Inside: Shine Awards 2014 • Competition • Update on benefits

Together

Issue 15

Raising the roof with Frank

Latest Shine Health developments inside...

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

BIG LOTTERY FUND
LOTTERY FUNDED

GIVE A GIFT. GIVE TO CHARITY. EVERYONE WINS!

£20 gift for the recipient to spend and £5 donation to Shine.

£40 gift for the recipient to spend and £10 donation to Shine.

Redeemable at over 21,000 shops and online stores!

Visit: www.shinegiftcard.org.uk to purchase yours today!

Reg Charity No 249338

The Shine MEGACYCLE Festival

Saturday 4th July 2015
Ferry Meadows, Peterborough

Join us for a family friendly cycle ride around Ferry Meadows, Peterborough, and then enjoy a festival vibe with music, stalls, games and entertainment at Oak Meadow.

BBQ and refreshments available
Sport challenges
Music
Traditional fete stalls and games
Win a Carrera bike worth £250!

Places limited – book now!
Check out our website for updates
shinemegacycle.org.uk

CONTENTS

Together Editor: Tom Scott
Deputy Editor: Amber Stokes

All enquiries and comments to:
Together **Shine**, 42 Park Road,
Peterborough, PE1 2UQ
T: 01733 555988
E: together@shinecharity.org.uk
W: www.shinecharity.org.uk
Reg Charity No 249338

Please let us know if you are happy to receive future mailings by email as this saves on postage and helps the environment.
E: serviceshq@shinecharity.org.uk

Submission dates for summer edition

- **Register of interest to submit:** 16/03/15
- **Final date for submissions:** 17/04/15
- **Publication date:** June 2015

Cover photo: Frank St John **Taken by:** Tom Scott

A Happy New Year to you all!

I hope 2015 has got off to a flying start.

We have started the new year where we left off the old – with lots going on across the **Shine** membership!

In this issue you will find exciting news regarding the progress of **Shine Health** (page 15), great photos from the 2014 **Shine Awards** ceremony and all the latest news from our ever-incredible **Shine** fundraisers!

Our features in this edition lead us to a meeting with rising stage star, Frank St John (page 16), and an honest challenge from Marcia Collins (page 13). Amber Stokes visited a pioneering new clinic serving our young members in Oxford – see her report on page 8.

Gobi Ranganathan brings us up to date with all his latest gossip and this issue is packed full of regional stories, activities from our thriving **This is Me** and **Shine40Plus** groups, all the latest campaigning news, and details of the latest **SAMC** developments.

You'll also find information on upcoming events, benefits updates, social media progress, and much, much more!

If you like what you see, or would like to see something different in the next *Together*, just get in touch. We love to hear your thoughts and ideas.

Tom Scott

E: together@shinecharity.org.uk

Give a gift. Give to Shine!

Shine has launched its very own gift card which means money is donated to **Shine** every time someone purchases a card as a gift. Redeemable in over 21,000 stores nationwide and online, the cards are available in two quantities: £10 is donated to **Shine** when you purchase a £50 card; and £5 is donated to **Shine** when you buy a £25 card. You can buy your card here –
W: shinegiftcard.org.uk

Commonwealth Scholarship

Shine is welcoming three visitors from Nigeria in March who have been awarded a Commonwealth Scholarship Commission (CSC) Professional Fellowship for three months.

One of the Fellows, Afolabe Fajemilo, contacted **Shine** in 2013 for support in developing services in Nigeria where he has founded the organisation, the Festus Fajemilo Foundation (FFF). Afolabe started the foundation after he and his wife experienced great medical and social difficulties when his son, Festus, was diagnosed with hydrocephalus.

Afolabi will be joined by his wife Adewumi Fajemilo and FFF Programme Officer Badejoko Fabamise, who hope to gain insight and learn key skills to inform the development of the organisation.

Shine has developed a comprehensive programme that aims to give the Fellows a detailed insight into our direct services, and they will be spending time with several **Shine** staff members during their stay.

Please join us in giving them a warm welcome!
facebook.com/festus.fajemilofoundation

Shine Member campaigns to take her trike on the tube

Ann Wright uses her trike regularly as a mobility aid, but has been refused on the tube, where they have a 'no cycles' rule.

Ann has therefore been campaigning for Transport for London (TfL) to allow her to use her trike on tubes, trains, and dial-a-ride buses. The TfL granted her use of the trike for one day on the Jubilee Line to attend its Access All Areas event in October 2014, which brought together disability charities, members of the public, and transport leaders to help raise awareness of the challenges of using public transport for people with disabilities.

Ann said: 'I enjoyed the day and we made a point, but we need to change people's perceptions. My trike is my mobility aid and I should be able to take it on the Jubilee Line every day.' Ann has since continued to raise the issue with TfL and other transport organisations to get better access in the future. Stay tuned for more on Ann's campaign!

Social media

Social media is a fantastic way for our members to keep in touch with us and to see what's going on across the growing Shine community. We love being able to see what you guys get up to and it's a great way for us to celebrate your fantastic achievements! Most of Shine's Health and Education teams, and Support and Development Workers, are on Facebook too, so it's an easy way for you to get in touch for advice.

Benny Bear
29 October 2014

The Benny Bear cake has arrived at the Shine office! Thank you Jo Stanley and Sharon Lapsley, we can't wait to have a slice!

Jessica Hodge
11 December at 10:23

WOW!!! Only gone and raised £3,514.00 I'm so emotional and shocked right now. I never thought in April when I started that I could raise anywhere this amount.
When I set up Emma's butterflies for shine I said I would be happy to make £150. So £3,500.00 is absolutely incredible. I am so grateful to everyone who has supported my fundraising by buying the butterflies, helping to sell them or just by spreading the word. Everyone has been so kind and supportive. I really couldn't... See More

Gill Yaz's social profile

Gill Yaz, **Shine**'s Health Development Manager, is available on Facebook and would be happy to help you with any questions you may have. Why not friend her on Facebook and get in touch?

facebook.com/Shine.Gill.Yaz
E: gill.yaz@shinecharity.org.uk

Did you know that there are numerous regional **Shine** support groups on Facebook? They're a great way to meet people in your area and to get advice from a **Shine** Support and Development Worker.

Shine Devon Support Group
Closed Group
For people, or parents of children, with Spina Bifida or Hydrocephalus in Devon to share snaps, thoughts and experiences! Plus, the Shin...
64 members

Shine Shropshire Support Group
Closed Group
For people, or parents of children, with Spina Bifida, IIH or Hydroce...
34 members
Tom Scott Shine is in this group

Shine Cambridgeshire Support Group
Closed Group
For people, or parents of children, with Spina Bifida, IIH or Hydroce...
63 members
Tom Scott Shine is in this group

Shine Lincolnshire Support Group
Closed Group
For people, or parents of children, with Spina Bifida, IIH or Hydroce...
55 members
Tom Scott Shine is in this group

Shine REFLECTIONS

Many people have started sharing their own short films as part of our #Shinereflections campaign. Watch the films here **W: http://bit.ly/Shinereflections**

Shine's social media presence in numbers...

10,886 **14,703**

If you need support to get involved, please connect with **Shine**'s Media Development Officer **Darren Fower** on **facebook.com/Shine.Darren.Fower** or **E: darren.fower@shinecharity.org.uk**

Finley's excellent family portrait!

Shine family portraits

Back in October 2014, Shine member Nikki Dalgarno, shared a fantastic picture on Facebook that her son, Finley, had drawn of his family. Nikki was so proud of Finley's picture that she got it printed onto a canvas.

Nikki said: 'Finley is the most caring, supportive and generous big brother! Being a sibling to a child with a disability can sometimes be tough, but it can also create an unbreakable bond. Everyday we treat our boys exactly the same, so we make sure Finley has special time just with Mum and Dad after Ethan's hospital stays.'

Here at **Shine** we loved how Finley had drawn Ethan on the wheel and it got us thinking. Perhaps your child has drawn a picture of your family at school, or perhaps you've got a painting stuck to your fridge door? We'd really like to see your family portraits and we want to give the opportunity for everyone to get involved – whether they have a disability or not.

Enter our competition: email us a photo of your family portrait drawing, or send a copy to us at the **Shine** Head Office. The lucky winner will win a canvas print of their family portrait!

Shine family portraits entry form

Name ______________________________

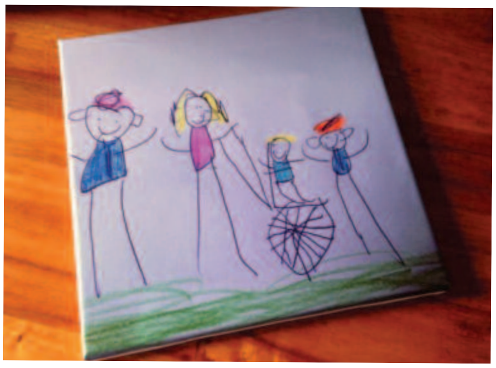
Address ______________________________

____

Postcode ______________________________

Telephone number ______________________________

Email address ______________________________



Send entries to: **Shine** 42 Park Road, Peterborough, PE1 2UQ or email **E: together@shinecharity.org.uk** by 13th April 2015

Awareness Week 2014

Thank you to everyone that got involved with Wear Yellow and Shine for Spina bifida and Hydrocephalus Awareness Week 2014. So many of you held events for Shine; here's a roundup of just a few:

Abigayle Bartaby was sponsored to dye her hair bright yellow during Awareness Week and raised £344.97. She also hosted a Benny Bear's Picnic at Irchester Country Park in Wellingborough, Northamptonshire. One of the raffle prizes at the picnic was the incredible Benny Bear cake, baked and donated by Jo Stanley. On her JustGiving page Abigayle says, 'This is my way of giving something back to such a great charity that has done so much for so many!'

The Skem Men-Aces are a Skelmersdale football team exclusively for adults with learning disabilities, led by **Shine** supporter Carl Eaton. They held a charity football match on 24th October against their local councillors and raised £1000 for **Shine**. On his JustGiving page Carl says, 'This charity is close to my heart as I have spina bifida and I am also a right-leg amputee, so it is really important that I always try to give something back and repay the superb support I was given through the hard times in my life.'

Hampton Vale Primary School in Peterborough had a **Wear Yellow and Shine** day on Friday 7th November. This event raised £299.21. **Shine** was invited and Benny Bear helped Tom Scott present a special school assembly, explaining spina bifida and hydrocephalus and **Shine**'s work. Benny said it was great to meet everybody and that he particularly loved the school song!

We have raised a HUGE £20,796.16 so far for Wear Yellow and Shine 2014 and still counting!

Hanna Hindmarsh, whose daughter has spina bifida, held a **Wear Yellow and Shine** event in Gutersloh in Germany at a second-hand book shop at her local army barracks where her husband is based. They had buy-one-get-one-free books, coffee and cake, and craft stalls. This event raised a fantastic £1000!

#Shinereflections

Last year, **Shine** launched a brand-new initiative to help boost awareness. **#Shinereflections** is an innovative film campaign which reflects what it's like living with spina bifida and/or hydrocephalus. Some of you have already shared your short films, but we'd love to see more! Find out more online at **W: http://bit.ly/Shinereflections**

Oxford John Radcliffe Children's Hospital Multidisciplinary Clinic

In November 2013, Oxford John Radcliffe Children's Hospital launched a new multidisciplinary clinic for children with spina bifida – the only one like it in the UK. Shine staff started attending the clinic in May last year, and have been given the opportunity to have a stand at each clinic. But what is so unique about this initiative? Amber Stokes caught up with hospital staff and a Shine parent member to find out more.

Angela Downer, Urology Nurse, Oxford John Radcliffe Hospital

'The more I saw patients with spina bifida and the more I heard them talk about having to see specialists at different times of the year, the more I found it unacceptable. While it might be common for them, it should not be normal, and we've proved that with our clinic.

'It first began with Leigh and her daughter Jamie – who has spina bifida. They both work here at the hospital and told me what would work from their perspective, having gone through similar challenges as the families who attend the clinic. So we got together and created the multidisciplinary clinic.

'We like to think of it as an MOT – a clinic you only have to attend once a year. We hold two clinics in a day and the children can see a range of specialists in just 3 ½ hours, including a urology nurse and neurosurgeon.

'It takes a lot of organising to arrange the appointments with the specialists, but we also try to make it personal, so that people who live near each other can come on the same day, for instance. Children that go to mainstream school, might not get to meet other children with spina bifida, so we have found that it has brought families together. People often meet here at the clinic and develop great friendships and stay in touch outside of the clinic – it's a real community now!

'The clinic has evolved and improved since its inception and we are now looking to expand it even further. We're hoping to get funding for a play specialist to come in to entertain the children while they are waiting to be seen, and we also want to get a psychologist to come in for each clinic, as well as an Occupational Therapist and a Physiotherapist.

We're also looking to introduce preventative approaches for things like toe curling. Parents might think, 'things can be much worse' with something like toe curling, but we want to help with and prevent, even the 'small things', to make even more of an impact on a child's life.'

Kate Mercer, Shine member and mother of Michael

'Michael is 4 and a half. He attends mainstream primary school and has myelomeningocele (covered) spina bifida. He uses a frame and sometimes a wheelchair. His prognosis at birth was that he'd have bladder and bowel difficulties with very limited mobility, but so far, he's surprising everyone. He is fully potty trained and can walk short distances unaided.

'We've been faced with a number of challenges when seeing specialists about Michael's health. We have to make several appointments with four different consultants, and have regular appointments with the orthotics department, physiotherapists and a community paediatrician. This interferes with Michael's schooling and weekly routines, and we also have to arrange childcare for his younger brother. Not to mention the problems it causes to our own patterns, as both my husband and I work full-time.

'Because of this, I find that we also sometimes have to act as a communicator between consultants. Whilst I'm confident notes are well recorded, we provide context and information from our visits from other specialists during the appointment. Sometimes this is difficult because we don't have the necessary expertise and it can be hard remembering the details when weeks or months pass between visits.

'The Oxford John Radcliffe Children's Hospital Clinic offers such a welcome and innovative approach to putting kids' and families' needs first. Because it runs like clockwork, we have undoubtedly saved an enormous amount of time having all the appointments in one day – I can't overemphasise the difference this makes – it means just one day off work, rather than eight! But more importantly, it means there is less impact on Michael missing school.

'The clinic also has a wonderful sense of community. When I've attended other appointments, you tend to be in a waiting room with a mixture of patients, which can be impersonal and can add to your isolation. At the clinic, however, we have met other children and their families who are facing similar challenges.

Michael Mercer

Because it runs like clockwork, we have undoubtedly saved an enormous amount of time having all the appointments in one day – I can't overemphasise the difference this makes...

'The whole team at the clinic are brilliant. The consultants are more immersed in the issues of spina bifida and they are much more prepared and need less context from us, which is great. The nurses and administrators are extremely skilled and you feel safe under their care. They're compassionate and talk to Michael directly, which is important, and they give honest information to us, rather than couching it. We moved further away, but we still take Michael to John Radcliffe because we don't want him under any other team – this is a testament to what we think of the clinic.'

If you are interested in getting an appointment at the clinic, speak to your GP to be referred.

Shine Awards

On the 20th November 2014, we celebrated all the fantastic people that make everything at Shine possible at the fourth annual Shine Awards. Fundraisers, volunteers, and professionals joined Shine staff and members at Coloplast, Peterborough for an emotional and inspirational afternoon of awards, which followed the Shine AGM.

Sisters Miriam and Joy Haizelden were joint winners of the Shine Young Achiever Award

Liverpool OT students jointly won Shine Volunteer of the Year

Sasha Burn won the Shine Professional of the Year Award

Coloplast

Hosts of the Shine 2014 Awards

Shine's Liz Cook presents Jessica Hodge with Young Fundraiser of the Year Award

Shine CEO presents Hannah Whitlock with the Fundraiser of the Year Award

Jackie Moore won the prestigious John and Lucille Van Geest Award for Outstanding Service to the Shine Community

Shine Chairman Richard Astle presents Jo Baxter with the Lifetime Contribution Award

The Bell, Dovey/Ratcliffe and Dalgarno families all won Shine Beacon Family Awards

Progress!

Go Folic!

By Martine Austin, Health Campaigns Officer

I can hardly believe that yet another year has flown past already, but it's great to be able to look back on 2014 and seen how **Go Folic!** has progressed onto another level with even greater recognition achieved!

You may remember in the last issue that I had been **Go Folic!**-ing in Northern Ireland. Things are progressing well, and there's a great deal of motivation to raise awareness of folic acid on an all-Ireland scale. I hope to be able to report back more on this next time. There is also growing support in Wales, and after conversations with the Chief Pharmaceutical Officer, we have been invited to tender for a pharmacy campaign in Wales for 2015.

Back in England, we continue to increase our profile amongst both women and health professionals. I have attended a number of professional events and held a series of 'refresher' sessions about folic acid for community midwives. As a result, we have been able to identify some additional barriers to communicating health messages within certain communities. We're now working with a Community Cohesion Manager to identify ways of engaging and training 'health champions' from within the community to help deliver important preconception messages.

The new Anencephaly Support Group has been a resounding success, with 128 members joining within the first three months.

Anencephaly Support Group

The new **Anencephaly Support Group** has been a resounding success, with 128 members joining within the first three months. I never anticipated such a response and have been overwhelmed by the lovely comments from our members about the much-needed support we're now providing.

Common themes have been the lack of support and information after diagnosis, both about the condition itself, and how to reduce the risk of recurrence; lack of information about the choices available; and also lack of support through future pregnancies. This confirms the need for this important work, and we are hoping to seek further funding to enable us to develop this area.

Many of our anencephaly mums are committed to raising awareness, and I must say a special thank you to Lisa Marie Chapman. Although open to all family members, the group mainly consists of mums, so I'm delighted to have recently added another admin to the group – dad, Ian. Ian and his wife have a young daughter, but have been through the devastating diagnosis of anencephaly three times, so he brings a lot of personal experience to the group and wants to help encourage more dads to participate.

facebook.com/groups/ShineAnencephalySupport

Body image

By Shine member, Marcia Collins

What do you think of when you hear the words ‘body image’? Do you think about the way you look? Your shape? Your posture? The way people look at you? Or do you think about how you come across to other people? Maybe it’s all of these.

I wanted to talk about how we think about body image, because it's a big thing in our society. Having perfect skin, the perfect body, being a certain size, cosmetic surgery to correct or enhance something about ourselves – these are all things people think about today. But as a disabled woman, I feel great sadness that we are getting to the point where we do not see what is beyond the superficial.

Often, for many of us, we have to fight against people who see our bodies as ‘imperfect’ or ‘deformed’, or something that needs to be changed because we do not look like able-bodied people.

We have to make ourselves proud of who we are as individuals. Body image isn't just about what we look like on the outside, it's how we feel on the inside.

Shine member Sonia Reains posted this great photo of her son, Dylan, on Facebook.

I have seen two wonderful photos recently. One was of a lady who was wearing a bikini and sunbathing. We are often inundated with these types of images, but what was different about this photo was that the lady had a colostomy bag. Her aim was to show that she is proud of who she is. She didn't want to hide the fact that she had a bag, but rather, that it was a part of her. We have been raised to believe that showing anything like this is wrong or something to hide, but there are thousands of people who have stomps like this, so why shouldn’t it be something that can be shown?

The second photo was posted on Facebook by **Shine** member Sonia Reains, who shared a photo and video of her teenage son, Dylan, showing off his back as part of the **#shinereflections** initiative. I could have cried with pride that he wanted to show his back to everyone, because this might be difficult for many of us to do. Could we feel comfortable enough with ourselves that we could say: ‘Hey, look – this is my back, it's got a few scars, but it’s my back and I am proud of it?’

We cannot change the way we look or how we are perceived by others. But we can think about how we feel about ourselves, which is the most important thing. If we know that we feel good, who cares what other people think? Who cares what words are given to describe us by others; it’s the words we choose to describe ourselves that matter. We have to make ourselves proud of who we are as individuals. Body image isn’t just about what we look like on the outside, it’s how we feel on the inside.

Shine Health

Shine CEO, Jackie Bland, explains some exciting new developments

Shine Health has taken some great strides forward since the last issue of *Together*, with the first pilot health checks taking place in our brand new health suite at Head Office.

Three members volunteered to be the first ever guinea pigs for this service, and by the time *Together* lands on your doorstep another group will have benefited from this exciting new development.

SAMC member Jason Merill was one of the first to volunteer, and was full of praise for the holistic health appointment offered by Health Manager Gill Yaz, Health Advisor Robin Barnatt, and Occupational Therapist Kathy Allen.

> **'It was great to have a check that looked at me as a whole person, and to know that the people doing the checks understood spina bifida/ hydrocephalus and really wanted me to get the best healthcare possible.'**

Shine's decision to raise the profile of its health support services and further develop its health work is driven by two important factors:

1. The inadequate level of health support offered to people with spina bifida and hydrocephalus

2. The lack of action by Government on the prevention of NTDs

Both issues are raised passionately and frequently by **Shine** members, both through social media, at events, and via the **Shine Adult Members Council (SAMC).**

Shine has responded by launching three new initiatives under the new '**Shine Health**' banner. These initiatives aim to help support members, improve services and protect both mothers and children from unnecessary risk from neural tube defects, which not only lead to spina bifida, but also to anencephaly, where the baby has no chance of life – a heartbreaking situation for expectant parents, as members of **Shine**'s new **Anencephaly Support Group** will testify.

Shine Health
Home Delivery

Shine Health Home Delivery

Building on a pilot relationship with Bullen Healthcare, **Shine Health Home Delivery** will offer a tailored service for **Shine** members who need regular stoma and continence products offering prompt home delivery which can include your prescription drugs too. We hope that by providing a service which provides all your continence and prescription requirements in one place, we'll take away some hassle that you don't need.

Staff specially trained in dealing with spina bifida and hydrocephalus issues will manage the service and be on hand to remind you when you need new products/prescriptions, guide you through checks on what you need, and be there for you if you have any difficulties. All **Shine** members will receive a letter from me explaining more about this service in March.

Health Hub

The **Health Hub** aims to offer all-round support to people with spina bifida and hydrocephalus, providing health checks for those able to visit the health suite, and telephone, and online support to anyone with SB/H in need of help. All **Shine**'s health services staff are fully qualified nurses or Occupational Health Practitioners. As well as offering general help, Robin Barnatt also specialises in keeping people mentally healthy. Gill Yaz, who manages our health services, has almost twenty years experience in working with people who have SB/H and parents diagnosed with an NTD pregnancy. We also have nurses on the staff in some of our regions and we hope there will soon be a regional health lead in each regional team.

We not only offer advice but can help you in managing your relationships with the health services that you access within the NHS and elsewhere.

Through our **Health Hub** work we can offer support with any health issue affecting our members. We not only offer advice but can help you in managing your relationships with the health services that you access within the NHS and elsewhere. To access these services you can contact our health staff via e-mail
E: robin.barnatt@shinecharity.org.uk
E: gill.yaz@shinecharity.org.uk
E: kathy.allen@shinecharity.org.uk
on the phone **T: 01733 555988** or via
facebook.com/Shine.Robin.Barnatt,
facebook.com/Shine.Gill.Yaz,
facebook.com/Shine.Kathy.Allen.

The health team welcome all your calls and enquiries.

MayB-baby

MayB-baby will build on **Shine**'s four year old and very successful **Go Folic!** campaign, extending advice beyond the need for folic acid prior to conception to include the other factors that contribute to a healthy conception, pregnancy and birth.

MayB-baby invites all women to acknowledge the possibility that they may one day become mothers (rather than just focusing on women who are trying for a baby) and aims to give them the best, most timely advice to help ensure they minimise their risk of both spina bifida and hydrocephalus.

Over the next year **Shine** Campaigns Officer, Martine Austin, will develop a range of materials and a new website which we hope will put all this advice and information in one place in an attractive and accessible format. Eventually we hope that **MayB-baby** will develop materials aimed at younger women and girls, gently preparing them for the day when they may one day have a baby, and beginning to reinforce the message to them about the role of folic acid and other healthy living measures in preparation for motherhood.

This will help to address the problem that many women have just not encountered adequate advice on planning and maintaining a pregnancy by the time they find themselves pregnant.

To contact Martine, who also co-ordinates
Shine's Anencephaly Support Group
E: martine.austin@shinecharity.org.uk or
T: 01733 421349.

To be Frank...

***Together* Editor Tom Scott gets tuned in to Shine member Frank St John who isn't going to let hydrocephalus or multiple shunt revisions get in the way of his singing career**

From the first moment with Frank I was instantly struck by how bright, enthusiastic, and incredibly polite he is – no doubt all attributes which have led to his considerable success.

We meet in the reception area at Chichester University, where Frank is studying for a degree in English Literature and Creative Writing. However, I haven't come here to read Frank's work; I've come to hear him sing.

Frank, who has hydrocephalus and impaired vision, sings with the University of Chichester Ensemble Group and is currently rehearsing with his fellow students as they prepare to stage Gilbert and Sullivan's musical 'Iolanthe'. After meeting we rush to the rehearsal space so that Frank can rejoin the session, where he shares a joke with friends whilst waiting to be called over to perform his part.

I have no idea what to expect in terms of the sound they are going to produce, but I don't have to wait long to find out. The twenty or so students separate into two groups and soon there is an impressive sound of hearty singing and choreographed footsteps reverberating around the room. It is at this point that Frank's mother, Angela, arrives from London, and we begin to chat.

For a moment we both watch Frank as the group chant their lines, breaking off in mid-flow to receive instruction, and then gathering back their choral momentum. Angela is armed with a catalogue of Frank-related memorabilia; cuttings, programmes, awards, and certificates bulge from multiple folders. We begin to work our way through them, Angela's soft Scottish accent proudly detailing Frank's impressive set of achievements.

We begin to work our way through them, Angela's soft Scottish accent proudly detailing Frank's impressive set of achievements.

At 21, Frank is already an award winner, having twice won the accolade of ‘St. Bernard’s School, Young Musician of the Year’ in both Year 12 and 13. These achievements at the Slough-based grammar school came in tandem with reaching grade six on the saxophone, despite at the age of nine being told by a hospital consultant that he would never pass a public examination due to memory problems!

Frank also sings as a part of both the National Youth Choir and the prestigious London Youth Chamber Choir. As a first year undergraduate he won the principal role in his university’s production of Mozart’s ‘The Marriage of Figaro’, and just as importantly (if not more so!) he sang with Mick Jagger and the Rolling Stones at their 50th anniversary concert in the O2 Arena.

The rehearsal eventually breaks for lunch and Frank dons the one-off t-shirt which was given to him at the Stones gig, and we talk more about his experience of combining his stage career with growing up having what his mum terms, ‘a brittle hydrocephalus.’

‘I’ve had twelve shunt revisions...I think!’ Frank recounts. He says he’s had his fair share of touch-and-go moments, with shunts failing, but with the help of some amazing neurosurgeons at the John Radcliffe and Great Ormond Street Hospitals, Frank has managed to forge on with both studies and extracurricular activities. As defining as the tough times can be, these really aren’t the focus for Frank and his family.

He beams about singing, compliments the help from the RNIB in supporting his singing over the years, and encourages others with hydrocephalus to ‘never compromise when you need extra support to achieve your goal.’ Frank cites an example of this – he once needed some music to be copied in a larger size to accommodate his low vision; initially this seemed a hassle to those in charge, but Frank stood his ground – after all, how was he going to sing if he couldn’t read the music?

At 21, Frank is already an award winner, having twice won the accolade of ‘St. Bernard’s School, Young Musician of the Year’ in both Year 12 and 13.

Frank undoubtedly has high ambitions, but he doesn’t expect anything to fall into his lap, and his last piece of advice sums up his attitude:

‘Whatever it is you are going after in life, really work at it. When I first started grammar school and explained to my dad how hard it was, his advice was clear: ‘You work harder’, he said. ‘You are disabled, but life doesn’t owe you anything; you’ve got to go out and grab it, so just work for it.’

I have no doubt that, in his pursuit of being a professional singer, Frank will indeed work for it, and will be lifting the roof on many a famous venue for a long time to come. It was a privilege to meet such a motivated and talented **Shine** member and I hope we’ll all be able to follow his on-going story.

Chairman's Challenge

Well, what a year we had in 2014!

In the last issue of *Together*, I had completed challenges seven and eight of the Chairman's Challenge – the Great North Run and Great Eastern Run – and was well on my way to meeting my ambitious target of £25,000.

Many of you will have heard that challenge nine, the Sahara Trek, ended in difficult circumstances. The whole team, including Peterborough Council CEO, Gillian Beasley, and Shine Treasurer Aidan Kehoe, had to be evacuated out of the desert following an outbreak of some as yet unidentified virus. The brave **Shine** team did at least manage three days of trekking through the desert, and together raised nearly £6,000 towards the Chairman's Challenge total.

My 10th challenge took me to the 5k Santa Dash at Burghley Park, Stamford, on Sunday 14th December 2014. An incredible 135 people joined my team on the day, including runners from local businesses Businesscoms, Rawlinsons, Royal HaskoningDHV, e4education, Premier Kitchens and Athene Communications. Altogether, 1,178 took part, all raising funds for many charities.

The Chairman's Challenge fundraising target at the start of 2014 was £25,000. Having run over 120 miles, and with the support of many 'challengers' along the way, I have now exceeded this by £10,000! With donations following the 10th challenge tipping the grand total over £35,000, I would like to extend a massive 'thank you' to everyone who made the Chairman's Challenge such a resounding success!

Official judges rule

However, there is some shocking news to announce! Following the annual review of the Chairman's Challenge, the official judges have ruled that challenge three, the Sheffield Half Marathon, does not count as the event was cancelled due to a lack of water for runners. Due to this, I have decided to sign up to run the Virgin Active London Marathon on the 26th April 2015. The Chairman's Challenge lives on!

W: justgiving.com/thechairmanschallenge14

Shine's Health Hub

The money raised through the Chairman's Challenge has helped to fund a new Health Suite at **Shine**'s Head Office, which has now seen much progress over the last few months. The consultation room is now complete and **Shine**'s health team conducted their first health consultations pilot on the 17th December with volunteers from the SAMC who provided feedback. The team will continue to run similar pilots before launching consultations to all **Shine** members, and we hope that work will also commence on an independence training kitchen, wet room, and accessible entrance door this year.

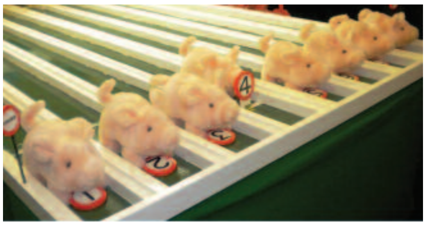
100% funded by you!

Last year was action-packed with all the events that our fantastic fundraisers took part in to raise money for Shine. It is only through your support that we can continue to provide support to everyone affected by spina bifida and hydrocephalus. Shine is 100% funded by voluntary donations, we can only do our work due to dedicated fundraisers – thank you!

Shine fundraisers organised bake sales and pub quizzes, took part in swimathons and skydives, and even dyed their hair yellow – all to raise money for and awareness of **Shine**.

Clare West organised a 10-mile sponsored walk around the Lincolnshire Wolds during the August Bank Holiday last year, which attracted 10 people. They raised an amazing £1,745 for **Shine**.

Since 2011, Sarah Renehan has raised over £10,000 for charity with 'Project Brain Drain'. Project Brain Drain's latest fundraiser was the release of a compilation album titled 'Musik Mayhem' on the 31st over the world who have agreed to donate their music to raise money and awareness for hydrocephalus (some bands have members who have hydrocephalus or a direct connection to the condition). The CD is available on Project Brain Drain's online store with proceeds going to Shine, Hydro Angels in America, and Hydrocephalus Support Association in Australia. Get yours here **W: http://projectbraindrain.org**



Staff at the Springfield Hotel in Darlington have completed a number of fundraising events/collections for Shine. On the 22nd November 2014 they held a Charity Pig Racing night, where they raised £303 to be split equally between **Shine**, Breast Cancer Campaign, and the Cystic Fibrosis Trust. They will also be running a charity race night for **Shine** on the 14th March!

We're already hearing from lots of you who are planning fundraising events for 2015 – thank you for the support and keep up the good work! If you would like to take part in fundraising for **Shine**, just email us at
E: fundraising@shinecharity.org.uk

London marathon 2015

We've got a great team of runners who are raising money for **Shine** again in this year's London Marathon, which will be held on the 26th April 2015.

Good luck to all our runners: Kerry Fitzpatrick, Matthew Gibson, Richard Astle, Stephen Vickers, Jonathan Ramsden, Daniel Jolley, Jessica Pratley, Amber Kirk and Adrien Prigent.

SAMC update

Hello everyone and welcome to all the latest news from the Shine Adult Members Council (SAMC). By Michael Bergin

Spring is nearly upon us; the clocks will soon be going forward, the bright nights are coming, and it's time to start making plans for those summer holidays!

SAMC meetings

The SAMC's last meeting of 2014 was in November at **Shine** Head Office and was well attended. Gill Yaz, **Shine**'s Health Development Manager; Martine Austin, **Shine**'s Health Campaigns Officer; and David Isom, **Shine**'s Development Manager (National HQ Services & Midlands Region), joined us. We had our first meeting of 2015 in January – more about that in the next edition.

The Shine Youth Council

Developments

One of our roles as **Shine**'s representative group of adult members is to communicate issues or suggestions that members may have about **Shine** and its services. We often receive suggestions for new leaflets to provide guidance to our members on various issues, and it is our job to work with **Shine**'s Health and Education Development teams to get these produced.

Following a suggestion from a member, the SAMC has been working with Kate Steele on a guide to help adults with spina bifida/hydrocephalus to understand direct payments. SAMC health lead, Patricia Adley, has had meetings with Gill Yaz regarding a leaflet on pain management, as well as **Shine**'s leaflet, Taking Care of Yourself With Spina Bifida. Benefits lead, Helen Robinson, has been working on updating the Severe Disablement Allowance leaflet, and there are two useful information sheets on filling in the forms on the **Shine** website. We are also hoping to get a link to Disability Rights on the **Shine** website in the near future – head to page 22-23 for more information on changes to Disability Living Allowance (DLA).

More news

Jason Merrill will be our link from the SAMC to the new **Shine** Youth Council and he has been liaising with Nic Shaw, **Shine**'s Youth Work Coordinator, on updates. I have been to meet some members in the Hull and surrounding areas, and I shall be at the Family Opportunity Weekend in March. Sadly, SAMC member Asif Shah has had to resign from the council for personal reasons, but I am pleased to announce that Sue Skinner, who many of the members will already know, will be joining us as his replacement.

Got a question? Is there something you would like to see the SAMC doing on your behalf? Please feel free to make contact at anytime!

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

This is Me

By Nic Shaw, Shine's Youth Work Coordinator

I can't believe the difference in the temperature between Belfast, where I am now living and studying, compared to Cambridgeshire, where I moved from. It was so much warmer down there! Since my move, things here at Shine have certainly been cooking over...

Shine's Youth council

We had the very first **Shine** Youth Council in Coventry during the weekend of the 10th-12th of October 2014. There were six **This is Me** members in attendance: Aaron McKane, Amy MacDonald, Rosie Booth, Megan White, Rowan Ford and Simeon Wakely. The rest of the team was made up of Andrea Daye who volunteered and Elaine Adams, our **Shine** Support and Development Worker from Coventry.

The weekend was great fun. It was also a time of learning, getting our heads around what we are embarking on, and beginning to forge some concrete ideas as to what our roles are on the council. One of the best things for me over the weekend was having Radio Plus come in and interview us. The guys were really good and to be put on the spot like that with a microphone pushed in front of you is not easy. I was so proud of the guys being able to get that recording onto Facebook. That weekend holds some great memories for me and, I'm sure, all those who attended too!

The mascot

During the end of November I was working outside and heard this tiny little whimper. I could not work out where it was coming from, until I put my hammer down and started hunting around. Underneath a planter box was this little tiny grey kitten! I thought this would be a great addition on the farm but also a fantastic mascot for **This is Me**. Rowan Ford was keen for a mascot and here it is! I decided to call it 'TIM' after **This is Me**. I'll send you updates on his progress!

Warner Bros Studio Tour London – The Making of Harry Potter

October 25th 2014 was Spina Bifida and Hydrocephalus Awareness Day. It was on this day that we took some lucky **This is Me** members over to the Harry Potter Studios in London. I have never seen young people with eyes and mouths gaping that wide before! The sets and the props that were on display were absolutely superb. It was really exciting to go through and see some of the weird and wonderful creations from the Harry Potter films. Because of the success of the day, we are going to be running it again this year – keep your eyes peeled for more information soon!

It was really exciting to go through and see some of the weird and wonderful creations from the Harry Potter films.

Changing to Personal Independence Payment

If you are 16 or over and claiming Disability Living Allowance (DLA), your benefit will change to Personal Independence Payment (PIP), if it hasn't already happened. People living in Northern Ireland will also be reassessed at some stage, but we do not know when yet. You will have to be assessed for PIP, even if you have a lifetime or indefinite award.

Re-assessment will start first for people who live in: Carlisle, Chester, Cumbria, Darlington East Anglia, East Midlands, Harrogate, Huddersfield, Lancaster, Liverpool, Manchester, Wales, West Midlands, and York.

AND

- Your fixed period of DLA ends
- You report a change in your care or mobility needs
- You reach the age of 16.

For most other people, except in the groups above, you will be re-assessed sometime between October 2015 and late 2017.

There are some special circumstances, which include:

- Children getting DLA, reaching 16 and not living in the areas above can continue claiming DLA but will be re-assessed at some point – we do not yet know when this will be.
- People who are getting DLA and were 65 or older on 8th April 2013 will not be re-assessed for PIP or be able to claim it. You can continue to receive DLA.

However, if you are getting DLA and were under 65 on 8th April 2013 but have since reached the age of 65, you will be re-assessed for PIP. If you do not get PIP, you may be able to claim Attendance Allowance.

Completing the PIP application form

As well as asking for information about your disability/disabilities, the PIP application form asks you to describe your ability to carry out daily living and your mobility. It is important that you highlight how your spina bifida and/or hydrocephalus affects how you do things, how you think and how you learn. You should seek help to fill in the forms if you feel you have difficulty expressing yourself.

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

shinecharity.org.uk
info@shinecharity.org.uk
42 Park Road
Peterborough
PE1 2UQ
01733 555988

Personal Independence Payments (PIP) for adults who have spina bifida
Note there is a separate sheet for adults who also have hydrocephalus

These notes are intended to assist you to fill in the application form for PIPs. Please note that if you also have a sight impairment or hearing loss, there are separate notes to assist you on the information sheet for PIPs for people who have hydrocephalus.

Do seek help to [illegible] if you feel that you have difficulty in expressing your needs. Citizens Advice Bureau or your local Welfare Rights Adviser – sometimes employed by Adult Care & Support (Social Services), may be able to assist.

You will need to phone them to ask for an appointment.

You must be able to carry out all of the activities safely, to an acceptable standard, repeatedly and in a reasonable time – this is no more than twice the time that a person without a disability would normally take to complete the activity.

If you have any reports from Adult Social Care, Occupational Therapists, General Practitioners and Specialists, and/or a care plan, make a copy and send them in with your completed application form, list any reports sent in on page 3 of the form.

Daily living activities:
1) Preparing and cooking food: This is a cooked, one-course meal for one person, using fresh ingredients. Do ensure that you make it clear that when you have mobility problems, resulting in you requiring to use a wheelchair or crutches at all times in the kitchen, that you have difficulty in carrying or lifting anything hot at /or above waist height. Explain if you have impaired feeling in your legs and that there is a risk of burning yourself if you spill any hot liquid onto your legs; provide details of how often this happens. List any aids used in the kitchen e.g. perching stool, lever taps, kettle tipper etc. Note down any adaptations made to your kitchen, such as a low-access sink or adapted equipment.

2) Taking nutrition: This includes drinking. Do explain if you have impaired kidney function, and need to be prompted to take on adequate fluids to preserve your kidney function.

3) Managing therapy/monitoring a health condition: Include any information regarding any assistance that you require to carry out physiotherapy exercises, how often, and how long this takes. Provide details of epilepsy/seizures in this section. If you are diabetic, explain any equipment you use to monitor your blood sugar levels. If you have a recent history of pressure sores, explain where they are and the assistance that you need to monitor your skin and to provide treatment to the sores.

Important: Shine has produced two separate information sheets specifically to assist adults with spina bifida and/or hydrocephalus to fill in the PIP claim form. The information is available to download from the Shine website
W: http://bit.ly/ShineBenefits or you can contact **T: 01733 555988** or
E: info@shinecharity.org.uk for copies.

The Assessment

Once you have filled in your PIP form, a healthcare professional will assess your claim and may contact a medical professional who knows you for further information. Most people will have to attend a face-to-face consultation. After this, your case is sent to the Department for Work and Pensions (DWP), who will make the final decision regarding your claim.

Like DLA, PIP has two components: the daily living component, and the mobility component.

The healthcare professional will assess how you can manage 10 daily living activities (like washing and dressing) and two regarding mobility. They will give you between 0 and 12 points for each one, depending on how you can do it. You need to score at least 8 points on a particular component to get the "standard" rate award, and 12 points to get the higher or "enhanced" rate.

If you are called in for a face-to-face assessment, and you have hydrocephalus resulting in you having difficulty with understanding information, or have problems with expressing yourself, you can make a request to be assessed by a specialist assessor known as a cognitive and mental health champion. **BUT** you must arrange this as soon as you receive your letter asking you to attend an assessment.

Important: Do not turn up for the assessment without making a request to be seen by a specialist assessor. You must arrange this as soon as you receive your letter asking you to attend an assessment.

The face-to-face assessment

The assessor may come into the waiting room to meet you. They will ask you how you get about and how you travelled to the assessment centre. Do make it clear if you had to be dropped off at the door of the assessment centre, or the assessor may assume that you are able to walk the distance from the car park.

They will ask questions about:

- Your daily life
- Your home
- How you manage at work if you have a job
- About social and leisure activities that you engage in – or have had to give up

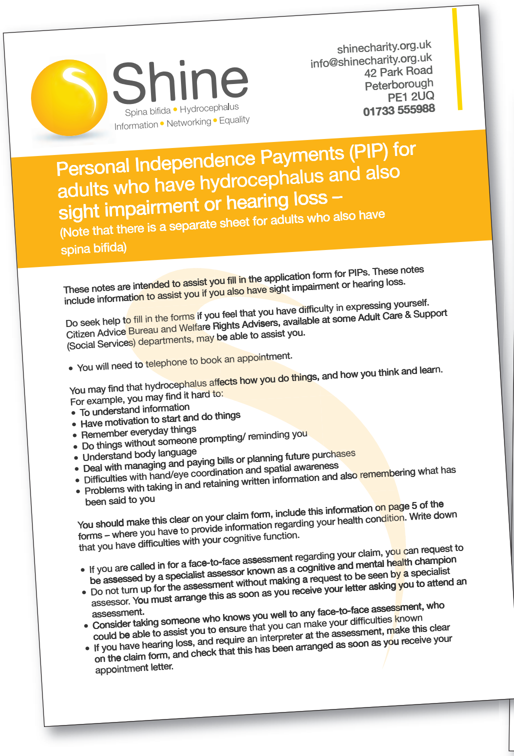
They may carry out a brief physical examination. They will also assess how well you can concentrate, answer questions and express yourself if these things are affected.

When you are explaining what you can do, be sure to tell them what you need help with, and why, tell them if you need reminding or encouraging to do things. Explain any aids and adaptations that you use in your home. If it takes you more than twice the time as someone without a disability would take to complete an activity, explain why this is. It may help to take someone who knows you well in to the consultation. they will not be able to answer for you, but may be able to help you to explain your difficulties.

If your claim is unsuccessful or reduced, the DWP will write to you to tell you how many points you got and why. They will then telephone you shortly after, so that they can talk through the decision with you.

If you are unhappy with the decision, you can ask for it to be reconsidered BUT you must do this within one calendar month from the date of the decision.

For further advice or support, contact agencies such as your local Citizens Advice Bureau, a Welfare Rights Advisor, or **Shine**'s Support and Development Team
T: 01733 555988



Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

shinecharity.org.uk
info@shinecharity.org.uk
42 Park Road
Peterborough
PE1 2UQ
01733 555988

Personal Independence Payments (PIP) for adults who have hydrocephalus and also sight impairment or hearing loss –
(Note that there is a separate sheet for adults who also have spina bifida)

These notes are intended to assist you fill in the application form for PIPs. These notes include information to assist you if you also have sight impairment or hearing loss.

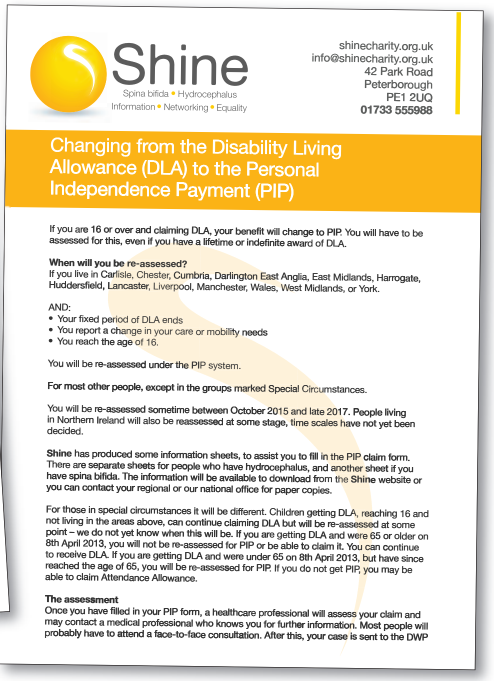
Do seek help to fill in the forms if you feel that you have difficulty in expressing yourself. Citizen Advice Bureau and Welfare Rights Advisers, available at some Adult Care & Support (Social Services) departments, may be able to assist you.

- You will need to telephone to book an appointment.

You may find that hydrocephalus affects how you do things, and how you think and learn. For example, you may find it hard to:
- To understand information
- Have motivation to start and do things
- Remember everyday things
- Do things without someone prompting/ reminding you
- Understand body language
- Deal with managing and paying bills or planning future purchases
- Difficulties with hand/eye coordination and spatial awareness
- Problems with taking in and retaining written information and also remembering what has been said to you

You should make this clear on your claim form, include this information on page 5 of the forms – where you have to provide information regarding your health condition. Write down that you have difficulties with your cognitive function.

- If you are called in for a face-to-face assessment regarding your claim, you can request to be assessed by a specialist assessor known as a cognitive and mental health champion
- Do not turn up for the assessment without making a request to be seen by a specialist assessor. You must arrange this as soon as you receive your letter asking you to attend an assessment.
- Consider taking someone who knows you well to any face-to-face assessment, who could be able to assist you to ensure that you can make your difficulties known
- If you have hearing loss, and require an interpreter at the assessment, make this clear on the claim form, and check that this has been arranged as soon as you receive your appointment letter.



Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

shinecharity.org.uk
info@shinecharity.org.uk
42 Park Road
Peterborough
PE1 2UQ
01733 555988

Changing from the Disability Living Allowance (DLA) to the Personal Independence Payment (PIP)

If you are 16 or over and claiming DLA, your benefit will change to PIP. You will have to be assessed for this, even if you have a lifetime or indefinite award of DLA.

When will you be re-assessed?
If you live in Carlisle, Chester, Cumbria, Darlington East Anglia, East Midlands, Harrogate, Huddersfield, Lancaster, Liverpool, Manchester, Wales, West Midlands, or York.

AND:
- Your fixed period of DLA ends
- You report a change in your care or mobility needs
- You reach the age of 16.

You will be re-assessed under the PIP system.

For most other people, except in the groups marked Special Circumstances.

You will be re-assessed sometime between October 2015 and late 2017. People living in Northern Ireland will also be reassessed at some stage, time scales have not yet been decided.

Shine has produced some information sheets, to assist you to fill in the PIP claim form. There are separate sheets for people who have hydrocephalus, and another sheet if you have spina bifida. The information will be available to download from the **Shine** website or you can contact your regional or our national office for paper copies.

For those in special circumstances it will be different. Children getting DLA, reaching 16 and not living in the areas above, can continue claiming DLA but will be re-assessed at some point – we do not yet know when this will be. If you are getting DLA and were 65 or older on 8th April 2013, you will not be re-assessed for PIP or be able to claim it. You can continue to receive DLA. If you are getting DLA and were under 65 on 8th April 2013, but have since reached the age of 65, you will be re-assessed for PIP. If you do not get PIP, you may be able to claim Attendance Allowance.

The assessment
Once you have filled in your PIP form, a healthcare professional will assess your claim and may contact a medical professional who knows you for further information. Most people will probably have to attend a face-to-face consultation. After this, your case is sent to the DWP

It is important that you highlight how your spina bifida and/or hydrocephalus affects how you do things, how you think and how you learn. You should seek help to fill in the forms if you feel you have difficulty expressing yourself.

Benny's Blog

are you keeping up to date with Benny Bear's busy life?

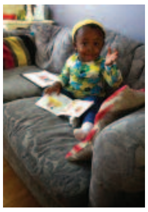
As Benny gets ready for a fun-filled 2015, we thought it would be great to feature some recent highlights taken from Benny's ever popular blog!

Christmas was a really fun time, and this one was extra special for Benny and his family. If you haven't already heard, Benny has a new friend called Bella Bear. Benny wrote this on his blog at Christmas:

It is Bella's FIRST Christmas this year and I am so excited for when she sees all the pretty lights twinkling for the first time. Mummy said that we can make some paper chains to put up around Bella's bedroom. I know she will love looking at the different colours, as the paper chains twirl around her room.

Benny and Bella had a great Christmas and Benny took some time to think about some of his blog highlights from the end of 2014.

In November Benny met a very special little girl called Hannah:



Two weeks ago, Hannah Cross invited me to have lunch with her at her Montessori Nursery. She introduced me to all her friends and we had great fun at 'circle time', singing lots of songs and counting games. The children all had lunch and Hannah made sure she drank a beaker of water and ate some fruit out of her lunchbox – as well as her sandwich and her favourite cheesy crisps!

October was Benny's best month with Awareness Week, the **Shine** AGM, the **Shine** Awards, and **Wear Yellow and Shine** all grabbing his attention:

Evie and Martha Littlewood-Hillsdon, who are twin sisters, raised a 'brilliant' £215 at their school, Lympsham First School in Somerset. They baked cakes and wore yellow. And, even their mummy Katy, Nanny, and big sister Anna joined in too.

Since Christmas Benny has been doing his best to stick to his New Year's resolutions. Here are the things Benny is trying to stick to for 2015:

1. **Drink more water to keep me hydrated and healthy**
2. **Have one piece of fruit in my lunchbox every day**
3. **Put my clothes and/or my school uniform ready the night before. (Mummy says this will help me get ready much quicker and they have more time for breakfast!)**
4. **Tell Mummy, Daddy, or a grown up if I am feeling sad or worried.**

Benny is really looking forward to hearing from you during 2015, keep the emails, letters and Facebook comments coming!

Be brilliant! – Benny

Benny

CODMAN NEURO
DePuy Synthes

We are delighted to share with you that **Shine** are working with Codman Neuro DePuy Synthes to develop normal pressure hydrocephalus (NPH) information materials and another print run of the ever-popular Benny Bear story books.

We would like to offer our sincere thanks to Codman Neuro DePuy Synthes for their sponsorship of the latest batch of Benny Bear bears, your contribution is making hundreds of children very happy indeed!

Gobi's gossip

Hello to you all! Here we are well underway in 2015! It doesn't seem that long ago that I was greeting you all in 2014 – how the last year has flown by!

It's fair to say the previous 12 months haven't be the easiest for me and 2015 hasn't given me the easiest start either, as I'm likely to be recovering from open-heart surgery to fix a leaking aortic valve when you come to read this. Not great, but the only way to look at it is like a hurdle. Let's face it, life is full of hurdles to overcome – some higher than others. All going well, by the time you read issue 17 of *Together*, I'll be back to **Shine** duties, back to training, and back to playing competitive Badminton. Bring it on!

Looking back, it's been a hectic time since my ramblings in the last issue of *Together*. As always, I had a busy schedule with a number of activities – inside and outside the world of **Shine**.

I had a very successful trip to Newcastle where I visited Bede Burn Primary School, and I was kindly invited to speak to students in their assembly. The school has raised almost £1000 for **Shine** – a special thanks to Head Teacher, Mr Arthur, who has encouraged the fundraising due to Grace Mcintosh, who is a student at the school. Following my trip to the North East, I also headed to Wales for a break with our very own Media Development Officer, Darren Fower, for company. Fun times!

I also had the pleasure of attending the unveiling of the Stevenage Sports Personalities Mural. I'm proud to be featured on this, along with Manchester United and England footballer Ashley Young (who did the official unveiling), PGA Golfer Ian Poulter, and two-time F1 World Champion, Lewis Hamilton!

I also sent out the **Shine** members' online survey, which had a wonderful response. I know surveys aren't everyone's cup of tea, but the feedback really does help us massively, so 'thank you' to all to those who completed it. I've had the challenging task of going through them all, but it's given me a great insight into the important matters we at **Shine** must look into when putting on events for you.

Gobi with ex footballer Les Ferdinand and Benny Bear at 'An Evening with Les Ferdinand'

Gobi and Ashley Young at the Unveiling of the Stevenage Sports Personalities Mural

Gobi at Bede Burn Primary school

Once again time and space has beaten me for this issue, but look out for more gossip from me in the future. You may just hear from me sooner than you think!

Contact Gobi **E: gobi.ranganathan@shinecharity.org.uk**
facebook.com/Shine.Gobi.Ranganathan

Gobi repping Shine at The Mumbles, a small coastal town near Swansea in Wales

Talking about my generation

By Alison Mahraj

I find it really helpful in the **Shine40Plus** Facebook group because views and feelings are shared about issues that don't usually get talked about. Subjects discussed are wide-ranging. Here, we offer a summary of a discussion on ageing with spina bifida:

1. We go through the ageing process quicker than our peers so we go through it earlier than they might.
2. Because we were born disabled, people think we can cope better with loss of independence. But we all have a starting point and adjusting to loss is the same, whether disabled or not.
3. We are more likely to put on a brave front without realising it.
4. We are more aware of our bodies and therefore feel loss of bodily functions more acutely.
5. We are the first generation of people with spina bifida to go through this ageing process, so we are learning as we go – whilst others are learning from us.
6. Spina bifida is a specialist area, however, that mainstream advice doesn't allow for this nor with what we are going through.
7. All these things above lead us to feel more isolated in our loss, so we are more likely to become depressed.
8. We're not alone. Many of us are going through something similar, being able to do it as a part of **Shine40Plus** can be very helpful.

I got my degree after 10 years

by Paulette Rogers

I am 46 and was born with hydrocephalus and epilepsy. I was bullied at school and I ended up in hospital with a nervous breakdown at 13. I was keen to make up for missing so much school, so I applied to go to university at the age of 36.

It wasn't easy to get in, but eventually, Liverpool Hope University accepted me onto the Business and Tourism degree course. I had lots of health problems while I was studying. I had a severe infection in 2009 and nearly died, but the support I received was fantastic! The lecturers were great and a Support Worker went out of her way to provide me with the right assistance. It turned out I also had dyslexia; this was very important to discover. My family were also a vital part of my support network, as were health professionals.

> **The lecturers were great and a Support Worker went out of her way to provide me with the right assistance.**

On 22nd July 2014, I received my degree at Liverpool Metropolitan Cathedral. My mum was crying, she was so proud! I took my family for a meal afterwards – it was one of the best days of my life. I would say to other people – don't be put off by anyone that says, 'You'll never do it'. You can achieve your personal goals with the right help and support.

Getting a job and flexible working

By Mark Simpson

Having largely lived my life with little or no contact from a support group, I have for a long time assumed that everyone has shared my experience of going through the education system and finding a job. Only through contact with **Shine** have I appreciated that, in fact, finding regular, constructive, and meaningful work is a significant challenge for many.

Before starting to look for your ideal job, my advice is to decide what you can do. This may or may not be limited by your disability, academic qualifications or even mobility (for example, can you travel to and from the advertised job?).

Then comes the CV. This is your chance to sell who you are, your experience, and your skills. Remember, employers only rent your skills because they need them in their organisation. There are many books and online guides; some are free and others ask you to pay for them to rewrite your CV.

Since June 2014, all employees have the legal right to request flexible working hours – not just parents or carers. For more information, go to: **http://bit.ly/FlexibleOverview**

You may also find these links useful:
www.evenbreak.co.uk
www.remploy.co.uk
www.disabilityrightsuk.org/careers-and-work-disabled-people
www.disabilityjobsite.co.uk

Speaking out

By Ashish Patel

For most of my younger life I was quiet; it's only in the last few years that I have finally found my voice and defended my corner. I attend various meetings and put my experiences to the local authority, and it's a real boost to hear people thank me for my contributions.

I was brought up by my grandparents in London. When my grandmother became too frail to manage our home she had to move to a flat that was not accessible for me, so I moved into a special sheltered housing complex. For 13 years I worked for HM Revenue and Customs, but I neglected my physical and mental health after my grandmother died and there was organisational change at work. I then had a lot of hospital admissions, which led to a period of depression. It was a very difficult time for me and culminated in a life-threatening infection and two months in a coma.

That was in 2010. Since then, I have turned a corner. I took early retirement as I realised my health was more important. Since getting involved with **Shine**, I have joined the London Social Group. I run the Tenants Amenity Fund and organise local social and fundraising activities.

I sit on a number of council panels regarding Disability Housing and Adult Social Services. I have also lost a stone in weight this year and spent time catching up with old friends from primary school. It has been a tough few years, but I feel stronger for my experiences and will continue to speak up. Watch this space!

Sêr Bach – Shine's 'little stars' in Wales

Sêr Bach is a new initiative that provides opportunities for our younger members under 10, their siblings and friends to play as well as developing confidence, reducing feelings of isolation and enabling parents to support one another through practical advice and experiences.

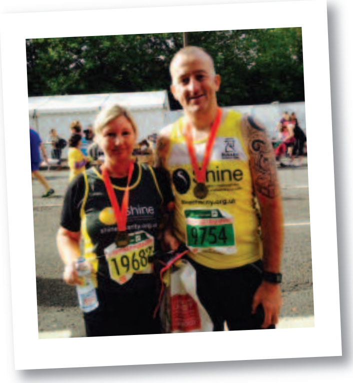
Piloted in South Wales in 2014, **Sêr Bach** has now received funding from Awards 4 All Wales, which means we can run more events, more of the time, across Wales.

Contact Sian Prince on **T: 02920 813847** or **E: sian.prince@shinecharity.org.uk** for more information on **Sêr Bach** in 2015. Members from England or Northern Ireland are always welcome if you are in the area!

Fantastic fundraisers

West Wales member, Emma Lewis Thomas, organised a fundraising folk evening on 8th November 2014 with legendary Welsh singer, Dafydd Iwan, raising a massive £1327.50.

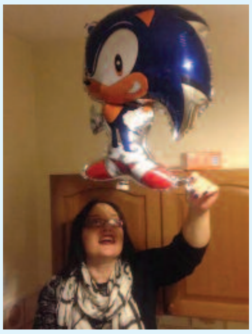
Llanfyllin High School in Powys raised £477 following their successful **Wear Yellow and Shine** day, and Cyfartha High, Merthyr Tydfil donated £150 from their Sports Awards evening in September 2014.



Thanks also to Nic and Keri Williams, and Allun Thomas for completing the Cardiff Half Marathon, and Karen Taylor for the Nos Galen race on New Year's Eve!

Catrin's geeky business venture!

By Catrin Griffiths



I was born with spina bifida and hydrocephalus, and North Wales ASBAH (as it was known then) was really helpful and supportive to me and my parents. I still keep in touch with my former Field Worker, Elin Ifan, and have a friend with spina bifida who is great to chat to about things that maybe others wouldn't understand.

I had been thinking for a while that I needed a challenge because my full-time job wasn't really fulfilling. So my partner, Dan, suggested a new business venture for me. We didn't have any experience setting up our own business, so between two jobs in September 2014, I attended a Business in Focus workshop, where I learnt about the basics. In the same month, we launched Cardiff Geek Party, the first company of its kind in the UK. We offer computer game party services in and around Cardiff, including hiring of consoles and computer games, human-sized cutouts of Sonic the Hedgehog and Mario, plus geeky goody bags!

My advice to anyone thinking of setting up their own business is to go for it as long as costs are fairly low. It's about making a go of something, especially if you really believe in it. With work conditions being quite unsettled in many sectors, setting up your own business is another way of learning new skills, earning a little extra, and taking responsibility for yourself.

For more details, check out their Facebook page **W: facebook.com/CardiffGeekParty** or email **E: bookings@geek-party.co.uk**

Celebrating World Spina bifida and Hydrocephalus Day

To mark World Spina Bifida and Hydrocephalus Day, **Shine NI** hosted a handshake chain to demonstrate support and acceptance of diversity within our community, whilst celebrating our members' achievements. Everyone gathered at the Guildhall, Derry/Londonderry, where we were greeted by Lord Mayoress Cllr Brenda Stevenson, and **Shine** members who were taken on a guided tour of the Mayor's Office.

Even Benny Bear joined us on the day and, despite the rain, our members did not allow this to dampen their spirits – there was a fantastic celebratory atmosphere throughout the day.

Following the Guildhall event, we enjoyed a family fun day at the Millennium Forum. The hall was a hive of activity throughout the afternoon, with several craft and entertainment stalls for members, including a clown show which proved very popular with the children (and the adults!). Jo Jingles also popped in to entertain us all and **Shine**'s Marie McGonnell held a flower demonstration assisted by Mark Durkan MP, producing halloween flower displays. **Shine NI** would like to thank everyone who attended for donating items and their time to make the day a great success!

Raising awareness of Shine

As part of Spina bifida and Hydrocephalus Awareness Week 2014, **Shine NI** held an information morning in Parliament Buildings, Stormont, which was sponsored by First Minister Peter Robinson MLA and Pat Ramsey MLA. Mr Robinson opened proceedings, and having met many of our members, he remarked on how positive each and every individual had been in overcoming their own individual challenges to reach their personal goals.

Shine NI Director Cathy McKillop followed, emphasising the importance of the prevention of neural tube defects. Four **Shine** members also spoke about their life experiences, including Lisa Haddock and Blaise Hughes, who have spina bifida and hydrocephalus, and have been involved with **Shine** since birth. Lisa stated, 'For as long as I can remember, support for both my parents and myself has been there from the staff at **Shine NI**. I consider these people as not only staff who in effect work for me, but moreover as valued friends.'

I consider these people as not only staff who in effect work for me, but moreover as valued friends.

Fearghal McKinney MLA closed the session and spoke of how amazed he was at how resilient the speakers were and what a fantastic impact staff had on those they worked with.

Shine's Lifelong Opportunities Programme 2015

Shine's Summer Rez!

Monday 10th August – Thursday 13th August 2015

A residential event for young people aged 12 – 16 years with spina bifida, hydrocephalus or intracranial hypertension.

Organised lively activities including archery, music workshop, taiko drumming, kite flying, arts and crafts (including glass painting) and jewellery making. There will also be lots of opportunities for socialising.

Venue:
Hannahs @
Seale-Hayne,
Newton Abbot,
Devon
TQ12 6NQ

The subsidised charge to each participant is £200. Payment can be made by cheque or debit/credit card or by pre-arranged instalments.

Places are limited so please register your interest as soon as possible. Closing date for applications 27th March 2015

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

Reg Charity No 249338

Shine's Lifelong Opportunities Programme 2015

Shine – Independent Futures

8th-10th May 2015

Venue: Herewood College, Coventry CV4 9SW

A residential event for a small number of adult members and a carer/parent to identify some important steps and skills towards achieving independence in the future. This is also a social opportunity for members to meet new people in a relaxed and informal environment.

- Basic cooking skills
- Budgeting and managing money
- Time management, organisation, and planning skills
- Enable learning of personal care skills on an individual basis
- Information on working towards and maintaining independence

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

Reg Charity No 249338

For an application form and payment details please contact Maureen Jobson –
Shine, 42 Park Road, Peterborough, PE1 2UQ. **T:** 01733 555988 **E:** maureen.jobson@shinecharity.org.uk
Places are limited so please apply as soon as possible. Closing date for applications is 14th March 2015

Shine's Lifelong Opportunities Programme 2015

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

Hydrocephalus – Understanding Your Child in the 21st Century

Wednesday 20 May 2015 • 10.00 am – 3.00 pm

An opportunity for parents/guardians to develop a greater understanding of the effects of hydrocephalus and how it may impact on your child's development and learning.

Cost £10.00 per person (we regret there are no facilities to accommodate children)

To include light lunch and refreshments

Fully accessible facilities. No parking on site.

This event will include:

- Information sessions for parents to help understand the behaviour of a child with hydrocephalus.
- Strategies to assist a child's development in the 21st century.
- Learning through interactive play and resources available.
- The opportunity for a question and answer session in an informal and confidential environment.

Shine
42 Park Road
Peterborough
PE1 2UQ

Closing date for applications Friday 1st May 2015

Reg Charity No 249338

To book your place, receive an application form and / or make payment please contact Maureen Jobson **T**: 01733 555988 **E**: maureen.jobson@shinecharity.org.uk

---

Shine's Lifelong Opportunities Programme 2015

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

Shine in the South Family Day

25 April 2015 • 10am – 6pm

Howletts Wild Animal Park,
Bekesbourne Lane, Bridge,
Canterbury, Kent CT4 5AE

HOWLETTS
THE ASPINALL WILD ANIMAL PARK

A family fun day in the South to enable parents/carers, children with disabilities and siblings to meet and socialise in an informal and relaxed environment.

Bringing Shine families together and promoting lasting friendships

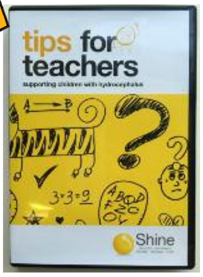
Adults: £10
Children (3 – 15 years): £5
Under 3s: free

To book please E: joanne.tailor@shinecharity.org.uk or phone the Southern office on T: 01959 534618
Payment to be made at time of booking via cheque or postal order (payable to Shine).
Closing date for bookings: 6th April 2015.

Reg Charity No 249338

Shine Merchandise

Spina bifida • Hydrocephalus
Information • Networking • Equality



Item	Sizes	Price
Yellow t-shirt	S-2XL	£7.50
Kids t-shirt	1-2 - L	£6.50
Polo shirt	S-XL	£10.00
Sports vest	2XS-3XL	£15.00
Cycling jersey	2XS-XL	£35.00
Fleece	S-2XL	£25.00
Hoodie	S-2XL	£20.00
Baseball cap	One size	£10.00
Sunglasses	One size	£4.00
Tips for Teachers		£9.95

Item	Price
Tips for Teachers	£9.95
Wristbands	£1.00
Pin badge	£1.00
Pen	£1.00
Shine cookbook	£10.00
Car sticker	£2.50
Ribbons	£1.00, £1.50 for two
Trolley key ring	£2.00
Water Bottle	£5.00 (p&p free for up to 6 bottles)

Check out our eBay store - ebay.co.uk/usr/shineukcharity