Inside: #shinereflections • Awareness Week 2014 • Shine AGM

Issue 14

Together

Lottie sets her sights on Tokyo 2020

Meet Benny Bear's new friend – Bella Bear!

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

BIG LOTTERY FUND
LOTTERY FUNDED

Bespoke Shine jewellery now available!

We can now offer you a fantastic opportunity to purchase quality jewellery designed exclusively for Shine.

Necklaces

1. **Tinkerbell necklace** £14.99 • 2. **Letter (of your choice) necklace** £10.99

Earrings

3. **Angel wing stud earrings** £12.99 • 4. **Star stud earrings** £10.00 • 5. **Tinkerbell stud earrings** £13.99

Bracelets

6. **Star bracelet** £16.99 • 7. **Angel wing bracelet** £16.99

Each item comes with its own individual message card and beautiful presentation box.

If you have any questions or would like to place your order, please contact Zoe Bentley on **T: 01733 421347** or **E: zoe.bentley@shinecharity.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 spring edition

- **Register of interest to submit:** 10/11/14
- **Final date for submissions:** 12/12/14
- **Publication date:** February 2015

Cover photo: Lottie and Velvet **Taken by:** Tom Scott

Boosting awareness

Well, as usual we have a packed edition of *Together* to share with you! We have everything from Royal garden parties to the latest social media news!


I'm ready to Wear Yellow and Shine – are you?!

As we start to think about getting ready for Christmas, you will find a Christmas card order form included on the back cover. We have six great designs to choose from – make sure you place your order in plenty of time!

In no time at all we will all be involved in Spina bifida and Hydrocephalus Awareness Week which runs this year from 19th-26th October. As well as everyone signing up to **Wear Yellow and Shine**, we are inviting you to submit film clips as part of our **#shinereflections** initiative – see pages 8-9 for more information.

Benny Bear fans will be very excited to read about his new friend Bella Bear who was born recently with spina bifida and hydrocephalus. Benny will be telling us about Bella's development in future issues and you can read the latest on page 11.

Gobi is back with his gossip on page 15, and you can meet our feature stars, Lottie and Velvet, on pages 15 and 16. You can catch up with all the latest health, campaigns, education, and regional news, as well as what's happening in the SAMC, in this fill-to-the-brim edition of *Together*.

Tom Scott

E: together@shinecharity.org.uk

Chairman's Challenge storms past £20,000!

Now past the halfway mark in his mammoth charity challenge, **Shine** Chair Richard Astle is nearing his £25,000 target, after completing another set of gruelling races.

Richard was in Rio de Janeiro for the 2014 World Cup in July and completed a 10k-run along Copacabana beach together with **Shine** patron and former Premier League footballer, Danny Mills.

Richard's donations reached an impressive £20,000 after he endured a demanding 40-mile hike across Derbyshire in August. Now having also completed the Great North Run, Richard joined nearly 30 other **Shine** runners in the Great Eastern Run, which took place in Peterborough on 12th October. To donate please visit:
W: justgiving.com/thechairmanschallenge14

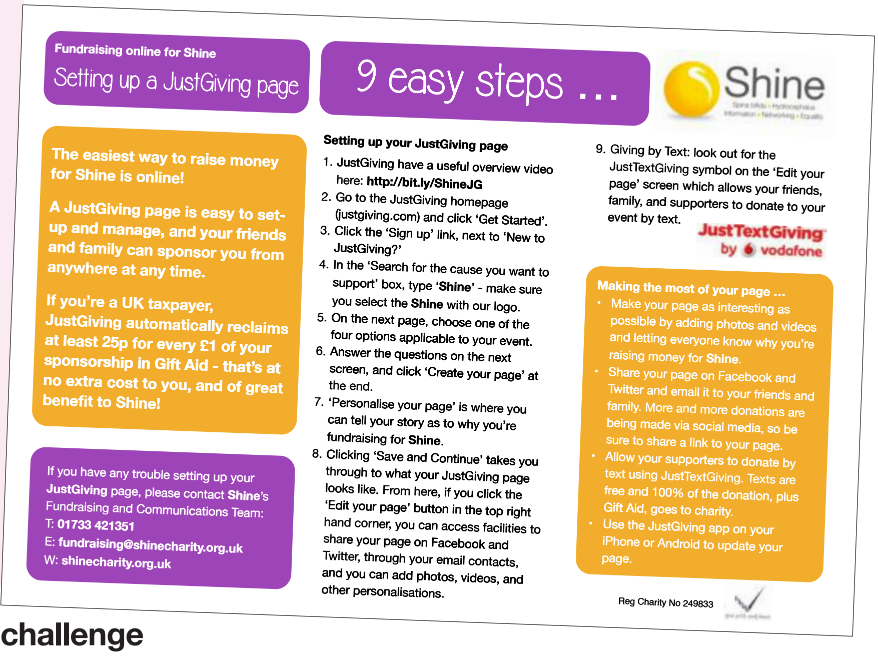
facebook.com/chairmanschallenge
@athenenoctuara

Bullens sponsorship

We're really pleased to announce that Bullens Healthcare have agreed to sponsor our running vests again this year. 'Thank you' from everyone at **Shine**!

JustGiving made simple

We've now drawn up a handy leaflet that helps you to set up your own JustGiving page when you want to raise money for **Shine**. To download the leaflet, visit:
W: shinecharity.org.uk/fundraising/on-line-sponsorship



Fundraising online for Shine

Setting up a JustGiving page

9 easy steps ...

The easiest way to raise money for Shine is online!

A JustGiving page is easy to set-up and manage, and your friends and family can sponsor you from anywhere at any time.

If you're a UK taxpayer, JustGiving automatically reclaims at least 25p for every £1 of your sponsorship in Gift Aid - that's at no extra cost to you, and of great benefit to Shine!

If you have any trouble setting up your **JustGiving** page, please contact **Shine**'s Fundraising and Communications Team:
T: **01733 421351**
E: **fundraising@shinecharity.org.uk**
W: **shinecharity.org.uk**

Setting up your JustGiving page

1. JustGiving have a useful overview video here: **http://bit.ly/ShineJG**
2. Go to the JustGiving homepage (justgiving.com) and click 'Get Started'.
3. Click the 'Sign up' link, next to 'New to JustGiving?'
4. In the 'Search for the cause you want to support' box, type **'Shine'** - make sure you select the **Shine** with our logo.
5. On the next page, choose one of the four options applicable to your event.
6. Answer the questions on the next screen, and click 'Create your page' at the end.
7. 'Personalise your page' is where you can tell your story as to why you're fundraising for **Shine**.
8. Clicking 'Save and Continue' takes you through to what your JustGiving page looks like. From here, if you click the 'Edit your page' button in the top right hand corner, you can access facilities to share your page on Facebook and Twitter, through your email contacts, and you can add photos, videos, and other personalisations.
9. Giving by Text: look out for the JustTextGiving symbol on the 'Edit your page' screen which allows your friends, family, and supporters to donate to your event by text.

JustTextGiving by vodafone

Making the most of your page ...
- Make your page as interesting as possible by adding photos and videos and letting everyone know why you're raising money for **Shine**.
- Share your page on Facebook and Twitter and email it to your friends and family. More and more donations are being made via social media, so be sure to share a link to your page.
- Allow your supporters to donate by text using JustTextGiving. Texts are free and 100% of the donation, plus Gift Aid, goes to charity.
- Use the JustGiving app on your iPhone or Android to update your page.

Reg Charity No 249833

Attendance Allowance

Attendance Allowance is a benefit for people over the age of 65 who need extra help with the costs of their personal 'care' needs. You must have had these needs for at least six months. Having a diagnosis for a medical condition alone will not automatically qualify you to get Attendance Allowance; you must also have personal care needs. However, you do not already have to be receiving help for your care needs in order to qualify. To find out more, or to claim Attendance Allowance, call the Attendance Allowance helpline on **T: 0345 6056055** or go to **W: gov.uk/attendance-allowance**

Palm Tree Cottage

by Michael Jones

It is very difficult to find suitable accommodation with disabled access. I recently spent some time searching for somewhere, and was pleasantly surprised when I discovered the Palm Tree Cottage in Shoreham-by-Sea, West Sussex. The adapted cottage has fantastic facilities all round: the beds are laid out with a wheelchair in mind, there's a wheelchair-accessible shower room, and an accessible toilet with lift bars. The cottage is very close to the beach, and there is a wooden ramp onto the beach too. Plus, the owners helped out when we needed anything. For more details, go to **W: http://bit.ly/PalmTreeCottage**

2016 Heritage Project

We're fast approaching the launch of this project, and there's much to do! Lyn and I are sifting through the many archived boxes in the attic at **Shine** HQ, and recently we found some old large canisters of film; it will be interesting to see what's on them!

We'd now like items of equipment going back over the years, so it's time to clear out the shed or attic to see what you have! Please let one of us know if you have any items to donate by using the contact details below.

Joan Pheasant T: 0113 2556767
E: joan.pheasant@shinecharity.org.uk
Lyn Rylance T: 01733 421316
E: lyn.rylance@shinecharity.org.uk

The Royal Garden Party

Rebecca Morris, Liz Potts, Heather Doughty and Joan Pheasant represented **Shine** at the Royal Garden Party in Buckingham Palace in June. They were presented to our Patron the Duchess of Gloucester and spent time talking to her about **Shine**'s forthcoming anniversary. After enjoying afternoon tea, the team then joined guests in meeting some of the Royal party including the Queen, Prince Philip, and the Duchess of Cambridge!

Annual General Meeting 2014

All members of Shine aged 16 years or over are warmly invited to Shine's Annual General Meeting and the Shine Awards Ceremony on Thursday 20 November 2014. The event will take place at Coloplast Limited, Nene Hall, Peterborough Business Park (Lynchwood) Peterborough, PE2 6FX.

The meeting will be an opportunity for members to meet **Shine**'s trustees, staff, and other members of the **Shine** community. Coffee will be served from 11am and the meeting will begin at 11.30. Lunch will be provided.

The 48th meeting will include a presentation and adoption of the Annual Report and Accounts for the year 2013/2014, and the election/re-appointment of Board of Directors 2014/2015. **Shine** Chief Executive, Jackie Bland, will also provide a review of the year 2013/2014. The presentation of the **Shine** awards will take place at approximately 2pm, after lunch. Please visit our website for a full agenda **W: www.bit.ly/AGMAgenda**
To attend the meeting, please contact Lyn Rylance by Friday 14 November 2014 to allow us to plan catering:
E: lyn.rylance@shinecharity.org.uk or
T: 01733 421316. Or you can write to us at Lyn Rylance, **Shine, 42 Park Road, Peterborough, PE1 2UQ.**

Appointment of proxy

If you're unable to attend the meeting but would like to appoint a proxy to vote for you, you can do so online **W: www.bit.ly/ShineAGM2014** or by completing the form below and returning it to Lyn Rylance at the address above by Friday 14th November.

News in brief

Paper tax discs scrapped

Tax discs are no longer being issued because the DVLA and police can rely on the electronic database now. This means each local authority now has to decide how wardens are to check if a vehicle is a disabled-class vehicle or entitled to free parking. Speak to your local authority to find out more. Apply for a blue badge at
W: gov.uk/apply-blue-badge

Your rights to fly

Under European law, if you are disabled or have difficulty moving around, you can receive assistance when you fly to and from Europe. The Equality and Human Rights Commission has produced guidance to ensure disabled air passengers are fully informed about their rights. To find out more, or to fill in their short questionnaire about your flying experiences, go to
W: equalityhumanrights.com/airtravel

I ______________________________ member of **Shine**

Hereby appoint ______________________________
as my proxy to vote for me and on my behalf at the Annual General Meeting held on Thursday 20 November 2014, and at any adjournment thereof.

Signed ______________________________ Date ______________

With thanks to Coloplast for agreeing to host our AGM again this year.

Social media

Our social media channels have been more alive than ever with messages, news, and photos in recent weeks. Not only is it a great way for you to see what the Shine community is getting up to, but people are even starting to donate, raise awareness, and seek health advice on social media too.

Robin Barnatt's social profile

Robin is a dab-hand at social media and even organises Google Hangout sessions for people to discuss health issues online. Why not friend him on facebook or tweet him a question?

facebook.com/Shine.Robin.Barnatt
@ShineRobinBarnatt

Robin Barnatt @ShineRBarnatt · Sep 2
CHECK out our #SpinaBifida section of the website - ift.tt/V42Mys

Lorraine Watson preparing for her Shine skydive last August

Have you heard @TomScottShine on @BBCCambs talking about the Ice Bucket Challenge? Listen again at **W: audioboo.fm/ShineUKCharity**

Even Benny Bear has completed his Ice Bucket Challenge!

facebook.com/BennyBearShine

@SHINEUKCharity Sep 10 • Trio set for Trek in Morocco! By Shine Charity **http://bit.ly/ShineGooglePlus**

To be a part of the **Shine** story, please visit:
facebook.com/ShineUKCharity **@SHINEUKCharity** **W: shinecharity.org.uk**

Shine's social media presence in numbers...

f	**8,203**
🐦	**14,231**

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**

Spina bifida and Hydrocephalus Awareness Week 2014

Shine
REFLECTIONS
#shinereflections

This year Shine is launching a brand-new initiative that aims to help boost awareness.

Shine’s third Spina bifida and Hydrocephalus Awareness Week will take place across England, Wales, and Northern Ireland from 19th-26th October 2014.

This year, in addition to **Wear Yellow and Shine**, we want to boost awareness even more through a new innovative film campaign that will reflect what it’s like living with these conditions.

#shinereflections

Our new initiative is called **#shinereflections** and it will help us to share the stories of people living with spina bifida and/or hydrocephalus, whilst also demonstrating the capacity of **Shine** members to overcome adversity.

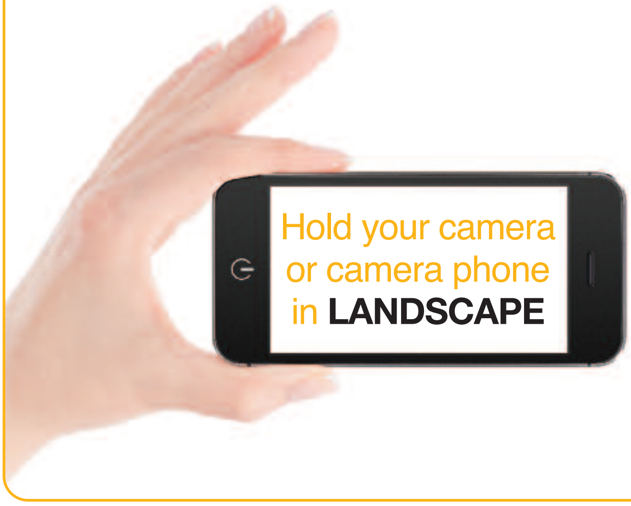
With funding from Roald Dahl’s Marvelous Children’s Charity, **Shine** has made three short **#shinereflections** films, which follow the lives of some of our members and highlight their achievements. We’re now calling on the rest of our **Shine** community to create their own **#shinereflections** videos and share them across our growing online community.

More and more people are turning to video and social media today to support their chosen charity, so we think **#shinereflections** could be a really popular initiative and an excellent way for our members to help raise awareness with **Shine**. Simply create a short video of approximately two-three minutes, upload it to your Facebook profile for everyone to share, and be sure to use the essential hashtag **#shinereflections** – it’s that simple!

For more information on how to share your **#shinereflections** video, email Darren Fower
E: darren.fower@shinecharity.org.uk

5 tips for making a great film clip...

1. Hold your camera or camera phone in **LANDSCAPE** rather than portrait
2. Keep the camera as still as possible when filming, ensuring your movements aren’t too jerky, you may even want to rest the recording device on a solid surface
3. Keep your clip between 30 seconds and 2 minutes in length
4. When you are recording someone saying something, try to limit the amount of background noise
5. Where you can, include something with **Shine** written on it so that people know you are making the clip as part of **#shinereflections**



This charity needs you to Wear Yellow and Shine!

Wear Yellow and Shine will still play a major role in helping us to raise essential funds that allow **Shine** to provide support to people living with spina bifida and/or hydrocephalus. It's a simple way for supporters of **Shine** to raise awareness and funds by wearing yellow for a day with their family, friends, work, school, or community contacts. We hope that this year will be even more successful than 2013 when together we raised £20,000!

To sign up for **Wear Yellow and Shine** online please go to
W: shinecharity.org.uk/wyas
For support and information about **Wear Yellow and Shine** initiatives, please contact Chloe Marsh on
T: 01733 421351 or
E: chloe.marsh@shinecharity.org.uk

Welcome Baby Bella Bear

Benny has a brand-new friend!

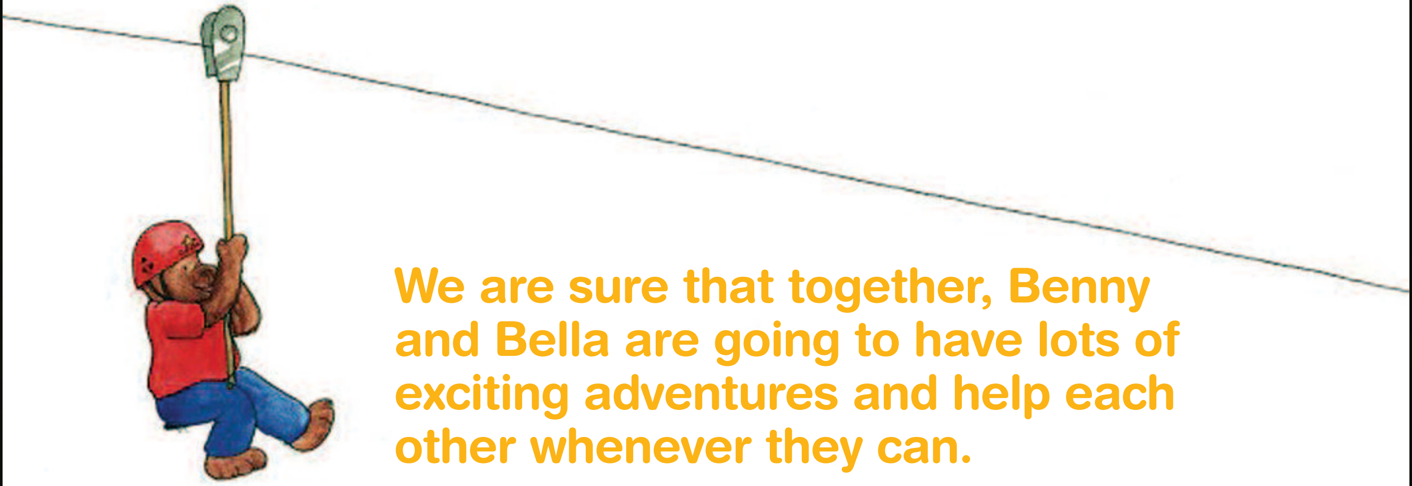
At last the day Benny has been waiting for has come – Baby Bella Bear has been born!

Young *Together* readers chose the name for this unique baby before she was born this Summer, and Benny is very excited because he now has a little bear friend to share his life with.

Bella Bear is already eight weeks old, and last month she came home from hospital to start enjoying life with her mummy and daddy.

Like Benny, Bella has hydrocephalus and like many members of **Shine** she also has spina bifida. We are sure that together, Benny and Bella are going to have lots of exciting adventures and help each other whenever they can.

Because Bella has spina bifida, some special things happened to her after she was born. When you have spina bifida it often means your back has a little open place when you are born. So, some very clever doctors did a special operation to help mend Bella's back and help it close up. If you are a little boy or girl with spina bifida then this probably happened to you – you might even be able to find your special scar.



We are sure that together, Benny and Bella are going to have lots of exciting adventures and help each other whenever they can.

Because Bella is so tiny, she didn't really know anything about the operation, she just wanted to be back with her Mummy for a cuddle as soon as she could. A few days after the operation on her back, Bella had another operation, this time for her hydrocephalus. Some more clever doctors and kind nurses put a shunt into Bella's head, which will help her live with her hydrocephalus. If you are a little boy or girl with hydrocephalus you might already know about shunts and have one yourself, just like Benny and Bella.

Some more clever doctors and kind nurses put a shunt into Bella's head, which will help her live with her hydrocephalus.

After Bella had her operations, Benny was told he could go and see her for a very short visit in the hospital. He couldn't wait, especially when he heard that Bella had a shunt just like him. He wanted to tell her not to worry, and that living with a shunt was easy-peasy most of the time. Benny thought hard about what to take Bella for a present, and then had the greatest idea...what about her own Benny Bear? Yes, Bella could be an extra special member of the Benny Bear Club!

Although Bella was a bit too little to understand how special it is to be a Benny Bear Club member, Bella's mummy was thrilled and told Benny what a kind bear he was. She put the little Benny Bear toy in Bella's hospital cot.

Benny felt very happy – he had pleased Bella's mum and he also had a brand new friend! He loved all his other friends of course, but somehow he knew that Bella was going grow up to be his very best friend forever and ever.

Remember – the Benny Bear Club is open to children up to the age of 11. You can become a member by filling out the form at W: shinecharity.org.uk/bennybearclub

To keep up to date on Benny's exciting life with Bella, check out his blog at W: bennysblog.co.uk and, dont forget to find Benny on Facebook f facebook.com/ShineBennyBear and Twitter 🐦 twitter.com/ShineBennyBear

You can still download copies of your favourite Benny Bear books online. Head to W: sellfy.com/ShineUKCharity to download the books for just £1 each!

The Gainsborough Golf Club raised £1,600!

A big thank you to our fundraisers!

So many of you have raised money and awareness for Shine in the last few months. Here are just a few shiny examples...

Sita's challenge

On the 27th September, Sita Patel took part in a 26-mile trek through London in her arm-powered chair. Inspired by the Chairman's Challenge Trek in Morocco, Sita had already beaten her target of £250 by the beginning of September. Well done Sita!

Sita Patel

Emma Jade McDonnell Memorial Golf Competition

On the 22nd July, the Gainsborough Golf Club in Lincolnshire welcomed 48 golfers to compete in the Emma Jade McDonnell Memorial Golf Trophy.

Emma, who was born with spina bifida and hydrocephalus, sadly passed away on the 7th February this year at the age of 21 after a brave battle with pneumonia. Emma and her proud parents Pete and Lyn McDonnell have been supported by **Shine** on several occasions throughout Emma's life.

The day was organised by Peter and Tracy Chappalow, and the Texas Scramble Rules were used for the competition. Emma's dad, friends and colleagues from West Burton Power Station, competed in teams of four to win the trophy. After six hours of golf, the trophy was won and an impressive £1,600 raised for **Shine**! They hope to continue raising funds and make it an annual event.

Shine Surrey picnic

Shine Surrey held a picnic on the 22nd June in the grounds of The Old Pheasantry at Lower Kingswood. The picnic welcomed 53 people, including many new faces. People came from as far away as Worthing and Hertfordshire. Benny Bear enjoyed himself on the zip wire and helped the children do the prize draw.

Support and Development Worker, Angela Bailey, was able to put three families, whose children were going to have the same medical procedure, in contact with each other which was very helpful. The group were also visited by Suzanne Bull, CEO of charity Attitude is Everything, which aims to improve deaf and disabled people's access to live music by working in partnership with audiences, artists, and the music industry.

Why we fundraise for Shine

Shaun and Dawn Smith are from Oswaldtwistle, near Accrington in Lancashire, and have been Shine members for nearly six years. Together, with their friends and family, they have raised thousands of pounds for Shine. We catch up with them to find out why.

Harrison Smith

Why do you support Shine?

Shaun: We have a six year old boy with hydrocephalus. When Harrison was diagnosed at three weeks old, we did not have a clue what he had and we were put in touch with **Shine** (ASBAH at the time). **Shine** gave us relevant information that helped us cope in the early days.

Dawn: We had never heard of hydrocephalus when Harrison was born, and I still don't think people are aware of it. The Benny Bear books have helped my children understand a little more. I think we need to help raise money to benefit children and adults with spina bifida and/or hydrocephalus who need **Shine**'s support.

What kinds of fundraising have you completed?

Shaun: We have done all kinds of events! Our daughter Mollie did a sponsored haircut when she was seven years old. We've put on a sponsored swim, a pub crawl, two 12.5-mile walks along the Leeds-Liverpool canal, two family auction nights, and non-uniform days at local schools. One of my daughters is responsible for the 'Pout for **Shine**' initiative which was a success for **Shine** on Facebook and Twitter.

Dawn: We have raised approximately £16,000 altogether over the five years we have fundraised. We are very lucky to have good friends, and family who are always willing to help in some way. Facebook also helps a great deal to raise awareness of the events we put on.

What do you enjoy about fundraising?

Dawn: We love getting everybody together, it's always fun. We enjoy the laughter, and seeing everyone enjoying themselves.

Shaun: We always try to do something different. We've already been asked what our plans are for next year's event, even though we have only recently finished this year's! We enjoy seeing if we can beat the previous year as well, because all funds are needed to help **Shine**'s cause.

What would you say to someone who is thinking about raising money for Shine?

Dawn: Just go for it! We love it; organising the walk is easier, but the auctions are a lot of fun and really worth doing.

Shaun: Try and do something different. Use your skillset to decide what will work, enlist as many enthusiastic people as you can for ideas, and get them involved as they will take as much pride as you with what you can achieve.

Fundraising and Communications team – who's who?

There have been some changes in the Fundraising and Communications team here at Shine Head Office. We want to make sure you know who to contact when you have a question, so here are the new members of the team in all their glory!

Name: Shelley Green
Role: Fundraising Officer: Active
facebook.com/Shine.Shelley.Green

Responsibilities: Shelley looks after all active fundraising – anything from skydives and bungee jumps, to marathons and sponsored walks.

Name: Chloe Marsh
Role: Fundraising Officer: Community
facebook.com/Shine.Chloe.Marsh

Responsibilities: Chloe looks after the community fundraising – anything from bake sales and pub quizzes, to sponsored haircuts, Wear Yellow and Shine, and coffee mornings.

Name: Amber Stokes
Role: Fundraising and Communications Officer
facebook.com/Shine.Amber.Stokes

Responsibilities: As well as helping to collate and edit *Together*, Amber is responsible for generating press releases and copy for Shine's marketing activities.

Name: Heather Gott
Role: Fundraising and Communications Officer: NI
facebook.com/Shine.Heather.Gott

Responsibilities: Heather is responsible for fundraising initiatives for Shine NI, as well as communications activity to help raise Shine NI's profile in the region.

Name: Liz Cook
Role: Fundraising Officer: In Memoriam, Regular Givers, Individual Appeals
facebook.com/Shine.Liz.Cook

Responsibilities: Liz is our new fundraising officer and will be responsible for other fundraising initiatives such as In Memoriam, Appeals, as well as remaining a Shine database guru for the team!

Got a question or want to get in touch? Find us on Facebook and message us or call T: 01733 555988

Gobi's Gossip

Hi everyone! It's great to be back writing my gossip column again. Some of you may have noticed my absence in the last edition of *Together*.

Unfortunately, due to an unexpected diagnosis of a serious heart condition, I had to slow down considerably and was unable to do much. You may be wondering how this all came about, as things had been going rather well with me travelling all over the place for **Shine** duties, badminton and of course, supporting my beloved QPR!

However, throughout all of this, I had symptoms not too dissimilar to a chest infection – feeling breathless and wheezy. It got so bad I needed a trip by ambulance to Lister Hospital's Accident and Emergency department. After a number of tests, an Echocardiogram revealed I had Cardiomyopathy and so was told to stop all activities that involved any sort of exertion. It's a condition that's not linked with spina bifida, and not generally found in people my age (I'll leave you all guessing what that is!). Needless to say, almost everything ground to a halt. Added to this, I had the double-whammy of being told I may never compete in badminton again, it was a tough time even by my standards.


Gobi meets with Shine members in Birmingham

I still have lots to overcome and contend with over the coming months, but for now, I'm back and looking forward to seeing you all again!


This charity needs you!

Since then, further tests indicate that a 'leaky' heart valve may be the culprit, so I'm now facing the prospect of open heart surgery to fix it. Bit of a shocker, but once fixed, I'll be able to get back to doing pretty much everything. Every cloud has a silver lining as they say, except this one seems to be a large thundery looking cloud at the moment!

Prior to the diagnosis, my travels took me to Brighton, Birmingham, and Middlesbrough, and I had a great time meeting members in these areas. The feedback I've had from some of you has been great too. Keep 'em coming!

Unfortunately all my **Shine** and badminton activities had to stop after my diagnosis; however, I was still fortunate enough to get to Wembley to watch QPR win promotion to the Premier League in the Championship Play-off Final. Happy days!

So here I am, feeling somewhat better and getting back to some sort of routine, and I'm already back on the road, with RAF Scampton and Burton-upon-Trent amongst many other trips. I still have lots to overcome and contend with over the coming months, but for now, I'm back at work and looking forward to developing the membership with you all!

A winning team

Words and photos by Tom Scott

It was back in March that I first became aware of the story of Lottie Wilcocks and her assistance dog, Velvet.

At the time Lottie and Velvet were on their way to Crufts, the world-famous dog show. The pair had been put forward by the organisation Dogs for the Disabled to show what a great relationship they have together.

At Crufts, Lottie and Velvet came third in the online/ telephone vote and a number of people in the **Shine** community were asking who this amazing young lady was, and what having an assistance dog is all about.

With this in mind I travelled to West Yorkshire to meet Lottie and Velvet to find out more about how they met and what a difference it has made to Lottie's life as someone who has spina bifida and hydrocephalus.

> **With her chair she goes where she wants to with great independence and, with the help of Velvet, Lottie is becoming less reliant on Mum, Dad, and her brother Noel, and increasingly reliant on her own ability to adapt and learn.**

Loyal companions

The first thing that strikes you about Lottie is that she is full of a beautiful enthusiasm for life; whatever she applies herself to, she does it with great energy and an expectation of success.

I ask Lottie what her favourite subjects are at school, (a question which is often met with a lack of interest by someone approaching 13), 'Art, English, Maths, Science, PE, …' her response indicating that all subjects are interesting to her! Most of Lottie's life is shared by Velvet, her specially trained assistance dog but 'unfortunately' (according to Lottie) the one place she isn't allowed to take Velvet is school. Outside of school the duo go shopping, hang out with Lottie's friends, and travel on holiday together. The beloved dog also gets a brief rest when Lottie trains for various sporting events including Boccia, DisSport, and athletics. In most other respects, though, Velvet helps Lottie both at home and in Lottie's life out and about as she approaches the teen years and seeks an increasing level of independence.

Watch out Tokyo 2020!

As we chat about Lottie's sporting achievements on the track and at school, Lottie's proud younger brother, Noel, skips off to the bedroom and retrieves a champions quota of medals. Lottie talks me through them – there are a host of different races and competition successes, including two trophies for second place at the mini Great North Run wheelchair race for 2012 and 2013 respectively.

It is with sport that Lottie's greatest ambitions lie, 'I want to go to the Paralympics and race in the 100m, 200m, 400m, 800m, 5k, and marathon.'

I would defy anyone who meets Lottie to doubt that this dream will become a reality. With her chair she goes where she wants to with great independence and, with the help of Velvet, Lottie is becoming less reliant on Mum, Dad, and her brother Noel, and increasingly reliant on her own ability to adapt and learn. This foundation will be essential if the early signs of dedication are to be nurtured and developed into world-conquering medal-winning feats!

As I leave, I am moved by the strength of character that beams so obviously from Lottie. Though her spina bifida and hydrocephalus challenge her, these challenges are met with a resilience that shifts the focus away from obstacles and shines the spotlight instead on what can be achieved.

To find out more about Dogs for the Disabled please visit W: www.dogsforthedisabled.org

To watch the full interview with Lottie please visit W: shinecharity.org.uk/shinespotlight

...Velvet helps Lottie both at home and in Lottie's life out and about...

Advice on early puberty

By Gill Yaz, Health Development Manager

Puberty is a difficult time for most young people, with changes to your appearance, hormones, and feelings.

The challenges

Starting puberty early can make it harder to deal with, and for young people with learning challenges it can be very hard indeed. As well as the difficulties of mood swings and periods at a young age, children must also cope with having physical changes ahead of their classmates, such as breast development or body hair. They may also start to show sexualised behaviour, which might be difficult for the child, and others, to understand.

Early puberty also results in short stature in adulthood, because we stop growing once puberty has ended. This means the younger – and therefore shorter – we are when puberty begins, the shorter we will be as adults.

Most girls with bladder problems find it is worse (with more leakage) around the time of their period because the hormones relax the pelvic floor, which is crucial for keeping the bladder neck closed.

Having first signs of puberty before ten years old for boys, or nine years for girls, is known as Early Puberty. Showing signs of puberty under the age of nine for boys, or eight for girls, is classified as Precocious Puberty. This is common amongst children with hydrocephalus, and spina bifida with hydrocephalus. Recent research found that puberty started early, or very early, in around three quarters of girls and two thirds of boys in children with shunts (but without spina bifida). For children with spina bifida, around half of girls and a third of boys experienced early puberty.

Why does this happen?

Because we don't fully understand how puberty is controlled in typically developing children currently, we're not sure exactly why this happens. The organ responsible for coordinating puberty and hormones (the pituitary gland) is found at the base of the brain. It's thought that increases in pressure in this area, either before shunting, or during shunt malfunction, can change the pituitary gland and cause early puberty. Early puberty is also seen in children with third ventriculostomies (ETVs), which would support this theory.

It's possible to delay precocious puberty for a few years, by giving the child a hormone that blocks the action of the body's natural hormone. By delaying it the child is able to cope better with the changes when puberty is allowed to begin.

Timing can be difficult. By the time the earliest physical changes are spotted puberty is underway. However, the growth spurt that heralds puberty usually begins around six months before puberty begins. Spotting this can provide time to arrange to see your paediatrician, or get a referral to an Endocrinologist (a doctor specialising in hormones) to see if puberty can be delayed. It may not always be possible or desirable to delay puberty, but getting an opinion could be helpful. So, measure your child's height every few months. If you think growth is especially rapid, you can measure arm span if it is difficult to measure height accurately.

If you have any questions, please contact Gill Yaz – **E: gill.yaz@shinecharity.org.uk**
T: 0208 8054181

Boosting health services for our members

The Health Hub, which is currently under construction at Shine's Head Office, will, for the first time, enable the Shine Health Team to offer individually tailored health checks in physical and mental health, and activities of daily living.

We know that in order to be healthy and feel good, many aspects of our lives have to come together; our physical health can affect our relationships, which impacts our emotional health, and so on. By looking at each individual in this holistic way, and by using our specialist knowledge of spina bifida and hydrocephalus, we hope to be able to work with you to develop plans of action and support, and ultimately help you improve your health.

The **Shine** Health Team firmly believes that in order to make the most of what life has to offer, you need to feel as good as you can, both physically and emotionally. You also need the right support and access. Spina bifida and hydrocephalus can both create challenges in health and wellbeing, with hydrocephalus in particular causing problems with recognising when things are wrong, and following healthcare routines etc.

We have been working to devise a health check system that will give you the chance to explore your conditions, find out more about how to care for yourself, help you improve communication with your healthcare professionals, and discover what equipment or adaptations could improve your quality of life. In addition, we are looking at opportunities to use the space for health-related activities, such as exercise, stress busting, mindfulness, and weight management.

We realise that not everyone can get to the Head Office with ease, so we are exploring ways to make our services more accessible than ever. Building on the success of Robin's Google Hangout sessions, we are looking at ways in which members can join in wherever they are by logging in online.

We are working closely with the SAMC to ensure we really are going to meet members' needs, and have had some fantastic suggestions already. We are hoping to pilot the health checks very soon – we look forward to seeing you there!

Contact the Health Team on
T: 01733 555988
E: info@shinecharity.org.uk

Robin, Kathy, and Gill are working together on a health check system

Raising awareness of Go Folic!

By Martine Austin, Health Campaigns Officer

I'm happy to say that it has once again been a very busy few months at Go Folic! HQ, with lots of new opportunities to spread the folic acid message and some exciting new plans in the pipeline for the future.

Impressive achievements

In June, I was delighted to be asked to speak at a seminar in Belfast on the primary prevention of Neural Tube Defects (NTDs). Researchers and experts in the field of congenital anomalies from across Europe attended the event, along with a variety of other health professionals, all of whom were keen to learn more about **Go Folic!** and our achievements. Everyone was impressed with what we've been able to achieve to date, and there was a general feeling of encouragement that we had been able to demonstrate a change in women's behaviour as a result of our activities, such as the Norfolk pharmacy campaign. Due to the success of this event, we hosted our own seminar on Folic Acid and Genetics in Northern Ireland in September, which was open to both health professionals and **Shine** adult members.

Student health

July saw me travel to Bristol University for the Student Health Association (SHA) Conference, which was a great opportunity for me to chat to GPs and nurses who either worked on university campuses, or within surgeries serving their local university. Unsurprisingly, **Go Folic!** was well received and there was an overwhelming consensus that consultations about student sexual health were an ideal opportunity to either introduce or reinforce the folic acid message. I was delighted that so many people asked to be sent packs of **Go Folic!** leaflets, posters and wristbands there and then! I look forward to developing our relationship with the SHA as we further our work with students.


Bristol University

New Facebook group

On a different note, we have launched a new Facebook group, **Shine Anencephaly Support**, to help raise awareness of the support available to families who have been affected by a diagnosis of anencephaly. The group is run by **Shine**, with the help of Becky Elliott, an anencephaly mum, and will be a unique source of professional advice and support, and peer support. We hope that this will help us reach families that aren't aware of **Shine**, and also enable us to advise and support women who are anxious about planning future pregnancies.

facebook.com/groups/ShineAnencephalySupport

Martine at the SHA conference

Education in England

Shine's Education Team previously highlighted proposed Government changes to the 'statementing' process in England from September 2014. So what do we know so far?

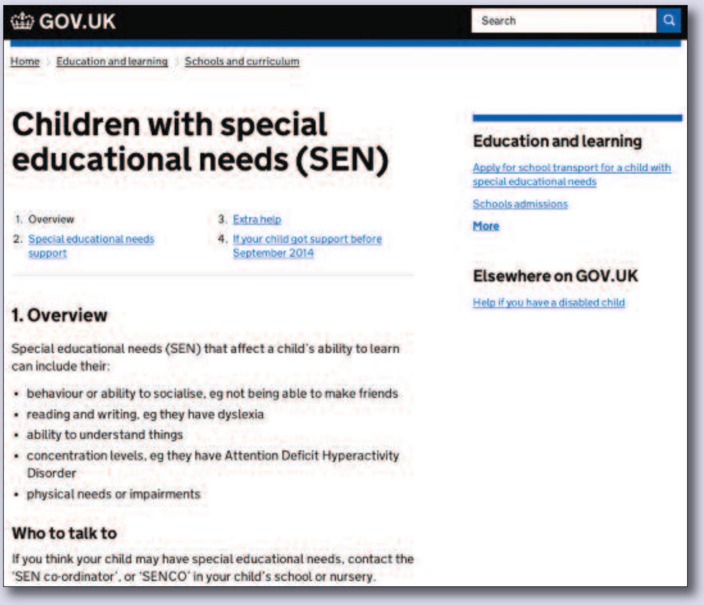
1. As part of the Children and Families Act, changes are being made to the way children with special educational needs are being supported. These changes include gradually transferring children and young people from statements to EHC Plans (Education, Health and Care plans). This will require Local Authorities and Health bodies to work in partnership. Local Authorities will also publish a 'local offer' of services, to provide information on what services children, young people, and their families can expect from a range of agencies.

2. EHC plans will encompass children and young people in education who require additional support and/or training up to the age of 25. This will ensure that education and training providers will have a duty to meet additional needs for those children or young people who have an existing statement and who wish to go onto further education or training.

3. EHC plans will only apply to children and young people who are (or would be) 'statemented'. Families will be entitled to request the support of an Independent Supporter to help them through the process.

4. EHC plans are being phased in over the next 3 1/2 years. This means that if your child currently has a statement, the arrangements in the statement will continue until your next Annual Review.

5. The Children's and Families Act states that Local Authorities need to take the views of children and young people with special educational needs and disabilities and their families into account, particularly in relation to the support they are given.



Children with special educational needs (SEN)

1. Overview
2. Special educational needs support
3. Extra help
4. If your child got support before September 2014

1. Overview

Special educational needs (SEN) that affect a child's ability to learn can include their:

- behaviour or ability to socialise, eg not being able to make friends
- reading and writing, eg they have dyslexia
- ability to understand things
- concentration levels, eg they have Attention Deficit Hyperactivity Disorder
- physical needs or impairments

Who to talk to

If you think your child may have special educational needs, contact the 'SEN co-ordinator', or 'SENCO' in your child's school or nursery.

Further information

Shine's Education team in England will be building up their knowledge and expertise of EHC plans, offering specialist support and advice on how you can get the best out of the new process to support your child's education and training. A number of organisations across England have been funded by the Government to play a role in reforming and delivering services for disabled children, young people with special education needs, and their families. All Local Authorities must have an Information, Advice and Support Service for special educational needs and disabilities (SENDIASS) to provide information on the changes and processes, and Independent Supporters if requested.

Contact details for organisations in your area are listed on the Council for Disabled Children website **W: http://bit.ly/CouncilDC**

Special educational needs in Wales

Wales is proposing changes to the law covering special educational needs (SEN) which will apply to young people up to the age of 25. As yet, there is little detail on the changes or the timescale for their introduction, but we will be keeping a watchful eye!

Contact us for more information about **Shine**'s Education Team on **T: 01733 555988**

Nic's got a new base...

Until now, I'ꞌve been working at Shine Head Office in Peterborough, while traveling around the UK to meet you guys. But by the time you read this, I will have moved over to Belfast in Northern Ireland.

But don't worry – I will still continue to work for **Shine** and meet up with young people wherever they are, at whatever **Shine** event they attend. It has been great meeting the **This Is Me** group, whether it was through a crisis, or for one of the many fun events we've held.

ASPIRE weekend

Chipping Ongar has a great old school called the Zinc Arts Centre. It was here that we got together with a bunch of young people from all over the UK. Over the weekend there were various activities that engaged our volunteers and teens. They got involved in soap making, CV writing, a music session, and a session on animation.

It was great to get to know peers, have some quality time together, and do something that we wouldn't normally do. At the end of the weekend we collaborated some of the activities, and we played a little cartoon that the guys had made in one session, which had a soundtrack made in a separate session. Well done folks!

> **It was great to get to know peers, have some quality time together, and do something that we wouldn't normally do**

Movers and Shakers

We had our first meeting of our youth council, which was held on 11-12th October at Hereward college in Coventry. Thank you to everyone who has shown an interest! The team will be a great asset for **This Is Me**, and hopefully the movers and shakers for things to come.

Get in touch with me on –
E: nic.shaw@shinecharity.org.uk or
T: 07456 669205
facebook.com/Shine.Nic.Shaw

High Ashurst

On June 27th some of us went to High Ashurst outdoor centre in Surrey. I met up with Brandon, Joshua, Abigail, Felix and Kaela from the **This is Me** club, who all showed their fantastic skills in archery. There were a couple of competitions for accuracy, and I even offered Brandon a chance to stand near the target with an apple on his head! He declined. The best part about the archery was that my team won!

After lunch we had a session on a huge climbing tower. We first put on our helmets and harnesses, and went out to climb a man-made mountain. The guys were really impressive, not only in their skills in climbing, but also in their encouragement for those who were unsure and needed a confidence boost.

I even offered Brandon a chance to stand near the target with an apple on his head!

Shine members, carers/parents, and volunteers

There was even time for a bit of fun!

Making steps towards independence

The cooking classes were really successful

As part of Shine's Lifelong Opportunities Programme 2014, adult members, and carers/parents were invited to attend a new event in May that aimed to identify crucial skills needed for achieving and maintaining independence in the future.

The idea was originally raised by **Shine**'s Adult Members Council, which suggested that we could do more to help members make essential first steps towards independence. Held on the 9th-11th May 2014 at Hereward College in Coventry, Independent Futures brought together nine adult members and their parents/carers, all of which had their own individual ideas on how they would like to become independent.

Members were able to attend many classes throughout the weekend, including steps towards basic cooking skills; addressing everyday domestic skills required to live independently; planning for budgeting; managing personal finances; and enabling learning of personal care skills on an individual basis. People often have different ideas of how they would like to address their independence, and so there was also the opportunity for them to speak to a member of staff on a one-to-one basis. The weekend of course also provided a great opportunity for members to mix together with others who share the same aspirations, and also have fun at the same time!

The cooking classes held on the Saturday, which were run by **Shine**'s Occupational Therapist, Kathy Allen, were particularly beneficial. Members cooked all sorts, from flans and pizzas to pasta dishes that were very welcome to the carers and parents who returned from a trip to the local transport museum with rumbling bellies!

> **'The event was fantastic! I realised that we are all in the same boat with hydrocephalus problems. I really enjoyed the cooking, and being able to understand finance a bit more. I set personal targets and I'm still sticking to some of them! It was great to make new friends and socialise, which is not always easy in normal day-to-day life. It was also a great opportunity to meet Shine staff to help with future problems.' Craig Jones**

The weekend was a great success, and members made fantastic first steps towards their independence. We will be running another 'Independent Futures' event next year. More details will follow, but if you would like to discuss the event, or any questions you may have on independence, please contact Kathy Allen –
E: kathy.allen@shinecharity.org.uk

Taking care of yourself with spina bifida

by Patricia Adley, SAMC Health

Last year as a **Shine50Plus** volunteer I helped produce new health information for adults with Gill Yaz, **Shine**'s Health Development Manager, called 'Taking Care of Yourself with Spina Bifida'. This is an important checklist covering how to look after your kidneys, skin and tissues, joints, general health, heart, and mental health. The information leaflet 'Older Adults with Spina Bifida – Information for General Practitioners' is also available and may be useful to give to your GP.

I had a childhood friend with spina bifida who was a doctor. He suddenly became ill, was on dialysis and had a kidney transplant, but he sadly died from a rare infection. He told me I should have the health of my kidneys checked regularly, but no other doctor had ever said this to me.

> **He told me I should have the health of my kidneys checked regularly, but no other doctor had ever said this to me.**

For many years I asked my GP for a creatinine blood test, which is one way to check kidney health. One day I was called back and told I had kidney failure. There is no doubt if it had not been caught at that stage, I would have been on dialysis, but thankfully my kidneys recovered considerable function because the problem was caught in time.

This is why I am keen that we spread the message to other people like me with spina bifida about how important it is to have regular kidney and other health checks. Our GPs don't always have clinical pathways to follow, so I believe it is critical that we take responsibility for our own health.

For a copy of 'Taking Care of Yourself with Spina Bifida' visit **W: http://bit.ly/TakingCareSB** and for a copy of 'Older Adults with Spina Bifida – Information for General Practitioners' visit **W: http://bit.ly/OlderAdultsSB** or call **T: 01733 555988.**

Thank you Shine

By Anita Estwick

I was born with hydrocephalus, which meant as a baby I had long stays in hospital. My parents were not given any information about my condition or where to go for help. As an adult I have been able to search the internet and find out more about hydrocephalus through **Shine**, who sent me a useful factsheet all about it and put me in touch with a lovely local Support and Development Worker who visited me. I am so glad I found this organisation and I'm proud to wear the t-shirt – thank you **Shine**!

Getting connected with Craft4Shine

By Jackie Moore

I was born with hydrocephalus but wasn't diagnosed until ten years ago. I had to finish work, so got involved with paper crafts – I was hooked, but found it hard to keep up. Then I found **Shine** and began making cards for the Benny Bear Club. I also started a club for older people with spina bifida and/or hydrocephalus to share their interest in crafting. That has since become **Craft4Shine**, which has dozens of members from across the country.

Craft4Shine is a private Facebook group for **Shine** members and friends. As well as learning from each other, we make cards and knit blankets for **Shine**'s charity shops. The group has encouraged many people to start making things again where they had lost confidence and motivation, and has given many a renewed interest in life.

To get involved, join Craft4Shine on Facebook –
f facebook.com/groups/Craft4Shine or contact
Angie Coster, Development Coordinator Shine40Plus:
T: 01308 426372 or E: angie.coster@shinecharity.org.uk

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

Shine40Plus Conference 2015

A lifestyle event for adult members with spina bifida and/or hydrocephalus

Following the success of the Pioneering Generation Conference earlier this year, **Shine** will be hosting another national one-day conference for adults aged 40 and over with spina bifida and/or hydrocephalus.

The conference will take place on 5th March 2015 in Bristol. There is a fee of £10 per person.

Conference to include:

- Keynote speaker, Ian Pople, Consultant Neurosurgeon
- Workshops on mobility, continence, welfare rights and benefits, mental health
- Specialist advice from Shine's Health Team

Shine40Plus: sharing experiences, celebrating achievements

To register your interest in booking a place please contact Lynn Hart
T: 01733 555988 or E: lynn.hart@shinecharity.org.uk

For more details contact Angie Coster, Project Coordinator
T: 01308 426372 or E: angie.coster@shinecharity.org.uk

Reg Charity No 249338

Fundraising success in Wales

Marshfield School in Castleton, near Cardiff, laid the Yellow Brick Road for **Shine Cymru** as part of their **Wear Yellow and Shine** day. Sian Prince, Support and Development Worker at **Shine Cymru**, delivered a talk to the whole school with the help of Benny Bear – what a welcome!

Shine member, Louise James, from the Wonky Bar in Bedwas, near Caerphilly, ran a pub quiz and raffle. Louise raised £200 on the night with plans for more activities later this year!

Megan Soffe, sister of **Shine Cymru** member Bronwyn, organised a sponsored swim on the 30 June with her friends and raised over £350 for us – see Meg's story on the **Winners Wear Yellow** blog at **W: www.bit.ly/MeganSoffe**

The North Wales Friends of **Shine Cymru** have been very busy again with the annual Susie Sunshine Walk in Llandudno, and a phenomenally successful fundraising lunch with **Shine Cymru** Patron, Natalie Povey, as the guest speaker.

Our wheelchair athlete extraordinaire and great supporter of **Shine**, Graham Catherall, completed a 10k push with a big smile, and an even bigger sigh of relief as he passed the finish line! Well done, Graham!

A big THANK YOU to everyone for your fantastic support! Take a look at our facebook page for more stories like this facebook.com/shinecymru

Shine Cymru's Campaign for Change

We want to make accessing health services in Wales easier

We are aware how difficult it is for members in Wales to get the health services you need in your local area or further afield when you need them. From GPs, to specialists, and getting second opinions in emergencies, or for routine care, the stories we hear are often unacceptable, so it's time to try and do something about it.

We have sent out a survey to members – by email, social media, and post – to gather information and get a picture of what is happening across Wales, in order to highlight health service inequalities for people with spina bifida and/or hydrocephalus, and lobby the Welsh Government and Local Health Boards for change.

If you haven't received a survey and would like to be part of **Shine Cymru**'s Campaign for Change, contact the Wales office **T: 02920 813847** or **E: wales@shinecharity.org.uk**

It's a hard rock life!

By Heather Gott, Fundraising and Communications Officer NI

Our summer scheme commenced on Monday 11th August. Organised by Belfast Voice and Dance, the grand finale was a fantastic live performance of *Annie* the musical.

On the first day, a very shy and quiet group of young people arrived...that didn't last long! Music was very quickly flowing around the venue with lots of laughter and fun, as well as serious line learning.

Mid week the excitement continued with a visit from UTV Live to record rehearsals. All the children were delighted to sing for the cameras, and see themselves that evening on the news!

On 17th August, audience members arrived and were greeted by Benny Bear. It wasn't long until a packed house at Lagan Valley Civic Centre came alive to the sound of our members performing *Annie*. The performance was magnificent and thoroughly enjoyed by everyone in the audience. Many tears were shed by family members as they watched our members' week of hard work culminate in a vibrant production.

Everyone involved – staff, members, and families – had a superb week! Many new friends were made and it was fantastic to watch each child's confidence grow throughout the week. The children had so much fun and it was enjoyed by all who got involved with one actress stating she 'wished summer scheme could be on everyday of the year'. The performance was so well received by all in attendance, and we hope that those who took part in the performance continue to develop their acting and drama skills. We may even one day have some Hollywood stars in our midst!

Contact us on **T: 01733 555988**
E: northern.ireland@shinecharity.org.uk

Family fun day

Despite the wet Antrim weather, we had a superb fun-filled day at Greenmount College on 7th June. The recreation centre was a hive of activity and laughter!

We had fantastic attendance with members and their families taking part in a multitude of activities including face painting, card making, cake decorating, and wildlife exploration. Of course a very busy area was the **Shades4Shine** craft table. There were some magnificent original sunglasses designs!

Cathy McKillop, Director Shine NI, with Shine members

For those feeling more energetic, members had great fun with the indoor sports including crazy golf, ten pin bowling, and hula hooping. A huge 'thank you' to our volunteers on the day for making the event so much fun!

SAMC update

Hello everyone and welcome to all the latest news from the SAMC.

I hope you've all had a great Summer!

SAMC Meeting

The **Shine** Adult Members Council (SAMC) met at **Shine** Head Office on Saturday 19th July.

Developments

The SAMC will be working with the **Shine** Health Team to develop a leaflet on pain management. SAMC members will also work with Kathy Allen, **Shine**'s Occupational Therapist, on developing a leaflet helping members to choose the right wheelchair. SAMC committee member, Helen Robinson, and **Shine** Support and Development Worker, Lynne Young, are looking at leaflets on benefits for members, covering things such as Personal Independence Payment (PIP).

Events

Various members have been invited to attend events on behalf of the SAMC. Liz Potts attended the **Shine** Independent Futures event, which was held at Hereward College in Coventry (see page 23 for a full report). The event aimed to identify crucial steps and skills towards achieving and maintaining independence in the future and was really beneficial to some of our members. Some members of the SAMC have been selected to front up the advisory group for **Shine40Plus**, including Liz Potts, Heather Doughty, Helen Robinson, and Mike Bergin. Bryn Roberts, Shine Support and Development Worker, will also join the group.

SAMC meeting at Shine July 2014

The event aimed to identify crucial steps and skills towards achieving and maintaining independence in the future and was really beneficial to some of our members

New Member

Joe Mount has joined us in our last available post on the council. Joe comes from Cheltenham, and is a very welcome addition to the group.

As always, the SAMC always want to hear from members! So please do get in touch if there is anything you'd like to see your council doing, or if you have any questions.

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

Calling Shine members – help build and strengthen our membership

We value our members above all else – please make sure everyone who can benefit is signed up. It's been great to watch Shine's membership grow over the past four years and to experience the huge sense of community which is developing between people throughout England, Wales, and Northern Ireland.

Shine members pay nothing to join and automatically become a part of that community, able to receive *Together*, access our free health and education advisory services, get to know our regional Support and Development Workers and attend our support groups. Members can stand for election to the **Shine** Adult Members Council (SAMC) and put themselves forward for election to the Board of Directors. Many members have also become part of peer support networks events or formed friendships at a local level.

The SAMC, elected by **Shine**'s membership, monitors membership issues, advises on what is important and highlights issues of concern. At a recent meeting, the SAMC noted that many people with spina bifida and/or hydrocephalus (SB/H) were not aware of **Shine**, and that many of these would want to benefit from our services and our community if only they knew. We know that some members who 'discover' **Shine** have felt tragically isolated for years before they realise there is a supportive community available.

At the same time, we noticed that a lot of individuals with SB/H and their families who were getting really involved with our social networks thought they were members of **Shine**, but had never actually filled in the membership form.

Finally, we have some parents who think they are members but in fact they are not. If your child is under 16, then the membership is through you as a parent. Once a young person reaches the age of 16, they become a member in their own right, and we communicate with them directly. If, as a parent, you want to be a member of **Shine** as an individual, then please complete the application form.

We value our members above all else

So we'd like *Together* readers to help us by taking the following actions:

1. Please make sure you are a registered as a member of **Shine**. You can do this by calling First Contact on T: 01733 555988. If you regularly get *Together* via post or email, then you are a member. If you are not a member, please fill in a form – remember membership is free.
2. If you are a parent and want to be a member in your own right, please fill in an application form.
3. If you know of anyone with SB/H who might like to join **Shine**, but may not know much about us, please encourage them to fill out an application form and we'd love to welcome them.

To make this much easier than before, we have developed an online form. This is available on our website at
W: www.shinecharity.org.uk/membership

Or you can call First Contact and we can send you a form in the post **T: 01733 555988**

Shine's Lifelong Opportunities Programme 2014

Great minds!

Promoting mental wellbeing

November 21st 2014 • 10am-4pm

Can you recognise signs of anxiety or depression? Do you know how to get help when you're struggling?

Learn more about coping strategies and therapies, including an introduction to Mindfulness.

Here's a chance to meet other people: You are NOT alone in struggling with anxiety and low mood! **Come along and join us!**

Venue:
Harlequin Theatre
Warwick Quadrant,
Redhill, Surrey RH1 1NN

Closing date for applications:
November 7th 2014. Places are limited so please register your interest as soon as possible.

There will be a charge of £10.00 per person to include refreshments and lunch.

The event is aimed at members over 16. No children, please.

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

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

FRSB FundRaising Standards Board

Reg Charity No 249338

Shine's Lifelong Opportunities Programme 2014

Shine Cadbury World Tour 2014

Saturday 13 December 2014

Back by popular demand! We are giving any **Shine** member – adult or child – the chance to attend the Cadbury World Tour in Birmingham!

- **£3 for Shine young members 6-15 years (sorry no siblings)**
- **£4 for Shine adult members**
- **£4 for accompanying parent, partner or carer (one only)**

Cadbury WORLD

For a booking form please contact Maureen Jobson –
E: maureen.jobson@shinecharity.org.uk T: 01733 555988
Closing date for completed applications 28/11/14. Places are limited.

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

Reg Charity No 249338

Shine's Lifelong Opportunities Programme 2015

Family Opportunity Weekend 20-22 March 2015

An event for families with a child 0-5 years with spina bifida/hydrocephalus or IH

£170 per family

- Information sessions for parents/carers
- Workshops for parents/carers
- Crèche facility
- Supervised indoor and outdoor activities for all children
- Choice of an organised family trip
- Family swimming session or complementary therapies for parents/carers
- Benny Bear's Birthday party celebration

Not forgetting – family fun, family portraits, and social time for families together in a safe, friendly enviroment

The event offers social and learning opportunities for the whole family, including siblings, and the opportunity for families to engage closely with **Shine** staff/volunteers and one another.

Places are limited so please register your interest as soon as possible

Venue Holiday Inn, Coventry (M6 Junction 2).
Closing date for applications: January 9th 2015

Payment can be made by cheque or debit/credit card. Payments can be made in instalments by agreement.

For an application form please contact Denise Richardson or Joan Pheasant
Shine 64 Bagley Lane, Farsley, Leeds LS28 5LY
T: 0113 255 6767 E: office@shinecharity.org.uk
Reg Charity No 249338

Shine is proud to be working in partnership with Holiday Inn.

Shine's Lifelong Opportunities Programme 2014

Google Hangout Programme

October 2014 – February 2015

This is an online event with the opportunity to share your concerns on various issues

Tuesday 14th October 2014
Bladder & Bowel Issues

Thursday 30th October 2014
Shunt Talk

Friday 7th November 2014
Skin Care & Pressure Sores

Wednesday 26th November 2014
Friendships & Relationships

Wednesday 3rd December 2014
Shunt Talk

Friday 12th December 2014
Occulta and Tethered Cord Issues

Monday 19th January 2015
Healthy Eating, Diet & Shopping

Monday 26th January 2015
Helpful Equipment for People with Spina Bifida

Thursday 5th February 2015
Shunt Talk

Thursday 19th February 2015
Mood & Sleep

Contact Robin Barnatt for further details, and to receive invitation link
E: robin.barnatt@shinecharity.org.uk or T: 01733 555988

For technical queries, contact Darren Fower
E: darren.fower@shinecharity.org.uk or T: 01733 555988

Reg Charity No 249338

For a full list of all our upcoming social events and support groups, please contact Shine Head Office on T: 01733 555988 E: info@shinecharity.org.uk or visit W: www.shinecharity.org.uk/events

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

Shine Christmas Cards

We have six wonderful Christmas Card designs for you to choose from.
Each pack contains 10 cards with envelopes.
Thank you for supporting Shine this Christmas.

£2.50

Bright Doves (15cmx15cm)

£2.50

£2.50

Praying Angel (15cmx15cm)

All Too Much (17cmx12cm)

£2.50

£2.50

Going To Church (12.5cmx12.5cm folded)

£2.50

The Christmas Gang (21cmx10cm)

Kissing Under The Mistletoe (10cmx21cm)

Free delivery on orders of packs of 10 or more

To order your **Shine** Christmas Cards, please complete the order form below or call **T: 01733 421310**

ORDER NOW • ORDER NOW • ORDER NOW • ORDER NOW

Please send me:	**Qty**	**Price per pack**	**Total (£)**
Kissing Under The Mistletoe		£2.50	
Bright Doves		£2.50	
Praying Angel		£2.50	
All Too Much		£2.50	
Going to Church		£2.50	
The Christmas Gang		£2.50	
Number of packs		**Postage**	
1		£1.00	
2		£1.50	
3		£2.00	
4 to 9 packs		£2.50	
10		£5.00	
Over 10 packs		FREE	

Total order *(inc. postage and packing)* £ ☐

Payment *(Please tick/fill in your preferred method of payment and complete your name & address details)*

☐ Cheque/Postal order made payable to **Shine** enclosed

☐ VISA ☐ Mastercard Security code ☐☐☐

Card no. ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐

Start date ☐☐☐☐ Expiry date ☐☐☐☐

Signature: ....

Name: ....

Address: ....

.... Postcode: ....

Tel: ....Date:.............................

Email: ....

Please return the completed order form together with your payment to: **Shine, 42 Park Road, Peterborough PE1 2UQ**

Reg Charity No 249338

FRSB give with confidence