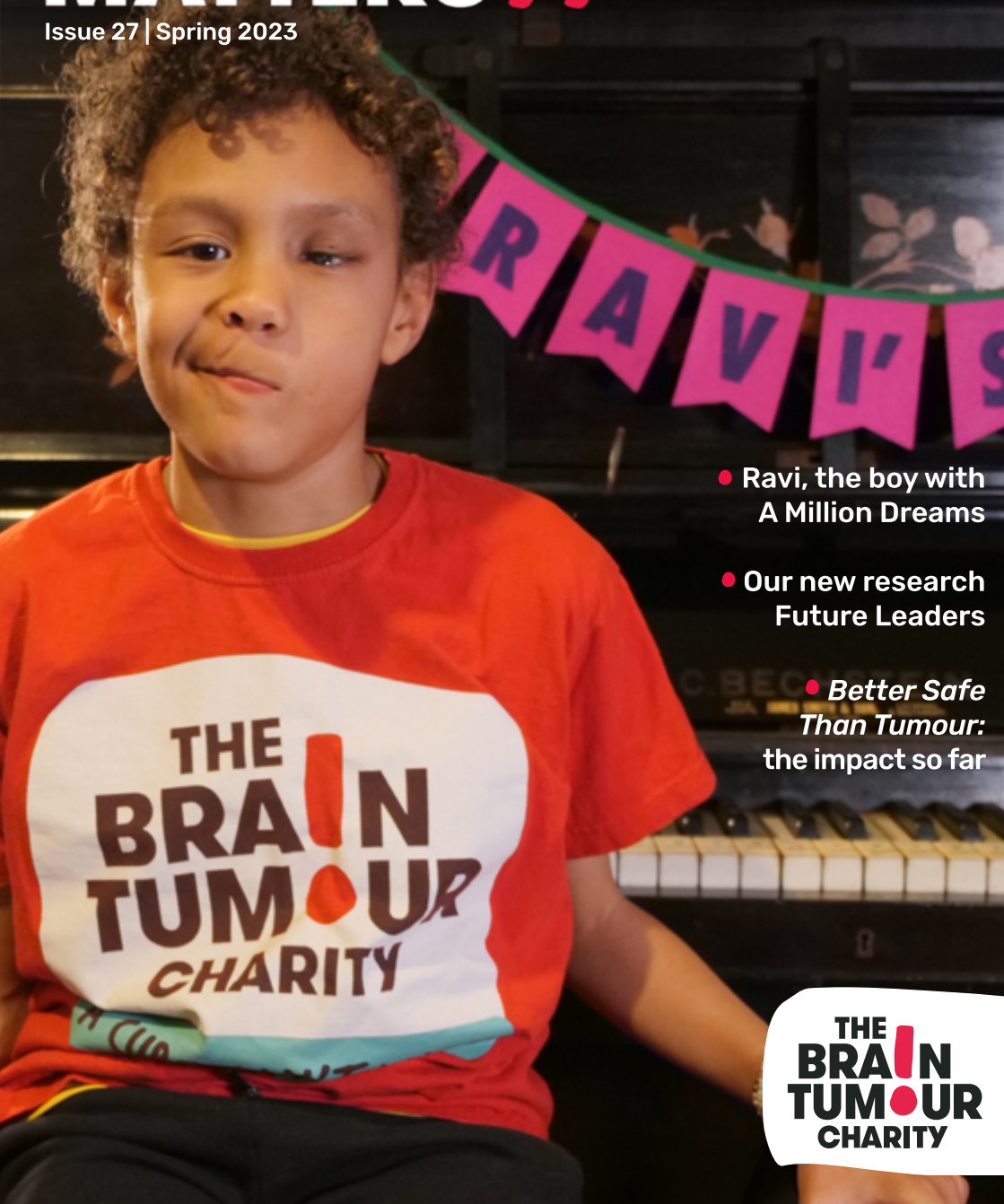


“THE GREY MATTERS”

Issue 27 | Spring 2023



● Ravi, the boy with
A Million Dreams

● Our new research
Future Leaders

● *Better Safe
Than Tumour:*
the impact so far

THE
BRAIN
TUMOUR
CHARITY



HELLO!

This year not only marks the tenth birthday of The Brain Tumour Charity, but has already seen us launch our bold new strategy for the next seven years – *Living Longer and Better* – co-created with you, the brain tumour community.

As we forge ahead in building a better future for everyone affected by a brain tumour, we're excited to bring you an issue packed with evidence of the amazing impact we've made together recently – as well as inspirational stories from change-makers in our community.

You'll read about three of our new research Future Leaders and the pioneering projects they'll be working on, which you've helped us fund (p. 6). You'll meet Ravi, the boy with 'A Million Dreams' (p. 12), whose charity single has touched hearts across the globe and raised a phenomenal amount of money to help support others diagnosed with a brain tumour.

You can also read about the impact our *Better Safe Than Tumour* campaign has had so far (p. 16), raising crucial awareness of the signs and symptoms of brain tumours, and find out how you can help spread awareness in your community.

We do hope you enjoy reading this issue and that you'll join us this year as we push forward with our new strategy. By raising our voices together, we'll take steps towards our shared vision of a world where people with a brain tumour live longer and better lives.

Thank you,

Graham Norton, Interim CEO

When you've finished with this magazine, please share it!

It will show others the difference we make, together. We rely 100% on voluntary donations to help us drive change.

If you receive this magazine and would like to join our movement, you can make a donation in the following ways:

Online: thebraintumourcharity.org/donate

Phone: **01252 237792**

Post: **The Brain Tumour Charity, Fleet 27, Rye Close, Fleet, Hampshire GU51 2UH.**

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THE CHARITY TURNS TEN !

The Brain Tumour Charity was created in 2013 following the merger of Brain Tumour UK, The Samantha Dickson Brain Tumour Trust and the Joseph Foote Trust. That means that this year – 2023 – is our tenth birthday! Since then, we've undergone rapid expansion and established ourselves as a global influencer in the field, growing our income from £1.4 million to a jaw-dropping £11.5 million in 2021-22. And that's all down to your incredible support.

We want to say a huge thank you for standing with us over the last decade and helping us become the force for change we are today. Together, we can take our new strategy forward and continue creating a better future for everyone diagnosed with a brain tumour.



WE PARTNER WITH WICKES !

There's no 'do-it-yourself' when it comes to defeating brain tumours – working together is the key to accelerating a cure. So we were absolutely thrilled, in February, to hear that the wonderful DIY retailer Wickes has picked us as their next charity partner!

We'd like to say a huge thank you to everyone at Wickes for making this transformative partnership happen. Together, we can step up our impact, continue to improve life for people affected by this disease and build a better future.

Thank you Wickes – we can't wait to get started!



WE WIN CHARITY OF THE YEAR 2022

October saw us win big at the JustGiving Awards, taking home the award for Charity of the Year 2022! We were so proud to be awarded the top prize and want to say a big thank you to all of you for helping to make it happen.

One of the reasons we were picked was The Twilight Walk 2021. The pandemic meant we couldn't come together in person, but that didn't stop you taking your own strides towards a cure, raising an awe-inspiring £295,000 in the process!

You were there for us again when the voting for this award opened. Despite being up against some stiff competition, your votes helped us come out on top. We're incredibly grateful – you really are the driving force behind our success.

OUR NEW STRATEGY LAUNCHES

Over the past year, we've been working together with the brain tumour community to co-create our new organisational strategy for 2023-2030 – *Living Longer and Better*.

This new strategy is a bold step forward towards a better future for everyone affected by brain tumours, and commits

us to accelerating cures, driving the best lifelong care and raising our global voices to create change over the next seven years.

We couldn't have done this without the community's invaluable input – so from all of us, a huge thank you to those of you who were involved! We were thrilled to officially launch *Living Longer and Better* on 13 April, and can't wait to work closely with all of you to take this shared vision forward.

TOM DONATES COSY KNITS FOR A CURE

In November, we were excited to have Olympian, activist and now knitwear designer Tom Daley donate four cosy knits to us as prizes, created and worn exclusively for his book, *Made with Love* – with all proceeds kindly coming to us.

The draw opened on 30 November and ran until the new year, giving winners a lovely present after Christmas. From a long scarf and stylish cable sweater to a cosy chevron throw and fun Fairisle jumper, the beautiful pieces all feature in Tom's book of 30 knitting and crochet patterns.

We're so grateful to Tom – whose dad, Robert, died of brain cancer in 2011 – for once again supporting our cause and helping us push further towards a world where brain tumours are defeated. We managed to raise a yarn-believable £6,380 from the competition!

OUR NEW RESEARCH FUTURE LEADERS

As part of our ambitious new strategy to help people diagnosed with a brain tumour live longer and better lives, we need to attract exceptional scientists to the field of research into brain tumours. Our step-changing Future Leaders programme is designed to do just that, providing excellent early-career academic and clinical researchers with the funding and support they need to set up their own lab.

Early last year, we began the exciting process of inviting applications for our new Future Leader grants – and we're thrilled to report that we've now awarded six of these!

Over the next three pages, you'll meet three of these remarkable researchers and read about the innovative and inspiring work they're doing to help increase survival and improve quality of life for adults and children diagnosed with a brain tumour. Forming part of our research strategy, 'Accelerate a Cure', these projects aim to give more hope to those diagnosed in the future and give families more time together.

Check out our upcoming Autumn issue to hear about the work of Dr Christopher Mount, Dr Mara de Marion, and Dr Angel Alvarez-Prado. Can't wait that long? Head to our website at thebraintumourcharity.org/our-research/what-were-funding



Dr Ola Rominiyi is a Lecturer in Neurosurgery and Speciality Register in Neurosurgery at The University of Sheffield. His current research focuses on combating cancerous cells' ability to repair themselves.

He has already made a significant contribution to research into brain tumours by creating a large biobank of patient-derived glioma samples, which are used by researchers and industry in the UK.

COMBATING DNA REPAIR IN CANCER CELLS

High-grade gliomas are diagnosed in over 2,000 people every year in the UK and survival rates have improved

little over the last few decades. New treatment strategies are urgently needed – and Dr Rominiyi's research is dedicated to discovering these.

Cancerous gliomas can never be fully removed during surgery as their cells can spread deep into the surrounding brain tissue. This is why these tumours so often regrow. Currently, treatments aimed at killing these remaining cells by damaging their DNA often fail, because the cells have a peculiar ability to repair their DNA.

Dr Rominiyi aims to investigate tens of thousands of cells, using samples retrieved from surgery, to find out how different cells repair their DNA. Collaborating with national and international experts, he will use state-of-the-art technologies to identify weaknesses in the cells' DNA-repair abilities.

Following this, he aims to develop new treatment strategies using DNA-repair inhibitor drugs, which work by switching off the key mechanisms that cancerous cells use to mend their DNA after chemotherapy and radiotherapy treatment. He will test these drugs directly in cells grown in the lab.

This exciting research has the potential to extend the lifespans of people with this aggressive type of brain tumour. New targeted therapies could also reduce the side effects caused by current therapies, helping patients live better, as well as longer, lives.





DR CLAIRE VINEL

QUEEN MARY UNIVERSITY OF LONDON, UK

Dr Claire Vinel is a Postdoctoral Fellow in Neuroscience at Queen Mary University of London. She has a strong track record of publication in molecular and cell biology journals, with research expertise in both muscle physiology and glioblastoma.

Her ambition is to launch an exciting new research programme bridging the two fields of muscle and glioblastoma research.

MINI BRAINS AND MINI MUSCLES

Research into glioblastoma has traditionally focused on the tumour itself and its surrounding environment, neglecting the potential involvement of the rest of the body.

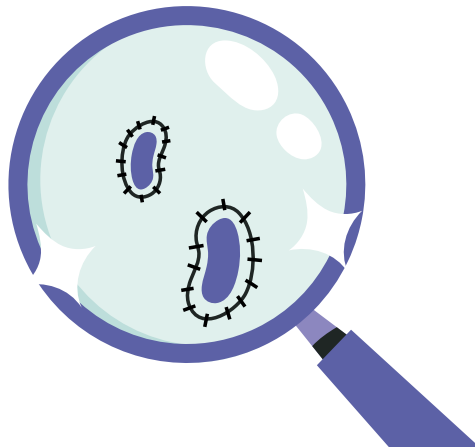
Patients with glioblastoma often present with loss of muscle, which is not influenced by the patient's age. It's believed that muscle health could influence brain function and that the brain tumour could induce muscle loss – with this communication potentially occurring through molecules in the bloodstream.

Dr Vinel will use cells from tumour samples to generate 'mini brains' (with a tumour) and 'mini muscles' in a dish, made from brain and muscle cells taken from the same patient. She will stimulate the mini muscle to contract and then explore the relationship between different types of contractions and the production of 'anti' or 'pro' glioblastoma molecules.

Dr Vinel then plans to bring these molecules into contact with the mini brain and its tumour, assessing the effects this has on the cancer's behaviour, such as growth or invasion. She will also test the effect the tumour has on the mini muscle.

The results of this highly innovative research will inform the designs of future experiments and could lead to the development of important new drugs.

If Dr Vinel finds molecules with anti-tumour properties produced by the muscle during exercise, she could then develop a drug mimicking the effects of exercise to improve or replace physical activity for less-mobile glioblastoma patients. In addition, understanding the changes that happen in the muscles of glioblastoma patients could help predict severe outcomes and better prepare patients.



DR JESSICA TAYLOR

UNIVERSITY OF CAMBRIDGE, UK

Dr Jessica Taylor works at the Cancer Research UK (CRUK) Children's Cambridge Institute and the CRUK Brain Tumour Centre. She has produced a large amount of data working on paediatric neuro-oncology and has won multiple awards for her achievements in the field.

With our funding, she hopes to help children with a subtype of medulloblastoma called 'WNT' to avoid the significant side effects of unnecessary surgery.

HELPING CHILDREN AVOID SURGERY SIDE-EFFECTS

Medulloblastoma is the most common type of high grade brain tumour in children, and it has four main subtypes. Currently, the only way to tell which type of medulloblastoma a child has is to test a sample of the tumour – which requires surgery.

Dr Taylor's research is aimed at avoiding this step. It focuses on a subtype called WNT-medulloblastoma. Though WNT-

medulloblastoma is very curable with chemotherapy, the surgery needed to identify it unfortunately comes with a high risk of significant, long-term side effects due to the way the brain tumour grows.

Dr Taylor will use a novel strategy called ADCIPs, which uses antibodies injected into the bloodstream to recognise specific proteins on the surface of WNT-medulloblastoma cells and bind to them. These antibodies will be designed in such a way that they can be seen using an imaging technique called PET scanning.

What's more, Dr Taylor will design the antibodies so that they could be bound with drugs that can treat the WNT-medulloblastoma, specifically targeting the drugs to the tumour and quickly curing patients without the current risks of surgery.

By aiming to diagnose these tumours without surgery, Dr Taylor's crucial research has the potential to spare children and their families the devastating impact of posterior fossa syndrome (PFS), which affects 1 in 4 children who undergo this surgery. PFS can cause long-term memory difficulties and speech issues.

If Dr Taylor's research is successful, her novel ADCIPs strategy could also be tested on different types of tumour.

By setting up a regular donation, no matter the size, you'll help us fund research projects like our Future Leaders grants, helping us recruit the brightest minds in the field on our path towards a cure:
thebraintumourcharity.org/donate

ADVANCING TOWARDS A CURE

DCVAX-L DISCOVERY
NOW PEER-REVIEWED

In the last issue, we updated you on the promising results of a trial which found that adding personalised vaccine DCVax®-L to chemotherapy could offer nearly three months of additional life on average for patients with newly diagnosed or recurrent glioblastoma, compared to standard treatment.

At that time, we cautioned that these results hadn't yet been reviewed by other experts in the field. But we can now report the extremely exciting news that the discovery has been peer-reviewed and found to be accurate – a landmark breakthrough in the treatment of this aggressive disease, which will give those diagnosed precious extra time to spend with their loved ones.

We must now do everything we can to ensure this long-awaited hope is able to reach patients as soon as possible, at a price the NHS can afford. Stay tuned for more updates.

TARGETING GLIOMAS IN CHILDREN

Exciting new research, part-funded by us, shows that the inhibitor drug ulixertinib may offer one of the first targeted therapies for children diagnosed with low grade gliomas, which commonly recur after treatment. Ulixertinib is a potent, orally-administered drug that works by blocking proteins ERK 1 and 2 from sending signals to tumour cells to promote their growth.

Experts have described the findings as “a very promising step towards the first targeted, kinder treatment” for families affected and for our wider mission to accelerate a cure.

“A VERY PROMISING
STEP TOWARDS THE
FIRST TARGETED,
KINDER TREATMENT”

NEURO-ONCOLOGY CHAIR APPOINTED

We were absolutely delighted, in the autumn, to announce the appointment of the first ever The Brain Tumour Charity Chair of Translational Neuro-Oncology at The University of Manchester's Cancer Research Centre.

Professor Petra Hamerlik, a world expert in neuro-oncology, has taken on this role alongside her post at AstraZeneca, where she is a Director and Bioscience Lead in Oncology R&D. She brings with her a wealth of knowledge and expertise in research into brain tumours.

Funded by a grant from us worth £1.35 million, her research will focus on the development of novel ways to treat and understand central nervous system tumour biology, in addition to the discovery of new drug and immunotherapy treatments.

This new role supports the Manchester Cancer Research Centre's ambition to bring together world-leading experts to tackle cancer, and we're so proud to be able to support this.

ORIGIN OF MEDULLOBLASTOMA UNCOVERED

In a fantastic step forward for children diagnosed with a common type of high grade brain tumour, research part-funded by us has uncovered the origin of groups 3 and 4 medulloblastoma – a discovery that could open new doors for treatment.

The study, published in *Nature*, found that these tumour subtypes both originate in the rhombic lip. This is a part of the embryonic brain which contributes to the development of the cerebellum (responsible for movement and balance).

Over 65% of medulloblastoma diagnoses in children are group 3 or 4 tumours, and understanding their development and genetic hallmarks will open doors for new drug discovery. This is particularly important as effective targeted therapies are largely non-existent.

This new, in-depth understanding could also enable specialists to reduce side effects for children diagnosed with these types of medulloblastoma and help to protect their quality of life.



RAVI'S DREAM

RAVI'S STORY

Like many seven-year-olds, Ravi Adelekan is a boy with 'A Million Dreams'. But in September 2021, his dreams were interrupted by the shocking news that he had a low grade tumour in his brain stem.

"Ravi is a force of nature – he's a smart, thoughtful ball of energy, loves sports but loves reading and maths and science as well. It was a complete shock when we got his diagnosis."

Gbenga, Ravi's dad

Despite a gruelling ten hours of surgery, doctors weren't able to remove the whole tumour, so Ravi and his family still live with its effects every day.

But that hasn't stopped Ravi. Within a week of his surgery, he went from being unable to get out of bed to being in a wheelchair, taking his first steps again and being able to feed himself again.

Determined to return to his passions of music, maths and sport, Ravi has since been living his life to the max, with bravery, fun and inspirational strength.

Photos taken by Richard Boll

RAVI'S DREAM

"I asked my mum, what's the silver lining to having a brain tumour? She said, you could do something, because a lot of people want to hear more about people with disabilities. She said, what do you want to do? And I chose a charity single."

Ravi

For the anniversary of his diagnosis, Ravi wanted to share his dream of a world where all children with brain tumours can get the help and support they need.

So he and his family brought together a cast of celebrities and musicians to create a charity musical performance of *The Greatest Showman's* 'A Million Dreams', alongside famous names including Bastille, Paloma Faith, Mary Berry, Coldplay, Hugh Jackman and ABBA's Björn Ulvaeus.

With the help of this star-studded crew, the music video aims to raise awareness of the impact of brain tumours and the difference funding can make to the diagnosis and treatment of those affected.

We're honoured to be one of the charities that Ravi's Dream supports, with all proceeds raised through his JustGiving page going to The Brain Tumour Charity and Brainstrust, two charities close to Ravi's heart.



"I love songs and music, and I think this song is a special song because it's about your dreams coming true, just like I dream that having a brain tumour doesn't mean you can do anything less than other people."

Ravi



MAKING SOUNDWAVES FOR BRAIN TUMOUR AWARENESS

Since the launch of his single in November, Ravi has achieved so much, raising over £72,000 in donations, being featured across multiple media outlets from the BBC to ITV, and raising awareness of brain tumours across the globe.

“People see Ravi and they see how brave he’s being. It’s amazing for him to have wanted to do something like this at such a young age – and it really connects with people.”

Gbenga

January saw Ravi and his family embark on ‘Dream Week’ (9 – 15 January), a week focused on sharing your dreams with others, looking at how we can help others’ dreams come true, and being inspired by how others have achieved their dreams.

Dream Week kicked off with a launch at The House of Commons in London, where our Interim CEO Graham and Community Fundraiser Claire joined Ravi and his family alongside MPs, musicians, authors, journalists and TV executives to see in a week designed to inspire positivity, community service and helping others achieve their dreams.

Photos taken by Richard Boll

Ravi’s story has touched so many hearts with his resilience and determination to follow his dreams and raise awareness of brain tumours.

We’re so inspired by him, his family, friends and all those who have contributed to make Ravi’s Dream a reality, uniting the community with this wonderful idea. Thank you Ravi, Gbenga, Bethan and Maya!

“We as a family want to say thank you to everyone who’s donated to Ravi’s campaign, to all the amazing people who’ve supported us, people who helped us put the song and the video together, and to The Brain Tumour Charity who’ve been a great support to us since Ravi’s diagnosis.”

Gbenga

HELP MAKE RAVI’S DREAM COME TRUE

You can watch Ravi’s charity music video on his website, ravidream.com, or listen to the single on all major streaming platforms.

To donate to help make Ravi’s dream a reality, visit ravidream.com/donate



HOW WE SUPPORT CHILDREN, FAMILIES AND YOUNG ADULTS

Our Children and Families Team and Young Adults Team provide dedicated support to those aged under 30 and their families who are affected by a brain tumour diagnosis.

HERE ARE JUST SOME OF THE WAYS WE CAN HELP ...

Online and telephone support – Whether you prefer to call, email or talk to us via live chat, we’re here to help every step of the way. We can provide information, support and signpost to relevant services.

Connect with others – We have several online groups which provide a safe space to connect with others who understand. This includes our Facebook groups specifically for parents, young adults and young adult carers as well as a private Instagram account for teenagers aged 13-16.



Meet others who understand – We hold Family Days throughout the year and regular online meet ups for young adults. These provide a fun, relaxing and supportive experience and the opportunity to meet others.

Animations for children – Our child-friendly videos help explain brain tumours and what to expect, featuring the characters of Jake and Charlie.



Education resources – Our resources help children and teachers prepare for going back to school after a brain tumour diagnosis or treatment.

Brainy Bags – A free gift, handpicked for each child by our volunteers, full of treats and useful resources for their families and carers! They are available for all children up to 18 with a diagnosis in the UK.



Wellbeing packs – Each box contains a little activity to help improve your wellbeing. You’ll receive one box each month for three months and they’re available for young adults aged 16 to 30 with a diagnosis.



Find out more and get support at: thebraintumourcharity.org/get-support

BETTER SAFE THAN TUMOUR.

Our impact so far

We launched our *Better Safe Than Tumour* campaign to raise crucial awareness of the signs and symptoms of a brain tumour.

Now, nearly a year on, let's take a tour of its incredible impact so far...

**22
MILLION
IMPRESSIONS**

(The number of times
our campaign has
been displayed)

**17.4
MILLION**
PEOPLE OUR SOCIAL MEDIA
CAMPAIGN HAS REACHED

OUR TV AD REACHED
12.3%
OF PEOPLE
IN THE UK

66
INFORMATION PACKS
DOWNLOADED

**2
MILLION**
LISTENS ON
HEART RADIO

4,902
PEOPLE USING THE
SYMPTOM CHECKER
Check yours here!



HELP US RAISE MORE AWARENESS

We're not slowing down in our mission to drive down diagnosis times for brain tumours. If you're keen to help spread the campaign even further, turn to page 18 to find out how you can get involved in your own community!

Find out more at: headsmart.org.uk

**5
MILLION**
VIDEO VIEWS
ONLINE





RAISING AWARENESS DOOR TO DOOR

WE NEED YOUR HELP !

Get out and about in your local community and help us spread awareness of the signs and symptoms of brain tumours.

We launched our Better Safe Than Tumour campaign to raise awareness of the signs and symptoms of brain tumours as far and wide as possible. By taking part in our campaign, you'll distribute potentially life-saving information – and help to drive down diagnosis times!

We'll send you everything you need to get out and about and start raising awareness, including 100 envelopes containing symptoms cards and a tote bag to carry it all. There are bigger packs available too to share with your workplace or child's school.

All we need you to do is **distribute your envelopes around your community**, from your daily walk to community groups, schools – everywhere and anywhere!

Why not make it a family outing? See the page opposite for some fun activities to try with kids. And don't forget to take some snaps of your efforts and share them with us on social media!

To find out more and order your pack, visit:
headsmart.org.uk/help-us-spread-the-word

Thank you!

BETTER SAFE THAN TUMOUR GET INVOLVED

Getting out and about in the community can be fun for all the family.

If you're taking children along to help raise awareness in your community, make sure you take this page with you – can they complete our I Spy Challenge and Car Bingo game?

Let us know how you got on – and share your pictures – by tagging us on social media!

 @BrainTumourOrg

 thebraintumourcharity

 thebraintumourcharity

COMMUNITY I SPY CHALLENGE

How many of these things can you spot on your walk? Keep a tally!

- Post Box
- Traffic Light
- Dog
- Cat
- Bus
- Bus Stop
- Cyclist
- Lorry

CAR BINGO

Can you spot one car in each of these colours?

RED	WHITE	BLACK	BLUE
PURPLE	GREEN	GREY	YELLOW



GET TO KNOW OUR VOLUNTEERS



Nicola and her brother Neil

Our volunteers are an inspiring group of people who give their time and energy to help us move closer to a cure. We caught up with **Nicola Boulton**, who received a very well-deserved nomination for Volunteer of the Year at our Celebrating You Awards 2023!

WHY DID YOU START VOLUNTEERING?

I lost my brother, Neil, to a high grade brain tumour. The Charity was a huge source of support for us and, when he died, I knew I didn't want that connection to end.

WHAT HAVE YOU DONE SO FAR?

I started off gently by reviewing brain tumour information, then I got involved with the Policy Involvement Team, attended focus groups and did some e-campaigning!

In 2021, I saw a position for a Support Line Triage Volunteer and felt I had skills and experience I could bring to the role. I've now moved to assessing people who'd like access to the Counselling Service. I'm still here six months down the line and still enjoying it!

WHAT DO YOU ENJOY ABOUT IT?

It's that real sense of teamwork and connectedness – the feeling that we're all coming together to make a better future for people facing this disease. You come away from it and, even if it's been tough, you know you've made such a difference to someone's day and that really means something.

WHAT WOULD YOU SAY TO SOMEONE WHO'S CONSIDERING VOLUNTEERING?

Definitely give it a go! It doesn't cost anything, only a bit of your time, it makes a huge difference and you get such a sense of reward.

FEELING INSPIRED?

Find out more about volunteering for us at thebraintumourcharity.org/get-involved/volunteering

GIVING THEIR TIME TO CHANGE LIVES

Our amazing community volunteers demonstrate incredible dedication, commitment and compassion. We sat down with our Community Fundraising Team to chat about just some of the ways these volunteers have helped us drive progress.

“We had a group of eight volunteers go along to the Glenn Roeder Race Day in Newmarket. They got stuck into everything from bucket collecting to raising awareness – with the event raising a whopping £160,000! We were blown away by their incredible energy and enthusiasm.”

Liam,
Community Fundraiser (East of England)

“Our volunteers give their time to support others going through similar experiences – such as sharing what it's like to have an awake craniotomy with others who are about to have the same operation.”

Claire,
Community Fundraiser (South East)

“We've had volunteers go along to support fundraisers taking on epic challenges, cheering them on and celebrating with them at the finish line. They've held virtual meetups for fundraisers to connect and foster peer support. And we even had a volunteer join our team for six months to help us develop a social media plan!”

Francesca,
Head of Community Fundraising

“We were so fortunate to have some amazing volunteers attend the Edinburgh Marathon and Half Marathon. The Supporter Group 'Unite to Fight' was there with their entire family, our Young Ambassadors Madeline and Victoria, and a former member of the team, Shona. We were definitely the charity making the most noise!”

Evie, Community Fundraiser
(Scotland, Ireland, Cumbria and Lancs)



OUR NEW COUNSELLING SERVICE

WE'VE LAUNCHED A FREE COUNSELLING SERVICE FOR ANYONE AFFECTED BY A BRAIN TUMOUR.

It can be an incredibly difficult time when you, or someone you know, is diagnosed with a brain tumour. In fact, over **90%** of people told us that a brain tumour diagnosis had affected their emotional or mental health, and, even 10 years after treatment, **54%** of cancer survivors still suffer from at least one psychological issue.

This is why we've launched a free counselling service for anyone affected by a brain tumour – whether it's you that's been diagnosed or a loved one, or you've been bereaved.

Counselling can offer a confidential space for people to talk freely to someone objective about their thoughts and feelings, and can help them to process their experiences and find more manageable ways to cope.

“Being able to talk to someone outside of my situation was exactly what I needed. I feel like I have the tools to cope with things better as my problems feel shared instead of all on me.”

Feedback from our pilot counselling service

In a survey we carried out before launching our pilot service, we found that over half of respondents had not had counselling. Yet **88%** experienced anxiety or worry, **63%** experienced sadness or depression. Of the people who had not had counselling, **89%** said they weren't offered it or did not know where to access it. Our new service aims to change that!

OUR PILOT SERVICE

We ran a pilot counselling service from July to October 2022, open to anyone diagnosed with a brain tumour or their loved ones. It was available at any point in a person's journey from diagnosis to end-of-life care and bereavement support.

So – how did it do? We think the results speak for themselves...

- **100%** rated the counselling service “very good” (85%) or “good” (15%).
- **75%** said their counselling had made quite a lot of difference, or a complete difference, to their emotional wellbeing and ability to cope.
- **89%** said they were likely or extremely likely to take action or do something differently as a result of their counselling.
- An amazing **100%** of people said they'd recommend the counselling service to others affected by a brain tumour!

“I am really grateful for the service. It was something I could depend on when lots of things felt out of my control and gave me a chance to discuss issues important to me at that time.” Feedback from our pilot counselling service

OUR FREE COUNSELLING SERVICE

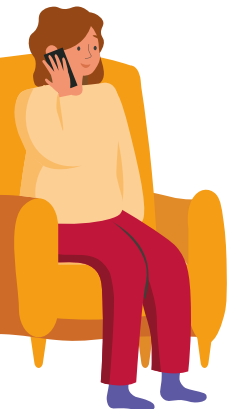
Following the successful pilot service, we're delighted to roll out an expanded service to our community. We're offering up to eight free counselling sessions, via phone or webcam, to anyone diagnosed with a brain tumour or their loved ones.

Our professional counsellors are all appropriately qualified and have relevant experience and training to support those affected by a brain tumour diagnosis.

To access our counselling service, you will need to complete a self-referral form and book yourself in for an initial assessment with a member of our Support Team. We also offer specialised relationship counselling in partnership with Relate. This is aimed at individuals or couples whose relationship has been affected by a diagnosis.

You can read more and self-refer at thebraintumourcharity.org/counselling

If you have any questions about the service, you can contact the Counselling Team on **counselling@thebraintumourcharity.org**, or by calling **01252 237136** (Mon-Fri, 9am-5pm).



DRIVING FASTER DIAGNOSIS

We know that for many people, the path to being diagnosed with a brain tumour (or having one ruled out) is too long and can be a very distressing experience.

We've heard far too many stories of people being misdiagnosed, sent away from their GP multiple times, experiencing multiple delays or being passed from one healthcare team to another. And all of this can be made even worse when things aren't communicated clearly to the person going through it.

That's why, during Brain Tumour Awareness Month, we launched our policy report on faster diagnosis, *Brain Tumours: Fighting for Faster Diagnosis*. This report makes a series of recommendations to policy-makers in government and the NHS that, if enacted, would make serious improvements to diagnosis times.

To help us make sure the right people see our recommendations, we'd love you to get involved by joining our group of campaigners. You'll be sent more information about how you can write to your MP and ask them to take action on improving the brain tumour diagnosis experience.

So whether you've been impacted by this or not, if you want to help us fight for faster diagnosis, raise your voice for change today!

Visit thebraintumourcharity.org/fighting-for-faster-diagnosis to find out more.



LESS SURVIVABLE CANCERS AWARENESS DAY

The second ever Less Survivable Cancers Awareness Day took place on 11 January – and we were busy in London and Edinburgh raising awareness of brain tumours!

The six less survivable common cancers are brain, lung, stomach, pancreatic, oesophageal and liver cancer.

Most other cancer treatments have come on leaps and bounds in the last 40 years, but the six less survivable cancers have been left behind with hardly any improvements in survivability.

With an average five-year survival rate of only 16%, we as members of the Less Survivable Cancer Taskforce are working hard to create much-needed change in diagnosis, treatment and care for brain tumours.

The Less Survivable Cancers Taskforce launched in December 2018 with a mission to double the survivability of the six less survivable cancers in the next ten years.

Our focus is to increase earlier detection, boost research, measure quality of life and patient experience, and improve pathways for everyone diagnosed.

Support from the UK government is crucial for our Less Survivable Cancers Taskforce. So, in Edinburgh, Young Ambassador Maddie accompanied our Healthcare Engagement Manager, Shona, to a drop-in event for Members of the Scottish Parliament.

While in London, Steph from our Policy and Campaigns team went to Westminster to speak to MPs about what needs to change.



WHAT DOES FASTER DIAGNOSIS MEAN?

We want people who display symptoms of a brain tumour to receive a definitive diagnosis as quickly as possible after first visiting a healthcare professional about their symptoms.

WHAT ARE THE BENEFITS OF FASTER DIAGNOSIS?

The main benefit of faster diagnosis is that treatment, care and support can be provided at the earliest opportunity – which could lead to people living better lives after their diagnosis.

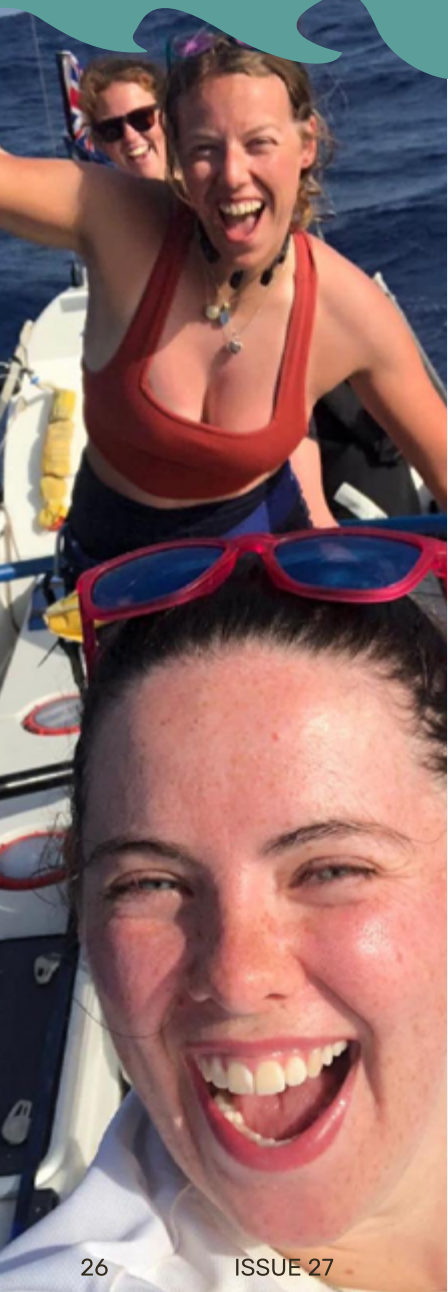
HOW TO GET INVOLVED

Be a voice for change! Campaigning is a great way to meet likeminded people and influence decision makers to improve treatments and help accelerate a cure.

To find out more, visit thebraintumourcharity.org/get-involved/campaigning-for-change



ROWING THE ATLANTIC FOR A CURE



We're in *oar* of the all-women's rowing team who took on the Atlantic to raise funds for us over winter...

The team of three – Laura-Jayne Pattinson, Millie Frith and Frankie Tuck – took on the epic challenge of rowing over 3,000 nautical miles across the world's second biggest ocean for the Talisker Whisky Atlantic Challenge. And they did it to raise money for The Brain Tumour Charity – *water* way to make a difference!

The Talisker Whisky Atlantic Challenge is an annual ocean rowing race beginning in the Canary Islands and ending in Antigua and Barbuda. And it's certainly not plain sailing – more people have climbed Mount Everest than have rowed unsupported across this ocean!

Rowers from all over the world and from all walks of life take part, with up to 40 crews participating each year.

Laura, 35, Millie, 26, and Frankie, 31, met at university where they discovered their shared love for rowing. The Brain Tumour Charity is close to their hearts, as some of their family and friends have sadly been affected by brain tumours.

MAKING THE CROSSING

The girls took to the seas in their 'eco-boat', Vaquita – the first of its kind to have ever been made, named after the world's rarest marine mammal. The materials and manufacturing processes used to build Vaquita were adapted to reduce environmental impact.

Laura, Millie and Frankie began their incredible feat of endurance on 12 December, reaching the halfway point on 9 January.

After an incredible 46 days and 21 hours at sea, they finished their epic 3,000 nautical mile journey on 28 January – a monumental achievement!

“ It's hard to put into words how incredible crossing that finishing line was. However, the three of us know we wouldn't have been able to cross it without a very long list of people we will forever be grateful for. ”

The Atlantic Girls

The girls raised over £5,000 for us, a life-changing amount that could fund a refrigerated centrifuge for use in one of our paediatric (childhood) brain tumour research projects.

We're so grateful to Laura, Millie and Frankie for taking on this heroic challenge and for helping us speed up progress towards a cure.



A CHALLENGE

LIKE NO OTHER...

We asked you to LIMBER UP AND LUNGE into the New Year with Challenge 88 – and you did us proud!

At the end of last year, we set you a mission for January: complete 88 exercises a day, or an 88-related challenge of your choosing, to support the 88,000 people living with a brain tumour in the UK.

You duly stepped up to take on Challenge 88, raised an incredible £31,000 and made a life-changing difference for people diagnosed with a brain tumour! Here are just some of the community's imaginative and inspiring achievements...

“ I was diagnosed with a brain tumour last year and took on Challenge 88 as a way to make me do something active every day. My challenges were all movements from CrossFit, which I'm mad about, and I slowly built back up to returning to CrossFit, which was a real win!

I had a few days where I was sick, including due to side effects of my radiotherapy, but I always managed to catch up after by combining the exercises into little workouts.

I was expecting to really struggle but I've enjoyed seeing how much better I am with my fitness than I thought I'd be!

MARTIN



“ I took on Challenge 88 because The Charity helped me immensely during my diagnosis, treatment and recovery. I felt ready to give something back, hopefully helping others through their journeys.

I did 88 different daily exercises on a weekly rotation. It's been squats, planks, lifts, etc. I even tried 88 seconds on my son's segway!

I decided to use social media as my fundraising platform and have been blown away by the support and donations from my Facebook and Instagram friends - together we're hopefully making a difference.

CAROLINE



“ I was diagnosed in November with an optic nerve meningioma. Doing this challenge is so important to me - I want to raise awareness and help where possible.

My challenges have been different every day. Just some of them include getting 88 jokes sent to me, doing 88 punches on a punch bag, 88-second planks, 88 squats, 88 leg lifts and leaving 8 inspirational cards in random places!

Doing these challenges has given me focus at such a challenging time - it's given me a purpose to push forward.

STACEY



We'd like to say another huge thank you to everyone who took part up and down the UK – you're all heroes!

If you're feeling inspired and fancy a challenge, take a look at the events we have coming up on page 30, or visit our website for other ideas on how to get involved.

THANK YOU

EVENTS FOR YOUR DIARY

- 13 MAY 2023 - Jurassic Coast Challenge
- 27 MAY 2023 - Edinburgh Marathon Festival
- 27 MAY 2023 - London 2 Brighton Challenge
- 2 JUNE 2023 - National Three Peaks Challenge
- 10 JUNE 2023 - Lake District Challenge
- 14 JUNE 2023 - London to Paris Cycle
- 17 JUNE 2023 - Snowdon by Night
- 24 JUNE 2023 - Cotswold Way Challenge
- 8 JULY 2023 - Peak District Challenge
- 22 JULY 2023 - North Downs 50 Challenge
- 5 AUG 2023 - South West Coast 50 Challenge
- 2 SEPT 2023 - South Coast Challenge
- 9 SEPT 2023 - Thames Bridges Trek
- 10 SEPT 2023 - London to Brighton Cycle
- 10 SEPT 2023 - Great North Run
- 8 OCT 2023 - Royal Parks Half Marathon
- 15 OCT 2023 - Bath Half Marathon
- 15 MARCH 2024 - Machu Picchu Trek



To find out more about our events visit:
thebraintumourcharity.org/events

THANK YOU



THANK you, **GlobalLogic**
A Hitachi Group Company

GlobalLogic is a Hitachi Group Company and a leader in digital engineering. They help brands across the globe design and build innovative products, platforms, and digital experiences for the modern world.

In November, we were shortlisted to be their 2023 Charity of the Year and could receive a potential £40,000 in funding towards a better future for everyone diagnosed with a brain tumour.

We want to say a massive thank you to everyone who voted for us. We can't wait to accelerate progress towards our goals together.

It's been a busy six months for our fundraisers! We simply couldn't do what we do without you, so we want to take this opportunity to say how grateful we are to everyone who's helping us move further, faster towards a cure...

YOU GAVE THE GIFT OF TIME

We want to say a huge thank you to everyone who donated to our Christmas Appeal, including through The Big Give Christmas Challenge 2022. In total, the community came together to raise a remarkable £235,000!

We're so grateful – this amazing amount could pay for nearly two years of pioneering research, and enable researchers to continue moving us towards a world where families affected by a brain tumour have more time together.

If you gave a gift inspired by someone affected by a brain tumour, you can still celebrate or remember them by leaving them a dedication online: thebraintumourcharity.dedicationpage.org/voicesforchange



A TRULY MAJESTIC PARTNERSHIP



OUR YEAR-LONG PARTNERSHIP WITH MAJESTIC WINE HAS BORNE FRUIT!

You've likely heard of Majestic Wine, Britain's largest specialist wine retailer with over 1,000 staff and 200 stores across the UK.

In 2021, we were delighted to be selected by employee vote to be Majestic's Charity of the Year for 2021-22, after being nominated by a member of staff who was living with a brain tumour.

From originally hoping to raise £80,000 for us, the marvellous team at Majestic raised an astonishing £138,400 over the year, in spite of the significant challenges posed by the pandemic.

This fabulous amount could pay for our specialised one-to-one support services for people affected by a brain tumour for a whole month, including our telephone hotline, email support, live chat, equipment and the compassionate staff at the other end of these technologies, responding to our community with the highest standard of care.

FROM CYCLING AND GOLF TO A BLACK TIE DINNER . . .

The team at Majestic have taken on extraordinary feats of exertion – and organisation – to raise funds to help us defeat brain tumours!

In September 2021, Majestic's directors took on the gruelling 'Le Tour de Stores', cycling in relay the entire length of the country on static bikes – from the northernmost store in Inverness to the southernmost in Falmouth, an epic distance of 1,200km.

This punishing fundraiser brought in £17,600 in total and even inspired other companies to take on similar challenges!

Then, in March 2022, Majestic took on the mammoth task of planning and holding its inaugural Supplier Awards Dinner, with a programme of events and activities designed to drive fundraising. These included a charity golf day and black tie dinner, which were a roaring success and raised £65,000 in total!

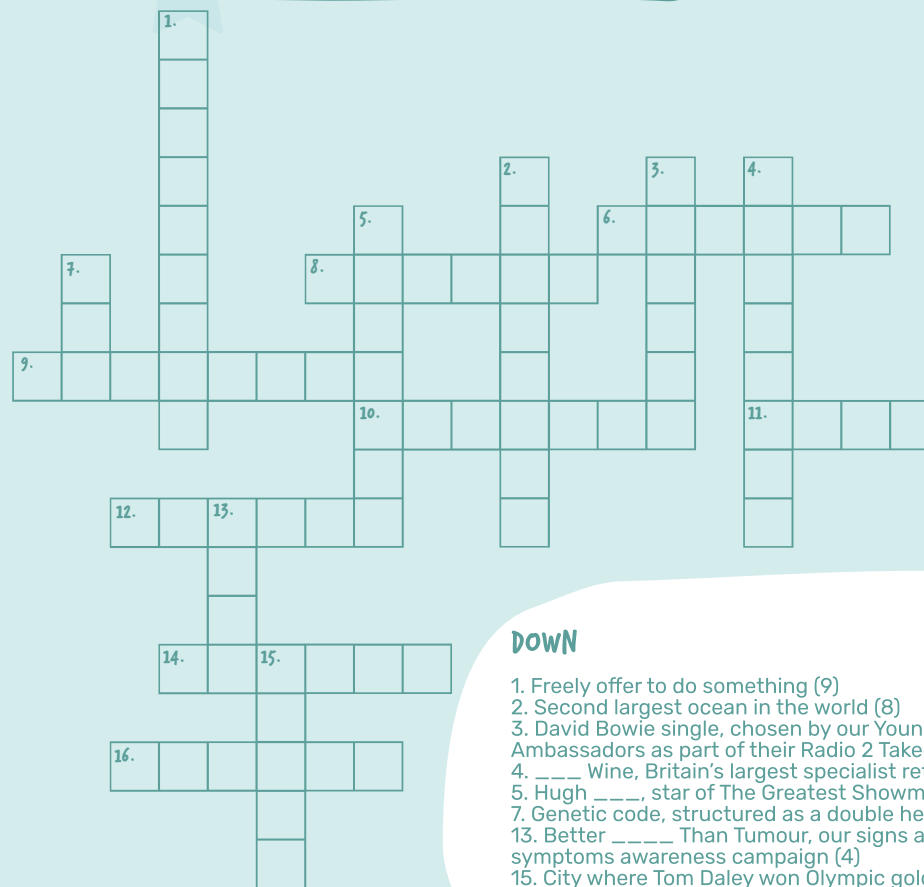
“Majestic hopes this money will make a real difference to the fight against brain tumours, and the support offered to those living with the disease and their carers.”

Liz Fleming, Majestic Wine

We want to say a huge **thank you** to Majestic Wine for their extraordinary efforts – what a year!



BRAINTEASER



DOWN

1. Freely offer to do something (9)
2. Second largest ocean in the world (8)
3. David Bowie single, chosen by our Young Ambassadors as part of their Radio 2 Takeover (6)
4. ____ Wine, Britain's largest specialist retailer of wine (8)
5. Hugh ____, star of The Greatest Showman film (7)
7. Genetic code, structured as a double helix (3)
13. Better ____ Than Tumour, our signs and symptoms awareness campaign (4)
15. City where Tom Daley won Olympic gold in 2020 (5)

ACROSS

6. A period of ten years (6)
8. Raising money by selling numbered tickets (6)
9. Social media website, home to a number of our online community groups (8)
10. The Grey ____, our supporter magazine (7)
11. The Gift of ____, title of our 2022 Christmas Appeal (4)
12. US city, home of Harvard Medical School (6)
14. Living Longer and ____, title of our new co-created strategy (6)
16. DIY retailer, recently announced as our new Charity partner (6)

Answers
1) Volunteer 2) Atlantic 3) Heroes 4) Majestic 5) Jackman 6) Decade 7) DNA 8) Raffle 9) Facebook 10) Matters 11) Time 12) Boston 13) Safe 14) Better 15) Tokyo 16) Wickes

TOP PICKS FROM OUR ONLINE SHOP

Raise awareness out and about with our brilliant Better Safe Than Tumour range and The Brain Tumour Charity branded items. Every purchase you make from our online shop helps us accelerate change for people affected by brain tumours!

To browse our entire range visit:
shop.thebraintumourcharity.org

NEW FOR 2023!



Insulated travel mug
£10.99



Sticky notes
£1.50



Foldable phone grip
£2.50



TIME Tea Towel
£10.99



12-in-1 snood
£6.99



Greetings cards collection
£9.99



Window sticker
£1.20



Notebook
£6.99



Metal ball pen
£2.50



Bandana pet collar
£12.99



Sports bottle
£9.99



Folding bottle
£3.99



WANT TO BE
OUR FIRST
EVER WINNER ?

SCAN HERE TO PLAY
raffle.thebraintumourcharity.org



**Enter our raffle before 26 May 2023
and you could win one of four cash
prizes - including a £4,000 top prize!**

18 +

thebraintumourcharity.org 01252 749990

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