



Brain & Spine
Foundation

The Brain & Spine Foundation Annual Accounts and Trustees Report 1 April 2022 – 31 March 2023

Registered Charity no. 1098528. Registered Company no. 04432677

The Brain and Spine Foundation

Report of the trustees

For the year ended 31 March 2023

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Letter from our Chair

In our 30th Anniversary year, I am very pleased to report that the Brain & Spine Foundation continues to deliver much needed support to our community of people affected by a neurological condition across the UK in more effective and impactful ways than ever before. This in a period when the demand for services is at an all-time high and the need is so great.

Our strategy of investing in developing and expanding our professional services has been well received by our service users and recognised by our supporters – the growth of our peer-to-peer groups, the enhanced emotional support and guidance from our nurse led Helpline and the distribution of accessible health information helps to build knowledge and confidence for our service users and also reduces their sense of anxiety and isolation.

Our innovative programmes related to building community (Neuro Changemakers) and social research (NeuroLifeNow) gather real-world insights from people affected and allows us to not only refine our own services but also influence the improvement of treatment, care and support in the wider community.

I am very aware that none of this would be possible without the generosity of our supporters, the engagement of our community, and the energy, passion and talent of our team of professionals, staff and volunteers. Thank you to each and every one.

I am excited by the establishment of our new Development Board, launched at an event held at Downing Street in March. The Development Board has been tasked with accelerating the strategic goals of the Brain & Spine Foundation, including the creation of an Institute of Neuro Life Science that will drive data-informed improvements to services and care for people affected and to undertake long-term medical research related to pan-neurological challenges. It will also be instrumental in raising awareness for the need to improve care for those who are affected by neurological conditions and delivering new sources of funding to support our objectives. We look forward to the coming year and beyond, working with this highly experienced and committed group under our new campaign brand, Neuro UK.

Mark Luce

Mark Luce

Chair of Trustees

Our charity in 2022/23

Why we are needed

According to the recently published My Neuro Survey¹, 1-in-6 people in the United Kingdom are affected by a neurological or neurodegenerative condition.

This includes dementia, stroke, motor neurone disease, neuromuscular diseases, brain cancers, Parkinson's, multiple sclerosis, and epilepsy to name just a few of the most prevalent diseases. There are over 600 known neurological conditions, including the very rare – and more may be identified post-pandemic and with the emergence of Long Covid. The Brain & Spine Foundation exists to support anyone affected by these neurological conditions.

A neurological problem can impact every aspect of a person's life, including their physical, mental, and social wellbeing. Friends and family can also be affected, and some may need to provide full-time support as a carer.

Altogether, there is a community of over 11 million people who have experienced or are living with a neurological condition that may have life-changing, and often life-long effects – and every year a further 600,000 people are newly diagnosed.

Despite some regional centres of excellence, the stark reality for anyone affected by a neurological problem is that services are scarce, limited in scope, and fragmented – and significantly under-resourced compared to other major health conditions, like cancer and heart disease.

The Association of British Neurologists and others, estimate that the disruption caused to the delivery of neurological support services by COVID-19 and under-investment in NHS resources during 2022 has increased the number of people waiting to see a specialist neurologist from 35,000 to over 200,000 in the UK. A further 60,000 are waiting for neurosurgery. With fewer than 1,000 specialist consultants in England, this backlog will take many years to clear.

Meanwhile, the health and wellbeing of our community is getting worse, and so is their access to and experience of health and social care.

In this increasingly diverse, complicated, and complex landscape, there is an ever-growing need and demand for support, and accessible information: from individuals, their families, friends, and carers and the healthcare professionals who look after them.

¹ Neurological Alliance (2022), *Together for the 1 in 6: UK findings from My Neuro Survey*. Available at: <https://www.neural.org.uk/publication/together-for-the-1-in-6-uk-findings-from-my-neuro-survey/>

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What we do

As an independent health charity, the Brain & Spine Foundation plays several crucial and influential roles in supporting the health and wellbeing of people affected by a neurological problem living within the United Kingdom.

Founded in 1992, we draw from over 30 years of experience and accumulated expertise to deliver person-centred support, accessible information, and research directly to those who need it; and we continue to listen to and learn from our community, allowing us to identify and respond to their unmet needs and ensure that our work remains relevant.

We are there for someone at any stage of their journey; from when symptoms first appear, throughout their wait to see specialists or receive a diagnosis, and in the long-term when there can often be a lack of specialist or community care available to support their chronic conditions or long-term effects.

We are also pan-neuro and for many people, the support and information they find through our services simply does not exist anywhere else.

We help to bridge the gaps between different parts of the health and social care systems, and we work to ensure that those who need to are able to interact with these systems effectively and efficiently. This work makes a real difference; it gives immediate help and on-going support to individuals and relieves pressure on the NHS. This was especially valuable at a time of national emergency during the COVID-19 pandemic and continues to be equally important during the aftermath.

We also work with our community to drive long-term, meaningful change.

Together, we raise awareness of the challenges faced by people affected by a neurological condition and co-create opportunities and solutions that enable more and more people to improve their own lives and the lives of others.

Through gathering and reporting on people's real-world experiences, we deliver evidence of the unwarranted variations in people's access to and experience of care across the UK – and we engage with key stakeholders to ensure these research insights can influence the design and delivery of healthcare services going forward.

Our strategy in 2022-23

Our vision

A society where people affected by a neurological condition are recognised, respected, and can flourish.

Our mission

Transform the daily reality of each person affected by any neurological condition, anywhere in the UK; through frontline professional services, innovative social research, and bold campaigning for change.

Our purpose

As a changemaker organisation, to build, enable, and support a vibrant, resilient community of people who are focused on driving the changes that they want to see.

Our aims

Through our distinct programmatic structure and a holistic, person-centred approach, we aim for change on four different levels: **Individual**, **Community**, **System**, and **Society**.

Level	Organisational aim
Change at the individual level	Supporting people to manage and make decisions about their own health and wellbeing
Change at the community level	Building and supporting resilient communities of people with meaningful and valued roles
Change at the system level	Transforming the Health and Social Care systems , and public policy
Change at the societal level	Greater empathy, awareness, and understanding in wider society

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Our programmes

We are a person-centred, changemaker organisation – this means our community and the people who use our services are at the centre of everything we do.

As an organisation, we currently run three core programmes:

- Neuro Changemakers
- Professional Neuro Services
- NeuroLifeNow

To deliver these programmes we work in partnership with our community to co-produce effective, sustainable solutions and achieve long-lasting, positive change. We recognise and respect that everyone is an individual and that people's preferences, needs, and values should guide what we do and how we respond to them.

In March 2023, the Brain & Spine Foundation established a Development Board to support our strategic goals, and to accelerate our ambition to establish an Institute of Neuro Life Science with leading academic partners. To achieve this, we launched our initiative under a new campaign brand, Neuro UK. This will become our fourth core programme in 2023 and beyond. The Development Board is comprised of highly experienced individuals from the world of Health, Business, Media, Sport and Entertainment.

Neuro Changemakers

A programme of activities and campaigns focused on building and engaging a community of people (changemakers) who are supported to prioritise their wellbeing and drive change for people affected by a neurological condition.

Professional Neuro Services

Our helpline, health information, and peer support services provide safe and trusted spaces in which people can access expertise, information, and support delivered by experienced professionals and trained volunteers.

NeuroLifeNow

Developed in collaboration with the Neurological Alliance, our NeuroLifeNow programme combines social research and a digital engagement platform to enable our community to contribute to representative data and insight which highlights their lived experience.

Neuro UK

A new campaign and appeal to support the establishment of an Institute of Neuro Life Science at a leading academic institution.

The campaign will seek to harness & unify the voices of those living with a neurological condition in the UK – making it heard alongside other public health priorities such as cancer and heart disease.

The campaign will point towards our unique solution – to establish and support the Institute of Neuro Life Science.

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The new Institute will identify opportunities for improvements in neuro care, services and support using unchallengeable real world health economic data and peoples' lived experience – provided in part by our Neuro Life Now programme.

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Our approach

Across our programmes, we have adopted a holistic approach to improving people's wellbeing and are actioning this through three key activations:

- Self-care and community
- Support and information
- Research and influence

Our approach recognises that alongside supporting people to manage and improve their physical and mental health, we need to create spaces and opportunities which allow people to:

- Belong to a community.
- Feel a sense of value and purpose, and
- Make positive changes for themselves and others.

More widely, we also need to drive changes that make people feel part of a society that validates and respects their identities and lived experiences; and where the systems and services they rely on are designed to meet everyone's needs.

Self-care and community

We want people to be able to change their day-to-day lives and to be part of a caring, resilient community that is bringing about the changes they want to see.

Through our **Neuro Changemakers** programme and our **Professional Neuro Services** we are bringing people together and creating spaces that champion and encourage self-care, nurture, and facilitate social connections, and provide people with inspiration and opportunities to make a difference.

Support and information

We believe everyone affected by a neurological condition, including family, carers, and friends, should be supported to understand their condition and symptoms, make informed decisions about their care, and better manage their own health and wellbeing.

Through our **Professional Neuro Services**, we are providing access to a range of personalised, person-centred support and independent, evidence-based information.

Research and influence

We must grow the public understanding of neurological conditions and ensure that the design and delivery of public policy and services meets the needs of our community.

Through our **NeuroLifeNow** programme we are creating and contributing to representative data and insight that captures the lived experience of our community and provides a platform for their voices.

Our work in 2022-23

In the face of unprecedented challenges, we are proud of what we have achieved in 2022-23 through working with and alongside our community, whose strength, resilience, and determination continue to be our inspiration.

Throughout 2022-23 we continued to deliver:

- Our free, professional Helpline, now open Monday – Friday, focusing on the quality of engagement with all our callers, supporting them in the here-and-now and for the journey ahead
- Our independent health information made available, free-of-charge, in printed formats and online via our website
- Our popular Neuro Social, Neuro Carers, and Neuro Creatives online peer-support groups
- Our community building campaign, Neuro Changemakers
- Our innovative social research programme and digital engagement platform, NeuroLifeNow (launched in partnership with Neurological Alliance England in 2021) which uses real-world, real-time data, and insight provided by our community, to influence improvements across the neuro landscape

We also engaged with and listened to our community for feedback and direction, and responded to their needs and insight by growing our programmes and services through:

- Co-developing new regional and national, volunteer-led Neuro Social groups in the Southeast, Midlands, and Scotland, and a new Neuro Writing group
- Recruiting additional resource to address a growing demand for emotional support and wellbeing counselling, and piloting an Enhanced Emotional Support Service

Our reach

In 2022-23 we are proud to have reached more than 600,000 people across all our services and programmes:

- 257 people registered to join a peer support group (We added 4 new groups in the year, and now run 7, including regional groups supervised by volunteers)
- 1,686 people contributed to NeuroLifeNow research (With 16 reports published based on over 4000 individual surveys in the 2 years since launch)
- 15,660 people were directly or indirectly supported by our Helpline, including family, friends, and carers
- 21,647 booklets and factsheets were posted to our community and to hospitals or downloaded from our website
- 41,293 showed their support by being part of our social media community
- 532,000 people visited our website to access professional, tailored support and health information, or to join our community through Neuro Changemakers

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Neuro Changemakers

When we launched Neuro Changemakers, we said that we believed any person affected by a neurological condition is a Neuro Changemaker, alongside everyone who gives their time and energy to drive positive change for this community.

These last two years have shown us that this is not just a statement, it is an imperative.

Following the launch of our Neuro Changemakers programme, we have witnessed people take on new challenges, find renewed purpose and motivation, and flourish within a welcoming community of care; and we have seen in people the compassion, understanding, and experience that we know is required to improve people's lives.

These experiences have emboldened our commitment to supporting each person affected by a neurological condition to feel capable of taking action to improve their own lives and the lives of others.

They have also helped us to better understand the challenges we must overcome to fulfil our ambitions for Neuro Changemakers.

Changemaking can be stressful and emotionally challenging when dealing with personal or distressing issues, and lasting and effective change can take time to bring about and may require ongoing action .

Many members of our community must also commit a significant amount of their time and energy to managing their conditions, their symptoms, and their care – and often they do this in isolation or with limited support from those around them.

Through working with our ambassadors, volunteers, and wider community we have identified two key components of taking Neuro Changemakers to the next level:

- Self-care, and
- Community

It is essential that we support people to value, maintain, and improve their wellbeing and provide them with the skills and connections they need to avoid burnout.

We began in 2022-23 by holding ourselves accountable to these ideals and improving upon our own internal processes.

Following consultation with our current ambassadors, we arranged quarterly meetings for them to share learning and discuss their experiences and created an online space for them to stay in touch and support one another outside of these group meetings.

We have invested in developing our volunteer training, supervision, and safeguarding to help people maintain healthy boundaries as they continue to provide life-changing support to others within their community.

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Alongside this internal work, we engaged with other organisations to explore how we can nurture the ideas of self-care and community in wider settings, such as the workplace. We are particularly excited to start taking this further in 2023-24 as part of our 3-year corporate partnership with Irwin Mitchell.

Across all our programmes and channels, we have continued throughout 2022-23 to celebrate and highlight the many ways in which people are making a difference or challenging the status quo, whether they achieved this through:

- Seeking support and information to make informed decisions
- Learning to better manage their own wellbeing, condition, or symptom
- Supporting and inspiring one another as part of peer support and volunteer groups, or
- Sharing their own experiences to help drive change and raise awareness of the daily reality of living with a neurological condition

Each person's efforts, whether focused on improving their own life or the lives of others, have been a vital step in moving towards a more sustainable, empowering, and inclusive culture that prioritises and values everyone's wellbeing.

Our community are at the heart of everything we do – and, together, their actions are some of the most powerful and important drivers of change.

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Professional Neuro Services

We know how crucial it is for people to be able to ask questions and connect with others as part of managing and improving their health and wellbeing – and we understand that asking for help is not always easy.

Our Professional Neuro Services offer safe and trusted spaces in which people can share their experiences and speak with others who understand. We provide people with access to expertise, information, and support delivered by experienced professionals and trained volunteers.

Neuroscience nurse-led Helpline

In 2022-23 our national Helpline run by experienced neuroscience-trained professionals responded to 2,610 enquiries, providing support and information that will have benefitted over 15,000 people directly or indirectly.

We helped people make sense of complex information and specialist medical terminology, supported them to access the right services, and enabled them to ask key questions to get the most out of their appointments and care. We allowed people the time and space they needed to express themselves and to develop a sense of trust and rapport; and by acknowledging their experiences and concerns, we were able to reassure them that these were valid.

Most importantly, however, whenever someone contacted us, we related to them as a person first and foremost - recognising that their challenges are not limited to their symptoms or condition, but also come from how these can impact a person's ability to work, their independence, their relationships, and other wider personal and socio-economic issues.

'Thank you, I don't think I know of anywhere else I could have gone for information- I searched up quite a bit on the Internet and that is where I found the brain and spine foundation so that was very useful that you have a website and that you are easily accessible. Thanks very much for your assistance'.

'Normally I'd Google for ideas / contact information and not reached out, out of embarrassment (the age of technology we live in has almost removed human interaction) but I'm glad I plucked up the courage to call, speaking to a person from Brain & Spine foundation over the phone was much more of a comfort and much more helpful than reading information on a page. I feel like I have more renewed hope in my efforts to get help and treatment'.

'I am very pleased that I contacted the Brain and Spine foundation. The neurological nurse that I spoke to was extremely helpful and gave me a way forward. It is very difficult for us as we live in Northamptonshire. I have been to the Dr several times to ask for help, but nothing has emerged. The nurse I spoke to was very reassuring and opened up many possibilities. There is a lot of difficulties in the counties finding places that deal with their particular problems. They have either closed down or don't exist. Through various means I came across the Brain and Spine Foundation. It is good to talk to someone who knows what they are talking about and to be reassuring and give me a number of options to choose from as well. Thank you very much'.

Messages of thanks from people who use our Services.

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In financial year 2021-22 we recruited a new Specialist Support and Information Nurse to increase our capacity and enable us to address a pressing need for greater emotional support and guidance on mental wellbeing. This work continued with much success in 2022-23, supporting 41 individuals in this period.

We piloted an Enhanced Emotional Support Service using an internal referral process via our Helpline. As part of this service, we have been providing up to six scheduled one-to-one sessions to people who are experiencing high levels of anxiety and who would benefit from focused support at a critical part of their journey. These series of planned sessions offer us more time to get to know someone, to understand their situation, and to explore their problems and concerns. It also provides us the opportunity to more actively work with them to find and implement solutions.

This pilot scheme was developed in direct response to requests and feedback from our community, as well as supporting Helpline data which showed that out of the 2,311 enquires responded to during 2021/22, 1,122 (48.6%) were related to mental health and mental health support, and 769 (33.2%) enquiries were related to health anxiety.

“December last year, after 13 years, I (Joanna) was finally diagnosed with Gluten Ataxia. It’s a rare autoimmune disorder. I would not be here if it wasn’t for the B&SF nurse and the support service.”

EEES Service User

Healthcare professionals and other charitable organisations continued to hold our neuroscience nurses' expertise in high regard, referring people to our services, and seeking insights into neurological conditions and community-based support.

“Thank you for the incredible work that you are doing with this group of clients – they are lucky to have someone so passionate advocating for them.”

Clinical Psychologist

We have continued to successfully build relationships and grow awareness of our services within many of the specialist neurology centres across the UK, and engaged with a broad range of healthcare professionals and the public by attending:

- UCL World Stroke Day forum in October 2022
- British Neurovascular Group conference in February 2023

This past year we also participated as an external stakeholder in Healthcare Improvement Scotland's development of a self-evaluation tool designed to complement the General Standards for Neurological Care and Support.

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Independent health information

'From being in hospital back in March 2020 the B&SF SAH booklet was fantastic for me and my family to read in the immediate aftermath of what had happened to me but also since'.

Message of thanks from people who use our Services.

During 2022-23:

- We sent out 3,800 copies of our booklets – 662 directly to members of our community and 3,128 to health and social care professionals who shared them with the people they support.
- Our booklets and fact sheets were downloaded over 17,800 times from our website for people to view and keep on their digital devices.
- Our health information pages on our website were viewed over 554,000 times in total by over 532,000 people.
- Our animations on head injury and Chiari malformation were viewed over 45,900 times.

As part of this we sent out booklets to wards and services at over 41 hospitals in the UK, including specialist neuro centres and services run by other charitable organisations such as Macmillan, Maggie's, Air Ambulance Wales, The Brain Charity, and Headway.

This year we collaborated with Boston Scientific to improve our information offering for people affected by chronic pain. The focus of this work has been on raising awareness of the different treatment and management options available and how people can get seek referral for more specialist support. We are looking to produce a new leaflet on chronic pain as well as expand our listings within our A-to-Z.

We were also delighted to connect with the London Interdisciplinary Doctoral Programme, delivered by the London Interdisciplinary Biosciences Consortium, and hosted a 3-month internship during which we gained the invaluable support and expertise of a neuroscience PhD student. As part of their internship, the intern supported us to review and develop our health information whilst also having the opportunity to engage with and learn from other teams within the organisation.

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Online peer support

Throughout 2022-23, we ran seven different weekly, bi-weekly, and monthly online peer support groups. Alongside our existing Neuro Social, Neuro Carers, and Neuro Creative groups, this included four new peer support groups established in the period:

- Three groups – Neuro Social Scotland, Neuro Social Midlands, and Neuro Social Southeast – that allow people to connect with others living in the same region or area of the UK, providing a space in which they can share local knowledge and discuss any challenges unique to where they live.
- Neuro Writing, a creative group exploring autobiographies, poetry, and creative writing to support people's wellbeing.

More than 257 people registered for one or more of our peer support groups across 2022-23 – this was a 17% increase on registrations received during 2021-22.

These groups enable members of our community to share their personal experiences of neurological conditions, forge new connections and friendships, and tackle widespread loneliness and isolation:

"I really enjoy the interaction with other people that don't judge me & can relate to me being with people who have neurological disorders and can therefore understand my problems."

Neuro Social participant

Many of our peer support groups have been co-produced with our community and are co-led or moderated by experienced volunteers (we have 8 peer support volunteers across our services now, up from 3 last year) and always with supervision and support from our Professional Neuro Services team to ensure everyone's safety and wellbeing.

Our Neuro Creatives programme is led by an experienced arts counsellor and continues to help people improve their emotional, social, and physical wellbeing. Using different art forms such as painting, drawing, and collage, these arts for wellbeing sessions have supported group members to express their emotions, reduce stress, and increase self-awareness. Being part of the group has also improved people's social connections and provided a sense of belonging and community.

Within our Neuro Social groups, 93% of participants agreed or strongly agreed that they felt part of a community and 82% of participants agreed or strongly agreed that they felt more able to communicate how they feel and what they need to others.

"I was nervous making the first contact with B&S Foundation (>6 months post hospital discharge) but needn't have worried as the nurse that answered my telephone call was fantastic and instantly put me at ease allowing me time to talk in a way I felt comfortable with. When I joined my first meeting it was a big step forward for me, feeling (guilty) that I was a survivor of a neuro condition. I was emotional during the meeting and it was a huge comfort to feel listened to and supported by the group - at that time complete strangers to me. It is the highlight of my week - I look forward to the meeting, friendly faces and voices, picking up any hints and tips and it gives me a boost (even when I've not had a good week I leave feeling much better)."

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"I so enjoy the group and get so much from it. It's so nice people understand the effort and achievement. I have won awards in my past for work and got law qualifications but out of everything my painting today brings me the most joy and is my biggest achievement because I thought I couldn't do things like this anymore and I did and I did it with joy."

Feedback from Neuro Social and Neuro Creative participants

During 2022-23 we invited nine guest speakers to join our Neuro Social and Neuro Creatives online sessions. Speakers included artists, clinical psychologists, nutritionists, and neuro-physiotherapists, and they covered a range of topics such as mindfulness, nutrition, and relationships.

We also continued to welcome members to our two, condition-specific Facebook groups that provide peer support for people living with a Chiari malformation and for survivors of subarachnoid haemorrhage (SAH). These groups connect people with shared experience of these comparatively rare conditions, offering a safe and welcoming space where they can discuss experiences, share advice, and offer mutual support. By the end of 2022-23, we had 1,969 and 2,633 members in our Facebook groups for Chiari malformation and Subarachnoid haemorrhage, respectively.

Overall membership of our social media community, including our online peer support groups for subarachnoid haemorrhage and Chiari malformation, grew to 41,293 people last year.

We are incredibly grateful to the volunteers and moderators that contribute towards our peer support groups who provide ongoing care and dedication to their community and peers.

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NeuroLifeNow

Since launching NeuroLifeNow, and as of date of this report, we have collected nearly 4,000 first-person surveys and published 16 monthly and bi-monthly reports and two annual impact reports.²

Headline findings from our community's experience during 2022-23 include:

- Nearly 2 in 3 people reported having feelings of anxiety or hopelessness.
- On average, about 1 in 5 people reported having poor or very poor healthcare experiences overall – with an increasing trend from 1 in 14 people in our January-February 2022 results, to about 1 in 3 people in our November-December 2022 results.

NeuroLifeNow also allowed participants to share their experiences in their own emotive, often stark, and powerful words. Below are some examples of the experiences shared with us over the last year:

"It is really difficult to get answers and support after diagnosis/medical treatment. I had a 6-minute phone call with my specialist 8 weeks after brain surgery. That is the only contact I have had, and I have so many questions. I had no face-to-face contact with a specialist. After being classed as having a disability, I have had no support financially after having to leave my career due to my neurological condition."

"I feel trapped in my home as I cannot afford to keep my car on the road or afford public transport but can't walk to work. I can't afford to go out. I have a hole in my roof I can't afford to repair. That's before the worries of food and energy."

"I'm not sure how to run all of my medical equipment. I'm tube fed on a pump, have breathing machines, air mattress, hospital bed, ceiling joists, through floor lift - all need electricity."

NeuroLifeNow participants

Throughout 2022-23, we have continued to share the voices of our community and advocate for them within public policy and service design. We achieved this through our collaborations with other organisations and our membership of the Neurological Alliance.

Over this past year we saw significant progress and achievements, including:

- Securing a recommitment to publish a high-level UK Government strategy for acquired brain injury (ABI) and other neurological conditions. This strategy could have been under threat, following the abolition of other long-term condition strategies e.g., cancer, dementia, and mental health. Thanks to a strong and vocal ABI and neuro community, we prevented this from happening.
- Working with NHS England on a new neurology outpatient dashboard, which sets out key metrics of care. This is the first time such a dashboard has been developed at a national level. We are working with the NHS England team to ensure the dashboard captures patient experience data.

² Available at: neurolifenow.org/hub-neuro/

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- Working with NHS England to secure the continuation of the NHS England neuroscience transformation programme to improve equity of care and access to neurology and neurosurgery services in England.
- Collaborating with charities across the sector to secure a much-needed uplift in disability benefits, as announced by Chancellor Jeremy Hunt in November 2022. This followed feedback from NeuroLifeNow participants about the impacts of the cost-of-living crisis, and to ensure financial support for the extra costs of living with a disability were paid in line with inflation. More than 10 million people in total will see their benefit payments rise from April 2023 as a result. In addition, 6 million people across the UK on eligible 'extra costs' disability benefits, Personal Independence Payment (PIP) will receive a further £150 Disability Cost of Living Payment in 2023-24. According to the latest available public data (January 2023), 412,289 people with neurological conditions were claiming PIP.
- Securing the appointment of New National Clinical Directors (NCD's) for neurology and, spinal surgery and neurosurgery, in response to substantial pressure from the Neurological Alliance, the Brain & Spine Foundation, and our other allies within the neurological sector.

Alongside publishing influential data and insights and engaging with key stakeholders, we also continued to develop and invest in NeuroLifeNow programme to ensure its relevance and sustainability going forward.

NeuroLifeNow was launched using a digital app that could capture the lived experience of our community in real-time and provide insights that could support the recovery of health and social care services during, and after, the COVID-19 pandemic.

Our ambitions for NeuroLifeNow have since grown and we have established it as a broader social research programme that continues to gather unique evidence into the ongoing daily reality of accessing and receiving neurological treatment, support, and care throughout the UK.

At the beginning of 2022-23 we took a series of decisive actions regarding NeuroLifeNow:

- We retired the first iteration of our NeuroLifeNow app at the end of March 2022
- We transitioned our data gathering activities to a new web-based platform that was launched in May 2022
- We initiated the development of a new version of the NeuroLifeNow app that would meet the needs of our community, and we sought to achieve this through a process of co-production.

These actions reflect how seriously we take the contributions our community are making through NeuroLifeNow, as well as the importance we place on listening to and working with our community when creating solutions to the problems they face.

Community feedback about the existing app highlighted several limitations with the current user experience. These limitations were affecting how people engaged with the app and, in turn, impacting their ability to contribute their voice and drive change.

The Brain and Spine Foundation

Report of the trustees

For the year ended 31 March 2023

We also recognised that we cannot ask our community to continue to wait for change considering the many powerful and meaningful insights they have given to us in their lives. As such, we have committed to developing the NeuroLifeNow app to be one that “gives back.”

Throughout 2022-23 we have been working with our community, alongside other key stakeholders, and partners, to improve the user experience and to explore relevant functionality which will ensure our users feel connected to what is important to them.

We hope to be able to provide access to further support and information through the app, as well as current and engaging content that will make a tangible difference to people’s lives in the here and now.

We would like to thank UCB, The Peter Sowerby Foundation, and the National Lottery in particular for their support of our NeuroLifeNow programme during 2022-23.

Special acknowledgment and thanks our strategic partners, the Neurological Alliance England for their tireless contribution and practical support in the second year of the programme – together with our community participants, we go from strength to strength in capturing and evidencing the value of real-world lived experience.

The Brain and Spine Foundation

Report of the trustees

For the year ended 31 March 2023

Operations

During 2022-23 we launched a revised website and following an operational audit and review of our IT and office systems in 2021-22, we have made continual and ongoing improvements to how we secure and manage our services and data.

We have also been exploring and developing integrations between our new website, our CRM, and other cloud-based platforms that will enhance the delivery of our services and deepen our community stewardship.

Monitoring and evaluation

We made significant strides during 2022-23 in reviewing and developing our approach to monitoring and evaluating our services.

Working alongside our volunteers and the people using our services, we have evolved our approaches to capturing feedback to better meet their needs and reflect the changes that have been most meaningful to them.

Diversity, equality, and inclusion

The 1-in-6 people in the UK who are affected by a neurological condition, represent a cross section of society, and some conditions disproportionately impact people from groups that are traditionally disadvantaged – for example older people and women.

To ensure that, as an organisation, we can be more relevant to the people we support, reach more people, and better deliver our public benefit, we have begun directly focussing on diversity, equality, and inclusion within our work.

In July 2022, we established a working group consisting of volunteers, community members, Trustees, and staff members, with recently appointed Trustees, Asli Gunner and Carolyn Turner agreeing to act as Co-Chairs.

During 2022-23, this group has met to discuss a Board paper prepared by former Trustee, Sarah Vibert, and have been working on terms of reference and an on-going plan of activity.

We aim to be representative and include a wide range of voices around our Board table and are pleased to have recruited two new Trustees in 2022-23 who bring their own lived experience to inform our discussions. Our Trustee Board now numbers 11.

Our people and partners in 2022-23

Our regular staff now numbers 13 people (7 full time, 6 part-time) and 2 specialist consultants who regularly contribute to our work. We are also supported by 8 volunteers who regularly lead, co-lead or moderate peer-to-peer groups, and over 50 Ambassadors and volunteers across the UK.

We enjoy a “one team” mentality with our committed Board of 11 Trustees and feel proud to have a combined team of over 30 people who contribute their expertise regularly and frequently to the benefit of our work.

We have continued to work in a hybrid manner which has allowed us to continue to minimise office costs and invest in effective remote working solutions.

As members of the Neurological Alliance in England and Scotland, we are proud to contribute to policy development and attended forums including the National Neurosciences Advisory Group (NNAG) on Mental Health and Neurology, the Development of the Rare Conditions Report and the Development of Mental Health in Neurology Report.

Marc Smith, our CEO, has been a Trustee of the Neurological Alliance (England) Board since November 2019 and was re-elected Vice Chairman in November 2022. This brings mutual benefits and facilitates a closer working relationship e.g., the Neurological Alliance has been a co-sponsor and significant collaborator in NeuroLifeNow.

With the increased external threats related to cyber security and data protection, we retained the services of an independent Data Protection and Cyber Security Officer to consult on and oversee related risk identification and mitigation.

Our fundraising and financial performance in 2022-23

The Brain & Spine Foundation operates entirely from voluntary income and the strategy is to maintain this independence. We aim to generate income from multiple channels, including Individual Giving, Legacies, Trusts and Foundations, Major Donors, Corporate and Community activities so that we have a balanced and sustainable funding model.

In 2022-2023, our financial performance, like so many other charities in the UK, has been impacted by the challenging external economic environment. However, we are pleased to report total fundraised income of £718,621.

Expenditure was £799,864 a managed decrease in line with anticipated income, although timing of funds received has led to reporting a deficit of £81,243 in the period.

Our expenditure and costs were managed to be line with our strategic plans and focused on programme and service delivery. Our cost ratios in the period are Service Delivery 81%, with cost of raising funds at 14% and governance 5%. These are within our acceptable parameters and targets.

Income from Trusts and Foundations continues to be our strongest channel and we receive significant support from a wide range of grant-giving organisations like The Edward Gostling Foundation, The Childwick Trust, The Macdaibhidh Charitable Trust and many others. We also received six-figure grants from three funders, and these are referenced below.

We are also very grateful to supporters who remember us in their Will – legacy income makes a valuable contribution to our funding mix – and we aim to develop this further.

We are aware that the charity income base will need to be strengthened and diversified in the coming period, and that the external environment will continue to be very challenging into 2023-2024 and beyond. To achieve this, we have developed a strong funding pipeline and we are working on securing transformational funding from several new sources.

We were thrilled to see large-scale fundraising events taking place once again. In October 2022, the TCS London Marathon saw a team of 36 incredible runners take on the 26.2 mile challenge and in total raise £70,000. Joining them was a dedicated group of volunteers who cheered on from the sidelines and helped make the day unforgettable. This event remains a key source of income for the charity. We know already that the 2023 marathon has significantly exceeded this target – it is an amazing achievement given the two events are so close together.

Across our community, we have wonderful volunteers and people who go to great lengths to fundraise for the work we do from sporting events to bake sales.

In the year, we are particularly grateful for the donations and support from new supporters such as Boston Scientific and UCB, and for the continued support of the Garfield Weston Foundation, The Peter Sowerby Foundation, and the National Lottery, in particular. We are also proud to have developed a new and exclusive 3-year corporate partnership with Irwin Mitchell.

The Brain and Spine Foundation

Report of the trustees

For the year ended 31 March 2023

The newly created Development Board, established in March 2023, has committed to sourcing funds in support of key strategic initiatives that will benefit overall organisational financial stability.

Fundraising approach

The Brain & Spine Foundation is registered with the Fundraising Regulator and subscribes to their standards for fundraising. We have an engagement philosophy that informs our fundraising approach, looking to build long-term relationships with supporters, volunteers, and service users. We value all contributions, whether financial or non-financial.

Reserves policy

The Trustees are again mindful of the charity's need for financial reserves and have reviewed our Reserves Policy. Whilst the goal is to keep unrestricted funds equivalent to approximately 6 months of running costs, in this period of external economic difficulty and cashflow challenges, we have not been able to achieve this. The Trustees mitigated risks by regular review of the cash position and managed costs and expenditure carefully in 2022-23. As of 31st March 2023, we held £101,474 free reserves which equates to approximately 1.5 months of running costs. Trustees were comfortable with this situation considering strong fundraising pipeline forecasts for Q1 & Q2 2023-24.

Our financial strategy for 2023-24 includes the goal of building reserves of at least 6 months, accumulated as quickly as possible. We will, once again, balance this objective with maintaining on-going operations in the coming year.

Our ambitious plans on behalf of our community, including the new initiatives proposed under Neuro UK campaign, are underpinned with confidence in the organisation's enhanced ability to generate required funding via the establishment of the Development Board.

Our plans for 2023-24

We are pleased to continue to work with our community in growing and developing our programmes throughout 2023-24.

We are also excited by the establishment of the Development Board in March 2023, and the initiatives that will be driven under the Neuro UK campaign that it will support.

We hope to see the continued growth of our Neuro Changemakers campaign and engage with more members of our community, supporting them to work together, locally, and nationally, to make a difference to their lives and the lives of others.

As part of our Professional Neuro Services, we aim to:

- Grow the role and contributions of volunteers within the development and delivery of our services
- Reflect on the success of our pilot Enhanced Emotional Support Service and incorporate our learning as part of a plan for further development in the future
- Continue our professional outreach activities in an effort to link with more health and social care professionals across the UK
- Develop and grow our A-to-Z of neurological topics, alongside our other information resources, to ensure that we are able to support more of our community in finding the support and information they need

In terms of our NeuroLifeNow programme, we will build on our successes and:

- Grow the number of people contributing to NeuroLifeNow and widen participation to ensure better representation
- Continue development of NeuroLifeNow, including co-design and co-production of a new app and online platform

Having established a Development Board to support our strategic goals, including the growth of NeuroLifeNow and scoping conversations with potential academic partners, alongside securing philanthropic backing for an ambitious expansion of this work and a nationwide campaign, Neuro UK, that will make the case for establishing a Neuro Life Sciences Institute.

The Development Board is recognised and appreciated as being transformational and we thank our President and Founder Peter Hamlyn for leading this initiative and all those who have voluntarily joined the Development Board.

From listening to our community, we know that they also face significant challenges in the workplace. We have developed a new initiative, Neuro Inclusive Workplace, to address this issue and we will be working with corporate partners to build the pilot programme.

Our structure, governance & management

The Brain & Spine Foundation is a company limited by guarantee and is registered as a charity with the Charity Commission. It is governed by its Articles of Association (and updated on 22 March 2017). The Board of Trustees is responsible for determining the overall strategic direction of the charity and for developing policies and plans to support the delivery of charitable objects. The Board monitors progress across all areas of activity including legal requirements and financial performance. Meetings take place five times per year and the Finance and Governance sub-committee, a sub-group of the Board, meets up to four times each year to consider finances and good governance. Other sub-committees are created by the Chair to support and give oversight of strategic initiatives as required.

A Chief Executive Officer (CEO) is appointed by the Trustees to manage the day-to-day operations of the charity. To facilitate effective operations, the authority for operational matters including financial management, employment and performance relating to agreed key objectives is delegated to the CEO.

Any decisions outside of the strategic direction agreed by the Board or outside of the agreed budget are referred to Trustees for approval.

The pay and remuneration of the CEO is reviewed by the Board each year and any changes made are based on performance, an assessment of the market, the financial position of the organisation and relativity across the team.

In the previous year we developed a code of conduct for Trustees and updated the Trustee role description. The code sets out the conduct and practices required to ensure the highest standards of integrity and stewardship in this role.

In 2018, the charity introduced the honorary positions of President and Vice-President.

Trustee recruitment and appointment, induction, and training

We aim to represent the community we serve at all levels of the organisation and are actively reviewing our policy and practice related to Equality, Diversity and Inclusion.

The Articles of Association include terms of office for Trustees, so that an initial appointment is made for a 3-year term and Trustees will be eligible for reappointment for one further term of 3 years.

Our Board of Trustees currently number 11 (of 12) and we have been steadily improving the diversity of the Board across all relevant dimensions in order that we can better represent the communities we serve. Details of Trustees are to be found in the appendix.

Risk management

An organisational risk review sets out the major risks and uncertainties facing the organisation. This is monitored periodically by the Board's Finance and Governance Committee and systems and policies have been established to mitigate exposure to those risks. In the year, we have appointed an independent Data Protection and Cyber Security Officer.

The Brain and Spine Foundation

Report of the trustees

For the year ended 31 March 2023

Public benefit

When planning the activities for the year, the Trustees have regard to the Charity Commission's guidance on public benefit in accordance with the duties set out in Section 17 of the Charities Act 2011. The benefit is to a specific group of individuals who have a neurological condition, or who have a friend or family member with such a condition, or who are involved in the treatment and care of these people. This report illustrates the activities provided for this group.

Statement of responsibilities of the Trustees

The Trustees (who are also directors of the charity for the purposes of company law) are responsible for preparing the Trustees' report and the financial statements in accordance with 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).

Company law requires the Trustees to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charity and of the income and expenditure of the charity for that period. In preparing those financial statements the Trustees are required to:

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

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and which enable them to ensure that the financial statements comply with the Companies Act 2006. The Trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

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.

Members of the charity guarantee to contribute an amount not exceeding £1 to the assets of the charity in the event of winding up. The Trustees are members of the charity, but this entitles them only to voting rights. The Trustees have no beneficial interest in the charity.

The Brain and Spine Foundation

Report of the trustees

For the year ended 31 March 2023

Independent examiners

Godfrey Wilson Limited were re-appointed as independent examiners to the charitable company during the year and have expressed their willingness to continue in that capacity.

Approved by the Trustees on 14 December 2023 and signed on their behalf by

Mark Luce

Mark Luce – Chairman

The Brain and Spine Foundation

Reference and administrative details

For the year ended 31 March 2023

Company number	04432677																												
Charity number	1098528																												
Registered office	Canopi Borough 4th Floor 7-14 Great Dover Street London SE1 4YR																												
Trustees	Trustees, who are also directors under company law, who served during the year and up to the date of this report were as follows: <table><tr><td>Anthony Amato-Watkins</td><td>resigned 15 December 2022</td></tr><tr><td>Ian Basden-Smith</td><td></td></tr><tr><td>Kavita Basi</td><td>appointed 31 January 2023</td></tr><tr><td>Joseph Bedford</td><td></td></tr><tr><td>Peter Brickley</td><td></td></tr><tr><td>Lauren Downie</td><td>appointed 28 June 2023</td></tr><tr><td>Paul Fleming</td><td></td></tr><tr><td>Asli Guner-Paul</td><td></td></tr><tr><td>Jeroen Huysinga</td><td></td></tr><tr><td>Mark Luce (Chair)</td><td></td></tr><tr><td>Elizabeth Manuel</td><td></td></tr><tr><td>Carolyn Turner</td><td>appointed 31 January 2023</td></tr><tr><td>Sarah Vibert</td><td>resigned 9 November 2022</td></tr><tr><td>Alistair Watkins</td><td>resigned 28 July 2022</td></tr></table>	Anthony Amato-Watkins	resigned 15 December 2022	Ian Basden-Smith		Kavita Basi	appointed 31 January 2023	Joseph Bedford		Peter Brickley		Lauren Downie	appointed 28 June 2023	Paul Fleming		Asli Guner-Paul		Jeroen Huysinga		Mark Luce (Chair)		Elizabeth Manuel		Carolyn Turner	appointed 31 January 2023	Sarah Vibert	resigned 9 November 2022	Alistair Watkins	resigned 28 July 2022
Anthony Amato-Watkins	resigned 15 December 2022																												
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Kavita Basi	appointed 31 January 2023																												
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Lauren Downie	appointed 28 June 2023																												
Paul Fleming																													
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Jeroen Huysinga																													
Mark Luce (Chair)																													
Elizabeth Manuel																													
Carolyn Turner	appointed 31 January 2023																												
Sarah Vibert	resigned 9 November 2022																												
Alistair Watkins	resigned 28 July 2022																												
Charity president	Peter Hamlyn BSc MB BS MD FRCS FISM																												
Charity vice presidents	Alistair Watkins																												
Chief executive officer	Marc Anthony Smith																												
Company secretary	Marc Anthony Smith																												
Bankers	<table><tr><td>CAF Bank 25 Kings Hill Avenue Kings Hill West Malling Kent ME19 4TA</td><td>NatWest Bank PO Box 158 214 High Holborn London WC1V 7BX</td></tr></table>	CAF Bank 25 Kings Hill Avenue Kings Hill West Malling Kent ME19 4TA	NatWest Bank PO Box 158 214 High Holborn London WC1V 7BX																										
CAF Bank 25 Kings Hill Avenue Kings Hill West Malling Kent ME19 4TA	NatWest Bank PO Box 158 214 High Holborn London WC1V 7BX																												
Independent examiners	Godfrey Wilson Limited Chartered accountants and statutory auditors 5th Floor Mariner House 62 Prince Street Bristol BS1 4QD																												

Independent examiner's report

To the trustees of

The Brain and Spine Foundation

I report to the trustees on my examination of the accounts of The Brain and Spine Foundation (the charitable company) for the year ended 31 March 2023, which are set out on pages 32 to 46.

Responsibilities and basis of report

As the trustees of the charitable company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the charitable company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of the charitable company's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

Independent examiner's statement

Since the charitable company's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales (ICAEW), which is one of the listed bodies.

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- (1) accounting records were not kept in respect of the charitable company as required by section 386 of the 2006 Act; or
- (2) the accounts do not accord with those records; or
- (3) the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination; or
- (4) the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Laura May Richards

Date: 14 December 2023

Laura Richards ACA

Member of the ICAEW

For and on behalf of:

Godfrey Wilson Limited

Chartered accountants and statutory auditors

5th Floor Mariner House

62 Prince Street

Bristol

BS1 4QD

The Brain and Spine Foundation

Statement of financial activities (incorporating an income and expenditure account)

For the year ended 31 March 2023

	Note	Restricted £	Unrestricted £	2023 Total £	2022 Total £
Income from:					
Donations and legacies	3	90,419	179,620	270,039	393,556
Charitable activities	4	224,000	104,950	328,950	223,350
Other trading activities	5	-	119,353	119,353	87,950
Investments		-	279	279	22
Total income		<u>314,419</u>	<u>404,202</u>	<u>718,621</u>	<u>704,878</u>
Expenditure on:					
Raising funds		-	115,305	115,305	151,641
Charitable activities		<u>339,419</u>	<u>345,140</u>	<u>684,559</u>	<u>659,213</u>
Total expenditure	7	<u>339,419</u>	<u>460,445</u>	<u>799,864</u>	<u>810,854</u>
Net expenditure		(25,000)	(56,243)	(81,243)	(105,976)
Transfers between funds		-	-	-	-
Net movement in funds	8	(25,000)	(56,243)	(81,243)	(105,976)
Reconciliation of funds:					
Total funds brought forward		<u>25,000</u>	<u>157,717</u>	<u>182,717</u>	<u>288,693</u>
Total funds carried forward		<u>-</u>	<u>101,474</u>	<u>101,474</u>	<u>182,717</u>

All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in note 15 to the accounts.

The Brain and Spine Foundation

Balance sheet

As at 31 March 2023

	Note	£	2023 £	2022 £
Fixed assets				
Tangible assets	11		-	1,721
Current assets				
Debtors	12	71,722		56,337
Cash at bank and in hand		<u>53,033</u>		<u>156,206</u>
		124,755		212,543
Liabilities				
Creditors: amounts falling due within 1 year	13	<u>23,281</u>		<u>31,547</u>
Net current assets			<u>101,474</u>	<u>180,996</u>
Net assets	14		<u><u>101,474</u></u>	<u><u>182,717</u></u>
Funds	15			
Restricted funds			-	25,000
Unrestricted funds				
General funds			<u>101,474</u>	<u>157,717</u>
Total charity funds			<u><u>101,474</u></u>	<u><u>182,717</u></u>

The directors are satisfied that the charitable company is entitled to exemption from the provisions of the Companies Act 2006 (the Act) relating to the audit of the financial statements for the year by virtue of section 477(2), and that no member or members have requested an audit pursuant to section 476 of the Act.

The directors acknowledge their responsibilities for:

- (i) ensuring that the charitable company keeps proper accounting records which comply with section 386 of the Act; and
- (ii) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of the financial year and of its profit or loss for the financial year in accordance with the requirements of section 393, and which otherwise comply with the requirements of the Act relating to financial statements, so far as applicable to the charitable company.

These accounts have been prepared in accordance with the special provisions applicable to companies subject to the small companies' regime.

Approved by the trustees on 14 December 2023 and signed on their behalf by

Mark Luce

Mark Luce - Chairman

The Brain and Spine Foundation

Statement of cash flows

For the year ended 31 March 2023

	2023	2022
	£	£
Cash used in operating activities:		
Net movement in funds	(81,243)	(105,976)
<i>Adjustments for:</i>		
Depreciation charges	1,721	7,195
Dividends, interest and rents from investments	(279)	(22)
Increase in debtors	(15,385)	(6,335)
Increase / (decrease) in creditors	(8,266)	(5,230)
Net cash provided used in operating activities	<u>(103,452)</u>	<u>(110,368)</u>
Cash flows from investing activities:		
Dividends, interest and rents from investments	<u>279</u>	<u>22</u>
Net cash provided by investing activities	<u>279</u>	<u>22</u>
Decrease in cash and cash equivalents in the year	(103,173)	(110,346)
Cash and cash equivalents at the beginning of the year	<u>156,206</u>	<u>266,552</u>
Cash and cash equivalents at the end of the year	<u><u>53,033</u></u>	<u><u>156,206</u></u>

The charity has not provided an analysis of changes in net debt as it does not have any long term financing arrangements.

The Brain and Spine Foundation

Notes to the financial statements

For the year ended 31 March 2023

1. Accounting policies

a) Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities in preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

The Brain and Spine Foundation meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note.

b) Going concern basis of accounting

The accounts have been prepared on the assumption that the charity is able to continue as a going concern, which the trustees consider appropriate. The charity ended the year 2022-23 with £101,474 (2021-2022 £157,717) of free reserves, which equates to 1.5 months of running costs. Whilst this represents a significant reduction on the previous year, the charity has a strong funding pipeline and has continued to secure major grants including multi-year arrangements. Additionally rigorous cost controls are in place to ensure that new financial commitments cannot be entered into unless appropriate funds are in place. For these reasons the trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern.

c) Income

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the items of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income from the government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor to the Trust that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

Income from fundraising events and other trading income is recognised when the event or conference takes place and is deferred where the income relates to future periods.

The Brain and Spine Foundation

Notes to the financial statements

For the year ended 31 March 2023

1. Accounting policies (continued)

d) Donated services and facilities

Donated professional services and donated facilities are recognised as income when the charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use by the charity of the item, is probable and the economic benefit can be measured reliably. In accordance with the Charities SORP (FRS 102), general volunteer time is not recognised.

On receipt, donated professional services and donated facilities are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

For Google AdWords, the charity measures the value of the gift at the market value provided by Google. Where the market value is given in foreign currency, this is translated in line with the charity's foreign exchange policy (note 1 (o)).

e) Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity: this is normally upon notification of the interest paid or payable by the bank.

f) Funds accounting

Unrestricted funds are available to spend on activities that further any of the purposes of the charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations which the donor has specified are to be solely used for particular areas of the charity's work or for specific projects being undertaken by the charity.

g) Expenditure and irrecoverable VAT

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

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

h) Allocation of support and governance costs

Premises costs, office costs, depreciation and consultancy fees have been allocated to raising funds, charitable activities and support costs on an allocation of staff time spent on each activity.

	2023	2022
Raising funds	11.2%	14.5%
Charitable activities	84.6%	80.6%
Support costs	4.2%	4.9%

The Brain and Spine Foundation

Notes to the financial statements

For the year ended 31 March 2023

1. Accounting policies (continued)

h) Allocation of support and governance costs (continued)

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Governance costs are the costs associated with the governance arrangements of the charity, including the costs of complying with constitutional and statutory requirements and any costs associated with the strategic management of the charity's activities. These costs have been allocated between cost of raising funds and expenditure on charitable activities on the following basis, which is an estimate of resources spent on each activity:

	2023	2022
Raising funds	10.0%	10.0%
Charitable activities	90.0%	90.0%

i) Tangible fixed assets

Depreciation is provided at rates calculated to write down the cost of each asset to its estimated residual value over its expected useful life. The depreciation rates in use are as follows:

Computer equipment	4 years straight line basis
Database and website	4 years straight line basis

Items of equipment are capitalised where the purchase price exceeds £1,000.

j) Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

k) Cash at bank and in hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

l) Creditors

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

m) Financial instruments

The charitable company only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently recognised at amortised cost using the effective interest method.

n) Pension costs

The company operates a defined contribution pension scheme for its employees. There are no further liabilities other than that already recognised in the SOFA.

The Brain and Spine Foundation

Notes to the financial statements

For the year ended 31 March 2023

1. Accounting policies (continued)

o) Foreign currency transactions

Transactions in foreign currencies are translated at the period average rate. Balances denominated in foreign currencies are translated at the rate of exchange prevailing at the year end.

p) Accounting estimates and key judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying values of assets and liabilities that are not readily apparent from other sources. The estimates and underlying 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 if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

There are no key sources of estimation uncertainty that have a significant effect on the amounts recognised in the financial statements.

2. Prior period comparative: statement of financial activities

	Restricted £	General £	2022 Total £
Income from:			
Donations and legacies	72,003	321,553	393,556
Charitable activities	135,000	88,350	223,350
Other trading activities	-	87,950	87,950
Investments	-	22	22
Total income	207,003	497,875	704,878
Expenditure on:			
Raising funds	-	151,641	151,641
Charitable activities	210,003	449,210	659,213
Total expenditure	210,003	600,851	810,854
Net expenditure and net movement in funds	(3,000)	(102,976)	(105,976)

The Brain and Spine Foundation

Notes to the financial statements

For the year ended 31 March 2023

3. Income from donations and legacies

	Restricted £	Unrestricted £	2023 Total £
Donations and appeal income	20,000	158,680	178,680
Legacies	-	20,940	20,940
Gifts in kind - Google AdWords	70,419	-	70,419
Total donations and legacies	90,419	179,620	270,039

Prior period comparative

	Restricted £	Unrestricted £	2022 Total £
Donations and appeal income	-	241,710	241,710
Legacies	-	44,465	44,465
Gifts in kind - Google AdWords and KPMG	72,003	-	72,003
Major donors	-	35,378	35,378
Total donations and legacies	72,003	321,553	393,556

4. Income from charitable activities

	Restricted £	Unrestricted £	2023 Total £
<i>Grants > £5,000:</i>			
National Lottery Community Fund	109,000	-	109,000
Peter Sowerby Trust	75,000	-	75,000
Garfield Weston Trust	-	34,000	34,000
UCB Pharma	20,000	-	20,000
The Edward Gostling Foundation	-	25,000	25,000
Boston Scientific grant	15,000	-	15,000
Childwick Trust	-	15,000	15,000
<i>Grants = £5,000:</i>			
The February Foundation	5,000	-	5,000
The MacDaibhidh Trust	-	5,000	5,000
The Rainford Trust	-	5,000	5,000
29th May 1961 Trust	-	5,000	5,000
<i>Grants < £5,000:</i>			
Sandra Charitable Trust	-	4,000	4,000
Persula Foundation	-	3,000	3,000
Other small grants < £3,000	-	8,950	8,950
Total charitable activities	224,000	104,950	328,950

The Brain and Spine Foundation

Notes to the financial statements

For the year ended 31 March 2023

4. Income from charitable activities (continued)

Prior period comparative

	Restricted £	Unrestricted £	2022 Total £
<i>Grants > £5,000:</i>			
Garfield Weston Trust	100,000	-	100,000
Peter Sowerby	25,000	-	25,000
The MacDaibhidh Trust	-	20,000	20,000
CAF	-	20,000	20,000
FND Hope Corporation	10,000	-	10,000
The Adint Charitable Trust	-	10,000	10,000
The Eveson Charitable Trust	-	10,000	10,000
<i>Grants = £5,000:</i>			
The Edward Gostling Foundation	-	5,000	5,000
29th May 1961 Trust	-	5,000	5,000
<i>Grants < £5,000:</i>			
The D'Oly Carte Foundation	-	3,000	3,000
Persula Foundation	-	3,000	3,000
Other small grants < £3,000	-	12,350	12,350
Total charitable activities	<u>135,000</u>	<u>88,350</u>	<u>223,350</u>

5. Income from other trading activities

	2023 Total £	2022 Total £
Fundraising events	<u>119,353</u>	<u>87,950</u>

All income from other trading activities in the current and prior year is unrestricted.

6. Government grants

The charitable company received government grant funding in the year from the National Lottery. In the prior year the charitable company received government grant funding from the Coronavirus Job Retention Scheme. The total value of such grants in the year was £109,000 (2022: £1,163). There are no unfulfilled conditions or contingencies attaching to these grants in the current or prior period.

The Brain and Spine Foundation

Notes to the financial statements

For the year ended 31 March 2023

7. Total expenditure

	Raising funds £	Charitable activities £	Support and governance costs £	2023 Total £
Direct costs	22,991	113,077	11,414	147,482
Staff costs (note 9)	57,824	438,535	21,971	518,330
<i>Allocated costs:</i>				
Premises costs	3,975	22,071	1,353	27,399
Office costs	8,128	34,029	3,517	45,674
Depreciation	250	1,386	85	1,721
Consultants	17,614	34,755	6,889	59,258
Sub-total	110,782	643,853	45,229	799,864
Allocation of support and governance costs	4,523	40,706	(45,229)	-
Total expenditure	115,305	684,559	-	799,864

Governance costs in the year were £3,900 (2022: £3,720).

Prior period comparative

	Raising funds £	Charitable activities £	Support and governance costs £	2022 Total £
Direct costs	23,352	61,779	8,969	94,100
NeuroLifeNow gift in kind	-	20,263	-	20,263
Staff costs (note 9)	73,678	408,947	25,091	507,716
<i>Allocated costs:</i>				
Premises costs	3,597	19,965	1,225	24,787
Office costs	13,677	73,874	8,005	95,556
Depreciation	1,044	5,796	355	7,195
Consultants	31,446	24,966	4,825	61,237
Sub-total	146,794	615,590	48,470	810,854
Allocation of support and governance costs	4,847	43,623	(48,470)	-
Total expenditure	151,641	659,213	-	810,854

The Brain and Spine Foundation

Notes to the financial statements

For the year ended 31 March 2023

8. Net movement in funds

This is stated after charging:

	2023 £	2022 £
Depreciation	1,721	7,195
Trustees' remuneration	Nil	Nil
Trustees' reimbursed expenses	647	Nil
Trustees' indemnity insurance	110	110
Independent examiners' remuneration (including VAT):	<u>3,900</u>	<u>3,720</u>

Trustee reimbursed expenses relate to travel and subsistence costs for 3 trustees.

9. Staff costs and numbers

Staff costs were as follows:

	2023 £	2022 £
Salaries and wages	452,109	444,247
Social security costs	44,256	41,715
Pension costs	<u>21,965</u>	<u>21,754</u>
	<u>518,330</u>	<u>507,716</u>

	2023 No.	2022 No.
Employees earning more than £60,000 during the year		
£60,000 - £70,000	-	-
£70,000 - £80,000	1	1
£80,000 - £90,000	<u>1</u>	<u>1</u>

The key management personnel of the charitable company comprise the trustees, chief executive and senior management team. The total employee benefits of the key management personnel were £348,215 (2022: £330,818).

Staff numbers were as follows:

	2023 No.	2022 No.
Average head count	12	13
Full time equivalent	<u>10</u>	<u>11</u>

10. Taxation

The charity is exempt from corporation tax as all its income is charitable and is applied for charitable purposes.

The Brain and Spine Foundation

Notes to the financial statements

For the year ended 31 March 2023

11. Tangible fixed assets

	Computer equipment £	Database and website £	Total £
Cost			
At 1 April 2022 and at 31 March 2023	<u>37,601</u>	<u>52,800</u>	<u>90,401</u>
Depreciation			
At 1 April 2022	36,463	52,217	88,680
Charge for the year	<u>1,138</u>	<u>583</u>	<u>1,721</u>
At 31 March 2023	<u>37,601</u>	<u>52,800</u>	<u>90,401</u>
Net book value			
At 31 March 2023	<u>-</u>	<u>-</u>	<u>-</u>
At 31 March 2022	<u>1,138</u>	<u>583</u>	<u>1,721</u>

12. Debtors

	2023 £	2022 £
Prepayments	27,052	20,382
Accrued income	<u>44,670</u>	<u>35,955</u>
	<u>71,722</u>	<u>56,337</u>

13. Creditors: amounts due within 1 year

	2023 £	2022 £
Trade creditors	1,932	9,196
Accruals	8,669	9,363
Other taxation and social security	<u>12,680</u>	<u>12,988</u>
	<u>23,281</u>	<u>31,547</u>

The Brain and Spine Foundation

Notes to the financial statements

For the year ended 31 March 2023

14. Analysis of net assets between funds

	Restricted funds £	Unrestricted funds £	Total 2023 £
Tangible fixed assets	-	-	-
Net current assets	-	101,474	101,474
Net assets at 31 March 2023	-	101,474	101,474
Prior period comparative			
	Restricted funds £	Unrestricted funds £	Total 2022 £
Tangible fixed assets	-	1,721	1,721
Net current assets	25,000	155,996	180,996
Net assets at 31 March 2022	25,000	157,717	182,717

The Brain and Spine Foundation

Notes to the financial statements

For the year ended 31 March 2023

15. Movements in funds

	At 1 April 2022 £	Income £	Expenditure £	Transfers between funds £	At 31 March 2023 £
Restricted funds					
Google AdWords	-	70,419	(70,419)	-	-
National Lottery	-	109,000	(109,000)	-	-
The February Foundation	-	5,000	(5,000)	-	-
Boston Scientific	-	15,000	(15,000)	-	-
UCB Pharma	-	20,000	(20,000)	-	-
Peter Sowerby Foundation	25,000	75,000	(100,000)	-	-
Neuro Life Now	-	20,000	(20,000)	-	-
Total restricted funds	<u>25,000</u>	<u>314,419</u>	<u>(339,419)</u>	<u>-</u>	<u>-</u>
Unrestricted funds					
General funds	<u>157,717</u>	<u>404,202</u>	<u>(460,445)</u>	<u>-</u>	<u>101,474</u>
Total unrestricted funds	<u>157,717</u>	<u>404,202</u>	<u>(460,445)</u>	<u>-</u>	<u>101,474</u>
Total funds	<u>182,717</u>	<u>718,621</u>	<u>(799,864)</u>	<u>-</u>	<u>101,474</u>

Purposes of restricted funds

Google AdWords - Represents the value of advertising donated by Google to support access to information.

National Lottery - Three year grant of £330,000 allocated equally between Professional Neuro Services and NeuroLifeNow.

The February Foundation - One off grant of £5,000 towards the costs of our national helpline.

Boston Scientific - An educational grant that has been used to support Public Healthcare Awareness Campaigns.

UCB Pharma - Grant of £20,000 to support the NeuroLifeNow programme in 2022-23.

Peter Sowerby Foundation - £100,000 one year grant, spent in 2022-23 towards the development of Version 2.0 of the NeuroLifeNow platform and Professional Neuro Services.

Neuro Life Now - donations towards work on Neuro Life Now.

The Brain and Spine Foundation

Notes to the financial statements

For the year ended 31 March 2023

15. Movements in funds (continued)

Prior period comparative

	At 1 April 2021 £	Income £	Expenditure £	Transfers between funds £	At 31 March 2022 £
Restricted funds					
Birmingham Hospital Saturday Fund	28,000	-	(28,000)	-	-
FND Hope Corporation	-	10,000	(10,000)	-	-
Garfield Weston	-	100,000	(100,000)	-	-
Google AdWords	-	51,740	(51,740)	-	-
KPMG NeuroLifeNow	-	20,263	(20,263)	-	-
Peter Sowerby Foundation	-	25,000	-	-	25,000
Total restricted funds	28,000	207,003	(210,003)	-	25,000
Unrestricted funds					
General funds	260,693	497,875	(600,851)	-	157,717
Total unrestricted funds	260,693	497,875	(600,851)	-	157,717
Total funds	288,693	704,878	(810,854)	-	182,717

16. Related party transactions

During the year trustees donated £20,000 to The Brain and Spine Foundation (2022: £nil).

Marc Smith, Chief Executive of the charity, is also a trustee of the Neurological Alliance. During the year ended 31 March 2023, the charity paid £5,000 to the Neurological Alliance for support with the Neuro Life Now project.

17. Contingent assets

There is a legacy which has been notified to the charity at 31 March 2023 for which the amount is still not reliably measurable. Indications are that the estimated value of the legacy is in the region of £65,000 (2022: £85,000).

The Brain and Spine Foundation

Trustee biographies

For the year ended 31 March 2023

Our Founder and President, Peter Hamlyn MB BS BSC MD FRCS FISM

In a medical career that has spanned 40 years, Peter has led change at the elite level of both neurosurgery and sports medicine. He has headed neurosurgical teams in some of London's elite teaching hospitals such as St Bartholomew's Hospital and The Royal London Hospital, academic units in leading universities such as Queen Mary University London and University College London. He has worked at the elite level in multiple sports medicine, including motor sports, equine sport, combat and collision sports as well as the performing arts – everything from the NFL to the Royal Ballet. He has chaired Ministerial Working Groups and was pivotal to the creation of Sport and Exercise Medicine as a recognised specialty.

He has worked as medical advisor to the Society of British Neurological Surgeons (first Safe Neurosurgery working group), General Medical Council, Trigeminal Neuralgia Association of Great Britain, British Olympic Association, British Boxing Board of Control, The Jockey Club of Great Britain, UK Sport, Royal Ballet, GB rowing team, England Rugby, plus numerous premier league football and rugby clubs.

Peter was a member of the 2012 Olympic Bid Advisory Panel and has worked as a correspondent for the sports section of The Daily Telegraph newspaper. In 1996, he was awarded Fellowship of the Institute of Sport Medicine for work in the field of head injury in sport. He is founder and president of the Brain and Spine Foundation, has been the Chair of the Football Association's Expert Medical Panel since 2016 and has been a Trustee of the Grand Prix Trust since 2005. Most recently, Peter has been appointed Medical Director and Trustee of Podium Analytics.

Vice President, Alistair Watkins

Alistair has spent the last 25 years working in the world of international sport at the highest level. He started his career working as the FIA's Formula One Press Officer 1995 – 1999, an era a great change in sport with safety becoming a primary objective. A change of direction into the commercial side of the sports world followed a year of study and an MBA from the Management School of Imperial College in London. Two year of working for leading consultancy Oliver & Ohlbaum on Premier League media rights valuations led to Alistair joining Kirch Media, who acquired Formula One, and subsequent work on the sports long term business plan.

Alistair re-joined the sport of Formula One in 2002 as Marketing Director of Lucky Strike BAR Honda's Formula One team, which saw Alistair leading the team's global marketing operations for five years. He was then head hunted to be Marketing Director of Swiss America's Cup sailing team, Alinghi. Created by Swiss biotech billionaire, Ernesto Bertarelli, Alinghi was the first European team to win the America's Cup and defend it successfully in Valencia in 2007.

Alistair founded Influence Associates in 2008 with two other directors, which saw the marketing and PR agency offer corporate clients PR, investor relations, marketing and sponsorship services. Since then he has created Influence Sports & Media for sports clients.

Alistair stepped down as Trustee of Brain & Spine Foundation after six years and was elected as Vice President in 2022. He will be working on projects with our Founder and President, Peter Hamlyn.

The Brain and Spine Foundation

Trustee biographies

For the year ended 31 March 2023

Chair of Trustees, Mark Luce

Mark joined the Board of Trustees in July 2017, stepping up to his current role as Chair in July 2018. Mark spent the last 20 years working for global beer giant SABMiller and now runs his own marketing consultancy. Continuing his passion for change, his ambition is to transform the care provided to those living with neurological conditions and in doing so, to make a meaningful difference to many more people. He is a wine maker, avid traveler, and motorsport fan.

Trustee, Ian Basden-Smith

Ian is a chartered accountant who worked in the banking industry following a period with KPMG. He worked for Samuel Montagu, Morgan Grenfell and Deutsche Bank across finance and operational activities in the UK, Europe and the Far East. Ian joined the Board of Trustees in 2012 and is both excited by the current plans for the charity and committed to achieving our organisational aims. Ian is a keen golfer and fisherman and enjoys the outdoors and travelling as well as spending time with his children and grandchildren.

Trustee, Kavita Basi

Kavita has over 25 years of experience in the fashion industry. In 2015 she suffered a subarachnoid brain haemorrhage and was told she had a 50% chance of survival and could be left with life-changing disabilities.

After four brain operations and extensive rehabilitation, Kavita made it her mission to make a positive difference in the fashion industry, be a role model to the next generation and help others that have suffered a similar illness. She has been a Brain & Spine Foundation Ambassador since 2015, is an author of two books about surviving brain haemorrhage and has shared her story through her podcast and social media. Her two ethical brands promote vegan and gender-neutral fashion. She donates 5% of profits from her brand Ration.L to the Brain & Spine Foundation.

Trustee, Joe Bedford

Joe has been a corporate lawyer for over 20 years and is a partner and strategy board member at Stevens & Bolton LLP. Joe was a founder member of the steering committee of the Association for Corporate Growth (ACG UK), an organisation focused upon supporting middle market M&A activity and driving the growth of that sector. Joe joined the Board of Trustees in May 2020 having heard the ambitious plans which the Brain & Spine Foundation has to expand its footprint and enhance its ability to make a positive difference to those affected by neurological issues. He is now a member of the Finance and Governance Sub-Committee.

Trustee, Peter Brickley

Peter leads the Business Process & Technology organisation at Coca Cola European Partners. Peter has over 25 years' experience leading technology for global businesses including Heineken, Centrica & BAT. Before Coca Cola Peter was the Global CIO and Managing Director of Global Business Services at SABMiller. Peter is also the non-executive chairman of Newbury Building Society and a Parish Councillor.

Peter joined the Board of Trustees in April 2020, given his enthusiasm for the cause.

The Brain and Spine Foundation

Trustee biographies

For the year ended 31 March 2023

Trustee, Lauren Downie

After suffering a subarachnoid haemorrhage in 2004, Lauren was discharged from hospital and given a leaflet from the Brain and Spine Foundation. A few months after, she realised her recovery was taking longer than expected and as she had no follow up appointments booked with the hospital, Lauren called the Brain & Spine Foundation's Helpline. The advice she received was extremely helpful, explaining what Lauren might expect in terms of recovery time.

She went to meet the team and was invited to support the Brain and Spine at the London marathon. She was asked to run a 5k to raise funds, and that was her introduction to running.

After a follow up procedure in 2006, Lauren was persuaded to run the marathon to raise funds for the foundation again. This is when she met all the team and was inspired by the charity throughout her

Along the way, Lauren has contributed to a book written by Alison Wertheimer, called "A Dented Image, Journeys of Recovery from Subarachnoid Haemorrhage", and attended conferences run by the charity.

She was appointed an ambassador several years ago as she raised awareness of the charity by getting running friends to join her on fundraising runs.

More recently Lauren has been working as a peer support volunteer for the Neuro Social group where survivors of neurological illnesses meet once weekly online.

Support for people with neurological conditions is lacking throughout the UK and Lauren feels very grateful to the Brain and Spine Foundation for the support the charity has given her in the past. She is so happy to help in any small way towards improving services for others!

Trustee, Paul Fleming

Paul has spent the last twenty years working as a financial restructuring lawyer, based in London but travelling around the world. He has worked on a variety of cases including the fall out from the Lehman collapse in 2008. He likes difficult problems! Paul joined us in 2020 with an enthusiasm to support the crucial role the Brain & Spine Foundation plays in covering significant gaps of neurological health and wellbeing.

Trustee, Asli Guner-Paul

Asli is currently working as Associate General Counsel at Lightsource BP, a global solar company, heading up projects in the EMEA region. She holds a Bachelor of Law (with first class honours equivalent) from Galatasaray University and an LLM degree (with merit) in corporate and commercial law from the London School of Economics and Political Science. She speaks Turkish, French and German. Asli joined the Board of Trustees in May 2020 after a close family member was diagnosed with a neurological illness. She is passionate about contributing to the invaluable work of the Brain & Spine Foundation. Asli enjoys spending time with her family, travelling, pilates and collecting vintage crockery.

The Brain and Spine Foundation

Trustee biographies

For the year ended 31 March 2023

Trustee, Jeroen Huysinga

Jeroen has spent 35 years working as a portfolio manager covering equity markets globally. He was a Managing Director at JPMorgan Asset Management for 20 years.

In 2020, Jeroen chose to retire from his work in the City and embark on a Master's degree in Charity Accounting and Financial Management at the Cass business school. His ambition is to combine commercial experience and rigorous learning to make a difference and to build a second career in the charities sector. Jeroen joined the Board of Trustees in April 2020 and is passionate about the potential to create positive change.

Trustee, Elizabeth Manuel

Elizabeth survived a subarachnoid haemorrhage (SAH) in 2011. Having grappled with the failings of a health service that neither prioritises nor generally meets the needs people affected by neuro conditions, Elizabeth has sought to make things better for others. She has a LLB (Hons), was a barrister for twenty years, a Judge for sixteen years, and gives motivational speeches to educate and inform health professionals and patients about how to achieve better outcomes. She has given TV and media interviews about her experiences and made short films to highlight disability and petition Parliament about the need for better rehab. Elizabeth is testament that improvement can be made at any stage and life can be better. She loves to paint and has exhibited her art (most recently at the 2021 Bloomsbury Festival). She enjoys exercise, improving her French and Spanish, and travelling the world.

Trustee, Carolyn Turner

In 2008 Carolyn was diagnosed with a spinal cord tumour. She lived with it for 5 years before having complex spinal surgery in 2013. In 2014, she reached out to the Brain and Spine Foundation for support and began fundraising in 2015. This is when she became an Ambassador for the charity.

Carolyn comes from a nursing background, having worked as a staff nurse at the Leicester Royal Infirmary NHST for 15 years, initially in the Central Operating department. She then transferred to Ophthalmology, gaining experience in theatres, on the wards and clinics before joining the hospital agency and working in the recovery suite of the Women's Hospital.

Following her surgery, she worked as support staff at a pre-school and now dedicates her time to the Brain & Spine Foundation. She is the Volunteer Facilitator for the charity's peer support groups: Neuro Social, Neuro Creative, Neuro Social Midlands and Neuro Writing.

Carolyn also joined the Brain & Spine Foundation's Equity, Diversity and Inclusion working group. She was appointed to the Board of Trustees in 2023.