

T@gether

Spring 2022 **Issue 30**



Then and now...

17 years on, we revisit baby Beth!

The Care Act

How to access the support you need

Hospital stays...

How to make sure you're prepared

Your child and hydro...

The results of our recent survey revealed

Plus lots more exciting **Shine** news inside!



Shine

Spina bifida • Hydrocephalus
Information • Networking • Equality

An update from Kate...

Two years after the start of the pandemic and things don't seem to be getting any easier. Vital health and care services are coming back, but slower than we all want and need. We know that statutory services continue to face huge challenges. The cost of living is rising. As a result, our teams have been busier than ever, supporting and advising many of our members, and their families, on a whole host of issues.



On a brighter note, we have filled this edition of Together with updates and snippets of interesting information, as well as bringing you stories from our members – including Beth who first featured in ASBAH's Link magazine when she was just a tiny baby. She is 17 now!

We're particularly grateful to the companies that have renewed their partnerships with us again this year as they are vital in helping us develop and improve the services we can provide. We are also pleased to announce a new partnership with Vitabiotics which will help us reach wider audiences to tell them about the importance of folic acid prior to pregnancy.

Spring is here and Summer is on the horizon at last! I look forward to sharing more news again in the Autumn.

Best wishes

Kate Steele
Chief Executive

Shine launches new Corporate Plan

Read it now at shinecharity.org.uk/corporateplan

In 2017, Shine launched a five-year plan which sets out ambitious goals to transform our work, increase engagement with new and existing members, and ensure that the charity could continue to offer support, advice and information long into the future.

Over the past 5 years, we have made significant progress in many areas of our work, understood more about the gaps in our service provision and delivery approaches, and identified the need for improved age and condition specific services.

Our new corporate plan 'Engage, Enable, Empower...The Next Steps' provides a structured 5-year pathway to build on these successes and to continue in our efforts to support those with the conditions, their families, and the wider shine community, across the many facets of their lives.

To learn more about our plans, read our new corporate plan at <http://www.shinecharity.org.uk/corporateplan>



We have moved...



Earlier this year, Shine bid farewell to its longtime headquarters at Park Road in Peterborough, moving to new premises at the beginning of March.

No other contact details have changed, but should you need to write to us, our new address is:

Shine – Unit 4, The Forum, Minerva Business Park, Peterborough, PE2 6FT

For more information about the move, and why it represents a great opportunity for the charity, visit <http://www.shinecharity.org.uk/newoffice>

Try before you buy...

The Whizzybug loan scheme provides FREE powered wheelchairs to young disabled children (aged 14 months to 5 years) throughout the UK.

Over 1,000 Wizzybugs have already given children mobility from an early age, helping to build independence and confidence and encouraging development.

Find out if a Wizzybug powered wheelchair is the most appropriate form of mobility for a child in your care, and to apply visit: <http://www.designability.org.uk/meet-wizzybug/>



Fortification, finally.

In the last edition we noted that a decision on Shine's long fought campaign for the fortification of flour with folic acid was rumoured to be imminent.

Though not confirmed when the magazine went to press, we're delighted to announce that on the 20th September 2021, UK Government announced that it would implement the mandatory fortification of folic acid for all non-wholemeal flour in a move which has seen a reduction of up to 50% in the number of pregnancies affected by neural tube defects in over 80 countries worldwide where fortification already takes place.

The decision marks the culmination of over a quarter century of campaigning by Shine, though we continue to work hard to raise awareness of the importance of supplementation.



In December Shine hosted our first online conference for healthcare professionals.

The conference was a great opportunity for the 212 attendees to learn more about the latest research and clinical developments in spina bifida from some of the most eminent professionals, and about Shine's work and priorities. Shine members also shared their stories on the day, giving the professionals valuable insight into living with spina bifida. Feedback from the conference was excellent: the average rating for the conference overall was 9 out of 10, every attendee said it had improved their knowledge of spina bifida, and all were likely or very likely to recommend the conference to their colleagues.

The videos from the conference are available to professionals through our website so if you would like your health professionals to learn more about your condition, you can invite them to watch the videos here: <https://www.shinecharity.org.uk/e-learning/e-learning-courses>

Professionals can also sign up to be professional members of Shine which gives them access to advice and information resources to help them in supporting you.

To become a professional member online they can visit: <http://www.shinecharity.org.uk/professionals> or contact Shine via email: professionals@shinecharity.org.uk

Shine's legal service is here to help!

Two of the most frequently asked questions about clinical negligence are:

Question: How long do I have to make a claim?

Answer: Any person with capacity (i.e. individuals who are able to handle their own legal and financial affairs) will have three years to start court proceedings for a medical negligence claim from the date of the alleged negligent treatment. If the person bringing a claim does not have capacity, the three-year time limit won't apply, and that person can bring a claim at any point.

If a claim is brought on behalf of a child, court proceedings must start within 3 years of their 18th birthday.

Question: How long will it take from the time I make a claim to the time a decision is made?

Answer: Even though clinical negligence claims can often take years before they conclude, you will not have to manage any part of the process alone. Your expert solicitor will be there every step of the way to make sure that the process takes as little of your time and energy as possible so you can focus on the things that matter the most. Despite cases often taking a long time from start to finish, your solicitor will try to secure you interim payments (immediate payments for immediate needs) to make sure you have the funds you need to access treatment and rehabilitation services, buy equipment and get the support you need as soon as possible.

Shine works with expert medical negligence law firms who understand the complexities and complications that spina bifida, hydrocephalus and other conditions bring.

For further information on Shine's Legal Service, visit <https://www.shinecharity.org.uk/legal-service/shine-legal-service>

Adult Engagement and Wellbeing

Katie Hall, our new Adult Engagement and Wellbeing Coordinator explains her role...

Since joining the England services team in January 2021, I have been making welcome calls to new members and well-being calls to our existing members. I've also been gaining feedback from members on how we can improve our services for you.

We want to keep making sure that we listen and work with you to keep creating the services and information you want.

Some examples of how I am doing this include:

- A survey to members with Normal Pressure Hydrocephalus (NPH) to find out what services they need from us and how these differ from the needs of other groups of members.
- The factsheet we put together on 'Staying Well in Winter and Cold Weather' after calls from many of you asking for information and tips on dealing with the increasing rise in energy, fuel and food prices.

As my role develops, I will be looking more at improving wellbeing support for our adult members. This will include expanding the Staying Well initiative to look at: Eating well, Getting Active, Life skills, Mental Health and Well-being, and Men and Women's health. I will be working with our Health team to make sure I am using all of the information that members gave us in response to the '1000 Voices – ageing with spina bifida' survey. This will both inform members about ageing well, and help support younger members who are becoming young adults.

If you are interested in getting involved in any of the above or would like to find out more then please contact me at: katie.hall@shinecharity.org.uk



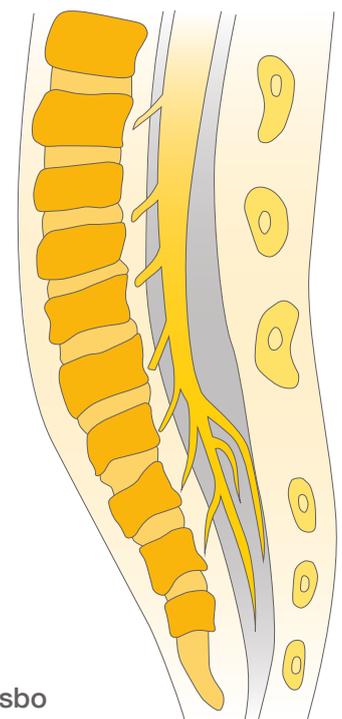
New Spina Bifida Occulta Information...

Shine has recently updated its website information on spina bifida occulta, (SBO). It is very common to have a gap in one of the vertebrae, without other complications such as fatty lumps or tethered cord, and most people will be unaware they have this.

However, it is clear from talking with our members that occasionally SBO can cause issues as the spine can be less stable. Shine's Health Team did some digging on the internet, and found that people with spina bifida occulta were more prone than the general population to back conditions (such as Pars Defect, a fracture of the thin parts of a vertebra that connect the backbones together) which may cause pain, or lead to compressed nerves.

With MRI, it is easier than ever to diagnose and direct people with symptoms to the correct support, and crucially, reassure the vast majority of people with no symptoms. Our information on closed spinal dysraphisms, such as lipomyelomeningocele, is unchanged.

You can review our new look information at <http://www.shinecharity.org.uk/sbo>



Right: Spina bifida occulta; Closed asymptomatic NTD in which some of the vertebrae are not completely closed

NPH: Information and Opportunities...

Normal Pressure Hydrocephalus (NPH) is a form of hydrocephalus that develops more commonly in older age. People with NPH usually struggle with their balance, walking, memory or continence. It is usually diagnosed quite late as symptoms appear slowly and can resemble other conditions, such as Alzheimer's and Parkinson's Disease.

Importantly, for some people, NPH can be reversed or slowed by having a shunt. Because NPH is a potentially reversible cause of dementia, early diagnosis is essential and can result in a better improvement in health. Shine is designing some online training for GPs, and next month during Carers week we will be launching a new information sheet on NPH for members.

Shine is partnering with Dr. Clara Belessiotis-Richards, an Academic Psychiatrist working at University College London who is preparing a study to see if mood disorders such as depression and anxiety may be early signs of NPH. Clara is looking to involve people with NPH or their carers in her work to make sure the experiences and needs of people with NPH are included. This would involve online meetings to discuss the proposed research and the impacts of NPH. No previous experience with research or science is needed.

Please contact Clara by email at c.belessiotis@ucl.ac.uk for more information

New health updates...

When Shine carried out the survey for 1000 Voices, on ageing with spina bifida, it became apparent that many of our members were missing out on important health checks, especially regarding bone health, kidney function and cancer screening. As a result, the Health Team are planning to email our members, beginning this Summer, with health information and reminders to get your health checked out.

Although many of the messages will be about the specific needs of adults with spina bifida, some will go to all our members who might be interested, to remind them about prostate checks and breast screening.

We wanted to let you know about them ahead of time and hope you will find the messages helpful. We would like to know what you think when they begin to arrive, so do open them and let us know.

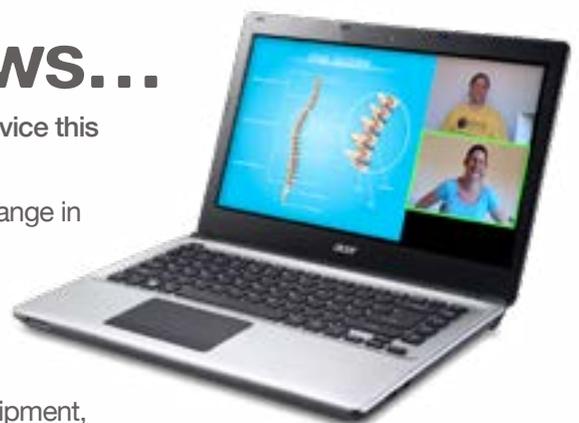


'Virtual' Health Hub news...

Shine's Health Team are launching a new 'virtual' health check service this Summer!

Owing to difficulties with travel, the coronavirus pandemic, and a change in Shine's facilities, we needed to find a better, more inclusive way of delivering our Health Check experience for our adult members. The team will be offering an online check-up, via Zoom or Microsoft Teams, to support you with understanding your condition more fully, setting your health goals, and supporting your relationships with your healthcare professionals. Kathy, our OT can advise on equipment, mobility, adaptations and other challenges of daily living. Gill and Sheryl can discuss your health goals. You will need access to a computer or tablet with audio and a camera for the health check.

If this would be of interest to you, email Firstcontact@shinecharity.org.uk, to request an appointment, and we'll get back to you to arrange.



Billy's story...

We recently caught up with Team GB's Billy, who shared his thoughts on competing at the Paralympics, and his plans for life after sport...

Growing up, how did you become involved in sport and was it always a smooth progression to the top?

Growing up with a disability it was difficult for me to participate in sport with my friends, I tried my best, but it was never enjoyable but more of a burden. It was at the age of 12 when my mother noticed my mental health was being affected due to this, she looked around for disability sports clubs. It was then we found a local wheelchair basketball team in the area and one Saturday went to try it out. I instantly fell in love with the game, it made me feel normal and on equal playing levels with those around me.

“... experience was surreal, no matter how much I dreamt of how good it would feel, the reality topped it in every aspect. The pride I felt putting the jersey on was something I had never felt before...”



The speed and skill level were like nothing I had seen before. It was 2 years later at the age of 14 I was invited to a GB junior training camp, from then until now with the exception of a few breaks. In-between it's been nothing but hard work and training. I've sacrificed many things, from family events, birthdays, holidays, but winning that bronze medal in Tokyo made it all worth it. It

hasn't been an easy ride achieving what I have in the sport, there have been many times I felt like giving up, or I felt I wasn't good enough, but I stuck with it and continued to work hard, and the rewards came.

Are you happy to chat about your disability?

Being born with spina bifida made me the man I am today, it made me stronger and more determined

to prove to the world I am capable of achieving whatever I want.

I was raised in a family and community that never treated me any different than an able-bodied child, all the same rules and principles applied, I believe this gave me my “get on with it” attitude. I am the youngest of 4 and my siblings and me were all treated exactly the same by my mother, disability or no disability. I have a great support network of friends and family that really pushed and inspired me to excel.

What was the Paralympic experience like, especially with the Covid restrictions?

Ever since I started playing wheelchair basketball my main ambition was to compete at a Paralympic Games for Great Britain, last summer I was able to make that dream a reality. The experience was surreal, no matter how much I dreamt of how good it would feel, the reality topped it in every aspect. The pride I felt putting the jersey on was something I had never felt before. It was a little different with there being no fans due to COVID restrictions, but the Japanese helpers and staff made it feel like the venues were full. They were tremendously friendly and helpful, it truly was something I will never forget.

What are your post sport career plans?

I'm planning on finishing my degree in the next couple of years and looking at life after basketball. I would like a job teaching or working with disabled children, it's a passion of mine. I'm really thankful for my time in the sport and it's given me some great memories and friends for life. But I think it's time to start looking ahead soon...

I also have an important spinal operation that is overdue that I would like to get sorted, nothing is more important than your health and wellbeing. Whenever I speak to younger children with disabilities I always try to drill into them how important it is to look after yourself and your body.



Shine Working Closely with the NHS to Support our Members

To provide more meaningful support to families across the West Midlands, Shine's Support and Development Worker Laura Varma has been working collaboratively with the Birmingham Children's Hospital multi-disciplinary clinic team since March 2018. Laura works closely with both Kate Herbert and Amy Drew, the incredible Neurosurgery Clinical Nurse Specialists.



The purpose of the clinic is to assess, review and signpost newly diagnosed patients (who were generally around 3 months of age, having had a surgical repair shortly after birth) and their parents and families.

Pre-pandemic, Laura met parents in the clinic reception area prior to their clinic appointment. Laura supported families pre and post their clinic attendance and was a knowledgeable and informed advocate amidst a very worrying and challenging time.

“... These challenges are made easier daily knowing that Tiffany is under the care of an amazing team at Birmingham Children's Hospital and that Shine walk every step of her journey with me...”

In total, from the first clinic on 29th March 2018 to date, 78 new patients have attended this clinic. In the same timeframe, 87 new members were registered with Shine from the catchment area. The difference in these figures reflects the limited clinics held in 2020 due to the pandemic restrictions but positively illustrates that families were still signposted to Laura and Shine, regardless of the lack of a physical clinic.

This great working relationship has meant that families have received both their medical health care support whilst in hospital, and the social and emotional support required when taking their baby

home for the first time, needing information and advice on daily living.

Laura says, “Both Kate and Amy go above and beyond to support families, but where their medical roles stop, they make sure the family is followed up by Shine. They recognise what a scary time it can be taking a newborn home but with the added complication of spina bifida, they want to make sure that they are not alone. That's where Shine comes in. Even though Covid restrictions have been in place, they have continued to work closely together throughout, with consent from families. By being clear on what each other's role is, they have tried to provide a robust and coherent support system for families.



“ Tiffany is one of the children who attends the clinic and Sam is her mum. Sam says,

“Tiffany isn't my first child but having a child with spina bifida has thrown me a whole world of challenges; her physical health and my emotional health, to name just 2! These challenges are made easier daily knowing that Tiffany is under the care of an amazing team at Birmingham Children's Hospital and that Shine walk every step of her journey with me. It's a bonus that the hospital team and Shine team work so closely together and really does give me reassurance. It's been so hard for me; I was given a Shine card straight away but took a while to make contact because I was in denial. I'm so glad I have made contact now and I don't know where I'd be without Shine's support. They've been an advocate and shoulder to cry on when I needed one, helped get Tiffany into nursery, applied for grants for specialist equipment and made a referral to home start for family support.

In Tiffany's few short years, we have spent a lot of time in hospital, I trust this team completely to operate on my daughter.

Between Shine and the hospital, my beautiful, determined daughter is wonderful, she's doing so many things that I never thought she would do and it shows how important all this support has been on our journey. We've come a long way together by working together”.



Getting the care you need...

Lots of you have been telling us about issues with care packages and the barriers to accessing the right support and care to meet your needs.

We wanted share more about care entitlements under the Care Act and/or Health and Social Care (Reform) Act in England, and similar Acts in Wales and Northern Ireland to help you in discussions with Local Authorities about your care.

What are the relevant Acts in England, Wales and Northern Ireland?

The Care Act in England came into effect on 1st April 2015. In Wales it was 2016. Northern Ireland has the 2009 Health and Social Care (Reform) Act. These Acts outline the way a Local Authority should carry out Needs Assessments, Carers' Assessments, how Local Authorities should decide who is eligible for support and how Local Authorities should charge people for services.

Needs Assessments

Under the act anyone aged over 18, who might have care needs, must receive a free assessment. This can be requested by calling your Local Authority Adult Social Care Department or via the online option on their website.

You should hear within 4 – 6 weeks.

The assessment will be carried out by a social worker or a member of the adult team, and you can have someone with you at your assessment.

If deemed eligible for care and support, you will receive a draft support plan that focuses on meeting the specific care needs identified. This is called a person-centered approach. Your plan should be reviewed 6 - 8 weeks after it has been set up and then yearly. You can ask for a review if there are any

changes in circumstances.

It is important to remember during an assessment that they are assessing what you can do without support.

In Northern Ireland you can request an assessment from your local Health and Social Care Trust, or you can ask your GP or hospital social worker to request on your behalf.

Carer's Assessment

The Care Act recognises the importance of supporting carers as well as those who need or are receiving care. This means that carers have the right to have their caring needs assessed. The assessment must consider the carer's needs in relation to things like work commitments, taking part in education, or attending their own health appointments. This applies to carers of any age including young carers (i.e. children 18 and under who are caring for family members).

Financial Assessment for care and support

In England, if the Local Authority says you are eligible for support under the Care Act criteria, they will carry out a financial assessment.

This is to see if you have to contribute to the cost of providing support. Not all Local Authorities charge, but those that do must not charge more than you can pay.

They will consider your income, savings and capital. Capital can include ISAs, money in your current account, money invested in a business etc. The lower capital limit for both residential care and community care is £14,250 and the upper capital limit is £23,250 (2021-22). You would only be expected to use your home to fund care if you were going to move to a residential setting. You should receive paperwork outlining your contribution and how to pay.

If you have savings of over £23,250 you will be expected to cover any cost of services that you have been assessed for. The Local Authority however still have a duty to provide information and advice about the services that might be available to you.

In Wales people are usually charged for care and support but there is a maximum charge of £100 a week.

In Northern Ireland people are not usually charged for home care however there are some exceptions such as home help schemes and meals on wheels.

Care Package Payments

Care packages can work in different ways:

1. You can receive your support from a package that is funded directly by the council. They will have a list of preferred providers and will help you set up support with them. You can request to use a provider you feel more comfortable with.
2. You can also use Direct Payments to pay care providers or a support worker directly (often called PA's). This means the council transfer money to you each month that you then manage to cover the care and support needed. The money must only be used for care and support. Having direct payments means that you are responsible for training, DBS checks (this is a criminal record check to help decide whether someone is a suitable person to work for you), holiday and sick pay for any support staff you employ directly. There are support groups that can give you advice on managing a direct payment.

Bear in mind that Care / Support Workers are in short supply. If the Local Authority are unable to find you a care package, they may offer you a Direct Payment. This means you will have to find your own support and often pay more per hour - this reduces the number of hours available to you. You do not have to accept this option if you do not feel it will work for you.



Young People's rights to a needs assessment

The Care Act 2014 in England introduced a new duty on local authorities to carry out Child's Needs Assessments (CNA) for young people where there is 'likely to be a need for care and support' after they reach 18 (even if this will not amount to them having eligible needs under a Care Act Needs Assessment). The CNA should look at what adult community care services a young person might qualify for when they turn 18 and should include a predicted personal budget, so that young people can plan and make informed decisions about their future.

Young people or their carers can request a CNA at any time before a young person turns 18 and it should happen at a time when it is of 'significant benefit' to a young person's preparation for adulthood.

The Care Act in England also ensures that if the local authority has not carried out a CNA, they must continue to provide community care services to the young adult until they have been assessed and do not qualify for services, or the care they have been assessed as needing is actually in place.

The Children and Families Act 2014 Part 3 was set out to create a process for disabled children and young people so that services consistently support the best outcomes for you.

The reform created a system from birth to 25 by developing assessments, Education Health and Care Plans (EHCPs), improved working between services and giving parents and young people choice and control over their support. From age 13 Local Authorities should be using the Pathway to Adulthood process to plan support for education, careers, health & independence.

Please note: England, Wales and Northern Ireland all have slightly different approaches to care needs assessments and support. Local Authorities (and Health and Social Care Trusts in Northern Ireland) do too.

Our Support and Development Workers can offer specialist advice on the systems and processes, depending on where you live – for more information or advice, email firstcontact@shinecharity.org.uk or call 01733 555988.



Preparing for hospital stays

When Shine carried out the 1000 Voices survey into the experiences of our adult members with spina bifida, one of the revelations that concerned us most was that 25% of you told us you had acquired a pressure sore whilst in hospital. People with spina bifida of all ages may be prone to pressure sores, reduced skin sensation, reduced mobility, bladder or bowel leakage, and cognitive issues can all put someone at risk from skin and tissue damage, and the risk may increase with age, owing to tethered cord or weight changes.

Although it can be difficult to prevent pressure sores, it should be possible to prevent them in hospitals with planning and good care. Sharing information about you and your condition with hospital staff will help. Last year we launched our **Hospital Passport**, which some members may find useful to collect all the information into one document.

Before admission

If you know you are going into hospital for surgery, there should be a pre-op check. Use this appointment to explain what care and equipment you need to prevent pressure sores, such as air mattresses, equipment to help you transfer safely without dragging or scraping your skin (shearing) and your bladder/bowel care regime. Staff should then ensure the equipment is available for admission. It is a good idea to take a good supply of catheters or trans-anal irrigation equipment with you, in case the hospital does not keep supplies of the type you use. You may need to place an order early with your supplier, to ensure you have them in time.



Keep your Hospital Passport up-to-date, particularly details of your skin health, and pressure relieving equipment. If you have any skin problems, make a careful note of them, maybe take photos with your phone.

Importantly, if your skin is free of pressure sores on the day you go into hospital, record this, with the date.

On admission

When you are admitted to a ward, nursing staff should assess your risk for pressure sores and record it on your notes as part of your admission procedure. During this assessment, draw attention to any pressure damage you have, including reddened areas (Grade 1). If your skin is clear of pressure sores, ensure this is recorded in your notes, and ask the nurse to initial your Hospital Passport by the completed pressure sore section. If your equipment is not adequate to prevent pressure sores, speak to the nurse in charge and explain why it is needed.

Hospitals and other care facilities have a legal duty to report the development of pressure sores of Grade 3 (full thickness skin loss, where the underlying fat may be visible to the naked eye) or Grade 4 (full thickness skin loss which has exposed bone, tendon or muscle) to the Care Quality Commission (CQC), who are in charge of monitoring standards of care.

If you have a pressure relieving/reducing mattress, the bed sheet should lie quite loosely over the mattress, (although without wrinkles); if it is pulled tight it reduces the effectiveness of the mattress. Even with pressure relieving equipment, it is still important to change position regularly, to drink plenty of water (dehydration can make skin damage more likely,) and have regular checks of areas of your body that might become damaged (including ears, elbows, hips, heels and any prominent bones on your back). Staff may support you in this, but setting an alarm on your phone can be a useful prompt to change position.

You should have the support you need to carry out your regular bladder and bowel regime, as bladder or bowel leakage can damage the skin and make pressure sores more likely.

If you are not getting the support you need when in hospital, ask to speak with the continence team and/or someone from the Dignity Team, and involve PALS if needed.



Beth's story...

Hi, I am Beth and 17 years ago my mum and dad had been told that they should terminate the baby (me) as I would have no quality of life and would be, in the surgeons' own words, 'a cabbage'. Well how very rude! Because here I am - sassy, bossy and loving life, I may not walk due to my spina bifida which is at T12-S2 but I've had a wheelchair since I was two years old and am pretty nifty in it! I also have a VP shunt for my hydrocephalus, my first shunt was inserted a week after my back closure, my mum made a diary whilst we were in hospital, and this was printed in the Spring edition of the Link magazine 2005 and I was pictured on the front cover!

I am a student at Malbank Sixth Form College, Nantwich. Having spent five years at Malbank I achieved grades 5 & 6 in all of my GCSEs I am now studying Btec Performing Arts, Btec Business and A Level History. My favourite part of college life is taking part in all things music! I sing and play guitar and ukulele and I am very fortunate to have a vocal coach as well as a guitar tutor. I absolutely love performing solo as well as singing in the choir at Malbank and I have just been cast as 'Killer Queen' in the school's production of We Will Rock You, I am excited and very proud of this as it is my first lead role.

One of the first challenges I have faced was being turned down for my local primary school as my parents were told by the head that one of the midday assistants would be changing me at lunchtime and that would do me until I got home! (The head decided that maybe my mum was more than she could handle, and my mum decided that we would find a school who deserved me.) I found Brierley Primary instead and absolutely loved it!

I had the best time and didn't want to leave....ever! I was there for 7 years including reception and had some big operations during my time at Brierley, they never failed to keep me smiling and when I left High

School last year my headteacher from Brierley came to wave me off for my prom!

Finding a High school...I was again told no to my first choice of school because the disabled toilet was used by staff and if I took too long to use it the staff would have to queue! Along with other silly reasons the school refused me a place.... We went looking for a school who would treat me with respect, dignity, and equality and somewhere that had more than one staff toilet! I found Malbank and the rest is history, from the start the school found ways to make life easier for me. They even made a ramp up to the stage for me to perform with the choir in my first concert!

I have had some serious medical challenges too and these include a mitrofanoff, colostomy, bladder stone removal, knee and ankle surgery and the worst of all 4 failed shunts during lockdown having had 15 years with no issues, so in all 22 operations so far!

"...I achieved grades 5 & 6 in all of my GCSEs I am now studying Btec Performing Arts, Btec Business and A Level History..."

When I leave I college I have a couple of ideas for my future which include setting up a Performing Arts business or working as a museum guide – I really enjoy bible history and love visiting National Trust venues and museums - which is a challenge sometimes with all those grand staircases!

My claim to fame is being a flower girl and presenting The Queen with a bouquet for the three millionth car handover for Motability. I got to meet some of the Paralympians at the same time. I have also been in an episode of Mister Maker Comes to Town!

I struggle with anxiety too, since lockdown things have been quite tough but If I could tell other Shine members who are the same age as me one thing, I would say to never let anyone make you feel less than you are. Give your best smile to everyone and ignore the haters, they are just jealous of your good looks and super personality! Life is what you want it to be and you need to push yourself a little sometimes to be the best you can be!

Caring For Children with Hydrocephalus



Monaé Lees is a Developmental Psychology Masters Graduate from The University of Derby. In 2021 she conducted a research project on the impact a child's hydrocephalus diagnosis has on the psychological wellbeing of parents.

This topic is close to Monaé's heart as her niece is a Shine member, and through her research Monaé aimed to shed light on the challenges parents face when caring for a child with hydrocephalus.

We are pleased to report that 181 Shine parents completed a questionnaire measuring their psychological wellbeing, parental concerns regarding hydrocephalus, and parental self-efficacy (belief in their ability to perform the parenting role successfully).

There were three main research findings:

1. Parents caring for a child with hydrocephalus experience high levels of anxiety and of concern for their child. This may be due to uncertainties around diagnosis and/or worrying about how to best manage their child's condition.
2. The more difficult behaviours a child displays, the less confident parents are in dealing with the emotional and behavioural challenges. Children with hydrocephalus may become frustrated with the aspects of their condition that limit their ability to do the things they want or need to do. This frustration can cause behaviour changes that can be difficult for parents to control.
3. The level of concern that parents feel about their child's hydrocephalus seems to be linked to their employment status. The reasons for this are not yet known but it is something Monaé would like to investigate further.

The research shows that a diagnosis of hydrocephalus in a child has an impact on the mental health and parenting confidence of their caregivers.

We have put together a list of resources that may help parents/carers to feel more informed and confident in looking after their child, and to help those who may be struggling with anxiety.

Your Child and Hydrocephalus: written by our health

team, this book contains 80+ pages of information covering every aspect of development from birth to 11 years old. Download a digital copy or order a free hardcopy from our website: <http://www.shinecharity.org.uk/for-parents/your-child-and-hydrocephalus>

Hydrocephalus resource hub: we have a wealth of useful online resources that can help you learn more about your child's condition and to help communicate their needs to others: <http://www.shinecharity.org.uk/hydrocephalus-resources-hub/hydrocephalus-resources-for-carers-1>

Hydrocephalus and behaviour: a Shine online resource covering the reasons behind challenging behaviours in hydrocephalus and different strategies to tackle them: <http://www.shinecharity.org.uk/for-parents/hydrocephalus-and-behaviour>

Little Stars Facebook, WhatsApp, and Zoom

Groups: Connecting with other Shine parents is a great way to reduce feelings of isolation and to improve parenting confidence. It can help you find out what challenges other parents faced, how they felt, and how they managed. To find out more or to join one of our peer support groups email: littlestars@shinecharity.org.uk

Every Mind Matters: expert NHS advice and practical tips to help you look after your wellbeing and manage your mental health: <http://www.nhs.uk/every-mind-matters>

NHS Inform: Anxiety Self Help Guide: Cognitive behavioural therapy (CBT) is an effective treatment for anxiety, this CBT-based guide can help you to understand more about anxiety and find ways to manage or overcome the condition: <http://www.nhsinform.scot/illnesses-and-conditions/mental-health/mental-health-self-help-guides/anxiety-self-help-guide>

Caring for a child with hydrocephalus can be challenging at times. Even extremely experienced caregivers need somewhere to turn for advice and support. Shine is here to help so don't hesitate to reach out either by phone: 01733 555988 or email: firstcontact@shinecharity.org.uk.

Monaé and Shine are very grateful to all the parents who took part in the research. If you would like a copy of the report or would like to discuss anything further, you can email: monae.estelle@gmail.com



Introducing The Trusts and Foundations Team...

Left to right: Ruth Ottley
Foundation Manager, Vinci Foundation
Nicola Graves
Trusts and Foundations Manager at Shine
Russell Crampin
Managing Director of Axians (a Vinci company) -
our project sponsor

The Trusts and Foundations team at Shine consists of Nicola Graves – Trusts and Foundations Manager, Rebecca Henning – Trusts and Foundations Development Officer, Jamie Burnett – Trusts and Foundations Admin Officer and John – Trusts and Foundations Volunteer Member.

We apply for pots of funding and build relationships with funders to help keep Shine's services alive. We have close relationships with many of our funders and frequently report back to them on how their donations help to support Shine's members.

There are lots of reasons for a trust or foundation to be set up. Sometimes they're created in memory of someone, or as a legacy, particularly if they were a known philanthropist in their lifetime. Sometimes the founder might spot a need in a particular area and want to help or realise that they have an existing platform on which they can raise funds to help others (think Comic Relief or BBC Children in Need).

Much of our time is spent writing to funders to let them know about Shine: who we are, what we do and how we do it. Funders can open opportunities for funding anytime during the year, so when we spot one it's all hands-on deck to submit a grant application before the deadline!

We are proud to have worked with some incredible funders, both regional and national – there are some who have supported Shine for nearly 30 years! These long relationships are very special, because funders can see the evolution of work that they have supported, in some cases growing from an idea to reality.

Funder support

Trusts and foundations typically contribute around 25% of our fundraising income each year and have helped to bring many of our projects to fruition. Usually, we make an approach to trusts, foundations and other funding bodies, but what we are seeing increasingly is funders getting in touch with us because a member or supporter

has nominated or recommended us.

We are lucky enough to have been nominated recently for awards from funders including the Yorkshire Building Society Charitable Foundation, the Vinci Foundation, the Apax Foundation, the Maximus Foundation UK and Northumberland Village Homes Trust. These brilliant funders all have a personal or meaningful connection with Shine. They have helped to fund our SDW work, supporting everything from help with completing benefits claims forms and finding appropriate housing to our work in schools and with healthcare providers. These funders have also supported work that has improved and strengthened our internal processes and helped to fund Little Stars activities, ensuring no child is left behind.

Our funders have also backed our COVID-19 response, supporting our ability to connect with you virtually through WhatsApp, Facebook and email, helping us in our work to put together Facebook Lives and webinars and in understanding why it was so important that we began making proactive calls during the pandemic and its aftermath.

How you can help?

Due to the broad and diverse nature of our work we are often eligible for all sorts of funding opportunities, and we have been tremendously fortunate in the support we have received over the past 66 years. Seeing the difference made by our many achievements in that time has only inspired us to further strengthen our services to do even more.

If you work for an organisation that has a foundation or know someone else who does, why not take a look and see if you could nominate us for an award?

You could be igniting our next 30-year relationship! For more information, please contact us at grantsandtrusts@shinecharity.org.uk

Leave a lasting legacy...

A gift in your Will would help Shine to be here for future generations affected by Spina Bifida and Hydrocephalus.

Writing a will is an important step towards making sure your wishes can be respected. Once you have taken care of your family and friends, it's also the perfect way to ensure that a charity like Shine can continue to be there for the people and families who will need us in the future.

For over 50 years, we have helped change the lives and futures of so many people affected by Spina Bifida and Hydrocephalus, but there is still so much more we need to do. None of this work is possible without the kindness of our supporters and for many, the most lasting and meaningful way to help is to leave a legacy to Shine in their Wills. Legacies really do make a huge difference and every single legacy gift, large and small, will mean we can continue to be there for our members today, tomorrow and long into the future.

If you've already left a gift or are considering it and have any questions, we'd love to hear from you, please contact our friendly team on 01733 555988 or email fundraising@shinecharity.org.uk.

You'll also find more information on our website <https://www.shinecharity.org.uk/donate/leave-a-gift-in-your-will> including some frequently asked questions



SUPERHEROES Wanted!

#TeamShine are calling all Superheroes to run, walk, push, pedal, hand cycle, swim or tow in this fantastic, all-inclusive family event!



20th August to Dorney Lakes and 20th July – 20th August to the At Home challenge.

Taking place at Dorney Lakes, Windsor, The Superhero Tri – powered by Marvel, is part of the UK's one and only disability series.

And if you can't make it to Windsor, take on the At Home Superheroes challenge and choose your own distance to complete in your local area.

<https://www.shinecharity.org.uk/events/events/at-home-superheroes>

There are three distances to choose from and you can take part solo or with a team. There are no cut-off times & all types of gadgets and gismos are welcome on the course, from day chairs, handcycles, and trikes to tandems, race runners and bikes.

Anyone can take part, we just ask that one team member considers themselves to have a disability of any kind. Visit <https://www.shinecharity.org.uk/events/events/superhero-tri>



Fabulous Fundraisers!



Raised £1,600

Katja Leniham

Katja, her friends and family have been busy holding Facebook birthday fundraisers, taking part in a 5k run/walk and organising an Easter Fair. Katja has also signed up to do the Yorkshire 1 Peak and is rallying friends to do it with her.



Raised £4,500

Lizzie Burgess

Lizzie ran every day for a year and ended her challenge with 5 family members joining her for the final 10k race. The year also included Lizzie running the London Marathon with her brother Tom completing the Virtual London Marathon on the same day.



Raised £7,000

Finley Murphy

Finley took part in an open water swimming challenge and encouraged his friends to join him.

He's now in training to swim the length of Lake Windermere.



You can join Katja and #TeamShine and take on the Yorkshire 1 Peak challenge or if you're looking for a bigger challenge take on the 3 Peaks on July 22
<https://www.shinecharity.org.uk/events/events/yorkshire-1-peak-2022>

**Thank you to everyone that took part in 28k in February for Shine.
 TOGETHER WE RAISED OVER £1,100 AND COVERED OVER 450 KM!**



LRL Roofing Solutions
 Raised £1,500



SBAW & HAW
 Combined over £23,000



Cardiff Half Marathon
 Raised over £3,000



Julia Mclean & family
 Raised over £3,000



Carrie Thompson and Alison Reid
 Raised £1,045



London Marathon Live and Virtual
 Raised over £30,000



Casey Travers and family
 Raised over £960



Carson Mcilhatton
 Raised over £1,200



A very big thank you to Citi Belfast who raised an amazing £140,090 over 2 years

Get involved!

Would you like to meet people your own age?

Shine is now offering closed zoom groups for young people. If you are 12 – 18 years old, we would love you to join us.

We would also love to hear from young people aged 12 to 18 so that you can be more involved in developing our young people's service to support you in the way you want to be supported.

If you want to join an online group, work with us to shape our services or help us to design literature, website pages and resources which answer the questions you want answering, please do get in touch by calling **01733 555988** or you can contact us by sending an email to: **firstcontact@shinecharity.org.uk**

If you are if under 16 years old, please ask your parent to get in touch with us first!



“...Zoom sessions are a great place to meet people like me! Thanks for introducing me to the group, now I don't feel so alone. It's great to have new friends...”



“...The Teen Zoom is very fun. I love the quizzes and it is nice to know that other people are going through a similar thing to me...”



“...When Shine reached out to us, it was like a weight lifted from my shoulders! My daughter had never met anyone like her before - since being introduced to a social group on zoom she doesn't feel so alone!! She looks forward to her meetings and has lots of fun with teenagers just like her...”



Here to help...

Please do send any comments or enquiries to us:
P: Shine, Unit 4, The Forum, Minerva Business Park
Peterborough, Cambridgeshire, PE2 6FT



☎ 01733 555988 🌐 <http://www.shinecharity.org.uk> 📘 ShineUKCharity 🐦 [Twitter.com/SHINEUKCharity](https://twitter.com/SHINEUKCharity)

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