

link

The magazine for people with
hydrocephalus and spina bifida

More
awareness
of folic acid

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- Know your rights - DDA
- Have your say - discussion session
- Your Voice - who we are and what we do

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For further information and to register your interest contact:

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Peterborough PE1 2UQ
Email: markh@asbah.org
Telephone: 01733 421322



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The delegate rate is being subsidised by Your Voice

To read more about Your Voice see page 25

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the lifestyle magazine for
people with hydrocephalus
and spina bifida



Subscription Form

Link is published quarterly
(Winter, Spring, Summer and Autumn)

Link (1 year subscription)	6.80
All Europe by airmail	10.50
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Rest of the world by surface mail	10.50

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Gill Winfield writes



Hello and welcome to the Spring issue of *Link*. It's been a long, cold winter – but spring is coming – so I hope the sun is shining by the time this reaches you.

It takes more than a cold snap to slow ASBAH down though and we've all been working hard to continue to provide you with the first class service you deserve.

As many of you may have heard, we have appointed a new Chief Executive following Andrew Russell's retirement at the end of March.

On page 6 we say farewell to Andrew and welcome his replacement, Jackie Bland.

The folic acid awareness campaign continues and on page 24 you'll find an update on the situation plus a Q and A session with leading expert, Professor Sir Nicholas Wald.

Thanks to the hundreds of kind-hearted supporters who continue to raise much needed cash for ASBAH, there's a wealth of fundraising stories (pages 8 - 12) revealing how some of our funds are collected.

Our special supplement this time is Employment. It's a huge topic to cover in just seven pages but we've done our best to include as much practical information as possible, with a few personal stories thrown in too.

We also take a look at the revamped Your Voice website and meet the new YV co-ordinator, Mark Harris (page 25).

Do keep sending your news and if there's an issue you'd like to raise, please get in touch at the usual address.

Gill Winfield

Marketing and Communications Manager
gillw@asbah.org

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

Designed and produced by Bluestation Communications

Link is published by ASBAH,
National Centre, 42 Park Road, Peterborough PE1 2UQ

All *Link* enquiries to:

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Tel: 0845 450 7755 Fax: 01733 555985
Link@asbah.org www.asbah.org

Subscriptions (four issues per year): UK £6.80

All Europe by airmail £10.50

Rest of the world: by airmail £16.50,
by surface mail £10.50

Registered charity number 249338

ISBN 1360-323X

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Celebrating Britain's Carers... the UK's secret service

National Carers week takes place from 8 – 14 June this year, celebrating the contribution the UK's six million carers make to individuals and communities.

Organisers plan to use the week to raise awareness of the valuable work carers do and to identify 'hidden carers' to enable them to access support and services.

The group will promote their work to decision-makers such as MPs and healthcare professionals to bring much-needed support and recognition to carers.

For more information about Carers Week and events planned for your area, go to www.carersweek.org or call the hotline on 0845 241 2582.

NAIDEX 2009

Don't miss out on the NAIDEX 2009 exhibition, the UK's leading homecare, disability and rehabilitation event.

The show, at Birmingham's NEC, will see more than 350 exhibitors – including ASBAH – showcasing the latest products and services to enable independent living.

Everything from wheelchairs and stair lifts, children's equipment and clothing, to beds and continence aids. There's plenty of information and advice on hand from the experts too.

NAIDEX 2009 takes place from 28-30 April at the NEC. Entry is free but you will need to register to get a visitor's badge. Pre-entry online is advised to save queuing at the event.

For more information go to:
www.naidex.co.uk

NEW CHIEF EXECUTIVE FOR ASBAH



Jackie Bland

ASBAH's new Chief Executive, is Ms Jackie Bland, who took up her post on 16 March 2009. This enabled Jackie to have 2 weeks' 'overlap' with Andrew Russell, before he retired on 31 March.

Jackie has significant experience of charity senior management and governance, including over 10 years as Chief Executive of Deafblind UK, a national charity also based in Peterborough.

Andrew said, "I am sure that the ASBAH Board, through its Succession Committee, has made a very good appointment, and I wish Jackie well in assuming her responsibilities."

Jackie told *Link*, "It is a huge privilege to have been invited to join ASBAH as its next Chief Executive. I have long been aware of the vital work of the Association and feel

passionately about the key issues that challenge the organisation as we look to the future. Not least among these are the continuing disadvantage and disenfranchisement of disabled people, the quality of screening and support services for pregnant women, the urgent need to achieve Government support for fortifying flour with folic acid and the fight to secure further funding for vital research. I am acutely aware that we face these continuing challenges in the context of a changing and uncertain economic and political future, but I am also confident that Andrew Russell, his staff team and ASBAH Trustees have achieved a huge amount in the past 18 years and have established strong foundations on which to build.

I am very much looking forward to developing ASBAH's future to the benefit of all its stakeholders."

In Case of Emergency

The Ambulance Service has launched a campaign to make it easier for people to contact the right person in an emergency.

Most people now carry mobile phones but in the event of an accident, the people attending would have no idea which of the many stored numbers to call.

Hence the new ICE (In Case of Emergency) campaign for a method of contact in emergency situations

The idea was thought up by a paramedic who found that when he went to the scenes of accidents there were always mobile phones with patients but they didn't know which number to call.

In an emergency situation, emergency service personnel and hospital staff would be able to quickly contact the right person by simply dialling the number you have stored as 'ICE'.

For more than one contact name simply enter ICE1, ICE2 and ICE3 etc.

Preventing NTDs – can you help?

ASBAH is hoping women will come forward to take part in a clinical trial of the vitamin Inositol, which may help reduce the risk of Neural Tube Defect (NTD) pregnancies.

An appeal for volunteers initially went out in our Spring 2008 issue but unfortunately the trials were delayed.

Victoria Shepherd, who is co-ordinating the Ponti Study, said: "After much delay, the tablets have now been manufactured and approved by the appropriate authorities so we are able to continue with the trial."

It has long been known that folic acid reduces the risk of spina bifida but now scientists believe that a lack of the vitamin Inositol can also cause the baby to develop an NTD such as spina bifida or even anencephaly (where the brain is largely absent).

There is some evidence that Inositol can prevent NTDs and ASBAH is keen to support the Ponti Study which is being funded by the Medical Research Council.

ASBAH is appealing for women who have experienced an NTD pregnancy to join the study and perhaps take the vitamin Inositol (as well as folic acid), if they are planning another pregnancy.

As many women as possible are needed in the study to give a meaningful result.

No dangers or side-effects of Inositol are known. It has been used in high doses to treat other conditions and is naturally widespread in many foods.

No problems have been found and it has been used safely in many other research studies with no ill effects.

The research study will run through

2009 and 2010 at the Institute of Child Health, London.

Anyone wishing to know more, or considering taking part, can contact Rosemary Batchelor, ASBAH Senior Medical Adviser, via the helpline on 0845 450 7755.

You can also get more information from the study web site at: www.pontistudy.ich.ucl.ac.uk or contact the clinical trial co-ordinator on 0207 905 2822 or 07772 258 243. Alternatively email: ponti@ich.ucl.ac.uk

What is Inositol?

Inositol is classified as one of the B vitamin complex (often referred to as B8), although it isn't strictly a vitamin as it can be synthesized by the body.

It is a carbohydrate that closely resembles glucose in structure and is found in many foods including cereals, nuts, beans and fruit such as cantaloupe melons and oranges. Humans eating a balanced diet usually consume around 1g of Inositol each day.

Inositol is a crucial constituent of living cells and participates in several physiological functions.

As well as being found to play beneficial roles in fertility and development, myo-Inositol has been used in the treatment of liver disease, respiratory distress syndrome and depression.

Reports of NTD pregnancies recurring in a family, despite a high dose folate intake, argue strongly that a proportion of NTD cases may be fundamentally resistant to folate.

Don't be isolated, get in touch with other families

ASBAH is often approached by parents and carers of a child with spina bifida and/or hydrocephalus who are keen to get in touch with families in a similar position.

When you or your family are affected by disability or a medical condition it can be an isolating experience. Often being able to contact someone who knows what you are going through can be the biggest help.

Makingcontact.org is an internet-run website set up by the Contact a Family charity which offers advice, information and support to the parents of all disabled children.

The charity has been putting families with disabled children in touch with each other for over 25 years. The makingcontact.org service gives families the chance to safely and easily get in touch with others who are affected by the same, or similar, disabilities or medical conditions.

Standard membership to the service allows you to list your story so others can get in touch free of charge

With thousands of medical conditions and disabilities listed and thousands of people signed up and looking for contact, this site could help you find the people you are looking for. It's free, safe and easy to use.

Standard membership to the service allows you to list your story so others can get in touch free of charge.

Enhanced membership, which allows you to contact up to five people per day, costs £5 per year.

Members contact others through the Making Contact website. Your email address, telephone number or home address are not given out to other members.

www.makingcontact.org



Andrew bows out after 18 years at the top

“I can’t think of another job which would have fascinated and fitted me so well.”

Chief Executive, Andrew Russell, retired in March after 18 years with ASBAH. Here he reflects on his time with ASBAH and the fantastic team he will miss.

“Even before I came to this job, I always liked the idea of leading a specialised, medium-sized disability association like ASBAH, where the organisation is compact enough to keep in touch with reality (for people with SB/H) and flexible enough to create our own agenda on activities and policies.

Also, because we’re unique, we could build a reputation and punch above our weight on policy issues and in professional circles.

I’ve been lucky in the strong support I’ve always had from all the key directions: the Chair and Hon Officers and Trustees, from all my colleagues on ASBAH’s staff, and from so many disabled people over the years.

They have helped me to manage the association loosely enough to encourage autonomy and creativity, but tightly enough to give shape and be financially viable.

Disability charities that specialise, like ASBAH, get to know families and disabled people well, and draw on their expertise for campaigning and service provision.

ASBAH has always been a provider of direct support and guidance, and I know this will continue: learning from disabled people and passing on that knowledge to individuals and families.

The adviser team, apart from being a pleasure to work with, are an interesting, warm and varied group and a source of strength, which I’ll greatly miss.

For me, the cause is important, but also what got me out of bed in the morning has been the opportunity for a wealth of different, challenging experiences.

There was the feet-on-the-ground aspect of knowing disabled people and their families, in good times and bad.

There’s been the opportunity to work with senior professionals and policy-makers, to form partnerships with like-minded organisations, and to get alongside the fundraising team. I was never a born fundraiser but I have come to respect the profession and have learnt a lot from them over the years.

And yes, I’m vain enough to have enjoyed the occasional high-status bits like an entree into 10 Downing Street, meeting ministers and Select Committees, or a Royal visit to ASBAH!

Since I started working in the field of ‘disability’ 35 years ago, there’s been huge progress in attitudes and inclusion, largely due to the efforts of disabled people.

But we do need to take a regular reality-check. I’ve become more sceptical about much of the political TALK around disability, choice and rights.

I know the principles are important and that my doubts identify me squarely as a grumpy old man, but we need to keep asking, “Is it actually getting better for long-term disabled people?” in terms of leisure and employment opportunities, care assessments, travel, housing, etc.

When Bert Massie came and spoke to our AGM a couple of years ago, (as Chair of the DRC) he observed that it was actually more difficult to arrange for his flat to be cleaned than 20 years ago! As well as rights, services are as important as they were when I started 35 years ago.

When I retire I’ll have worked for ASBAH for exactly 18 years. I can’t think of another job which would have fascinated and fitted

me so well.

The time has passed quickly, and the context has changed rapidly and will continue to do so.

I’m a hundred per cent certain that ASBAH will weather the present economic downturn, because of our roots and the quality of people we have as members, staff, committees and supporters.

So I’m sad to leave, and will miss you all, but I feel the time is right to hand over so that the Association stays sharp and adapts to changing times. Thank you to all of you for making ASBAH such an important part of my life for so long.

Many colleagues and friends of Andrew sent in tributes on the eve of his retirement from ASBAH. Here is a selection of their comments...

“Andrew has made an outstanding contribution during his time as Chief Executive, seeing the organisation through some difficult times as well as delivering many key achievements that will stand us in good stead for the future.

During my five years as Chairman alone, he has overseen the establishment of the Helpline as well as continuing his untiring efforts with the folic acid campaign.

Andrew has also worked with other organisations, such as the Neurological Alliance, to improve services for those with long term conditions including spina bifida & hydrocephalus.

I wish him all the very best for his retirement and thank him sincerely for everything he has done for ASBAH – both the organisation and the individuals it supports.”

Richard Astle, ASBAH Chairman

“Always a gentleman, Andrew facilitated and enabled our work and whatever ‘bright ideas’ we came up with, he always tried to help us to achieve them.

His list of contacts in the charitable

continued on page 9

continued from previous page

sector is impressive and he certainly knew more than his fair share of politicians!

His campaigning on folic acid fortification is legendary and unfailingly positive - we will miss him, and thank him for both his leadership and support."

Neil Watts, Education Advisory Committee Chair

Andrew joined our association at a time when we were endeavouring to improve the services we offered to our client base.

His background had been very much in the service area and the changes which were implemented under his watch enabled us to grow in so many ways.

His enthusiasm for the work of our association kept us very much abreast of the changes being introduced by government.

He will certainly be remembered for his work with the folic acid action - which he would not let go."

Austin Crowther Vice Chair of ASBAH and Chair of Services and Marketing Committee

"I have worked with Andrew as Chair of the Medical Advisory Committee and have seen at first hand his tireless efforts, with Carole Sobkowiak, to bring about folic acid fortification of flour for reduction of neural tube defects.

This has been a rocky ride, and Andrew has steered ASBAH's efforts through the various regulatory and government hurdles, so that hopefully we are now much nearer to a successful outcome."

Dr Roger Bayston, Medical Advisory Committee chair

"Andrew Russell has always been a friend to Your Voice.

He has helped the group grow in stature within ASBAH from a group of individuals getting together to a fully recognised committee and therefore an integral part of ASBAH.

He has helped members grow in self confidence and self esteem through the committee and events.

Personally I have worked with Andrew on the ASBAH Cymru Committee, where through Andrew's encouragement Wales has become a strong region of the ASBAH family."

Paul Manning, Present YV Chair, Chair Elect of ASBAH Cymru



Paralympian Ann hits the road

Ann Wild with Andrew Russell, ASBAH chief executive

Ann Wild, one of the most successful wheelchair basketball players in the country, is enjoying the luxury of a new car thanks to the Motability scheme.

Motability was set up in 1977 to help disabled people with their mobility needs through car and wheelchair schemes.

The scheme, which has provided more than two million vehicles to date, is a partnership between the charitable sector, government, leading banks and the motor and insurance industries.

Ann, who has spina bifida, was presented with the keys to her new car by Sir Victor Blank, Chairman, Lloyds Banking Group at the Lloyds Banking Group Head Office in London.

Ann, 35, from Ilford, has been playing wheelchair basketball since the age of 10 and has competed in the Seoul, Atlanta, Sydney and Athens Paralympic Games and captained the Great Britain Women's Wheelchair Basketball team. She has now set her sights on the London 2012 Paralympics.

She said: "Having a Motability car allows me to have total freedom without fear or worries."

"Knowing I've got transport right outside my door is very reassuring and I feel safe wherever I go with the support that comes with the car – breakdown cover, maintenance and insurance.

"I travel all over the country on a regular basis for club training and events so having a reliable car and that support is very important to me."

Ricability for practical consumer advice

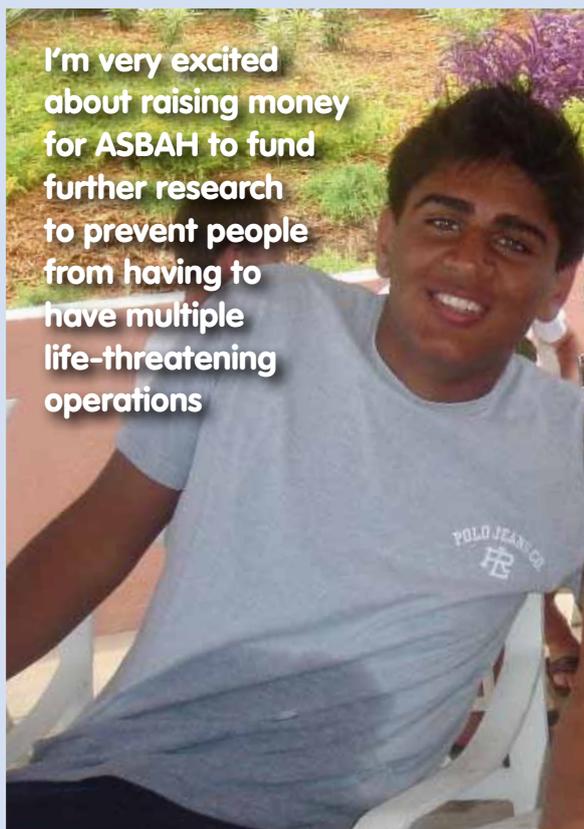
More and more disabled and older people are turning to Ricability for independent and practical consumer advice.

Ricability, a consumer research charity, provides free, practical and unbiased reports based on research with and among disabled people.

The charity also works with manufacturers, service providers, regulators and policy makers to improve products and services aiming to increase their awareness of the needs of disabled and older consumers through specialist research.

On its website you'll find reviews of a wide range of products and services under a range of headings from consumer reports, mobility, parenting and personal care, among others.

www.ricability.org.uk or telephone 020 7427 2460



I'm very excited about raising money for ASBAH to fund further research to prevent people from having to have multiple life-threatening operations

Mount Toubkal trek in aid of ASBAH

Maatin Patel will attempt the amazing feat of trekking to the summit of Mount Toubkal in the Atlas Mountain range, in Morocco, this summer.

Following an operation on his knee in November last year, Maatin felt the Trek – planned for 20 to 26 May – would be a great personal challenge and a way of raising money for a worthy cause.

Mount Toubkal is the highest mountain in North Africa at an astonishing 4167 metres high, with the promise of stunning views across the High Atlas and Sahara desert from its summit.

Currently volunteering in an orphanage in India, Maatin's training has been mainly based around rehabilitation but will become more intense in April when he returns to England.

He is aiming to raise £2500 for ASBAH and chose the charity after his 23-year-old cousin was diagnosed with hydrocephalus and had to undergo four operations in the space of two months.

Maatin said "I'm very excited about raising money for ASBAH to fund further research to prevent people from having to have multiple life-threatening operations, as well as help them manage with the condition that most definitely may change their life forever."

To help Maatin and ASBAH by donating, visit Maatin's fundraising page at www.justgiving.com/maatin



Work colleagues remember David

ASBAH has been presented with a £750 donation in memory of David Boulton.

David, whose granddaughter Emma Hodson has spina bifida and hydrocephalus, tragically died in January 2008 in a road accident as he travelled to work.

His colleagues won the money as part of an internal award at Portakabin and decided to donate it to ASBAH in memory of David, a well respected and loved colleague, husband, father and granddad.

Emma, who is five, and parents Kerry and Ian have been supported by ASBAH since before Emma was born.

The donation was presented to adviser Sylvie Bailey and David's widow Sue. The kind-hearted staff also handed over Christmas gifts for Emma and her baby brother Cameron.

Sylvie told *Link*, "It was a very moving experience for all concerned."



RUN for ASBAH

ASBAH is a registered charity that provides advice and support for over 15,000 babies, children and adults with spina bifida and hydrocephalus.

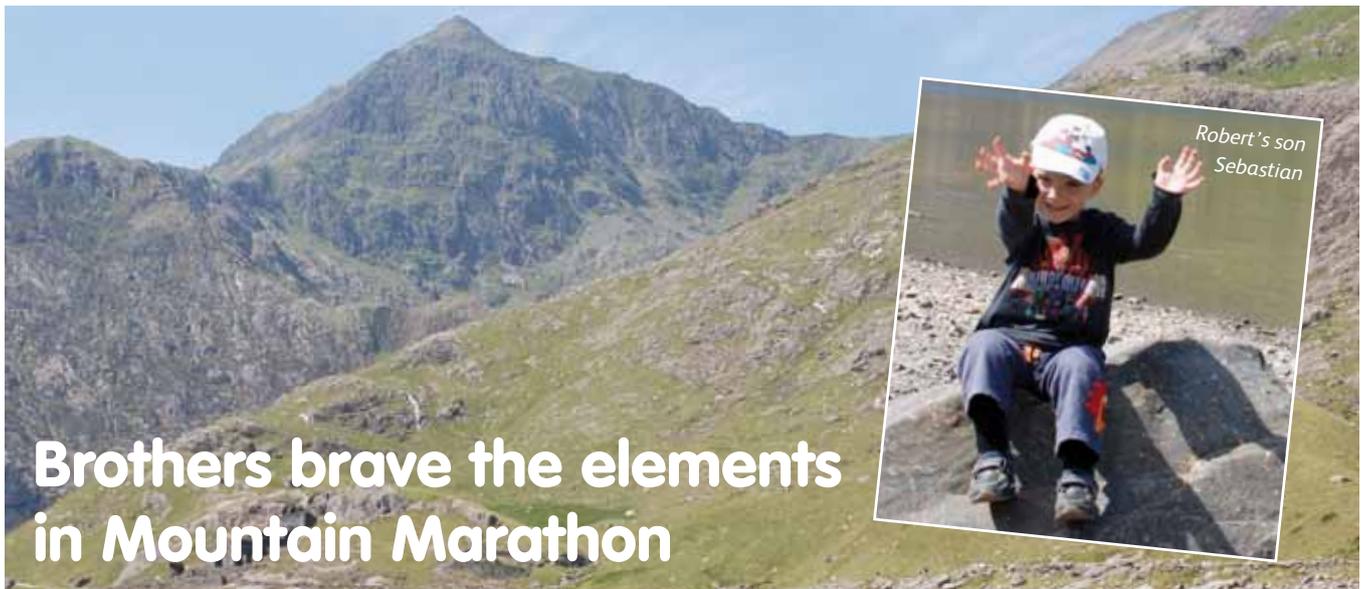
We need your help so we can continue to promote awareness, help families and carry out vital research.

For sponsor forms, please contact: Ian Morley, ASBAH, 42 Park Road, Peterborough PE1 2UQ

Tel: 01733 421328
Email: ianm@asbah.org
www.asbah.org



Registered charity no. 249338



Brothers brave the elements in Mountain Marathon

Four brothers faced tough weather conditions when they competed in a Mountain Marathon race, to raise money for ASBAH.

Robert, Stuart, Pete and Tom Riley took part in the Original Mountain Marathon in the Lake District in October.

The race involved teams of two, carrying all clothing, equipment and food for 36 hours. Runners also had to navigate their own route and camp out overnight.

The marathon was made even tougher by heavy rain. Initially the course was shortened, but as conditions worsened throughout the day organisers were forced to cancel the event altogether.

Unfortunately, many of the runners were already out on the course battling the elements. Among them were Robert Riley and his brothers who faced reduced visibility, driving rain and gale-force winds.

Despite the conditions, both pairs reached the finishing point on the first day but had an 8km walk back to their car.

The road, by this point, had turned into a river and the Rileys passed several flooded houses. As they waded up the track to their campsite they passed lines of cars half-covered in water from the burst river.

Fortunately, their car was in a field that only had six inches of river water running through it but they were forced to spend the night in the car waiting for the water to

subside.

Despite the uncomfortable night the brothers reflected they were relatively lucky

in comparison to other runners who camped in local barns.

Out of 298 teams in the C-class race, 136 teams completed the first day with Robert

and Stuart coming 60th and Pete and Tom finishing 72nd, respectively.

Robert said: "We all had an amazing experience and at no point felt in danger or were in any doubt of turning back. Our kit, teamwork and experience proved invaluable, as it did for other competitors.

"The toughest parts were making the

8km hike back over the Honister Pass, spending the night '4-up' in a hatchback in the path of a river and then pushing the car out of the field that was starting to resemble Glastonbury on the closing Sunday."

"We would like to thank everyone for their kind donations; they really spurred us on when the legs were aching and faces stinging from the rain. ASBAH will greatly benefit from their generosity."

The team decided to raise money for ASBAH because Robert's son Sebastian has spina bifida and the charity has supported his family through some tough times.

The team has raised over £4,760 for ASBAH and they have already entered the draw for this year's OMM race.

We would like to thank everyone for their kind donations; they really spurred us on when the legs were aching and faces stinging from the rain.



Virtual balloon races take off

ASBAH has launched virtual balloon races as an environmentally-friendly way of raising money.

Balloon races have proved a lucrative method of fundraising for ASBAH over many years. The in-house telesales department raises hundreds of thousands of pounds each year through 10 races in which companies sponsor balloons.

But in recent years there has been growing concern about the environmental impact of balloon releases and The Marine Conservation Society is actively campaigning to get them banned.

ASBAH, along with many of the sponsoring companies, shared this concern but couldn't come up with an alternative that would generate the same level of revenue for our service users...until now.

Colin Roberts, Director of Fundraising explained: "Last June we approached Purepages Group, who organised the ASBAH Webshop, to see if it was possible to replace real balloon races with virtual, on-line balloon races.

"I'm delighted to say that ASBAH's last real balloon race took place on 5 November and since January 2009 we have 'gone virtual.'

"Virtual balloon racing is not only better for the environment, but is much more interesting and fun for the sponsors."

On-line sponsors can design and decorate their own balloon, decide how much gas goes in and even the thickness of the 'virtual' latex!

They can watch the virtual launch and track their own balloon's progress throughout the race. They receive e-mails to tell them what's happening and when and why their balloon has gone down – or if they are the winner!

The winner will receive a real case of Champagne - not virtual!

Colin added: "I contacted The Marine Conservation Society to inform them of what ASBAH was doing and to see if the two charities could join forces in some way.

"We are now working together on an exciting joint venture where a new version of the virtual balloon racing software can be rented out to other organisations to replace their real balloon launches.

"Every time this happens – both charities will enjoy a royalty payment creating a new source of income."

Virtual balloon racing is not only better for the environment, but is much more interesting and fun for the sponsors.



Andy plans Channel swim

A keen sportsman from Surrey plans to make a big splash for his local ASBAH by swimming the English Channel.

Andy Butler came up with the idea after a leisurely swim at his local baths last year.

Andy, who chose Surrey ASBAH as his charity in memory of his brother Michael who had spina bifida, hopes to tackle the gruelling 21-mile course in June.

He said: "When I met ASBAH representatives they made me feel incredibly welcome. It brought back many happy memories of my brother and the years spent with someone who lived life with joy and happiness, no matter what physical difficulties he had to overcome. Remembering Michael makes this challenge all the more possible."

To train for the punishing event, Andy has visited his local baths four-to-five times a week. On weekdays he averages between 120 and 150 lengths, but at weekends he can clock up double this amount.

At the end of March his weekend training will progress to sea swimming at Dover, staying in the water for up to eight hours at a time.

Andy has also been running three to five miles and cycling a distance of ten miles a week to develop his strength and stamina in preparation for the 21-mile swim.

Andy has set himself a fundraising target of an incredible £10,000 – the first £5,000 to go to Surrey ASBAH and anything over this will be shared between the local association and national ASBAH -so he needs all the help, encouragement and support possible through donations.

To find out how to donate visit www.justgiving.com/andrewbutler3

To keep up-to-date with how Andy's training is going and how he is coping as the swim date looms, visit his blog at <http://manformatlantis.wordpress.com>

Robert raises £180

Robert Jones has recently raised £180 for ASBAH and plans to collect much more in the future.

Robert, from Betws in South Wales, has spina bifida and regularly uses the services ASBAH provide, especially the website. This motivated him to raise money for the charity so that he could give something back.

Robert donned a lion costume to make sure he attracted as much attention as

possible from passers by, and armed with a collection bucket, ASBAH stickers, balloons and banners, he headed down to Carmarthen town centre with some friends.

They set up a pitch and soon people were stopping to make a donation. Later on they also visited Ammanford.

Well done Robert. We look forward to hearing more about your future fundraising ventures.

STAR supporters

Zoe Burnay is fundraiser extraordinaire

Zoe Burnay has managed to integrate fundraising into every aspect of her life.

Zoe, whose daughter Hattie has spina bifida and hydrocephalus, wasn't content with making individual donations and has taken fundraising for ASBAH to the next level.

Her many fundraising activities have included the tough British 10k London Run race in 2006, raising £7000 for ASBAH.

Her involvement in generating donations for the charity did not stop there. Zoe has enrolled the help of her work colleagues at Mother London.

The main fundraising event is the Mother raffle/auction which takes place in January each year.

Initially the company raffled presents from suppliers, but this year, with fewer gifts due to the current climate, they added an auction and held bidding wars for a wide range of interesting and entertaining ideas.

These inventive prizes ranged from someone in finance completing your tax return, to someone else offering to drive a member of staff to work for a week.

One gentleman in Zoe's department even offered to have his head shaved in reception by another member of staff, if enough money was pledged (they made £300 for this alone!) The generosity of the staff has been overwhelming.

Zoe and her colleagues have also hosted a pub quiz bringing their total donations to more than £6000 to date.

Zoe's family have not escaped the fundraising bug. Her brother-in-law, Tom Burnay, participated in a sprint triathlon last year which amazingly raised over £1,000 for ASBAH.

Her mother-in-law raises money



(right to left) Hattie with her sister Polly

through her golf club and Zoe's own mum supports ASBAH by holding second-hand stalls and garage sales.

When *Link* asked Zoe about her fantastic fundraising achievements she said: "ASBAH has been a great support from the beginning of Hattie's life and I have really enjoyed my relationship with our adviser, Gill Yaz.

"Hattie is now six years old and has done really well to date, but it is always good to know that ASBAH are on hand.

"I care passionately about this charity as I know they carry out such wonderful work for others who are in need of support whether emotionally, financially or just to give out very knowledgeable advice.

"I am aware that they receive no government funding and yet are so vital to so many lives. We are very grateful to have them there."

Robert's festive lights are fantastic

Robert Petit has been helping to raise funds for ASBAH since 2001, and he hopes to continue for many more years to come.

Every year Robert decorates his bungalow in the village of Teversham, just outside Cambridge, with Christmas lights - lots of them!

People travel from far and wide to wonder at the marvellous display of more than 1,500 bulbs that almost completely cover the exterior of Robert's bungalow.

Preparations for the display take months and a lot of hard work and effort in order to get the lights up and ready for their switch on in late November.

Robert gets the lights out on 1 October so he can check that every single bulb is in working order - a task that Robert says often makes his eyes go funny!

Once the festivities are over it can then take another two-to-three months to store them away again ready for next year.

On the day of the big switch-on, the villagers of Teversham gather around Robert's house and a party is enjoyed by all. Robert gives the responsible task of switching on the lights to a child from the village. This year Pebbles was chosen to do the honours and she was very excited about doing so.

Robert sets up a collection box for people to make donations and he also puts out copies of *Link* so that people can learn more about spina bifida and hydrocephalus.

Robert had been putting up his wonderful Christmas display for years before he made donations to ASBAH.

He realised that there was an opportunity to raise money for a charity but didn't know which to choose.

One day in 2000 he was in his local convenience store and the young man behind the counter told him about ASBAH. The young man's brother has spina bifida and he told Robert how ASBAH had been a great support to the family.

Robert has given money to ASBAH every year from then on and to-date he has raised more than £2,000.

Well done Robert.

Royal Pigeon Racing Society is reaching for the sky

The British Homing World Show is a very important event on any pigeon fancier's calendar.

The annual event, held at Blackpool's Winter Gardens, is organised by the Royal Pigeon Racing Society (RPRSA) and is now in its 37th year.

Each year more than 20,000 visitors come from far and wide to visit the trade show, view the 'fancy' pigeon breeds on display and see the presentation of trophies for the year's races.

The RPRSA have been incredibly supportive of ASBAH throughout the years and by donating the profits from these events have raised an astonishing amount of money, £475,000 to-date.

It is hoped that by the end of 2010 this total could reach a whopping half a million pounds, and the £15,000 donation from this year's event, will certainly help towards this.

Brian Mead, Chairman of the RPRSA, presented a cheque to Colin Roberts, ASBAH's Director of Fundraising, at the

event. Colin was there to represent ASBAH, along with other staff members; Ian Morley, Sue Knickle, Gill Winfield, Cerys Long and Chris Wheatley.

The group also ran a tombola throughout the weekend which helped to raise a further £760 on top of the RPRSA's donation.

Peter Bryant was CEO at the RPRSA for almost a decade and he was instrumental in developing the relationship the RPRSA has with ASBAH.

Peter left the post last year, but maintains strong links with the organisation and was in attendance at this year's show. David Bills is the newly appointed CEO and he is set to continue where Peter left off.

Colin Roberts said: "We have thoroughly enjoyed working with Peter over the years; we are now looking forward to building the same relationship with David and working closely with the organisation for many more years to come."

ASBAH arranged for a very special cake to be made by the Sergeants' Mess at RAF



(pictured left to right) Brian Mead, Chairman of the RPRSA, presented a cheque to Colin Roberts



RAF Wittering cake

Wittering with the RPRSA logo on it. ASBAH presented it to the organisation's stewards at the Pigeon Show as a token of its appreciation for their dedicated fundraising.



Linda's line

Well, the days are getting longer, memories of being snowed up are rapidly fading, and I no longer look like I'm going on a polar expedition every night when I get into bed.

However some things are proving resistant to the warmer weather and the patch of vegetation at the back of house, formerly known as the lawn, still looks more like an elephant trail as a result of Andrew's frequent but necessary treks across the snowy tundra to defrost the pond during the winter months.

The only trekking I do in that sort of weather is from the front door to the car (after Andrew has shovelled a path through the snow), with a repeat journey in the evening when I get home from work.

Actually, now I come to think about it, that's all I do anyway whether we have snow or not - this exercise malarkey can be very overrated if you ask me.

I am therefore enormously impressed with Andy Butler who is intending to swim the English Channel this summer in aid of ASBAH.

I too have crossed the English Channel, although to speed things up a bit we went on a P&O ferry and I felt very sick for most of the crossing.

As an employee of the British Merchant Navy I feel obliged to add that this was not entirely P&O's fault as the sea was rather choppy.

To be honest, anyone who is going to swim heaven knows how many miles in freezing cold water with a totally inadequate number of chocolate breaks must be ever so slightly bonkers, but I can vouch for the fact that Andy

is genuinely committed to this mission so if I had a hat on, I would take it off to him.

Personally, I wouldn't even attempt a morning at work without a supply of cereal bars or a chunky KitKat to keep me ticking over.

It seems that other people in our neighbourhood are also doing sponsored events and we had someone knocking on the door the other day asking if I would sponsor a parachute jump in aid of their chosen charity.

I asked the chap if he would like to buy a chunk of Surrey ASBAH prize draw tickets in return and he went away again.

We have got some really good prizes this year so I will have to try that tactic again next time we get some more door-to-door sales people.

If you are not immediately rushing to find out where you can get your prize draw tickets from, make sure that you visit Andy's online blog to read the latest news about his plans for the marathon swim and his action-packed training regime – and not a chunky KitKat in sight!

Employment

In the latest in our popular supplements we turn our attention to an issue close to many of your hearts – employment.

We talk to *Link* readers Kevin Ogborne and Jamie Perratton about their positive employment experiences – both are lucky enough to have secured their dream jobs.

We also take a look at the four new ASBAH booklets which cover the transition to adulthood and employment which are packed with tips for employees and employers alike.

Below you'll find an article about the recent symposium on the White Paper on Welfare Reform and what the speakers said.

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The Welfare Reform Symposium: Removing barriers and raising aspirations

By Mary Malcolm, ASBAH's Director of Services

ASBAH was among the organisations which attended a recent symposium looking at the White Paper on Welfare Reform.

The Symposium, organised by the Centre for Parliamentary Studies part of Public Policy Exchange, was held on 3 March at One Whitehall Place, Westminster.

Chaired by the Rt Hon John Battle, Member of Parliament for Leeds West, the meeting was also attended by members of the voluntary sector and representatives from the Department of Health, Education and DWP.

The purpose of the day was to have an overview of the White Paper on Welfare Reform from as many angles as possible. The White Paper is currently on its second reading in the House of Commons.

The aim of the welfare reform is:

- To simplify the benefits system
- To provide support for those who need it
- To encourage the long term unemployed back into work
- To reduce the number of people currently claiming Incapacity Benefit
- No one will be written off
- To reduce the number of errors made in the current complex system.

John Battle MP opened the symposium by saying: "Don't let poverty go off the agenda through a recession. The people who suffer the most are those who have the least"

The speakers at the symposium were:

Ian Mulheirn, Director of the Social Market Foundation, is also an economic advisor at HM Treasury.

Ian said the current contracting out system has failed to meet targets and he believes the bidding process for commissioning of projects should be better monitored and controlled.

Dr Anne Daguerre, Senior Research Fellow at Middlesex University

Anne spoke in-depth about an active labour market policy in an international context: what works best? Outlining the link of an active labour market to combat unemployment.

She said that a highly-skilled workforce reduces the welfare benefit budget. The downside is that during a recession the most highly skilled are creamed off and the less skilled will remain within the benefits system.

Clare Lombardelli, Team Leader, Labour Market Policy Team, Person Tax and Welfare Reform Directorate, HM Treasury

Clare outlined the main changes that were in the Welfare Reform White Paper.

She also highlighted its aims - to simplify the benefits system, encourage the long-term unemployed into work and reduce the number of clients currently claiming Incapacity Benefit.

Clare added that the reforms would encourage lone parents to return to the job market.

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Bob Grove PhD, Sainsbury Centre for Mental Health

Bob spoke about the stigma and discrimination experienced by people with mental health problems in the work place. He said that getting people into work has not helped people with mental health issues and felt strongly that the inequalities in the work place must be addressed.

David Cragg, Regional Director, West Midlands Learning and Skills Council

David also talked about the need for the workforce to be better skilled. He believes this could be achieved by working in partnership with organisations and businesses to secure good work placements and apprenticeships.

Debbie Scott OBE DL FRSA, Chief Executive of Tomorrow's People

Tomorrow's People is a national employment charity that works in some of the most deprived communities in the UK, working with the long-term unemployed. The charity assists service users to overcome the barriers to work, help them find work and support them in any way possible for the first year of work.

Tomorrow's People campaign is to improve welfare to work and to support the long-term unemployed back into the work force.

Their mission is:

- To help long-term unemployed people to get and keep jobs
- To break the cycle of unemployed and dependency in deprived communities throughout the UK
- To transform the lives of the most excluded in society through work.

Since 1984 they have helped 400,000 long-term unemployed on their journey back to work.

The symposium ended with a panel discussion and debate.

Some useful websites for further information:

www.jobcentreplus.gov.uk

www.lsc.gov.uk

www.dwp.gov.uk

www.tomorrows-people.co.uk



It was sheer hard work and determination which earned Jamie Perrotton a dream position with Nottingham Forest's community coaching team.

He was offered the coveted role as part of his Modern Apprenticeship in sports coaching at South Nottinghamshire College and is keeping his fingers crossed that the position will become permanent when he qualifies this summer.

Jamie, 19, from Nottingham, was born with hydrocephalus and cerebral palsy, and had a VP shunt fitted when he was a few weeks old.

He said: "Thankfully I'm not really affected by my hydrocephalus; I am just limited in the sports I play. Rugby, for example, is out of the question.

"My cerebral palsy affects me mildly, along the right side of my body. It is definitely worse when the weather is cold, but luckily most of the coaching I do is in sports halls."

Jamie's work with Forest in the City includes football coaching for youngsters - including sessions with disabled children - and general fitness work with the Over-60s as part of the nationwide Extra Time initiative.

"I really enjoy my work," he told *Link*. "Every day is different and I interact with so many different people. The coaching team are great too. Very kind and supportive, I couldn't ask for more."

But Jamie said that it wasn't until he began his college course that he really had something to aim for.

"School didn't interest me at all and I didn't do much work," he said, "but because the college course is what I want to do, I want to learn and do the best I can."

Jamie said he was picked to join the Forest in the City team after bosses heard about his varied work experience. In the past few years he had helped out at local football clubs, eventually running training sessions for a local Under-10s team.

One unexpected bonus of the job is Jamie's local celebrity status after featuring in two Nottingham Forest match day programmes.

"Men have come up to me in the street to ask me about the Forest players and children often ask me for autographs. I have to admit that I like people who knew me as a child to know that I'm doing well for myself."

But as great as the job is, Arsenal remains Jamie's first love when it comes to football.

"I try to get to a match at least once a month," he revealed, "even though I always get a lot of stick from my colleagues."

I have to admit that I like people who knew me as a child to know that I'm doing well for myself.

KEY POINT

- Coaching deam for Jamie at Nottingham Forest
- Kevin breaking down the barriers



'We may look or appear different on the outside, but we are all the same on the inside'.



Kevin helps to break down barriers

Link reader Kevin Ogborne was dismayed when he was forced to use a wheelchair after previously enjoying mobility.

But his positive attitude and natural optimism prevailed, and having a wheelchair has led to Kevin being offered a dream job.

Kevin, 35, who has spina bifida and hydrocephalus, works as a presenter with the Just Different charity, which runs in-school workshops helping children and young people learn more about disabled people.

Kevin, from Bristol, explained: "As a child I was brought up to believe that I could do whatever I wanted. I attended a mainstream school and went on to become an electronic engineer.

"I worked in the family business for a while before becoming a bathroom and kitchen designer and salesman with Wickes.

"I had always been mobile but the pain and my balance had got progressively worse and in February last year I realised that I would have to use a wheelchair.

"It did take me a few months to adapt to the chair, but I'm a firm believer in making the best of what you've got. If I have to do things slightly differently, then so be it."

Kevin had mentioned to ASBAH adviser Ann Gillard that he was job hunting, but was still surprised when she called out of the blue to see if he could drive to Cheltenham to see a potential employer – within the next hour.

He said: "Ann was at a special employment day at the National Star College for disabled people where she met someone from Just Different. As she chatted to him she realised that this might be just the job for me."

The rest is history as they say, and Kevin is now doing what he calls his 'dream job'. Working three days a week, Kevin, as the only workshop presenter in the South West, travels far and wide, accompanied by wife Debbie.

He said: "I've always been very interested in promoting disability awareness and in my job I'm doing it at grass roots level.

"The workshops I run in schools are part of the children's PHSE (Personal Health and Social Education) and citizenship classes, with groups of up to 30 children.

"It is a fabulous job and I find the work extremely rewarding. Often when I go into a classroom the children are very quiet because they have never met a wheelchair user before.

"But by the end of our first session they realise that I'm the same as anyone else – I just use a wheelchair to get around."



Just Different

Just Different was started in 2006 to make a positive difference to the lives of disabled and non-disabled people.

Its founder, Toby Hewson, who has cerebral palsy, decided to use his years of voluntary experience as a springboard for creating an organisation educating children and young people about disability and difference.

During visits to primary and secondary schools, Toby found that children and young people responded to his physical difference with imagination and curiosity.

They view his wheelchair and communicator with fascination, learning that they are simply tools to assist him with his active life.

Just Different now runs in-school workshops to give pupils of all ages a memorable, thought-provoking experience, giving them a real understanding of disabled people and their daily lives.

These workshops are specifically designed to engage children and young people into thinking more imaginatively about the world they live in, and the diversity of the people within it.

The specially-trained disabled presenters bring a light-hearted attitude to disability and difference.

Just Different can be contacted by telephone on 01243 778 275. View their website at:

<http://justdifferent.org>

Gill Winfield, ASBAH

Marketing and

Communications Manager

said, "I know a lot of work

went into these booklets.

They started life as a single publication but we thought

it would be more useful

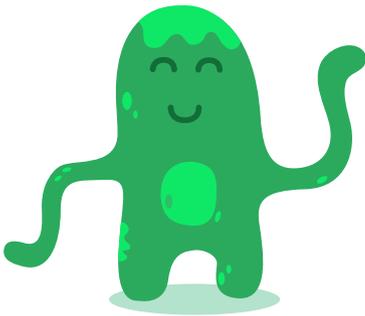
as four separate booklets,

and I hope parents, young

people and those, of any

age, seeking employment will order their copies from

the helpline."



New booklets smooth passage into adulthood

A series of four new booklets produced by ASBAH will provide a host of knowledge for service users.

The booklets, on transition to adulthood and employment for those with spina bifida and/or hydrocephalus, have been funded by The City Bridge Trust.

Each is packed with information to help the reader through the often difficult teenage years and into further education and employment.

They were written by ASBAH's education and employment adviser Naomi Marston with help from adviser Sharon Saville and a team of service users.

Naomi told *Link*: "There was a real need for these booklets as there isn't any other information out there which is specifically for people with spina bifida and hydrocephalus.

"Several years ago, before my appointment, the Independent Living project highlighted the need for more information on education and employment to be made available.

"A great deal of research and consultation has been carried out during the process, but we're all very happy with the end result."

While Naomi headed the project,

she's quick to praise the efficient team who helped her every step of the way.

"Sharon was wonderful," she said, "handling a great deal of the writing with me. We were also lucky in having several groups of service users who helped with suggesting the content, writing and the final checks. Several people also talked about their personal

experiences so we could include case studies."

Naomi said that months of research had gone into the content planning to ensure that every relevant aspect was covered.

"It is such a huge area and we wanted to make sure that nothing was missed out," she explained.

"The other hurdle we faced was keeping the information relevant and current, which can be a particular problem in the employment area because of frequent changes in the law and the many new government initiatives."

It is for this reason the resources at the end of the booklets give mainly website addresses for further information, as websites are more likely to be updated on a regular basis.

Naomi added: "It has been a great project to be involved with because I knew how vital these booklets are and because I had a great team behind me."

It is such a huge area and we wanted to make sure that nothing was missed out

Transition – a guide for young people with spina bifida or hydrocephalus

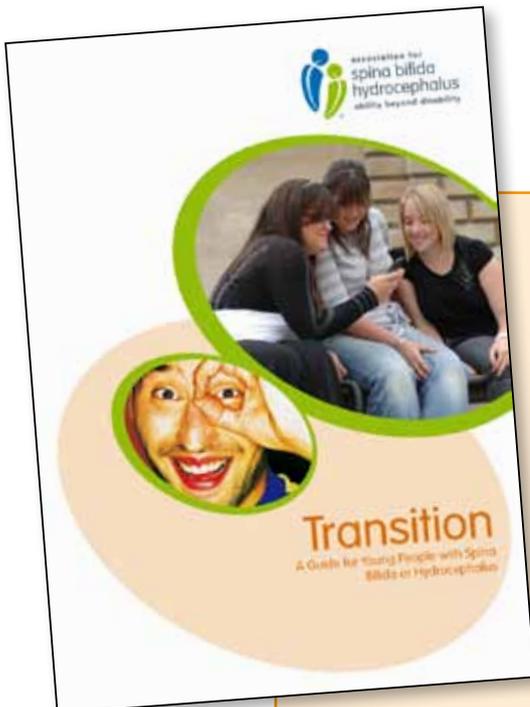
A 12-page booklet looking at the transition process to help the reader plan a smooth move into adulthood.

It gives information about transition plans and what you can expect from your first transition planning meeting to help allay any anxieties you may have.

There are suggested issues and questions you may want to think about before the meeting to make sure you get the most out of the session.

There's also a personal story from Suzy, who talks about how she drew up her transition plan and an action plan to give herself definite goals and challenges to work towards.

The final section looks at preparing for a career, outlining the different options available after school, and details of other useful resources.



A Guide for Employers – employing people with spina bifida and hydrocephalus

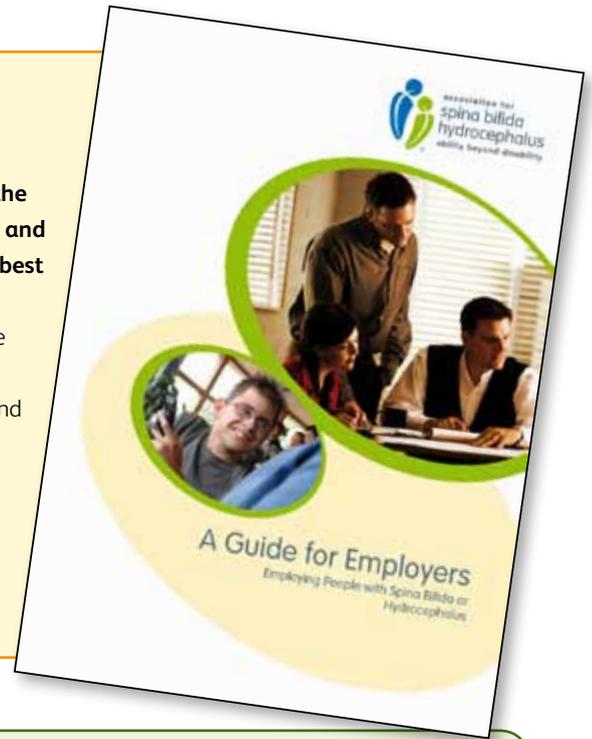
This eight-page booklet has been produced to help employers understand the possible effects of spina bifida and hydrocephalus in the work environment and how they can take these matters into consideration to ensure they get the best from their employee.

The guide explains what spina bifida and hydrocephalus are and highlights the skills and situations that may be affected and what can be done to help.

There are strategies to help performance plus tips to improve organisational and social skills too.

An Access and Mobility section outlines some of the issues an employer needs to consider, such as making sure walkways and office floor space are clear and wheelchair-friendly.

One employer tells how an ASBAH adviser put his mind at rest when he was considering a young man who had hydrocephalus, as an employee.



Getting a Job – a guide for people with spina bifida and hydrocephalus

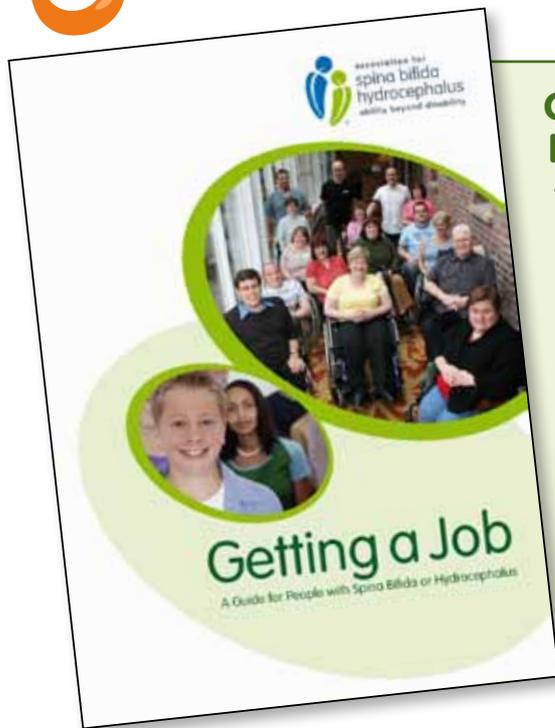
This 12-page guide is for those who are keen to work but don't know where to start looking.

There's an initial list of things to consider when trying to find something suitable for you, interview advice and checklists, plus things to think about to prepare you for an interview to help you give a great first impression.

Volunteering is a good way to get work experience and Keith Marshall talks about his experiences of voluntary work.

Other service users explain how their ASBAH adviser helped them with a range of employment problems from anxiety attacks to benefits and permitted earnings.

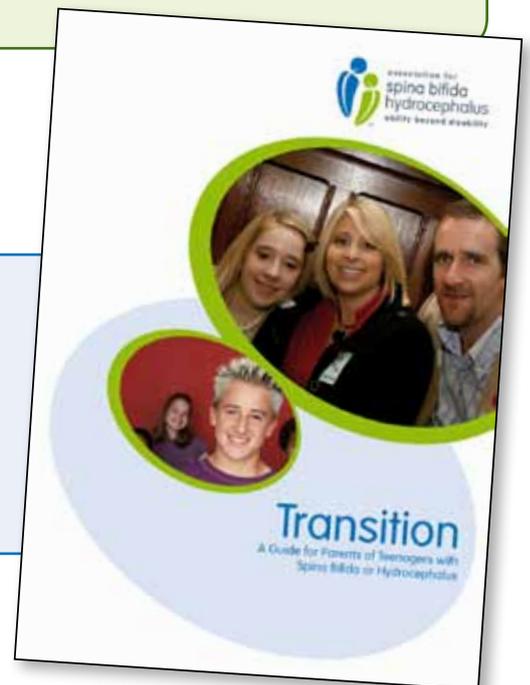
The final section – You've Got the Job – covers explaining to colleagues about your medical condition, if needed, and tips to make sure you get a great start in your new role.



Transition – a guide for parents of teenagers with spina bifida or hydrocephalus

An eight-page guide covering many of the issues raised during the transition years from Year 9 and upwards.

Preparation, developing a transition plan and tips for a successful transition are all included plus one parent's personal experience.



Sometimes parents try to 'protect' their children from reality by not communicating with them about disability in the family

Relationships - coping with disability



Denise Knowles, an experienced Relate Counsellor, spoke at a recent ASBAH study day on the effects of disability on relationships.

She began her talk by highlighting how essential relationships are to everyone's happiness and wellbeing and how physical and emotional wellbeing cannot really be separated.

When relationships are going well it allows us to relax but if something goes wrong then this can cause stress.

Relationships operate on a variety of levels in the home and work environment with spouses, siblings, parents, children and colleagues.

Having a child with a disability can impact on family relationships and communication is important in adapting to changing circumstances. Tensions can arise because of ignorance about the disability or difficulty with acceptance.

Denise suggests researching information together with other family members, asking for support, understanding changing needs and possibly seeing a family counsellor can all be useful.

Sometimes parents try to 'protect' their children from reality by not communicating with them about disability in the family - either in older relatives or in new brothers or sisters - but this can lead to children feeling left out.

However, we shouldn't assume that siblings want to be involved and should respect their feelings if this is what they prefer.

When breaking news to others about disability in the family, Denise advises that you need to be strong enough emotionally before telling others so that you can be ready for their questions and be prepared for unexpected reactions.

Having a supportive partner or friend with you can give you strength. If you plan to explain the situation to your children, having another adult present may also be helpful.

Denise also highlighted the need for carers to have interests outside the home, to make time for themselves and for their other relationships.

In adult relationships there can be a tendency to blame a partner's disability for any sexual dysfunction. But bear in mind that sexual problems are common in the general population and disability is not necessarily the cause of the problem. Of course disability can sometimes affect sexual functioning, but practical solutions can be sought.

Most relationships are improved when you talk and listen to each other. Sometimes a counsellor or therapist can help couples and families with this but when seeking help, remember that not all counsellors may have worked in the field of disability.

Relate offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support face-to-face, by phone and through its website.

To find your nearest Relate call 0300 100 1234 or go to its website at www.relate.org.uk

However, we shouldn't assume that siblings want to be involved and should respect their feelings if this is what they prefer.

Denise Knowles



Denise joined Relate in 1990, qualifying as a counsellor two years later. She has worked tirelessly over the last 18 years to expand the range of her interests and expertise.

She is a highly skilled practitioner and qualified psychosexual therapist, family counsellor, supervisor and trainer and runs a successful private practice.

As well as being a well-known media spokesperson, Denise is an integral member of the counselling and training team at her local Relate Centre, Northampton, offering courses such as Parenting Skills, Moving On and other life-skills workshops.



- The effects of disability on relationships
- Undiagnosed spina bifida and how ASBAH helped the Horsley family

Hayley and
Joshua Horsley

Bolt out of the blue

Today the incidence of undiagnosed spina bifida is quite rare, so hearing that their new baby son had the condition was a bolt out of the blue for Hayley and Trevor Horsley.

The couple, from Tewkesbury, already had a healthy daughter Mollie, now 3, and didn't anticipate any health problems during Hayley's second pregnancy.

Hayley said: "I actually felt much better second time round and the scans hadn't picked up any abnormalities so we presumed everything was fine.

"I had pre-eclampsia with Mollie and had an emergency C-section. In comparison Joshua's birth went very well until he was born and we could see the lump on his back.

"The midwives were very calm and said not to worry, but called the consultant in. At this point spina bifida still hadn't been mentioned."

That evening mother and baby were doing well so they were allowed home, although Hayley was asked to return with Joshua two days later for tests.

She said: "After Joshua was scanned the paediatrician told us that he had spina bifida, which was a huge shock even though we knew something was very wrong. We weren't prepared for the news at all."

Neither of us really knew anything about the condition and we automatically assumed Joshua would use a wheelchair all his life.

"Neither of us really knew anything about the condition and we automatically assumed Joshua would use a wheelchair all his life."

The couple left the meeting with very little information about spina bifida and it wasn't until an appointment at Bristol's Frenchay Hospital two weeks later that they were told more... and were given an ASBAH information leaflet.

"ASBAH was fantastic," Hayley said. "The information and support made a huge difference to us all. "I experienced some very dark days in the beginning," she added. "I didn't really bond with Joshua very well in the first couple of weeks and yet I was terrified of losing him.

Joshua was scheduled for a cord de-tethering operation when he was four months old but the operation was postponed for two weeks.

"We were all hyped up and ready, so it was a huge blow when the operation was postponed," Hayley said. "Then of course we had to prepare ourselves all over again."

"I would like to thank my mum and dad from the bottom of our hearts for everything they did in those first few months as they put their lives on hold to



Pictured from left: Mollie, Hailey, Joshua and Trevor

help. They were our rock, particularly since they'd been badly hit by flooding in recent weeks."

Joshua is now 16-months-old and when *Link* spoke to Hayley, she said he was beginning to take his first steps.

"Joshua does have a problem with his hips but we are so thankful that he is mobile," she said. "In the early days we never imagined that he'd be able to walk so everything extra is a bonus and we thank our lucky stars every day."

Hayley said she wished she had been able to talk to another mother about her fears and worries when Joshua was first born, and would love to offer support to any new mum or dad who is going through a similar experience.

If you would like to get in touch with Hayley contact The Editor at the usual address and we'll pass your details on.



There aren't many good roles for disabled actors out there so I decided to write something myself

David's gamble pays off

David Proud

David Proud knew he was taking a risk when he quit his safe job to try and make it as an actor.

But his hard work and determination paid off and he won roles in the ITV drama, *Secret Diary of a Call Girl* and the acclaimed film, *Special People*.

David, 26, got a taste for acting after being offered a lead role in the groundbreaking children's BBC TV programme, *Desperadoes*.

The 10-part series, first shown in 2006, was a drama about a wheelchair basketball team. Many of the characters were played by untried actors, recruited from real life

wheelchair basketball teams.

When filming was completed, David, who has spina bifida, returned to his day job at Peterborough's Job Centre.

"It was very difficult settling back into my job. It all seemed very subdued after an exciting few months," David said.

So he handed in his resignation, signed up with an acting agency, and determined to give it his best shot.

He was soon offered the coveted role of Scott in the film *Special People*, released last November, quickly followed by a role in *Secret Diary of a Call Girl*.

David said: "It's been an exciting two years and although, like most actors, I have had to do other work to make ends meet, I have no regrets.

"Filming *Special People* was an amazing experience and a huge learning curve for me. It was great fun to work on and I was really pleased with the end result.

"The cast got the chance to go to the

Moscow Film Festival last year where *Special People* won the award for Best Feature.

"Visiting Moscow was a real eye-opener for me because disabled people have far fewer choices than we do in England. Access and mobility is limited and they have fewer opportunities. In fact the

Russians seemed amazed that I could actually be employed as an actor.

"Things might not be perfect here but it really made me appreciate the rights and social inclusion we enjoy. Taking films which feature disability to other countries such as

Russia does help to influence change."

After the thrills of 2008 David told *Link*: "Things are pretty quiet at the moment although I have a few things in the pipeline.

"Every industry has been hit by the recession and the film industry is no exception. Films are still being made but when finances are tight production companies tend to go for safe storylines

The Secret Diary of a Call Girl is being shown in the States at the moment and the feedback is very good, so that may open a few doors for me.





Desperados



Actors
Dominic
Coleman
and Sasha
Hardway



Actor
Jason
Maza

Special People (12A)

Released on DVD
April 2009

Jasper is enlisted to teach a group of teenage wheelchair users about film-making. Unfortunately for him, he discovers his students know more about the subject than he does.

When one of the students, Scott (David Proud), suggests they make a documentary instead, Jasper merely blanks their indifference and ploughs ahead with a plan to take them up a hill to 'symbolise their daily struggle' – blissfully unaware of the comic complications that await.

What the critics said...

"Nicely observed and crisply played, gently confounding a gaggle of prejudices..."

The Guardian

"This film is, as the title suggests, a little bit special."

eyeforfilm.co.uk

"Now here's a little gem. Although shot for peanuts, it would take a very hard person not to thoroughly enjoy this heart-warming yarn."

Daily Mirror

You can view clips of *Special People* and *Secret Diary of the Call Girl* at www.youtube.com

rather than pushing the boundaries.

"It's a shame because I felt as though I was just hitting my stride, but that's the way life goes. *Secret Diary of a Call Girl* is being shown in the States at the moment and the feedback is very good, so that may open a few doors for me. In this game one small job can lead to another, and then it all snowballs."

For the last two years David has also been writing a screenplay and hopes to produce his first short film.

"There aren't many good roles for disabled actors out there so I decided to write something myself. I've got through the first round in terms of actually producing it and am hoping for some concrete news in the next few weeks.

"As an actor in *Desperados* I was thrown into a whole new world, but I've had to learn so much more, and very quickly, in terms of producing a film.

"There's a phenomenal amount of work behind the scenes in terms of planning and scheduling, calls to crew members and actors, checking the availability of make-up artists – the list goes on. Now I'm playing

the waiting game and keeping my fingers crossed."

But despite the excitement and anticipation of his new project, David says he still has a great affection for *Desperados*, the CBBC series that gave him his first break.

"The programme was ground-breaking at the time and every character was complete," he said. "An entire generation of children saw a slice of disabled life – which is just what it set out to do. I still get stopped in the street by all kinds of young people who enjoyed the show."

"I'm still in touch with everyone but even though I'd love to film a sequel, I think it's very unlikely to happen.

"This year's going to be an interesting one though - I've no idea where I'll be or what I'll be doing in 12 months time. But I've no doubts that I'm doing the right thing. I really believe that if you really want to do something you should try your hardest and just go for it."

New shunt aims to tackle world-wide infection rates

We hope that the Bactiseal® Universal Shunt with its effective infection control and simple and proven shunt design will provide surgeons and patients with a treatment solution to optimize the management of risk of a shunt infection.

Codman, part of Johnson & Johnson, is tackling the global impact of shunt infection rates with the launch of a new shunt designed specifically for use in poorer, developing countries.

The new Bactiseal® Universal Shunt is cheaper to produce than sophisticated shunt valves but has the same antimicrobial qualities as the shunts Codman currently produces for Western countries.

It is hoped that the new product will make antimicrobial shunts more accessible for a greater number of hydrocephalus patients around the globe.

It is estimated that around 10 per cent of all CSF-shunt surgeries are associated with infection and the shunt has to be removed and a replacement inserted (ref: Kestle 2006, Govender et al 2003) – all of which adds to medical costs. The risks in children are even higher (ref: Govender et al 2003, Bayston 1989).

If developing countries begin using the new Bactiseal® Universal Shunt, they have the chance to significantly reduce their revision rates and repeat hospitalisations. Benefits for the patients are also significant.

The new UniShunt is fully impregnated with two effective antibiotics (Clindamycin and Rifampicin) which target the majority of the organisms that are known to cause shunt infections.

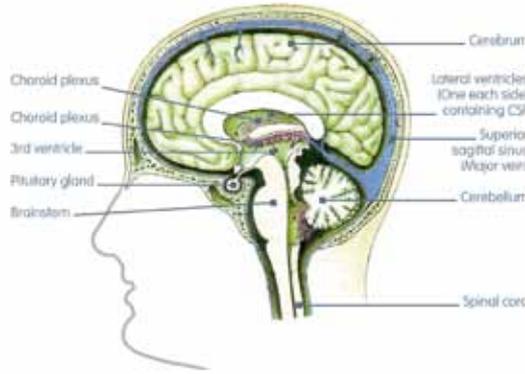
An early special prototype was studied in Durban, South Africa, where it successfully reduced shunt infections in children (ref: Govender et al, 2003)

The UniShunt will be sold in South Africa, the Middle East, Egypt, Turkey, Russia and the Commonwealth of Independent States, as well as a few other European countries.

Despite the efforts of all shunt manufacturers and neurosurgeons treating hydrocephalus, complications remain a concern for all



Codman - Working in partnership with ASBAH



Revised leaflet launched in Professional Area

An updated hydrocephalus leaflet aimed at GPs has been produced by ASBAH to give a clear overview of the condition including the diagnosis of shunt malfunctions and other problems.

Hydrocephalus - Guidelines for General Practitioners, will answer many of the questions ASBAH is frequently asked by medical professionals about the management of the condition.

It is viewable on the Professional Area of the hydrocephalus section of ASBAH's website which is open only to health professionals who register with ASBAH.

The leaflet can be ordered by service users, from ASBAH's Helpline, to be sent to their GP and is designed to be kept with the patient's medical records for easy reference.

As well as background information about the condition, there is information regarding shunt infections and prevention of complications, shunt malfunction symptoms and a diagram showing a typical

ventricular shunt in situ.

A lengthy section on 'Hidden Problems' covers the wide variety of learning disabilities hydrocephalus can cause such as limited spatial awareness and poor working memory.

Professional Area

Let your health professional know about the Hydrocephalus Action Professional Area, which is open to health professionals who register with ASBAH. It includes information on everything relating to hydrocephalus as well NTDs, from shunt surgery through to continence issues. Users can upload and download medical teaching materials, including videos and information sheets, published articles and case studies. A calendar of upcoming conferences will ensure users don't miss forthcoming events.

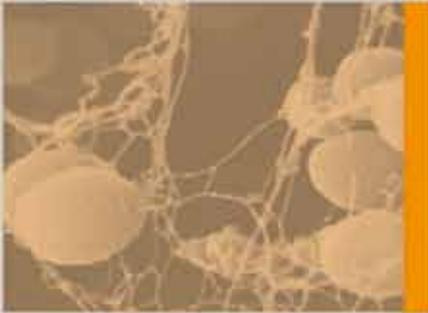
www.asbah.org/professional



hydrocephalus
action

ASBAH is working in partnership with Codman to promote 'Hydrocephalus Action', a campaign aimed at raising the awareness of hydrocephalus through many channels and events. This campaign aims to increase the

level of understanding amongst the general public, healthcare professionals and public policy decision makers throughout the UK. Look out for news and further information on the web site.



Graeme Loughlin, Codman's Market Development Manager for Europe, Middle East & Africa, told *Link*: "Despite the efforts of all shunt manufacturers and neurosurgeons treating hydrocephalus, complications remain a concern for all.

"We hope that the Bactiseal® Universal Shunt with its effective infection control and simple and proven shunt design will provide surgeons and patients with a treatment solution to optimize the management of risk of a shunt infection."

In 2000 Codman, launched a unique antimicrobial shunt catheter system aimed at reducing shunt infections.

These Bactiseal™ catheters have now been implanted in more than 120,000 patients around the world and several clinical publications have reported significant reductions in shunt infection rates with the use of these Bactiseal™ catheters (ref: Govender et al 2003, Sciubba 2007, Eymann 2008).

KEY POINT

- Effective infection control in a new shunt
- The professional area of the ASBAH website develops

Folic acid awareness campaign takes off

The Department of Health's long-awaited folic acid awareness campaign got underway in March to highlight how women planning a pregnancy should take a supplement before and after conception.

The campaign, delayed from its original launch last summer, comes as recent research, published in the British Medical Journal, revealed that still very few women planning a pregnancy take enough folic acid at the right time to make it effective.

For many years it has been well documented that a deficiency in folic acid is a major risk factor for neural tube defects (NTDs) such as spina bifida.

ASBAH is playing its role in the campaign and has put the campaign team in touch with five volunteer families, who have a child with spina bifida, to provide stories for women's magazines. Three leading magazines - More, Reveal and Closer – are publishing articles about the importance of taking folic acid supplements if planning a pregnancy.

It is also hoped that a host of other publications including Woman, Chat and Pick Me Up will include folic acid information and personal stories.

ASBAH is also promoting awareness by including a folic acid poster in a mailing to all GP practices this spring.

The campaign will be highlighted on the ASBAH website with the help of Professor Sir Nicholas Wald from the Wolfson Institute of Preventive Medicine.

Sir Nicholas, a long-time supporter of the flour fortification campaign, kindly agreed to be interviewed for a film clip for the website, answering ten of the most frequently asked questions about folic acid.

Mother Sonia Reains, whose son Dylan has spina bifida, also takes part in the film clip.

Sir Nicholas takes the hot seat

The new folic acid film clips on the ASBAH website feature an interview with Professor Sir Nicholas Wald from the Wolfson Institute of Preventive Medicine.

Sir Nicholas, a distinguished scientist who helped to prove that the vitamin folic acid can prevent spina bifida, anencephaly and other neural tube defects, kindly agreed to be interviewed for a film clip for our website.

He answers 10 of the most frequently asked questions about folic acid – three of which you'll see below.

Mother Sonia Reains, whose son Dylan has spina bifida, gives a mother's perspective, talking about her experiences and why she wishes she'd heard about the importance of folic acid.

If a woman or her partner have a family history of spina bifida, anencephaly or another neural tube defect should the woman take more folic acid when planning a pregnancy?

Anyone with a previous association with spina bifida and/or hydrocephalus should take a higher dose of folic acid – 4mg-5mg a day. The higher dose needs a medical prescription.

Other women can take a lower dose of 0.4mg each day. No prescription is needed and it is readily available at chemists and health food shops.

Is eating food which contains folate or which has been fortified with folic acid (such as some breakfast cereals) an alternative to taking a daily supplement as a tablet?

Eating foods which have been fortified with folic acid or a diet rich in folate is not a substitute for taking a folic acid supplement as it is extremely difficult to consume an adequate protective amount

Could someone get too much folic acid if they take a supplement and eat a diet rich in folate or folic acid?

Over-dosing on folic acid is extremely unlikely and has never been described in medical literature. Any woman eating a diet rich in folate, foods fortified with folic acid and taking a supplement, even at the higher dose, can be reassured that it is completely safe.

Sonia Reains is the mother of Dylan who has spina bifida and hydrocephalus.

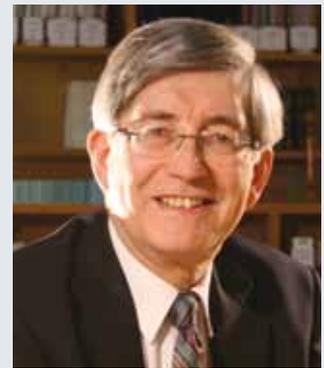
Did you know about folic acid before conceiving Dylan?

I'd never heard of folic acid until it was explained to me by my ASBAH adviser when I found out what was wrong with Dylan.

What is folic acid to you?

Folic acid is a means of preventing children being born with spina bifida, hydrocephalus and other neural tube defects (NTDs).

If I'd known how folic acid would have helped me I would have taken a supplement early on, but I didn't know anything about it.



Sir Nicholas Wald



Sonia and Dylan Reains

To view the Folic Acid film clips in full visit the ASBAH website at: www.asbah.org

YV website gets an upgrade



The Your Voice website has been revamped to make it more eye-catching and easier to navigate.

The new site was launched in February on its second birthday and has all the features of the previous website including the popular forums, where members can discuss any issue or subject with other YV members.

Also on the site are details of forthcoming events, advice and support on medical issues and lifestyle matters, a list of all the committee members, and much more.

Marketing and Communications Manager, Gill Winfield said: "The new-look website is brighter and more user-friendly than the previous website and has more capacity so we can expand it easily, as and when needed.

"We hope it will attract other adults with spina bifida and/or hydrocephalus to find out more about YV."

Check it out yourself at: www.yourvoicegroup.org

New face at Your Voice

Mark Harris has joined the ASBAH team as the new Your Voice Development Officer.

Mark, who formerly worked for the NHS as an electronic document management clerk, took up the position in early January. "I was looking for a new challenge and this position really appealed to me," he said.

His first few weeks were filled with all the admin associated with the revamp of the website, his first YV Committee meeting and the Cultural Diversity event in Greenwich planned for April.

Mark, who works on Mondays, Tuesdays and Fridays, said: "I attended my first YV committee meeting in January where I got the chance to meet the members and become more familiar with their work.

"I've obviously got a lot to learn and at the moment every day brings a fresh challenge, but everyone has made me feel very welcome and I'm really enjoying the job."

Your Voice members can contact Mark by calling 01733 421322, or email him at: markh@asbah.org

Your Voice presents

Open to all
over 16

Have a Lifestyle of Leisure

Date and venue:

Saturday 12 September 2009
Holiday Inn
Cardiff Bay
Cardiff

Book NOW

**£35 includes: workshops,
lunch & refreshments.**

About this event:

This event is to be run as a regional event, with people from throughout Wales attending. Disability Sport Wales will attend showing what leisure pursuits are available in Wales.

It is also hoped to have Wales Paralympians there and for them to share their experiences in being involved in Leisure in Wales.

For further information and to register your interest contact:

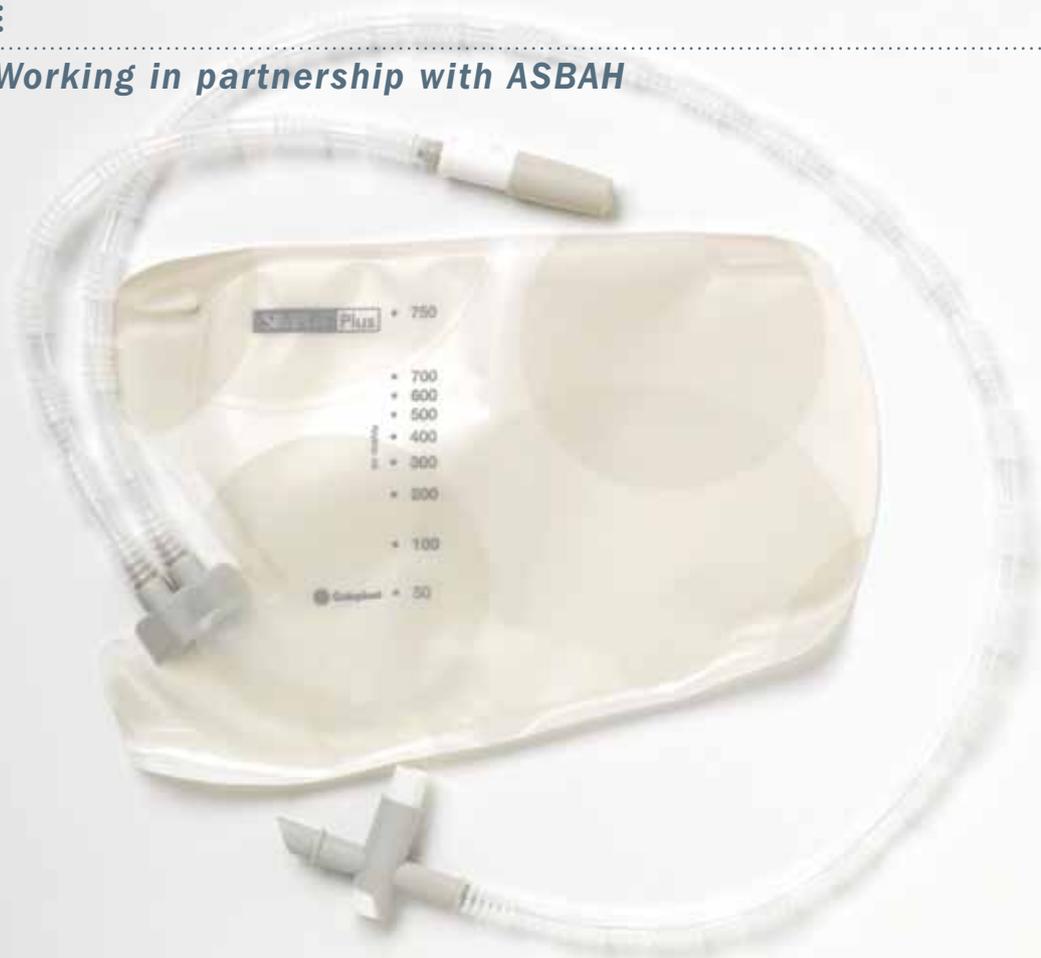
Mark Harris
ASBAH House
42 Park Road
Peterborough PE1 2UQ
Email: markh@asbah.org
Telephone: 01733 421322



Registered charity no. 249338

The delegate rate is being subsidised by Your Voice

Your Voice event: 'Celebrating Diversity' see inside front cover for more details



Discover Confidence

Coloplast tell us about their Simpla range of urine drainage bags which was first introduced over 25 years ago. Since that time there have been many developments to the Simpla range, new ranges have been introduced and various accessory items have been designed to ensure maximum discretion and comfort.

Our more recent urine drainage bags (*Simpla Profile* and *Simpla Plus*), are manufactured from strong, more environmentally-friendly materials which help to contain odours and incorporate some excellent features to make the system as trouble-free as possible.

- A needle-free sample port which is integral to the ridged-connector means the healthcare professional can take a safe urine sample, without the risk of a needle-stick injury. (*Simpla Profile* only).
- The anti-kink tubing is designed to ensure urine always flows down into the bag, even if the tube has kinked over, the urine will still flow into the bag.
- A sophisticated non-return valve is found

at the neck of the urine drainage bag and helps to prevent the backflow of urine up the anti-kink tubing, thus reducing the risk of infection.

- The fabric backing is designed to absorb any sweat and to reduce skin irritation, whilst ensuring the bag remains comfortable against your leg. You can still shower wearing the bag and simply pat the fabric backing dry with a towel.
- Multi-chambers in some of the ranges keeps the urine bag flat against the leg, ensuring it fills up evenly and reducing the sloshing noises.
- A variety of outlet taps are available and so whether you prefer a lever tap, slide tap, safety-lock tap or dial tap, the choice is yours! You can find what works for you!

In addition to all these features, and depending upon your lifestyle, you have a variety of sizes to choose from – 350ml, 500ml and 750ml leg bags are available. We can also provide you with specialist urine

drainage bags, such as the *Simpla Plus Syphon* and *Simpla Plus Knee* bag.

The *Simpla Plus Syphon* bag features a simple to use slide-action tap designed for both wheelchair users and for those with limited dexterity or balance providing greater independence and freedom. Worn on the upper thigh and with a larger capacity of 750ml the *Simpla Plus Syphon*



continued from previous page

bag offers greater flexibility, allowing the user to empty the bag at more convenient times.

- The unique syphon 'self-emptying' system gives greater independence by removing the need to bend down or lift the leg to empty the bag and as a result reduces the likelihood of spillages
- The anti-kink tubing and Non return valve allows continuous free-flow and no back-flow of urine
- A 750ml capacity provides greater flexibility between emptying allowing the user to choose when to empty the bag

The *Simpla Plus Knee* bag has been specifically designed for chair users who require a bag with a larger capacity that matches the profile of the users leg. With a capacity of 1500ml the *Simpla Plus Knee* bag offers greater flexibility, allowing the user to empty the bag when they choose to, not when they have to.

- The larger 1500ml capacity provides greater flexibility between emptying offering flexibility and choice
- Shaped to follow the lines of the user's leg for greater comfort and discretion
- The two stage 'safety-lock' tap designed to reduce the likelihood of accidental opening promoting security and peace of mind
- The anti-kink tubing and non-return valve allow both a continuous free flow and prevents the back-flow of urine
- The chambered design for greater discretion and the reduction of noise

For more information, or to receive a free sample of any of the items above, please call Charter Healthcare on freephone 0800 132787 and one of our customer care team will arrange for you to receive a complimentary sample.

KEY POINT

- **New continence information sheet now available: Bladder Augmentation - part of ASBAH's continence pack**

New continence leaflet offers information and advice

ASBAH had added a new leaflet on bladder augmentation to its range of continence publications available through the helpline and the website.

Bladder augmentation is a method of helping to manage continence and this operation may be suggested if someone needs to pass urine very often, or feels an urgent need to pass urine. Patients who have recurrent infections may be offered this treatment, if their urologist is concerned about their kidney function.

The operation is usually offered after other, less invasive, treatments haven't worked.

Bladder augmentation has been used for a number of years to improve the situation for people with this type of bladder problem (hyperreflexic bladder).

By adding a piece of clean small intestine, the bladder capacity can be increased and the tightness of the bladder muscle can be reduced.

During the operation, the surgeon will

make a cut along the top of the bladder, to form an opening like a clam shell (it is referred to as a clam cystoplasty).

Into this space, a length of the small bowel, which has been cleaned, will be sewn to form a large patch, so the bladder will be larger and able to hold more urine.

The contractions of this altered bladder will also be reduced, so the high pressures within the bladder, which can harm the kidneys, will be prevented.

A bladder augmentation operation is major surgery with a hospital stay of around 10 days. The recovery period is long too - patients usually won't feel fully well for around three months.

The leaflet can be downloaded from www.asbah.org/Spina+Bifida/continence/continenceinfo.

Anyone offered this surgery should also speak to their surgeon, continence adviser and ASBAH medical adviser if they need more help and information.

A number of other useful and informative information leaflets about continence issues are available on the ASBAH website - www.asbah.org/Spina+Bifida/continence/continenceinfo. All pages are available in a printable PDF format.

The leaflets available are:

1. Adaptations for Toileting
2. Antegrade Continence Enema (ACE) Procedure
3. Artificial Urinary Sphincter (AUS)
4. Bladder Augmentation
5. Botulinum Toxin - A Treatment for Neuropathic Bladders
6. Clean Intermittent Self-Catheterisation
7. Colostomy, Ileostomy Urostomy and Vesicostomy
8. Continence Issues for Adults with Spina Bifida
9. Continence Management
10. Dietary Advice
11. Mitrofanoff Procedure
12. Tests and procedures used to check function of the urinary system
13. Toilet Training and Hydrocephalus
14. Toilet Training and Spina Bifida



Buy Online

ASBAH has recently introduced an additional feature to its online publications sales.

Now you can order and pay online for all our publications using debit cards as well as credit cards at www.asbah.org just go to the home page and click on 'publications'.

There's a wide range of literature available on all aspects of living with the disabilities and the new series of booklets on transition and employment (see page 16) are the latest addition but it's worth taking a look to remind yourself of the different titles ASBAH produces.

For example, our Below the Belt book which looks at continence issues, relationships and much more for teenagers with spina bifida and hydrocephalus. This has just been reprinted, due to popular demand.

The continence pack has been fully updated and contains leaflets on all aspects of continence management, including ACE, adaptations for toileting, artificial sphincter, toilet training, CIC and, just added, bladder augmentation. You can buy the complete set but you can also download any of the sheets for free from the continence section of the site.

Hydrocephalus and its implications for teaching and learning, aimed primarily at teachers, is already being ordered online by teachers, and parents might want to make their child's teacher aware of its availability.

For young people thinking about applying for further or higher education courses, Leaving Home for University or College, could be a very useful booklet – again this can be ordered online.

Readers can also get our free information such as the Need to Go card, designed to make it easier to access toilet facilities for those with spina bifida or hydrocephalus.

For a full list of books, booklets, leaflets and other items see the listing on the website but if you prefer not to go online, call the helpline on 0845 450 7755 who have more information on all of the above and can process your order over the phone.



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.

During 2008 I experienced problems with faulty batches of a urostomy product I use.

The faulty products impacted heavily on my busy lifestyle - leakage of urine, worry and embarrassment about odour, extra washing and changing the appliance several times a day, the wet beds and the restriction on where I could go. The effect on the quality of my life was immense.

My pharmacist gave me a leaflet for MHRA, the Medicine and Healthcare products Regulatory Agency so I could make a complaint.

The outcome was not what I'd hoped for as the manufacturer was asked to test the product but could not find a fault, but I'd still like Link readers to be aware of the MHRA.

Name and address withheld
 The Medicines and Healthcare products Regulatory Agency (MHRA) is a government agency which is responsible for ensuring that medicines and medical devices work, and are acceptably safe. For more information go to: www.mhra.gov.uk or email info@mhra.gsi.gov.uk. Alternatively, call 020 7084 2000.

I would like to hear from anyone born in the late 1960s who has a VA Holter Shunt. Mine has since failed and has resulted in further surgery for my hydrocephalus, which I've had since birth. I also have Chiari 1 Malformation and seizures.

Emma Bosworth
 Anyone wishing to contact Emma should contact the Editor at the usual Link address.

Diary dates

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

Dunstable Support Group

For people with spina bifida and/or hydrocephalus and their carers. Meets: 1-3pm, usually on the second Monday of each month. Where: Disability Resource Centre, Poynters Road, Dunstable.

Dates for 2009:

11 May

8 June

13 July

Please come whenever you can. While there is no crèche, young children are always welcome.

Contact: Valerie Bottoms on 01582 757745

Suffolk / Norfolk Spina Bifida / Hydrocephalus Support Group

This group for adults with spina bifida and/or hydrocephalus and their carers meets every two months. Parents of teenagers with spina bifida and/or hydrocephalus are also very welcome. There is ample parking and disabled access at the hall. Do come and join us for tea/ coffee and a chat. Area adviser Val Meyer-Hall attends meetings whenever possible

Where: Roydon Village Hall, High Road, Roydon, Nr Diss, Norfolk.

For further details please contact Margaret & Alan Twyford on 01728 860916 or by email twyfords@aandmtwyford.plus.com

Northern Region York Drop-in 2009

Where: Low Moor Community Centre, Bray Road, Fulford, York YO10 4JG.

When: Second Wednesday each month -

13 May

10 June

8 July

Time: 10.15am - 12 noon.

For further information please contact the Northern Region office on 0113 255 6767 or email nro@asbah.org

Your Voice presents:

Celebrating diversity

Location: Forum, Greenwich

Date: Saturday 18 April 2009

Have a lifestyle of leisure

Location: Holiday Inn, Cardiff Bay

Date: Saturday 12 September 2009

Contact Mark Harris on 01733 421322 or email markh@asbah.org for information on all Your Voice events.

ASBAH AGM 2008

Date: Saturday 26 September 2008

For more details please contact Lyn Rylance at ASBAH by calling 01733 421356 or email lynr@asbah.org

Exhibitions:

Naidex

The UK's largest event for homecare, disability and rehabilitation.

When: Tuesday 28 April - Thursday 30 April

Where: NEC Birmingham

For more information contact: www.naidex.co.uk

Mobility Roadshow

A showcase of mobility and lifestyle products and services.

When: Thursday 4 June - Saturday 6 June

Where: Kemble Airfield, Cirencester, Gloucestershire

For more information contact: www.mobilityroadshow.co.uk

Please e-mail the editor (Link@asbah.org) with dates of your events for the next issue of *Link* by Friday 15 May 2009, giving the name of event, purpose, location, date, cost (if applicable), contact name, phone no. and email address.

Holiday lets

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

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

ROPERS WALK BARN, MOUNT HAWKE, TRURO, CORNWALL

Single storey accessible barn converted to a high standard. Visit Britain Mobility Level 3A & 4* Quality ratings. Sleeps 4/6 + cot. Short level walk to village, close north coast, 8 miles Truro.

Details: Liz/Peter Pollard, tel. 01209 891632

Email: peterandliz@roperswalkbarns.co.uk

Web: www.roperswalkbarns.co.uk



PRESTATYN, NORTH WALES

An adapted caravan for disabled holiday makers. Sleeps 6 people (2 wheelchair accessible bedrooms), wheel-in shower with seat, open plan lounge, dining, kitchen area. Caravan has ramp access and is 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 £130-£350 per week for members and from £150-£425 per week for non-members; for further information contact North & West Yorkshire ASBAH, c/o ASBAH North, 64 Bagley Lane, Farsley, Leeds LS28 5LY Tel. 07989 2453994, e-mail nandwyasbah@aol.com

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 15th May 09

Please send to: Editor, ASBAH
42 Park Road, Peterborough PE1 2UQ.
Tel: 01733 421361. Email: link@asbah.org

ASBAH offices

ASBAH
42 Park Road
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Tel: 01733 555988
Fax: 01733 555985
Email: info@asbah.org

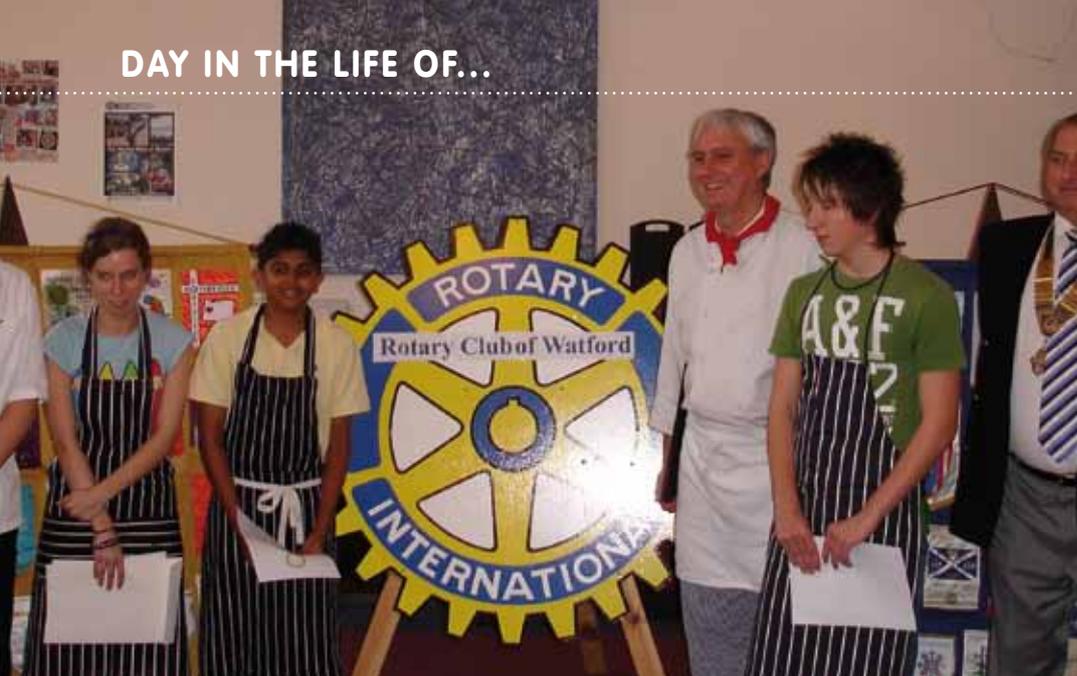
ASBAH EAST
42 Park Road
Peterborough PE1 2UQ
Tel: 01733 421309
Fax: 01733 555985
Email: ero@asbah.org

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

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

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

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



Cooking his way to success

Prashant Patel

Talented chef Prashant Patel beat dozens of other young hopefuls to earn a place in the local heats of Rotary Young Chef 2008.

Prashant, 13, who has hydrocephalus, was selected from 40 children at his school to go forward in the competition.

With the help of Mum Ela, Prashant planned a tasty three-course meal to cook after winning a place in the local final held at Watford's West Herts College.

The participants prepared a healthy meal for two people showing their ability to be creative without needing expensive ingredients and following the principles of a healthy diet.

The young chefs were judged on their healthy menu, planning and organisational skills, hygiene, preparation skills and, of course, the taste and presentation of the final dishes.

Prashant, from Stanmore near Harrow, was the youngest entrant and impressed judges with his creative cooking, planning and organisation which earned him a

respectable third place position.

He said: "It was great fun and I really enjoyed myself. I felt a bit nervous but it all went very smoothly. I managed to pace myself quite well so I finished with some time to spare.

"My Mum helped me to decide on the recipes and I practiced them a few times at home before the actual competition."

We are very proud of Prashant. He organised himself really well and was very prepared.

He explained: "I chose a starter with goat's cheese because my Dad is allergic to cow's milk, so it was something he could eat. The Mexican Quorn recipe I liked because it was a little bit different."

Ela told *Link*: "We are very proud of Prashant. He organised himself really well and was very prepared. He did very well winning the school heat especially as he was one of the youngest.

"At the local heats he had two and a half hours to prepare the meal and he finished with time to spare. We were thrilled with his efforts."

Prashant's winning menu

Starter – Wild rocket and goat's cheese salad served with cracked black pepper and olive oil.

Main course – Mexican-style Quorn with mixed peppers and onions served on a bed of rice and peas.

Dessert – Strawberry cheesecake

For more information go to www.filippoerio.co.uk/ryc



- Preparing a healthy, inexpensive meal
- Enjoying cooking, striving to become a young chef



Contacting ASBAH

NATIONAL OFFICE:

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Cambridgeshire PE1 2UQ
Helpline: 0845 450 7755
Fax: 01733 555985
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ASBAH NORTHERN REGION OFFICE:

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The Rotary Young Chef competition

The Rotary Young Chef competition, now in its 9th year, promotes the importance of healthy eating and the fact that healthy food doesn't need to be complicated to cook.

Students are tasked with creating, organising and preparing a well-balanced three-course meal, which has to not only taste and look great, but also has to follow the principles of a healthy diet.

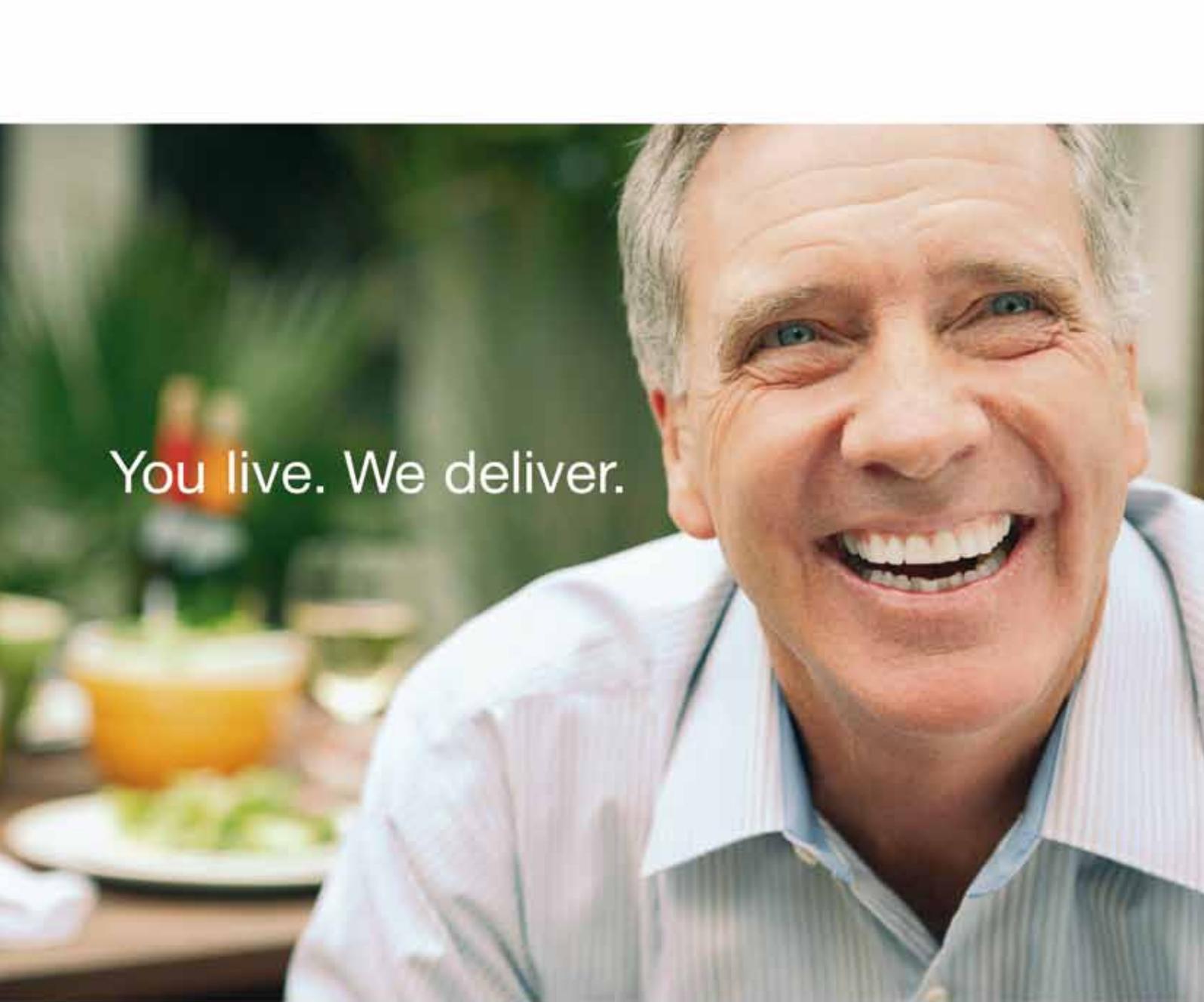
The competition, open to all secondary school children in the UK and Ireland aims to encourage more young people to experience the enjoyment of cooking and to understand the importance of a healthy diet.



Upholds the quality standards of the ASBAH Local Association Compact

Local Association secretaries requiring changes to this list should contact: *Link* magazine, 42 Park Road, Peterborough PE1 2UQ
Tel 01733 421361 Email Link@asbah.org

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