Together

Autumn 2021 **Issue 29**

The Year in Numbers
How Shine is making a difference

Spotlight on Shunts
Your common questions answered

Leaving a Legacy
The impact of a gift in your will

Little Stars Shine Bright
The success of early intervention

Plus lots more exciting Shine news inside!

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

An update from Kate...

I cannot believe we are just three months from the end of 2021. Time seems to be flying, and yet, when I look back over the months since our last edition of Together, I realise how much we have achieved again this year.

Membership of Shine has been steadily increasing this year. As a result, we have seen a greater demand for our services and support, and we are contacting and supporting a growing number of individuals and families, who tell us what a positive difference Shine is making to their lives.

We know how testing and challenging times have been for so many of you over the past 18 months, so this latest edition brings you updates on some of the work we have done to support you, is filled with positive member stories, useful tips, ideas for fundraising and dates for your diary. It also includes information on key pieces of project work and important developments, such as our flagship programme ‘Little Stars’, and the launch of Shine Professionals.

I have also been absolutely overwhelmed by the amount of support Shine is receiving from you, our members. More than ever-before you are getting involved – in shaping our services, sharing your experiences, helping to develop information and resources that will help others, joining our on-line groups, interacting on our live Q&A sessions and fundraising.

Simply fantastic! Thank you so much!

Kate Steele
Chief Executive

Shine’s annual report 2020/21 is available!

Read it now at shinecharity.org.uk/annualreport

Trustees' Annual Report and Financial Statements

Year ended 31st March 2021

Shine

An update on **Fortification**

July 2021 marked 30 years since the UK Medical Research Council’s funded research was published, showing that supplementing the diets of women before, and during the early stages of pregnancy with folic acid substantially reduced the chance of that pregnancy being affected by Neural Tube Defects (NTDs), such as spina bifida and anencephaly.

Shine, along with many others, have made repeated calls for the UK Government to introduce mandatory fortification of flour with folic acid, which would help reduce the chances of NTD-affected pregnancies.

Following a public consultation in 2019, we really believed we were close to getting an announcement but, due to general elections, Brexit and the pandemic, still nothing.

Shine continues to work with royal colleges, representative bodies, charities and individuals to keep the pressure up for an announcement from Westminster...and hope to have some positive news by the time you are reading this.

Shine **Health Direct** (SHD)

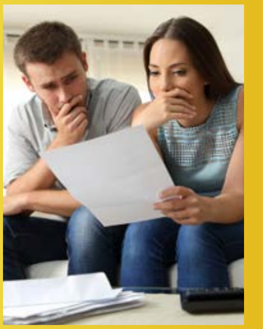
Shine Health Direct is exclusive to Shine members, offering discreet and efficient delivery of urology and stoma products, as well as your prescription medications.

SHD nursing and prescribing staff are working closer than ever with our health team to make sure that we are integrating our services as much as possible and making good use of the extensive knowledge across the teams to advise our members on how best to accommodate their bladder and bowel care.

Products change, bodies change and needs change, so if you want to find out if there are better solutions for you, or you want to explore how to change from your current provider and sign up with SHD, please contact Shine Health Direct on 0800 023 8857 to speak to a member of the team.

Shine's **Legal Service**

ENABLELAW fieldfisher THOMPSONS NI irwinmitchell



The decision to bring a claim for negligence can be a difficult one –it is not a quick nor easy process and it can mean having to recall painful experiences about the impact the mistake has had on you and your family.

Shine works with expert medical negligence law firms who understand the complexities and complications that spina bifida, hydrocephalus and other conditions bring. They will ensure you get the right legal advice and support as soon as possible.

One of the common questions that people ask is 'I have heard that I could claim compensation if I think I have experienced medical negligence but what is meant by compensation?'

The answer: The law aims to put you back into the position you were before your circumstances changed. If your symptoms are proven to be the result of negligence, you could be awarded compensation (usually referred to as 'damages'). This is a sum of money paid to you to represent any financial losses and in recognition of any physical and/or psychological pain you have experienced.

To find out more about medical negligence, or for help deciding whether you could make a claim, contact a Shine Legal Service Solicitor at shinecharity.org.uk/legal

Shine **Professionals**

We are pleased to announce the launch of Shine Professionals, our strategy to help us work more closely with the professionals involved in your lives and care. The aim is to boost the expertise and understanding of these professionals to improve the service and support you receive from them. A key part of this work has been creating a dedicated new area of the website: www.shinecharity.org.uk/professionals.

The new professionals' hub will provide information, resources, and training to anyone with a professional interest in spina bifida, hydrocephalus, normal pressure hydrocephalus, encephalocele, or anencephaly. The hub will be available to professionals from the health and social care sectors, and to those working in education and welfare. We will also use the professionals' hub to engage with researchers, so we can share more opportunities for you to get involved in research projects.

Shine Professionals will also include a conference series. Our first conference on spina bifida care from pregnancy to adulthood will be hosted online on Friday 3rd of December. If there is a professional you know whom you would like us to invite, please let us know by emailing us at firstcontact@shinecharity.org.uk, or calling us on 01733 555988.

Please share the Shine Professionals website link with any professionals that you'd like to know more about your condition, and to encourage them to join Shine as professional members so they can access further advice and support.

This year, our Spina Bifida Awareness Week on 18th October 2021 will include a call to action asking you to help us to educate the professionals whom you connect with – see page 13 for more details.

Hope Health Action Charity

Hope Health Action is a charity that provides disability care to those in need across Haiti and East Africa.

They need donated wheelchairs and supportive mobility equipment to give to those who cannot buy or access it. As many of our members have old equipment which they struggle to get rid of, this could be a perfect way to help another disabled child or adult to access the equipment they need to make them mobile.

To donate a piece of equipment please email info@hopehealthaction.org explaining what equipment you have and where you are based, and they will contact you to check the specifications of the equipment you have and let you know if and how they can arrange collection from you.

For more information visit hopehealthaction.org/18/Mission-Vision

Our year **in numbers**

Shine's financial year runs from 1st April until 31st March. Each year we publish our annual report and accounts, which highlights our achievements and how we have spent our money to deliver our services.

Here are some headline facts and figures about how we have been engaging with our members and supporting you through a strange and difficult year

To view the full report, visit www.shinecharity.org.uk/annualreport

Our service teams have supported

8,732

individual members

Made more than **20,000 contacts** with our members*

*includes email; letter; telephone; social media; online events

DEALT WITH

12,811 separate issues

This shows that we supported

144% more people than in 2019/20

Benefits	Education	Employment	Health	Housing	All other	Social
480	532	50	4,013	94	5,710	1,932

573 NEW MEMBERS to Shine since 1st April 2020

Total number of members

12,221 as of March 2021

Number of website visitors

146,412

Number of pages visited

401,480

Our closed anencephaly support group

for parents-to-be who have received a recent diagnosis of anencephaly,or who have lost a baby to anencephaly

♥ **Supports 671 individuals**

We are here... when you need us

The effects of the Coronavirus are still being felt and this has left many of our members with very difficult and complex problems in their lives to solve. We want you to know that we are here to support you however you need us and, if we cannot offer you the information or service directly, we will help you to find someone else who can.

We know it can be exhausting trying to get answers from some statutory services and to understand exactly what your rights are. There can be costs in attending medical appointments and buying essential equipment. There can be costs with your housing, and with your care needs. Sometimes you may feel that the professionals you engage with in education, care, social services or health do not fully understand your needs or your condition/s.

Let us know what you are facing and we will work with you to find a solution

Shine has various teams, all of whom are experienced in your condition/s.

Our health team includes our Health Manager who has over 25 years of knowledge specialising in the conditions, and we have our own Occupational Therapist and Physiotherapist as well as access to continence and prescribing nurses through our Shine Health Direct team.

We also have a network of Support and Development Workers (SDWs) and Early Intervention Project Workers working across England, Wales and Northern Ireland, who are there to help members of any age to find solutions to any of life's challenges.

See page 12 for an update on our Little Stars early intervention project

Opportunities for you to shape the services we provide

As a charity, it is important that we deliver services and support to meet the needs of our members of all ages, and with different conditions, no matter where they live so we are continually promoting ways in which you can have your say in what we should be doing, and how.

Your feedback helps to:

- shape year 3 of our Little Stars programme
- improve our engagement with professionals
- enhance our young people's offer for teenagers and young adults as well as our health offer for 20-30s and 40+ based on the findings of the 1000 Voices survey
- plan Spina Bifida Awareness Week this year (18th – 22nd October 2021) and Hydrocephalus Awareness Week (7th March 2022 – 11th March 2022)
- plan our services for the coming years
- show funders that we are listening to you and providing the services and support you need

Look out for opportunities to get involved!

You can also register your interest to get involved by emailing firstcontact@shinecharityorg.uk or call 01733 555988

COMING SOON!

We want you to get to know our teams who are working with you better, so look out for introductions on our new Facebook Groups for England, Wales and Northern Ireland.

Izzy's story...

Born in 2006, Isabella - known to friends and family as Izzy - hadn't been home long before her concerned parents took her back to hospital following a number of seizures.

Whilst there, Izzy had an MRI. The results showed a brain haemorrhage which resulted in hydrocephalus. At five months old, she underwent an unsuccessful endoscopic third ventriculostomy (ETV) and her head continued to grow.

Eventually, at 10 months old, Izzy had a shunt fitted. Now 15 she jokes "I dare not say this, but I still have the same shunt now!".

Living at home with her mum, dad and younger brother, Izzy lives a typical teenage girl's life. She loves to draw, swim, ski and be outdoors.

Izzy recently told her story in a 'Shine Voices' video but since going to print, Shine has learned that she recently underwent shunt revision surgery.

To hear her story in her own words, including what happened after her recent procedure, check out her video: shinecharity.org.uk/izzy

> **"..."I'm just a normal teenage girl with hopes and dreams..."**

Want to tell your story?

Head to shinecharity.org.uk/voices for details of how to create and upload your own video to our Shine Voices library, and share your experiences with the spina bifida and hydrocephalus communities.

Shunts. **Your questions answered**

Why don't doctors always put a shunt in immediately after diagnosis?

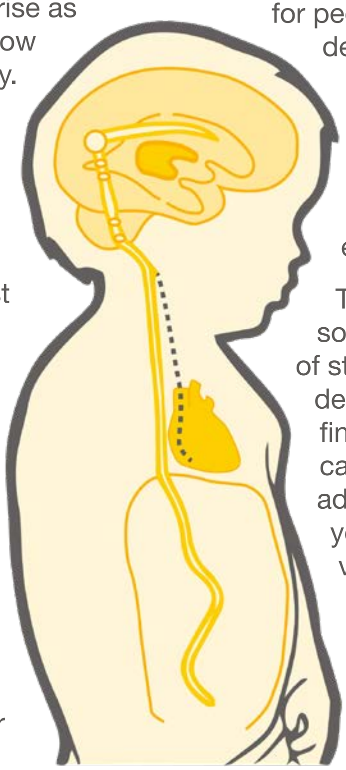
Very small or premature babies have very fragile skin, their immune system hasn't fully developed, and the risk of complications is high. The head circumference increasing means the pressures don't rise as quickly as in adults and waiting can allow doctors to be sure a shunt is necessary.

Adults are sometimes diagnosed with long-standing hydrocephalus, which is stable, even though the pressures may be high. Placing a shunt could lead to low pressure symptoms or serious complications and may be best left unless symptoms develop.

Why do I need to drink plenty of water when I have a shunt?

Although shunts remove fluid from the head, the fluid is eventually returned to the blood stream-you don't need to 'replace' the fluid drained by drinking. The shunt won't block if you don't drink, but you might get a headache or feel tired.

When you have a shunt, the pressures in your head varies more than for people without shunts; the pressure has to rise a little to open the valve, and the shunt may drain more when you're standing up. Keeping hydrated helps minimise these effects.



I had a shunt revision after years of having the same shunt, why don't I feel as well as I did?

When we're babies, our brains are very soft, and can expand or compress quite easily-this is called compliance. As we get older, our brain becomes firmer, and adjusts to new pressures less readily than in childhood. Sometimes shunts have not worked well for years before symptoms develop, and the pressures may need to be reduced over time by the new shunt. However, your brain will have been used to the higher pressure, even though this was not good for you, and you may get low-pressure headaches as the day goes on.

The reasons why you needed a new shunt can also affect how you feel after - for example meningitis can cause severe pain for months, even though your shunt is working well. Bleeds and injury can also cause pain.

Do I need to avoid magnets?

No, not if you have a fixed pressure shunt. And for people who have programmable shunts, it depends on the type of shunt you have. Some shunts, such as Miethke ProGAV/PaediGAV or Codman Certas Plus are designed to prevent unintentional resetting, so you would not have to be concerned with magnets in the environment.

There have been anecdotal reports of some other shunts resetting in the presence of strong magnets, such as airport metal detectors (the whole-body scanner is fine), the clasps on mobile phone or tablet cases, or large headphones, and it may be advisable to avoid having these too close to your valve. A distance of 5cm between the valve and the magnet greatly reduces the strength of the magnetic field across the valve.

Young children need to be supervised when playing with magnetic toys, iPads/tablets and similar.

So, it is important to find out what type of shunt you have, and where the valve is.

I need a shunt for Normal Pressure Hydrocephalus (NPH), but I'm worried about complications?

NPH is quite different to other forms of hydrocephalus. Pressures remain typical much of the time, but shunts can help remove excess pools of fluid and relieve symptoms for many.

The main complication for older people is bleeding outside the brain (subdural haemorrhage), but this is uncommon. Other complications, such as infection and blockage, are much less common in older people than children, and if your shunt does malfunction, you will notice a gradual return of your original symptoms (particularly walking difficulty) rather than a sudden illness needing urgent medical care.

NPH is the only potentially reversible cause of dementia, and shunts are the only treatment, so if offered, it's worth giving careful thought.

Leaving a legacy can change lives

The pandemic has led many of us to reflect on the things that matter the most – family, friends and the causes close to our heart.

For over 50 years, Shine has 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, whatever the value, will mean we can continue to be there for our members today, tomorrow and long into the future.

How Florence's gift is making a difference

Whilst much of our work is done by telephone and email (particularly during the pandemic), from experience we know that having a member of staff based in, or near, a geographical area can make such a difference in better supporting our members.

Our team of regional Support and Development Workers are much more familiar with local and regional services and networks in the areas they live, and can build contacts with professionals, and the wider knowledge of whose door to knock on to support members in getting access to the services they need.

Thanks to a wonderful legacy left by a lady called Florence Bartle, who wanted the funds to help people in the Southwest of England, particularly young people, we are delighted to have been able to employ a full-time Support and Development Worker, based in Cornwall.

Francesca Greaves, who our members in the area will know as "Chess" started with us mid-April this year. Chess has over 20 years' experience working across various social care settings, delivering support and information to people living with a wide range of needs and challenges. Much of her experience is in delivering person-centered support services for people with complex needs and both cognitive and physical disabilities.

Since joining, Chess has seen an ever-growing demand for support and advice from our members to tackle a wide range of questions on various issues such as housing, mental and physical health, access to social care services and employment. Being based in the Southwest means that Chess is well-placed to identify what other services and resources are available locally and regionally, get to know staff from other organisations, and to work directly with our members and their families to navigate and access the services and networks they need.

John is leaving a legacy… and here's why

Now 51, John didn't receive a diagnosis of spina bifida occulta until he was 20 years old. Having had his suspicions for a while, John headed to his local library where staff gave him information about Shine (then ASBAH), opening the door to information and advice which he would continue to benefit from to this day.

At various points in John's life, Shine has been on hand to provide support. Our health team has helped with a range of physical issues, and when the Employment and Support Allowance was introduced, John's Support and Development Worker was there to give advice, helping him to complete his application form and avoid the stress of a complex assessment interview. Most recently, John enjoyed a one-to-one call via Skype with a Shine physiotherapist, who recommended a number of exercises to help alleviate ongoing neck and shoulder pain.

We were delighted to learn that John has recently decided to leave a gift in his will which will help Shine continue to deliver these services and directly help those who'll need our support in the future.

"I find it reassuring to know if I have questions or concerns about my condition, I can contact someone at SHINE. It's been very helpful before and after hospital stays, in seeking advice about my recovery"

"I am also aware that SHINE, a lesser-known charity, is unlikely to benefit as much from legacies as some of the bigger ones and that any legacies received are probably more appreciated than they would be in some of the larger organisations"

Here’s what some other legacy leavers had to say…

“ Many years ago we were personally touched by spina bifida, and have been active supporters of Shine’s fundraising ever since, to help other people benefit from the research and help that Shine gives.

We feel that gifts left in our wills as a legacy will continue to provide funds long after we have gone… The benefits are twofold as they reduce the inheritance tax for our relatives and provide much needed help to the charity.”

Mrs L, Legacy Pledger

“ I wanted to leave a gift to Shine because it’s an organisation I approve of. Back in the 80’s my hope was to help towards funding research into the causes of spina bifida, but as medical science has moved on, so has the work of Shine (then ASBHA) and I realise that any contribution I’m able to make will be far more effective by supporting the work of Shine’s regional Support and Development teams”.

Andrew, Shine Member

Find out more about Andrew as he tells his story on page 10.

“ When our son had an ETV at three months old, we were told that we would know if there were problems with it or if it was failing.

At around four and a half months, I remember him crying and crying – a piercing, screaming cry. I didn’t know if the ETV had failed. I thought I was being a paranoid parent and didn’t want to ring the hospital – perhaps I was worried they would judge me or I was being a burden? I don’t know but I was in floods of tears not knowing what to do and I had a sense of panic that I thought was irrational. It was then that I rang Shine.

I spoke to a Support and Development Worker who listened, calmed me down, reassured me and told me to ring the hospital. I did and we took him in. The ETV had failed and he was shunted the next day. It was just a phone call, but it made me feel justified in being worried and reassured to ring the hospital. It was just a phone call – but it made a difference.

That is what giving legacies to Shine do. They make a difference. A legacy helps Shine to provide that person on the end of the phone to make everything feel ok; to support you through the most difficult times and to hold your hand when you need it.

We have left a legacy to Shine in our Wills because we know that Shine will make a difference for other families.”

Katherine, mother of a child with hydrocephalus.

Including a gift for Shine in your will

If you’d like to include Shine in your will, it is important that our full details are included, so please remember to include our full name, address and charity number to ensure we receive your gift

Name: Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE
Registered office: 42 Park Road, Peterborough PE1 2UQ
Registered charity number: 249338 Registered company number: 00877990

If you’re thinking about leaving a gift in your Will to Shine, or if you’ve already left us a gift 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**

More information and FAQs can be found at: shinecharity.org.uk/donate/leave-a-gift-in-your-will

Andrew's story...

"One of the things I'm proudest of in my life was being invited to join in the Zoom call with Maria which featured in the midsummer edition of 'Together'. I felt I was putting something back for all the support I've had over the years from family - my wife was also born with spina bifida - and friends over my 75 years.

I guess that, when you reach such a landmark, it's a natural reaction to look back and realise how many of the things we now take for granted didn't exist when I was born.

I'm a couple of years older than the NHS, you see; and that meant that if I needed to see a consultant in my very early days, my parents had to save up to pay his fee. And as my Dad was the only wage-earner in the house, that put a real strain on family finances.

And in those days children with disabilities were often labelled 'crippled', a word which, in my opinion, ought to be banned from the English language.

One of the things that went with that label was that my parents really had to fight for me to be allowed to attend our local primary school. Because I had a physical disability, the local education authority seemed to think that I was also mentally incapacitated.

But my parents fought, and won, a real battle to ensure that I went to our local primary school where I passed the 11+ exam to go on to a grammar school.

> "...I have to say how proud I am since I reconnected with Shine last year to have been to be involved in trying to help the national effort ..."

Probably more important to the 8-year-old me, however, was an illustrated talk given by a local man called Alfred Gregory. He'd been the official photographer on the 1953 expedition to conquer Mount Everest. His photos both of the climb, and what seemed the exotic city of Kathmandu fired my imagination. "I wanna go *there*!"

Another change in society that's affected parents of spina bifida children was the passing of the Abortion Act in the mid 1960s. It was illegal to terminate a foetus when I was born; but I learned from Maria during that Zoom call that it's now not uncommon for a pregnant woman who's gone for her 20-week scan to be told that she's carrying a foetus with spina bifida and given a leaflet about terminating her pregnancy. The thought sticks in my craw.

But there have been medical developments in my lifetime which would surely have been thought to be in the realms of science fiction when I was born.

I never forget that I was one of the lucky ones in that I wasn't born with Hydrocephalus in the 1940s, otherwise I wouldn't have been writing this.

And when I watch TV programmes about the developments in medical technology, I'm absolutely awestruck; I still can't properly get my head round how operations can be carried out in utero; but I'm really glad they can be.

As for the other big development to help families where one of the family was born with spina bifida; well, you're reading a magazine produced by it.

There was no ASBAH - Shine's predecessor - when I was born, so parents like mine had to fight for their - and my - rights with very little support.

And as someone who was a member of my local ASBAH committee in the late-1960s, I have to say how proud I am since I reconnected with Shine last year to have been to be involved in trying to help the national effort on behalf of all the spina bifida and hydrocephalus community."

Danielle's story...

My name is Danielle and I'm reaching the grand age of 40! I have 2 children and currently work in a school as a teaching assistant. I also have spina bifida occulta.

Throughout my life from being very young I remember I had issues, in particular 'toilet issues', and numbness in my leg. Back and forth my mum would take me to the doctors. Socially I was filled with anxiety. My family and friends didn't have the problems I had, especially with the toilet troubles, which warranted me to have my own 'special' key at school! I hated clothes shopping, especially shoes. I couldn't stand materials like jeans on my leg due to the difference in feelings - as a child, it was hard for me to explain the numbness, the 'lesser feeling'. I also always felt my left leg appeared slightly bigger and photos of when I was younger show I had a turned in right foot pose. I just learned to manage because what else could I do?

> "...Sometimes, my emotions get quite intense, and Mel is there to help me through it and also the support of other people who have spina bifida occulta..."

Roll on many years and I have a successful life and wonderful children. However, after the birth of my second child, I struggled with dull aches to my lower left side. I kept questioning but no tests appeared to bring a conclusion. That was the story of my life! In 2018 I had a running incident, and it was only then that my SBO was discovered. Could this SBO finally close the lid to my life's demons?

When I started researching SBO, it seemed as if there wasn't much support out there for people in my situation. I kept reading statements like 'not usually cause any problems' and 'most people are unaware they have it'. For me this was simply not the case.

I set up a campaign in February 2020 to bring the voices together and to collate information on SBO. I reached out to charities worldwide, including Shine. I was so pleased to find the Shine 'Occulta & Me' Group. It was lovely to talk with Mel who listened, and it was just helpful to have that person and the group. Sometimes, my emotions get quite intense, and Mel is there to help me through it, and also have the support of other people who have spina bifida occulta.

I appreciate it may only be a small defect of the bony structure of the spine, but I'm hoping that with my story, and others in time, there will be enough of us to show how SBO creates problems throughout life

Support groups are the key now in helping our voices find each other, and support for our emotional and physical wellbeing ... and to know I am not the only one with SBO. If only I had had an earlier diagnosis!

Shine's 'Occulta and Me' group

The Shine 'Occulta and Me' group meets monthly (and virtually), usually on a Wednesday evening, and aims to bring together our members who are often experiencing the effects and complications of SBO or who want to know more about things to look out for and ways to manage the condition.

For more information and a link to join this group which is open to all Shine members with SBO then please contact Melanie Hayes on melanie.hayes@shinecharity.org.uk or call First Contact on 01733 555988 to register your interest.

Little Stars

COMMUNITY FUND

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Shine's National Lottery Community Fund (NLCF) grant has allowed us to set up and run a "test and learn" early intervention programme in England, building on our earlier pilot schemes in Wales and Northern Ireland which means that Little Stars is now up and running for all our 0-12s, no matter where they live in England, Wales or Northern Ireland.

New Members and Engagement

We have welcomed more than 550 new 0-to-10-year-old new members, and referrals for support have more than doubled in the past 12 months, as a direct result of us contacting families to offer advice. We are responding more quickly to requests for information and support, at the same time as putting more focus on our work with members who have multi-layered and complex issues, which can take significantly more time and contact to understand and resolve.

E-newsletters

30 e-newsletters which give age-appropriate advice for parents to use to support their babies/ young children at 15 different age milestones have been launched. The newsletters will be automatically sent to parents as babies/children reach the relevant age for each newsletter. We will ask for feedback on the e-newsletters in our 3rd Little Stars Survey towards the end of this year.

If you are a parent of a 0-to-10-year-old and have not received the welcome email, or you would like to receive back copies of any of the newsletters, please do get in touch with the Little Stars team, by emailing **littlestars@shinecharity.org.uk** or by calling HQ on **01733 555988.**

Increasing the age of Shine's Little Stars

As a result of the pandemic, charities like Shine will be taking on an even greater role to support families in the future. We anticipate the fall-out from the pandemic on statutory services to last for some time. The challenge to us is how we continue to deliver this and fund the extension of this level of support to our members aged 11-18 years old.

Thanks to the success of our current programme, we are delighted to announce that NLCF in England have agreed that we can increase the age of our Little Stars programme to 12 years. We will also introduce this in Wales and Northern Ireland so that this will allow us to provide support for children as they transition to and in the early years of secondary school.

Virtual Activities

We established a way of delivering information and encouraging peer support between our member parents, which has included:

- 26 WhatsApp groups with 584 members in England, plus, a new Dandy Walker Syndrome WhatsApp group with 15 members
- Closed Facebook Parents' Forum to share information and make it easier for parents to interact and support each other now has 780 members
- Offering a weekly programme of closed zoom sessions to 149 parent/carers and a monthly programme to 24 dads/male carers
- Sharing our recorded Hydrocephalus and Learning webinar and our three Spina Bifida videos to support parents and schools
- Access to online continence and physiotherapy sessions

The future

We are looking closely at how we can secure further funding to assure the future of Little Stars, and also plan a similar approach to supporting our 13-to-18-year-old age group to help them gain qualifications, employment and independence.

If families would like to support us by fundraising, please do contact our fundraising team on fundraising@shinecharity.org.uk or call 01733 555988

Spina Bifida Awareness Week

18th - 24th October 2021

Join a **Facebook live** or closed Zoom session

Download exciting new resources+!

How will YOU get involved?

Join the conversation on social media, and **share, share, share!**

Encourage the Health Professionals you know to sign up to our free on-line conference*

Make a Shine Voices video and tell your story!

Will you dress... Back to Front?

Our third year of bringing your back to the front of people's minds, and raising awareness and money for Shine!

We know that YOU are the expert in your condition.

This year our aim is to give you the tools you need to talk confidently to people you know, particularly professionals, about your lives, and get access to the support and services you might need.

For more information on ways to take part, visit:
www.shinecharity.org.uk/sbaw

+ Printed copies also available * See page 3 for more information

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

How **you can support Shine**

Many of Shine's services are funded entirely by the generosity of the general public. This includes fundraising, donations, corporate supporters and gifts in wills just to name a few!

To support Shine, could you consider making a regular donation?

Scan the QR code or visitshinecharity.org.uk/donate to set up your monthly donation

You could choose to give £5, £10, £25 or any other amount as a monthly donation which will be donated automatically every month unless you decide to cancel. **THANK YOU!**

How Louise found her MOTIVATION!

Over £1,500 raised!

Louise has been a member of Shine in Northern Ireland for many years. She lives with her mum Julia and sister Amanda and attends the Adult Centre in Magherafelt.

Normally, Lousie attends the adult centre in Magherafelt but when Covid restrictions were introduced, she stopped attending. Like so many of Shine's members, Louise was confined to her home, couldn't see her friends and, as a result, saw her mobility, mood and motivation decrease.

Things started to change for Lousie in May this year when Heather, a volunteer from the local 'Share the Care' group started visiting Louise. With a change in routine, Heather helped Louise find her motivation. Even though Covid restrictions were still in place, Louise decided to follow the example of Captain Tom and set a goal of walking 100 times around her home whilst raising funds for Shine.

It was very difficult to start, but with perseverance and encouragement, Louise walked a little twice a week and eventually built up to walking the whole way around the house. On Monday 5th July Louise walked her course for the 101st time with some members of her family present to witness her achievement. She also raised a fantastic £1,535.00 for Shine. **What an achievement!**

Thanks to our star TREKKERS

Well done to our fabulous group of trekkers who conquered Yorkshire 3 Peaks and raised over £9,000.

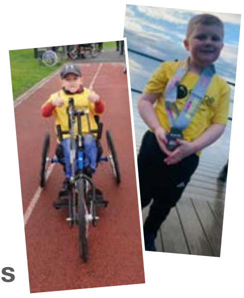
Inspired to take part next year? The Yorkshire 3 Peaks challenge is returning on Saturday 9th July 2022, now with a family friendly 1 peak challenge too!

Contact us to register your interest
fundraising@shinecharity.org.uk

Winter Wonderwheels!

We're looking for superheroes to follow Mason and Archie's lead from last year for the Winter Wonderwheels or at home Winter Wonderwheels challenge this Winter!

Find out more on our website:
www.shinecharity.org.uk/winterwonderwheels



Want to get involved?

Whether you know what you want to do or need inspiration, we'd love to hear from you!

Get in touch with our friendly fundraising team by calling 01733 555988 or visiting our website: shinecharity.org.uk/getinvolved

Fabulous **fundraisers!**


Maria's skydive **raised £1,659**


Liza completed her first ever triathlon, **raising £1,200**


Dawn and family climbed Moel Famau, **raising £1,076**


Jane took on an ultramarathon and **raised £1,463**


Chris **raised over £3,000** by cycling 1,000 miles throughout July

Austin conquered the Man Vs Lakes challenge, **raising £1,135**


Ian, Jen and Carrie **raised £1,923** cycling from Manchester to Blackpool


Four year old, Dara, **raised £,4059** walking round Craigavon Lakes

Do you work for or know a company that supports charities?

If so please send us their details so that we can get in touch to see if they would be able to support Shine.

fundraising@shinecharity.org.uk


Kate and Michael's **raised £1,281** with a 870 mile virtual row


Rainy's skydive **raised over £2,000**


Liam cycled 500km over four days and **raised £1188**

Business supporters!

30K YOUR WAY FOR SHINE

Citi Belfast are raising money for Shine through 2020 and 2021 due to the support received by Shine members who work at the organisation. **Their 30km in June challenge raised over £7k bringing their total to over £40,000.**

Tesco Extra, Northcott store in Northern Ireland chose to support Shine, as a thank you for the support given to the family of one of our Little Stars members. During the month of June several staff members took on 10,000 steps a day every day, they supported Go Yellow for Shine, had collecting pots on tills and donated proceeds from their secondhand book stall – **raising a fantastic £2,668.50.**

Go Yellow for Shine

Save THE DATE!

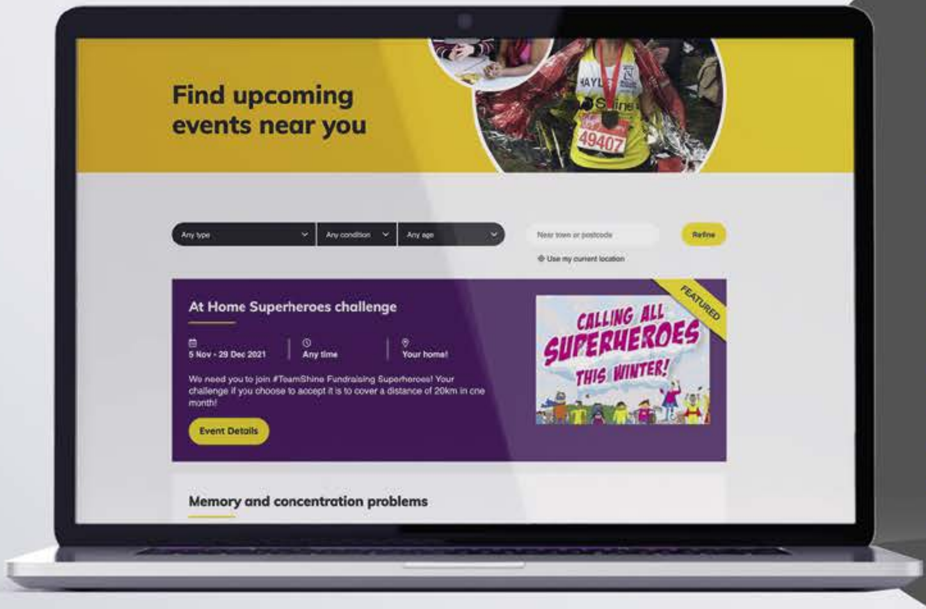
Our recent Go Yellow day was a smash hit, raising over £12,000!

You can help us smash that total next year, by joining in the fun on **Friday 17th June, 2022.**

Shine events are STILL online

Shine's virtual events will connect you to Shine, and to others.

Here's what we have to offer ...



Find upcoming events near you

At Home Superheroes challenge

5 Nov - 29 Dec 2021 | Any time | Your home!

We need you to join #TeamShine Fundraising Superheroes! Your challenge if you choose to accept it is to cover a distance of 20km in one month!

Memory and concentration problems

- Coffee and chat
- Spina Bifida focus group
- Occulta and Me
- Hydro and Me
- Dads/Male carers
- Adult social groups
- Teen Zoom sessions
- Book group
- Parents' sessions
- Little Stars online fun
- Quizes
- Facebook lives
- Closed Zoom sessions
- Shine Facebook groups

For more information call 01733 555988 or email firstcontact@shinecharity.org.uk

Launching in 2021, our new platform lets you see all events, activities and opportunities on offer from Shine, or choose from a list which is specific to your age and condition.

In the meantime, see what activities we're currently offering at:

shinecharity.org.uk/events

NEW Facebook Groups!

Shine recently launched new Facebook groups for our members in England, Wales and Northern Ireland. They've been very popular! Join the conversation at:

shinecharity.org.uk/groups

Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

Here to help...
Please do send any comments or enquiries to us:
P: Together Shine, 42 Park Road, Peterborough PE1 2UQ

☎ 01733 555988 http://www.shinecharity.org.uk ShineUKCharity Twitter.com/SHINEUKCharity