Superstar fundraisers • Tinchy Stryder • SAMC nominations

Together

Ian means business

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www.shinecharity.org.uk

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 Autumn edition

- **Register of interest to submit:** 28th September 2012
- **Final date for submissions:** 19th October 2012
- **Publication date:** 2nd November 2012

Hello again...

It's hard to believe that we are heading rapidly towards another Christmas but the cards that we have for sale on page 27 confirm that this is true!

We've packed as much news, information, features, and events into this issue as possible, there is so much going on in the **Shine** community that the demand for articles and photos for each edition is growing and growing – thank you for all your contributions!

You can catch up with our regular features including Gobi's Gossip, Gill Yaz's health column, Mike Bergin's feedback back on all the SAMC activity, and we welcome Emma Enfield's new spot which focuses on occupational therapy.

Our main feature focuses on Ian Laker and his success in running GBL, a company selling wheelchairs for over two decades. Ian talks about his time at school, his experience as a GB basketball player, and how establishing a business as someone living with spina bifida demands a certain outlook on life.

As usual, I would encourage you to get in touch and let us know what you like, what you want to see more of, and to share your news and photos with us. I look forward to hearing from you soon!

Tom Scott

***Together* Editor**

Cover photo: Gobi and Ian from GBL.
Photo: Tom Scott

Carl Kicks his Way to the Top

Shine Member, Carl Hodgetts 34, who has spina bifida, was awarded a black belt in kickboxing by the governing body, the World United Martial Arts Federation (WUMAF), in 2006. To facilitate Carl's disability, the federation rebranded his technique to 'freestyle martial arts', which involves using his arms and hands to kick opponents, instead of using his feet.

Carl told **Shine**, "I have been a member of what was ASBAH, now **Shine**, for as long as I can remember and I enjoy reading the stories in the magazine because I get extremely inspired by the things people have achieved!"

We are inspired by you too Carl, keep it up! Ed.

Benny's Big Birthday in Queensgate ...

On 15th September Benny Bear celebrated his birthday with a big party at Queensgate Shopping Centre in Peterborough. Many local people came to meet Benny and to share his birthday cake. Smiling bear faces were spotted around Queensgate throughout the day, thanks to the success of the Benny Bear face painting.

With a day of party games, face-painting and a bouncy castle, **Shine** had a very productive day raising vital awareness and a total of £672.82.

As you may know **Shine** Patron, Danny Mills was a contestant in the 2012 series of Celebrity MasterChef.

Competing against fifteen other well-known personalities, including Gareth Gates, Michael Underwood, Jamie Theakston and Cheryl Baker, all keen to be crowned 2012 Celebrity MasterChef Champion, Danny made it to the final, and was

Shine's Paralympic Reports

Shine Members, Daniella Jade-Lowe, Reporter for the Royal Bermuda Gazette and Nicholas Chiddle, Sports Journalism Graduate, share their experiences and views of the London 2012 Paralympic Games.

Above: Daniella with Jessica Lowe, Bermudian Paralympian, whilst sight-seeing in London. Photograph by Alex Michael.
Left: Nicholas with his Fielder of the Season trophy, for Hertfordshire Disabled County Cricket Club

Daniella Jade-Lowe

Travelling in London during the Paralympic Games was quite an adventure, and overall it was a positive experience. The public places I visited were wheelchair friendly, equipped with ramps and lifts, to make getting around easier for physically challenged people.

The Transport for London staff were very efficient. On one occasion when boarding a bus the ramp malfunctioned. The staff immediately reported this and requested a replacement ramp, which arrived really quickly and enabled me to board.

To read more about Daniella's experience please visit shinecharity.org.uk/RoyalGazette

Nicholas Chiddle

The Sport itself was a joy to behold, especially with GB surpassing their medal total expectations, and, if the action alone wasn't enough to inspire you, then how about 80,000 people chanting Jonnie Peacock's name?

The best thing about the Paralympics was the word disabled being essentially dropped and instead the ability of each athlete was discussed. This may seem like such a basic idea, but there is a huge difference a disabled athlete and an athlete who is disabled; the latter is what every competitor should be.

Congratulations to Danny Mills!

eventually beaten by Emma Kennedy's culinary skills.

Congratulations Danny from all at **Shine** on this great achievement!

However, Danny's extraordinary year of achievement didn't end there. In October Danny successfully completed the first Archie Mills Memorial Challenge, which involved cycling with Scott Nielsen from Leeds2London and then, the following day, completing an Olympic distance triathlon.

Danny is on course to raise over £10,000 for **Shine**, which includes £2000 from MasterChef and this year's series winner, Emma Kennedy. THANK YOU to everyone who made this event happen and those who donated so generously!

Shine Member Amar Dugal attends a recent event representing **Shine** Adult Members Council.

Getting YOU involved

Here at Shine we are working hard to find as many possible ways for people to be involved with your organisation. Gobi Ranganathan, Membership Development Officer, is out and about recruiting new members and raising awareness of who we are and what we do. To give you an idea of Gobi's work, 78 new members joined just last year.

Benny Bear now has 528 little members in his club, with some babies being enrolled while still in their incubators. There are amazing **Shine** volunteers up and down the country, fundraising or helping out in clubs and groups. Other organisations for spina bifida and hydrocephalus, whether local, national or international, work alongside us and help to shape what we do.

Disabled adults at the heart of the charity

Everyone is encouraged to play their part and have a say. One very significant group in all of this is the **Shine** Adult Members Council (SAMC). This group of members aged 18 and over, are elected by the Membership to represent them, and to provide accurate and up-to-date information on what it is like to live with spina bifida and/or hydrocephalus. The current members of the council have been involved in helping to shape the content of **Shine** 's Strategic Plan, the name change, the Go Folic! launch at the House of Commons, responses to Government consultations and attending and feeding back on **Shine** events across the country. Perhaps most importantly, the current group were also responsible for initiating the **Shine** Health Survey, which has provided so much information about the health issues faced by our members. Two SAMC members, the Chair and Vice-Chair, serve on **Shine**'s Board of Trustees, enabling the group to have a real influence at the heart of the charity.

Benny Bear now has 528 little members in his club ...

SAMC meets four times a year, usually at **Shine**'s HQ in Peterborough, or occasionally at other venues around the country. In addition members may attend events, training and local groups. Some members, if comfortable, may be asked to speak to the media, and all members will be asked to share their life experiences with **Shine**.

Shine pays all travel costs, meal costs and overnight accommodation costs, where necessary, to volunteers.

Time to find new SAMC members

Members serve three years on SAMC and then they stand down to allow a new SAMC to be elected. We have now reached that time in the election year when we ask for nominations for the new SAMC. We are looking for disabled people who really want to be involved, who have some time to give, who ideally can travel to a few meetings per year and who feel they can represent thousands of members who share their disability.

What to do if you are interested

There is a role description for SAMC members which describes what is expected of an SAMC member. If you would like to view the Role Description please contact Lynn Hart T: 01733 555988 or E: lynn.hart@shinecharity.org.uk and we'll make sure you receive a copy. If you feel that you fit the Role Description then we'd really welcome your interest. If you are not sure, you can call David Isom on 01733 421308 to discuss it further. Existing SAMC members can apply to stand again, but must follow the same process as new applicants.

How to apply

If you'd like to apply for the role, simply fill out the short questionnaire attached to the Role Description and send it to SAMC Recruitment,
Shine Charity, 42 Park Road
Peterborough PE1 2UQ, or
e-mail it to Lynn Hart, address mentioned previously.

What happens next?

Your application will be looked at by **Shine**'s Human Resources Manager and senior colleagues to make sure that it matches the role description. If you pass this stage, your name will go forward for election to SAMC. Your name and a few brief details about you will appear in the February issue of Together (don't worry, we'll talk to you about this first) and **Shine** adult members will be invited to vote for you. The 10 applicants with the most votes will become the next SAMC. If there are fewer than 10 applicants, the membership will be asked to support their election as a group.

Please think about it

If you think you have something to offer, please don't hold back. SAMC meetings are fulfilling and fun and it is a real opportunity to develop yourself whilst helping **Shine** at the same time. If you have ideas about what we should do, things we should encourage, or statements we should make about having spina bifida and/or hydrocephalus then this is a real chance to make yourself heard, represent the growing membership, and influence the future direction of **Shine**.

Emma Enfield

Shine's Occupational Therapist

In August I became the Lead Occupational Therapist/ Development Worker, on **Shine**'s Health Team. I already worked for **Shine** as a Support and Development Worker and, during my time in this role, it became apparent that a therapy service was greatly needed, so here I am….

I qualified as an Occupational Therapist (OT) in 1995 and have spent most of that time working as a Community OT in the NHS and Social Services. I am thrilled to have this opportunity to put my OT skills to work for **Shine**.

Some of you may have already spoken to me - I respond to requests relating to therapy, housing, mobility, equipment etc. So when you contact **Shine** in the future, you might hear back from me.

… I would love to know about your experiences with any therapy services …

I would like to develop the OT service to help **Shine** members as much as possible. To date, I have mostly received enquiries relating to problems with wheelchair services/provisions, and adaptations/equipment needed for people to live independently at home, or to reduce the strain on their carers. So these are two areas that I know I need to look into further.

I am going to be writing regularly for *Together* and I hope that you find my columns useful. If you have any ideas for subjects you would like to see, please email me and I will aim to cover these topics.

Going forward, I'll keep you updated with all of the exciting developments. To kick start my work, I would love to know about your experiences with any therapy services that you have been involved with, both good and bad! Are there any gaps in the service you have received, that you feel it would helpful for me to know about? What would be useful for you from a therapy service at **Shine**? I am looking forward to hearing from you.

E: emma.enfield@shinecharity.org.uk

Ian means business

Words and photos by Tom Scott

Since joining Shine 18 months ago I have met a lot of inspirational characters. However, it was on a recent visit to the wheelchair distributor, GBL, that I met someone who has taken such inspiration to the next level.

Twenty two years ago Ian Laker, with his two colleagues at the time, started a business selling wheelchairs. This was a unique venture in that Ian and his two business partners, Jamie and Steve, all have spina bifida.

Ian explains that in the beginning 'the phone didn't ring for three months!' Times were tough, the trio had committed themselves to a 2000 sq/ft starter unit, which was hardly filled by their first twenty wheelchairs.

Their fortunes, however, were soon to change – the phone started to ring and hasn't stopped now for over two decades. Over the years the shape of the business has changed and today, of the founding partners, it is only Ian that is still involved at GBL.

Earlier this month I went along to see the GBL service first hand as **Shine**'s Membership Development Officer, Gobi Ranganathan, was booked in to collect his new chair.

The first thing that strikes you upon arrival is the size of the business, this is no small time venture. Ian's unit houses every type of wheelchair you can think of, from the smallest children's wheelchair to large electric chairs with hoists and highly technical disability specific controls.

More important than this, though, is the warm welcome that the staff at GBL offer. You sense immediately that this is a business that genuinely values the customer, and this is a direct result of Ian's friendly and accommodating personality.

It hasn't only been success in business that has kept the Northampton born entrepreneur busy either. Until recently Ian had been involved in

wheelchair basketball for 32 consecutive seasons!

This included representing Great Britain in the sport and coaching some of the nation's more recent stars, including Anne Wild.

During the interview with Ian I was intrigued to know more about how he has become so successful; he has obviously experienced a great deal in life and conducts himself as someone who means business.

Ian identifies his parents as being instrumental to his development as increasingly he became an independent person. This attitude to life proved essential as Ian progressed beyond the doctor's opinion that he would die young.

… if people with disabilities want to work, then they need a work ethic that offers no excuses …

After a combination of study at both State school and the disability specific Treloars School, Ian wanted to pursue his love for sport at university. However, growing up in the 1970's meant that the options that we know today were not yet available. Ian was told that in order to complete his desired course he would first have to gain a degree elsewhere due to his perceived inability to complete the physical aspects of the course.

By the time he was eighteen Ian was already representing Great Britain as a wheelchair basketball player and he had his eyes set on improving his standard of living, starting with his car! With this in his sights Ian trained as an Accountant and went on to work for ASBAH until the charity moved to Peterborough. It was at this point, with no desire to move from his home in Hounslow, that Ian and two of his friends set up GBL. Since then a lot has changed, however Ian also talks about principles that have remained consistent over the years.

The importance of parents to encourage their children to be independent, in spite of their spina bifida and/or hydrocephalus, the necessity of striking a balance between independence and getting together with people who can genuinely identify with each other, the fact that if people with disabilities want to work, then they need a work ethic that offers no excuses, and the need for charities like **Shine** to collaborate with its membership effectively, all come across very clearly in what Ian communicates to those around him.

It was a pleasure to meet with Ian, and Gobi left a very happy man with his new wheelchair. To read more about Gobi's experience at GBL see page 14 and 15.

To find out more about the services GBL offer please see:
www.gblwheelchairs.com

Bladder and Bowel Day

Thursday 20th September

By Health Development Manager Gill Yaz

Ensuring that children and adults with spina bifida receive the very best care for their bladder and bowel issues has long been an important part of the **Shine** Health Team's work. I am fortunate enough to be in contact with some of the excellent clinical services who believe that continence, as well as kidney health, are the aims of bladder and bowel management for young children with spina bifida. Working closely with families, they aim for most children to be wearing regular underwear by the time they complete infant school.

On 20th September the Life Long Opportunity Programme welcomed Mr Pat Malone, Consultant Paediatric Urologist at Southampton General Hospital, to talk to parents about modern bladder and bowel management. For years, Mr Malone and his team have been working to improve bladder and bowel care for children with spina bifida, inventing the ACE procedure for bowel washouts.

In his talk, Mr Malone spoke about the importance of early assessment to check that the bladder is able to fill and empty urine (Urodynamics) in the first months of life. If the bladder function is affected, Mr Malone prescribes medicine to relax the bladder, and intermittent catheterisation to empty the bladder. Interestingly, Mr Malone informed us that since his centre adopted this approach several years ago, there is very little need for bladder augmentation, a major operation to enlarge the bladder. Likewise, Peristeen has reduced the need for the ACE.

Some other centres treat all babies born with spina bifida with medicine and intermittent catheterisation, stopping later if everything looks to be fine. These centres are also finding that there is a much lower requirement for surgery, as the bladder is much more able to fill properly. A relaxed bladder is a safe bladder; by keeping the pressures down there is a lower chance of kidney damage through reflux.

As well as medicine, some urologists are using injections of botulinum toxin, such as Botox, to relax the bladder muscle and increase the capacity. It is used more and more for adults, with good effect. It can be used in children too, however not all Paediatric Urologists are happy to use it as the child will have to go into hospital every 6 months for repeat injections.

The important message for parents who have children with spina bifida is that there should always be an active plan, not only to preserve the kidneys but also to promote continence, and planning for this should start within the first months of life. Hopefully with such models of excellent practice in many parts of the country, continence can be achieved by many children, without surgery. It won't work for everyone, but it's definitely worth pursuing. Your children will gain so much confidence through achieving continence, the sooner the better!

To contact Gill Yaz please
T: 0208 449 0475 or
E: gill.yaz@shinecharity.org.uk

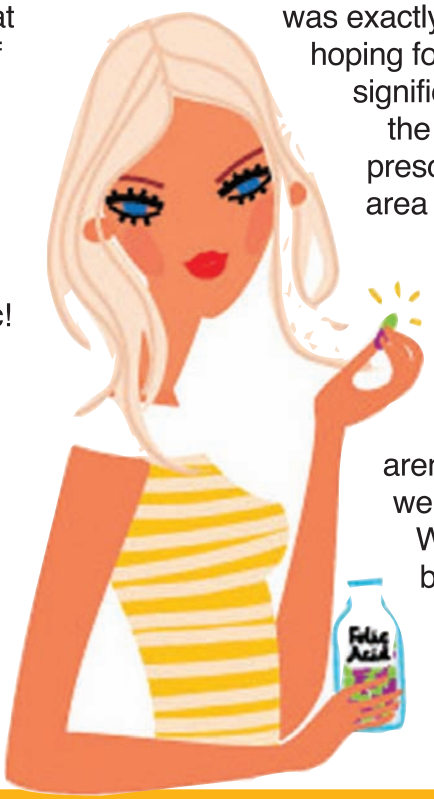
Family Planning Goes Folic!

Shine has formed an exciting new partnership with the Family Planning Association, which will see Go Folic! promoted in Family Planning Clinics throughout the UK. This new partnership will provide us with a unique opportunity to directly target large numbers of women of a childbearing age with the Go Folic! message before they're starting to think about pregnancy. Go Folic! literature will be available to all women attending the 3,000 Family Planning Clinics and 2,000 specialist family planning GP surgeries in the UK.

We are very fortunate to have been given such a great opportunity to promote Go Folic! on a national level and in such a targeted way. As a result many more women will be made aware of the importance of taking folic acid before they plan a pregnancy, so that when the time comes the concept of taking folic acid won't be a new one.

In addition to promoting the campaign in their clinics, our friends at the FPA are also promoting folic acid awareness on their website, and have also ensured that Go Folic! literature (along with some specially created Go Folic! branded folic acid tablets) form an integral part of their new fertility kits, which are available to purchase from their website fpa.org.uk

Partnerships with other organisations have already proved very successful for Go Folic! Earlier in the year we partnered with Norfolk and Waveney Primary Care Trust to develop a Go Folic! pharmacy campaign for the region. During the course of the 2 month campaign, pharmacists reported that displaying our information had prompted more women to ask questions about healthy pregnancy and taking folic acid, with some pharmacies noticing a definite increase in their over the counter sales of the supplement. This was exactly the result that we were hoping for. However, most significantly, we discovered from the Chief Pharmacist that prescriptions for folic acid in the area rose by a whopping 700 prescriptions during the quarter of the campaign! This has given us a tremendous boost, as it just goes to show that we are getting things right. We aren't just increasing awareness, we're changing behaviour too. We hope that the trust will become the first to adopt Go Folic! on an on-going basis and hope to roll out the campaign to other PCTs in the near future.



Thank you all for your continued support. Keep up the great work tweeting and sharing!

Can you *Make a Gift* to

My name is Aidan and my family have been members of **Shine** for a very long time. I've been raising money for them and telling people how brilliant they are since I was six years old – I'm 11 now.

At the time, everyone thought my Dad was going to die, but he didn't – luckily for all of us, he's still here with us.

I'd like to tell you why I do this, because I hope it might encourage you to send in a donation this Christmas, to enable **Shine** to keep helping families like mine. They really need our support.

When I was five, Dad suffered lots of severe strokes and developed hydrocephalus. He was seriously ill and had to go into intensive care after an emergency operation to insert a shunt from his brain into his abdomen. Dad was a Parish Priest and although he made a miraculous recovery, he never recovered enough to stay at work and so he had to retire. Mum had to give up work too. We ended up moving house, so I had to leave all my friends from Cubs and my old school behind. It was horrible and changed our lives forever.

One of **Shine**'s Support & Development Workers (SDWs) came and visited us lots, so we could ask questions and they could help us all understand why Dad behaves a bit differently now. Sometimes Dad gets stressed and anxious, and it's really helpful that I can tell people about his hydrocephalus – I can only do this, because our **Shine** SDW had explained it to me so clearly when it first happened. She gave me and my Sister 'Benny Bear' books to learn about what had happened to Dad, so that we weren't so scared of it all.

Mum says things like this cost a lot to produce, so I'm always keen to help raise money for **Shine** whenever I can, so that they can keep helping other families when they go through hard times.

Once, I sent **Shine** £10 from selling my homemade marmalade and coconut ice. They always send me a nice thank you letter telling me how every pound is important.

My family doesn't need any help from **Shine** at the moment, but Mum says you never know what the future holds. By making a donation today, we can make sure that every little boy or girl, or Mum or Dad living with spina bifida and hydrocephalus will always have somewhere to turn to when things get tough. The best way that you can help **Shine** to support other families like mine is to send a donation.

Mum said Shine was like a guardian angel, not just for Dad but for all of us.

Shine this Christmas?

Your donations will help Shine to continue providing the support and advice which is so desperately needed by other families like mine. For example, as part of its Lifelong Opportunities Programme, Shine organises an annual residential Family Opportunity Weekend. Please consider making a donation this Christmas, so that Shine can keep helping people like my Dad and me.

p.s. If you want my recipe for coconut ice - just put a note with your donation!

If you can't make a donation today, could you do something to raise money for **Shine** instead? You could bake some cakes and sell them to your friends and family, or perhaps you know someone who would like to run the London Marathon for **Shine**!

Whether you want to give regularly, or if you'd rather make a donation right now, all you need to do is fill in the form that's with this magazine and send it all back in the envelope provided.

The people in the Fundraising Team are always really friendly and happy to help – so you can always give them a call on **01733 421351** to talk about your ideas. I hope you all have a lovely Christmas and I promise to send you a nice thank you letter if you are able to make a donation today.

Love from Aidan

If you wish to make a regular donation please complete the form below and return it to: Monica Evans, Shine, 42 Park Road, Peterborough PE1 2UQ

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

Instruction to your bank or building society to pay Direct Debit

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Name(s) of account holder(s):

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Instruction to your bank or building society
Please pay **Shine** Direct Debits from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee.I understand that this instruction may remain with **Shine** and, if so, details will be passed electronically to my bank/building society.

Signature(s)

Date:

Bank and building societies may note accept Direct Debit instruction for some types of account

DD I 5

Hello everyone!

Following a fantastic summer of Olympic and Paralympic action, I hope that everyone still has the feel good factor that London 2012 brought us all as we head towards the festive period! Okay I know it's only November, but before we know it Christmas will be here and Auld Lang Syne will be ringing out from households across the nation, as we say farewell to 2012 and we welcome 2013!

Talking of the New Year, it really is scary how quickly time is passing. Even scarier is the number of activities that have taken place during 2012! You might find Christmas has been and gone by the time you finish reading this, as once again there's plenty to get through!

Since the last issue of *Together*, I've been involved in all sorts of exciting things. Following on from being an Olympic Torchbearer in Stevenage, I've been the Paralympic Flame Ambassador for Hertfordshire, taken part in the Welsh 4 Nations Para-Badminton Championships, completed a 5K

Fun Run at the Great Eastern Run with Darren ‘The Power’ Fower, visited more schools, and even had time to fit in getting a new wheelchair!

I had the very good fortune of being able to attend a number of Olympic and Paralympic events, meeting some past and present stars, such as David Clarke (Captain of the Paralympic GB 5-Aside football team), Louise Hunt (Wheelchair Tennis), 3 time Olympic medallist Kriss Akabusi and one of the greatest Paralympians of all time, Tanni Grey-Thompson. I also grabbed the opportunity to rub shoulders with a number of other celebrities including Prime Minister David Cameron, Mayor of London Boris Johnson, and pop star Tinchy Stryder.

You may remember, before the Olympics started I was making a number of school visits. These visits are great fun and it’s lovely to see the children showing so much support for **Shine**. Alexandra Infants School, in Kingston-Upon-Thames raised money for **Shine** a short time ago and since then have been getting involved in more fundraising. One of our younger members, Jack Keleman attends the school, and in September he took part in a Sponsored Bounce, the objective being to bounce as many times as possible on a bouncy castle. It’s fair to say there was a great deal of jumping around, with the school raising a fabulous total of £150 for **Shine**. Well done to the school for their efforts and also to Sarah Keleman for plugging **Shine** at every opportunity. Don’t forget if you want to organise any fundraising events get in touch with Hannah or Andrew in the **Shine** Fundraising team. Who knows, you may even get a cheeky little visit from your Membership Development Officer! E. Hannah.wysocki@shinecharity.org.uk or Andrew.ellis@shinecharity.org.uk

Above: Gobi with the Rio Dancers, part of the parade going through St Albans Left: Gobi with Tinchy Stryder, holding the Paralympic torch together.

September also saw the start of the new Para-Badminton Season and, after one of my best performances, I came away with Gold in the Men’s and Mixed Doubles, and Silver in the Singles, narrowly losing to my on-court rival and friend, Martin Rooke. It was disappointing to lose out again, but I’ll beat him soon enough! A special thanks to Kate Thomas from **Shine** Cymru, who came along to support me at the Welsh Institute of Sport in Cardiff.

Mid-October saw me take part in The Great Eastern Run after my **Shine** buddy and Media Development Officer, Darren Fower threw down the challenge of getting me to take part. Not being one to refuse a (reasonable) challenge, I accepted and set about entering the 5K Fun Run, with the additional challenge of raising £1000, just to make it interesting! It was a new experience for me and I’m definitely a long way off doing the London Marathon.
justgiving.com/DarrenandGobi

With all of this excitement and activity, I still found time for some important retail therapy when I visited GBL Wheelchair Services in Feltham, London. Having been needing a new every-day wheelchair for some time, I met with Managing Director of GBL, Ian Laker. Ian, who himself has spina bifida, assisted me in selecting a new wheelchair. After test driving a number of wheelchairs at GBL’s showroom, I selected my new mean machine – a Top End Crossfire! I can now say goodbye to the regular and rather painful back troubles I’ve been having as a result of my old chair. It just goes to show how important it is to have the right wheelchair. For more information on Ian and GBL see the feature in this edition on Page 8.

And there you have it. The last few months of activities condensed into a nutshell, albeit a rather large one! Once again, time and space have beaten me and I have to wrap up my column for another edition. After a hectic and enjoyable 2012, I hope that 2013 will be even better.

See you in the New Year!

Fundraising begins at 40!

I celebrated my 40th birthday this year by challenging myself and ten friends and family members to the Leicester Half Marathon on 14th October. We raised £2000 for **Shine**!

It's 9 years since we found that our daughter, Ella, had a spinal cord tumour and hydrocephalus. I would never have believed that 9 years later, Ella would be running around, keeping up with her twin sister, Lucy and her older brother, Sam. **Shine** provided not only vital information about hydrocephalus and a place to turn to with problems, but also made us aware that we are not alone. The new name and image at **Shine** have brought everything to life!

All the best, Anne Thomas

Virgin Active London Triathlon

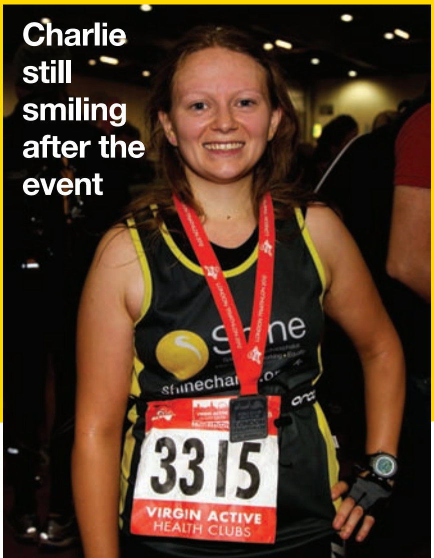
The weekend of 22nd and 23rd of September saw an awesome team of **Shine** fundraisers galvanized for the world's largest triathlon event at the Excel Centre and Royal Victoria Docks, London.

Triathlons are definitely not for the faint hearted, with those competing taking on particularly intense swimming, cycling and running challenges, over a range of distances, in the fastest time possible.

There were a number of individual competitors, as well as teams of three (each choosing to do an individual discipline) competing to raise money for **Shine** during the weekend.

So far, Team **Shine** have raised over £11,000 and there is still more money coming in!

So thank you to everyone who competed, supported, or donated to the Team.



Charlie still smiling after the event

Dear Tom,

In 1997, aged 18, I was diagnosed with congenital hydrocephalus. Over the next two years I underwent five operations and three shunt systems, but I was still in pain.

Having late onset hydrocephalus was difficult. I went from being a confident and active person, to spending most of my late teens in and out of hospital. Faced with constant pain and being unable to see my friends often, I would sometimes naturally feel down.

I realised that I had to look to the future, to what I could do in good health, and keep that goal as motivation for a speedy recovery. Understanding the need to distract myself from pain, I took up black and white photography and poetry writing.

That was 15 years ago and, over time, I have learned that I can do whatever I set my mind to. Having two tubes in my head (Torkildsen procedure) doesn't stop me. I have climbed mountains and, two years ago, I completed an *Ironman* for then ASBAH. No matter how bad things become, they will always improve and having a positive mind set and great, loving support are very powerful tools.

Yours sincerely, Johnny

Dear Editor,

I was born in 1979 with congenital hydrocephalus and had a shunt fitted at Great Ormond Street Hospital. I would like to fundraise for **Shine**, as I find them very inspiring, and I hope to take part in the 2014 London Marathon.

I believe that you must always live life to the fullest. If you are thinking about having an EVT procedure, whatever your age, I recommend that you go for it. It changed my life and helped me to achieve my dreams. I can now see my little girl grow and that's amazing!

Kind Regards,
Jodie Guest

Bon voyage, Simon!

Simon Tubb was born with spina bifida and is one of our latest fundraisers to have been bitten by the triathlon bug. Four years ago, struggling with his weight, Simon decided to sell his PlayStation, buy a bike 'and the rest' he says 'is history'.

Now 7 stone lighter, Simon is training for the *London to Paris Bike Ride* in April 2013 to raise money for **Shine**, and he is also competing in the *Slateman Triathlon* in May! Having been told that it was unlikely that he would even be able to run, Simon has disproved this diagnosis. Good luck Simon! Follow Simon through his training and preparation at: www.sjtubb.blogspot.com

SAMC Meeting August 2012

The SAMC met for their third meeting of 2012 on Saturday 18th August at **Shine** Head Office, welcoming CEO, Jackie Bland, Development Manager, David Isom, and Health Development Officer, Robin Barnatt.

Developments

Shine has drafted a description and person specification for the role of members wishing to be SAMC representatives, and used this to consult with the council members present. It was agreed that any new representatives must be 18 or over to be considered.

So, as we are coming up to the next election for the SAMC, there will be a selection process for those interested in joining. You can find out more by reading the piece in this issue on page 6 from **Shine**'s CEO, Jackie Bland.

SAMC also discussed plans for an event for adults to be held in July 2013. This will be an activity packed day event to be held called 'Rise and **Shine**' at Stoke Mandeville, with the option of staying overnight. You can get full details on how to attend this event in this issue; we will be looking at local and accessible hotels in case some members would like to stay. We will also be looking into transport options. I will keep everyone updated in the next issue.

Events

Paul Manning attended the Family Fun Day in Cornwall on Sunday 7 October. According to Paul: 'It was a great event. Seeing all the members and their siblings enjoying the whole day was a great sight.' Amar Dugal attended Understanding and Managing Challenging Behaviour (Associated with Hydrocephalus) on Thursday 4 October at **Shine** Head Office. I attended the **Shine** B&B Day in Southampton on Thursday 20 September (see below). It is nice that we can get to these events and meet the members/parents/carers and grandparents involved.

B&B Day Southampton

I attended this event and I have to say it was one of the best that I have ever been to. The event was opened and everyone welcomed by **Shine** Health Development Manager, Gill Yaz. Mr Patrick Malone, Consultant Urologist, at Southampton General Hospital, gave one of the best presentations I've heard and had everyone right in the palm of his hand with his every word as he explained everything.

Mr Malone then took time to answer many questions from the parents, which he managed with ease. Janice Bradley from Coloplast introduced the irrigation systems and again answered many questions on various issues. Pauline Gibbons, mother of Gabby, gave a great account of a parent's journey. It was so nice to hear a mother talk the way Pauline did; she too answered many questions and could have been there all day judging by the number of people keen to hear about her experience.

In addition, **Shine**'s Angie Coster, who is now Project Coordinator for the *Silver Dreams* Project was in attendance. David Isom and **Shine** volunteer and Trustee, Lorraine Watson, also talked to some of the parents and those who were attending a **Shine** event for the first time. They all said that by meeting other parents and sharing ideas the day was well worth attending.

Thank you to everyone who made the event possible.

I would like to thank Lee Fomeraill, General Manager at Riverside Volvo of Hull, who provided me with petrol for my visit to Southampton for the B&B Day. As a charity these gestures make such a difference and help to save on costs.

Get in Touch

Finally thanks to the members who have got in touch and I hope I have answered all your questions. Please keep those emails coming, as it is your SAMC, for you, the members.

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

Family Workshop

North & West Yorkshire ASBAH's Family Workshop *Hydrocephalus/Spina Bifida - What is it all about?* took place on Saturday 13th October 2012, in Bradford. Families with a child with hydrocephalus and/or spina bifida, up to the age of eleven, were invited to attend. The workshop was funded by grants from Jimi Heselden Fund, known locally as Jimbo's Fund, and The Freemasons of Yorkshire West Riding.

'It was priceless for me and for my children as well to participate that afternoon.'
Consultant Paediatric Urologist (came along with his two sons)

Fifteen families attended and parents took part in discussions with Mr Ramnath Subramaniam, Consultant Paediatric Urologist, and Mr John Goodden, Consultant Neurosurgeon (both from Leeds Children's Hospital) and Joanne Grenfell, **Shine** Education Adviser.

'Mummy that was an ace day out!'

Shine Begins at 50!

LOTTERY FUNDED

In association with Daily Mail

Shine has been chosen to manage an exciting new project involving people with spina bifida and/or hydrocephalus who are aged 50 plus. The Project is one of a number created nationally which are being funded by the BIG Lottery in conjunction with The Daily Mail as part of their *Silver Dreams* Programme.

The aim of the project is to reach out to our members in this age group so that they can create opportunities to share their experiences and make connections with each other. Previously there has been little attention given to the issues faced by people with spina bifida and hydrocephalus as they get older.

The idea is to gather information about getting older and living with the conditions; this could be about health-related problems, caring responsibilities, bereavement, financial concerns, mobility issues – anything that could affect this age group. We will also create opportunities for people to share practical tips and interests.

Project activities will include a newsletter written by members, online discussion groups, a befriending service, a new type of volunteering scheme, and a national event towards the end of 2013 to celebrate the achievements and explore the issues facing people as they get older with these conditions.

To register your interest in the project please contact Angie Coster, Project Coordinator.
T: 01308 426372 or
E: angie.coster@shinecharity.org.uk
or Lynn Hart, Project Administrative Assistant
T: 01733 421321
E: lynn.hart@shinecharity.org.uk

We look forward to hearing from you!

Latest Shine Cymru news round-up

Special educational needs – consultation events a first for Shine Cymru
The Welsh Governments proposals for reform of the provision of special educational needs prompted **Shine** Cymru to link forces with SNAP Cymru to deliver a series of consultation events for parents/carers.

As a result, **Shine** submitted a response to the consultation to ensure our members views were well and truly heard before any decisions were made.

- For further information or a copy of the response, contact Sian Prince, Educational Lead for Wales, at **sian.prince@shinecharity.org.uk or call our first point of contact on 01733 555988**

Spotlight on business
South Wales member, Veronika Bosbury, runs an on-line sports and leisurewear company verotti.co.uk

Shine members will receive a 10% discount on purchases - just mention you're a member when you place your order. Follow 'Verotti' on facebook.com/Verotti.co.uk

Shine Cymru's Ambassador programme
The WCVA-funded Volunteer project in Wales continues to go from strength to strength. Many members across Wales are gaining experience and support in their volunteering roles as fundraisers and events supporters for **Shine** Cymru.

2013 will see the introduction of an exciting new opportunity for **Shine** Cymru members, their families or friends to sign up and train to become Ambassadors for **Shine** Cymru.

If you are interested in finding out more, then please get in touch with Sally King-Sheard (Volunteer Development Officer) on **sally.king-sheard@shinecharity.org.uk or 01745 889457 / 07896 912340.**

Cooking fever reaches Wales
We've seen Danny Mills success in Celebrity Master Chef, Rebecca Morris' Cook Book with recipes from various celebrities, including Ainsley Harriott, Tanni Grey-Thompson, Rick Stein and Beth Tweddle, and now a group of enthusiastic volunteers in North Wales are busy making aprons and cookery sets to raise money for **Shine**.

Handmade Gifts
For Sale

Aprons (including Rolling Pin and Wooden Spoon) **£5.50**
Small Bags **£1.50**
Bottle Bags **£1.20**

Please contact Helen Aitken for more information:
Mobile: 07725594622
Email: helle1303@yahoo.co.uk

All proceeds to **Shine**
Thank you for helping us support families affected by spina bifida and hydrocephalus

Welsh stars of the future!

Both Harry Thomas from Pembrokeshire and Dan May from South East Wales were recently chosen to play for the Wales Under 15 basketball team at the National Junior Basketball Championships at Stoke Manderville. Special congratulations to Dan, who was team captain. Well done, boys!

Special congratulations to Dan, who was team Captain. Well done, boys!

Christmas and New Year at Shine Cymru

Shine Cymru are looking forward to the Christmas season and are holding several events that you could get involved with.

- West Wales are holding their Christmas meal on Thursday 6 December 2012 at 12pm in Aberystwyth
- South Wales are holding their Christmas get-together on Sunday 9 December 2012 at The Three Horse Shoes Country Inn, Moulton, Vale of Glamorgan, CF62 3AB (approximately 5 miles from Culver House Cross, Cardiff) from 4pm.
- North Wales are holding a Children's New Year's Party on Sunday 13 January 2013 at Craig-y-Don Community Centre in Llandudno from 2-4pm.

If you would like to book your place on any of these events please see the events listing on page 27 for the relevant contact details.

Reform of Disability Living Allowance

Disability Living Allowance for adults is being replaced. The government has announced that from next year, there will be no new applications for Disability Living Allowance (DLA) for adults. Furthermore, all existing adult claimants of DLA will be expected to apply for the new benefit which is called Personal Independence Payments (or PIP).

Q: When will this happen?

A: For new claims of PIP, people living in the pilot areas of the North West and the North East of England will be able to apply from April 2013. If you live elsewhere in the UK you will be able to apply from June 2013.

Existing claimants will be expected to apply for PIP between October 2013 and March 2014. The benefits office will get in touch with you about this (in writing and by phone) in due course.

Disability Rights UK
Go to the home page and scroll down to the 'fact sheets' section, and look for 'Personal Independence Payments'. These fact sheets are very detailed and good if you already know your way around the benefits system
disabilityrightsuk.org

ARIENNIR GAN Y LOTERI
LOTTERY FUNDED

Q: What about payments?

A: For existing DLA claimants, once you claim PIP, your DLA will continue until the decision to award PIP is made. If you are entitled to receive PIP, you will be transferred without a gap. However, it is important to note that if you fail to apply for PIP, your DLA payment will stop anyway. This is why it will be vital to apply once you have been given the invitation to do so. Unfortunately, if the amount you get is less on PIP than it was on DLA, you will not get a top-up to make up the difference.

Q: What are the key differences?

A: In many ways, there are close similarities between PIP and DLA. Like DLA, PIP will have two components: a 'Daily living' component (similar to DLA care); and a 'mobility' component (similar to DLA mobility). However, unlike DLA, PIP will have only two rates, a standard rate (similar to middle rate DLA) and an enhanced rate (similar to higher rate DLA).

The rate of PIP that you are awarded will be decided with reference to a list of activities and descriptors – each with its own score value. You will need to score at least 8 points for standard rate or 12 points for enhanced rate. As this new scoring system seems to reflect the middle and higher rates for DLA, some of the obvious losers will likely be those currently on the lower rates of care and mobility.

Significantly, the most prominent change will be that in most cases, you will be expected to attend a face-to-face assessment. At present we have little detail about how this assessment will be conducted, but we will keep you updated.

Q: Where can I get more information?

A: Other than speaking with your local advice agency, you can get some further information from the following trusted sources:

Official
Go to the home page and use the search function to locate web pages on DLA and PIP. There are plenty of official links and resources at direct.gov.uk

Shine
Go to the main **Shine** homepage and look for 'how we help' and 'welfare benefits'. You will see a downloadable fact sheet for PIP on the DLA webpage **shinecharity.org.uk**

Summer Fun in Northern Ireland

Although there wasn't much sun this summer, we certainly had lots of fun! Our younger members had two outings to the Donkey Sanctuary in Templepatrick, one in July and one in August. The little ones each rode on a donkey and dressed up in donkey costumes. The sensory room in the Sanctuary was also a great success.

Our adult Members went on an outing to Belfast Activity Centre. They tried wall climbing and abseiling – definitely not for the faint hearted. They also tried archery, but we have no budding Robin Hoods

We also went to see Footloose at the Waterfront. A fabulous night of entertainment and some of us met the cast!

Northern Ireland contact:
northern.ireland@shinecharity.org.uk

AGM will Ring in Changes

Shine's final AGM under the present constitution will be held at **Shine** HQ, 42 Park Road, Peterborough PE1 2UQ on 29th November beginning at 10.30am. The meeting will vote on a new constitution, which will allow all **Shine** members over the age of 16 to vote at future AGMs on key matters affecting the organisation, including who should serve on the Board of Directors. This change will make the organisation far more democratic and open up further opportunities for members (including family members and professionals) to play a role in **Shine**'s development.

Alongside changes to voting rights **Shine** has undergone a governance review, which will mean that Board members can only serve a maximum of two consecutive terms. There will be new opportunities to join **Shine**'s Board from the AGM in 2013. It is never too early to contact us if you think that you, or someone you know, might be interested in serving on the Board in the future. **Shine**'s Finance Director, Margaret Connor, welcomes all informal enquiries.

The AGM will be followed by the presentation of the 2012 **Shine** Awards, which recognise individual achievement and outstanding contribution to the charity.

Only individual members and **Shine**'s Directors are entitled to vote at the AGM, but anyone is welcome to attend, stay for lunch, and watch the **Shine** Awards being presented. If you plan to attend the AGM please contact **Lyn Rylance**
lyn.rylance@shinecharity.org.uk
tel: 01733 421356.

Benny's brilliant busy summer

What a busy summer I have had, travelling from place to place, meeting wonderful Benny friends and their families. I watched the Tour De France and the Edinburgh Tattoo, but my visit to the Paralympics was the most memorable. I was fortunate enough to accompany Gobi in carrying the Paralympic Torch.

I love to visit schools, where I can talk to children who have hydrocephalus, just like me. My Benny Bear books have now been re-printed and are also available to download for just £1.00 each. These books are fantastic in helping all children to understand hydrocephalus. I have also recorded the stories as audio books, so hopefully these will be available to listen to very soon.

Whilst I was out enjoying myself, hard work was happening all around me. A nursery in Brighton had a Teddy Bears Picnic and one of their staff is now training to run the Brighton Marathon for **Shine**! Hammerwood Cricket Club's 'veteran' players had a charity match and raised nearly £150.00! Thank you everyone, these fund raising activities are so important. I was involved in many *Wear Yellow and **Shine*** events for Spina Bifida and Hydrocephalus Awareness Week, October 22nd–October 28th. Don't worry if you missed these events, you can have a Wear Yellow and **Shine** day or a Benny Bear Birthday anytime! Just call Hannah on T: 01733 421351 to find out more.

Finally, welcome to Summer Finlay, born on 4th April 2012, the 400th member of the Benny Bear Club. My target is 600 members by December 2012, can you help? Ask your friends, schools and clubs. There are further details about how to join at bennysblog.co.uk

So, into Autumn we go, with lots of new ideas and enthusiasm. Thank you all for your support and I look forward to catching up with more news soon.

Be brilliant! Benny

Shine's Lifelong Opportunities Programme of National Events

Shine is continuing to develop its Lifelong Opportunities Programme [LLOP], including events such as:

- Family Opportunity Weekend
- Bowel and Bladder Day
- Teenage Residential Event
- Grandparents Day
- Hydrocephalus the Hidden Disability
- Family Fun Day
- Adult Lifestyle Event
- Understanding and Managing Challenging Behaviour associated with Hydrocephalus.

Please contact either **Dave Isom**
E: david.isom@shinecharity.org.uk
T: 01733 555988 or **Joan Pheasant**
E: joan.pheasant@shinecharity.org.uk
T: 01332 556767.

> **'We look forward to hearing your ideas.'**

Here at **Shine** we are keen to develop further LLOP events so we are interested to know what type of events members would benefit from in the future, for example event themes could be related to education, independent living, wheelchair services, etc.

If you have ideas for future national events we would love to hear from you and would also like to hear about possible suitable accessible venues local to you.

Rise & Shine

A lifestyle event for adult members with spina bifida/hydrocephalus.

Stoke Mandeville Stadium, Guttmann Road,
Aylesbury, Buckinghamshire HP21 9PP

Sat 20th - Sun 21st July 2013

Adult Member Lifestyle Event to promote getting involved in social activities including sports and other leisure pursuits.
Elements of the event will also cover health, wellbeing, and mobility/independence aids.

- **Saturday 20/7/13 to include:**

Healthcare: Hollister, Mitrofanoff Support Group, Nutrition advice, RN Sports Therapy, and Complimentary Therapy
Sports: Basketball, Badminton, Boccia
Misc: Wheelchair Services, Disability Holiday/ Breaks, Art workshop.
**All exhibitors subject to change/confirmation*

- **'Have a go' sessions & workshops**
- **Sunday 21/7/13 to include:**

Breakfast and coffee morning/social time.

LOTTERY FUNDED

Costs:
Weekend rate £120
(All Inclusive, overnight rate)
Day rate £15
(Lunch included)

Closing date for applications Friday 21st June 2013

Weekend rate includes lunch, dinner, fully accessible accommodation maximum 35 twin rooms and breakfast. A limited number of rooms can host 3 people. Details of additional off-site accommodation can be provided, at visitors own cost.

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

Family Opportunity Weekend 2013

Friday 15th – Sunday 17th March

A weekend residential for families with a child **(0 – 5 years)** with spina bifida/hydrocephalus, IH

Holiday Inn Hotel, Coventry M6 J2

Closing date for applications 11th January 2013

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

This event will include:

- Information sessions and workshops for parents
- Activities for all children and their siblings
- An organised trip for all of the family
- Benny Bear's birthday celebration
- Family portrait sessions
- Social times for families together
- Family swimming sessions
- Complimentary therapies for parents

£160 per family

***Shine** working in partnership with Holiday Inn.*

For an application form or to find out more about any of these events contact: Joan or Denise
T: 0113 255 6767 **E**: office@shinecharity.org.uk **Shine**, 63 Bagley Lane, Farsley, Leeds LS28 5LY
Please register your interest as soon as possible.

Time to Shine Adventure

A residential course for 12-16 year olds with Spina bifida, hydrocephalus or intracranial hypertension

Pioneer Centre,
Action Centres UK Ltd,
Cleobury Mortimer, Shropshire
DY14 8JG

Mon 12th - Thur 15th August 2013

Closing date for applications 18th January 2013

Please note that parents of those attending will have to arrange their child's transport to the Pioneer Centre. Some families consider staying in the area, therefore reducing travel time.

The course aims:

- To offer new and exciting experiences
- To give opportunities to meet new people and make friends
- To allow those attending to be themselves and have a fun time

The organised activities will be lively, and include Fencing, Abseiling, Treasure Hunt, working with Birds of Prey and a Camp fire on the last night. Other activities will also be planned. There will also be lots of opportunities for socialising.

Events 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

Shine Christmas Cards

If you would like to order some **Shine** Christmas Cards, please complete the order form below or call **01733 421328**

Each pack of 10 cards and envelopes comes with a traditional Christmas greeting inside.

Welly Xmas

Kings

Contemporary trees

Penguins

Carols in the snow

Hiding in the snow

Garden Robin

ORDER NOW ● ORDER NOW ● ORDER NOW ● ORDER NOW

Please send me:	Qty	Price per pack	Total (£)
Carols in the snow		£3.40	
Penguins		£2.30	
Garden robins		£2.80	
Hiding in the snow		£2.80	
Contemporary trees		£2.80	
Kings		£3.40	
Welly xmas		£3.40	
Number of packs		**Postage per pack**	
1		£1.00	
2		£1.50	
3		£2.00	
4 to 9		£2.50	
10		£5.00	
Over 10 packs		FREE	

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

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

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

☐ VISA ☐ Mastercard Security code

Card no.

Start date Expiry date

Signature: ....

Name: ....

Address: ....

.... Postcode: ....

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

Email: ....

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

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