

Together

Issue five 2012



This issue kindly
supported by





Now, I can decide....

... to go out with family and friends

Peristeen® For predictable bowel management

Now there's a way to get the predictability you want from your bowels. With Peristeen you no longer have to let constipation or faecal incontinence decide whether or not you can go out, or be with the people you care about.

Peristeen is an anal irrigation system. It only requires water and is an effective alternative to other bowel management methods. It can be administered either on your own or with assistance. Used routinely, daily or every other day, Peristeen offers you the confidence to do more in your everyday life.

For more information about Peristeen please contact your health care provider or fill out and return the coupon below for a free information leaflet and DVD.



To order, call Freephone 0800 220 622 (PERSHINE0512)

www.peristeen.co.uk

The Coloplast logo is a registered trademark of Coloplast A/S. © 2011-08. All rights reserved Coloplast A/S, 3050 Humlebæk, Denmark.



Coloplast Limited
First Floor, Nene Hall
Peterborough Business Park
Peterborough
PE2 6FX
Tel: 01733 392000
www.coloplast.co.uk

Please complete and return to: Charter Healthcare, First Floor, Nene Hall, Peterborough Business Park, Peterborough PE2 6FX

Title: _____ First name: _____

I am interested to learn more about Peristeen

Surname: _____

The information you provide to us will be used to process your orders and for general administrative and record-keeping purposes. We will only disclose your personal information (including details of the products you have purchased from us) to carefully selected third parties who provide services to us and/or if required by law. By submitting your information to us, you consent to Coloplast using your information in the manner described above and to us contacting you by email and/or telephone and/or post in order to keep you informed of Coloplast products and services that we think may be of interest to you. If you would prefer that we do not contact you in these ways, please let us know by ticking the appropriate box(es) below and returning the information to us.

Address: _____

Town/City: _____ Postcode: _____

Email: _____ Telephone: _____

please do not contact me by telephone please do not contact me by post please do not contact me by email

PERSHINE0512



Welcome to Issue 5 of *Together*. The past few issues have seen a major increase in the level of interest this magazine. In addition to the sponsorship we are now receiving throughout 2012, we have also received many emails and letters from you, our members.

This interest and feedback allows us to bring you the most relevant news, information, and feature stories, so please, keep it coming!

This Spring 2012 issue is the first *Together* to be sponsored by one of our supporters. Thanks to Bullen Healthcare whose CEO, Peter Bullen, features in our interview on pages 10 and 11.

We also have a feature interview with the inspirational Steven Plimbley, there are loads of photos from the excellent Family Opportunity Weekend in Leeds, and all the regular news stories from across your **Shine** community.

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.

Editor

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

Shine Together Issue 5 Apr 2012



8 family weekend



14 meet Steven



21 fundraising news

CONTENTS

History in the making	4
Employment and you	7
Family weekend photos	8
Bullen Healthcare	10
Understanding pain	12
Strength of character	14
Gobi's gossip	16
Go Folic! news	19
Fundraising news	21
An entrepreneurial life	23
SAMC news	25

Submission dates for Spring Edition

Register of interest to submit: 22nd June 2012
Final date for submissions: 6th July 2012
Publication date: 20th July 2012

Cover photo: **Shine** member, Alishba Kahn, photographed in the **Shine** photo studio at the Family Weekend in Leeds.

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

History in the making

The year 2016 will mark 50 years of **Shine** providing a service to people with spina bifida and hydrocephalus, their parents, carers and siblings. As an organisation, and as part of our five year plan, we would like to capture this history as a lasting record of the immense work that has been done throughout this time. I know many of you out there may have experiences and/or memorabilia that would enhance this.

How are we going to do this? Joan Pheasant, Development Manager in the North of England, will co-ordinate a small working group to look at

the different ways this could be achieved. For example we could do a timeline, an exhibition, or a booklet. We are open to your ideas and suggestions.

If you wish to be part of this working group, have anything you would like to donate to an exhibition, or if you have some memories you would like to share, please contact Joan Pheasant on:

E. joan.pheasant@shinecharity.org.uk
T. 0113 255 6767
A. 64 Bagley Lane, Farsley, Leeds LS28 5LY

Staff update

We have said a sad farewell recently to Paul Dobson who was our IT & Facilities Manager. Paul worked for **Shine** for over 30 years and has been a central figure and was well liked throughout. We also say goodbye to Cerys Long and Sue Knickle; and in June we will shortly be seeing Jo Francis leap enthusiastically into her retirement. We are grateful to all these staff and wish them well in the future.

Naomi Marston has been appointed as the new Development Manager for London and South and we wish her every success in that role.

We welcome Hannah Wysocki who started work with us as a Fundraiser just after Christmas. Hannah comes from a telesales background and has already got off to a flying start. Welcome also to Dolores Black who is our new Project Worker for **Shine** Northern Ireland. Dolores has come to us from the National Autistic Society where she worked as a Family Support Worker. Finally, Debra Turner has joined us as a Finance Administration Assistant.

Fairfield PHAB, Liverpool – Up and running again

Stephen Hunt, who has spina bifida and was a part of Fairfield PHAB in the 1980's, has written to the Editor to explain that the group is now active again and continues to go from strength to strength.

The philosophy of Fairfield PHAB is to offer an exciting program geared to the age, interest, and ability of its members, and this involves learning new skills, making new friends, and participating in the activities that they undertake.

Fairfield PHAB is an inclusive youth group, where both non-disabled and disabled children and young people aged 16 and over come together on equal terms.

Fairfield PHAB tries to offer a wide range of activities for members to participate in and enjoy. Activities currently on offer include pool, arts and crafts, board games, boccia, cookery, console gaming, and computing. They have also started their own independent film project, where they make their own movies!

If you would like to become a member of Fairfield PHAB then you need to be aged between 8 and 18, and live in Liverpool. Any potential new members should contact Phil Peel on:

E. phil.peel@fairfieldphab.com
T. 07523 951 253

Shine Awareness Week – World Spina Bifida day

We are always being told by **Shine** members that we need to raise awareness and so this year we are going to run the first ever Spina bifida and Hydrocephalus Awareness Week.

The week will run from October 22-28th inclusive and will include the existing World Spina Bifida Day on October 23rd.

There are already plans to launch a major photographic exhibition in the European Parliament during that week and **Shine** has contributed photographs of some of its members for inclusion in this. The International Federation for Spina bifida and Hydrocephalus will organise this exhibition and lobby Members of the European Parliament for better recognition of SB/H.

In England, Wales and Northern Ireland we want to encourage **Shine** members and local associations to make the most of this week by

promoting their work, holding events (where possible) and putting out the key messages we want people to hear.

Shine's Spina bifida and Hydrocephalus Awareness ribbons will be on sale widely and as many people as possible will be encouraged to wear them during the week. We'll also be organising special events and materials.

Shine's Communications Team is currently planning the activities for this week and is **asking for any ideas members might have for how we can make this week have real impact. We also want to know what you think are the key messages that the public should hear about these disabilities.**

Please get in contact if you have something to say – this is a week that involves all of us in some way.

E. tom.scott@shinecharity.org.uk

Hydrocephalus Survey

This issue of *Together* includes the second in our series of health surveys for some members.

If it applies to you please fill out the hydrocephalus survey and return it to us here at **Shine**.

Shine
42 Park Road,
Peterborough
PE1 2UQ

Charity of the year success!

We are delighted to announce that **Shine** will be the Charity of the Year for Queensgate – a huge shopping centre in Peterborough City Centre. This gives us a great opportunity to raise money and awareness. Look out for the exciting events that will take place in the coming months as we make the most of this great opportunity.

We will be wrapping presents over the Christmas period for donations and this will require a good number of volunteers. If you are local to Peterborough and think you could spare an hour or two, please give us a call and we can explain how to get involved - 01733 555 988

In partnership with

Queensgate
Peterborough

Shine needs YOU!

**Do you have a few hours spare?
Are you thinking about returning to work?**

If you answer ‘**Yes**’ to both of these questions, then you are the person we are looking for to volunteer at one of our three **Shine** Charity Shops – Chichester in West Sussex, Portchester in Hampshire, and the Gorseinon shop in Wales

Why volunteer?

Volunteers are a valuable and integral part of our being able to continue to run **Shine** Charity shops. Volunteers can bring new skills and perspectives, often those that reflect the views of the local community. In return, **Shine** can offer an induction training and development package, which may help provide the skills and confidence for those hoping to return to full or part-time employment.

Dee from our Chichester shop said ‘**I love it here, it has given me a new lease of life; it has given me back my confidence and a purpose.**’

Dee has been a volunteer for around two years now and her flair and creative skills have created some wonderful window displays for our shop.

For further information and an informal chat, please ring Sharon Saville on: T. **01273 419022**

To read Sharon’s full account of *A day in a Shine charity shop*’ please visit:

www.shinecharity.org.uk/CharityShopDay



If you haven’t already joined us on facebook, ‘like’ us today at
www.facebook.com/shineUKcharity

Shine Peer Support Volunteers

Shine now has two peer support volunteers working in the East of England to add greater value to its existing services.

The volunteers can offer peer support to individuals, parents and families on issues relating to spina bifida and/or hydrocephalus. We now have a peer support volunteer based in Norfolk and one based in Suffolk, so local contact is available in both counties.

Peer support volunteers can support you via email or telephone or meet with you in person. They are there to listen and to share your experiences, problems and achievements related to spina

bifida and hydrocephalus. They can easily tap into information and advice services **Shine** has to offer whilst supporting you locally.

If you live in Norfolk or Suffolk and would like to know more, or to be put in touch with the local peer support volunteer, then please contact Sharon Lapsley on: T. **01536 400959**

E. **sharon.lapsley@shinecharity.org.uk**

Or contact Shine Head Office on:

T. **01733 555988** E. **info@shinecharity.org.uk**

**Dave Isom.
Development Manager HQ Services and
Eastern Region.**

EMPLOYMENT – supporting our members

When the **Shine** Five Year Plan was launched one of the priority areas of work related to employment.

The Five Year Plan says:

'Survey the employment status of our disabled adult membership and develop appropriate support and initiatives based on the results.'

I took the lead role on this objective and began by asking for members' experiences.

They were many and varied – from the very positive, 'I have always worked and my employers have always done their best to ensure that I was enabled to carry out my work effectively.' – to the very negative, 'I hated mainstream school and always felt different and, when I applied for jobs, I never got any of them, so I gave up.'

In between those two extremes are a lot of comments about employers 'not understanding about hydrocephalus', and many responses along the lines of, 'I didn't mention I had hydrocephalus in case it was used against me'.

Listening and reading about the experiences of members' was very helpful, because good or bad it helps us look at how we should direct this area of our work.

This is what we have decided to do next:

- Produce information (both printed and downloadable) for employers on what they need to be aware of when employing people with spina bifida and hydrocephalus. (This needs to be upbeat and positive.)
- Produce information for our members on the routes into work (Volunteering, Disability Advisers at the Job Centres, apprenticeships etc.)
- Ensure that our Support and Development Workers are kept up to date on employment issues and can support members both in work and those looking for work.
- Have regular updates in all our communication outlets – website, Together magazine, Social media etc.
- Offer training to our members in work preparation skills.
- Liaise with other employment-related agencies (statutory and voluntary).

This is just the beginning – but in this difficult economic climate we need to ensure that our members are able to feel confident to seek out employment opportunities.

Jo Francis
Regional Development Manager
E. jo.francis@shinecharity.org.uk

Data Protection

As a member of **Shine** you receive the regular mailing of *Together* via post or email. Therefore your details are on our database and **Shine** will assume that you give consent to us holding your details etc.

Shine will make sure that your information is kept private and protected according to the Data Protection Act 1988. All the information we get from you will only be used for research

or collecting statistics, and to keep you up to date with **Shine** news and the benefits of being a member. We will never pass on your details to another person or organisation without you agreeing to this.

Tell us at any time if you don't want **Shine** to make contact with you anymore, and we will make sure we take you off our list within 28 days of you telling us.

The Shine Family Opportunity Weekend 2012 saw 16 families get together in Leeds for a time of learning, sharing and socialising.

In addition to the **Shine** staff members, we were joined by Psychologist, Yvonne Le Lorraine, who facilitated the session *Understanding Behaviour*.

As parents and friends of the children enjoyed the opportunity to discuss relevant topics with one another, the children enjoyed a programme of craft making, video games, and cake decorating.

There was plenty of time to relax and everyone departed for activities on the Saturday afternoon with a choice of either Tropical World, Bradford's Media Museum, or swimming in the hotel pool.

The feedback from the weekend was overwhelmingly positive and we are already looking forward to the next event.



Monica and Rosie cool off by the waterfall at Tropical World

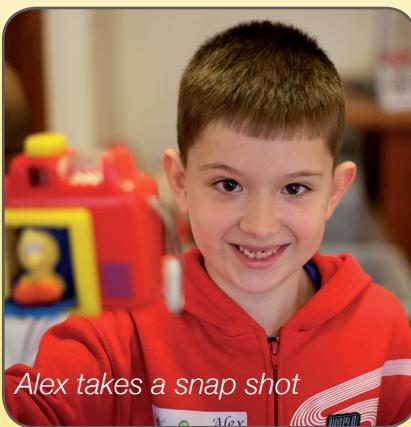


Joanna enjoys one of the great exhibits at the Media Museum in Bradford

Family Opport



Humzah deals the deck!



Alex takes a snap shot



Gill Yaz was on hand to answer questions from parents



Samuel keeps a close eye on his sisters



Alishba - brightening everybody's day

Community Weekend



Emma
enjoying her
colouring in

Benny Bear's Birthday
cake! Made by the
talented Rebecca Morris



*Being brilliant! Everybody enjoying
Benny Bear's Birthday disco.*

Mabel gets
stuck into the
crafts session



Peter looks after his little sister



Gobi - not a big
fan of the spiders!



Olivia enjoys some group games



David Isom and
his quiz team



Volunteer, Stacy O'Neill, reads with Ruth and Gracie



Yvonne Le Lorraine facilitates one of the parent
sessions

Bullen Healthcare

Words and images by Tom Scott

It's a beautiful sunny day in Liverpool when I arrive to interview the current CEO of Bullen Healthcare, Peter Bullen, and his son Paul who is MD of the medical supply company. It's a fitting backdrop for what would turn out to be a fascinating insight into a company that has managed to shine for the last 154 years.



Heritage

In 1966, after the death of his father, Francis Joseph, Peter Bullen took over Bullen Healthcare. In doing so he became the third generation to lead the company, a tradition which is maintained today through the involvement of Peter's three children, who all now play a part in running the company.

Based in Liverpool, Bullen Healthcare made its name through the supply of surgical appliances such as corsets and trusses to help patients with severe back pain, hernias, colostomy operations and, later on, with ileostomy and urostomy procedures.

From the outset Peter Bullen worked with a hands-on approach, training and practicing as an Orthotist, before going on to run the company. As technological advances in plastics developed, so too did the remit of Bullen Healthcare. Peter himself prepared and fitted orthotics which aided clients in their mobility and comfort, he remembers, 'We supplied everything from neck braces down to footwear and everything in between.'

From the late 1940's onwards the company introduced the provision of stoma care and urology products, a move which ultimately lead to the focus of Bullens today. Peter recounts stories of working with surgeons over the years that were at the forefront of developments in urological surgery. This wealth of experience is evident at every level today and goes some way to explaining how Bullens has survived many economic challenges over the years.



Having been in the business for over 55 years Peter Bullen is still constantly fascinated by the technological developments that are taking place, 'The advances being made in the standard of products are mind-blowing. As the pace of



Charles Sylvester Bullen



Francis Joseph Bullen

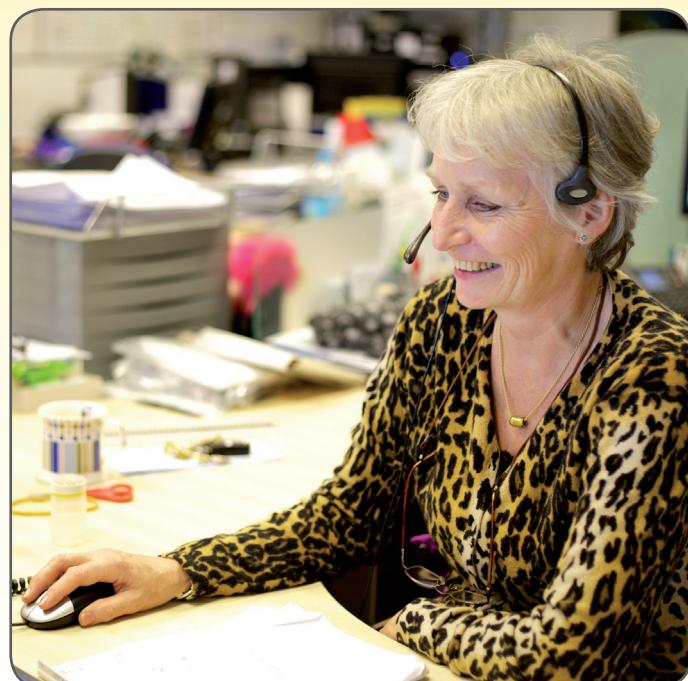
development accelerates, it is our aim to ensure that our clients access them with the minimal amount of hassle and unparalleled levels of care.'

Commitment to the future

Peter's son Paul represents the next Bullen generation to take the company forward, he explains how the focus for the company now is to ensure that it continues its legacy of offering a unique supply service to future generations.

This summer the Head Office in Liverpool will relocate to a newly renovated premises in the docklands area which will incorporate over 30,000 sq./ft. of storage space. This is all part of the vision being carried forward to enable Bullen Healthcare to be ever more efficient in their operations and offering best care and value to those who purchase supplies from them.

The company have now also established their own pharmacy and have the facility to dispense prescription medicines as part of the client's order. Paul is keen to let potential clients know that as a tax payer it is their right to have a prescription processed at any pharmacy and, if it is more convenient to the client, the prescription can be dispensed for home delivery by suitably qualified pharmacists.



The call centre staff offer a friendly, one-to-one service

A personalised service - how it works

- Every Bullen Healthcare client is assigned a personal contact within the call centre team.
- The Bullens representative not only keeps in close contact with the client, they also communicate regularly with the urology nurse responsible for the patient's stoma care.
- This communication link: Nurse – Bullen Healthcare – Patient, ensures that the patient receives the correct product at the precise time it is needed, and any changes to the patient's requirements are always accounted for.
- The Bullen Healthcare representative always calls 7 days ahead of your resupply date to ensure that everything is in order. This also serves as a useful reminder of exactly when your products will be replenished.
- Your products are then delivered to your home, on time and without hassle.

This unique approach is incredibly efficient and offers unparalleled standards in client service. Every phone call is recorded to ensure complete openness is maintained at all times, and to offer Bullens themselves the opportunity to keep improving their service.

To find out more about how you could benefit from the Bullen Healthcare service please call: **0800 269327** or log on to www.bullens.com/contact-us

Survey & Prize Draw

Shortly after this edition of *Together* is published Bullen Healthcare will send you a questionnaire. Complete yours to be in with a chance of winning some **amazing** prizes!



Understanding pain



Gill Yaz responds to your feedback on pain.
E. gill.yaz@shinecharity.org.uk

Thank you to *Together* readers who completed the first spina bifida health survey, and to those who have agreed to complete a more in depth survey later. We have gained a lot of information and some very powerful stories.

We understood that people with spina bifida may have mobility or bladder and bowel issues, but we were stunned to learn that 80% of the people who responded reported a consistent experience of pain. This went across all the age ranges, from children to older people. In the next survey, we want to know what types of pain, and what might be causing the pain, so we can think about what might help. If you haven't signed up already then please do so – it's not too late!

So, **what is pain?** Basically, it's an unpleasant feeling that tells us that part of our body might be getting damaged. It's not always that straightforward, as you'll see later in this article, but at its most basic level this is what we are feeling when we feel pain.

Our brain receives messages from our body via the spinal cord and sends messages back down the spinal cord in response. So, if a message

comes from the skin that 'it's a hot day', the message back adjusts the blood flow to the skin, and makes us sweat and cool down.

This is the way the body controls all our functions to keep us well. Pain is part of this system, alerting the brain that something is not quite right so it can respond. For example, if you put your foot on something red hot, the brain receives this message and responds by moving the foot away by sending messages to the leg muscles. This happens very quickly, before our 'thinking' brain knows what has happened, and helps us avoid harm.

However, in spina bifida, this link between the brain and the body might be disrupted. If the brain doesn't detect damage, due to a lack of sensation, then the signals to avoid the source of damage are absent and the harm continues to be done. This is one reason why people with spina bifida are so prone to skin problems such as pressure sores, or burn injuries; the 'safety system' part of pain just doesn't alert you in time. Your other senses have to take on the role, looking and checking that shoes and clothing don't leave red marks, that hot radiators or pipes at home are covered, and that any cuts or dry skin to the feet get promptly dealt with. It is worth checking that your wheelchair fits properly and doesn't leave marks on your legs, especially if you're growing or putting on weight.

Life with spina bifida can result in pain, from muscle/joint pain to pain from your internal organs. If you walk, make sure your legs are the same length, and get shoe-raises made if not, this will reduce pressure on your hip and knee joints. Using a wheelchair for longer distances can be better for your back in the long run than walking if this is a struggle. **If you use a wheelchair a lot, make sure you stretch out your arms, neck and shoulders throughout the day, and change positions as much as you can.**

Some of our members tell us that, after many years of using a manual wheelchair, their neck and shoulders become painful, and their hand function begins to deteriorate. Getting a power chair for outdoors can delay these changes,

and can lead to being independent for longer. There could also be other causes, for example, back pain may sometimes be caused by kidney stones and an ultrasound would pick these up. Let us know if there are any problems getting the equipment you need, we might be able to help you become more comfortable.

Pain is not always consistent; emotions can play an important part in how much pain is felt. Pain is worse when we are worried or anxious, and for people with shunts this can be difficult. Many people with shunts have headaches, even when their shunt is working properly. But after being told for their whole life that headaches can be a sign that the shunt is blocked, it can be hard not to worry, and the more they worry, the worse the headache gets!

Do get checked out, but, if after the investigations the shunt seems fine, ask for help to manage the pain properly. **Worries or upset in our everyday life can also affect how we experience pain;** make sure you have plenty to fill your day and make regular contact with family and friends. Exercising regularly can help with relaxing and feeling good, as well as reducing bodily aches and pain.

Sometimes pain goes on so long that extra pathways to the brain are opened up. This is **chronic pain**, and is important because the brain will continue to detect pain even when the original source of the pain has gone and can continue for a very long time. **These pathways are opened up relatively quickly in children, so it is very important that children's pain is dealt with effectively.** This pain is not 'all in the mind', but the management of it will be different to acute pain, using different medications (not traditional painkillers) and psychological therapies. Specialist pain clinics often use a range of techniques, including hypnosis and acupuncture, as well as medicines.

It may not be possible to take pain away completely and it may be that surgery wouldn't help. Sometimes people feel that there must be a 'cure' for what they are experiencing, but if there isn't, **the focus changes to managing the pain so you can live your life again.**



Come and join Benny Bear and the Shine Cymru team at St Fagan's Natural History Museum, Cardiff on Saturday 5th May 2012 11.30 am onwards

There will be some Bank Holiday fun and you can join Benny's Birthday Teddy Bear Picnic! Bring along a picnic and a Teddy, enjoy a slice of Benny's Birthday Cake, and take the opportunity to meet other **Shine** families. Everyone is welcome. To our neighbours over the Severn Bridge – do pop over if you can!

St Fagan's Museum is open to the general public from 10:00am and one of the **Shine** Cymru Team will be there to meet you at the main entrance from 11:30am.

The Museum is providing free art and craft activities throughout the day. There will also be a chance to see the raising of the Maypole and celebrate the Beltain Festival welcoming Summer by bringing back the sun with a bonfire and display at the Celtic Village.

If you are interested in attending contact Sian Prince for further details and directions on: T. 02920 514978 or E. sian.prince@shinecharity.org.uk.





Strength of character

Words and images by Tom Scott

In the words of his Personal Trainer, Steven Plimbley is 'a truly inspirational person, a pioneer!'

For the past two years Steven and Richard Stonier, who manages *M Club Spa and Fitness*, Stoke, have worked together to achieve a miraculous improvement in Steven's well-being. Steven has had hydrocephalus since birth and, though life has at times been very tough, he possesses a determination that we could all aspire to.

Like so many other people with hydrocephalus, Steven has experienced seizures, short-term memory loss, and a lack of physical strength in one side of his body from an early age. The longer his right-arm went without proper use, the less he was able to manipulate it and, after many years of guarding the affected limb, it restricted his level of activity and became very sensitive to touch.

Eventually Steven's consultant recommended that he begin to exercise to improve his health. When Steven and Richard first met they set about

trying to increase Steven's level of independence through building up the strength in his arm. This was no easy task, and it has taken two years of consistent work to realise a positive change.

The process began with Steven discussing his physical condition with Richard and then recognising that much of the 'pain' he was experiencing in his arm was actually psychological, his arm had become something for him to protect and the idea of touching it was unbearable.

The pair started slowly with sessions in the swimming pool coupled with light periods in the gym. Initially Steven's recovery time from each session was long and the gains in his strength were seemingly small. As an indication of where he once was, Steven remarks, 'I couldn't even squeeze this ball', as he explains he squashes a ball in the palm of his hand and offers a large, satisfied grin.

And Steven has lots to be smiling about, not only has he gained strength in his arm to the point of extending weights high above his head,

but the discipline of exercise is also beginning to enhance his short-term memory.

Richard explains, 'Through keeping an exercise diary to log his sessions and make sure he doesn't over do it, and by structuring station based circuits for Steven to complete each time, he is beginning to remember more for himself and become independent in this way.'

The gains don't stop there either, Steven explains, 'I am now able to use a knife and fork when eating, something I haven't been able to do properly until now.' The satisfaction Steven has gained is clear, he continues, 'With less frustration in my life I'm also having less seizures, I feel so strong.'

Steven is a great example of how exercise can be positive in so many ways, why not request a copy of the new Fit For Success brochure and find out how you can benefit from a healthier lifestyle – call 01733 555988 today!



Health Survey Feedback

Thank you to all of you who returned your Spina Bifida Health Survey, which was included with Issue 3 of *Together* ... we received over 500 responses.

Whilst there were many positive stories from members who are coping with the challenges that spina bifida, hydrocephalus and society impose, we were concerned to see some of the other findings of this survey.

Many members speak of experiencing pain without relief, and there are also members who feel isolated, and sometimes depressed. There are some **Shine** members who are having lots of problems with shunts, mobility, skin health, and bladder and bowel management - as well as many other issues unrelated to spina bifida and hydrocephalus. The **Shine** Health Team will continue looking at ways of addressing these issues.

It was also apparent that, at times, health and social services do not seem to offer adequate support to our members – it appears that some healthcare workers are not always showing as much concern and understanding as would be expected, and there is a lot of justified anxiety about issues like reduced services, especially for adults.

Some members also face challenges around their work, with some employers maybe not showing as much understanding as they could, this is often coupled with worries that people have about their income and issues such as benefits' reform.

This information is essential to the future of our membership and how we at Shine support you in this. Thanks again to all those who completed this survey and provided Shine with such valuable information.

In the coming months we will be carrying out similar surveys for members with hydrocephalus only and members with both spina bifida and hydrocephalus.

Robin Barnatt

Gobi's Gossip!



So here we are – my second update as Shine's Membership Development Officer.

It only seems like yesterday that I was the newbie in the **Shine** offices and I was updating you all on my progress, but time has flown by and I find myself well and truly settled into things and very much part of the community.

As always, the time whizzes past and we're already well into the first quarter of the year and needless to say, there's been plenty happening in the world of **Shine** and for yours truly!

I've been involved in a number of activities and had plenty of interaction with members which is great. With the help of good old Facebook and Twitter, we're able to do so more than ever, which is superb.

Facebook

Talking of Facebook, the number of friends I have has increased considerably and with the exception of the **Shine** Charity pages, I am now top of the leaderboard. This now means I've left Media Officer, Darren "The Power" Fower, trailing in my wake!

But seriously, it's great that you're all not just adding me but getting in touch with me too. As I've mentioned before, I'm here to help and get

involved and love the fact I can bring you the members and **Shine** closer together.

SUSS it out!

I've been helping colleagues Tom Scott and Annette Angell with the production of a student handbook and also establishing the **Shine University and Student Support Group - SUSS** for all you University and Higher Education students, and those of you with aspirations to make the step into further education.



Challenge Gobi

Challenge Gobi is coming along nicely with a couple of challenges already done, and plenty more to come!

The first of my challenges was at Peterborough Adaptive Cycling Club where I had a go at some



Challenge Gobi - art attack!

of the club's different hand cycles. It was good fun and definitely something I'd recommend. Taking one of the sportier cycles around the athletics track was an exhilarating experience!

Following on from my cycling escapades, I took part in something a little calmer and therapeutic – art! Credit to John Burke from our SAMC for suggesting something that was non-sport based, which was very much a blessing in disguise after the cycling!

With the guidance of our very own Marcoms Art Master, aka **Shine** Graphic Designer, Tony Nero, I got to work producing my very own masterpiece. You may be forgiven for thinking I'd be dressing up in an apron, beret, and holding an easel and paintbrush, but armed with nothing more than piece of paper and a HB pencil I got to work on a sketch of Benny Bear promoting some healthy eating, of which many of you will have seen on Facebook!

Needless to say, I haven't got the same skills as Mr Nero, and my efforts probably wouldn't win any prizes, but I'm still proud of my very own masterpiece (which one of you could own!). With a pencil and piece of paper, you too can emulate the likes of Van Gogh, Picasso ... or Nero! <http://on.fb.me/GobiBennyDrawing>

There are still more challenges for me to take on, so watch this space.

Family Opportunities Weekend

In March I attended the Family Opportunities weekend in Bramhope, Leeds which was an amazing weekend. Getting to meet Shine families and speaking with them in great depth was fabulous, especially the Higgins Family, Terry, Ginny, Tyler and of course Jaden. I also need to mention to the Stoner Family, Amanda, Emma, Nicholas and Patricia who made me feel like a celebrity after recognising me for my badminton exploits and appearance in Together!



Gobi and Samuel playing Scrabble in Leeds

If you thought the excitement for me this first quarter ended there, you'd be wrong! I've now been confirmed as one of the Torchbearers in the Olympic Relay taking place around the country.

I'll be one of 8000 people in the country with the honour of carrying the Torch, my route will take me through my hometown of Stevenage. The exact time and place of the relay on the 8th July are yet to be confirmed, but if you fancy coming along to show your support it'd be great to see you there. Watch out for my updates on my Facebook.



Gobi at No. 10 Downing St!

10 Downing Street

And if that wasn't enough excitement, I had yet more after a special visit to No. 10 Downing Street through BADMINTON England.

I was selected as the Para-Badminton representative for the visit and was handed the opportunity to meet the Prime Minister David Cameron, Olympic Gold Medallists Darren Campbell and Denise Lewis, and also HRH Princess Anne which really was an honour. Even Benny Bear got a look into No. 10, and his photo with Denise and Darren will be one for the archives!

It was a fabulous day, and the memories of playing badminton on the gardens of No. 10 will stay with me for a very long time.

Don't worry folks, mingling with VIP's was great, but the fun and games I have with you all, and my Marcoms buddies in **Shine** Head Office, is where it's really at!

That's all for now, but I have plenty to look forward to over the coming months. Until next time, have fun, stay safe, and in the words of Benny Bear, be brilliant!

You can contact Gobi on:
E: gobi.ranganathan@shinecharity.org.uk

Benny Bear writes ...

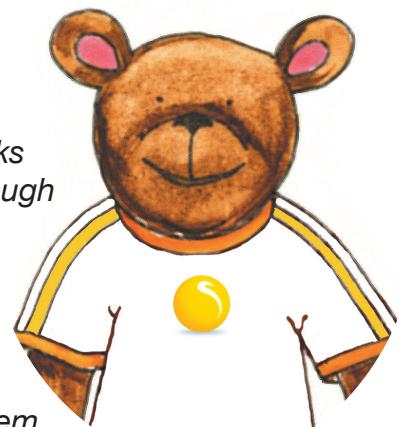
It's been a very busy few months for me here at Shine.

I have visited St. Paul's Church of England School in Nuneaton for a Teddy Bear's Picnic, St. George's Neighbourhood Nursery in Brighton for some fun and games, as well as having a Benny Bear Birthday Party at the Family Opportunities Weekend in Leeds! I really am a busy bear!

I now have my own monthly newsletter, it's called 'Brilliant News!' and it is sent out to all Benny Bear Club members. I also sent everyone a Benny Bear postcard so you can write to me and tell me all YOUR news!

*As if all that wasn't exciting enough, we now also have the Benny Bear books **available for download**. We have run out of the paper*

version of the books and there isn't enough money in my Bear Box to pay for more. BUT ... for just 99p each you can download the books and read them on your computer or print off your own copy to read as much as you like! Visit shinecharity.org.uk/BennyBearBooks to download the books.



To keep up with all my latest news, join the Benny Bear Club, or to download the Benny Bear postcard visit www.bennysblog.co.uk

Be brilliant!
Benny

Shine NI Update

As usual **Shine** Northern Ireland has been involved in many different activities:

Training

A series of four weekly training sessions for adults in Coleraine were provided and organized by the **Shine** NI team. The first week consisted of information giving, week two focused on healthy eating and diet, week three involved fitness, exercise and health screening (in conjunction with the University of Ulster), and the final week was all about pampering and stress relief. The sessions were well attended and very successful.

Hands Across the Peace Bridge

Shine NI is currently planning a 'Hands Across the Peace Bridge' event - which is fast becoming a bigger and higher profile event than we ever could have hoped for! We originally expected to mobilise about 500 volunteers to walk across a bridge and hold hands together – at the last count it now looks like we could easily end up with double that! The purpose is to raise both awareness and to raise money – we are aiming generate £10,000.



Fundraising

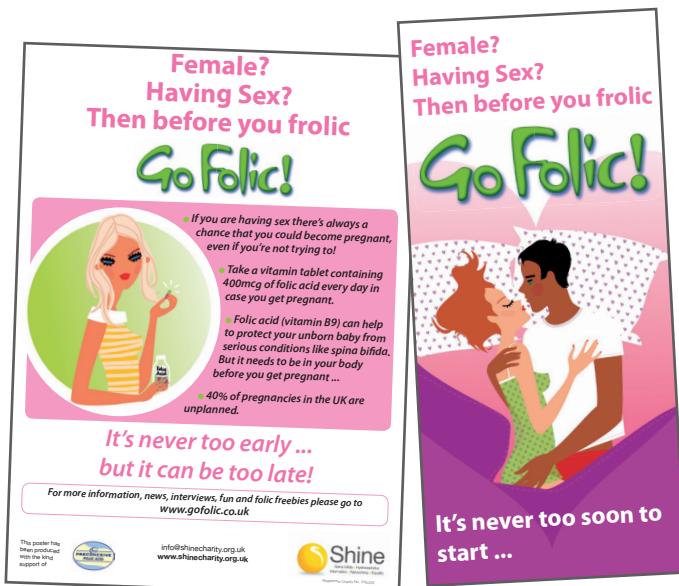
Shine NI has been selected by another **vintage car club** to be their nominated charity. On 1st April they will be holding their annual rally at which we hope to raise more funds and awareness. **Queens University Belfast** have also selected us as their chosen charity of the year, and this will hopefully lead to lots of entertaining, student-led fundraising. On 31 March we have a number of runners bravely doing the **Omagh half marathon** on behalf of **Shine** NI.

Cathy McKillop
Director **Shine** NI
E.cathy.mckillop@shinecharity.org.uk

Go Folic! news

The new Go Folic! materials have finally arrived! For those of you who have not seen them ... here they are ... I am sure you will agree that they are very eye-catching and they are already proving very popular. We now have 10,000 leaflets in circulation, which is a huge achievement in such a short space of time.

The Norfolk Pharmacy Campaign is now underway, and our lovely new Go Folic! leaflets and posters are taking pride of place in pharmacies and libraries throughout the county during April and May. Things are off to a flying start and we have already had orders in for a further 1,000 leaflets and 50 posters for the region. Requests have been coming in from midwives, GP surgeries, and sexual health clinics, so it really demonstrates that there's a high demand for this information.



You can help us by distributing leaflets within your own community. If you would like any leaflets or posters for your local group, college, pharmacy, surgery etc. please contact Martine Austin - [E. martine.austin@shinecharity.org.uk](mailto:E.martine.austin@shinecharity.org.uk) or T. 01733 421349.

Don't forget to look out for our new film, 'I am a ...' coming to YouTube and the Go Folic! website soon!

Thank you to Lanes Health who kindly sponsored these new materials.

Supermum Shelly's a star tweeter

I must add a special thank you to the truly inspirational Shelly Wall, who has been tirelessly tweeting and 'Facebooking' about Go Folic! and Shine. This support is made even more special given that Shelly has been in and out of hospital (more in than out!) since the birth of her beautiful son Noah early last month.



Beautiful baby Noah

Noah has spina bifida, hydrocephalus, and a porencephalic cyst and has already had to contend with a repeatedly leaking shunt, daily manual fluid drains and a csf infection. Shelly has a big social media following, and I'm sure that her open and honest accounts throughout her pregnancy and since Noah's birth have done a great deal to help increase awareness of spina bifida, hydrocephalus and the need to take folic acid. We wish the Wall family all the very best for Noah.

It only takes a couple of seconds to send a message or retweet one of ours (or Shelly's!). If you're on Facebook or Twitter, please try to take the time to do this – you will be helping us to make even more women aware of the need to take folic acid.

Follow **Shine** Go Folic! and Shelly on Twitter, search: @shineUKcharity @gofolicUK @Shellibobbins

Be sure to benefit:

Understanding the changes to welfare reform



Many of you tell us that you are concerned about the changes to the benefits system in terms of how they will impact on you financially and in respect of the Government's expectations of getting back to work etc.

This new, quarterly update will aim to keep you informed about what is happening, where you can go for support with your claims, and how you might contribute to changing the Government's mind!

So, what's happening?

A new **Universal Credit** system is being introduced.

A number of existing benefits, including income-based jobseeker's allowance (JSA), income-related employment and support allowance (ESA), income support (IS), housing benefit (HB), child tax credit (CTC), and working tax credit (WTC) will be replaced by this Universal Credit, which will in effect 'pull' all the benefits together.

The **Universal Credit** will be introduced by October 2013 with changes to eligibility rules for some of the above benefits already introduced.

In addition to the **Universal Credit**, new **Personal Independent Payments** (PIP) are being introduced to replace the Disability Living Allowance (DLA) for all those between the ages of 18-65. At the moment, DLA for under 18s and over 65s will remain as it is.

If you receive any of the above benefits, you may be affected by the changes so it is important to understand how the changes will affect you, and that you start planning for these changes in advance.

What can you do to plan for the changes?

If you receive a form for renewal, or a request for information from the Department for Work and Pensions (DWP), don't sweep it under the carpet. Tackle the changes head on.

Contact **Shine**'s First point of contact on 01733 555988 or email info@shinecharity.org.uk for details of your local Support and Development Worker.

He or she will be able to:

- Help you understand the changes – they can be quite complicated, so don't be afraid to ask for help
- Support you in any new claims for benefits
- Help gather evidence and information for claims forms and assessments
- Signpost you to specialist help for appeals, financial planning, and debt reduction.

For further information on Welfare Reforms, visit www.dwp.gov.uk or www.direct.gov.uk

What is Shine doing about the Welfare Reform and your concerns?

Shine has responded to several Government consultations on the reform of Disability Living Allowance (DLA) and Personal Independence Payments (PIP). These responses are also shared with other organisations, such as Disability Rights and Disability Wales, ensuring their responses reflect your views too!

We are also developing a benefits section for our website, which will highlight key information and have a section for further reading.

How can you get involved and have your say?

- Let your **Shine** Support and Development Worker know your views
- Add your name to our consultation list by contacting Kate Thomas on 01656 864102 or email kate.thomas@shinecharity.org.uk
- Sign up to any e-petitions on these issues.
- Contact your local Member of Parliament or Assembly Member and tell them how the changes will affect you.
- Contribute via social groups and other disability organisations.

A big thanks to everyone who fundraises for us, we really need you! Here is a selection of ways to get involved.

If you would like to fundraise for us, or nominate us to your company, please get in touch



Shine Skydivers

March 2012: Rich Balding and Nikki Trivitt bravely faced the elements and their fears by jumping out of a plane! The two of them had a fantastic experience, between them raising an incredible £1,734!

Well done Rich and Nikki you really are **Shining Stars!**

Upton-By-Chester High School



Upton-By-Chester High School raised a whopping £4,539.82 after Kiefer Jones nominated us as their charity of the year.

The sixth form organised some brilliant events including a five-a-side football tournament, a hot-dog eating contest, bake sales, sponsored waxes, stay-awakes, silences and even busking sessions! They had a great time fundraising for **Shine**, all the while looking fabulous.

Rebecca Morris

Rebecca needs your recipes for **Shine**! She is raising awareness and money for the charity by putting together a celebrity recipe book and would love to include recipes from **you** – our **Shine** community. So if you would like your favourite dish to be published as part of this great project, please get in touch to find out more.

Running

We would like to say a big thank you to everyone who has run for **Shine** this year, especially those who took on our places in the recent London and Brighton Marathons. Their fantastic efforts have raised £1000s and we really appreciate all their hard work.

If you would like to run for **Shine** then we have places in this year's Great North Run and Eastern Run up for grabs, and it's not too early to apply for London or Brighton 2013. Get in touch with the Fundraising team if you want to take on the challenge - we'll support you all the way.



Corporate

We are pleased to say that we have launched a new partnership with BetterlifeHealthcare who are a UK mail order and Internet distributor of healthcare aids, disability aids and mobility aids.

Our partnership gives **Shine** members the exclusive opportunity to get free next day delivery on all orders over £30. **Shine** will also receive a donation for all orders placed – so two good reasons to visit their site today.

To view their products, please click on www.shinecharity.org.uk/memberservices

To fundraise for **Shine** contact Annette Angell on: E. annette.angell@shinecharity.org.uk

Local Association news – Thank you to NWASBAH

The 31st March 2012 marked the end of an important and influential era in supporting people with spina bifida and hydrocephalus in North Wales.

North Wales ASBAH has closed its doors as a charity, but have re-emerged as **North Wales Friends of Shine Cymru**. They will work with us to continue to fundraise and help us organise events and information days for members across North Wales. Brilliant news!



New member of staff for West Wales and Swansea

Melanie Hayes, from St David's in Pembrokeshire, has been appointed as the new part-time Support and Development Worker for the West Wales Counties (Carmarthenshire, Pembrokeshire and Ceredigion) and Swansea.

Melanie is a former lecturer in Childcare at Pembrokeshire College and has volunteered and fundraised for many community projects. She brings considerable experience of working with individuals and groups to her new role.

One of her great passions is travel and her adventures include working in primary schools in Botswana and backpacking around Europe. Melanie has spina bifida and hydrocephalus herself, so will bring a wealth of understanding, personal experience and knowledge to the role.

Melanie can be contacted on:

E. melanie.hayes@shinecharity.org.uk
T. 01437 729089



Congratulations to member, Roger Price, and his wife Helen on the birth of their twins Evan and Lucy. They were born on February 10th at Royal Shrewsbury Hospital.

The Shine Cymru team are delighted to have had, and continue to have, the opportunity to work so closely with such a fantastic, dedicated group of people and wish to offer a BIG thank you to everyone for the difference they have made to others.

For anyone wishing to join the group, please contact Sally King-Sheard on:

E. sally.king-sheard@shinecharity.org.uk
T. 01745 889457

Events in Wales for 2012

Shine Cymru is putting together a calendar of events for 2012. The events will include some information days, adult member get-togethers and children's parties and fun days.

Contact Kate Thomas on 01656 864102 or email wales@shinecharity.org.uk if you have any ideas for events or wish to organise one yourself.

Social Groups

Our network of social groups for adults in Wales is developing and we now have groups in

- Swansea
- Ceredigion
- Pembrokeshire
- Newport
- Llandudno
- Cardiff/Caerphilly

We plan to set up some support groups for parents and children in the coming months so contact us if you are interested:

wales@shinecharity.org.uk

An Entrepreneurial Life: Joseph Waggott's Passion for Business Shines Through

Successful entrepreneur Joseph Waggott, who was born with spina bifida, will attest that his life is driven by persistence, passion and dedication.

Although he established his own successful business in Zimbabwe, where he was born, the political situation took a turn for the worse and he returned to the UK determined to find a new outlet for his passion for business.

Looking for a gap in the UK market, Joseph's contacts in Zimbabwe provided him with mops for polishing metals for re-sale in the UK. This resulted in the birth of Metal Polishing Supplies UK Ltd in 2007.

Expanding the range due to market demand, Joseph has overseen the rapid expansion of his business on eBay UK, Amazon UK, and his own website into a European market-leading supplier of DIY metal polishing kits.

Reflecting on his business' growing success, Joseph reveals that there is no substitute for a persistent entrepreneurial spirit, passion, and dedication in order to succeed against the odds.

His continued success stems from a focus on superior customer service and quality products. Joseph always puts the customer first – even when he is in hospital. An excellent team is always there to support him, especially on the rare occasions when he is 'out of action' – rare because Joseph always aims to be at the centre of his company whatever the circumstances.

Joseph was recently nominated for the 2011 Stelios Award for Disabled Entrepreneurs in the UK and was recognised by the judges as an exceptional entrepreneur, reaching the shortlist of finalists.

Joseph said: 'I'm delighted that my entrepreneurial qualities have been recognized by the wider business community. My strong passion, together with aptitude for establishing and growing my business,

has not been hindered by my disability – in fact the opposite is true as my personal challenges have resulted in a sharper focus on achievement and on building a fantastic team around me.'

**Metal Polishing Supplies
UK Ltd**

Metal Polishing Supplies UK Ltd:
www.metalpolishingsupplies.co.uk

Contact: Joseph Waggott,
MD, Metal Polishing Supplies UK Ltd
E. joe@metalpolishingsupplies.co.uk
T. 02392 751848



**Metal Polishing Supplies
UK Ltd**

Shine's Lifelong Opportunities Programme Family Fun Day - Cornwall



Activities include:

Indoor swimming pool,
soft play area, skittles, table tennis,
zip wire, adventure playground,
climbing wall, crazy golf & more.

Closing date for applications
1st September 2012

For more information please telephone
Lynne Young 01726 861062
lynne.young@shinecharity.org.uk

Sunday 7th October 2012

Sands Resort Hotel, Porth, Newquay TR7 3LX.

10:30am – 4:30pm

**For families who have a child aged 16 and under
who has spina bifida/and or hydrocephalus.**

Benefits of attending:

- A fun event with activities for children with disabilities, parents/carer's and siblings.
- An informal opportunity to meet other families, develop friendships and learn practical coping strategies.
- Access to Shine and Cerebra support workers and the opportunity to meet Benny Bear.

There will be a charge of £10 per family for this event to include lunch and drinks. Places are limited so please register your interest as soon as possible.

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

Shine's Lifelong Opportunities Programme Shine's B & B day



Shine working in partnership with Coloplast.



Thursday 20th September 2012

**Eastpoint Conference Centre, Burlesdon Rd
Southampton SO19 8BR**

A Lifelong Opportunities Event for parents and carers of children (under 18) with spina bifida

An information day on modern bladder & bowel management.

Special Guest Speaker -

Mr Patrick Malone, Consultant Urologist
at Southampton General Hospital.

Benefits of attending:

- To meet other parents, share stories, and find out what's new

10:30am - 4:00pm

Application form from: Denise Taylor, 209 Crescent Rd
Barnet EN4 8SB 0208 449 0475
denise.taylor@shinecharity.org.uk



Closing date for applications
24th Aug 2012

Sessions to include:

- A Parent's Journey
- Irrigation Systems

Cost £10 per person for parents,
£35 for professionals, including lunch
and refreshments

There will be no provision for children to attend this event.



Mike Bergin brings all the latest news from your SAMC -

SAMC Meeting Jan 2012

The SAMC met for the first meeting of 2012 at **Shine** Head Office on Saturday 21st January, welcoming Shine CEO Jackie Bland, Development Manager HQ Services & Eastern Region David Isom, and Membership Development officer Gobi Ranganathan.

Developments

Jackie reminded the SAMC that it was now representative of the whole membership, not just a small group of members. Its role is to represent the views of the membership, to advise on issues that affect members, and to ensure that the needs of members lay at the very heart of the organisation. There have been 630 responses to the recent spina bifida health survey, there is an initial report on page 14 with more to follow in the coming months.

Family Opportunity Weekend 2012

Liz Potts attended the family weekend on behalf of the SAMC and by all accounts it was a great event and a good time was had by all the children and parents. The weekend began with dinner on Friday and followed by a fun "Ice Breaker" in the form of a quiz for all. On the Saturday the children had a great time making Mothers Day cards, icing cupcakes, and playing with new friends.

There were also workshops on both the Saturday and Sunday with speakers covering education and health matters. The Saturday afternoon was a time for families to relax and go swimming or take in the Media Museum or the Tropical Gardens. The best event though was the disco with Benny Bear present to meet all the children. Families were also able to have their portrait taken in a professional photo studio. Liz has said when talking to parents they got a great deal from the talks and workshops and most of all from meeting other families.

Shine Action Group

This is a group that was proposed by **Shine** CEO Jackie Bland and has been headed up by Gobi Ranganathan, with 50% membership from SAMC and 50% selected from the wider membership.

The purpose of the group is to: be a steering group for the Lottery funded membership projects; raise the profile of **Shine**; increase membership numbers and involvement; and to raise awareness of spina bifida and hydrocephalus. The group will seek to identify and find solutions to other issues as they arise. I am happy to let everyone know the group held their first meeting on Sunday 1st April 2012.

As always, please get in touch and if there is anything the SAMC can be of any help with just

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

INBOX

Dear Editor,

My name is Ben Johnson and I am 22 years old.

I have had hydrocephalus since I was born. At the time the doctors did not know I would need a shunt. Whilst I was on holiday in Paris I fell ill. When I got back home we went to Great Ormond Street Hospital and I had the shunt fitted. That was 12 years ago when I was 11 years old.

Best regards

Ben Johnson

A letter from the past Chairman of the Essex Association of Spina Bifida & Hydrocephalus (EASBAH)

The national Association of Spina Bifida and Hydrocephalus (ASBAH) has a new name and the 'Link' Magazine, so important to its readers in the past is now called 'Together'. Change in every aspect of life is somewhat inevitable and often welcomed as nothing stands still. Change can however be a double edged sword because sometimes progress alters that which we have become used to, it can herald an end to tradition and established practice.

So it is with the Essex Association. A group of some 350 people and families connected to both spina bifida and hydrocephalus for which I and a committee of eight have worked continuously for 40 years. Our work is done. The internet now readily provides all required information and facebook or twitter offer a forum for people to meet and share experiences.

Doctors at specialised hospital clinic's, like the Chelsea and Westminster (under Dr. Morgan) now run surgeries for people with either condition and can offer a level of continuity to development not possible 30-40 years ago.

Contact with families in Essex has been minimal over recent years and in 2011 the Essex Authority Grant (which had supported the cost of a Fieldworker) was withdrawn. The decision to close therefore was a difficult but necessary one.

It is a sad but satisfying thought that we are no longer required and I would like to use this letter to say a big thank you to all the dedicated and hard working people who took the time to meet and administer our work without a break for so many years. I would also like to inform all the people and families living in Essex and the London Borough of Havering that on our closure we donated our final balance, the sum of £6703.63 to the National Organisation with the request that it be used in support of needs identified within those boundaries.

I send my kind regards to you all and my very best wishes to all those who are currently working on behalf of spina bifida and hydrocephalus wherever you are.

Regards

Robert Kite MA

Shine offers its grateful thanks to all those involved in the Essex Association.

Maison des Landes Hotel

Jersey holidays for the disabled

Maison des Landes is a charitable Trust set-up by the Lions Club of Jersey to provide holidays in Jersey specifically for the disabled.

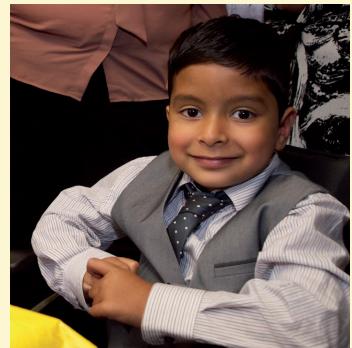
The Trust runs a holiday hotel catering for disabled guests and their families or escorts, in accommodation which has been specially designed to meet the needs of the disabled.

Children of disabled parents and the parents of disabled children are most welcome.
Other relatives are also welcome provided accommodation is available.



Apology

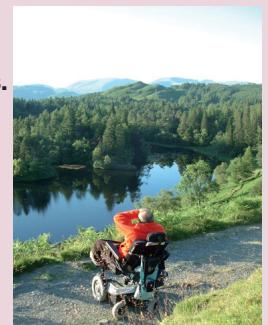
We apologise to Toheed Raza, who was incorrectly listed as Tahir in the last issue of *Together*.



Ratcliffe Disabled Holidays

Quadriplegic owner
Ceiling hoists, electric hi/lo beds
Wheel-in showers 4 destinations.
House and flats Heysham,
Great Morecambe Bay views
Spacious caravans Haven parks
Filey and South Lake District

Phone Allan or Jan
01274 588142



www.theukweb.com/disabledholidays

Programme of events

11th June. Members Day Reading

10:00am - 4:00pm. New Hope Centre

95 York Road, Reading RG1 8DU.

A chance to learn more about Spina Bifida and Hydrocephalus and meet other members.

Contact: London & South region office 020 8449 0475 contact@shinecharity.org.uk

24th June. Surrey ASBAH Picnic

From 4:00pm. The Old Pheasantry

Colley Hill, Nr Lower Kingswood, Tadworth KT20 7HF

An opportunity for families and members to come together for a fun-filled afternoon at a delightful venue

Contact: Liz Tadd 0208 6425082
taddfamily@btinternet.com

1st July. West London Picnic

3:00pm - 6:00pm. Enterprise Lodge, Stockgrove Way, Perivale, Greenford UB6 8TJ

An invitation to all our members in the area to join us for a picnic and a chat.

Contact: London & South region office 020 8449 0475 contact@shinecharity.org.uk

15th July. South London Picnic

1:00pm - 4:00pm. Horniman Museum and Gardens, 100 London Road, Forest Hill, London SE23 3PQ A get-together for families to share experiences and explore this child-friendly venue-whatever the weather. Contact: Diane Morgan 020 8659 3060 Diane.Morgan@shinecharity.org.uk

Shine's Lifelong Opportunities Programme Understanding and Managing Challenging Behaviour (Associated with Hydrocephalus)



Registered charity no.249338



Closing date for applications
3rd September 2012

To include: - seminars, workshops and opportunities for networking.

There will be a charge of £10.00 per parent/carer to include refreshments and a buffet lunch.

Please note there is no provision for persons under 18 years to attend this event and there is no parking available on site.

Thursday 4th October 2012 10:00am - 4:00pm

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

An Information day for parent(s)/carer(s) of children aged 11-18 years with hydrocephalus presenting with challenging behaviours.

Benefits of attending:

- Better understanding of some of the behaviours associated with hydrocephalus.
- Acquire strategies to help manage challenging behaviours in the family setting.
- Share experiences, exchange ideas and feel empowered.
- Increased confidence to challenge others' perspective on challenging behaviours associated with hydrocephalus.

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

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

Advance Plus

Touch Free Intermittent Catheters



The freedom to catheterise anytime, anywhere.

Sometimes finding a toilet or accessing one is difficult. This is where the Advance Plus Intermittent Catheter with its integral collection bag comes into its own. Featuring *Touch Free* technology the Advance Plus supports user mobility and promotes independence.

The **Advance Plus** catheter provides the following benefits:



- A unique *No-Touch* protective introducer tip helps reduce the risk of carrying bacteria up into the Urinary system
- An integral 1500mL collection bag for secure urine collection - anytime, anywhere
- The bag also shields the catheter from possible environmental contamination before and during insertion
- Ultra-smooth eyelets which help to ensure trouble free insertion and withdrawal for enhanced user convenience and comfort
- The bag handle is easy to grip and easy to hold, even for users with limited manual dexterity



To request a sample of the Advance Plus Intermittent Catheter call 0800 521 377 or visit cathetersample.co.uk

Confidence. Pure and Simple.