Team Whitlock • Bedroom Tax • Shine Awards

Issue 10

Together

Families that Shine!

Vote for your new Board

Shine

Spina bifida • Hydrocephalus

Information • Networking • Equality

BIG LOTTERY FUND

LOTTERY FUNDED

Shine CEO, Jackie Bland, and Bullens CEO, Peter Bullen, recently met to celebrate the sponsorship of the new WinnersWearYellow™ running vests. The sponsorship deal will enable the distinctive Shine brand to grow, whilst at the same time promoting the unique service offered by Bullens which ensures you receive all the ostomy and pharmacy products you require, delivered straight to your door. To find out more call 0800 269327 and mention you are a Shine member. For every Shine member that uses Bullens, Shine receives a 5% donation from sales.

As part of their extraordinary number of great fundraising events, Johnny Vinson and his amazing group scaled Snowdon earlier this month ... on their mountain bikes! Johnny was inspired to lead the challenge in memory of William-Edward Bye, who was the son of his close friends.

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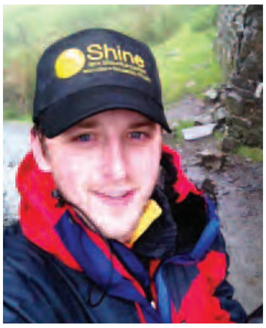
Registered Charity No. 249338

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

Submission dates for Summer edition

- **Register of interest to submit:**
  16th September 2013
- **Final date for submissions:**
  1st October 2013
- **Publication date:**
  November 2013

Issue 10... Our tenth copy!



Issue 10! That's right, this is the tenth copy of *Together* to be published and the ninth edition that I have had the pleasure of working on. Thanks to everyone who has contributed so far.

In this issue we have a great variety of features, photos, health information, and benefits advice. We're also asking you to send us your nominations for this year's **Shine** awards, and there are tips on how to get involved in the second Spina Bifida and Hydrocephalus Awareness Week this October.

Our features focus on two families who have taken their experience of **Shine,** and launched into dynamic fundraising to ensure that the support we offer is always available and life-changing. Our grateful thanks go to both of them.

With your copy of *Together* we have included a copy of our brand new fundraising brochure, Getting started as a **Shine** fundraiser. Here at **Shine** we owe everything we are able to do for our members to our funders and fundraisers, most of whom have great fun as they help raise money. If you feel could join these marvellous supporters in some way, this booklet is designed to help you take simple steps towards fundraising for **Shine**, whilst at the same time enjoying yourself and raising the profile of the charity. If you need any more information, or if you would like to sign up for an activity or event, please call Hannah on 01733 421351, she's always on hand to help and advise.

In the meantime, enjoy this packed edition of *Together* and please continue to send me your ideas, articles, and images, they really do make a difference to every reader that sees them.

Tom Scott

Cover photo: Nikki Dalgarno and Ethan Dalgarno. **Photo:** Tom Scott

Recognising the people who Shine in 2013

The 2013 Shine Awards will be presented at the Annual General Meeting on October 24th, during Awareness Week, and the search for nominations is on.

There are four award categories which are open to **Shine** member nominations. Please think hard about anyone whose work or contribution merits a nomination and follow the easy process 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 willingly gives 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 of more areas of their life
- **Shine** Professional 2013 – Is there a professional who you think has distinguished themselves in the world of spina bifida and hydrocephalus and 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 make Awards for Fundraisers of the Year, **Shine** Ambassador of the Year and the coveted Lifetime Contribution Award.

To nominate someone for an award please fill in the following form, making sure that you complete all the details. If you prefer, you can go straight to www.shinecharity.org.uk/shineawards and complete the nomination on-line.

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

Nomination Form – Shine Awards

Your name: ____________________

Your e-mail/telephone details: ____________________

The Award you want to nominate someone for: ____________________

The name of the person you wish to nominate: ____________________

Contact details for your nominee: ____________________

____

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. Please continue on a separate sheet if necessary.

____

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David Nicholson

We are saddened to inform you that David Nicholson, former member of the Your Voice committee and the Board of Directors, passed away on the 28th February 2013.

David was born with hydrocephalus and was a member and supporter of **Shine**. He was on the Your Voice committee from 1997-2010, as well as being a member of the Board of Directors from 2000-2010.

David played a very active role in fundraising and was part of the GMTV! Get up and Give appeal in 1999, which raised £140,000. He frequently appeared in the Your Voice magazine, writing articles and was often featuring in photographs.

David worked as a chartered accountant and brought his invaluable skills to his role with **Shine**.

We are very grateful for the bequest David left to **Shine** in his will; it will enable us to continue providing our vital services.

Staff news

It's been a busy time with staff changes here at **Shine** again. We have sadly said goodbye to Jane Bishop who was part of the Grants and Trusts Fundraising team, Christine Cousins, the Solent Area Shops Coordinator, and Denise Taylor who was the Secretary for the London and South Region. Finally, Ian Morley, our Collections Officer, who could often be tracked down somewhere in the community disguised as Benny Bear has also moved on to pastures new (hide this from our younger readers if you don't want to give away the secret!). We wish every one of our leavers all the best with their new ventures, and thank them for their many combined years of hard work and loyal service.

Joanne Tailor has joined us as the new London and South Administrator at our new office in Orpington; Sam Lyons is our new Fundraising Development Officer, and Cheyenne Graves and Siobhan McGowan are new additions to the Grants and Trusts Fundraising department. Welcome one and all – we look forward to working with you and wish you a long and happy career as part of the **Shine** community!

ASBAH to Shine – Celebrating 50 years in 2016

Our aim by 2016 is to remember the excellent work of this charity by having a lasting memorial. How are we going to achieve this? We are going to identify the most important landmark events throughout the history of spina bifida and hydrocephalus, and celebrate this in different ways. We could have a time line within the Peterborough Head Office, an exhibition of items from the past to the present. We will need stories told by members: written, recorded, or filmed. These need to be bite-sized, about specific issues and not life stories. They need to be positive and must reflect the remarkable achievements and, in some cases, the pitfalls experienced on the journey.

Please contact Joan Pheasant if you wish to be involved and are willing to talk about your experiences. This could be something that has inspired you, or something you have achieved against all odds. You can give a short synopsis of your story via phone or email T: 0113 2556767 or E: joan.pheasant@shinecharity.org.uk.

We are also looking for historic pieces of equipment and relevant objects of interest. Please send a photo of anything you have that you wish to donate or loan to the exhibition.

At **Shine**, we have many archived publications, including an almost full set of the Link Magazine but are missing the following copies - Issues 1, 10, 14, 44, 112 and 118. It would be great if we could find these. We would be pleased to hear if you have any other printed materials that we could use.

Do get in touch if you would like to be involved or have any ideas on how we can develop our Heritage Project to honour our 50 years of success.

Update on Specialised Commissioning

A huge thank you and congratulations to Shine members who have managed to get meetings with their MPs to discuss better healthcare.

As highlighted in previous issues of *Together*, the NHS has decided that spina bifida is not a condition that needs specialist national commissioning, whereas people with spinal cord injury have a specially designed resource.

Since the last report in Together, a national project group has been formed to take this work forward. This group met for the first time at the Chelsea and Westminster Hospital, home of the only adult multidisciplinary clinic in England.

The group comprises:

Mr Andrew Baird: Consultant in Adolescent & Reconstructive Urology, Aintree Hospital, Liverpool

Miss Maria Cartmill: Adult & Paediatric Neurosurgeon, Queen's Medical Centre, Nottingham

Mr Frank Lee: Consultant Urological Surgeon, St George's Hospital, London

Dr Richard Morgan: Clinical Director, Medicine and A&E Directorate, Chelsea & Westminster Hospital Foundation Trust, London

David Ash: Urology Nurse, Princess Royal Spinal Injuries Centre, Northern General Hospital, Sheffield

Jackie Bland: Shine CEO

Patricia Adley: Solicitor and Member of Shine, London

Liz Potts: Shine Support & Development Worker (North Staffordshire) and Member of Shine

Heather Doughty: Member of Shine and Shine Adult Members Council (Nottingham)

Gill Yaz: Shine Health & Development Manager

The group resolved that the current situation facing adults with spina bifida is unacceptable; we should pursue a recognised healthcare pathway for adults with spina bifida and address the inequality between patients with spina bifida and those with an acquired spinal injury.

A template letter has been produced for **Shine** members (and concerned parents) to send to their MPs. You can find this letter at www.shinecharity.org.uk/specialisedcommissioning or call 01733 421356 for a copy.

A number of members have already used the letter or written to their MPs independently. So far several have agreed to meet to discuss the issue and one MP has secured a meeting with the Secretary of State for Health. One MP received a letter from the NHS CEO, Sir David Nicholson, who explained that while the NHS was reviewing services which might be specially commissioned, expert clinical advisers decided to advise against spina bifida being a condition identified as needing specialised commissioning. This is new information; up to this point **Shine** had understood that spina bifida had not been considered. According to the NHS now, spina bifida was actually considered by experts, and their view was that it was not a 'special case' despite spinal cord injury being included.

A letter has now been sent from **Shine** to the NHS CEO asking for some information about how this decision was made, who the expert advisers were, and why **Shine** was not aware that this issue was being considered.

This is a very difficult time to be trying to get the NHS to change, so the efforts of the **Shine** community are really needed if we are going to bring about a better situation than we currently have. So please:

1. Talk to people about this issue;
2. Write to your MP;
3. Let us know your experiences of healthcare – where it hasn't worked so well, where it has worked and what would improve things for you as an adult with spina bifida;
4. Let us know what you think about this issue by emailing Lyn Rylance.

E: Lyn.rylance@shinecharity.org.uk

Bedroom tax

New rules mean that if you are a social tenant, you won't be able to get full housing benefit if your home is deemed to have ‘spare bedrooms’. This is being called the ‘bedroom tax’. Letters from the council may call it ‘under-occupancy rules' or 'size limit rules’.

How many bedrooms can you claim housing benefit for?

New rules mean that you can only claim housing benefit for:

- one bedroom for a couple
- one bedroom for a person aged 16 or over
- one bedroom for two children aged under 16 of the same sex
- one bedroom for two children aged under 10 (boys and girls are expected to share a room)
- one bedroom for any other child
- one extra bedroom if you or your partner needs an overnight carer to stay.

Who will be most affected by the ‘bedroom tax’ rules?

63% of those affected will be disabled, and around 180,000 will be Disability Living Allowance claimants. Those affected could lose between 14% and 25% of their housing benefit support.
You can’t claim housing benefit for ‘extra’ rooms for:

- children visiting a divorced or separated parent
- couples who use separate bedrooms because of illness or disability
- rooms used by disabled adults to store medical equipment.

Who will be least affected by the bedroom tax?

The ‘bedroom tax’ won't affect you if you (or your partner) have reached eligibility for Pension Credit age. On 1 April 2013, when the bedroom tax starts, you will have reached this age if you are aged 61 years and 5 months (male or female).

Successful Human Rights challenge – recent developments

There has been for some time a similar ‘bedroom tax’ rule operating in the private sector.

However, last year there was a challenge against the government based on human rights, arguing that these rules unlawfully discriminated against disabled people. One prominent case involved a family with two disabled children with very different care needs (one of whom has spina bifida).

As a result, a Court of Appeal judgment says that local authorities should now use their discretion to allow an extra bedroom for children who are unable to share because of their severe disabilities.

However, there was no ruling on the issues surrounding adapted homes and this means that many disabled adults may still face cuts to their housing benefit.

If you are affected, you may be entitled to a discretionary housing payment (DHP).

Housing/council tax benefit departments have funds to give discretionary housing payments (DHPs) to people who qualify for housing or council tax benefit, but are having trouble paying their rent or council tax. The council decides who should be given the payments. However, when the money for the year runs out, no more payments can be made.

You usually have to fill in a special claim form for a discretionary housing payment (DHP). Contact your local council housing/council tax benefit department for further information.

If you want more detailed information about the changes from DLA to PIP, Disability Rights UK has produced a comprehensive guide to help you through the claiming process. The guide covers information on:

- PIP rules
- Filling out claim forms, and much more including what to do if you’re not happy with your decision.

You can download a copy from the Disability Rights UK website, or a photocopied version is £4 including P+P. To order a copy, call Disability Rights UK on 020 7250 3222.

Get together!

There is nothing quite like getting together with people who share your life experiences, especially when those life experiences can make you feel a bit isolated at times.

Talking with others who have 'been there' already, or who day-to-day share the same highs and lows, is often more valuable than anything else.

This is why **Shine** has made its Support Groups a priority, with over 30 groups already operating throughout England, Wales and Northern Ireland.

The latest group to be formed met in Nottingham for the first time in early July. Seven families, including two Mums, two grandmothers, two Dads and a couple expecting their first baby, met at Nottingham's Beechdale Leisure Centre. As well as social time, the children were able to enjoy a ball pool, soft play area, and sensory room.

Shine's Regional Manager, David Isom, and Support and Development Worker, Collette Torrence, were on hand in case families had any questions (and there were many!) and to join in the discussions. It was a measure of how much a Support Group was needed, that families travelled from Leicester, Loughborough and Derbyshire, to join this first meeting, and all resolved that they wanted to meet again.

The group includes people with a range of abilities with everyone welcome, and group members supporting each other to overcome any challenges that might affect their taking part.

Discussions ranged from experiences of pregnancy and birth in support of the couple 26 weeks pregnant with their first child, to difficulties in getting holiday insurance for children with hydrocephalus (**Shine** staff reminded the group that **Shine** has a list of 'hydrocephalus-friendly' insurers). Almost everyone in the group spoke passionately about the pressure they felt from medical staff to terminate their pregnancy when a neural tube defect was diagnosed.

This new East Midlands Support Group is just one example of the ways in which the **Shine** community can be strengthened through Support Groups. In other areas, groups of people with more unusual conditions meet. There is an Intercranial Hypertension Group that meets in the Midlands, for example, and in other areas groups of adults meet to enjoy social activities together.

One such example of this is the Blue Blobbers, who meet regularly in the London area to develop friendships and visit places of interest or try activities such as bowling. This group is supported by volunteers, who help group members that cannot travel alone to get to the meeting venue.

The group includes people with a range of abilities with everyone welcome, and group members supporting each other to overcome any challenges that might affect their taking part. The Blue Blobbers are interested in meeting up with other groups within the UK (so please get in touch with the Shine office if you are interested in this) and also hope to eventually go away together for a few days.

Of course not all Support Groups actually meet up. Through social media such as

Many of the 'This is Me' group speak of feeling isolated in their own environments, not knowing anyone else with the disability and of experiencing huge challenges in their school lives.

Facebook, other groups enjoy communicating with each other from the comfort of their own homes. **Shine**50plus group is a thriving online community of individuals with both spina bifida and hydrocephalus who discuss a range of issues and experiences.

For the younger age group, there is the new 'This is Me' group for 11-14 year olds. This group has discovered that 'finding' each other via their closed Facebook page has been of great interest and reassurance. Many of the 'This is Me' group speak of feeling isolated in their own environments, not knowing anyone else with the disability and of experiencing huge challenges in their school lives. Just talking to other young people who are going through similar experiences has been a great boost to their confidence. www.thisisme.org.uk

If you would like to know if there is a **Shine** support group near you, or would like to join one of the groups mentioned here, please contact info@shinecharity.org.uk or call T: 01733 555988

Likewise, if you are interested in setting up your own **Shine** Support Group we can put you in contact with your nearest Regional Office who will be happy to help. Small-start up grants may be available to help you on your way.

Our challenges have made us stronger...

At Shine we hear many extraordinary stories about our members. These stories inspire us and make us ever more determined to provide the best services we can. We also know that sharing some of these stories inspires and encourages many others within the Shine community. Tom Scott went to hear one such story from Nikki and Luke Dalgarno

Nikki and Luke are parents to boys Finlay, 4, and Ethan, who has just turned 1 and has spina bifida and hydrocephalus.

It was at their 16-week scan that the couple were told that Nikki was carrying twins, and not only this, but that the twins were sharing a placenta.

They named the unborn twins Elliot and Ethan. At 23 weeks, Nikki underwent laser surgery to split the placenta. Afterwards it was presumed that Elliot had survived, but that Ethan had not made it through the operation.

However, in what would be the first of many extraordinary developments, it emerged that it was in fact Ethan, the baby with spina bifida and hydrocephalus, who had survived. Shortly after this, Nikki's waters broke and it looked to everyone involved that Ethan too would lose his fight for life.

However, as Nikki recalls: 'Ethan didn't come out! He stayed there until 36 weeks, 12 weeks after my waters had broken!'

At just 12 hours old Ethan was taken away for a back closure operation and after a week he underwent an ETV procedure to drain the excess fluid away from his brain. This would form the beginning of a journey through many procedures, including Ethan's first shunt at two weeks old, a shunt revision at five weeks, and another revision at six months, both due to blockages.

> **Liz is not just a Shine worker, she is our friend and she is now helping me to support others facing similar situations!**

Essential support

In addition to his hydrocephalus, Ethan was also undergoing various other operations including turning his feet to make them straight and overcoming swallowing issues related to his Chiari malformation.

Far from being a child troubled by his early experiences, Nikki tells of Ethan rising above his physical situation and charming the staff at Liverpool's Alder Hey Hospital: 'You'd find Ethan flirting with the nurses on the ward at their station; everyone is drawn to his bright eyes and charming ways!'

The delight that Ethan brings is something to which Shine Support and Development Worker, Liz Potts, can testify, 'It is always great to meet with Ethan and his family, they are a great example of a family not just overcoming the odds, but going beyond this and using their experience to benefit others.'

Nikki is equally as complementary of the support she receives from Liz: 'we really would have been lost without her, Liz is not just a Shine worker, she is our friend and she is now helping me to support others facing similar situations.'

As well as the support from the hospital and Shine, Nikki says Ethan and Finlay's grandparents have been invaluable. 'I don't know where we'd be without them, they have been with us every step of the way to make sure that we can get to every hospital appointment and to help us through the tough times, especially those we had in the beginning when Ethan was very young.'

However, it is Finlay, Ethan's four-year-old brother, whom Nikki describes as 'amazing, so caring and gentle.' Finlay is keen for others to understand what his brother is going through and at school he explains to others what spina.

Giving back

Not content with overcoming some of life's most difficult challenges, the Dalgarno family is also looking to give back. Enter husband and father, Luke, who works for the Davies Management Group in Stoke.

Like many companies, Davies Management Group offer their staff the opportunity to nominate a charity and then hold a staff vote to select a Charity of the Year. Nikki describes the feeling of Shine being chosen as 'overwhelming'. 'I don't even work there but they are so, so supportive.'

The fundraising by Davies Management Group is a great example of how communities unite to ensure that support from Shine is always available. Since starting in April this year Luke's employers have teamed together to raise over £1000 for Shine, a welcome and valuable start to our partnership together.

Powerful things happen when families with experience of spina bifida and hydrocephalus start to help others, and Nikki is now working with Liz Potts to make sure that parents of newborn babies with the conditions get as much sound advice as soon as possible. Nikki knows what it is like to struggle at the beginning and wants to make sure that other families get information and support as soon as they can. 'The information you're given when you're pregnant is a joke. It's so hard at the beginning and we want to be a part of anything we can to help others.'

The future

Nikki reflects on some advice she was once given when she and Luke found out that Ethan would have spina bifida and hydrocephalus. 'We were told that the challenges of parenting Ethan would make stronger or weaker, it's been hard, but it has definitely made us stronger – if we can take on spina bifida and hydrocephalus, we can take on anything!'

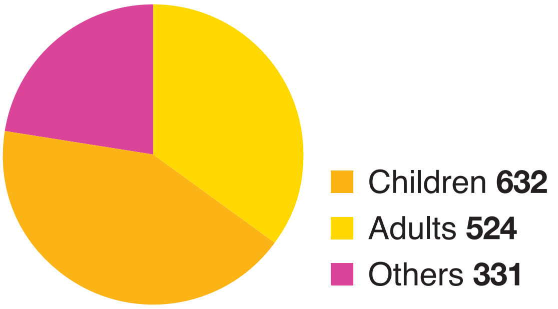
Membership numbers booming!

Shine has welcomed 1,488 new members in the past two years, which is great news because every new member strengthens our community.

But who are these new people? At the last meeting of **Shine**'s Adult Members Council, **Shine** staff were asked find out more about the people who choose to join us.

This is what we found:

We welcomed 1,115 disabled members. Not everyone told us their age, but we know there were 632 new child members and 524 new adult members.



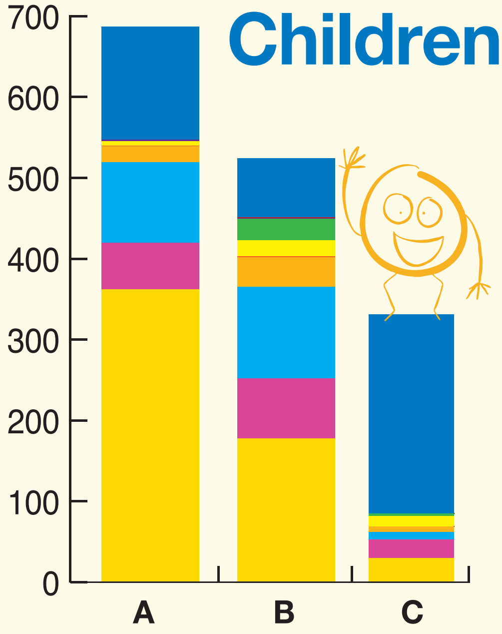
By far the most common disability among new members was hydrocephalus alone, with 178 new adult members and a significant 362 new child members. For people with spina bifida without hydrocephalus, the numbers were 74 adults and 54 children, whilst there were 113 new adult members with SB/H and 99 children.

Among the rarer conditions we welcomed 20 new adults and 5 children with Intracranial Hypertension, while 26 adults joined who have Normal Pressure Hydrocephalus.

The largest number of new members came from the North and West Midlands areas with 407 new members recorded. In Wales 117 new members joined, and in Northern Ireland, a total of 128.

So, a huge variety of members from far and wide. All coming with different needs and different things to offer the **Shine** community. This variety tells us

Children and adults by disability



	A Children by Disability	B Adult by Disability	C Others (professionals, family members)
🟨 Hydrocephalus	362	178	30
🟪 Spina Bifida	58	74	23
🟦 SBH	99	113	9
🟧 SBO	20	37	7
🟥 SBO with H	1	1	
🟨 IH	5	20	13
🟩 NPH		26	3
🟪 Dandy Walker Cyst	2	1	
🟥 Encephalocele		1	
🟦 No Condition	140	73	246

that we have to work hard to make sure all the different sections of our community are being considered and, in particular, we have to recognise what a big proportion of our membership is going to be people with hydrocephalus alone.

Our Adult Members Council also expressed concern that there might be many people and families whose lives are affected by SB/H, who have not heard of **Shine**, or who have not had the opportunity to join. They asked that we increase our efforts to reach these people and we have resolved to do this.

Together readers can help with this, and it will benefit us all if our community grows, as well as offering more support to new people joining us. If you know of people with SB/H who are not **Shine** members, please encourage them to join – it's completely free. If you are a **Shine** Facebook user, but haven't yet joined up, please do so now! And if you can think of places or networks where **Shine** membership can be advertised, then please do let us know – all suggestions welcome.

How to join **Shine**:
Phone Maureen Jobson on T: 01733 555988
E: Maureen.jobson@shinecharity.org.uk

What membership entitles you to:

- Free copy of *Together* magazine four times a year – mail or on-line
- Free health/education advice
- Services of your local Support and Development Worker
- Membership of Shine networks/groups
- Chance to vote for **Shine**'s Adult Members
- Council/Board and AGM resolutions
- Opportunity to be involved in **Shine** governing and advisory bodies
- Lively social media groups.

Great minds!

Promoting mental wellbeing

A lifestyle event for adult members with spina bifida/ hydrocephalus

Friday 11th October 2013
Time: 10am-4pm

Shine, National Office
42 Park Road, Peterborough, PE1 2UQ

Benefits of attending to include ...

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.

This is a great chance to meet other people: You are NOT alone in struggling with anxiety and low mood!
Come along and join us!

Closing date for applications 20th Sept 2013

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

To include: presentation, discussion and opportunities for meeting others.
*There will be a charge of **£10.00** per person to include refreshments and a buffet lunch.*

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

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

Times they are a-changin’

– what’s happening with welfare in your area in 2013

There are a number of changes which took effect from April 2013 onwards. For a quick guide to these changes, read on…

Universal Credit will be introduced. It is a new single benefit which will gradually replace most 'means-tested benefits' (and all tax credits) paid to working-age people. The new benefit, **Universal Credit**, starts in the Manchester and Cheshire areas and will gradually be rolled out nationally from October 2013.

However, OT departments may be based within the NHS or your local council depending on the area you live in. For further information about how to get it touch with them, ask your GP, consultant or social worker. Alternatively, Google Occupational Therapy and your area.

A new **localised Council Tax Reduction scheme** comes into force. For most of the UK this will mean a real reduction in support available for council tax. However, for the initial period 2013-14, most people in Wales will have more or less the same level of help as they did under the former Council Tax Benefit.

The Housing Benefit ‘**bedroom tax**’ for social housing tenants has been introduced. Housing Benefit will be reduced for working-age people who have an extra bedroom under the new rules.

The **Benefit Cap** starts in four London local authority areas and will be rolled out nationally between 15th July and 30th September 2013. Claimants of working-age will have a maximum limit on the total amount of benefit they can get. After a certain point, claimants will have their housing benefit (later housing credit as part of Universal Credit) reduced.

Claimants of working-age will have a maximum limit on the total amount of benefit they can get. After a certain point, claimants will have their housing benefit (later housing credit as part of Universal Credit) reduced.

Personal Independence Payment (PIP) is a new 'working-age' benefit for people who are very ill or disabled, and who have significant difficulties with mobility or need help with their day-to-day living. It will eventually replace all working-age claims for Disability Living Allowance.

For new applications, PIP was rolled out nationally from June 2013. Those on DLA will gradually be reassessed under the new criteria for PIP from October 2013. Lifetime award claimants of DLA will not be expected to be reassessed until 2015.

The ‘discretionary’ parts of the **Social Fund** will also be abolished, including Community Care grants and Crisis Loans. In the devolved parts of the UK, there will be new ‘discretionary’ funds which will provide grants and other help – but these will be limited; elsewhere in England there will be local schemes operated by local authorities. The ‘discretionary’ funds focus help on those who are most seriously vulnerable or in crisis. Budgeting loans will gradually be replaced by a similar ‘budgeting advances’ system as claimants move onto Universal Credit.

What to do now?
If you are concerned and would like to know how these changes may affect you or your family, please contact our team of Support and Development Workers through Shine’s First Point of Contact on 01733 555988.

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Housing Adaptations – some guidelines

by Emma Enfield, Shine Occupational Therapist

Whether you own your home, rent it from the council, housing association, or private landlord, you are entitled to have an assessment of your needs.

Everybody should have a Community Occupational Therapist (OT) who is responsible for community assessments regarding aids and adaptations that you might need at home. Most OT departments will accept self-referrals, so you don't need to go via your GP. However, OT departments may be based within the NHS or your local council depending on the area you live in. For further information about how to get it touch with them, ask your GP, consultant or social worker. Alternatively, Google Occupational Therapy and your area.

There is usually a long wait for an assessment. Remember to tell them if you think you need to be seen urgently. They will work to priority guidelines which you can ask to see but, ultimately, you might have to wait.

When the OT visits they follow quite strict guidelines on what they can and can't recommend for you. You are entitled to see a copy of their guidelines and the priorities they use to make their decisions. It is usual for them to have to carry out an assessment with equipment before they suggest any adaptations to your house. An example of this might be that they will give you bathing equipment to try before they will recommend a graded floor shower. If you can't manage and don't think it will meet your long-term needs, tell them why.

If you both agree that adaptations are the answer, then there are a few routes that might have to be followed. Some OT departments insist the OT writes a report which is then presented at an OT adaptations panel. They will either approve it, or write to let you know it hasn't been successful. If this happens and you don't agree, ask them to speak to you about this, or they might close your case down.

If it's agreed, then the OT will send the report with what you need to either the housing association to complete the works, your landlord, or the local council. Sometimes they just agree to do the works as soon as they get the report. But often you need to apply for a grant. For more detail on applying for a grant, please see: www.shinecharity.org.uk.

Although it's all quite long-winded, be assured that there are literally thousands of housing adaptations completed each year so they DO happen. If you need any further advice, please email: E: emma.enfield@shinecharity.org.uk.

Fundraising – it's about having your WHITS about you!

Introducing Team Whitlock

Every year the most popular charity-place running race applied for here at Shine is the Virgin Active London Marathon.

When we choose the five successful applicants we have to consider their connection to the charity, their experience as fundraisers, and their plans for raising money for **Shine** by completing the world's most famous marathon.

Taking her inspiration from her daughter Lucy-Rose, who has both spina bifida and hydrocephalus, Hannah Whitlock ran the London Marathon for **Shine** last April and raised an amazing £4800!

Not content with breaking the minimum sponsorship by £2300, Hannah then recruited her brother, Aaron, to apply for the 2014 race to ensure that next April Team Whitlock will generate even more donations to **Shine**.

The duo convinced the team at **Shine** that they could repeat Hannah's success through a combination of their energy and endless ideas for creating awareness about **Shine** and inspiring others to sponsor their fundraising ventures.

Hannah spoke to *Together* about Lucy-Rose and what it is that motivates her to run mile after mile for **Shine**.

Lucy-Rose is amazing, she's just like other girls her age, she loves her cats, playing the piano, cooking, and she's a huge Taylor Swift fan!

Hannah discovered at her 20-week scan that she was having a baby with spina bifida and hydrocephalus. Though she was offered a termination, and despite not being fully aware about what a life with spina bifida and hydrocephalus would be like for her daughter, Hannah took the decision to continue the pregnancy.

And it has been the best decision she has ever made.

Lucy-Rose has fought through surgery and multiple shunt revisions to become an incredibly bright, sweet young girl. Hannah is clearly very proud and, though the challenges are pretty constant, she says, 'Lucy-Rose is amazing, she's just like other girls her age, she loves her cats, playing the piano, cooking, and she's a huge Taylor Swift fan!

Lucy Rose continues to have issues relating to her bladder and bowel, not that you'd know it, she just gets on with life and never makes a fuss!'

Lucy-Rose is keen to speak openly about what life is like as a 9 year-old with spina bifida and hydrocephalus, and this has led to her bravely standing before her peers at primary school and explaining what it means to have to manage continence and look after her shunt.

It is so that children like Lucy-Rose can be supported with everything they need, that Hannah and Aaron are embarking on a year of fundraising for **Shine**. We wish them every success and can't wait to see them cross the finish-line next April!

Words and photos by Tom Scott

Gobi's Gossip

Hello everyone! Time has whizzed past once again, and we find ourselves already in the latter stages of summer.

In my last set of ramblings, I mentioned my "Big Op" was looming. With *Together* publication timescales as they are and at the time writing this, I've now had my Mitrofanoff Revision. I'm still recovering from the surgery and am now on the road to recovery. But before I go into more detail about my experience in hospital, let me start by updating you with events leading up to my admission.

Due to badminton tournaments and planning for Rise and **Shine**, the months leading up to surgery were unbelievably busy. Preparations were made to ensure things were organised and in place for handover to the rest of the **Shine** team before I was out of action. This didn't just apply for my **Shine** duties, but also in my personal life where I had to make sure my own admin, banking and other paperwork were all in order before going on sick leave.

Subathran, who is always full of smiles, posed with a Shine T-Shirt, along with Benny Bear, in their specially adapted home.

Doing all of this was a huge task, but it was a necessity in ensuring that I had fewer things to worry about during my recovery. It's fair to say things were non-stop, but it was great to get my teeth into Rise and **Shine**, and really focus my attention on finalising exhibitors, and also securing a guest speaker, former International Wheelchair Tennis player, Jayant Mistry.

Rise and **Shine** has passed by now, but I know that many of you attended, and had an enjoyable and worthwhile experience at Stoke Mandeville.

With a hectic schedule and lots of travelling to **Shine** events and Badminton tournaments, it was great to take some time out for **Shine** duties of a local nature, just days before I went for my operation.

I met up with **Shine** members, the Sivashankar family, who live in my home town of Stevenage. They very kindly made a donation to **Shine**, and it was great to go to their home and meet with them, particularly 7 year old Subathran, who has hydrocephalus and cerebral palsy. Subathran, who is always full of smiles, posed with a **Shine** T-Shirt, along with Benny Bear, in their specially adapted home. His parents are proud and pleased with his happy nature, despite having various difficulties with his condition. It was a lovely afternoon and an education for me too with regards to the extent of adaptations that can be made to a family home to accommodate a physical disability from a young age.

With the lead up to my operation being so busy, at times, it was all a bit of a blur, but I very quickly found myself sitting at home the night before my surgery, looking ahead at what I'd be facing. Having been under the knife on numerous occasions, I tried my best to ensure that I was physically and mentally ready for what lay ahead. However, it was still an unpleasant feeling to be waiting for the inevitable.

Regardless of my preparation, the surgery was out of my hands and was somewhat difficult for my consultant. Surgery took almost 6 hours before I finally got sent to intensive care.

I felt very sore and groggy, but I could now concentrate on getting the recovery phase underway. Unfortunately, my recovery plans didn't quite happen in the timescale I was hoping for. From the moment I came out of theatre I had a number of setbacks that proved to be uncomfortable, and delayed the progress of my recovery. It started with having an incorrectly inserted Nasal Gastric tube (which had to be removed and then re-inserted in ICU), catheters that didn't drain, my bowels and stomach going into shock, upset stomach for 10 days, severe dehydration (with some delirium), thrush in my mouth (caused by antibiotics and dehydration), and finally a cavity appearing in my wound needing daily dressing, even when I came home after my 3 week stay. Needless to say, an unpleasant time in hospital, but I should point out, it was definitely just one of those things and not caused by negligence, or poor healthcare. Surgery, in the main is 'routine' and most patients have little or no issues in their recovery. I've been one of those patients in the past, however, this time it wasn't to be.


A future Shine superstar...

It is never a great thing to experience and there really is no rhyme or reason why it happens. It can happen to the best of us, and is one of life's hurdles that have to be overcome. However, keeping yourself as fit as possible can help with recovery, and also allow your body to handle complications far better too.

At this moment, I still have a long way to go to complete my recovery, but I very much hope that by the time you're reading this, I'm back to my **Shine** duties and meeting all you members once again at various events and visits around the country.

I hope that everyone is having a great Summer and I look forward to being back with you in the next edition as I head into my 3rd Year as Membership Development Officer!

> **From the moment I came out of theatre I had a number of setbacks that proved to be uncomfortable, and delayed the progress of my recovery.**

Think about it...

The way that spina bifida and/or hydrocephalus, can affect how you think and act can make a much bigger difference to the quality of your life than your physical disabilities. Gill Yaz, Health Development Manager explains...

Many people with hydrocephalus, or open spina bifida, have differences in the way their brain processes information coming at them from the environment, and even their own internal thoughts, because of the way their brain developed from the beginning.

As the brain is developing in the womb, it's important that certain chemicals can flow freely within the cerebro spinal fluid (CSF). This is because these chemicals help the brain cells to organise into tidy layers. If the CSF is trapped, for example by a blockage, or because it is flowing in the wrong direction (which happens in spina bifida) then the layers of cells in the brain can be thinner, and untidily organised. When the brain is formed like this, rather than in the usual way, then it can affect the way it operates, which is why people with SB/H cannot always do all the usual things in the same way as other people.

The front part of the brain, which helps us organise ourselves, is often affected. This part of the brain also helps us check our behaviour or our performance against what we set out to do or what others expect us to do. The front of the brain also helps us remember information long enough to use it, to plan into the future and to imagine what is going to happen.

When this is affected, you may find it difficult to imagine things being different to how they are now. You might find your own view of your strengths and weaknesses very different to that of your family and friends; for example, you may find yourself disagreeing with family on applying for jobs or courses you think will be right for you. Some research by the University of Westminster suggests that people with hydrocephalus may not always be as aware of the effects of their condition, as people close to them.

For parents of children with spina bifida or hydrocephalus, it is advisable to start your child off from a young age by helping them to organise their belongings.

When the brain is formed like this, rather than in the usual way, then it can affect the way it operates which is why people with SB/H cannot always do all the usual things in the same way as other people.

This is very important when planning to live independently. You may have become used to prompting from friends or family to remember to look after yourself, like catheterising, or taking medication. It is helpful to experiment with different ways to remind yourself, without someone else being there. Electronic organisers and phone apps have been found to help some people with memory or organisation problems. For example, you can programme in an extra reminder a few minutes after the first, in case you forget. Getting into a routine, and using a checklist can all help; however you might need support until these become a habit.

For parents of children with spina bifida or hydrocephalus, it is advisable to start your child off from a young age by helping them to organise their belongings. Encouraging them to put things in their correct place means they don’t need to ‘work out’ where lost items might be. For school, help them colour code their timetable and equipment for that lesson; for example, a red sticker on maths books and equipment, and a red sticker on the timetable, with a checklist for each day. Don’t leave it till the tricky teen years to think about independence; build up to taking responsibility by starting early.

VP shunts and stomach problems

Professor Bayston comments on the account of a shunt infection written by James Weavin in the last issue of *Together*.

“James’ problem was a pseudocyst that formed at the lower end of his ventriculoperitoneal (VP) shunt, causing a shunt blockage. Such cysts are usually due to infection, as in this case. In the abdomen there is a membrane whose job is to seal off any irritant or infection and to prevent it from spreading. As the bacteria travel down the shunt catheter into the abdomen, this membrane wraps up the bottom of the catheter to contain the infection, and in so doing it forms a cyst. CSF can not now drain freely from the shunt.

It is therefore important to realise that VP shunt infections can appear as shunt blockage, with or without stomach symptoms. A simple blood test and an ultrasound examination, as was eventually used here, will help to diagnose the condition. One important aspect of James’ account is that GPs need to know that anyone with a VP shunt who experiences stomach problems such as these, over a period of more than a week or so, might have a shunt problem and that this needs to be top of the list before other diagnoses, such as irritable bowel syndrome or food allergy are considered.”

It is therefore important to realise that VP shunt infections can appear as shunt blockage, with or without stomach symptoms

Roger Bayston was the first recipient of the ASBAH national Research Fellowship in 1974, which allowed him to extend his studies of CSF shunt infections. Since then he has published over 120 research papers, 14 textbook chapters, and one textbook on shunt infections. He has served on the Medical Advisory Committee of **Shine** for several years, and is now Chairman; he is also a **Shine** Board Member. He has been a member of the International Society for Research into Hydrocephalus and Spina Bifida since 1975, and was made an Honorary Member in recognition of his work in the field. He served as President until last year. He is now Professor of Surgical Infection at the University of Nottingham School of Medicine.

Get a load of this!

by Martine Austin, Shine Health Campaigns Officer

Now that the dust has settled after all the activity and excitement surrounding our first Go Folic Awareness Day, it's time to get cracking on some new projects.

The next task is to increase the range (and accessibility) of our Go Folic! information, to help ensure that the message reaches even more women.

Over the past couple of years we have developed a great social media following, along with a steadily increasing flow of visitors to our website. Online communications have proved a very effective method of sharing our information, and so, with an ever increasing number of people accessing the internet with mobile devices, we felt that the time had come to update our existing website to make it both more accessible and more 'mobile device friendly'. The new look website will also see the launch of some attractive awareness – raising merchandise, including eye-catching wristbands (in the Go Folic! pink and green colours), and pink GF polo shirts! Keep a lookout on the website, Facebook and Twitter for news of the launch...

Go Folic! leaflets are still proving a real hit, with many of you kindly helping to distribute them via your local GPs surgeries, pharmacies, colleges and community groups, which is a fantastic help. I always carry a ready supply of leaflets with me wherever I go (yes, sadly I do stalk pharmacists in my spare time), but it's great to be able to walk in and see some already on display.

Our latest addition, a Welsh language version, is now available to download from the website (including all the latest guidance about B12), shortly to be followed by a Polish version, with further translations in the pipeline. If you know of anyone with fluent bilingual language skills who would be interested in donating some time to help with translating any Go Folic! or **Shine** materials, please do get in touch with us. Similarly, if you know of a particular need for materials in a specific language in your area, please let us know. It's so important that we make our information accessible to as many people as possible.

And finally... a huge 'Congratulations' to Go Folic! poster boy James Fox on winning a gold medal at the Rowing World Cup this month as part of the para-mixed coxed 4; his first international medal in senior competition!

Go Folic!

Keep a lookout for us on the website, Facebook and Twitter

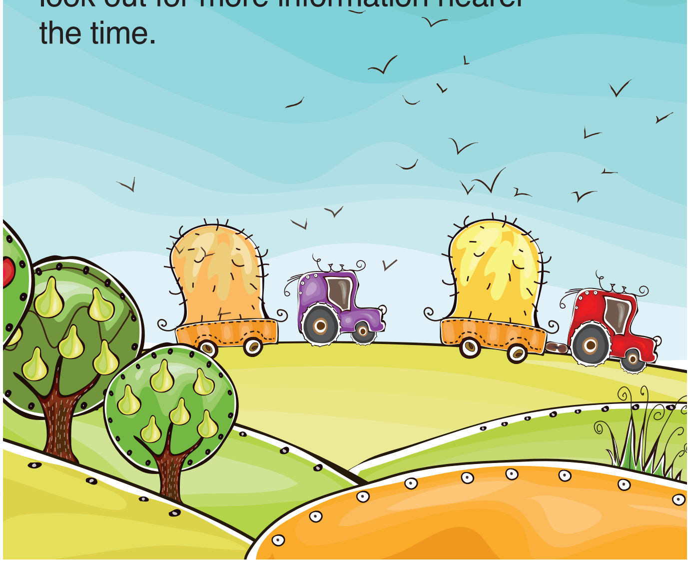
Wales Cymru update...

Fun at Folly Farm

Benny Bear made an appearance for a birthday tea at Shine Cymru's Fun Day at Folly Farm in West Wales at the end of June. 7 families from across South and West Wales came along, and spent the day exploring the farm, going on tractor rides, playing in the Pirate's Adventure area, visiting the new "Folly Zoo" and meeting small farm animals in "Cwtch Corner" ('cwtch' is Welsh for cuddle).

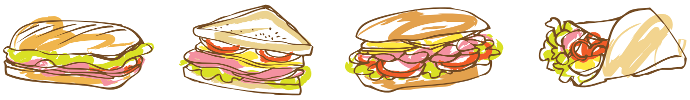
Several families swapped details and agreed to meet up again in the near future to support each other, and share information and experiences.

We hope to make this an annual event and will be planning to meet up on the same weekend next year (probably Sunday 22 June), so pop this date in your diary and look out for more information nearer the time.



Thank you!

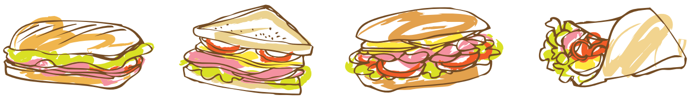
A big thank you to our member Paul Houlton who wrote to Langland Bay Golf Club in May, and asked them to support **Shine**. They donated a signed Osprey shirt which raised a whopping £127 for Shine Cymru. Diolch yn fawr, Paul!



Ladies that Lunch in Cardiff

Shine Cymru is setting up a 'Ladies that Lunch' group in Cardiff for our lady members. If anyone is interested in coming along, then please contact Sian Prince on
E: sian.prince@shinecharity.org.uk or
T: 02920 813847 to find out more.

We're also keen to set up groups in other parts of Wales for other members, so feel free to contact us to find out what we're planning!



Susie Sunshine, Llandudno

Val Conway has been a **Shine** Cymru fundraiser for the past 40 years. She is an active local fundraiser involved with a few charities. However, **Shine** Cymru holds a special place in her heart as her daughter Susie was born with spina bifida and hydrocephalus. Sadly, Susie passed away in 2001, which is when Val began organising the Susie Sunshine Walks in her home town of Llandudno. Now in its 11th year, the annual event has raised thousands of pounds, helping many Shine members and their families.

Thank you, Val – and a happy belated birthday for June!

News from Enniskillen

We met for ‘afternoon tea’ at the Killyhevlin Hotel, Enniskillen, last week, and had members from Co. Tyrone and Co. Fermanagh attending. We shared the dining room with a number of International media personnel getting ready to take their leave after the G8 Summit at the nearby Lough Erne Resort. This G8 Summit has earned its place as the ‘most peaceful’ on record, and it showcased the beauty of Fermanagh and the warmth and generosity of its people.

At an idyllic setting by the lakes, we enjoyed tea and spent a relaxing afternoon catching up with each other, meeting new friends, and planning together some future events of mutual interest.

Mary McCullagh who attended the event said:

‘The event was a recipe for good girlie chit-chat. The conversation was varied, interesting and delightfully aimless, and was fuelled by scrumptious sandwiches, scones, and pastries; weight watchers exit left!’

We look forward to meeting up together again, and inviting new members to enjoy these social events, bringing together adult members from Fermanagh and Tyrone. Please do get in touch with Sandra Campbell (T: 02871 354939) if you would like to join us.

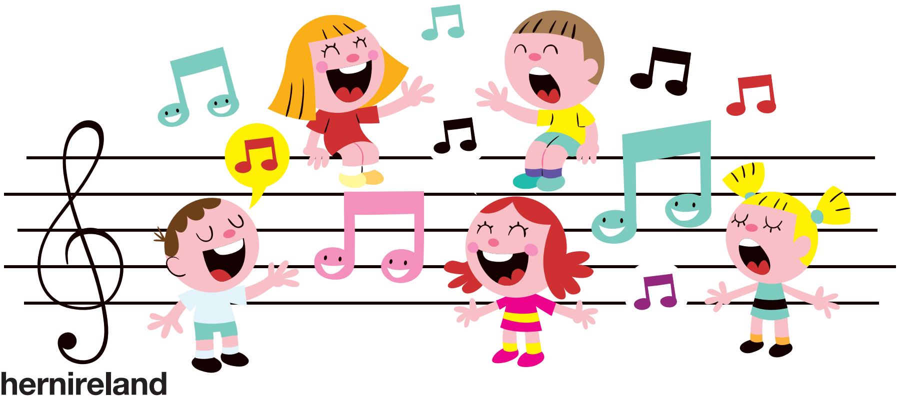
Jo Jingles

We are really enjoying the Music & Movement sessions with Maureen & Jo at Jo Jingles in Enniskillen.

Our children have been brilliant in singing, clapping and interacting with the songs and games. In each session we are learning new songs and rhymes and having a great time with the props. The huge parachute and bubble machine are particularly popular!

Maureen is very kind in providing a picnic for the children and refreshments for the adults after the session. Our young members are very good at helping Maureen to organise the picnic too!

Florencecourt Family Fun Day: Invitations on their way for an event on 4th August 2013, where we are planning a Shine Family Picnic 1pm – 4pm.



Summer's here!

and I have been partying with some of my Benny friends!

I started the party season by going to Vinnie Robyn's Tea Party. Vinnie decided to raise some money for **Shine**, and chose a lovely way of doing it by inviting all her friends and family to a tea party with me! We had so much fun chatting and munching on cakes, and Vinnie raised £458 for **Shine**. I think this is my new favourite fundraising idea. Maybe you could try it with your friends? But don't forget to invite me! (For more information go to www.bennysbirthday.co.uk)

I was very lucky to be invited by Lynn (**Shine**50plus Administrator) and Pete Hart to go with them to Glastonbury! I had the best time, as you can see from the pictures! My favourite bit was seeing the Arctic Monkeys, they were very good, but not like any monkeys I've seen in the wild! Thank you Lynn and Pete, it was a pleasure joining you!

By the time this is published, I will have been to the London Triathlon with Clara and Hannah. I'm really looking forward to cheering our winners in yellow across the line! They're all working hard training and fundraising, so good luck everyone, the **Shine** community can barely believe how great you are!

Lastly, please check out my blog, as the sun has finally got its hat on and I have put loads of tips for keeping safe in the sun. You can also buy some Shades for **Shine** for added sun protection, and they'll make you look very shiny and cool! You get your shades from here www.shinecharity.org.uk/shop.

Can you spot Benny?

SAMC

Hello everyone and welcome to summer. So let's update you with all the latest news from your SAMC, including details of our first meeting held on Saturday 21st April.

Induction Day

The new SAMC had an induction day at **Shine** Head Office on Friday 19th April; we were joined by CEO Jackie Bland, and several staff throughout the day. It was a good chance for the new people to find out how everything is carried out on a daily basis at Shine Head Offices.

Developments

At our meeting on Saturday 20th April, we were again joined by Jackie Bland, and Development Manager, David Isom. Apologies were received from Liz Potts, Amar Dugal, and by Membership Officer, Gobi Rangnathan. Also joining for their first meeting were Heather Doughty and Jason Merrill, who make up the new SAMC.

SAMC Membership Evaluation

The SAMC focused on key objectives within **Shine**'s membership scheme.
1. It was agreed that we need a further 'membership drive'. Centres for Independent Living and Wheelchair assessment centres were suggested; more general publicity to be investigated.
2. When promoting the benefits of membership, we should emphasise that it is free, and it isn't just for when people are in trouble. Moreover, that peer support is a big part of the future.
3. There will be a 'membership' article in (this) Together Magazine discussing the issue of increasing members. It was also noted that last year, 2012, 780 new members joined **Shine**, bringing the membership to 10,800. The aim for the Big Lottery project was to have at least 10,000 members by 2016, so as you can see this has already been achieved.

NHS Specialised Commissioning for Spina Bifida

Jackie Bland has been tackling the issue of national specialised commissioning for spina bifida (or rather lack of it), for some time now. Unfortunately, with little success due to a poor response from the powers that be within the NHS specialised commissioning teams. Therefore, what each member of the SAMC is doing is sending a template letter to his or her local MP, drawing attention to this issue. I will update everyone in the next issue of how many MPs actually get back to each of us.

Chair/Vice Chair

A new Chair and Vice Chair will be elected soon to cover the next 3 years. Any SAMC person can put themselves forward. Applications are assessed against set criteria and if necessary put forward to a vote.

Get in touch!

Remember your SAMC is here for you! So if there is anything we can help with or maybe you just want to ask a question, you only have to get in touch and we will do our upmost for everyone. You can contact me via the email address below.

Mike Bergin SAMC Communications Officer.

mike.bergin@shinecharity.org.uk

The Editor would like to apologise to Mike Bergin for incorrectly stating in a previous issue that he has two children. Mike has four children, we are sorry for any hurt or confusion caused by this error.

Wheelie Chix Competition

Calling all female members! Do you use a wheelchair or spend long periods sitting due to mobility issues? Does this make it hard for you to find clothes that fit comfortably?

Then we have a competition for you! **Shine** is teaming up with Wheelie Chix, to give two of our female members a stylist make-over! The prize will include an outfit, a hair and make-up session, and finish with a glamorous photo shoot!

The entry requirements are very simple. To enter you must be able to travel to Peterborough for the shoot (advance notice will be given to allow for travel arrangements), be a **Shine** member, and be a lady! **All you need to do is email louise.tyler@shinecharity.org.uk with your details and then we will draw two names from the hat.**

For further information about buying from Wheelie Chix go to www.wheeliechix-chic.com/

Don't despair gents! We will hopefully be running some styling competitions for you in the near future.

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

Spina Bifida and Hydrocephalus Awareness Week 2013

19th - 26th October 2013

Turn your school, workplace, or local group YELLOW this October with Wear Yellow and Shine for the next Spina Bifida and Hydrocephalus Awareness Week!

Last year you raised £10,000 through Wear Yellow and Shine events across the country. This year we want to beat this amazing achievement with even more people wearing yellow for the day.

Spina bifida and Hydrocephalus Awareness Week is an annual opportunity to raise the profile of the conditions which affect tens of thousands of people in England, Wales and Northern Ireland.

Schools and workplaces often book these charity days in advance so please speak with your contacts as soon as possible about signing up for this year's event!

You can hold your event at any time, one great idea might be to use the final friday of the school term – Friday 25th October – as the day for Wear Yellow and Shine.

To get your Wear Yellow and Shine supporters pack, or to find our more, please call Hannah Wysocki on 01733 421351 or email hannah.wysocki@shinecharity.org.uk

shinecharity.org.uk/wyas