

**Recruitment pack
Role: Trustee**

January 2025



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 brainstrustuk

14th January 2025

Greetings,

Thank you for your interest in joining the Board of Trustees at *brainstrust*. We are delighted that you are considering this opportunity to support the brain tumour community and help guide our charity.

brainstrust exists to empower everyone in the UK affected by a brain tumour to have the best possible quality of life. Our community has told us that this is possible with:

- Engagement with care and condition
- Reduced isolation
- A supportive community
- The tools to take control
- Knowing who to turn to for support

With this compass, we provide personal support via a coaching model to patients and their loved ones. We embrace depth and detail of need in our service, and as such can deliver innovative programmes to meet these needs. We advocate collaboratively for change with patient voice. We work tirelessly to improve lives in this community. We also fundraise relentlessly to fund this work.

We are entering an exciting new chapter. *brainstrust* is well-positioned for growth. With a dedicated team, robust financial reserves, and about to commence a new strategic period, we aim to deepen our impact, reach more people, and ensure long-term sustainability. To achieve this, we need passionate and skilled trustees who share our vision and values.

As a trustee, you will play a vital role in ensuring *brainstrust's* governance is strong and effective. You will help shape our strategic direction, oversee financial and organisational sustainability, and ensure we remain true to our mission.

In this recruitment pack, you will find everything you need to know about the role of a trustee and the impact you can have at *brainstrust*. We have also included information about our charity. If you are inspired by what you read and believe you can contribute, we would love to hear from you.

To apply, please send your CV and a cover letter outlining your interest and relevant experience to join.us@brainstrust.org.uk by 1200 on 21st February 2025. If you have any questions or would like an informal discussion about the role, please don't hesitate to contact me – will@brainstrust.org.uk.

Thank you for considering this opportunity to join *brainstrust* and help us make a lasting difference in the lives of those affected by a brain tumour. Together, we can achieve great things.

Yours sincerely,

Will Jones
Chief Executive, *brainstrust*



Regional office:

C19–C21, Joseph's Well
Hanover Walk, Leeds LS3 1AB

brainstrust is a registered charitable trust.
Registered with the Charity Commission
for England and Wales as Charity No. 1114634.
Registered with the Office of the Scottish
Charity Regulator as Charity No. SC044642.

The role

Role Title: Trustee

Reports to: Chair of Trustees

Location and time commitment: Board meetings are held 4 times a year, 2 are hosted online and 2 in person. Face to face meetings are typically held in Oxfordshire or London or Southampton. You will need to attend these 4 meetings each year, plus provide ad-hoc support as desired or required.

Purpose of the Role: We are seeking 2 passionate and committed individuals to join our Board of Trustees. With our board and executive team, you will ensure *brainstrust* is carrying out its work for the public benefit and you will be engaged in the planning and review of the charity's work on a regular basis.

Key Responsibilities:

1. Governance and Strategic Oversight:

- Act as a member of the Board, ensuring *brainstrust* remains compliant with its legal and regulatory obligations.
- Contribute to the strategic direction of the charity, with a focus on sustainability and growth.
- Support and challenge the executive team appropriately and where necessary to ensure the charity's objectives are met.

2. Advocacy and Networking:

- Act as an ambassador for *brainstrust*, raising awareness of our work and mission.
- Attend relevant events to represent *brainstrust* and foster new connections.

3. Board Engagement:

- Attend and contribute to quarterly Board meetings.
- Collaborate with other Trustees and the senior leadership team to support the development and execution of *brainstrust*'s strategic goals.
- Provide mentorship and support to the executive team where appropriate.

Person Specification

Essential:

- A commitment to the values and mission of *brainstrust*.
- Good self-awareness
- Willingness to devote time and effort to the Trustee role, including attendance at meetings and events.

Desirable:

- Previous experience as a Trustee or non-executive director
- Knowledge of brain tumour or cancer support and/or health or education sectors, or experience with health-related charities.

Terms of Appointment:

- This is a voluntary, unpaid role, although reasonable expenses will be reimbursed.

Application Process:

To apply, please submit your CV and a cover letter outlining your suitability for the role to join.us@brainstrust.org.uk

Selection Process

Familiarisation conversations will take place online via zoom or teams calls in February and March and will take place whilst the application window is open.

The deadline for applications is 12 noon on the 21st February 2025.

Proceedable applications will be progressed to formal interview in late March, with appointments made at the May meeting of our Trustees.

Diversity and Inclusion

We recognise that diverse perspectives, backgrounds, and experiences are essential to driving innovation and making meaningful impact. We are committed to building a Board fit for the communities we serve and reserve the right to consider applicants from all walks of life. We strongly encourage candidates from underrepresented groups to apply, as we value the unique insights and contributions that diversity brings to our organisation.



About *brainstrust*

A brain tumour diagnosis brings significant challenges to the patient and those around them. People find they can't walk; they can't talk; they can't see; they can't hear; they can no longer drive, and they can no longer work. Treatment is harmful and remains unchanged in 20+ years. Neurological fatigue is debilitating, and behaviour and personality change makes family life even harder.

brainstrust is a UK-wide charity uniquely dedicated to providing essential support and information to brain tumour patients and their families, and to supporting clinical research. With a mission to improve the quality of life for those affected by brain tumours, *brainstrust* offers a range of services, including coaching, patient and carer information, peer support, rapid-access counselling, and skills development for patients, their families and health care professionals.

By building communities, providing services and raising awareness, *brainstrust* makes a positive impact on the lives of individuals facing the challenges of brain tumours. People feel less alone, less afraid, more in control, better resourced, and more confident engaging with their clinical care.



About brain tumours

Every two hours, someone is diagnosed with a brain tumour in England
In the UK, 16,000 people each year are diagnosed with a brain tumour
Only 12% of brain tumour patients survive beyond five years of their diagnosis
Brain tumours are the chief cause of cancer deaths in children and young people
Brain tumours continue to kill more children and adults under the age of 40 than any other cancer
Brain tumours deaths are rising, representing 2.6% of all deaths from cancer
Brain tumours kill more men under 70 than prostate cancer and more women under 35 than breast cancer
Incidences of and deaths from brain tumours are increasing

There is a vibrant eco-system of charities, clinicians, companies and campaigners that are working to address these issues, of which *brainstrust* is proud to be an instigator and collaborator.

Our impact for brain tumour patients and their caregivers

Awareness of *brainstrust* and our work is increasing, with more people than ever before accessing our support and information.

The number of people with a brain tumour that we are helping each year is increasing, and the *rate* of increase is also increasing.

In 2023-2024, 897 people with a brain tumour and 617 caregivers contacted *brainstrust* for direct support. This support comprises coaching, counselling, phone and email support and event attendance. This total of 1514 people is a 17% increase on the year before.

Once people have contacted us for help, we are here for them wherever they are on their brain tumour journey, and whenever they need us. At the end of the year, we were helping around 400 people every month.

Last year our support team helped 4689 people, an 8% increase on the preceding year, and double the number of the year before that (2021-22: 2339 people).

In 2023-2024 125,405 people looked at 306,311 pages on *brainstrust.org.uk*. This is an increase of 27% in users on the preceding year (2022-23: 98253) and a 42% increase in pageviews.

More people are looking at more information on *brainstrust.org.uk*.

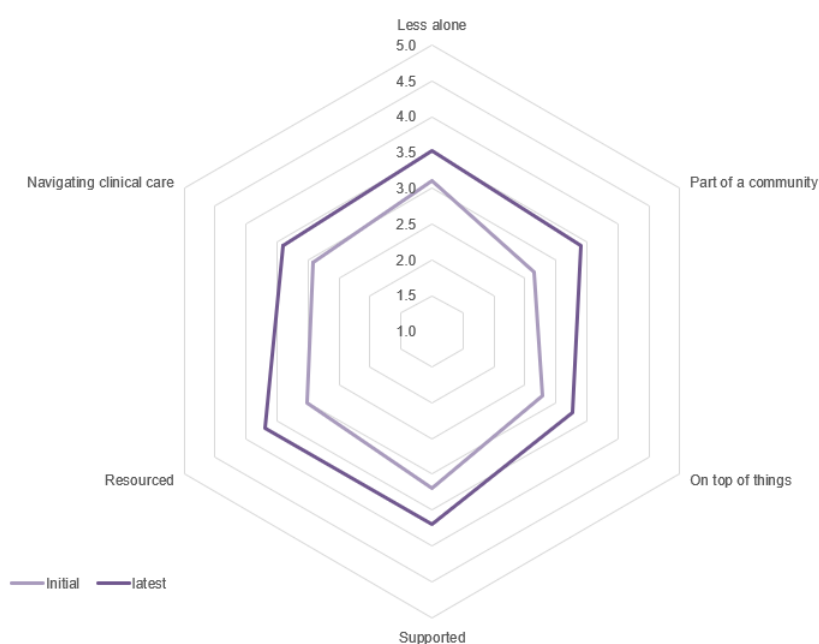
Anyone can access our information anyway they wish, and we are seeing a significant increase in downloads of digital versions of our revered printed information. 12,000 digital (PDF) resources were downloaded during the year, a 73% increase on the previous year (2022-23: 6928).

3000 people have now provided feedback on our online information. 89% of these people tell us that the information helped them to be more resourced, more confident or more in control.

We recognise that reach and impact are 2 different things. When people seek help from *brainstrust* we work with them to track their progress against 6 key impact indicators. These indicators are:

- engagement with care and condition
- reduced isolation
- engagement with communities
- creating control
- feeling supported
- feeling resourced.

You can see below how we have helped our community to navigate the complicated journey of living life with a brain tumour diagnosis in the last year.



Our impact on the research landscape

In 2021, we created the Patient Research Involvement Movement (PRIME) to bridge the gap between the clinical community and brain tumour patients and their caregivers. Through PRIME we improve the quality of clinical brain tumour research, ensure trials are more likely to be funded, and contribute to a healthier landscape of treatment for the brain cancer community.

We continue to see a healthy growth in our PRIME community, going from 57 volunteer advocates and partners in 2022, to 115 in 2023 and now 151 in 2024. This community of research-primed and informed individuals is expert by experience and has made huge contributions to brain tumour research with top-level patient involvement support.

We continue to improve the standard of PPI in clinical research, remaining thought-leaders in this space and continuing to grow our service. We do this by:

- Collaborating with other charities, including Brain Tumour Research
- Exploring new ways to share our services with clinicians
- Having more conversations with researchers and research funders regarding funding for this vital service
- Continuing to develop a training and webinar programme for our volunteers
- Learning and adapting methods of delivering the best patient involvement

Since its inception, PRIME has successfully supported research applications to the value of £28.2m



Organisational structure

Good governance is an essential component of our success, particularly as we grow. It underpins our integrity, reinforces the trust and confidence our patients and partners place in us and contributes to a strong high-performance culture.

Chris Baker, Chair of Trustees

brainstrust is constituted as a trust, governed by its Declaration of Trust, dated 4 March 2006.

The overall guidelines for the management and administration of the Trust are incorporated in the Declaration of Trust, dated 4 March 2006, as amended by Deeds of Amendment adopted by the trustees under the terms of the original deed and notified to the Charity Commission.

This places overall responsibility for the proper governance of the Trust with the appointed trustees. Day-to-day management of the Trust is delegated to the chief executive of the Trust. The chief executive, supported by the leadership team, makes recommendations to the trustees on the Trust's vision, patient and caregiver support, related research, financial fundraising, promotional activities and ensuring that funds raised are spent as efficiently as possible on resources that will be useful to people affected by brain cancer. *brainstrust's* trustees have had regard to the guidance issued by the Charity Commission on public benefit.

Our Board of Trustees

brainstrust's trustees are Christopher Baker (Chair of Trustees), Kevin Higgs, Stephen Warrington, Puneet Plaha and Jack Jarvis.



L to R – Puneet Plaha, Stephen Warrington, Jack Jarvis, Kevin Higgs and Chris Baker.

Four of the five members of our board have lived experience of a brain tumour diagnosis, professionally or personally. All are passionate about and committed to *brainstrust's* mission and governance and all bring diverse relevant professional and personal experience to our organisation, freely and with public benefit at heart.

About our Trustees

Chris Baker

Chair of Trustees

Chris is EMEA managing director at a leading global software company and has over 20 years' experience driving growth at some of the highest-profile companies in the world, including Microsoft and Salesforce. Chris has been a trustee for nearly 12 years and the chair of trustees at *brainstrust* for seven years.

Kevin Higgs

Trustee

Kevin is a financial adviser and has been a trustee for fourteen years. In a chance meeting while at a previous employer, Kevin was immediately taken by the dedication and commitment of the charity to

focus on the support and well-being of patients and families diagnosed with a brain tumour. He knew that he wanted to be a part of the journey that *brainstrust* has been on since 2006.

Stephen Warrington

Trustee

Stephen brings to the organisation extensive experience leading professional services businesses and consulting for major multinationals, and he has been a trustee for seven years. Stephen's teenage son was diagnosed with a brain tumour and underwent successful surgery.

Puneet Plaha

Trustee

Puneet is an associate professor and consultant neuro-oncology surgeon in Oxford, with a specialist interest in brain tumours, especially endoscopic minimally invasive surgery and awake surgery. He has been a consultant neuro-oncology surgeon lead for the Oxford brain tumour MDT and neuro-oncology lead for Thames Valley since 2012. Puneet joined *brainstrust*'s board of trustees in March 2021.

Jack Jarvis

Trustee

Jack is a serving British Army Commando, and world record setting transatlantic solo rower. Jack brings tenacity, energy and a high-performance mindset to our board. Jack is an ardent and successful fundraiser, motivated by personal experience of a glioblastoma in his family, as well as by his own experience navigating a complex rehabilitative journey after a serious accident. He understands the value, opportunity and impact that *brainstrust*'s work bears, and is our newest board member, joining in January 2024.

***brainstrust*'s senior team**

brainstrust has a stable, experienced and committed leadership team who are aligned in delivering our mission and who are the strongest advocates of our 'people first' vision and values. Day to day the leadership team work to promote, develop and instil purpose, autonomy and mastery throughout the organisation through a 'tight-loose' approach which is manifested in tightly defined objectives for each member of the team, but loosely defined method. This allows people to work the way that suits them best to achieve the right goals for *brainstrust* and our beneficiaries.

[Will Jones](#) – Chief Executive

Will joined *brainstrust* as Development Manager in 2009, having worked in strategy and account management in the publishing and marketing sectors. This included 4 years at one of the UK's largest independent communications agencies, collaborating with clients that included Action Aid; Seven Seas; Yorkshire Forward; Yorkshire Building Society; the Department for Children Schools and Families; and UK Trade and Investment. Will became Director of Development at *brainstrust* in 2011 and took on the broader responsibilities of Chief Executive in October 2016.

[Dr Helen Bulbeck](#) – Founder and Director of Services and Policy

Helen is co-founder of *brainstrust* and has experienced cancer as both a patient and a caregiver. She leads our Support Team and is passionate about using her experience to support the thousands of patients who have brain cancer. Her 360-degree view means that she is well placed to understand the perspectives of patients, caregivers and health care professionals; these are her key drivers with whom she interacts daily. Her ethos of 'none of us is as smart as all of us' is a core value for her.

[Kathy Springate](#) – Head of Finance

Kathy has worked in finance for over 40 years, including 20 years in the Treasury Division of Lloyds Bank plc. She joined brainstrust in 2016 as Finance Administrator and brings a range of experience to brainstrust working closely alongside the Trust Administrator to ensure the production of accurate & timely accounts conforming to the statutory requirements.

[Jodie Eveleigh](#) – Head of Support

Jodie, a trained ILM level 5 coach and mentor is our support team lead. She has long experience delivering *brainstrust*'s work by geography, and by diagnosis. She understands the value of networks and communities. She is motivated by her own experience of an astrocytoma diagnosis in the family, and her desire for *brainstrust*'s help to reach more people as soon as possible on their journey.

Supporting documents and further reading

You can read our latest, and recent full year reports and accounts here.

<https://brainstrust.org.uk/about-brainstrust/our-governance-and-reporting/>

Our governing document is available to read here:

<https://www.dropbox.com/scl/fi/c4ma9j9sn8nnuxgfpcobd/Brainstrust-Declaration-of-Trust.pdf?rlkey=l9v4ec0gzzn9aag9nzzb5ugpw&dl=0>

“The Essential Trustee” Government guidance on what's required of a charity trustee, including your responsibilities to your charity. This guidance explains the key duties of all trustees of charities in England and Wales, and what trustees need to do to carry out these duties competently.

<https://www.gov.uk/government/publications/the-essential-trustee-what-you-need-to-know-cc3>