

# THE BRAIN TUMOUR CHARITY



Chief Executive  
Officer



Starfish

# Welcome

Thank you for your interest in becoming our new Chief Executive.

Every day in the UK, 32 people are diagnosed with a brain tumour - that's over 11,700 people every year. Brain tumours are the biggest cancer killer of the under 40s, including children. Survival rates have not improved over the last 40 years - just 19% of people survive for five years or more and over 5,000 people lose their lives every year to a brain tumour. Yet, despite these facts, less than 3% of the hundreds of millions invested in national cancer research funding in the UK every year is spent on brain tumours.

We want to change this and have a clear vision for a world where brain tumours are defeated. We believe that no one should have to live with a brain tumour or lose a loved one to a brain tumour. Advances in both treatments and quality of life care need to be made – and they need to be made quickly.

A vibrant charity formed in 2012 as a result of a merger between three organisations, we are committed to investing £32.5million into world class research over the next five years, as well as driving down diagnosis times and improving life today through our vital support services. We are ambitious and clear in our goals. We want to double survival rates by 2025 and to drive a step change in improving the future for those affected by a brain tumours.

Our current CEO, Sarah Lindsell, is stepping down after a decade with the charity and, as we approach the end of our current five year strategy, we are looking for another inspirational leader to navigate us through to the next stage of our development to accelerate our path towards beating brain tumours.

In recent years, we have experienced rapid growth and success and Sarah will leave a strong platform for her successor to build on. But, like every charity, we have not escaped the impact of the Covid-19 crisis and we have had to be agile and adaptive in our response. However, while we will need to find ways to do more with less in the shorter-term, our vision and ambition remains unchanged and we are very fortunate to have a strong Board, a hugely talented team and an inspiring vision as well as strong reserves to help us weather this storm and achieve even more in the future.

We're looking for a progressive and experienced leader with a strong track record of income generation who can harness the talent and passion of our organisation. You will be highly commercial, with the creativity and understanding to commercialise opportunities that deliver financial returns. Digitally astute, you'll be excited by the opportunities to harness new technologies to deliver and champion our impact. Compassionate, with exceptional communication skills, you will enjoy being a visible leader, experienced in working with a diverse group of stakeholders focused on tackling complex issues. You will need the courage and patience to speak out, influence and change policy, and mobilise our movement to drive change in health practice, diagnosis and treatment. Strategic in your outlook, you will bring the ability to translate vision into operational plans and also be able to roll your sleeves up when necessary.

If you enjoy the challenge of leading a high performing team motivated by purpose and ambitious goals you will love it here. We were crowned Third Sector Charity of the Year in 2018 and this year BRIAN, our (Brain tumouR Information and Analysis Network) was nominated for Third Sector's prestigious 'Breakthrough of the Year' award. The impact of our work and disease area is not to be underestimated however, and you will require enormous sensitivity and resilience. Above all, you'll be pioneering in your approach, smart in your thinking, collaborative and inclusive in your leadership and passionate to lead change for everyone affected by a brain tumour.

If what you've read so far excites you and you can see how you can make a difference, we'd love to hear from you.

Best wishes

**Jack Morris CBE, Chair of Trustees**

# About us

Those whose lives have been devastated by a brain tumour diagnosis seek hope in the future through longer survival with the best possible quality of life. Our goals, as a charity, reflect: to double survival and halve the harm that brain tumours have on quality of life.

The global pandemic has further shattered the future of those with brain tumours, with significant, changing and unknown variations in levels of care at treatment centres. Research, which we fund in the UK and globally, was at a standstill in April, but is beginning to restart, although clinical trials aren't expected to be at pre-COVID levels until Autumn 2021. Our community is telling us that they desperately need the knowledge and tools to control their own experience and choose the treatment best for them, helping to drive up standards for all. It is vital that we share this knowledge, including how treatment centres are doing against these standards, so people can make informed choices and treatment centres improve. Our research community also needs us to demonstrate our longer-term commitment and remove barriers, such as lack of research data, to help research get back up to speed fast in the future. Therefore, while we endure the pandemic and its consequences, we will continue to be led by our goals to double survival and halve the harm that brain tumours have on quality of life. We will reset our focus on the following four aims:

- Mobilise a movement to accelerate change
- Harness the power of data to inform change
- Demand the best care everywhere to drive change
- Make it count every-day to enable change.

Delivering these as programmes led by a movement will require us to change the ways in which we work. It will require us to be leaner, more flexible, to work across teams and support one another; to learn new ways of meeting the needs of our diverse community. It will require us to rethink our plans, hopes, processes and structures that we had set in place for an already disrupted year. As a Charity we have always sought to be digital first. We will lean into this further, sharing and improving our digital and data skills.

With further government restrictions recently, the need for this new strategy is enhanced but our ability to implement it will be challenged: we will be unable to work physically in the small teams we had envisaged to deliver the projects needed in a time limited, focussed way. Therefore, our communication, culture, values and purpose will, once again be paramount in enabling us to achieve our goals. With the recent rise in COVID cases and the impact this will have on fundraising for the next year, we will also need to consider wider measure to reduce our costs further and will have to make some wider choices about the direction of the charity. We shall follow these aims for the time being, which we envisage to be at least 18-24 months, but revisit them should the current scenario change.



# About us

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours, making a difference every day to the lives of people with a brain tumour and their families.

- We fund pioneering research to increase survival and improve treatment options.
- We raise awareness of the symptoms and effects of brain tumours to get earlier diagnosis and to help families cope with everything that the diagnosis of a brain tumour brings.
- We provide support for everyone affected so that they can live as full a life as possible, with the best quality of life.
- We are committed to having the biggest possible impact for every person affected by a brain tumour, to defending the most amazing part of the human body, so that getting the diagnosis of a brain tumour no longer means a death sentence.

We provide support for everyone affected and we fund pioneering research.

Brain tumours are different to other cancers, as they affect the part of you that makes you who you are. Living with a brain tumour has a significant impact on quality of life, as evidenced through social research, resulting in the publication of 'Losing Myself: The Reality of Life with a Brain Tumour'.

We believe that fighting brain tumours on all fronts through research, awareness and support is the only way to save lives, reduce long term disabilities and help everyone with a brain tumour and their families cope with everything that the diagnosis of a brain tumour brings.

For more information about The Brain Tumour Charity, our work and our finances, please visit:  
[www.thebraintumourcharity.org](http://www.thebraintumourcharity.org)



**1 in 3**

people visit a  
GP over 5 times  
before they  
receive a  
diagnosis



**14**

people in  
the UK die  
from a brain  
tumour every  
day



**60%**

of those diagnosed  
with a brain  
tumour receive no  
information on  
plans for their care

# Our Research

We are the leading funder of brain tumour research in the UK, committing over £50 million to date on pioneering projects that will help adults and children with brain tumours.

We're committed to funding ground breaking research to discover new treatments, improve understanding, increase survival and bring us closer to a cure. So we were proud, in 2019–20, to spend £6.6 million on global research. This included funding for diverse and promising projects covering high and low grade brain tumours, adult and paediatric brain tumours and quality of life.

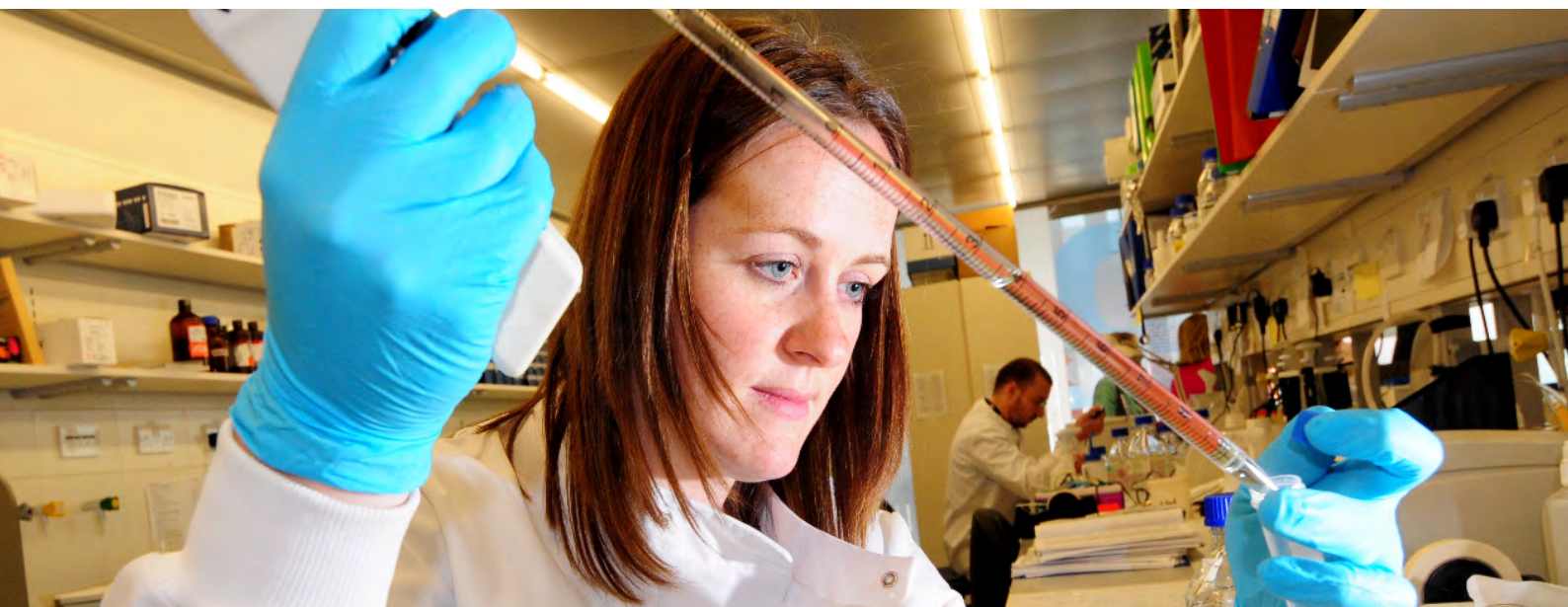
An example of how this manifests itself is in 2019, we were delighted to partner with Cancer Research UK to invest in the Brain Tumour Awards, the largest awards specifically designed for brain tumour research in the UK. We committed £3 million to a Brain Tumour Award for Professor Neil Carragher from the Cancer Research UK Edinburgh Centre – he and his team will carry out pioneering research into glioblastoma biology, aiming to reveal new drug targets and develop better and more efficient treatments. Such a substantial amount of funding allows us to make huge strides in finding the best treatment for each patient, giving them a better chance of survival.

Another vital project we funded last year is an investigation into whether a therapy called Acceptance and Commitment Therapy (ACT) can be adapted to help treat young brain tumour survivors. ACT incorporates aspects of other therapies such as cognitive behavioural therapy and mindfulness, and aims to help participants build a rich and meaningful life despite their ongoing difficulties. The study, led by Dr Sophie Thomas at Queen's Medical Centre, Nottingham, could have a big impact on support for childhood brain tumour survivors.

## Innovating to defeat brain tumours

Last year, we were thrilled to be the first ever UK charity to partner with the US-based Center for Advancing Innovation (CAI). Alongside Resonance Philanthropies (a Silicon Valley Community Foundation), we cofunded a pioneering initiative coordinated by CAI called The Brain Race, which asked researchers and inventors from across the globe to submit innovative ideas aimed at defeating brain tumours. CAI's approach is to build on great discoveries that have been made in research labs but left to 'gather dust'. These discoveries can be anything from patented chemicals that could be used to make cancer drugs, to magnetic helmets or even computer games. In 2019–20, voting to decide on the semi-finalists took place, and, going forward, we look forward to collaborating with the 15 winning start-up companies in our fight to defeat brain tumours.

For more information on our research and our work please visit our website and our Annual Reports.



# Our Research

## BRIAN: Defeating brain tumours through data

Last year, we were delighted to launch our pioneering online app and databank, BRIAN (Brain tumouR Information and Analysis Network), where people affected by a brain tumour can record their journey and access insights on others' experiences. Driven by the urgent need to get better information into the hands of patients, clinicians and researchers, BRIAN is making the best use of technology by harnessing the power of data and sharing this with our community in a way that's never been done before.

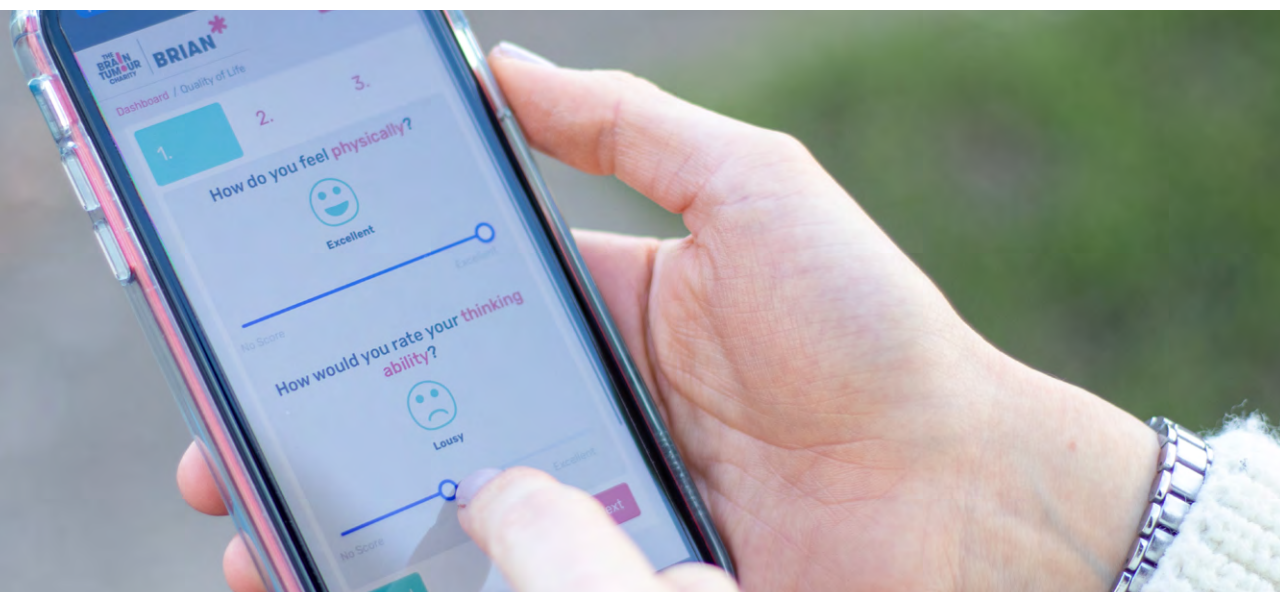
Accessing the right data, of the right quality, quickly enough has been a major barrier to brain tumour research and clinical advances. Too often, research is out-of-date before it even begins, and significant time and funds are wasted securing access to the data. It means progress has been slower than it needs to be. BRIAN is our innovative tech solution that addresses this complex challenge and puts patients in the driving seat of their own care. By combining national healthcare records with user-inputted data, BRIAN puts the knowledge people need into their hands while providing researchers with critical data.

BRIAN's objectives are:

- to enable our community to share data and make better informed decisions
- to build a platform for co-mingling quality-of-life data and national datasets
- to improve outcomes and accelerate a cure by giving open access to timely, high-quality data, securely and ethically.

BRIAN is driven by a mandate from our community to collect and share their data, ethically and responsibly, to accelerate a cure. The databank was built in time for our first data extracts in 2018: eight million hospital episodes from NHS Digital and 79,000 patient records from Public Health England, which fuel BRIAN's data insights. Phase 1 of the online app was launched in September 2019 and at the end of the financial year, we had 1,165 registered users signed up to BRIAN.

The range of functionality in BRIAN was, and is, driven by our community's needs. The national data insights around incidence, treatment and side-effects can be filtered by age, geography, treatment and tumour type. For the first time, patients can find the most relevant information for them, at their fingertips, to help inform decisions about their own treatment regimens. Users are also able to track appointments, medications and side-effects alongside quality-of-life data submitted through questionnaires and functional tests. Crucially, patients can choose to share their data with their healthcare team via BRIAN, presenting new, digital opportunities to enhance clinical care.



# Our values

Our values underpin our culture, the way we do things and what we believe in.

- We will always do what is needed, even if it's not easy, to achieve excellence.
- We respect and respond to every individual who supports us or who we support in our endeavour to find a cure.
- We will only make a lasting impact and drive change working together.
- We are the experts you can trust to give you the information you need to make a difference.

**Pioneering:** We are relentless and courageous in the pursuit of our vision, seeking new ways to make a difference. We are determined to remain at the forefront of this disease, funding pioneering, innovative research that makes breakthroughs to save lives.

**Passionate:** People are at the heart of our charity. We are passionate about finding a cure and ensuring that everyone affected has the highest quality of life and chance of survival.

**Collaborative:** We will achieve our vision by building networks, partnerships and a strong brain tumour community. We collaborate and value everyone's contribution - people with a brain tumour, families & friends, fundraisers, donors, researchers & healthcare professionals.

**Smart:** We are focused and intelligent in our approach to defeating brain tumours, providing accurate, relevant and valuable information and always learning, understanding and innovating to improve our charity.



# Job Description

**Role title:** Chief Executive

**Accountable to:** Board of Trustees

## Main responsibilities of the role:

### Leadership and Strategy

- Provide innovative, visionary and exceptional leadership to all staff to achieve the highest standards of performance against The Brain Tumour Charity's priorities, aims and objectives.
- Lead the development of the organisation's strategy; together with the Board and Senior Leadership Team colleagues.
- Lead a social movement to meet the needs of our diverse community.
- Articulate a clear and compelling vision for what The Brain Tumour Charity can achieve for all those affected by brain tumours.
- Manage, develop and support the Senior Leadership Team to be confident and high performing individually and together.
- Be an effective champion and ambassador for our charity, visible and connected to our diverse stakeholders and partners including healthcare professionals, the research community and policy makers as well as all those affected by brain tumours.
- Champion, advocate for, create and maintain an open, sharing culture that encourages and values diversity.
- Ensure that The Brain Tumour Charity's work continues to deliver impact and that we use donor funds optimally to fulfil our charitable purpose.

### Fundraising and Communication

- Drive our income growth and explore opportunities for increasing income each year from fundraised and commercial opportunities.
- Promote a collaborative internal culture focused on fundraising as the means for The Brain Tumour Charity to become a greater force for change and be better able to deliver the vision.
- Working with the Chief Engagement Officer, ensuring a strong and sustainable pipeline across multiple income streams and building excellent relationships with key funders.
- Ensure an effective communications strategy internally and externally which uses evidence to champion the voice of all of those affected by brain tumours.

### Grant Making

- Working with the Director of Research ensure the effective design and execution of a grant-giving strategy which gives us a valuable, impactful presence.
- Bring together the impacts of our grants to build a strong coherent communication plan which will support our fundraising work and build an engaged and loyal donor network.

### Governance and business management

- Work closely with our Board to ensure that all legal and regulatory responsibilities are carried out and support excellent governance of the organisation.
- Work with the Director of Finance and Governance, you will lead excellent financial management, budgeting, reporting and risk management.
- Ensure systematic, timely production of accurate management accounts and maintain appropriate financial controls.
- Ensure effective management of infrastructure including premises, IT, CRM and software with agreed budgets.



# Person Specification

## Part One

### Knowledge and Experience

- Outstanding track record of strategic leadership and management, including working effectively with a board and leading across different disciplines, teams, projects and responsibilities.
- Deep understanding of income generation and fundraising, with direct experience of building high value alliances that secure financial and wider support across fundraised and commercial income sources.
- Demonstrable experience of influencing and developing partnerships with a range of senior external stakeholders to deliver impact.
- Proven track record of successfully leading change and innovation – with a particular focus on maximising the opportunities of digital and technology.
- Experience of working with a Board and of developing and maintaining robust governance, including risk strategy and management, and financial management. Charity governance experience would be desirable.
- Experience of public speaking, including media appearances and comfortable in front of the camera, on a stage and at events.
- An appreciation of the medical, research and associated academic arenas, in particular the medicines research sector, would be useful (although not essential).
- An understanding of how the NHS works, and experience of influencing changes in clinical practice through partnership working would be desirable.

## Part Two

### Skills and Abilities

- A digital champion able to harness the opportunities created by social and technological advances to deliver outstanding impact for our stakeholders.
- Outstanding fundraising skills with the ability to build a strong pipeline and give funders, stakeholders and partners the courage and confidence they need to invest in us.
- Creativity to develop new ideas for delivering our work and championing our voice.
- Exceptional stakeholder skills with the sensitivity and care to work across a diverse stakeholder community.
- Commercial acumen to see how our assets could also generate an income for the charity and make a meaningful difference to our community.
- Collegiate and collaborative, with the ability to build a strong team committed to our purpose.

## Part Three

### Behaviours and Values

- Courage and patience.
- Ambition and drive.
- Sensitivity and empathy.
- Resilience.
- Integrity.
- Sense of humour.

# Terms of Appointment

|                       |  |
|-----------------------|--|
| <b>Salary</b>         | circa £110k set by the Trustees with pay reviewed by the Remuneration Committee, annually. |
| <b>Location</b>       | Our office is based in Fleet, Hampshire.   |
| <b>Pension</b>        | Contributions are 3% employee and 6% employer.   |
| <b>Annual leave</b>   | 25 days holiday + 8 Bank Holidays + 1 day Birthday leave.                                  |
| <b>Life Assurance</b> | Death in service x2 salary   |
| <b>Other</b>          | Perkbox subscription   |



# How to Apply

We hope you will consider making an application. If you have questions about the appointment and would find it helpful to have an informal conversation, please contact [Katy.Giddens@starfishsearch.com](mailto:Katy.Giddens@starfishsearch.com) or [Juliet.Brown@starfishsearch.com](mailto:Juliet.Brown@starfishsearch.com) by email.

To make an application, please go to <https://starfishsearch.com/jobs/tbtc-ceo/> and click on the apply now button, with the following prepared:

- Your CV (no more than three sides).
- A supporting statement of no more than three sides that sets out why you think this role is the right move for you and how you meet the Knowledge & Experience criteria.

We particularly encourage applications from those who are significantly underrepresented in our sector, including individuals from Black and Minority Ethnic communities.

**Closing date:** Friday 12th February 2021

**First stage meetings:** w/c 1st March 2021

**Interviews with The Brain Tumour Charity:** late March 2021



