



link



Families
get together

Take a challenge in 2011

If you're looking for a once in a lifetime adventure, or a personal challenge for 2011, then why not sign up for a charity trek or bike ride and raise funds for **ASBAH** too.



The range of challenges on offer has been designed so that there is something for everyone.

From Hadrian's Wall to the Great Wall of China, the hills of Scotland to the peaks of Peru – you can choose a trek that's UK based, or far away.

The adventure starts here – contact our fundraising team to find out how you can take part

Telephone: Cerys at ASBAH on 01733 421329 or
email: cerysl@asbah.org for further details.

Make ASBAH your Charity of Choice

By choosing ASBAH as your charity of the year your company can benefit from:

- Better staff morale
- Increased team spirit
- Improved communication
- Involvement in the community
- Raising your company profile
- Having fun raising vital funds for ASBAH

There are lots of things you can do:

- dress down days
- raffles
- cake sales
- sweepstakes
- team challenges
- quizzes
- payroll giving



For more ideas and details of how to become an ASBAH Charity of Choice contact Martine Austin on 01733 421349 or email: martinea@asbah.org



Although this is the last issue of Link magazine, all readers can be kept up-to-date with ASBAH and related news through the new ASBAH Together membership scheme. All you need to do is make sure you're signed up as an ASBAH member (see page 4) and then you will receive quarterly newsletters as part of the membership mailing. Don't miss out - membership is FREE - so if you haven't already received the first mailing make sure you get in touch and we'll put you on the membership list.

Gill Winfield

Gill Winfield
Editor
email: gillw@asbah.org

All Link enquiries and comments to:
Link, ASBAH, 42 Park Road,
Peterborough PE1 2UQ
Tel: 0845 450 7755
Fax: 01733 555985
Link@asbah.org www.asbah.org

Registered charity number 249338
ISBN 1360-323X

Designed and produced by
Bluestation Communications

Membership News
(see p4-5)



New role for
telesales team
(see p6)



Motorised buggies...
make sure you're insured
(see p10)



contents

Where are they now?...
Emma Tucker
(see p12)



Get fit for life...
at home
(see p14)



Make sure you're in full
working order
(see p19)



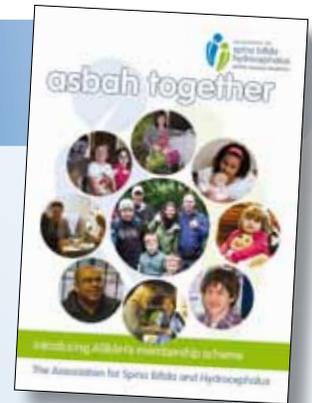
Regional round-up
(see p27-29)



Membership News

Are you a member?

At the end of September ASBAH launched its new FREE membership scheme, ASBAH Together, and all individuals and families known to ASBAH should now have received their first mailing in the post.



Why have a membership scheme?

Because ASBAH Together means:

- better communication with our community of families, individuals, friends and professionals
- keeping you up-to-date with the latest information
- making sure you know all about what ASBAH has to offer
- helping members to share valuable knowledge and experiences – both challenges and successes.

Being part of ASBAH Together is easy

- All individuals, parents and carers known to ASBAH are automatically members – though of course you can opt out at any time.
- We just ask you to let us know if you have any ideas to make the scheme better and will value every comment or view we receive.

Be part of it

- If you have not received the mailing but would like to, please call us on 0845 450 7755 so that we can put it in the post.
- Alternatively, you can sign up on our website at www.asbah.org and access the mailing online, or email us: info@asbah.org to join and receive mailings by email*

*Emails save paper and postage costs and are kinder to the environment. If emailing please put 'membership mailing' in the subject heading and include your name, address and dob and whether you are a family member or an individual with SB/H/NPH/IH.

ASBAH Together is for everyone:

Adults

Children and
Young People
(up to 18)

Parents and
carers of those
with any of
the conditions
ASBAH covers.

This family membership also includes other relatives, grandparents for example, and anyone whose family has in the past been affected by the disabilities and who would like to keep in touch with ASBAH.

What will ASBAH Together give you?

- You'll get regular mailings with a free newsletter and special offers and you'll be told about research and surveys you might like to take part in.
- Access to a members only area on the ASBAH website.
- You'll get information on any new ASBAH activities such as our Fit for Success initiative and our Lifelong Opportunities Programme.

New newsletter

As we now have the new membership scheme as a way of sharing information and news, this issue of Link magazine will be the last one. So if you want to stay in touch and read all about the ASBAH community make sure you're a member to ensure you get the new free newsletter which will be in every mailing (four times a year).

**Your Voice
Changes (see
page 18) for more
details about the
new ASBAH Adult
Members Council**

New role for ASBAH's telesales team

The faces may be the same, but our Telesales department has had a revamp to make the most of the many fundraising possibilities out there.

The former telesales staff have been given new job titles – Fundraisers – to reflect the broader spectrum of their new roles.

Balloon races will remain a key part of their work, but each of the department's nine members will take on new responsibilities to make the most of money-raising opportunities.

Fundraiser Zoe Bentley told Link: "The department has been given a revamp to allow us to work on new projects such as the Grand Prize Draw and Dust Off... Donate initiatives.

"There's an exciting atmosphere in here now with group discussions happening on a regular basis, to encourage people to come up with new suggestions, about how to raise more money and to improve projects we're currently working on."

Zoe and her colleagues, who are responsible for raising funds in different regions across England, Wales and Northern Ireland, are currently selling tickets for the Grand Prize Draw to businesses and individuals.

The department has sourced a wide range of fantastic prizes



including the top prize of two Virgin return flights to New York with £1,000 spending money.

With a fabulous SMEG FAB10 refrigerator up for grabs, two Eurostar return tickets, a tour of Parliament with tea on the terrace for four people, and other fantastic prizes, it's not surprising that tickets are selling well.

Zoe added: "Dust Off ... Donate is gathering momentum too and we have already raised £100 by auctioning off one of Danny Mills' football shirts.

"We've also had quite a few donations of CDs and video games which we can generate into cash.

"Of course our main role will still be promoting the Balloon

Races which raise a lot of funds for ASBAH and also raise our profile across the country."

dust off... donate!

ASBAH can convert ANY of your unwanted items into valuable funds to help maintain the essential services we provide to children, families and individuals.

If you or your company have items to donate, contact Zoe Bentley at zoe@asbah.org or telephone direct on (01733) 421341

What can you Donate?

- Compact Discs
- Vintage / Designer Clothing & Accessories
- DVD's & Games
- Art
- Sports memorabilia
- Collectables
- Unwanted gifts

Anything!

Call our donation line for more information 01733 421341

Your chance to win a great prize

Imagine enjoying a break in New York with £1,000 to spend, or a trip on Eurostar, or maybe you're a Boyzone fan and would love to go to their concert...

Well these are just some of the superb prizes on offer in ASBAH's first Grand Prize Draw.

Tickets are on sale NOW so contact Amanda on 01733 421334 or email amandas@asbah.org to get yours.

Full details and prizes on ASBAH's website at www.asbah.org Tickets £1 each, you must be 16 or over to purchase.

ASBAH's Angell heads Special Appeals

ASBAH's Telesales department has been given an overhaul with a new title and a fresh face at the helm.



The department, which raises hundreds of thousands of pounds each year from virtual balloon races and advertising, has been renamed Special Appeals to reflect its wider scope.

The team of 10 full-time and one part-time staff is headed by the new assistant director, Annette Angell, who joined ASBAH in mid-June.

Annette, who has a background in marketing and fundraising, hopes to take the department's success to new levels.

She said: "As Special Appeals we have more scope to generate funds beyond the traditional balloon races and selling advertising for booklets.

"There are many other ways of raising money for ASBAH and we are currently researching what we think will work best for us."

Already the team is looking at producing a Fit for Success booklet for service users which will be funded by sponsorship.

Another project already in motion is an appeal called Dust Off ... Donate where donations of unwanted items such as DVDs, CDs and memorabilia are sold online by the department with all revenue coming into ASBAH.

Annette said: "We are running a pilot scheme very soon to see how successful it is. The cost of placing items online is minimal so we haven't anything to lose."

Annette, who came to ASBAH from DHL Automotive, where she was marketing manager, said she was delighted to have been offered the role within Special Appeals.

She told Link: "When I left university I worked as a corporate fundraiser for East Anglia's Children's Hospices. After four years I felt I needed to gain some experience in a predominantly marketing role and moved to DHL.

"But I was desperate to return to the third sector," she said. "For me, I need to feel that I have made a difference. After a hard day in the office it is very rewarding to know that my efforts are helping a deserving cause."

She added: "It's still early days for me in this role but I am full of ideas which will hopefully prove very profitable for ASBAH."

Accentuate the positive



An ambitious new campaign is working to create opportunities for disabled people across the country and to create a permanent change in the way disability is viewed by society.

Accentuate is a programme of 15 projects inspired by the values and achievements of the Paralympic movement.

The campaign has brought together organisations from across the cultural and sporting sectors.

Funded by Legacy Trust UK, Accentuate's mission is to support a wide range of innovative cultural and sporting activities which will leave a lasting legacy in communities throughout the United Kingdom.

It aims to ensure that, through the variety of projects, disabled people will begin to fulfil their potential to be the leaders of tomorrow, in whatever field they choose. The programme also hopes to create over 200 new jobs.

The projects range from creating computer games and business skills to screen media and sport.

For more information about Accentuate and the 15 projects go to: www.accentuate-se.org or call: 01303 259777

Accentuate gets David's backing

Actor and ASBAH Patron, David Proud, is backing the Accentuate programme, with a particular interest in the uScreen project.

He took on the role of interviewer in a five-minute film commissioned by Screen South for the uScreen website on How To Do Audio Description.

David has also signed up to be a mentor for young people through the uScreen site.

He said: "I am passionate about opening up the industry to more disabled people. Opportunities that encourage disabled film makers, actors and directors should be supported and I am really excited to see how the ground breaking uScreen site will develop."

"It is essential that we get more disabled people visible and on the screen. I am excited by what Accentuate is trying to achieve – a cultural shift across the board and I think part of this has to be about engaging the media and film industries"

Tributes

Carys Bannister OBE



Miss Carys Bannister, who was the first female neurosurgeon in England, was known to many families throughout the North West for her work as a consultant paediatric neurosurgeon at Booth Hall and Royal Manchester Children's

Hospital (Pendlebury). She retired 10 years ago and was 75 when she died.

Her work as a neurosurgeon, with a particular interest in the care of children with spina bifida and hydrocephalus, required enormous dexterity and precision, yet at home on her farm she could frequently be found carrying bales of hay up to her livestock and wrestling with them when care and attention was needed. Her donkey attended fundraising open days at the hospitals and her corgis were patted by patients before PAT dogs were thought of.

A memorial and thanksgiving service was held in Rawtenstall and the large church was filled with medical colleagues and young adults who had been her patients. You could tell how much she was loved and appreciated because parents whose children were born more than 20 years ago attended the service and met up with nurses and ward staff that had worked with "Miss B" decades earlier.

Carys Bannister had the surgical skills of a neurosurgeon but she had an additional talent and that was the ability to convey to every family that they were important to her. She appeared on the ward at all hours of the day and night to check on her patients, spoke to them in the recovery room and listened intently to the concerns of parents when they believed their children were not well.

A prayer was read at the memorial service and she clearly lived by it,

"From inability to let well alone; from too much zeal for what is new, and contempt for what is old; from putting knowledge before wisdom, science before art, and cleverness before common sense; from treating patients as cases; and from making the cure of the disease more grievous than its endurance, Good Lord, deliver us." (Sir Robert Hutchison's prayer)

Mary Oughtred Legacy



Mary Oughtred, who died in 2008, was ASBAH's first director [General Secretary], when she was appointed in 1969. ASBAH's Trusts and Legacies officer, Jane Ayres, recently received the news that Miss Oughtred had generously left almost £105,000 to ASBAH in her will.

During the decades after her retirement from ASBAH, Mary kept in touch and gave regular personal donations. She was a great supporter of the work of ASBAH and the people who make up its community. As she said in her message for ASBAH's 40th anniversary

"...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 in the wider world."

We are sure that Mary would back ASBAH's plans to further involve all its people in the organisation with our new membership scheme, Lifelong Opportunities Programme and Adult Members Council and, of course, ASBAH's work is able to continue due to donations and legacies like hers.

You can read more about Mary and her great contribution to ASBAH's early years in an interview she gave to Link in 2006: 'Ambitious beginnings' is posted on our website in the About ASBAH section.



Teddies get wheels at Build-A-Bear

There can't be many parents of young children who aren't familiar with Build-A-Bear Workshop.

If you have managed to avoid the world-wide chain of shops yourself then the chances are your child has been invited to a Build-A-Bear party.

It's the place where youngsters can create their own bear and buy a host of clothes and accessories from sunglasses to wigs to personalise their new best friend.

What caught our eye was the latest accessory to be added to the store's massive range... a smart blue and yellow wheelchair.

So if your child is a wheelchair user then her best teddy friend can be too.

The teddy bear wheelchair costs £18.00 and is sized to fit all Build-A-Bear teddies.

For more information go to:

www.buildabear.co.uk

ASBAH Supports Motorpoint + Motorpoint Supports ASBAH

The UK's leading car supermarket and driving force behind the Motorpoint Pro-Cycling Team, paid a visit to Peterborough in the summer, as part of the Halfords Tour Series cycle race and ASBAH was there to meet them and offer support.

The nine-strong professional team (managed by Phil Griffiths, a former British Cycling Champion, who's helped get the team to the top of the this year's Halfords Tour Series standings) also boasted Olympic gold medal winner, Ed Clancy MBE and fellow Team GB star Andy Tennant.

The event took place in June and thousands of spectators witnessed the 10 competing teams navigate their way around the 1.1km Peterborough City Centre circuit.

ASBAH's Corporate Relations Officer, Martine Austin, who attended the race, said:

"The support for the event was fantastic. After soaking up the atmosphere in the hospitality area, we caught up with the team in the pits, warming up and 'getting in the zone' before the race.

"Olympic Medalist Ed Clancy presented ASBAH with an official team shirt, courtesy of Motorpoint, which has been signed by members of the team and will be auctioned on Ebay to raise funds for ASBAH. They finished the event equal 1st overall after an impressive 3rd place performance by the legendary Malcolm Elliott.

Motorised buggies... make sure you're insured

By ASBAH adviser, Emma Enfield



A motorised buggy was donated to one of our members. Recently she was using it in her supermarket and accidentally ran into another person. Unfortunately he was injured and is now suing her for compensation.

It's been very stressful for her and potentially quite costly.

Motorised buggies are readily available these days, thanks to donations and second-hand purchases making them more affordable.

People can also use part, or all, of their motability allowance to buy a scooter if they choose.

There isn't a legal requirement to have insurance although the Department of Transport – and ASBAH – would really recommend it.

As well as the obvious reasons such as damage to property – your own or other people's – and injuries to others, there is also breakdown to consider.

Many people rely on these buggies for their daily living tasks: shopping, GP appointments etc. A breakdown can be costly and cause real difficulties with getting daily tasks done. There is also the risk of the buggy breaking down away from home.

Insurance

Suitable insurance schemes aren't too costly and it would be good if people started to think in terms of that cost as well as the cost of the vehicle – in much the same way as a car. They can be as little as £75 per year, depending on individual circumstances. It is also worth checking with the insurance company whether your home insurance policy already provides cover.

One ASBAH member has just been informed by her insurance company that she is covered under her contents insurance.

Tax

Some mobility scooters also need to be taxed if they are Class 3 vehicles. To find out more information about the definition of a Class 3 vehicle and where it can be used, contact the DVLA or go to:

<http://www.dft.gov.uk/transportforyou/access/tipws/cod eofpracticeforclass3vehic6165?page=1#a1000>

Other considerations

Sometimes the companies which sell the vehicles don't explain about the insurance and tax implications.

Also, it can be important to make sure there is somewhere safe to store the vehicle, and where it can be charged. It should be protected from the elements.

If your home is level access or ramped, it can be kept indoors. Other people have secure scooter storage sheds. Things to remember are:

- There should be an electricity supply for charging
- People can safely get to and from where the scooter is kept, and get on and off it safely too!
- That it is secure from thieves.

Not all local authorities or housing associations will necessarily provide ramps for privately bought outdoor scooters, so it is worth checking with them prior to buying one.

Again, it might be necessary to think about the cost of storage, ramping etc, before the vehicle is bought.

http://news.bbc.co.uk/1/hi/wales/north_east/8607929.stm

Disability coverage boosted on BBC



The BBC devoted extra time to disability this summer with two new programmes.

The first, screened on BBC2, examined the portrayal of disabled people on television during the last 50 years.

From the end of June, BBC Ouch, the lively online disability site, featured a seven-week series called Dis Connected. Each week the previous interviewee became the interviewer.

Tanni Grey-Thompson plus Blaine Harrison from the Mystery Jets band, who both have spina bifida, were among the celebrities who participated in short films discussing what effect their disability has on their lives.

Senior producer Damon Rose said: "The series has a diverse cross-section of interesting people who have all achieved a lot whilst also dealing with those extra life challenges.

"Some of our interviewees embrace disability as an identity more than others, yet all find common ground. Underneath it all, we seem to accidentally be asking, 'What exactly is this thing called disability?' We hope it gave viewers lots to think about."

He added: "I particularly loved Tanni Grey Thompson's story about the first accessible loo in Cardiff and what a surprisingly life-changing moment that was for her. Paralympian or not, if you don't have an available toilet, you can't easily go out socialising with your mates."

David Proud

ASBAH Patron, actor David Proud said he thinks there still aren't enough roles available for disabled actors.

"The quality of the roles has definitely improved," he told Link, "they are portrayed in a way which is more real and less stereotyped, but unfortunately there still aren't enough roles out there.

"More should be done to encourage new talent and there should be enough roles so disabled actors can have a sustainable career."

David, who has appeared in the BBC series *Desperadoes* and played the role of Adam Best in *EastEnders*, is working on several writing projects to try and rectify the situation.

He has teamed up with actress Julie Fernandez, also a wheelchair user, who is best known for her roles as Brenda, in the BBC comedy, *The Office*, and Vanessa in the BBC soap, *Eldorado*.

David said: "We are working on the production of part one of a two-part drama I have written."

But despite his complaints that there aren't enough TV and films roles for disabled people, David said he wouldn't want to discourage any young disabled people who dream of being actors.

"My advice to any would-be-actors is to get as much drama training under your belt as possible.

"Studying drama is obviously a big help but you can't beat experience. I was lucky in being spotted for the role in *Desperadoes* and that led to many other parts.

"I thoroughly enjoyed my time on *EastEnders*. It really put me in the spotlight and got me noticed."



"More should be done to encourage new talent and there should be enough roles so disabled actors can have a sustainable career."

Where are they now?

Emma Tucker



In the latest in our Where are they Now? series we caught up with two people who featured in past issues of Link to see what they are up to now.

Emma Tucker

Emma Tucker made her Link debut at the age of six months old when her mother Sue spoke very openly about her daughter's ETV operation. Two years later Sue was interviewed again when Emma had a shunt fitted.

Those first few years had been worrying times for the family, but since her new shunt, Emma has progressed in leaps and bounds.

Sue told us: "Emma is now seven years old and is doing really well at mainstream school. Since she had her shunt fitted she hasn't experienced any problems apart from her gross motor skills, which we think have been slightly delayed – but she's catching up fast. She loves swimming and is a really strong swimmer now.

"Emma is a very outgoing child, very happy and chatty, taking everything in her stride. We have always talked to her about her hydrocephalus in a very matter of fact way so she knows it is a condition she has, but she doesn't see it as a disability.

"We have given her enough

information to help her take some responsibility for her health. She carries a shunt alert card and knows she can't play with magnets which could affect the settings on her shunt and she's happy to explain to her friends the reason why.

"Emma also knows it's important to drink plenty of water, especially in hot weather, otherwise she'll feel ill. Self-care is so important because if Emma doesn't look after herself, she is

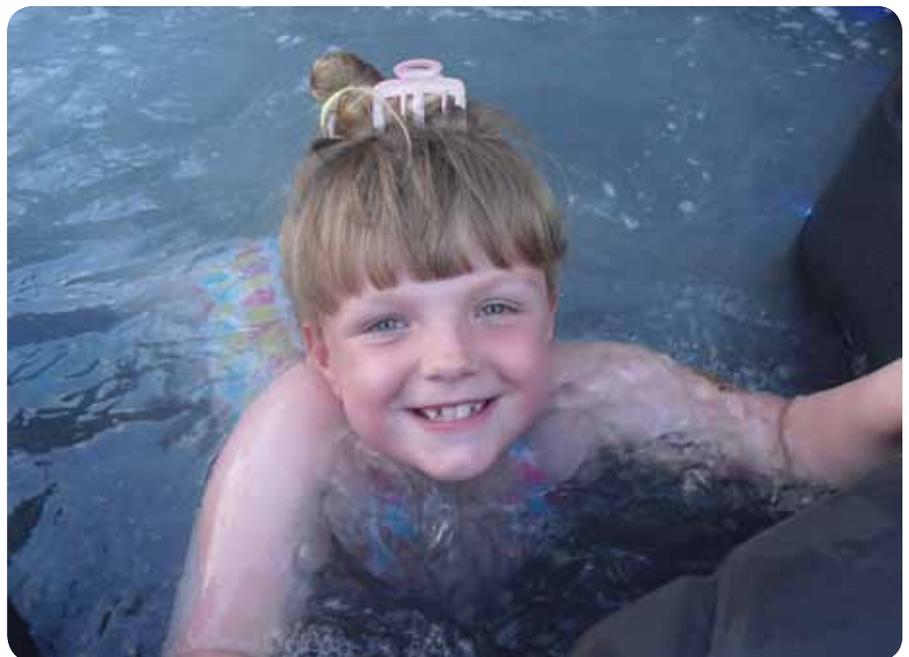
"Emma is a very outgoing child, very happy and chatty, taking everything in her stride."

the one who will feel ill.

"We know we have been very lucky because Emma leads a very normal life. When she was first diagnosed with hydrocephalus at the age of three months, we were so frightened, not knowing what the future would hold for her.

"I think parents must try to have faith that things will work out because while some children with hydrocephalus will experience ongoing problems, others will lead relatively normal lives.

"We were so grateful for the support we received from ASBAH, especially in the early days and it is still very reassuring to know that help and advice is still there if we need it."



Benny bear and Emma team up for awareness week

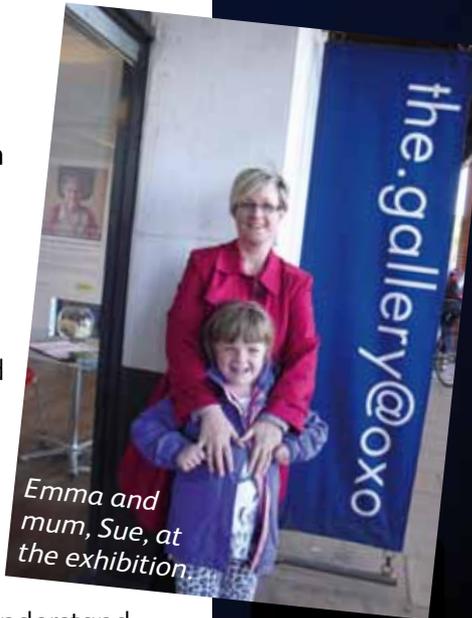
Remember a Charity, which encourages people to consider charities when making their Will, ran an awareness week in September. As part of this an exhibition of photographs was held in London – portraying the work of the many charities involved.

A professional photographer travelled round the country capturing aspects of the the work of different charities and how leaving a legacy helps them to continue to provide their services.

For ASBAH the photograph focussed on Benny Bear and how he is just one way that ASBAH helps families to understand hydrocephalus.

Emma Tucker, who has hydrocephalus, came along for the photo shoot at ASBAH House and visited the exhibtion to see the finished result.

Emma with Benny Bear.



Emma and mum, Sue, at the exhibition.

Where are they now?

Phillip Rogers

Six years ago Phillip Rogers appeared in Link after shedding an amazing five stone in weight following a healthy eating and fitness programme.

He admitted that it hadn't been easy but his hard work really paid off because his breathing improved and he felt much healthier.

When we caught up with him this summer, Phillip, who has spina bifida, said that ill health over the last two years had made it very difficult for him to continue working out at the gym and as a result his weight has crept back up again.

"I've had a lot of problems with my kidneys," he explained, "and recently had my fifth, and hopefully last, operation to remove kidney stones. I have been in a lot of pain so exercise hasn't been possible.

"It's been quite a tough time because I feel that my life has been on hold. I couldn't go anywhere or do anything. Hopefully the problem is sorted out now so I can get on with my life."

But despite his ill health Phillip's been no slouch when it comes to romance. After moving to a new

residential home in Worthing last year, he met and fell in love with fellow resident Emma Phillips. The couple will marry on 31 August 2011 and are busy making plans for their big day.

Phillip said: "Emma is a very sweet girl and we hit it off straight away but when I asked her out on a date, she refused initially. Luckily she changed her mind a few months later."

They plan to marry at Worthing Register Office as Phillip laughed: "A church wedding would be nice but manoeuvring two wheelchairs up the steps is a bit too much!"

The couple live at Lulworth House in Worthing, a 14-bedroomed residential care home. It offers round-the-clock support and although there are no facilities for couples sharing, Phillip said they had no plans to move.

"Unfortunately the rooms aren't really big enough to accommodate two wheelchairs so we won't be able to live in one room unless we move," he explained. "But at the moment we're very happy here so we're making no plans."

Get fit for life...at home

You don't need to leave the comfort of your own living room to start an exercise routine.

These simple exercises can be done by anyone. As you become stronger, repeat the steps for even better results.

Towel rowing

- Sit towards the front of your chair with your feet hip-width apart and facing forward
- Grasp a rolled-up towel and push outwards with your arms
- Keeping your body long rather than collapsing, breathe in and reach forwards, bending at the hips.
- Pull your shoulders down and squeeze your shoulder blades together as you slowly return to the start, breathing out.
- Check that you are tall before starting the next repetition.
- Try 12 repetitions to start with.

Easier option

- Only use your hands rather than the towel.

Harder option

- Use a heavier weight – a cushion is ideal

Overhead turns

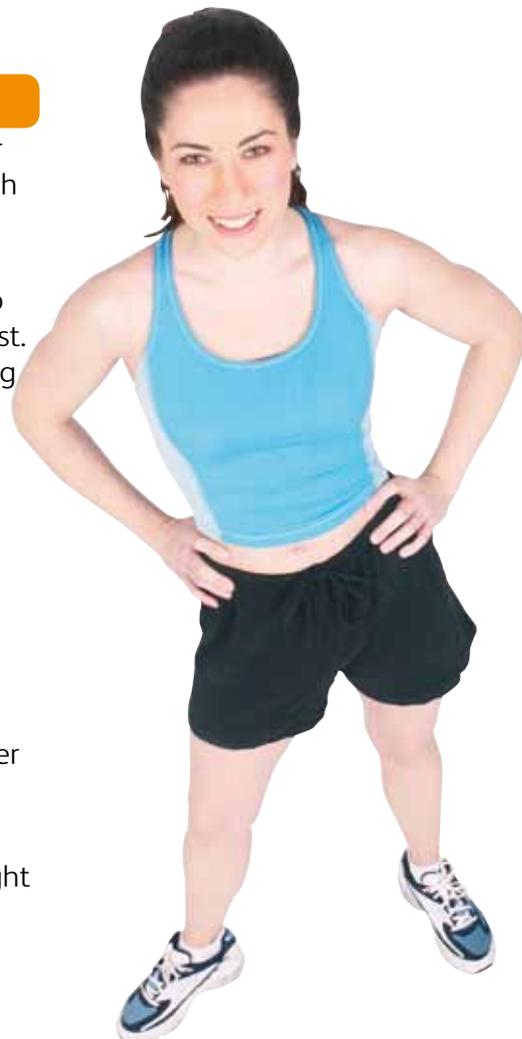
- Sit towards the front of your chair with your feet hip-width apart and facing forwards
- Clasp your hands together and turn your upper body to the right, hands by your waist. Your feet and legs stay facing forward.
- Lift your hands comfortably over your head as you turn your upper body to the left.
- Try 12 repetitions to begin with

Easier option

- Keep the hands apart
- Take the hands in front rather than over the head

Harder option

- Hold a small towel pulled tight or a small cushion



Wake up to workouts

Since 2001 the Inclusive Fitness Initiative (IFI) has been working with the fitness industry to create opportunities for disabled people to work out in an inclusive environment.

By the beginning of 2010 the IFI had launched 400 facilities across England, giving more disabled people than ever the chance to enjoy inclusive physical activity opportunities.

As well as providing accessible equipment and other facilities, the IFI has trained more than 1,000 members of staff in disability awareness... so you can be sure of receiving excellent support and encouragement.

What can you expect at an IFI site?

- Accessible facilities
- Positive support from staff
- Inclusive equipment to enable the majority of users to get a full body workout

The IFI website is packed with information including a section for first time users who may be daunted by going to the gym for the first time. You'll also find case studies and details of how to find your nearest facility.

For more information go to www.inclusivefitness.org or call 0114 257 2060.

Baroness Tanni encourages young people to take up sport

Baroness Tanni Grey-Thompson's maiden speech in the House of Lords called for greater access to physical activity for young people... especially those with disabilities.

The former paralympic athlete took part in a debate on preparations for the 2012 London Olympic and Paralympic Games.

She said: "We all need to grasp the opportunity of the games being on home soil to inspire our nation to think differently, and to include every part of our great nation."

She told the House of Lords that London led the way in organising a Paralympic games that would raise the bar in terms of sponsorship, sustainability, transport, and inclusion but said that it was behind the scenes where there is an opportunity to "promote real change" in attitudes towards sport.

She said: "What we do know from previous games is that in the Autumn of 2012 there should be a spike in participation rates in physical activity, but we need to work hard, right now, to maximise that because I believe, perhaps surprisingly, that elite competitive sport is not for all.

"Involvement in physical fitness can help lead to improved learning, greater confidence and general wellness; all the things we want for all our young people."

Wheelchair workouts will get you moving

There are many exercise DVDs on the market which are suitable for people with limited mobility.

We've done some of the hard work for you by trawling the net to find some of the best.

Leanne's Chair Workout

If you're looking for inspiration, check Leanne Grose's DVD which combines effective exercises to lively music.

Leanne, 29, from Cornwall, had a full leg amputation in 2004 but was determined to live life to the full and help others who have a disability.

Leanne's Chair Workout is a lively fitness DVD solution for anybody wishing to get into shape - it's designed to give you a physical and mental workout.

Her enthusiasm is infectious, the music catchy.

You can see a trailer and purchase the DVD at www.leanneschairworkout.com. Alternatively look at www.amazon.co.uk for new and used prices.



Chairobics

A chair-based exercise programme designed to improve your mobility, increase your strength and help you become more flexible.

Terri Bryant, Postural Stability Instructor, demonstrates a series of enjoyable routines that will leave you feeling healthy and happy.

Chairobics is available to order online for £11.99 + p&p at www.getactivenow.org.uk/chairobics-dvd.html

Alternatively call 01730 234390. Mention the Get Active website to get 50p off your order.



Get on yer bike... for fitness and fun

No matter what your age or ability, cycling is a fabulous way to take some exercise and have fun.

Being disabled should not be a barrier to enjoying the sport and there are a number of options available to suit many types of disability.

These include:

- bicycles fitted with stabilisers, giving riders that extra bit of confidence
- tricycles which have the option of a supported or recumbent seat
- hand-cycles, where the rider is able to power the front wheel by hand
- bicycles made for two, which allow side by side cycling.

Cycling for disabled groups are growing across England and Wales as popularity for the sport increases.

Organisations like the Cycling Project are providing cycling opportunities for everyone to enjoy.

Part of their work is a project called Wheels for All which encourages disabled people of all ages to have a go at cycling by showing the range of cycles available and by offering taster courses in various Wheels for All centres in the Midlands and Northern England.

To try the bikes contact one of the centres shown on the Cycling Project website at www.cycling.org.uk or call the Wheels for All Hotline on 0161 7459944.

Other useful websites:

www.cycle-n-sleep.co.uk/disabled.htm

www.crank-it-up.org.uk/pages/cycling/disabled.html

www.ableize.com/recreation-sports/cycling

www.disabledtraveladvice.co.uk/cycling-holidays-for-disabled-people



Geraint notches up the miles

Cycling is a way of life for ASBAH Adult Council member Geraint Catherall.

He regularly cycles the 10-mile journey to work each day, notching up a further 55-80 miles with his cycling club every weekend... sometimes, even more.

Time trials, and 12 and 24-hour challenges are all part of the fun for the 36-year-old, who lives near Mold in Flintshire.

Geraint, who has hydrocephalus, explained that he first got hooked as a child, when he found it easier to keep up with parents on long walks if he went by bike.

“For some reason I have better balance when I’m cycling than when I’m walking,” he said. “As a child I was never any good at skateboarding or roller skating, but I found cycling easy.”

He joined the Anfield Bicycle Club, the country’s oldest cycling club, in 1989 and never looked back.

Geraint said: “The sport is my hobby and, I suppose, my passion. I love getting out and exploring new places and I really enjoy the challenge of the 12 and 24-hour cycle marathons.

“I think you improve at the marathon event with age as your stamina and ability to stay awake gets better. I also found that with experience I became more disciplined. Many of the younger riders start off really fast and then tire after a couple of hours or don’t take on fluid and fuel regularly enough.”

Geraint said that his hydrocephalus means he is aware that his memory might not be as sharp as it should be and takes precautions to ensure he stays on course.

He said: “The time trials are always well marshalled but I always try to familiarise myself with the route beforehand, and take a map with me when I am riding alone in unfamiliar places.”

Cycling scheme takes off



Disabled people in Peterborough have rushed to sign up to a new cycling scheme which allows them to cycle independently.

The project, launched in June, enables disabled people with a range of different needs to use a variety of specially adapted cycles.

The Peterborough Adapted Cycling Scheme currently operates two induction sessions a week on a Thursday and Saturday to show disabled people and their carers how to set up and operate the bikes.

The specialised bikes the project provides vary from tricycles, quads and hand cycles, with more bikes on their way in the near future.

Tom Potts, Disability Sports Development Officer, said: "The initial take up has been very successful and this is thanks to the hard work of our volunteers and coaches.

"We aim to expand and develop the membership side of the project to allow disabled people greater access to the project in their own time.

"The enjoyment of disabled people when participating in cycling is evident for all to see and many have acknowledged the greater freedom and confidence they feel they have as a result."

The project was set up and is run in partnership between Vivacity Peterborough Culture and Leisure Trust; Nene Park Trust; Dial Peterborough; The Mobility Aids and Lakeside Leisure.

Tom added: "This project has the potential to positively improve the lives of disabled people and offer an opportunity to participate in an activity with their friends and families."

For more details on the project contact Tom Potts, Disability Sports Development Officer on (01733) 863807, e-mail tom.potts@vivacity-peterborough.com or visit the website at www.vivacity-peterborough.com.



Volunteers needed for cycling challenge

Keen fundraiser Ceri Parker is looking for company on a cycling adventure planned for 2011.

A recurring injury has forced Ceri, a keen runner, to hang up his running shoes for the final time... but he has vowed to continue raising cash by pedal power.

He is planning a marathon cycle challenge from North Wales – South Wales next year and is looking for volunteers to join in the fun and fundraising for ASBAH.

For more information check out his Facebook group – Ceri's Cycling Challenge at <http://www.facebook.com/#!/group.php?gid=102935419762786>



Facebook

Since its inception, ASBAH's Facebook page, www.facebook.com/ASBAH.charity - has seen fan numbers swell to well over 1400 people in just a few months! Why?

Well, the main reason is Facebook's clear popularity amongst large sectors of society. Facebook has more than 500 million active users as of July 2010, if Facebook were a country it would be the third largest in the world!

Secondly, of course there are the simple actions and statements that the application allows subscribers, including adding people as friends, sending them messages, updating their personal profiles to notify friends about themselves, joining networks organized by workplaces, schools, or colleges.

Facebook allows anyone who declares themselves to be aged 13 or older to become a member of the website.

On top of this, the ASBAH Facebook page is helped by a vibrant and vocal group of fans, who regularly submit details relating to problems they may be experiencing, questions they may have or events they may be holding. Some fans even use the page to promote their fundraising activities, others simply to enquire as to whether anyone else lives near to them.

The page also provides links to ASBAH's other websites: Twitter, Flickr, YouTube and our official homepage. Page fans are given a discussion forum to talk freely about the issues that matter to them, recent topics include: Working and having Hydrocephalus, Spina Bifida / Hydrocephalus and fatherhood, Growing Older with Spina Bifida, Spina Bifida and Pregnancy, to name but a few!

Coupled with the photos section, upcoming events section, the easy donate button, the regular updates from ASBAH and online response support from qualified ASBAH Advisers www.facebook.com/ASBAH.charity is fast becoming an integral part of the Association. Join our community now – the bigger we are the stronger we are and together we can take on those challenges.

Your Voice becomes Adult Members Council

ASBAH was originally established by parents of children with spina bifida and hydrocephalus, back in the 1960s. By the 1990s the children had become adults and 'Your Voice In ASBAH' was set up to give this group a voice in the organisation. Now things are moving on again with our adult membership becoming a leading part of ASBAH, as Mike Bergin explains:

"As you all know Your Voice held elections earlier this year and a new committee is in place, which has had two meetings to-date. What we are trying to do is to get more adults involved in ASBAH and the name of the committee has changed to reflect this. It will now be known as the ASBAH ADULT MEMBERS COUNCIL.

The reason behind this is to appeal to everyone and move forward. And for us, as a committee, to be there for all adults with spina bifida or hydrocephalus. As yet, the Council does not have a chairperson but when we do, the good news is that he or she will also take up a place on the Board of Trustees. This is a great move for the committee and all the adults in ASBAH, as it means we will have a voice present at all Board meetings to let our feelings be known. The new ASBAH Adult Members Council is already looking to the future and we hope that we can get to the heart of any matter and report back to members, as that is what I am sure you would like to see your Council doing.

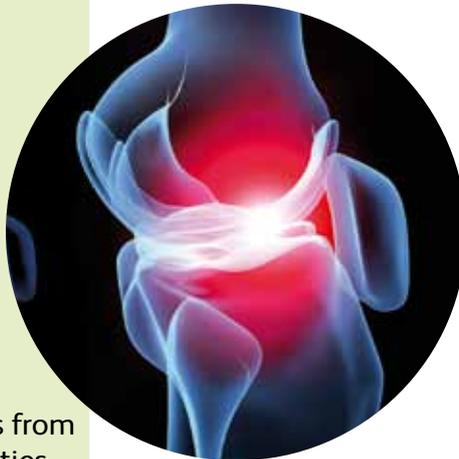
As with Link, there will no longer be a Your Voice, Your Choice newsletter in the same form. But news and information for adult members of ASBAH will be part of the new membership mailings and newsletter. So if there is anything you would like to see included or anything which you think may be of interest you can get in touch with me direct by email and I will be happy to be of help. I hope I have explained what the change means and that this will be best for everybody, until the next time do all take care and don't put off till tomorrow what you can do today." Mike Bergin, ASBAH Adult Members Council mikebergin@mikebergin.karoo.co.uk

Make sure you're in full working order

Adults with spina bifida, as well as their family and friends, are the target audience for a new book being published by ASBAH this autumn. 'In Full Working Order – a guide to keeping healthy for adults with spina bifida' – has contributions from all ASBAH's experienced health advisers.

The 48-page book, sponsored by Hollister, has sections on:

- Mobility
- Diet
- Exercise
- Staying healthy on holiday
- Options for continence
- Sex & spina bifida
- Pregnancy
- Osteoporosis
- Shunts & hydrocephalus
- Depression
- And there are personal views from adults living with the disabilities.



Rosemary Batchelor, ASBAH's senior health adviser, said: "Often there are things, as an adult with spina bifida, that you don't like to ask but really want to know about.

"We hope having a book like this which you can dip into from time to time will be helpful - especially useful if you have hydrocephalus and your memory is not too good.

"We can't promise that it will answer all your questions or tell you everything you want or need to know, but it will be a good place to start and will point you in the right direction to find out more."

In Full Working Order costs £6.50 (including post & packing) and can be ordered from the website at www.asbah.org or by contacting ASBAH on 0845 450 7755 (10am – 4pm).



Ironman Johnny brings in £3,600... and counting

Ironman Johnny Harris is living proof that hydrocephalus doesn't mean you can't be top of your game.

The 31-year-old personal trainer from London recently completed the gruelling Ironman UK challenge, raising more than £3,600 for ASBAH in the process.

The event, held in Bolton on 1 August, saw 1,400 competitors tackle the 140.6 miles event – a 2.4 mile open water swim, 112 mile bike race and 26.2 mile run.

Johnny completed the course in 12 hours 49 minutes which he said he was “very happy with. I didn't train as much as I would have liked because of a knee injury, so I expected to complete the course in anything from 14 – 17 hours.

“It was incredibly tough but the satisfaction and sense of achievement I felt at the end was incredible. I am entitled to call myself an Ironman now!

“When I decided to enter the event I thought I should do it for charity. ASBAH supported me and my family through five years of treatment so I was keen to give something back and increase awareness about hydrocephalus.”

Johnny's congenital hydrocephalus wasn't diagnosed until he was 18 when he started to develop symptoms including headaches and double vision.

He had five shunt operations in two years and his health

finally began to improve in 1998 when his last shunt was fitted.

Johnny said: “My motto is, ‘you don't appreciate your health until you lose it,’ and I am determined to stay in peak condition.

“Having been seriously ill myself for four years I understand that your health is the most important thing you can possess. I am passionate about health, fitness and the benefits of healthy living.

“Doctors told me I would never run again but I ran the London Marathon a few years later in 2002 and for the last 10 years have been working in the fitness industry.

“I appreciate that I am lucky and not everyone with hydrocephalus is as fortunate as I am, but I think it is important that people don't let the condition stop them from doing things. There are still a lot of physical activities that you can do.”

Johnny, who is based in Marylebone, runs Adeptio Fitness, where he works with a wide range of clients from cardiac rehabilitation patients to elite athletes.

He said: “I am very grateful to my family, friends and my clients who sponsored me. I am very happy to beat my fundraising target, and money is still coming in.”

www.justgiving.co.uk/johnnyharris



Keeley goes coast to coast for ASBAH



Congratulations to Keeley Hamilton who completed this year's gruelling 130-mile Coast to Coast bike ride.

Keeley, who has spina bifida, was determined to complete the challenging event to

raise cash for ASBAH.

The energetic lady, who works in the HR department at Northumberland Tyne & Wear NHS Trust, said "I've always fancied setting myself a challenge in aid of charity and the annual Coast 2 Coast event provides the perfect opportunity.

"ASBAH is an organisation that is very close to my heart and I hope that I can raise enough money to support the essential services that they provide around this area."

After a five-month training programme, Keeley was joined by five friends and relatives for the first three days of the ride, averaging 27 miles per day. The team dropped to four people for the final two days.

The ride saw Keeley cycle from Whitehaven in Cumbria to Tynemouth, on the North East coast, where she passed the finishing line on 3 August... raising a fantastic total of £1,250.



photograph published courtesy of the Cambridge News

Freemasons fund research

ASBAH was presented with a cheque for a grant of £40,000 from The Freemasons' Grand Charity at Freemasons' Hall, Cambridge on 11 August 2010. The grant will be used to fund research undertaken by Professor Griffiths, in Sheffield, into the use of MRI scans of pregnant women when it is suspected that their baby may have abnormal brain development.

Rodney Wolverson, Provincial Grand Master of Cambridgeshire, presents the cheque to ASBAH's Senior Health Adviser, Rosemary Batchelor, and Trusts and Legacies Manager Monica Evans, Cambridgeshire Freemasons - John Sherriff Provincial Grand Secretary and Peter Sutton Provincial Information Officer are also pictured.

The sky's the limit for Chris

High flying Chris Hunt had his heart in his mouth as he flew for five minutes upside down at 3,000ft to raise money for ASBAH.

Dare devil Chris, from Welland near Malvern, set himself the challenge in memory of his friend Martyn Lewis's daughter Katie, who had spina bifida.

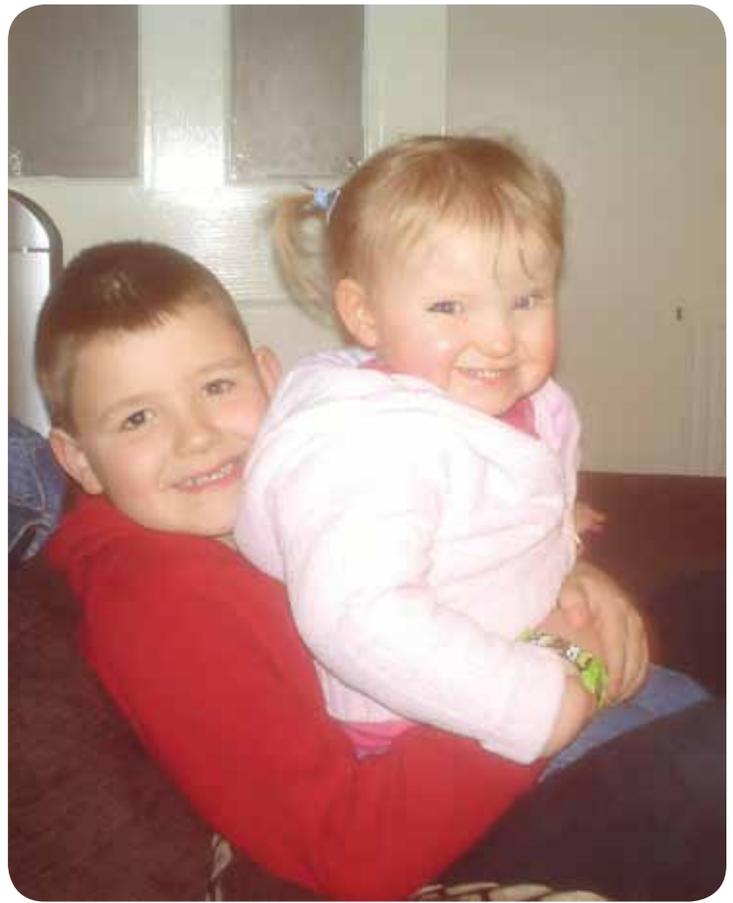
Friends and family watched as Chris, in a plane donated for the event by Tiger airways, flew over the Worcestershire countryside.

Chris, who works for Herefordshire Council, raised £847 in sponsor money, including £285 collected by the Marlbank Inn in Welland.

A giant cheque was presented to local adviser Geraldine Long at a special presentation at the Marlbank Inn in August.



Team Tia set to raise thousands



Energetic mum Teresa Goldsmith has set herself another mammoth fundraising challenge to boost ASBAH's funds with the help of her friends.

Teresa, from Welling in Kent, organised a charity auction in 2008, raising £4,500 for ASBAH.

In May this year she and four friends decided to arrange more fundraising, albeit on a smaller scale, under the name Team Tia, after her two-year-old daughter who has spina bifida and hydrocephalus.

Teresa said: "ASBAH has been such a great support since Tia was born that I enjoy doing something in return."

Team Tia's 2010 fundraising kicked off when four of Teresa's close friends Gill English, Zoey

Sharman, Lou Still and Jules Hill arranged to walk from London to Brighton on 30th July.

Teresa said "I was thrilled when the girls approached me and said they wanted to do their walk to raise money for ASBAH, which is obviously so close to my heart. Gill, Lou, Jules and Zoey were wonderful. By the end they were exhausted and covered in cuts and blisters, but it was a

"ASBAH has been such a great support since Tia was born that I enjoy doing something in return."

fantastic achievement. I was so proud of them all, and so were all of their friends and families."

Meanwhile Teresa and her sister Debbie have been devoting their energies into setting up a huge raffle ... with prizes worth

hundreds of pounds up for grabs.

Local businesses have responded to her letters with donations of theatre tickets, paintballing experiences, signed football items, Legoland passes... to name just a few.

When we spoke to Teresa she had already sold all the 150 tickets for the raffle evening at Goals football centre in Eltham, which donated the use of the room.

Teresa said: "With the £1,500 raised by the London to Brighton walk and the sale of tickets for the raffle evening, we are delighted to have already smashed through the £2,000 barrier.

"We were a bit late starting the fundraising this time and we didn't think we would be able to raise so much money, but everyone has been so supportive. People never cease to amaze me with their generosity."

Waddle challenge boosts ASBAH's funds

Father Paul Rainey and five friends completed a gruelling 100-mile Waddle (walk and paddle) to raise cash and awareness of spina bifida and hydrocephalus.

Paul, from Dollingstown in Northern Ireland, and his team travelled from the source of the River Bann to Portstewart Strand on the coast.

For the final stage of the journey they were joined by blind water ski world champion, Dr Janet Gray MBE.

Organised by Paul and friend Barry Jackson they completed their adventure in four days, using only their feet and canoes.

Paul said: "It was very tough, but we hope the event will become an annual event. My aim is to get more people involved of different abilities at different locations."

The team set themselves a fundraising target of £5,000, and to date have collected £4,500, with cash still coming in. The money will be donated to Royal Victoria Hospital for Sick Children in Belfast and ASBAH.

Paul first thought up the idea for Waddle on the first birthday of his daughter Zoe, now 18 months old, which was a milestone the family never thought they would see.



Paul said: "Zoe was born with spina bifida and hydrocephalus and in the first four months of her life had six life saving operations. We really didn't expect her to make her first birthday and to mark the occasion we came up with Waddle.

"Zoe has been back in hospital twice since her series of operations, thankfully for only a week on both occasions, and like many babies she is happy, eats, sleeps and keeps Pampers in business.

"She has made great progress physically and based on this a decision on a Spinal fusion surgery has been deferred. Her daily routine differs a bit however from our experience with her older sister Cara, now 3, at the same age."

Waddle's vision is to raise awareness of spina bifida & hydrocephalus in Northern Ireland and every penny raised will be donated to the Royal Victoria Hospital for Sick Children in Belfast and ASBAH.

Paul added: "Zoe is such a bright and wonderful child she is full of life. The whole family, including mum, Kirsty and big sister Cara, are just so lucky to have her."



Geraint's wheely good effort brings in £560

Congratulations and thanks go to ASBAH Adult Council member Geraint Catherall who raised £560 in sponsorship at a recent National 24 Hour Championship Cycling.

Geraint, who has hydrocephalus, is a keen cyclist and regularly competes in time trials and 12 and 24-hour challenges.

You can read more about Geraint and his passion for cycling by turning to page 16.



AGM looks forward

ASBAH's 44th AGM looked forward to increasing involvement of all those who make up the ASBAH community of individuals, family, friends, carers and professionals. The difficulties presented by the current economic climate in which all charities are facing challenges were acknowledged by Chief Executive Jackie Bland and in the report of the honorary treasurer. But both the trustees and ASBAH's auditors agreed that the organisation is well placed to continue its valued work with plans to seize every opportunity to increase its fundraising potential.

Launches

After the formal business came the launch of ASBAH's new membership scheme (see page four) which was greeted with

enthusiasm by local association representatives and individuals at the meeting.

Lifetime contribution

Another first for the Association, was the presentation of a Lifetime Contribution Award to Carole Sobkowiak. This award introduced an annual event which will be developed to include other categories - enabling ASBAH to recognise the contributions of all those in our community to the continuing progress and success of our organisation. Nominations for the 2011 awards will open in April.

The first award was presented by ASBAH Chair, Richard Astle, after he delivered a brief history of Carole's long association with ASBAH. A shortened version of the citation (which showed how apt and well deserved the award is) appears here.

Carole Sobkowiak

It is difficult to know where to begin to list Carole's achievements.

Her professional background is in paediatric physiotherapy and she is a Fellow of the Chartered Society of Physiotherapy.

But that is only part of the woman that is Carole Sobkowiak.

Her involvement with the world of spina bifida and hydrocephalus can be traced to her time at Sheffield Children's Hospital where she was on the staff from 1967 until 1974.

During that time, Carole worked closely with Professors Lorber and Zachary, both founders of ASBAH.

The team, that Carole was part of, realised that orthopaedic treatment in isolation was not the way forward for children with spina bifida.

A multidisciplinary clinic set up in Sheffield and the pattern rolled out to other regions meant that



children could be seen by all the specialists they needed on one day.

New ideas

The idea of walking at all costs was replaced with encouraging and teaching movement; programmes for developing spatial awareness were developed. In 1972, an orthopaedic hand clinic was set up in Sheffield for children with cerebral palsy but including those with spina bifida when it became apparent that children with spina bifida were not just paraplegic. Carole joined the team and later continued the work at The Hospital For Sick Children, Edinburgh, promoting the idea that children with spina bifida had upper limb problems.

Gradually parents were encouraged to become part of the team treating their children, to participate in making decisions about their treatment and to question those medical decisions that they did not consider correct for their children.

The shock of diagnosis was beginning to be understood. Don't forget, there were no scans, no antenatal diagnosis and the first that parents knew that their child had spina bifida was at birth.

The way that the news

was broken to parents had a real significance on the way they perceived their child and their ability to move on with rehabilitation.

Carole was involved in the guidelines for disclosing diagnosis, a 1994 publication supported by Scope and called "Right from the Start".

She has always been an advocate of early intervention in babies with spina bifida as the brain grows most rapidly in the first year of life making this the vital time to encourage early sensory stimulation, developing of spatial awareness and sequencing activities.

Carole and ASBAH

ASBAH was very fortunate when, in 1983, Carole was introduced to the organisation by Moyna Gilbertson who was the Chief Executive and a fellow physiotherapist.

She is a longstanding and valued member of the Medical Advisory Committee She was also a member of the Services and Marketing Committee.

Carole's interests and expertise are far reaching.

She was President of the Society for Research into Hydrocephalus and Spina Bifida from 2003 until

2006, having previously been the Hon Secretary.

She has published widely, presented papers at scientific meetings worldwide, acts as peer reviewer for scientific journals, and is now the Society's Spokesperson on Folic Acid. She has followed, and been part of the folic acid story in the UK since it's inception in 1991. She met with representatives of the Food Standards Agency, talked to international experts on folic acid and fortification and campaigned endlessly for fortification in the UK.

Now she is proving invaluable in helping with the folic acid campaign.

Carole has, on behalf of the SRHSB but always promoting ASBAH, contributed to meetings on folic acid in Brussels, Budapest and Bucharest and at the European Parliament. She visited Sudan in 2002 and 2003 and, is attending a Preconceptual Health conference in Budapest this month, followed by a trip to Bucharest to present to the Romanian Association for Spina Bifida and Hydrocephalus.

She has always been a tremendous support, always happy to give advice and to talk over difficult problems and if she doesn't know the answer she always knows someone who does.

(to read the full citation visit the About ASBAH section of ASBAH's website at: www.asbah.org)

ASBAH's AGM was held at Coloplast's prestigious offices in Peterborough and Marketing Manager, Martin Beynon, gave a warm welcome to delegates at the start of the meeting. Coloplast also kindly provided a sandwich lunch and refreshments throughout the day. Our thanks to Coloplast for their hospitality.

Experts reveal new findings at annual meeting



Experts from around the world presented their findings at the 54th annual meeting of the Society for Research into Hydrocephalus and Spina Bifida (SRHSB).

The annual event was held this time at the University of British Columbia, in Vancouver, Canada from July 7-10

Report by our senior health adviser, Rosemary Batchelor.

The society has a long history of attracting good speakers with interesting papers to their annual meeting and this one, set on the campus of the University of British Columbia was no exception.

Our host was Dr Bill Arnold, a paediatrician now retired, who is also a Director of the Spina Bifida association of British Columbia.

The scientists started early on the first day with the Experimental Hydrocephalus pre-meeting discussion. This is their opportunity to share their latest research - and often to ask for advice from their peers.

There were papers on tethered cord surgery in pigs, using the genetics of Zebrafish to study hydrocephalus and central nervous system fluid balance and a study of the make up of the choroid plexus.

It was well attended by the early comers and, as usual, their enthusiasm made the session over-run.

After an evening reception at the Museum of Anthropology on

the campus where we met new colleagues and caught up with those we only see once a year, we were in the lecture theatre at the Irving Barber Centre for an early start to the main meeting.

We started with a paper from the Netherlands on the role of urodynamics in diagnosing tethered cord in spina bifida; there was a paper on the outcome of a cohort of children in Sweden with spina bifida occulta; and another on the management of neuropathic bladder in children in India.

Special lecture - Uganda

Coffee was followed by a special lecture from Dr Ben Warf from Boston who goes to Uganda to carry out endoscopic third ventriculostomy in children, at a hospital he helped to found there.

It was a dynamic and moving talk and shocking to hear that there are an estimated 60,000 children a year who are born with or develop hydrocephalus. Most of these are not treated or treated with traditional

medicine. At Dr Warf's unit at the Children's Hospital of Uganda, 2000 of the more fortunate babies and children are treated each year.

The majority of the babies have hydrocephalus caused by dirty conditions when the mothers are giving birth - and by having cow manure rubbed on the umbilical cord stumps.

The number of babies born with spina bifida each year is largely unknown; many come from remote villages and most are untreated as the condition is considered to have been caused by a curse on the family. Around 100 a year are treated by Dr Warf. Those that are taken to the hospital often have infected wounds, severe hydrocephalus and are very ill.

Once they are treated, the parents usually take them home to villages many miles away and they are never seen in clinic again.

Dr Warf's presentation was followed by a general session on hydrocephalus, with speakers from Japan, the US and Canada.



Super Summer Picnic

ASBAH's adviser, Angie Coster, tells us about her first ASBAH event



As a new Adviser for ASBAH, working across Hampshire and Dorset, one of the things that struck me most was the need for parents of young children with spina bifida and/or hydrocephalus to have contact with other families. Parents spoke about their feelings of isolation at diagnosis and beyond and the huge difference to their lives that sharing experiences and information with other families could make.

With the help of local parent, Emma Inskip, from the New Forest, who was keen to see more opportunities for people to get together, a picnic in the Royal Victoria Country Park was arranged. Some funding from the local Southampton and District Association for Spina Bifida and Hydrocephalus and Hampshire Parent Voice was obtained to book a hall in the Park to use as a base (and in case it rained!).

The event turned out to be a fantastic day for the 13 disabled children and their families and those of us lucky enough to share it with them. Parents, carers, grandparents, brothers and sisters all came along with their picnics. Gill Yaz, ASBAH's health adviser, was on hand with special guest Benny Bear, to demonstrate how shunts work. Stan Fitzgerald, Chair of the local association came with the rest of their committee. Seeing the parents and children enjoying each other's company was like a reflection of how they had been 40 years ago when they were starting out. Representatives from Parent Voice, Contact a Family and Cerebra turned up to offer their support, armed with lots of information. Kim from the ASBAH Southampton

Charity Shop came with her family as did Amelia Denning, urology specialist nurse at Southampton General Hospital. And..... the weather was good!

As one parent said "It was a lovely day. It was great to meet so many other families with the same issues and facing similar challenges all living so close to each other".

A group of the parents who attended the picnic in July are now planning to get together to arrange more activities in the Southampton/Hampshire and East Dorset area.

Special thanks to Sugar Snaps Photography

Allison and Monika from Sugar Snaps Photography, in Southampton, attended at Emma Inskip's invitation and took the photos as well as commissions from parents on the day. They gave us the photos for free and are also donating half the proceeds of any sale of photos to ASBAH. So far we have received £122 from them. www.sugarsnapsphoto.co.uk



Youngsters rise to Barnstondale Challenge



Ten young people enjoyed a great summer experience after signing up for ASBAH's summer residential – the Barnstondale Challenge, (part of ASBAH's Lifelong Opportunities Programme)

The four-day course, held from 21 – 24 July, gave 10 young people aged 11 – 16 years the chance to spend time away from home, make new friends and try out a range of new activities.

The ASBAH team was made up of seven staff members plus seven volunteers, who were occupational therapy students from Coventry and Liverpool, acting as buddies for the young people.

It was the first time ASBAH had used the Barnstondale Centre, based in the heart of the Wirral, for its residential experience.

The Centre, set in 15 acres of countryside, offers log cabin facilities and an activity base to help assist group leaders run their own programmes to work on improving self-esteem, widening horizons and increasing motivation.

The ASBAH group was in a large log cabin, which had nine en-suite bedrooms on the ground floor and a lift to access the upper floor, which housed a large common room with small kitchen.

The youngsters, who were all allocated a Buddy for the stay, enjoyed a packed programme.

Activities included Taiko Dragon drumming, archery, football, crafts, dance & drama workshops, outdoor brainteaser activities, curling and orienteering.

The evening was less structured giving the teenagers time to mix and share experiences. The lads were out on the all-weather area playing football and girls chatted and played cards. Their stay ended with a barbecue and evening disco.

Joan Pheasant, ASBAH Regional Manager for the North of England & West Midlands, organised the residential. She said: "The teenagers developed lots of new skills throughout their stay and helped each other to achieve in the activities.

"There were a couple of boys that had been away with ASBAH before and it was good to see how they had developed in confidence and the ability to mix with others this year."

Joan added: "Our thanks go to the excellent volunteer occupational therapy students, ASBAH staff and our funders, without whose help the Barnstondale Challenge would not have taken place."

What they said:

"Thank you for inviting me to this trip I have enjoyed it here."

"Drama was great fun."

"Thank you a lot for this. I have loved every minute."

"Curling was good and it was good to experience a new activity."

"Archery was brilliant."

"All the hard work has been a fantastic success you should be proud of. When can I come again." Buddy



We are very grateful to the following sponsors for their generosity, which has enabled this course to take place.

Next PLC
Hedley Foundation
Good Neighbours Trust
Green & Lilian Ainsworth and Family Benevolent Fund
8th Earl of Sandwich Memorial Trust.



Families get together

A Family Fun Afternoon certainly lived up to its name when children and parents galore enjoyed a lively get-together.

The event on 25 July, organised by area adviser for Norfolk and Suffolk, Val Meyer Hall, was a great success and many new friendships were forged.

Val explained: "I arranged the family afternoon as many parents had told me they were keen to meet up with other families for mutual support.

"I tried to create a relaxed atmosphere where the children could meet up whilst having fun."

The afternoon was packed with activities to keep the children busy from mosaic making and a music roadshow to face painting and a Wild Encounters workshop - where the children could handle creatures from snakes to giant millipedes.

Brian Alldis, Paralympic wheelchair racer, was there to talk to families about getting involved in sport activities, while two Paramedics and a Community Responder taught basic life support techniques to the parents and older children.

Young Georgia Taylor showed her skills as a Majorette and later her Mum taught several moves to other children who were keen to have a go.

Val added: "The event was funded by the Norfolk and Suffolk Support Group and several members volunteered to help on the day.

"Feedback from parents has been positive - they said the children had a great time.

One parent told me that her little girl was convinced that she and Benny Bear were the only people to have a shunt!"



Fun in the sun to celebrate 40 years

Old friends met up and plenty of new friendships were forged at Northern Ireland's summer Fun Day which marked the Northern Ireland Association's 40th anniversary.

The event, organised by ASBAH in Northern Ireland and the NI Association (NIASBAH), attracted 240 people...not including staff and volunteers.

They met up at Springhill, a stunning National Trust property in Money more, County Londonderry, where plenty of entertainment and a barbecue were arranged.

With magic shows, children's flower arranging, fabric flower making for adults, exotic animals, face painting, a disco/dance and a treasure hunt, there was something for everyone.

Sid McDowell, CBE, NIASBAH's Vice-President said: "A brilliant day was had by all. The event was a great way to say thank you to all the people associated with NIASBAH for the help and support they have given over the years to help maintain essential services for children, families and individuals throughout Northern Ireland.

"The day was helped by our colleagues from ASBAH'S Regional Office and was supported by the Big Lottery Fund."



Isn't it amazing how quickly the stifling hot days of summer become a dim and distant memory?

I love the long warm summer evenings but we did have a few problems with our sleeping arrangements during those balmy weeks, mainly because; a) there is a huge difference of opinion between Andrew and I over what is considered to be an acceptable temperature and b) because I had an operation on my foot during the very hot weather and needed to avoid the bedclothes pressing on it.

Even in very hot weather, I like to have the duvet over me at night, so as soon as the temperature gauge notched up, we started an ongoing battle over who was having (or rather not having) Andrew's side of the duvet.

Most nights, it ended up banked up down the middle of the bed like a topographical map of the Andes.

The downside of this arrangement was that neither party had much space, as the duvet equivalent of Hadrian's Wall was rather bulky.

For a while, we also tried the folded-over approach, which meant that I had a double duvet and Andrew just slept under his Dr Who beach towel instead.

It isn't actually very restful

trying to go to sleep with a dalek waving its plunger in your face, added to which I had a huge bandage round my foot and didn't want 10 tons of duvet on top of it.

In fact, anyone looking at my bandaged foot would be forgiven for thinking that I had trodden on a landmine, when in point of fact, it was just a ganglion in a very unhelpful place, which meant that it had to be removed.

Apparently, in the old days, they used to be called "Bible Cysts" as the tried and tested (non-surgical) method for getting rid of them was bashing the offending lump with a bible. I did briefly consider whether this would be a quick way of dispensing with the services of an orthopaedic surgeon, but decided that knowing my luck, I would end up with a broken foot instead!

Being incapacitated meant a number of changes in the domestic routine over the summer, for example, Andrew became temporarily responsible for getting things in and out of my wardrobe. This was largely done on the basis of me describing what I wanted and Andrew then having around six attempts to pull out the required article, after which we then went through the same routine with the chest of drawers.

Fast forward several weeks and there has been much improvement on the foot front - I am now almost back to full strength and the bandaging has all gone. Sadly, so have those lovely hot summer evenings but with the return of temperatures to more normal levels, I have to admit it is easier to get to sleep now that Hadrian's wall has been dismantled and the dalek is safely back in the airing cupboard.

Diary dates

Contact your regional office for further information on any of the events below

Dunstable Support Group

For people with spina bifida and/or hydrocephalus and their carers. Please come whenever you can. While there is no crèche, young children are always welcome.

Where: Disability Resource Centre,
Poynters Road, Dunstable.

When: Usually on the second
Monday of each month.

Time: 1 – 3pm

For further information contact Valerie Bottoms
on 01582 757745

Meeting dates for the rest of 2010 are:
8 November / 6 December

ASBAH's Lifelong Opportunities Programme presents:

Hydrocephalus and Shunt Awareness Day

Date: Tuesday 30 November 2010

Time: 10.30am - 3.30pm

Location: Bridgend, Wales

If you are a parent, or carer, of a child or young person with hydrocephalus (under 18 years old) join us at this information day to learn more about hydrocephalus and shunt management. There is no charge for this event.

For further information contact: ASBAH Cymru

Tel: 01656 864102 email: wro@asbah.org

(Closing date for applications 12th Nov 2010)

Holiday lets

For classified rates, please
contact the *Link* Editor.
Email: link@asbah.org

ISLE OF WIGHT ASBAH - HOLIDAY BUNGALOW

Wheelchair-accessible bungalow, sleeps six. Open-plan lounge/kitchen, wetroom. Site facilities. Local heated accessible pool. Beautiful area. Transport advisable.

**Details and rates: Sylvia Griffiths,
3 Western Road, Shanklin, Isle of
Wight PO37 7NF Tel: 01983 863658
www.iwasbah.co.uk**

CYPRUS, PAPHOS - VILLA WITH HEATED INDOOR POOL & HOIST

4 bedroom Villa Ampelitis, level access & wheel-in shower rooms. Available all year. Also limited mobility friendly beachside villas, 2 - 5 bedrooms. Private pools (some heated). Reasonable rates.

**Contact Irene Hare. Tel: 020-84406219
Email: irene@sundancevillas.co.uk
www.sundancevillas.co.uk**

Opinions and views expressed in *Link* are not necessarily those of The Association for Spina Bifida and Hydrocephalus. While every care is taken to ensure accuracy of information published in *Link*, the publisher can accept no liability.



**ASBAH Helpline
0845 450 7755**

Back Care and Foam cut to size
Back & Neck
Supports

Pressure Relief Products

Memory Foam Products Customised Foam

Putnams
ENGLAND

01752 345678
www.putnams.co.uk
Showroom: Eastern Wood Road,
Langage Ind Est, Plympton, Plymouth PL7 5ET

Regional contacts

North of England & West Midlands

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

ASBAH East

42 Park Road
Peterborough PE1 2UQ
Tel: 01733 421309
Fax: 01733 555985
Email: ero@asbah.org

London and South

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

ASBAH Cymru

PO Box 325
Bridgend
Wales CF31 9LD
Tel: 01656 864102
Email: wro@asbah.org

ASBAH N. Ireland

PO Box 132
Cushendall
Belfast BT44 0WA
Tel: 0845 450 7755
Email: niro@asbah.org

For details of Local Associations contact your regional
office or ASBAH Helpline or visit www.asbah.org

More freedom
Same discretion



SpeediBag Compact. The discreet urine bag for SpeediCath Compact catheter

SpeediCath Compact catheter provides a unique sense of freedom for women who self-catheterise. This freedom is further enhanced by SpeediBag Compact – the new urine bag made exclusively for use with SpeediCath Compact. The urine bag is just as discreet, safe and easy to use and dispose of as the catheter.

And because you are no longer dependent on transferring to a toilet, SpeediBag Compact enables you to catheterise almost anywhere.



To receive a FREE sample of SpeediBag Compact, fill in this coupon and return it to: Coloplast Ltd, First Floor, Nene Hall, Peterborough Business Park, Lynchwood, Peterborough, PE2 6FX

Please send me a FREE SpeediBag Compact Sample pack containing one SpeediCath Compact catheter and a SpeediBag Compact

Name

Address

Phone/email

SpeediCath CH size: CH10 CH12 CH14

I understand that Coloplast will keep the necessary personal information on its database and I may ask to see this information. Coloplast will not disclose this information to a third party. If you do not want Coloplast to keep you updated with relevant information on products and services, please tick this box

 **Charter**
Delivery for life

Freephone 0800 220 622 or visit www.coloplast.co.uk
Please quote reference: SBAGLINK0410

SpeediBag

 **Coloplast**