Together

Issue 17

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

Bronté-Lei and Benny Bear are looking forward to 2016 – Our Golden Anniversary Year!

A Golden Year ahead!

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Shine – Spina Bifida and Hydrocephalus – Information Networking Equality

Shine is a national charity for people affected by Spina Bifida and Hydrocephalus, providing specialist advice, information, events, and peer support to help families and individuals cope with the daily challenges these complex conditions can bring.

Global will 'Make Some Noise' for Shine!

Great news! Global, the media and entertainment group, has chosen **Shine** as one of the charities to benefit from their Make Some Noise campaign, giving **Shine** the opportunity to talk to millions of people! Global is home to much loved commercial radio brands, including Capital, Capital Xtra, Heart, Radio X, Classic FM, LBC, Smooth, Smooth Extra and Gold.

The Global team have interviewed **Shine** staff and members around the country as part of the campaign, which runs until March 2016. Global will also be making a donation towards our Benny & Bella Bear Club for children with Spina Bifida and Hydrocephalus.

Right Wheelchair, Right Time, Right Now!

Will you help us to campaign for better wheelchair services?

As part of the 'Right Wheelchair, Right Time, Right Now' campaign, of which **Shine** is a member, we are calling all **Shine** members to petition for urgent improvements in wheelchair provision in the UK.

The campaign, launched by the Wheelchair Leadership Alliance, is calling for a better deal for the 1.2 million wheelchair users in England, including many of **Shine's** members.

Wheelchairs enable many people to live happier, fuller lives. Yet inappropriate seating can cause back and shoulder injuries and serious risk of pressure sores, and many wheelchair services are falling short, despite the efforts of local health teams.

Here are three important things you can do to help to change this:

- Sign up to the charter at **www.rightwheelchair.org.uk** The more signatures they have, the bigger voice we have with commissioners and politicians.
- Write to your MP and clinical commissioners who provide wheelchairs – there are templates on the site to guide you.
- Share your experiences with **kathy.allen@shinecharity.org.uk** of where wheelchair services have worked for you and when not. We can then use these as a powerful tool to help improve these vital services for all people with Spina Bifida.

Welcome...

to the newly named **Shine South**, formerly Southampton District Spina Bifida and Hydrocephalus Association, who have now joined up as part of **Shine**.

Do You Want to be WHEELY Fit?

If you use a wheelchair most or all of the time to get around, exercise can help to keep you in shape. Exercise helps to boost circulation, keep muscles strong and supple, and reduces the risk of pressure sores. It can be fun too! There is a lot out there to help you start. Contact **parasport.org.uk** or your local authority for details of a range sports to try. Fancy wheelchair basketball? **Shine** member, Rhys Walden, runs a club in Northampton: contact him via Facebook or on **07590 895991**.
For clubs near you try **britishwheelchairbasketball.co.uk**.
For wheelchair dancing or a fun fitness class, contact the Wheelchair Dance Sport Association on **0300 111 30 45** or **wdsauk.co.uk** or Wheely Good Fitness: **wheelygoodfitness.com**

Update on Benefits

Make sure you check your Employment Support Allowance (ESA)!

If you receive income-related ESA (Employment and Support Allowance), income-based job seeker's allowance, pension credit guarantee, or universal credit, you automatically qualify for help with certain NHS charges including prescriptions, sight tests and glasses, and free NHS dental treatment. However, if you receive contributory ESA you MUST complete a form annually – it won't happen automatically for you, and you could face penalties if you don't. Contact your **Shine** Support and Development Worker if you need advice about this or any benefit claim. Contact us on **01733 555988** or email **firstcontact@shinecharity.org** to find your SDW.

From expectant parents to great-grandparents, we are here for life.

Together – here for you

Welcome to *Together*.

Please let us know if any of your contact details have changed

You may spot that this new, lighter issue has fewer pages. There are lots of reasons:

- It reduces the print and postage cost – so more money can go to **Shine's** work
- It uses less paper, saving trees, so it's more friendly to the planet
- Many of you are already using other ways, such as Facebook, to share your news and stories. We aim to make more of those ways too, as well as paper
- The magazine will also be available on our website **www.shinecharity.org.uk/together**

Here to help…

Please do send any comments or enquiries to us:

By post to: *Together* **Shine**, 42 Park Road, Peterborough PE1 2UQ
T: 01733 555988
E: together@shinecharity.org.uk
F: Facebook.com/ShineUKCharity
W: www.shinecharity.org.uk

Registered Charity No 249338

Cover photo: Bronté-Lei Finny
Photo by Angharad Edwards

Let us know if you would like a large print (text only) version of *Together*.

Baby Bella is here!

Children across the country have been eagerly awaiting the arrival of Bella. Well, the first Bella Bear book is here! Beautifully illustrated by Alice Wood, *Our New Baby… Bella Bear,* reflects on Bella's early days. Bella has Spina Bifida and is the new special friend of Benny Bear, who has Hydrocephalus. Published 1st December – priced £2.50 – a perfect gift. To order, phone us on **01733 555988** or download the pdf for only £1 from our website **www.shinecharity.org.uk/bennyandbellabear** (Look out for the new Benny & Bella Bear Club, with fun and activities in the New Year too!)

Looking forward to a Golden Year!

2016 will be a special year – our Golden Anniversary! The charity ASBAH, which started in 1966 to help families with Spina Bifida and Hydrocephalus has grown and developed into the Shine we know today – now with 10,000 members!

In 2016 we will be celebrating all that has been achieved and looking forward to a great future – to reach and support even more Shine members. (See pages 4-5 for an overview of Shine services.)

Special Golden events in 2016 will include the 50th Anniversary Service in Peterborough Cathedral in April, a Summer Special event, and a Golden Anniversary Ball in November!

Look out for special events and ways to get involved next year. We will share details on the Shine website, Facebook, emails, and in a special 'Golden' issue of *Together* in April.

In July, the Spina Bifida and Hydrocephalus: Our Heritage exhibition will launch in Peterborough – the first of its kind in the UK! It will be fully open to visitors by the summer.

Shine – Here For Life

As we move towards a Golden Anniversary year, it seems a perfect time to reflect on the support that **Shine** has to offer, and our hopes for the future. Here **Shine's** Acting CEO, Kate Steele, explains...

I believe that **Shine** is special – even unique. We are the only national charity offering specialist health services to people affected by Spina Bifida and Hydrocephalus – the golden thread or 'SH' of **Shine**.

Our health and education expertise goes beyond that offered by national services, and ranges from general health advice to one-to-one support from our Health and Development and Education Teams. From expectant parents to great-grandparents, we are here for life.

Our deep understanding of our members' diverse needs allows us to tailor our support to the individual, and many say our help is life-changing.

Most of all, we work to ensure that you have the information and help you need, enjoy good peer support, and feel confident to try new things and look to the future.

Information – the 'I' in Shine

Whether it's learning how to manage a shunt, toilet train a child, or ensure your own health and mental wellbeing, our information is tailored to help you manage the daily challenges that Spina Bifida and Hydrocephalus can bring. You can find this on the **Shine** website **www.shinecharity.org.uk.** Over the next year we will be refreshing and developing our information and website, so that everything is even more useful and easy to find.

Networking – the 'N' in Shine

A Reassuring Voice

Shine's Support and Development Worker (SDW) team are here to chat with you about the changes you are going through as an individual or family. They are skilled at supporting people through change and loss, and enabling people to feel more positive about their future even when the going is tough.

There are SDWs all over the country, but you don't need to have one living near you – they are there for you at the end of a phone, email, on Facebook or at a **Shine** event (see back page).

'It's a privilege to work with **Shine** families and individuals' says SDW, Sharon. 'They go through so much. It seems relentless, especially for young families with children who have repeated surgery, or members facing changes in health as they get older. We're here to smooth the way as much as we can.'

SDW, Collette, adds: 'On any day we can be helping someone to claim a vital benefit, think about the questions they need to ask their GP or neurologist, or respond to enquiries on Facebook. A big part of what we do is helping young families come to terms with a new diagnosis, which can feel so isolating. Our events and Facebook groups help to connect members so they feel less alone. Sometimes, just knowing there is someone out there who understands and cares makes all the difference.'

Take Wendy, who's older son Connor has Hydrocephalus and younger son Reece has epilepsy. Wendy is one of the most capable people you could meet, but she admits: 'It feels as if you have to fight for everything! We have become experts in these conditions. What might be challenging for most people is our 'normal'. Looking back, I wouldn't change a thing. I love my boys to bits!'

Our team also work with schools so that teachers understand how Spina Bifida and Hydrocephalus affect daily life and learning, and how to support their young students to reach their potential and feel valued members of their classes.

Connecting you up

Shine also runs events around the country so that you can meet and share together, whether it's **Great Minds!** – supporting mental wellbeing, the **Summer Rez** for young people, family conferences or fun days out. Over time, we would love to have more events, funding permitting. See the back page of this *Together* for events planned up to Spring 2016.

Equality – the 'E' in Shine

Shine works hard, with you and on your behalf, to ensure better services and care. Here are some of the campaigns we are working on.

Specialist services – working with partner organisations to change the way health services are set up, so that you can meet all the experts you need in one go, at specialist centres. This will give you a better service, save time and stress, and be much more cost effective.

Better Continence Care – whether you use a toilet, catheter or stoma bag, going to the loo is an important and normal thing to do. But it can be more complicated for people with Spina Bifida and Hydrocephalus, and without the right support risks infections and other problems. We are campaigning for better services, especially in Wales.

Better wheelchairs – you can find more about this on page 2.

Prevention – working to prevent neural tube defects (NTDs) by promoting preparation for healthy pregnancies and our **Go Folic!** message among pregnant women and women of childbearing age.

Thank you!

Shine's work is enabled by the support of thousands of members and partners, including Trusts and Foundations. Here are just some of the services that have developed or been able to continue, thanks to this great partnership.

Giving Time to Shine – enabling members with Spina Bifida or Hydrocephalus to volunteer at events, as part of the **Shine Adult Members Council** or **Shine40Plus** thanks to funding from Awards for All England.

*'Thank you, **Shine**, for the lovely opportunity for the volunteers to meet and get some training (even if it was a tough subject at times), and for the appointment in your fabulous Health Hub – what an achievement! It is going to be such a blessing to so many!' Sarah Killick-Sturges*

Little Stars – thanks to funding from Awards for All Wales, the **Sêr Bach** support meetings and fun days across Wales are bringing encouragement for many families with children under 10 who have Spina Bifida or Hydrocephalus.

Shine's Summer Rez brought teenagers together for a great time, thanks to funding from the Boshier-Hinton Foundation and the John Horniman's Children's Trust.

Shine40Plus for adults with Spina Bifida and Hydrocephalus has engaged more people across South/South East Wales, thanks to funding from the Millennium Stadium Charitable Trust.

...and not forgetting our friends the Freemasons' Grand Charity for their continued support for **Shine40Plus**.

Your 'One And Only' Home...

Shine member, Michelle Elman has Hydrocephalus. Here she shares her experience of one aspect rarely talked about, and why body image matters…

'When I was born I was diagnosed with Hydrocephalus. Over the 21 years since then, I have had 15 surgeries, pain, medical trauma and a diagnosis of post traumatic stress disorder. One aspect is rarely spoken about: scars. I have scars from my head to my ankles. This has affected my confidence the most.

Growing up, I didn't know how to handle people staring on the beach or in changing rooms.

I am a believer that, 'It isn't what happens to you that defines you, but what you make of what happens to you'. Despite the many surgeries we 'hydrowarriors' undergo, your body is still there for you... It's time to treat it with respect, as your one and only home.

As a body confidence coach, I teach people to embrace their bodies. Scars are our badges of bravery and mementos of how strong and resilient we are.

Finally wearing a bikini was one of the hardest things I have done, but it was also one of the most liberating – to know that I was comfortable in my own body. Yes, there were still a few stares, but whether you have stretch marks, a C-section or scars through surgery, let's stand up and be proud of our scars and what they represent – our story.'

Read more at bit.ly/1EXAyDb or #scarrednotscared

A Legacy of Love

Gillian Coverley, Wills & Trusts Partner at Irwin Mitchell Solicitors – one of Shine's corporate partners – shares why it helps to plan ahead.

It may feel strange to think about what will happen when you are no longer around. But it is important to plan ahead, and more so if people depend on you. How would they manage without you?

The best way is to plan now, by making a Will. A well written Will can save your loved ones time, cost and anguish, and ensure they receive all the money or property you want them to.

Without a Will the law, not you, decides how to distribute your estate, and may not provide fully for your family. (For instance, a spouse may not receive all your estate, and under the current rules an unmarried partner receives nothing.) So making a Will is important.

After you have provided for your family and friends you may wish to leave a gift to a favoured charity, to help them carry on their valuable work. Gifts left to charity are also exempt from inheritance tax. Seek a qualified Solicitor to help you make your Will. (Sometimes you can do this via their website, or by completing a questionnaire in the comfort of your home.)

Gillian can be contacted at **gillian.coverley@irwinmitchell.com** or on **0370 1500 100**.

Earlier this year, a **Shine** member's father shared about leaving a legacy to **Shine**. He talked about his daughter and how they had been told she'd never walk, never have children, and would lead a restricted life because of her Spina Bifida. In fact, she has two children, goes horseriding and has fulfilled a lifetime's ambition to skydive over her home town.

He said: 'It won't be much, but we wanted to leave something to show our appreciation. We had wonderful support while my daughter was growing up. It makes such a difference knowing you've got someone in your corner.'

Remembered with Fondness

With sadness we report the death this year of **Shine** member Helen Barnett, an original member of the London based 'Blue Blobbers' social group, and Vanessa Wright, Consultant Paediatric Surgeon at Queen Elizabeth Hospital, Hackney (and later at the Royal London) who treated many of our members. Both will be greatly missed.

STOP PRESS!

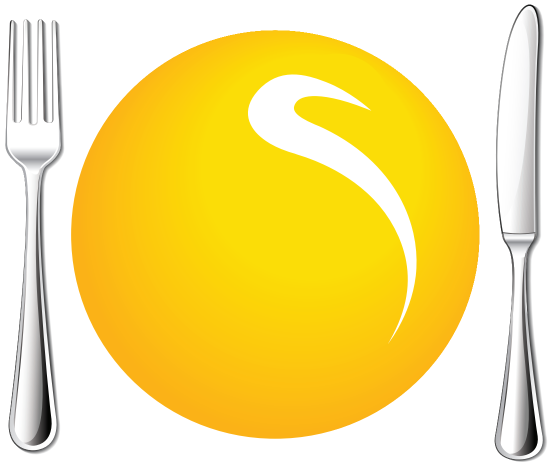
Mr & Mrs F have just celebrated their Golden Wedding Anniversary and asked for donations, instead of presents, in memory of their daughter. They raised a fantastic total of over £1,000 for Shine! If you are celebrating a special occasion in our Golden Anniversary Year please consider doing the same - thank you!

Help Us to Help Others Like Harry This Christmas

Read a personal message from our Acting CEO, Kate Steele, on the difference Shine makes to people's lives and how you can help by making a donation this Festive Season. (See the separate sheet with this issue of *Together*.)

Dine for Shine

We are asking restauranteurs to help **Shine** by donating 50p to **Shine** whenever anyone orders a specially selected dish, or by asking diners if they would like to add £1 to their bill to help towards the work of **Shine**.



If you have a relative or friend who owns a restaurant who could be interested in being part of this new initiative to help Shine, please contact Shelley Green on 01733 421328 or shelley.green@shinecharity.org.uk

Tell Us A Winter's Tale for Shine

Laptops, tablets, pens and pencils at the ready to write a short story!

The competition is open to everyone - Members and Non-members alike. There are three categories:

Children up to 10 years – Maximum 500 words. Entrance fee: £2.50

Teenagers 11–16 years – Maximum 500 words. Entrance fee: £2.50

Adults 16+ – Maximum 1,000 words. Entrance fee: £5.00
(If you are 16, you can choose which category you prefer – dependent on the length of your tale).

Your story must mention the word **SHINE** at least once. It can be funny, religious, a love story, a mystery – whatever you want to write about.

Closing date:
WEDNESDAY 6TH JANUARY 2016
You can submit your story and entry fee electronically on our website www.shinecharity.org.uk (just follow the step-by-step guide on the homepage), or post your entry and fee to: Shine, 42 Park Road, Peterborough PE1 2UQ. Your entries will be read anonymously to a judging panel, made up of members of Shine in the City.

Winners will be notified and announced on Facebook and the Shine website.

Prizes will be awarded to the Winner and a Runner Up in each of the above categories.

Shine Events Noticeboard

Shine runs events all over the country so that you can meet up with other members, have fun and share and learn together. Below are details of some of the events coming up. For more information or to book for our events, unless otherwise stated, please contact servicesadmin@shinecharity.org.uk or phone us on 01733 555988. You can also find details on our web calendar at www.shinecharity.org.uk/events

Normal Pressure Hydrocephalus Spring Study Day in Peterborough, April 2016.

If you haven't already, please remember to approach your local pub or social club to hold a quiz for **Shine** too!

Fancy a challenge in our Golden Anniversary Year? Shine is looking for individuals and teams (both wheelchair users and non-wheelchair users) to take part in walks, races, abseils and even Santa Dashes across the country, to raise money for **Shine.**

Cadbury World Tour, Birmingham, 12th December 2015. For **Shine** members aged 5-15 years (£3 children; £4 parents/carers).

Shine40Plus National Conference, Manchester, March 2016. A one day event for **Shine** members with Spina Bifida and Hydrocephalus aged 40 and over to meet and share experiences and information. Registration £10.

Shine's Golden Anniversary Events

Look out for **Shine's** Golden Anniversary events around the country in 2016! We will share details via the **Shine** website, Facebook, and in a special 'Golden' issue of *Together* in the Spring.

January - **Just for January** - give up something for **Shine** and ask your friends and family to sponsor you
February - **Love Desserts** - for anyone who loves desserts! Invite your friends to bring a pud to share, and charge them for the privilege!
March - **Easter Recipes for Shine** - we'd love to receive your favourite recipes during February to create a special Easter booklet
April - **Shine's Golden Anniversary Service**, Peterborough
Midsummer - **Shine's Golden Pedalfest** - a summer special event for all the family!
July - official launch of our **Heritage Exhibition**
November - **Shine's Golden Anniversary Ball**

...and many more to come!

Make sure you let us know if YOU'RE planning an event in your area and we will send you a fundraising pack! Contact us at **fundraising@shinecharity.org.uk**

Independent Futures, Coventry, 22-24th April 2016. A residential event for adult **Shine** members and a carer/parent to identify steps and skills that will help you to be more independent. Includes cooking, managing money, setting goals and looking after yourself. £180 per member, includes carer/parent, full board.

Shine Great Craft Getaway, Devon, 3-4th June 2016. A residential event for adult members to try various crafts and get together with like-minded people. £178.50 per person (15% single supplement), covers full board and tuition.

Shine Health
Home Delivery

Shine Health Home Delivery We now have nearly 400 adult members signed up to our home delivery service, which provides stoma and continence products and prescription medication to your door. The service is also open to our younger members. **Shine** will be writing to all parents of our under 16 members to explain more about the service, and how you can sign up if you wish. Please look out for the letter! For further information call us on **0800 023 8857** or via email at **info@shinehomedelivery.org.uk**

Spina Bifida and Hydrocephalus: Our Heritage
This event will be held in Peterborough, Summer 2016 – the first exhibition of its kind in the UK!
For further information contact maureen.jobson@shinecharity.org.uk or phone 01733 555988.