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Please let us know if you are happy to receive future mailings by email as this saves on postage and helps the environment.

Email: info@shinecharity.org.uk

Submission dates for Summer edition

- Register of interest to submit:
7th June 2013
- Final date for submissions:
21th June 2013
- Publication date:
July 2013

Issue 9... Our members Shine!

Hi everyone,

Together magazine has continued to go from strength to strength and we are delighted to share Issue 9 with you.

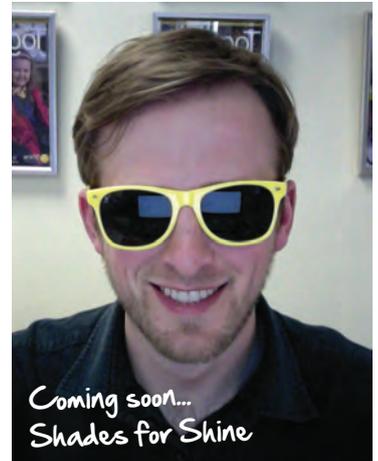
This edition is packed full of features and information which really reflect the powerful way that you, the members, make **Shine** such a dynamic and life changing organisation.

We have member contributions from Marcia Collins, who describes her experience in reporting a hate crime, and James Weavin, who talks about hydrocephalus and how you can be proactive in diagnosing pseudocysts.

We feature the stories of Mark Humphries, a.k.a Kray-z Legz, and Ahmed Suleman, two members at very different stages of life, but both with equally moving accounts of their experience of living with spina bifida.

We hear more about how you all pulled together in an amazing way to raise over £5000 in the Grand Prize Draw and how other fundraisers are making monumental efforts to ensure **Shine** continues to ... shine!

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!

Shine Board seeks new members

At Shine's AGM last year new governance arrangements were agreed which will make Shine a more democratic and representative organisation.

The changes involved creating opportunities for more people to serve on **Shine's** Board of Directors. We are now looking for potential new members of the Board, which sets the strategic direction for **Shine** and ensures that it is well run and meets its legal obligations. Board members work closely with the Chief Executive and senior staff to make the charity as effective as possible. Being a member of the Board is stimulating, interesting, and sometimes even fun! The position has the potential to be both rewarding and challenging.

The aim is to eventually have a Board whose members cover the broad range of the charity's activities, either through their expert knowledge, direct experience, or both. So, for example, we

We are now looking for potential new members of the Board, which sets the strategic direction for Shine and ensures that it is well run and meets its legal obligations.

would hope to have parents of a range of children of different ages; a young person with SB/H under 25 years of age; and directors with social care experience, health experience, legal expertise, and business experience. The Board also includes representatives of the **Shine** Adult Members Council and the Medical Advisory Council. One representative should be from Northern Ireland and one from Wales. At least 50% of the Board should have spina bifida and/or hydrocephalus.

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

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

Anyone interested is very welcome to contact either Jackie Bland or Margaret Connor for an informal discussion/e-mail exchange.

T: 01733 555988

E: margaret.conner@shinecharity.org.uk / jackie.bland@shinecharity.org.uk

Staff news

Louise Tyler started as Marketing & Events Officer in April – welcome aboard Louise! Louise is helping to edit *Together* magazine so you will be hearing more from her. Gail Howard has left the Marketing & Events team; we wish her luck with all her future endeavours. Eri

Mountbatten has now finished his contract as Benefits and Welfare Rights Adviser in Wales – thank you Eri for all your work and good luck with your new ventures. Helen Al-Sheba (Projects Coordinator) has decided not to return to work after maternity leave to the Grants

& Legacies Team – she will be doing other vital work at home with her children! Kathy Shaw has now stepped up to be Grants & Legacies Manager – this team is central to sustaining the income our charity needs. Congratulations Kathy and good luck in your new role.

At last! Specialised commissioning for people with spina bifida on the NHS agenda

Shine staff have now had two teleconferences with the NHS Head of Trauma Care Services Rachel O'Connor. The purpose of the discussions was to ask why spina bifida was not even considered as a condition which merited inclusion in the new NHS specialised commissioning arrangements, most of which come into force this Spring.

As reported in the last *Together* it has taken repeated attempts to find someone to answer our queries and a very long time to get anyone to engage with **Shine** on this issue. It was finally intervention by the Specialised Health Care Alliance last October that led to a dialogue with Ms. O'Connor on 22 March. These delays reflect the on-going lack of concern at a strategic level within the NHS about the health services delivered to our members, and a widespread misunderstanding of the issues affecting their health.

CEO Jackie Bland, Health Development Manager Gill Yaz, and **Shine** Adult Council member Liz Potts asked Ms. O'Connor, as the lead professional responsible for specialised commissioning in this area, why people with spinal injuries are automatically considered eligible for specially commissioned, multi-disciplinary services to address their complex needs, while people with spina bifida were not.

Liz Potts described how trying to access multiple services in different hospitals across different areas for many aspects of her condition had led to misdiagnosis and actual damage to her health. She also pointed out the complex transport arrangements that had to be made and the huge cost of delivering services in such a fragmented way. Jackie Bland presented Ms. O'Connor with examples, provided by **Shine** members from all over the country, of how their health needs were not being met because of disjointed services and lack of the appropriate knowledge and expertise amongst health professionals, ranging from GPs to specialist consultants.

Ms. O'Connor acknowledged that there was an issue which needed further investigation; the issues we raised were new to her and she could not say at this point whether spina bifida should qualify under the new arrangements or not. Jackie Bland argued that it could hardly be possible, once the issue was investigated, for people with traumatic spinal injury to qualify whilst people with spina bifida did not, pointing out that it was a fundamental inequality given that the needs of the patient groups are so similar.

Ms. O'Connor promised to investigate further but said that it would not be possible, whatever happened, for spina bifida to be included in the year 2013-14. However, it is possible to review

the matter for the future. She said that alongside discussions about whether spina bifida should qualify, work was needed to identify exactly which services might be needed and how these should be delivered. She acknowledged that a multi-disciplinary service akin to that offered to people with spinal injury was what **Shine** and its members were asking for. **Shine** offered to convene a group of medical professionals with experience in this area, together with NHS commissioners responsible for the relevant service, and **Shine** members, to begin to specify what a service for people with spina bifida should look like. This would enable the NHS to assess whether such a service/care pathway was something that should be managed nationally through specialised commissioning.

Whilst agreeing to look into this issue Ms. O'Connor said that any new arrangements would have to be delivered within existing, reduced, NHS budgets, although she did acknowledge that savings might be possible if the current arrangements were inefficient.

Thank you to all **Shine** members who sent in their experiences of disjointed/inappropriate health services and who wrote to their MPs. We need to keep the issue in people's minds so please continue to do all you can to help secure NHS specialised commissioning for our members.



Join us to Rise & Shine!

The Rise and Shine Adult members' event is one that will be fun and informative with a number of exciting exhibitors there for the day, some of which will also be providing demonstrations and tasters.

Disability Snow Sport UK, Badminton, Boccia, Basketball, Wheelchair Dance Association UK are just some of the sports and activities on show. For those of you who aren't particularly into sport or prefer something a little calmer, there'll be other activities such as complimentary therapy and an Art Session with our very own Tony Nero! There'll also be healthcare and well-being support from various organisations including Hollister, and the Mitrofanoff Support Group.

Rise and Shine is being held at Stoke Mandeville stadium, the home of wheelchair sport. The venue is fully accessible to wheelchair users, with the on-site swimming pool and gym facilities having hoists and accessible machines. These facilities are free

to use for those who are staying at Stoke Mandeville for the event, but also available for pay on the day use too.

The accommodation is just a stone's throw away from the venue and is fully wheelchair accessible; all rooms are spacious with a twin bed, and wetroom bathroom facilities. With free car parking available on-site and accessible taxis able to ferry people from Aylesbury Railway station, Stoke Mandeville has transport links that make Rise and Shine accessible for residents for the event, and those who want to come for the day.

It's great value at only £60 (based on two sharing) for the whole event or £15/day.

Rise & Shine

Stoke Mandeville Stadium, Guttman 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.

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



Weekend rate £60
(Based on two sharing an accessible room)
Single rate £120
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



How to report a hate crime...

In December 2012, Geoffrey Clark, a UKIP candidate, made a statement suggesting that the NHS should consider a blanket termination of babies affected by spina bifida and other impairments. He also suggested that we are a burden to society. I was horrified that someone could publicly make such comments, which I felt were not only deeply hurtful, but also could be against the law.

I knew that there was new legislation available to disabled people who felt that they were a victim of hate crime, and after some consideration I decided to have a Google and see how I could make a complaint to the Police.

I have to admit that I was undecided about making a complaint because I wasn't too sure how seriously I would be taken. However, I also thought, if someone can make such horrific comments, then we have to complain.

The Association of Chief Police Officers has created a website that is entitled http://www.report-it.org.uk/disability_hate_crime1 They define Hate crime as:

“Any crimes that are targeted at a person because of hostility or prejudice towards that person’s disability”

This was the site I decided to use as it was so easy to navigate. The form was really easy to complete and only took about five minutes.



I wondered how long it would take for a response. Within half an hour, Warwickshire Police had called me to listen to the details of the complaint and gave me an incident number. The following day, a PC came to take a statement and it was then

I was undecided about making a complaint because I wasn't too sure how seriously I would be taken.

discussed with a Chief Inspector who was in charge of Hate Crime. At each stage of the process, I was kept up to date as to how things were progressing and what decisions were being made regarding my complaint.

It was decided, after consultation with The Crown Prosecution Service and the lawyers for the Police in London, that the incident would be classed as a Hate Incident. This meant that Mr. Clark would not be prosecuted but that it was on file that he had made the comments – it was a Hate Crime Incident.

Was there a point to making a complaint? Yes, definitely and for many reasons. I wanted to do something to challenge what Mr. Clark stated. I felt that what he said had to be challenged. I wanted to see how seriously the Police took me and also, as this legislation is new, how much knowledge there was around hate crime and disability.

If you feel that you have been a victim of hate crime because you are disabled, please don't let it pass. Report it. It is not acceptable for any disabled person to be verbally or physically assaulted. It is not OK and you do not need to be worried about the consequences. The Police will listen and they will take action.

You can also make a complaint by calling your local Police station, you can call 999 if it is an emergency situation, or 101 if it is not.

**Shine Member
Marcia Collins**

Kray-z Legz Man of the Street

For Mark Humphries, a.k.a. Kray-z Legz, life has been tough.

The 24-year-old MC and rap artist from Street, Somerset may well have spina bifida, but his challenges have not been limited to his physical condition.

Like many who turn to rap music as a way to deal with their troubles, Mark has faced the turmoil of family break-ups, financial uncertainty, and having to live independently at an early age. These experiences have defined not only who he is, but also the music he produces.

Music became a part of Mark's life at the age of four when his Dad bought him a violin. In the years that followed Mark found that he could turn his hand to most instruments and by the time he was 15 he was proficient in writing his own songs.

Words and
photos by
Tom Scott



At the same time, the aspiring DJ was also undergoing a series of surgical operations, which are familiar to many people who live with spina bifida. Mark attended most of the hospitals in his locality, including the Frenchay Hospital, Bristol, for surgery and has been a wheelchair user since the age of four.

Although he enjoyed school, Mark explains that he missed a lot, 'I think it's the same for a lot of kids growing up with spina bifida; being in and out for surgery means that going to school can be quite disrupted, and I was home schooled most of the time.'

Mark believes that his childhood, and becoming independent at a young age, had a big influence on the shaping of his musical career. At just 15 Mark moved into a YMCA sheltered housing scheme. He was keen to leave the supported scheme and have his own place - upon his arrival his first question was: "How long will I be here for"?

The YMCA staff advised him that his stay could be up to two years. This made Mark motivate himself to get out of there as quickly as he could! The scheme was structured in such a way that if he demonstrated a positive attitude to course work then he stood a better chance of securing a place of his own.

'I got my head down. They wanted to see that I could be a responsible adult, and in six months they offered me a flat.'

Mark really appreciates his flat, especially as earlier in his life his family had lost an accessible home when going through a rough patch.



Mark and his producer Gavin Lambert



He's from the street

It is in this flat that Mark, through his industry name Kray-z Legz, now makes his music. 'Over the years we have saved enough money to buy studio quality equipment, we don't have a permanent space, which can be a problem, but we get on with it anyway.'

When Mark says they get on with it, he really means it! His latest album, 'Man of the Street', has just been added to iTunes and has been produced by renowned US-based producer Domini, who has worked with top artists including Eminem.

When talking about the successful completion of the album Mark reflects, 'There are quite a few things I can pull from life, I can play with them then, and use them in my music.'

'This means my music is based on emotion; there are sad tracks in memory of friends I've lost; happy tracks about hanging out with friends and having a laugh; songs which are about being angry – I figure this is what life is about and I use this in my music.'

Mark recognises that this is just the beginning of his career and continues to perform at high profile events around the UK. He hopes that this rise to success will continue, but ultimately knows what is most important, 'At the end of the day, crying don't get me no where, I've always had good friends and family around me, so I've been very lucky in that respect.'

'Man of the Street' is available for download via iTunes: itunes.apple.com/gb/album/man-of-the-street/id605628326

Family Opportunity Weekend

Our most recent Life Long Opportunities Programme (LLOP) event, the Family Opportunities Weekend 2013, was a resounding success with eighteen families enjoying a great mix of training, fun, and entertainment.



“Thank you for letting our family have this experience and knowledge”

The weekend included lots of interesting workshops from **Shine's** Health Advisors including, 'A child's first wheelchair' presented by Emma Enfield, OT Development Officer, and a 'Bladder and Bowel management' session led by Gill Yaz, Health Development Manager.

Saturday Afternoon was an opportunity to socialise with other member families with a trip to Coventry Transport Museum and Benny Bear's Birthday Party.



“We have had a fantastic, informative time. Great families and Shine staff”



Photos by Tom Scott

Gobi's Gossip



It seems an absolute age since my last quota of ramblings, and it probably has been seeing as we're already well past the first quarter of the year! Where is the time going? Scary!

These last few months, it's fair to say, have been manic and a bit of a blur! So, where do I begin?

I guess the obvious point would be from the beginning of the year which saw me face up to the realisation that I would be requiring major surgery for a Mitrofanoff revision. I knew it was coming, but it's still never easy to hear such news. As a result, much of my usual

Shine activities have been on hold, so I must apologise if any of you have been waiting for a response from me for a while or if you've not had any follow up contact from me.



Having visited Stoke Mandeville, I for one can say that I'm impressed with the accommodation and facilities which, even for me, were a big concern.

By the time you read this, I'll be less than a month away from my surgery date – 29th May (and I'll also have become a year older, although whether or not I'm wiser will remain to be seen!)

Whilst I've already had a minor operation for a Supra-Pubic Catheter insertion, the real "Challenge Gobi" starts after the revision operation. It'll be a long and difficult journey to recovery but I'll get there! I hope to keep a regular blog whilst I'm out of action, so if you want to follow my progress you can do so at: gobiranganathan.wordpress.com

After the disappointment of the need for surgery was confirmed, I also had the misfortune of injuring my back. The bad back didn't just stop me from playing and competing at the 4 Nations Para-Badminton Championships in Glasgow, but it affected my daily routine for almost 3 weeks. Those of you who've endured back trouble, will know exactly what I mean when I say the pain was so

excruciating that even sitting still was uncomfortable! Not good! So, not the best start to the year for me, but don't worry, it's not been all doom and gloom. Slowly but surely the clouds have lifted and my

optimistic mood has returned, although I have to admit, it was a battle to get back on track.

Having picked myself up and despite having the SPC insertion surgery in the middle of March; I still managed to get to Antalya in Turkey for the Enes Cup, the Turkish International Para-Badminton tournament. My preparation wasn't the best, with little training and with constant soreness from my surgery; I wasn't sure how well I'd perform. However, armed with painkillers, I took to the courts and managed to get to the Doubles and Singles Final, winning Gold and Silver in the two events respectively. I have





to say, it's probably been the toughest event for me to date, and I really had to battle through and win ugly at times, purely because the discomfort was affecting my play. Still, I'm happy enough with the outcome as it was a nice confidence booster for me after my tough start to the year.

I still have the Spanish International to look forward to and will tie that in with a much needed mini holiday afterwards. So all is looking a lot brighter and sunnier (unlike the weather we've been experiencing!). I'll probably have finished the tournament by the time you read this, so keep an eye out on Facebook and Twitter for the results.

Now that I'm getting back on track, my attention within **Shine** is now firmly on making the Rise and Shine Event in July a real success. We've managed to secure a number of exciting exhibitors, some of which will also be providing demonstrations and tasters on the day.

It is promising to be a fabulous, eye-opening occasion and with the venue being fully accessible for wheelchair users, there really is no excuse not to come along and have a taste of some fun activities.

For those of you who aren't particularly into sport, there'll be other activities available – it really will be an event with something for everyone.

Having visited Stoke Mandeville, I for one can say that I'm impressed with the accommodation and facilities which, even for me, were a big concern. I know many of you out there will be worried about parking, accessibility, disabled toilets and accommodation issues, but I can re-assure you that I'm delighted that we have such an ideal venue to host the event. It really is an opportunity not to be missed.

But don't let me influence you – check out the event for yourself. If you have any queries or concerns, drop me a line on my email, or on Facebook. I really am looking forward to it, and am hoping to have plenty lined up for you all to "Rise and Shine" and kick-start the summer months in style!

In the meantime, I hope the weather has improved and that we can all look forward to some much needed warmth and sunshine!

E: gobi.ranganathan@shinecharity.org.uk

FB: [facebook.com/Shine.Gobi.Ranganathan](https://www.facebook.com/Shine.Gobi.Ranganathan)

Grand Prize Draw 2013

Thank YOU! You've just raised over £5000 for Shine!

The **Shine** Grand Prize Draw 2013 was a resounding success and there is only one reason why – because you, the **Shine** membership, got behind this draw and sold thousands of tickets!

In previous years we have relied on sales through our Special Appeals Team, however this approach is not cost effective. With this in mind we sent every one of our 10,000 readers a book of five tickets.

Many of you called or emailed us asking for more books of tickets to sell and we were blown away by the demand. The total amount of money raised was £5043!



The winners of the top prizes on offer were:
£1500 – Sally Osborne – Nottinghamshire
iPad 2 – Dawn Bradbury – Stoke on Trent
£500 Next Vouchers – Abby Waldron – West Midlands

Next time we are going to run the draw for a longer period to give everyone more opportunity to sell and buy tickets. We have also listened to your suggestions for how the draw can be improved, including stating more information on the tickets and having the facility to buy tickets online.

Thank you again for getting behind this initiative and look out for the next Grand Prize Draw, we will be including tickets in *Together* again when this takes place.

Marathon Marvels

With both the Brighton and the Virgin London Marathon now behind us, everyone here at **Shine** would like to take this opportunity to thank all of our incredible athletes that have participated in these events.

The demand for places in the Virgin London Marathon was so high this year, we were overwhelmed by the amount of enquiries we received.

Special thanks must be given to the following runners who have raised a CHAMPION amount of money, making this year's events our most successful to date:

Hannah Whitlock
David Bird
Fiona Fulton
Dean Godwyn
James Gregson
Phil Gould
Don Gilliland
Emma Rapley
Anna Sorrel
Terry O'Neill
Rachel Turnbull
Steve Pollard



Dean Godwyn



Hannah Whitlock

To take part in either Brighton or London in 2014 please contact Clara at clara.gill@shinecharity.org.uk. We have limited places and demand is high, so please get in touch soon!

Community Fundraising – WE NEED YOU!

It is only with your help and the support of your friends and family that Shine is able to continue offering essential guidance and services.

You can fundraise for us in a variety of ways from organising a bake sale or coffee morning, to encouraging friends and family to complete a sponsored run, parachute jump, cycle or swim!

Paul and Sarah Rowe, the parents of Grace are a wonderful example of a family who have encouraged their community to fundraise for **Shine**.

Paul completed the Great North Run for us last year and encouraged work colleagues and friends to sponsor him, which in itself is a huge achievement, but the family didn't stop there! Next Sarah threw a huge party to raise funds for **Shine** called Grace's Charity Night. She contacted **Shine** and we arranged for posters, collection tins and merchandise to be sent. Sarah also organised a fantastic night with the help of her community at a local social club with a singer, DJ, raffle and a

number of competitions including guess how many lollies in the jar, and lots more! Prizes were donated by local businesses; friends and family came from far and wide to raise an amazing £2086.00!

There are many wonderful individuals and families who are working tirelessly to support **Shine**, helping us raise much needed funds and every little helps, so whether you can raise ten pounds with a local event or several thousand: we need you!

If you have an idea, want to complete a sponsored event or wish to discuss your ideas please contact Hannah Wsocki or Clara Gill via email.

E: hannah.wsocki@shinecharity.org.uk

E: clara.gill@shinecharity.org.uk

Charity of the Year Record Breakers

We have recently come to the end of a very successful Charity of the Year partnership with the Queensgate Shopping Centre in Peterborough. Throughout the last year of working together we have run a number of fundraising events. We ran a sponsored Christmas present wrapping stand and also made an amazing amount of money from selling the donated content from closed shops. In total we have raised over £19,000, which is a record amount for the centre.

We would just like to take this opportunity to thank all the staff at Queensgate, the shops that supported us in running our events and all the volunteers that provided their time and hard work which contributed to this wonderful achievement.



Queensgate
Peterborough

Amazing Ahmed!

Words and photos by Tom Scott

Just over a year ago I was contacted by **Shine** Support and Development Worker, Sharon Lapsley who told me about a family living in Peterborough who had just learned that the baby they were expecting had spina bifida and hydrocephalus.

As with many of the families we meet here at **Shine**, the news from their 18-week scan was a complete shock to parents Rashid and Jilu. The couple began to search the internet for information about the conditions and, although discovering a great deal of poor quality resources, they were successful in finding the **Shine** website.

Jilu was soon in touch with Sharon, who works as the Support and Development Worker for her area.

When a Support and Development Worker first receives contact from parents in this situation their first priority is to get more detail and ensure that the family is receiving the highest level of support available.

Once this consultation had taken place, Jilu and Rashid considered the future carefully, and decided that continuing the pregnancy was their only true desire. To get the specialist care needed they were directed towards Neurosurgeon Maria



His health has now improved but, as with lots of parents we communicate with at **Shine**, Jilu still has lots of questions about what Ahmed will need as he grows.

Cartmill at Queens Medical Centre, Nottingham ... fast-forward to April 2013 and the family visited us at **Shine** to introduce us to their beautiful new son Ahmed.

Although the last 12 months have been incredibly difficult for the family Jilu is clearly cherishes her new son, 'Before I was scared and we didn't know what to expect, now we know, and although it's been hard, he's our son and we love him.' For the first two months Jilu and Ahmed didn't leave the QMC, a hospital for which they have nothing but praise. Ahmed had various problems, including issues with digestion. After returning home for the summer months, in November Ahmed was readmitted to QMC for kidney problems.

His health has now improved but, as with lots of parents we communicate with at **Shine**, Jilu still has lots of questions about what Ahmed will need as he grows.

It is in working through these unknowns that **Shine** comes to the fore, offering expertise and support that other agencies cannot provide. Ahmed sleeps on a special mattress which was donated by New Life Charity after Sharon contacted them; this kind of assistance will be on-going as the family move on and search for a suitable new home and start to think about practicalities such as Ahmed's first wheelchair.



Get inside my head!

This summer Shine will be releasing an animation and accompanying booklet called 'Get inside my head'.

The two-minute animation will feature Ella, a character named after **Shine** member Ella Thomas, who provided a wonderful voiceover for the piece.

Ella is shown inside an artistic version of her own brain, and describes to the viewer what hydrocephalus is and how it affects her everyday life.

The aim of 'Get inside my head' is to educate a wider audience about hydrocephalus. The animated film will highlight what a hidden condition it can be, and show how important it is that other people understand the challenges that people with hydrocephalus can face.

The film will be released on YouTube and we encourage everyone to share the link through all social media channels, especially Facebook and Twitter.

A special thank you to Alan and Ella Thomas. Ella's father recorded the sound professionally for the project, and Ella supplied the brilliant voice over.

Once released, the video will also be located here: shinecharity.org.uk/getinsidemyshead



First Folic Acid Awareness Day Success

Martine Austin, Health Campaigns Officer

With so many successful Go Folic! projects under our belt, we decided that the time had come to establish a focal point in the year, to enable everyone to unite in awareness raising activities on a national level... So, 1st May was the launch of our first ever National Folic Acid Awareness Day! This year was mainly about getting the day into the calendar and hopefully attracting plenty of positive press attention. Darren and I walked the streets on the day, filming and interviewing women about their knowledge of folic acid and giving away free vitamin samples. We also had a fabulous new poster to promote the occasion.

Our information and resources have been highly praised by other organisations, and our literature is currently being used in Nigeria, with Poland and the Republic of Ireland soon to follow.

A huge thank you to James Fox who volunteered to model for the campaign. I am sure he will prove a great asset in helping us attract the attention of the ladies! Having just completed a Sports Science degree, James (a former junior GB rower) is currently trialing for the GB Paralympic rowing squad for Rio 2016. We wish James every success with his sporting ambitions, and maybe a new modelling career?!



It's so exciting to see how far we have come over the last two years. Not only are we spreading the word in England, Wales and Northern Ireland, Go Folic! is now starting to go global! Our information and resources have been highly praised by other organisations, and our literature is currently being used in Nigeria, with Poland and the Republic of Ireland soon to follow. A Welsh language version of the new leaflet will shortly be available, and our sister organisation in Poland is also working on a translation which will be available to download from the Go Folic! website.

Thank you to Vitabiotics for sponsoring this first Folic Acid Awareness Day, and for donating the free vitamin samples, and also Lanes Health for their continued support of our grass-roots community work.

Go Folic!

Overcoming the pressures of IIH

By Gill Yaz, Health Development Manager

In the last issue I talked about CSF and what it does. Some of our members have a condition called Idiopathic Intracranial Hypertension (IIH for short). This condition is still a bit of a mystery, with possibly more questions than answers. But for those people with the condition, it has a massive impact on their lives. Head pain, depression, fatigue, nausea, dizziness and possible visual impairment are just some of the symptoms; our members tell us what an unpleasant condition this is to live with.

In IIH, the pressures inside the head are too high, although the CSF can actually flow around, unlike obstructive hydrocephalus. The pressure builds up all round the head, but particularly around the top and inside the coverings of the optic nerves, which contain CSF. People with IIH are at high risk of their vision being permanently damaged because of this pressure. In addition, over time the area of brain around the ventricles becomes swollen and 'soggy'; resulting in a slowing of

messages around the brain. For most people, the causes are never discovered, but as more women than men have IIH, there might be hormones involved. Some medications, like tetracyclines (often prescribed for spots) might cause IIH in some people.

One theory, which Dr Deborah Grzybowski of Ohio, USA has worked on, is that some people have far fewer arachnoid granulations (the little structures on the brain's covering which absorb CSF) than others. Maybe some people just don't have enough to cope with all the CSF that's made? These arachnoid granulations are fragile and easily damaged, and seem to find Vitamin A very toxic. She has suggested that people with IIH cut out Vitamin A from their food for a month and see if they feel better.

For some people, the large veins in the head, which help drain the CSF away, may become kinked and surgery to place a stent (which is a small spring to hold the vein open) have been a success for some

One theory ... is that some people have far fewer arachnoid granulations (the little structures on the brain's covering which absorb CSF) than others.



people. For most people, diuretics (water tablets) are given to stop extra fluids accumulating in the brain. The side effects of these, ironically, include headaches, nausea, dizziness... Occasionally, LP (lumbar peritoneal, from the back to the belly) shunts are used to remove the CSF, these tend to be a last resort.

IIH seems to be associated with times of rapid weight gain, and there's some evidence that reducing body weight by 10% can improve symptoms for some people. 'Associated' does not mean 'caused by', so don't let anyone make you feel you've caused your own IIH. People have often told me that they only gained weight once the illness began and that they feel too ill to cook, eat, or exercise, but it is worth trying to lose weight if you can, as some people have shown a real improvement in their symptoms when they've managed it.

IIH used to be called Benign Intracranial Hypertension – I think you'll all agree there's nothing 'benign' about it!

Shine Cymru update...

Benny Bear's Birthday Picnic and Fun Day

at Folly Farm, Pembrokeshire
Begelly, Kilgetty, Pembrokeshire, SA68 0XA

Sunday 23rd June 2013
11am onwards (meet at Main Gate)

Come and have some fun, meet Benny Bear and other families from across the South and West Wales region.

Bring your own picnic and then share in a slice of Benny's birthday cake and some light refreshments.

We have secured fantastic group discounts at last year's prices – Adults – £5.50
Children and OAPs – £4.50. Carers and under 2s free of charge (proof needed). Please note these discounts only apply when you are part of the group so please ensure you arrive by 11am.

If you are interested in attending please contact Melanie Hayes on:
T: 01437 720089 / 07789616460
E: melanie.hayes@shinecharity.org.uk



Thank you, BIG Lottery Fund Wales

Since April 2011 Shine Cymru has been delivering a Big Lottery Wales funded project, to begin to address the impact of the Welfare Reforms, and to encourage more independence and social opportunities across Wales.

The project has now come to an end but it has provided the first steps in setting out Shine's benefits strategy which will help ensure:

- Support and Development Workers will have the information and knowledge to provide basic support on welfare reform and benefits advice.
- Members are signposted to other appropriate agencies for more complex queries and issues.
- That the DWP and other benefits agencies have access to important information on living with spina bifida and/or hydrocephalus.

We'd also like to thank Eri Mountbatten and wish him well. Eri has been Shine Cymru's Welfare Rights Adviser during the project and is now moving onto pastures new. Good luck Eri!

Having difficulty with transport? Then perhaps Traveline Cymru can help



Traveline Cymru provides information on access to public and private transport across Wales and has specific information on travelling with a disability and on local services that provide travel support.

W: traveline-cymru.info/travellers-with-a-disability

Go Folic! in Wales

Shine Cymru's West Wales Support and Development Worker, Mel Hayes, has been particularly proactive in promoting Go Folic! in Wales, and has recently gained the support of a health worker who will be distributing Go Folic! leaflets when conducting sex education talks in schools and colleges in her region.

Inspired by this and the success of our partnership with the Family Planning Association, Martine Austin, Shine's Health Campaigns Manager contacted the 'All Wales Sexual Health Network' who enthusiastically invited her to write an article for their quarterly newsletter 'Intersexion'.

The newsletter goes out to professionals involved in sexual health throughout Wales and provides a focus on key projects underway in Wales, as well as highlighting new resources (including a link to order our Go Folic! materials) and reports relating to sexual health. The article appeared in the March issue and has so far resulted in a request from Betsi Cadwaladr University Health Board for 1,000 leaflets, plus postcards, and posters to distribute in its clinics.

The article can be viewed at www.shnwales.org.uk
A Welsh language version of the leaflet will also be available from May 2013.

Please get in touch with Martine on
T: 01733 421349 or
E: martine.austin@shinecharity.org.uk
if you have networks through which you can help promote our Go Folic! campaign.

Go Folic!
Ffolig Amdanil

Community Fundraising and Volunteering in Wales

February and March 2013 have been promising fundraising months for Shine Cymru with over £1800 being raised through events and donations across Wales.

Thanks to ...

- The Ladies Senior Team at Whitchurch Golf Club in Cardiff has raised over £400 following a golf day
- The organisers and volunteers of the Nick Beer 10K race in Llandudno
- The Town and Community Councils of Abenbury, Gresford, and Llandinam
- Maesteg Lions, Bridgend
- Gwendraeth Social Club, Llanelli – with particular thanks to Jim Watherston, grandfather of one of our West Wales members, who nominated Shine Cymru as Gwendraeth's 'Charity of the Year'

Diolch yn fawr iawn



Melanie Hayes, Support and Development Worker for West Wales, with Malcolm Jones, Club Chairman and Dai and Malcom, who organised a charity quiz.

Celebrations and Awards



The **Shine** Northern Ireland award was won this year by the Rainey family. The Rainey family have been involved with us since Zoe was born. Dad, Paul, is a Member of our Northern Ireland Steering Committee. Kirsty and Paul have represented us at meetings in the education sector. They also started Waddle which is a major annual fundraiser for us. Congratulations to Cara, Kirsty, Paul, Zoe, and all the extended family.



We are delighted that one of our Millennium Volunteers won runner up for Community Service in the Credit Union Young People's Award. Hannah Campbell was nominated by her school for the award. Hannah has been involved in many activities for us, including helping to decorate cupcakes, making toy aeroplanes, helping at social events and, selling raffle tickets. Congratulations Hannah you are definitely a "**Shine** Star".



Shine NI held an event in Cookstown to celebrate our 3 year Big Lottery funding. We had two speakers with personal experience at the event, Perpetua O'Driscoll and Megan Gilbert. They described their experiences of living with spina bifida and hydrocephalus and their real "CAN DO" attitude. Dr John McCann, Consultant in Rehabilitation Medicine provided a question and answer session. He has been working in the Musgrave Park Hospital Spina Bifida Clinic for 20 years and has seen real changes in treatments during that time.



Our Spina Bifida and Hydrocephalus Lifelong Care Conference in Belfast in February, was attended by 145 professionals. Nine consultants covered all aspects of spina bifida and hydrocephalus. There was lively debate about many of the issues which face our members. We hope that the outcome is a healthcare workforce with a better understanding of our members.

Night, night... sleep right.

Emma Enfield, Head Occupational Therapist

People often ask what type of mattress to buy. Unfortunately, it seems that lots of us, including children, suffer from pain during the night. In turn that leads to tiredness, being unable to function properly, feeling depressed, stressed, irritability. Getting a good night's sleep is important.

Unfortunately, unless you need a mattress for problems with pressure relief, you have to provide it yourself. Pain and discomfort don't often meet the criteria for a mattress to be prescribed from the NHS.

A wide range of mattresses is now available to buy and although some of the advertised ones are very expensive, they don't have to be, so it's a good idea to shop around.

Basic memory-foam mattresses seem to be helping a lot of you. It is even possible to buy these just as a 'topper' to a standard mattress. However, there are a

few things to think about when buying a new mattress or topper to prevent problems such as the mattress slipping off the bed. Do you need your mattress to be waterproof? Does it fit the bed properly? Does it support you in exactly the way you need?

Be aware of the height, and check whether this will change the overall height of the bed when combined with the mattress. This is particularly important when considering how you transfer in and out of your bed. If you use a sliding technique from/to a wheelchair, or a sliding-board, then you might not want this height to be changed. Similarly, if you have a carer to help you, the height might be important for them too.

Finally, some types of mattresses aren't recommended for babies for safety reasons. Please check with your Health Visitor if you have any concerns, or contact us for advice. There are no specific mattresses recommended for babies after surgery for spina bifida, however, if you feel unsure we can try to help. Our safety advice indicates that a mattress should be firm, flat and have a waterproof cover that can be removed and thoroughly washed with antibacterial detergent. If you chose to use memory foam, ensure that it is still firm and that it cannot be indented easily by your baby's weight, otherwise there may be a risk of suffocation when the baby rolls.

This is Me

thisisme.org.uk



The new **Shine** network for 11-14 year olds, funded by the Roald Dahl Foundation, has now been named and there are already 150 members! The This is Me club was named by the young people themselves, and the winners of the naming competition were: Luke Taylor, Anna Holley, and Mathew Lee. Congratulations to all three! Membership packs have been sent out to every member – and information about events will follow later in the year.

Facebook (for the 13+ group) should be up and running by the time you read this too.

A new competition is now underway and the amazing prize is a visit to Britschool in Croydon to see how a performing arts school works! (Lots of famous artists like Katy Perry, The Feeling, and Rizzle Kicks went to Britschool). If you are not yet a member of This is Me and want to enter the competition, please email thisisme@shinecharity.org.uk for an application form – membership is free, but you must be 11-14 years old.

FB: [facebook.com/groups/536595889717738/](https://www.facebook.com/groups/536595889717738/)



Pseudocysts – the hidden danger!



My name is James and I was born with congenital hydrocephalus. About two years I began to experience some strange symptoms, certainly not your 'usual' hydrocephalus tell-tale signs. I experienced abdominal symptoms such as severe bloating and cramping.

The first episode lasted for a couple of days and we put it down to a stomach bug. However for the next 12 months the symptoms would return every 4-5 weeks; each time the symptoms would worsen, but I would recover

at a quicker rate. I went to my GP and was diagnosed with Irritable Bowel Syndrome (IBS). I followed the advice given by my GP, however, each month the symptoms would return. The diagnosis of IBS just didn't 'feel' right. There was one symptom that I experienced when

I went for a run my stomach would as though there was a 'sloshing' feeling, despite not eating or drinking beforehand.

I went back to the doctor's to ask for further tests; the next diagnosis was a possible food allergy. However, despite a new strict diet my symptoms continued to return each month, until one Sunday I deteriorated within a matter of hours and became critically ill, and I was rushed to the QE Hospital in Birmingham. The doctors discovered with a simple ultrasound that I had a large pseudo cyst (measuring 9.5cm x 13cm) at the abdominal end

of the shunt which had blocked the free flow of my CSF and had an infection in my brain, both of which had gone undetected. It was the cyst that had caused the 'sloshing' feeling and the shunt infection had caused nausea, fever, neck stiffness, and severe lethargy. Due to the seriousness of my condition the neurosurgeons quickly operated to remove my shunt and put in an external drain.

I'm pleased to say I have since recovered and returned to work. I'm incredibly grateful for the support I received whilst I was ill from my fiancé, family and employers (Contigo Energy). Following my illness the company decided to dedicate their fundraising effort to **Shine** and take part in the Blythe Valley Park 5k & 10k fun run.

Due to the seriousness of my condition the neurosurgeons quickly operated to remove my shunt and put in an external drain.

I will never be able to show the true extent of my gratitude to my friends and family for their support. Even more to my new wife Ashleigh, without her the whole experience would've been so much worse (thank you Ash, I love you!).

I want to share my experience with all **Shine** members and emphasise the message that if any of these symptoms seem familiar, talk to your doctor. Shunt infections and pseudo cysts can be easily treated, but if left can quickly become serious. If in doubt, talk to your doctor, it could save your life. It did mine.

**Shine Member
James Weavin**

The doctors discovered with a simple ultrasound that I had a large pseudo cyst (measuring 9.5cm x 13cm) at the abdominal end of the shunt which had blocked the free flow of my CSF and developed an infection in my brain, both of which had gone undetected.

SAMC

The SAMC last met in February 2012. When we were joined by CEO Jackie Bland, Development Manager David Isom, Membership Officer Gobi Ranganathan, Silver Dreams Project Assistant Lynn Hart, and Silver Dreams Project Coordinator Angie Coster.

Developments

The SAMC attended a media skills training day on Friday 30th November 2012. The reason for this was to learn some basic media and presentation skills. It is important for people with spina bifida/hydrocephalus to speak on behalf of **Shine** and our fellow members. It is also important that we gain these skills as it helps us when answering questions or giving interviews to the media.

Action Group

Gobi let everyone know that preparations for the Rise and **Shine** event in July 2013 are going well, with a budget being set and a number of exhibitors contacted. The closing date for people wishing to attend is Friday 21st June 2013.

Silver Dreams

We were joined via Skype by Angie Coster project coordinator, and Lyn Hart who is the administration support for the work. The project is for people aged 50 and over with SB/H, it was a good discussion and Angie answered many questions from the SAMC. So if you are 50 or over why not get involved. There is a Facebook page for daily interaction and you could meet new friends.



Final Meeting

The outgoing SAMC met for the final time on Saturday 2nd February 2013, after this the next meeting will be made up of the newly elected SAMC. On behalf of the SAMC I would like to thank all our members for their contribution over the last three years and hopefully we have made a difference through our work.

Sunday Telegraph

In late January 2013 some of the SAMC including myself, Paul Zickel, Amy MacGibbon, and **Shine** staff David Isom, and Darren Fower visited the offices of The Sunday Telegraph. We were given a full tour of the offices in London, and saw how everything is done on a day-to-day basis. It was very interesting and we met some lovely people throughout the day. **Shine** were the first charity to be ever given this opportunity, so I think that is worth front page news on any paper!

Here for You

As the newly elected SAMC, we are here for the next three years for all adult members. We think there is no better way to start than by asking you, our members, what concerns you would like the SAMC to address. Apart from our influence on work here at **Shine**, we examine significant issues so that we can be instrumental in making changes. We cannot do it without you the members, so, if there is anything you would like to see the SAMC doing, why not let us know?

Finally...

With all the Welfare changes that have started from 1st April for 2013 & 2014, we can all aspire to making things better by getting involved.

**Mike Bergin SAMC
Communications Officer**

E:
mike.bergin@shinecharity.org.uk

Benny Bear's adventures

As always I have been a busy bear, seeking out new adventures and meeting new Benny friends, so where to start...

I visited the Dalgarno family, whose son Ethan has SB/H. They asked me to help with their penalty shoot-out, it wasn't till I got there that I realised I was the goalkeeper! I tried my best, but they still managed to get quite a few in. It was an amazingly fun day and we raised nearly £200 for **Shine**.

Next I was back in Peterborough for **Shine's** Easter Extravaganza at the Queensgate Shopping Centre. I had lots of fun meeting new friends and painting eggs. This event marked the end of a very successful partnership with the shopping centre, as we have been their Charity of the Year and raised £19,000!

Continuing with the Easter fun, my biggest adventure recently was to go to Somerset **Shine's**

Easter party. It was a fun packed day, we made baskets and bonnets. My favourite bit was the dancing and party games, and getting to know Somerset **Shine's** younger members. Lots of new Benny friends made!

It's not all been fun and games though, I went to cheer on the dedicated **Shine** runners at the Brighton marathon and they did amazingly well. Congratulations to everyone that took part.

There are lots of outings planned for the rest of the year, so if you're going to any **Shine** events keep an eye out for me, I love it when the Benny Bear club members come and say hello! You can also keep up to date with what I'm up to on my blog, which also has details on how to join.

Shine' Lifelong Opportunities Programme Presents our 2nd

Grandparents' Day

Cheshire County Sports Club
County Lodge, Plas Newton Lane,
Chester CH2 1PR

Grandparents are an important part of every family but, when they are grandparents of children with spina bifida, hydrocephalus or IH (intracranial hypertension), they have an extra role - to support their son or daughter who is the parent of the disabled child.



For an application form please contact:
Denise Richardson on **T:** 0113 2556767 or
E: office@shinecharity.org.uk

Opportunities to:

- Access the specialist knowledge of **Shine** staff
- Learn coping strategies to improve relationships with grandchildren
- Talk openly about concerns, exchange ideas, and feel empowered and less isolated
- Gain confidence in dealing with complex issues associated with hydrocephalus, spina bifida, and Intracranial Hypertension.
- Share experiences with other grandparents in similar circumstances

**Wednesday 3rd
July 2013**

**Cost per person to include
lunch & refreshments £10**

*Closing date
for completed
applications
Saturday 8th
June 2013*

Please note there is no provision for children to attend

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

Time to Shine Adventure

A residential course for 12-16 year olds with spina bifida, hydrocephalus or Intracranial Hypertension

Pioneer Centre, Cleobury Mortimer, Kidderminster, Shropshire DY14 8JG

**Mon 12th -
Thur 15th
August 2013**

*Closing date
for applications
21st June 2013*

The subsidised charge to each participant is **£160**. Please don't let the cost put you off applying, let us know if finance is a problem.

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

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

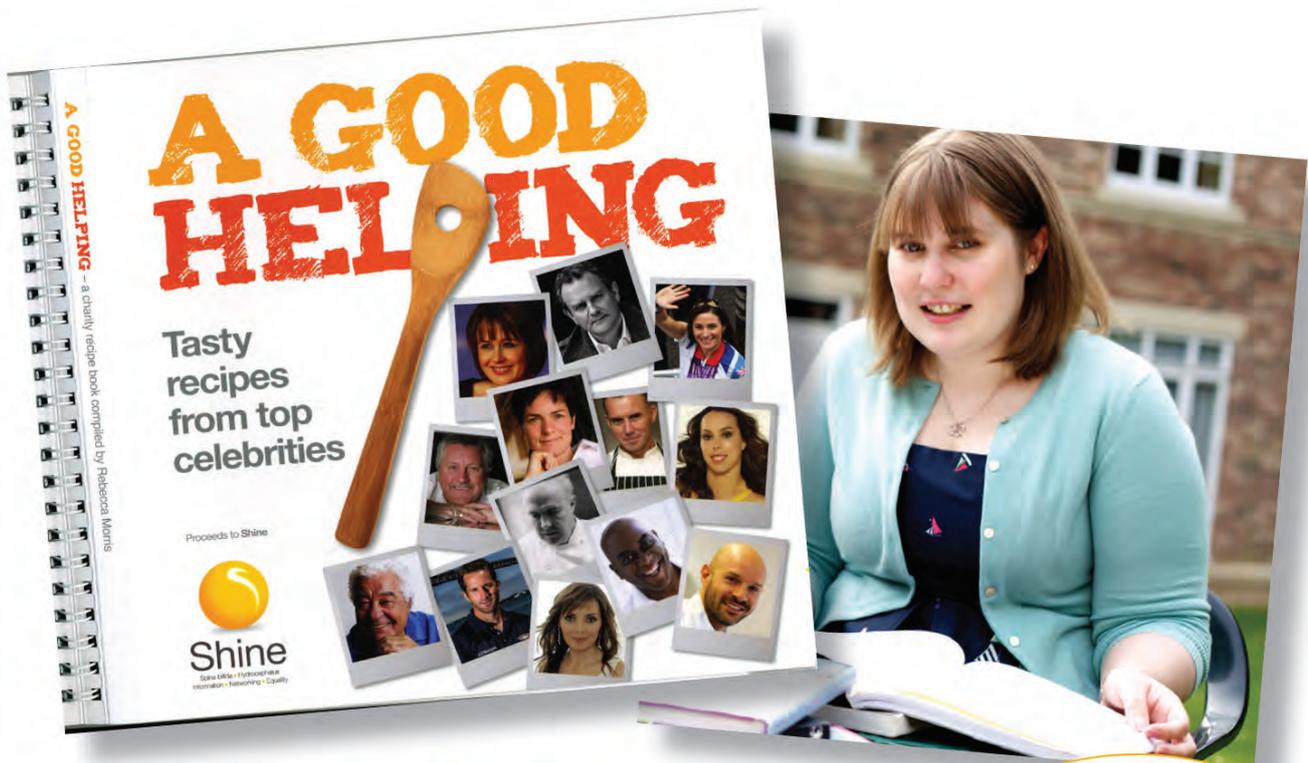
The course aims:

- 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.



Celebrity Recipe Book



**Stacked with recipes
donated by famous people
and compiled by 22 year
old Shine member
Rebecca Morris**

***Together* reader offer ...**

Just **£10.00**, includes p&p.
All profits go directly to **Shine**.

If you can sell more copies of the book, or if you know someone who can distribute the book, please contact Tom Scott: **01733 421361** tom.scott@shinecharity.org.uk



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www.shinecharity.org.uk/cookbook***