

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

England & Wales · Charity number 249338

Details

Other names	ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS, ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS LIMITED, SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE LTD., A S B A H
Status	Registered
Legal form	Charitable company
Company number	00877990
Registered	1966-10-01
Register	View on the Charity Commission register

Contact

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Activities

Objects: THE RELIEF OF PERSONS WHO HAVE SPINA BIFIDA AND/OR HYDROCEPHALUS OR ALLIED OR RELATED DISORDERS BY PROVIDING FOR THEIR CARE, WELFARE, TREATMENT, EDUCATION AND INTEGRATION INTO SOCIETY.

Activities: Shine's vision is a society where all those whose lives are affected by Spina Bifida and/or Hydrocephalus and associated conditions are empowered and enabled through choice and equality of opportunity. Our aim is to make a positive difference to the lives of people affected by the conditions.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities

Geography

- Northern Ireland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£2,466,856	£2,418,225	£1,804,117	52
2024-03-31	£2,155,115	£2,274,459	£1,794,472	48
2023-03-31	£2,347,350	£1,965,957	£1,859,724	44
2022-03-31	£1,894,487	£1,894,927	£1,521,744	45
2021-03-31	£2,343,079	£1,899,638	£1,350,711	47

Trustees

Name	Role	Appointed
Dr ROGER BAYSTON		
JENNY LOUISE GOY		2022-09-26
JOSEPH ANTHONY IAN WAGGOTT		2022-09-26
Joanne Frances Williams		2016-11-03
Joanne Ruth Sedgwick		2023-11-01
Michael Brown		2015-11-19
Prof. John Douglas Pickard CBE		2024-12-04
Richard Oakley		2023-07-05
Roanne Woodward		2024-12-04
Surekha Kukadia		2021-07-06

Linked charities

- FIVE OAKS FUND (249338-1)

Accounts

Shine Trustees' Annual Report and Financial Statements 2024/25

Year ended 31st March 2025



Shine

Spina bifida • Hydrocephalus
Information • Networking • Equality



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Welcome from the Chair and CEO

We are proud to welcome you to Shine's Annual Report for the year 2024/25.

As the Chair and the CEO, we are delighted to share details of the remarkable strides Shine has made throughout the year to support our members, their families and professionals. From enhancing educational support for children to empowering young people and adults, our initiatives have made a significant impact on the lives of our members across England, Wales and Northern Ireland.

We have reviewed and consolidated initiatives such as the 'Shall Wee Talk' continence support programme, which has been reshaped to better cater to different age groups, and introduced the Shine STAR school awards, aimed at educating nursery and school staff about spina bifida and hydrocephalus. Our staff have also dedicated efforts to improve transition support for young people and worked with the NHS to establish more specialist clinics and access to better services across the nations.

Whilst we have continued to build on our strategic goals, ensuring that our services are tailored to meet the diverse needs of our members, we have also turned our focus to research and innovation, including a transformative new treatment, Non-Invasive Spinal Electrical Stimulation (NISE Stim), which promises a new era in neurorehabilitation for people living with spina bifida. Additionally, our focus on raising awareness and providing support for normal pressure hydrocephalus (NPH) has led to the development of a specialised service in Shine that addresses the unique challenges faced by individuals to get a diagnosis of NPH, the ensuing treatment and on-going support needed when living with the condition.

The success of our campaigns, including the mandatory fortification of flour with folic acid, marks a major milestone in our efforts to prevent neural tube defects. This achievement is a testament to the dedication and perseverance of our team and supporters. In the coming years, it is our intention to

campaign for greater public awareness on how folic acid supplementation can help to reduce the chances of pregnancies being affected by anencephaly, a fatal condition, and spina bifida.

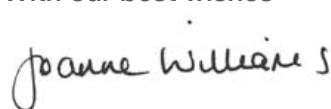
Shine's membership is at its highest ever, with over 14,500 babies, children, young people and adults living with hydrocephalus and/or spina bifida, and related conditions now registered with us.

We cannot thank the teams across Shine enough for the work they do. Ably guided by our senior leadership and management teams, they have once again risen to the challenge of delivering quality advice and support as our membership numbers have continued to grow – from the frontline service teams and our specialist leads to income generation and finance, from our communication and data staff to HR and internal services, EVERYONE has played their part in making 2024/25 a success.

Thanks must also go to the trustees, volunteers and supporters who make significant contributions to Shine, be they overseeing management and leadership of the charity, helping with day-to-day tasks such as admin or data checking, or fundraising and supporting us at the numerous events we are involved in throughout the year.

As we look ahead to the coming years, Shine remains committed to making a positive impact on the lives of those we support.

With our best wishes



Joanne Williams, Chair



Kate Steele, CEO



Our impact



Shine is continually working towards our vision of a society where all those whose lives are affected by spina bifida and/or hydrocephalus, and associated conditions are empowered and enabled through choice and equality of opportunity”.

We welcomed 923 new members to Shine, bringing our overall membership to

Last year, we provided one to one support to



4,650 people

We made a difference in the following areas...

Improving health and self-management

1681



We helped 1681 people to improve their condition knowledge, and 1489 people to manage their condition better.

1459



1459 enjoyed better health and wellbeing thanks to our support.

Reducing isolation and building community

1887



1887 people attended our events and engaged on our peer support forums.

3432



We enabled 3432 people to enjoy more positive relationships in their lives, and 3497 to feel better connected to others.

Enhancing access to essential services...

Our teams supported...

478 people

to have better access to education



1632 people

to access better care and support in their community



133 people

to get better accommodation to suit their condition



365 people

to have improved financial stability

87 people

to get into work, or get the support they needed to stay in work for longer



We also empowered people with the knowledge and confidence to seek support themselves.

As a result of our interventions, 1878 people felt more confident to self-advocate

Our achievements in the year

Consolidation

When we launched the Corporate Plan in 2022, our ambition was to create a structure and investment plan, which would ensure we were able to provide tailored support, advice and guidance for all Shine members and their parents/families/carers, no matter their age, condition(s) or location.

Three years in, and we have achieved this!

For each 'age and stage' in our members' lives, Shine offers:

- **1-2-1 Support and Guidance:** tailored to individual needs, and issues related to spina bifida, hydrocephalus, and associated conditions.
- **Online Events:** regular online sessions for information sharing and community engagement.
- **Face-to-Face Events:** regular in-person gatherings and attending conferences to foster community connections.
- **Regular updates:** on a host of condition-related, and social information such as welfare and benefits, housing, staying active and social opportunities
- **Health Advice:** sessions with our specialist health team to address concerns over physical health and mental well-being.
- **Clinic Attendance:** regular presence at NHS clinics to support our adult members, children and their families, complementing the NHS teams by offering additional support on a range of topics, as well as helping to understand medical terminology and information
- **Educational Support:** guidance on education and expectations of schools, understanding and support for children with spina bifida and hydrocephalus and shaping educational plans
- **Planning for the Future:** helping people consider options for independence, employment, staying and living well, finance and interests
- **Support for Parents/Carers of babies, children and young people:** WhatsApp groups and online sessions for parents to share experiences and receive support.
- **Shine40Plus Group:** a closed Facebook group for peer support and sharing experiences amongst our adult members over 40.
- **Promoting Specialist Information and Resources:** regular reminders and updates on available resources.
- **Awareness Weeks:** Spina Bifida, Hydrocephalus and NPH Awareness Weeks to raise public awareness and share members' stories.
- **Shine services:**



Shine Health Direct: a service providing urology and stoma products to members, delivered in partnership with Bullen Healthcare.



Legal Services: A partnership with leading law firms to offer legal advice and support.



Strategic Goal 1

Enabling Babies and Children (0 to 12 years old)

2,946 members
as of 31st
March 2025

1,428 children and
families who received
one-to-one support



Shine has been a tremendous support for us as parents, especially in the early days when we had no idea what to expect..." Parent of a young Shine member.'

Transition

It is important that our children with hydrocephalus and/or spina bifida, along with their families, have a positive experience of transitioning into new schools and environments, as they are more likely to feel connected, enjoy a sense of belonging and have a positive sense of social and emotional wellbeing, which allows them to learn and thrive.

However, our experience shows that transition plans can be disjointed and, in some cases, non-existent for babies and children living with hydrocephalus and/or spina bifida.

The knock-on effect is a lack of understanding of the conditions, and the potential cognitive impacts,

limited awareness of the needs of the individual child, and

a lack of adjustments and adaptations to ensure the child can get the best out of their new school and the education it provides.

We were, therefore, delighted to appoint Shine's

Education Officer in March 2024 to enhance our educational support.

12-months on, and in addition to more general education advice, Shine can consistently offer:

- Anytime specialist 1-2-1 support for parent/carers
- Information tailored to key transition times in a child's education
- Guidance and help to complete ECHPs (England), Individual Learning Plans (Wales) and Personal Learning Plans (Northern Ireland)
- Education newsletters
- Shine STAR school awards to engage and educate nursery and school staff to have better understanding of the conditions and strategies to enhance the school experience



Thank you to The Mackintosh Foundation and The Stockwell / Cliffe Charitable Trust for their support

“ Shine is an outstanding charity that has provided invaluable support to our school on our journey to achieving the SHINE School Award. Their guidance and assistance for both staff and parents have been truly exceptional, making a significant impact every step of the way...” (SENDCO, from school achieving the STAR Award)



Managing continence



Most people living with spina bifida will have some degree of continence issues with the bowel, bladder, or both. Early understanding of the importance of continence care can be life-changing for those children who have continence issues. Self-

management leads to a growth in self-confidence and longer-term independence.

An extensive review of our 'Shall Wee Talk' continence support programme informed a re-

shape of the service, which is now run as a six-week programme for different age groups, allowing the team to tailor information and language to the children's ages and levels of understanding. Once completed, the children will graduate from the programme but continue to have access to specialist support. Their place remains secure in the group if they are not ready to move on.

“ The difference just one session had on my son's mental state was huge. To know he isn't alone, that there are other boys like him, it was almost as if a visible weight was lifted from his shoulders.”

Thank you to BBC Children in Need and John Horniman's Children's Trust for their support

Spinal Stimulation – a new era of treatment

Shine has continued our ground-breaking research using Non-Invasive Spinal Electrical Stimulation (NISE Stim), which highlights a promising new era in neurorehabilitation. Developed in 2017 by Dr. Gad Alon and Gerti Motavalli, NISE Stim uses electrical impulses sent through electrodes placed over the spinal cord to stimulate sensory roots. This stimulation enhances neural connectivity within the spinal cord, impacting sensory, motor, and autonomic nervous systems.

NISE Stim strengthens neural connections and induces muscle contractions, promoting neuroplasticity. It offers potential improvements in muscle health, metabolic function, bone strength, circulation, and wound healing. Clinical studies since the 1980s have shown its safety, with rare instances of skin irritation under electrode.

The treatment is suitable for children with spina bifida and can begin as early as 8 weeks post-surgery. It is contraindicated for children with implanted electrical devices or uncontrolled epilepsy. The Shine NISE Stim Service, available in five locations across England, Wales, and Northern Ireland, has seen positive outcomes in children and adults, including increased circulation, sensation, and muscle strength.



It is still early days, but this innovative approach marks a significant advancement in neuro rehabilitation, which we hope to see rolled out to benefit more people living with spina bifida across the UK.

We truly believe that a combination of spinal

stimulation therapy and regular physiotherapy has improved our daughter's muscle tone and mobility, allowing her to do most of the things that any child of her age can do. With the help of Shine, we will continue to do spinal stimulation therapy to continue to help our daughter's mobility...

“ Our daughter has benefitted greatly from spinal stimulation therapy. Before we started, she had very limited sensation in the soles of her feet and her feet were in such a dorsi flex position that her toes were almost touching her shins. After a year of spinal stimulation, her sensation has improved dramatically. Whilst her foot positioning isn't 100% correct it now sits in a 90-degree angle, allowing her to crawl, climb and walk with a kaye walker.

Member story

At every spinal stimulation clinic we hold, we witness the real life impact this therapy has on children's comfort, mobility, and independence.

Recently, we saw a young man who had been following a tailored course of spinal stimulation aimed at strengthening the muscles in his trunk.

This approach was chosen to reduce any worsening of his existing scoliosis (curvature of the spine) and to reduce how hard he is having to work in sitting due to weak core and trunk muscles.

At his most recent appointment, we were thrilled to see that his independent sitting balance had improved when not wearing his back brace. Sitting with more stability has led to him feeling more confident when sitting and he is now working with his Occupational Therapist on learning independent dressing skills.

Following review from his medical team, the need

for a back brace may be reduced (currently he wears it 23 hours a day), and with it the need for surgery may be avoided.



We would like to extend our thanks to the following for their support of our spinal stimulation work

- ♥ Milles Charitable Foundation Limited
- ♥ The Casey Trust
- ♥ The Grace Trust
- ♥ The Hamamelis Trust
- ♥ Liam Fairhurst Foundation
- ♥ The Vandervell Foundation

Little Stars



Thank you for supporting our Little Stars:

- ♥ Baron Davenport's Charity
- ♥ The Charles S. French Charitable Trust
- ♥ Eastern Counties Educational Trust Limited
- ♥ Eleanor Rathbone Charitable Trust
- ♥ The Peter Harrison Foundation
- ♥ The Street Foundation

Strategic Goal 2

Empowering Young People (13 to 25 years old)

2,285 young people members

800

young people who have received **one-to-one** support

Similar to initiatives in goal 1 but for different ages, our teams have worked to more directly connect and communicate with our 13 to 17 year old members, and our 18 to 25 year old members,

encouraging them to take greater responsibility in advocating for themselves in accessing the services and support systems they want and need.



I used to think I was weak, that my conditions meant I couldn't do anything. Shine changed that." (Teen member)

Influencing pathways for transition

Improving transition support and access to services has been high on our agenda as experience tells us that there are large gaps in the system when young people reach the age of moving from children to adult health and other services.

The right services and good transition pathways will help young people adapt to the changes and challenges that come with adulthood. Shine has been working with clinics and professionals to find opportunities to improve existing services and identify potential partnerships and projects to create more opportunities to smooth the way for young people to continue receiving the necessary and tailored support and care as they get older.

We have also put a spotlight on transition in education. By combining the expertise, skills and

knowledge of our Youth Voice and Engagement Officer and our Education Officer, we have successfully supported many of our youth members at distinct stages of their education journey. This work is also shaping our future strategy to meet the needs of the young people we work with.



Before joining the teen socials, I never knew anybody with the same conditions as me. I was really worried at first about joining, but I cried with happiness after the first session because I no longer felt alone" (Teen member)

Developing Shine's services for Young People

Shine's Young People have been actively engaged in creating the framework for our young people's support service, which includes peer interaction, support through websites and social media, resources, and a network of partner agencies for signposting. This approach ensures that the work we do is tailored to their needs and preferences, promotes independence, self-advocacy and builds a sense of community.

“ I enjoyed being part of the video about school stresses. It was tough to talk about but it was good to have my voice heard. It was also nice to know I do not face these struggles alone. It was overwhelming to have so much in common with others after feeling alone with these issues for so long. It made me realise I am not the weirdo at school and other people struggle with the same things and it is down to my condition.



Innovative approaches to engagement and involvement

Our young people have been engaged in steering the direction of the services they wish to receive from us.

Drawing on their knowledge, experiences and needs, the groups have actively contributed to the development of co-produced e-newsletters, a toolkit to help with future planning and draft publications, the contents of which is relevant and resonates with their experiences, covering a range of topics including health updates, personal stories and practical advice.

Bringing the groups together not only provides valuable insight and information, but also fosters a sense of community and belonging, which also addresses our strategic goal 4 'a connected community'.

“ It's part of being something bigger... knowing we are not alone...”



Youth Work sessions

Set up to engage, empower and educate, these online and face to face sessions have provided safe spaces for our young people to meet others of the same age share experiences and explore areas of interest or challenge together, often focusing on their health and wellbeing.



It's helped us face challenges that once felt overwhelming..." (Shine teen members' feedback)

Member story – the difference Shine has made

"One of the many stand out moments for us as parents was the response from Shine at the point of diagnosis, when we discovered our baby had spina bifida at the 20-week scan. Within 12 hours of us reaching out we received a response and within 4 day we had a face-to-face meeting with a member of the Shine Team.

We have accessed a range of support over the years ranging from emotional support which has proved to be incredibly beneficial during challenging teenage years, vast input from Shines Specialist Health Team which has helped prepare Owain for independence, understand his disability and the confidence to manage his complex condition plus the importance of taking responsibility for his own health and wellbeing. Opportunities also for social interaction and develop friendships with other young people within the Shine community.

The support that Shine has put in place to Owain, ourselves, and professionals has enabled Owain to get the best out of life. Confidence has grown and he has a new found passion for wheelchair racing

he was recently been crowned Welsh Champion in the under 20 100M and 400 metre Wheelchair Racing. He has had a fantastic season and broken multiple club records at Newport Harrier Athletics in the T54 wheelchair racer category and has travelled across the country putting in some incredible

performances, winning both the Cardiff and Swansea 10K races! He is aiming for the Paralympics in 2028.

Owain has also just obtained his DofE Bronze award and Chief Scouts Platinum award and is due to return to his primary school and talk to pupils about accessing sport with a disability"

Owain's Mum and Dad

We would like to thank the following organisations, who have supported us in our work with our young people:

- ♥ Barnard Kenneth Hufton Charity
- ♥ The Basil Death Trust
- ♥ Sandra Charitable Trust



Strategic Goal 3

Adults of All Ages

9,324 adult members over 25

2,194 people who received one-to-one support

More than half Shine's adult membership has hydrocephalus, or hydrocephalus and spina bifida. In both conditions, understanding physical and/or mental health and the need for earlier intervention can prevent the escalation of issues that quickly become complex and difficult to treat or manage.

“ I can't believe the timing of this call. I was feeling so low. It's been so nice to talk to you, and I had no idea I could get all this support from Shine, thank you so much for calling me today...”

Our additional focus for adults has been on:

A new publication

Based on Shine's '1000 Voices' research, 'Understanding Spina Bifida in Adulthood' gives a wide range of insights and expert information into aspects of health and well-being, to improve approaches for early intervention and prevention of health complications.

'Shine on ...' health series

As part of our focus on improving self-management for adults, Shine introduced and piloted two new online courses for people living with spina bifida and/or hydrocephalus.

'Shine on Pain' and 'Shine on Wellbeing' are designed to run for small groups of members, with sessions taking place each week over several weeks to build knowledge and confidence in self-awareness and strategies for self-management.



“ I would highly recommend this sort of course to anyone in my situation. It was such a relaxed and welcoming atmosphere, and I wish all the best to all the other participants...” (Feedback from group participant)



Adult spina bifida clinics

The UK is still severely lacking in specialist spina bifida clinic provision for adults. This not only impacts access

to the right services at the right time for adults

living with the condition, but limits transition opportunities from child health to adult health services. We see so many fall through these gaps but know that, with the right statutory services in place, preventative medicine and healthcare can play a significant role in keeping our members in good health for longer.

Shine continued to build links with NHS services across England and Wales and had discussions with hospitals and health boards to progress the establishment of clinics across the nations. Progress has been slow, but we are pleased to have had the opportunity to build links and start discussions which we are confident will move forward in the coming 12 months.

Member story – Living with spina bifida

“Living with spina bifida in a two-story house was incredibly difficult. My bedroom and bathroom were upstairs, but my mobility issues made it impossible to access them safely. I slept in the living room and used the kitchen sink to



wash. Every day felt like a struggle, and my home, which should have been a place of comfort, became a source of stress and frustration. That's when Shine stepped in.

From the start, Shine was more than just a support service - they were my advocates. Laura and the team worked tirelessly, making countless calls and sending emails to occupational therapists and housing officers. It wasn't a quick process, but they never gave up.

Thanks to their persistence, I've now moved into a fully accessible home. Everything is designed with my needs in mind - from the layout of the rooms to the front and back gardens. The lift I have in the hall which leads up to the landing is just fantastic! I can hang washing on the line, enjoy the outdoors, and even go to the shops in my power wheelchair, which Shine also helped me secure funding for.

This move has completely transformed my life. I feel independent, safe, and empowered.

I'm so grateful to Laura and everyone at Shine. Honestly, this has changed my life big time. I have a new lease of life!”

Help with housing

A key issue for so many remains finding and keeping suitable and accessible housing.

Whilst this is not unique to Shine, it is a must that we work to support and guide our members on this issue so that they can live independently, if they so wish, and be safe and comfortable in their homes.

As well as up-to-date information and 1-2-1 support, our housing passport was reviewed and updated as a useful guide to finding the right accommodation for them and their families/dependents.

Normal Pressure Hydrocephalus

In the past 2 years, Shine has seen a significant growth in members with Normal Pressure Hydrocephalus (NPH).

Whilst we don't have any evidence to understand this increase in new members, anecdotally, more people are being diagnosed with the condition, and people are coming across Shine as the charity that delivers NPH-support services, via the website and information from NHS hospitals.

Both suggest a growing awareness of the condition, and better understanding of symptoms for referral to specialists for investigation.

To support this work, Shine introduced a new NPH Co-ordinator role in 2024, who has started to develop a specialist service to address the questions that so many ask, which commonly include:

- Understanding NPH and treatment options
- Continence concerns and support
- Cognitive changes and the impact on daily life
- Housing adaptations and home safety
- Support for unpaid carers to access respite and assistance with receiving care assessments/care packages
- Benefits for the person with NPH and their unpaid carer
- Future Planning and Care Needs

Links have been established with some lead neurosurgeons and NPH clinics across the country, to create referral systems, and increase awareness, provide information and direct support to individuals and their families.

Shine's first NPH awareness week took place in May 2024, with the next in May 2025.



What is Normal Pressure Hydrocephalus?

Normal pressure hydrocephalus (NPH) is a condition which mainly affects people over 60 years old.

Cerebrospinal fluid (CSF) is constantly produced and absorbed and flows through chambers within the brain (ventricles) and around the outside of the spinal cord. CSF protects the brain and spine, provides nutrients, and removes toxins. In NPH, the ventricles become enlarged by too much CSF building up, although the pressures inside the head are often found to be normal.

Symptoms of NPH include difficulty walking, cognitive impairment/dementia, and urinary incontinence. The dementia-like symptoms are often confused with Alzheimer's or Parkinson's diseases, leading to NPH being missed/misdiagnosed, but if picked up, NPH is a treatable and potentially reversible condition.

Therefore, our work on raising awareness across the general public and health and care professionals is vital to getting timely diagnosis and treatment, both of which can lead to improved patient outcomes in NPH.

Music legend Billy Joel (left) was diagnosed with NPH in 2025.



“ I live alone with no family or friends. The thought of having a shunt fitted was terrifying...you were so kind and reassuring explaining the procedure to me and the benefit it would bring to me. I cannot thank you enough.”
(Member quote shared with Shine Support and Development Worker).



NORMAL PRESSURE HYDROCEPHALUS

Member story

“SHINE came to my attention when I was initially diagnosed with “Hydrocephalus” in February 2023 in my mid fifties and looking for specialist support.

It seems I have had the condition since birth, and I’m aware hydrocephalus and spina bifida are closely related conditions.

Your colleague Francesca Greaves provided some excellent support to me after my diagnosis as I worked through with relevant clinical specialists including a Neuro surgeon whether I also had normal pressure hydrocephalus (NPH) and therefore needed surgical treatment.

I ended up having a Endoscopic Third Ventriculostomy (ETV) brain surgery in mid November 2024 after Surgeon agreed in September 2024 I most likely had early stage

NPH, to try and manage the symptoms, which went very well without complications and I am currently recovering from that, but benefiting from a reduction in symptoms.

I think its fair to say that the info and support SHINE provided to me helped me to realise I had NPH in combination with Hydrocephalus and work this through with the Neuro Surgeon, so I had the surgery at hopefully an early enough stage for it to make a difference in treating the symptoms”.



706

members with
Normal Pressure Hydrocephalus

301

people with NPH who
received one-to-one support

Strategic Goal 4

A Connected Community

1,887

people engaged with **Shine's social and peer support platforms**



It's helpful because it's a community. So few people live the way that I and other Shine members do. Having a place - a refuge - to speak about experiences or simply be, is comforting. It's also useful for answering questions about spina bifida that I wouldn't have been able to easily obtain otherwise."



Shine's membership continued to grow in 2024/25, and we introduced smarter ways of working to become more innovative and time-efficient to meet demand for our services.

WE

✓ Worked with our members to produce new and updated information and resources

✓ Improved data and development of our database

✓ Engaged people in helping to deliver our awareness weeks

✓ Started to review our website

✓ Consulted with our membership on how we communicate and what they need most from us

✓ Had support from volunteers in admin, fundraising and running groups and events

✓ Introduced regular, tailored and automated information by email

✓ Moved our Together magazine to mostly digital distribution

✓ Successfully delivered our Spina Bifida, Hydrocephalus and Folic Acid Awareness Weeks, and launched a new NPH Awareness Week



✓ Informed our members more often of our events with dates and times well in advance

Strategic Goal 5

Preventing Spina Bifida and Anencephaly

It may appear that Shine's work on primary prevention of spina bifida is at odds with how we value and celebrate the lives of all those living with spina bifida and/or hydrocephalus. However, it is crucial to recognise that spina bifida isn't the only condition prevented by folic acid. Folic acid also prevents the nearly as common, and always fatal condition, anencephaly.

Our goal of recommending folic acid is about making informed choices to increase the chances of a healthy pregnancy and a positive outcome for the baby. Preventing congenital conditions is not about devaluing anyone's existence, it is about enhancing the quality of life for everyone, including future generations.

Mandatory fortification

In November 2024, our campaign for mandatory fortification of flour became law at last!

Our CEO provided a quote for the official government press release:

“After more than 30 years of campaigning, Shine can finally celebrate the introduction of this very important public health initiative. This move will mean that far fewer families will have to undergo the trauma of a potentially fatal or life-affecting diagnosis for an unborn baby. This is a major milestone, and we are so grateful to everyone who has played a part in getting this legislation over the line”.

Shine had the opportunity to share our campaign experiences and lessons learnt on the international stage, participating in online sessions for the International Federation of Spina Bifida and Hydrocephalus.

Supplementation

Our Health team led on Shine's 'Folic for Life' campaign, which raises awareness of the importance and need for women of child-bearing age to taking folic acid supplements to reduce the chances of a pregnancy being affected by a neural tube defect, and that they need to take folic acid supplements for at least 8 weeks before becoming pregnant, and for the first trimester of pregnancy.

The work in 2024/25 focused on building our presence and engagement for the campaign via social media to spread the word as widely as possible. We were extremely grateful for the support we received from Vitabiotics for this work.

We also met with Public Health Wales for guidance on developing a strategy to engage governments and public health agencies across England, Wales and NI in a sustainable campaign about folic acid supplementation.



Folic for Life
Because you never know

Pregnacare
Vitabiotics

Strategic Goal 6

Changing Experiences of Pregnancies Affected by Neural Tube Defects

59 people we supported with Pregnancy advice

“ Shine was there for support and information whenever my husband and I needed it. You helped us through that time of our lives where we felt very lost and had so many fears...”

Pregnancy pathway

Shine's specialist health team take calls each week from parents to be, who have had a diagnosis of an unborn baby with spina bifida, or from individuals and couples wanting to prepare for a next pregnancy.

The team piloted an internal pregnancy care pathway to introduce a consistent, quality-assured pregnancy advice service. Requests for support are responded to within 24 working hours, and importantly we check

that antenatal services have discussed all the options for the pregnancy, including fetal surgery, with parents-to-be.

Part of our commitment to quality assurance for this service has been to meet with the Fetal Surgery Team commissioners and NHS service providers to share parents-to be/parents experiences and feedback of NHS prenatal services and the process for referrals to fetal surgery following diagnosis.



Training and development for professionals

Statistically, few health professionals will come across either spina bifida or hydrocephalus in their career. However, when they do, it is vital that they are aware of the conditions, possible prognosis and outcomes. This includes pre-natal diagnosis.

Shine has continued to promote our free CPD-accredited online antenatal training to healthcare professionals, to develop this awareness, and have provided training directly to nursing and midwifery undergraduates in several universities.

Anencephaly support

Anencephaly is a neural tube defect. It is not particularly well-known, and unlike spina bifida, it is always fatal.

Research suggests that circa 400 pregnancies¹ are affected by anencephaly each year.

Shine has been supporting a growing number of parents, who have lost a baby to anencephaly, for several years. Some losses date back decades, yet the memories and heartache remain with people forever.

In 2024/25, we welcomed 50 new members to our closed anencephaly support group, bringing the membership of bereaved parents and some grandparents of the group to 898.

It is important that we can offer support and information for anyone who needs us. As well as our existing online, closed anencephaly support group, we have opened up the opportunity for those in our anencephaly support group to engage with Shine, in different ways, if they so choose.

1. EUROCAT (2020): 5 per 10,000 = 1 in 2000 affected pregnancies [England & Wales]; ONS: 817,515 conceptions England & Wales in 2020

Strategic Goal 7

A major step forward in the past 12 months has been the increasing involvement and support we have had from, and have provided to, health, social care, education and many other professionals.

Closer working and partnerships aid Shine in quality-assuring the work we do, and the information we provide. It also helps us to reach wider audiences, to raise vital awareness and educate others about the conditions and the impact on people's lives.

Working with Professionals

Support from professionals	Supporting professionals
Shine • Launched our Health Advisory Panel, a team of experts who advise Shine's Health team. • review and validate our information and resources. • Began working in collaboration with four local authorities to develop a CPD-accredited course for social workers. • Presented at major professional conferences in the UK and Europe.	Shine • Provided our free professional membership to 1,590 individuals from across Health, Care, Education and other professions. • Gave our professional members access to 5 CPD-accredited specialist courses • Offered research support through study participant and PPI recruitment, letters of support • Shared research findings via our research blog throughout the year.

Society for Research into Hydrocephalus and Spina Bifida (SRHSB) – an overwhelming success for Shine Health!

Welcoming eminent clinicians and scientists from across the world, the Society for Research into Hydrocephalus and Spina Bifida highlights the latest 'knowledge, understanding and research into prevention, treatment and management of hydrocephalus and spina bifida'.

In September 2024, Shine supported the society to deliver its international conference in Manchester.

Shine's Health team had the opportunity to present on a few of the innovative projects they are leading on (ageing with spina bifida; spinal stimulation; continence management; collaborating with professionals) which culminated in the team being collectively awarded the President's Talk Prize for "outstanding talks capturing



the scope of Shine's activities".

This was such an honour for Shine, and well-deserved recognition of the incredible work the team are doing, led by Gill Yaz, Shine's Head of Health.

“ SRHSB is where I've met the most important people in my professional life, had my questions answered with patience and generosity, had my enthusiasm fired, and had more support than I could have ever wished. In turn, I've used this knowledge to inform members, parents, politicians, school staff, colleagues and other professionals, hopefully to make life with spina bifida or hydrocephalus a tiny bit easier. Gill Yaz, Shine's Head of Health

Being granted the opportunity to speak about our work to the Society was, as I said, the highlight of my career. For my team to be awarded the President's Prize was an honour I'm still trying to process. I'm immensely proud of my team, and Shine's wider community, and to have our work acknowledged this way is very, very special. But the partnerships and friendships forged at SRHSB have made it happen, and I'm truly grateful.

Thank you so much."

Shine also had the honour of launching the very first Dr Richard Morgan Prize, set up in memory of the late Dr Richard Morgan, who devoted much of his life to changing lives for people

living spina bifida and hydrocephalus through his holistic approach to better health management.

Hydrocephalus

Often referred to as a hidden disability, most people (professionals; the workplace/employers; the general public) are not familiar with the condition, nor its effects.

A key task for Shine over the past 12 months has been to gain even more insight into the experiences of our members of all ages, living with hydrocephalus, and to use these insights to educate and engage professionals to better understand what they can do to meet the needs, and wants, of those they come into contact with.



Research

Shine has continued to be actively involved in a breadth of research, being undertaken nationally and internationally, which will further improve the lives and experiences of individuals with spina bifida and hydrocephalus, NPH and associated issues.



Here's what we're currently involved in...

Spinal stimulation

ICP changes in eye veins

Global Fortification

Quality of Life Assessment Tool

Improvements in antenatal services

Health inequalities in children with spina bifida

Robotic mammography research

Fetoscopic vs Open Fetal Surgery

Ageing with spina bifida

Cognitive effects of hydrocephalus

Antenatal counselling

Investigating early signs of NPH at memory clinics

Folate Controversy: exploring public understanding of scientific information

Cognitive decline patterns in people with spina bifida

Quality of life for those living with NPH

Pressure Sore Prevention

Campaigns

Once again, Shine joined forces with other national charities and networks to add our members' voices to issues that matter to them most.

These included:

- Promoting the importance of access to NHS screening programmes, and breaking down the barriers that limit access
- Calling for improved continence services
- Promoting the rights of people living with disabilities, and those who support them, through the Disabled Children's Partnership and the Care and Support Alliance
- Challenging welfare reforms through the Disability Benefits Consortium
- Collecting shared experiences and lobbying through the Wales Neurological Alliance and Neurological Alliance England

International work - "Saving Lives! Improving Futures"

As well participation in conferences and webinars, Shine has continued its direct work with the Festus Fajemilo Foundation (FFF) in Nigeria.

Activity included a visit to Nigeria in July 2024, to provide specialist training to Nigerian nurses to teach clean intermittent catheterisation, bowel washouts and good hygiene for improved continence care and management across the country. Even though the service is often delivered with the most basic equipment, it is making a dramatic difference.

Here's how:

- 266 babies, children, young people and adults in Nigeria have been supported by the programme
- 89 nurses have been trained in continence care and management, learning the theory but also developing the practical skills
- 9 hospitals are running regular continence clinics
- FFF runs a regular clinic in Lagos, Nigeria's biggest city.
- An outreach programme to bridge the gap between the families, communities and hospitals is now in place.

We also secured a grant to fund successful shunt, and other surgery, for Nigerian children and young people.

We are extremely proud of our partnership with FFF, and we hope to continue long into the future. There is still much more to do in a country with over 234 million people!

Shine continued its membership of the International Federation for Spina Bifida and Hydrocephalus. Our CEO had the opportunity to participate in member events and online webinars, promoting the importance of folic acid, and sharing lessons learnt from the successful campaign for fortification across the UK.



Global Health
Partnerships
FORMERLY THET



INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

What's next?

Shine must continually evolve to meet the changing needs and expectations of its members and stakeholders.

As societal issues, economic conditions, and technological advancements shift, Shine needs to continually adapt our strategies, services, and communication methods to remain relevant and effective. This evolution ensures that Shine can provide the most impactful support to our growing number of members, whether through updated programmes, enhanced resources, or innovative solutions. By staying attuned to the latest trends and feedback from our community, we can foster stronger relationships, increase engagement, and build trust, which are crucial for long-term success and sustainability.

Financial stability is also critical. Diversifying funding sources, optimising operational efficiencies, and leveraging new fundraising techniques are essential to maintaining and growing financial health. As traditional funding streams fluctuate, Shine has started to explore alternative avenues such as digital campaigns, corporate partnerships, and other opportunities. Evolving and growing our income strategies will allow us to secure the necessary funds to expand our reach, innovate our services, and make a greater impact on our community.

Making an IMPACT!

In the coming 12 months, we will continue to deliver our existing core services mentioned in this report.

We will also ramp up our campaigning and influencing to improve the shape of services for people living with spina bifida, hydrocephalus and associated conditions to improve access and support to enable our members to get the right services at the right time.

living with spina bifida, hydrocephalus or associated conditions from across the LGBTQ+ community and minority groups.

Enhancing our offer to members

- Continue to meet growing demand for Shine's services
- Consolidate and tailor services for different ages and conditions across our membership.
- Undertake more research and gain greater insights
- Develop and implement a hydrocephalus-specific strategy
- Increase reach and engagement from individuals



- On-going campaigning on welfare reform and emerging issues

- Open more volunteering opportunities with the launch of a new volunteering strategy

Improving our specialist information and resources

- Launch our new book: 'Understanding Spina Bifida in Adulthood'
- Publish a 'Young Person's Guide' and regular news updates covering all aspects of living with spina bifida/hydrocephalus



- Review and update Shine's website for greater accessibility for all to our expert information
- Digitalise new member packs
- Increase the range of resources available through a variety of mediums
- Introduce an independently assessed quality mark for Shine's health information
- Publish information and advice on emerging issues which may affect our members

Campaigning

- Lobby public health agencies to promote the importance of folic acid supplementation
- Respond to the Government's green paper on welfare reforms
- Contribute to national campaigns to improve services and pathways for people living with hydrocephalus

Working with professionals, representative bodies and statutory services

- Increase Shine presence within NHS services across England and Wales.
- Collaborate with clinics to develop and implement pathways for transition from child to adult services.
- Call for nationally commissioned services and/or improved access to existing services for adults with spina bifida and/or hydrocephalus.

- Launch our new professional engagement strategy
- Grow our professional membership and tailor information, research and resources to specific areas of work
- Work to improve patient access and support to pre-and post-natal surgery services.
- Monitor the implementation of mandatory fortification.
- Raise awareness of the symptoms and routes to diagnosis for normal pressure hydrocephalus.

Research and development

- In addition to continuing to engage with the on-going research projects, we plan to gather data and gain greater insights into
- Shine members' experiences of living with hydrocephalus.
- The impact of welfare reform on people living with disabilities
- Promoting greater awareness of the UK consensus guidelines for the delivery of unexpected news in obstetric ultrasound



International work

- Working with SBH Scotland and SBH Ireland to strengthen opportunities for joint working
- Continuing partnership and links with international organisations
- Develop a framework for other international organisations to use on learning from the continence care programme in Nigeria
- Contribute to international conferences
- Have member representation on the International Federation's Ageing with Spina Bifida adult group.

Thank you

Thank you to everyone who has supported Shine financially again this year. Everyone has a particular reason for choosing to support Shine.

Mr Brian Marsh OBE, Chairman of the Marsh Charitable Trust tells us why the Trust continues to support Shine ...



“ We are pleased to be able to support Shine once again, in a grant-making relationship which has spanned almost 40 years. At the MCT, we value long-term relationships with organisations we support through our grants programme, and we are pleased to be able to support the important work of Shine in this way. We recognise the important support that Shine provide to those who seek their support, and we are pleased to contribute towards the continuation of their work.”



As always, we are extremely grateful to the thousands of individuals, companies, trusts and foundations and others who contribute vital funding which allows us to deliver the breadth of work we do.

Put simply, Shine could not do everything we do without this amazing support from so many!

The list is far too numerous to mention everyone, but we have highlighted just a few...

Corporates and Groups

Integra Neurosciences – Codman

Bullen Healthcare

Davies and Partners

Enable Law

British Homing World

Show of the Year

Vitabiotics Ltd

The Anderson Foundation

Queen's University Belfast

Individuals

Simon Cresswell
(Also Apex Foundation)

Katie and Sarah Philipson
and Terry Donnelly

Adam Smith

Alex Leo

Andy Williams

Bev Geary

Patrick Stokes

Phil Thompson

Ryan Kelly

Tom Stevenson

Joe and Tara Smith

Lucy Burgess

Ryan Donnelly

Stan Brown

The Milton Family

Louise, Georgia and Thea Evans
and Jack Kendall

Jon Clark

Steve Joynes

James Cadle

Gemma and Michael Milner

Heather Hughes

Mark Timms

Thomas McKeown

Daniel Townsend

Rhys Williams

Kerrie Moulton and Adam Williams

Olivia Newton and Lewis Soames

Nathan Adcock

Val Conway

Melissa Young

David Trippett





Trusts and Foundations

Addenbrooke's Charitable Trust

Apax Foundation

Doris Field Charitable Trust

G J W Turner Trust

Hadrian Trust

Homelands Charitable Trust

Marsh Charitable Trust

Medicash Foundation

Michael Cornish Charitable Trust

Oakdale Trust

PF Charitable Trust

Sir Donald and Lady
Edna Wilson Charitable Trust

Sir James Knott Trust

The Basil Brown Charitable Trust

The Belstead Ganzoni Charitable
Settlement

The Chandris Foundation

The Chapple Trust

The Davis-Rubens Charitable Trust

The Douglas Compton James
Charitable Trust

The Enkalon Foundation

The Eric Stanton
(Northampton) Trust

The Eveson Trust

The Fowler, Smith and Jones Trust

The Frazer Trust

The Gale Family Charity Trust

The Garfield Weston Foundation

The Geoffrey Watling Charity

The Gerald Palmer Eling Trust

The Gowling WLG (UK)
Charitable Trust

The Henry Smith Charity

The J Reginald Corah
Foundation Fund

The Jones 1986 Charitable Trust

The Joseph and Annie Cattle Trust

The Karen June Thornton
Charitable Trust

The Lawson Trust

The National Lottery Community
Fund for England

The National Lottery Community

Fund for Northern Ireland

The National Lottery Community
Fund for Wales

The Noble Charitable Trust

The Norman Family Charitable Trust

The Olive and Jesse Palmer Fund

The Paul Bassham Charitable Trust

The Peter Sowerby Foundation

The Pierrepont Trust

The Privy Purse charitable Trust

The Rest-Harrow Trust

The Roger and Douglas Turner
Charitable Trust

The Shanly Foundation

The Simon Gibson Charitable Trust

The Sir James Roll Charitable Trust

The Theodore Maxxy
Charitable Trust

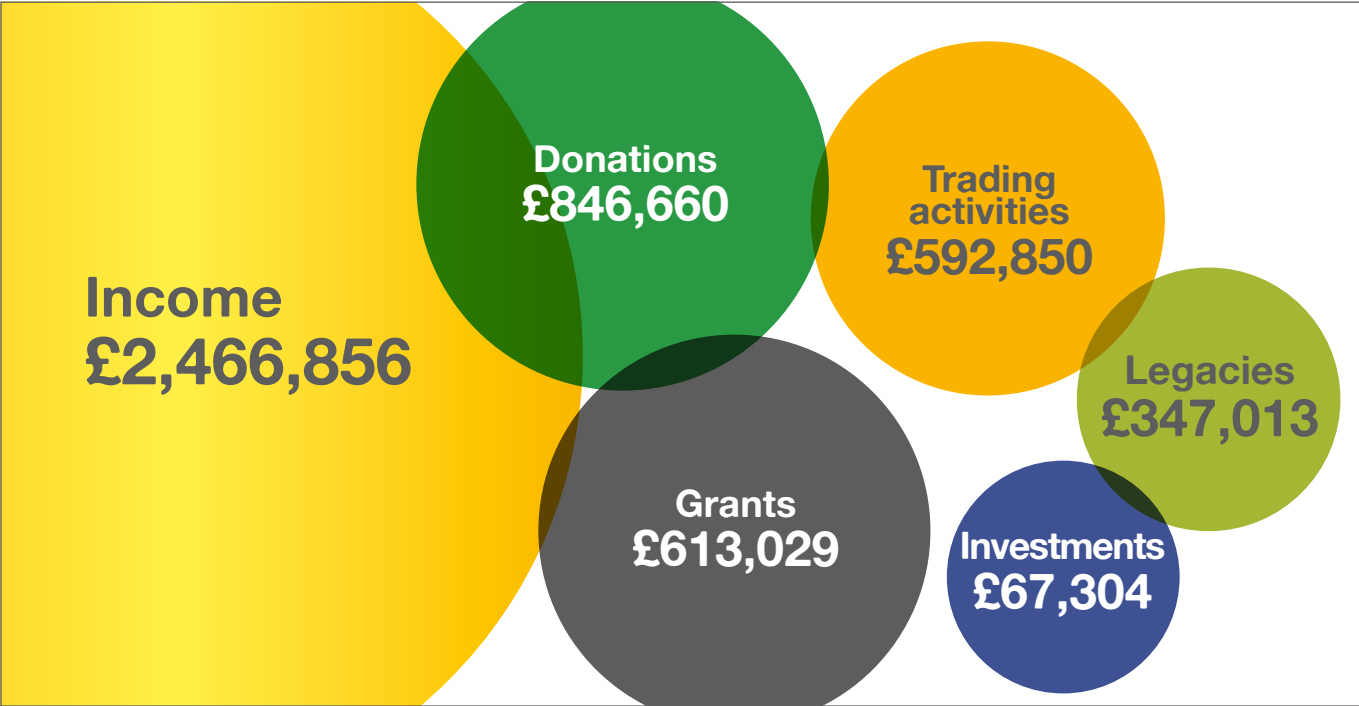
The Valentine Charitable Trust

Wynn Foundation Limited

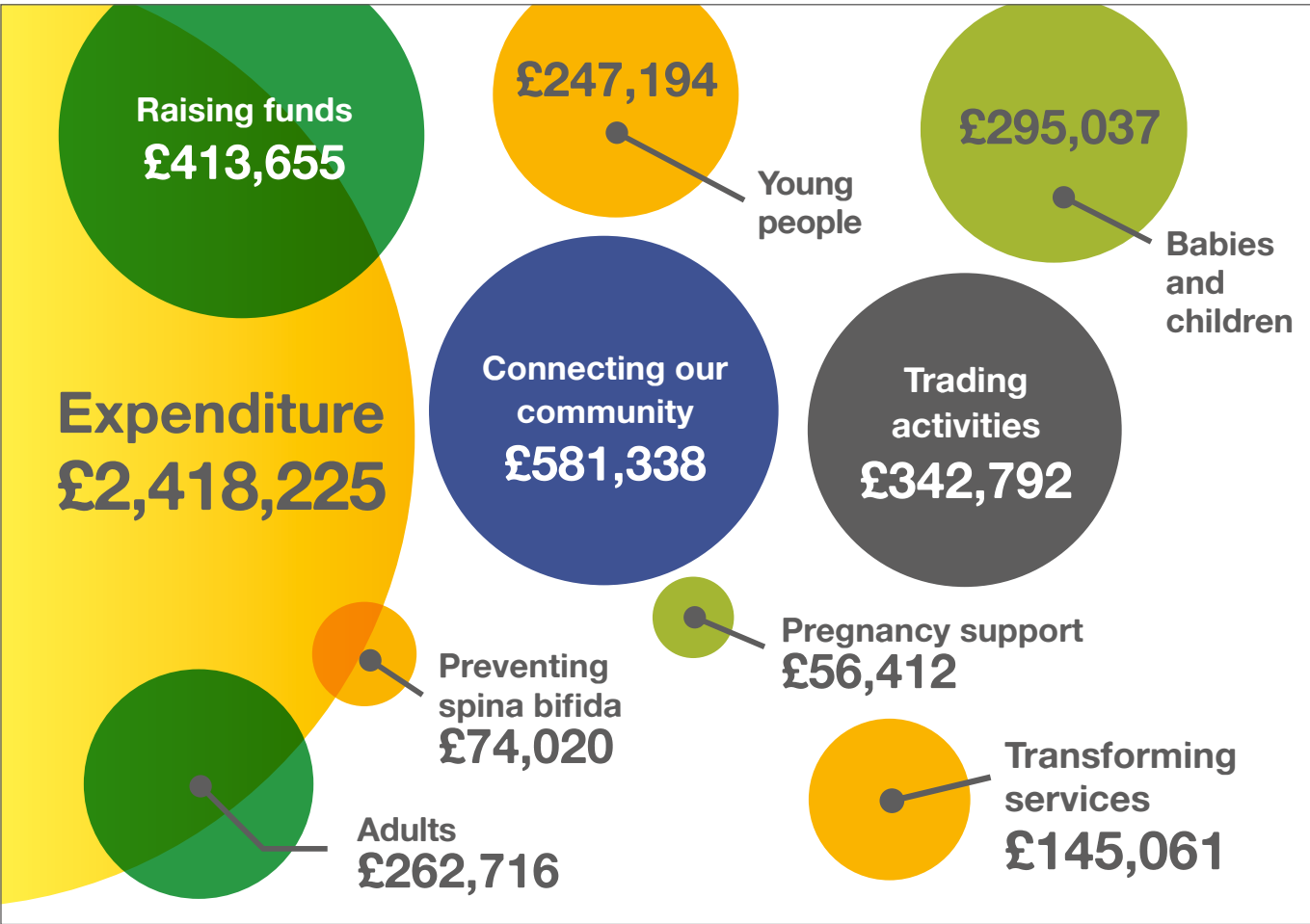
Yorkshire Building Society
Charitable Foundation

Income and expenditure 2024/25

Total Income



Total Expenditure





Financial Review

The table below provides a six-year financial summary, showing that we continue to deliver a robust financial position, as we seek to ensure long-term sustainability.

£000's	2024/25	2023/24	2022/23	2021/22	2020/21	2019/20
Income	£2,467	£2,155	£2,347	£1,894	£2,343	£2,192
Net movement in funds	£10	-£65	£338	£171	£506	£113

Trustees approved the 2024/25 budget with a deficit of £180,766 intending to use reserves generated from the sale of 42 Park Road to invest in new services for our members.

Shine reports an actual surplus of £9,645 (2023/24 £65,252 deficit), which consists of a £59,509 unrestricted deficit, a £64,406 designated surplus, and a £4,748 restricted surplus.

Total income for 2024/25 was £2,466,856 (2023/24 £2,155,115). This is a 14% increase year on year, although the charity did receive one off donations of £159,522 from two local groups (Teeside ASBAH and Shine Surrey) which closed down. Therefore, excluding these closing funds income nonetheless increased by 7% with growth in legacies, grants and investment income being partially offset by a decrease in individual donations and trading activities. The largest element of our trading activity continues to be our virtual balloon races and although this income stream faces several challenges and continues to

decline, nonetheless during the year 4,397 business supporters bought a balloon, many entering multiple races.

Public donations from individuals (excluding legacies), corporates and community groups (excluding the two local groups) recorded an 8% decrease year on year and we believe the cost-of-living challenges faced by many individuals is a factor, nonetheless annual income remained higher than the 4 years before COVID19.

The National Lottery community fund and other charitable trusts continue to fund an important part of Shine's work and income from charitable trusts and foundations recorded the highest annual income in the last ten years.

Legacies continue to be a major source of funding and were the highest value since 2020/21. We are incredibly grateful that people continue to remember us in their wills.

As mentioned two local groups decided to close in 2024, with balances of funds being transferred to Shine, upon which trustees have created designated funds to support members in Surrey and the North East, these funds are reported in note 21 and in relation to the North East a new support and development worker based in Northumberland has been appointed.

After many years of trading, our charity shop in Gorseinon closed its doors at Christmas. Trading conditions on the high street had worsened since the COVID pandemic and despite valiant efforts by the shop manager and volunteers we had been unable to maintain a financially viable shop, with some regret trustees agreed a managed closure, returning the property to the landlord.

Trustees remain confident that Shine has a broad income base and provides sufficient staff resources to deliver sustainable income levels.

Expenditure

Total expenditure in the year was £2,418,225 (2023/24 £2,274,459). Of this, expenditure on charitable activities increased by £118,297 (7.7%) to £1,661,788, representing 68.7% of total expenditure (67.9% in 2023/24). This reflects a conscious decision to invest in services with two new service staff positions created in the year. Expenditure on raising funds increased by a more modest amount of £25,469 to £756,447.

A reduced level of staff turnover was experienced, with 9 leavers in the year (12 in 2023/24). Recruitment efforts have however been successful and staffing levels in Shine's services increased during the year with 34 full-time equivalent posts compared to 31 in 2023/24.

Shine is confident it remains an attractive organisation to work for and has active recruitment plans which aim to maintain service staffing levels in 2025/26.

Under the accounting standard SORP (Statement of Recommended Practice) 2015, the full defined benefit pension deficit must be declared on the balance sheet. There was a 2024/25 actuarial loss of £38,477 (2023/24 gain of £1,382) and reflects the outcome of the 2023 triannual review. A payment plan to eliminate

this deficit remains in place, and the charity remains confident that it will meet the required pension contributions from its projected income without impacting its planned level of charitable activity. Further pension details are shown in note 19 of the accounts.

Financial Reserves Policy

Reserves are maintained at a level that enables the charity to manage financial risk and sustain services. Trustees have set a minimum free reserve to be held for the following purposes:

- Statutory obligations.
- Provide a 4-month commitment to our vulnerable members to wind up the affairs of the charity in an orderly fashion, in the advent that the trustees cease to be confident in Shine's ability to continue.
- Offset the risks of an unexpected shortfall in income and an adverse movement in the defined benefit pension scheme liability.
- A working capital facility.

The level of reserves required to meet these requirements is calculated to be £895,000.

The free reserves position is reported to trustees as part of the monthly management accounts and quarterly forecasting. To set our free reserves target, trustees have sought to balance the needs of Shine's members against financial risks. COVID19, the war in Ukraine and conflict in Gaza has demonstrated that our world is less certain than previously thought and our reserves target reflects this need for caution.

At the year-end Shine held free reserves of £1,108,978, being general unrestricted funds excluding designated funds. This represents 6.2 months of committed expenditure cover, which is above the reserves target and has been boosted by the one-off sum realised from the sale of 42 Park Road in April 2022.

To bring our reserves in line with our target the charity continues to utilise its reserves in a managed fashion investing in members' futures and in addition to the new posts created in 2022 and 2023, the charity has

appointed a Normal Pressure Hydrocephalus (NPH) & Dementia Coordinator, this is in response to an increase in members presenting this condition. Taken together, these changes have raised the service staff establishment to 34 FTE and compares to a pre COVID position of 27 FTE.

Restricted reserves must be applied to the specific purpose(s) intended by the donor so do not form part of the free reserves. Funds totaled £119,700 at the year end and are planned to be expended in 2025/26.

Designated funds have been established by trustees and are excluded from free reserves, these closed at £575,439 and consist of the following:

- Funds for 3 additional Support and Development Workers in the Southwest, East Anglia and the North East – who will enhance the support we can provide to our members in more rural, isolated areas. This first position has been made possible by the generosity of the late Florence Bartle who kindly chose to remember Shine in her will. The last post has been made possible by the transfer of closing funds from Teeside ASBAH.
- A fund to support our work in Gloucestershire – based on a legacy we have received.
- A fund for a Deputy Health Manager.
- A fund for an Education Officer.
- A fund for a Normal Pressure Hydrocephalus & Dementia Coordinator.
- A fund to support our specialist physiotherapy work.
- A fund to support research and development.
- A fund to support our digital development.

Notwithstanding the existence of the above funds, unrestricted funds continue to be used to cover the costs of some new posts; notably the deputy health manager, education officer and the East Anglian support and development worker.

Investment Policy

Under the governing document, the charity can make any investment the trustees see fit. R. C. Brown Investment Management plc are Shine's investment managers with the remit to manage

the investments in line with the policy outlined below.

Investments are held as part of the long-term reserves of Shine. The aim is that they should maintain their value and generate income for Shine.

The portfolio must only be invested in assets with a balanced risk profile. This will include utilisation of pooled funds, which provide diversification of assets, and ensures that the risk of losing a single holding is minimised.

- Investments may be held in a range of asset classes, including equities, corporate bonds, and gilts.
- There will be no direct investment in 'alternative' investments such as hedge funds or derivatives.
- There will be no direct investment in overseas equities. Any such investment must be made through pooled funds managed in the UK.

The trustees have agreed that the funds should be invested in a broad, balanced portfolio. On the advice of our investment managers, Shine works towards ethical investments, yet decisions have to be balanced with the charity's obligations for responsible investment to further our purpose and aims..

During the year R. C. Brown Investment Management plc continued to manage the Shine portfolio, funds performed below their benchmark, recording a 1.71% gain during 2024/25 versus the benchmark gain of 3.66 (ARC steady growth index), with earlier gains being partly offset by losses in the final quarter as markets responded adversely to US trade tariff announcements.

Investments are held to support the reserves policy.

Risk Management and Internal Control

The Board of Trustees is responsible for the identification and management of the major risks facing the charity. A Risk Register is maintained and shared annually with trustees (more frequently if a significant issue arises). Risk management at operational level is managed by the senior leadership team; major risks have been reviewed and systems established to manage these risks.

Therefore, the risk register currently covers five strategic areas.

1. Governance & strategy

2. Income generation

3. Services

4. Finance

5. External influences, including inflation and the war in Ukraine

6. International work

During the year there remains 1 red retained risk, which is members' access to statutory services, and Shine continues to support our members and families with information and guidance on their rights, and

avenues to access the services they need. Shine continues to make structural and strategic changes to the organisation to mitigate these and other risks.

Going Concern and Statement of Public Benefit

Going Concern

This report highlights Shine's financial performance over the last six years, the level of reserves held, and the principal risks and uncertainties faced. The activities of the charity, its objectives, and the policies for managing its capital and financial risk are detailed in the Trustees' Report.

The budget for 2025/26 was prepared by senior leadership and approved by the trustees in March 2025. The expectation is that income levels can be increased as we continue to invest in fundraising resources. Expenditure levels will be allowed to increase in line with the expansion in service provision, therefore a total deficit of £240,123 is budgeted which includes a restricted deficit of £37,354 as funds received in prior periods are expended and a deficit of £202,769 across unrestricted and designated funds.

We can do this because our reserves exceed the minimum level, the budget and its assumptions are reviewed against two key financial measures:

- In-year cash flow
- Free reserve cover

Management accounts are prepared by senior leadership and issued monthly to trustees; the current financial position and financial outlook are

reviewed at quarterly trustee meetings. Given the level of reserves and outlook, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future being at least twelve months from date of approval of these financial statements. Accordingly, they continue to adopt the going concern basis of accounting in preparing financial statements.

Statement of Public Benefit

The trustees confirm that they have complied with the duty in section 17 of the Charities Act 2011 to have regard to the Charity Commission's general guidance on public benefit, 'Charities and Public Benefit'.

Shine's charitable objects are enshrined within its memorandum and articles, and as such trustees ensure that the charity's activities are carried out for public benefit through its strategic goals. This report allows us to show how charitable funds are spent and the impact and benefits this has on the lives of people affected by spina bifida and/or hydrocephalus, and associated conditions.

Reference and Administration Details

Royal Patron **HRH The Duchess of Gloucester GVC**O

Trustees

The trustees of Spina Bifida, Hydrocephalus, Information, Networking, Equality – SHINE are the charity’s trustees under charity law and directors of the charitable company and throughout the report are collectively referred to as the trustees.

The trustees serving during the year were as follows:

Professor Roger Bayston
Michael Brown (Vice Chair)
Jenny Goy (Hon. Treasurer)
Surekha Kukadia
Dr Richard Oakley
Professor John Pickard CBE (appointed 4th December 2024)
Joanne Sedgwick
Joe Waggott
Joanne Williams (Chair)
Roanne Woodward (appointed 4th December 2024)

It is confirmed that none of the serving trustees had any beneficial interest in any contract with Shine in the year.

Senior Leadership Team
Chief Executive Kate Steele
Director of Services Gill Valentine
Director of Finance Stephen Ellen

Principal Professional Advisers

Auditors

Azets Audit Services

Westpoint
Lynchwood
Peterborough
PE2 6FZ

Bankers

The Co-operative Bank Plc

PO Box 250
Skelmersdale
WN8 6WT

Insignis Cash Solutions

St John's Innovation Centre
Cowley Road
Cambridge
CB4 0WS

Solicitors

Greenwoods GRM LLP

Westpoint
Lynchwood
Peterborough
PE2 6FZ

Investment Managers

R.C. Brown Investment Management PLC

1 The Square
Temple Quay
Bristol
BS1 6DG

HR

Vero HR

St James House
Flaxley Road
Kingston Park
Peterborough
PE2 9FT

Administrative Details

The full name of the charity is spina bifida, hydrocephalus, information, networking, equality – SHINE. We are commonly known as SHINE.

The registered charity number is 249338 (England and Wales)

The company registration is 00877990

Registered Office: SHINE, Unit 4, Minerva Business Park, Peterborough, PE2 6FT

Telephone 01733 555988 • Email firstcontact@shinecharity.org.uk • www.shinecharity.org.uk



Our Commitment to Quality Fundraising

Shine is registered with the Fundraising Regulator and proud to commit to the Regulator's Fundraising Promise.

We are committed to maintaining high standards of fundraising in line with the Code of Fundraising Practice:

- We will be clear, honest, and open.
- We will be respectful.
- We will be fair and reasonable.
- We will be accountable and responsible.

Our approach to fundraising consists of:

- marketing appeals to individuals who have already expressed an interest in Shine.
- running charitable events for which participants raise money.
- encouraging people to participate in other events to raise funds on our behalf.
- community fundraising; and
- soliciting donations from corporate partners, charitable trusts, and individual donors.

We also encourage people to remember us in their will with a gift or legacy.

We do not use third-party professional fundraising agencies.

Where people or organisations raise funds in aid of Shine, we request they follow our standards. Shine's fundraising team provides tools and resources to enable supporters to deliver fun, safe, and successful fundraising activities. The trustees are of the view that during the year to 31 March 2025 we have been compliant with these standards.

Unfortunately, despite procedures in place Shine is aware of one instance in the year of the misappropriation of donations totalling £580 at an event hosted by a Shine supporter.

To protect vulnerable people and other members of the public, Shine has a safeguarding policy, and our fundraising commitment is displayed on our website. We are careful to protect the personal data of supporters and give clear options to stop being contacted by us.

As part of our compliance with the code of fundraising practice, we ensure our approach to fundraising is not unreasonably intrusive or persistent and does not aim to solicit donations by pressuring potential supporters.

We take these steps to make sure people have a choice about whether to fundraise for Shine.

Shine and our members are incredibly grateful for the continued dedication and support of our fundraisers. From everyone at Shine, thank you for your ongoing generosity.



Structure, Governance and Management

Structure

Spina bifida, Hydrocephalus, Information, Networking, Equality – SHINE (Shine) is a company limited by guarantee registered in England and Wales (Registration No. 00877990) formed in 1966. Shine is registered as a charity with the Charity Commission for England and Wales (Registration No. 249338).

The charity owns the entire share capital of Shine (Trading) Limited, registered in England and Wales (No. 01031004). The consolidated accounts include Shine (Trading) Limited (see note 9). The principal activity of the company is to raise funds for charity. The board of directors of Shine trading meets separately and consists of the Chief Executive and two trustees. The trustees are not remunerated for this role.

Objects

The charity's objects are specifically restricted to the relief of persons who have spina bifida and/or hydrocephalus or allied or related disorders by providing care, welfare, treatment, education, and integration into society.

Governance

Shine is governed by Articles of Association, which were amended in 2018.

Organisational purpose

Shine has a clear, sustainable corporate strategy for 2022 to 2027 consistent with the charity's purpose and an evaluation and monitoring framework to monitor impact and measure outputs.

Shine consults with a wide range of stakeholder groups to determine the priorities for the charity.

Leadership

The trustee board is responsible for the charity's governance and its subsidiary.

Board Integrity

Appointment of trustees

New Articles of Association were adopted by special resolution in 2018 specifying that anyone willing to act as a trustee, and permitted by law to do so, may be

appointed by the board of trustees.

A trustee must be a natural person aged 16 years or older; the minimum number of trustees is 3, and the maximum is 16. Trustees are appointed for a term of 3 years; trustees are eligible for reappointment up to two subsequent terms (each of 3 years). No trustee can serve for more than 9 consecutive years unless the trustees consider it is in the best interests of the charity that a particular trustee should continue to serve. Professor Roger Bayston and Michael Brown continue to serve as trustees on this basis.

Trustee induction and training

During the recruitment process, the skills and experience are considered with a concerted effort to ensure we are drawing from all sections of society. An initial interview is conducted by members of the senior leadership team. Candidates are then interviewed by a panel drawn from the board of trustees.

This year we have appointed two new trustees, Professor John Pickard who amongst many honors is Emeritus Professor of Neurosurgery (Cambridge University) and brings to the board additional clinical expertise and extensive contacts within the NHS and wider international community; Roanne Woodward who is a young woman born with spina bifida and has first-hand experience of the challenges and triumphs faced by individuals with spina bifida and hydrocephalus.

New trustees undergo an induction; they are fully appraised of the full range of Shine's services, projects and campaigns and provided with relevant background literature. They receive awareness training, if required, on spina bifida and hydrocephalus. Depending on their specific skills and areas of expertise, they will be put in touch with relevant staff.

Trustees are briefed on their legal obligations under charity and company law, the Articles of Association and the Board's decision-making process. They are also informed about Shine's Corporate Plan, key risks, recent financial performance, and prospects for the charity.

Trustees do not receive any remuneration or financial benefit for acting as trustees of Shine; any expenses paid are disclosed in note 11 of the financial statements.

Decision making, risk and control

The Board of Trustees is the governing body with overall

legal responsibility for the charity. The Board sets the strategic direction for Shine. It meets at least four times a year, either in person or virtually.

The minutes of meetings are made available to all trustees on a timely basis. The board regularly reviews operational plans, budgets, performance, and Shine's main risks. The day-to-day management of the charity is delegated to the Chief Executive, who reports to the Board. The Chief Executive is assisted in the day-to-day management by the senior leadership team.

Senior Staff Remuneration Policy

The remuneration of senior staff is set by benchmarking with similar-sized charities, and the market rate required to attract the best people to the job.

Diversity and Inclusion

Shine has a transparent recruitment process, advertising widely and looking at how we can attract a diverse pool of candidates.

Safeguarding

Safeguarding policies and processes were reviewed and updated in 2024/25, and additional policies specifically focusing on online safety were introduced in June 2024 ensuring that we are continually improving our approaches to safeguarding, incorporating all updated legislation, and embracing current best practice to protect the welfare of our members, staff and volunteers.

An annual safeguarding plan is agreed by trustees. The plan is prepared by the Director of Services, who is Designated Safeguarding Lead for the charity, in conjunction with Joanne Williams and Jenny Goy, who are trustee leads for safeguarding.

Safeguarding training is provided for all staff, trustees, and volunteers. Incidents are reported, assessed, and enacted as appropriate with full consideration given to the requirement to report to the Charity Commission.

GDPR

Extensive work was undertaken to ensure Shine's ongoing compliance with the General Data Protection Regulation (GDPR). We have a designated GDPR lead, and the data management action plan is reviewed by trustees annually.

Section 172 Statement

The trustees must act in accordance with a set of general duties. These duties are laid out in s172 of the UK Companies Act 2006 which is summarised as follows: A

Director of a Company must act in the that they consider, in good faith, would be most likely to promote the benefit of its members, and in doing so have regard to:

- The consequences of any decision in the long term. The main purpose of our reserves policy is to ensure long-term financial sustainability.
- The interests of the charity's employees
- The need to foster the charity's business relationship with suppliers, customers, and others
- The impact of the charity's operations on the community and environment
- The desirability of the charity's maintaining a reputation for high standards of business
- The need to act fairly between members of the charity.

The trustees believe they have completed their duties under s172, taking care to balance competing interests for the overall good of the charity.

Related Parties

The charity collaborates with several local associations. These are independent charities for spina bifida and hydrocephalus and collaboration which may cover a range of activities. The charity also works in partnership with many other bodies, voluntary, statutory, and international, in carrying out work to support service users, undertake research and disseminate information.

Volunteers

In 2024/25, Shine had 58 registered volunteers (50 2023/24) to whom we remain eternally grateful and recorded 1,212 volunteered hours being a reduction versus 2023/24 (1,902 hours), reflected the closure of our one charity shop. The volunteering roles included:

- Working in our charity shop (up to December)
- Participating in the health advisory panel
- Giving talks and representing Shine
- Acting as peer support
- Supporting our members to grow in confidence and address the challenges of living with the conditions.
- Advising on the development of resources
- Fulfilling the role of Shine ambassador
- Fundraising
- Supporting our local groups

Statement of trustees' responsibilities

The trustees (who are also directors of Spina bifida, Hydrocephalus, Information, Networking, Equality – SHINE), are responsible for preparing the annual report and the financial statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice. Company law requires the directors to prepare financial statements for each financial year which give a true and fair view of the situation of the charitable group and of the net income or expenditure of the group for the year. In preparing these financial statements the directors are required to:

- select suitable accounting policies and then apply them consistently.
- observe the methods and principles in the Charities SORP
- make judgements and estimates that are reasonable and prudent.
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume

that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and the group and enable them to ensure that the financial statements comply with the Companies Act 2006.

They are also responsible for safeguarding the charity and group's assets and hence for taking reasonable steps to prevent and detect fraud and other irregularities.

Statement as to disclosure of information to auditors

As far as the trustees are aware, there is no relevant audit information of which the group's auditors are unaware. Additionally, the trustees have taken all the necessary steps that they ought to have taken as trustees to make themselves aware of all relevant audit information and to establish that the group's auditors are aware of that information.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website.

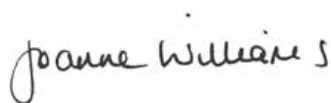
Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Appointment of Auditors

The continued appointment of Azets Audit Services Limited was confirmed by the Board of Trustees on the 3rd December 2024.

This report has been prepared in accordance with the special provisions relating to small companies within Part 15 of the Companies Act 2006.

By order of the Board of Trustees



Joanne Williams

Chair

4th September 2025

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

INDEPENDENT AUDITOR'S REPORT

TO THE MEMBERS OF SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

Opinion

We have audited the financial statements of Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE (the 'charity') and its subsidiary for the year ended 31 March 2025 which comprise the Group Statement of Financial Activities, the Group and Parent Charitable Company Balance Sheets, the Group and Parent Charitable Company Cash Flow Statements and the notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the Group and Parent Charitable Company affairs as at 31 March 2025 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the *Auditor's responsibilities for the audit of the financial statements* section of our report. We are independent of the Group and Parent Charitable Company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. The Trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE MEMBERS OF SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of our audit:

- the information given in the Trustees' report for the financial year for which the financial statements are prepared, which includes the directors' report prepared for the purposes of company law, is consistent with the financial statements; and
- the directors' report included within the Trustees' report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the Group and Parent Charitable Company and its environment obtained in the course of the audit, we have not identified material misstatements in the directors' report included within the Trustees' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the Trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemptions in preparing the Trustees' report and from the requirement to prepare a strategic report.

Responsibilities of Trustees

As explained more fully in the statement of Trustees' responsibilities, the Trustees, who are also the directors of the charity for the purpose of company law, are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the Group and Parent Charitable Company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities is available on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE MEMBERS OF SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

Extent to which the audit was considered capable of detecting irregularities, including fraud

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above and on the Financial Reporting Council's website, to detect material misstatements in respect of irregularities, including fraud.

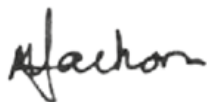
We obtain and update our understanding of the entity, its activities, its control environment, and likely future developments, including in relation to the legal and regulatory framework applicable and how the entity is complying with that framework. Based on this understanding, we identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. This includes consideration of the risk of acts by the entity that were contrary to applicable laws and regulations, including fraud.

In response to the risk of irregularities and non-compliance with laws and regulations, including fraud, we designed procedures which included:

- Enquiry of management and those charged with governance around actual and potential litigation and claims as well as actual, suspected and alleged fraud;
- Reviewing minutes of meetings of those charged with governance;
- Assessing the extent of compliance with the laws and regulations considered to have a direct material effect on the financial statements or the operations of the entity through enquiry and inspection;
- Reviewing financial statement disclosures and testing to supporting documentation to assess compliance with applicable laws and regulations;
- Performing audit work over the risk of management bias and override of controls, including testing of journal entries and other adjustments for appropriateness, evaluating the business rationale of significant transactions outside the normal course of business and reviewing accounting estimates for indicators of potential bias.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.

This report is made solely to the company's members, as a body, in accordance with section 391 of the Companies Act 2014. Our audit work has been undertaken so that we might state to the company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the company and the company's members as a body, for our audit work, for this report, or for the opinions we have formed.



Mr Mark Jackson FCA DChA (Senior Statutory Auditor)
for and on behalf of Azets Audit Services

15/09/2025
.....

Chartered Accountants
Statutory Auditor

Westpoint
Lynch Wood
Peterborough
Cambridgeshire
United Kingdom
PE2 6FZ

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2025

Current financial year

	Notes	Unrestricted funds 2025 £	Designated funds 2025 £	Restricted funds 2025 £	Total 2025 £	Total 2024 £
Income from:						
Donations and legacies	3	1,119,151	159,522	528,029	1,806,702	1,478,934
Other trading activities	4	592,850	-	-	592,850	635,710
Income from investments	5	67,304	-	-	67,304	40,471
Total income		1,779,305	159,522	528,029	2,466,856	2,155,115
Expenditure on:						
Raising funds	6	756,447	-	-	756,447	730,978
Charitable activities	7	1,053,716	31,375	576,687	1,661,778	1,543,481
Total resources expended		1,810,163	31,375	576,687	2,418,225	2,274,459
Net gains/(losses) on investments	12	(509)	-	-	(509)	55,474
Net outgoing resources before transfers		(31,367)	128,147	(48,658)	48,122	(63,870)
Gross transfers between funds		10,335	(63,741)	53,406	-	-
Net (outgoing)/incoming resources		(21,032)	64,406	4,748	48,122	(63,870)
Other recognised gains and losses						
Actuarial loss on defined benefit pension schemes		(38,477)	-	-	(38,477)	(1,382)
Net movement in funds		(59,509)	64,406	4,748	9,645	(65,252)
Fund balances at 1 April 2024		1,168,487	511,033	114,952	1,794,472	1,859,724
Fund balances at 31 March 2025		1,108,978	575,439	119,700	1,804,117	1,794,472

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

STATEMENT OF FINANCIAL ACTIVITIES (CONTINUED) INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2025

Prior financial year

		Unrestricted funds 2024 £	Designated funds 2024 £	Restricted funds 2024 £	Total 2024 £
	Notes				
Income from:					
Donations and legacies	3	1,074,858	-	404,076	1,478,934
Other trading activities	4	635,710	-	-	635,710
Income from investments	5	40,471	-	-	40,471
Total income		1,751,039	-	404,076	2,155,115
Expenditure on:					
Raising funds	6	730,978	-	-	730,978
Charitable activities	7	1,025,342	48,196	469,943	1,543,481
Total resources expended		1,756,320	48,196	469,943	2,274,459
Net gains/(losses) on investments	12	55,474	-	-	55,474
Net outgoing resources before transfers		50,193	(48,196)	(65,867)	(63,870)
Gross transfers between funds		(96,304)	72,500	23,804	-
Net (outgoing)/incoming resources		(46,111)	24,304	(42,063)	(63,870)
Other recognised gains and losses					
Actuarial loss on defined benefit pension schemes		(1,382)	-	-	(1,382)
Net movement in funds		(47,493)	24,304	(42,063)	(65,252)
Fund balances at 1 April 2023		1,215,980	486,729	157,015	1,859,724
Fund balances at 31 March 2024		1,168,487	511,033	114,952	1,794,472

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

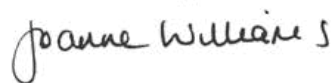
BALANCE SHEETS

AS AT 31 MARCH 2025

	Notes	Group 2025 £	Charity 2025 £	Group 2024 £	Charity 2024 £
Fixed assets					
Investments	15	847,083	847,086	834,112	834,115
Current assets					
Debtors	17	265,165	234,528	252,216	217,594
Cash at bank and in hand		905,322	891,066	885,550	870,690
		1,170,487	1,125,594	1,137,766	1,088,284
Creditors: amounts falling due within one year	18	(188,917)	(167,011)	(177,406)	(150,911)
Net current assets		981,570	958,583	960,360	937,373
Total assets less current liabilities		1,828,653	1,805,669	1,794,472	1,771,488
Net assets excluding pension liability		1,828,653	1,805,669	1,794,472	1,771,488
Defined benefit pension liability	19	(24,536)	(24,536)	-	-
Net assets		1,804,117	1,781,133	1,794,472	1,771,488
Income funds					
Restricted funds	20	119,700	119,700	114,952	114,952
<u>Unrestricted funds - general</u>					
Designated funds	21	575,439	575,439	511,033	511,033
General unrestricted funds		1,108,978	1,085,994	1,168,487	1,145,503
		1,684,417	1,661,433	1,679,520	1,656,536
		1,804,117	1,781,133	1,794,472	1,771,488

As permitted by section 408 of the Companies Act 2006, the charitable company has not presented its own statement of financial activities and related notes. The charitable company's surplus for the year was £9,645 (2024 - deficit for the year of £65,252).

The financial statements were approved by the board of directors and authorised for issue on 04/09/2025 and are signed on its behalf by:



Mrs J Williams

Trustee

Company Registration No. 00877990



Mrs J Goy

Trustee

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 31 MARCH 2025

	Notes	2025 £	£	2024 £	£
Cash flows from operating activities					
Cash absorbed by operations	26		(47,532)		(214,822)
Investing activities					
Interest and income from investments		67,304		40,471	
Net cash generated from investing activities			67,304		40,471
Net cash used in financing activities			-		-
Net increase/(decrease) in cash and cash equivalents			19,772		(174,351)
Cash and cash equivalents at beginning of year			885,550		1,059,901
Cash and cash equivalents at end of year			905,322		885,550

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2025

1 Accounting policies

Company information

Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE is a private company limited by guarantee incorporated in England and Wales. The registered office is Unit 4, The Forum, Minerva Business Park, Peterborough, Cambridgeshire, PE2 6FT, United Kingdom.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's governing document, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2019). The charity is a Public Benefit Entity as defined by FRS 102.

The financial statements have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a true and fair view. This departure has involved following the Statement of Recommended Practice for charities applying FRS 102 rather than the version of the Statement of Recommended Practice which is referred to in the Regulations but which has since been withdrawn.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

The consolidated accounts incorporate the results of the charity and of its wholly owned subsidiary.

1.2 Going concern

At the time of approving the financial statements, the Trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the Trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Designated funds comprise funds which have been set aside at the discretion of the Trustees for specific purposes. The purposes and uses of the designated funds are set out in the notes to the financial statements.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

1 Accounting policies

(Continued)

1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

Gifts donated for resale are included as income when they are sold. No amounts are included in the financial statements for services donated by volunteers.

Grant income is recognised according to the terms of each individual agreement.

All other income is dealt with on an accruals basis.

1.5 Resources expended

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement, and the amount of the obligation can be measured reliably.

Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges are allocated on the portion of the asset's use.

Direct expenditure is analysed and charged to the department incurring the cost. Expenditure is included when incurred, the majority of costs being directly attributable to specific activities. Costs that can not be directly attributable to particular headings, are allocated to activities on a basis consistent with use of the resources. Premises and other overheads have been allocated on a head count basis.

Fundraising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of charitable activities.

Governance costs are those incurred in connection with the governance arrangements of the charity and compliance with constitutional and statutory requirements.

1.6 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits repayable on demand and overdrafts. Deposits are repayable on demand if they are in practice available within 24 hours without a penalty. Liquid resources comprise assets held as a readily disposable store of value.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

1 Accounting policies

(Continued)

1.7 Financial instruments

Financial instruments are recognised when the charity becomes party to the contractual provisions of the instrument.

Financial assets are offset, with the net amounts presented in the accounts when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

1.8 Provisions

Provisions are recognised when the charity has a legal or constructive present obligation as a result of a past event, it is probable that the charity will be required to settle that obligation and a reliable estimate can be made of the amount of the obligation.

The amount recognised as a provision is the best estimate of the consideration required to settle the present obligation at the reporting end date, taking into account the risks and uncertainties surrounding the obligation. Where the effect of the time value of money is material, the amount expected to be required to settle the obligation is recognised at present value. When a provision is measured at present value, the unwinding of the discount is recognised as a finance cost in net income/(expenditure) in the period in which it arises.

1.9 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the company is demonstrably committed to terminate the employment of an employee.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

1 Accounting policies

(Continued)

1.10 Retirement benefits

For employees choosing to participate, the charity operates a defined contribution pension scheme providing benefits additional to those from the State. The assets are held in a separately administered scheme. The pensions cost charge represents contributions payable by the company to the pension scheme in respect of the year.

Previously, the charity were part of a separately administered defined benefit scheme and is still required to make contributions to fund a deficit in the scheme.

The cost of providing benefits under defined benefit plans is determined separately for each plan using the projected unit credit method, and is based on actuarial advice.

The net interest element is determined by multiplying the net defined benefit liability by the discount rate, taking into account any changes in the net defined benefit liability during the period as a result of contribution and benefit payments. The net interest is recognised in income/(expenditure) for the year.

Remeasurement changes comprise actuarial gains and losses, the effect of the asset ceiling and the return on the net defined benefit liability excluding amounts included in net interest. These are recognised immediately in other recognised gains and losses in the period in which they occur and are not reclassified to income/(expenditure) in subsequent periods.

The net defined benefit pension asset or liability in the balance sheet comprises the total for each plan of the present value of the defined benefit obligation (using a discount rate based on high quality corporate bonds), less the fair value of plan assets out of which the obligations are to be settled directly. Fair value is based on market price information, and in the case of quoted securities is the published bid price. The value of a net pension benefit asset is limited to the amount that may be recovered either through reduced contributions or agreed refunds from the scheme.

1.11 Leases

Rentals payable under operating leases, including any lease incentives received, are charged as an expense on a straight line basis over the term of the relevant lease.

2 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

3 Donations and legacies

	Unrestricted funds 2025 £	Designated funds 2025 £	Restricted funds 2025 £	Total 2025 £	Total 2024 £
Donations and gifts	687,138	159,522	-	846,660	713,637
Legacies receivable	347,013	-	-	347,013	276,221
Grants receivable	85,000	-	528,029	613,029	489,076
	<u>1,119,151</u>	<u>159,522</u>	<u>528,029</u>	<u>1,806,702</u>	<u>1,478,934</u>
For the year ended 31 March 2024	<u>1,074,858</u>	<u>-</u>	<u>404,076</u>		<u>1,478,934</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

3 Donations and legacies

(Continued)

	Unrestricted funds 2025 £	Designated funds 2025 £	Restricted funds 2025 £	Total 2025 £	Total 2024 £
Donations and gifts					
Individuals	391,884	-	-	391,884	425,059
Trusts	174,140	-	-	174,140	164,609
Corporate donors	83,457	-	-	83,457	85,928
Local associations	-	159,522	-	159,522	3,089
Health Trusts	37,657	-	-	37,657	34,952
	<u>687,138</u>	<u>159,522</u>	<u>-</u>	<u>846,660</u>	<u>713,637</u>
Grants receivable for core activities					
National Lottery Community fund					
Northern Ireland Shining Opportunities	-	-	99,974	99,974	97,696
National Lottery Community fund					
Cymru People & Places	-	-	112,520	112,520	57,867
Early Intervention (Community lottery & others)	-	-	185,927	185,927	172,174
Tropical Health and Education Trust	-	-	27,736	27,736	39,329
The Henry Smith Charity	60,000	-	-	60,000	60,000
Garfield Weston Foundation	25,000	-	-	25,000	25,000
Margaret Giffen Charitable Trust	-	-	-	-	5,000
BBC Children in Need	-	-	15,000	15,000	-
Peter Harrison Foundation	-	-	21,000	21,000	-
The Eveson Trust	-	-	12,500	12,500	-
Other	-	-	53,372	53,372	32,010
	<u>85,000</u>	<u>-</u>	<u>528,029</u>	<u>613,029</u>	<u>489,076</u>

4 Other trading activities

	2025 £	2024 £
Income of trading subsidiary	579,800	608,455
Donations sold through shops	12,413	25,913
Publications and attendance fees	637	1,342
	<u>592,850</u>	<u>635,710</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) *FOR THE YEAR ENDED 31 MARCH 2025*

5 Income from investments

	2025 £	2024 £
Income from listed investments	23,339	22,279
Interest receivable	43,965	18,192
	<u>67,304</u>	<u>40,471</u>

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2025

	2025	2024
	£	£
<u>Fundraising and publicity</u>		
Direct staff costs	273,817	263,697
Other fundraising direct costs	62,195	51,466
Support costs (see note 8)	77,643	80,677
Fundraising and publicity	413,655	395,840

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SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

7 Charitable activities	Enabling babies and children to achieve their potential		Empowering young people		Adults of all ages to have choices and opportunities		A connected community		Preventing Spina Bifida		Changing experiences of pregnancies		Transforming attitudes		Total 2025		Total 2024	
	£	£	£	£	£	£	£	£	£	£	£	£	£	£	£	£	£	£
Direct staff costs	227,354	190,486	202,447	447,976	57,040	43,471	111,783	1,280,557	1,173,433									
Other direct costs	32,365	27,117	28,820	63,772	8,120	6,188	15,913	182,295	165,212									
	259,719	217,603	231,267	511,748	65,160	49,659	127,696	1,462,852	1,338,645									
Share of support costs (see note 8)	30,182	25,288	26,876	59,471	7,572	5,771	14,840	170,000	173,041									
Share of governance costs (see note 8)	5,136	4,303	4,573	10,119	1,288	982	2,525	28,926	31,795									
	295,037	247,194	262,716	581,338	74,020	56,412	145,061	1,661,778	1,543,481									
Analysis by fund																		
Unrestricted funds - general															1,053,716	1,025,342		
Unrestricted funds - designated															31,375	48,196		
Restricted funds															576,687	469,943		
															1,661,778	1,543,481		

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

8 Support and governance costs

	Fundraising and publicity £	Trading costs £	Charitable activities £	2025 £	2024 £
Support costs					
Staff costs	18,480	23,689	40,527	82,696	70,581
IT costs	15,808	9,281	57,400	82,489	63,996
Premises costs	39,657	14,196	31,372	85,225	85,618
Other support costs	17,936	36,878	40,701	95,515	123,143
	<u>91,881</u>	<u>84,044</u>	<u>170,000</u>	<u>345,925</u>	<u>343,338</u>
Governance costs				2025 £	2024 £
Staff costs				12,971	12,571
Audit fees				15,214	9,624
Other governance costs				741	9,600
				<u>28,926</u>	<u>31,795</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

9 Commercial operations in trading subsidiary

The charity has one wholly owned trading subsidiary undertaking, Shine (Trading) Limited which sells balloons for virtual balloon races. The company gift aids virtually all its taxable profits to Shine. A summary of its trading results is shown below. Audited accounts have been filed with the Registrar of Companies.

Shine (Trading) Ltd Profit & Loss Account	2025 £	2024 £
Turnover	579,800	608,455
Cost of sales	(193,867)	(192,036)
Gross profit	385,933	416,419
Administration expenses	(65,286)	(60,677)
Operating profit	320,647	355,742
Amount payable by gift aid to Shine	(320,647)	(355,742)
Profit on ordinary activities	-	-
Shine (Trading) Ltd Balance Sheet	2025 £	2024 £
Current assets	130,896	164,816
Current liabilities	(107,909)	(141,829)
Net current assets	22,987	22,987
Total net assets	22,987	22,987
Aggregate share capital and reserves	22,987	22,987

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

10 Employees

Number of employees

The average monthly number of full time equivalent employees during the year was:

	2025 Number	2024 Number
Services	34	31
Fundraising and publicity	8	8
Shops	1	1
Administration	3	3
Shine (Trading) Limited	6	5
	<u>52</u>	<u>48</u>

Employment costs

	2025 £	2024 £
Wages and salaries	1,643,674	1,545,971
Redundancy costs	18,877	1,000
Social security costs	150,508	141,548
Other pension costs	55,339	51,324
Other staff related benefits	5,140	4,283
	<u>1,873,538</u>	<u>1,744,126</u>

The number of employees whose annual remuneration was £60,000 or more were:

	2025 Number	2024 Number
£80,001 - £90,000	1	1
£60,001 - £70,000	1	1

Pension contributions for higher paid employees were £12,475 (2024 - £10,465).

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

11 Trustees

None of the Trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

In respect of attending meetings of committees, travel expenses amounting to £741 (2024 - £1,401) have been reimbursed to 5 (2024 - 4) members of the Board of Trustees.

At the year end, £nil (2024 - £nil) of the above expenses are unpaid and included as a creditor.

The accounts include a charge of £2,413 (2024 - £3,312) to provide the Trustees with indemnity insurance.

12 Net gains/(losses) on investments

	Total 2025 £	Total 2024 £
Revaluation of investments	(14,986)	54,956
Gain/(loss) on sale of investments	14,477	518
	<u>(509)</u>	<u>55,474</u>

13 Taxation

Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE is a registered charity. It only applies its funds in accordance with its charitable objectives, and is not trading with a view to making distributable profits, therefore corporation tax is not chargeable.

The trading subsidiary has gifted its profits to Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE under Gift Aid therefore no corporation tax is payable

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

14 Tangible fixed assets

	Equipment £	Software and website £	Total £
Group Cost			
At 1 April 2024	11,830	25,757	37,587
At 31 March 2025	11,830	25,757	37,587
Depreciation and impairment			
At 1 April 2024	11,830	31,031	37,587
At 31 March 2025	11,830	31,031	37,587
	Equipment £	Software and website £	Total £
Charity Cost			
At 1 April 2024	9,191	18,728	27,919
At 31 March 2025	9,191	18,728	27,919
Depreciation and impairment			
At 1 April 2024	9,191	18,728	27,919
At 31 March 2025	9,191	18,728	27,919
Carrying amount			
At 31 March 2025	-	-	-
At 31 March 2024	-	-	-

The charity owns a freehold interest in some land that is leased to another charity at a peppercorn rent and used in furtherance of the charitable objects. The lease ends in 2084 and no value is included in the accounts for the property.

15 Fixed asset investments

	Group 2025 £	Charity 2025 £	Group 2024 £	Charity 2024 £
Investments in subsidiaries	-	3	-	3
Listed investments	847,083	847,083	834,112	834,112
	847,083	847,086	834,112	834,115

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

15 Fixed asset investments

(Continued)

Movements in fixed asset investments

Group and Charity

Cost or valuation

	2025 £	2024 £
At 31 March 2024	815,987	733,130
Additions within portfolio	84,344	160,726
Disposals within portfolio	(63,496)	(148,394)
Valuation changes	(11,906)	70,525
	824,929	815,987
Cash held for investment	22,154	18,125
At 31 March 2025	847,083	834,112

16 Financial instruments

	Group 2025 £	Charity 2025 £	Group 2024 £	Charity 2024 £
Carrying amount of financial assets				
Trade debtors	120,631	8,786	156,621	10,890
Accrued income	39,299	39,299	58,234	58,234
Amounts due from subsidiary undertakings	-	86,003	-	115,334
Bank and cash	905,322	891,066	885,550	870,690
Measured at cost	1,065,252	1,025,154	1,100,405	1,055,148
Fixed asset investments	847,083	847,086	834,112	834,115
Measured at market value	847,083	847,086	834,112	834,115
Carrying amount of financial liabilities				
Trade creditors	25,268	25,039	9,299	9,142
Accruals and deferred income	87,127	79,194	83,383	76,797
Other creditors	31,091	29,849	32,710	31,662
Other taxation and social security	45,431	32,929	52,014	33,310
Measured at cost	188,917	167,011	177,406	150,911

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

17 Debtors

	Group 2025 £	Charity 2025 £	Group 2024 £	Charity 2024 £
Amounts falling due within one year:				
Trade debtors	120,631	8,786	156,621	10,890
Amounts due from subsidiary undertakings	-	86,003	-	115,334
Prepayments and accrued income	144,534	139,739	95,595	91,370
	<u>265,165</u>	<u>234,528</u>	<u>252,216</u>	<u>217,594</u>

The net amount owed by the subsidiary includes amounts owing for gift aid receivable and payment for services provided.

18 Creditors: amounts falling due within one year

	Group 2025 £	Charity 2025 £	Group 2024 £	Charity 2024 £
Other taxation and social security	45,431	32,929	52,014	33,310
Trade creditors	25,268	25,039	9,299	9,142
Other creditors	31,091	29,849	32,710	31,662
Accruals and deferred income	87,127	79,194	83,383	76,797
	<u>188,917</u>	<u>167,011</u>	<u>177,406</u>	<u>150,911</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

19 Retirement benefit schemes

The Pensions Trust - The Growth Plan

SHINE participates in The Pension Trust's Growth Plan (The Plan), a multi-employer scheme which provides benefits to some 521 non-associated participating employers. The scheme is a defined benefit scheme in the UK.

It is not possible for the charity to obtain sufficient information to enable it to account for the scheme as a defined benefit scheme. Therefore it accounts for the scheme as a defined contribution scheme.

The scheme is subject to the funding legislation outlined in the Pensions Act 2004 which came into force on 30 December 2005. This, together with documents issued by the Pensions Regulator and Technical Actuarial Standards issued by the Financial Reporting Council, set out the framework for funding defined benefit occupational pension schemes in the UK.

The scheme is classified as a 'last-man standing arrangement'. Therefore the charity is potentially liable for other participating employers' obligations if those employers are unable to meet their share of the scheme deficit following withdrawal from the scheme. Participating employers are legally required to meet their share of the scheme deficit on an annuity purchase basis on withdrawal from the scheme.

A full actuarial valuation for the scheme was carried out at 30 September 2023. This actuarial valuation showed assets of £514.9m, liabilities of £531.0m and a deficit of £16.1m. To eliminate this funding shortfall, the trustees and the participating employers have agreed that additional contributions will be paid to the scheme as follows:

Deficit contributions

From 1 April 2025 to 31 March 2028:	£2,100,000 per annum (payable monthly)

Unless a concession has been agreed with the Trustee the term to 31 March 2028 applies.

Note that the scheme's previous valuation was carried out with an effective date of 30 September 2020. This valuation showed assets of £800.3m, liabilities of £831.9m and a deficit of £31.6m. To eliminate this funding shortfall, the Trustee asked the participating employers to pay additional contributions to the scheme as follows:

Deficit contributions

From 1 April 2022 to 31 January 2025:	£3,312,000 per annum (payable monthly and increasing by 3% each on 1st April)

The recovery plan contributions are allocated to each participating employer in line with their estimated share of the Series 1 and Series 2 scheme liabilities.

Where the scheme is in deficit and where the charity has agreed to a deficit funding arrangement the company recognises a liability for this obligation. The amount recognised is the net present value of the deficit reduction contributions payable under the agreement that relates to the deficit. The present value is calculated using the discount rate detailed in these disclosures. The unwinding of the discount rate is recognised as a finance cost.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

19 Retirement benefit schemes

(Continued)

Present values of provision

	31 March 2025	31 March 2024	31 March 2023
Present value of provision	38,148	16,884	36,146

An amount of £13,612 (2024 - £16,884) is included within short term creditors and £24,536 (2024 - £Nil) in long term liabilities.

Reconciliation of opening and closing provisions

	Year Ending 31 March 2025	Year Ending 31 March 2024
Provision at start of period	16,884	36,146
Unwinding of the discount factor (interest expense)	445	1,382
Deficit contribution paid	(17,214)	(20,657)
Remeasurements - impact of any change in assumptions	242	13
Provision at end of period	38,148	16,884

Income and expenditure impact

	Year Ending 31 March 2025	Year Ending 31 March 2024
Interest expense	445	1,382
Remeasurements - impact of any change in assumptions	242	13
Costs recognised in income and expenditure account	38,478	1,395

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

19 Retirement benefit schemes

(Continued)

Assumptions

	31 March 2025 % per annum	31 March 2024 % per annum	31 March 2023 % per annum
Rate of discount	4.84	5.31	5.52

The discount rates shown above are the equivalent single discount rates which, when used to discount the future recovery plan contributions due, would give the same results as using a full AA corporate bond yield curve to discount the same recovery plan contributions.

The following schedule details the deficit contributions agreed between the company and the scheme at each year end period:

Deficit contributions schedule

Year ending	31 March 2025	31 March 2024	31 March 2023
Year 1	13,612	17,214	20,657
Year 2	13,612	-	17,214
Year 3	13,612	-	-

The charity must recognise a liability measured as the present value of the contributions payable that arise from the deficit recovery agreement and the resulting expense in the income and expenditure account i.e. the unwinding of the discount rate as a finance cost in the period in which it arises.

It is these contributions that have been used to derive the charity's balance sheet liability.

The Plan is closed to new entrants and there were no active members of the scheme during the year.

The Scheme has identified a potential issue in respect of the calculation of benefits paid and has instigated a review. The outcome of the review is unknown and the potential financial impact of the review if an issue is identified is unknown. A potential liability may arise, but no provision is included in these accounts as the amount cannot be quantified.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

20 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

	Balance at 1 April 2023 £	Movement in funds			Transfers £	Balance at 1 April 2024 £	Movement in funds			Transfers £	Balance at 31 March 2025 £
		Income £	Expenditure £				Income £	Expenditure £			
National Lottery Community Fund – Early intervention programme across England	79,559	172,174	(209,292)		8,070	50,511	185,927	(205,744)		7,227	37,921
National Lottery Community fund Northern Ireland Shining Opportunities	35,064	97,696	(100,798)		-	31,962	99,974	(99,057)		(480)	32,399
International Projects: Contenance care and management project (Nigeria)	(1,570)	39,329	(28,234)		-	9,525	27,736	(36,427)		-	834
Coop Grant	2,118	-	(325)		-	1,793	-	(1,340)		-	453
National Lottery Community fund: Cymru People & Places	-	57,867	(63,841)		14,154	8,180	112,520	(134,845)		26,958	12,813
National Lottery Community fund: Cymru Shining lights	21,473	-	(23,053)		1,580	-	-	-		-	-
Regional Projects "Here for you"	15,121	5,000	(15,122)		-	4,999	57,000	(48,362)		-	13,637
Welfare Grants	(2,090)	6,790	(4,685)		-	15	-	-		-	15
Support Groups	1,835	-	1,306		-	3,141	-	(188)		-	2,953
South West Country SDW	-	8,500	(8,500)		-	-	-	-		-	-
NPH Coordinator	-	1,000	-		-	1,000	1,000	(2,000)		-	-
Spinal Stimulation	-	10,720	(6,894)		-	3,826	13,250	(32,769)		15,693	-
Margaret Giffen Charitable Trust - supporting our work in Northamptonshire	5,505	5,000	(10,505)		-	-	-	-		-	-
BBC Children in Need Contenance Support	-	-	-		-	-	18,000	(14,245)		4,008	7,763
Awards for All Pain and Wellbeing	-	-	-		-	-	12,622	(1,710)		-	10,912
	157,015	404,076	(469,943)		23,804	114,952	528,029	(576,687)		53,406	119,700

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

21 Designated funds

The income funds of the charity include the following designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes:

Group & Charity	Balance at 1 April 2023 £	Net movement £	Balance at 1 April 2024 £	Net movement £	Balance at 31 March 2025 £
Interest in land and property and other fixed assets	1,214	(1,214)	-	-	-
Florence Bartle fund	96,287	(28,876)	67,411	(32,680)	34,731
Services in Northern Ireland, Wales and Gloucestershire	29,228	(16,881)	12,347	(5,628)	6,719
Digital development	25,000	-	25,000	-	25,000
Research	50,000	-	50,000	(19,577)	30,423
North East Service Fund	-	-	-	139,333	139,333
Surrey Service Fund	-	-	-	1,440	1,440
- East Anglian SDW	75,000	-	75,000	-	75,000
- Deputy Health Manager	135,000	-	135,000	(2,317)	132,683
- Education Officer	50,000	-	50,000	-	50,000
- Physio service (Spinal Stimulation)	25,000	(1,225)	23,775	(14,468)	9,307
- Normal Pressure Hydrocephalus	-	72,500	72,500	(1,697)	70,803
	<u>486,729</u>	<u>24,304</u>	<u>511,033</u>	<u>64,406</u>	<u>575,439</u>

The designated funds comprise:

- the group and charity's interest in land and property and other fixed assets, net of the outstanding mortgage.
- the Florence Bartle fund which is part of a legacy that is to be spent on the relief of Spina Bifida in Cornwall and the South West.
- the services in Northern Ireland, Wales and Gloucestershire that is for work specifically in those areas.
- the digital development fund that is to develop a long-term IT/digital strategy to aid in future-proofing Shine's approaches to technology and automation.
- the research fund that is to improve access to health and care services in line with Shine's strategic goals.
- the service funds that are to fund new posts as detailed above.
- the North East and Surrey Service Funds are for work specifically in those areas.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

22	Analysis of net assets between funds	Unrestricted funds		Designated funds		Restricted funds		Total Unrestricted funds		Designated funds		Restricted funds		Total	
		2025	£	2025	£	2025	£	2025	£	2024	£	2024	£	2024	£
Group	Fund balances at 31 March 2025 are represented by:														
	Investments	847,083		-		-		847,083		-		-		834,112	
	Current assets/(liabilities)	286,431		575,439		119,700		981,570		511,033		114,952		960,360	
	Provisions and pensions	(24,536)		-		-		(24,536)		-		-		-	
		1,108,978		575,439		119,700		1,804,117		511,033		114,952		1,794,472	
Charity	Fund balances at 31 March 2025 are represented by:														
	Investments	847,086		-		-		847,086		-		-		834,115	
	Current assets/(liabilities)	263,444		575,439		119,700		958,583		511,033		114,952		937,373	
	Provisions and pensions	(24,536)		-		-		(24,536)		-		-		-	
		1,085,994		575,439		119,700		1,781,133		511,033		114,952		1,771,488	

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

23 Operating lease commitments

Group and Charity

At the reporting end date the charity had outstanding commitments for future minimum lease payments under non-cancellable operating leases, which fall due as follows:

	2025 £	2024 £
Within one year	45,460	48,420
Between two and five years	28,783	75,826
	<u>74,243</u>	<u>124,246</u>

24 Related party transactions

Remuneration of key management personnel

The remuneration of key management personnel, who on a full time equivalent basis are the 2.6 (2024 - 2.6) members of the senior management team, is as follows.

	2025 £	2024 £
Aggregate compensation including pension contributions	<u>190,093</u>	<u>187,045</u>

Transactions with related parties

Owing to the nature of the charity's operations, some of the Trustees may themselves, or may have family members that access services from the charity. Consequently there will be transactions between those Trustees or their family members. These are on the same basis as other service users of the charity.

25 Control

No one individual has overall control of the charity.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

26	Cash generated from operations	2025 £	2024 £
	Surplus/(deficit) for the year	9,645	(65,252)
	Adjustments for:		
	Investment income recognised in statement of financial activities	(67,304)	(40,471)
	Investment management fees recognised in statement of financial activities	(9,854)	(9,014)
	Gain on disposal of investments	(14,477)	(518)
	Fair value gains and losses on investments	14,986	(54,956)
	Depreciation and impairment of tangible fixed assets	-	1,214
	Movements in working capital:		
	(Increase) in debtors	(12,949)	(7,016)
	Increase/(decrease) in creditors	10,797	(19,547)
	Increase/(decrease) in pension liability	21,624	(19,262)
	Cash absorbed by operations	(47,532)	(214,822)
27	Analysis of changes in net funds		
	The group and charity had no debt during the year.		



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Charity number 249338, Company number 00877990



Shine

Spina bifida • Hydrocephalus
Information • Networking • Equality

Accounts

Trustees' Annual Report and Financial Statements

Year ended 31st March 2024



Shine

Spina bifida • Hydrocephalus
Information • Networking • Equality



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Message from Chair, Joanne Williams

This time last year, I wrote about our Corporate Plan and the hugely ambitious strategic goals we had set out. I am really pleased to see the progress that our teams in Shine have made in planning, developing and delivering against the objectives under each goal.

It hasn't been easy.

Demand for Shine's services is greater than ever. Our membership has increased by 8% over the past 12 months. Society continues to present unnecessary barriers for people living with hydrocephalus and / or spina bifida, and there is a continual lack of access to the right statutory health and care services when our members need them.

In her introduction, Kate talks about the importance of early intervention, empowerment, and education and what Shine is doing to implement preventative approaches wherever we can. These are a must if we are to help reduce the number of crisis situations some of our members find themselves in, such as the pressure sores which progress to the point where our members have emergency hospital admissions because the necessary community care is not in place; or the member with hydrocephalus, who became homeless and had to 'sofa surf' because there was no social housing available; or the young member who cannot go to the closest school with friends as it is simply not accessible.



Demand for Shine's services is greater than ever. Our membership has increased by 8% over the past 12 months

The examples above are all too often a reality for our members BUT we mustn't forget the whole host of positive stories and successes, which are reflected throughout this report.

As we go into 2024/25, we find ourselves in a stable position. We have managed our finances well and have invested in the future by growing our services team and introducing specialist roles, which will enhance our expertise and broaden our reach, both geographically and across areas of work.

On behalf of the Board, I would like to express my gratitude to each member of staff for their dedication and commitment to improving the lives of our members.

I look forward to the progress we can make during the next year and thank you all for your support.

With my best wishes

A handwritten signature in black ink that reads "Joanne Williams".

**Joanne Williams,
Chair**





“ Shine is continually working towards our vision of a society where all those whose lives are affected by spina bifida and/or hydrocephalus, and associated conditions are empowered and enabled through choice and equality of opportunity”.

Introduction from Kate

Our Corporate Plan has continued to guide us in the services we deliver, and greater engagement and consultation with our members means that our plans are ever evolving to meet changing needs and increasing demand for the work we do.

Once again, the charity has worked with thousands of individuals living with hydrocephalus and / or spina bifida, and their families, providing them with answers and guidance, advice and support, opportunities to meet and opportunities to learn across a wide range of issues that present challenges in health and day-to-day life.

The key themes across the work we have done with members of all ages in the past 12 months are those of early intervention, empowerment, education and preventative approaches to maintaining and improving health and well-being.

These have become the cornerstones of Shine's strategy.

Shine has been in existence for almost 60 years. We are therefore confident that we have insight, knowledge and experience which are second-to-none in terms of understanding the conditions, knowing the challenges that people with hydrocephalus and/or spina bifida face at different ages and stages of their lives, and what interventions can help to lessen or avoid complex health situations.

Yet, our work is not just about health and well-being; it is also about supporting our members to plan and put things in place to:

- access sound education and gain qualifications
- train, find a job, and stay in employment for as long as they want to
- have suitable housing
- be financially stable
- lead the lives they wish to

I am just so honoured to be part of Shine – and cannot thank everyone who is involved with this wonderful charity (members, families, friends, trustees, staff, volunteers, supporters and fundraisers) enough for your on-going support, guidance, time and willingness to make a difference.

We couldn't do what we do without you!

Kate Steele, CEO

Who is the Shine community?

Total number of members
as at 31st March 2024

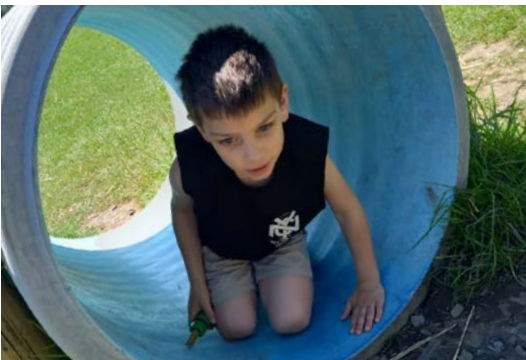
13,782
members

Membership growth

8%
in the past 12 months

The makeup of our membership

 Spina bifida	15%
 Spina bifida hydrocephalus	21.2%
 Spina bifida occulta	6.2%
 Hydrocephalus	49%
 Normal pressure hydrocephalus	4%
 Idiopathic Intracranial Hypertension	4.1%
 Encephalocele	0.5%



Members across the nations

England	86%
Wales	6.8%



N. Ireland	7%
International and others	0.2%



The difference Shine made

**Last year we directly supported
4056 Shine members**

✓ We provided information and support that meant 1,358 people understood their condition better, and 1,171 felt more confident to manage it independently

✓ We supported 81 people to have improved access to employment – whether getting a job or staying in work for longer

✓ We provided emotional support in all forms, that meant 1,167 of our members had improved health and wellbeing

✓ We helped 983 of our members to secure better care and support

✓ We secured better, more accessible accommodation for 117 members

✓ We supported with benefits applications, which led to 274 people having improved financial stability

✓ We trained teachers and supported families to ensure that 312 children had improved access to education

✓ We empowered our members so that 3,195 felt more confident to self-advocate for their needs

✓ We also connected to every one of our 13,782 members via our Together magazine, regular emails, letters, newsletters, social media and visits to our website

✓ We introduced members to the Shine community, which meant that 2,636 felt better connected and 2,545 enjoyed more positive relationships in their lives

Strategic goal 1

Enabling babies and children with spina bifida and/or hydrocephalus to achieve their potential (0 to 12 years old).

Our focus in 2023/24

1-2-1 support

Our Little Stars team, assisted by our network of Support and Development Workers and other colleagues provided direct support and advice to encourage improved approaches to care and management of the conditions, avoiding escalation of issues wherever possible.

Shall Wee Talk

Understanding and managing continence continued to be a significant topic amongst children, young people and families we support.

Throughout the year, we supported 221 young people from across England, Wales and Northern Ireland with continence advice. Our very successful online 'Shall Wee Talk' sessions continued and evolved in direct response to feedback from our members, with sessions for our older children/young people addressing puberty, gender-specific sessions, and other topics.

Spinal Stimulation

Shine launched a study on pioneering treatment which can aid in the development and mobility of children with spina bifida.

Based on initial research by our paediatric physiotherapist, spinal stimulation showed measurable improvements in sensation, mobility, strength, continence and healing, reduced secondary complications, and gains to independence and self-esteem.

We are gathering more evidence to showcase the benefits, as well as training more practitioners in its use, thus enhancing existing models of care for spina bifida, and improving the prospects of children who have it.



2835 LITTLE STARS MEMBERS

1295 DIRECT SUPPORT PROVIDED

46% OF LITTLE STARS MEMBERS PROVIDED WITH DIRECT SUPPORT

OUR Little Stars and their conditions

23.5% Spina bifida / spina bifida occulta

26% Spina bifida and hydrocephalus

49% Hydrocephalus

1% Encephalocele

0.5% Idiopathic Intracranial Hypertension

“ The difference just one session had on my son's mental state was huge. To know he isn't alone, that there are other boys like him, it was almost as if a visible weight was lifted from his shoulders. How children cope and 'own' their disabilities at a young age determines how well they live their lives as adults.' **”**



“ Teachers understand my spina bifida because they can see it – I’m in a wheelchair. But they don’t understand my hydrocephalus because they can’t see it. I want them to understand that my hydrocephalus makes it harder for me to process information – so they will need to tell me something more than once and help me to get it in my long-term memory.”

Touchpoints

Our ‘Touchpoints’ programme offers 1-2-1 sessions with our physiotherapist and occupational therapist to all parents of 0–2-year-olds with hydrocephalus and/or spina bifida, with specialist advice and practical solutions for their babies and children if parents have particular concerns or simply do not have access to statutory provision.

Attending NHS children’s clinics

A key part of our role is working alongside NHS professionals to support our Little Stars and their parents at specialist clinics across the country. Our attendance opens up opportunities for us to meet new, and connect with existing, members, all the while aiding families to navigate medical terminology and the plethora of services they need to access, providing useful information and resources to aid in improved understanding and management of their child’s health and well-being.

Educating schools about hydrocephalus

Shine’s young people tell us how frustrated they

become with the lack of understanding that some of their teachers have about hydrocephalus because ‘they can’t see it’. There is a lack of awareness about the effects that hydrocephalus has on learning, and this is where Shine was able to help.

We delivered training to 61 schools, to share our specialist knowledge and work with teachers, our children and young people, and their parents, to identify strategies and adjustments to improve learning and the overall school experience.

Our work with parent / carers

It is essential to empower parent/carers to understand and confidently discuss their child’s condition and enhance their ability to advocate for their child’s best interests with assurance and competence.

Shine achieved its goal by providing parents with 1-2-1 support, comprehensive resources and training sessions to better understand their child’s condition(s) and the support systems available to them. We also offered financial assistance, improving access to healthcare services, and emotional support through discussion and peer support.

Supporting a child with hydrocephalus and spina bifida at school

Shine staff member, Chris, provided two training sessions for staff at a local school, to improve support for a young person in Year 7. School told us that Chris helped them to understand things that affected this student specifically, but also some general information that no one at school has previously understood about his hydrocephalus.

Once the school had realised how fatigued this student could become, and the reasons why, they were able to adjust his timetable to let him concentrate on core subjects and have catch up time. They also built in capacity for things like toilet breaks. The school reported how useful it was to talk to Chris and for everyone to get a better understanding of the conditions, as although they could read up on hydrocephalus and spina bifida, it was Chris’ experience and knowledge that made the difference.

Case study

Linking families

Case study

Our Little Stars members tell us that the opportunity to meet and connect with other families living similar lives is one of the most valuable services Shine provides. We recently introduced two families with young sons, which meant that for the first time they could have a conversation with someone who understood what they were experiencing. The mother of one child wrote to us:

“I just wanted to say thank you so much for giving my details to Stephen’s mum! He and Edward even down to diagnosis are so similar, I couldn’t believe it when she told me. It’s so nice to have someone else understand everything. We are planning to meet up at some point. I finally don’t feel so alone!”

The mother of the other child wrote to us too:

“We were both nearly in tears finding someone else that understands....”

Our focus in 2024/25

Developing social skills and friendships

Developing skills for everyday life can be more challenging for children with spina bifida and / or hydrocephalus. These challenges can vary widely depending on the nature and severity of the disability. Our Little Stars team will lead a programme of opportunities for our younger members to begin acquiring important skills that will serve them well throughout life.

Launch of Shine’s STAR Awards

To build on the work we do with schools and designed to improve SEND provision through education and awareness across teaching and support staff, Shine’s STAR Awards will provide schools with opportunities to support all children and young people with hydrocephalus and / or spina bifida to achieve to the best of their potential.



Education newsletters

Linked to the STAR awards, Shine’s Education lead will create a series of e-newsletters, that will give an overview of a child’s journey through nursery and primary school, arming parents with knowledge and answers to secure the right support for their child at the right time.

Education touchpoints

In the same way as we have offered parents of our Little Stars access to dedicated time with our

physiotherapist and occupational therapist, a new programme of education touchpoints will give parents time for specialist advice from our Education Officer.

Sibling support

Shine has a growing group of brothers and sisters of Shine’s Little Stars who want to engage and participate more in our activities. We will be planning how we can open our work to better support siblings and launching a sibling support group in the coming 12 months.

Strategic goal 2

Empowering young people with spina bifida and/or hydrocephalus through knowledge, confidence and skills to manage their conditions and thrive.



Our teenage members and their conditions

20%

Teenagers with Spina bifida / spina bifida occulta

22.7%

Teenagers with Spina bifida and hydrocephalus

55%

Teenagers with Hydrocephalus

0.30%

Teenagers with Encephalocele

2%

Teenagers with Idiopathic Intracranial Hypertension

Our focus in 2023/24

The appointment of our Youth Voice and Engagement Officer enabled Shine to start placing a greater focus on our teenage members, engaging them in shaping the services they need and want from Shine, promoting young people's empowerment and ensuring their voices are heard.

1-2-1 support

Supported by our Youth Voice and Engagement Officer, our Education Officer and the Health Team, our Support and Development Workers provided answers to a whole host of queries from our youth members and their parents. Some were easily answered, others quite complex and required considerable intervention over longer periods of time.

A new youth panel

A youth panel for our teenage members was established with 24 members aged 14 to 18, who were actively involved in staff meetings, contributing to updates and insights, and feeding into discussions on various topics.

Resource development

The youth panel also helped to review and update existing resources, to make them more relevant and more appealing to their peer group. They also put together blogs and videos on issues that are important to them.

Youth groups

In addition to the youth panel, we also established youth groups in England, Wales and Northern Ireland to build connections across our network of young people.

The youth groups own and organise their own programme of face-to-face or virtual meet-ups.

Learning to self-advocate

Shine piloted a series of sessions on active listening, campaigning, coping with challenges, and on democracy, to empower and encourage self-advocacy and confidence-building techniques to aid young people in getting their voices heard.

“ I feel like one thing I’ve learnt, is never feel like you’re annoying people by communicating your needs. There have been times where each year, I’ve had to remind the lecturers of the support I need and I’ve felt like I’m annoying them. But over time, I’ve come to the realisation that the role of lecturers is to help you succeed. And by supporting you with your needs, they are doing just that.”

Reviewing our work with professionals and others

Our young people willingly attended Shine’s training sessions for professionals and took part in feedback sessions to highlight areas where Shine can embed their voices in our training. As a result, Shine created resources using their stories to form part of Shine’s professional training offer.

Shine Ambassadors

Teenage members delivered peer support sessions, acting as mentors for our younger members on various topics, such as preparing for exams and starting secondary school.

Our youth panel represented Shine at the House of Lords to share their experiences of education and

employment; others attended the Council for Disabled Children’s ‘Youth Voice Matters’ conference.

Shine’s Youth Groups also clinched the top spot in the national poetry competition at the TES SEND Show!



“ It was amazing to be nominated for the award and I was so shocked when it was announced that we won! I think its amazing that we came together to write something like this and I was so proud”

Our work with parent / carers

Parent / carers of our teenage members turned to us to enhance their ability to aid their teenage children to transition from childhood through the teenage years and into the start of adulthood. As with our Little Stars parent/carers, Shine provided comprehensive resources and online sessions to build self-advocacy, communication skills, and parenting strategies, with the aim of supporting their young people in making informed choices about their lives and futures.

Our 1-2-1 support and closed groups for parent/carers continued to provide a safe space for parents to share their experiences and challenges, and opportunities to explore solutions.

“ We really enjoyed coming and meeting other parents who have gone through a very similar time to us. It can be very isolating and difficult to relate to other parents at times, and having a community of parents I think is invaluable. I would really like a further meet-up to be organised as I think it’ll be really helpful to build relationships with other parents independently. Thanks for all that you’ve done for us”



Building friendships

Case study

“In November 2023, Shine teen members, their siblings and parents met up for Shine’s first Youth Club. The event, planned by teenagers themselves, focused on fun, games and the joy of making new friends. In addition to table football, food and a standout moment involving the ‘Marshmallow and Spaghetti Building Challenge’, this event was about forging connections. Friendships blossomed among our teenage members, with phone numbers eagerly exchanged to keep friendships going beyond the event.

Shine Youth Club is more than just the name suggests: it’s a community where bonds are formed and shared experiences are cherished.”

Our focus in 2024/25

Our young people shared their concerns about the lack of services and information at different stages of their teenage years, particularly when the time comes to transition from children to adult services. Based on their feedback and an on-going commitment to consult and co-produce, a large part of our work in 2024/25 will look at what Shine’s youth members want, and how we can deliver to meet their needs. This will include:

An internal working group

Learning from our members’ experiences and reflecting their needs to various audiences is fundamental to the work we do. Our plan, therefore, is to establish an internal working group to engage and consult with our teenage members to inform and shape a youth service that can meet their needs.



Transition clinics

The importance of preventative approaches to managing health and well-being doesn’t stop when a young person reaches the age of 18. Yet, unfortunately, our experience tells us that access to on-going statutory health and care services usually does. Shine will continue conversations with the NHS clinics to explore possibilities for establishing transition clinics across England and Wales. There won’t be the same focus in Northern Ireland as the NHS NI run both children and adult clinics in Belfast.

Resource development

Similar to the internal working group but on a wider scale, Shine will involve our young people in identifying and planning resources, such as a toolkit to facilitate person-centered education/career/life goal planning, and a designated youth area on our website, all designed in ways to appeal to our wider youth membership.

Developing skills and awareness

Shine will plan a series of sessions, training and events throughout the year to empower our young people to self-advocate and provide peer-to-peer support to one another. We will also link with other specialist charities that offer particular areas of expertise, such as the more sensitive topics of puberty, relationships, sexual health and future parenthood– topics that our young people tell us are very rarely discussed with them but they need to know more about!

Strategic goal 3

Our adult members

10,008 

Direct support provided

2,569 

25% of adults provided with direct support



Adult members with:

21%

• Spina bifida / spina bifida occulta

19%

• Spina bifida and hydrocephalus

48.5%

• Hydrocephalus

0.5%

• Encephalocele

5.5%

• Idiopathic intracranial hypertension

5.5%

• Normal pressure hydrocephalus

Our focus in 2023/24

Through active engagement, focus groups and consultation across the different age groups and conditions, our teams responded to the needs of our adult members by providing a variety of services in a variety of different ways

1-2-1 support

Questions from our adult members vary enormously

from person to

person, particularly as

so many new things come into play as our members move through different stages of adulthood. Our support ranges from light and medium to more intensive, depending on an individual's needs.

Promoting self-advocacy

Our members reminded us of the continual barriers they face in accessing the right health services when they need them. To assist with this, our teams reviewed and updated our health information on the Shine website, the GP information and encouraged use of our Hospital Passport – a tool designed to aid in preparing for medical appointments.

Delivering self-management programmes

With access to statutory services becoming more difficult, Shine's Health team launched two separate series of self-management sessions, centering on 1. Pain Management and 2. Mental Health and Well-being to aid our members in taking proactive steps to managing their health and well-being.

 It allowed me to admit things to myself and to be able to think about how to change – it was very powerful”



Condition-specific online support groups

One size never fits all across the range of conditions we work with. We set up condition-specific online support groups which not only offered tailored advice and information for individual conditions but provided a safe environment to discuss difficult issues, and encourage our members in feeling better understood and more able to share experiences with others who understand.



“ ‘Why do I attend Shine Zoom events?... there is a great sense of community, many of us have similar stories such as diagnosis later in life. We are group of like minded people that understand what each other is going through and we learn from each other’ ”.

Occulta and Me group member

Normal pressure hydrocephalus (NPH)

Shine's NPH membership saw a huge growth in the last 12 months, which increased the number of new enquiries, questions and requests for support coming through to Shine. In response, we developed

a service specification to define the scope of what Shine can offer and identified the priority areas to meet demand and better support our members.



Working with NHS specialist adult clinics

As part of the holistic approach to condition management and prevention at Chelsea and Westminster's Adult Spina Bifida Clinic, Shine's Head of Health continued to attend the clinic to offer advice and information on the more practical things that makes life with the conditions more complex than for people without spina bifida, both physically, cognitively, or often a combination.

Supported by a long-standing Shine volunteer. Nottingham's NHS Adult Hydrocephalus Clinic continued to offer specialist support to patients with hydrocephalus (H) normal pressure hydrocephalus (NPH) or idiopathic intracranial hypertension (IIH). Shine's role has once again been to help patients and their relatives understand their diagnosis, treatment, and the implications of having hydrocephalus, NPH or liH, as well as give answers to questions from old and new patients that are not strictly medical but relate closely to the condition(s).

Our work with parents / carers

By keeping abreast of changes to systems and policies, Shine was able to provide updates and advice to aid parents, who may still have caring responsibilities, in guiding their adult children towards independence and financial security, ensuring they are well-prepared for the future and have appropriate plans in place.

“I wouldn't have got through this without Shine - I felt so alone and uncertain but with the Shine staff and NPH whatsapp group I feel so supported” NPH carer

Our focus in 2024/25

As well as continuing the areas listed above, there are some key pieces of work that we plan to complete by the end of March 2025. These include:

The Spina Bifida Handbook

A much bigger task than we originally envisaged, 2024/25 will see this important guide for individuals living with spina bifida, and health and care professionals, come to fruition.

Improving NHS provision for people with hydrocephalus

Shine will map NHS clinic provision for adults with hydrocephalus across England, Wales and Northern Ireland, and build opportunities to working alongside these clinics to improve services.

A co-ordinator to lead our work on Normal Pressure Hydrocephalus

Demand for Shine's support has continued to grow. Therefore, we will seek funding to employ a specialist in dementia and experience of working with older people to provide a holistic support and information service to our NPH members, and their partners / carers with the aim of navigating the challenges when adapting to life with NPH.

Supporting employment

As our members get older, they find that opportunities to stay in their full-time jobs, or to secure a role they really want, become more difficult. Through improved links with specialist employment charities, connections with colleges and welfare-to-work type agencies and promotion of our employment passport, and starting small, Shine's employment opportunity programme will begin to provide resources and guidance to our members to gain employment or to stay in a job they love.



Strategic goal 4

A connected community

 **Ran 720 online and face to face events**
with 1629 individuals attending

Attended 166 NHS clinics and connected with **701 individuals and families**



 **Engaged 1098 individuals**
across 10 closed Whatsapp groups



997
new member calls



Shine offered multiple opportunities for members to connect across different age groups, conditions, geographical locations, areas of interest and lived experiences.

Our members told us that our approach continued to provide them with numerous benefits, which included understanding and empathy from others; reduced isolation and friendship; practical advice and coping strategies; improved mental health and well-being; and motivation and empowerment through a collective voice and raising awareness.

Our focus in 2023/24

New member calls

Formally introduced in 2022/23, these calls continued to offer new members time to talk and tell us about the support they wanted, and whether there were any pressing issues that had to be addressed. These calls also served as an opportunity to remind new members about the breadth of Shine services and how to contact Shine if they needed to.

Online and face to face information and social events

As we emerged from the lasting effects of the pandemic, face-to-face events became better established and allowed Shine to offer a balanced mix of in-person and online information and engagement opportunities, and tailor them to specific topics and members' needs.

Spina bifida and hydrocephalus Awareness weeks provided platforms to collaborate with other charities and organisations, and engage Shine members in shaping

and contributing to the events, and broadening our reach outside our community.

Online clubs

From craft sessions to making Christmas decorations, from Chatter Matters to quiz nights, Shine's programme of face-to-face events and online clubs continued as a regular feature in our annual calendar.

Improving access to Shine's service for members with different communication needs.

Language and ways of communicating can be a barrier to providing appropriate support at times so to break down some of these barriers, Shine's website was upgraded to allow visitors to translate the information into a variety of different languages or use it in a format that was more accessible to them.

We also continued to subscribe to Languageline, that provides access to translation and interpreting services. Several Shine staff and volunteers speak several languages, which improved the quality of services we were able to provide for members and their families where English is a second language.

Volunteering

As with previous years, volunteers contributed their time and expertise to enhance the work we do and aid in sustaining some areas of our work. Roles included painting, sorting and manning Shine's shop in Wales, coordinating and moderating our Shine40Plus closed Facebook group, providing administrative support to our team in Head Office, assisting at Shine events, fundraising and guiding our direction through our Board of Trustees.

During the year, we applied for funding from the national lottery Wales.

As part of the process, we went to our Welsh members and professionals and worked with them to refine an initial project draft. We talked in depth to 96 people (approximately 10% of our overall membership in Wales) and asked them for their views and suggestions to provide a service for members of all ages and stages of their lives.

The result: a successful application and funding for a 4-year project to provide a Wales-wide service.

Keeping our members informed

Emails and newsletters, with specific information and updates and tailored to meet the needs of members with different conditions and ages, are issued weekly and monthly. We also produced our Together magazine, which was sent out digitally and by post to over 12,000 individuals at the start of the year.

Keeping Shine informed

Over the past 12 months, we consulted with our members, their families and carers, and professionals through focus groups, project evaluations, online surveys and direct conversations to gather insight and information on evolving needs and emerging new solutions.

Our focus in 2024/25

A review of our membership offers

A large task to tackle, the team worked throughout the past year to better define the different membership categories and enhance the services we offer in each category. This work will be completed early in 2024/25.

A new social media and content strategy

Planned for 2023/24, this strategy has not yet come to fruition due to staff capacity and other priorities. This new strategy will be launched over the course of year.

E-newsletters for all membership types

Shine's various series of targeted newsletters are proving extremely popular, particularly as they provide regular, targeted communication, to keep our different membership groups informed and engaged.

We will be expanding our series of e-newsletters this year to reach new audiences.

Member engagement strategy

Our member engagement will undergo a review in 2024/25 and will consider how Shine can particularly increase the profile for children, young people and adults with hydrocephalus, who now represent over 50% of our membership.

Awareness weeks

We will continue with our ever-successful spina bifida and hydrocephalus awareness weeks, and mark world spina bifida and hydrocephalus Day on 25th October.

May 2024 sees the launch of a new Normal Pressure Hydrocephalus (NPH) Awareness Week to highlight this little-known condition and the fact that timely diagnosis and treatment, some of the effects of NPH can be reversed and people's lives improved significantly.

Other charities have awareness weeks too, and some link closely with the conditions Shine represents and the areas of work that we cover so we will join in and celebrate and promote their important messages and information across our networks.





Strategic goal 5

Preventing spina bifida and Anencephaly

Mandatory fortification of flour with folic acid

There was little news on the government's plans for mandatory fortification of flour with folic acid until January 2024, when the UK government announced the timescale for implementation as sometime in 2026.

We continued to link with key players in this field, as well as coordinating a network of charities, royal colleges of medicines and other partners to stay informed and updated on progress.



Folic for Life

Thanks to funding from Vitabiotics, Shine was able to strengthen our focus on our campaign on the importance of, and need for, folic acid supplementation for women who are planning a pregnancy, or who may become pregnant. We created a series of social media posts, which evolved into a programme of targeted communications for maximum awareness and impact.

We also worked with key stakeholders, such as Healthinote, to aid in getting consistent and correct messaging out to specific audiences, the general population and medical professionals.

This work will continue into 2024/25 to build our reach and greater awareness.



Strategic goal 6

Changing experiences of pregnancies affected by neural tube defects

Shine's pregnancy advice service continued to offer support and information for parents-to-be who have a diagnosis of an unborn baby with spina bifida, those whose previous pregnancy may have been affected by a neural tube defect and they were seeking help to prepare for a next pregnancy, and Shine members who wanted to explore plans to have children.



55 individuals (and sometimes their partners) were provided with pregnancy advice and support, and as a result:

21% felt more confident to self-advocate



85% felt better connected



71% had improved knowledge of conditions



89% reported more positive relationships



Our focus in 2023/24

1-2-1 advice and support

Shine's Health team provided tailored advice and information, exploring the options that are available for pre- and post-natal treatment, preparing for appointments with antenatal and fetal medicine services, and how to ensure a health pregnancy and on-going well-being.

Anencephaly support group

Anencephaly is a neural tube defect. Sadly, this condition is fatal. Most babies diagnosed with this condition will be born prematurely and die before, during or very soon after birth. Some babies may live for a few minutes or even a few hours, and very rarely for a few days. Shine has provided on-going support to 872 parents who have lost a baby to anencephaly through our closed online support group and direct support.

Working with NHS Commissioning and fetal surgery teams

Shine continued to meet with the teams at NHS Commissioning, University College Hospital in London (UCLH) and University Hospital in Leuven, Belgium to share information on best practices and surgical outcomes, as well as providing direct feedback from members on how the patient experience could

be improved. Together, we launched a survey on antenatal services to provide data and insight on how, or if, antenatal referrals, access to fetal medicine and subsequent care have improved since pre-natal surgery was commissioned in the UK. The results are due to be published in 2024 and will be used to work with our NHS partners to address areas for improvement.

Our focus for 2024/25

Continue the pregnancy advice service

Whilst the numbers of people who access this service are relatively low, it is nevertheless a vital area of work, which will continue. We will introduce a new system – 'a pregnancy pathway' to ensure consistency in the service we are providing, improving outcomes for our members and enhancing communication with statutory healthcare providers.

Review of our anencephaly support service

A full review of how we currently support parents who have lost a baby to anencephaly will be undertaken to identify how we can better support these members, how we can improve engagement within the group, and increase opportunities for peer-to-peer support. We will also develop a plan to increase this group's membership and work with external agencies to signpost to more specialist support when required.

Strategic goal 7

Transforming attitudes and improving access to health and care services through engagement, partnerships, research and campaigning.

Over the past few years, Shine has introduced a greater focus on engagement, partnerships, research, campaigning and training for professionals and organisations, as our view is that the more we can educate and inform those who work in health, social care, education etc. then the greater the chances that our members will have improved access to the right services at the right time.



1000+ professional members



500 PROFESSIONALS ON THE SHINE ACADEMY

Our professional members to name but a few...

Rehabilitation Clinical Nurse Consultant	SENCOs/ALNCOs	Paediatric Neurodisability Doctors
Consultant Neurosurgeons	Early Years Leads	
Health visitors	Head Teachers	Advisory Teachers for Physical Disability
Doctors	Education coordinators	Surgeons
Nurses	Specialist Advisory Teachers	Services Coordinators
Midwives	Teaching Assistants	Charity CEOs
Continence specialists	Training & Development Officers	Orthotists
Physiotherapists	Inclusion, Safeguarding And Wellbeing Managers	Social Workers
Occupational Therapists	Deputy Head/Inclusion Leads	Specialist registrars
Consultants	Sales, Marketing & Clinical Directors	GPs
University Professors	Paramedics	Housing Officers
Neuroradiographer	PhD Researcher - Learning Disability and SEND	Students
Breathe Coordinator	Outreach workers	Mechanical Engineer
Mental health Employment Practitioners		Lecturers
		Well-being Co-Ordinator

Our focus in 2023/24

Connections

Working with professionals who have expertise and experience in these conditions improves our ability to

support Shine members, whilst improving engagement and collaboration with professionals who perhaps do not have as much expertise and wish to learn more helps us increase knowledge and understanding of the conditions, and demonstrate how early intervention and prevention can improve our members' lives.

Conferences and events

Our visibility and credibility were raised, and opportunities for networking and partnership working increased, through attending, and presenting, at conferences and events up and down the country. We delivered training to staff in other organisations and held a highly successful conference for professionals in Northern Ireland.

CPD-accredited courses

165 professionals completed 228 courses from Shine Academy's CPD-accredited suite of professional courses - news which we are extremely proud to share.

Key campaigns

In addition to joining forces with others to campaign for change, Shine also launched our campaigns on important health issues to raise awareness and educate our members to look for signs of deteriorating health, and empower them to insist on the need for further diagnosis through their GP surgeries, to improve health outcomes for conditions that are more prevalent in people with spina bifida, than in the general population.

These included the launch of a bladder cancer campaign where we started to collect data and evidence about the prevalence of bladder cancer in people with spina bifida, work with Leeds University on prevention of pressure sores, and joining the Spinal Injuries Association's campaign for the introduction of bowel care policies into all health trusts.

We also made important links with social services teams to promote not just awareness of the conditions, but the positive difference social workers and social care staff can make through early intervention and preventative approaches to working with individuals and families.

Research

To support our call for increased access to adult clinics in the UK, our health team began to explore the scope of research for a cost-analysis of spina bifida and the positive difference that holistic and preventative approaches to managing the condition could have for our members, and also the difference it could make to NHS and care services.

Progress on research into cognitive effects of hydrocephalus has been very slow, and not yet complete. Shine is committed to supporting the teams at Chelsea and Westminster to publish this important piece of work.

Working alongside others, we also started to contribute to other research during the year, including:

- further exploring folic acid
- the One Spine project with Leed University, to consider the impact on early life outcomes for children with spina bifida due to health inequalities and deprivation;
- Research into NPH and whether changes in mood and behaviour can be detected before other features of NPH appear;
- Increased Intracranial Pressure (ICP) and pulses in eye veins.

International work

- Shine continued its partnership with the Festus Fajemilo Foundation, and secured funding to further the 'Saving Lives. Improving Futures' programme by training and development nurses and outreach workers, linked to eight public health hospitals to improve the continence care and management, for babies, children and adults with spina bifida in Nigeria.
- We were also successful in an application for a small grant to fund shunt operations in young children in Nigeria who would not have had access to this life saving treatment otherwise.
- Shine was represented at the Society for Research for Hydrocephalus and Spina Bifida, and the Annual Scientific Research meeting with a special interest in hydrocephalus and NPH. We continued our membership of the International Federation for Spina Bifida and Hydrocephalus and worked closely with Child-Help International.



Our lead solicitors
Kat



Claire



Shine's Legal Panel

An invaluable service, Shine's Legal Panel provides members with legal advice and support on clinical negligence if they need it.

We continued our partnership with Davies and Partners and Enable Law to offer access to



qualified and experienced solicitors, who understand the complexities and complications that spina bifida, hydrocephalus and their associated conditions bring.

The team provided training to all Shine staff, and created resources to let our members know more about what the service has to offer.

Shine Health Direct

A solid partnership that is now nine years old, Shine Health Direct is exclusive to Shine members over two years old, offering discreet and efficient delivery of urology and stoma products, as well as prescription medications.

In partnership with Bullen Healthcare, it continued to grow from strength to strength, with membership standing at 1009 registered Shine members at the end of March 2024.

One of our Support and Development Workers took part in an annual accessible ski trip to Italy, with the aim of developing future opportunities for Shine members.



Our focus for 2024/25

An online professionals' conference

Much more cost effective than a face-to-face event, and more likely to attract a bigger audience online, Shine is planning a professionals' conference to increase awareness and understanding further, share best practices and innovations, support continued education and professional development, all with the aim of improving health and life outcomes for our members.

New CPD-accredited courses

Following the success of our courses to date, Shine's Health Team is planning new courses to add to our Shine Academy.

Progressing areas of research

Research is such an important area of work to provide sound evidence, advances in knowledge, inform decisions and drive innovation so, in 2024/25, Shine will continue with the research projects it currently has on-going, and will also seek to engage in a wider range of research to aid in improving quality of life for our members.

We will promote the importance of patient and public involvement (PPI) to our members, so that research can be underpinned by their real-life experiences and knowledge of the conditions.

We will be presenting at the Society for Research for hydrocephalus and spina bifida, and are providing administrative support for their international conference being held in Manchester in September 2024.

International work

Two specialist nurses and our CEO will be visiting Nigeria in July to meet with project participants, providing expert knowledge, development opportunities and practical advice in continence care and management, as well as advocating for continence services to be mainstreamed into public health facilities.

“Families can talk to the Shine Support Worker at our clinics because they see her as independent. They are much more comfortable talking to her about difficult subjects, or things they didn't feel confident enough to address.”
Liaison Nurse Specialist Paediatric Neuroscience

Thank you

Throughout the year, thousands of individuals, companies, organisations, trusts and foundations contribute vital funding to support the work we do.

Without them, Shine would not be the charity we are. The list of supporters is too long to mention everyone individually, but we want to say a HUGE thank you to everyone who has given so generously of their time and money to support the work we do.

We wish to take this opportunity to acknowledge just a few...



“Shine really do deserve funding as without it, we would have no where to turn. There would be no one fighting our corner, assisting with filling in benefit forms, writing to doctors or helping us get the most out of a medical appointment.”

Companies

Integra Neurosciences – Codman

Devenish Patrons

Bullen Healthcare

Davies and Partners

Enable Law

Royal Pigeon Racing Association

Vitabiotics Ltd

Griffin Cycling Club

The Anderson Foundation

Little Rays Nurseries

The Millbrook Golf Club
(Captain John Mcloughlin)

Grays Town Bowling Club

Hurstpierpoint College

Individual and Family Supporters

Adam Smith

Joe Smith

Nick Luscombe

Simon Hodes

Max Marola

Emma Barrow

Abbie Frost

Charlotte Liddell

Gemma & Gavin Thornton

Michael Haddock

Matthew Hoddell

Jane Gillings

Jon Clark

Juliana Jemphrey

Simon Horne

Roisin Curran & Team Fishbourne

Laura Carr, Eileen Breen & Ursula
Keenan

Val Conway

James Quick & Daisy Quick

Will, Helen, Shaun, Dan Rich &
Gary (Wobbly Weavers)

Symon Ahn + family

Debbie Roberts + family

Mark Gostlow

Daphne and Nick Allen and family

Hakim Ahmed

“We chose to support Shine in 2023 because of the incredible support they offer to our local community, through meetings and communications no one must cope with this debilitating disease alone and that’s something we believe should be supported. The Shanly Foundation



Thank you (CONTINUED)



We chose to support Shine because the application fitted our criteria and the charity seemed to have such a positive and practical plan for making the most of the grant requested. We wish Shine all the best in the good work that it does throughout Berkshire” Englefield Charitable Trust



Trusts and Foundations who supported Shine in 2023-24

The Apax Foundation	The Alice Ellen Cooper Dean Charitable Foundation	The Healey Family Charitable Trust
The Cumber Family Charitable Trust	The Annett Trust	The Henhurst Charitable Trust
The Davis-Rubens Charitable Trust	The Basil Brown Charitable Trust	The Frazer Trust
The Douglas Compton James Charitable Trust	The Boshier-Hinton Foundation	The Norman Family Charitable Trust
The E F Bulmer Benevolent Fund	The Boutell Bequest	The Pierrepont Trust
Homelands Charitable Trust	The Cecil Rosen Foundation	The Rainford Trust
J Reginald Corah Foundation Fund	The Chapple Trust	The Roger and Douglas Turner Charitable Trust
The Marsh Charitable Trust	The Charlotte Bonham-Carter Charitable Trust	The Englefield Charitable Trust
The Michael Cornish Charitable Trust	The Clare Milne Trust	The Sir James Roll Charitable Trust
The Patrick Rowland Foundation	The D'Oyly Carte Charitable Trust	The Strangward Trust
The P F Charitable Trust	The Earl Fitzwilliam Charitable Trust	The Valentine Charitable Trust
The Plymouth Tamar Lions Club Charitable Trust Fund	The Evelyn Trust	The Vandervell Foundation
The Rothley Trust	The Ganzoni Charitable Trust	The Warwickshire Masonic Charitable Association
The Schroder Charity Trust	The Gerald Palmer Eling Trust	The Henry Smith Charity
The Scouloudi Foundation	The Grace Trust	The National Lottery Community Fund
The Sir James Reckitt Charity	The Hamilton Wallace Trust	The Eveson Trust



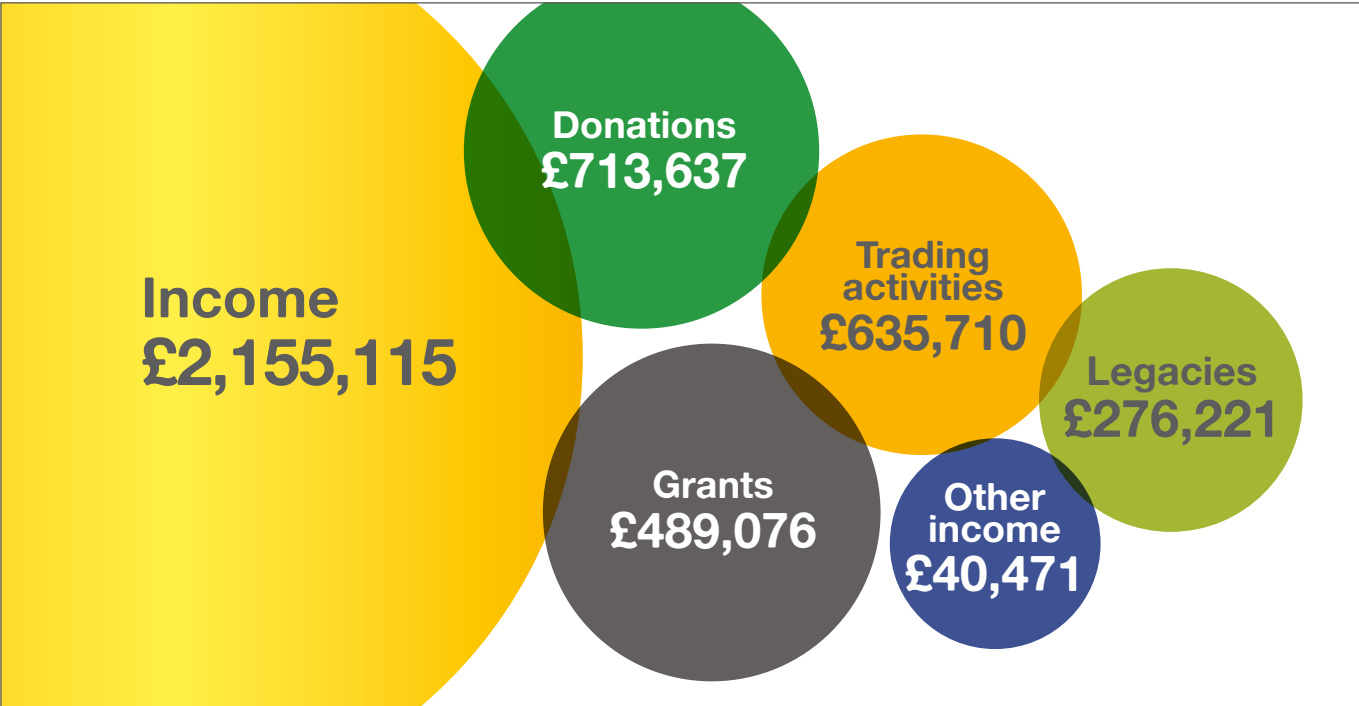
We chose to support Shine Cymru because of their vital work helping people affected by spina bifida and Hydrocephalus come together and live healthier lives.



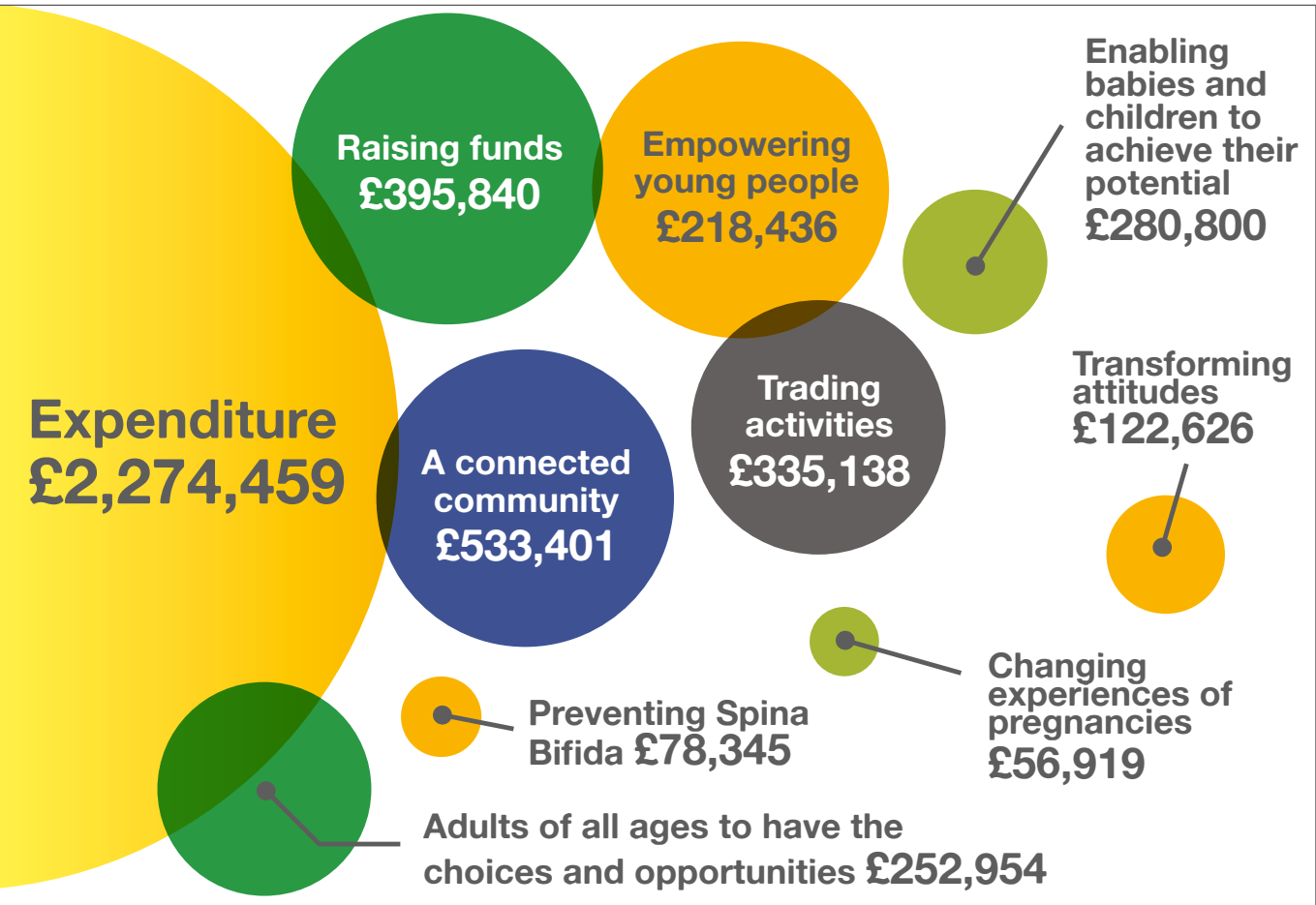
Thanks to National Lottery players, who raise over £30 million a week for good causes, we are proud to have awarded Shine Cymru a £350,000 grant, which has enabled them to offer one-to-one support, advice and information to their community to improve the quality of their lives.” National Lottery Community Fund for Wales

Income and expenditure 2023/24

Total Income



Total Expenditure





Financial Review

The table below provides a five-year financial summary, showing that we continue to deliver a robust financial position, as we seek to ensure long-term sustainability.

	2023/24	2022/23	2021/22	2020/21	2019/20
Total income	2,155	2,347	1,894	2,343	2,192
Net movement in funds	(65)	338	171	506	113

Trustees approved the 2023/24 budget deficit of £190,645 intending to use reserves generated from the sale of 42 Park Road to invest in new services for our members.

Shine reports an actual deficit of £65,252 (2022/23 £337,980 surplus), which consists of a £47,493 unrestricted deficit, a £24,304 designated surplus, and a £42,063 restricted deficit.

Total income for 2023/24 was £2,155,115 (2022/23 £2,347,350) although this is a reduction year on year, if the sale of 42 Park Road is excluded income has increased by 15% with growth in donations, legacies, grants and investment income offsetting a decrease in trading activities. The largest element of our trading activity continues to be our virtual balloon races and although this income stream faces several challenges, nonetheless during the year 4,713 business supporters sponsored a balloon, many entering multiple races.

Public donations from individuals (excluding legacies) and community groups recorded a 10% increase year on year, despite the cost-of-living challenges faced by many individuals and represents the second highest annual income in the last nine years.

The National Lottery community fund and other charitable trusts continue to fund an important part of Shine's work and a new 4-year grant from the Lottery was secured to fund services in Wales, this project "People and Places" commenced in October 2023. Giving from charitable trusts and foundations recorded its second highest annual income in the last ten years.

Legacies continue to be a major source of funding and was the highest value since 2020/21. We are incredibly grateful that people continue to remember us in their wills.

Trustees remain confident that Shine has a broad income base and provides sustainable income levels.

During the year two new fundraising positions were created, to invest in Shine's income generation capacity.

Expenditure

Total expenditure in the year was £2,274,459 (2022/23 £1,965,957). Of this, expenditure on charitable activities increased by £292,338 (23.4%) to £1,543,481, representing 67.9% of total expenditure (63.7% in 2022/23). This reflects a conscious decision to invest in services with several new staff positions created. Expenditure on raising funds increased by a more modest amount of £16,164 to £730,978. Although an increase in staff turnover was experienced, recruitment efforts have been successful and staffing levels in Shine's services increased during the year with 31 full-time equivalent posts compared to 27 in 2022/23. A staff survey was completed in the year and a pay award was made. Shine is confident it remains an attractive organisation to work for and has active recruitment plans which aim to maintain service staffing levels in 2024/25.

Despite the war in Ukraine and conflict in Gaza, financial markets responded well to falling rates of inflation and expectation of interest cuts in 2024. This had a positive impact on the value of our investments, and over the year we report gains £55,474 (loss in 2022/23 £42,342).

Under the accounting standard SORP (Statement of Recommended Practice) 2015 the full defined benefit pension deficit must be declared on the balance sheet. There was a 2023/24 actuarial loss of £1,382 (2022/23 loss of £1,071).

A payment plan to eliminate this deficit remains in place and the charity remains confident that it will meet the required pension contributions from its projected income without impacting its planned level of charitable activity. Further pension details are shown in note 21 of the accounts.

Financial Reserves Policy

Reserves are maintained at a level that enables the charity to manage financial risk and sustain services. Trustees have set a minimum free reserve target of £850,000, held for the following purposes:

- Statutory obligations.
- Provide a 4-month commitment to our vulnerable members to wind up the affairs of the charity in an orderly fashion, in the event that the trustees cease to be confident in Shine's ability to continue.
- Offset the risks of an unexpected shortfall in income and an adverse movement in the defined benefit pension scheme liability.
- A working capital facility.

The free reserves position is reported to trustees as part of the monthly management accounts and quarterly forecasting. To set our free reserves target, trustees have sought to balance the needs of Shine's members against financial risks. COVID19, the war in Ukraine and conflict in Gaza has demonstrated that our world is less certain than previously thought and our reserves target reflects this need for caution.

At the year-end Shine held free reserves of £1,168,487, being general unrestricted funds excluding designated funds. This represents 6.1 months of committed expenditure cover, which is above the reserves target and has been boosted by the one-off sum realised from the sale of 42 Park Road in April 2022.

To bring our reserves in line with our target the charity is utilising its reserves in a managed fashion investing in members' futures and has appointed new positions of Deputy Health Manager, a National Programs and Member Engagement Manager, an Education Officer, and a Youth Officer.

In the forthcoming year, Shine plans to appoint a Normal Pressure Hydrocephalus (NPH) and Dementia Co-ordinator. This is a new role and is in response to an increase in members presenting with this condition. Taken together these changes have raised the service staff establishment to 32.5 FTE and compares to a pre COVID position of 27.1 FTE.

Restricted reserves must be applied to the specific purpose(s) intended by the donor so do not form part of the free reserves. Funds totaled £114,952 at the year end and are planned to be expended in 2024/25.

Designated funds have been established by trustees and are excluded from free reserves. They are as follows:

- A fund for 2 additional Support and Development Workers in the Southwest and East Anglia areas – who will enhance the support we can provide to our members in more rural, isolated areas. This first position has been made possible by the generosity of the late Florence Bartle who kindly chose to remember Shine in her will.
- A fund to support our work in Gloucestershire – based on a legacy we have received.
- A fund for a Deputy Health Manager.
- A fund for an Education Officer.
- A fund for a Normal Pressure Hydrocephalus (NPH) and Dementia Co-ordinator.
- A fund to support our specialist physiotherapy work.
- A fund to support research and development.
- A fund to support our digital development.

Notwithstanding the existence of the above funds, unrestricted funds continue to be used to cover the costs of some new posts; notably the deputy health manager, Education officer & the East Anglian support and development worker.

Investment Policy

Under the governing document, the charity can make any investment the trustees see fit. R. C. Brown Investment Management plc are Shine's investment managers with the remit to manage the investments in line with the policy outlined below.

Investments are held as part of the long-term reserves of Shine. The aim is that they should maintain their value and generate income for Shine.

The portfolio must only be invested in assets with a balanced risk profile. This will include utilisation of pooled funds, which provide diversification of assets, and ensures that the risk of losing a single holding is minimised.

- Investments may be held in a range of asset classes, including equities, corporate bonds, and gilts.
- There will be no direct investment in 'alternative'

investments such as hedge funds or derivatives.

- There will be no direct investment in overseas equities. Any such investment must be made through pooled funds managed in the UK.

The trustees have agreed that the funds should initially be invested in a broad, balanced portfolio. The intention is to work towards ethical investments, with the advice of the investment managers, while being mindful of the charity's obligations for responsible investment.

During the year R. C. Brown Investment Management plc continued to manage the Shine portfolio, funds performed marginally below their benchmark, recording a 9.02% gain during 2023/24 versus the benchmark gain of 9.29 (ARC steady growth index).

Investments are held to support the reserves policy.

Risk Management and Internal Control

The Board of Trustees are responsible for the identification and management of the major risks facing the charity. A Risk Register is maintained and shared annually with trustees (more frequently if a significant issue arises). Risk management at operational level is managed by the senior leadership team; major risks have been reviewed and systems established to manage these risks.

During 2023/24, the risk from COVID-19 diminished in how the charity supported its members and the risks to income levels. Therefore, the risk register currently covers five strategic areas.

1. Governance & strategy

2. Income generation

3. Services

4. Finance

5. External influences, including inflation and the war in Ukraine

During the year, there remained 1 red retained risk, which is members' access to statutory services, and Shine continues to support our members and families with information and guidance on their rights, and avenues to access the services they need. Shine continues to make structural and strategic changes to the organisation to mitigate these and other risks.

Going Concern and Statement of Public Benefit

Going Concern

This report highlights Shine's financial performance over the last five years, the level of reserves held and the principal risks and uncertainties faced. The activities of the charity, its objectives, and the policies for managing its capital and financial risk are detailed in the Trustees' Report.

The budget for 2024/25 was prepared by senior leadership and approved by the trustees in March 2024. The expectation is that income levels can be increased as we continue to invest in fundraising resources. Expenditure levels will be allowed to increase in line with the expansion in service provision, therefore a total deficit of £180,766 is budgeted which includes a restricted deficit of £18,463 as funds received in prior periods are expended and a deficit of £162,303 across unrestricted and designated funds.

Statement of Public Benefit

The trustees confirm that they have complied with the duty in section 17 of the Charities Act 2011 to have regard to the Charity Commission's general guidance on public benefit, 'Charities and Public Benefit'.

Shine's charitable objects are enshrined within its

We can do this because our reserves exceed the minimum level, the budget and its assumptions are reviewed against two key financial measures:

- In-year cash flow
- Free reserve cover

Management accounts are prepared by senior leadership and issued monthly to trustees; the current financial position and financial outlook are reviewed at quarterly trustee meetings. Given the level of reserves and outlook, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future being at least twelve months from date of approval of these financial statements. Accordingly, they continue to adopt the going concern basis of accounting in preparing financial statements.

memorandum and articles and as such trustees ensure that the charity's activities are carried out for public benefit through its strategic goals.

This report allows us to show how charitable funds are spent and the impact and benefits this has on the lives of people affected by spina bifida and/or hydrocephalus, and associated conditions.

Reference and Administration Details

Royal Patron
HRH The Duchess of Gloucester GVC

Trustees

The trustees of spina bifida, hydrocephalus, information, networking, equality – SHINE are the charity’s trustees under charity law and directors of the charitable company and throughout the report are collectively referred to as the trustees.

The trustees serving during the year were as follows:

Rebecca Bates (Resigned 5th December 2023)	Richard Oakley (Appointed 6th July 2023)
Professor Roger Bayston	Joanne Sedgwick (Appointed 1st November 2023)
Michael Brown (Vice Chair)	Andrew Smart (Resigned 30th May 2023)
Jenny Goy (Hon. Treasurer)	Joe Waggott
Surekha Kukadia	Joanne Williams (Chair)

It is confirmed that none of the serving trustees had any beneficial interest in any contract with Shine in the year.

In memory of Dr Richard Morgan

It was with great sadness that we heard Dr Richard Morgan, founder of the Adult Spina Bifida Clinic in London, passed away suddenly in April.

Dr Morgan founded the clinic at Chelsea and Westminster as a transition clinic for local young people in the early 1990s. However, it quickly grew to take around 600 patients from all around England. The multidisciplinary approach was and still is unique in England, operating as a ‘one stop shop’ for check-ups and advice.

Dr Morgan will be fondly remembered, as a dedicated and highly respected doctor, and as a true gentleman. He will be greatly missed by many of Shine’s community, for whom he did so much.

Senior Leadership Team
Chief Executive Kate Steele
Director of Services Gill Valentine
Director of Finance Stephen Ellen

Principal Professional Advisers

Auditors

Azets Audit Services

Westpoint
Lynchwood
Peterborough
PE2 6FZ

Bankers

The Co-operative Bank Plc

PO Box 250
Skelmersdale
WN8 6WT

Insignis Cash Solutions

St John's Innovation Centre
Cowley Road
Cambridge
CB4 0WS

Solicitors

Greenwoods GRM LLP

Monkstone House
City Road
Peterborough
PE1 1JE

Investment Managers

R.C. Brown Investment Management

1 The Square
Temple Quay
Bristol
BS1 6DG

HR

Vero HR

St James House
Flaxley Road
Kingston Park
Peterborough
PE2 9FT

Administrative Details

The full name of the charity is spina bifida, hydrocephalus, information, networking, equality – SHINE. We are commonly known as SHINE.

The registered charity number is 249338 (England and Wales)

The company registration is 00877990

Registered Office: SHINE, Unit 4, Minerva Business Park, Peterborough, PE2 6FT

Telephone 01733 555988 • Email firstcontact@shinecharity.org.uk • www.shinecharity.org.uk



Our Commitment to Quality Fundraising

Shine is registered with the Fundraising Regulator and proud to commit to the Regulator's Fundraising Promise.

We are committed to maintaining high standards of fundraising in line with the Code of Fundraising Practice:

- We will be clear, honest, and open.
- We will be respectful.
- We will be fair and reasonable.
- We will be accountable and responsible.

Our approach to fundraising consists of:

- marketing appeals to individuals who have already expressed an interest in Shine.
- running charitable events for which participants raise money.
- encouraging people to participate in other events to raise funds on our behalf.
- community fundraising; and
- soliciting donations from corporate partners, charitable trusts, and individual donors.

We also encourage people to remember us in their will with a gift or legacy.

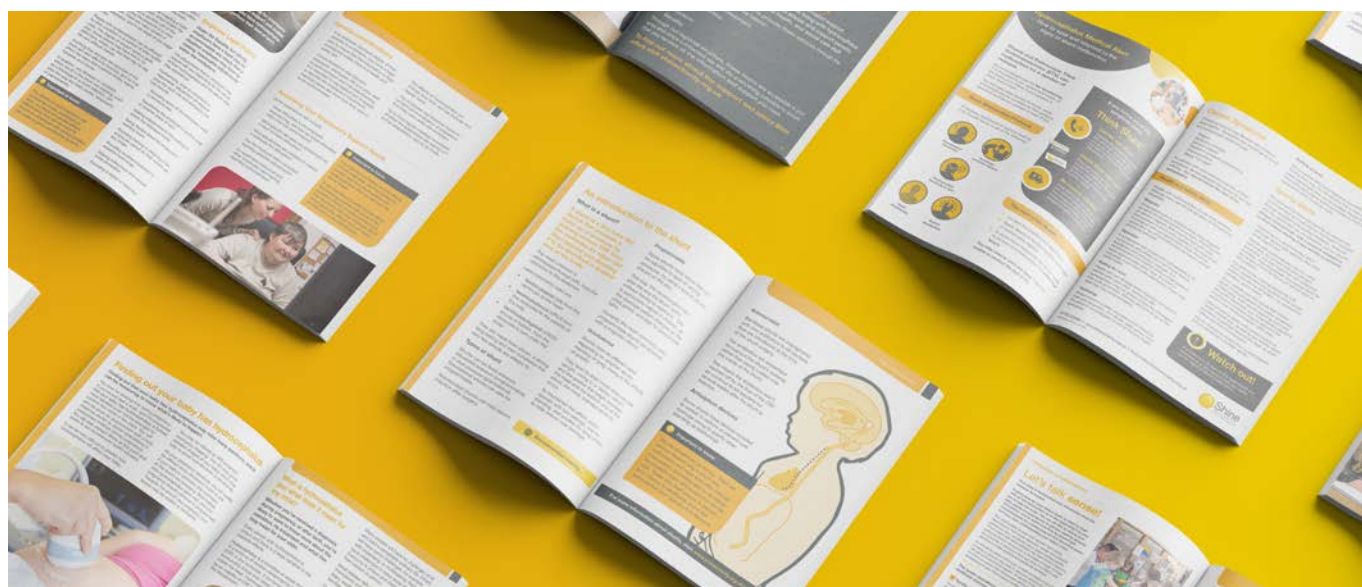
We do not use third-party professional fundraising agencies.

Where people or organisations raise funds in aid of Shine, we request they follow our standards. Shine's fundraising team provides tools and resources to enable supporters to deliver fun, safe, and successful fundraising activities. The trustees are of the view that during the year to 31 March 2024 we have been compliant with these standards. Unfortunately, despite procedures in place Shine is aware of one instance in the year of the misappropriation of donations totalling £150 at an event hosted by a Shine supporter.

To protect vulnerable people and other members of the public, Shine has a safeguarding policy, and our fundraising commitment is displayed on our website. We are careful to protect the private data of supporters and give clear options to stop being contacted by us. As part of our compliance with the code of fundraising practice, we ensure our approach to fundraising is not unreasonably intrusive or persistent and does not aim to solicit donations by pressuring potential supporters.

We take these steps to make sure people have a choice about whether to fundraise for Shine.

Shine and our members are incredibly grateful for the continued dedication and support of our fundraisers. From everyone at Shine, thank you for your ongoing generosity.



Structure, Governance and Management

Structure

Spina bifida, hydrocephalus, Information, Networking, Equality – SHINE (Shine) is a company limited by guarantee registered in England and Wales (Registration No. 00877990) formed in 1966. Shine is registered as a charity with the Charity Commission for England and Wales (Registration No. 249338).

The charity owns the entire share capital of Shine (Trading) Limited, registered in England and Wales (No. 01031004). The consolidated accounts include Shine (Trading) Limited (see note 9). The principal activity of the company is to raise funds for the charity. The board of directors of Shine trading meets separately and consists of the Chief and two trustees, the trustees are not remunerated for this role.

Objects

The charity's objects are specifically restricted to the relief of persons who have spina bifida and/or

hydrocephalus or allied or related disorders by providing care, welfare, treatment, education, and integration into society.

Governance

Shine is governed by Articles of Association, which were amended in 2018.

Organisational purpose

Shine has a clear, sustainable corporate strategy for 2022 to 2027 consistent with the charity's purpose and an evaluation and monitoring framework to monitor impact and measure outputs.

Shine consults with a wide range of stakeholder groups to determine the priorities for the charity.

Leadership

The ultimate responsibility for the governance of the charity and its subsidiary is entrusted to the trustee board.

Board Integrity

Appointment of trustees

New Articles of Association were adopted by special resolution in 2018 specifying that anyone willing to act as a trustee, and permitted by law to do so, may be appointed by the board of trustees.

A trustee must be a natural person aged 16 years or older, the minimum number of trustees is 3 and the maximum is 16. Trustees are appointed for a term of 3 years; trustees are eligible for reappointment up to two subsequent terms (each of 3 years). No trustee can serve for more than 9 consecutive years unless the trustees consider it is in the best interests of the charity that a particular trustee should continue to serve. Professor Roger Bayston continues to serve as a trustee on this basis and it is intended that Michael Brown will serve into a 4th term.

Trustee induction and training

During the recruitment process, the skills and experience are considered with a concerted effort to ensure we are drawing from all sections of society. An initial interview is conducted by members of the senior leadership team,

candidates are then interviewed by panel drawn from the board of trustees, on rare occasions exceptional candidates are appointed on recommendation of the Chief executive.

This year we have appointed two new trustees, Richard Oakley and Joanne Sedgwick who bring professional, commercial and lived experience. New trustees undergo induction. They are fully appraised of the full range of Shine's services, projects and campaigns and provided with relevant background literature. They receive awareness training, if required, on spina bifida and hydrocephalus. Depending on their specific skills and areas of expertise they will be put in touch with relevant staff.

Trustees are briefed on their legal obligations under charity and company law, the Articles of Association and the Board's decision-making process. They are also informed about Shine's Corporate Plan, key risks, recent financial performance, and prospects for the charity.

Trustees do not receive any remuneration or financial benefit for acting as trustees of shine, any expenses paid are disclosed in note 11 of the financial statements.

Decision making, risk and control

The Board of Trustees is the governing body with overall legal responsibility for the charity. The Board sets the strategic direction for Shine. It meets at least four times a year, either in person or virtually.

The minutes of meetings are made available to all trustees on a timely basis. The board regularly reviews operational plans, budgets, performance, and Shine's main risks. The day-to-day management of the charity is delegated to the Chief Executive, who reports to the Board. The Chief Executive is assisted in the day-to-day management by the senior leadership team.

Senior Staff Remuneration Policy

The remuneration of senior staff is set by benchmarking with similar-sized charities, and the market rate required to attract the best people to the job.

Diversity and Inclusion

Shine has a transparent recruitment process, advertising widely and looking at how we can attract a diverse pool of candidates.

Safeguarding

A full review of our safeguarding policies and processes began in 2020/21 with all policies further reviewed and updated in 2023/24, additional policies specifically focusing on online safety are being introduced in June 2024 ensuring that we are continually improving our approaches to safeguarding, incorporating all updated legislation, and embracing current best practice to protect the welfare of our members, staff and volunteers.

An annual safeguarding plan is agreed by trustees. The plan is prepared by the Director of Services, who is Designated Safeguarding Lead for the charity, in conjunction with Joanne Williams and Jenny Goy, who are trustee leads for safeguarding.

Safeguarding training is provided for all staff, trustees, and volunteers. Incidents are reported, assessed, and enacted as appropriate with full consideration given to the requirement to report to the Charity Commission.

GDPR

Extensive work was undertaken to ensure Shine's ongoing compliance with the General Data Protection Regulation (GDPR). We have a designated GDPR lead, and the data management action plan is reviewed by trustees annually.

Section 172 Statement

The trustees must act in accordance with a set of

general duties. These duties are laid out in s172 of the UK Companies Act 2006 which is summarised as follows: A Director of a Company must act in the that they consider, in good faith, would be most likely to promote the benefit of its members, and in doing so have regard to:

- The consequences of any decision in the long term, the main purpose of our reserves policy is to ensure long term financial sustainability.
- The interests of the charity's employees
- The need to foster the charity's business relationship with suppliers, customers, and others
- The impact of the charity's operations on the community and environment
- The desirability of the charity's maintaining a reputation for high standards of business
- The need to act fairly between members of the charity.

The trustees believe they have completed their duties under s172, taking care to balance competing interests for the overall good of the charity.

Related Parties

The charity collaborates with several local associations. These are independent charities for spina bifida and hydrocephalus and collaboration which may cover a range of activities. The charity also works in partnership with many other bodies, voluntary, statutory, and international, in carrying out work to support service users, undertake research and disseminate information.

Volunteers

In 2023/24, Shine had 50 registered volunteers (69 2022/23) and recorded 1,902 volunteered hours (2,134 2022/23), to whom we remain eternally grateful. The volunteering roles included:

- Working in our charity shop
- Giving talks and representing Shine
- Acting as peer support
- Supporting our members to grow in confidence and address the challenges of living with the conditions.
- Advising on the development of resources
- Fulfilling the role of Shine ambassador
- Fundraising
- Supporting our local groups

During the year, a volunteer catch-up meeting was held online to keep our volunteers engaged, we were not able to issue a volunteers' newsletter but plan to reintroduce it in 2024.

Statement of trustees' responsibilities

The trustees (who are also directors of spina bifida, hydrocephalus, information, networking, equality – SHINE), are responsible for preparing the annual report and the financial statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice.

Company law requires the directors to prepare financial statements for each financial year which give a true and fair view of the situation of the charitable group and of the net income or expenditure of the group for the year. In preparing these financial statements the directors are required to:

- select suitable accounting policies and then apply them consistently.
- observe the methods and principles in the Charities SORP
- make judgements and estimates that are reasonable and prudent.
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and the group and enable them to ensure that the financial statements comply with the Companies Act 2006.

They are also responsible for safeguarding the assets of the charity and the group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Statement as to disclosure of information to auditors

As far as the trustees are aware, there is no relevant audit information of which the group's auditors are unaware. Additionally, the trustees have taken all the necessary steps that they ought to have taken as trustees to make themselves aware of all relevant audit information and to establish that the group's auditors are aware of that information.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website.

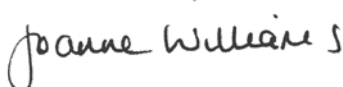
Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Appointment of Auditors

The continued appointment of Azets Audit Services Limited was confirmed by the Board of Trustees on the 5th December 2023..

This report has been prepared in accordance with the special provisions relating to small companies within Part 15 of the Companies Act 2006.

By order of the Board of Trustees



Joanne Williams

Chair

3rd September 2024

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

INDEPENDENT AUDITOR'S REPORT

TO THE MEMBERS OF SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

Opinion

We have audited the financial statements of Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE (the 'charity') and its subsidiary for the year ended 31 March 2024 which comprise the Group Statement of Financial Activities, the Group and Parent Charitable Company Balance Sheets, the Group and Parent Charitable Company Cash Flow Statements and the notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the Group and Parent Charitable Company affairs as at 31 March 2024 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the *Auditor's responsibilities for the audit of the financial statements* section of our report. We are independent of the Group and Parent Charitable Company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. The Trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE MEMBERS OF SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of our audit:

- the information given in the Trustees' report for the financial year for which the financial statements are prepared, which includes the directors' report prepared for the purposes of company law, is consistent with the financial statements; and
- the directors' report included within the Trustees' report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the Group and Parent Charitable Company and its environment obtained in the course of the audit, we have not identified material misstatements in the directors' report included within the Trustees' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the Trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemptions in preparing the Trustees' report and from the requirement to prepare a strategic report.

Responsibilities of Trustees

As explained more fully in the statement of Trustees' responsibilities, the Trustees, who are also the directors of the charity for the purpose of company law, are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the Group and Parent Charitable Company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities is available on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE MEMBERS OF SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

Extent to which the audit was considered capable of detecting irregularities, including fraud

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above and on the Financial Reporting Council's website, to detect material misstatements in respect of irregularities, including fraud.

We obtain and update our understanding of the entity, its activities, its control environment, and likely future developments, including in relation to the legal and regulatory framework applicable and how the entity is complying with that framework. Based on this understanding, we identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. This includes consideration of the risk of acts by the entity that were contrary to applicable laws and regulations, including fraud.

In response to the risk of irregularities and non-compliance with laws and regulations, including fraud, we designed procedures which included:

- Enquiry of management and those charged with governance around actual and potential litigation and claims as well as actual, suspected and alleged fraud;
- Reviewing minutes of meetings of those charged with governance;
- Assessing the extent of compliance with the laws and regulations considered to have a direct material effect on the financial statements or the operations of the entity through enquiry and inspection;
- Reviewing financial statement disclosures and testing to supporting documentation to assess compliance with applicable laws and regulations;
- Performing audit work over the risk of management bias and override of controls, including testing of journal entries and other adjustments for appropriateness, evaluating the business rationale of significant transactions outside the normal course of business and reviewing accounting estimates for indicators of potential bias.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.

This report is made solely to the company's members, as a body, in accordance with section 391 of the Companies Act 2014. Our audit work has been undertaken so that we might state to the company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the company and the company's members as a body, for our audit work, for this report, or for the opinions we have formed.



Mr Mark Jackson FCA DChA (Senior Statutory Auditor)
for and on behalf of Azets Audit Services

24 September 2024
.....

Chartered Accountants
Statutory Auditor

Westpoint
Lynch Wood
Peterborough
Cambridgeshire
United Kingdom
PE2 6FZ

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2024

Current financial year

	Notes	Unrestricted funds 2024 £	Designated funds 2024 £	Restricted funds 2024 £	Total 2024 £	Total 2023 £
Income and endowments from:						
Donations and legacies	3	1,074,858	-	404,076	1,478,934	1,186,664
Other trading activities	4	635,710	-	-	635,710	667,882
Income from investments	5	40,471	-	-	40,471	16,580
Other income	6	-	-	-	-	476,224
Total income		1,751,039	-	404,076	2,155,115	2,347,350
Expenditure on:						
Raising funds	7	730,978	-	-	730,978	714,814
Charitable activities	8	1,025,342	48,196	469,943	1,543,481	1,251,143
Total resources expended		1,756,320	48,196	469,943	2,274,459	1,965,957
Net gains/(losses) on investments	13	55,474	-	-	55,474	(42,342)
Net incoming/(outgoing) resources before transfers		50,193	(48,196)	(65,867)	(63,870)	339,051
Gross transfers between funds		(96,304)	72,500	23,804	-	-
Net (outgoing)/incoming resources		(46,111)	24,304	(42,063)	(63,870)	339,051
Other recognised gains and losses						
Actuarial loss on defined benefit pension schemes		(1,382)	-	-	(1,382)	(1,071)
Net movement in funds		(47,493)	24,304	(42,063)	(65,252)	337,980
Fund balances at 1 April 2023		1,215,980	486,729	157,015	1,859,724	1,521,744
Fund balances at 31 March 2024		1,168,487	511,033	114,952	1,794,472	1,859,724

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

STATEMENT OF FINANCIAL ACTIVITIES (CONTINUED) INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2024

Prior financial year

		Unrestricted funds 2023 £	Designated funds 2023 £	Restricted funds 2023 £	Total 2023 £
	Notes				
<u>Income and endowments from:</u>					
Donations and legacies	3	787,276	-	399,388	1,186,664
Other trading activities	4	667,882	-	-	667,882
Income from investments	5	16,580	-	-	16,580
Other income	6	507,724	(31,500)	-	476,224
Total income		1,979,462	(31,500)	399,388	2,347,350
<u>Expenditure on:</u>					
Raising funds	7	714,814	-	-	714,814
Charitable activities	8	711,303	105,502	434,338	1,251,143
Total resources expended		1,426,117	105,502	434,338	1,965,957
Net gains/(losses) on investments	13	(42,342)	-	-	(42,342)
Net incoming/(outgoing) resources before transfers		511,003	(137,002)	(34,950)	339,051
Gross transfers between funds		(19,385)	4,185	15,200	-
Net (outgoing)/incoming resources		491,618	(132,817)	(19,750)	339,051
<u>Other recognised gains and losses</u>					
Actuarial loss on defined benefit pension schemes		(1,071)	-	-	(1,071)
Net movement in funds		490,547	(132,817)	(19,750)	337,980
Fund balances at 1 April 2022		725,433	619,546	176,765	1,521,744
Fund balances at 31 March 2023		1,215,980	486,729	157,015	1,859,724

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

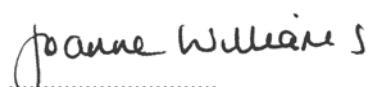
BALANCE SHEETS

AS AT 31 MARCH 2024

	Notes	Group 2024 £	Charity 2024 £	Group 2023 £	Charity 2023 £
Fixed assets					
Tangible assets	15	-	-	1,214	1,214
Investments	16	834,112	834,115	765,371	765,374
		834,112	834,115	766,585	766,588
Current assets					
Debtors	18	252,216	217,594	245,200	229,146
Cash at bank and in hand		885,550	870,690	1,059,901	1,028,214
		1,137,766	1,088,284	1,305,101	1,257,360
Creditors: amounts falling due within one year	19	(177,406)	(150,911)	(196,473)	(171,719)
Net current assets		960,360	937,373	1,108,628	1,085,641
Total assets less current liabilities		1,794,472	1,771,488	1,875,213	1,852,229
Net assets excluding pension liability		1,794,472	1,771,488	1,875,213	1,852,229
Defined benefit pension liability	20	-	-	(15,489)	(15,489)
Net assets		1,794,472	1,771,488	1,859,724	1,836,740
Income funds					
Restricted funds	21	114,952	114,952	157,015	157,015
<u>Unrestricted funds - general</u>					
Designated funds	22	511,033	511,033	486,729	486,729
General unrestricted funds		1,168,487	1,145,503	1,215,980	1,192,996
		1,679,520	1,656,536	1,702,709	1,679,725
		1,794,472	1,771,488	1,859,724	1,836,740

As permitted by section 408 of the Companies Act 2006, the charitable company has not presented its own statement of financial activities and related notes. The charitable company's deficit for the year was £65,252 (2023 - surplus for the year of £337,980).

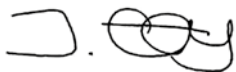
The financial statements were approved by the board of directors and authorised for issue on 03/09/24 and are signed on its behalf by:



Mrs J Williams

Trustee

Company Registration No. 00877990



Mrs J Goy

Trustee

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 31 MARCH 2024

	Notes	2024 £	£	2023 £	£
Cash flows from operating activities					
Cash absorbed by operations	27		(214,822)		(61,517)
Investing activities					
Proceeds on disposal of tangible fixed assets		-		1,271,240	
Purchase of investments		-		(425,000)	
Interest and income from investments		40,471		16,580	
Net cash generated from investing activities			40,471		862,820
Financing activities					
Repayment of bank loans		-		(362,216)	
Net cash used in financing activities			-		(362,216)
Net (decrease)/increase in cash and cash equivalents			(174,351)		439,087
Cash and cash equivalents at beginning of year			1,059,901		620,814
Cash and cash equivalents at end of year			885,550		1,059,901

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024

1 Accounting policies

Company information

Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE is a private company limited by guarantee incorporated in England and Wales. The registered office is Unit 4, The Forum, Minerva Business Park, Peterborough, Cambridgeshire, PE2 6FT, United Kingdom.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's governing document, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2019). The charity is a Public Benefit Entity as defined by FRS 102.

The financial statements have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a true and fair view. This departure has involved following the Statement of Recommended Practice for charities applying FRS 102 rather than the version of the Statement of Recommended Practice which is referred to in the Regulations but which has since been withdrawn.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

The consolidated accounts incorporate the results of the charity and of its wholly owned subsidiary.

1.2 Going concern

At the time of approving the financial statements, the Trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the Trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Designated funds comprise funds which have been set aside at the discretion of the Trustees for specific purposes. The purposes and uses of the designated funds are set out in the notes to the financial statements.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

1 Accounting policies

(Continued)

1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

Gifts donated for resale are included as income when they are sold. No amounts are included in the financial statements for services donated by volunteers.

Grant income is recognised according to the terms of each individual agreement.

All other income is dealt with on an accruals basis.

1.5 Resources expended

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement, and the amount of the obligation can be measured reliably.

Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges are allocated on the portion of the asset's use.

Direct expenditure is analysed and charged to the department incurring the cost. Expenditure is included when incurred, the majority of costs being directly attributable to specific activities. Costs that can not be directly attributable to particular headings, are allocated to activities on a basis consistent with use of the resources. Premises and other overheads have been allocated on a head count basis.

Fundraising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of charitable activities.

Governance costs are those incurred in connection with the governance arrangements of the charity and compliance with constitutional and statutory requirements.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

1 Accounting policies

(Continued)

1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses. Assets over £1,000 in value are capitalised at cost.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the straight line basis at the following rates:

Fixtures and fittings	20%
Equipment	20%
Software and website	20 - 33%

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

1.7 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible and intangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.8 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits repayable on demand and overdrafts. Deposits are repayable on demand if they are in practice available within 24 hours without a penalty. Liquid resources comprise assets held as a readily disposable store of value.

1.9 Financial instruments

Financial instruments are recognised when the charity becomes party to the contractual provisions of the instrument.

Financial assets are offset, with the net amounts presented in the accounts when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

1 Accounting policies

(Continued)

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

1.10 Provisions

Provisions are recognised when the charity has a legal or constructive present obligation as a result of a past event, it is probable that the charity will be required to settle that obligation and a reliable estimate can be made of the amount of the obligation.

The amount recognised as a provision is the best estimate of the consideration required to settle the present obligation at the reporting end date, taking into account the risks and uncertainties surrounding the obligation. Where the effect of the time value of money is material, the amount expected to be required to settle the obligation is recognised at present value. When a provision is measured at present value, the unwinding of the discount is recognised as a finance cost in net income/(expenditure) in the period in which it arises.

1.11 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the company is demonstrably committed to terminate the employment of an employee.

1.12 Retirement benefits

For employees choosing to participate, the charity operates a defined contribution pension scheme providing benefits additional to those from the State. The assets are held in a separately administered scheme. The pensions cost charge represents contributions payable by the company to the pension scheme in respect of the year.

Previously, the charity were part of a separately administered defined benefit scheme and is still required to make contributions to fund a deficit in the scheme.

The cost of providing benefits under defined benefit plans is determined separately for each plan using the projected unit credit method, and is based on actuarial advice.

The net interest element is determined by multiplying the net defined benefit liability by the discount rate, taking into account any changes in the net defined benefit liability during the period as a result of contribution and benefit payments. The net interest is recognised in income/(expenditure) for the year.

Remeasurement changes comprise actuarial gains and losses, the effect of the asset ceiling and the return on the net defined benefit liability excluding amounts included in net interest. These are recognised immediately in other recognised gains and losses in the period in which they occur and are not reclassified to income/(expenditure) in subsequent periods.

The net defined benefit pension asset or liability in the balance sheet comprises the total for each plan of the present value of the defined benefit obligation (using a discount rate based on high quality corporate bonds), less the fair value of plan assets out of which the obligations are to be settled directly. Fair value is based on market price information, and in the case of quoted securities is the published bid price. The value of a net pension benefit asset is limited to the amount that may be recovered either through reduced contributions or agreed refunds from the scheme.

1.13 Leases

Rentals payable under operating leases, including any lease incentives received, are charged as an expense on a straight line basis over the term of the relevant lease.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

2 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

3 Donations and legacies

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Total 2023 £
Donations and gifts	713,637	-	713,637	656,852
Legacies receivable	276,221	-	276,221	130,424
Grants receivable	85,000	404,076	489,076	399,388
	<u>1,074,858</u>	<u>404,076</u>	<u>1,478,934</u>	<u>1,186,664</u>
For the year ended 31 March 2023	<u>787,276</u>	<u>399,388</u>		<u>1,186,664</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

3 Donations and legacies

(Continued)

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Total 2023 £
Donations and gifts				
Individuals	425,059	-	425,059	328,621
Trusts	164,609	-	164,609	161,607
Corporate donors	85,928	-	85,928	128,455
Local associations	3,089	-	3,089	3,341
Health Trusts	34,952	-	34,952	34,828
	<u>713,637</u>	<u>-</u>	<u>713,637</u>	<u>656,852</u>
Grants receivable for core activities				
National Lottery Community fund Northern Ireland Shining Opportunities	-	97,696	97,696	99,219
National Lottery Community fund Cymru People & Places	-	57,867	57,867	-
National Lottery Community fund Cymru Shining lights	-	-	-	91,508
Early Intervention (Community lottery & others)	-	172,174	172,174	184,348
Tropical Health and Education Trust	-	39,329	39,329	-
The Henry Smith Charity	60,000	-	60,000	-
Garfield Weston Foundation	25,000	-	25,000	-
Margaret Giffen Charitable Trust	-	5,000	5,000	-
The Eveson Trust	-	-	-	12,500
The Lawson Trust	-	-	-	5,000
Florence Shute Charitable Trust	-	-	-	2,000
Other	-	32,010	32,010	4,813
	<u>85,000</u>	<u>404,076</u>	<u>489,076</u>	<u>399,388</u>

4 Other trading activities

	2024 £	2023 £
Income of trading subsidiary	608,455	625,654
Donations sold through shops	25,913	41,542
Publications and attendance fees	1,342	686
	<u>635,710</u>	<u>667,882</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

5 Income from investments

	2024 £	2023 £
Income from listed investments	22,279	12,694
Interest receivable	18,192	3,886
	<u>40,471</u>	<u>16,580</u>

6 Other income

	Total 2024 £	Unrestricted funds general 2023 £	Unrestricted funds designated 2023 £	Total 2023 £
Net gain on disposal of tangible fixed assets	-	507,724	(31,500)	476,224

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

7 Raising funds

			2024 £	2023 £
<u>Fundraising and publicity</u>				
Direct staff costs			263,697	250,879
Other fundraising direct costs			51,466	44,563
Support costs (see note 9)			80,677	82,181
			<u>395,840</u>	<u>377,623</u>
	Shine (Trading) Limited £	Shops £	Total 2024 £	Total 2023 £
<u>Trading costs</u>				
Direct staff costs	200,185	23,631	223,816	197,840
Other direct operational costs	19,375	2,327	21,702	46,261
Support costs (see note 9)	76,023	13,597	89,620	93,090
	<u>295,583</u>	<u>39,555</u>	<u>335,138</u>	<u>337,191</u>
Trading costs				
			<u>730,978</u>	<u>714,814</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

8 Charitable activities	Enabling babies and children to achieve their potential		Empowering young people		Adults of all ages to have choices and opportunities		A connected community		Preventing Spina Bifida		Changing experiences of pregnancies		Transforming attitudes		Total 2024		Total 2023	
	£	£	£	£	£	£	£	£	£	£	£	£	£	£	£	£	£	£
Direct staff costs	209,279	166,067	191,951	413,160	56,777	42,206	93,993	1,173,433	939,632									
Other direct costs	29,465	23,381	27,026	58,170	7,994	5,942	13,234	165,212	130,768									
	238,744	189,448	218,977	471,330	64,771	48,148	107,227	1,338,645	1,070,400									
Share of support costs (see note 9)	30,861	24,489	28,306	60,927	8,373	6,224	13,861	173,041	154,596									
Share of governance costs (see note 9)	11,195	4,499	5,671	1,144	5,201	2,547	1,538	31,795	26,147									
	280,800	218,436	252,954	533,401	78,345	56,919	122,626	1,543,481	1,251,143									
Analysis by fund																		
Unrestricted funds - general															1,025,342	711,303		
Unrestricted funds - designated															48,196	105,502		
Restricted funds															469,943	434,338		
															1,543,481	1,251,143		

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

9 Support and governance costs

	Fundraising and publicity £	Trading costs £	Charitable activities £	2024 £	2023 £
Support costs					
Staff costs	15,800	22,059	32,722	70,581	117,589
IT costs	12,431	9,805	41,760	63,996	53,344
Premises costs	40,342	12,240	33,036	85,618	89,562
Other support costs	25,701	31,919	65,523	123,143	69,371
	<u>94,274</u>	<u>76,023</u>	<u>173,041</u>	<u>343,338</u>	<u>329,866</u>
Governance costs				2024 £	2023 £
Staff costs				12,571	12,726
Audit fees				9,624	12,000
Other governance costs				9,600	1,421
				<u>31,795</u>	<u>26,147</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

10 Commercial operations in trading subsidiary

The charity has one wholly owned trading subsidiary undertaking, Shine (Trading) Limited which sells balloons for virtual balloon races. The company gift aids virtually all its taxable profits to Shine. A summary of its trading results is shown below. Audited accounts have been filed with the Registrar of Companies.

	2024 £	2023 £
Shine (Trading) Ltd Profit & Loss Account		
Turnover	608,455	625,654
Cost of sales	(192,036)	(184,526)
Gross profit	416,419	441,128
Administration expenses	(60,677)	(55,108)
Operating profit	355,742	386,020
Amount payable by gift aid to Shine	(355,742)	(386,020)
Profit on ordinary activities	-	-
Shine (Trading) Ltd Balance Sheet		
Current assets	164,816	170,277
Current liabilities	(141,829)	(147,290)
Net current assets	22,987	22,987
Total net assets	22,987	22,987
Aggregate share capital and reserves	22,987	22,987

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

11 Employees

Number of employees

The average monthly number of full time equivalent employees during the year was:

	2024 Number	2023 Number
Services	31	26
Fundraising and publicity	8	8
Shops	1	1
Administration	3	4
Shine (Trading) Limited	5	5
	<u>48</u>	<u>44</u>

Employment costs

	2024 £	2023 £
Wages and salaries	1,545,971	1,341,214
Redundancy costs	1,000	770
Social security costs	141,548	128,057
Other pension costs	51,324	45,014
Other staff related benefits	4,283	3,612
	<u>1,744,126</u>	<u>1,518,667</u>

The number of employees whose annual remuneration was £60,000 or more were:

	2024 Number	2023 Number
£80,001 - £90,000	1	1
£60,001 - £70,000	1	-

Pension contributions for higher paid employees were £10,465 (2023 - £6,560).

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

12 Trustees

None of the Trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

In respect of attending meetings of committees, travel expenses amounting to £1,401 (2023 - £1,421) have been reimbursed to 4 (2023 - 6) members of the Board of Trustees.

At the year end, £nil (2023 - £131) of the above expenses are unpaid and included as a creditor.

The accounts include a charge of £3,312 (2023 - £3,312) to provide the Trustees with indemnity insurance.

13 Net gains/(losses) on investments

	Total 2024 £	Total 2023 £
Revaluation of investments	54,956	(41,877)
Gain/(loss) on sale of investments	518	(465)
	<u>55,474</u>	<u>(42,342)</u>

14 Taxation

Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE is a registered charity. It only applies its funds in accordance with its charitable objectives, and is not trading with a view to making distributable profits, therefore corporation tax is not chargeable.

The trading subsidiary has gifted its profits to Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE under Gift Aid therefore no corporation tax is payable

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

15 Tangible fixed assets

	Equipment £	Software and website £	Total £
Group Cost			
At 1 April 2023	11,830	25,757	37,587
At 31 March 2024	11,830	25,757	37,587
Depreciation and impairment			
At 1 April 2023	10,616	25,757	36,373
Depreciation charged in the year	1,214	-	1,214
At 31 March 2024	11,830	25,757	37,587
Carrying amount			
At 31 March 2024	-	-	-
At 31 March 2023	1,214	-	1,214
	Equipment £	Software and website £	Total £
Charity Cost			
At 1 April 2023	9,191	18,728	27,919
At 31 March 2024	9,191	18,728	27,919
Depreciation and impairment			
At 1 April 2023	7,977	18,728	26,705
Depreciation charged in the year	1,214	-	1,214
At 31 March 2024	9,191	18,728	27,919
Carrying amount			
At 31 March 2024	-	-	-
At 31 March 2023	1,214	-	1,214

The charity owns a freehold interest in some land that is leased to another charity at a peppercorn rent and used in furtherance of the charitable objects. The lease ends in 2084 and no value is included in the accounts for the property.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

16 Fixed asset investments

	Group 2024 £	Charity 2024 £	Group 2023 £	Charity 2023 £
Investments in subsidiaries	-	3	-	3
Listed investments	834,112	834,112	765,371	765,371
	<u>834,112</u>	<u>834,115</u>	<u>765,371</u>	<u>765,374</u>

Movements in fixed asset investments Group and Charity

	2024 £	2023 £
Cost or valuation		
At 31 March 2023	733,130	338,944
Additions within portfolio	160,726	451,132
Disposals within portfolio	(148,394)	(24,531)
Valuation changes	70,525	(32,415)
	<u>815,987</u>	<u>733,130</u>
Cash held for investment	18,125	32,241
At 31 March 2024	<u>834,112</u>	<u>765,371</u>

17 Financial instruments

	Group 2024 £	Charity 2024 £	Group 2023 £	Charity 2023 £
Carrying amount of financial assets				
Trade debtors	156,621	10,890	165,272	30,849
Other debtors	-	-	750	750
Accrued income	58,234	58,234	27,500	27,500
Amounts due from subsidiary undertakings	-	115,334	-	122,536
Bank and cash	885,550	870,690	1,059,901	1,028,214
Measured at cost	<u>1,100,405</u>	<u>1,055,148</u>	<u>1,253,423</u>	<u>1,209,849</u>
Fixed asset investments	<u>834,112</u>	<u>834,115</u>	<u>765,371</u>	<u>765,374</u>
Measured at market value	<u>834,112</u>	<u>834,115</u>	<u>765,371</u>	<u>765,374</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

17	Financial instruments	(Continued)			
		Group	Charity	Group	Charity
	Carrying amount of financial liabilities				
	Trade creditors	9,299	9,142	21,658	21,462
	Accruals and deferred income	83,383	76,797	93,230	85,428
	Other creditors	32,710	31,662	36,796	35,885
	Other taxation and social security	52,014	33,310	44,789	28,944
	Measured at cost	177,406	150,911	196,473	171,719
18	Debtors				
		Group	Charity	Group	Charity
		2024	2024	2023	2023
	Amounts falling due within one year:	£	£	£	£
	Trade debtors	156,621	10,890	165,272	30,849
	Amounts due from subsidiary undertakings	-	115,334	-	122,536
	Other debtors	-	-	750	750
	Prepayments and accrued income	95,595	91,370	79,178	75,011
		252,216	217,594	245,200	229,146
The net amount owed by the subsidiary includes amounts owing for gift aid receivable and payment for services provided.					
19	Creditors: amounts falling due within one year				
		Group	Charity	Group	Charity
		2024	2024	2023	2023
		£	£	£	£
	Other taxation and social security	52,014	33,310	44,789	28,944
	Trade creditors	9,299	9,142	21,658	21,462
	Other creditors	32,710	31,662	36,796	35,885
	Accruals and deferred income	83,383	76,797	93,230	85,428
		177,406	150,911	196,473	171,719

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

20 Retirement benefit schemes

The Pensions Trust - The Growth Plan

SHINE participates in The Pension Trust's Growth Plan (The Plan), a multi-employer scheme which provides benefits to some 638 non-associated participating employers. The scheme is a defined benefit scheme in the UK.

It is not possible for the charity to obtain sufficient information to enable it to account for the scheme as a defined benefit scheme. Therefore it accounts for the scheme as a defined contribution scheme.

The scheme is subject to the funding legislation outlined in the Pensions Act 2004 which came into force on 30 December 2005. This, together with documents issued by the Pensions Regulator and Technical Actuarial Standards issued by the Financial Reporting Council, set out the framework for funding defined benefit occupational pension schemes in the UK.

The scheme is classified as a 'last-man standing arrangement'. Therefore the charity is potentially liable for other participating employers' obligations if those employers are unable to meet their share of the scheme deficit following withdrawal from the scheme. Participating employers are legally required to meet their share of the scheme deficit on an annuity purchase basis on withdrawal from the scheme.

A full actuarial valuation for the scheme was carried out at 30 September 2020. This actuarial valuation showed assets of £800.3m, liabilities of £831.9m and a deficit of £31.6m. To eliminate this funding shortfall, the trustees and the participating employers have agreed that additional contributions will be paid to the scheme as follows:

Deficit contributions

From 1 April 2022 to 31 January 2025:	£3,312,000 per annum (payable monthly)

Note that the scheme's previous valuation was carried out with an effective date of 30 September 2017. This valuation showed assets of £794.9m, liabilities of £926.4m and a deficit of £131.5m. To eliminate this funding shortfall, the Trustee asked the participating employers to pay additional contributions to the scheme as follows:

Deficit contributions

From 1 April 2019 to 30 September 2025:	£11,243,000 per annum (payable monthly and increasing by 3% each on 1st April)

The recovery plan contributions are allocated to each participating employer in line with their estimated share of the Series 1 and Series 2 scheme liabilities.

Where the scheme is in deficit and where the charity has agreed to a deficit funding arrangement the company recognises a liability for this obligation. The amount recognised is the net present value of the deficit reduction contributions payable under the agreement that relates to the deficit. The present value is calculated using the discount rate detailed in these disclosures. The unwinding of the discount rate is recognised as a finance cost.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

20 Retirement benefit schemes

(Continued)

Present values of provision

	31 March 2024	31 March 2023	31 March 2022
Present value of provision	16,884	36,146	56,698

An amount of £16,884 (2023 - £20,657) is included within short term creditors and £nil (2023 - £15,489) in long term liabilities.

Reconciliation of opening and closing provisions

	Year Ending 31 March 2024	Year Ending 31 March 2023
Provision at start of period	36,146	56,698
Unwinding of the discount factor (interest expense)	1,382	1,071
Deficit contribution paid	(20,657)	(20,657)
Remeasurements - impact of any change in assumptions	13	(966)
Provision at end of period	16,884	36,146

Income and expenditure impact

	Year Ending 31 March 2024	Year Ending 31 March 2023
Interest expense	1,382	1,071
Remeasurements - impact of any change in assumptions	13	(966)
Costs recognised in income and expenditure account	1,395	105

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

20 Retirement benefit schemes

(Continued)

Assumptions

	31 March 2024 % per annum	31 March 2023 % per annum	31 March 2022 % per annum
Rate of discount	5.31	5.52	2.35

The discount rates shown above are the equivalent single discount rates which, when used to discount the future recovery plan contributions due, would give the same results as using a full AA corporate bond yield curve to discount the same recovery plan contributions.

The following schedule details the deficit contributions agreed between the company and the scheme at each year end period:

Deficit contributions schedule

Year ending	31 March 2024	31 March 2023	31 March 2022
Year 1	17,214	20,657	20,657
Year 2	-	17,214	20,657
Year 3	-	-	17,214

The charity must recognise a liability measured as the present value of the contributions payable that arise from the deficit recovery agreement and the resulting expense in the income and expenditure account i.e. the unwinding of the discount rate as a finance cost in the period in which it arises.

It is these contributions that have been used to derive the charity's balance sheet liability.

The Plan is closed to new entrants and there were no active members of the scheme during the year.

The Scheme has identified a potential issue in respect of the calculation of benefits paid and has instigated a review. The outcome of the review is unknown and the potential financial impact of the review if an issue is identified is unknown. A potential liability may arise, but no provision is included in these accounts as the amount cannot be quantified.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

21 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

	Balance at 1 April 2022 £	Movement in funds			Transfers £	Balance at 1 April 2023 £	Movement in funds			Transfers £	Balance at 31 March 2024 £
		Income £	Expenditure £				Income £	Expenditure £			
National Lottery Community Fund – Early intervention programme across England	96,483	184,348	(203,409)		2,137	79,559	172,174	(209,292)		8,070	50,511
National Lottery Community fund Northern Ireland Shining Opportunities	18,737	99,219	(82,892)		-	35,064	97,696	(100,798)		-	31,962
International Projects: Continence care and management project (Nigeria)	11,723	-	(13,293)		-	(1,570)	39,329	(28,234)		-	9,525
Coop Grant	2,457	-	(339)		-	2,118	-	(325)		-	1,793
National Lottery Community fund: Cymru People & Places	-	-	-		-	-	57,867	(63,841)		14,154	8,180
National Lottery Community fund: Cymru Shining lights	14,100	91,508	(96,040)		11,905	21,473	-	(23,053)		1,580	-
South West Country SDW	6,802	1,000	(7,802)		-	-	-	-		-	-
Regional Projects "Here for you"	3,722	19,500	(8,101)		-	15,121	5,000	(15,122)		-	4,999
Database development	915	-	(2,073)		1,158	-	-	-		-	-
Welfare Grants	15	3,813	(5,918)		-	(2,090)	6,790	(4,685)		-	15
Support Groups	1,371	-	464		-	1,835	-	1,306		-	3,141
South West Country SDW	-	-	-		-	-	8,500	(8,500)		-	-
NPH Coordinator	-	-	-		-	-	1,000	-		-	1,000
Spinal Stimulation	-	-	-		-	-	10,720	(6,894)		-	3,826
Margaret Giffen Charitable Trust - supporting our work in Northamptonshire	20,440	-	(14,935)		-	5,505	5,000	(10,505)		-	-
	176,765	399,388	(434,338)		15,200	157,015	404,076	(469,943)		23,804	114,952

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

22 Designated funds

The income funds of the charity include the following designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes:

Group	Balance at 1 April 2022 £	Net movement £	Balance at 1 April 2023 £	Net movement £	Balance at 31 March 2024 £
Interest in land and property and other fixed assets	435,237	(434,023)	1,214	(1,214)	-
Florence Bartle fund	74,659	21,628	96,287	(28,876)	67,411
HR fund	7,500	(7,500)	-	-	-
Services in Northern Ireland, Wales and Gloucestershire	70,650	(41,422)	29,228	(16,881)	12,347
Dilapidations	31,500	(31,500)	-	-	-
Digital development	-	25,000	25,000	-	25,000
Research	-	50,000	50,000	-	50,000
Service funds:					
- East Anglian SDW	-	75,000	75,000	-	75,000
- Deputy Health Manager	-	135,000	135,000	-	135,000
- Education Officer	-	50,000	50,000	-	50,000
- Physio service (Spinal Stimulation)	-	25,000	25,000	(1,225)	23,775
- Normal Pressure Hydrocephalus	-	-	-	72,500	72,500
	<u>619,546</u>	<u>(132,817)</u>	<u>486,729</u>	<u>24,304</u>	<u>511,033</u>
Charity					
Interest in land and property and other fixed assets	435,237	(434,023)	1,214	(1,214)	-
Florence Bartle fund	74,659	21,628	96,287	(28,876)	67,411
HR fund	7,500	(7,500)	-	-	-
Services in Northern Ireland, Wales and Gloucestershire	70,650	(41,422)	29,228	(16,881)	12,347
Dilapidations	31,500	(31,500)	-	-	-
Digital development	-	25,000	25,000	-	25,000
Research	-	50,000	50,000	-	50,000
Service funds:					
- East Anglian SDW	-	75,000	75,000	-	75,000
- Deputy Health Manager	-	135,000	135,000	-	135,000
- Education Officer	-	50,000	50,000	-	50,000
- Physio service (Spinal Stimulation)	-	25,000	25,000	(1,225)	26,225
- Normal Pressure Hydrocephalus	-	-	-	72,500	72,500
	<u>619,546</u>	<u>(132,817)</u>	<u>486,729</u>	<u>24,304</u>	<u>511,033</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

22 Designated funds

(Continued)

The designated funds comprise:

- the group and charity's interest in land and property and other fixed assets, net of the outstanding mortgage.
- the Florence Bartle fund which is part of a legacy that is to be spent on the relief of Spina Bifida in Cornwall and the South West.
- the services in Northern Ireland, Wales and Gloucestershire that is for work specifically in those areas.
- the dilapidations fund that was for future leasehold dilapidations.
- the digital development fund that is to develop a long-term IT/digital strategy to aid in future-proofing Shine's approaches to technology and automation.
- the research fund that is to improve access to health and care services in line with Shine's strategic goals.
- the service funds that are to fund new posts as detailed above.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

23	Analysis of net assets between funds	Unrestricted funds		Designated funds		Restricted funds		Total Unrestricted funds		Designated funds		Restricted funds		Total	
		2024	£	2024	£	2024	£	2024	£	2023	£	2023	£	2023	£
Group	Fund balances at 31 March 2024 are represented by:														
	Tangible assets														
	Investments	834,112		-		-		834,112		-		-		1,214	
	Current assets/(liabilities)	334,375		511,033		114,952		960,360		466,098		157,015		765,371	
	Provisions and pensions	-		-		-		-		(15,489)		-		1,108,628	
														(15,489)	
		1,168,487		511,033		114,952		1,794,472		1,215,980		157,015		1,859,724	
Charity	Fund balances at 31 March 2024 are represented by:														
	Tangible assets														
	Investments	834,115		-		-		834,115		-		-		1,214	
	Current assets/(liabilities)	311,388		511,033		114,952		937,373		765,374		157,015		765,374	
	Provisions and pensions	-		-		-		-		443,111		-		1,085,641	
										(15,489)		-		(15,489)	
		1,145,503		511,033		114,952		1,771,488		1,192,996		157,015		1,836,740	

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

24 Operating lease commitments

Group and Charity

At the reporting end date the charity had outstanding commitments for future minimum lease payments under non-cancellable operating leases, which fall due as follows:

	2024 £	2023 £
Within one year	48,420	48,420
Between two and five years	75,826	124,258
	<u>124,246</u>	<u>172,678</u>

25 Related party transactions

Remuneration of key management personnel

The remuneration of key management personnel, who on a full time equivalent basis are the 2.6 (2023 - 2.5) members of the senior management team, is as follows.

	2024 £	2023 £
Aggregate compensation including pension contributions	<u>187,045</u>	<u>168,298</u>

Transactions with related parties

Owing to the nature of the charity's operations, some of the Trustees may themselves, or may have family members that access services from the charity. Consequently there will be transactions between those Trustees or their family members. These are on the same basis as other service users of the charity.

26 Control

No one individual has overall control of the charity.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

27	Cash generated from operations	2024 £	2023 £
	(Deficit)/surplus for the year	(65,252)	337,980
	Adjustments for:		
	Investment income recognised in statement of financial activities	(40,471)	(16,580)
	Investment management fees recognised in statement of financial activities	(9,014)	(7,845)
	Gain on disposal of tangible fixed assets	-	(476,224)
	(Gain)/loss on disposal of investments	(518)	465
	Fair value gains and losses on investments	(54,956)	41,877
	Depreciation and impairment of tangible fixed assets	1,214	1,223
	Movements in working capital:		
	(Increase)/decrease in debtors	(7,016)	55,636
	(Decrease)/increase in creditors	(19,547)	22,503
	Increase/(decrease) in pension liability	(19,262)	(20,552)
	Cash absorbed by operations	(214,822)	(61,517)
28	Analysis of changes in net funds		
	The group and charity had no debt during the year.		



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www.shinecharity.org.uk

Charity number 249338, Company number 00877990



Shine

Spina bifida • Hydrocephalus
Information • Networking • Equality

Accounts

Trustees' Annual Report and Financial Statements

Year ended 31st March 2023



Shine

Spina bifida • Hydrocephalus
Information • Networking • Equality



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Message from Chair, Joanne Williams

I was delighted to accept the role of Chair of Shine and look forward to working alongside my fellow trustees and Shine's staff and volunteers in the delivery of our Corporate Plan.

The 7 strategic goals, set out in the plan, are hugely ambitious. From experience, we know they will not be delivered overnight. The activities and projects have been mapped out in annual work plans, with milestones for delivery and review at key points throughout each year, and the lifetime of the Plan. We are fortunate to have such a dedicated team of staff at Shine, who are committed to making a difference and will do so with empathy, compassion and hard work.

Over the past 12 months, Shine, like so many other charities, has faced a considerable number of challenges such as the aftereffects of the pandemic, the cost-of-living crisis, the war in Ukraine, a buoyant job seekers market, less access to funds and increased competition from other charities vying for the same pot of money. But despite these many obstacles, the charity has successfully ridden the storm and proven resilient. My heartfelt appreciation goes to the staff for their fortitude and diligence in planning and delivering on our objectives and managing the budget so successfully.



We have experienced ever-increasing demand for our services, with our membership growing by 6% since April 2023.

In 2022/23, as well as all the service and support we provided to our members, their families, friends and professionals across England, Wales and Northern Ireland, Shine

- completed the sale of our head office in Peterborough, and re-located to a smaller, rented office on the outskirts of the city, reducing overheads and annual costs of running the charity
- reviewed and increased our levels of reserves to ensure Shine remains a going concern
- designated funds to strengthen and grow our services
- increased staff levels in our Services and Health teams to meet increasing needs, and future-proof our long-term sustainability
- maintained our focus on staff well-being and created opportunities for progress and personal development
- introduced a triage system and new member database to better serve our members

This bodes well for 2023/24. We have an exciting year ahead!

With my best wishes

**Joanne Williams,
Chair**





Introducing our new Corporate Plan 2022 – 2027

Kate Steele, CEO

'Engage, Enable and Empower ... The Next Steps' is informed by over 55 years of experience and expertise and builds on the successes and lessons learnt from our most recent five-year plan. Reflecting our members' feedback and ideas on the services, activities and campaigns they want Shine to deliver, the outcomes should see an ever stronger and growing community of engaged, enabled and empowered people, whose lives have been affected by spina bifida and/or hydrocephalus, and associated conditions.

It is 14 years in September since I started my first role with Shine, and 8 years since I took on the role of CEO for this wonderful charity.

Never a day goes by when I don't sit and reflect on the enormous challenges that some of our members of all ages face. Equally, there is rarely a day when I don't marvel at the inspirational stories Shine members are so willing to share, to encourage and inform others in similar situations as it is this shared experience, as well as Shine's many years of insight and experience, that makes us so unique.

Over the past 12 months, we have, once again, provided information, support, advice and networking opportunities to thousands of people across England, Wales and Northern Ireland, and have collaborated with others nationally and internationally to reach many more.

Our Corporate Plan 2022 – 2027 sets out our ambitions to see further change in the coming years, and focuses on 7 strategic goals:

Goals 1 – 4 set out our ambitions to improve and widen our services to work closely with our members of all ages, tailoring our services to meet the individual and collective needs of our Shine community.

Goal 5 details the work we are doing to reduce

the chances of pregnancies being affected by neural tube defects. Whilst this work may seem contradictory to the work we do to support, advise and guide our members who have spina bifida and/or hydrocephalus, we also need to raise awareness of the role of folic acid and B12 in preventing neural tube defects (NTDs), such as spina bifida. This enables choice – individuals and families are better equipped to make informed decisions, according to their values and beliefs.

Goal 6 outlines Shine's pregnancy advice service for our members who wish to explore possibilities and plan for children. It is also for those who may have had a previous pregnancy affected by an NTD (Neural Tube Defect) and for parents-to-be whose baby has been diagnosed with spina bifida, hydrocephalus or anencephaly.

Goal 7 highlights Shine's ambitions for campaigning and influencing on the national and international stages – to champion lasting improvements in statutory services so that everyone whose lives are affected by spina bifida and hydrocephalus, or associated conditions, can have access to the right services and support when they need them.

Shine has existed for 57 years. Over this time, we have seen enormous changes to health and care, societal attitudes and increased opportunities for our members to live the lives they want to. Yet, Shine's journey is far from over. There is still much to do, but I sincerely believe that, as a collective community, we will continue to make a vital difference to so many. This annual report shares some of the ways in which we have been able to do this in 2022/23.

A huge thank you to everyone across our community, for your on-going faith, trust and support for Shine.

Our community



Strategic goal 1

Enabling babies and children with spina bifida and/or hydrocephalus to achieve their potential (0 to 12 years old).



Early intervention and preventative approaches to improving health and well-being “can help children and young people to develop the skills they need to live happy, healthy and successful lives. It can improve the quality of children’s home lives and family relationships, increase educational attainment and support good mental health” (Early Intervention Foundation).



Thanks to funding from the Community Funds in England, Wales and Northern Ireland, other sources of funding and investment from our reserves, Shine’s ambitions, to provide these foundations for improved health, equal access to educational opportunities, social and emotional outcomes for Little Stars as they grow and develop and journey through key stages of life, have been brought to life.

This work builds on the past success of our Little Stars programme, which initially focused on

0–10-year-olds, but has been extended to include 11 and 12-year-olds.

Our new youth project also got off the ground, giving focus to our teenage members’ needs and wants, and providing a programme for progression from our Little Stars as they ‘graduate’ to become teenagers.



(online sessions; face-to-face get togethers; school presentations; support at clinics)



327 ONLINE SESSIONS DELIVERED

60

FACE-TO-FACE SESSIONS RUN



477

INDIVIDUALS PARTICIPATED



“ We asked our parents and carers of our Little Stars about their experience



“What you provide is brilliant for families in this situation”

“If you’re having a bad day you can go to Little Stars and get it off your chest”

“Thank you to Little Stars for making us feel a little bit less isolated”

“It’s a brilliant force, we are very lucky to have [you] to support our little children”

‘I found an hour on video chat with Shine’s physio was more useful than a year with our actual physio.’





What's **CONTINUED?**

1-2-1 support, advice and guidance

The core of our unique, specialist work has continued to be the offer of 1-2-1 tailored support, advice and guidance on a range of issues relating to spina bifida, hydrocephalus and associated conditions.

Number of people supported 1-2-1  



Very rarely do our teams know what questions are going to be asked, but whatever they may be, our service staff work diligently to find answers and provide support and solutions, referring to external organisations where more appropriate.

Online events

Since March 2020, we have turned our attention to online information and get-togethers to enable our younger members, and their parents, to keep in touch, talk to others and learn. Proven to be both a cost-effective way of engaging and connecting our community, it has also enabled so many more of our members to get involved, without the need to travel long distances, tackle public transport, or avoid last-minute cancellations due to ill health.

Health Hubs

Due to the funding structure in Wales, we have been offering access to Health Hubs for our Welsh members. Health hubs are face-to-face sessions with Shine's specialist continence nurse and/or physiotherapist, with additional input from one of our Support and Development Workers

Using others' expertise

Shine partnered with experts from other fields, such as the ADHD Foundation and the Pressure Ulcer Prevention and Intervention Service (PUPIS), to deliver online training sessions on specific topics, related to some aspects of spina bifida and / or hydrocephalus and associated conditions.

What's **NEW?**

Touchpoints

 **282 touchpoints were delivered**

Shine's touchpoints programme offers a support call to all parents of 0–2-year-olds in England and Northern Ireland, providing access to our specialist occupational therapist and physiotherapist, facilitating a better understanding of the conditions and how various therapies can make a difference, and preparing parents for meetings with NHS services.

Newsletters

 **2,375 families received the newsletters**

As part of the plans in our previous Corporate Plan 2017 – 2022, our Little Stars team created a series of

age and condition-specific newsletters to aid parents of children with spina bifida and/or hydrocephalus to better understand key milestones in their child's first ten years of life, providing information, guidance and prompts for planning next steps.

Newsletters have now been created to address the questions and needs of our 11- and 12-year-old members and will launch in 2023/24.

Clinic attendance

 **Regular attendance at 8 CLINICS**

Contact with 6 more to establish referral pathways and opportunities for attendance

NHS clinics have slowly, but surely, resumed over the past 12 months. Shine's presence at these clinics has offered additional support to the NHS staff organising and running the clinics but, more importantly, ensured that our teams are on hand to listen, answer questions and put medical jargon into plain language as well as offering support for other things such as benefits, education, housing and socialisation.

Shall 'wee' talk?

 **Shall wee talk 14 online sessions ran**

A fun play on words for a serious issue that affects so many lives, "Shall 'wee' talk" brings together groups of children online to talk about continence in a safe and trusted environment, sharing their stories, talking about their challenges and, ultimately, realising that they are not alone.

Educational support

 **219 enquiries for educational support for 0-12 years**
68% of the total education enquiries

Demand for advice and guidance on education and transition has been as great as ever.

Shine's Trustees, therefore, agreed to invest in a part-time Education Officer to lead on the development and delivery of Shine's education service for spina bifida and hydrocephalus, and be a central point of

contact for other Shine staff for complex education referrals, as well as continuing the existing education offer of presentations and awareness raising to support schools in tailoring approaches to teaching and extra-curricular activities to meet the needs, and improve outcomes, for individual children and their families.

What's **NEXT?**

- Widening the reach and sustainability of our "Shall 'wee' Talk" continence support programme
- A sibling support programme
- Greater engagement with NHS clinics
- A review of our education programme and resources, including 'education touchpoints'
- A review of our benefits service
- Upskilling parent/carers in understanding and managing behaviour and executive function in children with hydrocephalus and spina bifida



Strategic Goal 2



Empowering young people with spina bifida and/or hydrocephalus through knowledge, confidence and skills to manage their conditions and thrive.

A programme that focuses on our teenage members has been long overdue, especially as we know that our teenage members are one of the hardest to reach groups, and difficult to keep engaged as there are so many other things happening in their lives – transition from and to school; transition from child to adult services; transition from education to employment or other activities; changes in health and well-being; greater independence; friendships.

All of these can also create challenges, and it is important to know that Shine is here to help.

“Teen session really good – great to have an outside speaker to offer something different.”

What's **NEW?**

As a start to this work, in the past 12 months, the Shine teams have provided:



1-2-1 support

254 teens aged 13-17 were supported through 1-2-1 support, with 625 enquiries in total (an average of 2.5 enquiries each).

Tailored to the questions that our teenage members, and parents/carers ask, this service answers a huge variety of questions and provides advice on changes in health, better continence management, building confidence, transitions between schools, and from school to further studies and employment. Our teams have also linked with young people in NHS clinics across the country.



Online teen groups

108 teenagers engaged in 46 online sessions. The teams across England, Wales and Northern Ireland had a fantastic response to our shout out for our teenagers to join our closed zoom sessions, which are now running regularly.



WhatsApp groups and online zooms for parent/carers

Parents/carers need support too. The teams introduced two new ways of providing this, through a series of WhatsApp groups and online sessions. Proven to be very popular, parents and carers have had access to a network of expert staff and peer support to aid in their day-to-day lives, to address the challenges and frustrations, but also to share successes and good news.



Shine reached out to us and it was like a weight lifted from my shoulders!

My daughter had never met anyone like her before and 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”



Zoom sessions are a great place to meet people like me and Chris is such a funny guy!... Thank you for introducing me to the group. I don't feel so alone. It's great to have new friends"



Thanks to funding from the Community Fund England, and additional investment approved by our Trustees, Shine has employed a **Youth Voice and Engagement Officer** to champion this work, engaging the young people in shaping and directing the services Shine offers, with the content and delivery methods to meet their needs.



What's **NEXT?**

With involvement, advice and guidance from our teen members, we will:

- Develop the teen programme and activities
- Produce teen-appropriate information, resources and webpages
- Develop content for the 13 – 18-year-old newsletters
- Introduce a focus on transition from child to adult services
- Establish a peer-to-peer buddy support programme
- Put an annual programme of online and face to face events in place
- Work with external agencies to 'tap into' existing education and career programmes
- Support parents to develop their confidence and knowledge to empower their children through teenage years
- Offer emotional support



It is nice to know that other people are going through a similar thing to me."



Strategic goal 3

Adults of all ages with spina bifida and/or hydrocephalus have the choices and opportunities to live healthy and independent lives

Whilst health, well-being, lifestyle, finances and career support / employment feature as the top five primary issues that our adult members are likely to ask for advice, support and guidance on, Shine's work and intervention with our adult members is wide-ranging and differs from person to person.

Some have extremely complex health and care needs and cannot live independently. They require 24-hour care, which is sometimes provided through residential care, but often by their parents who are also their carers. Others live highly successful and very independent lives, are in employment, are in relationships, have families and wide circles of friends, and pursue the interests and activities they wish to.

There are others who live independently but whose choices are limited due to restraints on their health, finances, access to appropriate housing, equipment, and lack of access to appropriate health and other statutory services.

All need access to the right health and care services

at the right time, yet NHS resources are limited and there are very few specialist services for adults living with the conditions.

What's CONTINUED?



3,000 adult members received 1-2-1 support

1-2-1 support

As for our babies, children and young people, our network of Support and Development Workers across England, Wales and Northern Ireland provide tailored support, advice and guidance on a range of issues for our adult members.

Virtual health hubs

There are very few NHS adult clinics across England and Wales. Shine's virtual health hubs offer adult members the opportunity to join members of our health team for a 1-2-1 consultation and advice on health and well-being, either holistically or for a particular concern. Our members are supported to develop action plans to address their health issues and can request a supporting letter for their GP or other health professional to help access the NHS services they need.

Shine40Plus



660 ACTIVE MEMBERS

With an active 660 members on our closed Facebook group, Shine40Plus has continued to offer peer support, opportunities to share stories, ask questions and chat again this year to people living with spina bifida and hydrocephalus from all over England, Wales



The resources you have given me for work, are beyond fantastic! They have been so helpful, and I have an occupational health appointment booked in soon too, which I really really appreciate. Thank you millions, for all your help, I can't explain how much I appreciate it!"

and Northern Ireland. It is moderated by volunteers and is open for business 365 days a year.

Promoting our specialist information and resources

Shine has produced a wealth of information and helpful resources which can be used for planning and prompts to better manage conditions, prepare for appointments or help others, such as employers, understand the best way they can offer support.

These specialist resources sometimes get lost or

forgotten yet continue to serve a useful purpose. Shine used Spina Bifida Awareness Week and Hydrocephalus Awareness Week 2022/23 as an opportunity to remind our members, their families and professionals what we have available and how to access them.

Online clubs

From monthly book clubs to craft sessions for Easter, from coffee and chats to quiz nights, Shine's programme of online clubs has become a regular feature in our over 18s' calendar.

“ People said...

“I'm really enjoying reading everyone's stories. Thank you all for sharing”
“Thanks for a very informative session”

What's **NEW?**

Staying Well – newsletters and online sessions

The cost-of-living crisis has affected people in different ways, creating demand for a variety of information and support to meet individuals' and families' personal situations. In 2022, the Service team developed 'Staying Well' - a programme of regular newsletters, social media posts and associated online sessions to equip our members with tips and ideas for keeping warm, eating well, managing money and physical and mental well-being.

A focus on Normal Pressure Hydrocephalus (NPH)



Shine has seen an upsurge in requests for information and support for adults with NPH, and their carers.

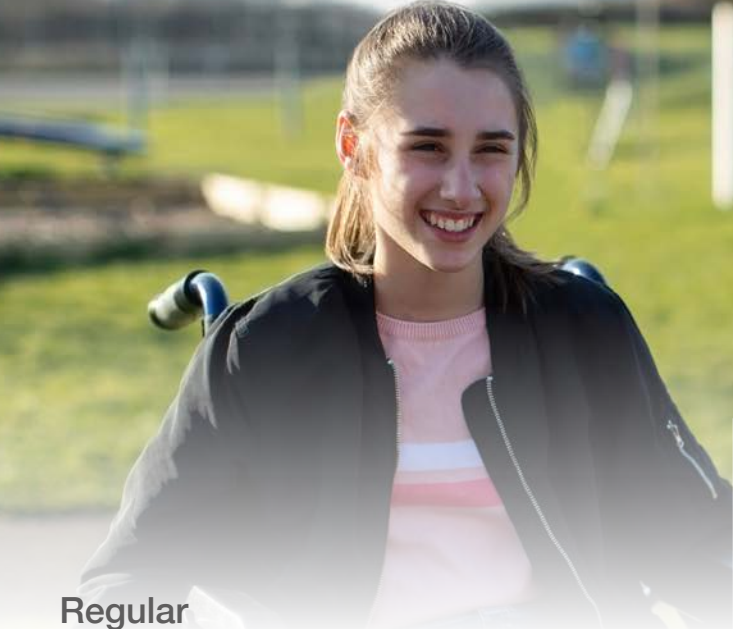
As well as setting up a support group and responding to individual queries, we have forged links with the Association of British Neurologists NPH Special Interest Group.



We also have an on-going presence at the Adult Hydrocephalus Clinic in Nottingham. Both provide Shine with opportunities to further develop our focus on NPH in providing specialist insight to aid people in understanding their diagnosis, treatment, the implications of having hydrocephalus and the care they might need from their support networks.

Managing mental well-being and anxiety

Increasingly, our adult members have sought advice on how to keep well, manage their anxiety, come to terms with a diagnosis, manage fatigue or how to ask for help. A series of online sessions have been developed and delivered with talks from external experts (e.g. solicitors' firms; sports development officers; consultants; nurses) and our specialist Health team. Themes and content for each session were driven and shaped by our members.



Regular reminders

Modelled on the success of the series of the Little Stars newsletters, the Health team developed a suite of information sheets for different ages and different stages of life for our adult members.

Filled with useful information and advice on well-being and preventative approaches to staying healthy, these will be launched in 2023/24.



What our members think of us:

- ✓ "The knowledge that I can turn to them for advice and support on issues that are important to me"
- ✓ "Very friendly and knowledgeable staff who are always willing to listen and help"
- ✓ "Shine 'has given me more confidence and courage to achieve some things I might not have done before"
- ✓ "I feel I learn a lot more about my condition on our ZOOM get together and understanding more about others who are dealing with the same condition"
- ✓ "I have my area support worker who is available to me if things are getting tough"
- ✓ "It's comforting to know there's a charity there, that offers support should I need it"



Without you it would be an even scarier place than it is"

What's **NEXT?**

A continued focus on health and well-being through:

- The publication of Shine's 'Spina Bifida in Adulthood' book
- Collaboration with Chelsea and Westminster clinic to support increased adult clinic provision in England
- Newsletter series
- Increased links to health professionals
- Resources and online support to prepare for medical appointments and hospital admission
- Developing an NPH-specific project
- Setting up a tethered cord support group

Addressing other issues through:

- Support, information and updated resources on preparing for independent living / accessing suitable housing
- Reviewing and strengthening Shine's benefit advisory service through more proactive information and resources
- Developing tools for financial budgeting for members and parent/carers
- Identifying and linking with specialist employment charities for improved access to work opportunities



“ I have really enjoyed the sessions with cooking and talking to other kids with similar disabilities to me. I’ve found it helpful to learn more about it, and ways in which other people deal with it and I’ve definitely found some helpful tips. It’s helped me to become more independent, because the other girls have motivated me to do more for myself”

‘Shall WeeTalk’ member

Strategic goal 4



A connected community

Shine provides diverse and inclusive opportunities for participation in our member-led approaches to co-producing the very services and solutions that will empower and enable them.

Shine develops accessible, best quality information through our website, literature, and digital communications and promotes peer support networks, online support and social groups and programme of events available to members to help inform and connect with them. Shine promotes volunteering opportunities for Shine's members and supporters

“ That feeling of knowing you are not alone is the best thing that Shine have done for me. Thank you for my Shine family’

All, however, offer experience and insight into ageing, which has aided Shine in further developing our expertise and understanding of the impact of Spina Bifida and/or Hydrocephalus on health, care, lifestyle, employment, friendships, finances and other life opportunities as people get older.

Our adult members have shared this information willingly, knowing others can learn from their experiences. Their stories can inform and influence, as well as providing insight for Shine's research and resources to encourage preventative approaches to health and well-being management.

What's CONTINUED?

Awareness weeks

An important part of our plans, Spina Bifida Awareness Week and Hydrocephalus Awareness Week provides us with opportunities to work with our members to raise awareness and share stories and experiences with the wider world – the aim being to

educate the general public and professionals about the conditions, and attract new members to Shine for support and advice when they need it.

Digital support



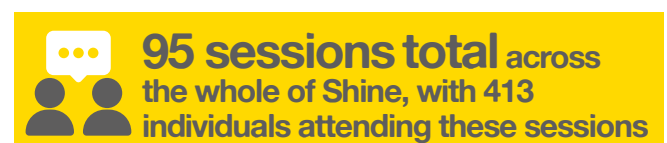
A new way of communicating and linking our members, we have established regional WhatsApp groups for our Little Stars parents/carers, for parent/carers of children and young people, and adult members to connect, ask questions and share information, as well as separate groups for our adult members.

Online events



Shine's ability to reach and engage many more members has opened up with the world of online events. People are more familiar and more comfortable with participating in online information sessions, presentations and coffee and chat groups than ever before. Where possible, we have aided with advice and guidance to get our members 'online'.

Face to face events



The teams have resumed some of the regular face-to-face get-togethers from pre-pandemic days, with our Shine Social London, specifically for our adult members, being one of the most popular. Alongside this, we have attended conferences and provided presentations to raise greater awareness of who Shine is, and what we do.

“ Having somebody to listen is great”

Volunteering



Our Shine volunteers have remained as committed as always, in a wide variety of roles including administration and research; shop assistants; online Facebook moderators; fundraisers, focus group and event support and Trustees. Shine's lead member of staff for volunteering has provided induction, regular training and supervision to ensure volunteers are gaining skills, experience and enjoyment from the time they are giving us.

What's **NEW?**

New member calls

Built on the legacy of the well-being calls that we introduced during the Covid-19 pandemic, the teams have introduced calls to newly registered parent/carers of our Little Stars and Teenage members, and our adult members, once they have registered. The calls are a quick check-in to say 'hello' and ask whether there are any immediate issues that need addressing. They also act as a reminder that Shine is here, whenever we are needed.

Hydrocephalus survey

In 2022, we surveyed our members with hydrocephalus and those with NPH to gain further insight into their challenges, to help shape our services.



293 individuals responded and highlighted several concerns which Shine addressed through our online support groups, reviewing and updating our information resources and putting a plan in place to deliver an NPH project for individuals and carers.

Co-production

Shine developed a greater focus on member engagement to shape and inform our services.

Members proactively signed up to online focus groups to contribute to developing resources, identifying themes for online sessions, and producing

videos and stories to share their experiences.

Five youth members helped us in recruiting our Youth Voice and Engagement Officer, first taking part in training and development, and then being involved in the interviews to find the right person for the role.

Improved accessibility

Shine invested in two new services to facilitate access to the support and information we provide:

- An accessibility app, which provides a range of options to read the website – such as different languages and dyslexia-friendly formats - has been added to our website
- A subscription to LanguageLine gives access to translation and interpreting services, for speakers whose first language is not English



Northern Ireland's Community Fund project steering group

Aimed at improving engagement, Shine NI set up a steering group to inform the development and delivery of this project, and provide a forum for discussion to ensure the project is reaching all Shine NI members, and meeting their needs through sharing experiences, identifying and promoting good practice and ideas, identifying gaps or challenges in statutory services and support in NI, and helping Shine NI to find solutions and receive first-hand advice from a cross-section of members to ensure that the project is accessible to and suitable for all our members.

What's **NEXT?**

- Review and improve our membership offer
- Scope Shine's services to meet demands of our growing membership base
- A new social media strategy for wider engagement
- Develop a plan to increase our reach across diverse communities
- Make further improvements to our website for enhanced accessibility to information and resources

Strategic goal 5

Preventing Spina Bifida and Anencephaly

Fortification of flour with folic acid.

For over 30 years, Shine has campaigned for mandatory fortification of flour with folic acid as it has been proven to reduce the chances of pregnancies being affected by neural tube defects.

In September 2021, we were delighted when the UK Government announced its intention to introduce folic acid into non-wholemeal flour. However, some two years later, this has yet to come to fruition.



What's CONTINUED?

- Responding to Government consultations, including the Bread and Flour Regulations 1998 and the Bread and Flour Regulations (Northern Ireland) 1998, which considered levels of folic acid and timescales for implementation.
- Collaborating with key partners in this campaign (e.g. Royal College of Obstetricians and Gynaecologists; British Dietetic Association; Spina Bifida Hydrocephalus Scotland)
- MPs and representatives in the House of Lords, who support fortification, regularly tabled oral and written questions in Parliament to keep fortification on the Government's agenda
- Supported the international call for the World Health Organisation to adopt a global resolution on mandatory fortification with folic acid and other micronutrients. This was passed in May 2023.

At the time of publication of our annual report 2022/23, there has been no further update from the UK government on progress.

What's NEXT?

Shine will continue its quest for the mandatory addition of folic acid to flour across the UK.



Folic Acid Supplementation

Supplementation sits firmly alongside mandatory fortification. Shine's Folic for Life campaign, part sponsored by Vitabiotics, promotes the importance of supplements which contain folic acid, in preparing for pregnancy as they are the most assured way of increasing folic acid in the body.

What's CONTINUED?

- Advice and information to individuals who came to us for support
- A social media campaign on Instagram to promote our messages as widely as possible
- Shine logo featured on Vitabiotics products which are widely available in major retailers and online

What's NEXT?

- Secure resources to increase impact of our Folic for Life work
- Engage with Public Health bodies to secure commitment for a sustainable public health campaign on the importance of folic acid supplementation

Strategic goal 6

Changing experiences of pregnancies affected by neural tube defects

Hundreds of pregnancies are affected by neural tube defects in the UK each year, yet there is very little statutory provision for support in preparing for a new pregnancy if a previous one has been affected by spina bifida or anencephaly. Moreover, our adult members highlight the lack of discussion, professional support and information for disabled people who may want to become parents.

Parents-to-be who have a diagnosis of a pregnancy affected by a neural tube defect also tell us that there is not enough information available to them at the point of diagnosis, and little understanding of the choices that are open to them.



What's **CONTINUED?**



56

**INDIVIDUALS HAD
TAILORED PREGNANCY
ADVICE AND SUPPORT**

- 1-2-1 support and advice to parents-to-be and those planning a pregnancy
- Support to 810 members, registered via our closed Facebook group, who have lost a baby to anencephaly
- Working closely with NHS commissioning and fetal surgery teams to enhance and promote the option for pre-natal surgery

What's **NEW?**

- Formally launched our pregnancy advice service to provide proactive, confidential and on-going support to those who need us
- Follow-up survey on antenatal experiences, in partnership with University College Hospital London's Fetal Medicine Team

- Improved referral pathways to other organisations
- Parents of under 13s surveyed to capture changes in experience since the introduction of NHS-commissioned fetal surgery service
- The launch of a CPD-accredited antenatal e-learning module for professionals

What's **NEXT?**

- Continue with 1-2-1 advice and support
- Identify and develop new resources
- Improved services for those who have lost a baby to anencephaly
- On-going promotion of the CPD-accredited training
- More professional awareness of the steps that can be taken to reduce pregnancies being affected by NTDs
- Continued work with NHS Commissioning and fetal surgery teams
- Publish results of the updated antenatal survey



I'm a doctor so knew a lot of the medical information already, but the Shine information is really helpful from a parenting perspective. My husband is non-medical and found the Shine information very easy to understand.

Strategic goal 7



“ Spina bifida is from birth, and there are so many transitional phases in a person’s life. To have a charity to support those transitions is key – particularly once they get older and are left to their own devices. **Shine are a lifelong focus point that people can come back to.”**

(Specialist Nurse for Pressure Ulcer Prevention and Intervention Service)

Transforming attitudes and improving access to health and care services through engagement, partnerships, research and campaigning

An important area of our work, our strategic partnerships, connections and campaign plans, that took a back seat during the Covid-19 years, slowly resumed, with new opportunities for collaboration with others being added to our list for further discussion and development. All with the aim of seeing significant step changes in access to, and quality provision of, statutory services for all Shine members.

What’s CONTINUED?

- Our Shine Health Direct service for members, in partnership with Bullen



- A presence at clinics across England and Northern Ireland
- Shine’s Legal Service, with existing partners Irwin Mitchell and Enable Law, and new firm, Davies and Partners
- Presentations to professional conferences to raise awareness and promote our professional membership
- Encouraging our members to join research programmes so that their views and experiences are fully represented
- Proactive support and promotion of campaigns run by other charities



“ Working with Shine, who have that wider knowledge of the conditions, means that we can help people reach the full extent of their potential.

For example, working with Shine meant we could support a young person to move from total reliance on continence pads to using catheters and bowel washouts.

She’s now about to go all day in her normal clothes and underwear and she’s thriving - you can see the change in her confidence and independence. Shine knew that this was possible and had the time and understanding to support her to get there.

It’s changed her life – now she can think about independent living when she’s older.” *(Community Paediatric Nurse)*



What’s **NEW?**

- Launch of a free professional membership service, which gives access to expert information, guidance and research



206 new professional members signed up

in 2022-23 (548 in total as at 31st March 2023)

- Research to gain greater insight into the conditions, particularly Hydrocephalus
- Draft research proposal to gather evidence to underpin our work in influencing improvements to statutory services

Development opportunities for professionals – CPD-accredited e-learning modules

Shine launched our suite of e-learning modules, that are accredited for continuous professional development, with an aim of reaching and upskilling more health, care, education, and other professionals to better understand the conditions, and improving support through prevention and changes in practice.

The modules are:

- Spina Bifida
- Hydrocephalus
- Occult Spinal Dysraphisms and Spina Bifida Occulta
- Neural Tube Defects – for professionals working in antenatal settings

Coming this year: Accredited professional training on Normal Pressure Hydrocephalus (NPH)

What’s **NEXT?**

- Support Chelsea and Westminster to publish research into cognitive effects of hydrocephalus
- Greater focus on campaigning for improved:
 - Access to statutory health and social care services
 - Continence care
 - Information and sensitive support at point of diagnosis
- A programme of support for people awaiting diagnosis, or having had a diagnosis, of Normal Pressure Hydrocephalus (NPH)
- Further engagement with professionals
- Stronger partnerships and greater influence with national networks



For me, this is where Shine come in.

By working with professionals and parents they offer expert advice in continence, mobility and potential – so professionals have the expert knowledge to perform their statutory duties correctly.”

(Occupational Therapist, Cardiff)

Our international work



IF (International Federation of Spina Bifida and Hydrocephalus)

Shine is a member of the International Federation of Spina Bifida and Hydrocephalus (IF) and has contributed to its work on a call for global fortification through membership of its advocacy group and presentations at online conferences.

Spina Bifida Hydrocephalus Scotland and Spina Bifida Hydrocephalus Ireland

We have continued links with our colleagues in Scotland and Ireland, sharing information, and linking to support individuals and families who move across borders.

Festus Fajemilo Foundation (FFF) in Nigeria

Since 2015, Shine has worked closely with FFF to secure funding to deliver a continence management programme for FFF members in different parts of Nigeria, and in 2022/23, the Welsh Government's Wales Africa Hub provided funding to re-establish the project after Covid-19 had disrupted so much.

Over the past 12 months, the project has:

- Supported 155 babies, children and young adults, and their families, with continence care
- Re-established clinics and support for families after the pandemic
- Re-established an FFF clinic at their offices in Lagos
- Expanded our project from 3 to 6 hospital facilities across Nigeria
- Trained 60 nurses
- Cascaded continence care knowledge to an additional 50 healthcare workers
- Secured supplies of continence care equipment, facilitating access to these for nurses and families
- Secured supplies of oxybutynin, a medicine essential in treatment of the neuropathic bladder
- Introduced data collection processes across all clinics to measure successes and outcomes.

What's **NEXT?**

We were unsuccessful in our bid for further funding from Wales Africa but are maintaining activity on the project with support from the hospital facilities, and the FFF clinic. We are seeking longer-term funding to sustain the project indefinitely.



The Future

We are just at the start of delivering our current Corporate Plan and have some very exciting plans, large research projects and other pieces of work, which should see a 'step change' in the breadth and ways in which we are able to engage and reach more and more people whose lives have been affected by spina bifida and hydrocephalus, and associated conditions. As importantly, we should see improvements in the

access to statutory services that our members currently have, or need, access to.

This will only happen if we have robust, planned and funded approaches to developing and delivering our initiatives in consultation and partnership with our members of all ages to guide and inform us about the work we do, and ensuring we have the staff, trustees and volunteers to help us to do this.



Thank you

Throughout the year, there are thousands of individuals, companies, trusts and foundations contributing vital funding to support our work.

Without them, Shine would not be the charity that we are. The list is far too numerous to mention everyone but we want to say a HUGE thank you to everyone who has given so generously of their time and money to support the work we do.

We wish to take this opportunity to acknowledge just a few...

Companies

Integra Neurosciences – Codman	Enable Law	Vitabiotics Ltd
Buckles Solicitors LLP	Irwin Mitchell	Belron Ltd
Bullen Healthcare	Field Fisher	The Anderson Foundation
Davies and Partners	Royal Pigeon Racing Association	Warrenpoint Fort

Supporters

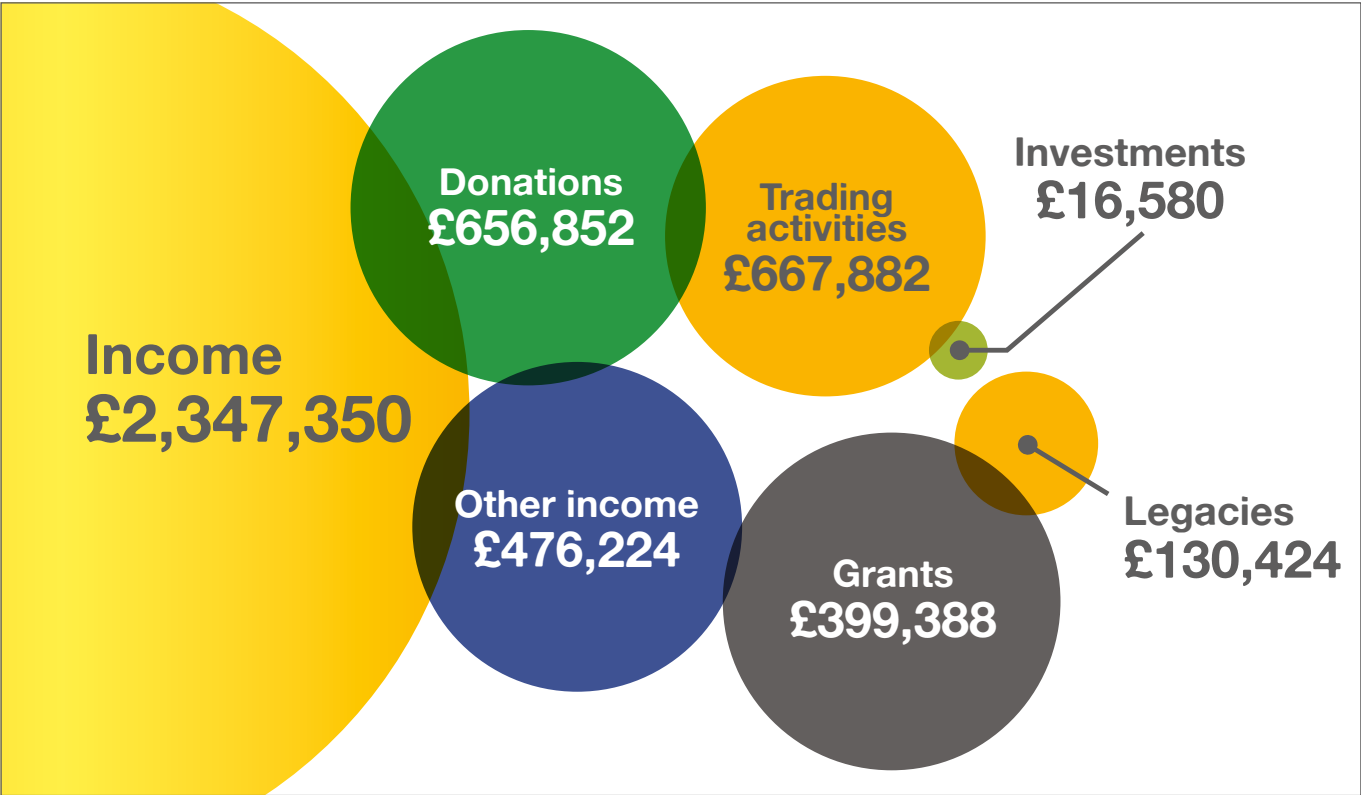
Joe Saunders	Toby Lamb	John Hale
Heather Hughes	Thomas Williams	Joe Smith
Ash Robinson	Greg Hammond	Jacqueline Braid
Peter Collins	Dave Hassett & Family Members	Terry Groves
Jane Moody	Coops Troop	Alex Nash
Lynn Arthur	Val Conway	Pia Paleologo
Kate Mercer	Nicole Allerd	

Trusts and Foundations

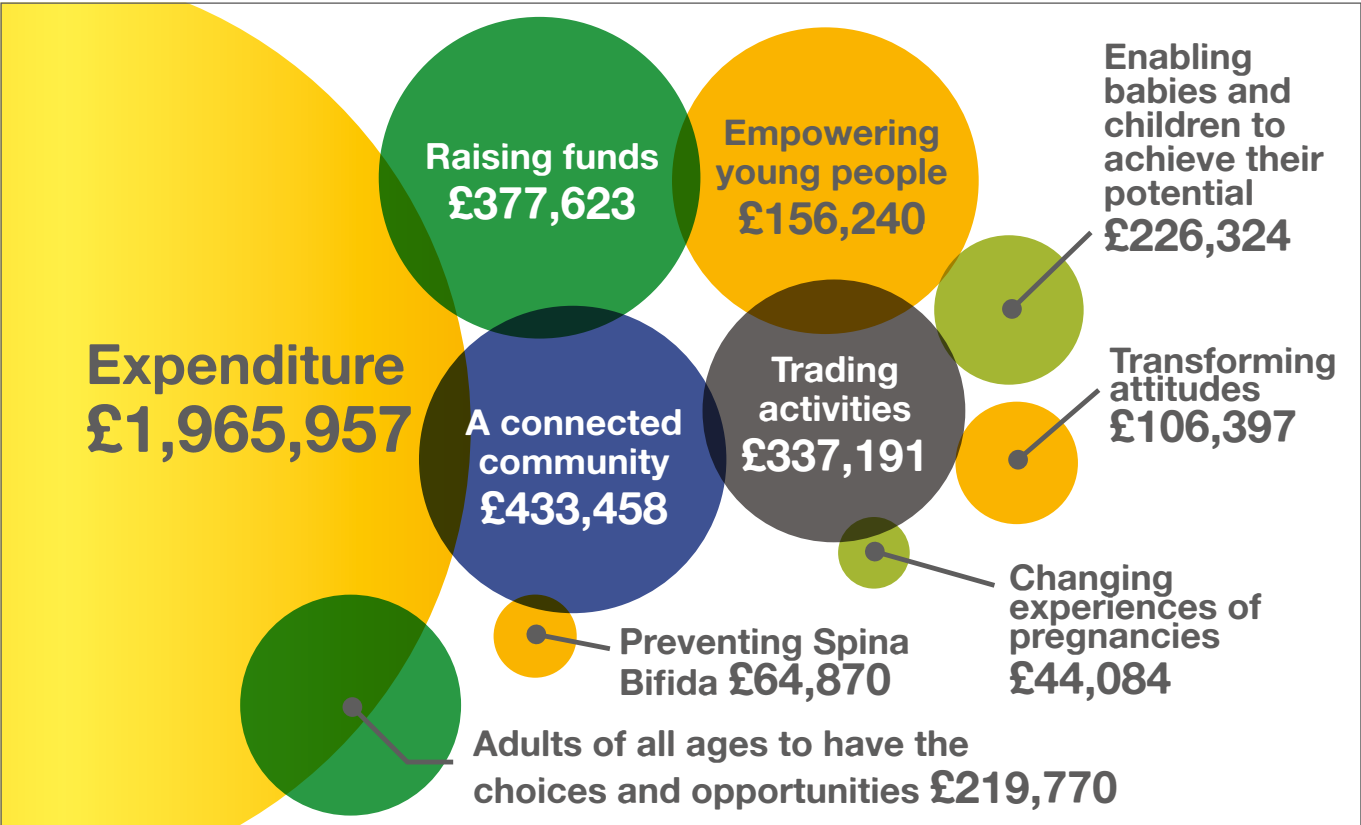
Apax Foundation	Rothley Trust	The Hospital Saturday Fund
Baron Davenport's Charity	The Alice Ellen Cooper Dean Charitable Foundation	The Lawson Trust
BDB Pitmans Charitable Trust	The Basil Brown Charitable Trust	The Marsh Charitable Trust
Charles S. French Charitable Trust	The Basil Death Trust	The National Lottery Community Fund - England
Doris Field Charitable Trust	The Cecil Rosen Foundation	The National Lottery Community Fund - Northern Ireland
Eastern Counties Educational Trust Limited	The Chandris Foundation	The National Lottery Community Fund - Wales
Garfield Weston Foundation	The David Gibbons Foundation	The Peter Stebbings Memorial Charity
J Reginald Corah Foundation Fund	The D'Oyly Carte Charitable Trust	The Pierrepont Trust
Karen June Thornton Charitable Trust	The Evelyn Trust	The Privy Purse Charitable Trust
Oakdale Trust	The Eveson Charitable Trust	The Rozel Trust
Provincial Grand Lodge of Warwickshire	The Frazer Trust	The Sir James Roll Charitable Trust
South Eastern Health & Social Care Trust	The Ganzoni Charitable Trust	The Valentine Charitable Trust
	The Gerald Palmer Eling Trust	
	The Hamilton Wallace Trust	
	The Healey Family Charitable Trust	

Income and expenditure 2022/23

Total Income



Total Expenditure





Financial Review

The table below provides a five-year financial summary, showing that we continue to deliver a robust financial position, as we seek to ensure long-term sustainability.

	2022/23	2021/22	2020/21	2019/20	2018/19
	£000	£000	£000	£000	£000
Total income	2,347	1,894	2,343	2,192	2,052
Net movement in funds	338	171	506	113	158

When trustees approved the 2022/23 budget deficit of £157,775, the sale of Park Road, although planned, was not guaranteed. In the 2020/21 annual report, trustees confirmed that a review of continued occupancy of 42 Park Road had been conducted and it was concluded to be in the best interests of the charity to sell 42 Park Road and relocate to a smaller office with some staff working a hybrid model of home working and office days. The move to a smaller leasehold office at Minerva business park was completed during January 2022 and the sale of 42 Park Road was completed on the 1st of April 2022. The sale price exceeded the qualifying valuation, whilst legal, professional and move costs were below original estimates.

The annual running costs of the smaller leasehold office are projected to be lower than 42 Park Road, and trustees are confident that the net sale proceeds can be used to develop and future proof Shine's services in a sustainable way.

Shine therefore reports an actual surplus of £337,980 (2021/22 £171,033 surplus), which consists of a £490,547 unrestricted surplus, a £132,817 designated deficit, and a £19,750 restricted deficit. This includes a £507,724 gain on sale of Park Road,

removing this one-off gain on sale, the underlying result would be a £169,744 deficit.

Total income for 2022/23 was £2,347,350 (2021/22 £1,894,487), with decreases in donations income being offset by the sale of 42 Park road and increases in trading, legacy and charitable trusts. Although donation income was below 2021/22, receipts remained higher than the five previous years. The largest element of our trading activity continues to be our virtual balloon races and during the year 4,929 supporters sponsored a balloon, many entering multiple races.

The National Lottery Community Fund and other charitable trusts continue to fund an important part of Shine's work and a new 5-year grant from the Lottery was secured to fund services in Northern Ireland. This project "Shining Opportunities" commenced in June 2022. A 3-year lottery grant was also secured to fund young people's services in England. This project, "Little Stars: the evolution" commenced in September 2022.

Legacies continue to be a major source of funding and whilst income remained low in comparison to recent years, we are incredibly grateful that people continue to remember us in their wills.

Expenditure

Total expenditure in the year was £1,965,957 (2021/22 £1,894,927). Of this, expenditure on charitable activities increased by £78,771 (6.3%) to £1,251,143, representing 63.7% of total expenditure (62.2% in 2021/22), whilst expenditure on raising funds increased by just £741 to £714,814. Although an increase in staff turnover was experienced, recruitment efforts have been successful and staffing levels in Shine's services increased during the year with 27 full-time equivalent posts compared to 26 in 2021/22. A staff survey was completed in the year and a pay award was made, Shine is confident it remains an attractive organisation to work for and has active recruitment plans which aim to raise service staffing levels in 2023/24

The war in Ukraine had a detrimental impact on the value of our investments, and over the year we report a loss of £42,342 (gain in 2021/22 £8,692).

Under the accounting standard SORP (Statement of Recommended Practice) 2015 the full defined benefit pension deficit must be declared on the balance sheet. There was a 2022/23 actuarial loss of £1,071 (2021/22 gain of £162,781). A payment plan to eliminate this deficit remains in place and the charity remains confident that it will meet the required pension contributions from its projected income without significantly impacting on its planned level of charitable activity. Further pension details are shown in note 22 of the accounts.

Financial Reserves Policy

Reserves are maintained at a level that enables the charity to manage financial risk and sustain services. Trustees have set a minimum free reserve target of £850,000, held for the following purposes:

- Statutory obligations.
- Provide a 4-month commitment to our vulnerable members to wind up the affairs of the charity in an orderly fashion, in the event that the trustees cease to be confident in Shine's ability to continue.
- Offset the risks of an unexpected shortfall in income and an adverse movement in the defined benefit pension scheme liability.
- A working capital facility.

The free reserves position is reported to trustees as part of the monthly management accounts and quarterly forecasting. To set our free reserves target, trustees have sought to balance the needs of Shine's members against financial risks. COVID19 and the war in Ukraine has demonstrated that our world is less certain than previously thought and our reserves target reflects this need for caution.

At the year-end Shine held free reserves of £1,215,980, being general unrestricted funds excluding designated funds. This represents 6.4 months of committed expenditure cover, which is above the reserves target and has been boosted by the one-off sum realised from the sale of Park Road.

To bring our reserves in line with our target the charity plans to utilise its reserves in a managed fashion investing in members' futures and has recently appointed new positions of Deputy Health Manager, a National Programmes and Member Engagement Manager, an Education Officer and a Youth Officer. In total these changes will raise the service staff establishment to 31.5 FTE and compare to a pre COVID position of 27.1 FTE.

Restricted reserves must be applied to the specific purpose(s) intended by the donor so do not form part of the free reserves. Funds totalled £157,015 at the year end and are planned to be expended in 2023/24.

Designated funds have been established by trustees and are excluded from free reserves. They are as follows:

- A fund for 2 additional Support and Development Workers in the Southwest and East Anglia areas – who will enhance the support we can provide to our members in more rural, isolated areas. This first position has been made possible by the generosity of the late Florence Bartle who kindly chose to remember Shine in her will.
- A fund to support our work in Gloucestershire – based on a legacy we have received.
- A fund for a Deputy Health Manager.
- A fund for an Education Officer – who will offer training and support to our members to access support.

- A fund to support our specialist physiotherapy work.
- A fund to support research and development.
- A fund to support our digital development.
- A fund to support services in Northern Ireland. This has been made possible by the generosity of supporters in this home nation, and in particular CitiBank Belfast.
- A fund to represent Shine's investment in fixed assets.

Investment Policy

Under the governing document, the charity can make any investment the trustees see fit. R. C. Brown Investment Management plc are Shine's investment managers with the remit to manage the investments in line with the policy outlined below.

Investments are held as part of the long-term reserves of Shine. The aim is that they should maintain their value and generate income for Shine.

The portfolio must only be invested in assets with a low risk profile. This will include utilisation of pooled funds, which provide diversification of assets, and ensures that the risk of losing a single holding is minimised.

- Investments may be held in a range of asset classes, including equities, corporate bonds, and gilts.
- There will be no direct investment in 'alternative' investments such as hedge funds or derivatives.
- There will be no direct investment in overseas equities. Any such investment must be made through pooled funds managed in the UK.

The trustees have agreed that the funds should initially be invested in a broad, balanced portfolio.

The intention is to work towards ethical investments, with the advice of the investment managers, while being mindful of the charity's obligations for responsible investment.

During the year R. C. Brown Investment Management plc continued to manage the Shine portfolio, regrettably funds performed below their benchmark, recording an 8.92% loss during 2022/23 versus the

benchmark loss of 6.04 (ARC steady growth index).

Investments are held to support the reserves policy. During 2022/23 the charity invested £450,000 of the sale proceeds of 42 Park Road into the investment portfolio, RC Brown actively managing the timing of placements.

Risk Management and Internal Control

The Board of Trustees are responsible for the identification and management of the major risks facing the charity.

A Risk Register is maintained and shared annually with trustees (more frequently if a significant issue arises). Risk management at operational level is managed by the senior leadership team; major risks have been reviewed and systems established to manage these risks.

During 2022/23, the risk from COVID-19 diminished in how the charity supported its members and the risks to income levels. Therefore, the risk register currently covers five strategic areas.

1. Governance & strategy

2. Income generation

3. Services

4. Finance

5. External influences, including inflation and the war in Ukraine

During the year there remains 1 red retained risk, which is members' access to statutory services, and Shine continues to support our members and families with information and guidance on their rights, and avenues to access the services they need.

Shine continues to make structural and strategic changes to the organisation to mitigate these and other risks.

Going Concern and Statement of Public Benefit

Going Concern

The activities of the charity, its objectives, factors likely to affect its future development and the policies for managing its capital and financial risk are detailed in the Trustees' Report. We have set out a review of Shine's financial performance, the reserves position and principal risks and uncertainties in this report.

The budget for 2023/24 was prepared by senior leadership and approved by the trustees in March 2023. The expectation is that trading and donation income levels can be increased as we continue to invest in fundraising resources. Expenditure levels will be allowed to increase in line with the expansion in service provision, therefore a total deficit of £190,645 is budgeted which includes a restricted deficit of £58,274 as funds received in prior periods are expended and a deficit of £132,371 across unrestricted and designated funds.

We can do this because our reserves exceed the minimum level.

The budget and its assumptions are reviewed against two key financial measures:

- In-year cash flow
- Free reserve cover

Management accounts are prepared by senior leadership and issued monthly to trustees; the current financial position and financial outlook are reviewed at quarterly trustee meetings. Given the level of reserves and outlook, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future being at least twelve months from date of approval of these financial statements. Accordingly, they continue to adopt the going concern basis of accounting in preparing financial statements.

Statement of Public Benefit

The trustees confirm that they have complied with the duty in section 17 of the Charities Act 2011 to have regard to the Charity Commission's general guidance on public benefit, 'Charities and Public Benefit'.

Shine's charitable objects are enshrined within its

memorandum and articles and as such trustees ensure that the charity's activities are carried out for public benefit through its strategic goals. This report allows us to show how charitable funds are spent and the impact and benefits this has on the lives of people affected by spina bifida and/or hydrocephalus, and associated conditions.

Reference and Administration Details

Royal Patron

HRH The Duchess of Gloucester GVC

Trustees

The trustees of Spina bifida, Hydrocephalus, Information, Networking, Equality – SHINE are the charity's trustees under charity law and directors of the charitable company and throughout the report are collectively referred to as the trustees.

The trustees serving during the year were as follows:

Gregory Smith

(Former Chair – resigned 7th March 2023)

Rebecca Bates (Hon. Treasurer)

Patricia Adley (Passed away 14 May 2022)

Professor Roger Bayston

Michael Brown (Vice Chair)

Andrew Smart (Resigned 30th May 2023)

Joanne Williams (Chair)

Lynn Aziza Dar

(Resigned due to ill health 5th February 2023)

Surekha Kukadia

Jenny Goy (Appointed 26th September 2022)

Joe Waggott (Appointed 26th September 2022)

Richard Oakley (Appointed 7th June 2023)

It is confirmed that none of the serving trustees had any beneficial interest in any contract with Shine in the year.

Remembering Patricia Adley.

Patricia Adley passed away on the 14 May 2022, at just 65 years of age. Since being appointed a trustee in 2015, Patricia brought a wealth of lived-in experience to the board, having been born with Spina Bifida.

Patricia was a retired solicitor, and therefore also brought a wealth of legal & professional skills, and jointly led safeguarding issues. She was immensely proud of Shine's work, and she is sincerely missed by us all.



Senior Leadership Team

Chief Executive Kate Steele

Director of Services Gill Valentine

Director of Finance Stephen Ellen

Objects

The charity's objects are specifically restricted to the relief of persons who have spina bifida and/or hydrocephalus or allied or related disorders by providing care, welfare, treatment, education, and integration into society.

Principal Professional Advisers

Auditors

Azets Audit Services

Ruthlyn House
90 Lincoln Road
Peterborough
PE1 2SP

Bankers

The Co-operative Bank Plc

PO Box 250
Skelmersdale
WN8 6WT

Insignis Cash Solutions

St John's Innovation Centre
Cowley Road
Cambridge
CB4 0WS

Solicitors

Greenwoods GRM LLP

Monkstone House
City Road
Peterborough
PE1 1JE

Investment Managers

R.C. Brown Investment Management

1 The Square
Temple Quay
Bristol
BS1 6DG

HR

Vero HR

St James House
Flaxley Road
Kingston Park
Peterborough
PE2 9FT

Administrative Details

The full name of the charity is Spina bifida, Hydrocephalus, Information, Networking, Equality – SHINE. We are commonly known as SHINE.

The registered charity number is 249338 (England and Wales)

The company registration is 00877990

Registered Office: SHINE, Unit 4, Minerva Business Park, Peterborough, PE2 6FT

Telephone 01733 555988 • Email firstcontact@shinecharity.org.uk • www.shinecharity.org.uk



Our Commitment to Quality Fundraising

Shine is registered with the Fundraising Regulator and proud to commit to the Regulator's Fundraising Promise.

We are committed to maintaining high standards of fundraising in line with the Code of Fundraising Practice:

- We will be clear, honest, and open.
- We will be respectful.
- We will be fair and reasonable.
- We will be accountable and responsible.

Our approach to fundraising consists of:

- marketing appeals to individuals who have already expressed an interest in Shine.
- running charitable events for which participants raise money.
- encouraging people to participate in other events to raise funds on our behalf.
- community fundraising; and
- soliciting donations from corporate partners, charitable trusts, and individual donors.

We also encourage people to remember us in their will with a gift or legacy.

We do not use third-party professional fundraising agencies.

Where people or organisations raise funds in aid of Shine, we request they follow our standards. Shine's fundraising team provides tools and resources to enable supporters to deliver fun, safe, and successful fundraising activities. The trustees are of the view that during the year to 31 March 2023 we have been compliant with these standards, and we are not aware of any instances where those acting in aid of the charity have failed to comply.

To protect vulnerable people and other members of the public, Shine has a safeguarding policy, and our fundraising commitment is displayed on our website. We are careful to protect the private data of supporters and give clear options to stop being contacted by us. As part of our compliance with the code of fundraising practice, we ensure our approach to fundraising is not unreasonably intrusive or persistent and does not aim to solicit donations by pressuring potential supporters.

We take these steps to make sure people have a choice about whether to fundraise for Shine.

Shine and our members are incredibly grateful for the continued dedication and support of our fundraisers. From everyone at Shine, thank you for your ongoing generosity.



Structure, Governance and Management

Structure

Spina bifida, Hydrocephalus, Information, Networking, Equality – SHINE (Shine) is a company limited by guarantee registered in England and Wales (Registration No. 00877990) formed in 1966. Shine is registered as a charity with the Charity Commission for England and Wales (Registration No. 249338).

The charity owns the entire share capital of Shine (Trading) Limited, registered in England and Wales (No. 01031004). The consolidated accounts include Shine (Trading) Limited (see note 9). The principal activity of the company is to raise funds for the charity.

Governance

Shine is governed by Articles of Association, which

were amended in 2018.

Organisational purpose

Shine has a clear, sustainable corporate strategy for 2022 to 2027 consistent with the charity's purpose and an evaluation and monitoring framework to monitor impact and measure outputs.

Shine consults with a wide range of stakeholder groups to determine the priorities for the charity.

Leadership

The ultimate responsibility for the governance of the charity and its subsidiary is entrusted to the trustee board.

Board Integrity

Appointment of trustees

New Articles of Association were adopted by special resolution in 2018 specifying that anyone willing to act as a trustee, and permitted by law to do so, may be appointed by the board of trustees.

A trustee must be a natural person aged 16 years or older, the minimum number of trustees is 3 and the maximum is 16. Trustees are appointed for a term of 3 years; trustees are eligible for reappointment up to two subsequent terms (each of 3 years). No trustee can serve for more than 9 consecutive years unless the trustees consider it is in the best interests of the charity that a particular trustee should continue to serve. Professor Roger Bayston continues to serve as a trustee on this basis.

Trustee induction and training

In 2022 we appointed two new trustees, Jenny Goy and Joe Waggott who bring professional, commercial and lived experience. A third new trustee Richard Oakley was appointed in June 2023. New trustees

undergo induction. They are fully appraised of the full range of Shine's services, projects and campaigns and provided with relevant background literature. They receive awareness training, if required, on spina bifida and hydrocephalus. Depending on their specific skills and areas of expertise they will be put in touch with relevant staff.

Trustees are briefed on their legal obligations under charity and company law, the Articles of Association and the Board's decision-making process. They are also informed about Shine's Corporate Plan, key risks, recent financial performance, and prospects for the charity.

Trustees do not receive any remuneration or financial benefit for acting as trustees of shine, any expenses paid are disclosed in note 12 of the financial statements.

Decision making, risk and control.

The Board of Trustees is the governing body with overall legal responsibility for the charity. The Board sets the strategic direction for Shine. It meets at least four times a year, either in person or virtually.

The minutes of meetings are made available to all trustees on a timely basis. The board regularly reviews operational plans, budgets, performance, and Shine's main risks. The day-to-day management of the charity is delegated to the Chief Executive, who reports to the Board. The Chief Executive is assisted in the day-to-day management by the senior leadership team.

Senior Staff Remuneration Policy

The remuneration of senior staff is set by benchmarking with similar-sized charities, and the market rate required to attract the best people to the job.

Diversity and Inclusion

Shine has a transparent recruitment process, advertising widely and looking at how we can attract a diverse pool of candidates.

Safeguarding

A full review of our safeguarding policies and processes began in 2020/21 and will be reviewed in 2023/24 ensuring that we are continually improving our approaches to safeguarding, incorporating all updated legislation, and embracing current best practice to protect the welfare of our members, staff and volunteers.

An annual safeguarding plan is agreed by trustees. The plan is prepared by the Director of Services, who is Designated Safeguarding Lead for the charity, in conjunction with Joanne Williams and Jenny Goy, who are trustee leads for safeguarding.

Safeguarding training is provided for all staff, trustees, and volunteers. Incidents are reported, assessed, and enacted as appropriate with full consideration given to the requirement to report to the Charity Commission.

GDPR

Extensive work was undertaken to ensure Shine's ongoing compliance with the General Data Protection Regulation (GDPR). We have a designated GDPR lead, and the data management action plan is reviewed by trustees annually.

Section 172 Statement

The trustees must act in accordance with a set of general duties. These duties are laid out in s172 of the UK Companies Act 2006 which is summarised as follows: A Director of a Company must act in the that they consider, in good faith, would be most likely to

promote the benefit of its members, and in doing so have regard to:

- The consequences of any decision in the long term
- The interests of the charity's employees
- The need to foster the charity's business relationship with suppliers, customers, and others
- The impact of the charity's operations on the community and environment
- The desirability of the charity's maintaining a reputation for high standards of business
- The need to act fairly between members of the charity.

The trustees believed they have completed their duties under s172.

Related Parties

The charity has partnerships with several local associations. These are independent charities for spina bifida and hydrocephalus. Partnerships are negotiated individually, which may cover a range of activities and services. The charity also works in partnership with many other bodies, voluntary, statutory, and international, in carrying out work to support service users, undertake research and disseminate information.

Volunteers

In 2022/23, Shine had 69 registered volunteers (53 2021/22) and recorded 2,134 volunteered hours (1,860 2021/22), to whom we remain eternally grateful. The volunteering roles included:

- Working in our charity shop
- Giving talks and representing Shine
- Acting as peer support
- Supporting our members to grow in confidence and address the challenges of living with the conditions.
- Advising on the development of resources
- Fulfilling the role of Shine ambassador
- Fundraising
- Supporting our local groups

During the year, two volunteer catch-up meetings were held online to keep our volunteers engaged, and the half-yearly volunteers' newsletter continues to provide updates and opportunities for them to get involved.

Statement of trustees' responsibilities

The trustees (who are also directors of Spina bifida, Hydrocephalus, Information, Networking, Equality – SHINE), are responsible for preparing the annual report and the financial statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice.

Company law requires the directors to prepare financial statements for each financial year which give a true and fair view of the situation of the charitable group and of the net income or expenditure of the group for the year. In preparing these financial statements the directors are required to:

- select suitable accounting policies and then apply them consistently.
- observe the methods and principles in the Charities SORP
- make judgements and estimates that are reasonable and prudent.
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and the group and enable them to ensure that the financial statements comply with the Companies Act 2006.

They are also responsible for safeguarding the assets of the charity and the group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Statement as to disclosure of information to auditors

As far as the trustees are aware, there is no relevant audit information of which the group's auditors are unaware. Additionally, the trustees have taken all the necessary steps that they ought to have taken as trustees to make themselves aware of all relevant audit information and to establish that the group's auditors are aware of that information.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website.

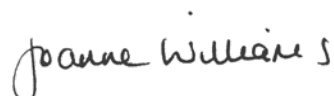
Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Appointment of Auditors

The continued appointment of Azets Audit Services Limited was confirmed by the Board of Trustees on the 6th December 2022.

This report has been prepared in accordance with the special provisions relating to small companies within Part 15 of the Companies Act 2006.

By order of the Board of Trustees



Joanne Williams

Chair

5th September 2023

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

INDEPENDENT AUDITOR'S REPORT

TO THE TRUSTEES OF SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

Opinion

We have audited the financial statements of Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE (the 'charity') and its subsidiary for the year ended 31 March 2023 which comprise the Group Statement of Financial Activities, the Group and Parent Charitable Company Balance Sheets, the Group and Parent Charitable Company Cash Flow Statements and the notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the Group and Parent Charitable Company affairs as at 31 March 2023 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the *Auditor's responsibilities for the audit of the financial statements* section of our report. We are independent of the Group and Parent Charitable Company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. The Trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE TRUSTEES OF SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of our audit:

- the information given in the Trustees' report for the financial year for which the financial statements are prepared, which includes the directors' report prepared for the purposes of company law, is consistent with the financial statements; and
- the directors' report included within the Trustees' report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the Group and Parent Charitable Company and its environment obtained in the course of the audit, we have not identified material misstatements in the directors' report included within the Trustees' report.

In the light of the knowledge and understanding of the company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' report. We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the Trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemptions in preparing the Trustees' report and from the requirement to prepare a strategic report.

Responsibilities of Trustees

As explained more fully in the statement of Trustees' responsibilities, the Trustees, who are also the directors of the charity for the purpose of company law, are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the Group and Parent Charitable Company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

A further description of our responsibilities is available on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE TRUSTEES OF SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

Extent to which the audit was considered capable of detecting irregularities, including fraud

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above and on the Financial Reporting Council's website, to detect material misstatements in respect of irregularities, including fraud.

We obtain and update our understanding of the entity, its activities, its control environment, and likely future developments, including in relation to the legal and regulatory framework applicable and how the entity is complying with that framework. Based on this understanding, we identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. This includes consideration of the risk of acts by the entity that were contrary to applicable laws and regulations, including fraud.

In response to the risk of irregularities and non-compliance with laws and regulations, including fraud, we designed procedures which included:

- Enquiry of management and those charged with governance around actual and potential litigation and claims as well as actual, suspected and alleged fraud;
- Reviewing minutes of meetings of those charged with governance;
- Assessing the extent of compliance with the laws and regulations considered to have a direct material effect on the financial statements or the operations of the entity through enquiry and inspection;
- Reviewing financial statement disclosures and testing to supporting documentation to assess compliance with applicable laws and regulations;
- Performing audit work over the risk of management bias and override of controls, including testing of journal entries and other adjustments for appropriateness, evaluating the business rationale of significant transactions outside the normal course of business and reviewing accounting estimates for indicators of potential bias.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.

This report is made solely to the company's members, as a body, in accordance with section 391 of the Companies Act 2014. Our audit work has been undertaken so that we might state to the company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the company and the company's members as a body, for our audit work, for this report, or for the opinions we have formed.



Mr Mark Jackson FCA DChA (Senior Statutory Auditor)
for and on behalf of Azets Audit Services

5 September 2023

Chartered Accountants
Statutory Auditor

Ruthlyn House
90 Lincoln Road
Peterborough
Cambridgeshire
United Kingdom
PE1 2SP

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2023

Current financial year

	Notes	Unrestricted funds 2023 £	Designated funds 2023 £	Restricted funds 2023 £	Total 2023 £	Total 2022 £
Income and endowments from:						
Donations and legacies	3	787,276	-	399,388	1,186,664	1,230,433
Other trading activities	4	667,882	-	-	667,882	655,838
Income from investments	5	16,580	-	-	16,580	8,216
Other income	6	507,724	(31,500)	-	476,224	-
Total income		1,979,462	(31,500)	399,388	2,347,350	1,894,487
Expenditure on:						
Raising funds	7	714,814	-	-	714,814	715,555
Charitable activities	8	711,303	105,502	434,338	1,251,143	1,179,372
Total resources expended		1,426,117	105,502	434,338	1,965,957	1,894,927
Net gains/(losses) on investments	13	(42,342)	-	-	(42,342)	8,692
Net incoming/(outgoing) resources before transfers		511,003	(137,002)	(34,950)	339,051	8,252
Gross transfers between funds		(19,385)	4,185	15,200	-	-
Net incoming/(outgoing) resources		491,618	(132,817)	(19,750)	339,051	8,252
Other recognised gains and losses						
Actuarial (loss)/gain on defined benefit pension schemes		(1,071)	-	-	(1,071)	162,781
Net movement in funds		490,547	(132,817)	(19,750)	337,980	171,033
Fund balances at 1 April 2022		725,433	619,546	176,765	1,521,744	1,350,711
Fund balances at 31 March 2023		1,215,980	486,729	157,015	1,859,724	1,521,744

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

STATEMENT OF FINANCIAL ACTIVITIES (CONTINUED) INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2023

Prior financial year

		Unrestricted funds 2022 £	Designated funds 2022 £	Restricted funds 2022 £	Total 2022 £
	Notes				
<u>Income and endowments from:</u>					
Donations and legacies	3	837,222	-	393,211	1,230,433
Other trading activities	4	655,838	-	-	655,838
Income from investments	5	8,216	-	-	8,216
Total income		1,501,276	-	393,211	1,894,487
<u>Expenditure on:</u>					
Raising funds	7	715,555	-	-	715,555
Charitable activities	8	649,363	121,205	408,804	1,179,372
Total resources expended		1,364,918	121,205	408,804	1,894,927
Net gains/(losses) on investments	13	8,692	-	-	8,692
Net incoming/(outgoing) resources before transfers		145,050	(121,205)	(15,593)	8,252
Gross transfers between funds		(203,091)	169,047	34,044	-
Net incoming/(outgoing) resources		(58,041)	47,842	18,451	8,252
<u>Other recognised gains and losses</u>					
Actuarial (loss)/gain on defined benefit pension schemes		162,781	-	-	162,781
Net movement in funds		104,740	47,842	18,451	171,033
Fund balances at 1 April 2021		620,693	571,704	158,314	1,350,711
Fund balances at 31 March 2022		725,433	619,546	176,765	1,521,744

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

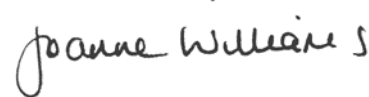
BALANCE SHEETS

AS AT 31 MARCH 2023

	Notes	Group 2023 £	Charity 2023 £	Group 2022 £	Charity 2022 £
Fixed assets					
Tangible assets	15	1,214	1,214	797,453	797,453
Investments	16	765,371	765,374	352,864	352,867
		766,585	766,588	1,150,317	1,150,320
Current assets					
Debtors	18	245,200	229,146	300,836	275,774
Cash at bank and in hand		1,059,901	1,028,214	620,814	603,115
		1,305,101	1,257,360	921,650	878,889
Creditors: amounts falling due within one year	19	(196,473)	(171,719)	(200,494)	(180,720)
Net current assets		1,108,628	1,085,641	721,156	698,169
Total assets less current liabilities		1,875,213	1,852,229	1,871,473	1,848,489
Creditors: amounts falling due after more than one year	20	-	-	(313,688)	(313,688)
Net assets excluding pension liability		1,875,213	1,852,229	1,557,785	1,534,801
Defined benefit pension liability	22	(15,489)	(15,489)	(36,041)	(36,041)
Net assets		1,859,724	1,836,740	1,521,744	1,498,760
Income funds					
Restricted funds	23	157,015	157,015	176,765	176,765
<u>Unrestricted funds - general</u>					
Designated funds	24	486,729	486,729	619,546	619,546
General unrestricted funds		1,215,980	1,192,996	727,897	702,449
		1,702,709	1,679,725	1,344,979	1,321,995
		1,859,724	1,836,740	1,521,744	1,498,760

The financial statements were approved by the board of directors and authorised for issue on and are signed on its behalf by:

5th September 2023



Ms J Williams
Trustee

Company Registration No. 00877990



Mrs R Bates
Trustee

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 31 MARCH 2023

		2023		2022	
	Notes	£	£	£	£
Cash flows from operating activities					
Cash (absorbed by)/generated from operations	29		(61,517)		13,412
Investing activities					
Purchase of tangible fixed assets		-		(2,877)	
Proceeds on disposal of tangible fixed assets		1,271,240		-	
Purchase of investments		(425,000)		-	
Interest received		16,580		8,216	
Net cash generated from investing activities			862,820		5,339
Financing activities					
Repayment of bank loans		(362,216)		(48,537)	
Net cash used in financing activities			(362,216)		(48,537)
Net increase/(decrease) in cash and cash equivalents			439,087		(29,786)
Cash and cash equivalents at beginning of year			620,814		650,600
Cash and cash equivalents at end of year			1,059,901		620,814

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2023

1 Accounting policies

Company information

Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE is a private company limited by guarantee incorporated in England and Wales. The registered office is Unit 4, The Forum, Minerva Business Park, Peterborough, Cambridgeshire, PE2 6FT, United Kingdom.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's governing document, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2019). The charity is a Public Benefit Entity as defined by FRS 102.

The financial statements have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a true and fair view. This departure has involved following the Statement of Recommended Practice for charities applying FRS 102 rather than the version of the Statement of Recommended Practice which is referred to in the Regulations but which has since been withdrawn.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

The consolidated accounts incorporate the results of the charity and of its wholly owned subsidiary.

1.2 Going concern

At the time of approving the financial statements, the Trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the Trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Designated funds comprise funds which have been set aside at the discretion of the Trustees for specific purposes. The purposes and uses of the designated funds are set out in the notes to the financial statements.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

1 Accounting policies

(Continued)

1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

Gifts donated for resale are included as income when they are sold. No amounts are included in the financial statements for services donated by volunteers.

Grant income is recognised according to the terms of each individual agreement.

All other income is dealt with on an accruals basis.

1.5 Resources expended

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement, and the amount of the obligation can be measured reliably.

Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges are allocated on the portion of the asset's use.

Direct expenditure is analysed and charged to the department incurring the cost. Expenditure is included when incurred, the majority of costs being directly attributable to specific activities. Costs that can not be directly attributable to particular headings, are allocated to activities on a basis consistent with use of the resources. Premises and other overheads have been allocated on a head count basis.

Fundraising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of charitable activities.

Governance costs are those incurred in connection with the governance arrangements of the charity and compliance with constitutional and statutory requirements.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

1 Accounting policies

(Continued)

1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses. Assets over £1,000 in value are capitalised at cost.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the straight line basis at the following rates:

Land and buildings	Buildings - 2%, land is not depreciated
Fixtures and fittings	20%
Equipment	20%
Software and website	20 - 33%

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

1.7 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible and intangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.8 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits repayable on demand and overdrafts. Deposits are repayable on demand if they are in practice available within 24 hours without a penalty. Liquid resources comprise assets held as a readily disposable store of value.

1.9 Financial instruments

Financial instruments are recognised when the charity becomes party to the contractual provisions of the instrument.

Financial assets are offset, with the net amounts presented in the accounts when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

1 Accounting policies

(Continued)

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

1.10 Provisions

Provisions are recognised when the charity has a legal or constructive present obligation as a result of a past event, it is probable that the charity will be required to settle that obligation and a reliable estimate can be made of the amount of the obligation.

The amount recognised as a provision is the best estimate of the consideration required to settle the present obligation at the reporting end date, taking into account the risks and uncertainties surrounding the obligation. Where the effect of the time value of money is material, the amount expected to be required to settle the obligation is recognised at present value. When a provision is measured at present value, the unwinding of the discount is recognised as a finance cost in net income/(expenditure) in the period in which it arises.

1.11 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the company is demonstrably committed to terminate the employment of an employee.

1.12 Retirement benefits

For employees choosing to participate, the charity operates a defined contribution pension scheme providing benefits additional to those from the State. The assets are held in a separately administered scheme. The pensions cost charge represents contributions payable by the company to the pension scheme in respect of the year.

Previously, the charity were part of a separately administered defined benefit scheme and is still required to make contributions to fund a deficit in the scheme.

The cost of providing benefits under defined benefit plans is determined separately for each plan using the projected unit credit method, and is based on actuarial advice.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

1 Accounting policies

(Continued)

The net interest element is determined by multiplying the net defined benefit liability by the discount rate, taking into account any changes in the net defined benefit liability during the period as a result of contribution and benefit payments. The net interest is recognised in income/(expenditure) for the year.

Remeasurement changes comprise actuarial gains and losses, the effect of the asset ceiling and the return on the net defined benefit liability excluding amounts included in net interest. These are recognised immediately in other recognised gains and losses in the period in which they occur and are not reclassified to income/(expenditure) in subsequent periods.

The net defined benefit pension asset or liability in the balance sheet comprises the total for each plan of the present value of the defined benefit obligation (using a discount rate based on high quality corporate bonds), less the fair value of plan assets out of which the obligations are to be settled directly. Fair value is based on market price information, and in the case of quoted securities is the published bid price. The value of a net pension benefit asset is limited to the amount that may be recovered either through reduced contributions or agreed refunds from the scheme.

1.13 Leases

Rentals payable under operating leases, including any lease incentives received, are charged as an expense on a straight line basis over the term of the relevant lease.

2 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

3 Donations and legacies

	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Total 2022 £
Donations and gifts	656,852	-	656,852	723,959
Legacies receivable	130,424	-	130,424	113,717
Grants receivable	-	399,388	399,388	392,757
	<u>787,276</u>	<u>399,388</u>	<u>1,186,664</u>	<u>1,230,433</u>
For the year ended 31 March 2022	<u>837,222</u>	<u>393,211</u>		<u>1,230,433</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

3 Donations and legacies

(Continued)

	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Total 2022 £
Donations and gifts				
Individuals	328,621	-	328,621	339,481
Trusts	161,607	-	161,607	134,308
Corporate donors	128,455	-	128,455	212,625
Local associations	3,341	-	3,341	2,966
Support groups	-	-	-	454
Health Trusts	34,828	-	34,828	34,125
	<u>656,852</u>	<u>-</u>	<u>656,852</u>	<u>723,959</u>
Grants receivable for core activities				
National Lottery Community fund Northern Ireland Bright Stars	-	99,219	99,219	64,589
National Lottery Community fund Cymru Shining lights	-	91,508	91,508	91,307
Early Intervention (Community lottery & others)	-	184,348	184,348	132,511
National Lottery Community Fund - Here for you	-	-	-	10,000
National Lottery Community Fund Northern Ireland - Here for you	-	-	-	10,000
The Edward Gosling Foundation - Here for you	-	-	-	5,000
Wales Council for Voluntary Action	-	-	-	11,621
The Clare Milne Trust	-	-	-	16,888
Vinci UK Foundation	-	-	-	6,975
Margaret Giffen Charitable Trust	-	-	-	30,000
The Eveson Trust	-	12,500	12,500	-
The Lawson Trust	-	5,000	5,000	-
Florence Shute Charitable Trust	-	2,000	2,000	-
Other	-	4,813	4,813	13,866
	<u>-</u>	<u>399,388</u>	<u>399,388</u>	<u>392,757</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

4 Other trading activities

	2023 £	2022 £
Income of trading subsidiary	625,654	615,096
Donations sold through shops	41,542	39,370
Rental income	-	597
Publications and attendance fees	686	775
	<u>667,882</u>	<u>655,838</u>

5 Income from investments

	2023 £	2022 £
Income from listed investments	12,694	6,144
Interest receivable	3,886	2,072
	<u>16,580</u>	<u>8,216</u>

6 Other income

	Unrestricted funds general 2023 £	Unrestricted funds designated 2023 £	Total 2023 £	Total 2022 £
Net gain on disposal of tangible fixed assets	<u>507,724</u>	<u>(31,500)</u>	<u>476,224</u>	<u>-</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

7 Raising funds

			2023 £	2022 £
<u>Fundraising and publicity</u>				
Direct staff costs			250,879	282,486
Other fundraising direct costs			44,563	43,902
Support costs (see note 9)			82,181	89,420
			<u>377,623</u>	<u>415,808</u>
	Shine (Trading) Limited	Shops	Total 2023	Total 2022
	£	£	£	£
<u>Trading costs</u>				
Direct staff costs	175,645	22,195	197,840	153,891
Other direct operational costs	41,864	4,397	46,261	34,766
Support costs (see note 9)	79,005	14,085	93,090	111,090
	<u>296,514</u>	<u>40,677</u>	<u>337,191</u>	<u>299,747</u>
Trading costs				
			<u>714,814</u>	<u>715,555</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

8 Charitable activities	Enabling babies and children to achieve their potential		Empowering young people		Adults of all ages to have choices and opportunities		A connected community		Preventing Spina Bifida		Changing experiences of pregnancies		Transforming attitudes		Total 2023		Total 2022	
	£		£		£		£		£		£		£		£		£	
Direct staff costs	169,972		117,339		165,053		325,532		48,720		33,109		79,907		939,632		918,958	
Other direct costs	23,655		16,330		22,970		45,304		6,780		4,608		11,121		130,768		92,590	
	193,627		133,669		188,023		370,836		55,500		37,717		91,028		1,070,400		1,011,548	
Share of support costs (see note 9)	27,966		19,305		27,156		53,559		8,016		5,447		13,147		154,596		145,487	
Share of governance costs (see note 9)	4,731		3,266		4,591		9,063		1,354		920		2,222		26,147		22,337	
	226,324		156,240		219,770		433,458		64,870		44,084		106,397		1,251,143		1,179,372	
Analysis by fund																		
Unrestricted funds - general															711,303		649,363	
Unrestricted funds - designated															105,502		121,205	
Restricted funds															434,338		408,804	
															1,251,143		1,179,372	

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

9 Support and governance costs

	Fundraising and publicity £	Trading costs £	Charitable activities £	2023 £	2022 £
Support costs					
Staff costs	25,730	28,515	63,344	117,589	138,817
IT costs	10,553	10,907	31,884	53,344	45,632
Premises costs	42,570	11,866	35,126	89,562	95,826
Other support costs	17,413	27,717	24,241	69,371	65,720
	<u>96,266</u>	<u>79,005</u>	<u>154,595</u>	<u>329,866</u>	<u>345,995</u>
Governance costs				2023 £	2022 £
Staff costs				12,726	13,647
Audit fees				12,000	8,690
Other governance costs				1,421	-
				<u>26,147</u>	<u>22,337</u>

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2023

The charity has one wholly owned trading subsidiary undertaking, Shine (Trading) Limited which sells balloons for virtual balloon races. The company gift aids virtually all its taxable profits to Shine. A summary of its trading results is shown below. Audited accounts have been filed with the Registrar of Companies.

Trustees' Annual Report and Financial Statements **Shine** 53

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

11 Employees

Number of employees

The average monthly number of full time equivalent employees during the year was:

	2023 Number	2022 Number
Services	26	26
Fundraising and publicity	8	9
Shops	1	1
Administration	4	4
Shine (Trading) Limited	5	5
	<u>44</u>	<u>45</u>

Employment costs

	2023 £	2022 £
Wages and salaries	1,341,214	1,334,511
Redundancy costs	770	12,068
Social security costs	128,057	119,187
Other pension costs	45,014	45,997
Other staff related benefits	3,612	3,642
	<u>1,518,667</u>	<u>1,515,405</u>

The number of employees whose annual remuneration was £60,000 or more were:

	2023 Number	2022 Number
£80,001 - £90,000	<u>1</u>	<u>1</u>

Pension contributions for higher paid employees were £6,560 (2022 - £6,560).

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

12 Trustees

None of the Trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

In respect of attending meetings of committees, travel expenses amounting to £1,421 (2022 - £nil) have been reimbursed to 6 (2022 - no) members of the Board of Trustees.

At the year end, £131 (2022 - £nil) of the above expenses are unpaid and included as a creditor.

The accounts include a charge of £3,312 (2022 - £2,880) to provide the Trustees with indemnity insurance.

13 Net gains/(losses) on investments

	Total 2023 £	Total 2022 £
Revaluation of investments	(41,877)	(1,792)
Gain/(loss) on sale of investments	(465)	10,484
	<u>(42,342)</u>	<u>8,692</u>

14 Taxation

Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE is a registered charity. It only applies its funds in accordance with its charitable objectives, and is not trading with a view to making distributable profits, therefore corporation tax is not chargeable.

The trading subsidiary has gifted its profits to Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE under Gift Aid therefore no corporation tax is payable

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

15 Tangible fixed assets

	Land and buildings £	Equipment £	Fixtures and fittings £	Software and website £	Total £
Group Cost					
At 1 April 2022	1,487,404	38,604	17,024	25,757	1,568,789
Disposals	(1,487,404)	(26,774)	(17,024)	-	(1,531,202)
At 31 March 2023	-	11,830	-	25,757	37,587
Depreciation and impairment					
At 1 April 2022	692,388	36,167	17,024	25,757	771,336
Depreciation charged in the year	-	1,223	-	-	1,223
Eliminated in respect of disposals	(692,388)	(26,774)	(17,024)	-	(736,186)
At 31 March 2023	-	10,616	-	25,757	36,373
Carrying amount					
At 31 March 2023	-	1,214	-	-	1,214
At 31 March 2022	795,016	2,437	-	-	797,453
	Land and buildings £	Equipment £	Fixtures and fittings £	Software and website £	Total £
Charity Cost					
At 1 April 2022	1,487,404	35,965	17,024	18,728	1,559,121
Disposals	(1,487,404)	(26,774)	(17,024)	-	(1,531,202)
At 31 March 2023	-	9,191	-	18,728	27,919
Depreciation and impairment					
At 1 April 2022	692,388	33,528	17,024	18,728	761,668
Depreciation charged in the year	-	1,223	-	-	1,223
Eliminated in respect of disposals	(692,388)	(26,774)	(17,024)	-	(736,186)
At 31 March 2023	-	7,977	-	18,728	26,705
Carrying amount					
At 31 March 2023	-	1,214	-	-	1,214
At 31 March 2022	795,016	2,437	-	-	797,453

The charity owns a freehold interest in some land that is leased to another charity at a peppercorn rent and used in furtherance of the charitable objects. The lease ends in 2093 and no value is included in the accounts for the property.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

16 Fixed asset investments

	Group 2023 £	Charity 2023 £	Group 2022 £	Charity 2022 £
Investments in subsidiaries	-	3	-	3
Listed investments	765,371	765,371	352,864	352,864
	<u>765,371</u>	<u>765,374</u>	<u>352,864</u>	<u>352,867</u>

Movements in fixed asset investments Group and Charity

	2023 £	2022 £
Cost or valuation		
At 31 March 2022	338,944	322,179
Additions within portfolio	451,132	78,408
Disposals within portfolio	(24,531)	(75,233)
Valuation changes	(46,335)	13,590
	<u>719,210</u>	<u>338,944</u>
Cash held for investment	32,241	13,920
At 31 March 2023	<u>751,451</u>	<u>352,864</u>

17 Financial instruments

	Group 2023 £	Charity 2023 £	Group 2022 £	Charity 2022 £
Carrying amount of financial assets				
Trade debtors	165,272	30,849	212,511	98,469
Other debtors	750	750	750	750
Accrued income	27,500	27,500	27,500	27,500
Amounts due from subsidiary undertakings	-	122,536	-	92,587
Bank and cash	1,059,901	1,028,214	620,814	603,115
Measured at cost	<u>1,253,423</u>	<u>1,209,849</u>	<u>861,575</u>	<u>822,421</u>
Fixed asset investments	<u>765,371</u>	<u>765,374</u>	<u>352,864</u>	<u>352,867</u>
Measured at market value	<u>765,371</u>	<u>765,374</u>	<u>352,864</u>	<u>352,867</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

				(Continued)
17	Financial instruments	Group	Charity	Group Charity
	Carrying amount of financial liabilities			
	Trade creditors	21,658	21,462	20,654 20,507
	Accruals and deferred income	93,230	85,428	48,467 41,590
	Other creditors	36,796	35,885	42,560 42,560
	Other taxation and social security	44,789	28,944	40,285 27,535
	Bank loans	-	-	362,216 362,216
	Measured at cost	196,473	171,719	514,182 494,408
18	Debtors			
		Group 2023	Charity 2023	Group 2022 Charity 2022
	Amounts falling due within one year:	£	£	£ £
	Trade debtors	165,272	30,849	212,511 98,469
	Amounts due from subsidiary undertakings	-	122,536	- 92,587
	Other debtors	750	750	750 750
	Prepayments and accrued income	79,178	75,011	87,575 83,968
		245,200	229,146	300,836 275,774
The net amount owed by the subsidiary includes amounts owing for gift aid receivable and payment for services provided.				
19	Creditors: amounts falling due within one year			
		Group 2023	Charity 2023	Group 2022 Charity 2022
	Notes	£	£	£ £
	Loans and overdrafts 21	-	-	48,528 48,528
	Other taxation and social security	44,789	28,944	40,285 27,535
	Trade creditors	21,658	21,462	20,654 20,507
	Other creditors	36,796	35,885	42,560 42,560
	Accruals and deferred income	93,230	85,428	48,467 41,590
		196,473	171,719	200,494 180,720
20	Creditors: amounts falling due after more than one year			
	Group and Charity	Notes	2023 £	2022 £
	Loans and overdrafts	21	-	313,688

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

21 Loans and overdrafts

	2023	2022
Group and Charity	£	£
Bank loans	-	362,216
Payable within one year	-	48,528
Payable after one year	-	313,688

The bank loan was secured by a first legal charge over the freehold property known as 42 Park Road, Peterborough. The loan was repaid in full on the sale of the property during the year.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

22 Retirement benefit schemes

The Pensions Trust - The Growth Plan

SHINE participates in The Pension Trust's Growth Plan (The Plan), a multi-employer scheme which provides benefits to some 638 non-associated participating employers. The scheme is a defined benefit scheme in the UK.

It is not possible for the charity to obtain sufficient information to enable it to account for the scheme as a defined benefit scheme. Therefore it accounts for the scheme as a defined contribution scheme.

The scheme is subject to the funding legislation outlined in the Pensions Act 2004 which came into force on 30 December 2005. This, together with documents issued by the Pensions Regulator and Technical Actuarial Standards issued by the Financial Reporting Council, set out the framework for funding defined benefit occupational pension schemes in the UK.

The scheme is classified as a 'last-man standing arrangement'. Therefore the charity is potentially liable for other participating employers' obligations if those employers are unable to meet their share of the scheme deficit following withdrawal from the scheme. Participating employers are legally required to meet their share of the scheme deficit on an annuity purchase basis on withdrawal from the scheme.

A full actuarial valuation for the scheme was carried out at 30 September 2020. This actuarial valuation showed assets of £800.3m, liabilities of £831.9m and a deficit of £31.6m. To eliminate this funding shortfall, the trustees and the participating employers have agreed that additional contributions will be paid to the scheme as follows:

Deficit contributions

From 1 April 2022 to 31 January 2025:	£3,312,000 per annum (payable monthly)

Note that the scheme's previous valuation was carried out with an effective date of 30 September 2017. This valuation showed assets of £794.9m, liabilities of £926.4m and a deficit of £131.5m. To eliminate this funding shortfall, the Trustee asked the participating employers to pay additional contributions to the scheme as follows:

Deficit contributions

From 1 April 2019 to 30 September 2025:	£11,243,000 per annum (payable monthly and increasing by 3% each on 1st April)

The recovery plan contributions are allocated to each participating employer in line with their estimated share of the Series 1 and Series 2 scheme liabilities.

Where the scheme is in deficit and where the charity has agreed to a deficit funding arrangement the company recognises a liability for this obligation. The amount recognised is the net present value of the deficit reduction contributions payable under the agreement that relates to the deficit. The present value is calculated using the discount rate detailed in these disclosures. The unwinding of the discount rate is recognised as a finance cost.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

22 Retirement benefit schemes

(Continued)

Present values of provision

	31 March 2023	31 March 2022	31 March 2021
Present value of provision	36,146	56,698	293,838

An amount of £20,657 (2022 - £20,657) is included within short term creditors and £15,489 (2022 - £36,041) in long term liabilities.

Reconciliation of opening and closing provisions

	Year Ending 31 March 2023	Year Ending 31 March 2022
Provision at start of period	56,698	293,838
Unwinding of the discount factor (interest expense)	1,071	1,694
Deficit contribution paid	(20,657)	(74,358)
Remeasurements - impact of any change in assumptions	(966)	(1,303)
Remeasurements - amendments to the contribution schedule	-	(163,173)
Provision at end of period	36,146	56,698

Income and expenditure impact

	Year Ending 31 March 2023	Year Ending 31 March 2022
Interest expense	1,071	1,694
Remeasurements - impact of any change in assumptions	(966)	(1,303)
Remeasurements - amendments to the contribution schedule	-	(163,173)
Costs recognised in income and expenditure account	105	(162,782)

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

22 Retirement benefit schemes

(Continued)

Assumptions

	31 March 2023 % per annum	31 March 2022 % per annum	31 March 2021 % per annum
Rate of discount	5.52	2.35	0.66

The discount rates shown above are the equivalent single discount rates which, when used to discount the future recovery plan contributions due, would give the same results as using a full AA corporate bond yield curve to discount the same recovery plan contributions.

The following schedule details the deficit contributions agreed between the company and the scheme at each year end period:

Deficit contributions schedule

Year ending	31 March 2023	31 March 2022	31 March 2021
Year 1	20,657	20,657	74,358
Year 2	17,214	20,657	76,589
Year 3	-	17,214	78,887
Year 4	-	-	67,711

The charity must recognise a liability measured as the present value of the contributions payable that arise from the deficit recovery agreement and the resulting expense in the income and expenditure account i.e. the unwinding of the discount rate as a finance cost in the period in which it arises.

It is these contributions that have been used to derive the charity's balance sheet liability.

The Plan is closed to new entrants and there were no active members of the scheme during the year.

The Scheme has identified a potential issue in respect of the calculation of benefits paid and has instigated a review. The outcome of the review is unknown and the potential financial impact of the review if an issue is identified is unknown. A potential liability may arise, but no provision is included in these accounts as the amount cannot be quantified.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

23 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

	Balance at 1 April 2021 £	Movement in funds			Transfers £	Balance at 1 April 2022 £	Movement in funds			Transfers £	Balance at 31 March 2023 £
		Income £	Expenditure £				Income £	Expenditure £			
National Lottery Community Fund – Early intervention programme across England	91,363	132,511	(161,064)		33,673	96,483	184,348	(203,409)		2,137	79,559
National Lottery Community fund Northern Ireland Bright Stars	31,411	64,589	(77,263)		-	18,737	99,219	(82,892)		-	35,064
International Projects – developing a continence clinic in Nigeria	262	11,621	(160)		-	11,723	-	(13,293)		-	(1,570)
Coop Grant	2,617	-	(160)		-	2,457	-	(339)		-	2,118
National Lottery Community fund: Cymru Health hub	4,915	-	(4,915)		-	-	-	-		-	-
National Lottery Community fund: Cymru Shining lights	14,214	91,307	(91,792)		371	14,100	91,508	(96,040)		11,905	21,473
South West Country SDW	-	16,888	(10,086)		-	6,802	1,000	(7,802)		-	-
COVID 2021/22 "Here for you"	-	32,613	(28,891)		-	3,722	19,500	(8,101)		-	15,121
Database development	-	6,975	(6,060)		-	915	-	(2,073)		1,158	-
Welfare Grants	-	6,253	(6,238)		-	15	3,813	(5,918)		-	(2,090)
Support Groups	1,025	454	(108)		-	1,371	-	464		-	1,835
Buchanan & Henry Allen – supporting our work in the North of England	7,572	-	(7,572)		-	-	-	-		-	-
Margaret Giffen Charitable Trust - supporting our work in Northampton	4,935	30,000	(14,495)		-	20,440	-	(14,935)		-	5,505
	158,314	393,211	(408,804)		34,044	176,765	399,388	(434,338)		15,200	157,015

There are 2 restricted funds with a negative balance at 31 March 2023. This position has reversed since the year end due to funding being received.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

24 Designated funds

The income funds of the charity include the following designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes:

Group	Balance at 1 April 2021 £	Net movement £	Balance at 1 April 2022 £	Net movement £	Balance at 31 March 2023 £
Interest in land and property and other fixed assets	412,408	22,829	435,237	(434,023)	1,214
Florence Bartle fund	114,121	(39,462)	74,659	21,628	96,287
HR fund	45,175	(37,675)	7,500	(7,500)	-
Services in Northern Ireland and Wales	-	70,650	70,650	(41,422)	29,228
Dilapidations	-	31,500	31,500	(31,500)	-
Digital development	-	-	-	25,000	25,000
Research	-	-	-	50,000	50,000
Service funds:					
- East Anglian SDW	-	-	-	75,000	75,000
- Deputy Health Manager	-	-	-	135,000	135,000
- Education Officer	-	-	-	50,000	50,000
- Physio service	-	-	-	25,000	25,000
	<u>571,704</u>	<u>47,842</u>	<u>619,546</u>	<u>(132,817)</u>	<u>486,729</u>
Charity					
Interest in land and property and other fixed assets	409,944	25,293	435,237	(434,023)	1,214
Florence Bartle fund	114,121	(39,462)	74,659	21,628	96,287
HR fund	45,175	(37,675)	7,500	(7,500)	-
Services in Northern Ireland and Wales	-	70,650	70,650	(41,422)	29,228
Dilapidations	-	31,500	31,500	(31,500)	-
Digital development	-	-	-	25,000	25,000
Research	-	-	-	50,000	50,000
Service funds:					
- East Anglian SDW	-	-	-	75,000	75,000
- Deputy Health Manager	-	-	-	135,000	135,000
- Education Officer	-	-	-	50,000	50,000
- Physio service	-	-	-	25,000	25,000
	<u>569,240</u>	<u>50,306</u>	<u>619,546</u>	<u>(132,817)</u>	<u>486,729</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

24 Designated funds

(Continued)

The designated funds comprise:

- the group and charity's interest in land and property and other fixed assets, net of the outstanding mortgage.
- the Florence Bartle fund which is part of a legacy that is to be spent on the relief of Spina Bifida in Cornwall and the South West.
- the HR fund that is for future restructuring and other staff related costs.
- the services in Northern Ireland and Wales that is for work specifically in those countries.
- the dilapidations fund that was for future leasehold dilapidations.
- the digital development fund that is to develop a long-term IT/digital strategy to aid in future-proofing Shine's approaches to technology and automation.
- the research fund that is to improve access to health and care services in line with Shine's strategic goals.
- the service funds that are to fund new posts as detailed above.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

Analysis of net assets between funds														
Group	Unrestricted funds 2023 £	Designated funds 2023 £	Restricted funds 2023 £	Total Unrestricted funds 2023 £	Designated funds 2022 £	Restricted funds 2022 £	Total							
								2022 £						
Fund balances at 31 March 2023 are represented by:														
Tangible assets	-	1,214	-	1,214	-	797,453	797,453							
Investments	765,371	-	-	765,371	352,864	-	352,864							
Current assets/(liabilities)	466,098	485,515	157,015	1,108,628	408,610	176,765	721,156							
Long term liabilities	-	-	-	-	-	(313,688)	(313,688)							
Provisions and pensions	(15,489)	-	-	(15,489)	(36,041)	-	(36,041)							
	1,215,980	486,729	157,015	1,859,724	725,433	176,765	1,521,744							
Charity	Unrestricted funds 2023 £	Designated funds 2023 £	Restricted funds 2023 £	Total Unrestricted funds 2023 £	Designated funds 2022 £	Restricted funds 2022 £	Total							
								2022 £						
Fund balances at 31 March 2023 are represented by:														
Tangible assets	-	1,214	-	1,214	-	797,453	797,453							
Investments	765,374	-	-	765,374	352,867	-	352,867							
Current assets/(liabilities)	443,111	485,515	157,015	1,085,641	385,623	176,765	698,169							
Long term liabilities	-	-	-	-	-	(313,688)	(313,688)							
Provisions and pensions	(15,489)	-	-	(15,489)	(36,041)	-	(36,041)							
	1,192,996	486,729	157,015	1,836,740	702,449	176,765	1,498,760							

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

26 Operating lease commitments

Group and Charity

At the reporting end date the charity had outstanding commitments for future minimum lease payments under non-cancellable operating leases, which fall due as follows:

	2023 £	2022 £
Within one year	48,420	24,215
Between two and five years	124,258	164,901
	<u>172,678</u>	<u>189,116</u>

27 Related party transactions

Remuneration of key management personnel

The remuneration of key management personnel, who on a full time equivalent basis are the 2.5 (2022 - 2.8) members of the senior management team, is as follows.

	2023 £	2022 £
Aggregate compensation including pension contributions	<u>168,298</u>	<u>206,828</u>

Transactions with related parties

Owing to the nature of the charity's operations, some of the Trustees may themselves, or may have family members that access services from the charity. Consequently there will be transactions between those Trustees or their family members. These are on the same basis as other service users of the charity.

28 Control

No one individual has overall control of the charity.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

29	Cash generated from operations	2023 £	2022 £
	Surplus for the year	337,980	171,033
	Adjustments for:		
	Investment income recognised in statement of financial activities	(16,580)	(8,216)
	Investment management fees recognised in statement of financial activities	(7,845)	(2,794)
	Gain on disposal of tangible fixed assets	(476,224)	-
	Loss/(gain) on disposal of investments	465	(10,484)
	Fair value gains and losses on investments	41,877	1,792
	Depreciation and impairment of tangible fixed assets	1,223	28,587
	Movements in working capital:		
	Decrease in debtors	55,636	77,537
	Increase/(decrease) in creditors	22,503	(60,604)
	Increase/(decrease) in pension liability	(20,552)	(183,439)
	Cash (absorbed by)/generated from operations	(61,517)	13,412

30	Analysis of changes in net funds Group	At 1 April 2022 £	Cash flows £	At 31 March 2023 £
	Cash at bank and in hand	620,814	439,087	1,059,901
	Loans falling due within one year	(48,528)	48,528	-
	Loans falling due after more than one year	(313,688)	313,688	-
		<u>258,598</u>	<u>801,303</u>	<u>1,059,901</u>
	Charity			
	Cash at bank and in hand	603,115	425,099	1,028,214
	Loans falling due within one year	(48,528)	48,528	-
	Loans falling due after more than one year	(313,688)	313,688	-
		<u>240,899</u>	<u>787,315</u>	<u>1,028,214</u>



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www.shinecharity.org.uk

Charity number 249338, Company number 00877990



Shine

Spina bifida • Hydrocephalus
Information • Networking • Equality

Accounts

Trustees' Annual Report and Financial Statements

Year ended 31st March 2022



Shine

Spina bifida • Hydrocephalus
Information • Networking • Equality



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Message from our Chair, Greg Smith

Whilst this report reflects on the achievements of the past 12-months, it is, in reality, a culmination of the successes and lessons learnt in the delivery of our 5-year 2017-2022 Plan.

“ ...I am so proud to see the progress that the teams across SHINE have made in delivering our objectives and working towards our strategic goals, making a difference to our members’ lives.

Despite the challenges of Covid-19 again this year, our Services teams have continued to engage and support new members and their families, and have re-engaged with those who we have not heard from for a while; we have reached wider audiences, raising awareness of Spina Bifida and Hydrocephalus; and have highlighted the need for a better understanding of early intervention and preventative approaches to condition management across professional communities to improve the health, well-being and opportunities for babies, children, young people and adults affected by the conditions.

Once again, this year, the volume and diversity of our work has showcased how essential our services are to so many.

This work would not have been possible without the contribution of SHINE’s members across England, Wales and Northern Ireland in shaping our services through their active participation in focus groups, surveys and socials. Our members have also supported each other through mentoring and peer support; parent/carers have done the same. We have also seen our number of volunteers grow to offer support where they can.

Like so many other charities, we experienced uncertainty in so many areas of fundraising due to on-going restrictions and the looming cost of living crisis, yet with careful management and a well-founded strategic plan, we have emerged in a stable financial position. I am eternally grateful to those who have fundraised, donated or awarded grant-funding to enable us to carry on our vital work across the SHINE community.

Our new 5-year Plan 2022 – 2027 has recently been launched. It sets out even more ambitious strategic goals, each building on the foundations laid by the wealth of knowledge, experience and tried and tested activities of the charity’s 50-year plus history, and each specifically planned to meet and adapt to our members’ needs and requests for support, advice, and information over the coming years.

With best wishes,

Greg Smith
Chair



A thanks from Kate, our CEO

Nothing would have been possible without the commitment of the teams in SHINE, our members, our trustees, volunteers, supporters and fundraisers.

Each of you has made a difference through individual and collective contributions to some aspect of the work we do, whether those are the vital frontline support services and information we provide, or the ‘behind the scenes’ activity which underpins everything we do.

A huge thank you to everyone for your continued support throughout the past 12 months.

Together, you make us SHINE!

Our impact in 2021-22

We have supported **5,377** individual members



Dealt with
20,000+
separate issues



A
DECREASE
FROM
2020-21

DUE TO:

- provision of more complex and time-intensive support
- reduced demand for proactive calls
- improved information and resources
- introduction of welcome calls
- data cleanse

INCLUDING

Finances



1,587

Education



731

Employment



206

Health



3,854

Wellbeing



7,581

All other



6,294

Total number of members

12,247 as of 31st March 2022



Number of website visitors

186,095

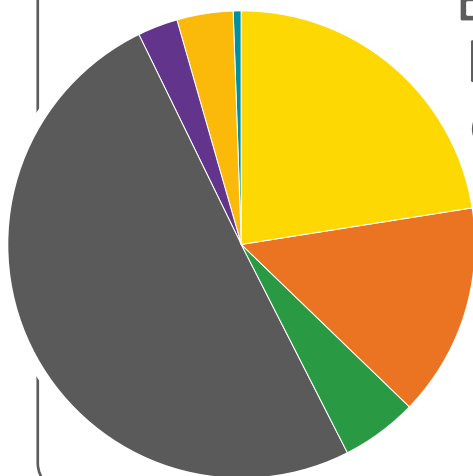


Number of pages visited

483,659

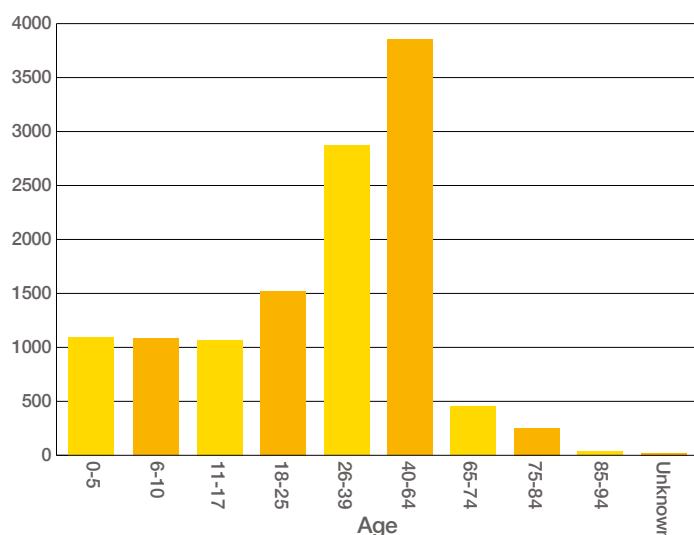


Breakdown
by primary
conditions



- Encephalocele 0.3%
- Hydrocephalus 51.0%
- Idiopathic Intracranial Hypertension 4.0%
- Normal pressure Hydrocephalus 3.0%
- Spina Bifida 15.0%
- Spina Bifida and Hydrocephalus 23.0%
- Spina Bifida Occulta 5.2%

Age of Shine
members (March 2022)



SHINE
Health Direct
membership

GREW BY **5.8%**

to 1262
this year



Our Little Stars...

In our most recent Little Stars survey, parents and carers told us that:



OVER
60% improved their understanding of the conditions

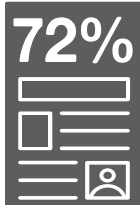


89%

rated SHINE's support as good to excellent



CHILDREN'S CONFIDENCE HAD INCREASED as a result of SHINE's support and engagement!



72% rated our age-specific newsletters as **VERY USEFUL!**

We helped

91%

access support from other organisations



71%



felt more confident in dealing with the challenges of their child's condition

62%

were less socially isolated as a result of support from SHINE

Our Young People and Adult Members...

Our adult members told us that, through support and engagement with SHINE



87% felt they better understood their condition(s)

63%

made new friends...



66%



felt less lonely or isolated

67%

improved their well-being



Professionals...



212

Professionals from various health, care and education disciplines

joined our virtual professionals' conference 'Spina Bifida birth to adulthood' in December 2021.



100% improved their knowledge of Spina Bifida

96% of people

were very satisfied or satisfied with the conference content.



87% OF PEOPLE

were very satisfied or satisfied with the online format

87.5%



were very likely to recommend the conference to colleagues



SHINE's vision

is a society where all those whose lives are affected by Spina Bifida and/or Hydrocephalus and associated conditions are empowered and enabled through choice and equality of opportunity

Our aim

to make a positive difference to the lives of people affected by the conditions

Our **five** strategic goals (2017-2022) were

- 1 Improving outcomes through early intervention and support:**
Babies and children from birth to 10-year-olds will have improved health, educational and social outcomes through specific approaches for support, intervention, and condition management
- 2 Access to better care and services for all:**
People with Spina Bifida and/or Hydrocephalus will have access to specialist services and treatments, which will enable better care and condition management
- 3 Improved lifestyle and choices**
People with Spina Bifida and/or Hydrocephalus will be enabled, engaged, and empowered to make informed choices about the lives they want to lead
- 4 Preventing Spina Bifida**
Greater focus on the causes of Spina Bifida and a call for Government and others to take decisive action in the prevention of Spina Bifida
- 5 Quality information and support**
People affected by Spina Bifida and/or Hydrocephalus, and other key stakeholders, will have access to high-quality information and support to meet their needs



Underpinned by our values

- Promote the empowerment and participation of people with Spina Bifida and Hydrocephalus, and associated conditions
- Value and respect all the different people with whom we work
- Challenge the ways in which society disables our members
- Work to achieve excellence
- Welcome challenge and review
- Use resources ethically, thoughtfully and responsibly







Goal 1: Improving outcomes for babies and children through early intervention and support

In 2021, we extended the Little Stars project from 0-10s to 0-12-year-olds, to better fit with the stages of development and transition during these childhood years. By March 2022, we had a membership of 2557 Little Stars. (England: 2228; Wales: 129; Northern Ireland: 200).

The teams continued with existing approaches and introduced new ways to engage and support our young members, their parents/carers and other family members.

Our work in the past 12 months included:

- Making over 300 welcome calls to new members to introduce SHINE's services and offer support where needed
- 2092 families signing up to receive condition-specific and age-related automated newsletters. Launched at the start of the year, the newsletters are packed with valuable information and advice on care and condition management, developmental milestones and education tips at key points throughout childhood
- Over 50 families accessing pilot 1-2-1 sessions for physiotherapy and occupational therapy
- 989 families joining the new closed Little Stars Facebook group for peer support and information
- Delivering 17 'Shall Wee Talk' virtual sessions. Developed to encourage children to understand more about their personal challenges with continence management, and give them greater confidence in managing those challenges, these sessions also facilitated peer support and friendships
- Distributing a further 164 copies of 'Your Child and Hydrocephalus' publication, and promoting access to the online version
- Holding on-line health hubs, providing the opportunity for a more holistic approach to advice and support for families from our physiotherapist, continence specialist nurse and Support and Development Workers
- 26 regional/county-based WhatsApp groups supporting over 760 families to connect, share information, ask questions and provide peer support
- Setting up a Dandy Walker support group
- Piloting a series of six closed zoom sessions for different age groups with 39 children attending, as well as a Facebook live on bowel and bladder care in partnership with Bullen Healthcare, and several sensory story telling sessions for online fun and laughter
- Over 300 parents attending a variety of closed zoom sessions, all of which focused on specific topics in relation to the conditions, care and/or managing behaviour
- Promoting our 'Hydrocephalus and Learning' webinar and Spina Bifida videos to parents and professionals

Our work with professionals

Our strategic goal 2 highlights much of our work with professionals throughout the year, but the Little Stars project specifically:

- Maintained and further built contact with professionals through children's networks, services, and relevant charities
- Kept close contact with children's clinics that have been slowly resuming face-to-face appointments; Staff have continued to attend the Children's Spina Bifida Clinic in Belfast throughout the past year
- Delivered training and support to special education/ additional learning needs staff through networks such as the Physical Disability Network regional groups, and The Neurodisability Community as well as directly to schools and colleges
- Collaborated with other organisations and networks, including Disabled Children's Partnership, Innermost Learning, Bullen Healthcare, ADHD Foundation and Northern Ireland Children's Health Coalition for improved services



What some of our members said...

“ The services you provide are invaluable. You have been with us even before our daughter was born and honestly without SHINE things would have seemed a lot harder. You gave us hope at the beginning when we were told not to expect much.

As a family we have all benefited from the work you all do, the last 4 years have been made easier with your ongoing support even during the pandemic. Through SHINE I have made forever friends who truly understand what life is like for our children on both good days and bad. That feeling of knowing you are not alone is the best thing SHINE have done for me, thank you for my SHINE family.”

“ Without you it would be an even scarier place than it is”

“ SHINE has just set up a group where the children can meet each other socially... I think that's going to help us the most”

“ The SHINE Little Stars Facebook page is extremely useful. It has helped to develop knowledge of my son's condition and to provide advice to other parent/carers. It is also nice to post about my son's achievements”

“ Knowing you're there makes you feel safe and reassured”

“ The chance to ask questions and learn how to best support my son. I also love meeting other parents + children at the meet ups etc”

Anencephaly support

An important part of our work is offering time and support to parents who have lost a baby to anencephaly – either 1-2-1 support or through our online anencephaly group.

Membership of this closed group grew by 138 people over the past 12 months.

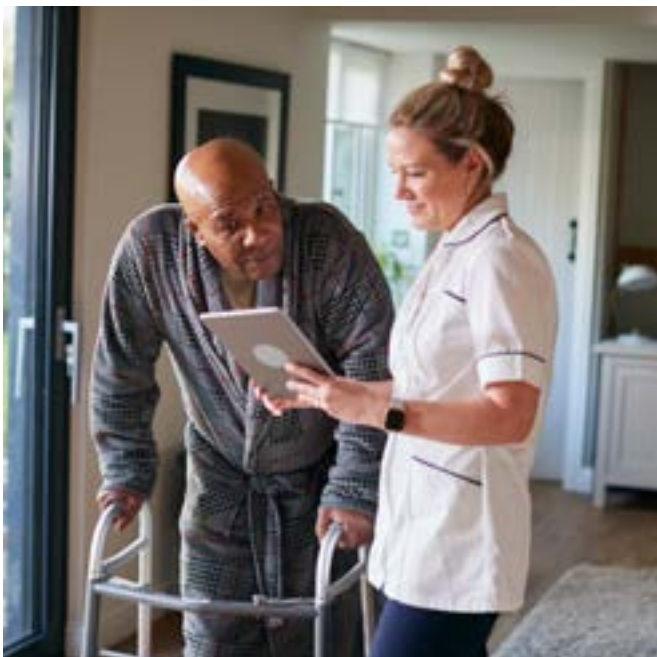


Goal 2: Access to better care and services

Our teams continued to support many members in understanding their rights to health and care provision, empowering them to ask for, and access, the services they needed. The on-going pandemic and continuing restrictions across the country hindered this as health services, medical appointments and care services were slow to resume, if indeed they resumed at all by the end of March 2022.

SHINE developed more projects and initiatives to address the wide range of our members' needs, working with key stakeholders to influence and improve access to better care and services.

Members' voices were very much at the heart of this work through direct engagement, research and focus groups.



In particular, our '1000 Voices' survey on ageing with Spina Bifida in 2020/21, and a more recent survey into Hydrocephalus, provided us with significant insight and evidence on the impact of the conditions on the health and lives of our members.

It is apparent that without improved approaches to care and condition management, opportunities to prevent deteriorating health and emergency hospital admissions will be missed.

In the past 12 months, we began to address the findings of the reports and surveys by:

- Setting up a project on 'skin and tissue' care
- Starting to develop an important guide on Spina Bifida in Adulthood, which includes information for members to use to prompt their GPs to ensure they obtain necessary preventative health checks. This will be launched in 2023
- Scoping key information for adult members, suggesting health checks and condition-specific health information at certain stages in their lives, as they age with the condition(s)
- Reviewing processes and improving the quality of SHINE Health Direct – a home delivery service for continence products and prescription medication
- Promoting SHINE's Legal Service, which provides members with access to legal specialists across the three nations

Engaging and influencing healthcare professionals and the services they provide

The more professionals know about Spina Bifida and Hydrocephalus, and associated conditions, the more likely it is that our members of all ages will have access to the right services and support at the right time – be that health, care, education or any other statutory service they might need.

Over the past 5 years, our focus on reaching professionals and raising awareness of the conditions has steadily grown.

In the past 12 months, this focus culminated in:

- Launching a new professionals' engagement strategy and professional membership
- Developing a professionals' area on SHINE's website, full of useful information and links to research
- Delivering an online conference for professionals
- Raising awareness and sharing knowledge and important health information directly to over 5000 GPs across England, Wales and Northern Ireland
- Further promoting our research into ageing with Spina Bifida and producing a report on the impact of unplanned hospital admissions on individuals and the NHS. Both provide supporting evidence to demonstrate the need for, and cost-effectiveness of, improved access to specialist healthcare for people with Spina Bifida in England, Wales and Northern Ireland.
- Obtaining CPD accreditation for two additional e-learning units for professionals on 'Hydrocephalus' and 'Normal Pressure Hydrocephalus'
- Continued membership of the Society for Research into Hydrocephalus and Spina Bifida (SRHSB) and the International Federation for Spina Bifida and Hydrocephalus



Keeping SHINE members' voices heard

It is no secret that there are not enough statutory services, and far too few staff in those services, to support our members' needs: referral pathways are not clear; access is often limited; and services do not always work together to provide the solutions that are so badly needed.

Through the enormous contribution of our members to various surveys, focus groups and direct contact with our members, SHINE was, once again, able to add our voice and strengthen calls for improvement in local, regional and national services and funding to support for people whose lives have been affected by disabilities.

For example:

- Continued membership of the Disabled Children's Partnership enabled SHINE to join forces with other charities to campaign for the rights of children with disabilities and call for improved health and social care services. The Children's Health Coalition in Northern Ireland enabled the same
- Membership of the Care Support Alliance, the Disability Benefits Consortium and other third sector networks
- Contributions from SHINE members to national research on understanding the demand for, and impact of, services for people living with neurological conditions across the UK
- Direct correspondence to statutory services to highlight poor provision and its impact on individual members' lives
- Collaboration with external organisations to better link our members into complimentary services offered by other partners
- Promotion of opportunities for members to be involved in research projects
- Contribution to research into the impact of COVID-19 on people's lives



Goal 3: Improved lifestyle and choice

We made fewer calls as restrictions from the pandemic eased, and supermarkets and others were able to offer more accessible delivery services for essential goods and medication.

However, our teams had another very busy year, working with members and their families to offer information, advice and support on a variety of issues from health and care, education and employment, housing, finances and benefits, relationships, and a host of other important issues that impact on our members' lifestyles and choices.

Health, well-being and lifestyle and benefits/finances were the top three areas of enquiries

Our membership engagement strategy, introduced in 2019, helped to keep our focus on widening our reach and impact, tailoring our services and support to members in a range of ways and more specifically, for their conditions and ages.

Our learning from 2020/21 on all-things social media stood us in good stead to offer a programme of online support, which reached our members and families in all corners of England, Wales and Northern Ireland to facilitate greater interaction, peer support and sharing of knowledge and information.

As well as the services provided directly to our individual members and families, our support and development activity in 2021/22 included:

- ✓ The introduction of welcome calls to newly registered SHINE members
- ✓ The launch of 'staying well' newsletters, providing information and links to other organisations who can assist with rising costs, energy providers and keeping warm in winter
- ✓ Issuing regular Covid-19 updates and guidance by email, social media and on our website to ensure that members were kept updated on current advice and guidance to help them manage and plan their lives as restrictions continued
- ✓ A new range of leaflets and resources
- ✓ Promoting a series of SHINE 'information passports' to document essential information that is often needed to share with services such as health, care or housing
- ✓ The launch of new Facebook groups for England, Wales and Northern Ireland, and continued interaction with our adult members through our existing SHINE40Plus group (with 2337 individuals now registered)
- ✓ A network of WhatsApp groups
- ✓ Education and information sessions on Zoom and Facebook live
- ✓ Focus groups to address pertinent themes and encourage discussion and feedback
- ✓ Online coffee groups and quizzes

Volunteering

SHINE could not do what we do without the support of our dedicated trustees, volunteers, supporters and fundraisers, and this year was no exception.



Over 50 volunteers directly supported various aspects of the services we deliver, and hundreds more supported us by raising the vital funds to deliver those services.

We opened up a greater variety of opportunities, strengthened our induction and on-going support for volunteers and improved our approaches to recognising volunteer contributions to the work we do.



“ John says, “I wanted to volunteer with SHINE to thank them and give something back for the help I have had from SHINE over the years and allow SHINE to help other members.

I find home-based volunteering suits me very well. The staff in the Trusts & Foundations team have made me feel very welcome and part of the team”

We asked ‘What do you like about SHINE?’



“ I have really enjoyed the sessions with cooking and talking to other kids with similar disabilities to me. I’ve found it helpful to learn more about it, and ways in which other people deal with it and I’ve definitely found some helpful tips. It’s helped me to become more independent, because the other girls have motivated me to do more for myself”

“ That someone is at the end of phone to answer any questions”

“ SHINE keeps you up to date with different things going on”

“ The sense of community and accessibility of support”

“ Thank you for today it was refreshing to have things explained in such a unique way”

“ I was so pleased to find the SHINE Occulta & Me Group. It was lovely to talk ...and it was just helpful to have that person and the group”

Goal 4: Preventing Spina Bifida

'Truly a momentous day!'

On 20 September 2021, the UK government and governments in Wales, Northern Ireland and Scotland jointly announced that fortification of flour with folic acid would become mandatory across the UK.

Alongside many others, SHINE had campaigned for over 30 years for this outcome. We were very much involved in the announcement, providing a statement for the UK Government's official press release and being involved in back-to-back TV and Radio interviews throughout the day.

Despite the positive news, the journey did not end in September as there was (and still is) still some way to go towards seeing this implemented, so SHINE continued to lobby key decision makers to see this come to fruition. More work needs to be done in 2022-23 but we are delighted to be several steps closer to achieving one of SHINE's key objectives of seeing fortification becoming a reality in the UK someday soon.

Alongside fortification sits the importance of folic acid supplementation in also helping to reduce the chances of pregnancies being affected by neural tube defects such as Anencephaly or Spina Bifida.

We promoted this message through

- Direct contact with individuals coming to us for advice on preparing for pregnancy
- Contact with the network of 5000 GPs and work with other professionals
- Social media.

We were also pleased to launch a 2-year partnership with Vitabiotics, which will enable us to further increase awareness and the uptake of folic acid supplements in 2022 and beyond.



Informing and improving access to antenatal support and treatments

In 2019-20, we reported on research into parents' experiences in antenatal settings and the journey from point of diagnosis of an unborn baby with Spina Bifida onwards, and our plans to use the findings to influence improvements in practice in antenatal care and support.



This work* has progressed considerably over the past 12-months with:

- The development of an accredited CPD e-learning module for antenatal care staff
- A presentation at our Professionals' Conference and a published review of the report in a professional journal

**With many thanks to Dr AR Hart for his significant contribution and support to this work*

SHINE also continued to actively contribute to discussions to GIFT-Surg, an international research project which focuses on in utero surgery for congenital birth defects such as Spina Bifida, and develops technology, tools and training necessary to make fetal surgery more effective.

Our partnership with the NHS teams providing specially commissioned fetal surgery continued, with SHINE providing insight on patient experiences of support. The initial diagnosis of an unborn baby with Spina Bifida, and referral pathway to further information and consultation to explore the options available to parents-to-be.

Why is fortification of flour with folic acid so important?

Mandatory fortification of flour with folic acid will improve public health for so many, now and in the future.

"In its simplest terms, the step will reduce the numbers of families who face the devastating news that their baby has anencephaly and will not survive. It will also prevent some babies being affected by Spina Bifida, which can result in complex physical impairments and poor health. This is truly a momentous day."

Kate Steele, CEO, September 2021



Goal 5: Quality information and support

As always, we remained committed to continually improving our information and communication, both to the outside world and across the organisation.

Our teams collaborated with our members to update and further develop a range of useful resources and publications to help our members learn more about their conditions, and also aid in talking to others about their conditions.

A planned programme of marketing and communication activity showcased the breadth of our services and expertise and enabled greater reach and engagement with existing and new audiences. We held successful, and separate, Spina Bifida and Hydrocephalus Awareness

weeks for the third year running, allowing an improved focus on the individual conditions.

The Spring and Autumn editions of our free membership magazine 'Together' were sent out to all of our members by post and email.



With investment in a new membership database, we made improvements to our data and data management processes, which will allow us to maintain better contact and improve engagement with members and allow us to tailor our communications to enhance the services we provide.

We also undertook an extensive review of our website, with new pages and sections added for improved accessibility to our specialist information. A plan for larger-scale improvements was also drawn up and will be implemented over the course of the next 12 months.

Important next steps for SHINE

Our new Corporate Plan 'Engage, Enable and Empower ... The Next Steps' is informed by over 55 years of experience and expertise, and builds on the successes and lessons learnt from our most recent five-year plan. Most importantly, it reflects our members' feedback and ideas on the services, activities and campaigns they want SHINE to deliver.

The new plan sets out our strategic goals and objectives from now until 2027, and how we intend to achieve them and ensure a membership which is engaged, enabled and empowered.



Spina Bifida Awareness Week

#BacktoFrail

18th – 24th
October 2021

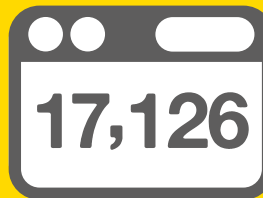
123,376
Social media reach



6,049 social media interactions



Unique SHINE
website visitors
6,357



NUMBER
OF UNIQUE
PAGES VIEWED

((.)) 223 PEOPLE attended our live sessions

Member,
supporter and
staff feedback...



“@ShineUKCharity have some incredible resources for Parents and Professionals, to help you get to grips with #SpinaBifida”

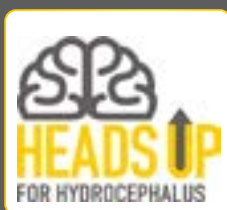
“Just wanted to say how proud we are of the amazing work that our friends at Shine are doing to improve the lives of everyone with #SpinaBifida. Thank you for everything that you do!”

“Henry has #spinabifida and #hydrocephalus so we've had to learn a lot fast @shineukcharity do great work supporting people (with both conditions) and have useful resources if you're not clued up (I wasn't).”





126,481
Social media reach



Hydrocephalus
awareness week

7th – 13th March 2022

 **7,896**
social media interactions

17,995 
unique page views

 **5,677** UNIQUE
WEBSITE
VISITORS

Five emails sent
to an average of

3,258 
members

 **237** People attended
our live sessions

**Member,
supporter and
staff feedback...**



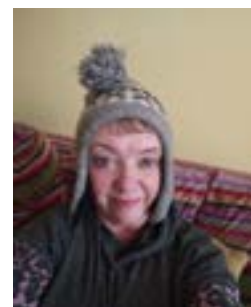
“ There are so many helpful
resources in here. The sensory
information is fascinating.”

“ It's great to talk with others with
the same conditions and has
become a part of my regular social
contact. Good for contacts at shine if I've
needed help too.”

“ I've spent the day running around
wearing a variety of hats, had a
shunt tattooed on me, visited my
children's school who are all taking part
and we've hit £1000!”

“ Informative. Good to share and
hear members experiences.”

“ Useful to have the latest info re
Hydrocephalus tips for Employers.”





Thank you...

On behalf of the thousands of individuals with Spina Bifida and/or Hydrocephalus and their families we are able to help each year, many thanks as always to the everyone - individuals, families, organisations, trusts and foundations, and volunteers, who have helped SHINE in so many ways, some of which are listed below.

Companies and Organisations

Integra Neurosciences – Codman	Hollister Limited	UK Custom Solutions	The Sylvia & Colin Shepherd Charitable Trust
Buckles Solicitors LLP	Fieldfisher	Danes Hill School	
Bullen Healthcare	Irwin Mitchell	Nomios / Infradata	The Worshipful Company of Gold & Silver Wyre Drawers
Citi Belfast	Royal Pigeon Racing Association	Promoting Independence Ltd	
Enable Law	Thompsons NI	Medico-Chirurgical Society	

Supporters

Alex and Victoria Wall	Chris Moralee	Carrie Thompson & Alison Reid	Phil & Sean Holland
Deanne Smith	The Galbraith Family	Hannah & Gethin Phillips	Richard Hynes, Daryl Hynes, Frances Twomey de Hoyos, Natalia Hoyos-Twomey, Christine Plews, Chris Plews (Team Hannah)
Kevin O'Neill	Jane Gillings	The Mager Family	
Matthew Taylour	Dara Haddock and Family	Finley Murphy	
Rebecca Bayliffe	Joanne Dickinson & Sam Howarth	Rainy Solanki	Lizzie Burgess
Emma Holland		Ian Shawcross	

Trusts and Foundations

The Eveson Charitable Trust	The David Solomons Charitable Trust	The P F Charitable Trust
The David Cutforth Charitable Trust	The Evelyn Trust	Gerald Bentrall Charitable Trust
Arihant Charitable Trust	Nottinghamshire County Council	Cambridgeshire Community Foundation
The Privy Purse Charitable Trust	The Ganzoni Charitable Trust	Vinci Foundation
The Pennycress Trust	Duchy Health Charity Limited	Moondance Foundation
The Walter Guinness Charitable Trust	The Jessie Spencer Trust	National Lottery Community Fund - Northern Ireland
The Nottingham General Dispensary	Hadrian Trust	National Lottery Community Fund - Wales
The George Henry Collins Charity	The Joseph and Lena Randall Charitable Trust	National Lottery Community Fund - England
The W. E. Dunn Charitable Trust	Doris Field Charitable Trust	Staffordshire Community Foundation
The Christopher Laing Foundation	The Walter Farthing Trust	Sir James Knott Trust
The Charles Littlewood Hill Trust	The Hospital Saturday Fund	The Souter Charitable Trust
Steven Bloch Image of Disability Charitable Trust	Patrick Rowland Foundation	Wales Council for Voluntary Action (WCVA, Welsh Government)
The Thales Charitable Trust	The Joseph Strong Frazer Trust	MAXIMUS Foundation UK
The Scarfe Charitable Trust	The Thomas Farr Charity	
The Austin Bailey Foundation	The Brian Wilson Charitable Trust	
The Rozel Trust	The Alice Ellen Cooper Dean Charitable Foundation	
The Evelyn Trust		

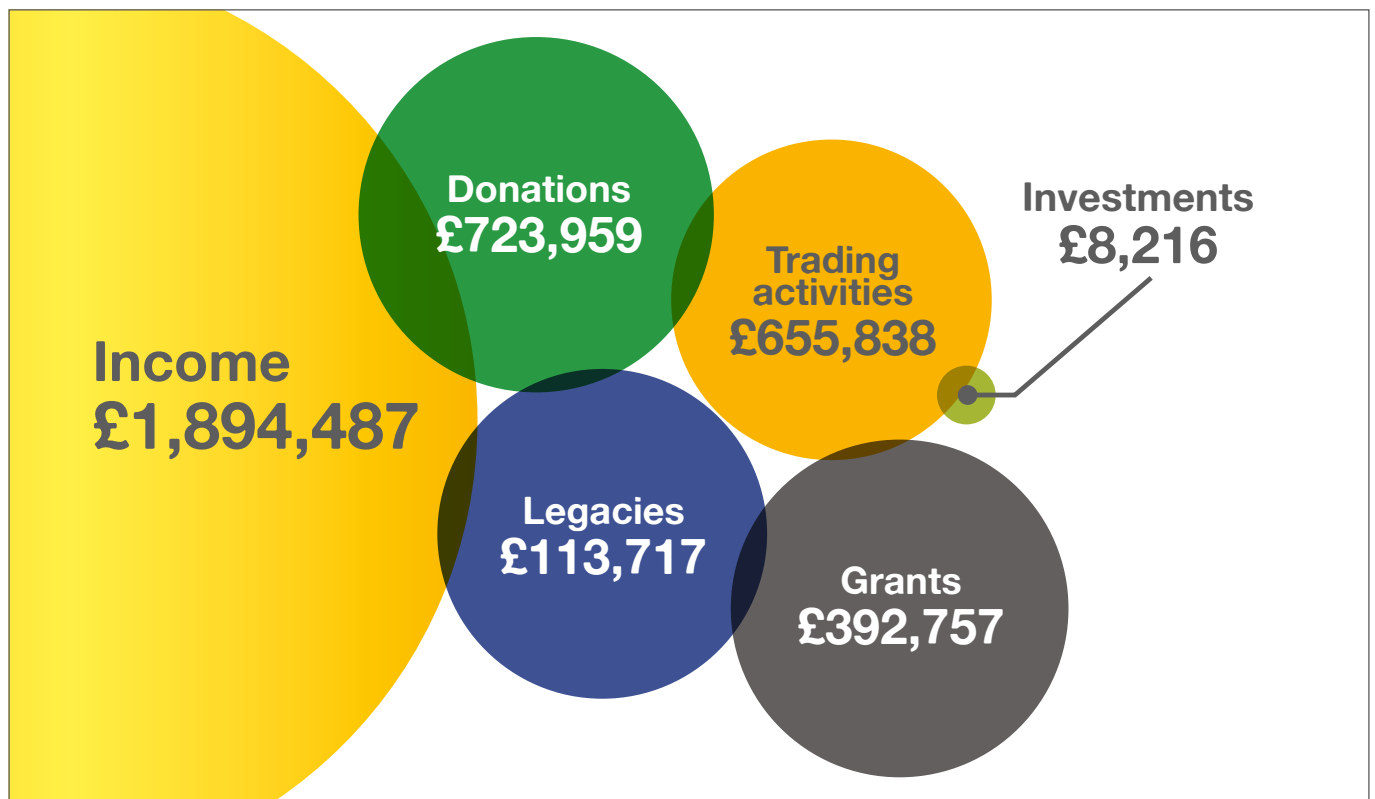


Special Appeals

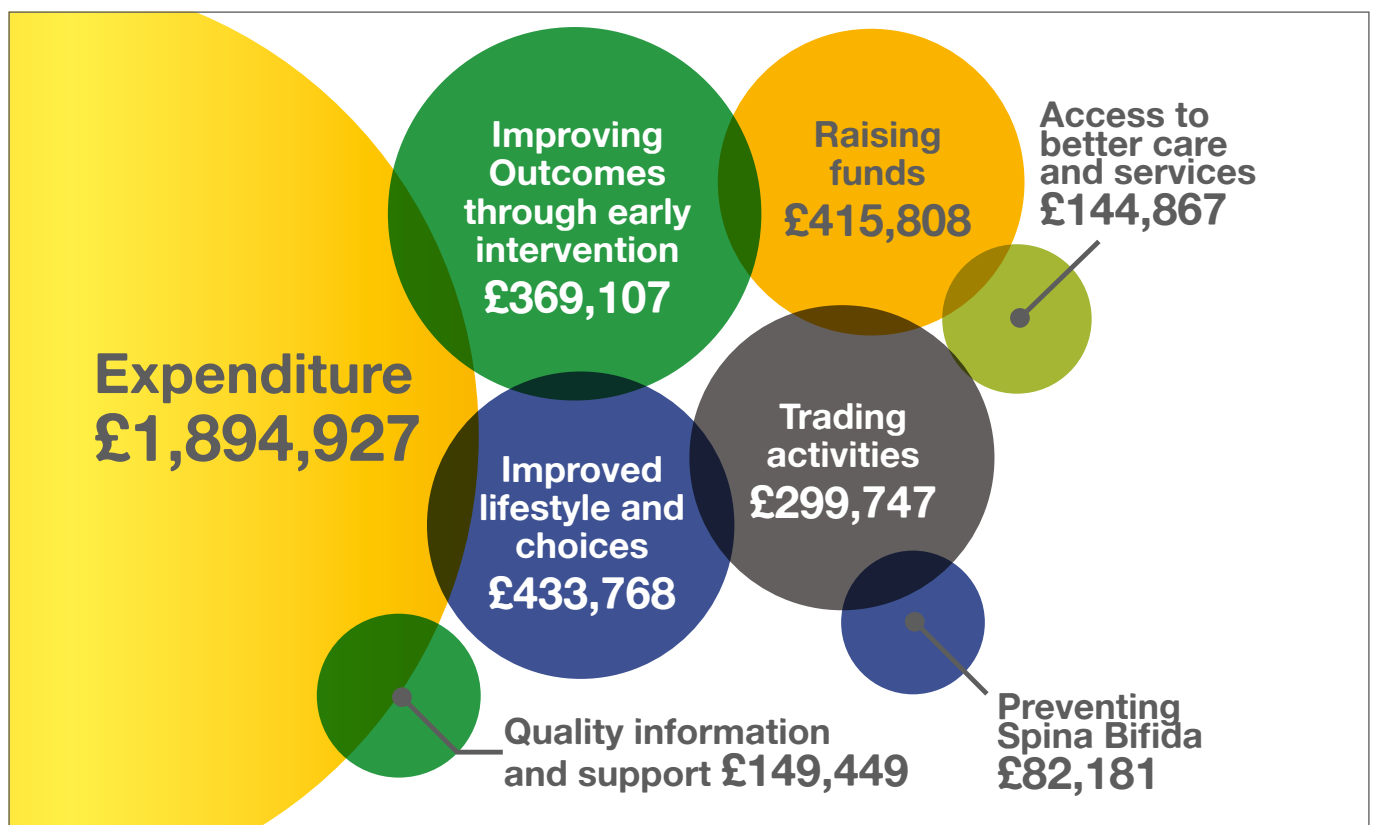
We would like to give special thanks to all of those that help with our balloon races; your support is very much appreciated.

Income and expenditure 2021/22

Total Income



Total Expenditure





Financial Review

Trustees approved a 2021/22 budget deficit of £73,462, reflecting an expectation that whilst donations and trading income would continue to recover from the COVID-19 lockdowns, an element of uncertainty would remain.

SHINE reports an actual surplus of £171,033 (2020/21 £506,730 surplus), which consists of a £104,740 unrestricted surplus, a £47,842 designated surplus, and a £18,451 restricted surplus.

Total income for 2021/22 was £1,894,487 (2020/21 £2,343,079), with decreases in grants and legacies being partly offset by increases in trading and donations. Donation income was most encouraging, recording the highest annual income level since 2015/16 as SHINE was nominated as Citibank Belfast's charity of the year.

Grant funding decreased from 2020/21, as COVID-19 support from the National Lottery Community Fund was not repeated. Nonetheless the National Lottery and other charitable trusts continued to fund an important part of SHINE's work and in the year a new 5-year grant from the Lottery was secured to fund services in Northern Ireland. The project "Shining Opportunities", will commence in June 2022. Legacies also continued to be a major source of funding and whilst income reduced in 2021/22, this follows strong receipts in each of the previous three years and we are very grateful that people continue to remember us in their wills.

Total expenditure in the year was £1,894,927 (2020/21 £1,899,638). We continue to prioritise spending on charitable services. Therefore, charitable expenditure

increased by £6,793 (0.6%) to £1,172,372 and represents 62.2% of total expenditure (61.7% in 2020/21), whilst expenditure on raising funds decreased by £11,504 (1.6%) to £715,555. Staffing levels in SHINE's services fell during the year with 26 full time equivalent posts compared to 27 in 2021/22, as an increase in staff turnover was experienced. At the year end, the charity had vacant staffing posts of 3.3 FTE. It is believed that some staff were reluctant to change employer during the pandemic and are now taking advantage of a buoyant labour market to change jobs. A staff survey was completed in the year and improvements to holiday allowances have been made, and an inflationary pay award was announced for April 2022. SHINE is confident it remains an attractive organisation to work for and has active recruitment plans which aim to raise service staffing levels.

Whilst the war in Ukraine had a detrimental impact on the value of our investments in the final weeks of 2021/22, over the year we report a gain of £8,692 (gain in 2020/21 £81,160). These gains are most welcome, but the charity remains cautious in using these gains to fund charitable services.

Under the accounting standard SORP 2015 the full defined benefit pension deficit must be declared on the balance sheet. There was a 2021/22 actuarial gain of £162,781 (2020/21 loss of £17,871). This reflects the outcome of the 2020 triannual review, which reported a funding level improvement to 96% (2017 86%). A payment plan to eliminate this deficit remains in place and the charity remains confident that it will meet the required pension contributions from its

projected income without significantly impacting on its planned level of charitable activity. Further pension detail is shown in note 21 of the accounts.

In the 2020/21 annual report, trustees confirmed that a review of continued occupancy of 42 Park Road had been conducted and it was concluded to be in the best interests of the charity to sell 42 Park Road and relocate to a smaller office with staff working a hybrid model of home working and office days. 42 Park Road had been SHINE's registered office since 1989 but in recent years the building (against which a charge is held) had become under-utilised. Prior to the marketing of 42 Park Road, a qualified surveyor's report was obtained, valuing the property at £1,300,000. The property was marketed for sale in the summer of 2021, four bids were received and in September trustees selected the preferred bid, for which an exchange of contract was made on the 17th of December. The move to a smaller leasehold office at Minerva business park was completed during late January and the sale of 42 Park Road was completed on the 1st of April 2022. The sale price exceeded the valuation, whilst legal, professional and move costs were below original estimates. Trustees intend to invest the net sale proceeds in future services, in a sustainable way.

Financial Reserves Policy

Reserves are maintained at a level that enables the charity to manage financial risk and sustain services. Trustees have set a reserve target of £850,000, held for the following purposes:

- Statutory obligations.
- Provide a 4-month commitment to our vulnerable members to wind up the affairs of the charity in an orderly fashion, in the advent that the trustees cease to be confident in SHINE's ability to continue.
- Offset the risks of an unexpected shortfall in income and an adverse movement in the defined benefit pension scheme liability.
- A working capital facility.

This target level of reserves represents an increase of £280,000 versus the previous policy (March 2020). Trustees must balance the needs of SHINE's members against financial risks. COVID-19 and the war in

Ukraine have demonstrated that our world is less certain than previously thought.

At the year-end SHINE held free reserves of £725,433, being general unrestricted funds excluding designated funds. This represents 3.2 months of committed expenditure cover and is below the total reserves target. Therefore, as reserves are expected to increase in 2022/23 some of the gain on sale of 42 park Road will be retained to meet the shortfall in reserve level.

Notwithstanding the above, the charity plans to utilise its reserves in a managed fashion through investment in strategic priorities. The charity has plans to expand its services in 2022/23 with the addition of a youth worker, a volunteer coordinator and additional health resources. In total these changes will raise the service staff establishment by 2.3 FTE.

Restricted reserves must be applied to the specific purpose(s) intended by the donor so do not form part of the free reserves; funds totaled £176,765 at the year end and are planned to be expended in 2022/23.

Designated funds have been established by the Board and are excluded from free reserves. They are as follows:

- A fund to represent SHINE's investment in fixed assets, net of the outstanding mortgage on the 42 Park Road (as at 31st of March).
- A fund to employ an additional full-time Support and Development Worker for the South West of England, enabling us to have a much greater reach to support children and adults with Spina Bifida and Hydrocephalus in that area, through one-to-one support and a network of social and support groups. This has been made possible by the generosity of the late Florence Bartle who kindly chose to remember SHINE in her will, with funds received in 2020/21.
- A fund to support services in Northern Ireland & Wales. This has been made possible by the generosity of supporters in these home nations, and in particular CitiBank Belfast.
- A fund to meet future property dilapidation obligations in relation to leasehold properties (Minerva Business Park, Peterborough and our charity shop in Gorseinon, Cardiff).

Investment Policy

Under the governing document the charity has the power to make any investment which the trustees see fit. R. C. Brown Investment Management plc are SHINE's investment managers with the remit to manage the investments in line with the policy outlined below.

Investments are held as part of the long-term reserves of SHINE. The aim is that they should maintain their value and generate income for SHINE.

The portfolio must only be invested in assets with a low risk profile. This will include utilisation of pooled funds, which provide diversification of assets, and ensures that the risk of losing a single holding is minimised.

- The investments may be held in a range of asset classes, including equities, corporate bonds, and gilts.
- There will be no direct investment in 'alternative' investments such as hedge funds or derivatives.
- There will be no direct investment in overseas equities. Any such investment must be done through pooled funds managed in the UK.

The trustees have agreed that the funds should initially be invested in a broad, balanced portfolio. The intention is to work towards ethical investments, with the advice of the investment managers, while being mindful of the charity's obligations for responsible investment.

During the year R. C. Brown Investment Management plc continued to manage the SHINE portfolio. The funds were fully invested; the long-term funds performed below their benchmark, recording a 3.39% return during 2021/22 versus the 4.73% benchmark

(ARC steady growth index).

In 2022/23 the charity intends to use some of the sale proceeds of 42 Park Road to increase the investment portfolio and RC Brown will actively manage the timing of funds being placed.

Risk Management and Internal Control

The Board of Trustees are responsible for the identification and management of the major risks facing the charity. A Risk Register is maintained and shared annually with trustees (more frequently if a significant issue arises). Risk management at operational level is managed by the senior leadership team; major risks have been reviewed and systems established to manage these risks.

During 2021/22 the most significant risk remained COVID-19 in terms of the way in which the charity supported its members and the risks to income levels. Therefore, the risk register currently covers six strategic areas.

1. Governance & strategy

2. Income generation

3. Services

4. Finance

5. COVID-19

6. Brexit

During the year the number of red retained risks declined from 3 in March 2021 to 1 in March 2022. SHINE continues to make structural and strategic changes to the organisation to mitigate these risks.

Going Concern and Statement of Public Benefit

Going Concern

The activities of the charity, its objectives, factors likely to affect its future development and the policies for managing its capital and financial risk

are detailed in the Trustees' Report. We have set out a review of SHINE's financial performance, the reserves position and principal risks and uncertainties in this report.

The budget for 2022/23 was prepared by senior leadership and approved by the trustees in March 2022; it included the financial benefits expected with the sale of 42 Park Road. The expectation is that trading and donation income levels are maintained as COVID-19 lockdown measures are removed. Expenditure levels will be allowed to increase in line with the expansion in service provision, the return of face-to-face contact and events for our members. A total deficit of £157,775 which includes expenditure against restricted and designated funds received in prior periods and an unrestricted deficit of £79,333 is planned as increases in service staffing levels are made. The budget and its assumptions are reviewed against two key financial measures:

- In-year cash flow
- Free reserve cover

Management accounts are prepared by senior leadership and issued monthly to trustees; the current financial position and financial outlook are reviewed at quarterly trustee meetings. Given the level of reserves and outlook, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future being at least twelve months from date of approval of these financial statements. Accordingly, they continue to adopt the going concern basis of accounting in preparing the financial statements.

Statement of Public Benefit

The trustees confirm that they have complied with the duty in section 17 of the Charities Act 2011 to have regard to the Charity Commission's general guidance on public benefit, 'Charities and Public Benefit'.

SHINE's charitable objects are enshrined within its

memorandum and articles and as such trustees ensure that the charity's activities are carried out for public benefit through its strategic goals. This report allows us to show how charitable funds are spent and the impact and benefits this has to the lives of people affected by Spina Bifida and/or Hydrocephalus, and associated conditions.

Reference and Administration Details

Trustees

The trustees of Spina bifida, Hydrocephalus, Information, Networking, Equality – SHINE are the charity’s trustees under charity law and directors of the charitable company and throughout the report are collectively referred to as the trustees.

Mark Noakes (Chairman – resigned 8 June 2021)	Michael Brown
Gregory Smith (Chair)	Andrew Smart
Rebecca Bates (Hon. Treasurer)	Joanne Williams (elected Vice Chair 7 June 2022)
Patricia Adley (passed away 14 May 2022)	Lynn Aziza Dar (appointed 21 July 2021)
Stuart Barrow (resigned 11 January 2022)	Surekha Kukadia (appointed 6 July 2021)
Professor Roger Bayston	

It is confirmed that none of the serving trustees had any beneficial interest in any contract with SHINE in the year.

Patricia Adley passed away on the 14 May 2022, at just 65 years of age. Since appointed a trustee in 2015, Patricia brought a wealth of lived-in experience to the board, having been born with Spina Bifida. Patricia was a retired solicitor, and therefore also brought a wealth of legal & professional skills, and jointly led on safeguarding issues. She was immensely proud of SHINE’s work, and she will be missed by all.

Royal Patron
HRH The Duchess of Gloucester GVCO

Senior Leadership Team	
Chief Executive Kate Steele	Director of Fundraising & Marketing
Director of Services Heidi Watson (left June 2022)	Teresa Hicks (left April 2021)
Director of Finance Stephen Ellen	

Objects

The charity’s objects are specifically restricted to the relief of persons who have Spina Bifida and/or Hydrocephalus or allied or related disorders by providing care, welfare, treatment, education, and integration into society.

Principal Professional Advisers

Auditors

Azets Audit Services

Ruthlyn House
90 Lincoln Road
Peterborough
PE1 2SP

Bankers

The Co-operative Bank Plc

PO Box 250
Skelmersdale
WN8 6WT

Unity Trust Bank

Four Brindley Place
Birmingham
B1 2JB

Insignis Cash Solutions

St John's Innovation Centre
Cowley Road
Cambridge
CB4 0WS

Solicitors

Greenwoods GRM LLP

Monkstone House
City Road
Peterborough
PE1 1JE

Investment Managers

R.C. Brown Investment Management

1 The Square
Temple Quay
Bristol
BS1 6DG

HR

Vero HR

St James House
Flaxley Road
Kingston Park
Peterborough
PE2 9FT

Administrative Details

The full name of the charity is Spina bifida, Hydrocephalus, Information, Networking, Equality – SHINE. We are commonly known as SHINE.

The registered charity number is 249338 (England and Wales)

The company registration is 00877990

Registered Office: SHINE, Unit 4, Minerva Business Park, Peterborough, PE2 6FT

Telephone 01733 555988 • Email firstcontact@shinecharity.org.uk • www.shinecharity.org.uk



Our Commitment to Quality Fundraising

SHINE is registered with the Fundraising Regulator and proud to commit to the Regulator's Fundraising Promise.

We are committed to maintaining high standards of fundraising in line with the Code of Fundraising Practice:

- We will be clear, honest, and open.
- We will be respectful.
- We will be fair and reasonable.
- We will be accountable and responsible.

Our approach to fundraising consists of:

- marketing appeals to individuals who have already expressed an interest in SHINE.
- running charitable events for which participants raise money.
- encouraging people to participate in other events to raise funds on our behalf.
- community fundraising; and
- soliciting donations from corporate partners, charitable trusts, and individual donors.

We also encourage people to remember us in their will with a gift or legacy.

We do not use third-party professional fundraising agencies.

Where people or organisations raise funds in aid of SHINE, we request they follow our standards. SHINE's fundraising team provide tools and resources to enable supporters to deliver fun, safe, and successful fundraising activities. The trustees are of a view that during the year to 31 March 2022 we have been compliant with these standards, and we are not aware of any instances where those acting in aid of the charity have failed to comply.

To protect vulnerable people and other members of the public, SHINE has a safeguarding policy, and our fundraising commitment is displayed on our website. We are careful to protect the private data of supporters and give clear options to stop being contacted by us. As part of our compliance with the code of fundraising practice, we ensure our approach to fundraising is not unreasonably intrusive or persistent and does not aim to solicit donations by pressuring potential supporters.

We take these steps to make sure people have a choice about whether to fundraise for SHINE.

SHINE and our members are incredibly grateful for the continued dedication and support of our fundraisers. From everyone at SHINE, thank you for your ongoing generosity.

Structure, Governance and Management

Structure

Spina bifida, Hydrocephalus, Information, Networking, Equality – SHINE (SHINE) is a company limited by guarantee registered in England and Wales (Registration No. 00877990) formed in 1966. SHINE is registered as a charity with the Charity Commission for

England and Wales (Registration No. 249338).

The charity owns the entire share capital of SHINE (Trading) Limited, registered in England and Wales (No. 01031004). The consolidated accounts include SHINE (Trading) Limited (see note 9). The principal activity of the company is to raise funds for the charity.

Governance

SHINE is governed by Articles of Association, which were amended in 2018.

Organisational purpose

SHINE has a clear, sustainable corporate strategy for 2017 to 2022 consistent with the charity's purpose and an evaluation and monitoring framework to monitor impact and measure outputs, which will continue against SHINE's new strategy for 2022 to 2027.

SHINE consults with a wide range of stakeholder groups to determine the priorities for the charity over the next five years. These groups advise the Board and senior leadership team on matters of policy and practice and respond to consultations and specific areas of interest.

Leadership

The ultimate responsibility for the governance of the charity and its subsidiary is entrusted to the trustee board.

Board Integrity

Appointment of trustees

New Articles of Association were adopted by special resolution in 2018 specifying that any person who is willing to act as a trustee, and who is permitted by law to do so, may be appointed as a trustee by a resolution of the trustees.

A trustee must be a natural person aged 16 years or older, the minimum number of trustees is 3 and the maximum is 16. Trustees are appointed for a term of 3 years; trustees are eligible for reappointment up to two subsequent terms (each of 3 years). No trustee can serve for more than 9 consecutive years unless the trustees consider it is in the best interests of the charity that a particular trustee should continue to serve. Professor Roger Bayston continues to serve as a trustee on this basis.

Trustee induction and training

New trustees undergo an induction where they would normally visit SHINE's registered office and meet the senior leadership team and other key employees. (In light of COVID-19 the induction of Lynn Aziza Dar and Surekha Kukadia was completed by virtual means.) They are fully appraised of the full range of SHINE's services, projects and campaigns and provided with relevant background literature.

They receive awareness training, if required, on Spina Bifida and Hydrocephalus. Depending on their specific

skills and areas of expertise they will be put in touch with relevant staff.

Trustees are briefed on their legal obligations under charity and company law, the Articles of Association and the Board's decision-making process. They are also informed about SHINE's Corporate Plan, key risks, recent financial performance, and prospects for the charity.

Decision making, risk and control

The Board of Trustees is the governing body with overall legal responsibility for the charity. The Board sets the strategic direction for SHINE. It meets a minimum of four times a year; due to the COVID-19 pandemic the board met by virtual means, but now plans to return to face to face meetings.

The minutes of meetings are made available to all trustees on a timely basis. The board regularly reviews operational plans, budgets, performance, and SHINE's main risks. The day-to-day management of the charity is delegated to the Chief Executive, who reports to the Board. The Chief Executive is assisted in the day-to-day management by the senior leadership team.

Senior Staff Remuneration Policy

The remuneration of senior staff is set by benchmarking with similar-sized charities, and the market rate required to attract the best people to the job.

Diversity and Inclusion

SHINE has a transparent recruitment process, advertising widely and looking at how we can attract a diverse pool of candidates.

Safeguarding

A full review of our safeguarding policies and processes began in 2020/21 to ensure that we are continually improving our approaches to safeguarding, incorporating all updated legislation, and embracing current best practice to protect the welfare of our members, staff and volunteers.

An annual safeguarding plan is agreed by trustees. The plan is prepared by the Director of Services, who is Designated Safeguarding Lead for the charity, in conjunction with Joanne Williams (and the late Patricia Adley), who are trustee leads for safeguarding.

Safeguarding training is provided for all staff, trustees, and volunteers. Incidents are reported, assessed, and enacted as appropriate with full consideration given to the requirement to report to the Charity Commission.

GDPR

Extensive work was undertaken to ensure SHINE's ongoing compliance with the General Data Protection Regulation (GDPR). We have a designated GDPR lead, and the data management action plan is reviewed by trustees annually.

Section 172 Statement

The trustees must act in accordance with a set of general duties. These duties are laid out in s172 of the UK Companies Act 2006 which is summarised as follows: A Director of a Company must act in a way most likely to promote the benefit of its members, and in doing so have regard to:

- The likely consequences of any decision in the long term
- The interests of the charity's employees
- The need to foster the charity's business relationship with suppliers, customers, and others
- The impact of the charity's operations on the community and environment

- The desirability of the charity's maintaining a reputation for high standards of business
- The need to act fairly between members of the charity.

The trustees believed they have completed their duties under s172.

Related Parties

The charity has partnerships with several local associations. These are independent charities for Spina Bifida and Hydrocephalus. Partnerships are negotiated on an individual basis which may cover a range of activities and services. The charity also works in partnership with many other bodies, voluntary, statutory, and international, in carrying out work to support service users, undertake research and disseminate information.

Volunteers

In 2021/22, SHINE had 53 registered volunteers and recorded 1,860 volunteered hours, to whom we remain eternally grateful. The volunteering roles included:

- Working in our charity shop
- Giving talks and representing SHINE
- Acting as peer support
- Supporting our members to grow in confidence and address the challenges of living with the conditions
- Advising on the development of resources
- Fulfilling the role of SHINE ambassador
- Fundraising
- Supporting our local groups
- Administration and research

During the year three volunteer catch up meetings were held online to keep our volunteer engaged. A volunteers' newsletter was also launched which provided updates and opportunities for them to get involved if so wished.

Statement of trustees' responsibilities

The trustees (who are also directors of Spina bifida, Hydrocephalus, Information, Networking, Equality – SHINE), are responsible for preparing the annual report and the financial statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice. Company law requires the directors to prepare financial statements for each financial year which give a true and fair view of the situation of the charitable group and of the net income or expenditure of the group for the year. In preparing these financial statements the directors are required to:

- select suitable accounting policies and then apply them consistently
- observe the methods and principles in the Charities SORP
- make judgements and estimates that are reasonable and prudent
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and the group and enable them to ensure that the financial statements comply with the Companies Act 2006.

They are also responsible for safeguarding the assets of the charity and the group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Statement as to disclosure of information to auditors

As far as the trustees are aware, there is no relevant audit information of which the group's auditors are unaware. Additionally, the trustees have taken all the necessary steps that they ought to have taken as trustees to make themselves aware of all relevant audit information and to establish that the group's auditors are aware of that information.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website.

Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Appointment of Auditors

The continued appointment of Azets Audit Services Limited was confirmed by the Board of Trustees on the 7th December 2021.

This report has been prepared in accordance with the special provisions relating to small companies within Part 15 of the Companies Act 2006.

By order of the Board of Trustees

Greg Smith

Chair

6th September 2022



SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

INDEPENDENT AUDITOR'S REPORT

TO THE TRUSTEES OF SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

Opinion

We have audited the financial statements of Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE (the 'charity') and its subsidiary for the year ended 31 March 2022 which comprise the Group Statement of Financial Activities, the Group and Parent Charitable Company Balance Sheets, the Group and Parent Charitable Company Cash Flow Statements and the notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the Group and Parent Charitable Company affairs as at 31 March 2022 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the *Auditor's responsibilities for the audit of the financial statements* section of our report. We are independent of the Group and Parent Charitable Company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. The Trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE TRUSTEES OF SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of our audit:

- the information given in the Trustees' report, which includes the directors' report prepared for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the directors' report included within the Trustees' report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the Group and Parent Charitable Company and its environment obtained in the course of the audit, we have not identified material misstatements in the directors' report included within the Trustees' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the Trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemptions in preparing the Trustees' report and from the requirement to prepare a strategic report.

Responsibilities of Trustees

As explained more fully in the statement of Trustees' responsibilities, the Trustees, who are also the directors of the charity for the purpose of company law, are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the Group and Parent Charitable Company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities is available on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE TRUSTEES OF SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

Extent to which the audit was considered capable of detecting irregularities, including fraud

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above and on the Financial Reporting Council's website, to detect material misstatements in respect of irregularities, including fraud.

We obtain and update our understanding of the entity, its activities, its control environment, and likely future developments, including in relation to the legal and regulatory framework applicable and how the entity is complying with that framework. Based on this understanding, we identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. This includes consideration of the risk of acts by the entity that were contrary to applicable laws and regulations, including fraud.

In response to the risk of irregularities and non-compliance with laws and regulations, including fraud, we designed procedures which included:

- Enquiry of management and those charged with governance around actual and potential litigation and claims as well as actual, suspected and alleged fraud;
- Reviewing minutes of meetings of those charged with governance;
- Assessing the extent of compliance with the laws and regulations considered to have a direct material effect on the financial statements or the operations of the entity through enquiry and inspection;
- Reviewing financial statement disclosures and testing to supporting documentation to assess compliance with applicable laws and regulations;
- Performing audit work over the risk of management bias and override of controls, including testing of journal entries and other adjustments for appropriateness, evaluating the business rationale of significant transactions outside the normal course of business and reviewing accounting estimates for indicators of potential bias.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.



Mr Mark Jackson FCA DChA (Senior Statutory Auditor)
for and on behalf of Azets Audit Services

23 September 2022

Chartered Accountants
Statutory Auditor

Ruthlyn House
90 Lincoln Road
Peterborough
United Kingdom
PE1 2SP

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2022

Current financial year

		Unrestricted funds 2022 £	Designated funds 2022 £	Restricted funds 2022 £	Total 2022 £	Total 2021 £
	Notes					
Income from:						
Donations and legacies	3	837,222	-	393,211	1,230,433	1,760,993
Other trading activities	4	655,838	-	-	655,838	575,094
Income from investments	5	8,216	-	-	8,216	6,992
Total income		1,501,276	-	393,211	1,894,487	2,343,079
Expenditure on:						
Raising funds	6	715,555	-	-	715,555	727,059
Charitable activities	7	649,363	121,205	408,804	1,179,372	1,172,579
Total resources expended		1,364,918	121,205	408,804	1,894,927	1,899,638
Net gains/(losses) on investments	12	8,692	-	-	8,692	81,160
Net incoming/(outgoing) resources before transfers		145,050	(121,205)	(15,593)	8,252	524,601
Gross transfers between funds		(203,091)	169,047	34,044	-	-
Net (outgoing)/incoming resources		(58,041)	47,842	18,451	8,252	524,601
Other recognised gains and losses						
Actuarial gain/(loss) on defined benefit pension schemes		162,781	-	-	162,781	(17,871)
Net movement in funds		104,740	47,842	18,451	171,033	506,730
Fund balances at 1 April 2021		620,693	571,704	158,314	1,350,711	843,981
Fund balances at 31 March 2022		725,433	619,546	176,765	1,521,744	1,350,711

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

STATEMENT OF FINANCIAL ACTIVITIES (CONTINUED) INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2022

Prior financial year

	Notes	Unrestricted funds 2021 £	Designated funds 2021 £	Restricted funds 2021 £	Total 2021 £
<u>Income from:</u>					
Donations and legacies	3	1,211,858	-	549,135	1,760,993
Other trading activities	4	575,094	-	-	575,094
Income from investments	5	6,992	-	-	6,992
Total income		1,793,944	-	549,135	2,343,079
<u>Expenditure on:</u>					
Raising funds	6	727,059	-	-	727,059
Charitable activities	7	563,350	45,754	563,475	1,172,579
Total resources expended		1,290,409	45,754	563,475	1,899,638
Net gains/(losses) on investments	12	81,160	-	-	81,160
Net incoming/(outgoing) resources before transfers		584,695	(45,754)	(14,340)	524,601
Gross transfers between funds		(278,181)	225,629	52,552	-
Net (outgoing)/incoming resources		306,514	179,875	38,212	524,601
Other recognised gains and losses					
Actuarial gain/(loss) on defined benefit pension schemes		(17,871)	-	-	(17,871)
Net movement in funds		288,643	179,875	38,212	506,730
Fund balances at 1 April 2020		332,050	391,829	120,102	843,981
Fund balances at 31 March 2021		620,693	571,704	158,314	1,350,711

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

BALANCE SHEETS

AS AT 31 MARCH 2022

	Notes	Group 2022 £	Charity 2022 £	Group 2021 £	Charity 2021 £
Fixed assets					
Tangible assets	14	797,453	797,453	823,163	820,699
Investments	15	352,864	352,867	341,378	341,381
		1,150,317	1,150,320	1,164,541	1,162,080
Current assets					
Debtors	17	300,836	275,774	378,373	339,989
Cash at bank and in hand		620,814	603,115	650,600	637,285
		921,650	878,889	1,028,973	977,274
Creditors: amounts falling due within one year	18	(200,494)	(180,720)	(253,790)	(222,614)
Net current assets		721,156	698,169	775,183	754,660
Total assets less current liabilities		1,871,473	1,848,489	1,939,724	1,916,740
Creditors: amounts falling due after more than one year	19	(313,688)	(313,688)	(369,533)	(369,533)
Net assets excluding pension liability		1,557,785	1,534,801	1,570,191	1,547,207
Defined benefit pension liability	21	(36,041)	(36,041)	(219,480)	(219,480)
Net assets		1,521,744	1,498,760	1,350,711	1,327,727
Income funds					
Restricted funds	22	176,765	176,765	158,314	158,314
<u>Unrestricted funds - general</u>					
Designated funds	23	619,546	619,546	571,704	569,240
General unrestricted funds		725,433	702,449	620,693	600,173
		1,344,979	1,321,995	1,192,397	1,169,413
		1,521,744	1,498,760	1,350,711	1,327,727

The financial statements were approved by the board of directors and authorised for issue on 6th September 2022 and are signed on its behalf by:



Mr G Smith
Trustee
Company Registration No. 00877990



Mrs R Bates
Trustee

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 31 MARCH 2022

	Notes	2022 £	£	2021 £	£
Cash flows from operating activities					
Cash generated from operations	29		13,412		328,060
Investing activities					
Purchase of tangible fixed assets		(2,877)		(2,346)	
Interest received		8,216		2,054	
Net cash generated from/(used in) investing activities			5,339		(292)
Financing activities					
Repayment of bank loans		(48,537)		(47,152)	
Net cash used in financing activities			(48,537)		(47,152)
Net (decrease)/increase in cash and cash equivalents			(29,786)		280,616
Cash and cash equivalents at beginning of year			650,600		369,984
Cash and cash equivalents at end of year			620,814		650,600

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2022

1 Accounting policies

Company information

Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE is a private company limited by guarantee incorporated in England and Wales. The registered office is Unit 4, The Forum, Minerva Business Park, Peterborough, Cambridgeshire, PE2 6FT, United Kingdom.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's governing document, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2019). The charity is a Public Benefit Entity as defined by FRS 102.

The financial statements have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a true and fair view. This departure has involved following the Statement of Recommended Practice for charities applying FRS 102 rather than the version of the Statement of Recommended Practice which is referred to in the Regulations but which has since been withdrawn.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

The consolidated accounts incorporate the results of the charity and of its wholly owned subsidiary.

1.2 Going concern

At the time of approving the financial statements, the Trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the Trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Designated funds comprise funds which have been set aside at the discretion of the Trustees for specific purposes. The purposes and uses of the designated funds are set out in the notes to the financial statements.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

1 Accounting policies

(Continued)

1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

Gifts donated for resale are included as income when they are sold. No amounts are included in the financial statements for services donated by volunteers.

Grant income is recognised according to the terms of each individual agreement.

All other income is dealt with on an accruals basis.

1.5 Resources expended

Direct expenditure is analysed and charged to the department incurring the cost. Expenditure is included when incurred, the majority of costs being directly attributable to specific activities. Costs that can not be directly attributable to particular headings, are allocated to activities on a basis consistent with use of the resources. Premises and other overheads have been allocated on a head count basis.

Fundraising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of charitable activities.

Governance costs are those incurred in connection with the governance arrangements of the charity and compliance with constitutional and statutory requirements.

1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses. Assets over £1,000 in value are capitalised at cost.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the straight line basis at the following rates:

Land and buildings	Buildings - 2%, land is not depreciated
Fixtures and fittings	20%
Equipment	20%
Software and website	20 - 33%

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in net income/(expenditure) for the year.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

1 Accounting policies

(Continued)

1.7 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible and intangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.8 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits repayable on demand and overdrafts. Deposits are repayable on demand if they are in practice available within 24 hours without a penalty. Liquid resources comprise assets held as a readily disposable store of value.

1.9 Financial instruments

Financial instruments are recognised when the charity becomes party to the contractual provisions of the instrument.

Financial assets are offset, with the net amounts presented in the accounts when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

1 Accounting policies

(Continued)

1.10 Provisions

Provisions are recognised when the charity has a legal or constructive present obligation as a result of a past event, it is probable that the charity will be required to settle that obligation and a reliable estimate can be made of the amount of the obligation.

The amount recognised as a provision is the best estimate of the consideration required to settle the present obligation at the reporting end date, taking into account the risks and uncertainties surrounding the obligation. Where the effect of the time value of money is material, the amount expected to be required to settle the obligation is recognised at present value. When a provision is measured at present value, the unwinding of the discount is recognised as a finance cost in net income/(expenditure) in the period in which it arises.

1.11 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the company is demonstrably committed to terminate the employment of an employee.

1.12 Retirement benefits

For employees choosing to participate, the charity operates a defined contribution pension scheme providing benefits additional to those from the State. The assets are held in a separately administered scheme. The pensions cost charge represents contributions payable by the company to the pension scheme in respect of the year.

Previously, the charity were part of a separately administered defined benefit scheme and is still required to make contributions to fund a deficit in the scheme.

The cost of providing benefits under defined benefit plans is determined separately for each plan using the projected unit credit method, and is based on actuarial advice.

The net interest element is determined by multiplying the net defined benefit liability by the discount rate, taking into account any changes in the net defined benefit liability during the period as a result of contribution and benefit payments. The net interest is recognised in income/(expenditure) for the year.

Remeasurement changes comprise actuarial gains and losses, the effect of the asset ceiling and the return on the net defined benefit liability excluding amounts included in net interest. These are recognised immediately in other recognised gains and losses in the period in which they occur and are not reclassified to income/(expenditure) in subsequent periods.

The net defined benefit pension asset or liability in the balance sheet comprises the total for each plan of the present value of the defined benefit obligation (using a discount rate based on high quality corporate bonds), less the fair value of plan assets out of which the obligations are to be settled directly. Fair value is based on market price information, and in the case of quoted securities is the published bid price. The value of a net pension benefit asset is limited to the amount that may be recovered either through reduced contributions or agreed refunds from the scheme.

1.13 Leases

Rentals payable under operating leases, including any lease incentives received, are charged as an expense on a straight line basis over the term of the relevant lease.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

2 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

3 Donations and legacies

	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £	Total 2021 £
Donations and gifts	723,505	454	723,959	596,326
Legacies receivable	113,717	-	113,717	585,388
Grants receivable	-	392,757	392,757	579,279
	<u>837,222</u>	<u>393,211</u>	<u>1,230,433</u>	<u>1,760,993</u>
For the year ended 31 March 2021	<u>1,211,858</u>	<u>549,135</u>		<u>1,760,993</u>
Donations and gifts				
Individuals	339,481	-	339,481	268,217
Trusts	134,308	-	134,308	141,368
Corporate donors	212,625	-	212,625	128,960
Local Authorities	-	-	-	20,000
Local associations	2,966	-	2,966	2,949
Support groups	-	454	454	167
Health Trusts	34,125	-	34,125	34,665
	<u>723,505</u>	<u>454</u>	<u>723,959</u>	<u>596,326</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

3 Donations and legacies

(Continued)

	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £	Total 2021 £
Grants receivable for core activities				
National Lottery Community fund Northern Ireland Bright Stars	-	64,589	64,589	108,338
National Lottery Community fund Cymru Health hub	-	-	-	9,830
National Lottery Community fund Cymru Shining lights	-	91,307	91,307	89,588
National Lottery COVID19 emergency response	-	-	-	100,000
Early Intervention (Community lottery & others)	-	132,511	132,511	206,198
National Lottery Community Fund - Here for you	-	10,000	10,000	-
National Lottery Community Fund Northern Ireland - Here for you	-	10,000	10,000	-
The Edward Gosling Foundation - Here for you	-	5,000	5,000	-
Wales Council for Voluntary Action	-	11,621	11,621	-
The Clare Milne Trust	-	16,888	16,888	-
Vinci UK Foundation	-	6,975	6,975	-
Margaret Giffen Charitable Trust	-	30,000	30,000	-
Coronavirus job retention scheme grant	-	-	-	48,894
Other	-	13,866	13,866	16,431
	-	392,757	392,757	579,279

4 Other trading activities

	2022 £	2021 £
Income of trading subsidiary	615,096	557,186
Donations sold through shops	39,370	10,715
Rental income	597	6,228
Publications and attendance fees	775	965
	655,838	575,094

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

5 Income from investments

	2022 £	2021 £
Income from listed investments	6,144	4,938
Interest receivable	2,072	2,054
	<u>8,216</u>	<u>6,992</u>

6 Raising funds

	2022 £	2021 £
<u>Fundraising and publicity</u>		
Direct staff costs	282,486	298,224
Other fundraising direct costs	43,902	32,731
Support costs (see note 8)	89,420	51,054
	<u>415,808</u>	<u>382,009</u>

	Shine (Trading) Limited £	Shops £	Total 2022 £	Total 2021 £
<u>Trading costs</u>				
Direct staff costs	132,923	20,968	153,891	145,512
Other direct operational costs	32,928	1,838	34,766	54,159
Support costs (see note 8)	102,129	8,961	111,090	145,379
	<u>267,980</u>	<u>31,767</u>	<u>299,747</u>	<u>345,050</u>
			<u>715,555</u>	<u>727,059</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

7 Charitable activities

	Improving Outcomes through early intervention	Access to better care and services	Improved lifestyle and choices	Preventing Spina Bifida	Quality information & support	Total 2022	Total 2021
	£	£	£	£	£	£	£
Direct staff costs	287,663	112,930	337,946	64,028	116,391	918,958	907,726
Other direct costs	28,979	11,379	34,052	6,452	11,728	92,590	121,590
	<u>316,642</u>	<u>124,309</u>	<u>371,998</u>	<u>70,480</u>	<u>128,119</u>	<u>1,011,548</u>	<u>1,029,316</u>
Share of support costs (see note 8)	45,541	17,878	53,505	10,137	18,426	145,487	120,543
Share of governance costs (see note 8)	6,924	2,680	8,265	1,564	2,904	22,337	22,720
	<u>369,107</u>	<u>144,867</u>	<u>433,768</u>	<u>82,181</u>	<u>149,449</u>	<u>1,179,372</u>	<u>1,172,579</u>
Analysis by fund							
Unrestricted funds - general						649,363	563,350
Unrestricted funds - designated						121,205	45,754
Restricted funds						408,804	563,475
						<u>1,179,372</u>	<u>1,172,579</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

8 Support and governance costs

	Fundraising and publicity £	Trading costs £	Charitable activities £	2022 £	2021 £
Support costs					
Staff costs	48,642	32,408	57,767	138,817	101,425
IT costs	8,003	14,633	22,996	45,632	35,150
Premises costs	22,737	37,212	35,877	95,826	83,415
Other support costs	10,038	26,837	28,845	65,720	96,987
	<u>89,420</u>	<u>111,090</u>	<u>145,485</u>	<u>345,995</u>	<u>316,977</u>
Governance costs				2022 £	2021 £
Staff costs				13,647	13,135
Audit fees				8,690	9,585
Other governance costs				-	-
				<u>22,337</u>	<u>22,720</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

9 Commercial operations in trading subsidiary

The charity has one wholly owned trading subsidiary undertaking, Shine (Trading) Limited which sells advertising space in various publications and balloons for virtual balloon races. The company gift aids virtually all its taxable profits to Shine. A summary of its trading results is shown below. Audited accounts have been filed with the Registrar of Companies.

Shine (Trading) Ltd Profit & Loss Account	2022 £	2021 £
Turnover	615,096	557,186
Cost of sales	(168,496)	(177,673)
Gross profit	446,600	379,513
Administration expenses	(71,503)	(107,594)
Other operating income	-	8,476
Operating profit	375,097	280,395
Amount payable by gift aid to Shine	(375,097)	(280,395)
Profit on ordinary activities	-	-
Shine (Trading) Ltd Balance Sheet	2022 £	2021 £
Fixed assets	-	2,464
Current assets	135,348	112,054
Current liabilities	(112,361)	(91,531)
Net current assets	22,987	20,523
Total net assets	22,987	22,987
Aggregate share capital and reserves	22,987	22,987

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

10 Employees

Number of employees

The average monthly number of full time equivalent employees during the year was:

	2022 Number	2021 Number
Services	26	27
Fundraising and publicity	9	10
Shops	1	1
Administration	4	4
Shine (Trading) Limited	5	5
	<u>45</u>	<u>47</u>

Employment costs

	2022 £	2021 £
Wages and salaries	1,334,511	1,334,398
Redundancy costs	12,068	12,999
Social security costs	119,187	120,056
Other pension costs	45,997	48,131
Other staff related benefits	3,642	3,803
	<u>1,515,405</u>	<u>1,519,387</u>

The number of employees whose annual remuneration was £60,000 or more were:

	2022 Number	2021 Number
£80,001 - £90,000	1	-
£70,001 - £80,000	-	1
£60,001 - £70,000	-	1
	<u>-</u>	<u>1</u>

Pension contributions for higher paid employees were £6,560 (2021 - £10,432).

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

11 Trustees

None of the Trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

In respect of attending meetings of committees, travel expenses amounting to £nil (2021 - £nil) have been reimbursed to no (2021 - no) members of the Board of Trustees.

The accounts include a charge of £2,880 (2021 - £2,304) to provide the Trustees with indemnity insurance.

12 Net gains/(losses) on investments

	Total 2022 £	Total 2021 £
Revaluation of investments	(1,792)	75,285
Gain/(loss) on sale of investments	10,484	5,875
	<u>8,692</u>	<u>81,160</u>

13 Taxation

Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE is a registered charity. It only applies its funds in accordance with its charitable objectives, and is not trading with a view to making distributable profits, therefore corporation tax is not chargeable.

The trading subsidiary has gifted its profits to Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE under Gift Aid therefore no corporation tax is payable

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

14 Tangible fixed assets

	Land and buildings £	Equipment £	Fixtures and fittings £	Software and website £	Total £
Group Cost					
At 1 April 2021	1,487,404	36,566	17,024	24,918	1,565,912
Additions	-	2,038	-	839	2,877
At 31 March 2022	1,487,404	38,604	17,024	25,757	1,568,789
Depreciation and impairment					
At 1 April 2021	674,892	34,621	17,024	16,212	742,749
Depreciation charged in the year	17,496	1,546	-	9,545	28,587
At 31 March 2022	692,388	36,167	17,024	25,757	771,336
Carrying amount					
At 31 March 2022	795,016	2,437	-	-	797,453
At 31 March 2021	812,512	1,945	-	8,706	823,163

	Land and buildings £	Equipment £	Fixtures and fittings £	Software and website £	Total £
Charity Cost					
At 1 April 2021	1,487,404	33,927	17,024	17,889	1,556,244
Additions	-	2,038	-	839	2,877
At 31 March 2022	1,487,404	35,965	17,024	18,728	1,559,121
Depreciation and impairment					
At 1 April 2021	674,892	31,982	17,024	11,647	735,545
Depreciation charged in the year	17,496	1,546	-	7,081	26,123
At 31 March 2022	692,388	33,528	17,024	18,728	761,668
Carrying amount					
At 31 March 2022	795,016	2,437	-	-	797,453
At 31 March 2021	812,512	1,945	-	6,242	820,699

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

15 Fixed asset investments

	Group 2022 £	Charity 2022 £	Group 2021 £	Charity 2021 £
Investments in subsidiaries	-	3	-	3
Listed investments	352,864	352,864	341,378	341,378
	<u>352,864</u>	<u>352,867</u>	<u>341,378</u>	<u>341,381</u>

Movements in fixed asset investments Group and Charity

	2022 £	2021 £
Cost or valuation		
At 31 March 2021	322,179	218,217
Additions within portfolio	78,408	77,164
Disposals within portfolio	(75,233)	(57,986)
Valuation changes	13,590	84,784
	<u>338,944</u>	<u>322,179</u>
Cash held for investment	13,920	19,199
At 31 March 2022	<u>352,864</u>	<u>341,378</u>

16 Financial instruments

	Group 2022 £	Charity 2022 £	Group 2021 £	Charity 2021 £
Carrying amount of financial assets				
Trade debtors	212,511	98,469	115,018	19,996
Other debtors	750	750	750	750
Accrued income	27,500	27,500	246,838	246,838
Amounts due from subsidiary undertakings	-	92,587	-	60,355
Bank and cash	620,814	603,115	650,600	637,285
Measured at cost	<u>861,575</u>	<u>822,421</u>	<u>1,013,206</u>	<u>965,224</u>
Fixed asset investments	352,864	352,867	341,378	341,381
Measured at market value	<u>352,864</u>	<u>352,867</u>	<u>341,378</u>	<u>341,381</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

				(Continued)
16	Financial instruments	Group	Charity	Group Charity
	Carrying amount of financial liabilities			
	Trade creditors	20,654	20,507	27,911 27,764
	Accruals and deferred income	48,467	41,590	37,787 29,677
	Other creditors	42,560	42,560	93,213 93,213
	Other taxation and social security	40,285	27,535	53,659 30,740
	Bank loans	362,216	362,216	410,753 410,753
	Measured at cost	514,182	494,408	623,323 592,147
17	Debtors			
		Group 2022	Charity 2022	Group 2021 Charity 2021
	Amounts falling due within one year:	£	£	£ £
	Trade debtors	212,511	98,469	115,018 19,996
	Amounts due from subsidiary undertakings	-	92,587	- 60,355
	Other debtors	750	750	750 750
	Prepayments and accrued income	87,575	83,968	262,605 258,888
		300,836	275,774	378,373 339,989

The net amount owed by the subsidiary includes amounts owing for gift aid receivable and payment for services provided.

18	Creditors: amounts falling due within one year				
		Group 2022	Charity 2022	Group 2021	Charity 2021
	Notes	£	£	£	£
	Loans and overdrafts 20	48,528	48,528	41,220	41,220
	Other taxation and social security	40,285	27,535	53,659	30,740
	Trade creditors	20,654	20,507	27,911	27,764
	Other creditors	42,560	42,560	93,213	93,213
	Accruals and deferred income	48,467	41,590	37,787	29,677
		200,494	180,720	253,790	222,614

19	Creditors: amounts falling due after more than one year			
	Group and Charity	Notes	2022 £	2021 £
	Loans and overdrafts	20	313,688	369,533

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

20 Loans and overdrafts

	2022	2021
Group and Charity	£	£
Bank loans	362,216	410,753
	<u> </u>	<u> </u>
Payable within one year	48,528	41,220
Payable after one year	313,688	369,533
	<u> </u>	<u> </u>

The bank loan is secured by a first legal charge over the freehold property known as 42 Park Road, Peterborough. The loan is repayable until 2027 with interest charged at 3.5% above base rate.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

21 Retirement benefit schemes

The Pensions Trust - The Growth Plan

SHINE participates in The Pension Trust's Growth Plan (The Plan), a multi-employer scheme which provides benefits to some 638 non-associated participating employers. The scheme is a defined benefit scheme in the UK.

It is not possible for the charity to obtain sufficient information to enable it to account for the scheme as a defined benefit scheme. Therefore it accounts for the scheme as a defined contribution scheme.

The scheme is subject to the funding legislation outlined in the Pensions Act 2004 which came into force on 30 December 2005. This, together with documents issued by the Pensions Regulator and Technical Actuarial Standards issued by the Financial Reporting Council, set out the framework for funding defined benefit occupational pension schemes in the UK.

The scheme is classified as a 'last-man standing arrangement'. Therefore the charity is potentially liable for other participating employers' obligations if those employers are unable to meet their share of the scheme deficit following withdrawal from the scheme. Participating employers are legally required to meet their share of the scheme deficit on an annuity purchase basis on withdrawal from the scheme.

A full actuarial valuation for the scheme was carried out at 30 September 2020. This actuarial valuation showed assets of £800.3m, liabilities of £831.9m and a deficit of £31.6m. To eliminate this funding shortfall, the trustees and the participating employers have agreed that additional contributions will be paid to the scheme as follows:

Deficit contributions

From 1 April 2022 to 31 January 2025:	£3,312,000 per annum (payable monthly)

Note that the scheme's previous valuation was carried out with an effective date of 30 September 2017. This valuation showed assets of £794.9m, liabilities of £926.4m and a deficit of £131.5m. To eliminate this funding shortfall, the Trustee asked the participating employers to pay additional contributions to the scheme as follows:

Deficit contributions

From 1 April 2019 to 30 September 2025:	£11,243,000 per annum (payable monthly and increasing by 3% each on 1st April)

The recovery plan contributions are allocated to each participating employer in line with their estimated share of the Series 1 and Series 2 scheme liabilities.

Where the scheme is in deficit and where the charity has agreed to a deficit funding arrangement the company recognises a liability for this obligation. The amount recognised is the net present value of the deficit reduction contributions payable under the agreement that relates to the deficit. The present value is calculated using the discount rate detailed in these disclosures. The unwinding of the discount rate is recognised as a finance cost.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

21 Retirement benefit schemes

(Continued)

Present values of provision

	31 March 2022	31 March 2021	31 March 2020
Present value of provision	56,698	293,838	348,159

An amount of £20,657 (2021 - £74,358) is included within short term creditors and £36,041 (2021 - £219,480) in long term liabilities.

Reconciliation of opening and closing provisions

	Year Ending 31 March 2022	Year Ending 31 March 2021
Provision at start of period	293,838	348,159
Unwinding of the discount factor (interest expense)	1,694	7,822
Deficit contribution paid	(74,358)	(72,192)
Remeasurements - impact of any change in assumptions	(1,303)	10,049
Remeasurements - amendments to the contribution schedule	(163,173)	-
Provision at end of period	56,698	293,838

Income and expenditure impact

	Year Ending 31 March 2022	Year Ending 31 March 2021
Interest expense	1,694	7,822
Remeasurements - impact of any change in assumptions	(1,303)	10,049
Remeasurements - amendments to the contribution schedule	(163,173)	-
Costs recognised in income and expenditure account	(162,782)	17,871

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

21 Retirement benefit schemes

(Continued)

Assumptions

	31 March 2022 % per annum	31 March 2021 % per annum	31 March 2020 % per annum
Rate of discount	2.35	0.66	2.53

The discount rates shown above are the equivalent single discount rates which, when used to discount the future recovery plan contributions due, would give the same results as using a full AA corporate bond yield curve to discount the same recovery plan contributions.

The following schedule details the deficit contributions agreed between the company and the scheme at each year end period:

Deficit contributions schedule

Year ending	31 March 2022	31 March 2021	31 March 2020
Year 1	20,657	74,358	72,192
Year 2	20,657	76,589	74,358
Year 3	17,214	78,887	76,589
Year 4	-	67,711	78,887
Year 5	-	-	67,711

The charity must recognise a liability measured as the present value of the contributions payable that arise from the deficit recovery agreement and the resulting expense in the income and expenditure account i.e. the unwinding of the discount rate as a finance cost in the period in which it arises.

It is these contributions that have been used to derive the charity's balance sheet liability.

The Plan is closed to new entrants and there were no active members of the scheme during the year.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

22 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

Group and Charity	Balance at 1 April 2020 £	Income £	Expenditure £	Transfers £	Balance at 1 April 2021 £	Income £	Expenditure £	Transfers £	Balance at 31 March 2022 £
National Lottery Community Fund – Early intervention programme across England	63,963	224,948	(232,426)	34,878	91,363	132,511	(161,064)	33,673	96,483
National Lottery Community fund Northern Ireland Bright Stars	12,830	108,338	(92,791)	3,034	31,411	64,589	(77,263)	-	18,737
International Projects – developing a continence clinic in Nigeria	4,031	-	(3,769)	-	262	11,621	(160)	-	11,723
Coop Grant	2,617	-	-	-	2,617	-	(160)	-	2,457
National Lottery Community fund: Cymru Health hub	-	9,830	(4,915)	-	4,915	-	(4,915)	-	-
National Lottery Community fund: Cymru Shining lights	-	89,588	(90,014)	14,640	14,214	91,307	(91,792)	371	14,100
South West Country SDW	-	-	-	-	-	16,888	(10,086)	-	6,802
COVID 2021/22 "Here for you"	-	-	-	-	-	32,613	(28,891)	-	3,722
Database development	-	-	-	-	-	6,975	(6,060)	-	915
Welfare Grants	-	16,431	(16,431)	-	-	6,253	(6,238)	-	15
Support Groups	1,025	-	-	-	1,025	454	(108)	-	1,371
Buchanan & Henry Allen – supporting our work in the North of England	10,040	-	(2,468)	-	7,572	-	(7,572)	-	-
Margaret Giffen Charitable Trust - supporting our work in Northampton	15,000	-	(10,065)	-	4,935	30,000	(14,495)	-	20,440
Carried forward to next page	109,506	449,135	(452,879)	52,552	158,314	393,211	(408,804)	34,044	176,765

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

22 Restricted funds

(Continued)

Group and Charity	Balance at 1 April 2020 £	Income £	Expenditure £	Transfers £	Balance at 1 April 2021 £	Income £	Expenditure £	Transfers £	Balance at 31 March 2022 £
Brought forward from previous page	109,506	449,135	(452,879)	52,552	158,314	393,211	(408,804)	34,044	176,765
National Lottery Community Fund - Shine voices	9,975	-	(9,975)	-	-	-	-	-	-
Wales Council for Voluntary Action - Volunteer and shine	621	-	(621)	-	-	-	-	-	-
National Lottery community fund COVID19 emergency response	-	100,000	(100,000)	-	-	-	-	-	-
	<u>120,102</u>	<u>549,135</u>	<u>(563,475)</u>	<u>52,552</u>	<u>158,314</u>	<u>393,211</u>	<u>(408,804)</u>	<u>34,044</u>	<u>176,765</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

23 Designated funds

The income funds of the charity include the following designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes:

Group	Balance at 1 April 2020 £	Net movement £	Balance at 1 April 2021 £	Net movement £	Balance at 31 March 2022 £
Interest in land and property and other fixed assets	391,829	20,579	412,408	22,829	435,237
Florence Bartle fund	-	114,121	114,121	(39,462)	74,659
HR fund	-	45,175	45,175	(37,675)	7,500
Services in Northern Ireland and Wales	-	-	-	70,650	70,650
Dilapidations	-	-	-	31,500	31,500
	<u>391,829</u>	<u>179,875</u>	<u>571,704</u>	<u>47,842</u>	<u>619,546</u>
Charity					
Interest in land and property and other fixed assets	387,273	22,671	409,944	25,293	435,237
Florence Bartle fund	-	114,121	114,121	(39,462)	74,659
HR fund	-	45,175	45,175	(37,675)	7,500
Services in Northern Ireland and Wales	-	-	-	70,650	70,650
Dilapidations	-	-	-	31,500	31,500
	<u>387,273</u>	<u>181,967</u>	<u>569,240</u>	<u>50,306</u>	<u>619,546</u>

The designated fund comprises

- the group and charity's interest in land and property and other fixed assets, net of the outstanding mortgage.
- the Florence Bartle fund which is part of a legacy that is to be spent on the relief of Spina Bifida in Cornwall and the South West.
- the HR fund that is for future restructuring and other staff related costs.
- the services in Northern Ireland and Wales is for work specifically in those countries.
- the dilapidations fund is for future leasehold dilapidations.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

24 Analysis of net assets between funds

	Unrestricted funds 2022 £	Designated funds 2022 £	Restricted funds 2022 £	Total Unrestricted funds 2022 £	Designated funds 2021 £	Restricted funds 2021 £	Total 2021 £
Group							
Fund balances at 31 March 2022 are represented by:							
Tangible assets	-	797,453	-	797,453	-	823,163	823,163
Investments	352,864	-	-	352,864	341,378	-	341,378
Current assets/(liabilities)	408,610	135,781	176,765	721,156	498,795	158,314	775,183
Long term liabilities	-	(313,688)	-	(313,688)	-	(369,533)	(369,533)
Provisions and pensions	(36,041)	-	-	(36,041)	(219,480)	-	(219,480)
	<u>725,433</u>	<u>619,546</u>	<u>176,765</u>	<u>1,521,744</u>	<u>620,693</u>	<u>158,314</u>	<u>1,350,711</u>
Charity							
Fund balances at 31 March 2022 are represented by:							
Tangible assets	-	797,453	-	797,453	-	820,699	820,699
Investments	352,867	-	-	352,867	341,381	-	341,381
Current assets/(liabilities)	385,623	135,781	176,765	698,169	478,272	158,314	754,660
Long term liabilities	-	(313,688)	-	(313,688)	-	(369,533)	(369,533)
Provisions and pensions	(36,041)	-	-	(36,041)	(219,480)	-	(219,480)
	<u>702,449</u>	<u>619,546</u>	<u>176,765</u>	<u>1,498,760</u>	<u>600,173</u>	<u>158,314</u>	<u>1,327,727</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

25 Operating lease commitments

Group and Charity

At the reporting end date the charity had outstanding commitments for future minimum lease payments under non-cancellable operating leases, which fall due as follows:

	2022 £	2021 £
Within one year	24,215	5,460
Between two and five years	164,901	20,475
	<u>189,116</u>	<u>25,935</u>

26 Related party transactions

Remuneration of key management personnel

The remuneration of key management personnel, who on a full time equivalent basis are the 2.8 (2021 - 3.8) members of the senior management team, is as follows.

	2022 £	2021 £
Aggregate compensation including pension contributions	<u>206,828</u>	<u>250,904</u>

Transactions with related parties

Owing to the nature of the charity's operations, some of the Trustees may themselves, or may have family members that access services from the charity. Consequently there will be transactions between those Trustees or their family members. These are on the same basis as other service users of the charity.

27 Control

No one individual has overall control of the charity.

28 Post balance sheet event

Following the end of the year the charity completed on the sale of its property. The sale resulted in a profit on disposal of approximately £530,000 and the bank loan has been repaid in full.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

29	Cash generated from operations	2022 £	2021 £
	Surplus for the year	171,033	506,730
	Adjustments for:		
	Investment income recognised in statement of financial activities	(8,216)	(6,992)
	Investment management fees recognised in statement of financial activities	(2,794)	4,174
	Gain on disposal of investments	(10,484)	(5,875)
	Fair value gains and losses on investments	1,792	(75,285)
	Depreciation and impairment of tangible fixed assets	28,587	28,917
	Movements in working capital:		
	Decrease/(increase) in debtors	77,537	(82,202)
	(Decrease)/increase in creditors	(60,604)	15,080
	Increase/(decrease) in pension liability	(183,439)	(56,487)
	Cash generated from operations	13,412	328,060

30	Analysis of changes in net funds Group	At 1 April 2021 £	Cash flows £	At 31 March 2022 £
	Cash at bank and in hand	650,600	(29,786)	620,814
	Loans falling due within one year	(41,220)	(7,308)	(48,528)
	Loans falling due after more than one year	(369,533)	55,845	(313,688)
		239,847	18,751	258,598
	Charity			
	Cash at bank and in hand	637,285	(34,170)	603,115
	Loans falling due within one year	(41,220)	(7,308)	(48,528)
	Loans falling due after more than one year	(369,533)	55,845	(313,688)
		226,532	14,367	240,899





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Charity number 249338, Company number 00877990



Shine

Spina bifida • Hydrocephalus
Information • Networking • Equality

Accounts

Trustees' Annual Report and Financial Statements

Year ended 31st March 2021



Shine

Spina bifida • Hydrocephalus
Information • Networking • Equality



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Introduction from our Acting Chair

What a year 2020/21 turned out to be yet, despite the upheaval caused by the worldwide pandemic, Shine's staff and volunteers did not waiver from our aim of

“...making a positive difference to the lives of people affected by spina bifida and hydrocephalus, and other conditions.”



In a strange way, the pandemic brought opportunities to try and test new approaches and initiatives.

We rallied quickly to adapt our services, proactively contacting members, reaching so many more individuals and families, and providing them with a wealth of health and other key advice to deal with the disruption caused by COVID-19 to so many aspects of their lives.

One of the overwhelming successes of 2020 was the 1082 responses from members to our '1000 Voices – ageing with spina bifida' survey. It is the largest survey of its kind in the UK and has provided a vast amount of insight and information to underpin the work we need to do to improve health, wellbeing and lifestyle outcomes for people of all ages living with spina bifida.

Members took part in our online information sessions and social events, and some accessed our pilot online health and advice hubs for more personal support and information. Many also actively engaged in a series of focus groups, providing insight and information to develop new hydrocephalus resources and plan and deliver our awareness weeks.

None of the above successes could have been achieved without the ongoing work to continually improve systems, processes and compliance procedures that are so necessary for the smooth running, efficiency and effectiveness of the charity, nor could it have happened without the incredible hard work and dedication from so many: all the staff at Shine; our many volunteers; our supporters and fundraisers whose generosity has enabled us to deliver the services we needed to; and Shine's Leadership Team and Board of Trustees who have worked closely to steer the organisation through this turbulent time in history.

In his introduction to last year's annual report, our Chairman commented that the breadth of our work, the diversity of skills, knowledge and experience, and our continual drive for improvement was providing Shine with a greater resilience to adapt and deliver the change we need to remain a charity that is 'fit for purpose'. The past 12 months have been testament to this.

Shine has risen to the challenges of the pandemic. We finish the year more certain than ever of the essential role Shine plays in providing the right information and support at the right time, keeping people connected and ultimately improving lives.

With best wishes

Greg Smith
Acting Chair

A handwritten signature in blue ink, appearing to read 'Greg Smith', written over a light blue circular background.



Shine's vision

is a society where all those whose lives are affected by spina bifida and/or hydrocephalus and associated conditions are empowered and enabled through choice and equality of opportunity

Our aim

to make a positive difference to the lives of people affected by the conditions

Our five strategic goals are

- 1 Improving outcomes through early intervention and support:**
Babies and children from birth to 10-year-olds will have improved health, educational and social outcomes through specific approaches for support, intervention, and condition management
- 2 Access to better care and services for all:**
People with spina bifida and/or hydrocephalus will have access to specialist services and treatments, which will enable better care and condition management
- 3 Improved lifestyle and choices**
People with spina bifida and/or hydrocephalus will be enabled, engaged, and empowered to make informed choices about the lives they want to lead
- 4 Preventing spina bifida**
Greater focus on the causes of spina bifida and a call for Government and others to take decisive action in the prevention of spina bifida
- 5 Quality information and support**
People affected by spina bifida and/or hydrocephalus, and other key stakeholders, will have access to high-quality information and support to meet their needs



Underpinned by our values

- Promote the empowerment and participation of people with spina bifida and hydrocephalus, and associated conditions
- Value and respect all the different people with whom we work
- Challenge the ways in which society disables our members
- Work to achieve excellence
- Welcome challenge and review
- Use resources ethically, thoughtfully and responsibly



How Shine responded to the global pandemic

No annual report for 2020/21 would be complete without mention of the global pandemic!

In this unprecedented year, where specialist clinics and essential health and care services have been impacted by the measures required to manage COVID-19, Shine was keenly aware of the importance of maintaining our focus to support individuals with spina bifida and/or hydrocephalus, and families and professionals, in whatever way we could across England, Wales and Northern Ireland.

As shielding began, and the UK went in and out of lockdown throughout the year, the pandemic created additional strains on key statutory services, which affected our members.

Requests for support were often complex and multi-layered as backlogs and delays in statutory systems caused unforeseen knock-on effects for our members' health, finances, housing, care arrangements, education and employment, often due to:

- Specialist NHS teams being re-deployed or adapting their services to virtual or COVID-safe services.
- A lack of access to physiotherapy, occupational therapy and basic health checks.
- Non-emergency surgical procedures being delayed, resulting in ongoing unresolved health issues.

- Orthotics, mobility and other essential equipment also being delayed, leaving more people with equipment which is not appropriate for their age or size.
- Social services being over-run with safeguarding enquiries and constantly emerging needs.
- Members unable to move from inappropriate housing, or get necessary adaptations for their homes due to systemic delays.
- Local Authorities turning their focus to emerging issues such as the distribution of emergency food supply. This meant staff, finances and planning being redeployed to this purpose causing other areas of their service to backlog, resulting in delayed care assessments.

Shine's priority over the past 12 months has been to keep our members, parents and carers safe and informed with the most up-to-date information, clarify their concerns, and support them in coping with anxiety and uncertainty. Our staff have worked incredibly hard to address the emerging issues as the true extent of COVID-19 unfolded. We advocated with Government and statutory services on members' behalf. We also delivered on the majority of the objectives that had been set out prior to the onset of COVID-19.



Goal 1: Improving outcomes through early intervention and support

With last year's investment to expand our early intervention team we continued to offer a focused and specialised service from birth up to 10 years old. This allowed us to ensure that parents were supported and proactively given all the advice and information they needed, over the past 12 months, to help their children meet developmental milestones and thrive throughout these crucial years.

Support has ranged from dealing with emergency situations like lack of food and essential supplies to specialist health advice, support with benefits, finances, education in school and at home, learning and behaviour, emotional support and help communicating needs to care staff or health/education professionals.

Although face-to-face playgroups and activities have not been safe to run, the Little Stars team engaged with children and parents in new and exciting ways.

Over the past 12 months, the Little Stars project has

- Re-engaged with thousands of existing members by proactively contacting Little Stars families across England, Wales and Northern Ireland to check how they were coping, and what support we could offer
- Established our Little Stars Facebook group
- Piloted 'Coffee and Chat' sessions in Wales
- Linked families to support each other through regional WhatsApp groups for parents
- Run regular Facebook Live sessions addressing a range of health and wellbeing topics for children
- Held weekly closed Zoom social and themed group sessions for parents
- Set up a monthly dads/male carers Zoom group
- Run virtual Health & Wellbeing hubs and offered bookable Zoom/phone 1:1 appointments as a 'one stop shop' for advice and support on issues such as physiotherapy, occupational therapy, specialist continence advice, sleep solutions, education and benefits
- Published 'Your Child and Hydrocephalus', an in-depth resource offering information on every aspect of your child's development from birth to 11 years old. The book is also available on our website
- Produced three videos with information for anyone with caring or oversight responsibility of children with spina bifida who are either fully mobile, part-time wheelchair users or full-time wheelchair users
- Launched condition- and age-related Little Stars e-newsletters. These are automatically sent out once a baby or child reaches a key age to provide advice, support and further reading for parents
- Continued to support our growing membership of our closed Anencephaly Support Group on Facebook



Support for professionals so that they could better understand the needs of the children and families we support. We:

- Maintained communication with professionals through our contact with children's clinics and networks
- Delivered training and support to special education/additional learning needs staff, other school and care staff, physiotherapy students and specialist health visitors to raise awareness of the conditions and related support needs, through presentations, videos and one-to-one advice
- Delivered workshops, webinars and presentations to other professional groups, including the Physical Disability Network (PDNet), Association of Chartered Paediatric Physiotherapists, Flying Start team (Wales) and others
- Collaborated with other organisations such as The Sleep Charity, Pressure Ulcer and Prevention Intervention Service, Bowel and Bladder UK and Family Fund to deliver virtual information and advice to our members

Collective action to ensure the needs of children were kept firmly on the agendas of governments and statutory services. We:

- Joined forces with the Disabled Children's Partnership along with 80 other charities so that we could jointly campaign for the rights of children with disabilities to improve health and social care. The key campaigning focus has come out of the 'Left in Lockdown' research showing the

disproportionate effect which the past year has had on disabled children and their families

- Joined the Children's Health Coalition in Northern Ireland to look at improving experiences for children and parents using acute services in both hospitals and community settings
- Continued to build our 'knowledge bank' as a central resource for our teams whenever we collaborate or signpost to an external organisation to better link our members into complimentary services offered by other partners

Co-production and continuous learning

- We are very grateful to members who took part in the Little Stars research, surveys and polls, as well as contributing to our steering and focus groups. This helped us to shape our services to meet the needs of our children and families

Next steps →→→→

- Continuing to proactively engage with, and support, our Little Stars and their families, and extend the project from 0–10-year-olds to 0–12-year-olds
- Launching our professional engagement strategy to grow understanding and improve services for children with spina bifida and hydrocephalus
- Enhancing our education offer to families and professionals
- Delivering a virtual events programme for parents and carers
- Developing and delivering interactive sessions for children
- Reviewing our support services for those who have lost a baby to anencephaly



Goal 2: Access to better care and services for all



In the first two months of the pandemic alone **20,000 people accessed the COVID-19 information on our website**, we posted essential information to around 3,000 members and sent four email updates to the 7,000 members who had given us email addresses

Over the last 12 months we have spoken to almost **7,500 of our members**



As always, **improving the health and wellbeing of people with spina bifida and hydrocephalus remained at the heart of everything we did in 2020/21**

In this exceptional and unprecedented year:

- Our health team turned their attention to collating research and key data from across the world to provide members with clear information to keep them as safe and well as possible
- We communicated through website updates and postal information or email to ensure that everyone had access to this crucial information
- Service teams proactively called our members to check how they were, prioritising those who were most likely to be vulnerable
- Staff delivered over 60 Facebook Live Sessions on condition-specific health advice and support across a range of topics

Lobbying and campaigning to maintain members' rights and access to services

Working jointly with others, Shine's campaigning helped to:

- Improve access for disabled people who need to shop in supermarkets or needed to access online shopping slots
- Highlight safeguarding issues with handing cash or banking details to volunteer shoppers
- Raise awareness of the lack of specialist foods such as gluten free, lactose free and other items, such as nappies, for disabled children
- Show the detrimental impact of lack of PPE for carers and the risks to disabled people

- Address the financial effects of lockdown in terms of increasing costs for disabled people and the need for increases to benefits to compensate, in addition to the £20 uplift to Universal Credit
- Champion the cause of unpaid carers, their increased costs and the urgent need for a one-off payment and a review of the carer's allowance to address financial hardship
- Highlight the concerning reports at the start of the pandemic of healthcare staff proactively contacting disabled people to suggest they complete Do Not Resuscitate Orders in case they went into hospital, which caused significant fear among disabled people
- Clarify the NICE decision-making guidance relating to urgent COVID-19 care priorities, which initially did not reflect the needs of disabled people
- Monitor the effects of the COVID-19 Emergency Legislation, how this played out in terms of Care Act Easements enacted by Local Authorities and working together to ensure that this did not result in Disability Law advances of the last 30 years being lost
- A large part of our focus was to join forces with the Disability Benefits Consortium, Care and Support Alliance, Disability Charities Consortium, Disability Law Service and Disabled Children's partnership to collaborate and lobby with a collective voice of 200 charities to tackle the emerging issues.

Shine also contributed to a joint response to the Women and Equalities Select Committee inquiry on 'Unequal impact: Coronavirus and the impact on people with protected characteristics', and provided information on the inequities for disabled people to the Equalities and Human Rights Commission.

A significant result from our campaigning was a request from Defra to work with them on a means of giving access to food and essentials for non-shielding vulnerable people who were unable to get supermarket shopping slots, finding it difficult or even impossible to go food shopping and who did not qualify for emergency food parcels from the Government or priority shopping slots for supermarkets as they were not shielding.

With a coordinated and sustained piece of work this led to the launch of a Government information portal on accessing food and essential supplies.

Shine Cymru was an important stakeholder in the influence and delivery of the Welsh Government's neurological conditions delivery plan (NCDP) and was represented on the Wales Neurological Association's (WNA) Executive Committee to provide a voice for our members across Wales.

Individual Shine Cymru members also contributed to WNA's Neuro-Voices Cymru co-production project and attended meetings to lobby and campaign for better services for the collective neurological community across Wales.

Research and Information

Our 1000 Voices survey, the largest research project into adult health and spina bifida in the world, was completed during this financial year. Key survey results were published to members on 20th October 2020 and a fully detailed report with all the relevant survey data has now been compiled.

This research will be used to inform the development of our health services, and our ongoing work to influence improved statutory health and care services provision for people with spina bifida across England, Wales and Northern Ireland.

Shine developed our professional engagement strategy and started planning work on a professionals' area of our website with an e-learning portal which will offer CPD accredited learning modules for professionals. This work will be completed in 2021/22.

The Service teams continued to develop networks of key professional contacts to further inform our work, and also focused on engaging members to contribute to key pieces of work and resource development through small working groups and email consultation.

Bringing people together



An example of Shine's collaboration and co-production

Shine's role is to empower our members to understand and take the preventative measures they should, inform them of the statutory support they can access, and provide them with information and insight to make the decisions that are best for them.

A significant piece of work on better skin care for people with spina bifida has emerged from the '1000 Voices' survey. However, the subject matter is vast, and a wealth of resources exist across the UK. There are numerous professionals and medical disciplines involved in preventing and treating serious skin issues.

Partnership and collaboration are vital to the successful delivery of this project. To do this, Shine has

- Set up an internal working group of health and services staff
- Developed a focus group for members to actively contribute to the development of this work
- Collated resources from across England, Wales and Northern Ireland
- Linked with various lead organisations, including the Tissue Viability Society and PUPIS (Pressure Ulcer Prevention and Intervention Service, Swansea)
- Developed a directory of key contacts in this field
- Engaged three student volunteers to begin mapping existing statutory, private and third-sector services in Wales to gain insight into what exists, with a view to extending this mapping to England and Northern Ireland
- Promoted Patient Participation for members to take part in external research

This work will then be used to inform a section of Shine's best practice guide on the prevention of health issues in the care of adults with spina bifida, which will be produced in 2022.

Access to Shine Health Direct (SHD)

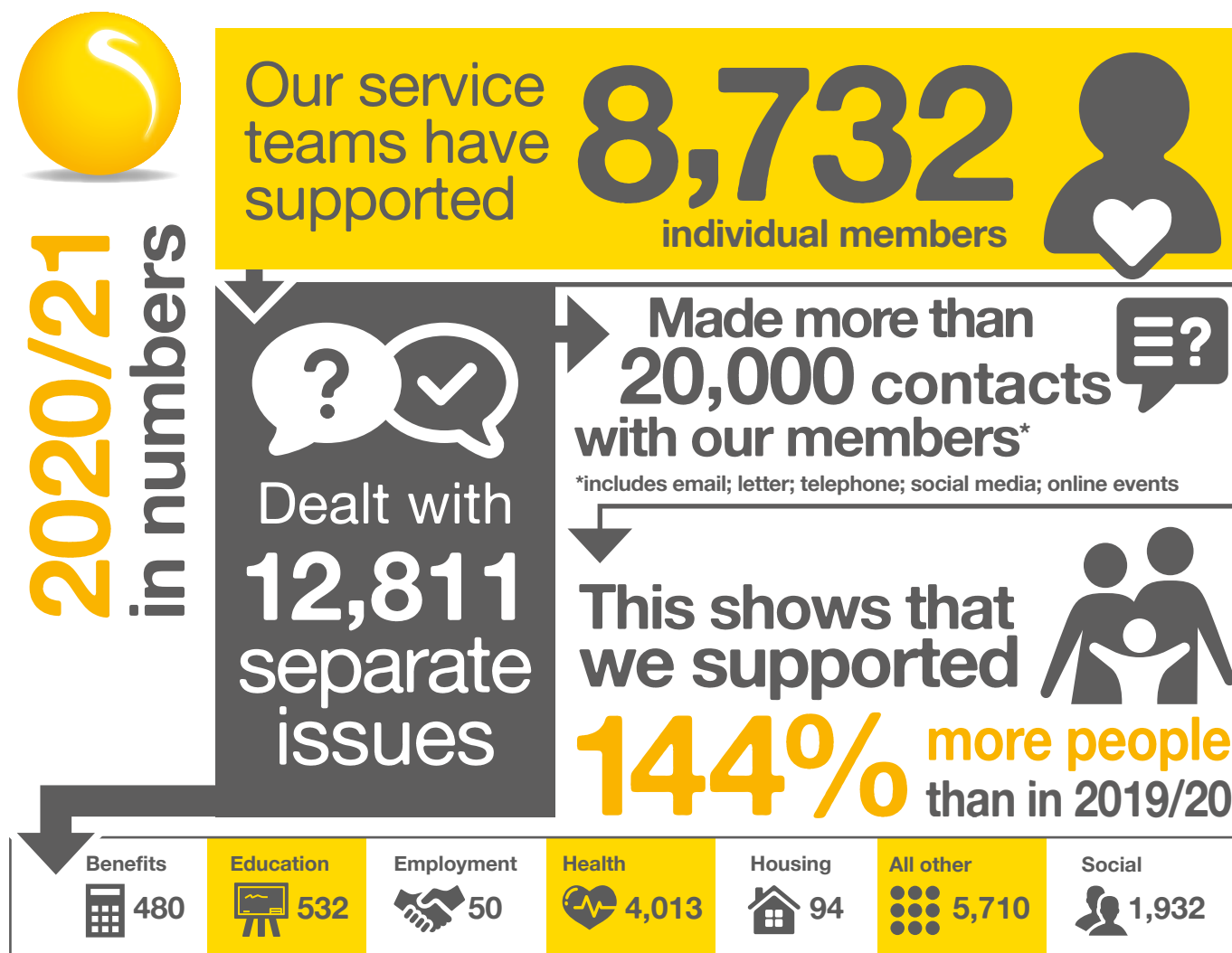
Shine Health Direct continues to be delivered in partnership with Bullen Healthcare, offering Shine members discreet and efficient delivery of urology and stoma products as well as prescription medications. Over 750 Shine members used the service in the past 12 months.

This service has been enhanced this year with increased investment to expand the specialist nursing team to provide advice to members with spina bifida on continence and skin care issues, as well as a prescribing and medication delivery service. SHD have also introduced a new delivery partner (DPD) to areas where there is no Bullen driver, in response to negative feedback regarding the former delivery provider.

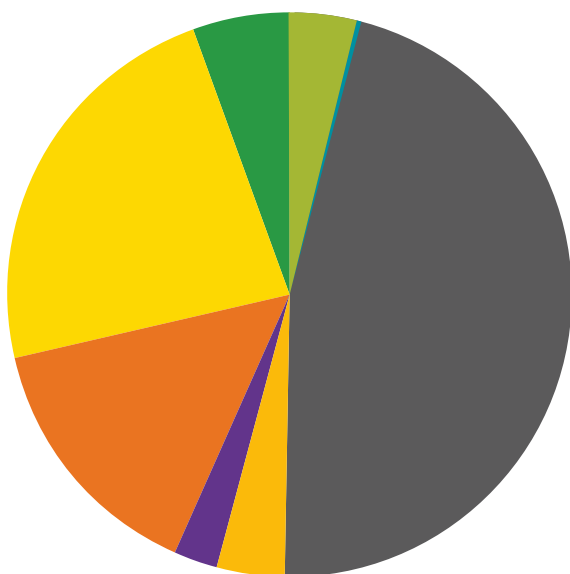
Next steps →→→

- Developing a guide for individuals with spina bifida of all ages, on maintaining good health and wellbeing
- Creating a GP guide to maintaining the wellbeing of individuals with spina bifida
- Further developing our services for people with hydrocephalus and normal pressure hydrocephalus (NPH)
- Launching Shine's professional area of our website
- Piloting a series of e-learning modules for professionals
- Continuing to increase the reach and impact of our services across our membership
- Promoting Shine Health Direct to a wider audience

Goal 3: Improved lifestyle and choice

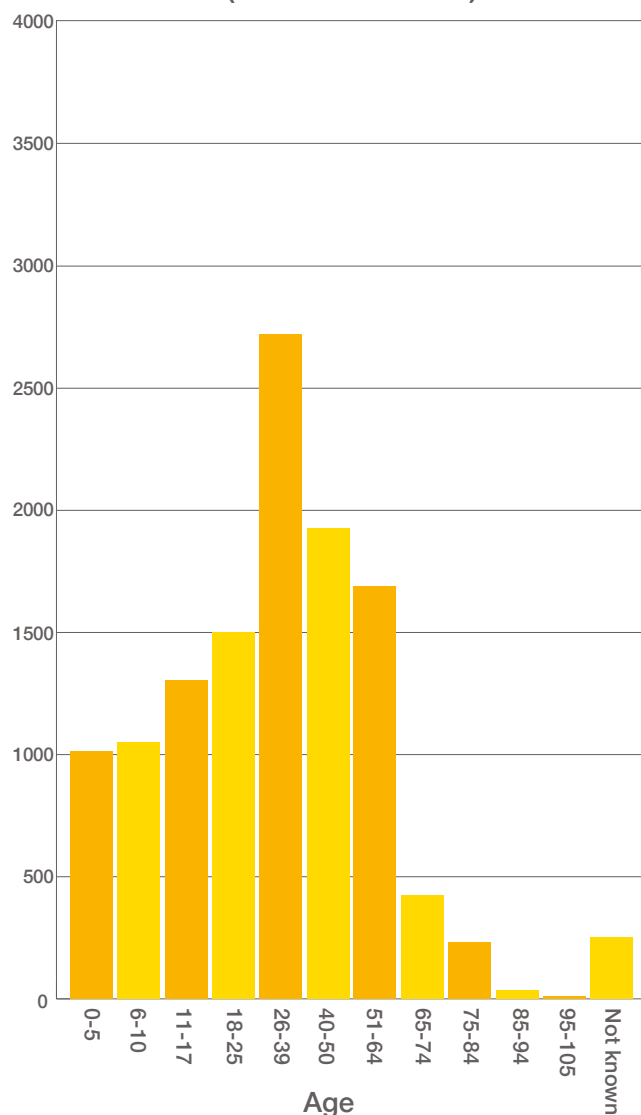


Registered members by condition



Encephalocele.....	0.3%
Hydrocephalus	48.2%
Idiopathic Intracranial Hypertension	3.7%
Normal pressure hydrocephalus	2.6%
Spina bifida.....	14.0%
Spina bifida & hydrocephalus.....	22.3%
Spina bifida occulta.....	5.1%
Not known	3.9%

Age of Shine members (March 2021)





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**



Our members asked... We delivered using virtual technology !

Our Facebook Live events covered a variety of topics to meet members' needs, including...



Maintaining health and wellbeing

Looking after your skin

Better bowel and bladder management

Managing your hydrocephalus

Maximising mobility

Managing your spina bifida

Mental health

In our busiest year ever, our network of Support and Development Workers (SDWs) have continued to find solutions to the challenges which our members across all age ranges, and their families, have experienced.

The Service teams took on the mammoth task of cleansing our membership database throughout the year. This was no mean feat. With thousands of contact details and contact preferences being updated, this has resulted in a very rich set of data.

It provided us with more accurate information on the members we engage with, and how and when we do. It allowed us to understand how we can better reach and engage with our members in a variety of ways. It will also improve reporting on the difference Shine's work makes.



- ✓ Our Benefits lead helped us to keep members informed of the changes to benefits assessment procedures and policy
- ✓ Our teams helped members apply for benefits, secure grants for equipment and deal with emerging financial issues
- ✓ We delivered a regular stream of online social groups and peer-support groups for members to join across England, Wales and Northern Ireland, as well as regular Facebook Live events
- ✓ Our specialist Health team offered 1:1 and group physiotherapy or occupational therapy sessions, as well as discussing members' specific health concerns
- ✓ The specialist Health team liaised with health practitioners on our members' behalf, as so many were unable to access the NHS services they rely on, due to delays or cancellations
- ✓ Shine employed a new Adult Engagement and Wellbeing Coordinator to develop a greater focus on the adult support and services we offer
- ✓ The teams engaged many members to develop and deliver messages for Spina Bifida Awareness Week and Hydrocephalus Awareness Week
- ✓ We supported volunteers to offer peer support, moderate online groups, maintain our links with the normal pressure hydrocephalus clinic, and contribute to research and disability focus groups

- ✓ We submitted consultation responses to ensure our members' voices were heard on how the pandemic had affected disabled children and families in England, how social care arrangements in Wales needed to be improved and to inform the Northern Ireland Mental Health Strategy, SEN Reforms and SEN Code of Practice. We also engaged with the Unplanned Admissions Consensus Body and the Prescription Charge Coalition
- ✓ We maintained our connection and collaboration with Spina Bifida Hydrocephalus Scotland and with Local Associations across England including Shine Surrey, North & West Yorkshire Association for Spina Bifida & Hydrocephalus and Sheffield Association for Spina Bifida and Hydrocephalus, as well as working closely with key partners like the Family Fund
- ✓ Our Support and Development Workers continued to build links with local statutory services, care providers, community groups and charity partners to make sure that their local support encompassed collaboration with other organisations to offer coordinated support
- ✓ Internationally we maintained contact with the International Federation for Spina Bifida and Hydrocephalus, supported the Festus Fajemilo Foundation in Nigeria and engaged with professionals at the Queensland Spina Bifida and Hydrocephalus Association

Research remained on our agenda too as we:

- Continued membership of the Society for Research into Hydrocephalus and Spina Bifida (SRHSB)
- Actively monitored relevant emerging external research to inform Shine's priorities and work plans
- Promoted opportunities for members to be involved in research projects (Patient and Public Involvement – PPI)
- Contributed to research into the impact of COVID-19 on people's lives

Collaboration

We reviewed our membership offer this year for all age groups to keep improving the services we offer our members, which will inform our next Corporate Plan 2022–27.

Next steps →→→

- Publishing the full report of our '1000 Voices – ageing with spina bifida' research
- Delivering a virtual conference for professionals to improve insight and understanding
- Enhancing and strengthening Shine's Health service for the future
- Developing age-appropriate projects to meet our members' needs
- Improving Shine's information for members with hydrocephalus
- Better understanding the challenges our members face in accessing care services and support; and consider how best Shine can influence improvement in statutory services

Goal 4: Preventing spina bifida

Our campaign for mandatory fortification

Despite the UK Government not having issued a response to the 2019 consultation on mandatory fortification of flour with folic acid, Shine took a decision not to actively pursue our campaign as the onset of the pandemic saw Government's attention diverted to so many other priorities.

Instead, we maintained contact with key stakeholders to ensure this vital public health issue remained firmly on agendas. Our campaign to press Government for a decision will re-launch in the next financial year.

Supplementation

Unlike 2019/20, promoting the importance of folic acid supplementation at events and in public places such as supermarkets or hospital concourses was not possible this year due to lockdown. Instead, social media was used as a platform to spread the word, with the Health Development team also taking every opportunity to reinforce the message when working directly to support individuals preparing for pregnancy.

We also began to explore the possibility of joining forces with others to test a city-based, pilot project to

promote folic acid and supplementation. Discussions are ongoing but, if successfully implemented, this approach will be tested as a model for wider dissemination.

Treatments for Spina Bifida

Whilst not a cure for spina bifida, fetal surgery is another treatment option for parents-to-be who have had a diagnosis of an unborn baby with spina bifida. Shine has met regularly with the NHS Commissioning team and the teams at University College London Hospitals NHS Foundation Trust (UCLH), with Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH), London, and with The University Hospitals Leuven, in Leuven, Belgium, to collaborate on the development of information and to ensure the 'wrap around' support needed for parents-to-be is in place, if they chose to explore pre-natal surgery as an option at the 20 week scan.

We have also continued to contribute actively to discussions in GIFT-Surg, an international research project which focuses on the treatment of congenital birth defects such as spina bifida, and develops technology, tools and training necessary to make fetal surgery viable.



Next steps →→→

- Continuing to lobby and campaign for the introduction of mandatory fortification of flour with folic acid
- Promoting the importance of, and need for, folic acid supplementation
- Continuing to engage with and inform research
- Collaboration with professionals for information on the latest developments in prevention and treatment

Goal 5: Quality information and support

Excellent, quality, informative and well-researched information. This is a key priority for us, and never more so than in the last 12 months where there has been so much confusion surrounding COVID-19.

As well as our regular COVID-19 website updates, we continued our programme of reviewing and updating our suite of resources throughout this year.

These included:

- What is encephalocele
- New parent pack – hydrocephalus
- New parent pack – spina bifida
- GP letter – hydrocephalus

We also created new resources for our members which included:

- Your Child and Hydrocephalus book
- Schools letter for hydrocephalus
- Information for Employers leaflet
- GP letter – spina bifida

To ensure that our service staff had all of the key

information they needed to support our members, we reviewed and improved our systems for sharing information and knowledge on equipment, grants, carer support and respite and a range of other topics through our centralised 'knowledge bank'.

The teams also benefited from an intensive programme of regular training to maximise our customer service, our communication and support for more intense and specialised problems such as bereavement and helping members through periods of anxiety, stress and poor mental wellbeing.

We launched our innovative and exciting new video-recording facility, Shine Voices, which offered members the chance to record and publish their own stories about their lives, experiences of their conditions, achievements and goals.

We held a very successful Spina Bifida Awareness Week (October 2020) and continued our winning format of holding a separate Hydrocephalus Awareness Week in March 2021.

Together

Our membership magazine

Shine produced two editions of our membership magazine and reverted to posting this to the majority of our members, following feedback that most preferred the printed format.

These went out by post to an average of 11,314 members and in digital format to over 3000 others.



Next steps →→→

- Improving the quality of our data for greater service effectiveness
- Continually reviewing and improving our website for greater accessibility to expert information
- Producing a wider range of condition-specific and age-specific information and resources
- Providing relevant training, information, and toolkits for staff to maintain and develop their knowledge and expertise in their individual and team roles

Spina Bifida Awareness Week

#Backtofront

Sponsored by
Hollister.

219,818
Social media reach



23rd – 29th October 2020

5000 information
packs distributed

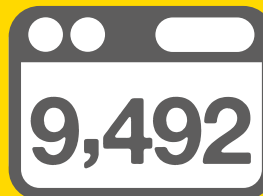


10,889 social media interactions



Unique SHINE
website visitors

3,889



**NUMBER
OF UNIQUE
PAGES VIEWED**

15,144 VIEWERS TUNED IN
TO OUR LIVE SESSIONS

**Member,
supporter
and staff
feedback...**

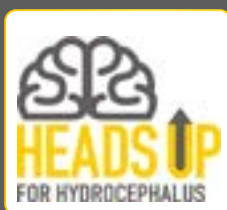


“The kids loved back-to-front non-uniform day today, in aid of Shine! Great idea”

“Really informative and interesting session from someone who has had some tough questions recently”

“I have just listened to Maria talk beautifully about Delilah, her gift of a daughter, and the support from Shine, a remarkable charity”





Hydrocephalus awareness week

8th – 14th March 2021

117,619
Social media reach

8,088 
information packs
distributed kindly sponsored by Codman

15,295 
unique page views

 **5,050** social media interactions

Emails sent to an average of

5,297 
members
4 TIMES

 **4,645** UNIQUE WEBSITE VISITORS

((•)) 1,090 VIEWERS TUNED IN TO OUR LIVE SESSIONS for longer than 1 minute

What some of our members said...

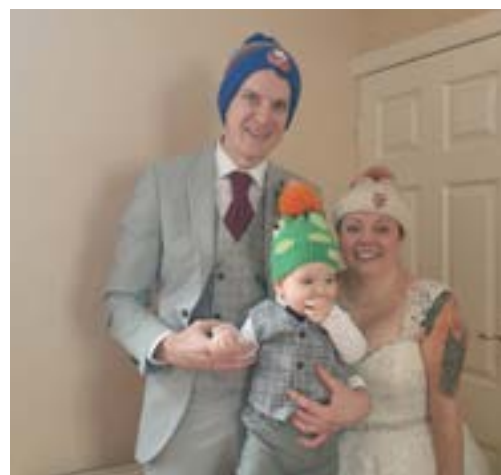


“ Shine have provided excellent training to school staff and have some really useful information available on the website”

“ Shine was an incredible resource and much needed support network for us at such a difficult time, and they continue to be so now”

“ I just happened to catch one of your online chats yesterday and learnt more on that course than I’ve learnt from the whole time I’ve been in and out of hospital I’m booked in for the session today too”

“ These resources are excellent and exciting well done”



Developing Shine's next Corporate Plan

Since 2017, the Corporate Plan has provided Shine with a clear structure for the delivery of our aim and strategic goals which has helped to consolidate and focus the work we do to meet the needs of our members, but also on the need to improve engagement with members and other key stakeholders.

The plan has also served to unite staff across the organisation into understanding the charity's purpose and recognising the importance that each internal function (e.g., services; income generation; operations; administration; finance) plays in the success of the services we deliver.

Our annual workplans, which have guided our priorities and provided a framework against which we could monitor progress and identify areas of risk and solutions for mitigation, have been ambitious.

The ambition for the 2020/21 workplan was set out

prior to the pandemic. Priorities changed very quickly before the start of the new financial year as teams responded to members' support and information needs as a result of the emerging situation. Despite the change in focus, Shine's staff made significant progress in delivering our objectives.

It was always inevitable that specific pieces of work would not be completed within our original timescales and our priorities for 2021/22 therefore include some activity originally planned for the previous 12 months.

It is also now time to reflect on the successes and learning of the past to develop our next Corporate Plan, 2022 and beyond.

We will work closely with members, through consultation and focus groups, to shape our projects and activities and guide us through the coming years to meet the condition-specific and age-specific needs of the individuals and families we support.



“It's also now time to reflect on the successes and learning of the past to develop our next Corporate Plan, 2022 and beyond...”
Chief Executive Kate Steele

Thank you...

On behalf of the thousands of individuals with spina bifida and/or hydrocephalus and their families we are able to help each year, we would like to thank the many individuals, families, organisations and volunteers who have helped Shine in so many ways, some of whom are listed below.

Trusts and Foundations

Amanda Lee Charitable Trust	The Fowler, Smith and Jones Trust	National Lottery Community Fund – England, Wales and Northern Ireland
The Alchemy Foundation	Frank Brake Charitable Trust	Northern Health and Social Care Trust (Northern Ireland)
The Alice Ellen Cooper Dean Charitable Foundation	The Gale Family Trust	The P F Charitable Trust
Baron Davenport's Charity	The Gerald Bentall Charitable Trust	The Privy Purse Charitable Trust
The Basil Brown Charitable Trust	Greenham Trust	The Rozel Trust
The Basil Death Trust	The Hadrian Trust	Shanly Foundation
Belfast Health and Social Care Trust (Northern Ireland)	The J P Jacobs Charitable Trust	The Soloway Trust
CAST – Centre for Acceleration of Social Technology	J Reginald Corah Foundation Fund	The Souter Charitable Trust
The Cecil Rosen Foundation	The John Swire 1989 Charitable Trust	Southern Health and Social Care Trust (Northern Ireland)
The David Gibbons Foundation	The Joseph Strong Frazer Trust	The Sylvia & Colin Shepherd Charitable Trust
Eastern Counties Educational Trust Limited	The Lady Hind Trust	The Worshipful Company of Gold & Silver Wyre Drawers
	Lord Barnby's Foundation	
	The Moondance Foundation	

Supporters

Maria, Harrison and Delilah Wall	Val Conway	Lexi Johnson and Family
Amy and Freya Dawson	Oliver Pearce and family	Kate and Michael Poynton
Barbara Smith	Gwyn Dafydd Hughes	Marie Taylor
Chivers Family and Friends	Charlie Ashby	Kevin O'Neill
Jo and Ian Barker	Thomas Williams	King David Primary School
Matt Tiner	Archie Cunningham and Family	Annie Newman and Oscar
Rosemary Martin	Mason Galbraith and Family	Hannah Phillips and Ella

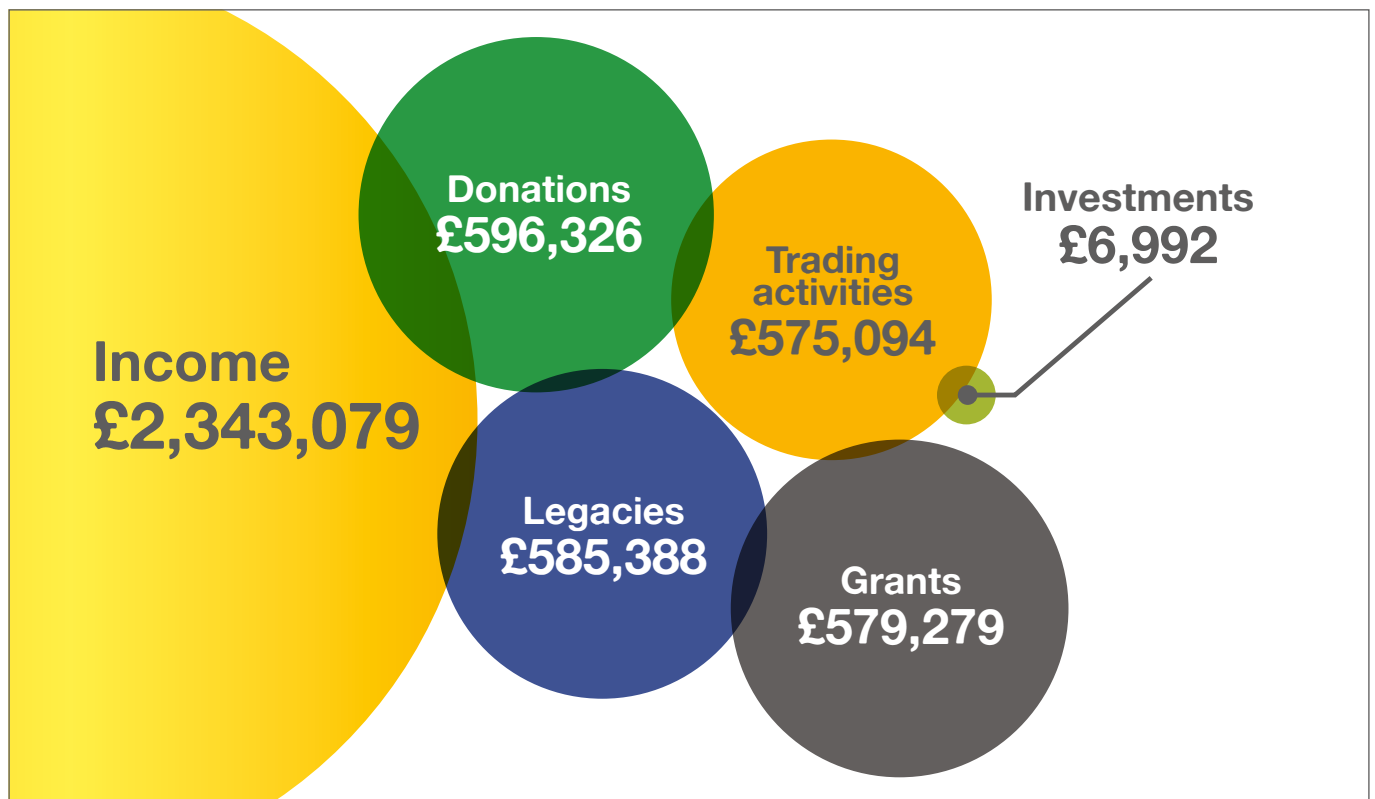
Corporates, organisations and individual supporters

BBC Radio 4	Enable Law	North Wales Running Club
BGL	GR Lane Health Products	Queensgate Shopping Centre
Buckles Solicitors LLP	Hollister Limited	Royal Pigeon Racing Association
Bullen Healthcare	Fieldfisher	Thompsons NI
Citi Belfast	Irwin Mitchell	

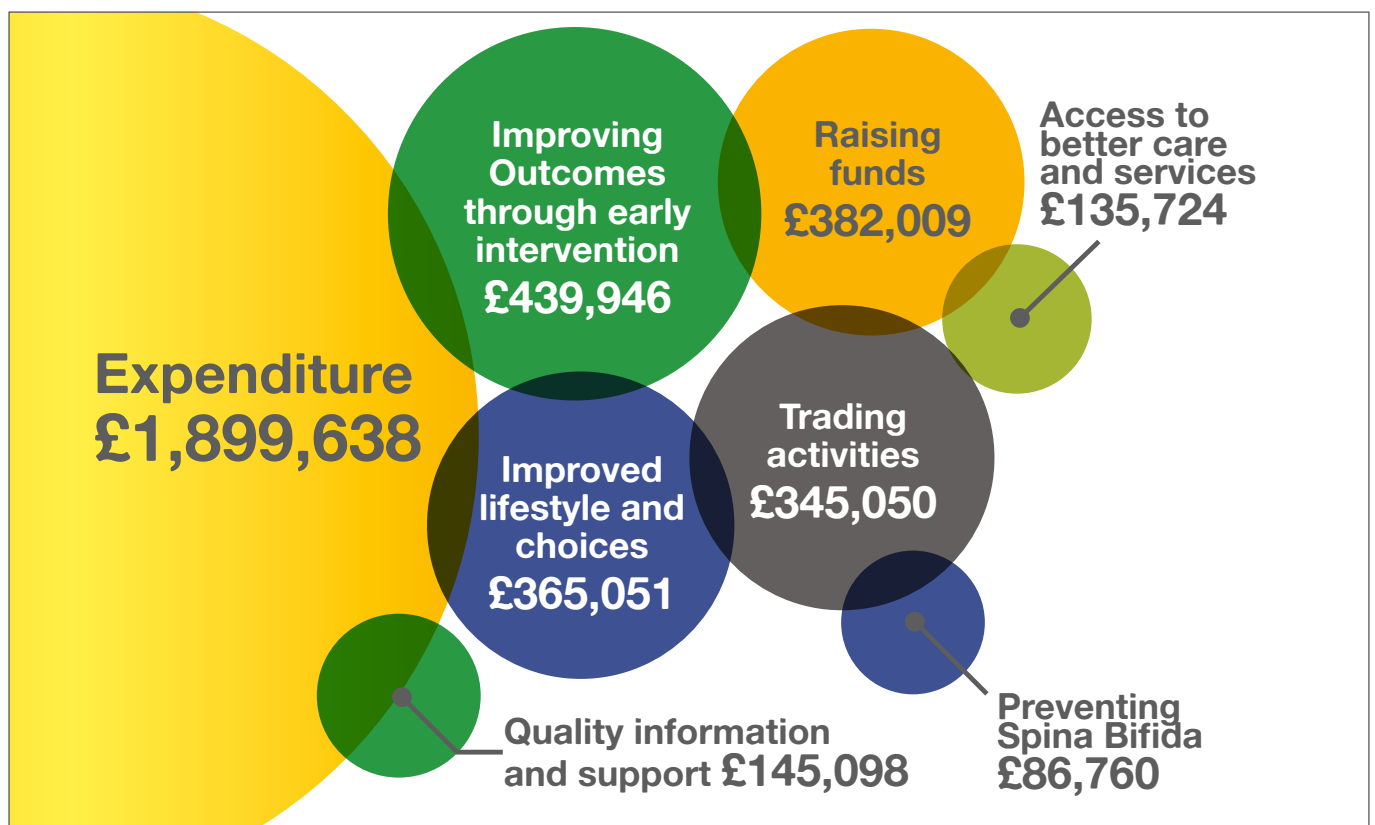
Our Chairman, Mark Noakes, stepped down from his role in June this year. Shine would like to thank Mark for his invaluable work and support as Chair since joining in December 2016.

Income and expenditure 2020/21

Total Income



Total Expenditure





Financial Review

The budget for 2020/21 was set before the UK Government announced the first COVID-19 lockdown. The pandemic created global economic uncertainty and raised serious concerns about the extent to which some of Shine's income streams would be adversely affected.

Therefore during April a contingency budget was prepared, and several measures were implemented, designed to mitigate the income reductions that were expected. These measures included seeking funding from new supporters, switching fundraising efforts to virtual events and planned reductions in expenditure. We sought to maintain services as best as possible, therefore cost of raising funds bore the brunt of the measures to reduce expenditure.

Charitable Activities

Shine reports an actual surplus of £506,730 (2019/20 £113,259 surplus), which consists of an unrestricted surplus £288,643, a £179,875 designated surplus, and a £38,212 restricted surplus.

Total income for 2020-21 was £2,343,079 (2019/20 £2,192,078), with increases in grants and legacies offsetting reductions in trading and donations income. Trading and donation income have been adversely affected by the COVID-19 lockdowns and resulting economic uncertainty, with a year-on-year reduction of 12%. The annual figures do however hide an improving picture with these income levels recovering since the Autumn of 2020. Therefore, whilst trading and donation income in the first six months of 2020/21 was 28% below the same period in 2019/20,

income levels in the second half of 2020/21 were just 5% below 2019/20. Grant funding from the National Lottery Community fund in the second half of the year was significant, which amongst other foundations increased annual grant funding to £579,279 (2019/20 £313,972) including a new 3-year project to fund early years services in Cymru and funds to support our COVID-19 response. Legacies continue to be a major source of funding providing £585,388 (2019/20 £530,973) and we are very grateful that people continue to remember us in their wills.

Total expenditure in the year was £1,899,638 (2019/20 £2,038,060), being a reduction of £138,422 (6.7%) and whilst cost-saving measures were implemented early in the year to mitigate anticipated shortfalls in funding, we sought to prioritise spending on charitable services. Therefore, whilst charitable expenditure reduced by £56,911 (4.6%), expenditure on cost of raising funds decreased by £81,511 (10%). Furthermore, most charitable savings made related to reduced levels of travel as our services sought to continue support to members by telephone and virtual means. Therefore, service levels were maintained as far as possible and average staffing levels increased during the year (27 full-time equivalent posts compared to 25 in 2019/20).

During March 2020, the COVID-19 pandemic had a significant impact on the value of our investments. During 2020-21 there has been a recovery in financial markets, and we report a gain of £81,160 (loss in 2019/20 £44,559). These gains are most welcome, but the charity remains cautious in using these gains to fund charitable services.

Under the accounting standard SORP 2015 the full defined benefit pension deficit must be declared on the balance sheet. There was a 2020/21 actuarial loss of £17,871 (2019/20 gain £3,800). The charity remains confident that it will meet the required pension contributions from its projected income without significantly impacting on its planned level of charitable activity. The charity still deducts next year's contributions when calculating its free reserves. Further pension detail is shown in note 21 of the accounts.

Financial Reserves Policy

A review of the reserves policy was concluded in March 2020 with approval as follows.

Shine holds reserves for the following purposes:

- Statutory obligations.
- Provide a 3-month commitment to our vulnerable members to wind up the affairs of the charity in an orderly fashion, in the event that the trustees cease to be confident in Shine's ability to continue.
- Working capital for ongoing activities.

The target level of reserves required for the above purposes is £570k and consists of three months of committed expenditure £495k plus working capital cover of £75k.

The pension deficit (due after 12 months) is excluded from the reserve's calculation. A payment plan to reduce the pension deficit has been agreed with the pension provider and is considered in all our financial planning.

At the year-end Shine held free reserves of £840,173 (general unrestricted funds excluding designated funds and pension deficit payments due after 12 months), which was above the reserves target and represents 4.6 months of expenditure cover. The charity plans to utilise its reserves in a managed fashion through investment in strategic priorities and, despite the uncertainty about the economic recovery in 2021/22, the charity is expanding its services in 2021/22 with the addition of a Deputy Health Manager and Adult Engagement Officer. These positions and other changes will result in a 15% increase in expenditure in 2021/22 compared to 2020/21.

Restricted reserves must be applied to the specific purpose(s) intended by the donor so do not form part of the free reserves; funds totalled £158,314 at the

year end and are planned to be expended in 2021/22.

Designated funds have been established by the Board and are excluded from free reserves. They are as follows:

- A fund to represent Shine's investment in fixed assets, net of the outstanding mortgage on the 42 Park Road (the registered office).
- A fund to employ an additional full-time Support and Development Worker for the South West of England, enabling us to have a much greater reach to support children and adults with spina bifida and hydrocephalus in that area, through one-to-one support and a network of social and support groups. This has been made possible by the generosity of the late Florence Bartle who kindly chose to remember Shine in her will, with funds received in 2020/21.
- A human resources fund to invest in staff and service teams in 2021/22.

Investment Policy

Under the governing document the charity has the power to make any investment which the trustees see fit. R. C. Brown Investment Management plc are Shine's investment managers with the remit to manage the investments in line with the policy outlined below.

Investments are held as part of the long-term reserves of Shine. The aim is that they should maintain their value and generate income for Shine.

The portfolio must only be invested in assets with a low risk profile. This will include utilisation of pooled funds, which provide diversification of assets, and ensures that the risk of losing a single holding is minimised.

- The investments may be held in a range of asset classes, including equities, corporate bonds, and gilts.
- There will be no direct investment in 'alternative' investments such as hedge funds or derivatives.
- There will be no direct investment in overseas equities. Any such investment must be done through pooled funds managed in the UK.

The trustees have agreed that the funds should initially be invested in a broad, balanced portfolio. The intention is to work towards ethical investments, with the advice of the investment managers, while being mindful of the

charity's obligations for responsible investment.

During the year R. C. Brown Investment Management plc continued to manage the Shine portfolio. The funds were fully invested throughout the year; the long-term funds exceeded their benchmark, recording a 31.55% return during 2020/21 versus the 24.79% benchmark (ARC steady growth index).

The charity also holds the freehold of the registered office, for which significant equity is held. At the onset of the pandemic most staff based at the registered office were moved to home-working arrangements.

A review of whether continued occupancy of 42 Park Road is in the best interests of the charity was already underway prior to COVID-19 and subsequently the Board of Trustees approved in principle a business case which seeks to market for sale the building and relocate to a smaller office with staff working a hybrid model of home working and office days.

The project is ongoing in 2021/22 and if completed offers the potential to release cash and reduce operating expenditure which could be invested in future services and strengthen reserves.

Risk Management and Internal Control

The Board of Trustees are responsible for the

identification and management of the major risks facing the charity. A Risk Register is maintained and shared annually with trustees (more frequently if a significant issue arises).

Risk management at operational level is managed by the senior leadership team; major risks have been reviewed and systems established to manage these risks.

During 2020/21 the most significant risk was COVID-19 in terms of the way in which the charity supported its members and the risks to income levels. Therefore, the risk register currently covers six strategic areas.

1. Governance & strategy

2. Income generation

3. Services

4. Finance

5. COVID-19

6. Brexit

The last two items of the risk register were reviewed at each quarterly trustee meeting as Shine continues to make structural and strategic changes to the organisation to mitigate these risks.

Going Concern and Statement of Public Benefit

Going Concern

The activities of the charity, its objectives, factors likely to affect its future development and the policies for managing its capital and financial risk are detailed in the Trustees Report.

We have set out in this report a review of Shine's financial performance, the reserves position and principal risks and uncertainties.

The budget for 2021/22 was prepared by senior leadership and approved by the trustees in March 2021; it does not include the financial benefits

expected should the project to sell 42 Park Road be completed during 2021 or beyond. The expectation is that trading and donation income levels continue to improve as COVID-19 lockdown measures are relaxed and the vaccine rollout continues to be a success.

Expenditure levels will be allowed to increase in line with the expansion in service provision, the return of face-to-face contact and events for our members. The budgeted unrestricted surplus is £32,807 whilst expenditure against restricted funds received in prior periods results in a restricted deficit of £106,270.

The budget and its assumptions are reviewed against three key financial measures:

- Bank loan covenant
- In-year cash flow
- Free reserve cover

Management accounts are prepared by senior leadership and issued monthly to trustees; the current

financial position and financial outlook are reviewed at quarterly trustee meetings. Given the level of reserves and outlook, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future being at least twelve months from date of approval of these financial statements. Accordingly, they continue to adopt the going concern basis of accounting in preparing the financial statements.

Statement of Public Benefit

The trustees confirm that they have complied with the duty in section 17 of the Charities Act 2011 to have regard to the Charity Commission's general guidance on public benefit, 'Charities and Public Benefit'.

Shine's charitable objects are enshrined within its memorandum and articles and as such trustees

ensure that the charity's activities are carried out for public benefit through its strategic goals.

This report allows us to show how charitable funds are spent and the impact and benefits this has to the lives of people affected by spina bifida and/or hydrocephalus, and associated conditions.

Reference and Administration Details

Trustees

The trustees of Spina bifida, Hydrocephalus, Information, Networking, Equality – SHINE are the charity's trustees under charity law and directors of the charitable company and throughout the report are collectively referred to as the trustees.

Mark Noakes (Chairman – resigned 8 June 2021)	Michael Brown
Gregory Smith (Vice Chairman)	Andrew Smart
Rebecca Bates (Hon. Treasurer)	Joanne Williams
Patricia Adley	Surekha Kukadia (appointed 6th July 2021)
Stuart Barrow	Aziza Darr (appointed 21st July 2021)
Professor Roger Bayston	

It is confirmed that none of the serving Trustees had any beneficial interest in any contract with Shine in the year.

Royal Patron

HRH The Duchess of Gloucester GVC O

Senior Leadership Team

Chief Executive Kate Steele	Director of Fundraising & Marketing
Director of Services Heidi Watson	Teresa Hicks (left April 2021)
Director of Finance Stephen Ellen	

Objects

The charity's objects are specifically restricted to the relief of persons who have spina bifida and/or hydrocephalus or allied or related disorders by providing care, welfare, treatment, education, and integration into society.

Principal Professional Advisers

Auditors

Azets Audit Services

Ruthlyn House
90 Lincoln Road
Peterborough
PE1 2SP

Bankers

The Co-operative Bank Plc

PO Box 250
Skelmersdale
WN8 6WT

Unity Trust Bank

Four Brindley Place
Birmingham
B1 2JB

Insignis Cash Solutions

St John's Innovation Centre
Cowley Road
Cambridge
CB4 0WS

Solicitors

Greenwoods GRM LLP

Monkstone House
City Road
Peterborough
PE1 1JE

Investment Managers

R.C. Brown Investment Management

1 The Square
Temple Quay
Bristol
BS1 6DG

HR

Vero HR

St James House
Flaxley Road
Kingston Park
Peterborough
PE2 9FT

Administrative Details

The full name of the charity is Spina bifida, Hydrocephalus, Information, Networking, Equality – SHINE. We are commonly known as Shine.

The registered charity number is 249338 (England and Wales)

The company registration is 00877990

Registered Office: Shine, 42 Park Road, Peterborough, PE1 2UQ

Telephone 01733 555988 • Email firstcontact@shinecharity.org.uk • www.shinecharity.org.uk



Our Commitment to Quality Fundraising

Shine is registered with the Fundraising Regulator and proud to commit to the Regulator's Fundraising Promise.

We are committed to maintaining high standards of fundraising in line with the Code of Fundraising Practice: <https://www.shinecharity.org.uk/downloads/fundraising-promise.original.pdf>

We will commit to high standards:

- We will be clear, honest, and open
- We will be respectful
- We will be fair and reasonable
- We will be accountable and responsible

Our approach to fundraising consists of:

- marketing appeals to individuals who have already expressed an interest in Shine
- running charitable events for which participants raise money
- encouraging people to participate in other events to raise funds on our behalf
- community fundraising; and
- soliciting donations from corporate partners, charitable trusts, and individual donors

We also encourage people to remember us in their will with a gift or legacy.

We do not use third-party professional fundraising agencies.

Where people or organisations raise funds in aid of Shine, we request they follow our standards. Shine's fundraising team provide tools and resources to enable supporters to deliver fun, safe, and successful fundraising activities. The trustees are of a view that during the year to 31 March 2021 we have been compliant with these standards and we are not aware of any instances where those acting in aid of the charity have failed to comply.

To protect vulnerable people and other members of the public, Shine has a safeguarding policy, and our fundraising commitment is displayed on our website. We are careful to protect the private data of supporters and give clear options to stop being contacted by us. As part of our compliance with the code of fundraising practice, we ensure our approach to fundraising is not unreasonably intrusive or persistent and does not aim to solicit donations by pressuring potential supporters.

We take these steps to make sure people have a choice about whether to fundraise for Shine.

Shine and our members are incredibly grateful for the continued dedication and support of our fundraisers. From everyone at Shine, thank you for your ongoing generosity.

Structure, Governance and Management

Structure

Spina bifida, Hydrocephalus, Information, Networking, Equality – SHINE (Shine) is a company limited by guarantee registered in England and Wales (Registration No. 00877990) formed in 1966. Shine is registered as a charity with the Charity Commission for

England and Wales (Registration No. 249338).

The charity owns the entire share capital of Shine (Trading) Limited, registered in England and Wales (No. 01031004). The consolidated accounts include Shine (Trading) Limited (see note 9). The principal activity of the company is to raise funds for the charity.

Governance

Shine is governed by Articles of Association, which were amended in 2018.

Organisational purpose

Shine has a clear, sustainable corporate strategy for 2017 to 2022 consistent with the charity's purpose and an evaluation and monitoring framework to monitor impact and measure outputs. A strategic review is currently underway to develop a corporate strategy beyond 2022.

Shine consults with a wide range of stakeholder groups to determine the priorities for the charity over the next five years.

These groups advise the Board and senior leadership team on matters of policy and practice and respond to consultations and specific areas of interest.

Leadership

The ultimate responsibility for the governance of the charity and its subsidiary is entrusted to the trustee board.

Board Integrity

Appointment of trustees

New Articles of Association were adopted by special resolution in 2018 specifying that any person who is willing to act as a trustee, and who is permitted by law to do so, may be appointed as a trustee by a resolution of the trustees.

A trustee must be a natural person aged 16 years or older, the minimum number of trustees is 3 and the maximum is 16. Trustees are appointed for a term of 3 years; trustees are eligible for reappointment up to two subsequent terms (each of 3 years).

No trustee can serve for more than 9 consecutive years unless the trustees consider it is in the best interests of the charity that a particular trustee should continue to serve. Professor Roger Bayston continues to serve as a trustee on this basis.

Trustee induction and training

New trustees undergo an induction where they would normally visit Shine's registered office and meet the senior leadership team and other key employees. (In light of COVID-19 the induction of Mr A. Smart and Mr S. Barrow was completed by virtual means.) They are fully appraised of the full range of Shine's services, projects and campaigns and provided with relevant background literature. They receive awareness training, if required, on spina bifida and hydrocephalus. Depending on their specific skills and areas of

expertise they will be put in touch with relevant staff.

Trustees are briefed on their legal obligations under charity and company law, the Articles of Association and the Board's decision-making process. They are also informed about Shine's Corporate Plan, key risks, recent financial performance, and prospects for the charity.

Decision making, risk and control

The Board of Trustees is the governing body with overall legal responsibility for the charity. The Board sets the strategic direction for Shine. It meets a minimum of four times a year; due to the COVID-19 pandemic the board is currently holding meetings by virtual means.

The minutes of meetings are made available to all trustees on a timely basis. The board regularly reviews operational plans, budgets, performance, and Shine's main risks. The day-to-day management of the charity is delegated to the Chief Executive, who reports to the Board. The Chief Executive is assisted in the day-to-day management by the senior leadership team.

Senior Staff Remuneration Policy

The remuneration of senior staff is set by benchmarking with similar-sized charities, and the market rate required to attract the best people to the job.

Diversity and Inclusion

Shine has a transparent recruitment process, advertising widely and looking at how we can attract a diverse pool of candidates.

Safeguarding

A full review of our safeguarding policies and processes began in 2020/21 to ensure that we are continually improving our approaches to safeguarding, incorporating all updated legislation and embracing current best practice in order to protect the welfare of our members, staff and volunteers.

An annual safeguarding plan is agreed by trustees. The plan is prepared by the Director of Services, who is Designated Safeguarding Lead for the charity, in conjunction with Patricia Adley and Joanne Williams, who are trustee leads for safeguarding.

Safeguarding training is provided for all staff, trustees and volunteers. Incidents are reported, assessed, and enacted as appropriate with full consideration given to the requirement to report to the Charity Commission.

GDPR

Extensive work was undertaken to ensure Shine's ongoing compliance with the General Data Protection Regulation (GDPR). We have a designated GDPR lead, and the data management action plan is reviewed by trustees annually.

Section 172 Statement

The trustees must act in accordance with a set of general duties. These duties are laid out in s172 of the UK Companies Act 2006 which is summarised as follows: A Director of a Company must act in a way most likely to promote the benefit of its members, and in doing so have regard to:

- The likely consequences of any decision in the long term
- The interests of the charity's employees
- The need to foster the charity's business relationship with suppliers, customers, and others
- The impact of the charity's operations on the community and environment
- The desirability of the charity's maintaining a

reputation for high standards of business

- The need to act fairly between members of the charity.

The trustees believed they have completed their duties under s172.

Related Parties

The charity has partnerships with several local associations. These are independent charities for spina bifida and hydrocephalus. Partnerships are negotiated on an individual basis which may cover a range of activities and services. The charity also works in partnership with many other bodies, voluntary, statutory, and international, in carrying out work to support service users, undertake research and disseminate information.

Volunteers

In 2020/21, Shine had 59 registered volunteers, to whom we remain eternally grateful. The volunteering roles included:

- Working in our charity shop
- Giving talks and representing Shine
- Acting as peer support
- Supporting our members to grow in confidence and address the challenges of living with the conditions
- Advising on the development of resources
- Fulfilling the role of Shine ambassador
- Fundraising
- Supporting our local groups

Statement of trustees' responsibilities

The trustees (who are also directors of Spina bifida, Hydrocephalus, Information, Networking, Equality – SHINE), are responsible for preparing the annual report and the financial statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice.

Company law requires the directors to prepare financial statements for each financial year which give a true and fair view of the situation of the charitable group and of the net income or expenditure of the group for the year. In preparing these financial statements the directors are required to:

- select suitable accounting policies and then apply them consistently
- observe the methods and principles in the Charities SORP
- make judgements and estimates that are reasonable and prudent
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and the group and enable them to ensure that the financial statements comply with the Companies Act 2006.

They are also responsible for safeguarding the assets of the charity and the group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Statement as to disclosure of information to auditors

As far as the trustees are aware, there is no relevant audit information of which the group's auditors are unaware. Additionally, the trustees have taken all the necessary steps that they ought to have taken as trustees to make themselves aware of all relevant audit information and to establish that the group's auditors are aware of that information.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website.

Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Appointment of auditors

The continued appointment of Azets Audit Services Limited was confirmed by the Board of Trustees on the 1st December 2020.

This report has been prepared in accordance with the special provisions relating to small companies within Part 15 of the Companies Act 2006.

By order of the Board of Trustees

Greg Smith
Acting Chair

7th September 2021

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

INDEPENDENT AUDITOR'S REPORT

TO THE TRUSTEES OF SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

Opinion

We have audited the financial statements of Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE (the 'charity') and its subsidiary for the year ended 31 March 2021 which comprise the Group Statement of Financial Activities, the Group and Parent Charitable Company Balance Sheets, the Group and Parent Charitable Company Cash Flow Statements and the notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the Group and Parent Charitable Company affairs as at 31 March 2021 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the Group and Parent Charitable Company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. The Trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE TRUSTEES OF SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of our audit:

- the information given in the Trustees' report, which includes the directors' report prepared for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the directors' report included within the Trustees' report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the Group and Parent Charitable Company and its environment obtained in the course of the audit, we have not identified material misstatements in the directors' report included within the Trustees' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the Trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemptions in preparing the Trustees' report and from the requirement to prepare a strategic report.

Responsibilities of Trustees

As explained more fully in the statement of Trustees' responsibilities, the Trustees, who are also the directors of the charity for the purpose of company law, are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the Group and Parent Charitable Company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities is available on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE TRUSTEES OF SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

Extent to which the audit was considered capable of detecting irregularities, including fraud

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above and on the Financial Reporting Council's website, to detect material misstatements in respect of irregularities, including fraud.

We obtain and update our understanding of the entity, its activities, its control environment, and likely future developments, including in relation to the legal and regulatory framework applicable and how the entity is complying with that framework. Based on this understanding, we identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. This includes consideration of the risk of acts by the entity that were contrary to applicable laws and regulations, including fraud.

In response to the risk of irregularities and non-compliance with laws and regulations, including fraud, we designed procedures which included:

- Enquiry of management and those charged with governance around actual and potential litigation and claims as well as actual, suspected and alleged fraud;
- Reviewing minutes of meetings of those charged with governance;
- Assessing the extent of compliance with the laws and regulations considered to have a direct material effect on the financial statements or the operations of the entity through enquiry and inspection;
- Reviewing financial statement disclosures and testing to supporting documentation to assess compliance with applicable laws and regulations;
- Performing audit work over the risk of management bias and override of controls, including testing of journal entries and other adjustments for appropriateness, evaluating the business rationale of significant transactions outside the normal course of business and reviewing accounting estimates for indicators of potential bias.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.



Mr Mark Jackson FCA DChA (Senior Statutory Auditor)
for and on behalf of Azets Audit Services

22.9.2021

Chartered Accountants
Statutory Auditor

Ruthlyn House
90 Lincoln Road
Peterborough
United Kingdom
PE1 2SP

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2021

Current financial year

	Notes	Unrestricted funds 2021 £	Designated funds 2021 £	Restricted funds 2021 £	Total 2021 £	Total 2020 £
Income from:						
Donations and legacies	3	1,211,858	-	549,135	1,760,993	1,440,551
Other trading activities	4	575,094	-	-	575,094	741,219
Income from investments	5	6,992	-	-	6,992	10,308
Total income		1,793,944	-	549,135	2,343,079	2,192,078
Expenditure on:						
Raising funds	6	727,059	-	-	727,059	808,570
Charitable activities	7	563,350	45,754	563,475	1,172,579	1,229,490
Total resources expended		1,290,409	45,754	563,475	1,899,638	2,038,060
Net gains/(losses) on investments	12	81,160	-	-	81,160	(44,559)
Net incoming/(outgoing) resources before transfers		584,695	(45,754)	(14,340)	524,601	109,459
Gross transfers between funds		(278,181)	225,629	52,552	-	-
Net incoming resources		306,514	179,875	38,212	524,601	109,459
Other recognised gains and losses						
Actuarial (loss)/gain on defined benefit pension schemes		(17,871)	-	-	(17,871)	3,800
Net movement in funds		288,643	179,875	38,212	506,730	113,259
Fund balances at 1 April 2020		332,050	391,829	120,102	843,981	730,722
Fund balances at 31 March 2021		620,693	571,704	158,314	1,350,711	843,981

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

STATEMENT OF FINANCIAL ACTIVITIES (CONTINUED) INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2021

Prior financial year

	Notes	Unrestricted funds 2020 £	Designated funds 2020 £	Restricted funds 2020 £	Total 2020 £
<u>Income from:</u>					
Donations and legacies	3	1,094,879	-	345,672	1,440,551
Other trading activities	4	741,219	-	-	741,219
Income from investments	5	10,308	-	-	10,308
Total income		1,846,406	-	345,672	2,192,078
<u>Expenditure on:</u>					
Raising funds	6	808,570	-	-	808,570
Charitable activities	7	873,794	51,935	303,761	1,229,490
Total resources expended		1,682,364	51,935	303,761	2,038,060
Net gains/(losses) on investments	12	(44,559)	-	-	(44,559)
Net incoming/(outgoing) resources before transfers		119,483	(51,935)	41,911	109,459
Gross transfers between funds		(68,950)	68,950	-	-
Net incoming resources		50,533	17,015	41,911	109,459
Other recognised gains and losses					
Actuarial (loss)/gain on defined benefit pension schemes		3,800	-	-	3,800
Net movement in funds		54,333	17,015	41,911	113,259
Fund balances at 1 April 2019		277,717	374,814	78,191	730,722
Fund balances at 31 March 2020		332,050	391,829	120,102	843,981

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

BALANCE SHEETS

AS AT 31 MARCH 2021

	Notes	Group 2021 £	Charity 2021 £	Group 2020 £	Charity 2020 £
Fixed assets					
Tangible assets	14	823,163	820,699	849,734	845,178
Investments	15	341,378	341,381	259,451	259,454
		1,164,541	1,162,080	1,109,185	1,104,632
Current assets					
Debtors	17	378,373	339,989	296,171	270,374
Cash at bank and in hand		650,600	637,285	369,984	353,678
		1,028,973	977,274	666,155	624,052
Creditors: amounts falling due within one year	18	(253,790)	(222,614)	(238,707)	(215,035)
Net current assets		775,183	754,660	427,448	409,017
Total assets less current liabilities		1,939,724	1,916,740	1,536,633	1,513,649
Creditors: amounts falling due after more than one year	19	(369,533)	(369,533)	(416,685)	(416,685)
Net assets excluding pension liability		1,570,191	1,547,207	1,119,948	1,096,964
Defined benefit pension liability	21	(219,480)	(219,480)	(275,967)	(275,967)
Net assets		1,350,711	1,327,727	843,981	820,997
Income funds					
Restricted funds	22	158,314	158,314	120,102	120,102
<u>Unrestricted funds - general</u>					
Designated funds	23	571,704	569,240	391,829	387,273
General unrestricted funds		620,693	600,173	332,050	313,622
		1,192,397	1,169,413	723,879	700,895
		1,350,711	1,327,727	843,981	820,997

The financial statements were approved by the board of directors and authorised for issue on 7/9/2021 and are signed on its behalf by:

.....
Mr G Smith
Trustee
Company Registration No. 00877990

.....
Mrs R Bates
Trustee

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 31 MARCH 2021

	Notes	2021 £	£	2020 £	£
Cash flows from operating activities					
Cash generated from/(absorbed by) operations	28		328,060		(16,355)
Investing activities					
Purchase of tangible fixed assets		(2,346)		(5,836)	
Interest received		2,054		2,455	
Net cash used in investing activities			(292)		(3,381)
Financing activities					
Repayment of bank loans		(47,152)		(42,466)	
Net cash used in financing activities			(47,152)		(42,466)
Net increase/(decrease) in cash and cash equivalents			280,616		(62,202)
Cash and cash equivalents at beginning of year			369,984		432,186
Cash and cash equivalents at end of year			650,600		369,984

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2021

1 Accounting policies

Company information

Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE is a private company limited by guarantee incorporated in England and Wales. The registered office is 42 Park Road, Peterborough, PE1 2UQ, United Kingdom.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's governing document, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2019). The charity is a Public Benefit Entity as defined by FRS 102.

The financial statements have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a true and fair view. This departure has involved following the Statement of Recommended Practice for charities applying FRS 102 rather than the version of the Statement of Recommended Practice which is referred to in the Regulations but which has since been withdrawn.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

The consolidated accounts incorporate the results of the charity and of its wholly owned subsidiary.

1.2 Going concern

At the time of approving the financial statements, the Trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future and so continue to adopt the going concern basis of accounting in preparing the financial statements. In arriving at this conclusion, the Trustees have considered the uncertainty regarding the ongoing impact of COVID. As described in more detail in the Trustees' report, the trustees have taken a number of mitigating actions to limit the financial impact and the charity's mortgage provider has indicated that they will adopt a common sense approach to any potential breaches of covenants. On this basis the trustees believe there are sufficient reserves to enable the charity to operate through this period.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the Trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Designated funds comprise funds which have been set aside at the discretion of the Trustees for specific purposes. The purposes and uses of the designated funds are set out in the notes to the financial statements.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

1 Accounting policies

(Continued)

1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

Gifts donated for resale are included as income when they are sold. No amounts are included in the financial statements for services donated by volunteers.

Grant income is recognised according to the terms of each individual agreement.

All other income is dealt with on an accruals basis.

1.5 Resources expended

Direct expenditure is analysed and charged to the department incurring the cost. Expenditure is included when incurred, the majority of costs being directly attributable to specific activities. Costs that can not be directly attributable to particular headings, are allocated to activities on a basis consistent with use of the resources. Premises and other overheads have been allocated on a head count basis.

Fundraising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of charitable activities.

Governance costs are those incurred in connection with the governance arrangements of the charity and compliance with constitutional and statutory requirements.

1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses. Assets over £1,000 in value are capitalised at cost.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the straight line basis at the following rates:

Land and buildings	Buildings - 2%, land is not depreciated
Fixtures and fittings	20%
Equipment	20%
Software and website	20 - 33%

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in net income/(expenditure) for the year.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

1 Accounting policies

(Continued)

1.7 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible and intangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.8 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits repayable on demand and overdrafts. Deposits are repayable on demand if they are in practice available within 24 hours without a penalty. Liquid resources comprise assets held as a readily disposable store of value.

1.9 Financial instruments

Financial instruments are recognised when the charity becomes party to the contractual provisions of the instrument.

Financial assets are offset, with the net amounts presented in the accounts when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

1 Accounting policies

(Continued)

1.10 Provisions

Provisions are recognised when the charity has a legal or constructive present obligation as a result of a past event, it is probable that the charity will be required to settle that obligation and a reliable estimate can be made of the amount of the obligation.

The amount recognised as a provision is the best estimate of the consideration required to settle the present obligation at the reporting end date, taking into account the risks and uncertainties surrounding the obligation. Where the effect of the time value of money is material, the amount expected to be required to settle the obligation is recognised at present value. When a provision is measured at present value, the unwinding of the discount is recognised as a finance cost in net income/(expenditure) in the period in which it arises.

1.11 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the company is demonstrably committed to terminate the employment of an employee.

1.12 Retirement benefits

For employees choosing to participate, the charity operates a defined contribution pension scheme providing benefits additional to those from the State. The assets are held in a separately administered scheme. The pensions cost charge represents contributions payable by the company to the pension scheme in respect of the year.

Previously, the charity were part of a separately administered defined benefit scheme and is still required to make contributions to fund a deficit in the scheme.

The cost of providing benefits under defined benefit plans is determined separately for each plan using the projected unit credit method, and is based on actuarial advice.

The net interest element is determined by multiplying the net defined benefit liability by the discount rate, taking into account any changes in the net defined benefit liability during the period as a result of contribution and benefit payments. The net interest is recognised in income/(expenditure) for the year.

Remeasurement changes comprise actuarial gains and losses, the effect of the asset ceiling and the return on the net defined benefit liability excluding amounts included in net interest. These are recognised immediately in other recognised gains and losses in the period in which they occur and are not reclassified to income/(expenditure) in subsequent periods.

The net defined benefit pension asset or liability in the balance sheet comprises the total for each plan of the present value of the defined benefit obligation (using a discount rate based on high quality corporate bonds), less the fair value of plan assets out of which the obligations are to be settled directly. Fair value is based on market price information, and in the case of quoted securities is the published bid price. The value of a net pension benefit asset is limited to the amount that may be recovered either through reduced contributions or agreed refunds from the scheme.

1.13 Leases

Rentals payable under operating leases, including any lease incentives received, are charged as an expense on a straight line basis over the term of the relevant lease.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

2 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

3 Donations and legacies

	Unrestricted funds 2021 £	Restricted funds 2021 £	Total 2021 £	Total 2020 £
Donations and gifts	577,576	18,750	596,326	595,606
Legacies receivable	585,388	-	585,388	530,973
Grants receivable	48,894	530,385	579,279	313,972
	<u>1,211,858</u>	<u>549,135</u>	<u>1,760,993</u>	<u>1,440,551</u>
For the year ended 31 March 2020	<u>1,094,879</u>	<u>345,672</u>		<u>1,440,551</u>
Donations and gifts				
Individuals	268,217	-	268,217	303,730
Trusts	122,618	18,750	141,368	147,233
Corporate donors	128,960	-	128,960	102,621
Local Authorities	20,000	-	20,000	-
Local associations	2,949	-	2,949	2,999
Support groups	167	-	167	1,200
Health Trusts	34,665	-	34,665	37,823
	<u>577,576</u>	<u>18,750</u>	<u>596,326</u>	<u>595,606</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

3 Donations and legacies

(Continued)

	Unrestricted funds 2021 £	Restricted funds 2021 £	Total 2021 £	Total 2020 £
Grants receivable for core activities				
Welsh Government	-	-	-	56,183
National Lottery Community fund Northern Ireland Little Stars	-	108,338	108,338	84,125
National Lottery Community fund Cymru Health hub	-	9,830	9,830	-
National Lottery Community fund Cymru Shining lights	-	89,588	89,588	-
National Lottery COVID19 emergency response	-	100,000	100,000	-
Early Intervention (Community lottery & others)	-	206,198	206,198	106,370
The Thomas Cook Children's Charity	-	-	-	27,805
National Lottery Community Fund	-	-	-	9,975
Wales Council for Voluntary Action	-	-	-	19,998
Coronavirus job retention scheme grant	48,894	-	48,894	-
Other	-	16,431	16,431	9,516
	<u>48,894</u>	<u>530,385</u>	<u>579,279</u>	<u>313,972</u>

4 Other trading activities

	2021 £	2020 £
Income of trading subsidiary	557,186	686,728
Donations sold through shops	10,715	41,732
Rental income	6,228	6,022
Publications and attendance fees	965	6,737
	<u>575,094</u>	<u>741,219</u>

5 Income from investments

	2021 £	2020 £
Income from listed investments	4,938	7,853
Interest receivable	2,054	2,455
	<u>6,992</u>	<u>10,308</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

6 Raising funds

	2021 £	2020 £
<u>Fundraising and publicity</u>		
Direct staff costs	298,224	288,801
Other fundraising direct costs	32,731	79,648
Support costs (see note 8)	51,054	80,334
Fundraising and publicity	382,009	448,783

	Shine (Trading) Limited £	Shops £	Total 2021 £	Total 2020 £
<u>Trading costs</u>				
Direct staff costs	125,628	19,884	145,512	172,395
Other direct operational costs	52,544	1,615	54,159	59,334
Support costs (see note 8)	132,029	13,350	145,379	128,058
Trading costs	310,201	34,849	345,050	359,787
			727,059	808,570

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

7 Charitable activities

	Improving Outcomes through early intervention	Access to better care and services	Improved lifestyle and choices	Preventing Spina Bifida	Quality information & support	Total 2021	Total 2020
	£	£	£	£	£	£	£
Direct staff costs	340,575	105,067	282,596	67,163	112,325	907,726	903,898
Other direct costs	45,619	14,074	37,854	8,997	15,046	121,590	133,741
	<u>386,194</u>	<u>119,141</u>	<u>320,450</u>	<u>76,160</u>	<u>127,371</u>	<u>1,029,316</u>	<u>1,037,639</u>
Share of support costs (see note 8)	45,227	13,953	37,528	8,919	14,916	120,543	165,349
Share of governance costs (see note 8)	8,525	2,630	7,073	1,681	2,811	22,720	26,502
	<u>439,946</u>	<u>135,724</u>	<u>365,051</u>	<u>86,760</u>	<u>145,098</u>	<u>1,172,579</u>	<u>1,229,490</u>
Analysis by fund							
Unrestricted funds - general						563,350	873,794
Unrestricted funds - designated						45,754	51,935
Restricted funds						563,475	303,761
						<u>1,172,579</u>	<u>1,229,490</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

8 Support and governance costs

	Fundraising and publicity £	Trading costs £	Charitable activities £	2021 £	2020 £
Support costs					
Staff costs	20,233	29,019	52,173	101,425	130,909
IT costs	6,667	9,397	19,086	35,150	43,370
Premises costs	13,539	50,983	18,893	83,415	108,645
Other support costs	10,615	55,980	30,392	96,987	90,817
	<u>51,054</u>	<u>145,379</u>	<u>120,544</u>	<u>316,977</u>	<u>373,741</u>
Governance costs				2021 £	2020 £
Staff costs				13,135	15,886
Audit fees				9,585	9,160
Other governance costs				-	1,456
				<u>22,720</u>	<u>26,502</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

9 Commercial operations in trading subsidiary

The charity has one wholly owned trading subsidiary undertaking, Shine (Trading) Limited which sells advertising space in various publications and balloons for virtual balloon races. The company gift aids virtually all its taxable profits to Shine. A summary of its trading results is shown below. Audited accounts have been filed with the Registrar of Companies.

Shine (Trading) Ltd Profit & Loss Account	2021 £	2020 £
Turnover	557,186	686,728
Cost of sales	(177,673)	(211,894)
Gross profit	379,513	474,834
Administration expenses	(107,594)	(114,352)
Other operating income	8,476	-
Operating profit	280,395	360,482
Amount payable by gift aid to Shine	(280,395)	(360,482)
Profit on ordinary activities	-	-
	<u> </u>	<u> </u>
	2021	2020
	£	£
Shine (Trading) Ltd Balance Sheet		
Fixed assets	2,464	4,556
Current assets	112,054	154,524
Current liabilities	(91,531)	(136,093)
Net current assets	20,523	18,431
	<u> </u>	<u> </u>
Total net assets	22,987	22,987
	<u> </u>	<u> </u>
Aggregate share capital and reserves	22,987	22,987
	<u> </u>	<u> </u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

10 Employees

Number of employees

The average monthly number of full time equivalent employees during the year was:

	2021 Number	2020 Number
Services	27	25
Fundraising and publicity	10	9
Shops	1	1
Administration	4	5
Shine (Trading) Limited	5	6
	<u>47</u>	<u>46</u>

Employment costs

	2021 £	2020 £
Wages and salaries	1,334,398	1,346,034
Redundancy costs	12,999	-
Social security costs	120,056	115,984
Other pension costs	48,131	47,183
Other staff related benefits	3,803	2,686
	<u>1,519,387</u>	<u>1,511,887</u>

The number of employees whose annual remuneration was £60,000 or more were:

	2021 Number	2020 Number
£80,001 - £90,000	-	1
£70,001 - £80,000	1	-
£60,001 - £70,000	1	-
	<u>1</u>	<u>1</u>

Pension contributions for higher paid employees were £10,432 (2020 - £6,560).

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

11 Trustees

None of the Trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

In respect of attending meetings of committees, travel expenses amounting to £nil (2020 - £1,086) have been reimbursed to no (2020 - 5) members of the Board of Trustees.

The accounts include a charge of £2,304 (2020 - £1,920) to provide the Trustees with indemnity insurance.

12 Net gains/(losses) on investments

	Total 2021 £	Total 2020 £
Revaluation of investments	75,285	(53,081)
Gain/(loss) on sale of investments	5,875	8,522
	<u>81,160</u>	<u>(44,559)</u>

13 Taxation

Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE is a registered charity. It only applies its funds in accordance with its charitable objectives, and is not trading with a view to making distributable profits, therefore corporation tax is not chargeable.

The trading subsidiary has gifted its profits to Spina Bifida, Hydrocephalus, Information, Networking, Equality - SHINE under Gift Aid therefore no corporation tax is payable

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

14 Tangible fixed assets

	Land and buildings £	Equipment £	Fixtures and fittings £	Software and website £	Total £
Group Cost					
At 1 April 2020	1,487,404	34,936	17,024	24,202	1,563,566
Additions	-	1,630	-	716	2,346
At 31 March 2021	1,487,404	36,566	17,024	24,918	1,565,912
Depreciation and impairment					
At 1 April 2020	657,396	33,588	14,860	7,988	713,832
Depreciation charged in the year	17,496	1,033	2,164	8,224	28,917
At 31 March 2021	674,892	34,621	17,024	16,212	742,749
Carrying amount					
At 31 March 2021	812,512	1,945	-	8,706	823,163
At 31 March 2020	830,008	1,348	2,164	16,214	849,734

	Land and buildings £	Equipment £	Fixtures and fittings £	Software and website £	Total £
Charity Cost					
At 1 April 2020	1,487,404	32,297	17,024	17,401	1,554,126
Additions	-	1,630	-	488	2,118
At 31 March 2021	1,487,404	33,927	17,024	17,889	1,556,244
Depreciation and impairment					
At 1 April 2020	657,396	30,949	14,860	5,743	708,948
Depreciation charged in the year	17,496	1,033	2,164	5,904	26,597
At 31 March 2021	674,892	31,982	17,024	11,647	735,545
Carrying amount					
At 31 March 2021	812,512	1,945	-	6,242	820,699
At 31 March 2020	830,008	1,348	2,164	11,658	845,178

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

15 Fixed asset investments

	Group 2021 £	Charity 2021 £	Group 2020 £	Charity 2020 £
Investments in subsidiaries	-	3	-	3
Listed investments	341,378	341,378	259,451	259,451
	<u>341,378</u>	<u>341,381</u>	<u>259,451</u>	<u>259,454</u>

Movements in fixed asset investments Group and Charity

	2021 £	2020 £
Cost or valuation		
At 31 March 2020	218,217	269,545
Additions within portfolio	77,164	64,946
Disposals within portfolio	(57,986)	(69,223)
Valuation changes	84,784	(47,051)
	<u>322,179</u>	<u>218,217</u>
Cash held for investment	19,199	41,234
At 31 March 2021	<u>341,378</u>	<u>259,451</u>

16 Financial instruments

	Group 2021 £	Charity 2021 £	Group 2020 £	Charity 2020 £
Carrying amount of financial assets				
Trade debtors	115,018	19,996	141,116	6,244
Other debtors	750	750	923	923
Accrued income	246,838	246,838	139,450	139,450
Amounts due from subsidiary undertakings	-	60,355	-	112,421
Bank and cash	650,600	637,285	369,984	353,678
Measured at cost	<u>1,013,206</u>	<u>965,224</u>	<u>651,473</u>	<u>612,716</u>
Fixed asset investments	<u>341,378</u>	<u>341,381</u>	<u>259,451</u>	<u>259,454</u>
Measured at market value	<u>341,378</u>	<u>341,381</u>	<u>259,451</u>	<u>259,454</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

				(Continued)
16	Financial instruments	Group	Charity	Group Charity
	Carrying amount of financial liabilities			
	Trade creditors	27,911	27,764	23,537 23,238
	Accruals and deferred income	37,787	29,677	39,686 32,260
	Other creditors	93,213	93,213	89,500 89,500
	Other taxation and social security	53,659	30,740	44,764 28,817
	Bank loans	410,753	410,753	457,905 457,905
	Measured at cost	623,323	592,147	655,392 631,720
17	Debtors			
		Group 2021	Charity 2021	Group 2020 Charity 2020
	Amounts falling due within one year:	£	£	£ £
	Trade debtors	115,018	19,996	141,116 6,244
	Amounts due from subsidiary undertakings	-	60,355	- 112,421
	Other debtors	750	750	923 923
	Prepayments and accrued income	262,605	258,888	154,132 150,786
		378,373	339,989	296,171 270,374

The net amount owed by the subsidiary includes amounts owing for gift aid receivable and payment for services provided.

18	Creditors: amounts falling due within one year				
		Group 2021	Charity 2021	Group 2020	Charity 2020
	Notes	£	£	£	£
	Loans and overdrafts 20	41,220	41,220	41,220	41,220
	Other taxation and social security	53,659	30,740	44,764	28,817
	Trade creditors	27,911	27,764	23,537	23,238
	Other creditors	93,213	93,213	89,500	89,500
	Accruals and deferred income	37,787	29,677	39,686	32,260
		253,790	222,614	238,707	215,035

19	Creditors: amounts falling due after more than one year				
	Group and Charity	Notes	2021 £	2020 £	
	Loans and overdrafts	20	369,533	416,685	

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

20 Loans and overdrafts

	2021	2020
Group and Charity	£	£
Bank loans	410,753	457,905
	<u> </u>	<u> </u>
Payable within one year	41,220	41,220
Payable after one year	369,533	416,685
	<u> </u>	<u> </u>

The bank loan is secured by a first legal charge over the freehold property known as 42 Park Road, Peterborough. The loan is repayable until 2027 with interest charged at 3.5% above base rate.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

21 Retirement benefit schemes

The Pensions Trust - The Growth Plan

SHINE participates in The Pension Trust's Growth Plan (The Plan), a multi-employer scheme which provides benefits to some 950 non-associated participating employers. The scheme is a defined benefit scheme in the UK.

It is not possible for the charity to obtain sufficient information to enable it to account for the scheme as a defined benefit scheme. Therefore it accounts for the scheme as a defined contribution scheme.

The scheme is subject to the funding legislation outlined in the Pensions Act 2004 which came into force on 30 December 2005. This, together with documents issued by the Pensions Regulator and Technical Actuarial Standards issued by the Financial Reporting Council, set out the framework for funding defined benefit occupational pension schemes in the UK.

The scheme is classified as a 'last-man standing arrangement'. Therefore the charity is potentially liable for other participating employers' obligations if those employers are unable to meet their share of the scheme deficit following withdrawal from the scheme. Participating employers are legally required to meet their share of the scheme deficit on an annuity purchase basis on withdrawal from the scheme.

A full actuarial valuation for the scheme was carried out at 30 September 2017. This actuarial valuation showed assets of £794.9m, liabilities of £926.4m and a deficit of £131.5m. To eliminate this funding shortfall, the trustees and the participating employers have agreed that additional contributions will be paid to the scheme as follows:

Deficit contributions

From 1 April 2019 to 31 January 2025:	£11,243,000 per annum (payable monthly and increasing by 3% each on 1st April)

Note that the scheme's previous valuation was carried out with an effective date of 30 September 2014. This valuation showed assets of £793.4m, liabilities of £969.9m and a deficit of £176.5m. To eliminate this funding shortfall, the Trustee has asked the participating employers to pay additional contributions to the scheme as follows:

Deficit contributions

From 1 April 2016 to 30 September 2025:	£12,945,440 per annum (payable monthly and increasing by 3% each on 1st April)

From 1 April 2016 to 30 September 2028:	£54,560 per annum (payable monthly and increasing by 3% each on 1st April)

The recovery plan contributions are allocated to each participating employer in line with their estimated share of the Series 1 and Series 2 scheme liabilities.

Where the scheme is in deficit and where the charity has agreed to a deficit funding arrangement the company recognises a liability for this obligation. The amount recognised is the net present value of the deficit reduction contributions payable under the agreement that relates to the deficit. The present value is calculated using the discount rate detailed in these disclosures. The unwinding of the discount rate is recognised as a finance cost.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

21 Retirement benefit schemes

(Continued)

Present values of provision

	31 March 2021	31 March 2020	31 March 2019
Present value of provision	293,838	348,159	422,347

An amount of £74,358 (2020 - £72,192) is included within short term creditors and £219,480 (2020 - £275,967) in long term liabilities.

Reconciliation of opening and closing provisions

	Period Ending 31 March 2021	Period Ending 31 March 2020
Provision at start of period	348,159	422,347
Unwinding of the discount factor (interest expense)	7,822	5,344
Deficit contribution paid	(72,192)	(70,090)
Remeasurements - impact of any change in assumptions	10,049	(9,442)
Provision at end of period	293,838	348,159

Income and expenditure impact

	Period Ending 31 March 2021	Period Ending 31 March 2020
Interest expense	7,822	5,344
Remeasurements - impact of any change in assumptions	10,049	(9,442)
Costs recognised in income and expenditure account	17,871	(4,098)

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

21 Retirement benefit schemes

(Continued)

Assumptions

	31 March 2021 % per annum	31 March 2020 % per annum	31 March 2019 % per annum
Rate of discount	0.66	2.53	1.39

The discount rates shown above are the equivalent single discount rates which, when used to discount the future recovery plan contributions due, would give the same results as using a full AA corporate bond yield curve to discount the same recovery plan contributions.

The following schedule details the deficit contributions agreed between the company and the scheme at each year end period:

Deficit contributions schedule

Year ending	31 March 2021	31 March 2020	31 March 2019
Year 1	74,358	72,192	70,090
Year 2	76,589	74,358	72,192
Year 3	78,887	76,589	74,358
Year 4	67,711	78,887	76,589
Year 5	-	67,711	78,887
Year 6	-	-	67,711

The charity must recognise a liability measured as the present value of the contributions payable that arise from the deficit recovery agreement and the resulting expense in the income and expenditure account i.e. the unwinding of the discount rate as a finance cost in the period in which it arises.

It is these contributions that have been used to derive the charity's balance sheet liability.

The Plan is closed to new entrants and there were no active members of the scheme during the year.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

22 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

Group and Charity	Balance at 1 April 2019 £	Income £	Expenditure £	Balance at 1 April 2020 £	Income £	Expenditure £	Transfers £	Balance at 31 March 2021 £
Welsh Assembly Government – early intervention work in Wales	-	56,183	(56,183)	-	-	-	-	-
National Lottery Community fund Northern Ireland Little Stars	19,658	84,125	(90,953)	12,830	108,338	(92,791)	3,034	31,411
International Projects – developing a continence clinic in Nigeria	4,533	-	(502)	4,031	-	(3,769)	-	262
Merchant Taylors' Company Grant - supporting our work in the London	7,000	7,000	(14,000)	-	-	-	-	-
29th May 1961 Charity – supporting our work in Birmingham	7,500	-	(7,500)	-	-	-	-	-
Welfare Grants	-	6,183	(6,183)	-	16,431	(16,431)	-	-
Support Groups	-	1,200	(175)	1,025	-	-	-	1,025
Buchanan & Henry Allen – supporting our work in the North of England	24,500	-	(14,460)	10,040	-	(2,468)	-	7,572
Margaret Giffen Charitable Trust - supporting our work in Northampton	15,000	15,000	(15,000)	15,000	-	(10,065)	-	4,935
Carried forward to next page	78,191	169,691	204,956	42,926	124,769	125,524	3,034	45,205

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

22 Restricted funds

(Continued)

Group and Charity	Balance at 1 April 2019 £	Income £	Expenditure £	Balance at 1 April 2020 £	Income £	Expenditure £	Transfers £	Balance at 31 March 2021 £
Brought forward from previous page	78,191	169,691	204,956	42,926	124,769	125,524	3,034	45,205
National Lottery Community Fund – Early intervention programme across England	-	106,370	(42,407)	63,963	224,948	(232,426)	34,878	91,363
The Thomas Cook Children's Charity – Early intervention programme across England	-	27,805	(27,805)	-	-	-	-	-
National Lottery Community Fund - Shine voices	-	9,975	-	9,975	-	(9,975)	-	-
Coop Grant	-	3,333	(716)	2,617	-	-	-	2,617
Wales Council for Voluntary Action - Volunteer and shine	-	19,998	(19,377)	621	-	(621)	-	-
National Lottery Community fund: Cymru Health hub	-	-	-	-	9,830	(4,915)	-	4,915
National Lottery Community fund: Cymru Shining lights	-	-	-	-	89,588	(90,014)	14,640	14,214
National Lottery community fund COVID19 emergency response	-	-	-	-	100,000	(100,000)	-	-
Other Trusts	-	8,500	(8,500)	-	-	-	-	-
	<u>78,191</u>	<u>345,672</u>	<u>(303,761)</u>	<u>120,102</u>	<u>549,135</u>	<u>(563,475)</u>	<u>52,552</u>	<u>158,314</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

23 Designated funds

The income funds of the charity include the following designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes:

Group	Balance at 1 April 2019 £	Net movement £	Balance at 1 April 2020 £	Net movement £	Balance at 31 March 2021 £
Interest in land and property and other fixed assets	374,814	17,015	391,829	20,579	412,408
Florence Bartle fund	-	-	-	114,121	114,121
HR fund	-	-	-	45,175	45,175
	<u>374,814</u>	<u>17,015</u>	<u>391,829</u>	<u>179,875</u>	<u>571,704</u>
Charity					
Interest in land and property and other fixed assets	370,089	17,184	387,273	22,671	409,944
Florence Bartle fund	-	-	-	114,121	114,121
HR fund	-	-	-	45,175	45,175
	<u>370,089</u>	<u>17,184</u>	<u>387,273</u>	<u>181,967</u>	<u>569,240</u>

The designated fund comprises

- the group and charity's interest in land and property and other fixed assets, net of the outstanding mortgage.
- the Florence Bartle fund which is part of a legacy that is to be spent on the relief of Spina Bifida in Cornwall and the South West.
- the HR fund that is for future restructuring and other staff related costs.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

24 Analysis of net assets between funds

	Unrestricted funds 2021 £	Designated funds 2021 £	Restricted funds 2021 £	Total Unrestricted funds 2021 £	Designated funds 2020 £	Restricted funds 2020 £	Total 2020 £
Group							
Fund balances at 31 March 2021 are represented by:							
Tangible assets	-	823,163	-	823,163	-	849,734	849,734
Investments	341,378	-	-	341,378	259,451	-	259,451
Current assets/(liabilities)	498,795	118,074	158,314	775,183	348,566	(41,220)	427,448
Long term liabilities	-	(369,533)	-	(369,533)	-	(416,685)	(416,685)
Provisions and pensions	(219,480)	-	-	(219,480)	(275,967)	-	(275,967)
	<u>620,693</u>	<u>571,704</u>	<u>158,314</u>	<u>1,350,711</u>	<u>332,050</u>	<u>120,102</u>	<u>843,981</u>
Charity							
Fund balances at 31 March 2021 are represented by:							
Tangible assets	-	820,699	-	820,699	-	845,178	845,178
Investments	341,381	-	-	341,381	259,454	-	259,454
Current assets/(liabilities)	478,272	118,074	158,314	754,660	330,135	(41,220)	409,017
Long term liabilities	-	(369,533)	-	(369,533)	-	(416,685)	(416,685)
Provisions and pensions	(219,480)	-	-	(219,480)	(275,967)	-	(275,967)
	<u>600,173</u>	<u>569,240</u>	<u>158,314</u>	<u>1,327,727</u>	<u>313,622</u>	<u>120,102</u>	<u>820,997</u>

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

25 Operating lease commitments

Group and Charity

At the reporting end date the charity had outstanding commitments for future minimum lease payments under non-cancellable operating leases, which fall due as follows:

	2021 £	2020 £
Within one year	5,460	5,200
Between two and five years	20,475	-
	<u>25,935</u>	<u>5,200</u>

26 Related party transactions

Remuneration of key management personnel

The remuneration of key management personnel, who on a full time equivalent basis are the 3.8 (2020 - 3.6) members of the senior management team, is as follows.

	2021 £	2020 £
Aggregate compensation including pension contributions	<u>250,904</u>	<u>248,963</u>

Transactions with related parties

Owing to the nature of the charity's operations, some of the Trustees may themselves, or may have family members that access services from the charity. Consequently there will be transactions between those Trustees or their family members. These are on the same basis as other service users of the charity.

27 Control

No one individual has overall control of the charity.

SPINA BIFIDA, HYDROCEPHALUS, INFORMATION, NETWORKING, EQUALITY - SHINE

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

28	Cash generated from operations	2021 £	2020 £
	Surplus for the year	506,730	113,259
	Adjustments for:		
	Investment income recognised in statement of financial activities	(6,992)	(10,308)
	Investment management fees recognised in statement of financial activities	4,174	3,834
	Gain on disposal of investments	(5,875)	(8,522)
	Fair value gains and losses on investments	(75,285)	53,081
	Depreciation and impairment of tangible fixed assets	28,917	31,287
	Movements in working capital:		
	(Increase) in debtors	(82,202)	(80,710)
	Increase/(decrease) in creditors	15,080	(42,284)
	Increase/(decrease) in pension liability	(56,487)	(75,992)
	Cash generated from/(absorbed by) operations	328,060	(16,355)

29	Analysis of changes in net funds/(debt) Group	At 1 April 2020 £	Cash flows £	At 31 March 2021 £
	Cash at bank and in hand	369,984	280,616	650,600
	Loans falling due within one year	(41,220)	-	(41,220)
	Loans falling due after more than one year	(416,685)	47,152	(369,533)
		(87,921)	327,768	239,847
	Charity			
	Cash at bank and in hand	353,678	283,607	637,285
	Loans falling due within one year	(41,220)	-	(41,220)
	Loans falling due after more than one year	(416,685)	47,152	(369,533)
		(104,227)	330,759	226,532





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Shine

Spina bifida • Hydrocephalus
Information • Networking • Equality