Inside: Facebook support groups • new Shine app • Shine Stars

Together

Issue 12

Greg widens horizons at ebay

New Health Hub plan launched

Challenging the Chairman

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

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Step 1: Visit www.shinecharity.org.uk/prize-draw
Step 2: Fill in the online form
Step 3: Wait for your tickets to arrive
Step 4: Find out if you're a winner on 30th May 2014!

For more information call Shine on: 01733 555988

Star prizes to be drawn on 30th May 2014

*Due to different licensing rules, competition excludes Northern Ireland

Shine
Spina bifida • Hydrocephalus
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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.
E: info@shinecharity.org.uk

Submission dates for summer edition

- **Register of interest to submit:** 17/04/14
- **Final date for submissions:** 02/05/14
- **Publication date:** 06/14

Cover photo: Greg Smith **Taken by:** Tom Scott

A packed 2014

The start of the year may seem a distant memory, but we are still very excited about 2014!

Fancy that!

In this, our 12th issue, you will find news about our new **Shine** App – download it to access all of **Shine** at the tap of a button!

We have a great feature on the life of **Shine** Board member, Greg Smith, as well as all the latest gossip from Gobi, and health information from Gill Yaz.

This year we are developing part of the Head Office facility into a Health and Wellbeing Centre, read more about this on page 8. To raise much needed funds for this, **Shine** Chair, Richard Astle, is embarking on a monumental series of runs and treks to raise £25,000 through the Chairman's Challenge, page 9.

If you've sold your Grand Prize Draw tickets already, or if you need more to sell, then simply visit our new online form at W: shinecharity.org.uk/GPD and request more – we really want to beat the £5,000 you all raised last year and there are some FABULOUS prizes, including £1,000 CASH!

So, enough from me! Get stuck into this issue and if there is anything you would like to add for next time then just get in touch –
E: tom.scott@shinecharity.org.uk

Tom Scott

FRSB give with confidence

Shine wishes you an 'Appy New Year!

Did you know Shine is developing a new app for your phone or tablet?

We are currently looking for members with Android phones to beta test it. What is 'beta testing'? This is the second phase of software testing in which a sample of the intended audience tries out the product.

The app is full of useful information about spina bifida and hydrocephalus. It also has links to our social media pages, and lots more; you can even read *Together* magazine on it!

Don't worry, if you haven't got an Android phone, a version for iPhones will be ready soon, whilst one for Windows 8 is currently being developed and will be out later this year.

Many thanks to Chris Ramsey at App Inc for designing our new app. **W: appinc.co.uk**

To download the app please visit one of the following APP stores

Play: www.bit.ly/ShineAndroidApp, Amazon: www.bit.ly/AmazonAndroid or Opera: www.bit.ly/OperaShineApp – and remember to leave comments on the pages, so that we can use your suggestions to improve the App!

Congratulations to the Bullen Prize Draw winners!

Shine's corporate partners, Bullen Healthcare, recently ran a prize draw exclusively for **Shine** members. They provided some fantastic prizes: first prize was £1,000 of High Street Shopping Vouchers, 2nd prize was £500 of High Street Shopping Vouchers, 3rd prize was an iPad 2, and five lucky runners-up received iPod Shuffles.

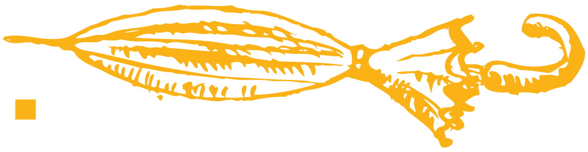
Don't forget that every time you place an order with Bullen Healthcare, 5% of the order value is donated to Shine – full details can be found in the insert you received with your copy of *Together* magazine.

1st Prize – **Sally Askey-Jones**
2nd Prize – **Andy Gray**
3rd Prize – **Gareth Roberts**
Runners up – **Lynn Doe, Devi Wood, Chloe Bright, Michael Bergin, Neil Carrol.**

Congratulations to the winners and thank you to Bullen for creating this opportunity for our members.

BULLEN

It never rains but it pours…



In recent months the news has been full of stories about large areas of the UK being flooded. This is terribly upsetting for anyone, but when you are living with a disability it can make the experience even more traumatic.

One of our members, Shelia Rodgers, experienced this first-hand on 5th December last year. At 4am she received an automated call from the environment agency giving a flood warning. At this point Shelia thought it was just precautionary as she lives quite a way from the sea.

Later that day Shelia was encouraged by sheltered housing staff to pack a bag. Luckily Sheila's former Girl Guide training kicked in and she decided to pack a little more than advised, ensuring that she would have sandwiches and a flask of coffee, just in case!

Later that day a tidal surge hit Lowestoft, Shelia's ground floor was completely flooded and she lost nearly all of her personal possessions.

Unfortunately, Sheila had no relatives nearby that she could stay with and she had to sleep in an armchair for the next four days, which really affected her IIH quite badly.

Sheila has now been rehoused 12 miles away from her former home; this loss of community connections has left her feeling isolated.

However, the **Shine40plus** group has now signed Shelia up to their telefriendship group and this allows her to have contact with other **Shine** members of a similar age – a really positive end to what has been a tough time for Sheila.

If you are feeling isolated and would like to join the telefriendship group, please contact Angie Coster on T: 01308 426372 or E: angie.coster@shinecharity.org.uk.

NHS still maintains adult services are adequate

It is over a year now since Shine first protested to the NHS that spina bifida remained excluded from conditions for which a national, specially commissioned service was available.

Together readers will remember that people with spinal cord injury are entitled to such a service but people with spina bifida, despite needing almost identical lifelong services, are excluded.

In spite of many representations to NHS officials, excellent lobbying of MPs at local level by **Shine** members, representations to the NHS from MPs and on-going correspondence with NHS Chief Executive Sir David Nicholson, we are seeing no progress at all.

The NHS seems adamant that spina bifida should remain subject to fragmented services at local level, dependent on GPs for identifying issues, and that these services are the most effective way of meeting the healthcare needs of people with spina bifida. There is no acknowledgment at all of our argument that services are inadequate in many areas, despite testimony and case studies from many **Shine** members.

> **He has yet to explain why spinal cord injury is treated so differently, i.e. if you acquire a spinal injury you get a better service than if you are born with one.**

Sir David argues that if spina bifida were recognised as a condition which merited a specialised service then all other neurological conditions would also make the same request (we are not sure what evidence he has for this). He has yet to explain why spinal cord injury is treated so differently, i.e. if you acquire a spinal injury you get a better service than if you are born with one.

Shine CEO Jackie Bland has written once more to Sir David to challenge his claims that care for spina bifida patients is best delivered through locally commissioned systems. In her letter she quotes the rationale used by the NHS to provide a specially commissioned service for spinal cord injury and points out that exactly the same rationale, word for word, could be used for spina bifida.

In the meantime please continue to put pressure on MPs and to send in/phone in with any examples of occasions when a lack of specialist understanding has resulted in less than acceptable health care for you – T: 01733 421356 E: sam.lyons@shinecharity.org.uk

Do we have your correct email address?

To bring you the latest news, or to deliver *Together* by email, we need your most up-to-date email address. You can send this to us at – E: info@shinecharity.org.uk

The 40+ age group now included!

The funding for one of Shine's most successful projects in recent years – the Silver Dreams – Shine50Plus project ends in March.

The project brought together hundreds of **Shine** members over the age of 50 who engaged in the development of health resources, friendship groups, craft groups, telephone support groups, a closed Facebook group and much more. The project will culminate in a weekend conference for the 50 pluses entitled 'A Pioneering Generation' at the end of March.

The end of funding will not mean the end of this group for our more 'mature' members, however, who say they have felt much more involved and valued by **Shine** through being part of the **Shine50plus** group.

Angie Coster, the project's inspirational and energetic co-ordinator, has agreed to stay on for two days a week to continue to support work with mature members, and we'll continue to produce a newsletter and find the funding for other events and activities as the need arises.

There will be a slight change though.

One of the things members have valued about this group is the opportunity to share thoughts, experiences and frustrations about health and other issues that arise as members with spina bifida and hydrocephalus grow older. We know that this a hot topic and that probably the biggest group of people with spina bifida in history is currently entering older age for the first time – a real 'pioneer generation'.

However, during the course of the project many people in the 40+ age group have been disappointed to find that they cannot be included because of the funding restrictions on the project. Many people in the 40-49 age group have said that they too are experiencing issues and anxieties about growing older that they would like to share.

For this reason, going forward, **Shine**'s group for more mature/older members will be open to anyone aged 40+ who feels they would benefit through being involved. If you are in this age group and would like to know more, please contact Angie Coster at
E: angie.coster@shinecharity.org.uk or call our central services on T: 01733 555988 and they can pass a message onto Angie.

We look forward to hearing much more from this group!

Shine's group for more mature/older members will be open to anyone aged 40+ who feels they would benefit through being involved.

Shine Health Hub and the Chairman's Challenge

If there's one issue that our members and their families constantly worry about it's the quality of the health services that they can access. We all know that amazing things can be achieved by our members and that disability is more about the environment than how your 'ability' compares to anyone else's.

But we all also know people whose lives are seriously disrupted when a health issue arises and services aren't quite what they might have expected.

Shine campaigns constantly to try to change NHS attitudes and improve services where we know they are lacking (we know there are some great ones too) but we also provide all the health support we can afford because we know our specialist staff understand where many mainstream professionals might not.

This year we are going to put a new emphasis on our health work to try to reach more people in more ways and increase the support, advice and information available to you all.

This year we are going to put a new emphasis on our health work to try to reach more people in more ways and increase the support, advice and information available to you all. **Shine Health** will include all our existing services both at national and local level. That's 31 Support and Development Workers divided into countries and individual regions – so we have **Shine** Cymru, **Shine** Northern Ireland, and then in England, three regions – the North, the Midlands and the South.

We also have two specialist health staff at national level – Gill Yaz, **Shine**'s Health Development Manager (see Gill's latest advice on page 18), Health Adviser Robin Barnatt and in Northern Ireland, Health Adviser Marie McGonnell. **Shine Health** will also include all our web/media and paper-based information and health-related resources, including new ones and updated ones this year.

But most significantly **Shine Health** will also include a 'health hub' here at head office which will include a health suite where people can attend for 'whole person' health and wellbeing checks; health and independence-related training courses and occupational therapy advice, including support for wheelchair users. **Shine**'s Health staff also want to include complementary therapies – relaxation, mindfulness, yoga (adapted to ability) etc in what they offer in the course of a year.

I was taken into hospital over Christmas – one doctor came to see me in my cubicle and said 'how long have you had spina bifida?'; then another came later and said 'I see you've had spina bifida – has it cleared up?'! Gobi Ranganathan, Shine Membership Development Officer.

For those for whom this is too far away, or who don't want to travel, there will be a range of remotely accessible services offered by our health advisers, including Google 'hangouts' (interactive health talks and seminars accessed via your computer, see page 15), Skype calls and of course 9-5, Monday to Friday telephone advice and fast responses to enquiries on social media and via e-mail. Of course we will also continue our programme of regional health-related events and get-togethers.

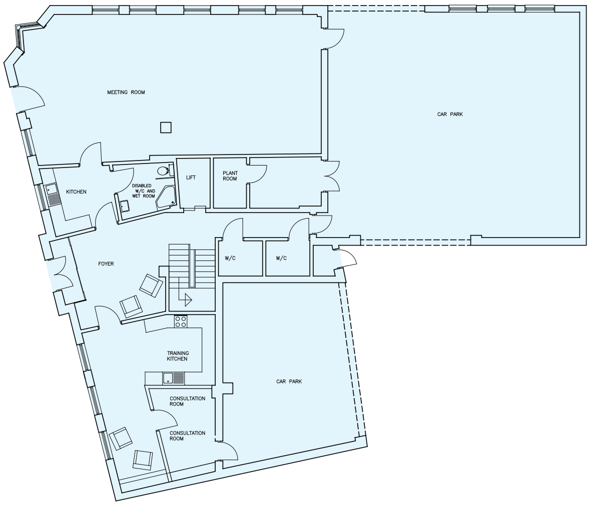
Through developing **Shine Health** in this way we hope not only to offer much more to our members, but also to continue to compile an accurate picture of the health needs that our members have and the gaps in current systems. Ideas for **Shine Health** are still being developed; if you have thoughts and ideas about this or want to follow progress then please do contact our health staff:

Gill Yaz T: 020 8805 4181
E: gill.yaz@shinecharity.org.uk

Robin Barnatt in England and Wales
T: 01733 421355
E: robin.barnatt@shinecharity.org.uk

Marie McGonnell in Northern Ireland
T: 028 8676 4748
E: marie.mcgonnell@shinecharity.org.uk.

Health suite plans



The Chairman's Challenge

To help raise funds for the 'health hub' in Peterborough, **Shine** Chair Richard Astle has decided to try to raise £25,000 in 2014, which coincides with his 10th anniversary as Chair of **Shine**.

Ambitiously, Richard has decided to really challenge himself and undertake ten gruelling events – one for every year that he's been Chair – including five half marathons, a forty mile hill walk, a trek across Morocco, and a Santa Dash!

For more information about the Chairman's Challenge visit www.chairmanschallenge.co.uk.

To sponsor Richard in this challenging endeavour, please go to www.justgiving.com/thechairmanschallenge14 Every £1 Richard manages to raise will help support **Shine** members' health needs.

'I really wanted to show, after 10 years as Chair, how much Shine matters to me – to really test myself and raise this vital money for our members' health.'

Fighting for equality

Greg Smith joined Shine's Board of Directors last year. In his position as Head of User Experience Research and Design for Europe at ebay, Greg helps drive the usability of the platform that we all now use to buy and sell any number of different items. *Tom Scott* visited ebay's offices in Richmond to find out more about him.

The path to Greg Smith's influential role within ebay has been by no means straightforward.

Greg, who has spina bifida, has overcome many life challenges, and he has done so not by determination alone, but also through a healthy dose of pragmatism.

Greg grew up in Eastbourne, his father worked as a butcher, his mother as a secretary. As a child he underwent procedures familiar to many **Shine** members. His parents, Barbara and Geoff, were determined for Greg to have as normal an upbringing as possible, both educationally and socially, rather than growing up as a protected disabled child. They ensured that he was admitted to a mainstream school, at a time when parents of disabled children had to really fight for this to happen.

Operations on his tendons to help Greg to walk meant that his mainstream schooling was interrupted by stays at Chailey Heritage, a residential hospital and school for children with a variety of conditions including spina bifida and hydrocephalus.

Whilst he was an able student and only spent limited amounts of time there, many of his peers were permanent residents and in common with many 'special' schools of the time, academic expectations were low. Despite his frustration with this disruption to his learning experience, Greg's last major operation was in his early teens and he went on to catch up, and completed his A-levels in mainstream school alongside his original school mates.

Although Greg's parents had laid great foundations for a fulfilling adult life, he decided, with the support of his family, that the best way for him to fully develop his independence was to move away from home to attend university. He opted for Sheffield Hallam and enrolled on an Engineering and Business degree course. Having always enjoyed designing and making things using his hands, this was an easy decision to make.

Reflecting on this period, Greg says, 'The time at university made me. It's just you, you get a better perception of how people see you, and you learn that not everyone is the same in terms of how they see you. You can find your own place, it widens your horizons'.

And his horizons have remained wide. As someone who now oversees teams of people based in several different countries for one of the world's most famous brands, Greg aims not only to prove himself, but also to improve the lives of others.

Greg secured a graduate management trainee position with Exel Logistics (now DHL) and then developed logistics for automotive supplier, Unipart. This was in the late 1990s and during the birth of the dot com era.

Through his experience with Unipart, Greg sensed the potential opportunities within e-commerce and was asked to help develop a website which brought together designers and manufacturers. Though the project came to an abrupt end, Greg reflects, 'It was a great idea, but it was ahead of its time – the important thing was I had seen the possibilities out there'.

After some time away travelling in South America, Greg began a postgraduate Product Design course, but it didn't live up to his expectations and he left the course to start work with the Disability Rights Commission (DRC) as their Strategy Manager, later becoming the DRC's Head of Strategy, Planning and Research.

The decision to join the DRC was more than just taking a job for Greg, 'I felt an impulsion to join,' he says, 'The role was about social change, I was

Greg's reflections on becoming a Director with Shine – 'I hope that my life experiences as someone with spina bifida, with work experience in multiple business sectors, as well as the disability rights and equality sector, will help me bring some specialist business and equality rights knowledge to the charity. As well as ensuring that Shine can and does support their members with spina bifida and/or hydrocephalus to make their ambitions come true, as equal citizens and contributors to society.'

suddenly working somewhere with a workforce that was 70% disabled and very different to any of my previous working environments. I also felt I was giving something back to the generation of campaigners that had transformed disability rights in the UK during the 70s and 80s'.

It was an inspiring time to be part of the team at the DRC; Greg was an integral part of the 'Access for All' campaign, which transformed access regulations for buildings and transport, and, in addition to this, he helped shape the Prime Minister's report into the life chances of disabled people.

All this work affirmed what Greg had learned from his own experience – that in order to gain equality, you have to fight. In terms of employment, Greg asserts that this fight is 'essential if disabled employees are to enter the work environment as equals'.

After two and half years at the DRC there were major changes afoot and at this point Greg chose to pursue another avenue and developed his own online business selling designer mobility products. The business thrived and after a couple of years Greg sold it on to an investor. The business still exists today – W: verko.co.uk

After a year of studying for a Masters degree in Human Computer Interaction, Greg worked for LBI Digitas, Europe's largest digital marketing agency, to cement the skills he had been developing in the IT sector. After three a half years with LBI Digitas, Greg was made aware of the role at ebay, he went for it, got it, and is now very much a part of this powerful global brand.

We end the interview in Richmond as ebay's offices in America wake up. Greg has to make a call to the US, and we close with a photo beneath a glowing neon ebay sign.
It is clear that Greg is both very proud of what he has achieved and very passionate about working with **Shine** to use his experience and play his part in ensuring that everyone with spina bifida and hydrocephalus should access opportunities to achieve on a field equal with everyone else.

We very much look forward to working with Greg to achieve this together.

Rugby fever!

There was great excitement in the Wales camp as **Shine Cymru** members of all ages went along to see the Wales Rugby team train at the Millennium Stadium in Cardiff the day before the International against Argentina. In a stadium that holds 72,000 we were part of a privileged crowd who met the squad, collected autographs, and had pictures taken – providing memories that will last a lifetime.

Everyone had a fantastic day and, as any Welsh rugby fan will tell you, meeting the team really is as good as it gets!

Get involved – join the North Wales Friends of Shine Cymru

The North Wales Friends of **Shine** Cymru meet every couple of months in Llandudno, and focus on raising awareness of hydrocephalus and spina bifida, organising fundraising activities, and having fun.

We alternate meetings with the more formal planning for fundraising activities and social get-togethers.

Both are co-ordinated by Bryn Roberts, the North Wales Support and Development Worker, so if you are interested in getting involved, contact Bryn on T: 01248 724944 or E: bryn.roberts@shinecharity.org.uk Bryn is also on Facebook if you'd rather connect with him that way – facebook.com/Shine.Bryn.Roberts

Thank you! Thank you!

Putting the spotlight on our fundraisers in Wales

Some of our services would not exist without the wonderful fundraising support from our members, their friends and families, so here is a big 'THANK YOU' from us to you…

Ysgol Dafydd Llwyd raised a fantastic £300 at their 'Wear Yellow and **Shine**' day.

Ian Sherwood from South Wales asked his friends and family for donations to **Shine** Cymru instead of presents for his 40th birthday – we've received £1,080 to date and still counting!

Little Rosie Williams from Llantrisant, whose grandparents and friends at Ynysmaerdy Community Centre, Pontyclun raised £455.30. This was then boosted by West and Wales Utilities, which is the company Rosie's dad works for. They donated a further £300. Wonderful!

Tina Davies from Tonyrefail took orders for some delicious Christmas chocolates from www.chocolates-for-chocoholics.co.uk and kindly donated the £70 commission to us. (N.B: our Wales Director bought some and managed to eat them all before the big day!).


Langland Bay Golf Club

Last year, the men's section of Langland Bay Golf Club donated an Ospreys' shirt and raised over £125 for us. The ladies' section has also come up trumps and donated £50. Just great!

South Wales Support and Development Worker, Sian Prince, roped in the help of her sister, the rest of the **Shine** Cymru staff, and one of our mums for a Craft Fayre in Barry, South Wales. We raised a whopping £400.

If you'd like to get involved and do some fundraising of your own for Shine Cymru, then contact Hannah Wysocki on T: 01733 421351 or E: Hannah.wysocki@shinecharity.org.uk for a fundraising pack to get you started.

New Sports opportunity for members in NI

Wheelchair Hurling – a great success!

Shine members in the Western Trust area had great fun at a wheelchair hurling taster session organised by Disability Sports Northern Ireland (DSNI) and **Shine** NI, and facilitated by Ulster GAA coach Paul Callaghan.

Wheelchair basketball coach Steve McCrudden, who helped organise the session, said that the event was a great success; 'the members had great fun at the event and the coaching was very professional. Members were able to get to grips with the basics of the game quite quickly and the equipment that was provided was designed specifically to meet wheelchair users' needs'.

> **'I had a fantastic time – can't wait for more sessions.'**

Feedback from members has been full of praise about this opportunity and as a result **Shine** NI, DSNI and Ulster Gaelic Athletic Association are pursuing further sessions and are hoping to establish a regular training session at the University of Ulster's Magee Campus. **Shine** NI member and North West Eagles Wheelchair Basketball Club member Perpetua O'Driscoll had this to say, 'I had a fantastic time – can't wait for more sessions.'

If you are interested in attending wheelchair hurling or wheelchair basketball with **Shine** at the University of Ulster, Magee (Derry/Londonderry), please contact **Shine** Support and Development Worker Sandra Campbell T: 028 7135 4939
E: sandracampbell@shinecharity.org.uk

Congratulations!

The Shine NI Award was presented to Michael McKernan.

Michael has been associated with **Shine** for many years. He is a member of the Portadown and District Local Association, the Northern Ireland Association, and is the Northern Ireland representative on the Board of **Shine**. Pictured is Michael, his wife Margaret, SDW Janet Davidson, and children from the local group. Congratulations Michael and thank you for all of your hard work over the years.

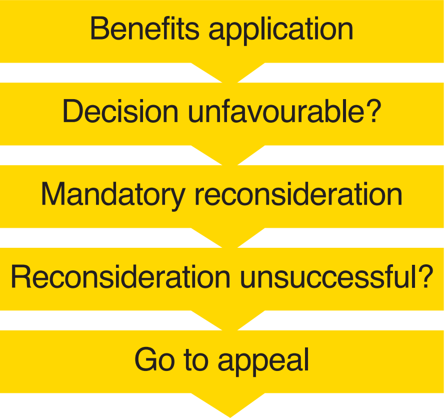
Benefits update

New appeals process for benefits awards.

Until recently, if you were unhappy with a decision made by the Department for Work and Pensions (DWP) about your benefits award, you could appeal. The process has now changed.

Instead of appealing, you first need to ask for a mandatory reconsideration. This simply means that you ask DWP to look at the decision again.

You will no longer have the option of going straight to an appeal.



You have one month to request reconsideration, beginning on the day after the date on your decision letter.

Shine recommends that you put any request for mandatory reconsideration in writing and keep a copy of the letter you send.

Do not miss the deadline for reconsideration as it is a required step on the way to making an appeal. You will not be able to make an appeal if the decision-maker refuses to reconsider because you are out of time.

The new rules are not expected to apply to HMRC benefits such as tax credits and child benefit until April 2014. These are not expected to apply to housing benefit decisions at all. The introduction of these new rules will be delayed in Northern Ireland.

Mandatory reconsideration and Employment Support Allowance (ESA)

If you have applied for ESA, or had your existing award reviewed by the DWP, it is important to note that your ESA will not be paid if your initial application was unsuccessful and you have requested mandatory reconsideration. Whilst you cannot avoid this, you may be able to claim other benefits such as jobseeker's allowance (JSA). If the reconsideration is not favourable you can then choose to go to appeal. You will be paid ESA during the appeal period.

Changes in timetable for introduction of Personal Independence Payments (PIP)

Plans for rolling out PIP to existing claimants is at a much slower pace than originally planned. The timetable for existing claimants with changes in circumstances is as follows:

October 2013 – Wales, East Midlands, West Midlands and East Anglia.

January 2014 – Postcode areas beginning DG (Dumfries and Galloway), EH (Edinburgh), TD (Galashiels) and ML (Motherwell).

3 February 2014 – Postcode areas beginning CA (Carlisle), DL (Darlington), HG (Harrogate), LA (Lancaster) and YO (York).

From October 2015 – All other postcode areas.

Late 2017 – DWP will have contacted everyone who needs to claim PIP.

New claims to PIP will continue throughout this period.

Universal Credit (UC)

There have also been delays in the roll out of Universal Credit and a revised timetable from 2014:

April 2014 – UC will start to include couples and families.
End of 2014 – UC will cover more of the North West.
2015 – Roll-out of UC programme continues.
2016 – 2017 – Most (but not all) existing benefit claimants will be moved over to UC during 2016 and 2017.

Northern Ireland is expected to be introducing Universal Credit from April 2014. However, the Welfare Reform Bill (Northern Ireland) has not yet been passed so details and dates may change.

Let’s connect!

Here at Shine we are always trying to think up new ways of connecting our members. We realise that often the best advice and support comes from those who can truly understand the challenges you face – your fellow members.

One of the easiest and most effective ways to connect with others is to use social media. Darren Fower, **Shine**’s Social Media Development Officer, has recently set up a variety of Facebook support groups; some cover a geographic area, whereas others focus on a particular condition.

The best way to find a group is to search ‘**Shine**’ + ‘your location’ or ‘your condition’, for example ‘**Shine** Nottinghamshire’.

If you cannot find a group that suits your needs or you have any questions about Facebook support groups, you can contact Darren by leaving a comment on **Shine**’s Facebook page – www.facebook.com/shinecharityuk – or via email E: darren.fower@shinecharity.org.uk

If joining a Facebook group doesn’t appeal, and you prefer face-to-face conversations, why not try a ‘Google Hangout’ with **Shine**’s Health Development Officer, Robin Barnatt?

A Google Hangout is a group video call. The first Hangouts have proved very successful with topics such as spina bifida occulta and shunt issues being discussed.

A Google Hangout is a group video call. The first Hangouts have proved very successful with topics such as spina bifida occulta and shunt issues being discussed. Whilst there is a definite topic for each talk, Robin comments that ‘because these are group discussions, we may start off talking about one topic, but this will bring up all sorts of questions, so we have covered bladder and bowel issues, mobility and lots more as the conversations have progressed’.

The easiest way to take part is by using a camera phone. All you need to do is download the Google Hangout app. If you would prefer to use a computer, you will need a web camera, a microphone, and to download the Google Hangout extension for your internet browser (if you have any problems with this, search ‘google hangout extension’ online, or contact Darren on darren.fower@shinecharity.org.uk).

If you’re interested in joining Robin for a Hangout, all you need to do is send him a message – E: robin.barnatt@shinecharity.org.uk.

Normal Pressure Hydrocephalus Shine Support Network: Frequently Asked Questions

Why is it called 'normal pressure' hydrocephalus and what is the difference between this and other types of hydrocephalus?

It is called normal pressure hydrocephalus because when Hakim and Adams first described it in 1965, the three patients that they mentioned in their paper all had normal pressure at initial lumbar puncture. NPH normally affects people in the sixth decade (there are, as always, exceptions); the excess CSF in the ventricles (spaces where the fluid is made in the brain) builds up slowly and the ventricles expand slowly to accommodate it. As the ventricles expand, they may damage the surrounding brain tissue leading to the symptoms of decreased mobility, some degree of dementia and, sometimes, urinary incontinence.

However the slow onset means that people with NPH do not have the symptoms of raised inter-cranial pressure (headache, vomiting, nausea, sight disturbances, seizures, etc.) that children and young people with hydrocephalus and an acute rise in inter-cranial pressure (ICP) experience.

Now I have a shunt in place, will my condition deteriorate?

No. Having a working shunt will control your NPH. It will not, however, prevent those conditions that are part of normal ageing.

Will I need my shunt replaced after a certain period of time?

If your shunt malfunctions, e.g. blocks (this is unlikely, but can happen), then it will need replacing. If everything goes as expected, your shunt should last you for life.

Is NPH hereditary?

No.

What are the short, medium and long term consequences of NPH?

You may need your shunt adjusted once or twice. Not everyone needs this. The main problem seems to be lack of confidence in walking – particularly if you have had previous falls. Some people have difficulty in remembering previously learnt skills i.e. finding their way around, map reading, etc. However, with practice these skills should return. Occasionally it is useful to have a neuropsychological assessment but this needs to be carried out by a neuropsychologist with an interest in NPH.

What limitations should I expect to arise?

You may get fatigued more easily than you expect to; depression is common in any long term condition.

How often should I have a check-up with the neurosurgeon?

Most neurosurgeons see their patients with NPH once or twice post-shunting. After that they usually discharge them with advice to go to their GP if they have problems and the GP will refer them back to the neurosurgeon.

Besides a shunt, are there any other medical and/or surgical remedies available to treat NPH?

A programmable shunt is the Gold Standard treatment for NPH. There have been trials of treatment with drugs such as acetazolamide, but these have not been very successful – and are only prescribed for people who are unfit for surgery.

How and when will my GP be able to help me, if and when I detect that my condition is gradually deteriorating?

Your shunt will stop your condition deteriorating. If your walking deteriorates, it can be a sign that the shunt needs adjusting so you should be referred back to your neurosurgeon. Your GP may not know this – the more common signs of shunt problems are those seen in people with other forms of hydrocephalus and these are the symptoms that most GPs will recognise (headache, vomiting, nausea, sight disturbance, seizures). NPH is different: if your shunt needs adjusting, your main complaint will be a gradual decline in walking.

Rosemary Ellis
former Principal Health Adviser, now Shine Volunteer at Adult Hydrocephalus Clinic

Flour power!

After a busy year with Go Folic!, we ended on a real high with the topic of flour fortification being brought to the fore in the House of Lords, having also been championed by the British Medical Association earlier in 2013.

Way back in December 2006, The UK Scientific Advisory Committee on Nutrition (SACN) recommended mandatory fortification of flour with folic acid in order to reduce the number of pregnancies affected by Neural Tube Defects (NTDs) like spina bifida. However, since then, successive Governments have made no steps towards adopting this proven primary prevention strategy, despite fortification having been safely (and successfully) implemented in 79 countries across the globe (including the USA and Canada who have been fortifying since 1998) with reported reductions in NTD-affected pregnancies varying from 26-50%.

Lord Rooker (who is also the ex-Chairman of the Food Standards Agency) shared our frustration at the Government's lack of action (both in terms of fortification and education regarding taking folic acid supplements) and has made it a personal mission to spur them into action. The debate that he initiated in the Lords received some passionate and high-profile support, most notably from Baroness Tanni Grey-Thompson (who very kindly participated in the debate) along with the Countess of Marr, Lord Turnberg and Lord Hunt. Since the debate, we have been involved in further communications with the Under Secretary of State for Public Health regarding the primary prevention of NTDs.

> **The debate (that he) initiated in the Lords received some passionate and high profile support, most notably from Baroness Tanni Grey-Thompson...**

Based on statistics in other countries, fortification of flour in the UK would mean that hundreds of late terminations could be prevented every year, plus up to 100 babies born without having to face the additional challenges of spina bifida. As the intention is to limit fortification to just white flour, individuals will have a choice, so that those wishing to avoid it can simply avoid white bread.

Although the fortification of flour would not be a complete answer, it would help to raise women's folate levels, providing increased protection to the 50% of pregnancies in the UK that are currently unplanned.

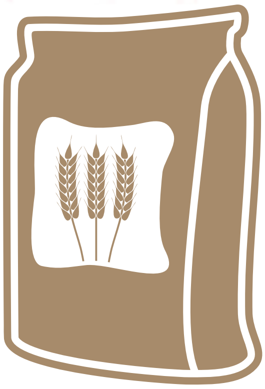
There would be no change to the long-standing advice regarding the taking of supplements, and all women who could get pregnant will still be advised to take 400mcg of folic acid daily along with B12 in order to ensure that they achieve the optimum protective levels of these important vitamins.

We will be sure to keep you updated of any progress as this work continues throughout 2014.

Martine Austin, Health Campaigns Officer.

If any members are interested in becoming more involved in our GoFolic! work please contact me at E: martine.austin@shinecharity.org.uk or T: 01733 421349.

Go Folic!



Who do I tell, and when?

Shine's Health Development Manager, Gill Yaz, on some common concerns.

Spina bifida and hydrocephalus can have a big impact on life. Working, driving, and relationships can sometimes seem more complicated, and I'm often asked 'When is the best time to tell people about my condition?' Well, it depends on what you want to do.

Work

It's now against the law for all employers (except the Armed Forces) to discriminate against disabled people. The Disability Discrimination Act defines disability as 'a physical or mental impairment which has a substantial and long-term adverse effect on the person's ability to carry out normal day-to-day activities'. Not everyone with hydrocephalus or spina bifida occulta would feel their condition has a significant impact on day-to-day activities, so you will have to decide whether this Act applies to you. Employers are only allowed to ask for limited information on your health or disability during recruitment, and it has to be relevant to the job you'll be asked to do. However, you need to be honest with yourself and your potential employers, about whether the job itself is within your capabilities; maybe, discussing your application with someone who knows you well beforehand can help.

If you are going to need 'reasonable adjustments' to be made to the job itself, such as working hours, or the workplace itself (such as needing to be near the loo, or a desk in a quiet area), you will need to tell your employer about your disability. You can suggest the changes which will help you succeed, or you can ask for Occupational Health Officers to help. Do consider sharing with someone if you have a shunt in case of an emergency at work, but make sure they know that this is unlikely to happen or they may worry needlessly.

Driving

You must tell DVLA if you have a condition which may affect your driving, and these include hydrocephalus, spinal problems, and sleep apnoea. The Medical Assessment form will give DVLA the information they need to decide whether you can drive, and for many people the answer will be 'yes'. You need to inform them if you have had any head surgery, such as a shunt revision, whether your consultant tells you to or not. Your licence will usually be surrendered for six months and you will need to reapply for your licence back at the end of this time. The reason for this is that head surgery can lead to blackouts or seizures during recovery which could put you or other road users at serious risk. Drivers are always responsible for ensuring they are fit to drive – if you have an accident because you are tired or feeling unwell, you will be held accountable.

There are heavy fines for not telling DVLA about your health. More information can be found at www.gov.uk/health-conditions-and-driving

Relationships

I often get told of people's anxieties around how much to tell about your condition when starting new relationships. My advice is always the same – take your time, get to know one another properly, and when you feel that you are relaxed and comfortable and in a trusting relationship, then the time will feel right. In the meantime, answer any questions honestly, giving as much information as you're happy to at that time. It's your body, you're in control. By and large, the details of your bowel regime or whether you can have babies are not the

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stuff of successful first dates. Concentrate on your partner, and find out about them, you'll then worry less about what impression you're making. People have told me they worry about their body, that people will find their scars or stomas a turnoff. Again, get to know each other. Most people aren't so superficial that this will matter if they really care for you.

Schools

For young children, I get asked whether the whole school should be told about their incontinence so they 'understand'. The answer to this is 'no'. Concentrate on getting their bladder and bowel management as good as it can be, as young as possible. Don't be fobbed off with 'we'll do something later' from your healthcare professionals. Children with bowel issues are more likely to develop self-esteem/anxiety issues, and challenging behaviour. Bladder and bowel management is private, and ownership of what information is given and when needs to stay with the child. Once the information is 'out', it can't be taken back.

Do consider sharing with someone if you have a shunt in case of an emergency at work, but make sure they know that this is unlikely to happen or they may worry needlessly.

Shine Stars

We know that when you lose someone you love, you might chose to dedicate a memorial plaque in a place of personal significance to commemorate the life of the person special to you.

Here at **Shine** we wanted to be able to offer families a unique and special way to remember those we love who have lived with spina bifida and hydrocephalus.

We are now proud to introduce **Shine Stars**, special plaques which are featured on the walls at **Shine**'s Head Office and offer a personal and permanent tribute in memory of your loved one.

Shine Stars are appreciated by everyone that visits **Shine**, they honour the love of our families, the achievements of our members, and show others why our work is so important for everyone affected by spina bifida and hydrocephalus. If you choose, your star can also represent your family's own personal fundraising by having a **Shine Star** Fund so you know how much is raised in honour of the star you dedicate.

Should you wish, every star can also have its own dedicated online memorial page on the **Shine** website so that your **Shine Star** can be viewed and shared with your family and friends at any time – go to www.shinecharity.org.uk /shinestars

There is no cost involved in dedicating a **Shine Star**. If you would like to talk about having a **Shine Star** placed in memory of someone who lived with spina bifida and hydrocephalus, please call Hannah on T: 01733 421351 or E: hannah.wysocki@shinecharity.org.uk

Stars are openings in Heaven where our loved ones shine bright and let us know they are happy – Inuit saying

Emma and James Lovelace

Emma and James Lovelace have been fundraising since their daughter Ava-Hope, was born sleeping last summer. Ava-Hope had spina bifida and hydrocephalus and to date they have raised over £2,000 for Ava's Shine Star in her memory.

Ava's big sister, Olivia

BRITISH SUGAR

A massive thank you to our latest Friend of Shine – British Sugar

British Sugar have generously donated £600 towards our top prize for the Grand Prize Draw and their generosity didn't end there! They also 'Decked the Halls', or should we say 'decorated the walls', on the top floor here at **Shine** Head Office just before Christmas.

This improvement to the building will enable us to use the space to accommodate meetings, and we desperately needed the area to have a bit of TLC so we can rent it out and raise funds.

This was provided by an army of British Sugar staff who came complete with paints, brushes, and Christmas-themed outfits! Now the space upstairs is a beautiful shiny yellow and we were able to welcome our first under 5s support group to Head Office, as it's now a warm and wonderful place for the little ones to play and the parents to get to know each other better.

April is the month of the marathon for Shine!

We have a record number of runners in both the Brighton and London marathons this year. We would like to wish our runners all the best for their challenges from everyone here at Shine.

Good luck to Mark Barton, Sanja Karanovic, Haydn Everson, James Burrows, Kevin Sedgley, Sarah Edwards, Andrew Kay, Emma Penfold, Andy and Anna Sorrell, Dawn Granger, Hannah and Aaron Whitlock (go Team Whitlock!), James Thompson, Alan Stanworth, Christos Eralleous, Rachel Sargent, Amy Hughes, Alan McKeegan, Sean Holland and Sian Wilkins.

We haven't forgotten of course about all our other wonderful active fundraisers, so a BIG 'good luck and thank you' to you all.

Don't forget if you want to run, swim, cycle, skydive or challenge yourself to a physical challenge to raise money for **Shine**, just contact Clara Gill on
E: clara.gill@shinecharity.org.uk or call
T: 01733 421307.

Shine Supporters

One of the growing areas of fundraising for us last year was in the field of business. These relationships varied from one man bands to international corporations, from one-off events to being either Charity of the Year or a Corporate Partner. The common thread was that these partnerships helped raise significant awareness of **Shine** as well as raising funds.

We would love to build on this success to help us reach more potential members as well as increase the services and support we can offer.

Do you work for or own your own business, or have friends and family that do? If so, please either contact Clara to discuss how we may be able to work together, pass on the details of your contact at the company, or pass on my details to the right person!

Contact Clara Gill on
E: clara.gill@shinecharity.org.uk or call
T: 01733 421307

The more businesses we work with, the brighter we can **Shine**!

We are proud to be working with...

DAVIES

BULLEN

Coloplast

ESSAR

Gobi’s Gossip

Hi All! I hope everyone is having a good start to the year. It’s fair to say 2013 was a difficult one for a lot of people – myself included.

In fact, even the last few days of year didn’t quite go as I’d planned as I ended up in hospital for the festive period. The good news was that my residency in Stevenage’s Lister Hospital wasn’t anything to do with my Mitrofanoff. The bad news was that I’d developed a septic chest infection – not good!

Despite my ‘hospitalisation hiccup’, the end of 2013 wasn’t all bad. I did manage a few high points starting with a Silver medal at the Para-Badminton World Championships in Dortmund, Germany. I then had an appearance on ‘Frankie Fryer’s Away Days’ feature on Sky’s Soccer AM. If that moment of glory on television wasn’t enough, I came away as the winner for the Hertfordshire Service to Sport Award, which was an unexpected surprise for me.

If 2014 can continue in that vein of success, I’ll be delighted! There’s lots being planned and I have a number of **Shine** projects which are proving to be a success too. With each region I visit, not only am I engaging with more of you **Shine** members, but, with the priceless help of Media Development Officer, Darren Fower, we’re setting up lots of support group pages on Facebook. This will help massively in identifying where you’re all located, which in turn will help bring many of you together from your surrounding areas. In addition to this, in each area I visit I’m engaging with a number of professional football clubs who are willing to help support me in raising awareness about **Shine**, spina bifida, and hydrocephalus.

All in all, there’s lots of progress taking place, with plenty more to come over the next few months. It looks as if now, more than ever, I’ll be able to meet more of the **Shine** Community. This will hopefully bring many of you closer together to not only support each other, but be better supported by **Shine** as well! So on that positive note, let’s **Shine** on in 2014 and move onwards and upwards!

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Can you name Benny's new friend?

Benny, has received some exciting news! His Mummy's friend is expecting a little baby girl bear. Just like Benny the little girl will have a special condition. Her condition is called spina bifida.

They have asked Benny to think up a name for her and Benny would like all of his club members to help him choose. He knows this is a very hard challenge (I'm sure your Mummies and Daddies will tell you that deciding on a baby's name is difficult because they will have it forever!). Benny is offering some great prizes for the club member who picks the best name!

All you need to do is send back the entry form below with your suggestion for the name of Benny's baby friend. Entries must be submitted by 1st May 2014

First Prize
£30 Toys 'R' Us Voucher

Runners-up Prizes
3 x £10 Toys 'r' Us Vouchers

Name

Address

Postcode

Telephone Number

Name suggestion

Send entries to: **Shine, 42 Park Road, Peterborough, PE1 2UQ.** **By 1st May 2014**

SAMC update

Hello everyone and a very warm welcome to 2014. I hope you all had a nice Christmas and New Year.

The weather is very adverse at this time of the year, so if you know a member, why not give them a call to make sure they are coping. That call could make all the difference.

SAMC Meeting

The SAMC met for their final meeting of 2013 on Saturday 16th of November at **Shine** HQ. In attendance was David Isom, Development Manager HQ Services and Midlands Region, apologies were received from Heather Doughty, Liz Potts and Gobi Ranganathan.

Developments

As previously reported in the last edition, the SAMC made a visit to the SIA (Spinal Injuries Association) in Milton Keynes on Monday 7th October 2013. We were made to feel welcome by many of the staff. Julie Braithwaite, Head of Information Services, gave a general introduction to SIA, and we heard more from Joy Sinclair, Advice Line Officer, Karen Mikalsen, Academy Co-Ordinator, Dan Burden, Head of Public Affairs, and Paul Smith, SIA CEO. The good news as a result of this visit is that membership is free, so there is an opportunity for our **Shine** members to join. There are many benefits to joining: access to Academy training courses, 10% discount on all SIA publications, event ticket discount, outreach services, telephone counselling, and much more. You can register as a member at www.spinal.co.uk or by calling T: 0845 678 6633.

Events

Lisa Cain and Jason Merrill attended the ‘Great Minds’ event in Peterborough on Friday 11th October 2013. This was **Shine**’s first event on Psychological Wellbeing and it was good to see members coming from as far away as York, London, and Somerset. A new event is planned for 2014.

Paul Manning attended the family event day in Liverpool on Saturday 9th November; again, this was a well-attended event.

Appeal upheld

In November 2013, a court of appeal upheld a legal challenge by five disabled people against the government’s decision to close the Independent Living Fund (ILF) in March 2015. A unanimous judgment from the court held that in December 2012, the Minister for Disabled People had breached equality duties when making the decision to close the ILF. It is not clear what effect this judgment will have on the future of the ILF, or the long-term implications for people who rely on the fund to provide their care and support, but I will update you all when we know more.

Finally…

The SAMC hope to recruit a new member shortly and I will be able to give an update in the next issue. As always, feel free to make contact regarding anything you would like to know or has been achieved on the members’ behalf.

Michael Bergin
Communications Officer SAMC
E: mike.bergin@shinecharity.org.uk

The good news as a result of this visit is that membership is free, so there is an opportunity for our Shine members to join.

This is Me

Shine's 'This is Me' Club members enjoyed getting to know each other better at Cadbury's World and at the Sea Life Centre in December 2013.

Shine Youth Worker
Nic Shaw

In fact, the trip to Cadbury's World proved so popular that some members were disappointed not to make it and a second opportunity to visit is being organised.

'This is Me' is a club within **Shine** which enables young members to get more involved. Those aged 13+ can chat to each other and **Shine**'s Youth Worker on a closed Facebook page, and all members receive a free newsletter in which young people can express their views on everything from computer games to school life.

In 2014 we hope to expand our youth activities at **Shine** to include young people aged 11-18, and to find ways of listening more to what young people want to do, what concerns them, and to work with them to find ways of really making things happen.

A new part-time Youth Worker, Nic Shaw has just joined **Shine** to take this work forward. Nic will join the This is Me Facebook page and will mail out to all young people aged 11-18 to introduce himself. Nic takes over from Sarah Harbour who has now left **Shine** for another post.

Nic has many years' experience of youth work in this country and in Germany and Canada. He's worked with young people in many settings and is an outdoor specialist and a gifted musician. He's also a trained carpenter! He hopes to use his experience and talents to develop a variety of work with young people, listening carefully to what they want.

If you are 11-18, or want to ask something about youth work at **Shine**, then please do get in contact with Nic. Suggestions for activities, or items you'd like to see in the newsletter, or things that concern you about being a young person with spina bifida/hydrocephalus are all very welcome.

Nic can be contacted at
E: nic.shaw@shinecharity.org.uk

‘This is me’ Activity Day at High Ashurst Outdoor Centre

Saturday 7th June 2014

Venue
High Ashurst Outdoor Education Centre,
Headley Lane, Dorking, Surrey, KT20 7LN
10:00am - 4:30pm

Event is open to members of the ‘**This is Me**’ group and those aged 11 to 15. Booking essential as places are limited (8 places). Activities to include; archery, climbing wall and team tasks, all lead by qualified instructors. Participants will need to bring lunch and wear appropriate clothing

This event is **FREE!**

Funded by

ROALD DAHL'S Marvellous Children's Charity

Closing date for applications 25th April 2014
To book a place contact Joanne Tailor
on T: **01959 534618** or
E: **joanne.tailor@shinecharity.org.uk**

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality
Registered charity no. 249338

Shine’s Lifelong Opportunities Programme 2014 Shine

Bowel and Bladder Day - The Last Taboo

An opportunity for members to receive up-to-date information on bowel and bladder issues and discuss any concerns/issues in a confidential environment.

Tuesday 25th March 2014

Venue:
The Harlequin Theatre, Redhill, Surrey, RH1 1NN

Time
10:30am - 4:30pm

- Morning session 11am - 1pm is for **parents**
- 2:00 - 2:30pm Presentation by Bullen Healthcare (open to everyone)
- Afternoon session 2:30 - 4:30pm is for **adults**

Sessions to be presented by Gill Yaz, Health Development Manager, and a representative from Peristeen.

Light lunches can be obtained from the coffee bar at the theatre.

Cost £5 per person
Closing date for applications 7th March 2014

To book a place contact Joanne Tailor T: **01959 534618** / E: **joanne.tailor@shinecharity.org.uk**

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

Shine's Lifelong Opportunities Programme 2014

Shine Independent Futures

Friday 9th – Sunday 11th May 2014

The Lodge, Hereward College, Bramston Crescent, Tile Hill, Coventry, CV4 9SW

Cost £180
for one member and a carer for two nights including meals and accessible accommodation

A 3 day/2 night residential event for a limited number of adult members and a carer/parent to identify some crucial steps and skills towards achieving and maintaining independence in the future.

This event will include:

- Steps towards basic cooking skills.
- Address everyday domestic skills required to live independently.
- Plan for budgeting and managing personal finances.
- Provide sources of information on working towards and maintaining independence.
- Enable learning of personal care skills on an individual basis.
- Address time management techniques / planning ahead and organising a daily routine
- Provide a social opportunity for members to mix together with others who share the same aspirations.

For an application form contact: Maureen Jobson, **Shine**, 42 Park Road, Peterborough, PE1 2UQ.
T: 01733 555988 E: maureen.jobson@shinecharity.org.uk
Places are extremely limited so please apply as soon as possible

Closing date for completed applications is 14/3/14

This event is aimed at members aspiring to live independently