Together

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and much more ...

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It's hard to believe that we are already well into January 2012 and here at **Shine** we are already planning a great year of action and activity.

In this issue of *Together* you will be able to see the success of our launch last October. It really was a great time of celebration and everyone involved sensed the progress that is being made. Last year also saw the launch of the first **Shine** Awards event and you can see our winners in all their glory on page 14.

Our new Membership Development Officer, Gobi Ranganathan, has his first reflection on a whirlwind start to his time with **Shine**, you can read all about his new work on pages 16 and 17.

We have plenty of news, views and information, including how to get involved with social networks such as Facebook (see page 13), and all the latest fundraising initiatives.

We are as keen as ever to hear what you have been up to and what you would like to see here in *Together*, if you would like to share anything then please contact me at **tom.scott@shinecharity.org.uk** - I'd love to hear from you.

Tom Scott

Editor

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Submission dates for Spring Edition
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info@shinecharity.org.uk **www.shinecharity.org.uk**

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A focus on your health

Shine's first ever comprehensive Health Survey of its members with spina bifida brought in 510 responses which is an incredibly helpful result.

The survey was included in the last edition of **Together** and members from all over England Wales and Northern Ireland shared their health information and concerns in order to help us build up an accurate picture of what people are dealing with day to day.

The survey now has to be fully analysed but we already know from those we have read that many members and parents are hugely concerned about aspects of their health. Amongst common concerns are a general 'fear of the future' and a lack of understanding of spina bifida on the part of many GPs.

It is not too late if you received a survey to fill it in and send it to us – the more we get the more accurate our information will be.

When we have more detailed results and insights we will include them in a future issue of Together.

Please note: If you have hydrocephalus only you will be receiving your own health survey in the next issue of Together.

All the entries received by the 19th December (the official deadline) were entered into a draw for £100 and £50 prize. The winner of the £100 prize was Dorothea Frances Pratt and the £50 Patrick Bailey. Congratulations to both winners!

Doctor, Doctor!

Shine would like to congratulate Dr. Joanna Smith on successfully gaining her PhD which focused on parents' management of their child's hydrocephalus and shunt awarded by the University of Leeds. As part of her research Dr. Smith interviewed Shine members in the Northern region,

Dr. Smith's thesis explored the experiences of parents living with a child with hydrocephalus and the contribution of parents and professionals to the diagnosis of shunt malfunction in acute hospital admissions.

Dr. Smith is currently a lecturer in Children and Young People's Nursing at University of Salford.

Explosive events!

A new mobility event is taking place at Explosion from Tuesday 28th February to Thursday 1st March 2012. Wheelchair users and their carers will be entitled to complimentary entry.

The event will be based throughout the atmospheric site that is part of the Historic Dockyard complex in Gosport. With a delightful café that overlooks the waterfront towards the Spinaker Tower and buildings dating back to a bygone era, the Museum features a number of interactive exhibits that demonstrate various dramatic aspects of firepower. The displays, café and museum are all indoors and Gowrings will have a range of vehicles on display around the site.

The aim of the roadshow, sponsored by Gowrings Mobility, is to inspire people with disabilities to experience attractions and places of interest they may not have otherwise considered. Stopping at top venues across the UK this year, including London and Bristol Zoos, Woburn Safari Park and the National Space Centre, the events are expected to attract many visitors.

Visitors wishing to take advantage of this offer during the Roadshow should request an invitation in advance from Gowrings Mobility by calling Janet Seward on 0845 608 8020.

Lord of the rings!

At the end of last year teenage baller Karl Hassel was appointed as a Sports Ambassador for the Lord's Taverners. The aim of the role is to promote disability sports and help raise the profile of the Taverners and the work that they do. This is a great honour for Karl, as the other wheelchair basketball players are all GB Under 22's.

Natalie Povey Update

Natalie Povey is continuing her success with horse Fizz. Competing at both the KBIS National Para Dressage Championships, and the Dressage Deluxe British Dressage National Championships, Natalie and Fizz won the Grade 1b championships with 68.55% and came sixth over all in the Championship class in which there were a total of eighteen riders. Keep it up guys!

Scott Nielsen – Video link and Award

For those of you who would like to hear more about Scott Nielsen's epic cycle ride last year checkout this link to an interview Scott recently had with Shine - http://youtu.be/z9va_IGuNOI or use an app on your phone to let this QR code guide you there –

The challenges and benefits of employment

Shine Health Development Manager Gill Yaz offers employment advice to Shine members

Shine Health Development Manager, Gill Yaz

Employment comes up time and time again as the biggest worry in my work with adults with hydrocephalus; finding work, dealing with new bosses, getting the right equipment, and many other issues all arise regularly, and the effects of hydrocephalus often make the world of work quite complicated.

So here are the most common problems I come across and some suggestions to think about.

Why work at all?

Work needn't be paid work, voluntary work can be just as rewarding. Work can give a structure to your week, a reason to get up, showered, dressed and leave the house. It gives opportunities to meet new people, (and hopefully have a bit of a laugh).

On the money side, you shouldn't really get less than your benefit payments, and you might end up with more! Earning your own money can be good for your self-esteem.

Don't wait until you feel more confident – we get confidence by doing the things we think we can't do, and the longer you wait, the less confident you'll feel.

Finding work

When you choose courses, careers or jobs to apply for, try asking someone who knows you well to help you decide if this is right for you. People often find it hard to know their strengths, or things they find difficult, and its no different for those with hydrocephalus. If you talk about it with someone, it will help you aim for jobs that suit your skills and personality.

If you have been out of work for many years, you may need to think about retraining; work itself is changing, especially in manufacturing, and you might not find similar jobs any more. Be positive when you apply, let the company know that you can do the work but that you may need some adjustments to let you achieve your potential.

Companies have to make 'reasonable adjustments' for people with disabilities under the Disability Discrimination Act; these can include changes in shift patterns, or extra 'acceptable' Sickness Absence, as well as addressing any access issues. 'Access to Work' may help with travel or equipment.

At work

People tell me that these things:

1. Remembering what they've been told
2. Handling interruptions
3. Multitasking

are their main problems at work. Don't be afraid to let others know how you work best. For example, asking for a desk in a quiet part of the office, carrying Post-its with you for people to write messages on, or asking colleagues to email you messages rather than just telling you, can all save interruptions.

Let others know how they can be a support to you. You might find that constantly asking if you are OK breaks your concentration, for example, but unless you tell them calmly, they won't know. Make sure your day has a definite structure, so you know exactly what you're meant to be doing and when, especially if you have difficulties making decisions or getting started.

Plan any personal care needs around your working day. If you know you'll be busy at a time you'd usually catheterise, do it earlier so you can be ready to work when you are needed.

It may be that the challenges of getting through an ordinary day are enough, without adding work on top, or maybe your health won't allow you to work at the moment, but if you can, the benefits of work really go beyond money!

To contact Gill please email:
gill.yaz@shinecharity.org.uk

Useful links

www.remploy.co.uk
www.disabledworkers.org.uk
www.abilitypath.org

Get *Shine On* your gift list

Shine is delighted to announce a new partnership with jewellery makers Sphere of Life.

To celebrate their pendant design ***Shine On***, Sphere of Life are now offering a 25% donation to **Shine** from the sale of each pendant.

Shine On is a sterling silver pendant with 18ct gold plating on a 16”-18” chain. This is a great way to give both a beautiful gift and make a generous contribution to **Shine**.

To order simply log on to
www.mysphereoflife.com/products/Shine-On
or call 0800 652 7211

Working it out

Shine member James Tadd, who has hydrocephalus, on the life changing opportunities of training and employment …

I'm a Junior 2nd Line Office IT Engineer. I started my career in May 2007 with a company who were prepared to give me the vital experience I needed in the area of technical support. I left this position in January 2009, due to the economic down turn, which was a real disappointment for me but I'm extremely grateful for the opportunities the experience generated.

Unfortunately I then spent a year unemployed due to the extremely competitive nature of technical support. I came to the realization that I didn't have enough qualifications to stand out. This is something I now regret as I was strongly advised to do something about this by a former colleague while I was still in employment.

In February 2011 I was given the opportunity to become an apprentice with a social enterprise group who's aim was to get young people aged 18 - 24 out of unemployment and, furthermore, keep them out of unemployment. This for me was a huge opportunity and one which has dramatically changed my life.

The apprenticeship gave me the opportunity to get some Microsoft & CompTIA qualifications, these qualifications are recognised qualifications in the technical support industry.

I left that job back in July due to the government cutbacks but fortunately I am now back in the corporate sector and have my first permanent job in technical support.

James winding down after a hard day's work

Life. Story.

Eva Story with Dad, Ben

Words and images by Tom Scott

At only 28 weeks old, baby Eva is already developing quite a life story.

Eva was born in Giessen, Germany in October of 2011 to parents Anna and Ben. But this was no ordinary birth. Before entering the world Eva underwent an operation to treat her myelomeningocele.

The discovery at Anna's 18 week anomaly scan in England, where the family were living at the time, that her baby had spina bifida led her and her husband to embark on a rapid journey in which they would have to decide on the best course of action to benefit their growing child.

From their base in the remote South Pacific Island of Vanuatu, Anna and Ben have come a long way in the past year. Now living with family near Northampton, and contemplating a move to the States, the family are reflecting on what has been a testing year for everybody involved.

Options

After learning that their baby would have spina bifida, Anna and Ben, like all parents in their situation, embarked on steep learning curve as they explored all of the options available to them.

As well as the traditional procedures, in which the baby is operated on through open surgery immediately after birth, Anna and Ben read of a pioneering approach under development at the German Center for Fetal Surgery and Minimally Invasive Therapy at the University of Giessen, Germany and were referred there, after consultation, by their doctors in Oxford.

Pre-natal surgery

The technique, which is practiced at the Center by Dr. Thomas Kohl, involves a repair to the lesion through keyhole surgery using a Gore-Tex patch to treat the affected area.

As **Shine**'s Principle Health Advisor Rosemary Batchelor explains, *'The theory is that, by operating pre-natally, damage from the spina bifida is limited. In particular, babies operated on between 22 and 26 weeks gestation are expected to have a lower incidence of hydrocephalus and* *are said to be better neurologically.'*

With time racing away the Story's opted for the surgery with Dr. Kohl in the hope that their baby would benefit from the new approach.

Anna flew to Germany with husband Ben and their son, Simon, expecting to be there for two weeks. During this time her unborn baby would undergo her operation at 25 weeks gestation and have time for recovery. The family would then return to the UK for the birth at the John Radcliffe Hospital, Oxford.

Complications

Having already experienced a dramatic birth with their first child, Simon, in which they were flown from Vanuatu to Australia for a premature birth, Anna and Ben knew all about unpredictable birth plans.

The 5-½ hour surgery was very complicated and, to add to the strain, Anna subsequently contracted the E-coli virus which led to Eva being born 8 weeks prematurely. The initial two week stay became three months, with Eva also having an ETV (Endoscopic Third Ventriculostomy) which failed, and was then followed by a shunt being fitted for her hydrocephalus upon their return to England.

Finally, after all of the dramatic events, the family were back safely in the UK with their beautiful baby girl.

The Future

Eva is a part of an unfolding story, the surgery she received in Germany is in the early stages of development and surgeons in the UK are watching the trials in Europe and in the US based MOMS (Management of Myelomeningocele Study) programme carefully before moving forward.

Eva's older brother Simon

In the meantime Eva and her family are welcomed new additions to the Shine community, with yet another fascinating story to tell. We look forward to hearing more about Eva's progress as she grows up.

Still so much to discover …

'In 1994 doctors began trying out various methods for closing [the gap created by] spina bifida while the baby is still in the mother's womb. Since that time, many improvements have been made in the procedure. It is still not known, however, whether it is better to operate on a baby with spina bifida before or after it is born.'

[Source:**http://www.spinabifidamoms.com**

In the next two years there are planned trials for prenatal surgery in both Belgium and Holland.

Shine Launch

Our charity launched its bright new future on October 20th last year with a sparkling launch event at our Peterborough HQ. Patrons Danny MIlls and David Proud joined Trustees, staff and representatives from affiliated associations as well as members from all over the country. At the same time **Shine** Northern Ireland was launched with three separate events and in our Leeds Office there were more cakes and launch celebrations a week later. Over 100 people who couldn't attend followed the celebrations live on Facebook.

Policy Adviser Laura Read shares a joke with guests

Shine Patron, actor David Proud with one of the London group 'Blue Blobbers'.

Benny Bear helps launch Shine with Patrons, members and staff

Chair Richard Astle and Patron Danny Mills

Alan Mostowyj baked a special Shine cake

Member and fundraiser Scott Nielsen chats to friends

SAMC member Geraint Catheral sports a Shine-yellow shirt

Dipa of Vitabiotics with staff

Member Heather Harmer and young fundraiser Aidan Fincham unveil the Shine logo

Member Jason Merille and friends

Member Brian Treadwell (right) spoke movingly

Member Rebecca Morris made the Shine North cake

Media Officer Darren Fower shares the event live on Facebook

SAMC member Amar Dhugal

Young Shine members Rachel Linney and Robert Whittle

Young members Emma and Tariq help councillor Lucinda Yeadon cut the Shine North cake

Jackie Bland and members at Shine North launch

A gift from the Royal Pigeon Racing Association

Young members share a moment at the Northern launch

Welcome to 2012! Here is the latest news from your SAMC ...

SAMC Meeting November 2011

The SAMC met at Shine Head Office on Saturday 26"‘ November 2011, welcoming some Shine staff to the meeting, namely Trusts & Legacies Manager Monica Evans, Policy Adviser Laura Read, and Administration Assistant Lynn Hart, also in attendance was David Isom, Development Manager HQ Services & Eastern Region. It was great for everyone to see what we as a group are about. The ladies enjoyed it that much they said they would like to be invited again.

Developments

Over the coming months SAMC members Amar Dugal, Amy MacGibbon and Geraint Catherall are going to be working with Darren Fower; Media Development Officer, on the **Shine** website. I will keep everyone up to date when I have more information. We are also trying to gather suggestions for SAMC events in 2013; watch this space for developments Spring 2012. It was also agreed to invite Marketing & Communications Coordinator Tom Scott, and Finance Director Margaret Conner, to a future meeting. At the latest meeting, which was held on Saturday 21st January 2012 at **Shine** Head Office, we were joined by Shine CEO Jackie Bland, and Membership Development Officer Gobi Ranganathan.

Family Opportunity Weekend 2012

Liz Potts will be the SAMC representative at the Family Opportunity Weekend which will take place from Friday Sunday 18th March at the Britannia Hotel, Leeds. I would also like to congratulate Liz on behalf of SAMC on her new role as Shine Support & Development Worker for the North & West Midlands, Liz will be working 7-8 hours a week.

New Member

Our new member is Lisa Law, who is 26 and comes from Antrim, Northern Ireland. She is already very involved with **Shine** and was one of the speakers at the launch of **Shine** in Northern Ireland, at which delivered the speech, My Experience of living with Hydrocephalus. Lisa is passionate and committed to promoting the education of others about equality and social inclusion for people with spina bifida and/or hydrocephalus. Lisa has a 2:1 BSc Hons in Psychology and a GNVQ and an AVCE in Health and Social Care. So, on behalf of SAMC, I would like to welcome Lisa on board and I'm sure she will be a great asset to the team. Lisa will be attending her first meeting on Saturday January 2012 at **Shine** Head Office.

Get in Touch

As always, if there is anything you would like to see your SAMC doing or we can be of any help in anyway, please let me know by emailing me at:
mike.bergin@shinecharity.org.uk.

Until the next time take care.

Michael Bergin
Communications Officer SAMC

Your guide to Social Networking – Come and join us!

With so many conversations now taking place over the internet, for some, getting involved can seem daunting. Here we have compiled some simple explanations of different applications and how to start using them.

facebook

Facebook is a place to share; what you've been up to, a link to something you like on the internet, a photo/video or simply message with other people who are also members. Or you can simply use it to see what your contacts are up to!

Once you have registered with Facebook you can then search for your friends and family members and 'Friend' them.

Once you have found your friends you might like to join a few of these friends through the 'Groups' section – you can even create your own group.

There is always a steady stream of stuff flowing through and all the updates telling you about this appear on your 'Wall', a space that shows you everything that is going on.

To sign up simply type in: **http://www.facebook.com** and fill in your details. You can then join the **Shine** Facebook page, by searching for **http://www.facebook.com/SHINEUKCharity** and pressing the 'Like' button, this way you can keep up to date with everything that is happening in the organisation.

twitter

Twitter allows you to write short sentences, of no more than 140 characters, about anything you care to mention. It also allows you to share links and photos.

If you want, you can then label, or tag, your Tweet with a topic – e.g. #spinabifida, so that others can see that your message is related to a particular subject or category.

In addition to this you can direct the Tweet at someone else by putting the @ sign before their username – e.g. **@SHINEUKCharity.**

To join Twitter simply type **http://twitter.com** and fill in your details. You can then search for **Shine** by typing **SHINEUKCharity** into the search box and pressing the 'Follow' button.

YouTube
Broadcast Yourself™

YouTube is an online facility which allows you to search and watch almost anything you can think of. Simply type what you want to see in the search bar and thousands of results will appear. So, whether its music videos, adverts, new skills or funny clips YouTube will have something to keep you informed and entertained.

To visit the **Shine** YouTube channel simply enter **http://www.youtube.com/SHINEUKCharity** and start viewing!

Most mobile devices now allow you to view content and post updates to both Facebook and Twitter from your mobile phone.

Nicky Boyle
today is grace and harrys first day at pre-school, they are 3 grace is SB and Hydro she had a cord detether last february and has astonished all her doctors with the progress shes made x

Unlike · Comment · about an hour ago

You and David Isom like this.

David Isom Lovely Nicky, Shine is always here to support you if you ever need us, has Grace joined the Benny bear club.
23 minutes ago · Like

Write a comment...

Shine Awards

The Professional Award went to Paediatrician Nan Hill from Northern Ireland

The first **Shine** Awards were presented at the AGM on November 19th. The Awards recognise outstanding achievements and contributions within our **Shine** community. This year the Lifetime Contribution Award given to **Shine** Vice-Chair Austin Crowther for his many years of dedication.

Shine vice-chair Austin Crowther with his Lifetime Contribution Award

Theresa Goldsmith was Shine Fundraiser of the Year

Maureen Jobson from Shine accepts the Unsung Hero Award on behalf of Shine volunteer Jo Pugh

Scott Nielsen was voted Young Achiever for 2011

Water way to go!

Super cyclist Holly Cobb completed an 8.7 mile sponsored bike ride around Grafham Water with her Mum, Diane last October and raised a tremendous £109.00 for **Shine**. Holly, who is 9 and lives near Papworth, thoroughly enjoyed the experience, she says 'I did the ride because **Shine** is a charity close to our hearts, it was for a good cause and my sister, Sarah, has hydrocephalus.' Great work Holly!

We are family

Here at **Shine** we are privileged to gain support from a few very special families that go to great lengths to fundraise for us. The Thomas family from **Melton Mowbray** is one such family. Last year Anne, Alan and twin daughters, Lucy and Ella, raised £796 and have raised over £2000 since getting involved.

Among their activities the family have been involved in a marathon, a village music concert and **Shine's** 2011 Christmas card competition.

We really appreciate everything the Thomas family are doing for **Shine** and look forward to a great 2012 together!

Benny Bear's Birthday

Why not combine learning, fun and fundraising in celebrating the birthday of Benny Bear?

A Benny Bear's Birthday party is simple and flexible to organise ... you choose the date of the birthday celebration, choose from our range of activities and off you go!

To take part please call: 01733 421329
Email: cerys.long@shinecharity.org.uk
or visit Benny's website
www.bennysbirthday.co.uk

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

Life is about transitions ...

complete the London Triathlon for Shine & help babies, children & adults with spina bifida & hydrocephalus progress through their challenges successfully.

Entry fee: *£75 including your own Shine running vest*
Min. sponsorship: £500
Free gift: Raise £1000+ & get a personalised Shine hoodie

To find out more call Cerys on
01733 421329 or email
cerys.long@shinecharity.org.uk
or visit shinecharity.org.uk/triathlon

Reg. Charity No. 249338

Gobi's Gossip!

Just when you thought it was safe to read Together again without seeing my face plastered everywhere, I'm back again in this New Year edition with the first of many articles for Together.

It's been a fast and furious few months here with the **Shine** launch events taking place across the different regional offices.

I've now well and truly settled into the **Shine** family and have been taking part in a number of activities from meeting members across the country, to travelling across the globe to Guatemala for the Parabadminton World Championships.

My first task however was to get to know members of the **Shine** community – both in-house as well as all you readers out there! I've met a number of members of the Adult Members Council, as well as staff across Shine NEWMO and **Shine** Cymru and needless to say, there's still plenty more of you to meet!

It's been all go since I started a few months ago. In October, I went along to the Great Eastern Run to support our very own Media Development Officer, Darren Fower,

Following swiftly on from this I was at the Mitrofanoff Support Group open day in Manchester as well a more informal coffee morning in Egham, Surrey. In attendance were specialist nurses from UCLH as well as some **Shine** members who recognised me from Together!

The event provided a great opportunity to meet some of you who are both in the **Shine** and Mitrofanoff communities, and allowed us all to share experiences. Both are worthwhile events to go to if the opportunity arises. For further information about the procedure, and any events visit – http://www.mitrofanoffsupport.co.uk/

As well as getting involved and creating networks on health issues, I've also been trying to gain valuable recognition for **Shine** by encouraging some high profile names to show their support. You'll hopefully have seen a number of faces backing **Shine**, including Neil Warnock, former Manager of Premier League team, Queens Park Rangers - a highly regarded and well known character in the world of football. Also amongst our supporters are David Strettle and Richard Wigglesworth who both play rugby for Saracens and represent England at international level.

I'm constantly looking for people to show their support for us, so if you know of anyone I could contact then please get in touch.

In addition to the whirlwind activities within **Shine**, I also had the good fortune to be able to attend and compete in the Parabadminton

World Championships in Guatemala. I don't always get to experience the sights and sounds of the places I go to for tournaments, but for a trip like this, it just had to be done! Check out my Facebook page for photos of the tournament as well as an insight into a country with a very different culture to ours.

If I thought the competition was intense in Guatemala, it was nothing compared to the competition I faced in the internal Table Tennis tournament at **Shine** Head Office. After getting dumped out in round 1 it's fair to say table-tennis isn't my forte! So if any of you out there are planning a table tennis challenge for me, I wouldn't expect big things from me if I were you! Talking of challenges the "Challenge Gobi" idea has got many of you thinking, and it's clear to see you're all bursting at the seams with ideas for me. There are some very interesting (and scary) challenges being thrown down and I really am starting to wonder what I've let myself in for! So far on the list we have Wheelchair tennis, swimming, and even some kayaking. Watch this space to see how I fare in these and other challenges.

In the meantime, keep those challenges coming! If you haven't already fallen asleep, then you've successfully passed my own challenge of keeping you interested with my ramblings! And for those of you that haven't passed … WAKEY WAKEY, rise and **Shine**!

Left to right Dan Wood (Urology Consultant), Sharon Fillingham (Urinery Diversion Specialist Nurse), Kyla Rogers (Founder and CEO of Mitrofanoff Support Group), Lucy Barron (Hollister).

Blue Blobbers

As part of my induction into the world of **Shine**, I was invited along to be part of the Blue Blobbers Bowling social. The Blue Blobbers are known as such because the social group meet on a monthly basis, based on the blue disabled access blobs on the map of the London Underground – a brilliant idea!

The Blobbers met at the newly opened Westfield Shopping Centre in Stratford – the venue for a bowling bonanza.

The group were soon in action, and the competitive streak within individuals (me included) was clear to see, with balls flying down the alley sending pin after pin crashing down – including one ball literally flying across onto another lane! Never mind James – knocking down pins, especially when they're on another lane is still impressive!

Strikes were being claimed across the lanes, however I couldn't quite manage the perfect 10 in any of my attempts.

The victor for the day was Brian Treadwell, who impressed once again. Having already stepped out of his comfort zone to speak in front of a large audience at the **Shine** Launch, he claimed the overall victory with his last attempt – winning by just 1 point!

I came in at a respectable 5th place but my challenge for the day was to beat Hilary Franklin, which I achieved - surely that counts as a successfully completed challenge?!

Organised by Amar Dugal, a great afternoon was had by all and we finished off the social with some much needed refreshments after commandeering a nearby food establishment!

Keep an eye out for the next Blue Blobbers social, and if you'd like to get involved, or want to organise something similar in your area, contact Hilary Franklin on **0208 449 0475** or email: **hilary.franklin@shinecharity.org.uk** for more details.

Go Folic! Launch in Wales

Elaine Saddington, whose daughter Tia has spina bifida, shares her story.

Janice Gregory (Assembly Member for Ogmore) voices her support for Go Folic!.

Janet Groves (Chairman of Lanes Health) presents a Go Folic! Preconceive Community Award to Graham Catherall.

Proud Tia shows off her mum's award.

Kate Thomas (Director, Shine Cymru) launches the event which was kindly sponsored by Vitabiotics

Harry Thomas prepares to do the honours!

Martine Austin on her new role as Health Campaigns Officer

After 17 years of working for ASBAH (and of course now **Shine**) I guess you could say that I've learned a fair bit about spina bifida and hydrocephalus. After many years in fundraising, I am delighted to have taken on a new challenge as Shine's Health Campaigns Officer - immediately taking the bull by the horns to drive forward the Go Folic! Campaign.

I've been involved with Go Folic! in one form or another since it began, and its exiting to see it now develop a momentum of its own. Our social media activity is increasing, and I'm now being asked to supply text and editorials for both websites and magazines. Each printed article gets us one step closer to our goal of ensuring that all women are being given correct, consistent and timely advice about taking folic acid.

March brings an exciting new campaign in conjunction with Norfolk Primary Care Trust (PCT), who will distribute Go Folic! leaflets, postcards, posters and stickers to all pharmacies and libraries within the region. It will hopefully lead to further regional campaigns with other PCT's across the country.

I must say a massive thank you to those of you who have been instrumental in helping us bring the campaign to life, kindly sharing your personal stories to help increase awareness. I know that this has not always been easy, but it has invariably been a rewarding experience for those involved. As a show of thanks, we have developed the Go Folic! Preconceive Community Awards (kindly sponsored by Lanes Health) which will recognise those individuals and organisations who help further the aims of the campaign. There are many ways in which you can help, whether it is by distributing information within your local community, volunteering to speak to local community groups, or by sharing your story on film or in print. If you think you can help please contact me on 01733 421349.

First things first

Margaret Twyford reflects on living with spina bifida, her late husband Alan, and their happy lives together.

I was born in Birmingham just after World War II and for 66 years I have lived with spina bifida – for me this means (I am) double incontinence and (have) mobility problems.

My parents were told that I would never walk, but I had a determined Grandmother! Every Sunday she would put her dining room chairs back to back, with a gap in the middle, and I would have to walk between them. To her credit, she got me walking, so then I could move on to wearing knee callipers.

I knew I was different from my younger brother. I remember, at 5, asking my Mother: 'When am I going to be able to walk properly'. There was a pause and she said, with no eye contact: 'Well maybe you never will'. From then on spina bifida became a part of what I was, and secondary to who I am.

When I was 8 we moved and I began to mix with able-bodied children more then ever, they stared and asked questions about my disability. This was a learning curve for me; it made me aware of always being answerable and different.

When I was 12 my surgeon recommended that I should go to Chailey Heritage Hospital/School in Sussex for a year. I was on a ward with other girls with spina bifida and whilst there I had surgery on my legs and a urosotomy fitted.

When I was 19 I learned to drive. I had a Ministry of Health tricycle, made of glass fibre and canvas - they were death traps! In a high wind, you could be blown from one side of the road to the other! I had a lot of fun with it, like when the engine fell out, and being told it wasn't April Fool's Day when I rang for help!

Around this time I joined my local ASBAH in Hampshire and met Alan who also had spina bifida. Friendship turned to love and we were soon married.

Alan and I became very involved with ASBAH. Although we decided not to have a family, we wanted to get involved with children. We fostered Tina who had S/B, and she stayed every week-end for 3 years until she went to college. She was a wheelchair user most of the time, although she could walk a little.

After Tina we had Janet. She stayed every other week-end for 5 years, until she too went to college. Tina tragically died at 36 of kidney failure. Fostering helped us experience parenthood and to understand what it was like for our parents to have a disabled child.

Alan decided to retire at 60, and we moved to Suffolk. Life was bliss.

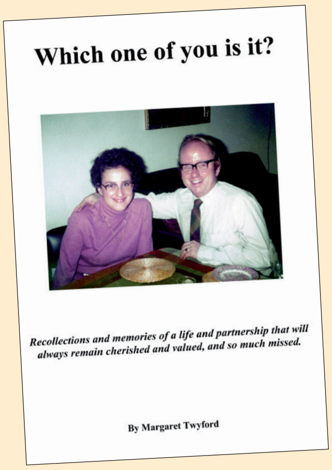
In 2009 Alan was diagnosed with a brain tumour. He was given 9 months to a year to live and he died in January 2010, aged 64.

When I was growing up I was encouraged to believe that I came first, and spina bifida second. When I met Alan I had nothing to prove anymore, we spoke the same language, trying to achieve normality, what ever that is.

Now I am a widow I'm having to prove that I can cope completely on my own, just the way Alan would have wanted. My quality of life isn't what it was, but I have wonderful neighbours, good close friends, and normality is still worth trying to live by.

Which one of you is it?

Margaet
and Alan's
fascinating
story is now
available as
a book. It is
priced at just
£7.50 inc p&p.



Which one of you is it?

Recollections and memories of a life and partnership that will always remain cherished and valued, and so much missed.

By Margaret Twyford

To order your copy please call
01733 555998 or
email info@shinecharity.org.uk

Mike flies solo over Menai Bridge.

Mike Mason, Chairman of North Wales ASBAH and flying enthusiast, recently had a dream come true when he got to take the controls of a Cessna 150 aeroplane. 'I've always had a secret wish to be able to fly, but never thought I would get anywhere near the controls, even for a short while.'

The opportunity arose thanks to Aerobility and the Eagle Wings Trust. Mike, who has spina bifida, says he thoroughly enjoyed the experience: '*I might have frightened the people of Menai Bridge as I flew over, and as I have threatened to go flying further afield next time, really, no one is safe!"*

If you fancy your chances as the next Biggles, visit Aerobility's website at www.bdfa.net or phone 0303 303 1230. Contact details for Eagle's Wing's Trust, who could help you become a pilot, are www.eaglewingstrust.org or phone 01286 830800

Graham wins Grey Fish of the Month Award

A day's fishing proved a memorable one for Graham Catherall when he hooked a 10Lb brown trout caught at Dragonfly Fishery in North Wales. Graham fished a dry fly to catch this magnificent specimen, which was safely returned to the water to fight another day!

Barbara's dream comes true

Barbara Leech was thrilled when North Wales ASBAH arranged an evening out for her and a friend in Llandudno. They dined in the Theatre restaurant, before seeing the comedy play 'The reluctant debutante', starring Jane Asher. Afterwards, Barbara was lucky enough to meet the star of the show and the rest of the cast backstage. She comments 'It was a lovely evening. I don't get out very often so it was a real treat'.

Big Lottery Wales

Big Lottery Wales supports Shine Cymru to develop its services and expertise in benefits advice and social activities

In 2011, The Big Lottery in Wales granted funding for a 2-year project to support the development of information, advice and services to address the variety of member queries and questions surrounding benefits and changes to the welfare systems.

Eri Mountbatten, **Shine** Cymru's Welfare Rights Adviser, says *'**Shine** has always supported members with benefits and finances. Thanks to the Big Lottery in Wales, this project is allowing us more time to get to grips with the issues, particularly the Welfare Benefits reform.'*

The project has also provided some funding for fun days and activities across Wales, encouraging members to come along, meet others, share experiences and have fun!

For further information, contact our 'First point of contact' on 01733 555988 or email info@shinecharity.org.uk

Shine welcomes new staff

Robin Barnatt, our new Health Development Officer, started work with us on December 19th. Robin is based at Head Office in Peterborough, he is a Registered General Nurse and has extensive experience in the field of mental health. He will be working closely with Health Manager Gill Yaz in developing our Health Team. Martine Austin has taken on a new role as Health Campaigns Officer, concentrating primarily on the Go Folic! campaign [See p18].

From January 2012, Support and Development Worker Sharon Saville will be broadening her role to concentrate on raising our profile and developing innovative new work and partnerships in the London & South Region.

Deborah Armstrong is leaving the Northern Ireland team for pastures new, whilst Sandra Campbell joins as a welcome new member of the team. Kim Evans (Shop Manager for the Southampton Shop) will be moving on after Christmas, as we are regrettably closing the Southampton Shop. Kim has worked consistently hard over the years and her contribution has been greatly valued.

Liz Potts has joined as a Support & Development Worker in the North and West Midlands Team. Liz has been a volunteer with us for a while already, and she is now working 7 hours a week. She has already made great progress in assessing the groups that she can bring together. Her role will help determine what the members of those groups would really like support with most. Liz is also a member of Shine Adult members Council (SAMC).

Hannah Wysocki has recently joined Shine, having worked in a large local call centre before. Hannah has a lively personality, a fantastic phone manner and is already securing donations in her new role as Telephone Fundraiser in the Special Appeals Department.

Robin Barnatt

Hannah Wysocki

Shine's Lifelong Opportunities Programme

Hydrocephalus: the hidden disability

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

Registered charity no.249338

Closing date for applications 2nd March 2012

TUESDAY 27TH MARCH 2012

Salvation Army International Headquarters
101 Queen Victoria Street, London EC4P 4EP

An Information day for adults with Hydrocephalus and professionals

Benefits of attending:

- Up to date information on the conditions
- Information from other service providers
- Share experiences
- An opportunity to meet the **Shine** Team and learn about our services

Cost to attendees will be £10 and £20 to professionals to include lunch and tea/coffee.

Starts 10.30 a.m. and finishes 4 p.m..

For an application form contact: Maureen Jobson,
Shine, 42 Park Road, Peterborough, PE1 2UQ
Telephone: 01733 555988 email: info@shinecharity.org.uk

Sessions to include:

- **Health Matters**
- **Lifelong Learning and Employment**
- **Living Life Well, an individual perspective of living with Hydrocephalus**

There will be no provision for children to attend this event.

Programme of events

London Social Group - the London Aquarium
12th Feb. For further information contact: Hilary Franklin 020 8449 0475

Half Term Bowling Day in Hampshire
16th February 2012
Southampton & District Spina Bifida and Hydrocephalus Association in partnership with Hampshire County Council. For tickets which cost £5 per family, please contact Emma Kelly on 07969 104367 or email emmejkelly@gmail.com

Hydrocephalus/Spina Bifida - What is it all about?
18 Feb and 31March 1pm - 5pm
The workshops will be held at Thornbury Centre, Leeds Old Road, Bradford, BD3 8JX.
For further details and booking form contact Jo Baxter 07932621809 or jo.baxter2@gmail.com

North Somerset Support Group
March 1st - kyla@mitrofanoffsupport.co.uk
Mobile: 07967004517

North Somerset Support Group
March 1st - kyla@mitrofanoffsupport.co.uk
Mobile: 07967004517

Surrey ASBAH AGM
25th March. Details from Liz Tadd
email: taddfamily@btinternet.com

Family Opportunity Weekend 2012
Friday 16 –Sunday18 March Britannia Hotel, Leeds
For information contact: Denise Richards or Joan Pheasant 0113 255 6767 office@shinecharity.org.uk

North & West Yorkshire ASBAH - Thornbury Centre, Leeds Old Road, Bradford, BD3 8JX
18 Feb and 31March 1pm - 5pm Adult Workshops
On Saturday 21 April 12-4pm Easter Party with disco
Drop in - first friday in every month
For further details and booking form contact Jo Baxter 07932621809 or jo.baxter2@gmail.com

York Drop-In - Low Moor Community Centre, Bray Road, Fulford, York YO10 4JG
2nd Wednesday in each Month – 1pm- 3pm
For further information please contact: Tel 0113 2556767
Email Sylvie.bailey@shinecharity.org.uk

Easter Fun in Somerset - Shine Somerset Easter Party, Perry Street Club, Waterlake Road, Knapp Mill House, South Chard, Somerset TA20 2SU
Saturday 7th April 2012 from 2- 5pm. Contact Tammy O'Dwyer 07593 830681 or 01460 66135 or email tammyodwyer@btinternet.com by Monday 2nd April

Womens Health Issues - Event for women with SB
Tuesday, February 21st, 2012, from 1.00pm
Cheshire County Sports Club, CH2 1PR
elizabeth.miers@shinecharity.org.uk 01490 450360

Shine's Lifelong Opportunities Programme

Hydrocephalus: the hidden disability

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

Registered charity no.249338

TUESDAY 24TH APRIL 2012

The Harlequin Theatre, Redhill, Surrey RH1 1NN.

An Information and Support Day for Parents of children under 18 with Hydrocephalus
From diagnosis, treatment and the effects of learning

Benefits of attending:

The ability to ask your un-answered questions from **Shine**'s Health and Medical Manager, our Education Adviser and the Support and Development Working Team.

An opportunity to meet and network with other families' and listen to personal journies and achievements. To discuss and exchange ideas and strategies, gain confidence and help deal with some of the complex issues associated with hydrocephalus.

10.00 a.m arrival for coffee and registration with a 10.30 a.m. start and a 4 p.m. finish.

For an application form contact: Maureen Jobson
Shine, 42 Park Road, Peterborough, PE1 2UQ
Telephone: 01733 555988 email: info@shinecharity.org.uk

Closing date for applications 23rd March 2012

Sessions to include:

- **The effects of hydrocephalus**
- **Transferable skills**
- **Planning and organisation**
- **Language and comprehension**
- **Question and answer session**

There will be a charge of £10.00 per person which includes tea/coffees and lunch.

There will be no provision for children to attend this event.

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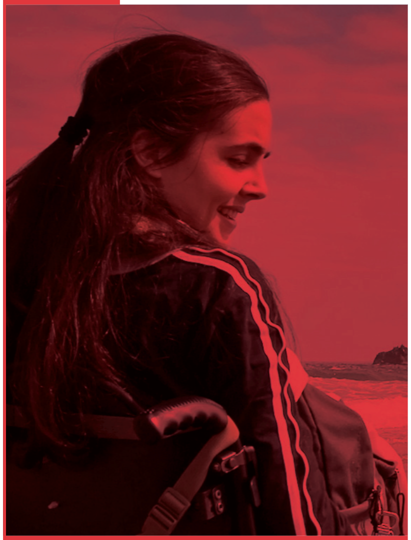

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- Ultra-smooth eyelets which help to ensure trouble free insertion and withdrawal for enhanced user convenience and comfort
- The bag handle is easy to grip and easy to hold, even for users with limited manual dexterity

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