Inside: Nominate now for the 2014 Shine Awards

Together

Issue 13

Wear Yellow and Shine

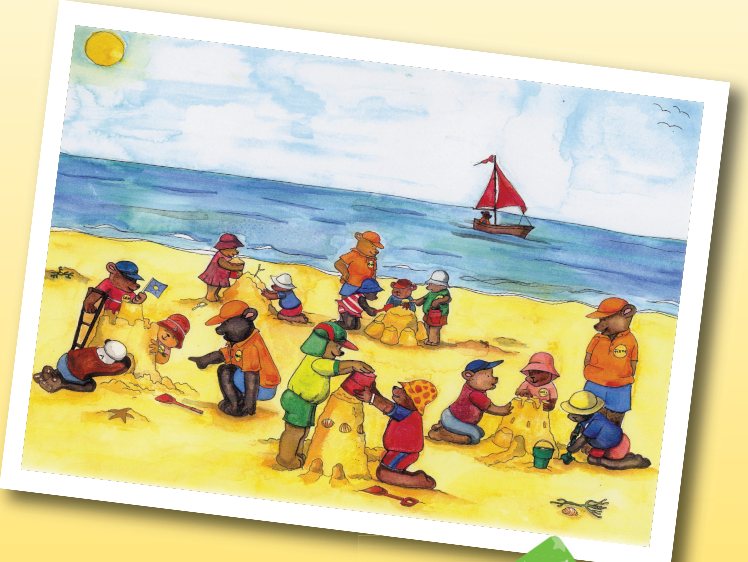
Introducing – new 32 page design!

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

BIG LOTTERY FUND
LOTTERY FUNDED

Name Benny Bear's friend

– competition results



Bella is beautiful!

We have the results from our '**Name Benny Bear's new friend**' competition! In the last issue of *Together,* Benny Bear let us know of his exciting news…that his Mummy's friend is expecting a little baby girl bear with a special condition called spina bifida. He asked his Benny Bear Club members to help him choose a name.

We had a fantastic response with lots of wonderful names to choose from but **'Bella'** was the favourite. The names of all the children who chose **'Bella'** were put in a hat and four winners were pulled out.

They are:

Scarlett from Herts - who wins a £30 Toys 'R' Us voucher.

Sebastian from Coulsdon, Job from Worksop, and **Ben from Fallowfield** who win one £10 Toys 'R' Us voucher each.

CONGRATULATIONS and watch out for more news on baby Bella in the next issue of *Together.*

Glossary of Terms

An explanation of some of the acronyms you might find in *Together*. If there are anymore you find that you'd like to know about, just email us! **E: together@shinecharity.org.uk**

AGM	Annual General Meeting
CEO	Chief Executive Officer
CSF	Cerebral Spinal Fluid
DLA	Disability Living Allowance
DoH (or DH)	Department of Health
DRC	Disability Rights Commission
DVLA	Driver and Vehicle Licensing Agency
DWP	Department of Work and Pensions
EHCP	Education, Health and Care Plan
ESA	Employment and Support Allowance
FAQ	Frequently Asked Questions
GP	General Practitioner
HAC	Health Advisory Council (**Shine**'s)
HMRC	Her Majesty's Revenue and Customs
HQ	Headquarters
ICP	Intracranial Pressure
ICU	Intensive Care Unit
IIH	Idiopathic Intracranial Hypertension
JSA	Jobseeker's Allowance
MP	Member of Parliament
NHS	National Health Service
NI	Northern Ireland
NPH	Normal Pressure Hydrocephalus
NTD	Neural Tube Defect
OT	Occupational Therapist
PIP	Personal Independence Payment
SACN	Scientific Advisory Committee on Nutrition
SAMC	**Shine** Adult Members Council
SB/H	Spina Bifida and/or Hydrocephalus
SBO	Spina Bifida Occulta
SCI	Spinal Cord Injury
SDW	Support and Development Worker
SEN	Special Educational Needs
SIA	Spinal Injuries Association
TIM	This is Me (**Shine**'s club for 11-18 year olds)
UC	Universal Credit
VP (shunt)	ventriculoperitoneal
WWY	Winners Wear Yellow
WYAS	Wear Yellow and Shine

CONTENTS

Together Editor: Tom Scott
Deputy Editor: Sam Lyons

All enquiries and comments to:
Together **Shine**, 42 Park Road,
Peterborough, PE1 2UQ
Telephone: 01733 555988
Textphone service: 01733 421395
together@shinecharity.org.uk
www.shinecharity.org.uk
Registered Charity No. 249338

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

Submission dates for summer edition

- **Register of interest to submit:** 15/08/14
- **Final date for submissions:** 29/08/14
- **Publication date:** October 2014

Cover photo: Maya **Taken by:** Tom Scott

We Need You!

Well! We have so much included in Issue 13 of *Together* that we've had to extend it to 32 pages!

As well as the regular news, education, health, SAMC, and events information, you can read about the results of the competition to name Benny's friend (page 2), some of our amazing London Marathon runners (page 18), and the latest youth information from the *This is Me* Club (page 29).

I was delighted to attend Oundle Primary School for their Wear Yellow and Shine event in May

In our two magazine features you can learn about *Mindfulness* from Dr Trudi Edington (pages 8-9), and **Shine** member Joanne Truby tells us about her flourishing floral design business on pages 20-21.

The only thing left to say is that 'We need you!' There are several pieces which ask you to get involved: on pages 6 and 7, we ask you to consider joining the **Shine** Board; you can nominate those you know for the **Shine** Awards (pages 10-11); and, although October may seem a long way away, we need you to pull out the poster on page 16 and get everyone you know to Wear Yellow and **Shine** in 2014!

If you have any news, photos, or stories you would like featured, or if you have any ideas for improving *Together*, then please just get in touch!

Keep **Shine**-ing!

Tom Scott

E: together@shinecharity.org.uk

FRSB give with confidence

Education in England – changes ahead

The Government is changing the way children's education needs are assessed

From September 2014, a child's 'Statement of Educational Needs' will transfer to an 'Education, Health and Care Plan' (EHCP). Your school or local authority, depending on where you live, will have three years to transfer your child's existing statement into an EHCP.

The aim of this change is to improve the cooperation between all the services that support children and their families, in particular, requiring local authorities and health authorities to work together.

The new plan will include young people up to the age of 25.

Support for the changes

At **Shine**, the Education Advisers, and Support and Development Workers (SDWs) will be following the changes. We will continue to support families with our free advice and information service, and will monitor how the changes may affect children and young people in education.

If you have any questions or experiences you would like to share with us, please contact:

Naomi Marston E: Naomi.marston@shinecharity.org.uk
Joanne Grenfell E: Joanne.grenfell@shinecharity.org.uk
Sharon Saville E: Sharon.saville@shinecharity.org.uk

Know your benefits

Accessing support and information for parents of disabled children

Since the introduction of changes to benefits by the UK government, parents tell us that they need information on the types of benefits they are entitled to, and help with completing benefit forms or letters to support benefits applications.

The charity **Contact a Family** has published a comprehensive range of information on a wide variety of issues for parents of a disabled child, outlining the benefits they are entitled to and services which can help them, their child and their family.

Visit W: cafamily.org.uk/know-your-rights

Social media

Connect with us!

Here at Shine, our social media channels are constantly buzzing with news, messages of encouragement, and great photos. Here is a selection from recent weeks:

Benny Bear and a young Shine member fundraise by POUTING for Shine

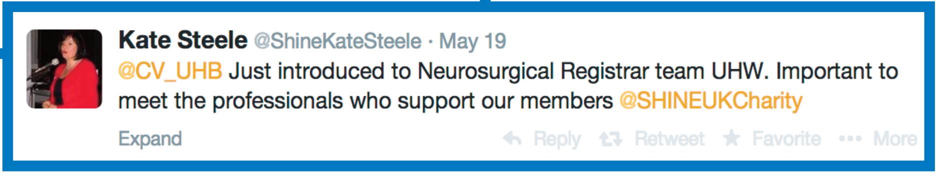
Shine young adults learn cooking skills at our Independent Living weekend

'Just wanted to share with you guys (at **Shine**), Maya walking with her Kaye walker at 2 years and 7 months!! Thank you all so much for your love, support, information and advice over the past 3 years. You helped make this happen!!! Forever grateful xxx' – *Facebook post from a* ***Shine*** *member.*

'After joining in (one of Robin's Google Hangouts), I realised that there was nothing to be sceptical about as it was an amazing chance to speak to and hear from other people living with the same or similar disability.' – *Facebook post from a* ***Shine*** *member.*

'Broken toes didn't stop me, a dislocated shoulder isn't stopping me, so I'm sure a bit of rain won't stop me. I will defeat total warrior for my baby India and **Shine** Charity – sponsor me if you can.' – *Facebook post from a* ***Shine*** *fundraiser training for an extreme assault course.*

Kelsey Plant Hire @KelseyPlantHire · May 13
#SO for my husband @aceverest climbing to the summit of Everest 2015 and raising money for @SHINEUKCharity. bit.ly/1hD6uKs



Kate Steele @ShineKateSteele · May 19
@CV_UHB Just introduced to Neurosurgical Registrar team UHW. Important to meet the professionals who support our members @SHINEUKCharity
Expand

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...

7,000 **14,000**

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

Do we have your correct email address?

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

Board seeks new members

At Shine's AGM in 2012, new governance arrangements were agreed making Shine a more democratic and representative organisation. In 2013, the first three Directors were elected by the membership and we now have three further vacancies.

One of these positions is reserved for a member from Northern Ireland as the current representative is standing down. As we already have a member from Wales, the remaining two vacancies can be filled from any of the countries in which we work.

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 is stimulating, interesting, and sometimes even fun! The position has the potential to be both rewarding and challenging.

A range of skills

Shine aims to have a Board whose members cover the broad range of the charity's activities, either through their expert knowledge, direct experience, or both. So, for example, we would hope to have parents of a range of children of different ages; a young person with SB/H under 25 years of age; and directors with social care, health, legal, HR, business experience or other skills that may help **Shine** meet its objectives.

There is also an aim that at least 50% of the Board should have spina bifida and/or hydrocephalus, and we would particularly welcome expressions of interest from members with the conditions who can also bring additional skills and experience.

Events and meetings

Board members are expected to attend four meetings per year in Peterborough and travel/subsistence expenses are paid. In addition to this commitment, there are opportunities for Board members to get involved in other events/initiatives and to apply their specialist skills/experience/expertise where appropriate. We are very grateful to all those willing to serve, or consider serving, on the Board.

Want to know more?

Anyone interested is very welcome to contact either **Jackie Bland** or **Margaret Conner** for an initial informal discussion or email exchange. If you then wish to pursue this opportunity, we will ask you to submit a letter of application outlining your skills and experience.

October election

Suitable candidates will be invited to meet the Chair of the Board, Chief Executive, and other senior staff or trustees to further discuss the requirements of the Board, your skills, and what you can offer **Shine**. Candidates who meet the skills set will be included in the election to be held this October, with the outcome announced at the AGM in November 2014.

‘Being a board member is about being able to give something back to a fabulous charity.’
Katrina Grounsell, trustee

‘It is a fulfilling role, contributing to good Governance and direction in a professionally run and worthwhile charity.’
Yvonne Lindsay, trustee

Chairman of the Shine Board, Richard Astle, Peterborough businessman (right) with our Patron, Danny Mills

Being a member of the Board is stimulating, interesting, and sometimes even fun!

‘Being a Shine board member is both a responsibility and a privilege.’
Greg Smith, trustee

Shine’s Honorary Treasurer, Aidan Kehoe (left), and Trustee, Paul Zickel, examine a shunt at the 2013 Shine Awards

To register interest

Please contact either Jackie or Margaret on T: 01733 555998 or E: margaret.conner@shinecharity.org.uk / jackie.bland@shinecharity.org.uk

Mindfulness

You may have come across the term ‘mindfulness’ recently and wondered what it is all about. The word seems to be applied to a variety of different topics including meditation, exercise, food, work, and education.

Members who attended the **Shine50Plus** conference earlier this year (see pages 26-27) are more familiar with the term, thanks to Dr Trudi Edginton, Senior Lecturer of Cognitive Neuroscience at the University of Westminster, who was a main speaker at the event. Trudi’s presentation stirred up a real interest in mindfulness, leaving many **Shine** members wanting to practice it themselves.

***Together* Editor Tom Scott visited Trudi recently to find out more...**

Mindfulness is said to change the way we think, feel, and act[1]. It is a process in which the person practising mindfulness is encouraged to increase their awareness of one moment becoming another moment, enabling more consciousness of thoughts, feelings, bodily sensations, and the surrounding environment.

Trudi begins by explaining that mindfulness is not a single thing, but ‘a collection of techniques which people can use to become more aware of the present moment’. This idea of becoming more involved in what is happening in the here and now is central to this way of being. Trudi elaborates: ‘By either thinking of the past or focussing on the future, we may not actually experience the present moment. So, mindfulness is about coming back to the present moment and trying not to worry about the future or focus too much on the past.’

Misconceptions

As with any new concept which sweeps the world via the internet, there are versions of mindfulness which have strayed from the original purpose. According to Trudi: ‘One of the most common myths about mindfulness is that you have to empty your mind – that’s actually quite difficult to do – and you don’t have to relax either.

‘Through the self-awareness mindfulness brings, we can realise that we aren’t actually our thoughts; for example, having a negative thought doesn’t have to define you … It’s all about choice and awareness, and paying attention, as opposed to emptying your mind.’

Further to this, there is the idea that mindfulness is intended to bring about a nirvana-like experience, but Trudi is keen to correct this misconception:

‘Mindfulness is very much about being, not striving, not trying to change anything, but just being aware of things. It’s very … very accepting and just about managing your experience on a day-to-day basis; it’s quite a gentle approach and this often surprises people when they come to it.’

To find out more about mindfulness, and to watch the full film of this interview with Trudi, please visit: shinecharity.org.uk/mindfulness

[1] bemindful.co.uk

The benefits of mindfulness …

Awareness of feelings You actually become aware of your everyday experience, your thoughts, and your feelings – it's amazing how much passes us by that we're not actually aware of.

Mindful eating To really pay attention in the moment of eating allows you to truly experience the whole range of different tastes, smells, and textures, and the feelings, thoughts, and memories associated with what you're eating.

Emotional perspective As people, we tend to either focus on an emotion, or to block out emotions. Mindfulness allows you, when you're ready, to encounter those emotions with choice. This brings a sense of perspective so that you can actually regulate your emotions and thoughts.

Managing pain and discomfort Mindfulness, as a technique, can also be really effective for the management of pain, discomfort, and distress, and obviously for people with hydrocephalus and spina bifida, there are times when managing these effectively are important. 'Bringing the breath' into those parts of the body to soften those areas and explore that sensation, doesn't necessarily mean the pain will just disappear, but it does bring a different relationship to pain and discomfort. After a while, with these techniques used regularly, mindfulness can be really effective for lots of people in terms of managing their pain and discomfort.

Mindfulness – real change

In response to those who are sceptical about techniques like mindfulness, thinking they are a bit 'out there' or unscientific, Trudi points out that research is proving its real effects.

'Mindfulness interventions are linked to very real changes in the brain itself, and the particular parts of the brain that change and grow are the ones that help us with our emotional wellbeing.'

In addition to this, she says, regular mindfulness practice can also lead to a reduction in some of the stress hormones in the body, and this reduction can in turn strengthen your immune function.

When mindfulness may not be appropriate

One important, and sometimes neglected, factor is that there are times when mindfulness might not be right for you at a particular time in life. As Trudi explains: 'If someone is feeling very depressed, it might not be the right time for mindfulness when difficult emotions or thoughts might be arising, so it's important to have effective guidance and support if you are thinking of trying mindfulness - there are lots of very good mindfulness instructors and courses available.'

Here is a link to the books of Jon Kabat-Zinn who is responsible for bringing mindfulness to the Western world: http://bit.ly/jonzinn

Mindfulness and hydrocephalus and spina bifida

Through her work with people with hydrocephalus and spina bifida, Trudi and her colleagues are very aware that some people experience memory difficulties, problems with organising, and planning ahead. Interestingly, Trudi says that this can sometimes lead to people experiencing high levels of anxiety...'It can be difficult to feel confident and comfortable if you're not quite sure what is going to be presented to you in the future.'

The **Shine** members to whom Trudi has introduced mindfulness have found it really beneficial. She says they report 'feeling quite grounded and comfortable with their body, and became comfortable with some of the experiences they had in the moment, so it can be a useful technique in terms of managing stress and negative emotions.'

Accessing mindfulness

To find out more about mindfulness, and to watch the full film of this interview with Trudi, please visit: shinecharity.org.uk/mindfulness

Shine Awards

Who will Shine in 2014?

The 2014 Shine Awards will be made at the Annual General Meeting on November 20th this year and the search for nominations is on!

These awards are a way for **Shine** to show its appreciation and gratitude to the people who contribute to its community in so many different ways. As you can see from the photo below of Toni Allen-Bewley receiving her **Shine** Young Achiever's Award at last year's ceremony, the winners are delighted to be recognised in this way.

Who would you like to nominate?

To nominate someone for an award, please fill in the following form, making sure that you complete all the details, and return to us by Friday 15th August. **If you prefer, you can go straight to www.shinecharity.org.uk/shineawards and complete the nomination online.** You are able to make a nomination for more than one award.

Whatever you do, please make sure you nominate someone who really deserves to be recognised. If your nominee is chosen, you will receive an invitation to come and see them receive their award.

Toni Allen-Bewley receiving her Shine Young Achiever's Award in 2013 (pictured with Shine Patron, David Proud)

Award Categories

There are four award categories for which **Shine** members can send in nominations. Please think carefully about anyone whose work or contribution merits a nomination by following the guidelines below. The categories are:

Shine Volunteer of the Year – do you know someone whose voluntary contribution is outstanding? Someone who goes the extra mile? Someone who has willingly given their free time to really make a difference to others?

Shine Young Achiever – this Award goes to a young person between the ages of 10 and 25 who is a real achiever in one or more areas of their life.

Shine Professional – is there a professional who you think has distinguished themselves in the world of spina bifida and hydrocephalus, whom you think deserves recognition for their work?

The John and Lucille Van Geest Award for outstanding contribution to the Shine Community – this award goes to a person of any age with spina bifida and/or hydrocephalus who has helped to make our community – at local or national level – a better place.

In addition to these open Awards, a **Shine** panel of judges will decide upon the recipients of the awards for Fundraisers of the Year, and the coveted Lifetime Contribution Award.

2014 Shine Awards Nomination Form

YOUR DETAILS:

Title: Mr/Mrs/Miss/Ms/Other ________ Full Name: ________________________________

Email: ________________________________ Tel: ____________________

Name of the Award you want to nominate someone for: ____________________

____

NOMINEE'S DETAILS:

Title: Mr/Mrs/Miss/Ms/Other ________ Full Name: ________________________________

Email: ________________________________ Tel: ____________________

Address: ____

____ Postcode: ____________

Please tell us why the person you have nominated deserves this award. Please give as much fact/detail as possible and write no more than 300 words (using additional sheets as necessary):

____

____

____

____

____

____

____

____

____

____

____

Please detach and return by **Friday 15th August to:**
Lyn Rylance, Shine Awards, Shine, 42 Park Road, Peterborough PE1 2UQ
Enquiries to E: lyn.rylance@shinecharity.org.uk

Nail Design of Peterborough, supporting our Go Folic! campaign

Martine (right) and Liz Cook, Fundraising & Communications Administrator, spreading the message on Folic Acid Awareness Day

Folic acid update

Go Folic!

by Martine Austin, Health Campaigns Officer

We have been keenly awaiting a decision, once and for all, by the Government as to whether or not they were going to fortify white flour with folic acid. Frustratingly the promised cut-off date of Easter came and went, with no announcement forthcoming! We have subsequently been informed by the Secretary of State for Health that a decision will now not be made until 2015. Whether the Government decides to fortify or not, we are just anxious for a decision to be made so that we know exactly where we stand in terms of a national long term primary prevention strategy.

Resounding success

On a more positive note, our second annual Folic Acid Awareness Day on 1st May was a resounding success. Building on last year's triumph, this year's event was even bigger and better, with awareness-raising activities taking place across England, Wales, and Northern Ireland. HQ activities were once again supported by local MP Stewart Jackson, Peterborough Council CEO Gillian Beasley, and the SAMC's Jason Merrill. Local retailers supporting this year's event included ASDA, Michael John Hair Artworks, and Nail Design.

Thunderclap campaign

Social media was also buzzing with activity with our **Go Folic!** Thunderclap campaign, reaching over 250,000 people in the two weeks building up to the campaign, and the hashtag #folicacidawarenessday reaching just short of one million people on the day itself! An amazing achievement, and thanks to all who posted, shared and retweeted, posts, messages and pictures.

I would like to say a huge thank you to all the staff, members, and businesses that gave their time and energy to help make the day such a success. A special mention must go to long time supporter Francesca Nield for all her hard work, and Jenni Robbins and her sister Emily who braved the soggy streets of Truro all day to spread the **Go Folic!** word to local women and businesses.

Anyone who is interested in becoming a regional Go Folic! volunteer/ambassador

please contact me on
T: 01733 421349 or
E: martine.austin@shinecharity.org.uk

Progress at last on National Specialised Commissioning

Shine representatives have finally had the opportunity to put the case for adult patients with spina bifida to have a specially commissioned service at national level.

Shine has campaigned vigorously over the last year to have multidisciplinary clinics for people with complex spina bifida provided by the NHS, in the same way that spinal injury centres are provided for patients with traumatic spinal cord injury.

As ***Together*** readers will be aware, many members have written to their MPs requesting that such a service be developed for people with spina bifida, and there has been significant correspondence between **Shine** Chief Executive, Jackie Bland, and senior NHS officials including former Chief Executive, Sir David Nicholson.

> In spite of many attempts to assure **Shine** that patients with spina bifida were receiving an adequate service by accessing support at local level, Sir David Nicholson finally conceded that this was an issue that should be discussed with the Head of Specialised Commissioning for the NHS, Pia Clinton-Tarestad.

Shine representatives, including members of the Board of Directors and professional medical advisers, managed to persuade Ms Clinton-Tarestad that there was a case to be heard, and she agreed that her staff could work with **Shine** to develop a proposal to be put to the ministerial group which makes final decisions on these matters.

Proposal to go to ministerial group

A proposal has now been sent to this ministerial group. It argues that complex spina bifida cannot be adequately supported at local level, because there are too few people who have the condition and not enough experts competent to recognise and prevent serious conditions.

The proposal further argues that it would be too expensive for every local Clinical Commissioning Group to develop services of sufficient specialism. Therefore, nationally commissioned services should be put in place to ensure that people with complex spina bifida should be subject to regular holistic checks in multidisciplinary clinics.

Potential for change

Although the opportunity to present this proposal is a major step forward in the battle to have specialised services for spina bifida, there is no guarantee that it will be approved. If it is approved, however, it would make way for a series of multidisciplinary clinics across the country where relevant experts would be available in one place to see patients, treating them as a whole person rather than a set of separate conditions, and offering much better opportunities for overall management of health.

Introducing our new OT

Shine's health team is delighted to welcome Kathy Allen.

Kathy comes to us with a wealth of experience as an occupational therapist in both children's and adults' services. Kathy has worked for the NHS and social services, and has a special interest in how brain conditions affect our ability to carry out day-to-day activities, which will be especially valuable to us. Kathy comments:

'People often seem to be coping on the surface, but you need take the time to really explore their lives'.

Kathy's role with **Shine** will include helping us develop the new Health Hub (see *Together* Issue 12, page 8), where she will be able to assess our members' needs for training in living skills, equipment, and other areas. She will also help us develop training courses for members around independence and promote our services to statutory services.

Leo uses his walker

Grant for Shine Health

A charitable trust based in Cambridgeshire has donated the first £10,000 to the new **Shine Health** initiative. The initiative aims to significantly expand and raise the profile of **Shine**'s health services throughout the country, as well as creating a 'health hub' at **Shine**'s HQ in Peterborough which people will be able to visit for free health checks and advice, as well as training courses and complementary therapists.

The health hub will include a health suite where examinations can be undertaken by **Shine**'s health staff, and also an independence training area where OT assessments can be done and people can learn the skills needed to live independently.

Creation of a health suite

The first £10,000, donated by the Harry Cureton Trust, will be used to create the health suite, and the first monies raised through the Chairman's Challenge, led by **Shine** Chair, Richard Astle (see www.shinecharity.org.uk/chairmanschallenge), will be used to create a disabled accessible wet-room with shower and toilet.

During a visit by **Shine** Chief Executive, Jackie Bland, to **Shine**'s Patron, her Royal Highness the Duchess of Gloucester, to update her about **Shine**'s plans, the Duchess agreed to open the new health centre sometime during 2015.

Focus on physiotherapy

by Gill Yaz, Health Development Manager

Gill Yaz at a Shine conference

Physiotherapy is a healthcare discipline which focuses on muscles and movement. Physiotherapists are trained to know how the body moves when we're healthy, and how illness, injury, or disability can be improved with targeted exercises. Physiotherapists are also experts in how the brain develops control over our movements from the time we are born. Conditions of the brain, such as hydrocephalus, can delay or alter this development, which then has a knock-on effect on our everyday activities, such as handwriting or dressing.

When a child is born with spina bifida, some muscles may not work because the nerve which controls them is below the spina bifida lesion. This may mean that surrounding muscles are not used and they then become weaker, which in turn can cause circulation/tissue problems like lymphoedema and cellulitis. Advice from your physiotherapist will help keep muscles as active and strong as possible.

Specialist neuro-physiotherapists promote movement through encouraging brain development, and this is particularly helpful for children with spina bifida or hydrocephalus. Learning to move promotes learning in other areas of development, and is especially effective in the first few years of life. Some organisations, such as Brainwave, or Snowdrop Development Trust, can carry out assessments for your child, and set you up with a programme of activities to encourage brain development and movement skills. Unfortunately, some physiotherapy techniques, commonly used in countries such as Germany and the USA, aren't available here on the NHS. Treadmill therapy and Galileo (a technique which uses a vibrating plate to help nerves and muscles work) are achieving great results. Hopefully, we will collect the evidence to get the NHS to offer these treatments.

For babies with hydrocephalus, physiotherapy may help develop head control (which is important for future motor development) if the head is a little heavier than average. Physiotherapists can also develop programmes to help people with poor balance, which is important for people with hydrocephalus or NPH (normal pressure hydrocephalus).

Shine member Maya gets to grips with play and learning at our Family weekend

Physiotherapists can help overcome back, shoulder, and neck problems which people can find an issue after many years of wheelchair use or walking with sticks. Over the years, posture can change, trapping nerves or causing pain. Targeted exercises, with the correct mobility aids, can make all the difference in keeping you mobile and pain-free. Myofascial release is a special massage technique used by some physiotherapists to help with pain arising from postural or muscle problems. Sometimes, the symptoms of tethered cord in older adults can be helped a little by physiotherapy, delaying the need for surgery.

So, explore what physiotherapy can do for you and your family. If you feel you're not getting what you need, ask why not? Keeping your muscles and joints in good condition is so important for your long-term wellbeing, and ensuring your baby's brain development is as good as it can be is an investment in their future that will last a lifetime.

Wear Yellow and **Shine** is a fundraising initiative in which you, your school, college, workplace, or community group commit to wearing yellow for one day with everyone donating to Shine at the same time.

THIS CHARITY NEEDS YOU

TO WEAR YELLOW & SHINE

Launched in 2012, the initiative raised £20,000 last year alone and we know that with your help we can eclipse this in 2014! To find out more, or to sign up, please visit shinecharity.org.uk/wyas or call T: 01733 421351.

We need YOU to Wear Yellow and Shine!

This year you are invited to help **Shine** celebrate its diverse and vibrant community of people with spina bifida and hydrocephalus as we once again **Wear Yellow and Shine!**

In 2013, **Wear Yellow and Shine** events across the country raised £20,000 for **Shine**'s vital services.

This year, we want to double this fantastic amount – with your help!

By getting your school, organisation or community involved with a fundraising event, or by encouraging everyone to pay a donation to dress-down or wear something (or everything!) yellow, you can help **Shine** reach out to even more families and individuals that will benefit from our life-changing services.

So, bake your cakes, blow up your balloons, and pull your (yellow) socks up – it's time to **Wear Yellow and Shine!**

More information

For more information or to register your school or organisation for a **Wear Yellow and Shine** event, please contact us on T: 01733 421351 or E: fundraising@shinecharity.org.uk

Fundraising Pack

Order your **Wear Yellow and Shine** fundraising pack online now!
www.shinecharity.org.uk/wyas

Inspiration and Ideas

Visit our **Wear Yellow and Shine** Facebook page to share your fundraising inspiration and stories, or for hints, tips, and advice on planning your event:
www.facebook.com/ShineWYAS

CUT ME OUT and PUT ME UP at school, work, or in your front room or car window.

Marathon month of fun

April is always a ‘marathon’ month for us here at Shine as we have places in both the Brighton and London Marathons, but this year has been our most successful year to date!

We have had more runners and raised more funds than ever before. We would like to thank our runners and their families for all the months of training and sacrifice that went into the preparation, and for pushing themselves to the edge of their endurance on the day.

We would also like to take this opportunity to remember Robert Berry who died at the end of the London Marathon this year. We are so grateful that all our runners made it to the end safely.

CONGRATULATIONS to you all and we’ll see you all again next year, OK?

Alan and his daughter

Sean

Christos (right) and family

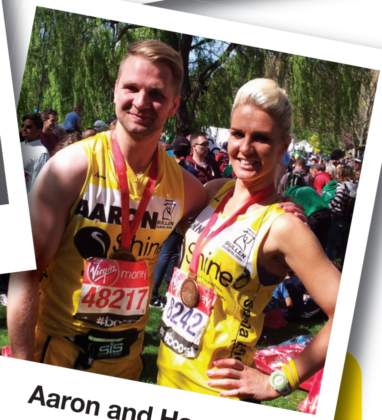
Dawn

Mark

Haydn

Hazel

Sanja



Aaron and Hannah

...a few of our amazing runners

If you are interested in running for Shine (at any distance!), contact Shelley Green on E: shelley.green@shinecharity.org.uk or T: 01733 421307

Chairman's Challenge Countdown

by Richard Astle, Shine Chair

In the last edition of *Together*, my Chairman's Challenge featured in the article about the exciting plans for **Shine**'s new Health Hub.

To celebrate the anniversary of my 10th year as Chair of **Shine** in 2014, I set myself ten active challenges to raise funds for the development of **Shine**'s health services, as I really wanted to show how much **Shine**, and the health of our members, matters to me.

Well, my ten challenges of five half marathons, a 40 mile hike, a Moroccan trek, two 10Ks and a Santa Dash for good measure, are turning out to be quite a … challenge! The good news is that we've hit the halfway mark of the fundraising target with £12,500 now in – fantastic! I'm so grateful to all of those that have donated, participated and supported my challenge – thank you!

Race round-up

So, my first challenge was the Nick Beer 10K in Llandudno, Wales, in February this year. I had run a few 10K races before but the challenge didn't bode well when, with just nine days to go before the race, I was in bed with a lurgy drinking Lemsip! However, race day arrived and I was there, ready to get on with my challenge, joined by my co-runner, Allun Thomas (who has completed 25 full marathons!).

Bright sunshine

The next challenge was the Larne half marathon in Northern Ireland this March, and not having been to Belfast for nine years or so, I was very much looking forward to visiting. As well as the race, I combined my visit with seeing our **Shine NI** team and attending a networking event for young people with SB/H. Despite a terrible weather forecast, I had a nice run along the seafront in bright sunshine.

Richard and his faithful running companion, Benny Bear

Next was the Sheffield half marathon in April – full of drama as the race was officially cancelled due to a lack of water for the runners at checkpoints. However, the good folk of Sheffield turned up with bottles of water to urge us 'Rebel Runners' on – I was utterly full of water by the end!

My latest completed challenge, the fourth of ten, was the Leeds Half Marathon in May which had its definite ups and downs, but I was pleased with my finishing time.

Track my progress

All in all, I am accumulating some wonderfully memorable experiences for a fantastic goal. If you'd like to keep up to date on my remaining challenges, please contact me on the details below.

Richard Astle @athenenoctuara · Mar 22
Sack all meteorologists! Perfect weather for Larne 1/2 marathon and lovely route along sea shore! 1h 47m.

E: running@shinecharity.org.uk to sign up to my newsletter
FB: facebook.com/chairmanschallenge
TW: @athenenoctuara
W: www.shinecharity.org.uk/chairmanschallenge
E: running@shinecharity.org.uk
B: http://chairmanschallenge.wordpress.com/

To donate: www.justgiving.com/thechairmanschallenge14/

Truby amazing!

With a First Degree in Floral Design and Event Management, and her own business which is going from strength to strength, we were incredibly keen to meet Shine Member Joanne Truby to find out more about her blossoming story!

A story of success

News of Joanne's success came initially from **Shine**'s Health Development Manager Gill Yaz, who first met Joanne in the **Shine** clinic which is overseen by **Shine** Lifetime Achievement Award Winner (2012) Dr Richard Morgan, at the Chelsea and Westminster Hospital, London.

Joanne's path to arranging flowers wasn't something that she intended from the beginning: 'I got into the flowers by chance, I'm not going to lie! I love it now, but it wasn't something I had always wanted to do.'

New horizons

Joanne's journey actually started when she took a few months out from her e-commerce work in the retail sector to travel with a friend through South America. The time away was great for Joanne's independence and it allowed her to really focus on the future – it was there and then that she decided that the first step would be to study for a degree.

The rest is history!

Driven by a desire to be fulfilled creatively, Joanne first considered a Visual Merchandising course. However, this course was discontinued and the young, south Londoner was instead offered the chance to study Interior Design. Not confident that her spacial awareness was up to scratch for this course, Joanne continued to read about alternative courses and found Floral Design and Event Management. She applied, got on well with her tutor at interview and, as she herself points out, 'the rest, as they say, is history!'

joannetrubyfloraldesign.com

Since graduating from the degree course, Joanne has used the invaluable experience of working with florists on placement during her studies to launch her own business, *Joanne Truby Floral Design*, a company specialising in creating beautiful floral arrangements for wedding and events.

Flowers in the press

Although only in business for two years, Joanne's beautiful work is already gaining the attention of industry professionals with spreads in *Wedding Flowers and Accessories* magazine, *Perfect Wedding* magazine, and a shortlisted place in the hitched.co.uk breakthrough awards.

Living with spina bifida

Joanne is keen to convey that although she has had a relatively hassle-free experience with her spina bifida, there are times when it can be quite difficult to get help when it is needed: 'The thing I find hard with it is that I'm not in a wheelchair and I don't need to use any walking aids or anything, and in an odd way, I think that sometimes goes against you, because sometimes you do need that bit of extra help … it can be hard to know where you fit in.'

Joanne explains that, for her, it can be difficult to know how much to tell friends because to them she is seen as the same, which she finds great, but sometimes she needs a bit of understanding and this would only come by sharing more about her condition.

Supportive parents

Of course, this is not a concern Joanne has with her parents, and she beams whilst describing the support they have always shown her: ‘My Mum and Dad are brilliant; my Mum’s always had this thing where she wouldn’t mollycoddle me, and personally, I feel it’s done me the world of good.’

‘They give me the support when I need it and they come to my hospital appointments, but at the same time, they know that I’m capable of a lot of things and they don’t want to hold me back.’

...and there clearly is no holding this young lady back! Having chosen to live at home during her time at university to reduce the debt she would be ladened with, Joanne has created a sustainable start to her flourishing career. Her workspace may only be a simple garage – a stone’s throw from her lovely flat – but, nevertheless, Joanne is dreaming big. Her initial plans are to expand her business, especially with the number of events she supplies to, then one day to open her own shop and produce her own floral design book.

A message for dreamers ...

Before we end the interview, Joanne gives a message to any member of **Shine** who has a dream: ‘It sounds really cliché, but if you enjoy doing something and you’re passionate about it, just follow it. Don’t ever think, ‘Oh, I can’t’, because of your situation or anything like that, because you really can – just go for it! It’s simple, but it’s true!’

To watch the full video interview with Joanne please visit shinecharity.org.uk/shinespotlight

Sêr bach

Supporting our under 10s and their families in South Wales

Easter week saw the first get-together of a new support group for our under 10s and their families from South Wales. Not only was ‘Sêr bach’ (which means ‘Little Stars’ in Welsh) an opportunity for younger members and their siblings to meet Benny Bear, make new friends, and have fun at a play park in Cardiff, it also gave parents, parents-to-be, and grandparents the chance to meet up, talk, and share experiences.

Feedback was exceptionally positive from the families who attended, and all are looking forward to this becoming a platform for more regular group support and social opportunities.

If you are interested in attending future meetings, please contact Siân Prince on E: sian.prince@shinecharity.org.uk or T: 02920 813847.

You can also contact Siân if you live elsewhere in Wales and would like to know more about possible activities in your area.

Sêr bach playmates have fun!

Benny Bear visits Sêr bach

Neurological Conditions Plan for Wales

The 8th of May 2014 saw the launch of the Neurological Conditions Delivery Plan for Wales. The plan sets out the Welsh government’s aims to help improve diagnosis, treatment, and awareness of neurological conditions, such as spina bifida and hydrocephalus. It places clear expectations on the Local Health Boards to say how they will improve services and how they will work with others to do this.

Shine Cymru will play its part in monitoring how the implementation of the Neurological Conditions Delivery Plan progresses through its work with the Wales Neurological Alliance (WNA). We will be calling on our members in Wales for feedback on their experiences of services to continue driving for change and improvement.

Number: WG20061

Llywodraeth Cymru
Welsh Government

www.cymru.gov.uk

Welsh Government

Consultation Document

Together for Health – Neurological Conditions Delivery Plan

A Delivery Plan up to 2016 for NHS Wales and its partners

Date of issue: 30 October 2013
Action required: Responses by 31 January 2014

Cathy McKillop, Director Shine NI (left), Richard Astle, Shine Chair, and Pamela Dickey, Shine SDW (right)

Having a go at canoeing

Ready to take the plunge at the Share Centre

Shine NI has cycling, family activities, half marathons and plenty of drama!

The Giro d'Italia is coming to Northern Ireland in May and everything is pink. The Giro d'Italia is part of cycling's prestigious three-week-long Grand Tours, which also includes the Tour de France. So, we are rolling out our **Go Folic!** signs and joining in the fun (hopefully in the sun)!

In April we had a family weekend in the Share Centre in Enniskillen. Ten families attended and the activities included canoeing on the lake, circus skills, and wall climbing. The main feedback from the weekend was that they all wanted to know when the next one is going to be.

We had the pleasure of a visit from our Chairman this year. As part of his Chairman's Challenge, he ran the Larne Half Marathon and he also took the opportunity to meet up with our members in Belfast and Derry/Londonderry. We wish him all the best for the rest of his adventures.

We had a Fun Day in early June at the Greenmount Agricultural College. There were opportunities to try out archery, show-off your skills at mini golf, hunt for treasure, and lots of crafts and sporting activities. The event was heralded as a **'Time to Shine'** - which it certainly was!

We will be running a summer scheme in August this year with the Belfast Voice and Drama Academy. The end result will be a presentation of the musical Annie in the MAC theatre on 17 August.

Shine families at the Share outdoor activity centre

For more information, contact
E: northern.ireland@shinecharity.org.uk

2016 Exhibition Launch

Could you be a part of its story?

We are planning a celebratory exhibition of our heritage which will culminate in 2016 – the year of our 50th anniversary.

Called the **Heritage Project**, we would love your contributions in the shape of equipment, devices, publications, or personal stories. If you would like to contact us to share your stories or donate/loan any equipment, please get in touch with Joan or Lyn as follows:

Joan Pheasant T: 0113 255 6767 or
E: joan.pheasant@shinecharity.org.uk

Lyn Rylance T: 01733 421316 or
E: lyn.rylance@shinecharity.org.uk

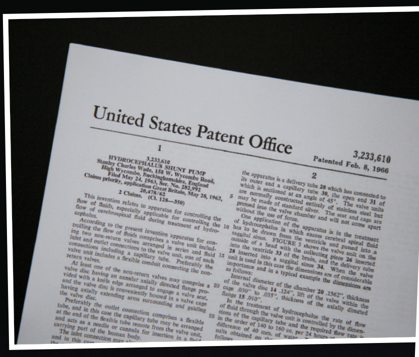
An example of some of our history...

The Wade-Dahl-Till valve

These pictures are of a cerebral shunt called the Wade-Dahl-Till (WDT) valve. It was developed in 1962 by hydraulic engineer Stanley Wade, author Roald Dahl, and neurosurgeon Kenneth Till.

In 1960, Dahl's son Theo developed hydrocephalus after being struck by a car. A standard Holter shunt was installed to drain excess fluid from his brain; however, the shunt jammed too often with serious consequences which Till worked out was because of debris clogging the valve.

Dahl knew Wade was an expert in precision hydraulic engineering so he coordinated the efforts of the neurosurgeon and the hydraulic engineer, resulting in a new mechanism using two metal discs, one at each end of a short silicone rubber tube. Over time, the device was perfected; the co-inventors agreed never to accept any profit from its invention.



United States Patent Office

3,233,610
Patented Feb. 8, 1966

1

3,233,610
HYDROCEPHALUS SHUNT PUMP
Stanley Charles Wade, 158 W. Wycombe Road,
High Wycombe, Buckinghamshire, England
Filed May 24, 1963, Ser. No. 282,992
Claims priority, application Great Britain, May 28, 1962,
20,478/62
2 Claims. (Cl. 128—350)

This invention relates to apparatus for controlling the flow of fluids, especially applicable for controlling the flow of cerebrospinal fluid during treatment of hydrocephalus.

According to the present invention apparatus for controlling the flow of fluids comprises a valve unit including two non-return valves arranged in series and fluid inlet and outlet connections to the valve unit, one of such connections including a capillary tube. Preferably the valve unit includes a flexible conduit connecting the non-return valves.

At least one of the non-return valves may comprise a valve disc having an annular axially directed flange provided with a knife edge arranged to engage a valve seat, and the valve disc is conveniently housed in a valve cage having axially extending arms surrounding and guiding the valve disc.

Preferably the outlet connection comprises a flexible tube, and in this case the capillary tube may be arranged at the end of the flexible tube remote from the valve unit, and acts as a needle or cannula for insertion in a fluid carrying part of the human body.

The inlet connection may

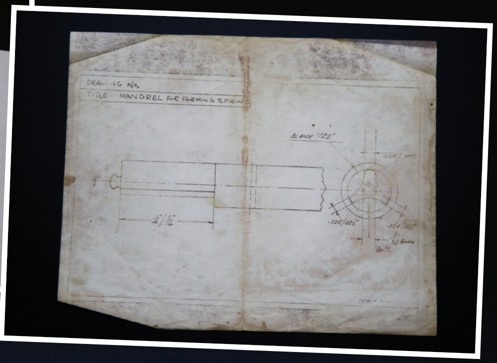
2

the apparatus is a delivery tube 28 which has connected to its outer end a capillary tube 30, the open end 31 of which is sectioned at an angle of 45°. The valve units are normally constructed entirely of stainless steel but may be made of standard silver. The seat and cage are pressed into the valve chamber and will not come apart without the use of force.

One application of the apparatus is in the treatment of hydrocephalus in which excess cerebral spinal fluid has to be drawn from the ventricle and passed into a saggital sinus. FIGURE 3 shows the valve unit on the outside of a head with the collecting piece 26 inserted into the ventricle 33 of the brain, and the delivery tube 28 inserted into a saggital sinus 34. When the valve unit is used in this case the dimensions are of considerable importance and in a typical example the dimensions are as follows:

Internal diameter of the chamber 20 .1562", thickness of the valve disc 14 .124", lift of the valve within the cage .030" to .035", thickness of the axially directed flange 15 .010".

In the treatment of hydrocephalus the rate of flow of fluid through the valve unit is controlled by the dimensions of the capillary tube and the required flow rate is in the order of 140 to 160 cc. per 24 hours



First national conference for pioneers!

Farewell for now to the Shine50Plus conference

Older people with spina bifida and hydrocephalus came together for the first time at a weekend conference held at the Holiday Inn in Coventry on 1 and 2 March 2014, to mark the end of the Shine50Plus Silver Dreams project, which was generously funded by the Big Lottery.

Chaired by **Shine50Plus** Core Volunteers, David Phyall and Liz Potts, this event saw some people meeting each other face to face for the first time, having got to know one another well online.

Exciting speakers

As well as **Shine**'s CEO, Jackie Bland, who opened the conference, we were fortunate to have Dr Richard Morgan, from the Chelsea and Westminster Hospital, to speak on 'Ageing with Spina Bifida'. Dr Morgan's multidisciplinary specialist clinic is the only one of its kind in the country, and he was able to give us a good overview of some of the issues facing people as they get older and how these can be addressed.

On day two, Dr Trudi Edgington, from Westminster University, presented on 'Cognitive and emotional issues in spina bifida and hydrocephalus across the lifespan'. From her research work with many individuals, she was able to explain the importance of understanding the cognitive profile that is often associated with these conditions. She outlined strategies to maximise strengths and reduce the impact of things like anxiety on understanding, behaviour, and mood.

> "Dr Edginton's presentation was clear and helpful in identifying problems and solutions."

> "Motivational – nice to feel I am part of a 'pioneering generation'."

> "It was nice to finally meet people older than myself as I now know I still have a future."

> "It was great to be able to meet and talk to people I have only previously had contact with via the Facebook Group."

Trudi also ran an extremely popular 'Tea, Cakes, and Tips' breakout session, during which people were shown how to practise 'mindfulness' as a way of bringing calmness to the mind and body (see also pages 8-9).

Other breakout sessions featured bladder and bowel care, pain management, using positive strategies to deal with anxiety, and getting the most out of the internet and social media.

Heritage Project

A cheese and wine evening and a quiz with a nod to the past (ie. the 50s, 60s, and 70s) rounded up the first day, and served as an introduction to **Shine**'s forthcoming Heritage Project to celebrate its 50th anniversary year in 2016. **Shine50Plus** members also shared their experiences of being involved in the project (see pages 24-25 for more details).

The conference also saw the launch of new health information for adults with spina bifida, and for their GPs and other healthcare professionals. 'Taking Care of Yourself with Spina Bifida' and 'Older Adults with Spina Bifida – Information for General

> "I found out how to get to attend a pain clinic."

> "Having Dr Morgan to speak was a real bonus."

> "Discussing things whether big or small with like-minded people was great."

Practitioners' are two new Information Sheets available on the **Shine** website W: www.shinecharity.org.uk or from First Contact on T: 01733 555988.

Wheelchair Day

March 1st was also International Wheelchair Day developed by Steve Wilkinson, one of our volunteers, and to mark the occasion, the Crafty Silver Dreamers (now Craft4Shine) had knitted and crocheted a wheelchair in bright yellow **Shine** colours, which was on display together with memorabilia from the early days of ASBAH. The conference ended with an uplifting presentation by the **Shine50Plus** Chair of Core Volunteers, David Phyall, on "The Sky's the Limit". As we all went our separate ways it certainly felt like it was!

As mentioned in our last edition of *Together* (Issue 12, page 7), **Shine50Plus** has transitioned to **Shine40Plus**. To join our closed Facebook page, message us at F: facebook.com/Shine40Plus

Hand-crafted by our Shine pioneering generation

In session at the conference

The work goes on!

Shine40Plus is an extension of the work we have engaged in with our over 50s. We are keen to develop opportunities for older adults to connect and share their experiences. Any suggestions as to how this can be done are welcome – we are always looking for ideas!

Current activities include:

- dedicated volunteers helping from home to increase connections and peer-to-peer support
- a lively closed Facebook group where people across the country can share information
- a national craft group, Craft4Shine, raising awareness and funds for **Shine**
- a '**Shine40Plus** and counting…' regional event in Liverpool
- development of an NPH Support Network
- planning for a second annual conference in 2015
- help with **Shine**'s Heritage Project (see pages 24-25 for more details).

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

SAMC update

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

Lots of good news to catch you up on this issue…

SAMC Meeting

The **Shine** Adult Members Council (SAMC) met for the first time in 2014 on Saturday 1st February at **Shine**'s Head Office. In attendance was Jackie Bland – CEO; David Isom – Development Manager Head Office Services and Midlands Region; Cheyenne Graves – Assistant Grants and Trusts Officer; Siobhan McGowan – Grants and Trusts Officer; Danielle Curtis – Assistant Grants and Trusts Officer; and new SAMC member Asif Shah. Apologies were received from Gobi Ranganathan – Membership Development Officer.

Developments

The SAMC discussed what needed to be achieved for 2014. Various topics were examined. The first topic discussed was how people with hydrocephalus are really affected due to lack of understanding from the wider public of their condition. To try and tackle this issue, the SAMC suggested that fact sheets on how to describe/explain hydrocephalus be included in appeals. Other topics discussed included how people with disability are frightened of losing benefit; political issues surrounding qualifying for social care/support; and spina bifida not being like any other condition, except spinal cord injury, and the relevance of this to NHS Specialised Commissioning. We will keep everyone updated on progress of these topics in the next issue.

Events

Some of the SAMC at the SIA!

Various members have been invited to attend events on behalf of the SAMC. Jason Merrill attended a regional conference in Peterborough with partnership support workers from the Department of Work and Pensions. Liz Potts represented the SAMC at the Sheffield Half Marathon, where Shine Chair, Richard Astle, was competing as part of the Chairman's Challenge. Paul Manning was at the Family Opportunities weekend in Coventry – the event was for children 0-5 years and their siblings, and by all accounts, a fabulous weekend was had by all. I went to a coffee morning in Hull on the 29th of March: it was nice to see many new members for the first time, not only from Hull but also North East Lincolnshire. Following on from this, there is now a Humberside Support Group on Facebook for members to get involved and keep in touch. At the coffee morning, we were joined by member Richard Simpkins, who completed the Sheffield Half Marathon for the Chairman's Challenge.

New Member

Asif Ali Shah attended his first SAMC meeting in February. Asif is originally from Nelson in Burnley, and now lives in the North-East with his three children. Asif graduated in journalism with a First Class degree and now writes as a hobby. In his spare time, he coaches boxing which he enjoys. Another new member, Patricia Adley, attended her first meeting in April. Members will know Patricia, who is from Barnet in London, by her involvement with the **Shine40Plus** group, and is a very welcome addition to the SAMC.

Finally, the SAMC are always keen to hear from members so if there is anything you would like to see your SAMC doing, or maybe you just have a question, please send me an email to the address below.

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

Nic's looking for 'Movers and Shakers'

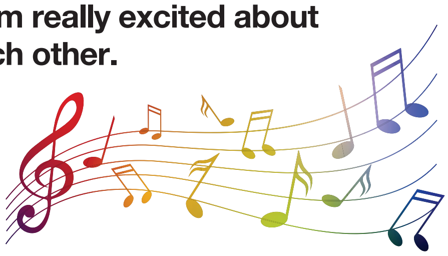
Hi everyone, I'm Nic Shaw, Shine's new Youth Work Coordinator. I am really excited about connecting with young people and helping them to network with each other.

From Devon to Brighton and beyond...

One way I'm helping young people to network is through my **Coffee Project**. I've been travelling around the country, meeting young people in coffee shops so that we have an opportunity to focus on teenage issues and help young people network. For example, when I was in Brighton, I met a young man who was interested in radio production. I also knew of another member in Devon with the same interest, so I was able to 'hook them up', and now they can encourage and support each other. If you'd like to meet up for one of these coffee get-togethers, contact me on the details below.

Move-it and Shake-it!

I'm also looking for young people aged around 11-18 to form a 'Movers and Shakers' group (like a **Shine** Youth Council) to work with me and other **Shine** staff to identify what is really important for younger members. It will be a chance to have a collective voice and empower our youth. 'Movers and Shakers' can report on what's going on in their local areas to keep **Shine** informed, and having a role on the group will help members to develop new skills. Please contact me asap if you are interested.



Getting creative

If you are aged 16-25, I would love you to join me and young **Shine** members Rebecca Morris and Stacie O'Neill who have organised an inspiring weekend away in Essex on 11-13 July. This is a residential event at the fabulous Zinc Arts Centre, Chipping Ongar. During the weekend, we will have sports activities, making music in a recording studio, production of animation, and coaching for writing CVs and finding employment.

Brilliant time in Northern Ireland

I had a fantastic time in Northern Ireland with ten families when we visited the Share Centre in Enniskillen in April. (see page 23). We had fun trying indoor wall climbing, canoeing, archery, circus skills, and laser tag. I also connected with some of our other young members at a bowling night in Londonderry – some photos from this are on the closed This is Me Facebook page at F: facebook.com/groups/Shine.ThisIsME

This is Me is a free club for 11-18s – please join!

You can join our closed Facebook page (13 years and above), receive our newsletter, and the membership pack contains a t-shirt, a wristband, membership card and lanyard.

Get in touch with me on E: nic.shaw@shinecharity.org.uk, T: 01733 421367 or M: 07456 669205

Shine's Lifelong Opportunities Programme 2014

Family Opportunity Weekend 17-19 October 2014

An event for families with a child 6-11 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.

Venue Holiday Inn, Coventry M6 Junction 2
Closing date for applications August 4th 2014

Payment can be 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
Registered Charity no. 249338

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

Shine's Lifelong Opportunities Programme 2014

Great minds!

Promoting mental wellbeing

July 9th 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:
The Dudson Centre,
Stoke-on-Trent ST1 5DD
Closing date for applications: June 27th 2014

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

There will be a charge of £9.50 per person to include refreshments and a buffet lunch.

The event is aimed at adult members. No children, please.

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

Reg Charity No. 249338

Shine's Lifelong Opportunities Programme 2014

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

Aim high Success Possibilities Imagine Realise Explore

with Shine

Residential weekend for 16-25 year old members

Zinc Arts Centre, Chipping Ongar, Essex, CM5 0AD
Friday 11 – Sunday 13 July 2014

£190 for residential
Carer's price £60 with separate programme
Day rates on request
Various payment methods available

Closing date 2nd June 2014

Have a go sessions include:

- **Writing CVs and finding employment**
- **Raising self esteem**
- **Selection of sports**
- **Making music**
- **Producing an animation**

...and more

zinc
arts without exception

For more information please contact Joan or Denise on 0113 255 6767, office@shinecharity.org.uk
64 Bagley Lane Leeds LS28 5LY

Events Events Events Events

Great news! We have so many great events happening throughout the **Shine** community that we don't have enough space to write about them all in *Together*.

To find out the date and time of your next support group or **Shine** social function, please contact **Shine** Head Office on **T: 01733 555988**
E: info@shinecharity.org.uk or visit the events page of the website
shinecharity.org.uk/events