THE GREY MATTERS

Issue 33 | Spring 2026

THE BRAIN TUMOUR CHARITY

- What is translational research?
- Celebrating our counselling service
- Investigating the financial cost of brain tumours

HELLO!

As Emeritus Founder Trustees of The Brain Tumour Charity, we're delighted to welcome you to the latest issue of *The Grey Matters.*

2026 marks 30 years since we set up The Samantha Dickson Research Trust after our daughter Samantha tragically died following a brain tumour diagnosis.

The Trust began life as just the two of us operating out of our own home and we could never have imagined the impact we'd have over the next three decades. Swept forward by the passion and commitment of the brain tumour community, The Trust grew and grew – and so in turn did Samantha's legacy. In 2013, we made the difficult decision to merge with two other charities to form The Brain Tumour Charity as it's known today.

While we'd have loved to keep working in Samantha's name, we knew that joining forces would allow us to move further, faster for people affected by brain tumours. And this hard choice has been vindicated many times over as our impact has continued growing.

Samantha's legacy now includes supporting nearly 13,000 people a year, providing a free professional counselling service and funding projects across the entire research pipeline.

But none of this is possible without incredible supporters like yourself. So, thank you for joining us on this journey over the last 30 years and we hope you enjoy reading about some of the impact you've helped us have.

ANGELA AND NEIL DICKSON OBE
Emeritus Founder Trustees
of The Brain Tumour Charity

CONTENTS

ON THE COVER

DON'T MISS

NEWS

AN UPDATE ON VORASIDENIB

In January, the National Institute for Health and Care Excellence (NICE) announced that the appraisal for a promising new drug called vorasidenib had been paused.

Draft guidance on whether vorasidenib will be approved to treat some brain tumours through the NHS is now expected 29 April 2026.

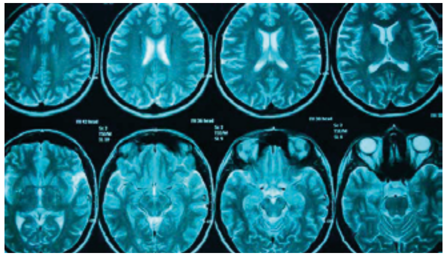
This delay comes at the request of the manufacturers of vorasidenib and we remain hopeful of a positive result for the brain tumour community.

NHS SCOTLAND PUBLISHES NEW GUIDANCE ON BRAIN TUMOURS

We were pleased to see NHS Scotland publish new guidance in 2025 that aims to ensure people receive a faster brain tumour diagnosis.

By giving GPs clearer tools and better recognition of symptom patterns, the new guidelines support more timely and accurate referrals.

We believe the updated guidelines represent meaningful progress for the brain tumour community in Scotland.



MOURNING THE LOSS OF SOPHIE KINSELLA

With heavy hearts, we paid tribute to beloved author Sophie Kinsella, who died in December following a glioblastoma diagnosis.

As one of our High Profile Supporters, Sophie did so much to increase awareness of brain tumours and raise vital funds for our work.

For all this and so much more, we're incredibly grateful, deeply saddened by her loss, and send our thoughts to her family, friends and fans at this difficult time.

ANNOUNCING FUNDING FOR AMBITIOUS NEW CONNECT TARGET CLINICAL TRIAL

In November, we announced that we're contributing £1.5 million to an ambitious international clinical trial called CONNECT TarGeT. The trial will test how different combinations of drugs can be used to treat some of the most aggressive childhood brain cancers.

Once enrolled in the study, participants will be screened to identify the genetic profile of their tumour. This will help researchers match them to a drug or combination of drugs that's most likely to be effective for them. They'll then be assigned to the relevant arm of the trial that's testing that drug or drugs, alongside standard surgery and radiotherapy.

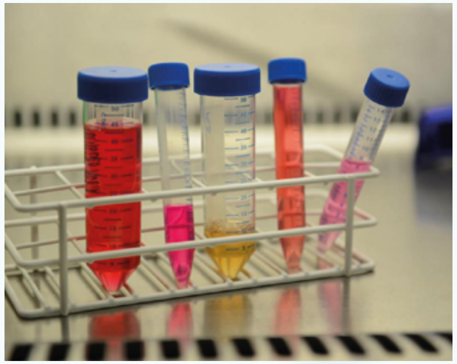
The information collected aims to help researchers understand why some patients respond to certain treatments and others don't - with the hope of developing better treatments in the future.

WHO'S ELIGIBLE TO TAKE PART?

CONNECT TarGeT will be open to people aged 1-25 years old who have been newly diagnosed with a paediatric high grade glioma, such as a Diffuse Midline Glioma (DMG), some ependymoma and embryonal brain tumours.

WHY'S THIS TRIAL IMPORTANT?

Less than 10% of people diagnosed with a paediatric high grade glioma survive for five years or longer after receiving a diagnosis. So, kinder, more effective treatments are urgently needed.



WHAT ARE WE FUNDING?

The Brain Tumour Charity is funding the screening protocol in the UK and the first arm of the trial that's due to open in the UK. This will test the drugs everolimus and ribociclib on people whose tumours match a specific genetic profile - alterations in the PI3K/mTOR pathways.

Key partners helping us to fund this work are The Albie Sugden Foundation, Eva's Angels, Joss Searchlight, The Samantha Dickson Fund, The Silas Pullen Fund and Shay's Smiles. We want to thank them for their support.

Find out more by visiting **thebraintumourcharity.org/connect-target**

OUR RESEARCH IN NUMBERS FOR 2025

Whether you raised funds through an event, donated directly or volunteered your time, generous supporters like you made 2025 an incredible year of accelerating cures for brain tumours.

Thanks to you, we were able to spend over £5.5 million on research and invest in projects that span the entire research pipeline.

Research to improve diagnosis

↓

Discovery research to increase our knowledge

↓

Translational research to bridge the gap between knowledge and clinical trials

↓

Clinical trials that aim to get new treatments to people sooner

↓

Research to improve care and support for people with brain tumours

£5.5M

is the equivalent of:

- **39 million microscope slides**
- **7 million test tubes**
- **57,000 hours of advanced brain tumour imaging**

Or it could buy 1.64 million coffees!

We fund the very best ideas - wherever they originate - and in 2025 we funded researchers on 48 projects across 11 countries.

We also committed more than £6.5 million over the coming years to 16 new research projects.

WANT TO HELP ACCELERATE CURES FOR BRAIN TUMOURS?

Regular gifts enable us to invest more into long-term research that accelerates kinder, better cures for brain tumours. By donating as little as £2 per month, you can help us move further, faster towards a world where everybody diagnosed with a brain tumour lives a longer, better life.

Set up a regular gift today by visiting **thebraintumourcharity.org/donate**

CELEBRATING OUR NEW

TRANSLATIONAL AWARD

In August 2025, we were excited to announce nearly £1.2 million in funding as part of our new Translational Award. This new dedicated funding scheme for translational research aims to bridge the gap between research and clinical treatments by helping existing projects gather the data and evidence needed to attract investment and move into late-phase clinical trials.

WHAT ROLE DOES TRANSLATIONAL RESEARCH PLAY?

When thinking about the role translational research plays, it can be useful to imagine a valley.

On one side of the valley, you have discovery research that aims to expand our understanding of brain tumours and identify promising new ways to treat them. These are usually in-vitro studies, which means they're performed using cells in a petri dish.

On the other side of the valley, you have late-stage clinical trials. These are studies that involve large numbers of people who've been diagnosed with a brain tumour receiving the new drug to definitively prove it's more effective than the current standard of care.

To bridge this gap, translational research is vital! Obviously, a human body is infinitely more complicated than cells in a petri dish, so translational research focuses on making sure the new treatment is safe for patients and the positive effects can be reliably and safely reproduced in people with brain tumours.

WHY IS TRANSLATIONAL RESEARCH IMPORTANT?

It's estimated that for every 10,000 promising drugs discovered in the lab, only five will make it to the clinical trial stage.

The vast cost of clinical trials means that life science companies are extremely selective about which projects they fund and they can be particularly averse to investing in research into brain tumours because of the difficulty in developing treatments that can cross the blood brain barrier.

> “Our Translational Award will ruthlessly evaluate and drive the best ideas forward. Projects successfully emerging from this pipeline will be in a strong position to attract the significant further funding required to move into clinical trials.”
>
> **- Dr Simon Newman, Chief Scientific Officer at The Brain Tumour Charity**

WHAT ARE WE FUNDING?

Enhancing CAR-T cell therapy for brain tumours

Prof John Anderson and his research group are focused on developing a new type of CAR-T cell therapy to use patients' immune systems to recognise and attack brain tumour cells.

Importantly, these new CAR-T cells have been designed to target a protein on the surface of many high-risk brain tumours that isn't usually found on healthy cells – so only the cancer cells will be targeted.

These CAR-T cells are currently being tested in a clinical trial, with this new funding being used to improve the CAR-T cells further and develop a new clinical trial.

Delivering drugs to brain tumours

A research team led by Prof Maya Thanou has developed a new small molecule technology called ActNano that's capable of delivering multiple drugs to tumours without affecting healthy cells.

The study we're funding will use focused ultrasound to briefly open the blood brain barrier surrounding the tumour so the ActNano molecules can reach the site of the tumour. The ultrasound also breaks down the molecules to release the drugs inside them, so they only affect the tumour cells.

Preventing glioblastoma recurrence

Dr Michael Hudson and his team are investigating whether a drug called MTL-004 can be used alongside current treatments to prevent glioblastomas from growing back following surgery.

MTL-004 will be applied as a paste to the area where the tumour was removed. It attaches to DNA and prevents it from being copied, hopefully killing cancer cells that are left behind after surgery.

Before they're able to move forward to clinical trials, the team will use this funding to run final tests to find the most effective dosage for patients and make sure MTL-004 is safe to use in combination with temozolomide and radiotherapy.

Find out more by visiting **thebraintumourcharity.org/ translational-research**

MARKING 30 YEARS OF PROGRESS

Join us in remembering Samantha Dickson and celebrating the incredible legacy that her parents - Angela and Neil - forged in her memory.

Samantha was a bright, lively girl who enjoyed school, music and sports. In 1996, she sadly passed away from a high grade glioma just days before turning 17.

After her death, Angela and Neil founded The Samantha Dickson Research Trust. It's no exaggeration to say they fundamentally changed the landscape for the brain tumour community.

Before, families facing this awful disease didn't have the support of a dedicated brain tumour charity. There was minimal research happening and no clear focus for an extremely passionate brain tumour community that was desperate for progress.

By harnessing this passion and steadfastly working with the community, Angela and Neil were able to have an impact far beyond the modest size of the organisation.

A 2013 merger saw three leading brain tumour charities unite behind shared goals under the name The Brain Tumour Charity. And with your support, our impact has grown and grown.

Today, Angela and Neil continue to build Samantha's legacy through The Samantha Dickson Fund, driving progress for families facing the same diagnosis they did 30 years ago.

OUR HISTORY TOGETHER

We've achieved many great things with your support and here are just a handful of Angela and Neil's favourites.

1996

The Samantha Dickson Research Trust is founded.

1998

Our Scientific and Medical Advisory Board is established to help identify the very best research to fund.

1999

Our Supporter Group model is launched – empowering people to create dedicated funds in the name of a loved one without all the admin associated with running a charity – and our first Supporter Group is established.

2001

The Charity successfully lobbies the **National Institute for Health and Care Excellence (NICE)** to approve temozolomide for treating high grade brain tumours.

2007

A major breakthrough from the University of Cambridge and Queen Mary University of London as the BRAF mutation in childhood brain tumours is discovered through research funded by The Charity.

2010

We fund a major breakthrough at the University of Newcastle that will later lead to changes in treatment for children with certain sub-types of medulloblastoma.

2011

Our **HeadSmart** campaign is launched to promote awareness of the signs and symptoms of childhood brain tumours. This would later evolve into our **Better Safe Than Tumour** Campaign for adults and children.

2013

The Brain Tumour Charity as we know it today is formed through a merger that united three charities under the name. We also held the first **Twilight Walk.**

2017

The Charity awards our largest grant to date - **£5m** - to The Everest Centre for Research into Paediatric Low Grade Brain Tumours.

2018

Our pioneering **Future Leaders programme** is launched to help fund the next generation of world-class researchers into brain tumours.

2020

The Samantha Dickson Fund is created, funding research into cures for high grade gliomas.

2021

Dr Gelareh Zadeh's research that's part-funded by us reveals a new way of classifying meningiomas that can more accurately predict how a tumour will behave and help identify patients who may benefit from more aggressive treatment earlier.

2023

Our free counselling service is launched.

2024

We unite 52,000 people behind our campaign for a **National Brain Tumour Strategy**.

NICE approves dabrafenib and trametinib to treat some childhood gliomas, the first new treatment for brain tumours available through the NHS in decades.

LAUNCHING OUR NEW REPORT ON THE FINANCIAL COST OF BRAIN TUMOURS

In December, we hosted an event at the Houses of Parliament to launch our new report capturing the financial burden of brain tumours and to call for change. New analysis commissioned by The Brain Tumour Charity shows that one year of new brain tumour diagnoses – currently around 13,000 per year – imposes a lifetime economic burden of around £18.7 billion on the UK.

That's the equivalent of around £1.47 million per person diagnosed.

While the majority (£13.5 billion) of this represents the wider economic impact of lost health and life, this new analysis also lays bare the steep cost to those personally affected by brain tumours.

The findings have been published in our new *The Cost of a Brain Tumour: The Economic Case for Urgent Action* report, through which we will influence policymakers in government to create meaningful change that benefits everybody affected by a brain tumour.

OUR SIX RECOMMENDATIONS

In the report, we've made a series of recommendations on how the government should take action to help decrease the negative economic impact of brain tumours on both the wider economy and those personally affected by the disease.

A National Brain Tumour Strategy is urgently needed to help reduce the significant human and economic cost of brain tumours in the UK. A unified, nationally coordinated approach can help transform outcomes for people affected by brain tumours and - with these six recommendations at its heart - deliver better value for the public purse.

1. Take measures to deliver faster and equitable diagnosis across all four nations in the UK so that fewer people are diagnosed through emergency presentation.

2. Improve access to care and support so that people's needs are met and ensure this access is consistent wherever somebody lives or is treated.

3. Prioritise education and lifelong potential by ensuring children and young people diagnosed with a brain tumour have the support they need to navigate the difficulties of an education interrupted by illness.

4. Improve economic inclusion and welfare support by making welfare work better for people with fluctuating neurological symptoms and making sure employers are doing all they can to help people with brain tumours return to work.

5. Greater investment in research and innovation so that we're creating the right environment for researchers to find the new treatments we so desperately need.

6. Accountable, national leadership for brain tumours so that the the brain tumour community are no longer unseen and unsupported.

One of our Involvement Champions, Nic, attended the launch event and had this to say:

> "I really enjoyed being involved in the launch of this report in Parliament. For seven years, I had to quietly manage and conceal the side-effects of my brain tumour to reduce the financial impact it was already having and protect my finances as a working parent - a reality many people in similar situations still face.
>
> Removing this invisible barrier will lift this weight, making life easier and kinder for patients, families, and everyone affected.
>
> Talking about these issues, particularly with MPs, Lords, medical teams, researchers and people affected, really builds those relationships to meaningfully help other people facing the same life-altering challenges and consequences."

CELEBRATING THREE YEARS OF OUR COUNSELLING SERVICE

A brain tumour diagnosis can turn your life completely upside down. Whether you're diagnosed yourself or a loved one is, coming to terms with this disease is an overwhelming prospect and many struggle to make sense of their feelings.

Unsurprisingly, this can have a significant impact on somebody's mental health. In fact, 91% of people who took part in our Losing Myself report said that a brain tumour diagnosis had affected their emotional or mental health.

Despite this, only 45% of people who responded said they had access to counselling.

LAUNCHING OUR COUNSELLING SERVICE

To help people navigate a brain tumour diagnosis and cope better with the impact, we launched our free professional counselling service for people affected by a brain tumour in the summer of 2022.

More than three years on, the service has grown significantly and we're now able to support more people than ever before with their mental health.

CELEBRATING THE IMPACT OF OUR FREE COUNSELLING SERVICE

Since launching our free counselling service pilot in 2022, we've provided counselling to nearly 2,000 people and delivered more than 13,000 counselling sessions.

In 2025 alone, we provided free counselling to 850 people and delivered more than 5,500 sessions.

99%

of people rated their overall experience of the counselling service as good or very good.

When asked if the counselling had made a difference to their emotional well-being and ability to cope, 81% of people answered either "Yes, completely" or "Quite a lot". People using the service also reported an average improvement of 41% in CORE-10 scores – a clinical measurement of psychological distress.

THANK YOU TO ALL OUR FUNDRAISERS AND VOLUNTEERS

Providing a service like this simply wouldn't be possible without the support of lots of different people – from the counsellors and volunteers to everybody who raises funds or donates money to The Charity.

So, we want to take this opportunity to thank everybody who's helped make our free counselling service such a success.

"The decision to launch our free counselling service came as a direct response to feedback from the community that they weren't receiving the support they needed with their mental health.

I'm extremely proud of the service and the fact that we've not just significantly increased the number of people we've provided free counselling to each year, but we've managed to do so without sacrificing the quality of the service we're delivering.

This is only thanks to the work of our brilliant team, and we're so grateful to everyone involved in creating and evolving our much-needed service."
- Jen Boilestad,
Counselling Service Manager

Whether you're facing a brain tumour diagnosis yourself, supporting a family member, or bereaved, we offer eight free counselling sessions online or over the phone. To make a self-referral for our counselling service, visit **thebraintumourcharity.org/counselling**

DEANNA'S STORY

Deanna is a 29-year-old mental health nurse from Derbyshire. She applied to our counselling service to help her come to terms with her shock meningioma diagnosis in July 2024.

"I was so shell-shocked, I didn't even ask any questions. A brain tumour is not something you expect to have. I didn't know how to process it at all. I just went home assuming the worst."

Just two weeks after the scan that revealed the tumour, Deanna had a successful surgery and found out that her tumour was a meningioma – but recovery was difficult. Deanna struggled to walk and couldn't do much for herself for a time. She also had bad side-effects from the steroids she was on and found the sudden contrast to her previous, highly active life very hard to cope with.

It was during her recovery that Deanna applied for our counselling service. She opted to have her sessions via video call.

"Video was a good choice for me. It was nice to see the person I was talking to. Although I had support around me, I felt very much alone when I tried to process my diagnosis. I had never heard of anyone else with a brain tumour, let alone anyone my age."

THE IMPACT OF OUR FREE COUNSELLING SERVICE ON DEANNA

"In the counselling sessions, I was allowed to talk quite openly about what worried me the most – my fear of dying. I never felt pressured – even if sometimes, I would just sit and cry. I felt listened to and understood.

"It also helped that the service is geared to people with brain tumours. You wouldn't expect a more general counselling service to necessarily understand the impact of the disease."

Deanna is now back at work full-time and has been able to return to all her usual activities. She credits the counselling with helping her reflect and understand what's happened to her.

"The counselling really helped me process what had happened. I'd certainly recommend the service to anyone affected by a brain tumour diagnosis."

HELP US SUPPORT MORE PEOPLE LIKE DEANNA

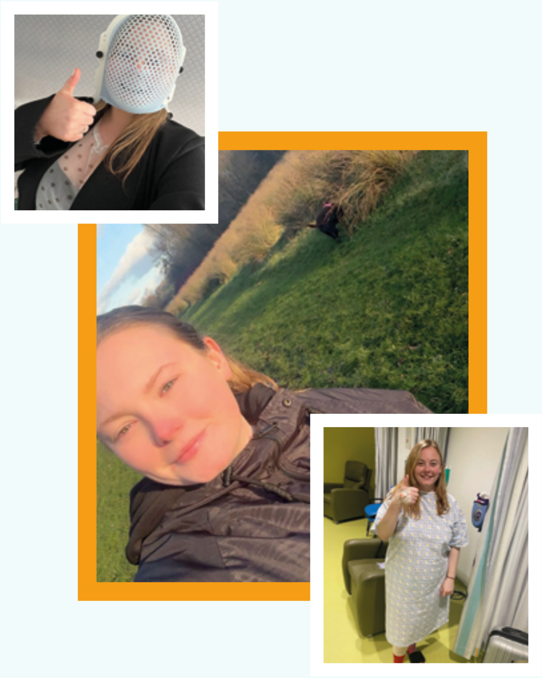
In 2024/25, we helped more than 12,000 people on a one-to-one basis through our Support and Information services.

This year, we want to be there to provide support for even more people affected by a brain tumour. But this simply isn't possible without the generosity of incredible supporters like yourself.

Donate today by visiting
thebraintumourcharity.org/donate

> “In the counselling sessions, I was allowed to talk quite openly about what worried me the most – my fear of dying. I never felt pressured – even if sometimes, I would just sit and cry. I felt listened to and understood.”

AMY'S ACTIVE AUTUMN



After Amy's shock brain tumour diagnosis and the gruelling treatment that followed, she found it difficult to adjust to her new normal.

Two years after her first surgery, she was still experiencing side-effects that affected her day-to-day life - the worst of which was overwhelming fatigue. She was also struggling to come to terms with the fact that not all the tumour could be removed, meaning there was a chance it could grow back.

GETTING SUPPORT FROM THE CHARITY

To help her cope with how she was feeling, Amy applied for our free counselling service and joined our Online Brain Tumour Support Groups.

Amy said:

> “I'll always be grateful to the Charity for the support I received. My counsellor was amazing from the start, and I could see how much my mood was improving. It helped me into a routine and to get some independence back.
>
> Being part of the peer support group was also valuable. Not just for emotional support, but also practical things, like what to do about your driving licence or travel insurance.”

TAKING ON ACTIVE AUTUMN TO GIVE BACK TO THE CHARITY

Amy took on one of our new community fundraising events - Active Autumn - because she wanted to raise funds to help other families affected by brain tumours. She didn't just smash the challenge; she smashed her fundraising target too and has now raised an incredible £1,000!

> “To make sure I moved every day, I mixed things up. I did gym workouts, dance workouts at home, and I'd swim if it was raining. I really enjoyed going for walks with my dog. She was a good motivator!
>
> I definitely recommend doing Active Autumn or a similar challenge. Knowing that I had raised funds and so many people had donated to The Charity, helped me to keep going and find the energy and motivation.”

COULD YOU BE OUR NEXT SUPERSTAR COMMUNITY FUNDRAISER?

From bakers and bikers to gamers and gardeners, absolutely anybody can help accelerate cures for brain tumours by holding a community fundraising event.

WHAT IS COMMUNITY FUNDRAISING?

In short, community fundraising is any fundraising event or activity that isn't organised by The Brain Tumour Charity (for example, The Twilight Walk London) or a third party (for example, the London Marathon).

There really is no limit on how you fundraise. You can take a more traditional approach through something like holding a Twilight Walk Own Walk, doing a sponsored head shave or hosting a bake sale.

Alternatively, you could try something a little more unconventional by holding a board game tournament, a streaming marathon or fundraising concert.

WHO CAN BECOME A COMMUNITY FUNDRAISER?

Absolutely anybody! There's no age restriction when it comes to accelerating cures for brain tumours – from nine-year-old bakers to 80-year-old long-distance walkers! You could also fundraise at work, at school, or within your local community.

WHAT ARE THE BENEFITS OF COMMUNITY FUNDRAISING?

The best thing about community fundraising is that you have complete control over how you fundraise, but you still get the full support of our Community Fundraising team.

You can take part in one of our flagship community fundraising events, like The Big Bake and Wear It Red, or you could take on a fundraising event of your own creation by turning your passion into pounds.

READY TO BECOME OUR NEXT COMMUNITY FUNDRAISER?

We're here to support you every step of the way - from fundraising tips and helping you prepare to cheering you on at your event.

To find out more, contact our Community Fundraising team by emailing **communityfundraising@thebraintumourcharity.org**

THANK YOU!

THANKS FOR HELPING ACCELERATE PROGRESS LAST CHRISTMAS

A massive thank you to everyone who donated at Christmas, including through The Big Give Christmas Challenge 2025! Altogether, you raised more than £225,000! Your generosity will help to accelerate research and drive more life-changing discoveries.

A HUGE SHOUT OUT TO ALL OUR WONDERFUL VOLUNTEERS

In 2025, more than 400 of you volunteered your time to support our work and there were more than 2,539 contributions from Involvement volunteers.

Thank you so much, we simply couldn't do what we do without you generously donating your time and skills to help people affected by a brain tumour live longer, better lives!

THANK YOU TO ALL OUR DONORS AND FUNDRAISERS!

A huge thank you to everybody who helped us raise money in 2025. Every penny that you raised helps us move further, faster for everybody affected by a brain tumour.

Last year, more than 20,000 of you donated to help accelerate cures for all brain tumours and made a total of more than 102,000 donations.

And more than 8,000 of you took on some fundraising on behalf of The Charity, receiving nearly 200,000 contributions to your fundraising campaigns.

TOP FIVE FUNDRAISING EVENT TYPES IN 2025

1 RUNS

2 WALKS & TREKS

3 CYCLES

4 BAKES

5 COMMUNITY GATHERINGS

EVENTS
FOR YOUR DIARY

APRIL/MAY 2026

25-26 April
Kiltwalk Glasgow

16-17 May
Jurassic Coast Challenge

23-24 May
London 2 Brighton Ultra Challenge Walk

JUNE/JULY 2026

7 June
Kiltwalk Aberdeen

8-15 June
World Brain Tumour Day Skydive Week

4-5 July
Peak District Ultra Challenge

11-12 July
Race to the Stones

AUGUST/SEPTEMBER 2026

16 August
Dundee Kiltwalk

12 September
Thames Bridge Trek

13 September
Great North Run
London to Brighton Cycle Challenge

14 September
Kiltwalk Edinburgh

OCTOBER 2026

3-4 October
Snowdon by Night

11 October
Royal Parks Half Marathon

18 October
Great South Run

Find out more and sign up by visiting:
thebraintumourcharity.org/events

FILL YOUR WILL WITH HOPE

Andrew was looking ahead to his 30s with excitement when a shock brain tumour diagnosis changed his life completely.

Ten years on, Andrew is happy and mostly healthy, although he still lives with the everyday effects of his diagnosis and the knowledge that the tumour is likely to return.

> **“By leaving a gift in my Will, I hope that fewer families in the future will have to face the shock, fear and uncertainty that comes with a brain tumour diagnosis.**

Learn more about Andrew’s story by visiting
thebraintumourcharity.org/andrews-story

thebraintumourcharity.org **01252 749990**

Registered office: Fleet 27, Rye Close, Hampshire
GU51 2UH.
Registered Charity no. 1150054 (England and Wales)
and SC045081 (Scotland). Company no. 08266522.

Registered with FUNDRAISING REGULATOR