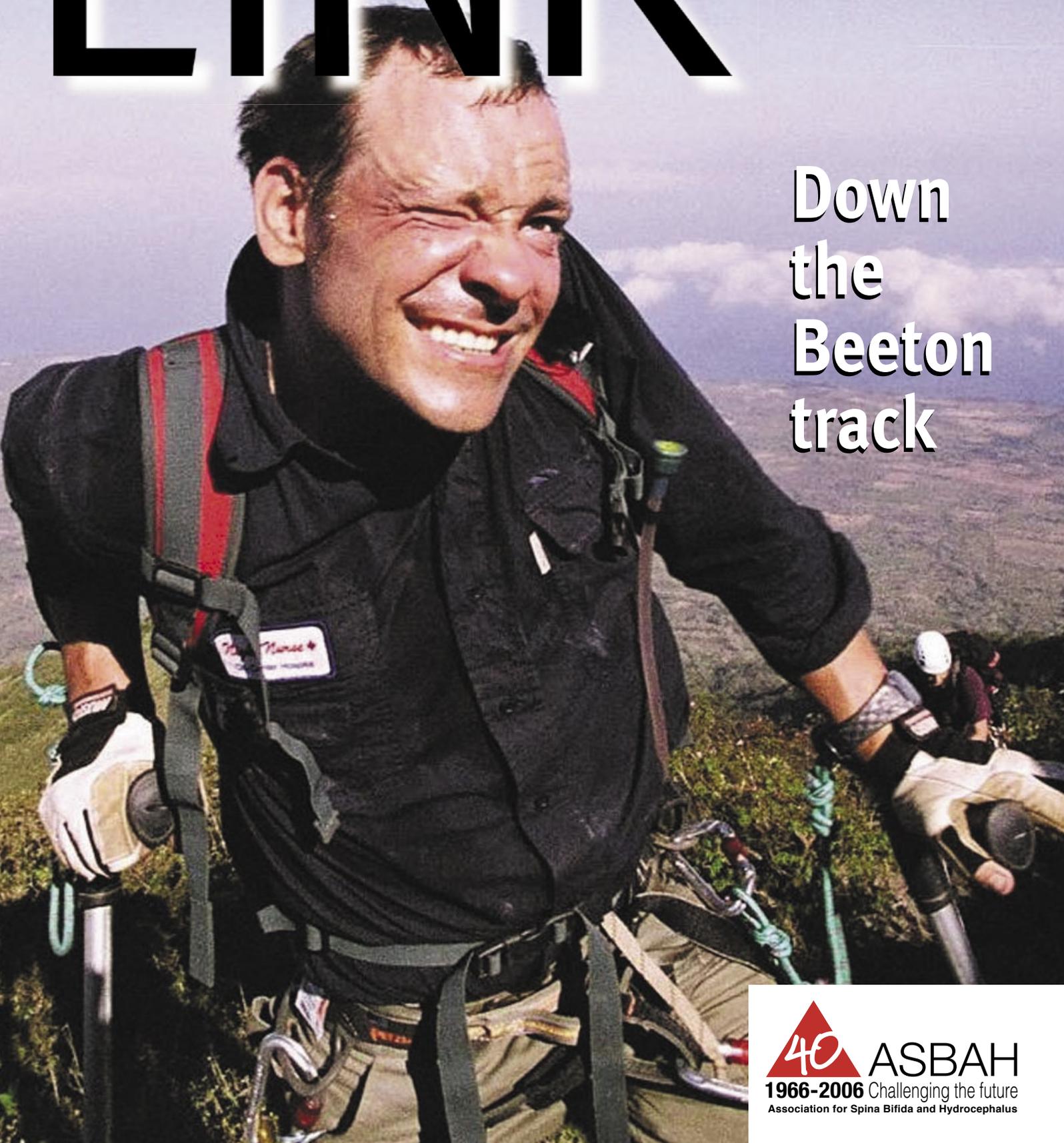
- Access to health and fitness
- Hydrocephalus Action update

- News round-up
- Helpline Appeal gathers pace

LINK

*The magazine for
people with
hydrocephalus and
spina bifida*

Down the Beeton track



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Driving For Perfection

Peter Farrall writes

Welcome to *Link* 216, the first issue of 2006.

This year is an important one in the history of ASBAH, as it marks our 40th anniversary year – a huge achievement for us considering our humble beginnings.

In this edition, and others throughout the year, we'll be looking back to the early years to remind ourselves just how far we've come in providing support and helping to improve the quality of life for people with spina bifida and hydrocephalus. Equally we'll be looking forward to the next 40 years to continue our work and tackle the challenges that no doubt lie ahead.

Messages of congratulation and support have come in from many notable people, including the Prime Minister, Tony Blair, Tom Levitt, Chair of the All Party Parliamentary Group on the Community and Voluntary Sector and Patrick Daunt, former Chair of ASBAH.

ASBAH's President, Dr Jeffrey Tate CBE also sent in words of congratulation and also talks about his illustrious career as a conductor on pages 6 and 7.

To mark our 40th year ASBAH is concentrating on our fundraising appeal to create a national Helpline and Information Service. We hope you will want to help (see page 10 and 11).

Of course this issue also includes the usual round up of news, medical and fundraising features.

You'll also get the chance to read about Daryl Beeton, who featured in the BBC's *Beyond Boundaries* series (page 30).

So there's plenty of material to inspire you during 2006.

Happy New Year.

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

*Best wishes,
Peter*

Patron:

HRH The Duchess of Gloucester GCVO

President: Jeffrey Tate CBE

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

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ASBAH's president Dr Jeffrey Tate CBE (see p 6 & 7)



40th year messages of support for ASBAH (see p 8)



Helpline Appeal gathers pace (see p 10 & 11)



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The sky's the limit: disabled flying with the BDFA (see p 16 & 17)



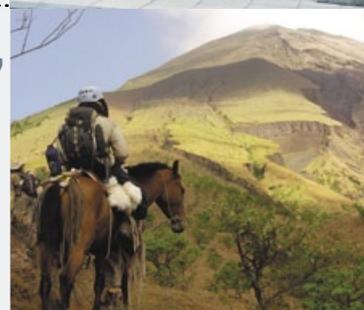
Lewis' Superheroes (see p 18)



Government proposals threaten services (see p 26)



Daryl's 'Beyond Boundaries' adventure (see p 30)



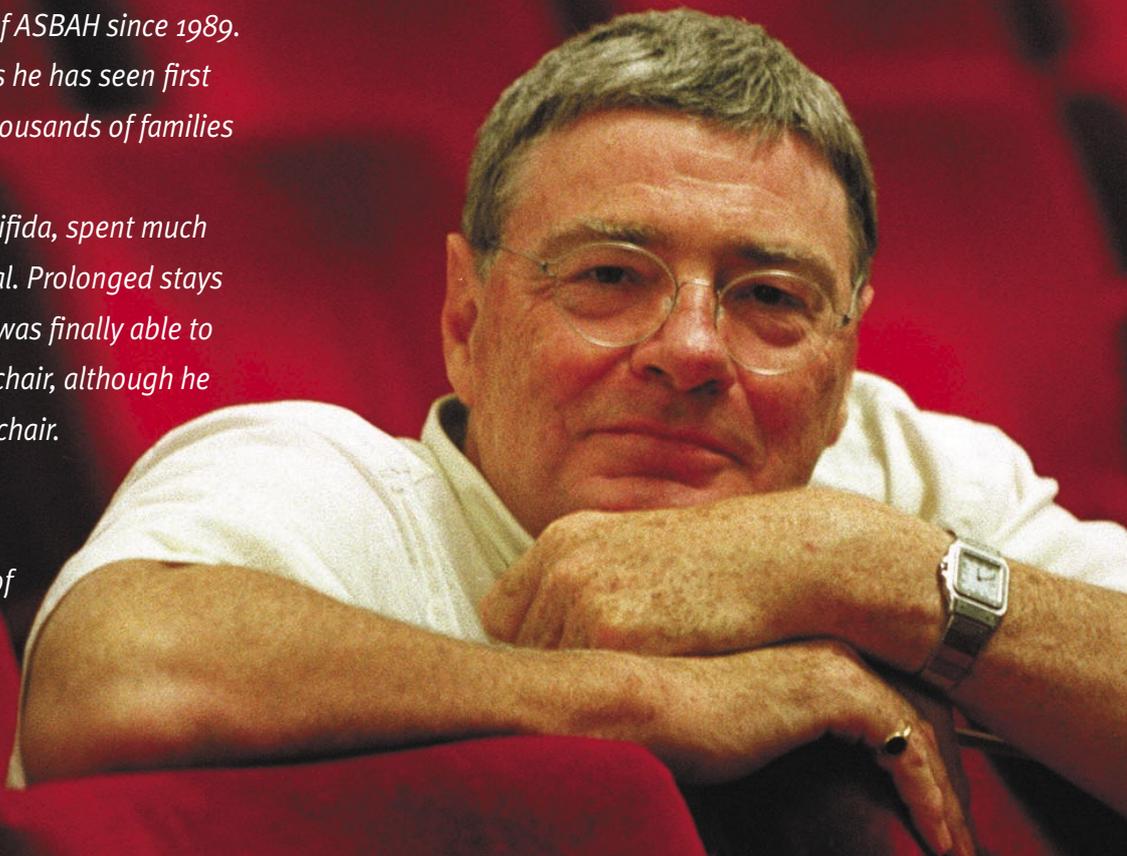
World renowned conductor Dr Jeffrey Tate, CBE, has been President of ASBAH since 1989.

During the past 16 years he has seen first hand how ASBAH helps thousands of families and individuals each year.

Jeffrey, who has spina bifida, spent much of his childhood in hospital. Prolonged stays and treatments meant he was finally able to walk away from his wheelchair, although he conducts on stage from a chair.

But these experiences were formative for Jeffrey, influencing both his love of music and medicine.

Here he talks to Link about his illustrious career.



Jeffrey Tate

“I still have this element of pinching myself that it has all happened,” says Jeffrey, looking back on his many achievements. And I never lose the sense of being slightly in the wrong place.

“If people had told me that I would have the stamina to conduct *Ring Cycles*, I would have been amazed.” He pauses, then adds, “I still am, for that matter.”

The renowned conductor says life has been wonderful, but adds that he is not obsessional about his music.

Jeffrey explained: “I do get enormous fulfilment from conducting, but I cannot admit to getting total fulfilment from it. Music is only one element of my life.”

He decided as a youth to work in medicine to try to give back something

for all the treatment he received as a child enabling him to walk.

For a while medicine won out as Jeffrey’s career choice, but throughout his studies at Cambridge and later at London’s St Thomas’s Hospital, music continued to lure him.

He finally decided to take a year out and studied coaching at the London Opera Centre “to get it out of my system”. Jeffrey’s career has been centred around music ever since.

At the end of the 12 months Jeffrey was offered a job as principal assistant at Covent Garden, where he stayed until 1977. He revelled in the work which brought him into contact with some of the world’s leading conductors and

orchestras.

In 1978, whilst working as an assistant director of the Cologne Opera, Jeffrey heard the Gothenberg Opera in Sweden was looking for someone to conduct *Carmen*. Jeffrey applied and got the job.

“As the music moved under my hands, I suddenly felt that I was doing something I had been waiting to do all my life,” he said.

A year later he made his North America debut replacing James Levine on just three hours notice for *Lulu* at the Metropolitan Opera, New York. He earned a standing ovation from both the audience and the musicians.

“Suddenly I found myself a professional conductor,” Jeffrey remembered.



“As the music moved under my hands, I suddenly felt that I was doing something I had been waiting to do all my life.”

Jeffrey Tate biography

1944

Born in Salisbury, England

1954

Jeffrey makes his broadcasting debut – playing Galway Boy on the piano for hospital radio

1969

Qualified as a doctor, St Thomas’s Hospital, London

1970

Joined the music staff at Royal Opera, Covent Garden

1978

Jeffrey makes his conducting debut of Carmen at the Gothenberg Opera, Sweden

1979

Makes his debut as a conductor in 1979 at the Metropolitan Opera

1985 – 2000

Principal Conductor, English Chamber Orchestra

1986 – 1993

Senior Director of Music, Royal Opera, Covent Garden

1986 – 1992

Principal Guest Conductor, Covent Garden

1990 – 1993

Music Director, Rotterdam Philharmonic

1991 – 1998

Principal Guest Conductor, Orchestre National de France

1994

Produces a new Wagner “Ring” cycle in Paris – perhaps the most demanding operatic work. He later presents the Ring cycle again in Australia and Germany

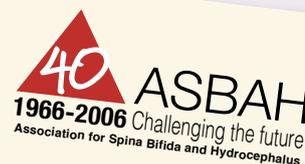
2003

Principal guest conductor of the Orchestra Nazionale della RAI (Torino, Italy)

2005

Music Director Teatro San Carlo, Naples

Message from the President



In 2006 ASBAH celebrates its 40th anniversary. It is a remarkable achievement and one which has only been reached through the hard work and dedication of ASBAH's unstinting supporters. Over the past four decades thousands of families and individuals with spina bifida or hydrocephalus have been helped every step of the way.

From the trauma of the initial diagnosis through to helping parents with spina bifida or hydrocephalus to bring up their own children, ASBAH is there from cradle to grave.

It was with great pride that I accepted the title of ASBAH's President in October 1989.

Over the past sixteen years I have seen close up the unstinting efforts of ASBAH's staff, trustees and supporters, who provide a lifeline for so many people.

I, along with the thousands of people who have been helped over the years, give my thanks and praise to you all.

As ASBAH celebrates this milestone anniversary, we can all look forward to an even more successful future.

Dr Jeffrey Tate CBE
President

His musical career has taken him largely overseas, but the lifestyle has its ups and downs.

“The longest time I’ve ever spent anywhere in the last five years was four-and-a-half months in Australia doing *The Ring*. I do get a little tired of travelling, but I do enjoy the stimulation of different orchestras and cultures.”

But he revealed: “Even now people still call me the eternal amateur. Professionals are supposed to be able to conduct everything, but I can’t unless I feel some connection inside.

“I don’t have enough time to conduct repertoire that I’m not interested in. I’m old enough to say, “I don’t need that now.”

40th year messages of support

“One of the best strokes of good luck in my life was to become Chairman of ASBAH soon after my retirement from Brussels in 1987. ASBAH seemed to me then, as it does unreservedly now, an example of everything which a Voluntary Organisation should be, free of all pretension, guided by clarity of vision and objectives, blessed with a high commitment of trustees and staff. As Chairman I was naturally most directly aware and so appreciative of the loyalty of my fellow trustees and the excellent work of senior officers under Andrew Russell’s outstanding leadership.”

Patrick Daunt - ASBAH Vice President, former Chairman



“Congratulations to ASBAH on your 40th Anniversary. Delighted to see the organisation going from strength to strength. Best wishes for the future.”

Lord Rix - President, MENCAP

“I congratulate ASBAH on the splendid work it has done over 40 years and hope they continue their good work over many more years because they have been enormously helpful to a great many people who suffer from spina bifida and hydrocephalus and to their families and carers.”

Baroness David - a member of the All Party Parliamentary Disability Group

“ASBAH has never been busier doing all the work it can for people with neural tube defects. Long may they prosper and we must look forward with hope for greater medical strides in this speciality.”

Claire Rayner

“It’s been a privilege to be working with ASBAH on the medical Advisory Committee for the last couple of years and I am very conscious of the many years of excellent work that we are currently building on. My congratulations to ASBAH on reaching its 40th anniversary.”

Dr R Forsyth - Consultant Paediatric Neurologist

“No organisation reaches its 40th birthday unless it is doing something right and doing that ‘something right’ well. My warmest congratulations to all the team who are continuing the fine ASBAH tradition of care, service, research funding and advocacy on behalf of its deserving clientele. May it continue as long as there is a need.”

Godfrey Bowles - former ASBAH Chairman

“ASBAH has achieved so much over the past 40 years. It has been a real pleasure to be involved directly with its excellent work over the last few years and to raise almost £75,000 in that time. I wish you every success in the future and look forward to ASBAH’s new Helpline service being launched.”

Danny Mills - Manchester City FC and England footballer



“There are some things which the voluntary sector does better than others could. One of these is harnessing the efforts of those with first hand knowledge of particular disabilities in order to make life better for those who follow. In this respect, ASBAH is a classic example of turning passion into practice in the interest of disabled people. With best wishes for the next 40 years.”

Tom Levitt MP, Chair, All Party Parliamentary Group on the Community and Voluntary Sector



The Prime Minister

I am very pleased to have this opportunity to offer my support to the Association for Spina Bifida and Hydrocephalus in its 40th Anniversary year. We very much appreciate the positive contribution ASBAH has made in advising and supporting people affected by these conditions. I pay particular tribute to your members who I know have, and continue, to work so hard to improve the quality of life for so many people.

Tony Blair

“I should like to congratulate ASBAH for its 40 years of success.

“ASBAH campaigns endlessly with government on legislation concerning disability to ensure that the rights of people with spina bifida and/or hydrocephalus are represented. Their efforts too have been tireless in the attempt to persuade the government to fortify bread with folic acid as part of a programme to prevent neural tube defects. Such programmes have been successful in other countries.

“This year will mark the 50th Anniversary of the Society for Research into Hydrocephalus & Spina Bifida (SRHSB) and we are planning to share our celebrations with ASBAH at the Annual Scientific Meeting that is to be held at Queen’s College, Cambridge in August.

“ASBAH is a flagship that is always looking to the future and I wish it every success.”

Carole A Sobkowiak - President of the Society for Research into Hydrocephalus and Spina Bifida

“My best wishes and thanks for all the good work that ASBAH does.”

Ian Hislop

“It gives me great pleasure to be given the opportunity to send greetings to all connected with ASBAH – members, officers, both national and those of local associations and staff at head office and in the regions – at the start of this 40th anniversary year.

“It is fitting that the vehicle for this message should be *Link*, which goes back to the 1960s and well fulfils its title by LINKING members and families in their joys, anxieties and successes.

“Writing this around Christmas time emphasises the importance of anniversaries. For me and some of you, an ASBAH milestone was our tenth anniversary when over a thousand members came to Stoke Mandeville Sports Stadium to celebrate, in the presence of our caring and lovely patron, HRH the Duchess of Gloucester. Her encouragement was again evidenced at the 25th Anniversary in Peterborough Cathedral, as well as in the years between.

“For me, writing this is, of course, ‘Memory Lane’ as the building bricks of an association like ours is PEOPLE. But in a few lines, it is impossible to pay individual tributes to the galaxy of people whose skills and devotion have established for ASBAH the place it now holds among the organisations caring for areas of disability both in this country and, with the Research Society, in the wider world.

“So, to all, both past and present members who have done so much in these forty years. Congratulations, and for the years to come blessings and all good wishes.”

Mary Oughtred - ASBAHs first Executive Director

As ASBAH celebrates its 40th anniversary, *Link* looks back to the organisation's humble beginnings and developments over the first twenty years. This article has been adapted from a piece written by ASBAH's co-founder Duncan Forrest who died in December 2004.



The first twenty years

It wasn't until the 1960's that figures were published revealing that infants with spina bifida, whose backs were closed surgically within a few hours of birth, actually gained some improvement in the power of their legs.

This naturally encouraged many surgeons to operate on almost all cases as soon as possible.

Since these babies were given the best nursing care in specialised neo-natal surgical units they often survived when they would not otherwise have done so.

In centres where active treatment was being undertaken, groups of parents began to come together for mutual support and information, seeking the help of healthcare professionals for the expert advice they so desperately needed.

ASBAH was founded in April 1966 by Duncan Forrest, paediatric consultant at Westminster Children's Hospital, and Professor Robert Zachary, a paediatric surgeon at Sheffield Children's Hospital. The idea was mooted during one of many meetings in Robert's Sheffield home.

The Association was initially made up of three medical professionals and eleven parents under the Chairmanship of Robert Zachary. The Executive Committee met for the first time on May 8 1966.

With only £250 in the bank, the Committee confidently agreed that

the Association should aim for a target budget of £100,000.

The response from around the country was enthusiastic. By November,

fifteen local Associations had been affiliated and fundraising began in earnest.

The following year ASBAH was able to employ a secretary and rented offices in Craven Street, Charing Cross.

By 1968 ASBAH had outgrown its office and moved to larger, but rather scruffy premises in City Road. By then it

had 34 affiliated associations.

tube defects in humans. Of course these pioneering developments generated grave ethical problems which led to agonising debate.

By the late 1970's, ASBAH met another new challenge as it saw the average age of its members steadily rise, bringing with it unexpected problems.

As many reached adult life, they needed help to take them into an independent life in the community – new and unchartered territory for ASBAH.

Another key problem was providing support for people who had hydrocephalus alone. By the early 1980's it became clear that their needs, although not so obvious, were just as intractable and worthy of detailed study.

In 1986 ASBAH celebrated its 20th anniversary and was able to look back with pride on its achievements... and marvel that it had come so far.

The future was bright, although no-one said it would be easy.

Follow ASBAH's progress through the next two decades in the Spring issue of *Link* magazine.

"In 1966 we were often asked why we needed to form yet another charity for handicapped children. The answer of course was that none of the existing charities had sufficient special interest in our particular combination of problems."

Duncan Forrest



had 34 affiliated associations.

The need for continuous fundraising became too onerous for unpaid members so an Appeal Director was taken on, putting ASBAH on a more professional footing and ensuring financial security.

In 1972 ASBAH received a huge boost when Her Royal Highness the Duchess of Gloucester graciously consented to become its Patron.

From the start the Association was keen to invest in research, particularly to develop methods of screening for spina bifida before birth.

The first realistic idea concerning one of the causes of spina bifida was first investigated by Dr Laurence who first received an ASBAH grant in 1968. He researched the role of folic acid deficiency in producing spina bifida and other neural



Robert Zachary

Are you 40 this year as well?

To tie in with our 40th anniversary celebrations this year, we're keen to hear from all ASBAH service users who turn 40 in 2006. It's a milestone year and we'd like you to celebrate it with us. So if you're preparing to hit the big 'FOUR O' this year, then do get in touch. Contact *Link* – either by email link@asbah.org or by writing to *Link* magazine ASBAH, 42 Park Road Peterborough, PE2 2UQ.

The future direction of ASBAH

**Comment from Andrew Russell,
Executive Director**

As we enter ASBAH's 40th anniversary year, it is gratifying to write that ASBAH is in good heart and ready to meet the challenges of the next 40 years. Appropriately, in our 40th anniversary year, there are definite signs of progress in our field.

We now have the National Service Framework for Long-Term Neurological Conditions which for the first time identifies these conditions as worthy of attention and quality services. It may only be on paper at the moment, but it gives us something to work with, nationally and locally. Both social care and the NHS are often pretty dire, in spite of some heroic staff, but at least we're used to that, and there are gradual improvements like the removal of the means-test on disabled facility grants in England, an issue that ASBAH, along with others, has been campaigning on.

We are also making progress with our folic acid campaign, with the Scientific Advisory Committee on Nutrition's (SACN) recent recommendation to the Food Standards Agency in favour of mandatory flour fortification. We have other interesting progress in ASBAH- research, for example on the biochemistry of CSF and the possibility of effective drug therapy in the future; also, on MR imaging for antenatal diagnosis, with far more accuracy than existing techniques.

The day-to-day challenges and problems faced by our service-users of course continue and our services staff are on hand to offer professional advice and support.

In our 40th Anniversary year ASBAH is expecting a year of positive, forward-looking progress whilst also taking stock of 40 years of rapid change in our field, which is delivering a better quality of life and a longer life-expectation to most people with spina bifida and/or hydrocephalus. We can push that forward more and, through the dedication of ASBAH's staff, trustees and local associations look forward to doing so in the year ahead.

40th Anniversary Help

ASBAH is marking its 40th anniversary with a fundraising drive to raise the £300,000 needed to launch a national Helpline and Information Service Appeal.



Spina Bifida & Hydrocephalus

HELPLINE Appeal

The appeal was launched on GMTV by soccer star Danny Mills. The England and Manchester City player was keen to help after experiencing first-hand the need for a dedicated information service after suffering the loss of their son Archie in November 2002.

A routine scan revealed that Archie had spina bifida and hydrocephalus so severely that he was not going to survive.

Thanks to Danny's efforts the Appeal funds have had a flying start. Now ASBAH hopes a new publicity drive will help bring in enough cash to get the service up and running.

The appeal target of £300,000 would set up the Helpline and Information Service throughout England Wales and Northern Ireland and run it for the first three years.

Fundraising is planned at both national and local level amongst the business community as well as

appealing to existing service users.

Assistant Director (Services), Mary Malcolm told *Link*: "Whenever people pick up the phone we want to make it as easy as possible for them. And while we provide the best possible service we can, we can't guarantee that there's always someone free to listen.

"A one-to-one conversation can do so much to allay people's fears and put their minds at rest. Knowing that there's someone at the end of the phone can be reassuring, even if there's no immediate need to pick up the receiver and dial."

ASBAH's Helpline and Information Service will provide help and support on all aspects of spina bifida and hydrocephalus – from antenatal enquiries, health and social care, education, transition to independence, through to bereavement support.

Helpline and Information Service Appeal

What our service users think!

"ASBAH has made what would have been a bleak world for Beth so much more exciting. It has opened doors that we would never have known were there.

"The support we have received from ASBAH and other families has been fantastic.

"I urge people to support the Helpline and Information Service to make it easier for other people to access the help they need."

Sam Copeland, mother of Beth, 11 months old



"ASBAH's Helpline offers yet another string to ASBAH's bow - opening up a further channel of communication for potential service users. The hope is that the Helpline will reach more adults with spina bifida and or hydrocephalus."

Paul Zickel, Chair, ASBAH's Your Voice steering group



"We wish ASBAH's Helpline Appeal every success as we are confident it will enhance and add an extra dimension to the already high standards of service we have experienced from the ASBAH Service network."

Lisa Cain, Chair, ASBAH Disabled Users Advisory Committee (DUAC)



"We would definitely not have got through the last nine and a half years with out the advice, help and support we received from ASBAH.

I hope many people support the Helpline and Information Service Appeal so ASBAH can continue to help families."

Helen Hassall, mother of Karl, 9



You can help ASBAH to help the hundreds of people who need support, information and advice!

We need your help to reach our £300,000 target to get the Helpline and Information Service up and running for three years.

To make a donation now complete the attached form.

Or you could plan some sort of fundraising event - for ideas and tips about raising cash check out the fundraising section on www.asbah.org or call our fundraising team on 01733 555988

"When Wendy came out of hospital we had no one to turn to for help and advice on normal pressure hydrocephalus, but she still had symptoms that needed explaining. An ASBAH helpline is the best thing that could happen and will be such a relief to many people."

Bob Simons



HELPLINE APPEAL

Donation

I would like to give ASBAH a gift of: £ today

Title _____ Name _____

Address _____

_____ Postcode _____

I would like to pay by:

Cheque, postal order or CAF charity voucher payable to ASBAH,

or

Credit card. Please debit my (circle one) Mastercard/Visa/CAF

Card

Start date

/

Expiry date

/

Signed _____ Date ____ / ____ / ____

Gift Aid Declaration

If you are a UK tax payer, please make every pound you give to ASBAH worth almost a third more at no extra cost to you by signing this Gift Aid Declaration.

I would like ASBAH to reclaim the tax on all donations I have made since 6 April 2000 and any donation I might choose to make hereafter.

Signed _____ Date ____ / ____ / ____

Please note: to Gift Aid your donations you must pay income and/or capital gains tax at least equal to the tax that ASBAH reclaims on your donations in the tax year.

Please complete and return this form to

ASBAH, 42 Park Road, Peterborough PE1 2UQ

Registered Charity No 249338 Registered in London No 877990



Young Knights scoop UK title

Northern Ireland's Under 15's Knights Wheelchair Basketball team celebrated after clinching the UK Junior title.

The team – all bar one have spina bifida - pitted their skills against the nation's best in the Great Britain Regional Championships in September.

The event, held in Stoke Mandeville,



Joy at Jessica's safe arrival

Congratulations to the Ding family who celebrated the birth of Jessica in October.

The family, from Harlow in Essex, suffered heartache when two of their unborn babies, Joshua and Danielle, died of spina bifida.

But Anita Ding and husband Richard were determined to have another child and were thrilled when Jessica was born on 7 October.

Anita said: "I got in touch with ASBAH when a routine 20 week scan showed that Joshua had spina bifida. It was a horrendous time but the information and support I received was incredible and helped me to deal with things.

"At my 12 week scan with Jessica I was terrified. Even when I was told that everything seemed fine I couldn't take it in. I only really relaxed when she was born."

birthplace of the Paralympic Games, saw each team play every team in their age group. Northern Ireland won five of their six games to finish in first place.

In their final game of the tournament, the team showed their skills to easily beat Wales.

Thrilled coach Jason Kennedy told *Link*: "It was a great win for our club and for Northern Ireland.

"It is such an important achievement for these children. Four years ago we took them to a tournament in Liverpool and we were happy if they just managed to get the ball up the court and take a shot once in a game. Now they are British Regional Champions, which is fantastic".

The Knights launched its Junior Club in 2000 and 15 children with spina bifida who are regular team players. Training is held every Tuesday from 7-8pm at Antrim Forum.

Children aged 8 or over who are interested in joining in are welcome to come along. For more information about the Junior Club call Aubrey Bingham on 028 2586 1998 or 028 9050 8255.



Kicking off Christmas early, John Edwards, pictured here with Tanni Grey-Thompson and her daughter Carys, joined over 4,200 other Santa look-alikes on 3rd December to take part in the annual Great Santa Run in Newport, Wales.

The one-of-a-kind event follows a four-and-a-half mile course around the town and this year the world record attempt for the largest gathering of Father Christmases was once again broken by the participants.

John raised over £300 for Mid Wales ASBAH and last year he raised £500 for national ASBAH.



ASBAH on show... thanks to Bolton & Bury



Northern region staff flew the flag for ASBAH at the Kidz up North exhibition with a stall generously funded by the Bolton and Bury local association.

The annual exhibition, held at the Reebok Stadium in Bolton, is dedicated to products, aids and services for disabled children.

There was plenty for visitors to see and do with stands run by many major companies. The exhibition also boasted an extensive seminar programme for professionals.

Visitor numbers were high with a good mix of professionals and families – many who had travelled long

distances.

Joan Pheasant said: "Since management of the event was taken over from the commercial sector by Manchester's Disabled Living Centre, we in the voluntary sector have felt less the poor relations and were well represented.

"We felt very professional and were easily identified thanks to our new spina bifida / hydrocephalus display stand.

She added: "As always it was good to greet the familiar faces of some of our service-users, many of whom were amazed at the range of goods on offer – if only they had the money!"



Family Fund support

The Family Fund is a registered charity which provides grants to UK families to pay for things that relate to the needs of their disabled child.

In 2004/05 alone, around £27.7 million was distributed to more than 45,000 families.

Shirley Young, Chair of the Trustees, said: "Families look to the Fund for help with practical things such as holidays, computers or play equipment.

"Our grants are not huge amounts, but what we give often has a significant impact because we work with what the family identifies are their main concerns."

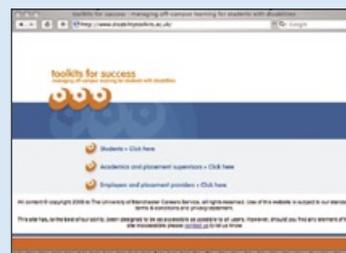
Help can only be offered for children and young people aged 15 and under.

Website resource centre

The Fund will consider any request on its merits and within its grant making criteria.

For more information contact The Family Fund at: Unit 4, Alpha Court, Monks Cross Drive, Huntington, York, YO32 9WN. Telephone: 0845 130 4542.

Or visit the website at:
www.familyfund.org.uk



Disability Toolkits to help disabled students

A new website has been launched to help disabled students gain work experience to further their future careers

Disability Toolkits, developed by the University of Manchester, is an interactive web-based service providing dedicated information, advice and resources for students with disabilities and prospective employers.

It will help students to identify disability-friendly employers, plan and manage their placement and ensure they receive the right support from their university and employer.

There are also many links to other websites to search for work placements.

www.disabilitytoolkits.ac.uk



Help for the over 16's

If you or your child is approaching their 16th birthday, then it's worth checking out the After 16 website.

The site is dedicated to the opportunities and services available to young disabled people when they leave school.

After 16 is for people with a wide range of abilities and disabilities, so not all of the sections may apply.

But it has plenty of valuable information on a range of areas from learning and work to housing, transport and law.

Check out the site at
www.after16.org.uk



Benefits of a break

Second Space is an inspirational charity which organises holidays for parents of severely disabled or terminally ill children.

People with holiday homes donate one week a year to Second Space which then allocates them to parents, so they can benefit from a respite holiday with or without their child.

One grateful mother said: "It is amazing how a week's holiday without any extra financial worries can ease the burden and recharge the batteries."

If you would like to know more about Second Space, or have a holiday home you can offer, call 020 7792 9043 or see the website at www.secondspace.net



Go online for info

The Disabled Workers Co-operative now offers an online database of skills, products and services that disabled people have to offer.

Registration to the database is free and is available for anyone to use.

The Jobs Portal is aimed at disabled job seekers, where vacancies are advertised and job hunters can register their details.

The website includes a directory of useful service providers, products and organisations.

For more info check out the website at www.disabledworkers.org



York event

Know Your Shunt

ASBAH members widened their knowledge of hydrocephalus and related issues at two Know Your Shunt information days.

The Your Voice steering group organised information days in York and Ascot to give people with hydrocephalus the chance to learn more about their condition.

The events, held in November, covered topics including the types of shunts available, coping strategies, related medical issues and how to develop independence.

Visitors also got the chance to discover more about Your Voice and become involved in planning future events.

Barbara Robinson, Your Voice co-ordinator, told *Link*: "We had an excellent response from the visitors. Everyone learnt a lot and enjoyed themselves."

"One of the speakers was a representative from Codman who brought in examples of shunts for people to see. It was the first time any of the visitors had actually seen a shunt, so they found it fascinating."

Other speakers included ASBAH's Rosemary Batchelor (York) and Gill Yaz (Ascot) who talked about medical matters. Student Joanna Clyne (*Link 214*) gave a presentation on coping strategies at the York event, with Alan Twyford speaking on the same subject at Ascot.

Barbara said: "We asked all the visitors to complete evaluation reports and their comments were extremely positive."

"It is very difficult to make events like this interesting and enjoyable, but organisers Lisa Cain and Mary King and the rest of the team did just that."



Ascot event pictured below



LINK

the lifestyle magazine for people with hydrocephalus and spina bifida



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Committee members discuss their new information leaflet

30th

ANNIVERSARY FOR SOMERSET

We often hear that local associations struggle to survive, with small committees and low participation at events.

So it was great to hear that after 30 years the Somerset local association is still going strong.

The Association was founded in November 1975 when George Earl arranged an open meeting at the Dr. Barnardo's Princess Margaret School in Taunton. A group of parents and interested people met to form a support group for local families and carers.

National officer Harold McFarland (Mac) addressed the group and advised them to form a local association.

The first committee was set up with Alan Jenkins as Chairman and George Earl a committee member – both of whom remain committee members today.

George said: "We decided that in the absence of Associations in adjacent counties that we should cover these areas, and we currently have two committee members who live over the border in Devon."

For many years the Somerset local

association has supported Dr and Mrs Lorber's, The RICHARD Fund for the Sheffield Children's Hospital. It purchased a six-berth caravan in Looe, Cornwall which was administered by The John Grooms Association for ten years, giving preferential bookings for Somerset families.

Like many organisations we have difficulty making local families aware of our existence

Over the years the committee has organised numerous outings to a variety of places. Regular skittles and ten pin bowling evenings are always popular.

But George said: "Like many organisations we have difficulty making local families aware of our existence.

"In an attempt to improve this situation, we have produced a new Somerset Association leaflet, and are looking into the possibility of producing a local association DVD."

Somerset does miss the service of a local adviser, who helped to run educational and advice days, as well as giving day-to-day support to families in the area.

But the association is built on stalwarts, who have given an enormous amount of time and energy over the years.

Take Cynthia Dawes, for example. She

kept an eagle-eye on the books for 28 years until 2004when she took the post of Chairman.

George added: "We have only had three people holding the post of Secretary before Peter Harling volunteered...and it may possibly be a job for life for him!"

But while the association may be founded on a few long serving members, new faces are welcomed with open arms. And with the help of the new leaflet, everyone hopes 2006 will be the start of another successful decade for Somerset.



(left) Chairman Cynthia Dawes



(right) Another stalwart of the Somerset association was David Stacey who died in 1996. David, known as Mr Independence, was seldom seen without a smile, and was a great help with fundraising.



Steve Derwin



The BDFA, based at Biggin Hill in Kent, has more than 200 members on its books, who regularly fly from 14 airfields around England.

It is dedicated to helping disabled people achieve their individual aviation ambitions by making flying as accessible as possible and continually developing control adaptations and technical aid.

Another important role for the BDFA is giving specialist advice to training schools to help them overcome disability issues, as well as offering scholarships for would be pilots each year.

Steve Derwin, Chairman of the BDFA, told *Link*: "The BDFA works very hard to serve disabled people interested in flying. We do everything we can to live up to our objective of "providing opportunities in aviation for disabled people"

Steve added that the future for the organisation looks exciting, with its profile continuing to grow in strength.

Support comes from a wide cross-section of society, from its celebrity Patrons, Dame Tanni Grey-Thompson and Judy Leden, MBE, multiple world hangliding champion.

The organisation also enjoys the backing from the Jordanian Royal family, who presented the BDFA with four Bulldog training planes in 2004.

Steve said: "We have also developed strong commercial sponsorship which has enabled us to put our new Bulldog aircraft in the air for the benefit of disabled people. We hope that sponsorship will eventually enable us to develop a specially designed flying and training facility for the disabled.

"We also plan to introduce a range of specialist training programmes and improve the employment potential for disabled people in aviation."

He added: "Never has the future looked so bright and exciting for our organisation, and never before has our profile been as strong. We look forward to helping many other disabled people achieve their dreams."

Qualifying as a pilot

To qualify for a JAR PPL, the standard license which allows you to fly in the UK and to mainland Europe, requires a minimum of 45 hours of training.

At least 10 of those will be solo (minimum to first solo is 35). The training will include no less than 2 hours stall/spin training, a degree of instrument only flying, and a 5 hour solo cross country trip to 2 new airports.

Many people take longer than these minimums. In addition you will need to pass a JAA medical before first solo flight. Costs vary, but expect to pay £120-£140 per hour.

Few among us haven't wondered what it would be like to soar into the skies and escape the daily grind.

Until 12 years ago piloting an aircraft was an unobtainable dream for the disabled.

But the pioneering work of the British Disabled Flying Association (BDFA) has helped to open up the skies to disabled people who don't just want to be passengers.

The sky's the



Adrian Ellerby

CASE STUDY

Name: Adrian Ellerby
 Located: Ingleby Barwick,
 North Yorkshire
 Age: 39
 Job: Event Management
 BDFA role: Regional co-ordinator
 for the North East

As a small boy, Adrian was fascinated by planes. But it wasn't until the age of 33 that he was even aware that disabled people could pilot an aircraft.

He spotted an article about the British Disabled Flying Association (BDFA) in Mobility magazine which stirred his imagination.

Adrian, who has spina bifida, went along to a BDFA event in Yorkshire where trial flights in a glider were on offer.

He grabbed at the chance to take a flight and, as they say, the rest is history.

"I was instantly hooked," he laughed. "The flight was amazing and as soon as the glider landed, I went over to sign up with the gliding club.

"Gliding is a more cost effective way of flying, but of course flights are very much dictated by weather conditions. It was a 125-mile round trip to the nearest airfield with a glider with hand controls

too, so it took me quite a while to do the 18 flight hours I needed to get my licence."

Adrian then applied for a much-coveted BDFA flying scholarship which took him to South

Africa for two months to have 40 hours flying training towards his private pilots licence. Adrian said: "Once I'm in the air the sense of freedom is amazing.

I'm totally in control and am on equal footing with able-bodied people. Flying has completely changed my life and has given me more confidence and makes me feel that I can achieve almost anything."

He added: "I'd recommend that anyone give it a try. Trial flights in gliders and aircraft are usually available at BDFA air shows around the country."

Although Adrian is busy setting up an events management business, he still devotes much of his free time to the BDFA through his role as Regional Co-ordinator for the North East.

But he explained:

"Being involved in a flying club is a lot of fun and there is a very lively social scene. Flying is my hobby so whatever time I spend on it is never a chore."

Once I'm in the air the sense of freedom is amazing. I'm totally in control and am on equal footing with able-bodied people



e limit

**To contact the BDFA call 07967 269 345
 or email info@bdfa.net**

ACTION MAN MIKE



Taking part in a 10km run is gruelling enough for many, add a 1500m swim on top you'd be a glutton for punishment, but how about crowning all that off with a 40km bike ride. Well, that's exactly what Mike Smith did one day in July to raise money for ASBAH.

His Olympic effort took place in Chester at the Royles Deva Triathlon event. Having already completed two marathons before, Mike knew that his running skills would be up to scratch so he spent six months prior to the event, improving his swimming technique.



Mike said; "The day itself went as well as I had hoped. The swim was hard, as expected, with an out and back

course in the River Dee – against the current for the first half!" The rolling Cheshire countryside was the backdrop for the cycling route whilst two Chester city centre parks and the banks of the river formed the running course.

"By the time it came to the run my legs were rapidly tiring but I made it to the end and was welcomed with a full family turn out including my eight-year-old twins, my wife, and my parents."

Mike's decision to embark on this exhausting challenge may have had something to do with turning 40 last year but more that his son, Ben, has a VP shunt fitted to control his hydrocephalus. Mike wanted to raise money to help fund ASBAH's research into shunt infections by Dr. Roger Bayston, which may be a direct benefit to Ben in the future.

ASBAH thanks Mike for taking on such a tough quest and raising £530.



LEWIS' SUPERHEROES

Lewis Hine's Mum, Emma (pictured above as Bat Girl), became his hero for the day when she and seven of her friends and family, dressed as superheroes in a phenomenal effort to raise cash for ASBAH.

Four-year-old Lewis, who has hydrocephalus as a result of a brain tumour, is normally the main fundraiser in the Hine's household but this time he was an onlooker cheering his Mum and the team on as they raced around the 10-mile Great South Run, in Southsea, raising £1,478.

Such was the surprising sight of eight fictional characters, Channel Five News couldn't resist including them in its days highlights, and even the local paper made them front page news.

ASBAH can't thank Emma and the team enough for their gallant efforts. They really entered into the spirit of the occasion, but something tells us that Lewis was the true source of their inspiration for his sensational superhero strength!

Feathered friends

Once again ASBAH is being supported by the Royal Pigeon Racing Association, (RPRA) and we will be attending the British Homing World Show at Blackpool Winter Gardens to receive another handsome cheque.

The British Homing World Show of the Year has been raising money for

ASBAH since its very first show in 1973 and, as our longest serving and largest donor, we'd like to offer our sincere thanks and appreciation for all the hard work the Show committee and its general manager, Peter Bryant does, and continues to do for us.



MARATHON MUM

Watching his Mum cross the finish line of the Robin Hood Half marathon at Victoria Embankment, Nottingham was a day that five-year-old Thomas Davies won't forget.

Waving his Mum off at the start, Thomas, along with his twin brother William, sister Georgia (7), Dad Russ and Grandparents, made sure they were all there at the finish line to give Mum, Bethan, a victorious hug...and admire her medal too.

Bethan, who raised £750 for ASBAH, said: "I was very proud to wear the ASBAH t-shirt on the day and raise money for the charity. My local ASBAH medical adviser, Catherine Mayfield, has always been at the end of the phone if we have needed her and she is now going to Thomas' school to talk about hydrocephalus so I wanted to give something back."

Thomas is clearly very proud of 'Marathon Mum' and has taken the medal she won into school to tell all his friends about the day she took part in. As he so sweetly puts it, her "running race".



Thomas Davies with his mum Bethan

See page 23, for a profile on runner/fundraiser Malcolm Henderson and how to book your place in the British 10K London Run – much of which will follow the London Marathon course



'PUTTING' THEIR HANDS IN THEIR POCKETS

Thanks to the success of the White Bros and Speed Ltd golf charity day at Llanwern Golf Club in Newport, Wales, ASBAH has been presented with a cheque to the sum of £2,800.

Following the evening dinner, the 80 golfers battled it out to get their hands on the best auction prizes, including a signed rugby ball by the Welsh Grand Slam

winning squad. With a few keen Rugby supporters in the room, the money raised from the auction came to £1,475 up on last year's total!

In fact, since the inaugural event back in 2001, nearly £6000 has been raised in aid of ASBAH. Thanks to everyone involved in organising and supporting the golf day and good luck for next year.

ROWE RACES TO RAISE CASH

ASBAH Trustee, Bev Rowe (pictured below), entered this year's Great South Run in Southsea, Portsmouth with fellow competitor, Gabriel Gutierrez, and raised a great £310 for ASBAH!



NPH research hope

A small research team is making big strides in the diagnosis of normal pressure hydrocephalus.

The team, based at the Royal Preston Hospital in Lancashire, began its work in 2003 studying NPH which usually occurs in people aged 60 and over.

Many of its symptoms are the same as those of dementia, Alzheimer's and Parkinson's Disease – making it difficult to diagnose. As a result, the condition may go untreated.

Link met Mr G. Balamurali, a registrar in the Neurosurgery department, the main researcher leading the study to learn more about the man and his pioneering research

Where did you do your medical training?

I did my training and qualified in India. I came to the UK in 1997 and since then I've trained as a surgeon and now as a neurosurgeon at Hope Hospital, Manchester.

Why did this field interest you?

Some of my predecessors were dealing with patients with suspected NPH. They were trying to identify the most appropriate tests.

When I did a review to see what practices were used throughout the UK and the rest of the world we found very different methods were used to diagnose NPH.

Most of the work was research based which was very expensive and cannot be done at smaller centres. So we devised a protocol which could be used in any centre with minimal expertise and equipment. Because of the difficulty in diagnosis it makes it more challenging.

What other studies have you carried out?

We've carried out mainly three tests in this research. One is the gait assessment with balance and walking problems.

The second are the memory assessments to differentiate NPH memory problems from other conditions such as Alzheimer's and other dementias.

The final test we do concerns the lumbar pressure studies and drainage of fluid from the spinal space. We repeat all three



Mr G. Balamurali

tests to try and identify which patients may respond to a shunt.

What has your research achieved or shown so far?

Of the 50 patients involved we have been able to identify a group who would respond to a shunt.

Of course we can't be 100% sure if they will respond, but we are trying to identify the ones who are more likely to respond and those who aren't.

I think that is one of our biggest achievements because fitting a shunt can have serious complications and if you do this operation on someone inappropriately, they could be left with serious damage if complications occur.

CASE STUDY



Julia Crabtree from Sheffield was diagnosed with normal pressure hydrocephalus in 2002, three years after she first experienced neurological problems.

Here Julia and husband John talk to *Link* about their experiences.

Julia: "The earliest symptom was urological - flooding with urine and it was around 18 months before the other symptoms kicked in. That was when I started falling over, losing my balance

Normal Pressure Hydrocephalus

and began to get vertigo and severe headaches. At one stage I was on eight paracetamol a day just to keep going.

But it took a very long time for the NPH to be diagnosed. I first experienced the neurological problems in 1999 but it was 2002 before I saw a neurologist.

I had heard of hydrocephalus because I used to work for the school library service. I knew of special schools which dealt with children who have spina bifida and hydrocephalus. But hydrocephalus was something I never thought would happen to me.

When I finally had a programmable shunt fitted it took some time to become

mobile because I also had a catheter in.

I know if my shunt isn't working properly because I find my ability to walk almost disappears overnight and I get terrible headaches.

My shunt has been adjusted several times although my surgeon did warn us that

She gets headaches from time to time now but the neurosurgeon did explain that she could still have what they call a low pressure headache

programming it can be trial and error and they have to keep adjusting it until its right. Every person is different."

John: "Julia finally saw a neurologist when our local

hospital did an MRI scan because she was having problems with her balance.

The ENT consultant said she appeared to have an increased fluid level in her head and that she ought to see a neurologist. A

Codman - Working in partnership with ASBAH

How many people are in your research team?

The research team is mainly a multidisciplinary team made up of people from the Royal Preston Hospital and the University of Central Lancashire. I coordinate everyone and get advice from all.

Where does the funding for the research come from?

The funding has mainly come from the Sidney Discroll Foundation in Preston. We have received good funding so far, but we haven't carried out any expensive tests, so costs are minimal.

How much contact do you have with people with NPH?

We have a good relationship with the patient and their family. All the patients in our research have a card showing what pressure the programmable valves are set at so if they have problems they can always contact the hospital.

Can you describe a typical day?

It's more of a typical week because these patients stay in hospital for three or four days.

We tend to bring them in on a Monday morning for gait and memory tests. We then

perform pressure studies and insert a drain into their back to drain fluid from the spinal space. We take 100mls of fluid every 24 hours for a couple of days then retest their gait and memory. Depending on the results we try to determine whether they will benefit from a shunt. Discussion with the family and patients takes place at every stage.

What do you find enjoyable?

My patients are a very nice group of people. If you sit and talk to them for more than ten minutes, you begin to build up a good relationship with them.

What are the most rewarding aspects of your job?

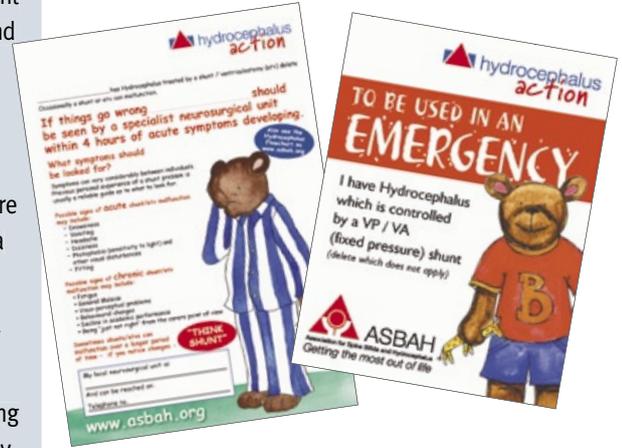
Achieving good results. It is very rewarding when patients and their family tell us they can now walk properly or remember things which they had forgotten.

It really makes me think I am doing something worth while.

What are your hopes for the future of managing and treating Hydrocephalus?

Improving awareness of NPH is my main hope. Once we can identify NPH patients we can test them and help them. Developing a simple methodology which can diagnose NPH is another of my hopes.

Be alert – get your new Benny Bear shunt card



Benny Bear features on a new child friendly shunt alert card for children, together with a new "Think shunt" poster for parents and carers of children – explaining the symptoms of shunt failure and a course of action.

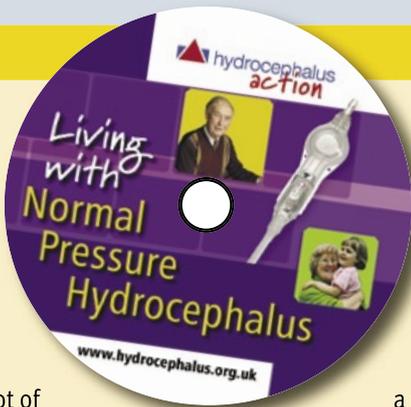
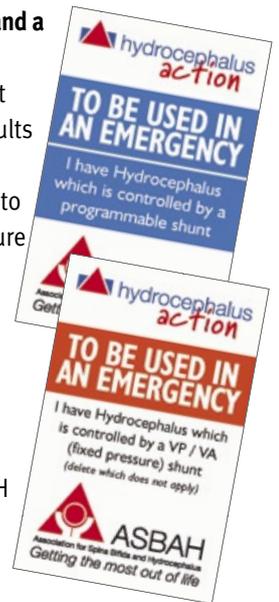
There are two new shunt alert cards available for adults - a card for programmable shunts which allow people to fill in the details and pressure setting of their shunt, and a new look fixed pressure shunt cards.

Adult management of hydrocephalus is featured on an updated information sheet available from ASBAH information section and shortly on the ASBAH website.

ASBAH members who have shunt alert cards can now apply for updated ones.

To receive a new shunt alert card write in (enclosing a stamp) to Diane Gardner, services department, ASBAH, 42 Park road, Peterborough, PE1 2UQ.

If you are not on ASBAH's database and do not have a card, then individuals or parents should contact ASBAH's Service team to request a confidential record application form and shunt alert card which will be sent out to them. Either telephone us on 01733 555988, or email us, dianeg@asbah.org



few weeks later Julia also saw a urological consultant and he also came out with same diagnosis.

But Julia still didn't see a neurologist until 10 months later – and that was after a lot of pushing.

There were a lot of problems with the shunt at first, but things finally got better in March 2004. Since then Julia's mobility has really improved, but continence is still very much a problem.

She gets headaches from time to time now but the neurosurgeon did explain that she could still have what they call a low pressure headache. They aren't too much of a problem at the moment, but we

are going back to see the neurosurgeon very soon and will mention them.

It did take a long time to get things sorted in the early stages, but once we saw

a neurosurgeon, things moved fairly quickly. We have

never had any problems accessing the neurosurgeon. If we do think the shunt isn't functioning properly, we can phone his secretary and it will be sorted out."

Julie and husband John speak of their experiences on the new Normal Pressure Hydrocephalus CD ROM available from ASBAH's information section or order on line at www.asbah.org



Linda's line

In days of old, winter was the time of year when you would gather round a crackling log fire and tell tales of daring deeds and breathtaking bravery, so I thought I would regale you with the story of my dreams of becoming an ice skater.

(To be honest, this would be better classified as breathtaking stupidity, and I'm not too sure about the daring deeds bit either). Anyway, rewind to the 1980s – the era when women had pencil thin eyebrows and ridiculously large glasses, when the Rubik Cube was the latest

must-have toy, and the kids from Fame were always dancing on the tables in their school canteen.

Fuelled by the national excitement surrounding first John Curry and then Robin Cousins, I avidly watched every ice skating programme I could keep awake for (sadly we were a no-video household in those days and ice skating was often mysteriously on late at night).

The problem was, the more I watched their seemingly effortless spins and jumps, the more I yearned to have a go and I even managed to convince myself I'd be good at this! To this day I have no idea why – I'm not particularly co-ordinated on dry land, never mind on ice!

However, my opportunity for glory came when a friend invited me to Richmond Ice Rink and the timing was perfect – I was due to go into hospital the week after so it was my one and only chance and I couldn't wait.

Setback number 1: - Ice skates come ready paired in the same size and I have odd sized feet. Brushing aside this minor

difficulty, I chose the size that fitted my largest foot and laced up ready for the off.

Setback number 2: - Tradition dictates that the correct posture required for ice skating is feet on the ice, arms held gracefully in the air. Instead, I seemed to naturally gravitate towards a bum on the ice, feet in the air arrangement. In a word, rubbish! My personal best was a wobbly circuit of the rink clinging on to my friend's arm.

My short-lived ice skating career would have rested there but for the hospital appearance the following week. As the consultant uttered that familiar phrase "do you mind getting undressed?" I could see by his expression that I was going to have to explain how I had acquired these extensive but colourful bruises. Well, if you're going to stand around in your underwear, you might as well do it in style!

Advertorial

Customers enjoy Freedom

Wheelchair users across the country are enjoying a better quality of life thanks to their new Fiat Freedom cars.

The Freedom, from Allied Vehicles, is a spacious, fully wheelchair accessible car with room for the wheelchair passenger and two others, plus driver.

It has an electric winch system which takes away the struggle of pushing the wheelchair into the car. The wheelchair passenger is then secured using a four-point wheelchair restraint system.

Extra headroom with large windows means that all passengers enjoy excellent visibility.

Purchasing a Freedom has given a new lease of life to Paul Ward from Billinge, Lancashire.

His carer, Mark Lant explained: "It has made such a difference. Now I can take Paul out and we travel much further afield. It's a great car, very nippy with amazing fuel consumption."

Joyce Nandra from Manchester has also enjoyed the benefits of the Fiat Freedom.

She explained: "I have cared for my husband for the past 11 years and because he uses a wheelchair, I couldn't get him in and out of the previous car.

"Having the Freedom has made a huge difference to our lives. I can't rate it highly enough. We were like prisoners before."

Bill Bailey from Sutton, Surrey, is another satisfied customer. He said: "The Freedom is much easier to use than the last car we had. I find it much easier to get

Having the Freedom has made a huge difference to our lives. I can't rate it highly enough.



my wife Tina's wheelchair in now so we do go out and about far more often."

Allied Vehicles Managing Director Gavin Gillies told *Link*: "People are our most important concern. It is important to us to find the ideal vehicle for both the driver and passenger."

Allied Vehicles have Mobility Advisers throughout the UK who will bring demonstration vehicles to your home for a free demonstration.

To arrange a free, no-obligation demonstration contact Allied Vehicles on 0800 916 3062. You can find the website at www.alliedvehicles.co.uk

RUNNER - MALCOLM HENDERSON



I always enjoy running for ASBAH knowing that I'm helping to raise money for such a good cause



Flying Scotsman

If you read Malcolm Henderson's impressive list of annual running achievements, you'd never imagine that 26 years ago a stroke left him unable to walk.

But it would take more than that to put the determined Scot off his stride.

In just two years – much quicker than doctors predicted – Malcolm was on his feet again and training for the 1981 Great North Run.

Since then he has competed in a variety of marathons and half marathons in both England and Scotland.

But if his face doesn't seem familiar to *Link* readers, then perhaps his tartan tam o'shanter and red wig will.

For fleet-footed Malcolm, from Adlington near Bolton, makes annual appearances in *Link* for his fundraising efforts in the Great North Run.

Malcolm, 49, has competed for ASBAH three times and never fails to delight the crowds as he sprints by, red hair blowing in the breeze.

"I suppose the hat and wig have become my trademark," he laughed. "I'm a Scot so it seemed appropriate."

Malcolm's relationship with ASBAH came by chance when he was searching for a charity to run for.

He explained: "A friend mentioned that

ASBAH had a few places in the Great North Run, so I gave them a call. I take part in several races each year, but only fundraise for one; otherwise I worry that my family and friends will get charity fatigue."

For a man who competes in a variety of long distance events, he has an unexpectedly relaxed training regime.

His job as a geologist often leaves him with little time to prepare for events. "I recently took part in a half marathon but hadn't run for three weeks," Malcolm said.

"I suppose I'm lucky in that I am at a relatively high level of fitness, and it doesn't take too much to maintain that level.

"But because I did have a stroke when I was younger, I am very conscious that I shouldn't overdo things. If I get warning signs I always take notice."

He added: "I find running so relaxing, especially if I have things on my mind. But competing in races can be a little strange. It often feels as though you've stepped onto a conveyor belt, as you run shoulder to shoulder with people all along the route.

"This year's Great North Run was more challenging than I expected because of it being so warm on the day. I had hoped to run it in under two hours, but I finished in 2 hours 6 minutes.

"But I always enjoy running for ASBAH

knowing that I'm helping to raise money for such a good cause. We all had ASBAH T-shirts this year which helped us advertise the charity and really made me feel part of a team."

New race for runners

Each year ASBAH is forced to turn away people who ask for a place in the London Marathon.

"Competition amongst charities for places in the London Marathon is fierce," explained Ian Morley, ASBAH's events fundraiser.

But in 2006 ASBAH will have places available in the British 10K London Run – much of which will follow the London Marathon course.

Anyone interested should contact Ian at ASBAH on: 01733 421328.

demonstrating more understanding *

We are a leading law firm who specialise in investigating Hydrocephalus and medical issues surrounding Spina Bifida claims.

Medical issues are often highly complex as well as daunting.

If you have concerns regarding medical treatment you have received then please contact **Anthony Fairweather** (Law Society Clinical Negligence Panel Member) for a free consultation

on **0117 916 9352**

or email: afairweather@clarkewillmott.com

A new initiative is helping to make health and leisure facilities more accessible for disabled people.

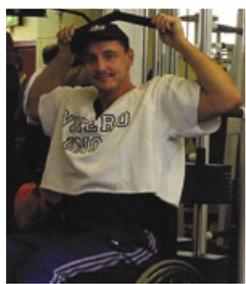
SPORT FOR ALL

Since 2001 the Inclusive Fitness Initiative (IFI) has provided grants to gyms across the country to help them encourage disabled people to sign up.

Research carried out in 1998 revealed that the majority of fitness suites around the country were not accessible for the disabled because of a shortage of suitable equipment and a lack of disability awareness among staff.

A spokesman for the IFI said: "For too long now fitness has been presented to disabled people as exclusive. The IFI, under the auspices of the English Federation of Disability Sport, is working to provide a range of solutions to these barriers."

The main scheme has targeted 150 gyms across England to ensure that disabled people will have an IFI facility within reasonable travelling distance.



CASE STUDY

Name: Anna Thomson
 Located: Crewe
 Age: 24
 Medical history: Spina bifida and hydrocephalus

"I never did much sport at school because I have difficulty walking and sometimes use a stick. That meant I was excluded from most things, which didn't do my confidence any good at all. I tended to be sent out for a walk with a teacher while everyone else was playing rounders or hockey.

I have belonged to gyms in the past but I always found the staff unfriendly and felt that I was being watched.

I joined the Total Fitness gym in Crewe

about a month ago and have found staff to be very friendly and helpful.

There is obviously certain gym equipment I can't use, such as the rowing machines, which would put too much strain on my back, but there is a good range I can use.

I also enjoy swimming, which is great exercise because the water supports my body, and I find it very relaxing.

Although I've only been with the fitness centre for a few weeks, already I feel much healthier. I have more energy and although I still have aches and pains, they have eased off.

I feel more confident too as my self esteem has improved. I'd certainly recommend joining a fitness club to everyone, although you may have to take a look around before you find one to suit you."

Tell your story

At ASBAH we're always looking for people to tell their story to help us in our work promoting awareness of spina bifida and hydrocephalus.

Your experiences of these conditions can be put together as case studies which

we can use in a variety of ways.

They can be put out to the media when we're looking to publicise new initiatives or could be used on leaflets or in *Link* as real life experiences to back up medical articles.

If you are willing, we may also ask you to speak to a journalist on certain issues you feel strongly about.

We do have a number of people who are willing to help, but as always, we're looking for more volunteers.

You could write your story and send it in. Or you may find it easier to speak to a *Link* reporter on

the telephone. Of course you will see the finished article and have chance to change anything you aren't happy with.

We always respect your right to privacy and will always check with you before passing your information on to a journalist... and we'll never put any pressure on you to do an interview. You and your family will always come first.

If you can help, please contact

Peter Farrall on 01733

555988 or email him at

peterf@asbah.org or write

to him at the ASBAH address shown on the contents page.



Government proposals threaten services

Representatives from companies which produce and supply continence and stoma products have criticised new Government proposals regarding the pricing and delivery of their products.

A consultation paper, published by the Department of Health in October, recommends that to reduce costs, products and dressings should no longer be delivered direct to peoples homes.

The white paper also proposes that companies should lower the price of their products, which include incontinence and stoma appliances, dressings and other accessories.

A spokesman from one of the leading manufacturers and suppliers told *Link* that if these cost-cutting measures were brought in, they would jeopardise patient care.

He said: “The proposed options relating to the dispensing of prescriptions will probably mean that companies will not find it viable to continue to deliver the much needed services from dispensing appliances to millions of people in their homes.”

The majority of patients receive dressings and appliances through the post or by courier. The patient or their carer phones their supplier, who then calls the patients GP for a prescription. The order is then despatched.

If the government’s proposals come into force, the patient or carer will have to collect their prescription and take it to a

Link reader Kate Sadler, 43, from Wyndham in Norfolk relies on home deliveries for her continence products and would be horrified if she had to collect them from the chemist.

Kate, who has spina bifida, said: “My prescriptions have been delivered to my door for the past two years, and this service has made a huge difference to my life.

“Previously I had to plan to call my GP to sort out a repeat prescription, collect it and then take it to the chemist, where, nine times out of ten, most of the items would be out of stock.

“If I ran out of supplies I’d be really stuck. So I had to be very organised – which isn’t easy when you have a full-time job and two teenage children.

“Collecting the products from the chemist was a nightmare in itself because I didn’t want anyone seeing me.

“Wyndham is a very small town so I was constantly worrying that someone I knew or my children’s friends would spot me. Smuggling out six large boxes every fortnight wasn’t easy.

“I think home delivery of continence products is vital. It is more convenient and discreet.

“Continence problems never seem to be seen as a disability by people in government, but they are. It is really important that people who would be affected by the proposed changes campaign to prevent the proposals going through.”

The proposed options relating to the dispensing of prescriptions will probably mean that companies will not find it viable to continue to deliver the much needed services

chemist.

The spokesman added: “This proposed system would be inconvenient for most people and their local chemist is unlikely to stock everything they need.

“We believe that these government proposals could have a negative effect on patient care. The neediest patients could find their condition exacerbated, leaving them debilitated and confined to their homes.

“There would also be an increased chance that stoma care and continence patients could be readmitted to hospital.”

The industry, which includes more than 50 UK-based companies, has formed an action group through the Patients Industry

Professionals (PIPs) and the British Health Trade Association (BHTA).

A lobbying and media campaign has been launched to put its many concerns to the Department of Health.

The spokesman told *Link*: “The Department of Health seems prepared to listen to our concerns, but it must understand in greater detail the services we provide and the challenges our patients face.”

How you can help

If you feel that the proposed changes will lead to a reduction in the quality of services, speak out now.

Write to your Member of Parliament to raise this issue with them directly. If you do not know who your MP is or how to contact them, call the Patients Industry Professionals helpline on 020 7796 6733.



Researchers believe a dietary supplement taken during pregnancy could lower the risk of hydrocephalus.

Hydrocephalus future hopes

Hydrocephalus has been seen simply as a build-up of excess cerebrospinal fluid in the brain which can impair brain development.

But studies by teams at Manchester and Lancaster Universities suggest that the hydrocephalus could actually be caused by chemical changes to the fluid in the brain.

They believe that it is this chemical change that prevents normal cell division, resulting in a build up of fluid in the brain and arrested brain development.

It is hoped that a dietary supplement taken during pregnancy could cut the risk of hydrocephalus but further research is needed.

But the researchers hope their work will eventually lead not only to a reduced risk of hydrocephalus, but also new treatments for those who survive with the condition.

Parents of children who have hydrocephalus in the US have raised money to fund the next stage of the research programme.

The money will finance a research laboratory at the University of Central Florida, which will be staffed by the UK teams.

Lead researcher Dr Jaleel Miyan told *Link*: "This procedure is based on the established clinical view that this fluid is nothing more than a mechanical support system within the skull with little, if any, physiological properties and that

hydrocephalus is simply a build-up of excess cerebrospinal fluid in the brain.

"But our studies have shown that the condition may in fact cause a change in the composition of the fluid, and that it is this chemical change that prevents normal cell division, resulting in arrested brain development."

He explained that tests had shown that it might be possible to correct this problem, using a dietary supplement during pregnancy.

If the research yields further positive results it could mean an end to surgical intervention to treat the condition.

Carole Sobkowiak, President of the

Society for Research into Hydrocephalus & Spina Bifida, called the research "exciting and potentially far reaching".

She said: "It is the first real potential breakthrough in the treatment of hydrocephalus which is a condition that can seriously affect brain development.

"If successful then such advances in research would allow babies to have a more normal development of their brains.

"In order to reach this goal however, it is planned that the safety procedures are robust and will need to be checked rigorously."

However, Dr Hazel Jones, honorary secretary of the Society, stressed the research was only at the hypothesis stage.

"To give out false hopes to people with children suffering from hydrocephalus is premature," she said.

This the first real potential breakthrough in the treatment of hydrocephalus

Papers from the 2005 Barcelona conference of the Society for Research into Hydrocephalus & Spina Bifida will be published in due course on the following website:

www.cerebrospinalfluidresearch.com

Book Reviews

Surviving the special educational needs system By Sandy Row

Published by Jessica Kingsley Publications www.jkp.com

This is the 'story' of a family with four adopted siblings and their struggle with the SEN system. Three of the children are on the autistic spectrum and one is dyslexic but there is plenty in this book for families with children who have other disabilities, learning or behavioural difficulties.

There is lots of practical advice including clear, highlighted explanations of jargon, definitions, legal aspects of SEN provision and even sample letters, to help you find your way through the system.

But, perhaps, most importantly, it is all from a parent's perspective and this could help to restore your faith in yourself and your child when you are having difficult times trying to ensure their needs are met.

There is no doubt that it was a hard fight for Sandy Row and her husband and their children: Alice, Alex, Richard and Jack.

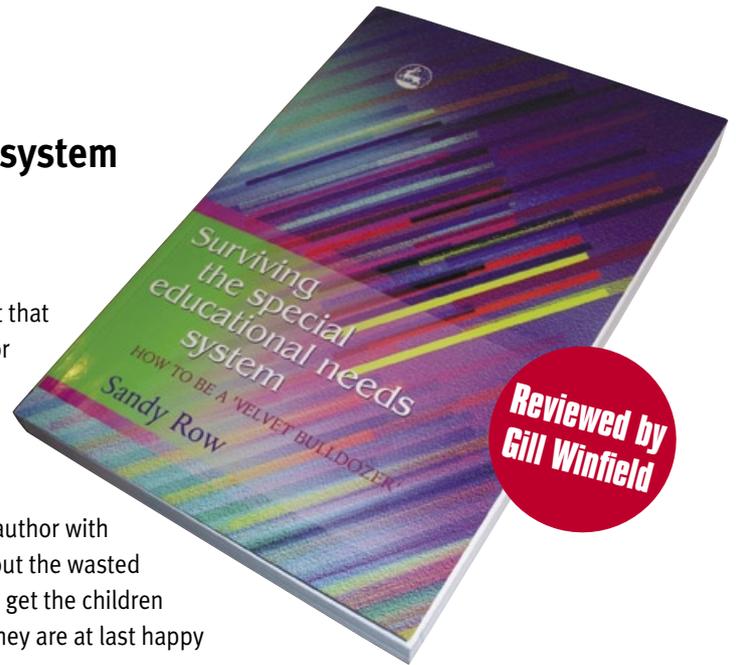
This has left the author with some bitterness about the wasted years it has taken to get the children placements where they are at last happy and successful.

Her aim is to save readers from going through so much trauma and to show you how to overcome hurdles to success - all done in a way that make you feel Sandy is talking directly to you - a fellow parent facing the same challenges.

She explains how she felt before a

tribunal: "I felt scared. I'm not telling you this to put you off but I want you to know if that is how you feel you are not alone."

This book is designed for busy parents to "dip into" but if you get the time you may find this an absorbing read which is hard to put down.



Reviewed by
Gill Winfield

So young, So sad, So listen By Philip Graham and Carol Hughes

Published by Gaskell (The Royal College of Psychiatrists)

www.rcpsych.ac.uk/publications/gaskell

This book is a useful tool in helping parents and teachers to address the problem of depression in young people.

It recognises that depression is a common and serious problem in today's school-age population, and gives a helpful description of triggers and signs of depression.

It supports the value of listening, of supporting and helping young people to challenge negative thought patterns, and offers a description of professional help which may be available.

I found the book to be an accessible guide for families and teachers who

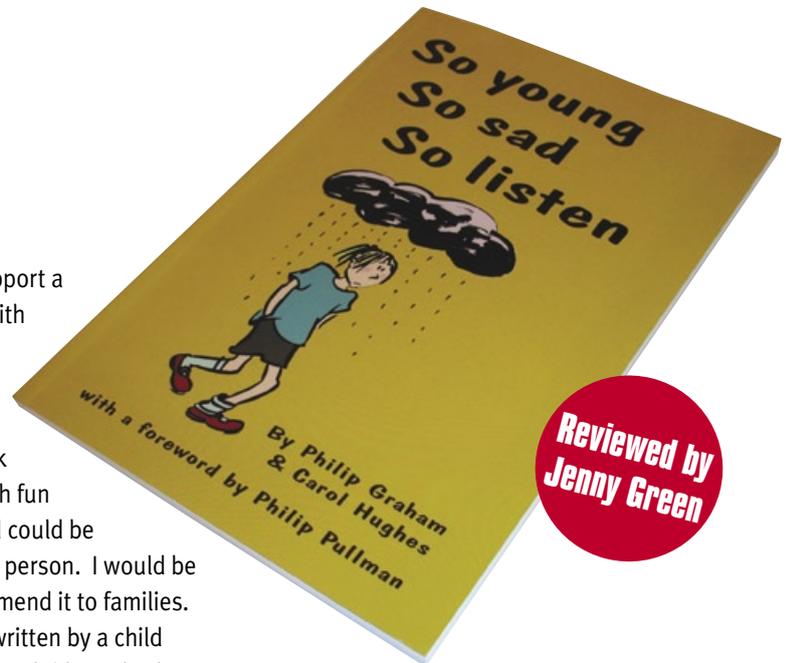
are trying to support a young person with depression.

Although it is a serious subject the book is attractive, with fun illustrations and could be read by a young person. I would be happy to recommend it to families.

The book is written by a child psychiatrist and a child psychotherapist and produced by the publishing branch of the Royal Society of Psychiatrists.

Other leaflets and fact sheets published

by the Royal College of Psychiatrists are also useful and can be accessed on line at www.rcpsych.ac.uk/info/dep.htm



Reviewed by
Jenny Green

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.

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 facilities, 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.baxter2@btinternet.com

TRENNERY LODGE, CORNWALL

Farm bungalow, mobility level 1 accessible. Sleeps 4, open all year. Short and long breaks.
Details: Angela Parsons tel: 01872 553755
www.babatrenergy.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**

ORLANDO, FLORIDA

Home with a heart for disabled travellers! Spacious, luxury, adapted bungalow situated on 18 hole golf course. 3 double bedrooms-sleeps 6, 2 bathrooms (Mangar bathlift installed). Custom furniture, patio & conservatory, cable TV. Telephone. Free Country Club membership. 24 hour 'on-call' management company. 15 minutes from Orlando Airport; 20 mins Disney. For current availability contact paraplegic owner. **Sue Fisher, 5 Park Lane, Broughton Park, Salford M7 4HT. Tel/Fax: 0161-792 3029 or email: rita.sue.fisher@ntlworld.com website: <http://homepage.ntlworld.com/susan.fisher33>**

ROPER'S WALK BARN, MOUNT HAWKE, CORNWALL

Opening August 2005, single storey accessible barn converted to a high standard by family of wheelchair user. Sleeps 4/5+cot. Short level walk to village, close north coast, 8 miles Truro.
Details: Liz/Pete Pollard, tel: 01209 891632
www.roperswalkbarns.co.uk

 **ASBAH**
1966-2006 Challenging the future
Association for Spina Bifida and Hydrocephalus

Diary dates

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

Midlands

Wednesday 22nd February

Behaviour Patterns in the Child with Hydrocephalus
The Hub, Hazelwell, Kings Heath, Birmingham.
10.30- 3.00pm
Costs £10.00 per person to include refreshments and a light lunch.
For further information and a booking forms please contact: Geraldine Long 01789 763090 or Jenny Green 01926 511206

Wales

Wednesday, 8th March

Hilton Hotel, Newport, South Wales

Hydrocephalus Awareness Parents Day (based on the *Your Child and Hydrocephalus* book)
10.30am – 2.30pm
Speakers include: Mr Ian Pople Consultant Neurosurgeon, Frenchay Hospital, Bristol
Cost: £15 per family and £50 per professional.
For further information and booking contact ASBAH in Wales on 01248 671345 or email elini@asbah.org

North West

Monday 13th March, 2pm

Managing Hydrocephalus
An event for adults with hydrocephalus
Glaxo Neurological Centre, Liverpool
Main speaker: Mr. Neil Buxton, Consultant Neurosurgeon at Walton Centre for Neurology and Neurosurgery.
For further information / booking details contact Angela Lansley on 0151 733 8392 or email angela@asbah.org

Please e-mail the editor (link@asbah.org) dates of your events for the next issue of *Link* by Friday 17 March 2006, giving the name of event, purpose, location, date, cost (if applicable), contact name, phone no. and email address.

Classified rates

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

Cheques and postal orders should be made payable to 'ASBAH'. Classified adverts for the next issue of *Link* should be submitted by Friday 24th March 2006

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Daryl Beeton

Having trekked across 180-miles on Nicaragua jungle and climbed a 5500 foot active volcano, you can forgive Daryl Beeton, star of BBC's 'Beyond Boundaries' documentary, for feeling a little tired - but we managed to catch a few minutes with him to talk about the unique journey involving a team of ten other disabled people.

Were you nervous before the trip and were there any points when you thought you'd struggle because of your spina bifida?

"I only found out I had got a place three weeks before I flew out to Nicaragua so it was all a bit rushed and I had no time for nerves. My main concern was being bitten by something scary below my knee because I have limited feeling from below the knee, so I wouldn't know if I'd been bitten. Also, due to my walking style, I get pressure sores on my feet easily, so I was worried I would get one and have to be sent home - this is what happened to one of the guys in week two. I had some new insoles made for my feet and these seemed to keep my feet sore free."

Has the trip inspired you in any way?

"The trip has had an influence on every aspect of my life, from realising my body is tougher than I used to give it credit for, to

being thankful that I live in a place where I don't need to dig a hole in the ground before I go to the toilet."

What was the biggest high point of the journey?

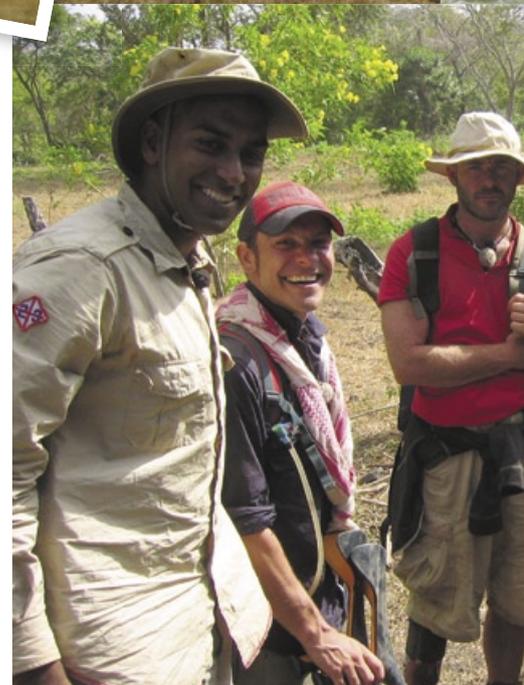
"Reaching the top of the volcano and looking out over where we'd travelled from. If you were feeling down you only had to turn a corner before you saw something so amazing. The country was a big high point too - the people, the scenery. Also going in the military plane and helicopter, it was something straight out of a James Bond film - a lot of the time I had to remind myself that this was really happening to me."

And what was your lowest point on the journey?

"The volcano broke me on the way up it, I found it really tough and it was the one and only time I cried - I was feeling exhausted. When we got to the foot of the volcano I just burst into tears - it was all very emotional. We'd been trekking for over three weeks and it finally got too much for me. That's why getting to the top of the volcano was so special - it was the first time I knew I could make it to the end."

Have you done anything like this before?

"I've never done anything on this scale



Daryl Beeton second left

before, my experience has just been independent travelling around Europe, in fact I heard about the programme when I was in Budapest. I didn't know if I'd be able to do it. I was concerned my body would let me down but I thought I'd never know unless I gave it a go."

Are you planning to do anything like this again?

"I'm not planning anything on this scale but I would love to do something like this again. I've also been looking into volunteering overseas for a few months, that's something I'd like to do.

"My day job is also keeping me busy

Contacting ASBAH



right now. I am a theatre director and I'm progressing the play I produced 'Moments in Motion' to take on tour, I'm also hoping to create a new show for younger audiences. Having worked as associate director at Half Moon Young People's Theatre company I saw how easily young people took to the notion of being different, so theatre for young audiences is a good place to help develop positive views of a mixed and equal society."

If you'd like to find out more about the BBC Beyond Boundaries documentary and how you could take part, visit www.bbc.co.uk/ouch/tvradio/beyondboundaries

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hamrock@supanet.com

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29 The Crescent
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Leicestershire LE16 7JJ
Tel: 01858-432967

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"Pinfold", Chapel Lane
North Scarle
Lincoln LN6 9EX
Tel: 01522 778781

LINCOLNSHIRE SOUTH

Mrs P Mason
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Heckington
Sleaford, Lincs
Tel: 01529-460322
(after 6pm)

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Mrs Maggie Nichols
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Blackheath
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Tel: 01474-536202

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London W7 1LQ
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SOUTHAMPTON & DISTRICT

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Upholds the quality standards of the ASBAH Local Association Compact

Local Association secretaries requiring changes to this list should contact:

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Tel 01733 555988 Email link@asbah.org



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