

Engage, Enable, Empower... The Next Steps

Supporting people affected by
Spina Bifida and Hydrocephalus



Shine's Corporate Plan 2022-2027

England, Wales and Northern Ireland

Registered Charity No. 249338



Shine

Spina bifida • Hydrocephalus
Information • Networking • Equality



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Foreword from HRH The Duchess of Gloucester, Shine's Royal Patron

Shine is a unique charity working to support people whose lives have been affected by neural tube defects such as Spina Bifida or Anencephaly, or by Hydrocephalus.

It is testament to Shine's ethos that the charity works throughout England, Wales and Northern Ireland to support individuals and families from birth - and for the rest of their lives.

As Patron since July 1973, I have witnessed the difference Shine has made in educating professionals, raising greater awareness of the impact and challenges of these conditions and encouraging improvements in prevention, treatment and services; I am proud of Shine's ambitious goals to improve the lives of all affected by the conditions.

Whether you are someone whose life has been affected by the conditions, a willing volunteer, a professional, a fundraiser or donor, there is a part for us all to play. Together we can continue to help Shine engage, enable and empower all of those living with these conditions, now and into the future.





Introduction

As conditions without cure, the challenges for those living with Spina Bifida or Hydrocephalus are lifelong – from providing the best start during the early years, to organising education, living independently and planning for later life.

Shine will not rest until everyone living with Spina Bifida and Hydrocephalus can lead a life of their choosing – a life of possibility and of opportunity, but to do so people need expert advice and support and the strong campaigning voice that Shine provides – from pre-birth onwards and whenever we are needed.

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

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

Shine's Corporate Plan Engage, Enable, Empower...the next steps

This new corporate plan provides a structured 5-year pathway to build on our successes of the past, and to continually engage, enable and empower individuals with Spina Bifida and/or Hydrocephalus, their families, and the wider Shine community across the many facets of their lives:

Health and well-being

Social interactions and relationships

Developing confidence

Educational involvement and attainment

Lifelong learning and development opportunities, including higher or further education

Transition to adulthood

Access to employment and career options

Living independently

Opportunity for choice

Self-advocacy

Ageing

Contact with professionals





The conditions we represent...

Spina Bifida

Open Spina Bifida

Myelomeningocele • Meningocele • Myeloschisis

Closed spinal dysraphisms

Lipomyelomeningocele • Diastematomyelia

Spina Bifida Occulta

Chiari II

Tethered cord

Anencephaly

Encephalocele

Hydrocephalus

Normal Pressure Hydrocephalus

Idiopathic intracranial hypertension (IIH)

Dandy Walker

Any other condition which requires a shunt

The Shine community

Our work focuses primarily on enabling and empowering babies, children and adults living with the conditions, and their parents/carers, and supporting those who may have lost a baby or child to the conditions.

However, the Shine community reaches far wider, offering support and advice to women and their partners preparing for pregnancy, siblings and other family members, and raising awareness amongst professionals from the Health, Social Care, Education sectors and many other services.





Shine's vision

A society where all those whose lives are affected by Spina Bifida and/or Hydrocephalus, and related 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 Spina Bifida and/or Hydrocephalus, and associated conditions

Strategic goals

1

Enabling babies and children with Spina Bifida and/or Hydrocephalus to achieve their potential

2

Empowering young people with Spina Bifida and/or Hydrocephalus through knowledge, confidence and skills to manage their conditions and thrive

3

Adults with Spina Bifida and/or Hydrocephalus have the choices and opportunities to live healthy and independent lives

4

A connected community

5

Preventing Spina Bifida and Anencephaly

6

Changing experiences of pregnancies affected by neural tube defects

7

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

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

♥ Work to **achieve excellence**

♥ **Challenge** the ways in which society disables our members

♥ Welcome **challenge and review**

♥ Use resources **ethically, thoughtfully and responsibly**





STRATEGIC GOAL 1

Enabling babies and children with Spina Bifida and/or Hydrocephalus to achieve their potential

Each baby or child is different, and there is a huge variation in ways that babies and children are affected by their conditions. Parents often feel anxious or daunted, and sometimes overwhelmed, after the birth of their baby, or at different stages of their child's early years. So much is new to them. So much is still unknown. There are always so many questions and sometimes not enough answers. They wonder what the future holds, and whether their child will grow up to be an independent and successful individual in their own right.

Parents need support and information to understand what Spina Bifida and/or Hydrocephalus are, and the additional complications and associated issues the conditions can bring and what that means for their little one in the first years of their life, but also for their future.

However, our experience tells us that it is not just the parents who need to understand. The earlier that babies and children themselves start to develop awareness and knowledge of their conditions, the easier it may be to encourage them to start learning aspects of their care as they grow.

Shine's 'Little Stars' programme provides the foundations for lifelong learning, behaviour, and improving health, social and emotional outcomes for babies and children with Spina Bifida or Hydrocephalus. It also helps parents/carers and other family members to develop insight and greater confidence in understanding their child's needs to better manage the condition(s) and the impact on day-to-day life, celebrating every achievement along the way!

▶▶▶ OBJECTIVES

Babies and children:

- Understand their conditions and learn about self-care to develop autonomy from an early age and are encouraged to develop through movement and play
- Meet new people and enjoy social interactions and relationships with their peer groups, family and friends
- Are offered an inclusive educational experience which facilitates full access to the right school and support, the full curriculum and activities

Parents/Carers

- Understand and can talk with confidence about the conditions to their children
- Have access to the necessary support so that they and their children can thrive in an environment where they are financially, physically, and emotionally secure
- Have support and information to guide them in meeting their child's educational choices and needs

STRATEGIC GOAL 2

Empowering young people with Spina Bifida and/or Hydrocephalus through knowledge, confidence and skills to manage their conditions and thrive

Teenage years can be difficult for young people. For a young person with Spina Bifida or Hydrocephalus, it can be even more so. They have all the challenges that everyone else faces (for example, puberty; learning about friendships and relationships; peer pressure; mental health issues; school and transition) but these challenges are often compounded by their disabilities. Living with a disability can bring increased isolation, poor health, reduced mobility, physical and learning barriers, and discrimination.

From our work with young people, we know how important it is to give them access to the tools, resources and support networks they want (and need) to develop confidence in taking the steps to realise their ambitions for the future. They also need to learn the skills and knowledge for improved condition-management, preventative health routines and self-advocacy. Providing parents with access to information and increasing their understanding of the conditions plays a big part too.

Shine's plan for the next 5 years is to raise the profile of the difference our services and support can make, and to work with the young people and their parents to develop and deliver the initiatives and resources that will help them thrive through their teenage years and beyond.



▶▶▶ OBJECTIVES

Young people:

- Understand and manage their conditions, know their rights and responsibilities and can self-advocate to access the appropriate treatment, equipment and services.
- Will successfully transition from children to adult services and develop into adults who are physically and emotionally thriving.
- Communicate effectively, and enjoy social interactions and positive, secure relationships with their peers, family and friends
- Actively participate in their education, have career goals and work towards attaining qualifications which underpin their aspirations. They believe in life's opportunities and have support plans in place to meet their life's goals.

Parents/carers:

- Are supported to develop the confidence and knowledge to empower their children through their teenage years and help them successfully transition into self-advocating, independent adults who understand their conditions and have the knowledge to make their own choices.
- Are offered emotional support and understanding at challenging times in life and are signposted to bespoke external support services where applicable

STRATEGIC GOAL 3

Adults with Spina Bifida and/or Hydrocephalus have the choices and opportunities to live healthy and independent lives



Shine has almost 9,000 members over the age of 18, living in cities, towns and rural communities across England, Wales and Northern Ireland.

Whilst all face the challenges of living with disability, Shine's work and intervention with our adult members is wide-ranging and differs from person to person.

Some individuals living with Spina Bifida and/or Hydrocephalus 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.

Through unique insight and close connections with our members, Shine is able to better support adults living with Spina Bifida and/or Hydrocephalus individually and collectively by providing targeted interventions to minimise the impact of ageing on health and quality of life, and to improve their well-being and have greater choices and opportunities to live independently and realise their ambitions.

▶▶▶ OBJECTIVES

Adults

- Understand their physical and mental health and well-being needs, and are equipped with age-specific knowledge, information, and support to enable more preventative approaches to condition management
- Know their rights, and can self-advocate for timely access to the statutory health and care services they need to stay well
- Choose the living arrangements to suit their personal needs, with appropriate support and equipment if required
- Have financial independence, or are supported to access appropriate benefits and other financial services
- Have the confidence and skills to establish healthy, enjoyable and enduring social interactions and relationships.
- Access learning and career opportunities, and are supported to gain qualifications, and sustainable employment.

Parents/Carers

- Have access to financial and emotional support and are assisted to develop the confidence, knowledge and skills to enable the person living with Spina Bifida and/or Hydrocephalus to make their own life choices, follow their own interests, be more independent and enjoy their own lives

STRATEGIC GOAL 4

A connected community

Experiences of living with the condition(s) can be different for everyone. However, many will face barriers and challenges in their day-to-day lives that often only others whose lives are affected by the condition(s) will understand.

Working to better connect our community - across ages, across conditions, across cultures and across geographical locations - will enable our members, parents/ carers, families and friends to link with one another, share experiences and foster friendships. Together, we will be a supportive and powerful community in tackling common issues and influencing services, be they the services provided by Shine, or those of statutory providers at local, regional, and national levels.

Greater membership engagement will also continually shape and develop our work, and improve our services, reach and impact.



▶▶▶ OBJECTIVES

Shine

- Provides diverse and inclusive opportunities for members to participate in our member-led approaches to co-producing the very services and solutions that will empower and enable them.
- Develops accessible, best quality information through our website, literature, and e-communications and promotes the peer support networks, online support and social groups and programme of events available to members to help inform and connect them.
- Promotes volunteering opportunities for Shine's members and supporters

STRATEGIC GOAL 5

Preventing Spina Bifida and Anencephaly

Whilst the causes of Spina Bifida are still not known, there is very clear evidence to suggest that increasing folate levels in a mother's diet prior to and during early pregnancy can help to reduce the chances of a pregnancy being affected by a neural tube defect such as Spina Bifida or Anencephaly.

Taking folic acid supplements before and during early pregnancy will help. Fortification of flour, used in white bread and other baked products, provides a wider reach to all groups of the population, and has been proven to reduce the number of neural tube defects in over 80 countries across the world. The UK Government announced its intention to introduce mandatory fortification of flour in September 2021. It has yet to be implemented.

▶▶▶ OBJECTIVES

- Mandatory fortification of flour with folic acid is implemented
- More women of child-bearing age are aware of the importance of taking folic acid before and during early pregnancy





STRATEGIC GOAL 6

Changing experiences of pregnancies affected by neural tube defects

Shine estimates that over 1200 pregnancies are affected by neural tube defects in England, Wales and Northern Ireland each year, and so, in addition to driving the agenda on folic acid, we will develop a wider support and information service for parents-to-be, to help them in preparing for pregnancy through offering information, advice and guidance.

Over our many years of experience and research, parents-to-be who have received an antenatal diagnosis of Spina Bifida or Anencephaly tell us that there is often a lack of information, compassion and sensitivity from health professionals who are delivering the news.

Those who have had a pregnancy affected by a neural tube defect want support and guidance to help them prepare for future pregnancies and reduce the chances of another NTD-pregnancy, but there is limited knowledge and understanding within NHS services to provide this.

It is not just those who have had a pregnancy affected by an NTD who have experienced this. Many of our members with the conditions have too, as so often their desire to explore the possibilities of parenthood are dismissed by others, and so they turn to Shine for expert advice on preparing for pregnancy and becoming parents.

▶▶▶ OBJECTIVES

- Parents-to-be, both those with Spina Bifida, and those without are more informed and emotionally supported before and during pregnancy through Shine's pregnancy advice service, including being offered information and advice on all of the applicable pre- and post-natal pathways available to them at point of diagnosis (including pre-natal surgery) and referral to other appropriate agencies if required
- Parents who have a diagnosis of, or have lost a baby to, Anencephaly, have access to expert, confidential and on-going support, are referred to appropriate external agencies for additional support and are supported to prepare for future pregnancies
- Professionals have increased awareness, information and understanding of the conditions, and can deliver unexpected news with greater kindness and compassion
- Professionals have a greater awareness of neural tube defects and the steps that can be taken to reduce pregnancies being affected by NTDs
- Professionals have closer links and greater collaboration across the NHS, and with Shine, to ensure optimum outcomes for babies and families are achieved through pre-natal or post-natal treatment

STRATEGIC GOAL 7

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

There are many stakeholders in the world of Spina Bifida and/or Hydrocephalus. Some have expert knowledge and understanding of the condition(s) and the challenges our members sometime face. Others do not. Many make policies and decisions on statutory services provision which impacts our members' lives. Others provide services to facilitate and support those living with disabilities.

Through greater reach and engagement with individuals and organisations, Shine will work with our membership to improve professional understanding of the conditions and influence the services that people with Spina Bifida and/or Hydrocephalus (and associated conditions) need and want.



▶▶▶ OBJECTIVES

Shine

- Engages widely with individual professionals, organisations and representative bodies at local, regional and national levels to raise awareness of the conditions and the needs of the people we work with
- Builds effective links to influence and improve members' access to the right statutory services at the right time, engaging with new and emerging approaches to integrated health and social care across England, Wales and Northern Ireland
- Provides access to an enhanced service offer through Shine's partnerships with others (e.g., Shine Health Direct, Shine's Legal Service)
- Contributes to, and supports relevant national and international research that relates directly to the conditions and/or our members and facilitates member contribution to a wide range of external research projects through promotion of Patient Participation Involvement (PPI) opportunities
- Works in partnership with other charities and organisations, nationally and internationally, to improve the lives of people living with Spina Bifida and/or Hydrocephalus in the UK and different parts of the world and forges supportive relationships with key disability partnership groups to campaign collaboratively in the UK if change is needed.

DELIVERING OUR PLAN

The above strategic goals will be underpinned by internal enablers which will have objectives and development plans in place to ensure that we are managing our infrastructure, supporting our staff, delivering annual plans, and are prepared for the future.

Governance

To have an effective and diverse Board of Trustees, which is committed to continuous improvement, transparency, accountability and compliance.

And

To act in the charity's best interests in leading Shine towards achieving our overarching purpose and aims.

And

To ensure that Shine's commitment to equality and diversity, and to safeguarding our members, staff and volunteers is integral in everything we do.

People

To develop and deliver a HR strategy which meets Shine's short and long-term business needs, and creates and maintains an environment to support, motivate and develop a skilled and diverse workforce of employees and volunteers, making Shine an employer of choice.

Financial management

To continually assess Shine's financial needs and the resources required to support and meet our objectives, as well as plan for continued growth to enable business success and sustainability.

Income Generation

To maintain and continually improve a well-planned, robust income generation strategy across multiple funding streams to enable delivery of Shine's annual work plans and ambition for growth.

IT and Systems

To identify and invest in the systems and technology to improve effectiveness and efficiency, and communication, in our day-to-day work, and our long-term plans

And

To improve the quality of member, volunteer and supporter data to enable better and simplified processes for engagement, provision of statistical information and evidence to support funding applications, demonstrate impact of the work we do and meet funders' requirements.

Marketing and Communications

To provide excellent internal and external communications and marketing messaging which is cutting edge and accessible in its delivery and reaches desired audiences using the communication methods most important to them.

Workplace Management

To create an effective working environment to enable staff to work effectively in safe, well-managed and compliant workspaces.

Services Administration

To deliver high quality, effective and responsive customer and administration services.



Making a greater impact together...

Donate... every donation to Shine has the potential for profound impact. Your gift will enable us to continue to provide vital early intervention, support groups, training events, information, reassurance and much more...

Fundraise... from marathons to quizzes, baking to skydiving, there are so many ways to have fun, use your talent and fundraise for Shine. The experience you've been dreaming of could help to change someone's life - and yours!

Leave a legacy... by remembering Shine in your will, your wishes now can make a difference way into the future and help us to plan new services with confidence.

Work with us...

Get involved in our campaigns...

by working together we can change the world around us to improve access and equality for people with Spina Bifida and Hydrocephalus. The more we work together the greater our voice will be.

Work in partnership with us... whether sharing your services, expertise, resources or influence, the involvement of businesses and organisations is a growing and exciting area for Shine.

It's corporate social responsibility that keeps on giving.

Get Involved...

Work for us... ever thought of joining our professional team? We promote new vacancies on our website and social media so if you have the skills, experience and initiative we are looking for, please get in touch!

Volunteer... whether helping with events, fundraising, advocacy or admin, volunteering is a great way to use your skills, and learn new ones, to make a difference. We are developing our volunteering programme, so if you want to know more please get in touch.

Join us...

Access specialist support and advice today by becoming a Shine member.

Membership is free!

**Find out more at www.shinecharity.org.uk
or call 01733 555988**

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