Together

Issue three 2011

Inside this issue

Introducing Gobi

Inspirational students

and much more

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Information • Networking • Equality

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It may only have been a few weeks since you received the second edition of *Together* but we were keen to get back on track with our quarterly publishing date so here we are in issue three!

Everybody at **Shine** is working flat-out to be ready for the launch on 20th October and you can read all about this and all our other developments in this 24-page edition of *Together*.

In this issue we warmly welcome Gobi Ranganathan, our new Membership Development Officer. Gobi will become a very familiar face to all of the **Shine** membership and you can get to know him better in our feature interview on page 8.

We also hear from inspirational students Casey Bottono and Ashleigh Parry who will both start their studies at university this October – see pages 14 and 18 for more.

We are as keen as ever to hear what you have been up to and what you would like to see here in *Together*, if you would like to share anything then please contact me at **tom.scott@shinecharity.org.uk** - I'd love to hear from you.

Tom Scott

Editor

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Submission dates for Autumn Edition

Register of interest to submit: 23rd December 2011
Final date for submissions: 7th January 2011
Publication date: 21st January 2011

All enquiries and comments to: Together
Shine, 42 Park Road,
Peterborough PE1 2UQ
Telephone: **01733 555988**
Textphone Service: **01733 421395**
info@shinecharity.org.uk **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

Registered charity no. 249338

Somerset Shine

The Somerset Association for Spina Bifida and Hydrocephalus has become the first local association to adopt the new **Shine** name and logo style. The decision was made at the charity's AGM on 20th September and **Shine** Somerset will be launched at the same time as national **Shine**, on October 20th 2011.

Shine
Somerset
Spina bifida • Hydrocephalus
Information • Networking • Equality
Formerly the Somerset Association for Spina Bifida and Hydrocephalus

Employment prospects

We have heard from some of you about your experiences with employment. As part of our new five year strategy we want to find out more and come up with ways of improving the employment prospects of our members.

So, can I ask you to let me have your personal experiences of employment, so that we can begin to look at what we can do? You can write to me at the Regional office, telephone me, or send me an e-mail. I look forward to hearing from you. *Jo Francis,* London and South Region Development Manager, 209 Crescent Road, New Barnet, Herts. EN4 8SB Tel: 0208 449 0475 E-mail **jo.francis@shinecharity.org.uk**

Volunteers at Head Office

You may sometimes wonder how we manage to get 9,500 copies of Together posted out to you every three months. Well, we have a team of volunteers that come in from PCVS and work non-stop until the job is done. We really appreciate all they do and offer a big 'THANK YOU'! to all involved.

Congratulations to Scott Nielson

Huge congratulations to cyclist Scott Nielsen on completing his epic 2000km ride from Copenhagen to Liverpool. Scott, who is 18 and has hydrocephalus, raised a tremendous £2000 for **Shine**. You can still add to this total by visiting Scott's JustGiving page here - **http://www.justgiving.com/Scott-Nielsen**

Shine awards

The first **Shine** Annual General meeting on November 17th 2011 will also see the first **Shine Achievement Awards.** As well as the **Shine** Lifetime Achievement Award, this year will see the introduction of four new awards, **Shine** Young Achiever, **Shine** Professional, Shine Fundraiser of the Year, and **Shine** Unsung Hero.

The **Shine** Unsung Hero will be decided based on nominations from the **Shine** membership. If you are reading this before November 10th there is still time to send in your nomination for the person, aged over 18, who you think deserves an award for their hard work and dedication in the field of spina bifida and hydrocephalus. It could be a member with spina bifida and/or hydrocephalus, a parent, carer, local association or support group volunteer, sports coach or any other person whose outstanding efforts deserve recognition.

To nominate someone please send in the person's full name, address and contact details. Then, in no more than 400 words, please explain what they do and why you think they deserve to be the winner of the first **Shine** Unsung Hero Award. The award winner will be invited to the AGM on 17th November to be presented with their Award and commemorative certificate by **Shine** Chair Richard Astle.

You can e-mail your nomination to **tom.scott@shinecharity.org.uk** or write to **Shine Unsung Hero Award, Tom Scott, Marketing and Communications Officer, 42 Park Rd, Peterborough PE12UQ.** Or, if you prefer, you can call on **01733 421361** and we will record your nomination for you.

Hydrocephalus event 'inspirational'

More than 70 parents, carers and professionals attended 'Hydrocephalus – the hidden disability' a **Shine** event held at Westpoint Conference Centre, Exeter.

The day focused on equipping those attending with an understanding of how hydrocephalus can affect learning, development and behaviour. Delegates were also introduced to strategies for helping children with hydrocephalus to achieve their true potential.

Feedback rated the event as 'inspirational' and 'better than I could have hoped for.'

Speakers included Consultant Neurosurgeon Ian Pople, from Bristol's Frenchay Hospital, who explained the causes and treatment of hydrocephalus, and parent Jane Jones, who is the mother of Jacob, aged 11 who has hydrocephalus. Casey Botono aged 19 gave a moving speech about how she had overcome many challenges to achieve a place at university this year *(see Casey's article on page 18)* and **Shine**'s Health Development Manager, Gill Yaz, provided information and insight into shunt malfunction and how hydrocephalus can affect a child's cognitive behaviour.

Finally, a range of workshops explored issues such as sleep management, welfare benefits, cognitive processes, education, and practical solutions to support children with processing difficulties.

Delegates left asking for 'more of the same' and **Shine** is now looking into ways of developing a regional programme of such events so that participants from all over the country have the opportunity to attend.

Jane Jones shares fron her experience

An evening of reflexology

Thanks to support from the Big Lottery Fund in Wales and the Volunteering in Wales Fund, South Wales members of all ages enjoyed an evening of reflexology in Cardiff in September.

Tracy Wheeler, a **Shine Cymru** qualified reflexology practitioner from Cardiff-based Take Sixty, gave an extremely interesting and witty talk about her experiences of reflexology and its potential uses in managing conditions associated with spina bifida and hydrocephalus (including urine infections, constipation, anxiety and stress).

Members were then treated to reflexology taster sessions by Tracy and two of her colleagues, who generously volunteered their time for the evening.

The evening also gave our members, family and friends an opportunity to meet others and share experiences.

For further information on reflexology and services offered by Take Sixty, visit www.takesixty.co.uk or contact Tracy at enquiries@takesixty.co.uk

Restricted Funds Release

Shine has two appeal funds with value of £85,000 which cannot currently be utilised effectively. The funds were set up so that any income generated could be used, but not the original capital. Income generated in recent years has been much reduced due to falling investment returns. The trustees wish to remove the restrictions and include the remaining funds as part of the general reserves so that they can be applied to Shine's wider charitable purposes.

In 1973, £55,000 was raised by ASBAH from an appeal to set up a Research Fellowship Fund. Since then, income has been generated from the fund and over £90,000 paid out in grants. Nothing has been paid out since 2003, as the income generated is too low to fund an effective fellowship.

In 1989, £30,795 was raised from an appeal for funds to set up a bursary fund to give educational grants. £63,000 has been paid out in grants over the years as the fund was topped up by the Trustees.

Charity Commission regulations specify that any change to restricted funds requires the consent of the original donors. Any members who donated to the original appeals are asked to email Margaret Connor on margaret.connor@shinecharity.org.uk by 30th November 2011 with your details advising whether you agree to the change of use of the funds or any concerns you have.

AGM Date

The first **Shine** AGM will take place at Head Office on November 17th 2011.

Former Eastenders star gains freedom of London

Shine is proud to share the news that as well as becoming a member of **BAFTA**, our Patron, actor David Proud, has been awarded the prestigious honour of the Freedom of London.

David, who has spina bifida and has been involved with **Shine** since a young age, received the award at a special ceremony on 16th September at London's Guildhall.

The former Eastenders star is thrilled to have been chosen for the honour and commented, 'It is going to be a very special honour for me. I really hope I can use this role to highlight the fantastic work of the many charities I work with.'

Explaining the special regard he holds for **Shine**, David said, 'I have spent a lot of time working with **Shine**, meeting people with spina bifida and hydrocephalus from all over the country. The staff at **Shine** do such a vital job and support the lives of so many families. It has, and always will be a great honour to be their Patron.'

Appointments

Staff changes are afoot at **Shine** and we have 2 new enthusiastic members of staff to welcome on board. The first is **Gobi Ranganathan**, our new Membership Development Officer who started work with us on September 19th. You can read more about Gobi in the interview with him on page 8. **Sandra Campbell** is the new Support & Development Worker to join the Northern Ireland team - welcome too, to Sandra! Sandra comes from a background in education, and her most recent position involved advocacy and support for the The Progressive Supranuclear Palsy (PSP) Association. Sandra's experence means she is well matched to her new role, and will bring some excellent experience to the **Shine** NI team. Sandra started with us on October 1st.

Benny Bear 200 Members

Benny writes: As the Summer comes to an end it's time for me to look back on a great few months.

The Benny Bear Club continues to keep on growing. There are now over 200 members in the Benny Bear Club and I'm looking forward to the future – we are going to have so much FUN!

I have visited people all over the country and I can't wait to see you all again soon. In October I will be involved in various events as we celebrate the launch of **Shine**.

We are about to launch our new fundraising scheme – Benny Bear's Birthday – so watch out for more on this in the coming weeks. Your school, community group or your friends can get together and host a Benny's Birthday event, have FUN and raise some money for **Shine**!

To find out more please visit:
www.bennysbirthday.co.uk
or contact Cerys Long on **01733 421329 / cerys.long@shinecharity.org.uk**

Gobi Ranganathan takes up his role

As Gobi Ranganathan takes up his role as Shine's new Membership Development Officer, Tom Scott learns more about how living with spina bifida has both challenged and shaped the character of a truly inspiring person.

Born in Singapore and raised in Stevenage, England, from the age of three, Gobi's journey has been one of test, turmoil and triumph. He has literally been to the brink and yet continues to defy all the odds and maintain his place as a top para-athlete.

Gobi admits that it hasn't been easy to achieve what he has – succeeding at school and then gaining a degree, competing as a top para-athlete and establishing a successful career, whilst undergoing multiple operations for mobility and continence control. **'But'** he says, **'it's definitely been character building!'**

Freedom

Gobi could only walk short distances as a child and attended Lonsdale Special Needs School, Stevenage. After a year the staff suggested that he might benefit more from a mainstream primary school environment and he successfully made the transition.

At secondary school Gobi began to use his wheelchair more frequently, **'Moving between classrooms it was necessary to be in the chair. To be honest, I found it liberating; to be able to move myself and decide where I was going without anyone pushing me gave me a great sense of freedom.'**

Sports star

Gobi also began to explore his interest in sport. He developed a passion for swimming and was soon competing in para-swimming competitions. He enjoyed this but it was a tough environment to be in: **'The thing was, there were a lot of politics in swimming in terms of how they categorise para-swimmers. For example, I was competing against guys who were diving in and could push off the wall with their legs at the turn. I just got on with it, but after a while you see guys getting selected over you with their advantage and it just isn't worth it.'**

Gobi continued swimming throughout university but it was badminton that became his main focus, and he rapidly demonstrated remarkable talent and dedication. Before long he was regularly winning against both disabled and able-bodied players. Then, in 2007, Gobi made it to the Parabadminton 4 Nations Championships

in Cardiff and won a Gold medal in the Men's Doubles.

As a high performance athlete Gobi still trains 4-5 times a week on the court as well as working in the gym. **'I use the hand bike a lot to keep my cardio fitness up. The gym I go to have been great, they even removed the bike's pedals that used to spin around and hit my legs.'**

To the brink

As Gobi was developing his academic and athletic potential he was also periodically undergoing serious surgery. 'Keeping healthy definitely helped me deal with the operations I was having. After my surgery for a Mitrofanoff revision in May 2011, I was told the recovery could take up to 4 weeks – I was out in 2. The Urology team were impressed with my recovery, and knew I would be better off at home. It wasn't long before they gave me the green light to get back into light training again.'

At 18 Gobi had been one of the first people to have a Mitrofanoff* procedure to enable him to self-catheterise. This was relatively problem free, until his need for a revision of the operation earlier this year.

However, his most dramatic experience followed a visit to a walk-in clinic in 2005 to check out a lump in his stomach. The diagnosis of a strangulated hernia led to a six-month stay in hospital.

Continued on next page

What is a Mitrofanoff procedure?

Creation of a urinary tract using the appendix or urethra, enabling intermittent self-catheterisation.

After surgery Gobi became violently sick. He was diagnosed with an infected abscess and recalls being rushed into theatre only to find that the emergency list was too long. Gobi heard his consultant say to a colleague **'Yeah, his body's shutting down.'** Thankfully the theatre was kept open and Gobi underwent life saving surgery.

A week later something was still very wrong. As Gobi says, **'When you can see what you're eating coming out of your stomach, it ain't great!'** This time Gobi had a fistula – a ruptured bowel - and had to have a colostomy operation. Life as a top sportsman now seemed like a distant memory.

However, a colostomy reversal operation followed in February 2006, and despite then becoming infected with the MRSA bug, he pulled through to make a recovery.

In March 2006, six months after entering the walk-in clinic, Gobi was able to go home. It was another three months before he was feeling well again. Far from finding reasons not to get on with life, Gobi remarks, **'I'm one of those people, I get on with it, I cope with it.'**

Today, Gobi is once again at the top of his game, having just regained the UK Men's Para-badminton No.1 spot.

The future

In his work with **Shine** members, Gobi hopes his own experiences and resilience will provide inspiration: **'People are quite scared of what they don't know … it is a big wide world out there but it's not that scary!'**

'My experience is that there are people and systems out there to help and I want to help people plug into this so that they gain opportunities to do their best in life.'

Gobi will be engaging with every aspect of the **Shine** membership over the coming months in an effort to hear what you have to say and what you would like to see happen. To contact Gobi direct you can email him at: **gobi.ranganathan@shinecharity.org.uk**

facebook

Keep in touch with Gobi on facebook

facebook.com/shine.gobi.ranganathan

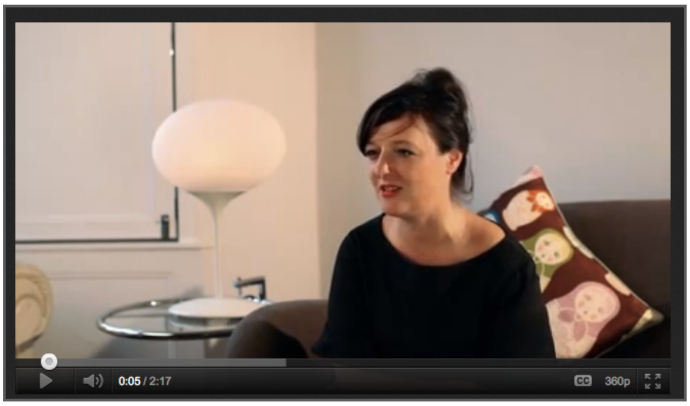
About Para-badminton
Para-badminton is played at domestic and international level, with various International Opens, including European Championships and World Championships (the next being this year in November in Guatemala).

Go Folic! – Folic Fred

‘Hilarious’, ‘Saucy’, ‘Great fun’ – Folic Fred is going down a storm. Complete with a dodgy French accent, Folic Fred the seducer, sets out to charm women into taking folic acid before they get pregnant... ‘Take me, take me now!’

Watch him, watch him now!

Go Folic! – Zoe Burnay



Go Folic!’s latest video is equally memorable and completely different. A very poignant film, it features a mother speaking about her daughter who has spina bifida and hydrocephalus. Mumsnet have been helping us to promote the film which people tell us they find very moving.

The videos have already had over 4000 views on you tube. Thank you to everyone who has passed these links on to their contacts ... keep going as we want Go Folic! to Go Viral!

To view these films visit
gofolic.co.uk

Thanks to Vitabotics

The Go Folic! Campaign receives contributions from various supporters. We would like to take this opportunity to thank everyone at Vitabiotics and Pregnacare for their funding for the first two Go Folic! films.

Proudly supported by:
Vitabiotics
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Fit For Success is **Shine**’s programme to encourage our membership to keep fit and healthy and achieve success in sport.

As part of this initative we are introducing ‘**Challenge Gobi**’ - you can challenge Gobi to try a new activity and he will feedback on how approprate it is for disabled participants.

To challenge Gobi email your suggestions to **tom.scott@shinecharity.org.uk**

A day in the life of **Shine**'s Health Development Manager

What is a day in my life like?

Good question, as no two days are the same, which is why I love the job so much.

Today, for example, I'm off to Liverpool to meet with a group sharing their experiences of staying healthy with spina bifida which follows on from a successful and enjoyable group meeting of adults with hydrocephalus in Exeter last month.

At the moment I'm looking at ways of keeping in touch with the groups using modern technology, like Skype, although it's not quite the same as meeting you in person!

Getting to grips with a shunt with the help of Benny Bear

Tomorrow I'll be catching up with my messages and talking to members who have health questions for me. I particularly enjoy talking to people about their bladder and bowel challenges, knowing how big an impact they have on health and how people feel about themselves. I'll have a look at our Facebook page too, in case someone has posted a problem I might be able to help with (don't forget you can always contact us directly).

Since starting my new role as Health Development Manager earlier this summer, I've been working on some exciting new projects, including some new surveys looking at the health issues you face and what you think about the services you receive. This will help us look at better ways to support you to stay well and highlight any concerns you have about your local health services. I'm still attending some clinics, which gives me the chance to meet families. I always learn something new there too.

I hope this gives you a glimpse of my 'typical' day, I look forward to hearing from you in the future if you have any health questions, or if you want to add your voice by completing one of our questionnaires in the coming months.

Contact Gill on:
0208 449 0475 or email
gill.yaz@shinecharity.org.uk

Discontinued Catheters

News that *Scott catheters*, a plain catheter for intermittent catheterisation, is no longer to be manufactured has caused a stir amongst some of our members.

We have been contacted by several ladies trying to find a suitable replacement, and it's proving quite a challenge! Coloplast, who have been making the Scott, blame lack of demand for the product for it's discontinuation, and suggest trying their Self-Cath range.

Suggestions from other services iclude SafetyCat from Hunter Urology, and Coloplast's Speedicath Compact might be worth trying.

If you are having trouble finding something to replace your Scott catheters with, please contact me on **gill.yaz@shinecharity.org.uk**, and I'll arrange to have some samples sent out.

Shining a Light on the Printed Word

As we say farewell to 'ASBAH' and hello to the new organisation of '**Shine**', I feel sure that we all hope that the best facets of the old organisation will be transferred to the new, but also be accompanied by many new initiatives to further encourage members to develop independent and rewarding lifestyles and play a fuller part in the organisation itself.

As a member of the **Shine** Adult Members Council, and a Support and Development Worker for **Shine**, perhaps I should point out to readers who don't know me, that I have spina bifida. I also have hydrocephalus for which I had surgery in the mid-1950s, leaving me visually impaired due to nerve atrophy.

Throughout the majority of my life, whether being served by Braille, audio formats or email, I have had to rely on the written word being edited by the transcriber. My father, for example, almost driving himself hoarse reading me literature of various kinds, would even occasionally say: '**Oh you don't want that, it's rubbish.**' Thereby almost acting as a censor!

I have many times raised the issue of printed material about our organisation, our conditions and other information being available to anyone who is 'print disabled'. Being print disabled due to visual impairment, dyslexia, a learning disability or an inability to hold a written document, *Link Magazine* was occasionally read to me by members of staff onto cassette outside working hours. I gather that it was also available in large print (if read on-screen)

If we are to address this matter of the lack of access to **Shine** literature to such members, then the first step must be to accurately establish how many print disabled people **Shine** has in its membership. If they are denied this opportunity, they may not be so easily encouraged to overcome the many other barriers in society to independent living.

Statistics on the database are sadly lacking in this respect because information about supplementary conditions and disabilities is often not available. Thus far, there are 9 people identified as having a visual impairment, 35 who are blind and 9 who have a learning disability. Dyslexia is not even identified as a disability at present. There will also be a number of others whose additional disabilities have not yet been recorded.

I would respectfully suggest that if any individual has difficulty reading *Together* and the other literature produced by **Shine**, they should contact the National Office to have these specific difficulties noted. Alternatively, contact your Support and Development Worker and make sure that you receive printed material in the format that most suits you.

John Richards.

Shine Support & Development Worker
Bedfordshire, Hertfordshire and
Buckinghamshire.

Beginning my Life as a Hydrocephalic Oxonian

By Ashleigh Parry

Who, three years ago, would have thought that I would be here now?

At that time, I had been severely ill with shunt malfunction for around a year, and could see no sign light at the end of the tunnel. I had weathered all the uncertainty of A-levels while still picking myself up from missing GCSE's, often exhausted and struggling to come to terms with what I had experienced. When results came, I was ready for them to possibly not be what I had hoped, despite all of the work that I had done. Upon finding my actual results, it was with a brimming feeling of such happiness at what I had managed.

Now, though, here I am readying myself to go to Oxford, the university of my dreams, at Worcester, my dream college. With regards to my hydrocephalus, I feel better now than I have felt in years. Recently I visited Mr. Mallucci at Liverpool's Walton Centre (a brilliant consultant, by the way), and had CT scans for the purpose of check-up. **Seeing the perfect position of my catheter in ventricles of an acceptable size on that image was almost enough to make me well up.** But, when it comes to looking ahead, every day my excitement for going away is growing, as I hear more and more about the cultural, academic and "recreational" opportunities that will be open to me. Freshers' week beckons through flyers and Facebook invites for events, club nights and meals out.

However, before I can even get there, there is the mountain of preparation to be overcome, all of which has had to be accompanied by hundreds of post-it note lists just for me to keep track of them. Some of these experiences I will share in common with other students at my college, irrespective of whether they have hydrocephalus or indeed any disability. These include, among other things, the need to actually think about everything that one would normally borrow from parents or siblings and is actually going to have to buy now, such as toothpaste, make-up,

In the gardens at Oxford

shower gel and paper, to name but a few. Then, one other issue I will share with the six others who have been selected to study my subject (English language and literature) namely the huge reading list, which includes some formidably long Dickens novels. But this, considering how much I love reading, has not posed the greatest problem for my pre-university organisation.

What has been a terrible bugbear, though, and will particularly affect those with disabilities, maybe those with hydrocephalus a little more so than some, is the paperwork: a disability disclosure form, two medical forms and information to be supplied to Student Finance. With a disability as complex as hydrocephalus, which can have so many different and often subtle effects, that adds up to a lot of writing, and photocopying of letters and information. I think that Mum and I have used three large black ink cartridges since we began. I have been very impressed, though, by the sheer range of special considerations provided by the college, not only spanning to extra time in exams and rest breaks, but also permission to photocopy set texts from the library, and to record lectures. The Disabled Students' Allowance aspect of Student Finance has a similarly wide and useful provision, including certain equipment and software that I had never even considered. For example, because of the difficulties which I experience in written communication, as compared to verbal, voice recognition software has been recommended by my assessor for easier notation and essay-writing, something which I had never thought of as a possibility.

Mum, who has been my lifelong secretary, has also been a Godsend when it comes to organising this paperwork – her patience with it has been legendary. She has also helped hugely with organising my packing: she has thought of things which I had not even considered, for example, biscuits – not just for snacking, but for bonding too. Mum will also probably be my best hope of fitting my copious wardrobe into the suitcase which now resides in the corner of my bedroom. But, alas, with perfect foresight, I know that I will still struggle to find anything to wear once I arrive and unpack.

Now, my matriculation gown is sent for, my various forms and contracts in the post, and the next task lies in alerting the John Radcliffe Hospital of myself, my proximity and my condition, although fingers crossed, it won't be necessary. I also need to do something about all of my belongings which are "sorted" in a drawer and a few shelves, just to ensure that they won't be hastily squished into a suitcase at the last minute come October!

Visiting Worcester College with mum, Denise

Christmas Cards

If you would like to order some **Shine** Christmas Cards, please complete the order form below.

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

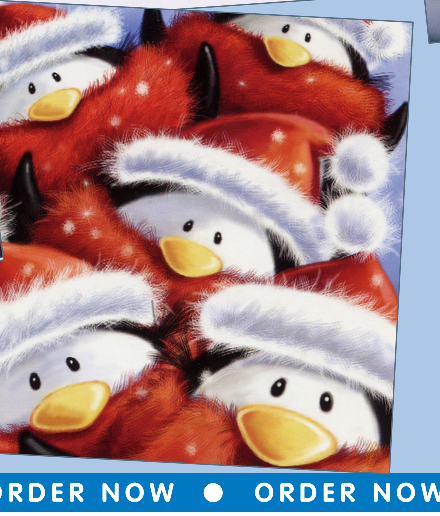
Welly Xmas

Carols in the snow

Hiding in the snow

Garden Robin

Kings



Penguins

Contemporary trees

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		£0.70	
2		£1.40	
3		£2.10	
4 to 9		£2.40	
10		£3.15	
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 ☐☐☐

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

Shine Merchandise

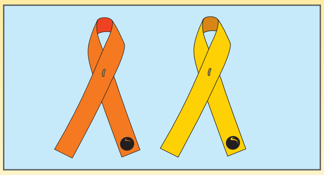
Bags of Life	£2.50
Pens	£1.00
Pin Badges	£1.00
T-Shirts	£6.50
Ribbons	£1.00
Ribbons (1 of each)	£1.50
Balloons x 20	£1.00
Mugs & box available to pre order	£5.00
Sweat shirts	£35.00

p+p details on order

Bags for Life

Shine Sweat shirts, front and back

Shine Pin badges



Ribbons

Shine T-shirts, front and back

To order call Andrew or Cerys on 01733 421307

Transylvanian Challenge

exclusive trek for Shine

13th – 18th September 2012

This is a fantastic opportunity to take on this stunning challenge to help raise money to support the vital work of Shine.

The adventure begins in the beautiful Piatra Craiului National Park with a scramble and large ascent to wet your appetite, before continuing on to a remote village and a warm welcome.

Be prepared for some steep climbs and rough ground, but expert guides will assist you every step of the way, through the spectacular scenery in the heart of the mountains. A night in the country's highest mountain hut will be an experience that will leave you with a tale to tell on your return.

Our fundraising team will help you every step of the way, including sponsorship forms and online giving facilities, PR advice and plenty of tips to help you exceeding your target.

To find out more please contact Cerys on 01733 421329 or email cerys.long@shinecharity.org.uk

Grand draw

It's that time of year again ... tickets are now available for our 2011 Grand Draw!!

Last year we raised £15,000 from the Grand Draw and this year we hope to do even better. Please help us to raise as much as possible by selling to friends and family - you may even want to take them to work!!

Please note that as the draw will be taking place on 19 December, the tickets are printed with our new name **Shine**.

Our wonderful list of prizes:

- 1st prize: £1,500 cash
- 2nd prize: £500 Next vouchers
- 3rd prize: Two return Eurostar tickets to Paris, Brussels or Lille
- 4th prize: Helicopter ride with afternoon tea and overnight stay at Broadoaks Country House in Cumbria

Plus

- Two Skoda rally jackets
- DC25 Dyson vacuum cleaner

Registered charity no.249338

To request your Grand Draw books
(5 tickets per book)
please contact Amanda Sanderson on amanda.sanderson@shinecharity.org.uk or call 01733 421334

Life without limitations

In this special piece for *Together* Casey Bottono talks about her life with hydrocephalus as she gets ready to begin her degree studies at Falmouth College.

When I was younger I went from nursery to mainstream primary school, with some friends I already knew, and I'm sure that this familiarity helped me feel secure. I walked with the aid of splints and the other children were always keen to help and include me in all activities and play. I benefitted from full time one to one support.

I also took part in Drama Club, enjoyed all creative writing exercises, and expressed myself further creatively through verse speaking competitions. I began guitar lessons at school at the age of ten, which has helped to increase my co-ordination and fine motor skills.

The transition from primary to secondary school brought new opportunities and challenges. A transition review ensured that I received all the physical and academic support that I needed to access a full education and pursue extra-curricular activities. I'd always taken part in sports activities with my peers at primary school and fully expected this to continue in secondary school.

There were some instances that knocked my confidence – once I asked if I could take part in the general hundred metres race, rather than the segregated 'special needs' events. My helper at the time suggested that I 'might make a fool of myself' if I did. Ironically, a couple of years later, this helper gave her notice before she was dismissed for getting drunk at school camp!

By now my talent in writing resulted in my being recognised as a Gifted and Talented student. I had poems published in educational books and was selected for workshops with local authors. I also enjoyed, and achieved highly, in the study of foreign languages. In year 10, I was put forward to study Critical Thinking at AS level part time at Truro College. I was also selected to be a Prefect in my final year.

At fifteen, I joined a group known as Active8, where for one weekend a month, I stayed at a hostel with fellow disabled people and took part in physical activities and life skills, which enhanced my independence and confidence.

When it came to work experience the local paper, The West Briton, reluctantly gave me a week in their office, whereupon I cleared their desks of backlogged work and made quite an impression. I know this, as during the summer holidays of that year I received a call asking if I would work for the summer at their office. In this period, I researched and wrote many articles which were attributed to me and eventually secured the front page story in my final week.

I decided to progress to Truro College to study A levels. **The transition review ensured that support would continue, allowing me to access all aspects of college life and education.** I chose to study English Language, French, Spanish and Religious Studies. I achieved nine GCSEs at grades B and above, unfortunately I only achieved a D in Maths and would have to retake this at Truro College.

The challenges intensified at Truro College, although I had one to one physical support, negotiating the campus and dodging fellow students took some getting used to. Getting from one building to another in a limited amount of time meant I forfeited some of my break times. **It had been suggested by the physio that I made use of a wheelchair to save me getting tired, but to me that was too much like giving in.** Study was intense – I often needed tutors to clarify instructions, but they were mostly helpful, and I generally felt confident to ask for support.

By now I had finished Active8, and had established friendships within the group. This led to us meeting regularly for meals, bowling and other activities. I also engaged in singing, swimming, and guitar lessons, so life was pretty full.

I had always hoped to do an English degree and, with the support and guidance from my tutors at the college, I applied to University College Falmouth to read English with Creative Writing. To my delight I was successful in gaining a place and I will begin studies this October.

As I am not yet ready to live independently, the short distance to Falmouth will allow me to commute. **Embarking on this new journey will provide me with new challenges and obstacles, but I am determined to achieve my dreams.** I plan to train to teach English as a foreign language and feel the degree will provide an excellent basis for this.

I plan to live my life without limitations.

Shine's Lifelong Opportunities Programme

presents

Family Opportunity Weekend 2012

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

Registered charity no.249338

A weekend residential for families with a child 5-11 years with SB/H & IIH

16 - 18th March 2012

at

Britannia Hotel, Bramhope Leeds LS16 9JJ

The event offers social and learning opportunities to the whole family including siblings and the opportunity for families to engage closely with the **Shine** staff and one another. The event will include a range of information sessions and workshops for parents, activities for children and siblings, an organised trip for all the family, and Benny's Birthday celebration, family portraits and social time for families together.

£150 per family

For an application form please contact Denise Richardson or Joan Pheasant at **Shine**, 64 Bagley Lane, Farsley, Leeds LS28 5LY
0113 255 6767
office@shinecharity.org.uk

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

Closing date 11th January 2012

Tribute to Eric - 'A friend to many'

The following is an edited version of a letter sent to Shine by Eilean Lander, in which she describes her late husband Eric, their lives together and why donations from his funeral were given to Shine on Eric's passing.

Eilean writes;

After choosing Shine to receive a small benefit from the death of my much-loved husband, Eric, I thought I would share some of the reasons for making this decision. There is more than one reason but the primary one is that Eric had spina bifida and suffered from the associated constraints and problems of the condition. **Although my grief is profound I have decided to write this letter because Eric's life was inspirational and may provide some encouragement to others in his situation.**

Eric and his precious daughter

I was 15 years old and Eric was 17 when we met. **He was a handsome lad, full of fun and charm and I fell for him straightaway.** I soon realised that he had an artificial leg but that made no difference. As our courtship progressed he told me some of his medical history. I thought that he was giving me full information but was to discover that there was a lot more to come, some of which Eric didn't know.

We married, against my parents' wishes, when I was 16 and Eric was 19 and, two years later, we had our first child; a beautiful little girl. Eric was terrified that she would have inherited his spina bifida but she was and is, perfect. By this time I had encountered one of the problems that would become part and parcel of our lives – topical ulcers.

At this stage in our lives Eric and I had completed our training to be Hairdressers; ladies and gents. When our daughter was two years old Eric rented his first shop and I became the first hospital hairdresser in Britain (excluding psychiatric hospitals). With the help of my mother, who looked after our daughter, we worked very hard and prospered. We had given up hope of having any other children but then, ten years after our marriage, we had our second child, a son. We felt that we were complete.

When our children were aged 12 and 4 we decided to move from the west of Scotland to the midlands of England – a huge step for us. Eric's parents were both dead but my family was devastated that we planned to take ourselves and our children 350 miles away. However, Eric was adamant; he was convinced that we could give our children a better life in England as the economy of the west of Scotland was very much depressed. **We scraped together every penny that we could find and bought a hairdressing business.** It flourished and, within a couple of years, we were able to put a deposit on our bungalow. Eric died here - 33 years later. He loved our house, often commenting that he still got a little thrill when he turned the corner into the driveway.

When Eric was 36 years old he passed his driving test. He had previously held a licence to ride a motorbike but this gave him a full licence to drive both manual and automatic gear change cars. He was delighted with this achievement and was so proud of the 7-Series BMW cars that he chose to drive. He drove our children to wherever they wanted to go then picked them up and brought them back home. He told them that it was to save them taxi fares but, in fact, it was to know where they were, whom they were with, and to ensure that they and their friends got home safely!

Eric riding high on holiday

Our entertainment was travel and we travelled the world. We spent time in many countries but our stay in the Cipriani Hotel in Venice and the trip that we took on the Orient Express were particularly wonderful. Our last trip – to Zimbabwe, was of special importance because we visited Victoria Falls; Eric was a descendant of David Livingstone.

Our life sounds as though it was idyllic and, while we had some fantastic experiences, we worked harder than most, often putting in 16-hour days as well as weekends and most Bank Holidays. We came through some very difficult times in business, but we survived. We sacrificed much to be able to travel with our children and on our own and to provide our children with the motivation and belief that they, too, could experience the wider world.

Many things were dominated by Eric's health: he was never free from ulcers and many other health issues associated with spina bifida. Eric concealed many aspects of his medical problems from everyone, including me. Had he lived for just weeks longer we would have celebrated our Golden Wedding - 50 years of marriage, yet he was still too proud to reveal, even to me, all of his problems. He endured many things with no complaint. He went to work when most others in his situation would have sat back and lived off the State.

Eric was a fantastic father to our children, even though he worried that they would be ashamed of him – he used crutches, wasn't always able to stand straight and was sometimes adversely affected by his incontinence. Our daughter and her husband gave us three terrific grandchildren and, relatively recently, one of our granddaughters and her husband gave us two beautiful great-granddaughters! Eric loved all of them deeply and was at his happiest when he was surrounded by his family.

When Eric was born, his parents were told that they should not hope for him to live, that he would not walk and would never lead a 'normal' life. Eric's determination, forbearance and ability to endure with stoicism all that was thrown at him meant that he showed that he was the exception that proved the rule. He succeeded in spite of his disabilities, in spite of the attitude of some people towards him, in spite of his medical problems until he was met with the last, insurmountable problem.

In April 2010 Eric was diagnosed with cancer and, until November, he was not badly affected. However, after that the disease took hold and he began to lose a lot of weight. In May, he passed away, aged 69. Eric lead a full life – he had a good, strong marriage, two intelligent and compassionate children, three loving grandchildren and two beautiful and healthy great-grandchildren. He had a nice home and a successful business.

His epitaph is, 'He was a friend to many' and it describes him well.

I hope that this summary of what was a full and satisfying life will bring some encouragement to others who may feel that they are not capable of succeeding.

Kind regards,
Eilean Lander (Mrs.)

Myself and Eric in Cairns, Australia

Hello everyone - Here is all the latest news from your Shine Adult Member's Council (SAMC).

A warm welcome

As you will have seen from the interview on page __ of Together, we are pleased to extend a warm welcome to Gobi Ranganathan who started as the new Membership Development Officer in September. This appointment was made possible after Shine was successful in gaining a Big Lottery Grant for £250,000 to improve member services across the organisation.

The aim is for communication between **Shine** and its members to increase through Gobi's role as he networks across the country. Gobi, who has spina bifida himself, is keen to hear what you have to say as members and you can email him at **gobi.ranganthan@shinecharity.org.uk**

A big part of Gobi's role will be to develop the membership's involvement in sport and, as a para-badminton champion, there is no better person for the job.

New members for the SAMC

The SAMC is keen to recruit some new members onto the council and you could be just the person we are looking for.

If you are over 18 years of age, a good communicator, willing to attend meetings mainly at the Shine Head Office in Peterborough and are prepared to get involved in making positive changes within the organisation then please get in touch.

We are especially eager to hear from members in Northern Ireland so that we can gain the input of members in this region. We can assist with travel so please don't let that put you off.

If you think you would like to get involved , or even to find out more, please contact David Isom on **01733 421308** or email **david.isom@shinecharity.org.uk**

Health and Wellbeing Questionnaire

SAMC member Liz Potts is currently working alongside Shine staff members Kate Thomas, Rosemary Batchelor, Gill Yaz and Geraldine Long in order to formulate a Health and Wellbeing Questionnaire. You will find a letter enclosed with this edition of Together which encourages all members to feedback some basic information ahead of a more detailed survey in the coming months.

The Family Fund

Earlier this year I was fortunate enough to meet Clare Kassa, Network Development Manager at The Family Fund. Clare was sharing information at the Grandparent's Day and is keen for people to know about the services on offer from The Family Fund.

They are the UK's largest provider of grants to families raising disabled children aged 17 and under. To find out more please visit www.thefamilyfund.org.uk

Get in touch

If you have anything you would like to ask the SAMC members, or if there is something you think we can assist with, please get in touch by emailing me at
mike.bergin@shinechairty.org.uk

Michael Bergin,
Communications Officer SAMC

Programme of events

2011

November

Free Conference for Parents and Carers - The Bridge, Shirley
Legal Rights of disabled children and their Families
2nd at 10:00am - 2:30pm
To book a place please call ‘Contact a family’ on 0121 415 4624

London Social Group – Bowling
6th
For further information contact: Hilary Franklin 020 8449 0475

Support Group – Disability Resource Centre, Dunstable
14th at 1:00-3:00pm
On the second Monday of each month
For further information contact: Valerie Bottoms 01582 757745

York Drop In for Parents and Adults - Low Moor Community Centre, York YO10 4JG
9th Nov and 14th Dec
For information contact: Joan Pheasant 0113 255 6767

December

London Social Group – Christmas Party
11th at 13:30pm
For further information contact: Hilary Franklin 020 8449 0475
hilary.franklin@shinecharity.org.uk

Support Group – Disability Resource Centre, Dunstable
14th at 1:00-3:00pm
On the second Monday of each month
For further information contact: Valerie Bottoms 01582 757745

2012

March

Family Opportunity Weekend 2012
Friday 16 –Sunday18 March Britannia Hotel, Leeds
For information contact: Denise Richards or Joan Pheasant 0113 255 6767
office@shinecharity.org.uk

ISLE OF WIGHT ASBAH - Holiday Bungalow
Wheelchair-accessible bungalow, sleeps six. Open-plan lounge/kitchen, wetroom. Site facilities. Local heated accessible pool. Beautiful area. Transport advisable. **Details and rates: Sylvia Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF Tel: 01983 863658** ***www.iwasbah.co.uk***

The Editor would like to apologise to Christmas Card Competition finalist Isabella Moody for mistakenly crediting her Mum, Jane Hart, with the great artwork.

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[1] *Results from SpeediCath Compact Male pre-evaluation, Nov. 2010 to Dec. 2010.*

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