Inside: Shine in the City • Latest News • Commonwealth Fellows

Issue 16

Together

Shine Heritage – an exhibition in the making

Nominations now open for Shine Awards 2015

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

BIG LOTTERY FUND
LOTTERY FUNDED

Could you serve on Shine's Board?

Shine's new governance arrangements, agreed at the AGM in 2012, aim to make Shine a more democratic and representative organisation. In 2013, the first three Directors were elected by the membership. We now have two further vacancies...

Rewarding and challenging

The Board is responsible for **Shine**'s overall strategy while ensuring that it is well run and meets its legal obligations. Board members work closely with the Chief Executive and senior staff to make the charity as effective as possible. Being a member of the Board can be stimulating, rewarding and challenging - even fun!

Representing Shine's membership

To reflect the membership, at least 50% of the Board should have spina bifida and/or hydrocephalus (SB/H). As one of our trustees with SB, Katrina, is stepping down, we would particularly welcome expressions of interest from members with the conditions who can bring additional skills and experience. One must be from Northern Ireland (as the post is now vacant) and one from any of the countries in which we work.

A range of skills

Shine aims to have a Board whose members cover the broad range of the charity's activities, and bring relevant knowledge and experience. So, for example, we would hope to have parents of children with SB/H, a young person with SB/H, and Directors with social care, health, legal, HR, business experience, or other skills that may help **Shine** to meet its objectives.

> **'It is a fulfilling role, contributing to good Governance and direction in a professionally run and worthwhile charity.'**
> **Yvonne Lindsay, Trustee**

Events and meetings

Board members are expected to attend four meetings each year in Peterborough and travel/ subsistence expenses are paid. In addition to this commitment, there are opportunities to get involved in other events/ initiatives and to apply specialist skills and experience where appropriate.

We are very grateful to all those willing to serve, or consider serving, on the Board.

Want to know more?

If you are interested, please contact Kate Steele or Margaret Conner for an informal discussion or email. If you then wish to apply, we will ask you to submit a letter of application outlining your skills and experience.

Suitable candidates will be invited to meet the Chair of the Board, Chief Executive, and other senior staff or trustees to discuss the requirements of the Board, your skills, and what you can offer **Shine**. Candidates who meet the skill set will be included in the election to be held this October. The outcome will be announced at the AGM in November 2015.

To register interest please contact either Kate or Margaret

- Telephone: 01733 555998
- Email: margaret.conner@shinecharity.org.uk / kate.steele@shinecharity.org.uk

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Submission dates for summer edition

- **Register of interest to submit:** 20/07/15
- **Final date for submissions:** 21/08/15
- **Publication date:** October 2015

Cover photo: Iona Ganderton **Taken by:** Tom Scott

A huge 'Thank you!'

It is hard to believe that Issue 16 of *Together* is in your hands and that this will be my last time editing the magazine. At the end of June I will be leaving **Shine** and I'd like to take this opportunity to say a huge 'Thank you!' to everyone who has contributed to *Together* over the past four years - you really are the reason it is such a great publication!

We have another packed edition with the usual spread of news, views, features, and images to reflect the dynamic **Shine** community! You can read our three varied feature articles and see some of the images from another great Family Opportunity Weekend (page 16-17). We've also packed in all the regional news, updates from our various member groups and, of course, Gobi's Gossip (page 29).

Please keep your stories, images, and questions coming so that the new editorial team have lots to include in the next issue. Keep **Shine**-ing!

Tom Scott

E: together@shinecharity.org.uk

Farewell Jackie Bland

May 2015 saw Jackie Bland step-down as CEO of **Shine.** We would like to thank Jackie for everything she has done for the organisation and wish her all the very best for the future.

Caroline Sanders receives MBE

Consultant Nurse, Caroline Sanders, has been awarded an MBE for her work over the last 23 years with children who experience neuropathic bladder, which has included children born with spina bifida.

Caroline Sanders receives her MBE

Specialising in paediatric urology and gynaecology, Caroline is passionate about ensuring quality continence services and support for children and their families. Her work has included developing a toolkit for rectal irrigation which encourages best practice and choice, with an aim to minimise the need for surgery in some children. Caroline was also winner of the 'Wellchild Nurse of the Year' award in 2007.

Caroline's nomination was supported by parents including **Shine** member Christine Anderson:

'Caroline is always going the extra mile – visiting us at home, undertaking and involving families in research, and challenging the healthcare and education systems to improve practice. If she doesn't know something she'll find out.

'When my son Christopher was born, there was no urology consultant, so we slipped through the net. We came home and wondered 'what next'? Being a parent of a child with spina bifida or hydrocephalus can be quite lonely – you can feel stranded. Finding Caroline was a godsend, and she has supported families to set up a facebook group and meet together.

'When Christopher was five we were told he needed surgery. With support from Caroline we felt confident to challenge this. Now, Christopher has botox injections every few years, rather than needing any surgery or medication, and he's doing really well!'

Caroline also goes into schools and runs training events for parents and health teams.

Christine explains,'Caroline's a really good link, arranging events so that we can share our experience as parents, and the professionals can share the latest developments with us. She's involved families in lots of practice based research too.'

Caroline was delighted to receive the award: 'We all need to work together, especially health and social care. It's hard to change policies, but worth the effort, so that children can engage fully in life – and keep healthy in adulthood too.'

Who will Shine in 2015?

Nominations are now open for the 2015 **Shine** Awards! Deadline for nominations: Friday 14th August.

The four categories are **Shine Volunteer, Shine Young Achiever, Shine Professional,** and the **John and Lucille Van Geest Award for outstanding contribution to the Shine community**. If your nominee is chosen, you will receive an invitation to come and see them receive their award at the Annual General Meeting on 19th November. For more information and to make a nomination, go to **W: www.shinecharity.org.uk/shineawards** or contact Val Stokes on **E: val.stokes@shinecharity.org.uk** or **T: 01733 421356**

The other special awards – Fundraisers of the Year and Lifetime Contribution – will be decided by a **Shine** panel of judges.

The Orthotics Campaign Needs You!

Rebecca Loo is on a mission: to revolutionise orthotics care in the UK. This will help many people with spina bifida.

Children and adults with disabilities or medical conditions need to get quality, well fitting orthotics such as splints and footwear quickly, in order to carry on living their lives to the full. However, delays, poor materials, or lack of funding often mean they don't get what they need in time. The Orthotics Campaign aims to change this by challenging the system and educating health commissioners about what patients need.

Rebecca knows why this matters. Her son, David, has cerebral palsy and talipes (club foot). When David was nine he needed lots of plaster casts to straighten his feet, but the splints that he needed to keep his feet straight afterwards took so long to arrive that David had outgrown them. By then he was unable to get around unaided and had missed out on school.

Rebecca explains, 'For children especially, delays mean they may be in pain, unable to walk or stand, or to carry on with school life. It can also mean having surgery or amputation that could be prevented. All this can badly affect sleep, behaviour, and overall wellbeing.

'We want the NHS to set clear guidance so that patients have good, consistent care. In some areas you have to pay for orthotics, while some services will not fund cheery designs on children's splints, which then discourages children from wearing them!'

'NHS England are now listening to us but have limited power. Every £1 spent on orthotics saves the NHS £4 elsewhere - but often in another budget, so it's complex. If an orthopaedic surgeon only gets paid every time he operates, the incentive is to go for surgery rather than prevention. Commissioners need good information, or how else will they know what to do?'

Rebecca would love to hear from **Shine** members. 'The more we shout, the more we'll be heard!' You can get in touch via **www.nsoc.org.uk** or twitter **@orthotics_campaign**

David Loo (playing football); David and Rebecca Loo

Health Advisory Council launches for Shine

Shine's new **Health Advisory Council** held its first meeting on April 29th.

The new council brings specialists together to advise and help **Shine** shape its policies on matters of health and wellbeing.

The council will bring together **Shine**'s own health specialists, including Gill Yaz, Health Development Manager, and Martine Austin, Head of Prevention, with other eminent specialists such as Richard Morgan, Consultant Physician, Chelsea and Westminster Hospital; Trudi Edginton, Senior Lecturer in Neuropsychology, University of Westminster; Roger Bayston, Professor of Surgical Infection, QMC Nottingham; Dr Ann Molloy, Associate Professor, School of Biochemistry and Immunology, Trinity College Dublin; Richard Edwards, Consultant Neurosurgeon, Bristol, and Ann Yates, Director of Continence Services, Cardiff and Vale UHB.

Go Folic!

It hardly seems possible that another year has passed, and yet here we are celebrating our third National Folic Acid Awareness Day!

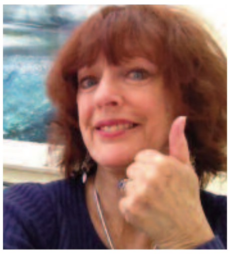
Team **Go Folic!** was out in full 'pink' force at HQ, in the Northern and Southern Regions, and Wales and Northern Ireland. As usual, our very own Robin Barnatt needed no encouragement to don a pink T-shirt and hit the streets - all in the name of awareness raising of course!

Despite the upcoming election, Conservative Parliamentary Candidate for Peterborough (and long time folic acid awareness supporter) Stewart Jackson came along to show his support, along with Peterborough City Council CEO Gillian Beasley, amongst others. It was also great to be able to share such an important day with our Festus Fajemilo Foundation guests from Nigeria, who threw themselves fully into the day's activities.

In addition to all the awareness raising events that were taking place in supermarkets, hospitals, colleges, and city centres across England, Wales, and Northern Ireland, we were also, as usual, very active on Facebook and Twitter. Last year we achieved an impressive social reach of one million people on social media, and we've smashed that again this year! It's truly amazing to see what we can achieve in just one day.

Of course, we couldn't do it alone. I would like to say an extra special 'Thank you' to all of our amazing volunteers who gave up their time to help us spread this important message, not forgetting all those who shared, re-tweeted, and joined in our Thunderclap campaign on social media. We couldn't do it without you! It's so exciting to see how the event has developed and grown over the last three years, and I'm looking forward to achieving even bigger and better things next year!

If you would like to be involved in next year's event, or would like to help with **Go Folic!** in any way, please contact me on **T: 01733 421349** or
E: martine.austin@shinecharity.org.uk



Journalist and broadcaster, Bel Mooney, supports the Go Folic! campaign

'Thank you to all our amazing volunteers – and to everyone who shared, re-tweeted, and joined in our Thunderclap campaign on social media – we couldn't do it without you!'

Anencephaly Support Group

The new **Anencephaly Support Group**, which is still growing rapidly, is dedicated to raising awareness of the condition and ensuring that families have the support and information they need. Find out more at **facebook.com/groups/ShineAnencephalySupport**

With thanks to our event sponsor

Shine has launched the Peterborough-wide initiative called Shine in the City to develop new partnerships and support, and to raise awareness of spina bifida and hydrocephalus.

Shine in the City launches in Peterborough

Shine in the City aims to inspire businesses, organisations, schools, and colleges in Peterborough to participate in fundraising activities, sponsorship and volunteering, while **Shine** provides opportunities for work experience and learning, for example, on disability awareness.

The law firm, Irwin Mitchell (IM), became the first **Shine in the City** corporate partner, and sponsored the launch. IM Partner, Guy Forster, said 'We are delighted to be actively involved in **Shine in the City** from the start. As **Shine** is based in the heart of Peterborough, it is a great opportunity to share their heart for people with spina bifida and hydrocephalus through this city-wide scheme.'

Born from the highly successful **Chairman's Challenge** year in which **Shine** Chairman, Richard Astle, undertook physically challenging fundraising events and engaged support from local businesses and individuals, **Shine in the City** will ensure the momentum from events such as the Sahara trek, half marathons, and Santa Dash is maintained.

Their efforts, and a generous donation by the Harry Cureton Trust, enabled the new **Shine** Health Suite to be built and successfully piloted by the end of 2014. An early target for **Shine in the City** will be to raise the funding needed to equip the health suite fully.

The Invisible Heritage of Spina Bifida and Hydrocephalus: an exhibition in the making

The Shine Heritage exhibition is set to launch in April next year. Marc Lupson, Heritage Project Development Officer, explains why this event is so important and the care being taken to prepare for it.

Since joining the **Shine** family as Heritage Project Development Officer back in February, my journey has been one of learning, appreciation, respect, and enjoyment in getting to know all of you out there!

Coming from a background of environmental and social grants management, as well as being an academic trained in heritage, my knowledge and awareness of spina bifida and hydrocephalus was limited to say the least.

So, being asked to design and deliver a permanent exhibition about the heritage of spina bifida and hydrocephalus is a big challenge.

Where do I start?
How do I choose what to put in it? How do I make it accessible and interesting to everyone? These were just some of the many questions that I asked myself on my first day!

What's it all about?
The original idea was a smaller exhibition on the history of ASBAH/**Shine** to celebrate its 50th anniversary in 2016. However, there is a huge amount of wider history attached to spina bifida and hydrocephalus that can't be ignored.

This discovery has paved the way for a successful £60,000 bid to the Heritage Lottery Fund to bring this wider history to life.

The history and contribution of ASBAH/**Shine** will be recognised as part of the exhibition, but to have it as the primary focus would not tell the full story, a story that needs to be shared and for people to learn about.

Why do it?
Having spoken to many people since I joined **Shine**, the question 'Why are we doing this?' has been asked from time to time.

Doing an exhibition could be seen as 'something nice to do', but with no real significant benefits. So why do it?

> **'I truly believe that it is a fantastic opportunity to do something unique which will greatly increase the exposure and awareness of spina bifida and hydrocephalus to the wider community, both in and outside the UK'**

I truly believe that it is a fantastic opportunity to do something unique which will greatly increase the exposure and awareness of spina bifida and hydrocephalus to the wider community, both in and outside the UK.

It is a heritage that has such depth but has never been looked at, and it is an opportunity to give the spina bifida and hydrocephalus community a voice.

On a personal level, I have learnt so much already and I have barely scratched the surface!

What's going in it?
I am hoping to make the exhibition an informative and interesting experience for everyone, as it will be open for anyone to visit its permanent display at **Shine**'s Head Office in Peterborough. Some sections will also be mobile and taken around the UK.

I am very conscious that it needs to be fully accessible to cater for many different audiences and I really want people to engage with it. I promise it will not be 'medically focused' and there will be things to see, watch, listen, and to touch!

Once the exhibition is up, that's not the end of it. History and heritage are constantly being written, so there will be additions in the future to ensure nothing is forgotten.

Support and help

As I am writing this I am still only nine weeks into my role, and I am learning more and more every day. An exhibition is a subjective experience, so it really helps to have as many perspectives as possible in preparing for it, which is why I really welcome your input and support along the way.

I am always sharing what I am doing on my Facebook page **facebook.com/shine.marc.lupson** so please come and find me if you want to know more and get involved, or contact me on **marc.lupson@shinecharity.org.uk**

Any messages of support are welcome and in my time at **Shine** I aim to do the very best job I can for you!

Bees
Shine On!

A Championship match day collection for **Shine** raised £450, when Brentford FC took on Nottingham Forest FC at Griffin Park on Easter Monday. The idea for the collection came about when **Shine**'s Membership Development Officer, Gobi Ranganathan, met Bees CEO, Mark Devlin, to explore the potential to form a partnership between the club and the charity.

'**Shine** wants to be there for every person affected by spina bifida or hydrocephalus,' says Gobi. 'This new partnership is exciting, and the money raised will help us to run support groups, events, and provide clear information so that our members feel confident and able to get the support they need.'

Shine volunteers helped out at the event and enjoyed an exciting game, which resulted in a 2-2 draw.

If you would like to contribute to the Matchday collection, text GIFT42 followed by £3 to 70070.

The Freemasons' Grand Charity

The Freemasons Grand Charity has made a £35,000 donation to fund the salary of a Development Coordinator for the **Shine40Plus** network. Since the Freemasons Grand Charity began operating in 1981 it has been a keen supporter of **Shine**.

Shine40Plus allows people over 40 to share their experiences; providing daily social interaction, comfort, and information about managing their condition and looking after themselves. This is the first group of people experiencing spina bifida and hydrocephalus to reach their later years and the creation of this network will enable them to share their knowledge and experience with one another, helping to alleviate feelings of isolation and anxiety.

Laura Chapman, Chief Executive of the Grand Charity, commented, 'It is wonderful to be able to help bring people together, ensuring they receive the guidance and support they need to move into the next stage of their lives with happiness and a sense of belonging. Helping vulnerable people in our community is central to Freemasonry and we wish this project every success.'

www.grandcharity.org

The Shine MEGACYCLE Festival

Join **Shine** in Peterborough on Saturday 4th July for a family-friendly bike ride and summer festival. Accessible route options available. BBQ, entertainment, stalls, games and a raffle with the top prize of a Carrera bike to be won! For more information, go to **www.shinemegacycle.org.uk** or catch us on Facebook search for: **Shine MEGACYCLE Festival 2015**

Wandering the Wolds for Shine

Clare West organised a 10 mile sponsored walk around the Lincolnshire Wolds which attracted 10 other people and raised a fantastic £1,745! Clare has an 18 month old daughter with spina bifida.

Gareth Picken's 200 mile arms only challenge

By Shine member, Marcia Collins

Gareth Picken has spina bifida and hydrocephalus, and is a keen sportsman. This year, 15 year-old Gareth from Cheltenham took on the amazing challenge of completing 100 miles swimming and 100 miles wheelchair racing in aid of **Shine**. Gareth uses only his arms for these sports. Over six months, Gareth has used every training session and competition to rack up the incredible distance, and completed his final three miles of wheelchair racing at the London Mini Marathon on 26th April. He has raised £790!

Wheelchair racing is a relatively new sport for Gareth, who got his first racing chair in June 2014. He trained hard and soon reached the England Nationals – covering 100m in 20 seconds. Micky Bushell, paralympic silver medallist, holds the record at 14.69 seconds. Now Gareth is focusing on wheelchair racing and seated throwing. Mum Nici recalls how, even though he was number one in his category (S7) for swimming in 2014, 'he would be placed with the 10 year olds at the local swimming club, because he can't keep up with the non disabled adults.' Gareth first became a member of **Shine**, after attending a **Shine** short break in 2013. 'It was great fun – and a relief not to have to keep explaining my disability.'

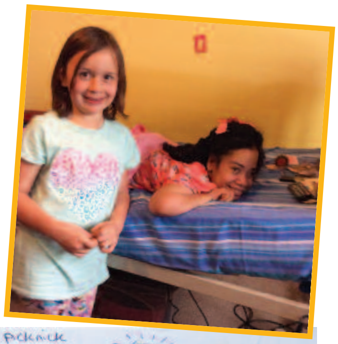
Now Gareth wants to encourage other young people with disability to try new sports and overcome barriers. After finishing his GCSEs he plans to go to college to study for a BTEC Diploma in Sports Science. His advice for budding young **Shine** sportspeople?

'Don't think you can't do things – you can, but differently. If you want to do something just do it – don't let your disability stop you.' To support Gareth, go to his Justgiving page: **www.justgiving.com/Gareth-Picken**

Wear Yellow and Shine

As many *Together* readers are already aware, **Wear Yellow and Shine** is a fundraising initiative which last year raised over £20,000 to help everyone affected by spina bifida and hydrocephalus. We are excited to tell you that in 2015 we will be unveiling a new look **Wear Yellow and Shine**! This is advance notice to get ready for what's coming! All the information you need to take part, whether as an individual, a school, or an organisation, will be available on the website **wearyellowandshine.org.uk** and in the next issue of *Together*, as well as via social media forums. Please make a note that Spina Bifida and Hydrocephalus Awareness Week is 19-25th October. We'd love it if you took part in **Wear Yellow and Shine** events that week, but you can also choose any day of the year, we really don't mind!

If you would like to receive information when it comes out, please email Ali Coutts, Community Fundraising Officer, **E: ali.coutts@shinecharity.org.uk** Or visit **wearyellowandshine.org.uk**



Shine Family Portraits Competition Winner

We are delighted to announce that Nicola Cope and her friend Amelia Cook of Haddington, Lincoln, are the lucky winners of the **Shine** Family Portraits Competition. Nicola's mum, Janette, said that she is 'proud and delighted!'

'Nicola and I always enjoy reading the news and information in *Together*, and Nicola and Amelia had great fun thinking up the idea for the portrait.'

They both win a canvas print of their super portrait!

Give a gift. Give to Shine!

Shine receives a donation everytime someone purchases a **Shine** card as a gift. Redeemable in over 21,000 stores nationwide and online, the cards are available in two quantities: £10 is donated to **Shine** when you purchase a £50 card; and £5 is donated to **Shine** when you buy a £25 card.

You can buy your card at **W: ShineGiftCard.org.uk!**

Great North Run 2015

Join Team Shine and run in this year's Great North Run on 13th September 2015!

Last year 57,000 people took part – don't miss out on being a part of the action in 2015! Ballot entries now closed – last chance to enter!
Contact Cheyenne Graves T: 01733 421307 or E: cheyenne.graves@shinecharity.org.uk

Shine runners get a FREE **Shine** t-shirt or running vest and sponsorship pack!

Great Eastern Run and 5k Fun Run 2015

11th October 2015 • Start 10:30am Peterborough, Cambridgeshire

Join the Great Eastern Run and run a half marathon or the 5k fun run for **Shine!** This course is flat and fast and suitable for wheelchair users.

Visit **www.perkinsgreateasternrun.co.uk** to sign up. Closing date for entries is 5th October 2015.

Route to Independence

Shine member, Claire Houseman, tells us how direct payments have made a difference to her life.

I feel very strongly about telling my story so that other **Shine** members, who need help with daily living, know about direct payments and where to go for further information.

I lived on a farm with my parents and sister. In 2001 I moved away from home to Cumbria University to study tourism. I sourced a good care agency that assisted me with personal care – I had a brilliant time living the student life and achieving a Higher National Diploma (HND).

Returning home in 2003, I realised that no help was available for me, except from my parents. I contacted my care manager who introduced me and my family to direct payments. (See the box for information about these).

My care manager assessed me as to what I could and couldn't do. I was then allocated about 15 hours a week of funding which I could use to pay for some of my care. These hours have increased over the years following re-assessments and changes in my circumstances. I currently have 37.5 hours worth of funding.

One of my first steps was deciding who I would employ to help with my care. The options were to use an agency or to employ someone myself. I opted to employ someone from the local area, as this let me choose who I wanted.

The only snag to this option is that all of a sudden I became an employer. I had to think about tax, national insurance, sickness and holiday pay, and liability insurance.

Luckily I found that there are organisations that are set up to help with all of this. I use the Independent Living Scheme who have been brilliant all the way. Without their help I would not have been able to complete the wages and legal information.

I now live on my own in a ground floor flat in York. With the combination of four carers and an agency I live a very full and active life. I work two days a week as a visitor receptionist at a museum taking money for admissions - my carers take me in my adapted car, stay with me and then bring me home again. They help me access the gym and go swimming at least twice a week! They help with the everyday things such as personal care, shopping, housework and cooking but the one thing that is very important to me is they enable me to meet up and go out with my friends.

I am Honorary Secretary for North and West Yorkshire ASBAH, attend committee meetings, and help with the activities that members take part in.

Living with spina bifida, hydrocephalus, and epilepsy could so easily stop me from living an independent life, but I have been lucky to have been able to use direct payments – they changed my life!

Want to know more?

To search for details for your nearest direct payment, have a look at their website which has lots of helpful information
W: https://www.gov.uk/apply-direct-payments

Shine's Support and Development Workers will also be able to offer support and information – **T: 01733 555988**.

Commonwealth Fellowship brings hope for Nigeria

Shine has recently enjoyed the presence of three Commonwealth Fellows, Afolabi Fajemilo, his wife, Adewumi, and Badejoko Fabamise ('BJ') from the Festus Fajemilo Foundation (FFF) in Nigeria. Here they share what this experience has meant to them.

Afolabi and Adewumi's son, Festus, was born with hydrocephalus. Unfortunately, lack of immediate medical care such as surgery to insert a shunt, meant that fluid built up in his brain causing damage from the pressure and his head to swell in size.

Festus' parents found it hard to get any information and support, and his condition worsened, seriously limiting his development. Now he needs continuous, complex care. Appalled by the lack of affordable care, inadequate medical facilities, harmful taboos, and negative attitudes about spina bifida and hydrocephalus in Nigeria, Festus' parents decided that urgent action was needed. They joined up with many other families who were facing the same challenges and in 2006, FFF was born.

The opportunity to visit **Shine** brought about by the Commonwealth Scholarship Commission (CSC) Professional Fellowship has enabled them to gain insights into services for people with spina bifida and hydrocephalus, which they will use to develop the work in Nigeria.

The trio have had a busy programme, spending time with members, visiting **Shine** support groups, taking part in events such as the **Shine40Plus** conference and family weekend, and learning about health campaigns such as **Go Folic!**

While here, **Shine** has supported their fundraising and marketing by developing a new logo, promotional leaflet, Facebook page, and website.

Afolabi shares:
'We have learnt so much, which we will use in Nigeria. Most of all, how important it is to sustain the vision, be membership driven, and generate strong support and ideas.

'In Nigeria, there are no benefits, and families affected by spina bifida and hydrocephalus are left alone, exposed to risk, with no support. Many of us simply can't afford the care our children desperately need. Parents bring their children to hospital, to be told they need surgery such as having a shunt fitted, then go away again, because they can't afford it. Delays mean the conditions get worse – often, much worse, and this can be life threatening or can seriously harm a child's development.

'This is a public issue. We need good policies, legal protection, medical facilities, affordable healthcare, and public support to ensure that people with SB/H get the care they need, when they need it. Many people with disability are marginalised and that must change.

'At the **Shine** events it has been great to experience the shared sense of belonging. Before coming here, I thought no-one with spina bifida could survive beyond the age of 30! Now we know that there are probably many people with SB/H over 30 in Nigeria and will work with them to raise awareness and support.'

Festus Fajemilo Foundation
festusfoundation.org
Transforming the lives of everyone living with Spina Bifida and Hydrocephalus in Nigeria
CAC/IT/No.24051

BJ continues, 'The level of involvement of **Shine** members is impressive. It's a close network and you work together to achieve results – that's a big plus! It's not all about money.'

Adewumi shares, 'We've experienced and learnt so much that we will put into practice, such as the **MayBbaby** and **Go Folic!** campaign to prevent Neural Birth Defects.

'In Nigeria, many children die through untreated complications. We need to set up a continence clinic and training for professionals, and will work with a neurosurgeon who is passionate about this.

'If we had a wish list it would be to have sponsorship for a representative from Nigeria to come to the **Shine** 50th Anniversary celebrations!'

Afolabi expressed sincere thanks on behalf of the Fellows.

'We'd like to say a huge thank you! The funding from the CSC, and all the support from **Shine**, is going to make such a difference to the lives of people with spina bifida and hydrocephalus in Nigeria. Thank you, **Shine!**'


Afoloabi and Adewumi meet Benny!


The FFF team get Shine-d!


The Commonwealth Fellows meet Shine Chairman Richard Astle

Shine Family Opp

Children, parents, and partners from all parts of the country took part in the Shine Family Opportunity Weekend in Coventry this Spring – a fantastic weekend event! Part of the Shine Lifelong Opportunities Programme, this event aimed to help parents who have children with spina bifida and hydrocephalus feel more confident and equipped to manage the daily challenges that these conditions can bring – and to have some fun and relaxation along the way!

Here are some snapshots from another great weekend...

ortunity Weekend

Shine's new Health Suite now open

On April 21st Shine's new Health Suite was officially opened in Peterborough, where we shall be holding regular clinics. So we are now ready to start taking referrals.

The idea for the Health Suite arose after our 2011 survey showed that lots of members are not getting regular health checks, and have few opportunities to speak to professionals who understand their conditions.

A visit to the clinic will give you a chance to talk to three **Shine** staff members who are familiar with the health challenges faced by many of you: Gill Yaz will address various aspects of physical health and conduct health checks, Robin Barnatt will look at mental wellbeing issues, and Kathy Allen will consider factors such as coping with daily living, difficulties with cognition and memory, and help that might be available for you.

If concerns come up, we can discuss these in a little more detail, and think about ways of dealing with things that arise, such as looking at activity planning or goal-setting. If it seems that you could benefit from further help, we would be able to support you in contacting your GP, health professionals, or relevant organisations.

The Health Team will also be present at various **Shine** events, including regional support groups to promote awareness of the conditions and their effects, and we regularly hold sessions as part of national events, such as the **Shine40Plus** conference and Family Opportunities Weekends. Further 'Great Minds: Promoting Mental Wellbeing' events are planned, which give members the chance to meet one another and share experiences, as well as learning more about mental health and coping techniques.

To refer yourself to the Clinic, please contact **Shine** on **01733 555988**.

If you would like more details about the Clinic or the Health Team, please contact us:

Gill Yaz, Health Development Manager:
E: gill.yaz@shinecharity.org.uk

Robin Barnatt, Health Development Officer:
E: robin.barnatt@shinecharity.org.uk

Kathy Allen, Occupational Therapist:
E: kathy.allen@shinecharity.org.uk

Planning a Holiday?

It's holiday time again, and for many of us, it's a time to travel and explore new places. Travelling when you have spina bifida or hydrocephalus might need a little more preparation, but for most people it will be possible to get away for a great holiday. Here, Gill Yaz, Shine Health Development Manager, gives some tips to help you prepare.

Destination

For a first trip abroad, or if your health means you need to be within easy travel of certain facilities, such as a neurosurgical centre, pick the country you want to visit, then search the internet for neurosurgery (paediatric if you need something for your child) in the various regions. It will then be easier to pick a resort within a couple of hours travel, should you need such services while on holiday. For example, Spain's large coastal cities all have neurosurgical centres. Long cruises might be fine if your condition is stable, but they can be difficult to get off if you become ill.

Flying

Flying is fine for most people with shunts; if you were told years ago not to fly, it's worth asking again as things have changed. Some people will have been told by their neurosurgeon not to fly for specific reasons.

Insurance

Do make sure your insurance covers you for your existing conditions, and that you give them accurate information about appointments and confirmed future investigations. Don't rely on the European Health Insurance Card (EHIC) when travelling to EU countries; it won't guarantee access to the right facilities, or that staff will speak your language, and it won't help with the extra costs of getting home if you can’t get your flight. Companies such as Freedom Insurance Services – **T: 01223 446914** – may be able to help.

Getting ready to go

You might want to ask your hospital for a copy of your most recent scan on a CD-ROM or a memory stick, so if you need a scan on holiday, they can compare it to your last one. Get any prescriptions you will need ahead of time, with spares, just in case, and a copy of your prescription, should you need to show why you are travelling with certain medicines. Signing up to **Shine Health Home Delivery** might help you get these things ready. You can find out more at
W: shinehomedelivery.org.uk or
T: 0800 023 8857 or
E: info@shinehomedelivery.org.uk

Pack your tablets in your hand luggage, and if you have liquid medicine, put some in a 100ml bottle, clearly labelled, and place it in a clear plastic bag at the airport. Pack some headache tablets, and Imodium (for upset stomachs). If you use ISC (intermittent self-catheterisation), all-in-one kits, with bags, can be convenient.

At the airport

The whole body scanners which use X-rays should have no effect on your shunt, but the magnetic security arches have been reported to reset certain programmeable valves. It is safer to err on the side of caution and avoid airport scanners.You should show your Shunt Alert Card (available from **Shine** on **T: 01733 555988**) and follow the guidelines for people with heart pacemakers.

On holiday...

If it’s very hot, be sure to drink plenty - bottled water is best. Most importantly, have fun!

SAMC update

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

It's almost summer and time to start thinking about how we are all going to spend those glorious days out in the sun, providing that we get some!

SAMC Meeting

The SAMC held their first meeting of 2015 on Saturday 31st January at **Shine** HQ. Former CEO Jackie Bland, Development Manager, David Isom, Health Campaigns Officer, Martine Austin, Health Development Officer, Robin Barnatt, and Executive Assistant, Val Stokes, joined us.

Developments

SAMC priorities: **Shine** has achieved most of what was set out in the current five-year plan, which is great news. One issue outstanding is Independent Living/Housing, which will carry forward to the next five-year plan.

Independence and Employment will be a priority by the SAMC, as people with SB/H can have difficulty in maintaining employment. We discussed several ideas, including how changes in your workplace can affect you, occupational health ignorance, and how volunteering can help in gaining employment. We will keep you updated on progress.

More News

Paul Manning, Lisa Cain, and Heather Doughty all attended the **Shine40Plus** conference in Bristol. I attended the **Shine Family Opportunity Weekend** in Coventry – a fantastic weekend – and met many children, parents, and partners from all parts of the country who all enjoyed the event.

Liz Potts will attend the **Shine Independent Futures** residential event for adult members at Hereward College, Coventry, in May, and Jason Merrill will be attending the **Shine Summer Rez**! In Devon for young people aged 12-16 in August. We have also heard from members raising questions about various issues. It is always good to hear from members so keep them coming!

Finally… a special thank you

On behalf of the SAMC I would like to say a fond farewell to CEO Jackie Bland who left **Shine** in May, and to thank Jackie for all the support that she has always given to the SAMC. Special thanks also to Lyn Rylance who has given **Shine** many years' service and also retired in May.

As always feel free to get in touch via the link below.

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

This is Me

By Nic Shaw, Shine's Youth Work Coordinator

Now that the holidays are approaching, I'm really looking forward to getting out in the sun and having some fun! From the chats that I've been having with some of you guys over Facebook, it seems like you have had the same idea!

Summer Rez

Summer Rez is going to be happening on August 10th-13th. The venue at Hannah's in Seale-Hayne, Devon is brilliant! I've been there a few times and am always surprised at the stuff that you can get involved with. If you are not signed up on that trip, get yourself on it, it will be a blast!

Shine Coffee Project

This summer whether you live in England, Northern Ireland or Wales, **Shine** wants to get a coffee project in your area, to meet up with each other, hang out and have a laugh! To get involved, you can:

1. Respond to a **Shine Youth Council** member's advert on Facebook
2. Send me a message on Facebook
3. Write, 'I want a Coffee Project' on the **This is Me** Facebook group page

ScottishPower Foundation gives a boost to Shine's Youth Council

The ScottishPower Foundation, which supports charitable work throughout Britain, has given a generous donation of £9,779.65 to support the **Shine Youth Council** this year. This is fantastic news! I am so excited to see what this grant will help us do - in teaching and developing young leaders within the **Shine Youth Council**, and providing a better service and new events for **This is Me** members as a result.

The ScottishPower Foundation grant will enable each of the council members, who live in different parts of the UK, to meet together. The passion of these young leaders is very evident and it's so important to be able to meet in person, to encourage, enthuse and then 'send them out' with a fresh vision of how they can use their experience to help other young people with spina bifida and hydrocephalus.

Watch this space!

Foundation SCOTTISHPOWER

T.I.M - the mascot

I promised to give you an update, so here's the latest from our furry friend!

'How the weeks whiz by! My ninja skills have improved considerably, my speed has improved to the point of being insane and I still love to use my claws. Now I'm looking to improve on my climbing skills, and am discovering new ways to wind up the dogs in the yard and do a runner!

If I don't get to see you before, have a puuurfect summer and don't eat too many mice!'

Europe Tour by Motorcyle

Shine member Mandy Smith explains why being six inches off the ground and 'on the wrong side of the road' for 4,000 miles can be a good thing!

I am a wheelchair user with spina bifida, hydrocephalus, a colostomy, and catheter.

In 2003, my husband and I decided to do a camping tour of Europe on our Goldwing motorcycle and sidecar. After many months of planning we set off in June 2004. We lived in West Wales at this time and it was off to Southampton for the 36 hour ferry crossing to Bilbao in northern Spain. The crossing was a bit rough at night but otherwise OK. This was my second time in Spain on the bike – being six inches off the ground and on the wrong side of the road was quite challenging! By 8am we were off the ferry and had started the 540 mile journey to my parents' villa near Murcia, where we arrived in the early evening. We spent a week there lazing in the sun and eating and drinking.

It was soon time to pack up the bike and head off. We travelled north on the east coast and in the late afternoon started looking for a campsite as we had not booked any! Then we travelled through Spain into France, northern Italy, and Austria, where we stopped for a few days before going onto Germany and the Czech Republic, where we spent five days for a meeting with bikers from all over Europe.

Then back into Austria for another bike meeting. Five days later, and with a punctured air bed, we started to head for home, going back through Germany and heading for Belgium. (We saw some of the Netherlands as hubby took his only wrong turn of the tour WITHOUT sat nav – impressive!) Then we were onto Calais and the ferry home. It was great to be on the the correct side of the road again!

4,000 miles and one month later, what a fab time we had!

For my Grandmother

By Chris Fleming

When we look back and reflect on our journey it can sometimes seem overwhelming to see how far we have come and the trials and tribulations we have gone through to get here. Our success is partly due to the people who have worked so very hard to help shape our lives.

I feel the influence of my late maternal grandmother every day. I am from an Anglo-Irish Catholic background. My grandmother lost her husband during the Second World War and raised five children on her own, refusing to give them up to the orphanage as she had been advised.

She stepped up to the plate again when I was about six years old and the situation with my parents was difficult. She gave me a home when my parents couldn't cope, although at the time it felt like I was being kicked out of the nest and I wasn't very grateful. Her actions in taking me in meant that the family were not completely torn apart and there was no need for Social Services to get involved.

My grandmother was instrumental in getting me into mainstream school which was difficult at that time. I owe her so much. We all need a little help along the path of life and for all our victories need to acknowledge that behind them there was someone special who believed in us.

We'd love to hear from any members over 40 about someone special who has helped in your life. Contact E: angie.coster@shinecharity.org.uk

Shine40Plus National Conference

By Sarah Killick-Sturges

The **Shine40Plus** Conference in Bristol on March 5th was a celebration of our generation, many of whom have survived beyond expectations into middle and older age. **Shine** events offer far more than just information and this was no exception.

Ian Pople, Consultant Neurosurgeon at Southmead Hospital, talked about what to expect as we get older with spina bifida and hydrocephalus. He explained what issues may affect those of us with hydrocephalus – balance, distance, spatial awareness, concentration, executive skills and secondary anxiety, and depression. He looked at what the future may hold, suggesting shunts should be reviewed on a five yearly basis and to have regular eye checks. He suggested asking for a USB stick with our baseline scans on, and a resume of our past medical history to help other clinicians, should we become poorly outside of our home area.

Shine staff led sessions on benefits changes, anxiety and depression, choosing a wheelchair, and looking after legs, feet and tissues. Dr Trudi Edginton, from the University of Westminster, and Robin Barnatt from **Shine** did an introduction to Mindfulness, and Kris Saunders-Stowe from Wheely Good Fitness had a group of us exercising to music with great enthusiasm.

Alison Mahraj, a **Shine40Plus** member, gave a presentation called ‘Dear Body, Dear **Shine**’ which vividly illustrated what it is like to live with spina bifida. There was also a great panel discussion with **Shine**’s Health Team and Dr Trudi Edington on the challenges of getting older.

The whole event was really positive. It showed how we are already making adjustments to our lives to enable us to remain independent, and also what else may be available, should we need it.

It was a wonderful day, for which we each paid very little and gained so much!

You can find out more on Youtube:
bit.ly/AlisonMahraj
bit.ly/IanPople

With grateful thanks to the Freemasons Grand Charity for their support for the Shine40Plus Network.

Planning for the Future

is something we all think about but often never get around to

A bit of thought and financial planning can ensure that you keep control of all you own (your assets). A solicitor can advise you and make the necessary arrangements for you. Here are some things that you may want to think about.

Wills

By making a Will you have the opportunity to decide who inherits your assets, such as your family, friends, favourite charities, or a mixture of these.

We will all die one day. Yet if anyone dies without having a valid Will, what they leave behind won't go where they want it to, but where the government wants it to go. So making a Will can give you peace of mind that what you want to happen after you die will be taken care of for you, especially important if you care for a person who is vulnerable or has a disability.

Probate and Estate Administration

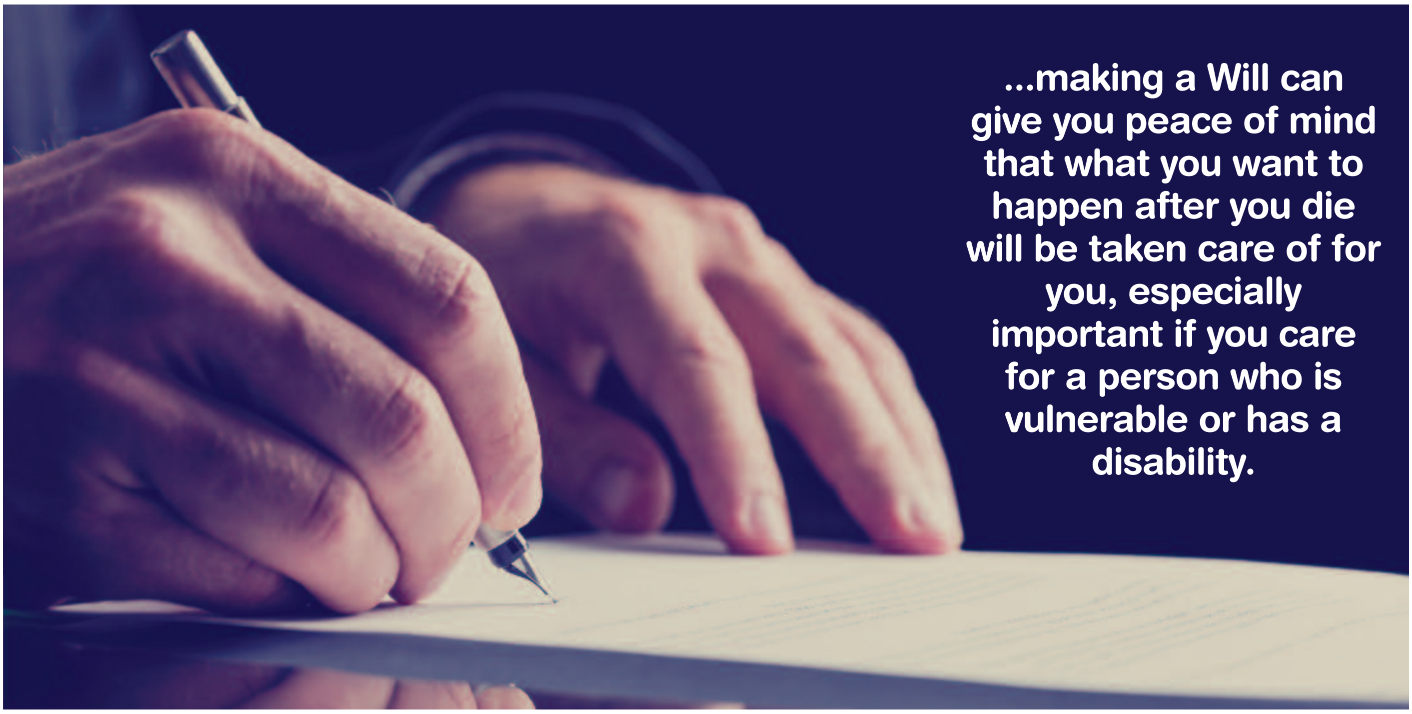
If someone dies without leaving a Will, there is a special procedure to obtain a 'Grant of Probate' so that a family can access the person's assets, but this is more complicated than having a Will.

Trusts

Trusts are a popular arrangement where someone's assets are legally owned and controlled by trustees for the benefit of others, including to benefit charities. Trusts may be created during a person's lifetime or once they have died, following the instructions in their Will.

Care, Capacity and Court of Protection

The Court of Protection, established under the Mental Capacity Act 2005, deals with issues in relation to people who cannot make decisions for themselves because they lack mental capacity. They may be elderly or vulnerable, have a congenital condition, dementia or mental illness, or have had a head injury. Through the Care Act 2014, local authorities have a duty to provide for a vulnerable adult's wellbeing. However, all these issues can be complicated, so it is wise to seek legal advice from an expert if you are not getting what you are entitled to.



...making a Will can give you peace of mind that what you want to happen after you die will be taken care of for you, especially important if you care for a person who is vulnerable or has a disability.

Attorneys and Deputies

Powers of attorney, known as ‘LPAs’ (formerly EPAs) are usually made to give another person authority to act on your behalf should you lose mental capacity. By having an LPA in place, there will be trusted people, called ‘attorneys’ to look after your affairs if you are not able to.

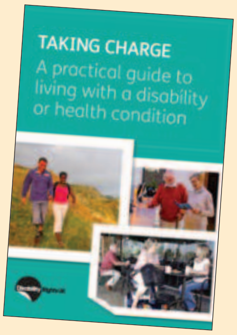
You may make an LPA covering your property and financial affairs, and/or your health and personal welfare. You can also provide guidance for your attorneys and instructions about the actions they can take.

If you become unable to make decisions on your own behalf and have not made a Power of Attorney, a law firm can help your family and friends to apply to the Court of Protection to be appointed as your deputy, though this is more time-consuming and costly than making a LPA.

With thanks to Royds Solicitors of London for their contribution to this article. For more information, Sarwan Ghuman and Tony Millson of Royds can be contacted on **T: 020 7583 2222,**
E: enquiries@royds.com or **W: www.royds.com**
If you are looking for a solicitor near you, the Law Society have a free database and information to help at **http://solicitors.lawsociety.org.uk/**

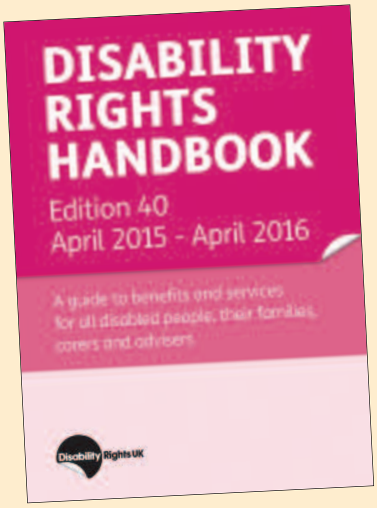
Royds Solicitors

New guides on benefits and disability rights



TAKING CHARGE
A practical guide to living with a disability or health condition

Disability Rights UK provide information and guidance for disabled people on accessing good services and support, including education, work, independent living, benefits and health services, and what to do if services fall short. DRUK has just published a new guide on the rights that anyone living with a disability or health condition should expect from services, education and employment, and what to do if services fail to meet expectations. The guide, called Taking Charge, gives an overview on planning and managing your life, for instance after an accident or diagnosis, or as life changes. It covers aspects such as personal health and social care, technology and equipment, managing at home and with family, travel and mobility, leisure and sport, and learning, working and contributing. The guide costs £13.99 and complements the new 40th edition of the Disability Rights Handbook, which costs £18 if you receive benefits. For more information contact:
W: www.disabilityrightsuk.org
T: 020 7250 8181 or
E: enquiries@disabilityrightsuk.org



DISABILITY RIGHTS HANDBOOK
Edition 40
April 2015 - April 2016
A guide to benefits and services for all disabled people, their families, carers and advisers
Disability Rights UK

By having an LPA in place, there will be trusted people, called ‘attorneys’ to look after your affairs if you are not able to.

Shine Cymru's Sêr Bach group is now one year old!

By Sian Prince

After our inaugural event in Easter 2014, we've met regularly over the last twelve months with trips to Parks, Zoos, and Science Museums in North and South Wales.

It's been fabulous to see friendships forming and is the perfect opportunity for parents to share experiences and knowledge. We're a friendly bunch and would love to see our group go from strength to strength.

An exciting programme of events has been planned for the year ahead.

Shine's Summer Picnic is taking place on August 6th at the seaside resort of Barry Island. Whilst we will pray for sunshine, no matter what the weather there's plenty to keep both young, and young at heart, entertained! We've hired one of the beautiful beach huts for the day. It will be a perfect meeting point for everyone and a safe location to leave belongings, have a cup of tea and a chat, before exploring what Barrybados (as it's locally known!) has to offer.

We're also planning an exciting event in the Autumn for families in the Devon/Cornwall area and are hoping to replicate the **Sêr Bach** group by establishing our **Shine Little Stars** group.

Look for us on Facebook: **Shine**'s **Sêr Bach** group. New members are always welcome, no matter where in the UK you happen to live.

For further details contact Sian Prince on
E: sian.prince@shinecharity.org.uk or
T: 02920 813847

Shine Cymru fundraising events not to be missed in 2015!

Like rugby? Like to be entertained?

Phil Steele, BBC Wales' Scrum V Pitch-Side reporter and well-known after-dinner speaker, is supporting our fundraising in Wales.

4th July – Phil will be Guest Speaker at the North Wales **Friends of Shine Cymru**'s annual dinner and charity auction at the St George's Hotel in Llandudno.

Tickets are £25 each. Contact Graham Catherall on 01352 752890 for information and tickets.

24th September – 'Phil Steele's World Cup' – an evening of songs and stories from rugby nations around the world to mark the start of the Rugby World Cup, featuring the award-winning Bridgend Male Voice Choir, Phil, and some of his famous rugby friends.

Tickets are £20 each, including light refreshments. Contact Sian Prince on **T: 02920 813847** or **E: sian.prince@shinecharity.org.uk** to purchase your tickets.

Shine runs a number of support and social groups for children, young people and adult members across Wales, England and Northern Ireland – in a place near you or via a Facebook group. If you are interested in joining one of our groups, contact **T: 01733 555988** or **E: info@shinecharity.org.uk**

Inaugural World Birth Defects Day

By Mark Simpson

The First World Birth Defects Day was marked in Northern Ireland by a joint event with Rare Diseases Day. The event took place in the Lough Erne Resort in Enniskillen.

Shine's Cathy McKillop presented information about spina bifida, and Martine Austin, our Head of Prevention, presented on the importance of folic acid. The event was opened by Gerard Guckian Chair of the Western Health and Social Care Trust and in his address he also mentioned the importance of folic acid. When taken at least three months before conception and until at least the first three months of pregnancy, folic acid can greatly reduce the risk of Neural Tube Defects.

'This was a great opportunity to speak at an event which was attended by healthcare professionals, patients/clients, carers and researchers.'

On the evening before, an event was held for **Shine** members in the Westville Hotel in Enniskillen. Marie McGonnell and Martine Austin spoke at this event.

Changes in SEN

Sometime ago the Department of Education and the Northern Ireland Assembly conducted a review of Special Educational Needs (SEN). The Special Educational Needs and Disabilities Bill is expected to become law in 2016-2017 and will change how the support and resourcing of children and young people with disabilities in education is processed and resourced.

Along with representatives from several voluntary organisations in the Children with Disabilities Strategic Alliance, **Shine NI** Education Adviser, Catherine McCurry, has presented concerns about some of the inclusions in the Bill to the Education Committee, on behalf of **Shine** and our service users.

We will keep you informed of progress and any implications, and how you can best advocate on behalf of the child or young person in your care, with support and information from **Shine**.

In the meantime, it is very important to follow in detail all current Statements of Special Educational Need, and the Statutory Assessment Process which facilitates them being drafted.

If you have any queries or require further support with this, do contact Cathy on
T: 07789 616486 or
E: catherine.mccurry@shinecharity.org.uk.
No concern is too small, so lift the phone or send an email!

Benny's Blog

Hello Benny Members,

I was soooo excited when I was asked to write a small piece for TOGETHER! I feel like a proper 'author' now, writing in a real magazine.

I know many of you already read my regular postings on **Benny's Blog**, but I thought it would be nice for you to tell your friends how they can become a Benny Friend too! Just ask a grown up to log onto **Shine**'s website and complete and return the Benny Membership form – simple! Members receive a miniature Benny Bear and a birthday card each year and Benny picks a Birthday of the Month, each month – so it could be you! Keep reading my blog, **www.bennysblog.co.uk** to keep up with all the news, fun activities, and healthy eating tips.

Like many of my members, I have hydrocephalus too. When I was only three weeks old, I had a shunt fitted to help me feel better. I have several books written about me to help children understand hydrocephalus. I am really proud of 'Benny Gets Better' and proud of myself too. I have had lots of hospital appointments and learnt so many long and strange words from the Doctors. Words like: Neurosurgeon, MRI scan, shunt and of course, hydrocephalus – but all of these are explained in my little book. Daddy said I am extra clever as I have learned to speak Greek too! 'Hydro' means 'water' in Greek, and 'Cephalie' means 'of the brain' in Greek. Amazing!

Do you remember my friend Bella who was born with spina bifida? She is doing really well and out of hospital now and I cannot wait to introduce her to you all. I am hoping that she too may have some Bella Books, which would help children with spina bifida understand their condition too. I think she is a little too young to be an 'author', so as a very experienced 'author', I may have to help!

I have had lots of fun meeting members and children in school and at **Shine** events. I have visited many schools, been on Teddy Bears Picnics, opened supermarkets, and cheered on the Brentford football team! Having hydrocephalus doesn't stop me doing everything I want to do – but oh, one thing, I must remember to keep 'hydrated' by drinking water.

If you have ideas about what you would like me to write about, where to visit, or to tell me about what you have been doing, I would love to hear from you!

Until next time, 'Be Brilliant'!

Benny

STOP PRESS!

We are delighted to have received a cheque for £11,848 from the DM Thomas Foundation for Young People (formerly known as Hilton in the Community Foundation) to pay for new Bella Bear resources and the new 'Benny and Bella Club' – more about this in the next issue!

Gobi's Gossip

Hey everyone! It seems like an age ago since my last update and, as always, there's plenty of gossip to pass on to you all!

Since the last issue of *Together*, there's been a number of events (and non-events!) that have been taking place in the world of **Shine**.

Firstly, I was expecting to have had surgery back in the Spring, which didn't happen (very frustrating!) but at the time of writing I've finally been given a date for surgery, which is a massive relief, and am hoping to be well on my way to a full and long awaited recovery before my next lot of ramblings!

Despite the health niggles, I've been cracking on with my **Shine** duties. I've had a Matchday collection at Burton Albion F.C, and Brentford F.C, visited Caddington Village School, and Tring School, and have met up with members in the West Midlands, including Gemma Caldwell, Em Lifford and Lyn Townsend (who is taking part in the **Shine Megacycle Festival** this July!).

The Matchday Collections have been a first for me and **Shine**, and have proved to be great days for awareness and fundraising. Whilst the clubs aren't the biggest names in football, they provide great opportunities to reach thousands of supporters leading up to a match, as well as at the match itself. Hopefully these connections will be long-term and not just for a one-off bucket collection. I hope to get other clubs on board, which will really help to spread the word about **Shine**.

Talking of Birmingham, I was fortunate to take part in the Para-Badminton demonstration at the Barclaycard Arena during the annual All England Badminton Championships. Better still, I took part in my first tournament since February 2014, when I played in the Herts Para-Badminton Championships at Sir Frederic Osborn Sports Centre (Welwyn Garden City) in April. I took part in the Doubles and Mixed Doubles events, and came away with a Silver and Gold Medal respectively! Get in!

At present I'm looking forward to an event at Lonsdale School in Stevenage where our Herts members, and also students and parents from the school who have SB/H, can come along and get together. This may also lead to some exciting plans for **Shine** to form a partnership with the school, which has amazing facilities. Watch this space!

STOP PRESS!

We're delighted to report that Gobi has had his surgery and is recovering well!

Shine's Lifelong Opportunities Programme 2015

Shine's Summer Rez!

Monday 10th August – Thursday 13th August 2015

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

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

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

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

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

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

Reg Charity No 249338

Shine's Lifelong Opportunities Programme 2015

Google Hangout Programme

June 2015 – September 2015

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

Wednesday 3rd June 2015
Men's bladder and bowel issues

Wednesday 10th June 2015
Women's bladder and bowel issues

Friday 10th July 2015
Hydrocephalus issues – ETVs, shunts and effects on thinking

Monday 3rd August 2015
Spina bifida and tethered cord issues

Friday 4th September 2015
Shunt talk

Tuesday 22nd September 2015
Friendships and relationships

NB: Dates subject to change; to confirm details, contact Robin Barnatt at least two days before stated date.

Contact Robin Barnatt for further details, and to receive an 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

CITY OF LONDON

Working in
partnership with
City Bridge Trust

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

Healthy Living Skills Workshop

Wednesday 22nd July 2015
10:30-15:30

Venue: Motability Operations,
City Gate House,
22 Southwark Bridge Road,
London SE1 9HB

Topics to include:

- Lifestyle
- Diet
- Fitness and exercise
- Wellbeing

Cost: £10 per head to include a buffet lunch and refreshments

Please contact Joanne Tailor by 14th July 2015 to book a place.
T: 01959 534618 E: joanne.tailor@shinecharity.org.uk

Reg Charity No 249338

Other events coming up soon:

New **Shine** events are regularly created, so see **W: shinecharity.org.uk/events** for information. Here are just a few below, with the person to contact in **Shine** for more information:

Shine in the South Family Afternoon and Teddy Bear's Picnic, Brooklands Pleasure Park, Worthing, Sunday 5th July, 2pm, contact **E: joanne.tailor@shinecharity.org.uk**

Great Minds, Taunton, Friday 18th September (time and venue to be confirmed) contact **E: robin.barnatt@shinecharity.org.uk**

Shine NI Day trip to the Zoo, Wednesday 12th August, 10.30am
E: pamela.dickey@shinecharity.org.uk or **T: 07816 966863**
or **E: dolores.black@shinecharity.org.uk** or **T: 07816 966866**

Shine40Plus Health & Wellbeing Event, Thursday 8th October, Sports Wales National Centre, Sophia Gardens, Cardiff. For further details, contact Sian Prince, Regional Co-ordinator, Wales and South West England, on **E: sian.prince@shinecharity.org.uk** or **T: 02920 813847**

Family Fun Day, Newquay, Cornwall, October 2015 (date and venue to be confirmed). For further details, contact Sian Prince on **E: sian.prince@shinecharity.org.uk** or **T: 02920 813847**

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