Inside: Shine Awards • The Chairman's Challenge • AGM

Issue 11

Together

Winifred Shines on

99 and still going strong

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Together Editor: Tom Scott
Deputy Editor: Louise Tyler

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
Registered Charity No. 249338

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- **Register of interest to submit:** 20th December 2013
- **Final date for submissions:** 3rd January 2014
- **Publication date:** February 2014

Cover photo: Winifred Connolly. **Photo:** Tom Scott

Welcome to *Together*

The Editor flying the flag for Awareness Week

In recent months we have seen a huge growth in the profile of **Shine**. This is not just based on a feeling, this is due to actually seeing new developments unravel before our own eyes! These developments include the great success of the second annual Spina Bifida and Hydrocephalus Awareness Week which saw the highest number of monthly hits to the **Shine** website... ever!

We also had over 100 individuals, schools, workplaces, nurseries, and community groups sign up to **Wear Yellow and Shine** during Awareness Week – this was four times the number involved last year!

On the 24th October, during Awareness Week, our AGM was very kindly hosted by **Coloplast** at their Peterborough Head Office, and everyone involved agreed that the experience was unique - there was so much positivity and genuine reason for celebration that all attendees left the building beaming about the successful work of **Shine**.

The same afternoon, we enjoyed the annual **Shine** Awards at which we celebrated the fundraisers, volunteers, and professionals who make **Shine** the vibrant life-changing community which it continues to develop into.

All of this great news is reflected in this, the eleventh issue of *Together*. As well as regular features on aspects of health, occupational therapy, benefits, your SAMC, and fundraising, we also have inspiring features from the world's oldest person with spina bifida, and inspired coach Carl Eaton, who runs a vibrant football club in Skelmersdale.

Have a great Christmas
and New Year!

Tom Scott

10th anniversary celebrations

The Chairman of Shine's Board of Trustees, Richard Astle, will be celebrating his 10th anniversary as Chair in 2014.

To mark the occasion, Richard will be embarking on a year-long awareness and fundraising initiative, which was announced at the recent AGM and will be officially launched at a high profile reception in December.

Activities will include a wide variety of events and fundraising endeavours including running events, the first ever 'Big Yellow Ball', and the year will culminate with a sponsored trek, which will see Richard and his keenest supporters make their way across Morocco.

This appeal is a huge undertaking and we need all **Shine** members to support it as much as possible by promoting it via the social networks, so please keep your eyes peeled for updates!

Activities will include the first ever 'Big Yellow Ball' and culminate with a sponsored trek

Shine Chair, Richard Astle

Obituary Margaret Holmes

We recently received the sad news that former ASBAH Fieldworker, Margaret Holmes, passed away on 16th October 2013.

Margaret, who had spina bifida had been involved with her local association for a number of years, holding the position of Chairperson for five of those. Margaret then became a fieldworker for ASBAH in the Bromley, Bexley and Croydon area between 1988 and 1995.

After retiring, Margaret resumed her active role in the South Thames Association as Secretary and was known for her insight, empathy, and generosity. Margaret was an avid volunteer who was dedicated to serving her community, working with a bereavement group and her local Church. In her personal life her passions were travelling, cooking and cricket.

Shine recognises and appreciates the impact Margaret made to the London and South Region. Our collective condolences go to Margaret's family and friends at this time.

Margaret was an avid volunteer who was dedicated to serving her community, working with a bereavement group and her local Church

AGM welcomes new Directors

Coloplast

Shine's AGM took place during the most high profile Awareness Week yet. The event was generously hosted by Shine's corporate partner Coloplast at their impressive and friendly Peterborough base.

As 60 members, friends, and family met to hear the results of Board elections, more than 100 groups up and down the country were taking part in 'Wear Yellow and **Shine**' events to raise awareness of spina bifida and hydrocephalus and precious funds for **Shine**.

Three new Directors were elected to the Board: Sally Hesling has been a practising solicitor for 13 years; and is the mother of twin boys one of whom has a rare form of spina bifida, Yvonne Lindsay, has a 19 year old daughter with spina bifida and is a qualified GP currently working freelance; and Peter Serjent, who worked for 18 years as a marketing expert developing behaviour changing multi-media campaigns, including campaigns on disability issues. These were the first directors to be elected by the whole membership under **Shine**'s more open, democratic structure. Professor Roger Bayston, Chair of **Shine**'s Health Advisory Council, gave a short presentation on how a shunt works, whilst CEO Jackie Bland reflected on a year of increasing profile and activity for **Shine**. As part of her presentation she played the new 'Get Inside My Head' animation, which features a little girl explaining how hydrocephalus affects her. Jackie explained that the animation would be played throughout the world as part of the international PUSH initiative (more info about PUSH at **www.IFglobal.org**).


Professor Roger Bayston addresses the AGM


New Treasurer Aiden Kehoe


Patron, actor David Proud

The event was generously hosted by Shine's corporate partner Coloplast at their impressive and friendly Peterborough base.

2013 Shine

– reflecting inspiration and dedication

Now in their fourth year, the 2013 Shine Awards once again gave the charity a chance to honour the people who make it all possible. Fundraisers, volunteers, professionals and inspirational young people were celebrated in a warm hearted and emotional occasion shared by relatives, friends, Shine staff and Directors, and of course, Shine members who had stayed on after the AGM.

Professor Roger Bayston won the prestigious 'Lifetime Contribution' Award for his lifelong dedication to the health of people with spina bifida and hydrocephalus, whilst **Shine** Patron Danny Mills was presented with a one-off 'Outstanding Ambassador' Award for his dedicated pursuit of opportunities and funds for **Shine**.

▲ Clara Gill presenting Dean Godwyn with the Fundraiser of the Year Award

▲ Stephen Collett receiving the John & Lucille van Geest Award for Outstanding Service to the Shine Community

▲ Toni Allen-Bewley receiving the Shine Young Achiever's Award

▲ Chairman Richard Astle presenting Danny Mills with the Shine Outstanding Ambassador Award

Awards

Coloplast

Sponsors of Young Achiever and Shine Professional Awards

▲ Shine Patron, David Proud and Coloplast representative, Hayley Porter, presenting Laura Dennis with the Shine Young Achiever Award.

▲ Rebecca Morris presenting Stacie O'Neill with the Volunteer of the Year Award

▲ Tom Scott presenting Phoebe Ashworth with the Young Fundraiser of the Year 2013

▲ Amar Dugal presenting Professor Roger Bayston with the Lifetime Contribution Award

Gobi's gossip

Hi everyone! Since my last gossip page, I've been making steady progress, although slower than I anticipated. However, as you read this, I should be back in full swing of my Shine duties and usual routines.

To be honest, my recovery has been slow and arduous. A lot of my efforts have been focused on my mobility, as that was the key to getting me back on track. By increasing mobility, I was able to start driving again, albeit with assistance when taking the wheelchair in and out of the car. But this at least gave me some fresh air and some much needed freedom from sitting at home all day waiting in for the district nurse.

Once I had my mobility, there was no stopping me and, by the end of August, I managed to restart in the gym. The start of September saw me return back to badminton training too! It's fair to say this has been a long haul, even by my standards. But I've now come out the other side and am making great progress. Although I hadn't officially returned back to my **Shine** activities, I've been keeping tabs on things and still been raising awareness of **Shine**. I've also had the good fortune of introducing our very own Benny Bear to a couple of VIPs! I, along with Benny, not only met and had a photo with ex-Manchester United, Leeds United and England star, Lee Sharpe, but also Mr Paul Mitrofanoff. The latter meeting was particularly special to me, as it was his creation of the Mitrofanoff Procedure that has allowed me to get where I am today. Without my Mitrofanoff, I doubt very much that I would have achieved half the things I have done to date.

With Spina Bifida and Hydrocephalus Awareness Week having taken place at the end of October, it seems I returned to work at the perfect time! The fire in my belly has returned and I'm looking forward to developing and growing the membership in many exciting ways – I hope to see many of you when I'm back on my **Shine** travels soon!

Get Inside My Head

In an effort to overcome the fact that hydrocephalus remains a largely unknown condition, Shine has produced an animation called ‘Get Inside My Head’.

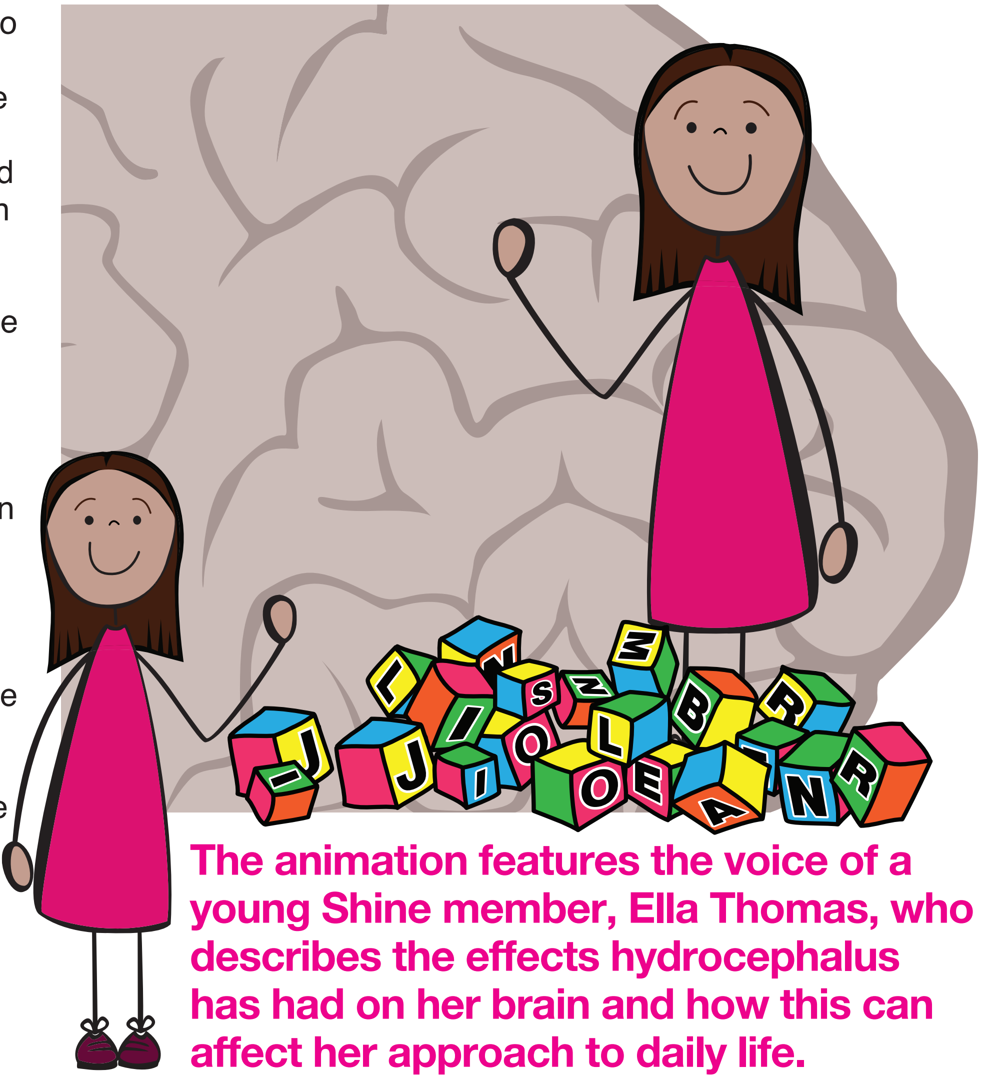
The aim of the short feature is to increase awareness and help the wider public understand the problems faced by those who live with the effects of brain fluid retention. A book has also been produced to complement the animation and ensure the widest possible audience for the piece.

Hydrocephalus affects 1 in 1,000 live births in the UK and can also be experienced later in life, especially after an injury to the head. Hydrocephalus occurs when the body fails to drain away the right amount of fluid from the brain, a substance known as cerebrospinal fluid.

The build-up of pressure on the brain can have a variety of brain injuring effects such as problems with memory, organisation, and behaviour.

Most people who experience hydrocephalus in the UK will have a shunt, a thin rubber tube, fitted in order to drain the fluid away to the abdomen. Although the procedure is significant and leaves a scar, there are often no obvious signs that a person is living with these effects.

Significantly, a shunt does not cure hydrocephalus and cannot repair the injury caused to the brain by this excessive pressure.



The animation features the voice of a young Shine member, Ella Thomas, who describes the effects hydrocephalus has had on her brain and how this can affect her approach to daily life.

The animation features the voice of a young **Shine** member, Ella Thomas, who describes the effects hydrocephalus has had on her brain and how this can affect her approach to daily life.

Shine believes the animation will be helpful to the friends, family members, teachers, and classmates of those living with the condition, helping them to understand what life is like and how they can help.

The animation was launched at the beginning of Spina bifida and Hydrocephalus Awareness Week. It is available to view on **Shine**’s website and YouTube channels, and DVDs have been produced to ensure that everyone can access the film. **http://bit.ly/ellafilm**

The secret to being 99?

Tea and laughs!

by Tom Scott

'Was I behaving myself?', Winnie asks with a mischievous grin. Winnie and her daughter Joyce are looking over some old photographs and the one in hand shows a group photo from Winnie's 95th birthday party. Now aged 99, we believe Winnifred Connolly could be the world's oldest person living with spina bifida.

Winnie with two of her three children, Joyce and Les, and (left) as a young child on her mother's knee

In her own humble way, Winnie is an extraordinary woman. Born with spina bifida occulta in 1914, on the eve of the First World War, twice widowed, the mother of three children, a munitions worker during the Second World War, a grandmother to six, and great grandmother to five, it's fair to say that Winnie has lived an incredibly full life.

As the interview proceeds, it is clear to see that Winnie's sense of humour is a major source of her vitality. We move through accounts of school-age adventure, foreign travel stories, and precious family memories, all the time laughing loudly and reflecting on the past with fondness.

Almost in passing, Winnie recalls what she was told of the procedure to treat her spina bifida occulta. 'They say that when I was born there was like a little pimple on my back, and that the midwife nipped it off with her nails.' As she got older she was encouraged by an Aunt, who worked as a Sister in a local hospital, to see a consultant due to on-going back pain, but Winnie recalls, 'My mother went crackers, oh, she went mad. She said, 'You're not going!' She had a thing about hospitals; she didn't believe in them and none of us have ever been immunised. I've never had a flu jab.' After discussing the possible plans for her 100th birthday celebration next June, Winnie offers her thoughts on the secret to a long life, her answer is inevitably a canny mix of the serious and the hilarious, 'Cups of tea! No, just behave yourself!' [Loud laughs] 'Don't take life too seriously, try and help each other.'

With this, our time together ends, Winnie prepares for her regular trip to see her daughter, Doreen, in Wales and finishes her tea with Les and Joyce, her two older children, the memories of hurricanes in America and taking part in Radio 4 interviews still reverberating around the room.

Winnie is an extraordinary woman. Born with spina bifida occulta in 1914, on the eve of the First World War, twice widowed, the mother of three children, a munitions worker during the Second World War, a grandmother to six, and great grandmother to five...

Skem Men-aces – a club with a difference

Here at Shine, we hear so many positive stories and see great things happening daily, especially on our social networks.

However, there are some stories which have to be seen to be believed. I was recently invited to visit Skelmersdale, Lancashire, by Carl Eaton and everyone involved in the Skem Men-aces, a football team with a difference in the North of England.

Carl, along with his wife, daughter, brother, and friends, established this dynamic football club for men with a variety of disabilities back in June 2009. The initial idea was to provide a few lads with a bit of a kick around; however, the idea soon took on a life of its own.

Inspirational! Carl and family

I visited the Skem Men-aces on the last day of Spina bifida and Hydrocephalus Awareness Week, and was in for a real surprise! The whole club were wearing Shine yellow t-shirts and had been busy fundraising for us. The group raised an amazing £650, as well as generating unmissable awareness in their striking **Wear Yellow and Shine** outfits.

I spoke with Carl, who himself has spina bifida, about the Skem Men-aces and exactly what has made the club such a success.

‘One of my brothers, Harry, has a learning disability and we wanted to start something that he could be involved in. The conversation started and in less than a week a football club was mentioned. We started with 12 lads, and coats for goals, and now look at us – 40 lads training, playing matches, getting fit, and having something to focus on!’

‘The really powerful thing is that many of these lads have nothing else to focus on in the week; this club gets them out, they’re losing weight, having a laugh, and travelling the country – some of them had never been outside of Skelmersdale before the club got going!’

Although there are a variety of conditions represented, the group includes three members who have hydrocephalus. Carl reflects, ‘I’ve won volunteer awards, some national, but it’s not ultimately about that – it’s about giving these guys an identity, some dignity, and an opportunity to believe in themselves whatever their level of ability.’

Tom Scott

To learn more about the Skem Men-aces, please visit: **W: skemmen-aces.org.uk**

A co-ordinated approach

Occupational Therapy Officer, Emma Enfield explains fine motor skills.

Fine motor skills involve the small muscles of the body that enable functions such as writing, grasping small objects, and fastening clothing. Weaknesses in fine motor skills can affect a child's ability to eat, write legibly, use a computer, turn pages in a book, and perform personal care tasks.

You might already have a treatment programme for your child prescribed by an Occupational Therapist, but there are plenty of activities which you can do at home. Here is an idea that will help to work on a toddler's fine motor skills and hand-eye coordination:

Give the child a colander and some coloured pipe cleaners, and let them poke them through the holes. Show your child how to do it as often as needed, take turns, or just let them have fun working it all out. You might be surprised at just how entertained they will be.

This activity is ideal if your child can grasp objects with their whole hand or with the thumb and index finger, but isn't able to do more refined fine motor activities such as lacing beads on a string. You may well find they can pull them out easier than put them in to start with.

Encourage your child to hold the pipe cleaner with their fingers pointing toward the tip and you're moving towards the dexterity required to hold a pen. Depending on your child's age and skill level, you can change the game slightly by adding in colours, sizes, etc. But always be aware of your own child's abilities, as play should be fun and not stressful.

Another nice game is pom-pom pushing. All you need is a plastic food container and some little woolly pom-poms. You need a lid on the food container and to not mind having holes cut into it! A large ice cream container or something similar would do.

Cut some holes in the container just a little bit smaller than the pom-pom. This allows them to practise putting the pom-pom onto the hole and then encourages them to use their index finger and thumb as they push down. Again, this is also good practice for holding a pen.

If you place the pom-poms on different sides of the boxes, then your child will be moving from side to side to reach them. This is really good balance practice. Don't worry if they can't sit unaided, this can be practised with them sitting on your knee and supporting them as they reach forwards and backwards, so once all the pom-poms are in, they can practise trying to get them all out again!

Happy playtime!

Emma Enfield
Occupational Therapy Development Officer
E: emma.enfield@shinecharity.org.uk

Hydro shunt issues

By Gill Yaz, Health Development Manager

Hydrocephalus describes conditions in which the fluid in and around the brain, CSF, is trapped and causes high pressure. The pressure can harm the delicate brain tissue, so needs treating with a shunt to remove the fluid from the head, or a Third Ventriculostomy to divert the fluid to the outside of the brain to be absorbed.

There are many causes of hydrocephalus, such as Aqueduct Stenosis, head injury, haemorrhage or tumours, and each one of these causes has its own effect on the brain. Brain cells can react to pressure by forming lots of small scars, which can alter the way the brain and learning develop.

In addition, the speed at which the pressure rises in the head can have different effects on the brain tissue itself. When pressure builds slowly, extra small blood vessels begin to form in the brain, which ensures blood and oxygen continues to get into the brain despite the high pressure in the head. This helps the blood supply, but over time makes the brain tissue stiffer, and less able to adapt to changing pressures.

With so much research going on over the world, it’s possible that prevention or cure for some forms of hydrocephalus is just over the horizon.

This is important, as the brain is in an almost enclosed bony box, and when shunts are fitted, pressure changes beyond the usual ranges are inevitable, even with the best, most appropriate shunts which are working fine. And, because of all the changes to the brain tissue itself, it will be different for almost everyone.

Shunts drain fluid using a combination of pressure to open the valve, gravity to drain the fluid, and properties of the tubing and the fluid to control the flow. This means that for many shunts, they will drain more when you are upright, and less when lying down. Overdrainage and underdrainage symptoms, like headaches and dizziness, can be more troublesome at different times of the day or during different activities. ‘Life with a shunt’ doesn’t mean ‘living without hydrocephalus’. Many of our members tell us they get unpleasant symptoms, even when their shunt is working ‘fine’.

Shunts have saved many thousands of lives since the late John Holter designed one with Dr Spitz to treat his young son Casey. Over the 55 years since the invention of the shunt, the design has only changed a little. The principle is the same, with CSF flowing from the head to another part of the body (which used to be the heart, but now most commonly the abdomen) and is controlled by a one-way valve.

Some UK hospitals are using sub-galeal shunts in tiny babies, who might not need a full shunt, but who need some temporary drainage for a few days. This shunt drains fluid into a pocket on the scalp between the skin and the skull, where the fluid is absorbed over time. This is proving to be better than removing the fluid with a needle, which can only be done for a few days before a VP shunt is needed.

According to Dr Pat McAllister of the University of Utah, in the future, it may be possible to implant a tiny pressure sensor to work with valves to control flow and pressure far more accurately than at present. Dr McAllister is also working with mathematician Professor Kalyan Raman, to see if the shunt design can be improved.

Looking a long time into the future, it may be possible to reverse early hydrocephalus with stem cell technology, which the lab Professor Esteban Rodriguez is working on in Chile.

With so much research going on over the world, it’s possible that prevention or cure for some forms of hydrocephalus is just over the horizon. Until then, for most people, treatment with a shunt, even with its problems, is the best that we can hope for.

Innovation in Catheterisation

Coloplast would like to thank everyone who has provided us with feedback and suggestions for improving products and we're pleased to tell you that we've listened and responded to your needs. We're proud to launch the latest addition to the SpeediCath family – the innovative SpeediCath Compact Set solution.

The SpeediCath Compact Set addresses the need for convenience and discretion for anyone requiring a compact catheter and integral bag solution; so it's an ideal solution for people catheterising from a wheelchair, or even for people with dexterity or mobility challenges that are looking for extra security and confidence from the potential for less risk of spillage. It's also great for those that travel or have trouble finding wheelchair accessible toilets.

Ease of use:
The product is opened and ready in 3 fast and easy steps and is instantly ready-to-use. The hydrophilic catheter coating is already activated and the opening and preparation of the product is very simple and intuitive. The cylindrical tube of the catheter makes it easy for people to grip and twist to open the product, and the handle of the catheter is larger than a standard connector which provides a firm and dry grip.

Discretion:
SpeediCath Compact Set is compact and has an appealing, non-medical design. You don't have to bring along any further accessories as SpeediCath Compact Set is a compact all-in-one solution. There is less risk of spills or leakage as the bag comes already pre-connected to the catheter. The 750 ml capacity bag is more than adequate to empty the bladder and be sealed until ready to be emptied.

Your feedback and suggestions have enabled us to create a new sleek design which has already led to it winning several awards. One of the most recent awards has been the international Red Dot Design Awards, which is the world's most prestigious design award – where the design jury picked SpeediCath Compact set out of 4,662 entries from 54 countries!

- The only compact and discreet catheter with an integrated and sterile bag
- Simple and intuitive for everyday use in and out of home
- A unique coating for instant and easy use

We've already launched SpeediCath Compact Set in several countries across the World and feedback tells us that SpeediCath Compact Set provides:

If you would like a sample, then please visit www.TRYset.coloplast.co.uk or call us on 0800 220 622.

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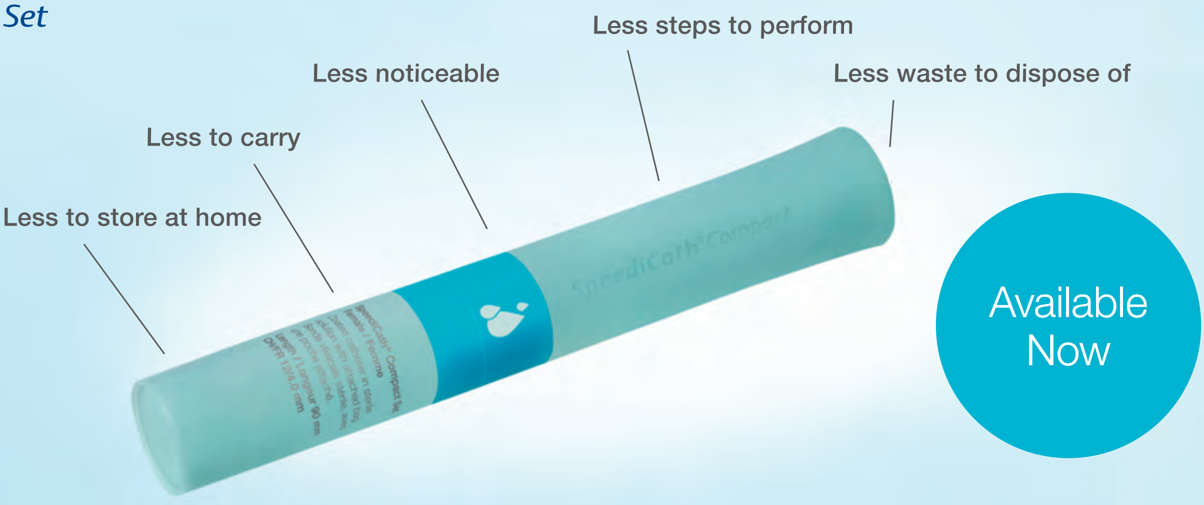

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TRYSET-06/11

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Winners Wear Yellow

It's been a busy summer for our fundraisers, who have taken on a variety of rough and ready physical challenges to earn sponsorship for **Shine**. Special thanks for the outstanding achievements of Phoebe Ashworth (British 10K Run), David Graney (Wiltshire 100 Cycle Ride), Jenny Taylor (Ipswich Half Marathon) and David Armour (Great North Bike Ride), who have raised over £10,000 between their individual events this summer! Finally, a special hot chocolate toast in honour of all our Great North Run and Great Eastern Run participants and the **Shine** Teams who went to the race. This year, they had to brave the worst weather that the events have ever seen. Your dedication knows no bounds – thank you.

Wear Yellow and Shine for Awareness Week 2013

With the second Spina Bifida and Hydrocephalus Awareness Week (19th – 26th October) having just finished, we would love to take the opportunity to thank everyone for the incredible response we have had in support of this event.

At the time of writing, we have had over four times the number of events planned compared to this time last year!

There will be a full update on this year's 'Wear Yellow and Shine' in the next edition of *Together*. Watch this space and THANK YOU!

Wetley Rocks Male Voice Choir and Audley Brass Charity Concert

On Saturday 28th September, a group of well-voiced men from Stoke-on-Trent gathered with the 'Audley Brass' band to present a charity concert in aid of **Shine**.

Inspired by young member Harry Smith (aged 5), the concert was led by Musical Director Ian Jones (Harry's Granddad), who wanted to thank **Shine** for the support that their family has received. The concert has raised over £2,500 for **Shine** and considerable awareness for spina bifida and hydrocephalus, with a great response from the local community and coverage in the regional press. Thank you to everyone involved with a fantastic event – it has been our pleasure to support you and we are very proud to be associated with all your hard work.

Awareness Week 2013

Thank you to everyone who got involved with 'Wear Yellow and Shine' for Spina Bifida and Hydrocephalus Awareness Week 2013.

We have so many amazing photographs – here are a few, but check our dedicated Facebook page (the link is at the bottom of this page) for more pictures and stories, to share your own, or just to congratulate everyone on their astounding fundraising achievements.

The dedication we have seen from all of you has been amazing. Thank you so much!

Craig benefits from 1949 welfare system

by Louise Tyler

Earlier this year, Craig Newman felt that life was pretty unfulfilling with few prospects. Then a friend asked him if he'd take part in a documentary series called 'Benefits Britain 1949'.

The series follows people in different social situations as they try to live by the rules of the 1949 welfare state. This particular episode featured Craig, who has spina bifida, as a person with long term sickness, and a pensioner. Little did Craig know how much this experience would affect him. He told Louise Tyler what happened.

Before taking part in 'Benefits Britain 1949', Craig had applied for over 1,200 jobs and only been offered 5 interviews. However, the documentary didn't tell the whole story. Before filming started, whilst Craig was in hospital, his benefits were suspended. He was left depressed and worried about how he would pay his bills or where his next meal would come from.

His benefits were suspended because his 'full-time' college course wasn't what the Department of Work and Pensions considered full-time. This was an enormous blow to Craig because the course was a first step towards fulfilling his dream of going to university. Today's benefit system had left him in a desperate position, where his only chance of survival was to give up on improving his prospects.

Then Craig was approached to be part Benefits Britain. He explained: 'I was interested due to the historical aspect, the contrast really; what was it like for a disabled person in 1949? Were people better or worse off?'. He was told that he would be asked to complete a series of tasks: 'I said I'd give 100%'. He visited the supposed 1949 DWP office first and was met with a shock. He had not contributed to National Insurance and therefore was not entitled to any financial support. He was given £7.80 from the 'emergency fund' and sent away.

'I was quite surprised not to receive any financial help under the 1949 system, but at that time the focus was more on war veterans. People born with disabilities just had to get on with it', Craig explains. Luckily for Craig, the 1949 system did reward a willingness to work and there he had plenty of it. He agreed to attend an Industrial Training Centre and was given an allowance of £100.

Craig is now living his dream. The job he was offered has enabled him to earn money whilst doing his access course, and having successfully finished that, he started studying at University in October – all thanks to systems that were in use 64 years ago!

'Surprisingly it was more than my current Jobseekers Allowance. I enjoyed going to the 1949 training centre; it gave me the chance to prove to myself and everyone else what I was capable of.'

Craig started to believe that the 1949 Welfare system was much

Photos: Laura Read

more caring than the 2013 one. ‘In 1949 everyone was treated as an individual. It helped that the person assessing me had a good knowledge of spina bifida, so they knew what would be challenging and were more interested in what I could do.’

Craig’s 1949-style assessment suggested that he was best suited to office work and this was accepted by present-day Welfare Officers who were on hand during the filming. They helped Craig to find a day’s work experience in a call centre. As with every task presented to him, Craig gave 100% and shortly afterwards he was offered a job. Benefits Britain viewers witnessed Craig’s emotional response – ‘My first ever job offer! I feel like a capable human again.’

The film revealed that everything that the current welfare system had taken away from Craig – the opportunity to improve his prospects, money to complete training, support in finding work – was given back by the 1949 system.

What does the future hold for Craig? Well, now he is living his dream. The job he was offered enabled him to earn money whilst doing his access course, and having successfully finished that, he started studying at University in October – all thanks to systems that were in use 64 years ago!

Accessing services in West Wales

In the last *Together* magazine, Jackie Bland wrote about the work Shine and our members are doing to help improve access to specialised services so… What are we doing in Wales?...

We've gradually been discovering that our members in West Wales often have difficulty being referred to see specialists in other hospitals. We don't know why yet, but it seems that one of the possible reasons is that funding is controlled by individual Local Health Boards, and that they are reluctant to send people to another Health Board area for services.

We may be wrong so we need to gather more evidence to find out. **Shine Cymru** met with the Community Health Council in the Hwyel Dda Local Health Board area to raise members' concerns. They have agreed to undertake a survey of people in West Wales to identify where the problems lie. We have asked them to then address the issues to the Head of the Local Health Board and ask for a solution to these on-going problems.

If you have had difficulty accessing health or social care services, please let us know more on
T: 02920 813847 or
E: wales@shinecharity.org.uk

Screening for Life – don't bury your head in the sand!

The 'Screening for Life' campaign in Wales is aimed at raising awareness and encouraging men and women of certain ages across Wales to take up free testing for NHS breast, cervical and bowel cancer screening. The campaign also promotes the recently launched Wales Abdominal Aortic Aneurysm (AAA) Screening Programme.

The Screening for Life team tell us that there is not enough uptake, so please have a look at the website www.screeningservices.org.uk/ or contact the local Screening Engagement Team for further information.

South East Wales: 02920 397222
South West Wales: 01792 459988
North / Mid Wales: 01492 860888

Remember, if you go for screening, it is important that you let the team know about your disability, as they should ensure the screening is carried out in a way that meets your needs.

Physiotherapy services across Wales

Shine Cymru is a member of the Wales Neurological Alliance, which enables us to be part of a bigger platform for awareness raising and strengthening members' voices to lobby for better services.

Some of our members completed a questionnaire last year about physiotherapy services in Wales and, again, this has proved another big issue for our members.

As a result, a report has been produced and all Directors of Local Health Boards have been asked to provide information on how they are meeting the needs of our members who need specialist physiotherapy services. They have also been asked to tell us how they plan to address the needs that are not being met, so watch this space and we will update you when we can.

Volunteering in Wales

The North Wales Friends of Shine Cymru held a celebratory 'Cream Tea' to thank volunteers for their volunteering and fundraising efforts over the last year, which has been supported by the Volunteering in Wales Fund.

Shine Cymru, Office 10, Unit 2,
Ynysbridge Court, Gwaelod-Y-Garth,
Cardiff. CF15 9SS
T: 02920 813847
E: wales@shinecharity.org.uk

Fundraising in Northern Ireland

On a very wet day, Steve Gelty, Mark Finlay, Fionnuala Black and Ben Doherty abseiled down the Europa hotel. Between them they raised over £1,100!

Why not sign up for our Shine Abseil next year and make the Europa yellow?

We have also had marathon runners in several events across Northern Ireland. The photo to the left is of Amanda McNeilly (with Chloe) completing the Belfast half marathon.

We had 6 cyclists Lap the Lough for us this year. The course is 85 miles and goes round Lough Neagh which is the largest fresh water lake in Great Britain.

Baffled by Benefits

Important information about Disability Living Allowance (DLA)

You will probably be aware that Disability Living Allowance (DLA) is gradually being phased out and replaced with Personal Independence Payments (PIP). This move includes people who have an indefinite or lifetime DLA award, but they should not need to make a claim for PIP until after October 2015.

However, from October 2013 until October 2015, the Department for Work and Pensions (DWP) will invite you to make a claim for PIP if:

- your DLA is due for a renewal
- you turn 16
- you want to have your claim for DLA re-assessed
- you report a change in your circumstances*.

When you are invited to apply for PIP, it is important that you do so within four weeks as you will not automatically transfer from DLA to PIP.

Usually your DLA won't be affected if you go:

- into hospital or a care home for less than 4 weeks
- abroad for less than 13 weeks
- abroad for less than 26 weeks to get medical treatment for a condition which began before you left.

If in doubt, contact the Disability Benefits Helpline on 08457 123 456 to check.

Council Tax Reduction scheme

The Council Tax Reduction scheme replaced Council Tax Benefit from April 2013.
It is used to help you meet the cost of your council tax bill, and the amount of help awarded depends on how much income and savings you have, your family circumstances and the amount of your Council Tax. If you are awarded help, it is paid directly to your Council Tax office.
Application forms should be requested from your local council office.

NB: the Council Tax Reduction scheme only applies in England and Wales. It does not apply in Northern Ireland.

Welfare reform – key dates for more changes October 2013 – Universal Credit

Universal Credit will start to be rolled out for new claimants in England and Wales in October 2013. Existing claimants will be moved over at a later date. It is expected to be introduced in Northern Ireland from April 2014.

Universal Credit Helpline number: 0845 600 0723

March 2014 – Incapacity Benefits

All existing claimants on incapacity benefits (i.e. Incapacity Benefit, Severe Disablement Allowance and Income Support on disability grounds) will be transferred to Employment and Support Allowance by the end of March 2014.

April 2014 – Jobseeker's Allowance

Changes include:

- extending the waiting period for first claims from three days to seven
- longer initial interviews for new claimants, who must provide a CV
- claimants with poor spoken English required to attend classes, or face sanctions
- weekly meetings, instead of fortnightly, with Job Centre advisers for those deemed to not be doing enough to find a job.

Where to go for more information

Citizen Advice Bureau: For residents in Northern Ireland, visit **www.citizensadvice.co.uk/getadvice** and for England and Wales **www.citizensadvice.org.uk**
Government information: **www.gov.uk**
Disability Rights UK: **www.disabilityrightsuk.org**
Turn2Us: **www.turn2us.org.uk**
Entitledto: Visit **www.entitledto.com**
Shine's team of Support and Development Workers through **Shine's** first point of contact on **01733 555988**.

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*Please note: the DWP advises that you should report a change in your circumstances if your condition improves or you need more help. These changes can affect how much DLA you get and when you'll be affected by PIP.

Shine Christmas Cards

2013 Christmas Cards now available. 6 new designs to choose from!
Each pack contains 10 cards with envelopes.
Thank you for supporting Shine this Christmas.

£4.00

Kissing Under The Mistletoe (10cmx21cm)

£4.00

Bright Doves
(15cmx15cm)

£3.50

Praying Angel
(15cmx15cm)

£4.00

Going To Church
(12.5cmx12.5cm folded)

£3.50

All Too Much (17cmx12cm)

£4.00

The Christmas Gang (21cmx10cm)

Free delivery on orders of 10 packs or more

Order your **Shine** Christmas Cards on ebay: **stores.ebay.co.uk/shineukcharity**
Call **T: 01733 421310** or **E: info@shinecharity.org.uk**

Shine's Lifelong Opportunities Programme 2014

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

Friday 21st – Sunday 23rd March 2014

Holiday Inn Hotel, Coventry M6 J2

£160 per family

Shine
working in partnership with Holiday Inn

Closing date for applications 10th January 2014

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

This event will include:

- Information sessions and workshops for parents/carers
- Crèche facility
- Supervised indoor and outdoor activities for children and siblings
- Choice of an organised family trip
- Family swimming session or complementary therapies for parents/carers
- Benny's birthday party celebration
- Family fun
- Family portraits and social time for families together in a safe, friendly enviroment

For an application form contact: Joan or Denise,
Shine, 64 Bagley Lane, Farsley, Leeds LS28 5LY
T: 0113 255 6767 **E**: office@shinecharity.org.uk
Places are limited so please register your interest as soon as possible.
Priority will be given to those who have not attended previously.

Second event for 6-11 year olds
17-19th Oct 2014
Info to follow Jan 2014

SAMC update

Hello and welcome to everyone with an update on all the latest news from the SAMC.

SAMC Meeting August 2013

The SAMC met at **Shine** HQ on Saturday 3rd August 2013, welcoming Shine CEO Jackie Bland and David Isom, Development Manager for National HQ Services. Apologies were received from Membership Development Officer, Gobi Ranganthan, and Amar Dugal, SAMC member.

Developments

Jackie Bland is still trying to make progress with Sir David Nicholson about the specialised commissioning for people with spina bifida. After some SAMC members had written to their local MPs, a few received replies. The SAMC would encourage all members to write to their local MP as the more people do this, the more it will help **Shine** and its members' voices to be heard.

The SAMC visited the SIA (Spinal Injuries Association), Old Brook, Milton Keynes, on Monday 7th October. A full report on the visit and what was achieved and will be in the next issue of *Together*.

Events

I was fortunate to attend the Time to **Shine** adventure – a wonderful event held at the Pioneer Centre in Kidderminster from Monday 12th to Thursday 15th August. This event was attended by many of the younger members, with ages ranging from 12-16 years. Every one of the young people enjoyed all the activities which included abseiling, fencing, birds of prey, and many others; and some fun was had on the night of the camp fire. For me, it was so nice to see all the young people making friends and most of all, having some fab fun time. I can't wait for the next one – you can count me in, guys!

SAMC Chair and Vice Chair

An election was held at the meeting in August and as from January 2014, there will be a new chair and vice chair in place at the SAMC. There was one applicant for the chair position, that being Paul Manning, and one for the vice chair, Lisa Cain. Therefore Paul and Lisa have taken up their respective positions and these posts will run for 3 years.

Potential new SAMC members

The SAMC are actively recruiting young **Shine** members, who might consider putting themselves forward to be part of the SAMC. So, if you are 16 years or over and you would like to find out more on how you can get involved, why not contact myself and I will be happy to advise regarding what is required and how to go about it.

The SAMC are here for you, the members...

Finally…

The SAMC are here for you, the members, and we would like to hear from anyone, whether it is something you would just like to know or maybe something you would like the SAMC to be doing. Please do not hesitate to make contact using the details below.

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

Attitude is Everything ... but receiving an MBE is nice too!

You may not have heard of the charity *Attitude is Everything*, but there are 95,000 Facebook 'Likers' who have, and we think that **Shine** members should also know about the great work of this organisation and their recently honoured CEO, Suzanne Bull.

The purpose of Attitude is Everything is to support the music industry to make live music venues and festivals more accessible. Venue managers and event organisers are encouraged to go beyond the legal obligations set out in The Equality Act and implement Best Practice, providing a fair and equal service to their Deaf and disabled customers, artists and employees.

Since the launch of a pilot project in 2000, Suzanne Bull has led the organisation to become a fully independent charity and a part of Arts Council England's National Portfolio of Organisations.

Earlier this year, Suzanne was awarded the MBE for services to music, the arts and disabled people, an achievement for which everyone at **Shine** offers a huge 'Congratulations!'

Thirteen years ago, Suzanne set up Attitude is Everything to challenge the music industry to improve their access to Deaf and disabled audiences, artists and employees. The organisation has since overseen more than 70 venues and festivals signing up to a Charter of Best Practice, thousands trained in disability equality, and a huge increase in the numbers of Deaf and disabled people accessing live music events.

Reflecting on the impact of her work, Suzanne says: 'My ultimate goal is for Deaf and disabled people to be able to attend, work or perform at any event that they wish. It's a utopian view, I know, but this is genuinely because I don't understand why there should be any barriers to this, attitudinal or physical: music without barriers.'

attitude is everything

To find out more, or to sign up to be a 'Mystery Shopper', please visit **W: www.attitudeiseverything.org.uk** or email Mandi **E: mandi@attitudeiseverything.org.uk**

The This is Me club continues to grow!

We have more than 160 members now. If you are aged 11-14 with spina bifida and/or hydrocephalus and would like to join, email us for a membership form. (You are also welcome to join if you are a bit older or younger too – our oldest member is 17 years old…!)

Since the last edition of Together, our two competition winners, Rosie and Charlotte, have enjoyed their trip to Britschool. They learned how a performing arts school really works (and yes…you still have to do your GCSEs!). A club meeting was held at the 'Time to **Shine**' residential event, where 15 young people told us exactly what they want from the club. We have a fantastic trip to Cadbury World coming up on December 14th and the third This is Me newsletter has just landed on members' doormats!

URGENT REQUIREMENT – We know you are often asked to think about your CVs as you approach GCSE time. We have a really good opportunity for 2 young people aged 15+ to join our **Shine** 'Members Council'. If you join, you will help influence the charity, you will learn about how the charity works, and you will get excellent experience for your CV that will help you later in your working life. We will give you all the support you need to fulfil the role, so if you think you are responsible, good at both listening and talking, and able to come to three or four meetings a year – then please email **E: thisisme@shinecharity.org.uk** to find out more.

Are you a Supporter?

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality
SUPPORTERS
many hands make bright work

Shine Supporters is the simplest way to get involved with **Shine** and give via a simple one-off donation. We have a number of different ways that you can get involved, whether it is as an individual or as a larger organisation or company.

Friend: give £25 a year and receive a Supporter certificate, a selection of **Shine** merchandise, a Benny Bear cuddly toy, and a quarterly copy of *Together* magazine, to keep up to date with everything that is happening in the **Shine** community.

Supporter: as a supporter you give £75 for the year and in return we send everything included in the Friend package with the addition of more **Shine** goods including a polo shirt and baseball cap.

Corporate Partner: as a corporate partner who contributes £250 per year, you will receive a selection of our merchandise, in addition to this your organisation will benefit from a 'Thank You' feature in *Together* magazine, and a logo on our foyer-based Partner Banner.

Corporate Sponsor: at £2,500 a year the Corporate Sponsor is our premium Supporter package. This opportunity offers all the great benefits of the Partner programme with the addition of a visit from a **Shine** motivational speaker and high-profile sponsorships of *Together* magazine.

Busy, busy Bear!

Phew! It's nice to be able to sit down for a few minutes whilst I write this – I have been such a busy bear recently! Everyone here at **Shine** has been getting ready for Spina Bifida and Hydrocephalus Awareness Week. This year was amazing as members and fundraisers really got behind the initiative. Hannah has received over four times the amount of enquiries as last year! I'm really looking forward to sharing with you how much we have raised in the next issue! By the time you read this we will have had Awareness Week, so thank you so much for all of your efforts!
I have been up and down the country in the past few weeks supporting **Shine** events. One of the highlights was going to Karina's Masquerade Ball; it was so much fun and they raised a phenomenal amount of money for **Shine**.

It's not all been partying though as I've been working hard fundraising too. On the 13th October I completed the Great Eastern Fun Run. The rain poured down, but it was still so much fun catching up with our dedicated member families, the Bells and Doveys, and we raised lots of money too!
One more bit of exciting news is the smart people at **Shine** have started making children's T-shirts, with a picture of me on the back! So now I'm even more famous! It's a great way to let people know about **Shine** and hydrocephalus. They cost £6.50 and are available from the **Shine** eBay shop.
Remember, be brilliant!

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

A lifestyle event for adult members with spina bifida/hydrocephalus

A Pioneering Generation

Shine
Shine50Plus

Are you aged 50 or over?

Shine are holding their first ever conference for people in this age group with spina bifida and/or hydrocephalus as part of the **Shine50Plus** Project and Shine's Life Long Opportunities Programme

The Academy, Holiday Inn, Coventry, M6 Junction 2

Hinkley Road, Walsgrave, Coventry CV2 2HP

From 12:00pm **Saturday 1st March** until 12:00pm on **Sunday 2nd March 2014**

Conference to include:

- Presentation by leading medical specialist in spina bifida
- Latest research on impact of hydrocephalus
- Workshops on mobility, continence and social media

Come along and hear other peoples' experiences and celebrate the achievements of this pioneering generation!

Closing date: 10th January 2014

£10
Registration Fee

To book your place contact Lynn Hart at
Shine 42 Park Road Peterborough PE1 2UQ
E: lynn.hart@shinecharity.org.uk or
T: 01733 421321

For more details contact Angie Coster,
Project Coordinator (Silver Dreams)
E: angie.coster@shinecharity.org.uk
or **T**: 01308 426372

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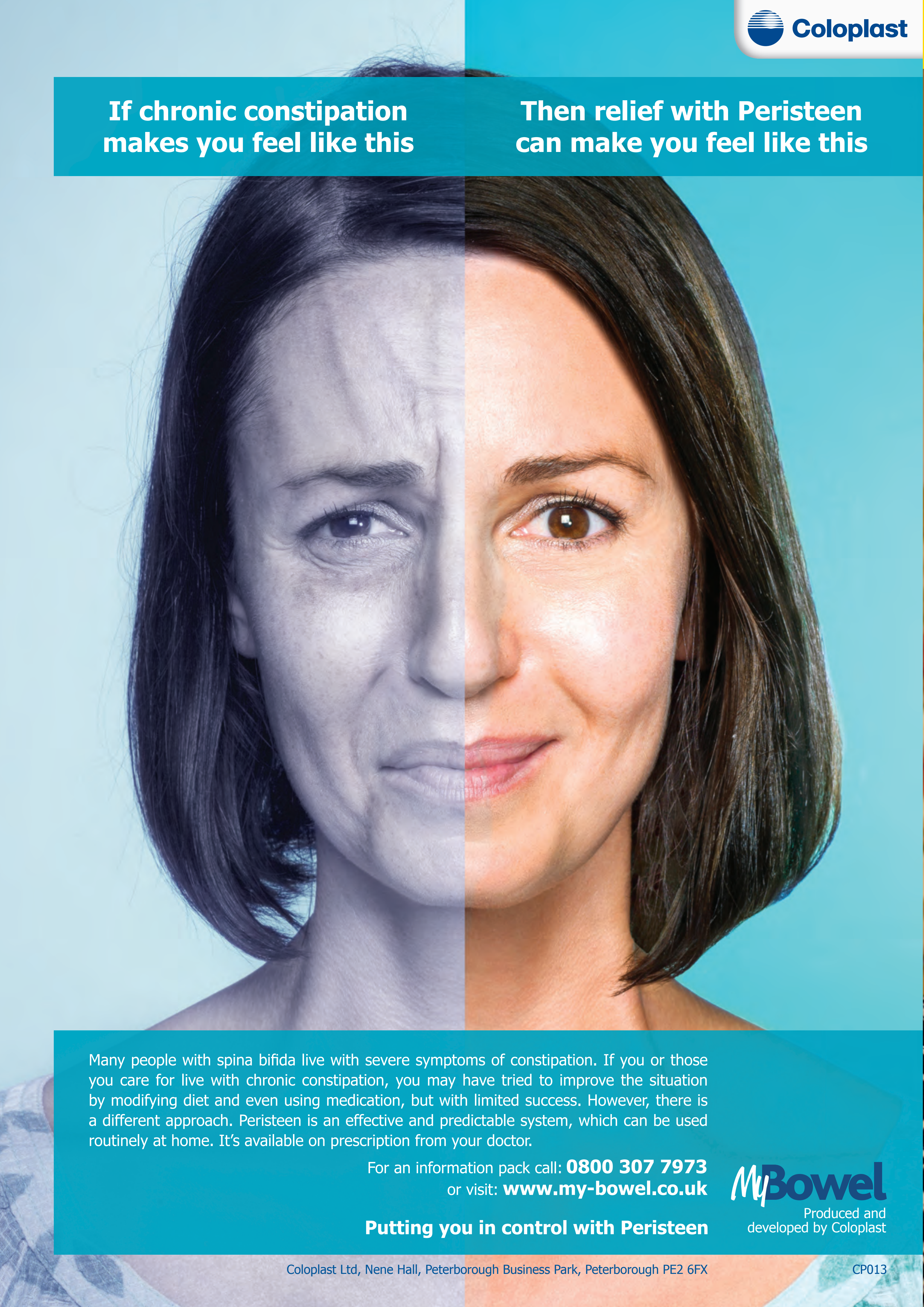

Coloplast

If chronic constipation makes you feel like this

Then relief with Peristeen can make you feel like this

Many people with spina bifida live with severe symptoms of constipation. If you or those you care for live with chronic constipation, you may have tried to improve the situation by modifying diet and even using medication, but with limited success. However, there is a different approach. Peristeen is an effective and predictable system, which can be used routinely at home. It's available on prescription from your doctor.

For an information pack call: **0800 307 7973**
or visit: **www.my-bowel.co.uk**

Putting you in control with Peristeen

MyBowel
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