



## Trustees' annual report and accounts

*brainstrust* – the brain cancer people

1 April 2022 – 31 March 2023



.....  
*When you become a caregiver, you suddenly have to make decisions about someone's health and wellbeing that you never thought you'd have to. Suddenly everything falls to you.*

**Caregiver to a low grade glioma patient**  
.....

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# Our challenge

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*'I struggle with multiple issues - fatigue, physical and mental problems - but I try to focus on healing and the road to recovery.'* **Patient**  
.....

*'What am I not struggling with? I suffer daily symptoms, which range from tinnitus, dizziness, head pressure and pain, which frightens my husband.'* **Patient**  
.....

*'Following on from my father's diagnosis yesterday myself and my family are in a state of shock, while trying to navigate what lies ahead so as to ensure that my father has the best possible care.'* **Caregiver**  
.....

*'I had to be on the drugs for two years at least, as my tumour was small, but in an area associated with seizures. It devastated me. Everything caught up with me. It was the identity shift that was difficult - I wasn't prepared for going from a "surgery survivor" to "epileptic".'* **Patient**  
.....

*'My diagnosis was delivered over the phone by my GP, which was incredibly hard to deal with. The best way to describe my feelings at the time is a mixture of fear paired with an overwhelming sense of confusion. As how could this be happening to me? I had just finished my degree, which I had worked hard for. I was starting a new job that I was excited for at the end of the week, and I had just turned 24 years of age a few weeks prior. It felt like such a cruel twist of fate for this to happen as my life was just coming together how I wanted.'* **Patient**  
.....

**Over 80,000 people are living with a brain tumour in the UK. Only 12% of adults survive beyond five years following a diagnosis. Brain tumours reduce life expectancy by an average of 27 years, and they kill more children than any other cancer, yet treatment for a brain tumour is brutal and harmful. It hasn't changed in 40 years.**

The impact of brain tumours is under-reported, support and research under-funded, and the true impact of the disease under-acknowledged and misunderstood.

When you hear the words 'you have a brain tumour', you face both a potential cancer diagnosis and also the prospect of progressive and debilitating neurological disease. You are afraid, you are alone, you are confused, and your life changes dramatically in an instant.

Today, *brainstrust* is here to help everyone live their best possible life with a brain tumour in the face of these stark facts. We help people thrive and have their best possible day. We are also here for tomorrow. We hope for a world in the future where brain tumours have little impact. But we know that hope is not a strategy. We support clinical research and work with our community of experts to improve investment and build capacity so that harm is reduced, care is improved at hospital and at home, and people are more confident and able to take control. Only then can life with a brain tumour be fulfilling and enjoyable, and people who have heard the words 'you have a brain tumour' are living the lives they want, because they are people first and patients second.

**This is our challenge.**



# Strategic report



**Will Jones**  
*Chief Executive*

**Chris Baker**  
*Chair of Trustees*

## Letter from chair and CEO

Thank you for taking an interest in our mission and passion for helping people with a brain tumour to have the best support available so that they can live their lives as people first and patients second.

Following a strong year on all fronts in 2021–22, this year has been one of planned investment to build capacity. We have grown our team, expanded our collaborative relationships and developed our skills to meet demand, which has increased steadily each quarter. And with this growth, we have sustained impact.

While from an organisational and governance perspective, this paints a picture of positive progress, we are only too aware that for those diagnosed with a brain tumour, the challenges of isolation, fear, confusion in the face of complex treatment, lack of support and poor clinical outcomes are as present as ever. There are over 80,000 people living with a brain tumour in the UK, and we still have much work to do to reach everyone who needs us.

## But we are rising to this challenge.

We are reaching more people every day, with beneficiary numbers growing over the year at 15% each quarter, and we have grown our skills and capacity to meet new needs in the brain tumour community. Perhaps the most pertinent of these is the impact of the cost-of-living crisis.

Working with volunteers, we have been able to provide welfare and benefits support, which has helped those that need it secure £94,760 in vital support over the year.

Leaning into where we know we have the most impact, we have formalised our intensive coaching offer, in partnership with Thrive Partners and made possible thanks to our Rank Foundation Golden Award. With the funding from The Rank Foundation, we have been able to pilot the Thrive platform, bringing structured online coaching to the cancer care and charity space for the first time. Feedback and outcomes are good, with people scoring their experience as 10/10, from 164 completed sessions. Our expert coaches have been scored 5/5 from these sessions.

Fundraising is an equally important part of our work. To be able to support everyone who needs us and sustain our impact, we need to raise over £1.5m every year.

Our diverse portfolio of fundraising continues to sustain our work, with our community as passionate as ever about giving back and enabling us to help others. While at face value not a record year for income, the period in review carries a high level of unrestricted income, which is vital in helping us cover our core costs and deliver our service. Funds raised over the year total £691,706. This has been derived from a traditional mix of charity fundraising channels. The fourth quarter of the year did bring a slowdown in community fundraising and trading activity as our supporters bore the weight of the cost-of-living crisis.

Looking to the year ahead, and in the face of a challenging social, economic and political climate, we are planning to consolidate our expanded scale following this period of investment, sustain or grow our impact, and inspire more people and organisations to get behind our mission to help people with a brain tumour to live their lives as people rather than patients.

# Our purpose and our work

## Our strategy: First, we are people

In April 2019, we launched our current strategy. Thirteen years in the making, this strategy, 'First, we are people', puts laser focus on the human, practical and cultural contexts in which people find themselves following a brain tumour diagnosis. It sets out our journey to help people living with a brain tumour become less isolated, more in control, more involved with their clinical care and condition, and better resourced.

The human context sees a forgotten group of people who, following diagnosis, see themselves fall into a chasm between improving clinical care and the scientific pursuit of a cure. In acknowledging that before we are patients, we are people, we can help people navigate this void, for when we are patients, we are only patients for a small amount of the time. We want to do things that people want to do, not always the things that patients have to do.

.....  
*The “all together, stay calm in a crisis and sort out anything” me has been completely taken off guard. I am so lost. Patient*  
.....

In practical terms, we know from our intimately close work with our community of people with a brain tumour, and their caregivers, that a brain tumour is isolating, the journey is confusing, communicating well is hard, behaviour and personality change devastates relationships, fatigue impacts 95% of those diagnosed, and there is a huge financial impact as work stops. These are just some of the challenges, and these challenges are not addressed in either the laboratory or the hospital. They are addressed at home, where help is hard to find.

## How we got here

Our direction has been set in consultation with our community. We 'asked the experts' what they needed, to understand what matters most.

We heard:

- You spend more time being a person than you do being a patient.
- As a person, you are more resourceful, more proactive and more confident in the face of challenges.
- Emotions and values drive your behaviour, not just clinicians. What matters to you is more important than what is the matter with you.
- People look at opportunities. As a person, you grow. Patients tend to focus on problems, and barriers are hard to overcome unless they can be treated or medicated.

Our current strategy has been co-created with our community and delivered with its support. This strategy is helping us to achieve our mission – we are here for a world in which people with a brain tumour are involved, resourced, supported, confident and connected. They are living the lives they want, because they are people first and patients second.



## The experts we asked

The conclusions and decisions reached in the development of our strategy result from conversations and day-to-day meetings and experiences over a six-month period with the following stakeholders:

- beneficiaries – people living life with a brain tumour and their caregivers
- supporters
- current and prospective philanthropic funders
- other charities
- *brainstrust* team members and trustees
- national research bodies
- local and national research funders
- clinical experts from all specialities
- campaign groups.





# Key achievements

## Our support

*This year we have grown our team to meet increasing demand and build capacity so that we can continue to help more people than ever before with brainstrust's unique and impactful support.*

*Riding the momentum we carried through the pandemic, this year has seen us move forward, with and for our community at pace, and without compromising our impact.*

*Every day the resourcefulness and resilience of our community inspire and motivate us, and our strategy and structure have enabled us to scale our work across new regions. We hoped that this year would be exciting for brainstrust, for our community and for our team, and it has been. This is not to make light of the devastating challenges faced by the people we are here for, but it is a comment on how we have never felt more confident, single-minded and committed to our mission to make life better for people post-diagnosis.*

**Helen Bulbeck**, Co-Founder and Director of Services

During the year, **3,439 people accessed our help** by phone or email, webchat or video call. An increase of 47% on last year (2,339), and 172% on the year before (1,264).



**1,306 people accessed our help for the first time** during the year. 739 of these people were brain tumour patients. 567 were caregivers or close friends or family members seeking support. This is a 58% increase on last year (825).

*I'm having a bad day. I feel very demoralised and very down. Hard with the "simple" day-to-day things and even harder with more difficult days, like today. I find it easier to put things in writing. I can take as much time as I need to explain. I just wouldn't be able to find the words in a phone call. I am so glad I can turn to you for help. You understand. I don't feel so alone. I'm starting to feel better now, and calmer.*

**Brain tumour patient**, south-east England

We were able to send **368 brain boxes** to people who needed them. This is 34 fewer than last year.



Our volunteer-led welfare and benefits support service **helped 41 people to access financial support worth £94,760**. This comprises Personal Independence Payments (PIP), Disability Living Allowance (DLA) and one-off grants from local organisations.





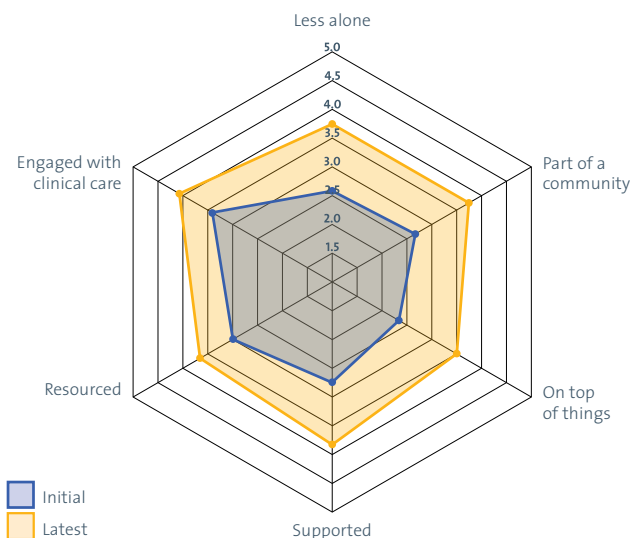
Between 1 April 2022 and 31 March 2023, we provided **372 counselling sessions to 62 people** via our network of specially trained and professionally qualified counsellors.



On average, those that have accessed counselling through us have progressed by 0.97 across our impact indicators **This represents a 24% improvement.**

**24%**

People who accessed counselling with *brainstrust* reported feeling more on top of things and less alone – where for both indicators we enabled a 29% improvement.



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*When I found out about brainstrust, it was nice to speak to like-minded people who were in a similar position and stage of a brain tumour diagnosis. They kindly sent out a brainstrust brain box, which meant a lot to me at the time, as I didn't feel so isolated, as I wasn't on my own going through this. This must have cost a lot, so I donated – as I still refer to one of the books that was sent to me, it is a very small price to pay. There is a Zoom meeting that I can attend if I want to and speak to other people, where you can vent off frustrations, amongst lots of other things that concern you. I have attended the Liverpool event held recently, which consisted of people working in different fields of brain tumours in the morning session, and in the afternoon we could ask questions amongst other activities held, and I found this INVALUABLE. Long may they continue, as they do a sterling job.*

**Brain tumour patient, Liverpool**

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### Online support and information

**120,668 people came to brainstrust.org.uk** for the first time for information during the year, a 9% increase from 110,928 the previous year.

**9%**



These people accessed **270,716 pages** and downloaded **9,384 copies of long-form health information** from our website.

During the year, the **most popular information** has been about diagnosis, brain tumour types, patient stories, end-of-life care and glioblastoma trials and treatments.



Of the 2,469 people who have provided feedback on our information, 2,219 (90%) tell us that what they have read has **helped them to feel better resourced and more in control.**

The most highly rated information on our website is our content about end-of-life care, the brain box, anatomy and tumour types and brain tumour symptoms and diagnosis.



Feedback and outcomes are good, with people scoring their experience as 10/10, from 164 completed sessions on the platform. Our expert coaches have been scored 5/5 from these sessions.

## Thrive with *brainstrust*

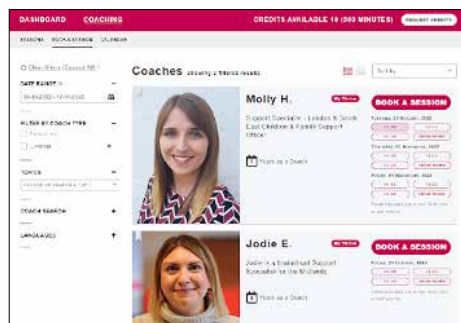
*I found it helpful to lay out all the things I'm feeling overwhelmed about and what I do and don't have control over and work out the places where I can get more support/information around my treatment and what the next steps are. The exercise of writing things down and categorising those areas was useful and helped get everything out of my head, and I felt supported and heard.*

**Brain tumour patient**, London

During the pandemic, we accelerated our plans to make our coaching service available online. This work progressed at pace during the year in review, culminating in the launch of the 'Thrive' coaching platform.

On this platform, people can select a coach, book sessions and attend via secure video call. Goals and topics are set prior to the call, and evaluation takes place within the platform.

Coaching via the Thrive platform gives users structure and direction in the support they receive. The platform allows people to choose when the sessions take place and to set the focus. This sets a clear pathway to attaining their goals. As it is a video platform, people get to see their *brainstrust* support specialist during the sessions, so they can feel as connected as possible with their coaching journeys.



## Madi's story

Madi's story shows the significant impact this work can have. Madi has lived with brain tumours for nearly 30 years and is a survivor of multiple surgeries. She recently came to *brainstrust* for support as her third surgery approached and she faced ill-health retirement from a career she had worked hard for and loved.

Madi engaged with our coaching service through the Thrive platform and told us: 'There is something about there being a particular place to go that adds value to the sense of belonging and community. It also reminds me that there are other *brainstrust* resources, such as the fatigue book, that I can go back to. The follow-up emails my coach sends me after each session provide me with an opportunity to respond in writing, as do the feedback and booking forms on Thrive. Writing is a very helpful reflective tool for me and helps me consolidate what I am taking away from each of the face-to-face online sessions. The online sessions are helpful to me, as I don't need to travel and can rest before or after sessions, depending on my fatigue.'

Madi told us: 'I feel empowered and have the sense of being held in a kind of soft safety net. The questions I've been asked and the relationship I've built with my coach provide an inner voice to challenge some of the less helpful thoughts I may have. I have achieved a sense of relative calm whilst waiting for information about my ill health, retirement and next surgery.'

Using our progress tracker tool over the four-month period she was engaged in online coaching, Madi improved her overall well-being by 76% from an initial total score of 17 out of 30 across all six of our key indicators to her most recent maximum total score of 30 out of 30.

# Our impact

## Background

There are nine pillars that drive our efforts to understand the impact of our work.

**Accountability:** We are entrusted with resources, often donated by individuals, corporations or governments. Measuring impact allows charities to demonstrate how effectively we are using these resources to achieve our goals.

**Resource allocation:** Limited resources are a common challenge for charities. By measuring impact, we can identify which of our efforts are delivering the most significant results. This information guides informed decision-making on where we allocate resources for maximum effectiveness.

**Improvement:** Regularly assessing impact enables us to identify areas for improvement. By understanding what is working well and what isn't, we refine our strategies, modify programmes, and enhance our approach to better serve the people we are here for.

**Learning and adaptation:** The landscape in which we operate changes rapidly. Measuring impact helps us to stay agile and responsive to evolving needs. When we can track changes in our beneficiaries' lives, we are better equipped to adapt our work appropriately and with confidence.

**Advocacy with evidence:** When we are pushing for policy changes or increased funding, measuring impact provides tangible evidence of the outcomes we are achieving, or demonstrates the gap that we need to close.

**Effective communication:** Sharing our impact data allows us to communicate our achievements effectively. It makes our stories relatable

and understandable, enabling us to connect with a broader audience and inspire people to join our cause.

**Engaged supporters:** People and institutions want to know that their contributions are making a difference. Impact measurement provides donors with a clear picture of how their support is creating positive change.

**Strategic planning:** Impact data informs our planning. We can set more realistic and achievable goals when we have a clear understanding of the outcomes we can deliver based on past performance.

**A learning culture:** A focus on impact cultivates a culture of continuous learning and improvement. We are more open to experimentation and innovation as we seek out the best possible ways to achieve our mission.

Measuring impact is about maximising the effectiveness of our work, ensuring that our resources are used efficiently in generating positive change for people with a brain tumour.

We have worked hard over recent years to create a culture where impact is not only at the centre of our processes but also a central part of the conversations we have with the people who need us. Tracking impact is mutually beneficial.



## Methodology

We track progress against six indicators. These have been defined as being important to quality of life by our community of patients and their caregivers. In turn, these indicators support the four priorities in our strategy. These six indicators are:

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

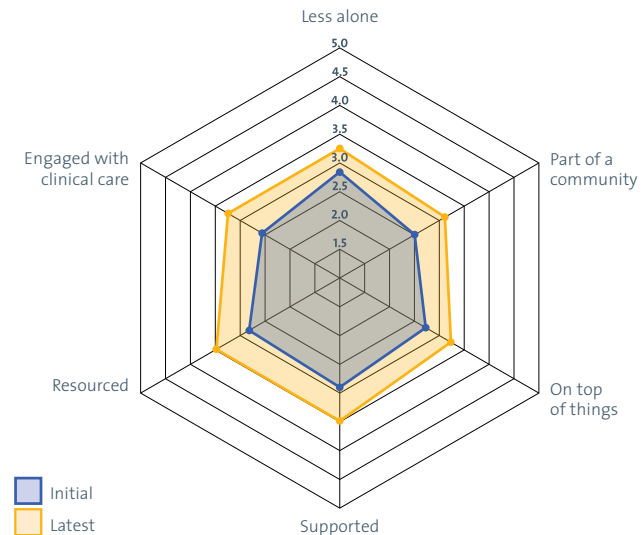
We learn how people are doing against these indicators using our bespoke progress tracker tool. This gives us a simple, flexible and human approach to understanding impact. Progress trackers are completed and monitored collaboratively with our beneficiaries. The process isn't unobtrusive, but it is helpful. In completing a progress tracker, or multiple progress trackers, we help people to establish where the focus of our support needs to be to help them move forward. To complete a progress tracker, patients and caregivers provide a score of how they are feeling on a scale of 1 to 5 for each of our indicators. They complete multiple progress trackers on their journey with *brainstrust*, and this paints a picture of their progress.



## The impact we're having

People who have come to us for help in the last year have made progress against our six key impact indicators.

On average, people have progressed by 0.57, on a scale from 1 to 5. This equates to a 14.25% average increase in well-being across the board. This is even greater for some indicators.



- We helped people improve the most with feeling able to navigate their clinical care, where we saw a 17.25% increase.
- After that we saw a 16.25% increase in feeling resourced.
- An area our focus should turn to from here is helping people to feel less alone, as we saw our smallest increase, of 10%, here.

In total, during this given period, we had 84 people complete their second progress trackers and 328 people complete their first.

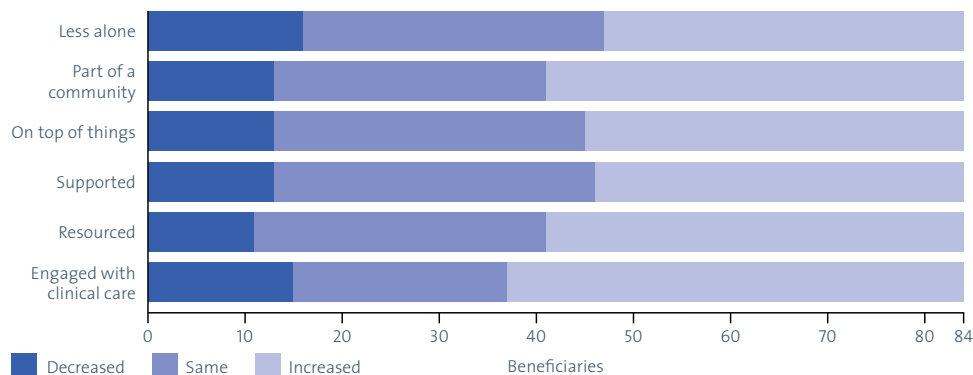
We have worked hard over the year to close the gap, ensuring we are collecting as many second trackers as possible to get an accurate picture of the impact of our services.



*I've been feeling really alone since my last consultation as I feel like I'm burdening friends and family by discussing it over and over but at the same time it's such a huge decision I don't want to make it on my own.*

**Patient**

**Beneficiary change 2022-2023**



Over the year, we helped the vast majority of people who contacted us to sustain or improve well-being in the face of progressive neurological disease where, by all clinical measures, regression is more than likely.

*It is important that we are realistic in our expectations, given the context in which many of the seriously or terminally ill people with whom we work find themselves. For many in this space, maintenance of well-being is an important and ambitious goal, and we are proud to help people achieve this.*

**Adam Thomson**, Patient Involvement Officer and Impact Lead

Numbers alone don't always shine a light on the powerful outcomes that *brainstrust* creates for people, or the challenging circumstances they face. Over the year we heard a lot about the impact our work is having directly and unprompted from the people that need us:

*I am now at the stage where I really want to share all that I have learnt on my brain tumour journey, and give back to the community. With that in mind, it was perfect timing when I bumped into the lovely team from brainstrust at a brain tumour conference I'd been asked to speak at. Combining my coaching qualifications and experience on my brain tumour journey, I can now support others in coming to terms with where they are at, and then help them start to take powerful, positive action to live their best lives possible.*

**Damon**, *brainstrust* volunteer and brain tumour patient



## Area of impact Beneficiary feedback

<b>Less alone</b>	<ul style="list-style-type: none"> <li>• <i>That's the first time I've been able to talk with other brain tumour patients in person, and I found it very therapeutic.</i></li> <li>• <i>I do feel so incredibly blessed and lucky to have found you and brainstrust. It really does feel so comforting knowing you are there. Thank you from the bottom of my heart.</i></li> <li>• <i>I remember when I got my brain box, it felt like a warm hug and stopped me from feeling alone. I hope someone else gets to feel the same.</i></li> </ul>
<b>Supported</b>	<ul style="list-style-type: none"> <li>• <i>I'm still in shock, but it's because of all the amazing people in my life, like you, who continue to encourage and support me. Thank you for your ongoing support and encouragement. I am very lucky to have such amazing people around me and wouldn't be where I am without you, I am sure.</i></li> <li>• <i>You have been a real beacon of hope for me when I felt all at sea at the beginning of this journey.</i></li> </ul>
<b>On top of things</b>	<ul style="list-style-type: none"> <li>• <i>I found the session very useful. I now feel I am heading in the right direction to be as in control and on top of things as I can be. Mariel put me at ease, as this was the first online interactive thing I have ever done, and she also teased out the positive things I didn't realise I was already doing and some issues that we could address at a later date. Thank you for your advice today.</i></li> </ul>
<b>Resourced</b>	<ul style="list-style-type: none"> <li>• <i>The hypnotherapy helps me to focus on my needs, relax, find a calm place in my head. It reminds me that I need to look after myself. The 'meningioma matters' sessions give me relevant information and keep me up to date, allowing me to learn from others' experience as well as providing a support network who 'get it' in relation to lived experience. The information on the website has been useful in researching things like radiotherapy. The Facebook site gives me that community again; it's nice to feel I can occasionally offer understanding or suggestions to others.</i></li> </ul>
<b>Part of a community</b>	<ul style="list-style-type: none"> <li>• <i>For the first time, I felt the group really knew what I was feeling. Acoustic neuromas are rare, so I haven't been able to find people who have been through similar experiences, and this forum was supportive, friendly and informative. I am so grateful to have the opportunity to learn and share ideas with this group. Looking forward to the next one.</i></li> <li>• <i>I have found the online 'family and friends' Meetup very helpful and supportive. It has been interesting to connect with other people who are experiencing similar situations but who obviously have different ways of coping. I have found it a very useful platform for exchanging management/coping skills, and it helps me to feel less alone with my situation.</i></li> <li>• <i>Reading other people's stories has really helped me not feel so alone with the life-changing nature of this diagnosis. I've learnt to accept the new me, and know that while I'm different to how I was – there are certain situations I now find difficult, and I don't have as much energy as before – that's OK. A brain tumour affects different people in different ways. Accepting this, and accepting help from everywhere it's offered, plus talking about it and telling your story, can really help.</i></li> </ul>
<b>Confident navigating clinical care</b>	<ul style="list-style-type: none"> <li>• <i>You should know that your advice was instrumental in us obtaining a treatment that saved Caroline's life. I'll always be grateful to you for that.</i></li> <li>• <i>The information webinars (understanding scans) help me understand and ask questions. The information sheets are really useful (radiotherapy, uncertainty) and the new meningioma information is great.</i></li> <li>• <i>In the short time of contacting brainstrust, you changed my future instantly, and you helped me get the care I needed and knew I deserved. I am forever grateful to you for that.</i></li> </ul>

## Meet Hannah, caregiver for her dad

When my dad got diagnosed with a grade IV glioblastoma last year, our lives turned upside down. My dad and I have always been close, and it hit me really hard.

*brainstrust* sent us a brain box as soon as we got our diagnosis, and their resources really helped, but a few months in, I realised I needed extra support. I reached out to *brainstrust* who instantly set me up with Molly, one of their coaches. Molly was amazing, and we spoke lots about my dad, all my concerns, and sometimes (read: regularly) the sessions just allowed me to have a really big (and much-needed) cry.

After a couple of months, we reached the decision that I was ready to start counselling. I was just going back to university after the summer, and we decided that the summer holidays would be a good time to do it. As soon as I sent the email, Molly and *brainstrust* put me in touch with a counsellor, who helped enormously. Even now, Molly still checks in occasionally to make sure I'm doing okay and to let me know that support is still there if I need it.

Through *brainstrust* coaching with Molly for many months, and her helping me take the steps for reaching out for counselling over the summer, I felt like I was able to come to terms with my dad's diagnosis. Their support means I can enjoy my time with him, however long that may be. I feel more able to navigate my dad's ups and downs and the harsh reality of what we are dealing with. I feel like I have taken steps to come to terms with everything now. This has meant that I can now enjoy the time I have left with my dad without dealing with anticipatory grief and guilt.





## PRIME – bringing people closer to research

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. This work improves the quality of clinical brain tumour research and its design.

This time last year, 57 volunteer research partners and advocates were supporting PRIME with top-level patient involvement. Over this year, we have more than doubled this number, with a combined total of 115 individuals lending their insight and knowledge to clinical trial design.

The PRIME community is expert by experience. And this expertise has been used to test and design intervention tools to support mental well-being, influence studies that explore how treatment prior to surgery may improve outcomes, and provide guidance on how patients should be stratified into a trial comparing photon and proton therapy, just to name a few.

At any given time, PRIME supports 15 to 30 studies. There is a range of opportunities for the patient and caregiver community to be involved, ensuring that researchers working in the field have access to strong patient involvement.

In the future, we will continue to improve the standard of patient and public involvement (PPI) in clinical research, remain thought-leaders in this space and continue to grow our service. We will 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.

We have continued to work in partnership with the charity Brain Tumour Research to grow this work to mutual benefit. We have also received generous support from Naseem’s Manx Brain Tumour Charity in the previous year to bring people with glioblastoma closer to relevant research.





PRIME has successfully supported research applications to the value of £20m, with partners who include:



## The story of a trial: PORTRAIT

Working with Dr Gerben Borst, we inputted into the PORTRAIT study, which is to explore how using Optune prior to and following surgery might improve surgical outcomes.

We worked together to plan for the patient and public involvement and engagement (PPIE) strategy, which began with setting up focus groups.

We organised, recruited for and facilitated focus groups for Dr Borst, where he shared the study design with the community and they fed back their thoughts and ideas.

Following review of the study design, a PRIME research partner, Grant Stobart, was recruited to help produce patient-facing materials for the study.

The PRIME team, Grant and the PORTRAIT team met regularly to work on informational videos for those recruited to the study.

This also determined language, accessibility and preferences for those enrolled. Throughout the design process of the study, Dr Borst would refer to Grant and the PRIME team at *brainstrust* for input and discussion.

Dr Borst can use our ongoing PPI input to support his funding application, increasing the strength of the study proposal.

## The story of a trial: APPROACH

### Analysis of Proton vs. Photon Radiotherapy in Oligodendroglioma and Assessment of Cognitive Health.

- Dr Louise Murray, Professor Susan Short et al., University of Leeds
- Funded by the National Institute for Health Research (NIHR): £1,499,803
- Start date: June 2021
- End date: June 2031

*brainstrust's* role as co-investigator involves support of the Trial Management Group (TMG) with two further experienced patient advocates, each from two participating centres. These individuals form the PPI panel that advises APPROACH researchers and fully participates in the decisions needed as the study proceeds.

This PPI panel is self-organising, ensuring that it is fully integrated throughout preparation, execution and dissemination, and in the governance structures. *brainstrust* assisted with establishing the terms of reference and methodology for PPI so that PPI is truly in the DNA of the trial. This will be facilitated through a PPI panel. At regular touch points, a focus group of patients, caregivers and the public is consulted to ensure that value is added and impact is made. The panel ensures that patient opinion, experience and insights are garnered and heard, and it provides a bridge for dialogue between patients and clinicians.

The activity is discursive and participative in its consideration of evidence emerging from the trial, and it identifies areas of patient impact where further information is needed. *brainstrust* also assists with dissemination of trial news and results. Developing dissemination strategies is a core part of our work. This is done through established networks that include the NCRF consumer forum, charities, neuro-oncology societies and, in the case of this trial, radiotherapy organisations.

# Our influence – informing change in the future

Brain tumours present severe challenges to society in the UK, not only affecting individuals and families but also our healthcare systems and government. These broader challenges include:

**Healthcare burden:** Diagnosing and treating brain tumours involves complex procedures, including surgery, radiation therapy and chemotherapy. These treatments require specialist medical expertise and equipment, which strains resources.

**Limited treatment options:** Brain tumours are difficult to treat, and in many cases, there are limited effective treatment options. This leads to frustration among patients and their families, as well as healthcare professionals, who are trying to provide the best care possible.

**Long-term care needs:** Brain tumour survivors require expensive long-term care and support due to ongoing medical and psychological needs. This strains families and systems alike.

**Research and funding:** Brain tumours remain an area of active research, but funding for brain tumour research is limited compared to other diseases. This hinders the development of new treatment options and innovative therapies.

**Public awareness and stigma:** There is a lack of public awareness and understanding about brain tumours, leading to stigma and misconceptions. This impacts patients' social interactions and ability to access support.

**Access to care:** As highlighted by the Tessa Jowell Brain Cancer Mission and our experience supporting people, inequalities in access to gold-standard healthcare and treatment are a challenge.

**Impact on employment and finances:** A brain tumour diagnosis is expensive to families, and to the state. Diagnosis and treatment lead to disruptions in employment and financial stability. Patients face challenges in maintaining employment, due to treatment schedules, cognitive impairments and physical limitations.

We are here to address these challenges, participating in a collaborative, multidisciplinary ecosystem striving for better support services for patients and their families, improved access to care, increased research funding and enhanced public awareness. Collaborative efforts between charities, healthcare professionals, researchers, policymakers and advocacy groups are making progress in managing the societal challenges posed by brain tumours in the UK.

We are conscious that as a charity, we are here not just to alleviate challenges that the brain tumour community faces in the here and now, but also to work for a better world tomorrow, for people diagnosed with a brain tumour in the future.

In acknowledgement of our relatively small size, we conduct our campaigning and influencing activity collaboratively, carefully and with a laser focus on patient needs.

We proactively partner with clinical bodies, hospitals and clinical teams, other charities and community interest groups, notably Brain Tumour Research, the Tessa Jowell Brain Cancer Mission, the All-Party Parliamentary Group on Brain Tumours, One Cancer Voice, the Children and Young People Cancer Coalition, the International Brain Tumour Alliance and Cancer52, to make sure brain tumour patients and their caregivers have a voice.

Key concerns we are looking to be addressed are:

- quality and equality of care inside and outside the clinic
- prompt diagnosis
- addressing delays in follow-up and treatment
- NHS workforce shortages
- cost of living after brain tumour diagnosis and access to support
- implementation of shared decision-making

- access to novel treatments and therapies and adaptive trial design
- better access to funding for brain tumour researchers.

We go about this work with a positive approach and the belief that ‘none of us is as smart as all of us’. If something is not working for our community, we are quick to acknowledge, slow to blame and swift to seek a solution, with every effort to bring the power of our ecosystem to bear on a solution.

Please refer to the ‘Collaborations, networks and advisers’ section of this report for more information about who we are working with.



## Award winning work that improves patient experience

We have been working collaboratively with two NHS trusts in Liverpool and Preston to improve the patient pathway, both in terms of experience and service effectiveness. Issues included no brain site-specific team based at acute trusts, which led to a fragmented pathway and poor patient experience. Patients were falling between the emergency department, acute medical units, acute oncology and palliative care, so that nobody had responsibility for the patients. This meant a lack of follow-up, no central point of contact and a lack of information, so patients didn't know what timescales they could expect or what the next steps were. Patients and their caregivers were interviewed by *brainstrust* support specialists in focus groups and by telephone so that we could work with the NHS trusts to improve the patient experience and service effectiveness based on their feedback. We are very grateful to everyone who has given us the time and honesty to deliver this work.

The outcomes of this work have led to:

- the establishment of a brain tumour pathway, so that everyone receives coordinated care and a management plan
- the allocation of a key worker
- the point of referral to neuro-oncology from the emergency department to within 72 hours to allow optimisation of steroids and accurate information being available for the MDT meeting
- all patients having a holistic needs assessment with an acute oncology support worker
- All patients being tracked by a cancer care navigator
- improved communication with additional information written and produced by *brainstrust* about what to expect when diagnosed with a suspected brain tumour

- delivery of the pathway being increased from five days to seven, so that weekend referrals are overseen
- improved length of stay – patients are being discharged earlier when appropriate following first review.

This work has been shared at a local level and is easily transferable to other NHS trusts. It won a Nursing Times Award in 2022, and acute oncology teams from London, Birmingham, Barnsley, Wigan and Oxford have expressed a desire to replicate this work. The work also won a Macmillan Professional Excellence Award.



**By bringing patients closer to their clinical teams we have been able to help develop award winning patient experience in hospitals.**



# Collaborations, networks and advisers

## ‘None of us is as smart as all of us’

Indeed, meaningful collaboration and co-creation is central to our strategy and ethos as we work to secure the best outcomes for anyone who is living with a brain tumour. Our partnerships, of which we nurture around 80, are global and fall into four themes:

### Patient-focused

These partnerships include clinical engagement with the 35 neuroscience and neurosurgical centres and organisations that are relevant to our community, such as Use My Data and the Patient Information Forum. Clinical engagement is a priority, as this is one way in which we can reach the community. It is, however, a two-way relationship, as healthcare professionals can visit our website and order resources for their patients, signpost coaching and other support services, and take advantage of training opportunities, such as our expert-led webinars and coaching programme.

### Clinically focused

Clinical collaborations are hubs of clinical practice and research, such as the British Neuro-Oncology Society (BNOS), the National Cancer Research Institute (NCRI) and the Cochrane Collaboration. We are very proud of our



clinical network, which has been pivotal in the success of our webinar programme and the growth of our clinical research activity under the banner of PRIME.

This community's involvement in our educational events has been transformative for our beneficiaries. We have built a community of over 20 clinical experts, who have selflessly given up their time and knowledge to help people living with a brain tumour understand more about their condition, why at times it is hard to make a choice about treatment, and how to live better with a brain tumour. This community continues to grow, and we are so grateful for the valuable and transformative expertise so generously gifted by this network.

### Public Health

We work across the four Public Health nations. This year, this work has been particularly significant, as we have worked closely with the Public Health government departments to ensure that our community is well supported during the return of services following the Covid-19 pandemic. This work has included advocating for cohorts of people living with a specific type of brain tumour to ensure the treatment and surveillance that they need has been accessible. Furthermore, by using data from the National Cancer Registration and Analysis Service to reassure the community that waiting times and urgent referrals are returning to normal, our work with Public Health has enabled us to keep our community updated in a meaningful and relevant way.

## Charities

We have always worked closely with charities when we have recognised that it is in the best interests of the community. Our collaborations with charities have become stronger and deeper during the pandemic, and we have worked hard this year to continue to build these relationships.

We are actively involved in the Cancer52 network of charities; we represent children and young people with brain cancer through our role on the steering group of the Children and Young People with Cancer Coalition; we work closely with Cancer Research UK on matters relating to brain cancer and clinical research; and we work in partnership with charity Brain Tumour Research on a variety of projects, including our PRIME initiative, and on activity to inform UK governments on the importance of addressing brain tumours at the highest levels possible.

Notably, we have enjoyed our ongoing relationship with the Tessa Jowell Brain Cancer Mission. *brainstrust's* chief executive, Will Jones, brings our experiences, insights and the voices of our communities to the Joint Strategy Board of the mission.

## Organisational partnerships and collaborations

Our team also maintains a broad portfolio of strategic and commercial relationships outside the health and charity sectors. These relationships with companies and individuals enhance our capabilities, capacity and expertise, and they all contribute meaningfully to our mission and our impact. We would like to express our specific appreciation to:

- Baker McKenzie
- Charisma Charity Recruitment
- Class Networks
- Eric Callister
- Google UK
- Greenberg Traurig, LLP
- Harrison Black
- Irene Clarke
- J Pullan & Sons
- Louise Baker
- McQueenie Mulholland
- Nifty Communications
- Rhys Coren, RA
- Salesforce
- Smarter Not Harder (SNH)
- TechSoup
- Think Creative Consultants Ltd
- Thrive Partners.

.....  
*Reaching out to all available support networks is key. We were in such shock at the time of my son's diagnosis and found charities later.*

**Caregiver to a low grade glioma patient**  
.....



# Your support

This year our supporters raised £691,706 to fund *brainstrust's* mission. This income remains from a diversified mix of traditional charity fundraising activity. Our funding comes from:

- trusts and foundations
- direct and regular giving
- companies who support our work
- sponsored events and challenges
- community fundraising
- Gift Aid recovery
- in-memory giving
- trading
- government support relating to the Covid-19 pandemic
- special-purpose fundraising to enable communities to access novel treatments and therapies.

We have limited income from legacy fundraising and high-net-worth individuals, and we have minimal investment income, instead keeping cash available to provide liquidity and flexibility so that we can react promptly to the needs of our community.

With all public fundraising cancelled at the outset of the Covid-19 pandemic, we have since worked hard to reignite supporter fundraising. We have been delighted to see activity and income from community fundraising channels build on last year. This focus is bringing our work closer, once more, to the community we are here to serve.

This being said, we remain in a challenging, and changing fundraising environment. Our three-year year planning post-Covid anticipated a rapid return to a fundraising mix that relied heavily on supporter fundraising, as it was before the pandemic – 80% supporter income, 20% grants.

However, our short-term planning and activities have had to adapt in response to changes in the fundraising landscape, where headwinds during the year have included cost-of-living pressures for supporters, political uncertainty in society, increased competition for grant fundraising, combined with unforeseen increases in operational costs across our whole organisation.

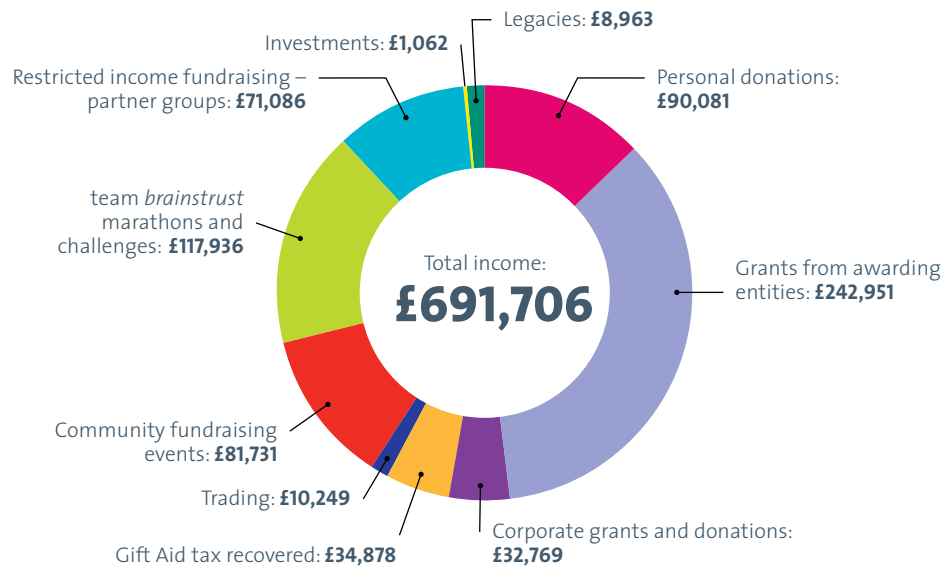
Our short-term planning anticipates these challenges – support from philanthropic and grant-giving partners remains as important as ever as our loyal community supporters struggle with cost-of-living pressures and uncertainty at home and work.

We continue to work hard to rebalance our fundraising mix, but to achieve the healthy and sustainable balance of 2019, we will need the wider societal pressures to ease.

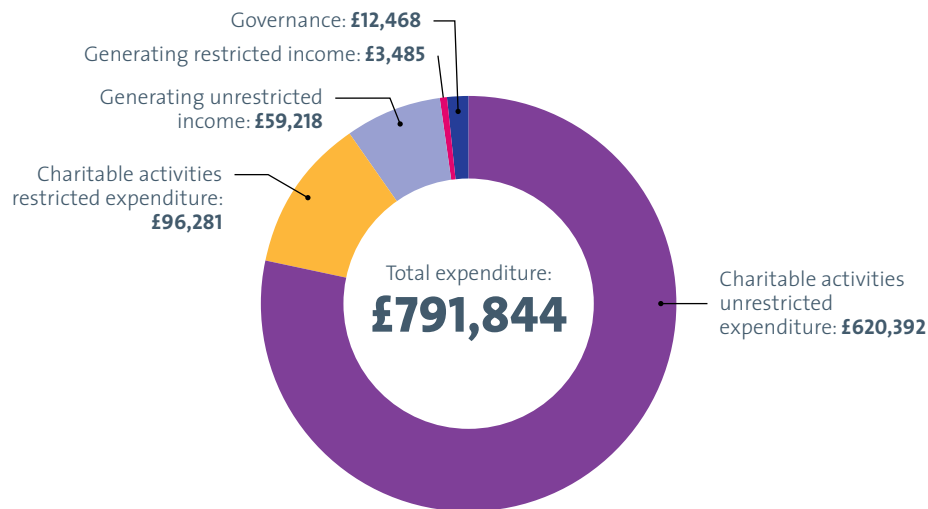
Hand in hand with the fundraising challenges that we anticipate will play out for at least the rest of the year, we are actively controlling costs wherever possible without compromising on the impact of our work in the communities that we serve.

In-memory fundraising, team *brainstrust* (marathons and challenges) and trust and foundation fundraising remain areas of growth for *brainstrust* despite these challenges.

## Our income 2022-23



## Our expenditure 2022-23



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*As we reflect on another year of remarkable achievements, we are reminded that the true measure of our success lies not just in the numbers we've raised but also in the countless lives we've touched and the stories of transformation we've authored together. With gratitude for all those who have joined us, we move forward, inspired by the light of our community, which illuminates the darkest of moments that come with a brain tumour diagnosis.*

**Will Jones, Chief Executive, *brainstrust***

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## Thank you to our community of supporters

### 'Be more Reesh' – Donna's Cardiff Half Marathon

Donna signed up with team *brainstrust* early in the year, taking inspiration from her friend Areesha, who was sadly lost to a brain tumour this year. Donna describes Areesha as someone who 'never shied away from a challenge'. Donna chose to set herself a fundraising target of £1,500.



*Turns out running a half marathon is pretty damn hard.*

*Thanks to everyone that donated to my fundraising efforts. Thank you to everyone who has asked about my training, checked in on me and said good luck to me. Thank you to everyone that came out and cheered today. Thank you to everyone that told me I could do it even when I didn't think I could. Thank you to everyone who's asked about why I'm doing it and let me talk to them about Reesh. And a special thanks to Laura for being the best training*





*buddy I could have asked for. I'm so glad you let me tag along with you on this ride.*

*And lastly, to Reesh, I miss you so much, but it felt like I had you with me today. And that in itself was worth this entire journey.*

*Thank you so much for your support along this journey. I'm so glad I picked brainstrust to fundraise for.*

Prior to taking part in the half marathon, Donna shared her thoughts on her upcoming challenge with team *brainstrust*.

The Cardiff Half Marathon took place on 2 October, and although Donna has admitted she's 'most definitely not a natural runner, or an experienced one', she trained hard, and with less than a month to go, we invited Donna to share her motivation for running and to reflect on her training so far.

*I've been sitting in front of a blank screen for the last half an hour, trying to figure out how to start to write what motivated me to run the Cardiff Half. And with tear-stained cheeks, I reluctantly admit it was grief. That kind of grief that is all-encompassing and physically painful. That kind of grief that just makes you wish there was something, anything, you could do to make it go away, but there isn't.*

*On 19 February 2022, I lost my dear friend Areesha to a brain tumour that she was diagnosed with less than a year before. Reesh was not like anyone I'd met before. She was wildly extroverted, loud, dramatic and absolutely hilarious. And she said yes to everything. Once, she flew to New York, then drove to Philadelphia on her own to meet up with our roller derby team and play the*

*last two games on our first USA tour. Then she flew back home 48 hours later. To say Reesh lived life to the fullest is an understatement – she packed more into 35 short years than most do in a much longer lifetime. And I'm so glad she did.*

*I knew I wanted to do something to honour her 'say yes' attitude, and when my friend Laura said she was running the Cardiff Half in memory of Reesh, I asked if she wanted someone to do it with her. And the next thing I know, I'm signing up to run 13.1 miles, having not run in over six months and never having run more than seven miles in my entire life. But one thing I knew for sure was that if Reesh was still here, she'd be our biggest cheerleader.*

*Training has been full of ups and downs. It started off fairly well, and I was following my training plan, and it wasn't too hard to motivate myself to put my trainers on and get some miles in. But unfortunately, after avoiding Covid for 2.5 years, my luck finally ran out. It hit me pretty hard, and I wasn't able to run, or exercise at all, for five very long weeks. But patience (not one of my virtues) prevailed, and I managed to lace my trainers back up towards the end of August and restart training. It's been humbling to not see the progression I wanted to. I've had to dramatically adjust my goals for the race, but it really has brought me back to the bigger picture of why I'm running. I am running for Reesh, for someone that was so incredibly full of life, so ready to take on any challenge and so willing to help her friends when they needed it. And I guess this is what running the Cardiff Half for brainstrust feels like to me: helping a friend.*

*I am so incredibly grateful for the generosity people have shown with their donations. Whilst I am nervous about the race, there is no doubt in my mind I can do it. And on the day, when I hit that inevitable wall, I'll think of Reesh cheering me on and every single person who has supported me along the way.*

Donna, you're an inspiration – we can't thank you enough for your amazing support and for smashing your fundraising target by raising a huge £1,630.

## Kerstin Kramer's 3 Pistes Cycle Sportive

On Saturday 4 June, Kerstin Kramer took on the 3 Pistes Cycle Sportive (the UK's highest cycle sportive) in support of *brainstrust*. In an epic challenge, she tackled eight categorised climbs, five of the UK's six highest roads and three Scottish ski centres – all spanning 103 miles.

When the ride was originally planned, Kerstin and her close friend and fellow GP, Margaret, had pledged to conquer this incredible challenge together. But sadly, last November Margaret was diagnosed with a brain tumour and suddenly had to face a very different type of challenge. In this moment, Margaret and her family reached out to *brainstrust* for support and found an understanding community ready to welcome them with open arms. While Margaret had to withdraw from the challenge, Kerstin chose to ride in her honour and raised over £2,200 in support of her chosen charity, *brainstrust*, and the wider brain tumour community.



## The inaugural Jim Woods Memorial Ride

'A great ride in memory of a great man' is how one Alton Cycling Club member described the Jim Woods Memorial Ride.

The inaugural Jim Woods Memorial Ride took place on Sunday 10 July. The ride was organised by John Heath in memory of club member Jim Woods, who sadly died of a brain tumour in 2020, and who is fondly remembered by many.



### In memory of Jim Woods

Jim was a keen club cyclist, joining ACC in 2010 on his return from France. Always good company on and off the bike, Jim loved cycle touring, Sunday club rides and all things social.

Jim was diagnosed in September 2018 with a malignant brain tumour and sadly passed away in April 2020. He is hugely missed by his many friends and family. His gentle humour and keen intellect live on in the memories of all who knew him.

### The day of the ride

The ride began on Sunday morning, with the team enjoying excellent weather and quiet lanes. For many at the club, this was their first ever Audax ride, and the first organised by Alton Cycling Club since 2006, and it was a great success.

Considering the warm weather, the team of 60 friendly cyclists completed an impressive 100 km and raised an incredible £773.31 for *brainstrust*.



Alton Cycling Club are looking forward to organising this as an annual Audax event from now on. The next ride will be in July 2024. We cannot wait!



## Dreaming big with Ravi Adelekan

In December 2022, 8 year old brain tumour patient Ravi Adelekan launched his fundraising campaign 'Ravi's Dream' in support of 2 charities close to his heart – *brainstrust* and The Brain Tumour Charity. His goal was to raise £250,000 for the work of the charities so that all children with brain tumours can get the help they need.

Ravi's fundraising journey began in his home town of Brighton with the launch of his charity music video – a cover of the song 'A Million Dreams' from The Greatest Showman. With appearances from Hugh Jackman and Michael Gracey of Greatest Showman fame, the video also features an amazing array of internationally acclaimed musicians including Bastille, Damon Albarn, Paloma Faith, The Big Moon, and Metronomy.

You can watch the video here:

<https://www.youtube.com/watch?v=NDETq8P88SI>

Ravi has since won a Pride of Britain award for his courage, reaching millions in his mission to help children with a brain tumour to be better supported.



## Thank you to our trust and foundation supporters

Your support is invaluable and vital to us; it has allowed us to widen and strengthen our local communities. We value our relationships with all our generous and compassionate funders and are grateful to The Rank Foundation for its ongoing support.

We are also indebted to the National Lottery Community Fund and players of The National Lottery. Their grants helped us support many more people with our high-impact coaching, allowed us to reach more people in Scotland and to plan free all-day health and well-being events.

In addition, we are incredibly privileged to have been supported by these very generous funding partners:

- The Edward Gostling Foundation
- Garfield Weston Foundation
- The Hospital Saturday Fund
- St. James's Place Charitable Foundation
- Wyseliot Rose Charitable Trust
- Sir Jules Thorn Charitable Trust
- The Moondance Foundation
- The February Foundation
- The Meikle Foundation
- The Thistledown Education Trust
- The Hobson Charity
- The Mishcon Family Charitable Trust
- Sandra Charitable Trust
- The Hodge Foundation
- The Oakdale Trust.

Thank you, all, for your generosity, and for the incredible kindness of an anonymous trust donor. Your funding has allowed us to be there for an ever-increasing number of people who need us and to help them live their best possible lives.





# Financial review

The Trust's published statutory accounts for the year ended 31 March 2023 are incorporated in this Trustees' Annual Report and include considerable detail on the source and application of funds, and the financial position of the Trust at 31 March 2023, as required by the SORP for UK charities published by the Charity Commission. This report comments on the main points contained in the accounts.

In summary, gross income generated in 2022–2023 was £692K (2021–22: £952K), of which £71K related to restricted income funds. The net deficit for the year was £100K (2021–22: £289K surplus), of which £32K related to restricted income funds.

While, as reviewed elsewhere in the Trustees' Annual Report, *brainstrust's* charitable impact has been significantly increased, thus increasing our reach and effectiveness. We have had to invest in meeting demand and scaling our efforts over the year, and this has come at an increased cost due to new, planned-for recruitment and an increase in live events. Overall expenditure in 2022–2023, at £792K, of which £100K related to planned expenditure of restricted income funds, has naturally increased year on year, alongside a higher level of activity, from the previous year of 2021–22 (£663K).

The Trust's gross income for 2022–23, at £692K, was, as noted above, a decrease on the £952K raised in 2021–22. However, it is only £16K short against our targets. We have not yet seen a return to a 'normal' twelve months since before Covid-19, but our supporters, through grants, donations and, in many cases, the hard physical graft of traditional fundraising through, for example, sponsored and testing walks and marathons, have raised this money despite the ongoing economic uncertainty and external factors, such as recruitment and cost-of-living pressures in our team and for

our community. This has made for a challenging fourth quarter in terms of fundraising and planning/pipeline development, but the significant growth in our reserves last year has helped us to weather the storm.

Most of the Trust's income, both general and restricted, is applied to supporting patients and their caregivers and families, from the point of a brain cancer diagnosis. Our support team provides UK-wide coverage, supported by the National Lottery Community Fund and other substantial funders.

The Trust has only cash investments, deposited with NatWest Bank and The Co-operative Bank. At 31 March 2023, the Trust had net reserves, including our restricted income funds, of £604K (March 2022: £704K), which included unrestricted reserves of £205K (2022: £274K) and net restricted reserves of £399K (2022: £430K). The unrestricted deficit for the year in review has been deducted from our general charitable funds.

The Trust has a long-standing policy of holding unrestricted reserves to cover four months of defined core costs. As at 31 March 2023, unrestricted reserves were sufficient to cover just over five months of core costs, the excess providing a useful cushion as the UK, and especially the charity sector, continues to operate in a very unusual and unpredictable environment.

# Our structure, governance, leadership and management

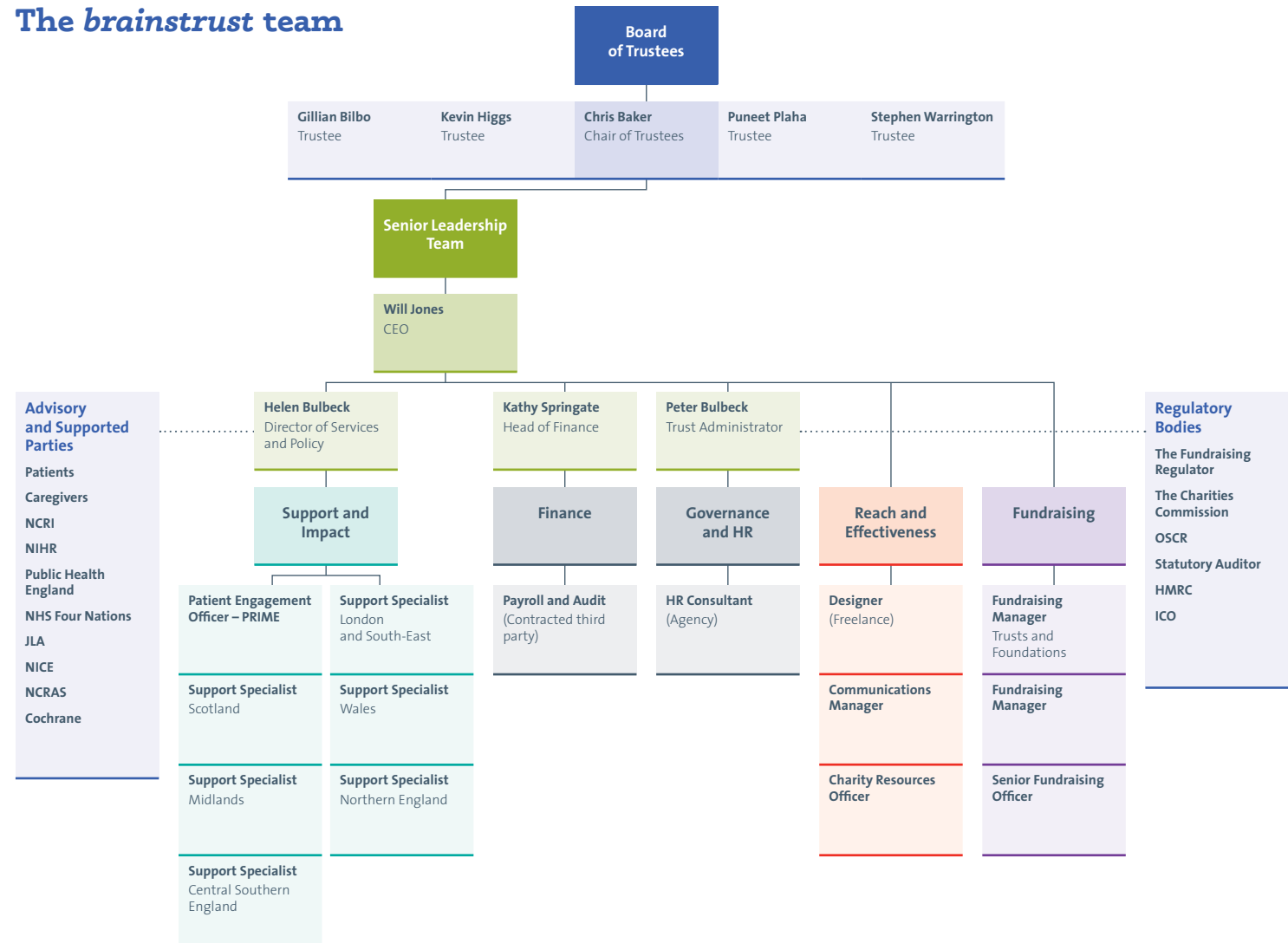
## Our structure

*brainstrust* is a mature organisation. We are confident in our abilities, our purpose and our impact. As we near the end of our current strategy, we are more focused than ever on our purpose and the needs of our beneficiaries.

We are proud that we have catalysed a new ecosystem in the brain tumour charity and advocacy landscape that is focused on improving life for people with a brain tumour.

Our professional and highly trained team supports people across the UK, and these people can access impactful, accredited *brainstrust* resources. We are a resilient organisation that has transitioned well over the last five years from being a ‘large small’ operation to a ‘small big’ charity with a scalable, professional and resilient structure.

## The *brainstrust* team



## Our governance

*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

*Focused discussions, an agile and adaptable approach to planning and sound cooperation between the appointed trustees and the managers of the Trust have ensured that brainstrust has continued to provide support and guidance for our patients, in accordance with its aims, while maintaining a secure financial footing.*

### Gillian Bilbo, Trustee, brainstrust

*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 William Jones, who has been appointed 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.*

## Leading the way

*brainstrust has a stable, experienced and committed leadership team who are aligned in delivering our mission and who are the strongest advocates of our 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.*

This leadership team and trustees have a clear mandate to:

- **Set an example** – It is important to demonstrate our values in everything we do. We set high standards of behaviour and inspire colleagues, supporters and beneficiaries to do the same. We demonstrate fairness, integrity and resilience, and we build trust with our actions.
- **Look after people** – At *brainstrust*, we promote the well-being of individuals, teams and communities. We encourage a supportive culture and inclusive working arrangements. We prioritise one-to-one time with people to listen and understand their needs. We support and defend colleagues in difficult situations. We identify and deal with poor performance and bad behaviour.
- **Take ownership** – We welcome responsibility and accountability. We're proactive, pick up things that need doing without being asked and push to finish the job in hand. We're the first to admit mistakes, apologise when wrong and learn for next time.
- **Provide clarity** – We must communicate clearly and concisely through the right channel. We question any decisions, goals or explanations that are vague or ambiguous, and we work to clarify them. We're open, honest

and straightforward in what we say and write. And we provide specific, understandable and useful feedback.

- **Make good decisions** – We use evidence and judgement to make good decisions. We know that timely decisions are important, so we don't procrastinate or fudge. We commit to collective decisions, particularly when we originally disagreed. We consult broadly, seek out contrary opinions and listen to quieter voices. We make sure we can explain our decisions, with context, rationale and evidence.
- **Point the way** – We share an inspiring vision for the future of the charity and everyone's part in it. In our work, we make sure that colleagues understand the outcomes we want to achieve and the value that they will create.
- **Build the future** – We bring great people on board. We actively look for the widest range of candidates to strengthen our diversity. We encourage our colleagues to learn, develop new skills and pursue their career aspirations, whether at *brainstrust* or elsewhere. And we give people opportunity and responsibility at the right pace for them. We continually improve *brainstrust's* capability and the effectiveness and efficiency of our delivery. We try out new approaches and technologies and give others the time and space to do the same.

## Our board of trustees

*brainstrust's* trustees for the year in review are Christopher Baker, Kevin Higgs, Stephen Warrington, Gillian Bilbo and Puneet Plaha.

### 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 eleven years and the chair of trustees at *brainstrust* for six 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 six years. Stephen's teenage son was diagnosed with a brain tumour and underwent successful surgery.

### Gillian Bilbo

*Trustee*

Gillian is a retired headteacher and is now a school inspector, and she has been a trustee for ten years. She brings a listening ear and an objective viewpoint to the board and is supportive of fundraising initiatives.

### 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.



The board of trustees meets formally four times a year to ratify the broad strategy and areas of activity for the Trust. In addition, trustees may meet with members of the team to work on specific projects. All trustees give their time freely, and no remuneration is paid.

In accordance with clause 9 of the Declaration of Trust, dated 4 March 2006:

- (i) There must be at least three trustees. Apart from the first trustees, every trustee must be appointed by a resolution of the trustees passed at a special meeting called under clause 15 of this deed.
- (ii) In selecting individuals for appointment as trustees, the trustees must have regard to the skills, knowledge and experience needed for the effective administration of the charity.
- (iii) The trustees must keep a record of the name and address and the dates of appointment, reappointment and retirement of each trustee.
- (iv) The trustees must make available to each new trustee, on his or her first appointment:
  - (a) a copy of this deed and any amendments made to it
  - (b) a copy of the charity's latest report and statement of accounts.

There are no exemptions from disclosure applicable to or within this report, and neither the charity nor any of its trustees are acting as custodian trustees.

Now in our 17th year of operation, we have an established national footprint across all elements of our activity. This is delivered with public benefit at the heart by a professional team with a professional leadership structure.

## **brainstrust senior staff contacts**

**Will Jones**, *Chief Executive*,  
will@brainstrust.org.uk

**Dr Helen Bulbeck**, *Director of Services and Policy*,  
helen@brainstrust.org.uk

**Kathy Springate**, *Head of Finance*,  
kathy@brainstrust.org.uk

**Jodie Eveleigh**, *Head of Support*,  
jodie@brainstrust.org.uk

## **Incidents and reporting**

For the year in review, and indeed for the duration of the organisation's history, we have had no reportable incidents relating to our fundraising, our service or our internal operations. We have in place policies and procedures for managing, reporting and escalating incidents and complaints. The following are available on request:

- Whistleblowing policy
- Complaints procedure – patient services
- Complaints procedure – fundraising
- Complaints policy – staff
- Complaints policy – volunteers

# Report of the Trustees and Audited Financial Statements for the year ended 31st March 2023 for *brainstrust*

Harrison Black Limited  
Statutory Auditor  
East Quay  
Kite Hill  
Wootton Bridge  
Isle of Wight  
PO33 4LA

## *brainstrust* – Contents of the Financial Statements for the year ended 31st March 2023

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## **brainstrust – Report of the Trustees for the year ended 31st March 2023**

The trustees present their report with the financial statements of the charity for the year ended 31st March 2023. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

### **Structure, governance and management**

#### **Governing document**

The charity is controlled by its governing document, a deed of trust and constitutes an unincorporated charity.

### **Reference and administrative details**

#### **Registered Charity number**

1114634

#### **Principal address**

4 Yvery Court  
Castle Road  
Cowes  
Isle of Wight  
PO31 7QG

#### **Trustees**

C Baker  
K Higgs  
G Bilbo  
S Warrington  
P Plaha

#### **Auditors**

Harrison Black Limited  
Statutory Auditor  
East Quay  
Kite Hill  
Wootton Bridge  
Isle of Wight  
PO33 4LA

*brainstrust* is also a Scottish Charity, SC044642, regulated by the Scottish Charity Regulator (OSCR).

### **Trustees' Responsibility Statement**

The trustees are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

## **brainstrust – Report of the Trustees for the year ended 31st March 2023**

### **Trustees' Responsibility Statement – continued**

The law applicable to charities in England and Wales, the Charities Act 2011, Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed 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 incoming resources and application of resources, including 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 Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They 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.

Approved by order of the board of trustees on **5th October 2023** and signed on its behalf by:



**C Baker** – Trustee

## Report of the Independent Auditors to the trustees of *brainstrust*

### Opinion

We have audited the financial statements of *brainstrust* (the 'charity') for the year ended 31st March 2023 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31st March 2023 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

### Basis for opinion

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

### Conclusions relating to going concern

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

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

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

### Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements

## Report of the Independent Auditors to the trustees of *brainstrust*

or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

### Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- the information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

### Responsibilities of trustees

As explained more fully in the Trustees' Responsibilities Statement, the trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

### Our responsibilities for the audit of the financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

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

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

As outlined above, our objective is to give reasonable assurance that the financial statements are free from material misstatements and irregularities. Whilst not a guarantee that such instances will be detected, our risk based approach, using systematic testing methods, judgement, communication with management, professional



## Report of the Independent Auditors to the trustees of *brainstrust*

scepticism, observation of controls and systems, and audit experience/knowledge, allows us to be satisfied that our procedures are highly capable of detecting irregularities, including fraud.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our Report of the Independent Auditors.

### Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.



Harrison Black Limited  
Statutory Auditor  
East Quay  
Kite Hill  
Wootton Bridge  
Isle of Wight  
PO33 4LA

Date: 13th October 2023

## *brainstrust* – Statement of Financial Activities for the year ended 31st March 2023

	Notes	Unrestricted fund £	Restricted funds £	2023 Total funds £	2022 Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and legacies	2	409,642	–	409,642	337,854
Other trading activities	3	209,966	71,036	281,002	608,240
Investment income	4	1,062	–	1,062	26
Other income		–	–	–	6,083
<b>Total</b>		<b>620,670</b>	<b>71,036</b>	<b>691,706</b>	952,203
<b>EXPENDITURE ON</b>					
Raising funds	5	59,218	3,485	62,703	90,184
<b>Charitable activities</b>					
Charity activities	6	620,392	96,281	716,673	558,284
Other		12,468	–	12,468	14,963
<b>Total</b>		<b>692,078</b>	<b>99,766</b>	<b>791,844</b>	663,431
<b>NET INCOME/(EXPENDITURE)</b>		<b>(71,408)</b>	<b>(28,730)</b>	<b>(100,138)</b>	288,772
<b>Transfers between funds</b>	17	2,563	(2,563)	–	–
<b>Net movement in funds</b>		<b>(68,845)</b>	<b>(31,293)</b>	<b>(100,138)</b>	288,772
<b>RECONCILIATION OF FUNDS</b>					
Total funds brought forward		273,874	430,371	704,245	415,473
<b>TOTAL FUNDS CARRIED FORWARD</b>		<b>205,029</b>	<b>399,078</b>	<b>604,107</b>	704,245

The notes form part of these financial statements

## brainstrust – Balance Sheet 31st March 2023

	Notes	Unrestricted fund £	Restricted funds £	2023 Total funds £	2022 Total funds £
<b>FIXED ASSETS</b>					
Tangible assets	11	1,957	–	1,957	2,824
<b>CURRENT ASSETS</b>					
Debtors	12	77,711	–	77,711	39,522
Cash at bank		188,630	399,078	587,708	730,827
		266,341	399,078	665,419	770,349
<b>CREDITORS</b>					
Amounts falling due within one year	13	(39,796)	–	(39,796)	(35,655)
<b>NET CURRENT ASSETS</b>		226,545	399,078	625,623	734,694
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		228,502	399,078	627,580	737,518
<b>CREDITORS</b>					
Amounts falling due after more than one year	14	(23,473)	–	(23,473)	(33,273)
<b>NET ASSETS</b>		205,029	399,078	604,107	704,245
<b>FUNDS</b>	17				
Unrestricted funds				205,029	273,874
Restricted funds				399,078	430,371
<b>TOTAL FUNDS</b>				604,107	704,245

The financial statements were approved by the Board of Trustees and authorised for issue on 5th October 2023 and were signed on its behalf by:



C Baker – Trustee

The notes form part of these financial statements

## brainstrust – Cash Flow Statement for the year ended 31st March 2023

	Notes	2023 £	2022 £
<b>Cash flows from operating activities</b>			
Cash generated from operations	1	(133,533)	277,073
Interest paid		(969)	(818)
Net cash (used in)/provided by operating activities		(134,502)	276,255
<b>Cash flows from investing activities</b>			
Purchase of tangible fixed assets		–	(3,469)
Interest received		1,062	26
Net cash provided by/(used in) investing activities		1,062	(3,443)
<b>Cash flows from financing activities</b>			
Loan repayments in year		(9,679)	(7,169)
Net cash used in financing activities		(9,679)	(7,169)
<b>Change in cash and cash equivalents in the reporting period</b>		(143,119)	265,643
<b>Cash and cash equivalents at the beginning of the reporting period</b>		730,827	465,184
<b>Cash and cash equivalents at the end of the reporting period</b>		587,708	730,827

The notes form part of these financial statements

1. Reconciliation of net (expenditure)/income to net cash flow from operating activities

	2023 £	2022 £
<b>Net (expenditure)/income for the reporting period (as per the Statement of Financial Activities)</b>	<b>(100,138)</b>	288,772
<b>Adjustments for:</b>		
Depreciation charges	867	2,675
Interest received	(1,062)	(26)
Interest paid	969	818
Increase in debtors	(38,189)	(14,134)
Increase/(decrease) in creditors	4,020	(1,032)
<b>Net cash (used in)/provided by operations</b>	<b>(133,533)</b>	277,073

2. Analysis of changes in net funds

	At 1.4.22 £	Cash flow £	At 31.3.23 £
<b>Net cash</b>			
Cash at bank	730,827	(143,119)	587,708
	<u>730,827</u>	<u>(143,119)</u>	<u>587,708</u>
<b>Debt</b>			
Debts falling due within 1 year	(9,558)	(121)	(9,679)
Debts falling due after 1 year	(33,273)	9,800	(23,473)
	<u>(42,831)</u>	<u>9,679</u>	<u>(33,152)</u>
<b>Total</b>	<b>687,996</b>	<b>(133,440)</b>	<b>554,556</b>

The notes form part of these financial statements

1. Accounting policies

**Basis of preparing the financial statements**

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

**Income**

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Donations are recognised when the charity has been notified in writing of both the amount and settlement date. In the event that a donation is subject to conditions that require a level of performance before the charity is entitled to the funds, the income is deferred and not recognised until either those conditions are fully met, or the fulfilment of those conditions is wholly within the control of the charity and it is probable that those conditions will be fulfilled in the reporting period.

Grant income is recognised when received. In the event that a grant is subject to conditions that require a level of performance before the charity is entitled to the funds, the income is deferred and not recognised until either those conditions are fully met, or the fulfilment of those conditions is wholly within the control of the charity and it is probable that those conditions will be fulfilled in the reporting period.

Legacy gifts are recognised on a case by case basis following the granting of probate when the administrator/executor for the estate has communicated in writing both the amount and settlement date. In the event that the gift is in the form of an asset, recognition is subject to the value of the gift being reliably measurable with a degree of reasonable accuracy and the title to the asset having been transferred to the charity.

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.

**Expenditure**

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

**Tangible fixed assets**

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Fixtures and fittings                      -25% on cost

continued ...

**brainstrust – Notes to the Financial Statements for the year ended 31st March 2023 – continued**

**1. Accounting policies – continued**

**Taxation**

The charity is exempt from tax on its charitable activities.

**Fund accounting**

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

**2. Donations and legacies**

	2023 £	2022 £
Donations	90,081	57,896
Grants from awarding entities	242,951	175,831
Corporate grants and donations	32,769	53,576
Gift aid tax recovered	34,878	50,551
Legacies	8,963	–
	<b>409,642</b>	<b>337,854</b>

**3. Other trading activities**

	2023 £	2022 £
Fundraising events	81,731	75,417
Sale of 'brainstrust' items	10,249	12,472
Sponsored activities	117,936	174,339
Activities of partner groups	71,086	346,012
	<b>281,002</b>	<b>608,240</b>

continued ...

**brainstrust – Notes to the Financial Statements for the year ended 31st March 2023 – continued**

**4. Investment income**

	2023 £	2022 £
Deposit account interest	<b>1,062</b>	26

**5. Raising funds**

	2023 £	2022 £
Raising donations and legacies		
Fundraising fees	11,077	33,129
Promotional expenses	31,318	26,782
	<b>42,395</b>	<b>59,911</b>

Other trading activities

	2023 £	2022 £
Trading costs and purchases	4,755	7,972
Event costs	5,941	11,433
Sponsored activities costs	9,612	10,868
	<b>20,308</b>	<b>30,273</b>

Aggregate amounts

	<b>62,703</b>	90,184
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**6. Charitable activities costs**

	Direct Costs £	Support costs (see note 7) £	Totals £
Charity activities	714,187	2,486	<b>716,673</b>

continued ...



**brainstrust – Notes to the Financial Statements for the year ended 31st March 2023 – continued**

**7. Support costs**

	Governance costs £
Other resources expended	12,468
Charity activities	2,486
	<u>14,954</u>

**8. Trustees' remuneration and benefits**

There were no trustees' remuneration or other benefits for the year ended 31st March 2023 nor for the year ended 31st March 2022.

**Trustees' expenses**

There were no trustees' expenses paid for the year ended 31st March 2023 nor for the year ended 31st March 2022.

**9. Staff costs**

Total gross salaries, benefits in kind and employers national insurance costs for the year ending 31st March 2023 were £483,632 (2022 – £431,130).

The average monthly number of employees during the year was as follows:

	2023	2022
Fundraising	4	4
Charitable Activities	9	9
Governance	1	1
Other	1	1
	<u>15</u>	<u>15</u>

No employees received emoluments in excess of £60,000.

continued ...

**brainstrust – Notes to the Financial Statements for the year ended 31st March 2023 – continued**

**10. Comparatives for the statement of financial activities**

	Unrestricted fund £	Restricted funds £	Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies	337,854	–	337,854
Other trading activities	262,228	346,012	608,240
Investment income	26	–	26
Other income	6,083	–	6,083
<b>Total</b>	<u>606,191</u>	<u>346,012</u>	<u>952,203</u>
<b>EXPENDITURE ON</b>			
Raising funds	66,402	23,782	90,184
<b>Charitable activities</b>			
Charity activities	538,688	19,596	558,284
Other	14,963	–	14,963
<b>Total</b>	<u>620,053</u>	<u>43,378</u>	<u>663,431</u>
<b>NET INCOME/(EXPENDITURE)</b>	(13,862)	302,634	288,772
<b>Transfers between funds</b>	20,000	(20,000)	–
<b>Net movement in funds</b>	6,138	282,634	288,772
<b>RECONCILIATION OF FUNDS</b>			
Total funds brought forward	267,736	147,737	415,473
<b>TOTAL FUNDS CARRIED FORWARD</b>	<u>273,874</u>	<u>430,371</u>	<u>704,245</u>

continued ...

**brainstrust – Notes to the Financial Statements for the year ended 31st March 2023 – continued**

**11. Tangible fixed assets**

	Fixtures and fittings £	Website £	Totals £
<b>COST</b>			
At 1st April 2022 and 31st March 2023	<u>1,905</u>	<u>11,176</u>	<u>13,081</u>
<b>DEPRECIATION</b>			
At 1st April 2022	<u>1,502</u>	<u>8,755</u>	<u>10,257</u>
Charge for year	<u>103</u>	<u>764</u>	<u>867</u>
At 31st March 2023	<u>1,605</u>	<u>9,519</u>	<u>11,124</u>
<b>NET BOOK VALUE</b>			
At 31st March 2023	<u>300</u>	<u>1,657</u>	<u>1,957</u>
At 31st March 2022	<u>403</u>	<u>2,421</u>	<u>2,824</u>

**12. Debtors: amounts falling due within one year**

	2023 £	2022 £
Trade debtors	1,000	(90)
Other debtors	39,462	15,499
Prepayment	<u>37,249</u>	<u>24,113</u>
	<u>77,711</u>	<u>39,522</u>

**13. Creditors: amounts falling due within one year**

	2023 £	2022 £
Trade creditors	10,832	12,840
Other creditors	<u>28,964</u>	<u>22,815</u>
	<u>39,796</u>	<u>35,655</u>

continued ...

**brainstrust – Notes to the Financial Statements for the year ended 31st March 2023 – continued**

**14. Creditors: amounts falling due after more than one year**

	2023 £	2022 £
Other creditors	<u>23,473</u>	<u>33,273</u>

**15. Loans**

An analysis of the maturity of loans is given below:

	2023 £	2022 £
Amounts falling due within one year on demand:		
Other loans	<u>9,679</u>	<u>9,558</u>
Amounts falling due between two and five years:		
Other loans – 1–5 years	<u>23,473</u>	<u>33,273</u>

**16. Leasing agreements**

Minimum lease payments under non-cancellable operating leases fall due as follows:

	2023 £	2022 £
Within one year	<u>–</u>	<u>13,990</u>

continued ...

**brainstrust – Notes to the Financial Statements for the year ended 31st March 2023 – continued**

**17. Movement in funds**

	At 1.4.22 £	Net movement in funds £	Transfers between funds £	At 31.3.23 £
<b>Unrestricted funds</b>				
General fund	273,874	(71,408)	2,563	205,029
<b>Restricted funds</b>				
Fund A	710	2,566	(2,563)	713
Fund E	79,003	3,255	–	82,258
Fund H	27,034	5	–	27,039
Fund I	323,624	(36,664)	–	286,960
Fund J	–	2,108	–	2,108
	<u>430,371</u>	<u>(28,730)</u>	<u>(2,563)</u>	<u>399,078</u>
<b>TOTAL FUNDS</b>	<b>704,245</b>	<b>(100,138)</b>	<b>–</b>	<b>604,107</b>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
General fund	620,670	(692,078)	(71,408)
<b>Restricted funds</b>			
Fund A	2,566	–	2,566
Fund E	5,070	(1,815)	3,255
Fund H	119	(114)	5
Fund I	19,040	(55,704)	(36,664)
Fund J	2,141	(33)	2,108
Fund K	42,100	(42,100)	–
	<u>71,036</u>	<u>(99,766)</u>	<u>(28,730)</u>
<b>TOTAL FUNDS</b>	<b>691,706</b>	<b>(791,844)</b>	<b>(100,138)</b>

continued ...

**brainstrust – Notes to the Financial Statements for the year ended 31st March 2023 – continued**

**17. Movement in funds – continued**

**Comparatives for movement in funds**

	At 1.4.21 £	Net movement in funds £	Transfers between funds £	At 31.3.22 £
<b>Unrestricted funds</b>				
General fund	267,736	(13,862)	20,000	273,874
<b>Restricted funds</b>				
Fund A	677	33	–	710
Fund E	76,895	2,108	–	79,003
Fund H	30,031	(2,997)	–	27,034
Fund I	40,134	303,490	(20,000)	323,624
	<u>147,737</u>	<u>302,634</u>	<u>(20,000)</u>	<u>430,371</u>
<b>TOTAL FUNDS</b>	<b>415,473</b>	<b>288,772</b>	<b>–</b>	<b>704,245</b>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
General fund	606,191	(620,053)	(13,862)
<b>Restricted funds</b>			
Fund A	33	–	33
Fund E	5,069	(2,961)	2,108
Fund H	3	(3,000)	(2,997)
Fund I	340,907	(37,417)	303,490
	<u>346,012</u>	<u>(43,378)</u>	<u>302,634</u>
<b>TOTAL FUNDS</b>	<b>952,203</b>	<b>(663,431)</b>	<b>288,772</b>

continued ...

**brainstrust – Notes to the Financial Statements for the year ended 31st March 2023 – continued**

**17. Movement in funds – continued**

A current year 12 months and prior year 12 months combined position is as follows:

	At 1.4.21 £	Net movement in funds £	Transfers between funds £	At 31.3.23 £
<b>Unrestricted funds</b>				
General fund	267,736	(85,270)	22,563	205,029
<b>Restricted funds</b>				
Fund A	677	2,599	(2,563)	713
Fund E	76,895	5,363	–	82,258
Fund H	30,031	(2,992)	–	27,039
Fund I	40,134	266,826	(20,000)	286,960
Fund J	–	2,108	–	2,108
	147,737	273,904	(22,563)	399,078
<b>TOTAL FUNDS</b>	<b>415,473</b>	<b>188,634</b>	<b>–</b>	<b>604,107</b>

**brainstrust – Notes to the Financial Statements for the year ended 31st March 2023 – continued**

**17. Movement in funds – continued**

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
General fund	1,226,861	(1,312,131)	(85,270)
<b>Restricted funds</b>			
Fund A	2,599	–	2,599
Fund E	10,139	(4,776)	5,363
Fund H	122	(3,114)	(2,992)
Fund I	359,947	(93,121)	266,826
Fund J	2,141	(33)	2,108
Fund K	42,100	(42,100)	–
	417,048	(143,144)	273,904
<b>TOTAL FUNDS</b>	<b>1,643,909</b>	<b>(1,455,275)</b>	<b>188,634</b>

**NATURE AND PURPOSE OF FUNDS**

**General Fund**

The 'free reserves' after allowing for all restricted funds.

**Restricted Funds**

All other restricted funds have been created through fundraising or donations for the benefit of individual brain tumour patients. The charity uses the funds for direct treatment or to support research relating to the patients needs.

**18. Related party disclosures**

During the year the charity purchased services from Fitton Holman Creative Limited totalling £14,985 (2022 – £10,462). The company is directed by one of the co-founder's sister, Catherine Fitton.

During the year the charity paid the co-founders and management employees of *brainstrust*, Peter and Helen Bulbeck, £3,960 (2022 – £4,320) for administrative use of their property.

The co-founder's daughter, Leonora Bulbeck, supplied editorial services during the year to the charity totalling £2,100 (2022 – £1,890) at a commercial rate.

*continued ...*



**brainstrust – Detailed Statement of Financial Activities for the year ended  
31st March 2023**

	2023 £	2022 £
<b>INCOME AND ENDOWMENTS</b>		
<b>Donations and legacies</b>		
Donations	90,081	57,896
Grants from awarding entities	242,951	175,831
Corporate grants and donations	32,769	53,576
Gift aid tax recovered	34,878	50,551
Legacies	8,963	–
	<b>409,642</b>	<b>337,854</b>
<b>Other trading activities</b>		
Fundraising events	81,731	75,417
Sale of 'brainstrust' items	10,249	12,472
Sponsored activities	117,936	174,339
Activities of partner groups	71,086	346,012
	<b>281,002</b>	<b>608,240</b>
<b>Investment income</b>		
Deposit account interest	1,062	26
<b>Other income</b>		
Gov grants – Furlough claimed	–	6,083
	<b>691,706</b>	<b>952,203</b>
<b>EXPENDITURE</b>		
<b>Raising donations and legacies</b>		
Fundraising fees	11,077	33,129
Promotional expenses	31,318	26,782
	<b>42,395</b>	<b>59,911</b>
<b>Other trading activities</b>		
Trading costs and purchases	4,755	7,972
Event costs	5,941	11,433
Sponsored activities costs	9,612	10,868
	<b>20,308</b>	<b>30,273</b>

This page does not form part of the statutory financial statements

**brainstrust – Detailed Statement of Financial Activities for the year ended  
31st March 2023**

	2023 £	2022 £
<b>Other trading activities</b>		
<b>Charitable activities</b>		
Medical grants and costs	1,400	3,000
Patient support and staffing	463,460	318,242
Salaries	159,660	163,094
Travel	22,243	8,972
Administration	35,241	31,803
Office rent & rates	31,316	30,498
Fixtures and fittings	103	9
Depn of website	764	2,666
	<b>714,187</b>	<b>558,284</b>
<b>Support costs</b>		
<b>Governance costs</b>		
Auditors' remuneration	3,225	3,000
Insurance	2,486	2,196
Other	8,274	8,949
Bank loan interest	969	818
	<b>14,954</b>	<b>14,963</b>
Total resources expended	<b>791,844</b>	<b>663,431</b>
<b>Net (expenditure)/income</b>	<b>(100,138)</b>	<b>288,772</b>

This page does not form part of the statutory financial statements

# Get in touch

## Helping you

Talk to our team 24/7 on **01983 292 405**, or email [hello@brainstrust.org.uk](mailto:hello@brainstrust.org.uk).

## Helping us

Make a donation at [brainstrust.org.uk/donate](https://brainstrust.org.uk/donate), call us on **01983 292 405** during office hours, or email [fundraising@brainstrust.org.uk](mailto:fundraising@brainstrust.org.uk).

## Registration

*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.

## Registered address

*brainstrust*, 4 Yvery Court, Castle Road,  
Cowes, Isle of Wight PO31 7QG

[www.brainstrust.org.uk](https://www.brainstrust.org.uk)  
[www.braintumourhub.org.uk](https://www.braintumourhub.org.uk)

## Regional office (north of England)

*brainstrust*, C19–21 Joseph's Well, Hannover Lane,  
Westgate, Leeds LS3 1AB

# Declaration

The trustees declare that they have approved the trustees' report above.  
Signed on behalf of the charity's trustees.

Signature: 

Full name: **Christopher John Baker**

Position: **Chair of the Board of Trustees**

Date: **5 October 2023**



.....

*When I was feeling overwhelmed after my husband's craniotomy, I reached out to the team at brainstrust. Their support has been reassuring and the family and friends Meetups have provided an opportunity for me to connect with others in a similar situation. All the team at brainstrust have been amazing at keeping in touch and I am very grateful for the brain box and the informative booklets in it.*

**Caregiver**

.....

*braintrust* 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.  
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