THE GREY MATTERS

Issue 32 | Autumn 2025

THE BRAIN TUMOUR CHARITY

Coping with bereavement: **Lottie's story**

New funding to enhance **quality of life**

Campaigning to save and **improve lives**

HELLO!

From incredible strides forward in our campaigning to news of the latest promising research we're funding and fantastic fundraising achievements, this issue of The Grey Matters is packed full of progress on so many fronts.

Our research (pages 4-5) has seen lots of exciting activity recently. Just one example is the £380,000 of new funding we've awarded to projects looking to improve quality of life for children and teenagers living with a brain tumour.

While investing in vital research today, we're also investing in tomorrow's leading researchers into brain tumours. In June we were delighted to bring together the 13 early-career researchers on our Future Leaders programme for two days of learning and networking.

We also launched a new report in March that explores recent NHS England guidance on giving GPs the ability to directly refer people experiencing brain tumour symptoms for diagnostic scanning. Turn to pages 8-9 to read more about our campaigning successes.

On pages 10-11 we hear from Lottie, who's hoping to help others cope with bereavement by bravely sharing her story of losing her beloved father, Russell. Here at The Brain Tumour Charity we're always here to support you, including through bereavement.

Finally, a huge thank you to everyone who took part in The Twilight Walk in March – whether you joined us in London or took part in one of the Own Walks held across the UK (see pages 14-15). This was an incredible effort from everybody involved and helped us raise more than £500,000.

Thanks so much for all your support. I hope you enjoy this issue, and you'll continue to help us find new treatments, offer the highest level of support and campaign for urgent change. Buying your cards and more from our Christmas shop is a great way to contribute – see pages 12-13 for more.

Thank you,
Dr Michele Afif, CEO

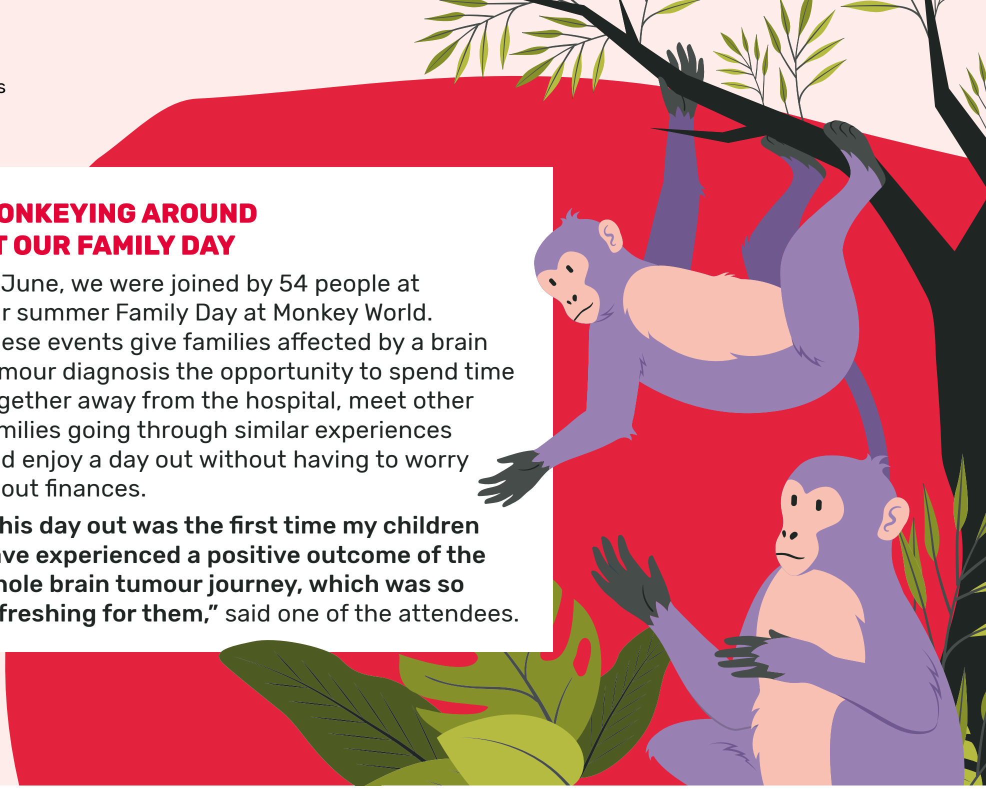
ON THE COVER

DON'T MISS

MONKEYING AROUND AT OUR FAMILY DAY

In June, we were joined by 54 people at our summer Family Day at Monkey World. These events give families affected by a brain tumour diagnosis the opportunity to spend time together away from the hospital, meet other families going through similar experiences and enjoy a day out without having to worry about finances.

"This day out was the first time my children have experienced a positive outcome of the whole brain tumour journey, which was so refreshing for them," said one of the attendees.



NEW TEST COULD DIAGNOSE A BRAIN TUMOUR IN AS LITTLE AS TWO HOURS

A new test, developed at the University of Nottingham, could reduce the time to molecularly diagnose brain tumours from 6-8 weeks to as little as two hours.

The research team used the approach during 50 brain tumour surgeries to deliver rapid diagnoses during the procedures. It achieved a 90% success rate, providing accurate results in under two hours from biopsy.

By taking a tumour biopsy, the type and grade can be diagnosed. This is vital to determine the most effective treatment and a person's prognosis.

Although it looks promising, the test needs further validation and comparison to current techniques before becoming widely available.

COLLABORATING WITH WORLDWIDE CANCER RESEARCH

We've partnered with Worldwide Cancer Research to co-fund research into Diffuse Midline Glioma (DMG), investing £160,000 as part of a joint £400,000 commitment to tackle this devastating childhood brain cancer.

These aggressive tumours develop in the midline of the brain and, due to their location, are often inoperable. Treatment options remain extremely limited, underscoring the urgent need for new research.

Through this partnership, Dr Maria Alieva and Professor Luciano di Croce have both been awarded funding to explore new ways of understanding and treating DMG, offering hope to families affected by this diagnosis.

NEW FUNDING TO IMPROVE QUALITY OF LIFE

We're delighted to announce £380,000 of new funding for research into improving quality of life for children and young people living with a brain tumour.

We're funding four exciting new projects in this area, including:

- A study to identify what's working in schools, and what's missing, for children returning to education following a brain tumour. Dr Sarita Depani at Great Ormond Street Hospital is leading this work.
- Research into the most effective supportive and lifestyle strategies to improve quality of life for children living with a brain tumour, headed by Dr Faye Didymus.
- A study investigating how genetics may influence quality of life in children with brain tumours, and to understand why some children have more long-term effects than others. Dr Debbie Hicks and Dr Akanksha Senapati are leading this research.
- A project led by occupational therapists Vicky King and Sharon Tuppeny testing how effective and practical a fatigue management therapy called SpoonieKids is in children living with the effects of a brain tumour.

Our Quality-of-Life Sandpit event in 2024 made these new projects possible. The event brought together experts from many different areas of research and care to collaborate, develop new research ideas and form new project teams.

We'll be closely following the progress of all this research and sharing updates in the months and years ahead.

BACKING INNOVATIVE NEW IDEAS

We're pleased to announce that Dr Elizabeth Cooper and Dr Youri Hoogstrate are the latest recipients of our Expanding Theories grants. We've awarded £150,000 to each of them over two years to support their promising research exploring innovative ideas to help people with brain tumours.

Dr Cooper, from the University of Cambridge, will explore a newly discovered blood cell produced in the skull bone marrow. She believes that understanding more about these cells could lead to new ways of harnessing the immune system to target brain tumours – specifically focusing on ependymomas.

In the Netherlands, Erasmus Medical Center's Dr Hoogstrate is developing a computer programme to predict outcomes for patients with IDH-mutated gliomas. His research focuses on patterns of DNA changes that can predict tumour progression and patient survival better than current methods.

He also hopes to uncover new targets for treatments and explore the role of key proteins involved in these changes, offering new hope for improved care.

SUPPORTING THE FUTURE LEADERS OF RESEARCH INTO BRAIN TUMOURS

We held a two-day event for the 13 brilliant early-stage researchers on our Future Leaders funding programme in London in June.

The event was a celebration of our Future Leaders programme that aims to fund outstanding early-career researchers and give them the support they need to establish themselves as leading experts in research into brain tumours.

As well as connecting with each other, the event was an opportunity for our Future Leaders to receive vital mentorship from senior researchers in the field, meet some of the donors funding their research and collaborate with people personally affected by brain tumours – including members of our Involvement community.

OUR YOUNG AMBASSADORS' CRUCIAL ROLE IN OUR RESEARCH

Our Involvement community, including our Young Ambassadors, play a vital role in our research, sharing their lived experience and views with researchers to help guide the design of their work.

By sharing their time and insights, through conversations with researchers or lay reviews, people with lived experience ensure that research into brain tumours stays grounded in real needs, with the voices of the community always front of mind.

EMMA, ONE OF OUR YOUNG AMBASSADORS, SAYS:

> “I feel so inspired by the research work happening at the charity. Being involved in the research through supporting lay reviews and promoting scientists' work means that I feel I can contribute to important work without being a researcher myself.
>
> I really look up to the amazing academics and researchers who dedicate their time and expertise to support The Brain Tumour Charity. To support in any small way is a fantastic opportunity.

Donate now and help fund research into brain tumours: thebraintumourcharity.org/donate

REMEMBERING ALEX AND EVANNE

We're very sorry to share the news that two of our much-loved Young Ambassadors, Alexander Bernard-Bell and Evanne Hughes, have passed away following their diagnosis of a brain tumour. This is a moment to remember them, to honour all they did for The Charity and to thank their families for the continued support they so kindly give.

Alexander was diagnosed with a Diffuse Leptomeningeal Glioneuronal Tumour in 2021. Despite every effort, and after six incredibly tough months in ICU at Charing Cross Hospital, he passed away at the end of January 2025, aged just 23.

His strength, grace and resilience throughout this time were extraordinary.

“Alexander was radiant with creativity, kindness and quiet strength. His passion was music, he performed under the name Syren, which he poured his heart and soul into. Even as he faced his diagnosis, he found meaning through songwriting, often expressing his experience through his lyrics. He also loved making music videos and films with his close friends, creating beautiful, thoughtful visuals that reflected his imagination.

To those who knew him, Alexander will always be remembered as a cheeky, funny and fiercely loving soul. Beneath his playful exterior was someone with exceptional emotional intelligence, a deeply empathetic person. His kindness, wit and loyalty touched everyone who crossed his path.

In his honour, our family has created Team Syren, a group that takes on various challenges, from Everest in the Alps to the London Marathon, to raise money for vital brain cancer research.”
Hannah Bernard-Bell, Alex's sister.

Evanne was an incredibly kind, creative and courageous young woman whose impact will never be forgotten. Since her diagnosis six and a half years ago, she became a passionate advocate for young adults, especially around the emotional toll of delayed diagnoses and lack of support. At university, she set up peer support groups and helped others feel seen and heard. To many of our Young Ambassadors, Evanne was more than an advocate - she was a friend, a confidant and someone who could always be counted on to lift the mood with her sharp sense of humour.

She bravely shared her story with our team, encouraging us to listen, learn and do better. She also used her creativity to express her experience, working with our social team to create a powerful ice cream themed awareness post that raised vital funds. Her legacy lives on in her advocacy, her art and the deep friendships she built.

“Evanne was a creative genius, having used her art to express the trauma of having a brain tumour and one of her biggest dreams was to raise awareness of brain cancer with the public through art. She displayed several poignant pieces at university, including one with hundreds of colourful origami and a spine-tingling immersive digital and physical art feature with a poetic voiceover.

Evanne showed extraordinary humility after she was diagnosed in her first year of university. Despite this, it was incredible to see her blossom into a young woman of immense character, wisdom and deep compassion. She lit up every room with her witty, down-to-earth humour. She was a hilarious housemate, and she would always be there for you, even if she was struggling herself. We had a close connection due to our shared experiences, and she gave me the confidence to become a Young Ambassador with her.”
Rebecca Unwin, fellow Young Ambassador

RAISING OUR VOICES FOR CHANGE

From better treatment to fairer financial support, we're fighting to improve life for everyone affected by a brain tumour. Our campaigns have seen incredible progress over the past year. Here are just some of the highlights:

01

PUSHING FOR A NATIONAL BRAIN TUMOUR STRATEGY

Current strategies to tackle cancer aren't working for people affected by brain tumours, who face unique challenges. This is why we've called for a National Brain Tumour Strategy to save lives and reduce suffering.

Over 3,500 of our supporters have now contacted their local MP on this issue. This groundswell of action has led to a Prime Minister's Questions intervention, a host of written parliamentary questions and engagement with 94% of all MPs. Thanks to our campaigners, we've kept brain tumours firmly on the political agenda and demonstrated just how strong our collective voice can be.

02

REMOVING BARRIERS TO TAKING PART IN RESEARCH

In June we published our Barriers to Participation in Research report, revealing challenges still preventing many people with brain tumours from joining trials or donating tissue. From inconsistent communication to postcode lotteries, the system isn't working for those who want to support vital research into brain tumours.

We've made six key recommendations to make participation more inclusive, supported and equitable, and we'll keep pushing to embed these changes.

03

HELPING SHAPE THE FUTURE OF RARE CANCERS IN THE UK

We proudly shaped and supported the Rare Cancers Bill, working with its architect, Dr Scott Arthur MP. This is a vital piece of proposed legislation aimed at improving research, data collection and access to clinical trials for rare cancers. As brain tumours continue to receive a fraction of cancer research funding, this Bill is a much-needed step forward.

04

SPEAKING OUT AGAINST WELFARE BENEFITS REFORMS

Earlier this year, over 200 people affected by brain tumours took part in a survey to inform our submission to the UK government's Pathways to Work Green Paper. Their message was clear: proposed changes to Personal Independence Payment (PIP) and Universal Credit risk harming those with complex, fluctuating conditions like brain tumours.

Our submission stressed the urgent need to fix a system often marked by inaccessible assessments, complex processes and poor understanding of fluctuating neurological conditions - all barriers raised by those who shared their experiences. Following sustained advocacy, the Government scrapped the proposed "four-point rule" for PIP eligibility - a welcome step forward.

05

INFLUENCING BETTER DIAGNOSIS

In April, our Exploring GP Access to Imaging in England report shed light on the delays people face when trying to access timely brain tumour diagnoses. Based on evidence from patients, GPs and other health professionals, the report highlighted the issues with GPs getting access to scans, use of decision-support tools and variation across regions. Our findings are now informing discussions with leaders across England to help deliver faster, better diagnosis for everyone.

WHAT'S NEXT?

Looking ahead, we're working on two major reports. One will explore the personal and wider economic cost of a brain tumour diagnosis, helping to make the case for long-term investment in research, care and support. The other will examine the barriers stopping innovation across the patient pathway. Both will be critical in shaping our future strategy and influencing decision-makers.

THANK YOU

Thank you for everything you've done this year to support our campaigning. Every action you take strengthens our collective voice and increases pressure on decision-makers to deliver the changes we all want to see.

“I HOPE THAT THREE YEARS ON FROM LOSING MY DAD, I CAN HELP SOMEONE ELSE WHO NEEDS IT DURING THESE HARD TIMES”

Bereavement takes many different forms, and everybody experiences it in their own way. Lottie shares her story.

My dad Russell was the most caring, intelligent man who would do anything for his two girls. He was a family man and true role model, deeply loved by us all. At weekends, he would take us to various sports activities while he sat in his car working. He had an incredible career in education.

He first noticed something was wrong in August 2020 when he noticed a loss of peripheral vision and went to get checked out. The eye specialist referred him straight to the hospital for scans. They showed a mass on his brain.

Worse, he was diagnosed with an aggressive brain cancer – a grade 4 glioblastoma. We were in shock.

It turned our world upside down. He was given six to 24 months to live, and I couldn’t comprehend that he wasn’t going to be in my life.

Watching Dad battle through radiotherapy and chemotherapy was hard, but he was so inspirational throughout that time. When taking his tablets, he would sit in his car and blast out his favourite music. He encouraged me and my sister to keep living our lives and to study for our degrees, which he was so proud of.

I considered taking a year out so I could be at home, but Dad told me to go out there and start living. So I moved to London to study fashion marketing, and dad was my biggest cheerleader from hospital.

No one should face grief alone. By donating today, you can help us be there for everyone who needs us: **thebraintumourcharity.org/donate**

FINDING SUPPORT

I was just 17 when dad was diagnosed. I didn’t know anyone with a brain tumour and had no idea how life-threatening it is. I felt isolated and thought no one could understand what I was going through.

But my family found out about The Brain Tumour Charity, and I got great support by reading and listening to other young people’s stories. I hope that five years on, I can now be that inspiration to others and help even one other person who needs it during these hard times.

Dad died 14 months after his diagnosis. I went back to university, as he would have wished, and carried on with my degree, but I felt like I had this dark cloud following me – grief.

DEALING WITH GRIEF

No one can tell you how grief will affect you and there’s no right way to grieve.

Grief is a rollercoaster, and it can hit you at any time. You might walk into a cafe and discover they’re playing the song from your dad’s funeral, or you see a father and daughter enjoying a meal together and it sets you off.

I know now that grief will always be a big part of my life, a cloud that follows me around.

But that cloud reminds me of the love I have for my dad – my biggest cheerleader, and now my mission in life is always motivated by him.

YOU WILL HAVE HOPE AGAIN

I hope I can inspire other young people going through a similar experience. You’re not alone and there are people who feel exactly how you feel.

I sometimes felt like I had to put on a brave face to people who will never be able to comprehend what I was going through – but just know that in those times, there are people at The Brain Tumour Charity who you can talk to.

I wanted to raise money for The Brain Tumour Charity because it helps raise awareness of not only brain tumours, but of the underfunding and gets people talking. So, throughout May 2021 I walked 15,000 steps every day and raised £3,000.

I knew my dad was with me every step of the way and now, just over four years since losing our dad, we’re learning to find the joy in life again. I’m so proud of us, and I know he would be too.

We provide free bereavement support and resources, including grief counselling. Find out more at **thebraintumourcharity.org/bereavement-resources**

CHRISTMAS GIFTS THAT GIVE BACK

From Christmas cards to gifts that give back, browse our seasonal shop selection and get that fuzzy, warm feeling that comes with doing some good this winter. Every purchase accelerates change for those affected by brain tumours. Shop our full range of Christmas products online: **shop.thebraintumourcharity.org**

CHRISTMAS CARDS

All Christmas cards come in a pack of 10.

1

Christmas Barn
Blank Inside

2

Countryside Christmas
Season's Greetings

3

The Christmas Present
Merry Christmas

4

Arts & Crafts Pheasant
Blank Inside

5

All in a Row
Blank Inside

6

Santa's Banner
Blank Inside

7

Santa Express
Happy Christmas

8

Off We Go
Happy Christmas

9

Golden Partridge
Season's Greetings

10

Christmas Post
Merry Christmas

11

In the Town Square
Happy Christmas

12

Ornate Robin
Happy Christmas

MONEY WALLETS

13

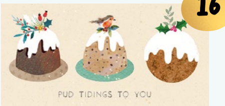
Winter Robins

14

Santa's Party

15

Christmas Village



16

Christmas Pudding

CHRISTMAS WRAP

17

Christmas Tree

18

Winter Robins

19

Candy Cane

20

Winter Foliage

COSY CHRISTMAS PICKS

21

22

23

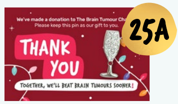
24

VIRTUAL GIFTS

Donate on behalf of your loved ones and they'll receive a beautiful e-card. Head to our website to donate either £5, £10 or £30.

FESTIVE FAVOURS

Our tasteful pin badges on seasonal backing cards are a physical keepsake of a donation you make on someone's behalf. For much more, please visit **shop.thebraintumourcharity.org**



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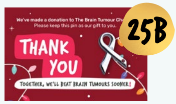

25B

TAKING STRIDES, SAVING LIVES

From Buckingham Palace to Hyde Park, an incredible 1,150 people joined forces at The Twilight Walk in London for Brain Tumour Awareness Month in March.

And over 1,600 of you took part in more than 171 of your Own Walks all over the country, united by the collective aim to make a difference for everyone affected by brain tumours.

Your efforts raised an outstanding £502,251. That's enough to fully fund our new award dedicated to research focusing on improving quality of life for children and teenagers living with a brain tumour. Thank you to everyone for taking steps to accelerate a cure.

CHANGING THE STORY FOR EVERYONE AFFECTED BY BRAIN TUMOURS

Thanks to the generosity of our inspiring supporters, our Summer Appeal campaign raised over £148,400. All these generous donations make vital progress in changing the story for everyone affected by this devastating disease.

A MARATHON EFFORT

A massive well done and thank you to our 147-strong team of runners who pounded the pavement this April in the 2025 TCS London Marathon. In total, they raised a momentous £520,800! Thank you to everyone who supported us.

EVENTS FOR YOUR DIARY

15-16 NOVEMBER 2025

Run Alton Towers

12 APRIL 2026

London Landmarks Half Marathon and Brighton Marathon

24-25 JANUARY 2026

London Winter Walk

19 APRIL 2026

Manchester Marathon

21 MARCH 2026

The Twilight Walk

17 MAY 2026

Hackney Half Marathon

PRE-REGISTER FOR THE TWILIGHT WALK

Join us as we march through London or take on your Own Walk somewhere special to you. Find out more and pre-register now: **thebraintumourcharity.org/thetwilightwalk**

ARRANGE YOUR OWN FUNDRAISING EVENT OR CHALLENGE!

From fundraising tips to cheering you on at your event – we're here to support you every step of the way. Find out more about DIY fundraising: **thebraintumourcharity.org/fundraise-for-us**

FILL YOUR WILL WITH HOPE

Nicola lost her brother, Stephen, to a glioblastoma in 2008. Ten years later, her husband David was diagnosed with the same type of tumour and sadly passed away a year later.

> “It was shocking and upsetting to learn that – despite more than a decade passing – treatments and outcomes hadn’t changed at all.
>
> By filling my Will with hope, I believe that families facing a brain tumour diagnosis in the future will be able to feel more hopeful thanks to the research funded by The Brain Tumour Charity.

Fill your Will with hope for everyone affected by brain tumours by requesting our guide: **thebraintumourcharity.org/gift-in-will**, email **mygift@thebraintumourcharity.org**, or call us on **01252 749990**.

thebraintumourcharity.org **01252 749990**

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