

Together



Amy's song *Smile* set to Shine

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Please let us know if you are happy to receive future mailings by email as this saves on postage and helps the environment.

Email: info@shinecharity.org.uk

Submission dates for Summer edition

- Register of interest to submit:
7th March 2013
- Final date for submissions:
10th April 2013
- Publication date:
30th April 2013

A little birdie told me...

... that 2013 is going to be a bumper year!

If this edition of *Together* magazine is a reflection of the year to come then we are in for a great time in the **Shine** community.



We continue to be blown away by the generosity of our fundraisers, without whom none of our work would be possible. This includes another generous cheque for £10,000 from the Royal Pigeon Racing Association and news of £10,000 raised through Wear Yellow and **Shine** events during the first Spina bifida and Hydrocephalus Awareness Week.

In our feature interview we meet the amazing Amy Burns, who has recorded her own song and will be fundraising for **Shine** over the coming weeks.

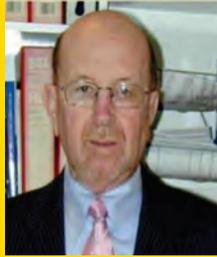
The Grand Prize Draw this year is stacked full of amazing prizes, be sure to sell your ticket booklet enclosed and let us know if you need more!

We also have all the in-depth information and advice from our professional staff, sharing their knowledge and expertise in the hope that you can benefit.

As usual, I would encourage you to get in touch and let us know what you like, what you want to see more of, and to share your news and photos with us. I look forward to hearing from you soon!

Together Editor

Obituary Professor John Scott



It is with great sadness that we share the news of the death on 29th December 2012 of Professor John Scott.

Prof. Scott was one of Ireland's most accomplished scientists and was Professor of Biochemistry, a Senior Fellow of Trinity College, and a member of the Royal Irish Academy. He was internationally recognised, winning numerous honours including being the first non-American to be awarded the Lederle Award from the American Society of Nutritional Science.

The impact of his lifetime of pioneering work in the field of folic acid, B12, and Neural Tube Defects is incalculable.

Prof. Scott shared a long relationship with our organisation. Between 1999 and 2003 ASBAH worked with Prof. Scott and Prof. John Burn (Newcastle University), on a large-scale research study into the genetics of neural tube defects in the UK and Ireland. Over the years he was involved in many ASBAH/**Shine** meetings, conferences and symposiums, speaking on the issues of folic acid and in latter years, B12. In 2002, he was a keynote speaker at a reception held at the House of Commons to promote the benefits of folic acid and flour fortification.

Prof. Scott remained a committed supporter of our work until the end, producing a report for **Shine** on the additional benefits of taking vitamin B12 in conjunction with folic acid to help prevent more Neural Tube Defects. Just a few months prior to his death Prof. Scott had planned to present his report at **Shine**'s press conference in October 2012 and was greatly disappointed when illness prevented him from doing so.

Professor Scott will be sorely missed by his family, friends and colleagues.

Shine staff news

Monica Evans and Andrew Ellis have left **Shine** for new ventures, Clara Gill replaces Andrew in the Marketing and Events Team. Bill Manwaring has joined the **Shine** Northern Ireland team as a Fundraiser. Katie Horn is our new Charity Shop Assistant based in our Chichester Shop, and Christine Cunningham is our new Support & Development Worker for the London & South Region.



We continue to go from strength to strength on our social media work here at **Shine**. We currently have 3400 Likes on Facebook and 12600 Followers on Twitter. We also have thousands of views on our YouTube films. We are seeing great interaction between members, fundraisers, and campaign contacts through all our online media.

To get involved please see:

f Facebook: facebook.com/shineUKcharity

🐦 Twitter: [@shineUKcharity](https://twitter.com/shineUKcharity)

📺 YouTube: youtube.com/shineUKcharity



**If you would like to find out more please email
Darren Fower – darren.fower@shinecharity.org.uk**

The Silver Dreams Team is up and running!

Shine's Silver Dreams Project for those aged 50 plus is now up and running. We have recruited 10 core volunteers from **Shine's** membership in this age group who have skills in charity governance, events management, public speaking, social work, campaigning, website and social media development, fundraising, disability awareness training, crafting, and creative writing to name just a few.

Over 70 members have said they would like to get involved with the Project in some way and over the next 6 months we hope to launch a couple of tele-friendship groups; a new volunteering scheme with activities

that people can do from home, including a crafting group; and a national event towards the end of the year, celebrating the achievements and highlighting the issues that older people with spina bifida and/or hydrocephalus face.

...we hope to launch a couple of tele-friendship groups; a new volunteering scheme with activities that people can do from home, including a crafting group; and a national event towards the end of the year...

We have already established a successful online support group on Facebook called *In Touch Over 50* with members enjoying lively discussions, sharing information, and supporting each other. So far a couple of people have also told us that they would

like to try the internet and we are helping them do this as part of the Project. It is going to be an exciting year!

For more information contact the Project Coordinator: Angie Coster T: 01308 426372 or E: angie.coster@shinecharity.org.uk To follow us see: W: shinesilverdreams.wordpress.com

Shine Recipe Book

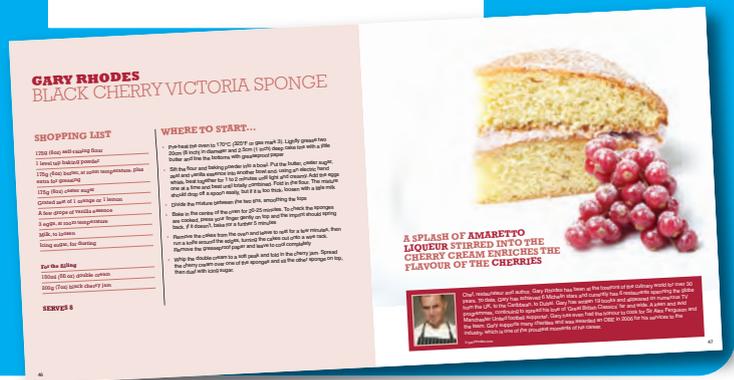
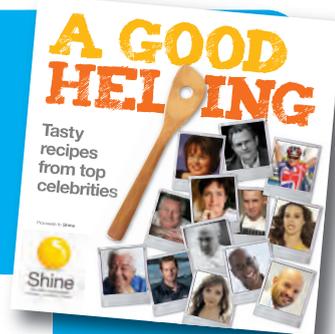
We have been hearing from some members who experience intracranial hypertension (IH) who would like the condition to feature more in *Together*. This is something we are working towards as we seek to also work in partnership with IiH UK in the future – for more see iih.org.uk

In this edition of *Together* we are delighted to announce the arrival of *A Good Helping*, a celebrity recipe book which has been collated by **Shine** member, Rebecca Morris.

Rebecca, who has IH, has produced a beautiful recipe book featuring over 30 delicious meals and desserts from top celebrities including sports stars, professional chefs, actors, and television personalities.

To read more about the project please see shinecharity.org.uk/cookbook

To order your copy for just £12.50 (inc p&p) please visit eBay.co.uk/ShineUKCharity or T: 01733 421307



Good news for members who have current awards for Disability Living Allowance (DLA)!

Shine has received many queries about the introduction of Personal Independence Payments (PIP) and re-assessments for members who have been awarded lifetime or indefinite awards as the plan seemed to be that everyone would be re-assessed from 2013.

Shine now understands that this has changed and that working-age disabled people with a lifetime or indefinite DLA award will now not be reassessed until October 2015 at the earliest, six months after the next general election.

For further information or questions on welfare reform, please contact your local Support and Development Worker.

Direct payments – a Welsh Assembly member speaks out in support!

Direct payments are payments from the local council for people who have been assessed as needing help from social services, and who would like to arrange and pay for their own care and support services. These payments are made directly to the disabled person (or to someone acting on their behalf), to arrange their own care package.

Direct payments offer:

- Choice: allowing people to make more of the decisions which affect their lives.
- Control: If a person receives Direct Payments they can

decide how their needs will be met, by whom, and at what time.

- Independence: allowing for care that is flexible and encourages independence.

Despite this, it seems as if not many people in Wales, who may benefit from direct payments, actually access them.

Welsh Conservative Member for North Wales, Mark Isherwood, wants to see wider development of the direct payment scheme across Wales. His views have been informed by 'the

amount of people who have approached him with concerns about their care packages.'

Mark Isherwood will introduce a private members bill on reforming direct payments in Wales, moving from the current 'opt-in' approach to one where individuals will 'opt-out'.

Shine Cymru has responded to a request for information on this issue and will keep members informed of developments. For further information on direct payments, contact your local Social Services office.

John's in the hot seat!

I was pleased to represent **Shine** at a Medtronics conference recently as they had approached the charity asking for someone to talk to their staff about the benefits of a shunt, one of the products which they make. The purpose is that everyone in the company appreciates the value of the work they do and

how their contribution can in some way affect people's lives.

I was interviewed by Paddy Haycocks in a 'Parkinson-style interview' for fifteen minutes and remarks afterwards suggested that my comments had been appreciated. In return, my personal assistant and I enjoyed an overnight



stay at an hotel at Heathrow, where we were royally treated and enjoyed Limousine travel both ways. Not bad eh?

John Richards

Act now on PIP proposal

By Shine member
Pam Stock

As a 54 year old female with spina bifida and significant mobility issues, I am very concerned about the planned distance reduction from 50m to 20m for the Mobility assessment of the new Personal Independence Payment (PIP) which replaces Disability Living Allowance (DLA) in April this year.

This change will mean that a lot of people with very significant difficulty in moving about will fail to qualify for the higher rate of the component and so will not qualify for vehicles or other mobility aids under the Motability scheme.

It will also mean that many more people who currently qualify for the Motability scheme under current DLA rules, will lose the higher rate on assessment for the new benefit, and will have any existing Motability vehicle or mobility aid removed.

Disability representative groups including **Shine** need the support of their membership in

please do whatever you can to help before it's too late, and the proposals pass into law.

Volunteer of the Year Award A day I will never forget

We arrived at the Telegraph building where we were met by the Managerial Editor who provided us with a chauffeur-driven car for an exciting two-hour sight seeing tour of the capital city, where we got to see all the sights London has to offer. Later we were taken to the fabulous Telegraph offices and into the theatre room for champagne and canapés – too posh for this scouse lad! The room was filled with very distinguished people including General Lord Datton, former boss of the British Army, Baroness Campbell, Katherine Grainger MBE, and Ian MacGregor, Editor of the Sunday Telegraph, amongst others.

Each winner was invited to the stage whilst a brief insight into their voluntary work was read aloud. My nerves were shattered by the prospect of going on stage. Finally General Lord Datton invited me up and I am not too clear about what I actually said, but I brought both my wife and daughter to tears. After the Awards we went to a very lavish buffet. My daughter Sammy spoke to Katherine Grainger and was able to wear Katherine's gold medal! We left the Telegraph Offices feeling like royalty as we had been treated like Kings and Queens.

Carl Eaton, Shine Member

order to improve public awareness of the issues facing disabled people, so that they can lobby effectively to have this change reversed. If you would like to add your voice to the protest please visit W: wearespartacus.org.uk where you can find more information on how you can help as an individual, and also links to various letter templates you can use to write to people such as Disability Rights UK, or your local MP.

You can also visit the Department for work and Pensions (DWP) at W: dwp.gov.uk/pip where you will find links to the full government response to the PIP consultation, including the final draft of the assessment criteria – there is also a link to a Q&A of commonly asked questions as well as a 'mythbuster' of misconceptions regarding PIP.

This change will mean a loss of support and independence for some of the most severely disabled among us, **so please do whatever you can to help before it's too late, and the proposals pass into law.**

Honours and changes at Shine's AGM

Shine's AGM, held on 29th November, was a historic and happy occasion, with a new constitution being voted in and deserving winners being presented with their coveted Shine Awards.

Members from all over the country came to vote on proposals which included giving all **Shine** members over the age of 16 a vote at future AGMs, and rotation of the Board of Directors which will allow more people the opportunity of serving on the charity's governing body.

If you are a *Together* reader and want to check whether you are a Shine member or not please contact Maureen Jobson on 01733 555988.

Anyone with spina bifida, members of their family, and carers and professionals involved in this area of work can now qualify to be full voting members of **Shine**, but to get a vote you must be registered in your own right.

With so many people contributing so much to **Shine**,

and achieving so much in their lives, selecting the winners for the third year of **Shine** Awards was a tough challenge. Thanks to everyone who nominated a friend, family member or professional for an award – all were very deserving suggestions. Below are the 2012 winners:

Shine Volunteer of the Year – Lorraine Watson. Shine director and tireless volunteer Lorraine was honoured for her huge contribution to the **Shine** community.

Shine Young Fundraisers of the Year – Upton-By-Chester High School. Students at this amazing school raised a total of £4700 for **Shine** with their interesting and original fundraising activities.

Shine Fundraiser of the Year – Charlie Miller. Charlie has inspired us all by taking on an incredible range of fundraising challenges this year, in memory of her son George.

Shine Young Achiever – Rebecca Morris, who has Intracranial Hypertension was the creator and producer of **A Good Helping** the brilliant celebrity recipe book which is currently raising funds and awareness for **Shine**.

Shine Professional of the Year – Dr Richard Morgan, founder of the Chelsea and Westminster Clinic for people with spina bifida and hydrocephalus, was honoured this year for his pioneering work in providing the best for people with both conditions.



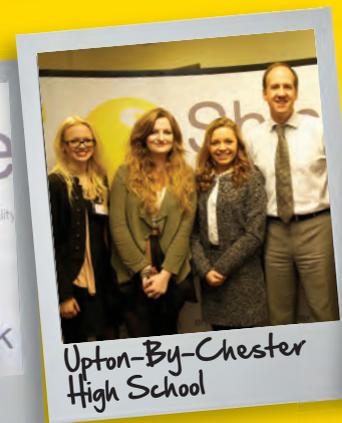
Lorraine Watson



Rebecca Morris



Charlie Miller



Upton-By-Chester High School



Dr Richard



Rosemary Batchelor

The first ever **John and Lucille van Geest Award for outstanding contribution to the Shine community** went to **Linda Corbett of Shine Surrey** for her longstanding support for local associations and her outstanding example of making the most of life whilst living with spina bifida.

And finally, the **Shine Lifetime Contribution Award** went to **Shine's** former Principal Health Adviser, **Rosemary Batchelor** who retired last July after a quarter century of service to **Shine's** members. Many of today's adult **Shine** members were supported by Rosemary as babies and her contribution to the world of spina bifida and hydrocephalus both nationally and internationally has been immense.

Many congratulations to all our winners!



Morgan



Linda Corbett

New NHS arrangements need to include spina bifida

Shine has raised concerns with the NHS Specialised Commissioning Board that the specialist needs of people with spina bifida have not been accounted for.

Last year, under widespread changes to the NHS, a process was launched to identify conditions which should be commissioned nationally and for which specialised services should be provided. Conditions such as cleft lip and palate and traumatic spinal injury are

of different issues which arise from spina bifida.

Shine Chief Executive Jackie Bland has been promised a meeting with NHS commissioners to 'explain why these conditions have not been included' but so far no firm arrangements have yet been offered.

As things stand, for now, spina bifida will remain a condition where services and treatment will be decided and commissioned at local level,

As things stand, for now, spina bifida will remain a condition where services and treatment will be decided and commissioned at local level...

included within specialised commissioning and people with these conditions can expect specialised services at specialised clinics or Spinal Injury Centres.

However, despite repeated questions, **Shine** has received no assurance that spina bifida has been identified as requiring specialised commissioning and it looks increasingly likely, for adults at least, that no new specialised arrangements will be made available. This is despite repeated calls for improved services for adults with spina bifida, including multi-disciplinary clinics where people are treated as a 'whole person' rather than being 'divided up' into the range

where new local Health and Well Being Boards will have greater powers to decide what the health priorities for their area will be. This is in contrast to services for people who sustain a serious spinal injury after birth, where a high level of specialist service is available, according to nationally agreed specifications.

Shine is continuing to develop work in this area to bring about improvement. Feedback from members, direct to Jackie Bland, is welcome –

jackie.bland@shinecharity.org.uk

Raising the issue with MPs will also be helpful to this work.

Go Folic!

This year got off to a flying start when we were asked to take part in a Radio 5Live show, reflecting on the biggest medical research successes of the last 100 years. It was amazing that folic acid was included alongside such discoveries as antibiotics, organ transplants and MRI scanning, and just goes to show the significance that scientists place in the discovery that folic acid prevents NTDs.

Shine Mum, Josephine Wilding, bravely agreed to chat live on air about the importance of taking folic acid before pregnancy and described her two beautiful daughters, Amelia and Alaina (pictured here during Spina Bifida and Hydrocephalus Awareness Week 2012), the youngest of whom has spina bifida. Rarely do we get such exposure, and Josephine proved an amazing ambassador for Go Folic!

It seems hard to believe more than 20 years after the ground-breaking Medical Research Council study proved that folic acid helps reduce the risk of NTDs



**Amelia and Alaina
During Spina Bifida
and Hydrocephalus
Awareness Week 2012**

by up to 72%, that we are still trying to get this simple but vital message across to women.

So, why is it so difficult? ...

Unplanned pregnancies, a lack of available information and education, an array of conflicting information online, and a lack of promotion by healthcare professionals, to name but a few. Not to mention the many women who do know about folic acid, but still see it as an 'optional' thing to take whilst they're pregnant that's 'good for the baby', rather than something that is essential before and during pregnancy, to help prevent serious consequences.

As we progress, I would like to say a massive thank you to everyone who

has shown support over the past year, through sharing your stories, distributing leaflets and postcards, sharing posts on Facebook or retweeting (and of course not forgetting our fantastic sponsors Vitabiotics and Lane's Health). Every little bit helps and we couldn't do it without you.

Martine Austin, Health Campaigns Officer

If any other parents are interested in helping Go Folic! by sharing their story, please contact me on T: 01733 421349 E: martine.austin@shinecharity.org.uk or message me on Facebook or Twitter @martineaustin

Striking the right balance

Having a fall isn't an inevitable part of getting older, or as a result of having a disability.

Falls are frightening, embarrassing, and can be serious. They could mean a long hospital stay, loss of independence, decreased confidence with walking or transfers, feeling safer indoors and refusing to go out. The effects are multiple.

Here are some things you could do if you have a fall, or feel you are more at risk.

- Tell somebody. Your GP should be able to refer you to somebody who can help. Ask if there is a Falls Service in your area for assessment
- Try to work out if there is somewhere in particular you are falling, or something in particular you are doing. Your local Occupational Therapy service will be able to help with environmental factors such as grab-rails, or just general advice in terms of things like loose rugs, uneven paving, emergency lifelines, etc.
- See an optician if you feel it might be related to your eyesight. Some people notice an increase in balance

Cerebro-Spinal Fluid

By Gill Yaz, Health Development Manager

When I first started working for **Shine**, not much was known about cerebro-spinal fluid (CSF), the fluid in the head which becomes trapped, causing hydrocephalus. I was originally told that it contained a bit of salt, a bit of sugar, and its main function was to cushion the brain during impact. How things have changed! Scientists are beginning to reveal some fascinating facts, and are working hard to find out just what CSF does. The tissue that produces CSF, the choroid plexus, has a very rich blood supply, and pumps vitamins and other nutrients into the CSF, which feeds the brain tissue. It then collects waste chemicals and returns them to the bloodstream for disposal. We know that conditions where CSF flow is reduced, for example normal pressure hydrocephalus in which toxins build up in the brain, can lead to dementia.

In the developing brain of unborn babies, the CSF contains growth factors which tell the brain cells to divide and migrate to the correct areas of the brain. Dr Jaleel Miyan, of Manchester, found that removing the CSF in rats with congenital hydrocephalus, and putting it in rats without hydrocephalus stopped the brain cells from dividing and moving to form the usual structured layers in the previously unaffected rats. When he reversed the process, the cells began to divide again. Different growth factors are added to the CSF at different points in the pathway around the head, so the effects on brain development depend on the location where the CSF becomes blocked. In open forms of spina bifida, CSF flows into the sac of the spina bifida lesion, instead of onto the outside

surface of the brain, where it should be absorbed. Vital chemicals fail to reach the outside of the brain, and the development of some of the uppermost layers may be thinner than usual, accounting for some of the cognitive issues experienced by some people with spina bifida.

CSF is produced in pulses, each pulse creating a little wave of pressure. Scientists have found that the high pressure wave from CSF coincides with the low pressure phase of the blood being pumped into the head by arteries, and that these two waves cancel each other out to create a constant pressure. It would be uncomfortable if we could feel every pulse of blood entering our brain, and some scientists believe that some people with hydrocephalus have CSF waves out of synch with their blood pulse.

So CSF is far more important than we thought, controlling our brain's environment, nourishing and cleansing it, while equalising the pressure in our heads. I'm sometimes asked 'why can't the surgeon just remove the choroid plexus to reduce the CSF, instead of diverting it with a shunt or ETV?' This surgery is occasionally carried out in the UK, for people who produce excessive CSF, but rarely for people who have the usual quantity of fluid; we just don't know what the long term effects might be.

What will they discover next? Watch this space!

E: gill.yaz@shinecharity.org.uk

- problems when they have a new pair of glasses
- Are you rushing and falling as a result? Unfortunately, rushing to the toilet, and going to the toilet during the night, can cause people to fall. A small plug in night-light may help, but also see your GP/Continence Advisor if necessary
 - Be aware of your footwear – slippers can sometimes cause falls
 - See your local Physiotherapist who can carry out an assessment of your walking and discuss any appropriate walking equipment that might help
 - Are you falling or losing consciousness? Please speak to your GP or consultant if you need to

- Changes in your blood pressure can lead to feeling dizzy and falling. Again, see your GP or district nurse if you think this might be happening. People often notice this when standing up from sitting or lying down
- Being overweight can have a big effect on mobility and falls.

Please let me know if you would like more help regarding problems with balance and falls. Stay Safe!

Emma Enfield, Shine's Occupational Therapist
E: emma.enfield@shinecharity.org.uk



Making a song and dance about it!

Words and photos by Tom Scott

Late last year I received a phone call from a dance instructor who was calling to tell me about an inspirational girl called Amy Burns.

As the director of the dance and movement workshop group, Little Movers, Melanie Buck has met thousands of children, but, as she rightly says, 'There is no one quite like Amy.'

Despite the New Year snow, I made the visit to Gateshead to meet with Amy, her Mum Kate, Melanie, and Louise from Gateshead County Council at Amy's school, St. Joseph's RC Primary School.

Amy was born with spina bifida and has overcome many difficult experiences including operations to close over her myelomeningocele, a cyst removal, and the ACE procedure. However, in the face of these challenges Amy has only two

things on her mind ... singing and dancing!

Mel explains that in the beginning she wasn't sure how having Amy in the class would be, 'I remember Amy's Mam calling me and asking if it would be alright for Amy to come to Little Movers, and to be

In the coming weeks Amy will be recording a song in a professional studio and it is a song that very much reflects her wonderful personality.

honest I didn't know anything about spina bifida. But, after we spoke about it, we decided to see how it went and it's been amazing.' This isn't to say that there weren't concerns. Although Amy has a high level of mobility there are still instances where she struggles with

her balance, and on longer journeys Amy uses a wheelchair. Mel remembers being very cautious in the beginning, 'In the warm-up, when the children run around the room, I would follow Amy with my arms hovering around her, I didn't want her to get hurt. But now she is fine, and if she falls she gets back up and carries on with the warm up, it's not a bother to her.'

This protectiveness is something Amy's Mum, Kate, identifies with, 'Amy was our first child and for the first 12 months we were just scared! I think most parents feel something like this, but with Amy's spina bifida we were extra cautious.' The family's first contact with **Shine** came around this time when Amy was having kidney problems at 14 months, Kate said, 'Our worker was great in helping us get the right care for Amy.'

As Amy grew it was clear that her

character was going to be the overriding factor in how she coped with her spina bifida. Parents, Kate and Michael, recognised this and are fully behind anything Amy wants to try. Amy may only be 7 but she has already taken part in horse riding, gymnastics, tennis, and trampolining. However, it is singing and dancing that has really captured her imagination.

In the coming weeks Amy will be recording a song in a professional studio and it is a song that very much reflects her wonderful personality. As a result of the special relationship Amy has with her dance group, her class mates were asked to write down words that describe their friend. Unsurprisingly the list included words such as love, strong, proud, and happy. The team at Little Movers then turned the selection into the song *Smile* and Amy has used her vocal talent to bring the project to life.

This song project, and indeed the story of Amy's life so far, is very much one of support leading to triumph. Amy's family are always there for her, including younger sister Erin, with whom Amy is very close. The Little Movers group have been there as she has developed into a confident young performer. In addition to this, Amy's school, under the very progressive support of Head Teacher Mr Hattam, have accommodated her in every way they can within the constraints of a system which makes Special Needs support increasingly difficult to access.

The concern of everyone involved here is that Amy is



given every opportunity to discover who she is according to the enthusiasm that exudes from her unique personality. Amy is a girl who isn't phased by her condition and seizes life without even thinking about it; it is this facet which lies behind her infectious smile and draws you to her.

The time with Amy and those close to her was a real privilege, and I couldn't end this article without acknowledging Amy's closest friend, Little Winnie. Little Winnie is a pink Winne-the-Pooh

who has been through everything with Amy ... and I mean everything! From hospital appointments to bowel washouts, Little Winnie has been there with Amy, her comfort during the most testing times.

I'm sure Little Winnie will be there with Amy over the coming months as she promotes the sales of her new song to raise money for **Shine** – maybe she can meet Benny and share some stories too!

To get your copy of *Smile* please call
T: 01733 421307 or visit the Shine eBay shop here
W: stores.ebay.co.uk/ShineUKCharity



Hello everyone!

A big 'Hello' and 'Happy New Year' to you all in what I hope will be another great year for everyone connected with **Shine**.

With 2012 being my first full calendar year as Membership Development Officer, it was both an exciting and hectic year – with a steep learning curve for me in the process. But it's been a great experience and I'm already looking forward to 2013 with great anticipation.

However, before I look forward to the year ahead, let's take a quick look back at how 2012 ended. As I mentioned in the last edition of *Together*, Darren 'The Power' Fower and I took part in the Perkins Great Eastern Run. When I last wrote, the amount raised was unknown, but I'm pleased to say we reached a grand total of £1019 – exceeding our £1000 target. It was great to see donations

flooding in even after the event. A massive 'Thank you!' to those who contributed through text, cash or online donations ... bring on PGER 2013!

After the GER (Gobi's Exhilarating Roll!) came a trip across the Irish Sea to Northern Ireland where, as well as the 4 Nations Championships in Lisburn, I spent some time with **Shine** NI members.

To start my trip I met Karen Tilson, who's doing some challenges of her own and fundraising for **Shine** in the process. A coffee morning followed the next day in Lisburn with **Shine** staff as well as members Donna and Ryan Green. Then, accompanied by my Mum, Esther, I headed off to Derry to meet more members at the Brunswick Moviebowl.

Over 30 people got together for ten-pin bowling and, after dinner, many stayed to socialise further with a



few games of pool. I also had the pleasure of meeting some coaches and players from the North West Eagles Wheelchair

Nothing like doing a bit of wheelchair abseiling on the UK's steepest Wheelchair accessible abseiling wall!

Basketball Team. So here's a big shout out to Keiran Doherty, Elaine Brolly, Conor McGrotty, Perpetua O'Driscoll, Steve McCrudden, and also to the Gillon Family, particularly Diane and her daughter Chloe, who completely wiped the floor with me on the basketball machine! Needless to say, I'm seeking revenge so have a bit of business to sort out there!

It was an absolute pleasure to meet so many members and I should give a special mention and thanks to Support and Development Worker, Sandra Campbell who arranged the evening and gave my Mum and myself a mini tour of Derry City Centre. Both Mum and I were made to feel very welcome throughout the stay so thank you **Shine** NI.

Upon returning to England, normal service resumed as everyone at **Shine** HQ started to gear up for Christmas, however I still managed to squeeze in a final challenge for the year. With all of the events pre and post London 2012, my Challenge Gobi events had been on hold. However I restarted the challenges with something nice and simple to ease myself back into it. Nothing like doing a bit of wheelchair abseiling on the UK's steepest Wheelchair accessible abseiling wall!

I was given the opportunity to be a guinea pig at the So Challenging Ropes Centre at Fairland's

Valley Park, Stevenage. When asked if I'd be up for trying it, my mind was saying 'No', but somehow my mouth didn't engage my brain and said 'Yes!' Hmmm! Having never done anything like this, it's fair to say I was a little apprehensive. I'm not really one for heights and dangling from the side of an abseiling wall on a winter's day, so I was definitely out of my comfort zone. Still, I'm alive and well and writing once again!

With all the excitement of the exploits of 2012, I did however come back down to earth with a bump in December. As much as

things were going well for me, a few health issues arose, and troubles with my Mitrofanoff soon reminded me that I am still human. Difficulties with this resulted in me requiring a Mitrofanoffscopy under general anaesthetic, so not an ideal end to the year. It could well lead to an interesting and tough year – if there's a Challenge Gobi that I'll need to overcome in 2013, then this is right up there!

Despite the hiccup, one of the main focal points for 2013 will be making the 'Rise and **Shine**' Adult Members event at Stoke Mandeville in July a real success. With a number of exhibitors already confirmed, there should be something for everyone. However, there is lots of organising to do and I'll be working hard to make it a great experience for all, ensuring as many members as possible can come and have a thoroughly enjoyable and memorable time.

If you are planning on attending, please don't forget to get your applications in, especially if you're staying overnight as onsite accommodation is limited. I'm hoping it'll be an event to remember! So here we are – the end of another column entry done and out of space! But as always, if you want to keep up to date with the development of the **Shine** membership on a regular basis, follow me on Facebook, and on Twitter with @Gobi_r. See you all soon! gobi.ranganathan@shinecharity.org.uk



Christmas Appeal

The first **Shine** Christmas Appeal to you, our members, saw a very generous contingent donate over £800 during the festive period!

We would like to thank all those who gave and we are already looking forward to next year's appeal.

Grand Prize Draw

The **MUST HAVE** ticket of 2013 is definitely the one for our amazing Grand Prize Draw. In our 3rd year we are aiming to make this the most successful draw yet!

Please find tickets **FOR £1 EACH** included with *Together* and sell them to your friends, neighbours, and colleagues (don't forget to buy some for yourself too!). There are fantastic prizes just waiting to be won.



The beautiful Sands Resort, Cornwall

Top three prizes

£1500 CASH
Apple iPad2 (16GB/WIFI)
£500 NEXT Vouchers

You could also win...

A family **RETURN** ticket for 2 adults & 2 children on Eurostar to **Paris, Lille or Brussels**

A **weekend stay** for 2 adults and up to 3 children (under 14) including breakfast and dinner at the beautiful **Sands Resort, Cornwall**

A relaxing stay for two at **Whittlebury Hall**, Northamptonshire for **1 night B&B including Leisure/Spa facilities**

18 holes for four on the Championship Course at Forest Pines Golf and Country Club in North Lincolnshire

Two adult tickets to any of the **Battle Proms** venues in 2013

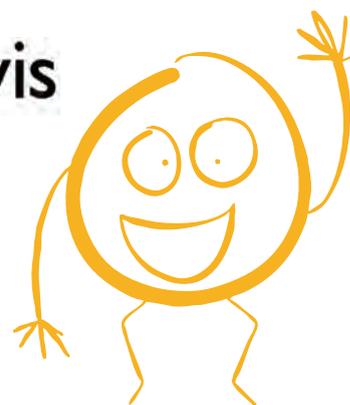
Hitachi Projector CPX4 suitable for home or office use

The draw is to be held on **March 30th 2013**. Don't delay, make your Easter the best ever and get your tickets now!

TICKETS ARE £1 EACH – fill in the details of the person buying on one half and return to: Clara Gill, 42 Park Rd, Peterborough PE1 2UQ. If you need to order more tickets please call T: 01733 421307.

ASDA Waitrose John Lewis

Community Matters Scheme



Shine have recently been donated the fantastic amount of £255 by Hall Green Waitrose after being nominated by a local member to benefit from their branch Community Matters Scheme.

This is a brilliant fundraising initiative that many large chain supermarkets are now starting to introduce in order to give something back to the members of their local

communities that rely on charitable organisations, or those who nominate a charity they have a personal connection to.

So if you live near, or regularly shop in a Waitrose, John Lewis, Asda or any other local store that may offer a similar charitable incentive, please don't hesitate to nominate **Shine**, as not only does it provide a fundraising

opportunity, it also gives you the chance to raise awareness of spina bifida and hydrocephalus in your local community!

If you would like to discuss how to nominate Shine for one of these schemes, or have any other similar ideas that you think would help, please contact the Marketing and Events team for further details – T: 01733 421351

Awareness Week 2012

Last October brought us the first Spina Bifida and Hydrocephalus Awareness Week, and with it **Shine**'s very first national Wear Yellow and **Shine** event.

Schools, nurseries and offices up and down the country took part by having dress-down days and wearing items of yellow clothing, all to help raise money and awareness for **Shine**. We had a fantastic response from so

many of you, and raised nearly £10,000 this year from separate events up and down England, Wales, and Northern Ireland.

Thank you to everyone that took part, and particular thanks to everyone that sent us fantastic photographs of their events, we really enjoyed seeing what everyone had been up to. Hopefully 2013 will see us increase the number of people

taking part, and we can look forward to going from strength to strength with 'Wear Yellow and **Shine**', and build upon the strong foundations established in 2012.



If you want to get involved in your very own Wear Yellow and Shine event, you don't have to wait until next October, so please contact Hannah on E: hannah.wysocki@shinecharity.org.uk or T: 01733 421351, for ideas on how your friends, family, school, or work place can hold an event to benefit Shine.

Shine raises £4000 through Bullens partnership



Readers may remember receiving a competition-survey from Bullens Healthcare last year which offered the chance to win a trip to Disney World for a family of four or £3000 worth of equipment to the winner. The survey also offered entrants the opportunity to talk to Bullens about receiving their prescription products from their free personalised on-line service.

Member Steve Leathart from Wisbech was the lucky winner and chose to have £3000 of equipment as his prize. We are also very pleased to learn from Bullens Healthcare that around 140 **Shine** members took up the opportunity of having their prescription products delivered to their door, at no cost to themselves.

The reason that Shine is so pleased is that 5% of the value of each order is donated to Shine, an arrangement that raised £4000 for Shine in just over six months. This money goes directly into helping us provide our nationwide services for members and is highly valued in these difficult times.

Bullens are happy to talk to anyone about their service at any time. Their personal healthcare staff are on hand to discuss your prescription needs and explain how their service works – and remember it is free to **Shine** members but **Shine** still gets a cash donation from each order.

If you use prescription items of any sort and would like to find out more, you will find a freepost reply card with this issue of *Together* – just fill it in and send it back. There is no obligation on anyone, Bullens customer care staff will call you and answer all your queries and then it's up to you. Or you can simply contact Bullens, saying you have seen this article in *Together*, by calling T: 0800 269327

We hope that this partnership will go from strength to strength and raise even more in 2013. A big thank you to everyone who used the Bullen Healthcare Service and helped us raise these valuable funds for our work.

Shine Associations

As the months go by we are seeing a steady increase in the number of local associations who are changing their name to **Shine**. So far these include:



If you would like support from **Shine** as a local association then please call T: 01733 421361



ATTENTION ALL 11-14 YEAR OLD MEMBERS!

Shine is starting a new network for 11-14 yr old members with SB/H. We have asked young people in this age group what they would like from a 'club' and they say they want to be brought together. Lots of 11-14 year olds said they feel lonely or isolated and that it would be great to meet other teenagers who also have SB/H.

We can help! If you join the club you will get membership to a new network designed especially

for your age group. You will then get the chance to enter competitions with great prizes, contact other young people like you, read articles on issues that you care about, and go to events where you can meet up with each other.

It's your club, so it's up to you to choose the name. Everyone who completes the form below to vote for a name will be entered into a prize draw.



First Prize: FREE DAY PASS FOR 2 ADULTS & UP TO 4 CHILDREN TO WOBURN SAFARI PARK! (Valid until 31 October 2013).
If you are unable to finance travelling to Woburn and you win first prize, we will arrange for a suitable alternative

Second Prize: £25 Amazon vouchers

Third Prize: £10 Amazon vouchers

Please complete and post this form to 'Shine 11-14', 42 Park Road, Peterborough, PE1 2UQ. Closing date for entries is 28 February 2013 and the winning name will be announced on 4 March 2013.



Cut here



I think the new club for 11-14 year olds should be called:

- | | |
|---|--|
| <input type="checkbox"/> 'This is Me' | <input type="checkbox"/> 'Shine Youth' |
| <input type="checkbox"/> 'Just as I am' | <input type="checkbox"/> '11-14 No Limits' |
| <input type="checkbox"/> 'Shine 11-14' | |

(Please tick only one box, only one entry per person allowed).

Your name _____ Your age _____

Your address _____



Shine's new Adult Members Council appointed

Nine Shine members have been appointed to serve on the Adult Members Council for the next three years. The members, who all applied through the process described in the last *Together*, have been appointed directly because the number of applications was too low to allow an election to run; there were nine applications for 10 places.

Shine HQ Services Manager Dave Isom said that although the number of applications was disappointing, he was delighted to welcome some excellent new members onto the SAMC, as well as to welcome back some experienced members.

"We hope that as the work of the newly elected SAMC gains a higher profile, other members will come forward whom the group can consider co-opting at a later stage" he said. "The

SAMC has had a big influence on our work since we became **Shine**, bringing significant issues to the fore. It was instrumental in last year's major health survey which will be the subject of a hard hitting report this year."

The existing Adult Members Council will meet one more time before disbanding, and the induction process for the new SAMC will begin in the Spring. This year the Council is likely to be considering the impact of health service and benefit changes on members, as well as looking at ways of increasing and developing **Shine's** membership. There is also a major event for adult members in July.

Anyone who might have missed the article in the last *Together* and is interested in the Council is welcome to contact Dave

Isom on T: 01733 421308. The new **Shine** Adult Members Council members are:

Lisa Cain (Chair) Essex

Lisa has spina bifida and hydrocephalus and is also a Director of **Shine**. She works for the London Borough of Redbridge Blue Badge scheme and is experienced at representing **Shine** and its issues nationally and internationally. Lisa is also a keen skier.

Mike Bergin (Hull)

Mike has served both on SAMC and on Your Voice, the body that existed before SAMC. He is the Council's Communications Officer and represents **Shine** both nationally and internationally at events and conferences. Mike has spina bifida. He has two grown up children.





Geraint Catherall (Wales)

Geraint has hydrocephalus and frequently speaks at **Shine** events explaining his condition to others. Geraint has worked hard to overcome the challenges arising from his hydrocephalus, and is keen to share his experience. Geraint is a keen cyclist and has served on the committee of his local cycle club for over 15 years and is currently the club captain and race secretary.

Paul Manning (Wales)

Paul has spina bifida and hydrocephalus and is an active representative of **Shine** Cymru. He is also a Director of **Shine** representing interests in Wales. Paul volunteers for Mencap and has a basic understanding of deafness and BSL.

Heather Doughty (new member, Nottingham)

Heather is new to the SAMC. She has spina bifida and has worked for a variety of organisations of disabled people, including Independent Living Centres. Currently Heather works for Disabled People's Advocacy in Nottingham. She is passionate about equality for disabled people and endeavours to be a strong advocate when she needs to be.



Jason Merrill (new member, Peterborough)

Jason has spina bifida and hydrocephalus and is very active in promoting the rights of disabled people at local level. He is active in his local Phab Club and has won a trophy for being a role model as a disabled person for 'pushing boundaries'. Jason

This year the Council is likely to be considering the impact of health service and benefit changes on members...

wants to work with **Shine** to change the way that disabled people are perceived and is keen to share his experiences with **Shine** members.

Liz Potts (Cheshire)

Liz has spina bifida and hydrocephalus and currently works for **Shine** part-time as a



Support and Development Worker. Liz is married with two grown up children. She is keen to work towards social change/integration for disabled people, and to continue **Shine's** work seeking a more holistic approach to healthcare for its members.

Amar Dugal (Middlesex)

Amar has spina bifida and hydrocephalus and has represented **Shine** both nationally and internationally. He also represents disabled and elderly people at events in his Sikh temple in Shepherds Bush. Amar works in his family's businesses and has a good understanding of business operations.

Helen Robinson (Northumberland)

Helen has spina bifida and has had '65 years of living with SB'. Together with her husband, she has devoted much of her life to volunteering for groups which support disabled people, including setting organisations up from scratch. She has been presented to the Queen to honour her voluntary work. At the age of 45 Helen learned to 'sit-ski' and still enjoys this hobby now. Helen works for the Ministry of Justice Tribunal Service and is involved in **Shine's** 'Silver Dreams' Project.

Focus on Shine Cymru

Tell us what you think...



Shine Cymru organised information sessions, social groups and fun days in 2012.

These events

were advertised through letters to our members, emails, Facebook and the website but we had to cancel some of the events, due to lack of interest.

So... Shine Cymru staff and volunteers would like you to tell us what sort of support, events and get-togethers you would like us to facilitate, and why.

Please call us on T: 02920 813847 or E: wales@shinecharity.org.uk

Social Services in Wales are changing

The Welsh Government is reviewing the way in which social services operate in Wales.

Gwenda Thomas (Assembly Minister for Children and Social Services) says that the aim is to create a framework that supports the delivery of services in a much more integrated way to ensure that both individuals who need care, and those who care for them, have access to the right support and services.

This means that social services must work closely with other public services and also with voluntary organisations such as **Shine** Cymru and the independent sector, and that care will not be the responsibility of social services alone. The proposed new approach is set out in the new 'Social Services and Well-being (Wales) Bill', which will be presented to the Welsh Government at the end of January 2013.

Shine Cymru will be monitoring developments and will endeavor to keep members informed as the changes progress.

Become a Shine Cymru Ambassador



The WCVA-funded Volunteer project in Wales continues to go from strength to strength. Many members across Wales are gaining experience and support

in their volunteering roles as fundraisers and events supporters for **Shine** Cymru.

2013 welcomes the introduction of an exciting new opportunity for **Shine** Cymru members, their families and friends, to sign up and train to become Ambassadors for **Shine** Cymru. If you are interested in finding out more, then please get in touch with Sally King-Sheard, Volunteer Development Officer, on E: sally.king-sheard@shinecharity.org.uk or T: 01745 889457 / 07896 912340.

Coming soon to South Wales... Your benefits are changing

If you are aged between 16 and 64 and get DLA, incapacity benefit, severe disablement allowance or income support (disability related) – you need to be prepared for the changes.

Shine Cymru is planning an information session in South Wales to explain the changes – date and location to be confirmed.

Please contact Margaret Stanton or Sian Prince on T: 02920 813847 or E: wales@shinecharity.org.uk

Northern Ireland

A great reception

As part of **Shine** awareness week **Shine** NI held five Mayor's receptions across Northern Ireland. The events took place in Derry City Council, Ballymena Borough Council, Ards Borough Council, Belfast City Council, and Craigavon Borough Council.

At each reception we launched our Northern Ireland Go Folic! promotional video featuring Eilish Briggs and her son Michael, both of them also attended the Belfast City Council event.

During the week we sold yellow ribbons in shopping centres across Northern Ireland as well as encouraging as many people as possible to 'Wear Yellow and **Shine**' for the first Spina Bifida and Hydrocephalus Awareness Week.

We had a lot of support from our Members throughout the week. They helped us in the shopping centres and were in attendance at the Mayor's receptions. At each event a representative Member talked about their personal story of living with spina bifida and hydrocephalus. The Members all had very powerful messages about their experiences and about their connection with **Shine**.

We were also delighted that Diane Dodds MEP joined us for our final event. Diane had sponsored the International Federation for Spina Bifida and Hydrocephalus (IFSBH) event that took place in the European Parliament, Strasbourg last October and on her return home attended the Mayor's reception in Craigavon.

We are very grateful to all the Mayors who hosted these receptions, to our members who attended and spoke on our behalf, and to all the people who wore yellow during the week.

cathy.mckillop@shinecharity.org.uk



Rise & Shine

Stoke Mandeville Stadium, Guttman Road,
Aylesbury, Buckinghamshire HP21 9PP

Sat 20th - Sun 21st July 2013

Adult Member Lifestyle Event to promote getting involved in social activities including sports and other leisure pursuits. Elements of the event will also cover health, wellbeing, and mobility/independence aids.

- Saturday 20/7/13 to include:**
Healthcare: Hollister, Mitrofanoff Support Group, Nutrition advice, RN Sports Therapy, and Complimentary Therapy
Sports: Basketball, Badminton, Boccia
Misc: Wheelchair Services, Disability Holiday/Breaks, Art workshop.

**All exhibitors subject to change/confirmation*

- 'Have a go' sessions & workshops**
- Sunday 21/7/13 to include:**
 Breakfast and coffee morning/social time.



A lifestyle event for adult members with spina bifida/hydrocephalus.



Costs:
Weekend rate £120
 (Including Saturday night accommodation)
Day rate £15
 (Lunch included)

Closing date for applications
Friday 21st June 2013

Weekend rate includes lunch, dinner, fully accessible accommodation maximum 35 twin rooms and breakfast. A limited number of rooms can host 3 people. Details of additional off-site accommodation can be provided, at visitors own cost.

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

Shine' Lifelong Opportunities Programme Presents our 2nd

Grandparents Day

Cheshire County Sports Club
 County Lodge, Plas Newton Lane,
 Chester CH2 1PR

Grandparents are an important part of every family but, when they are grandparents of children with spina bifida, hydrocephalus or IH (intracranial hypertension), they have an extra role - to support their son or daughter who is the parent of the disabled child.



For an application form please contact:
 Denise Richardson on **T:** 0113 2556767 or
E: office@shinecharity.org.uk

Opportunities to:

- Access the specialist knowledge of **Shine** staff
- Learn coping strategies to improve relationships with grandchildren
- Talk openly about concerns, exchange ideas, and feel empowered and less isolated
- Gain confidence in dealing with complex issues associated with hydrocephalus, spina bifida, and Intracranial Hypertension.
- Share experiences with other grandparents in similar circumstances

Wednesday 3rd
July 2013

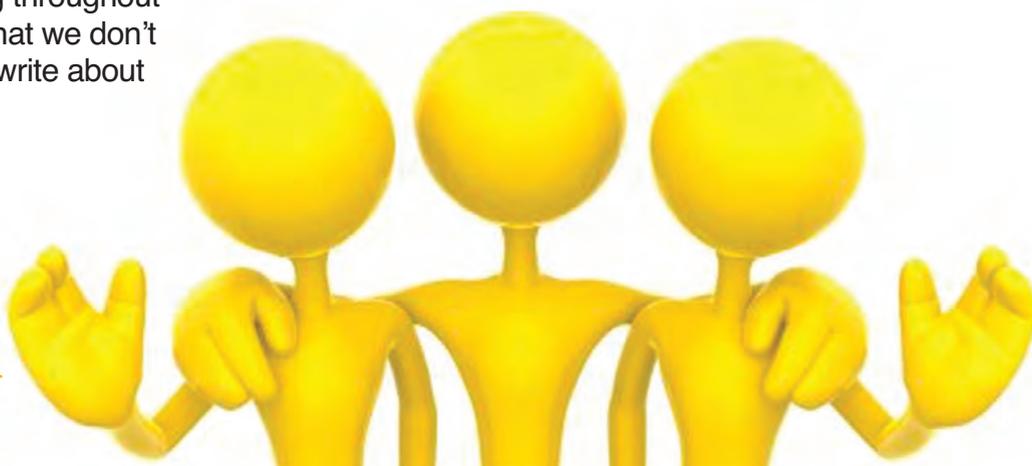
Cost per person to include
lunch & refreshments £10

Closing date for completed applications
Wednesday 27th
March 2013

Please note there is no provision for children to attend

Events Events Events Events

Great news! We have so many great events happening throughout the **Shine** community that we don't have enough space to write about them all in *Together*.



To find out the date and time of your next support group or **Shine** social function, please contact **Shine** Head Office on **T: 01733 555988**
E: info@shinecharity.org.uk or visit the events page of the website
shinecharity.org.uk/events

Time to Shine Adventure

A residential course for 12-16 year olds with spina bifida, hydrocephalus or Intracranial Hypertension

Pioneer Centre, Cleobury Mortimer, Kidderminster, Shropshire DY14 8JG

**Mon 12th -
Thur 15th
August 2013**

**Closing date
for applications 28th
March 2013**

The subsidised charge to each participant is **£160**. Please don't let the cost put you off applying, let us know if finance is a problem.

Please note that parents of those attending will have to arrange their child's transport to the Pioneer Centre. Some families may consider staying in the area, therefore reducing travel time.

For an application form or to find out more about the residential contact: Joan or Denise
T: 0113 255 6767 E: office@shinecharity.org.uk Shine, 64 Bagley Lane, Farsley, Leeds LS28 5LY

The course aims:

- To offer new and exciting experiences
- To give opportunities to meet new people and make friends
- To allow those attending to be themselves and have a fun time

The organised activities will be lively, and include Fencing, Abseiling, Treasure Hunt, working with Birds of Prey, and a Camp Fire on the last night. Other activities will also be planned. There will also be lots of opportunities for socialising.



Hello everybody and welcome 2013! Below you will find all the latest news including feedback from the SAMC meeting in December 2012. We were joined by CEO Jackie Bland, Development Manager, David Isom, Membership Officer, Gobi Ranganathan, Silver Dreams Project Assistant, Lynn Hart, and via SKYPE by Silver Dreams Project Coordinator, Angie Coster.

Developments

The SAMC attended a Media Skills Training Day on Friday 30th November 2012. The reason for this is to learn some basic media and presentation skills, it is important for people with spina bifida/hydrocephalus to speak on behalf of **Shine** and our fellow members. It is also important that we gain these skills as it helps the SAMC to learn about personal presentation, speaking to a room full of people, as well as increasing our skills and competency when answering questions or giving interviews to the media.

It was a worthwhile day for everyone, and we were joined by **Shine** staff David Isom, Gobi Ranganathan, and Gail Howard. By the time you are reading this we will have had another training day on Friday 1st February 2013, at **Shine** Head Office.

SAMC Selection and Election Process

David Isom explained this process in the last *Together* magazine, and what this means is that the next group of the

SAMC gets media friendly



SAMC will be reduced from 15, to 10. See page 20-21 for details of your new SAMC.

Action Group

Gobi let everyone know that a budget for the 'Rise and **Shine**' event in July 2013 has been set, and a number of exhibitors have been contacted. The closing date for people wishing to attend the event is Friday 21st June 2013.

Silver Dreams

We were joined Via Skype by Angie Coster and Lyn Hart who are working on the new Silver Dreams Project. The project is for people aged 50 and over with SB/H, it was a good discussion and Angie answered many questions from the SAMC. So, if you are 50 or over why not

get involved? There is a new web page where you could find out more please see – shinesilverdreams.wordpress.com

Final Meeting

The current SAMC met for the final time on Saturday 2nd February 2013. The next meeting will be made up of the newly elected SAMC.

So on behalf of the SAMC I would like to thank all our members for your contributions over the last three years and trust we have made a positive difference.

**Mike Bergin SAMC
Communications Officer**
mike.bergin@shinecharity.org.uk

The Work Programme

What is the Work Programme?

The Work Programme is the new official back-to-work support programme. It was introduced in the summer of 2011 and it aims to provide benefit claimants with tailored support with preparation for returning to work. It replaces the main elements of the former programme, such as New Deal, but supports some other employment preparation programmes such as Work Clubs and the Youth Contract.

The programme is being delivered by the Department for Work and Pensions (DWP) via a mix of private, public and voluntary sectors service providers such as Mind, A4E and Working Links. Providers are primarily paid for supporting claimants into sustained employment, with higher payments for supporting the hardest to help.

Providers have been given complete autonomy to decide how best to support participants whilst still meeting contractual minimum delivery standards; this is intended to encourage personalised support. The main type of support available is work experience or training, or a mix of both.

Which types of benefit claimants are affected?

There are voluntary arrangements for some claimants, however, in most cases, you might be compelled to join the Work Programme; namely:

- If you've been getting Jobseeker's Allowance (JSA) for more than 3 months; or,
- If you get Employment and Support Allowance (ESA) and you're in the Work-Related Activity Group. Those in the Support Group are currently exempt.

The idea is that if a JobCentre Plus Personal Advisor considers it appropriate, claimants may be referred to do compulsory work-related activity. For all JSA claimants and some ESA claimants, such activity can even include actual work; for example, work experience in a charity shop. Importantly, failure to participate without 'good cause' will result in a benefit sanction.

The rules for sanctions have changed recently on 22nd October 2012. They have been revised to be considerably more punitive with new escalation rules punishing claimants with sanctions for up to three years if they repeatedly fail to participate. Sanctions may be applied where there is a failure to participate in a mandated activity such as failing to turn up to an interview, failing to apply for a job, or failing to turn up for training.

Issues with the Work Programme

Although many claimants find referrals into the programme useful, there is some evidence to suggest that the DWP are, in some cases, applying sanctions inflexibly and are not taking into consideration mitigating circumstances, such as conflicting appointments or mental/physical ill-health.

For all JSA claimants and some ESA claimants, such activity can even include actual work; for example, work experience in a charity shop.

Our brief advice to you

Firstly, if you are referred to the Work Programme, we advise you to ensure that the Work Programme Provider is fully aware of the nature and difficulties that you face; where possible, it is best to supply medical evidence or supporting letters.

Secondly, if at any given moment you are unable to attend, or complete a particular activity expected of you, we advise you to seek immediate advice with regard to demonstrating good reason within the vital five working day window. If you do so, you can help to avoid a sanction, appeal and/or any related financial difficulties.

Eri Mountbatten, Welfare Rights Adviser
E: eri.mountbatten@shinecharity.org.uk



Shine

Spina bifida • Hydrocephalus
Information • Networking • Equality

Grand Prize Draw 2013

Let's raise over £15,000 ... *Together!*

Loads of great prizes. Tickets just £1!

Purchase tickets yourself
or sell a book to those you know

For more information see page 16
or call **Clara** on **01733 421307**

Star prizes ...



Plus more from ...

