

# THE GREY MATTERS

ISSUE 26 WINTER 2022

THE  
BRAIN  
TUMOUR  
CHARITY

Inside:

The Twilight  
Walk is back!

The latest  
research

Better Safe  
Than Tumour

BETTER SAFE  
THAN TUMOUR.



We can all get these symptoms occasionally, but if you or a loved one are getting a combination of them regularly, see the GP and get checked out. To find out more about all the possible signs of a brain tumour, visit [headsmart.org.uk](https://www.headsmart.org.uk)

THE  
BRAIN  
TUMOUR  
CHARITY

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## HELLO

Welcome to issue 26 of *The Grey Matters*!

Firstly, I need to thank you, and everyone in the brain tumour community, for your support over the past year.

Despite the challenging circumstances that have impacted so many of us, the overwhelming generosity of our supporters means we've been able to make some incredible progress over the past 12 months.

Inside this issue of *The Grey Matters* you'll find plenty of updates about what we've been able to achieve, thanks to your collective energy and drive.

Highlights include our exciting new research strategy (page 9), improvements to our BRIAN app (page 14-15) and the launch of our long-awaited campaign to raise awareness of the common brain tumour signs and symptoms (page 12-13).

Perhaps most exciting of all has been the co-creation of our next organisational strategy, *Beyond Brain Tumours* (page 20-23). We wanted to bring together as many people as possible to create a strategy that unites the brain tumour community to defeat brain tumours – and we've been blown away by the response, with more than 1000 of you joining in to create meaningful change.

We hope you enjoy reading this issue and that you'll keep standing alongside us over the next year, as we continue to bring the brain tumour community together to move us further, faster towards a cure.

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](https://thebraintumourcharity.org/donate)

Phone: 01252 237792

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



# NEWS



## CELEBRATING OUR FOUNDERS

We recently welcomed our Founders, Neil and Angela Dickson MBE, to our new offices to celebrate their achievements since founding The Samantha Dickson Research Trust in 1996.

Neil and Angela founded The Trust, which would later become known as The Brain Tumour Charity, in memory of their daughter Samantha, who passed away from a rare form of glioma when she was just 16.

We were joined by some of The Charity's nearest and dearest supporters to pay tribute to Samantha's legacy – including family and friends who've stood with us from the very beginning.

## WELCOMING OUR NEW YOUNG AMBASSADORS

We were delighted to welcome our fourth cohort of Young Ambassadors to The Charity in 2021!

Our Young Ambassadors are an integral part of The Brain Tumour Charity, working tirelessly to raise awareness and create a better future for everyone affected by a brain tumour.

Already they've helped run our meet ups for teens affected by a brain tumour, played starring roles in our marketing campaigns and engaged with change-makers, corporate partners and healthcare professionals to raise the profile of The Charity.



**Tessa Jowell**  
Centre of Excellence

## SIX NEW TESSA JOWELL CENTRES OF EXCELLENCE ANNOUNCED

In May 2022, six new NHS neuroscience centres were awarded Tessa Jowell Centre of Excellence status – an award given to centres that achieve excellence in treatment, research and care.

To achieve this award, the centres made a range of service improvements following feedback from the Tessa Jowell Brain Cancer Mission that included experiences submitted by the community via our Improving Brain Tumour Care surveys.

This means there are now 17 Centres of Excellence across the UK, marking an important new milestone in our mission to make sure the best treatment and care is available to everyone.

**Turn to page 25 to learn more about our work with the Tessa Jowell Centres of Excellence.**

## AN AWARD-WINNING PARTNERSHIP!

In May 2022, we were thrilled to accept the ThirdSector Business Charity Award for Marketing Partnership of the Year for our work with marketing automation juggernauts Salesforce Marketing Cloud!

We were kindly donated 650 hours of project time to help us redefine our supporter experience, so that every single one of our supporters gets the news, updates and information they need, when they need it.

As part of the project we launched a campaign, where we turned Young Ambassador Jeremy Daubeney's epic eight-week Tour de Full English cycling challenge into a bite-sized email journey that enabled the reader to 'travel' with him and find out more about what he experienced, straight from Jeremy himself.

Thank you, Jeremy, Marketing Cloud, Third Sector and, of course, all our supporters who engaged with the campaign – we really do have the most amazing people riding with us!

## REMEMBERING TOM PARKER

On March 30 2022, the world lost an incredibly talented and kind young man when Tom Parker passed away after being diagnosed with a glioblastoma.

We've been so inspired by everything that Tom and his loved ones did, and are still doing, for others affected by the disease. His warmth, campaigning heart and determination to continue living life with cancer in the face of such a devastating diagnosis have given hope to so many and he'll be so sorely missed.

A huge thank you to Tom, his wife Kelsey and his band members in The Wanted for their generosity in donating £1 from every ticket sold to their 'Most Wanted' UK tour.

We also want to thank Jay, Max, Nathan, Siva, everyone at The Wanted and Island Records and the song's writers and producers for generously donating all net proceeds for the first 12 months from sales of the single they released in Tom's memory – *Forever Gold (for Tom)*.

# SPOTLIGHT ON DCVAX-L

A recent clinical trial suggests that adding DCVax®-L to treatment could offer nearly three months additional life on average for patients with newly diagnosed or recurrent glioblastoma, compared to the current standard treatment.

However, these promising results haven't been reviewed by other experts in the field, so they need to be interpreted with caution at this point in time.

## WHAT IS DCVAX-L?

DCVax-L is a type of immunotherapy known as a dendritic cell vaccine. Developed by Northwest Biotherapeutics, DCVax-L is a personalised vaccine made from each patient's own dendritic cells – a type of cell that helps the immune system recognise and attack cancer cells.

For some time now, experts have hoped that DCVax-L may represent the first emerging therapy proven effective in treating glioblastomas since temozolomide chemotherapy in 2005.

## WHAT DID THE RESULTS SHOW?

The trial data suggests that adding DCVax-L to existing treatments could offer 2.8 months additional life on average for patients with newly diagnosed glioblastomas.

The vaccine seemed to be even more effective in patients with MGMT-methylated glioblastomas (something that can be identified through biomarker testing) as DCVax-L seemed to offer nearly 9 months additional life compared to the existing standard of care.

Patients in the trial whose glioblastoma had recurred survived 13.2 months on average from recurrence, compared to 7.8 months on average among the external control group – which suggests DCVax-L could offer 5.4 months of additional life after a recurrence.

The results from the trial also suggest that DCVax-L could significantly improve the five-year survival rate in newly diagnosed patients. 13% of patients who took part in the trial were still alive five years later, compared to just 5.7% of patients in the external control group experiencing the existing standard of care.

It was also encouraging to see that only five “severe adverse events” occurred during the trial (out of 2,193 doses of the vaccine) and no significant immune reactions were reported, suggesting that DCVax-L may be very well tolerated by patients.

## WHY DO THESE RESULTS STILL NEED TO BE INTERPRETED WITH CAUTION?

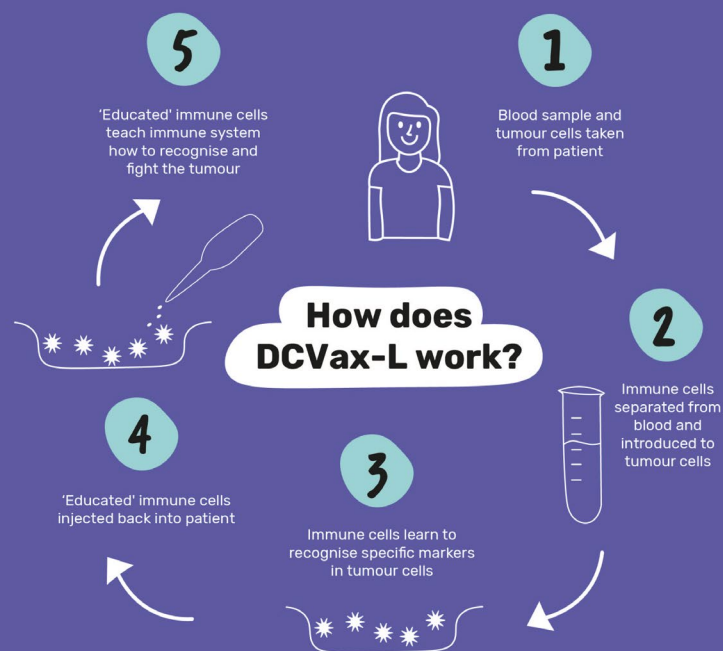
While these results are extremely promising, the trial data still needs to be reviewed by other experts in the field of brain tumour research and published in a scientific journal – an important step in verifying the results.

## IS DCVAX-L AVAILABLE IN THE UK?

In February 2022, the manufacturer announced it was now able to produce DCVax-L in the UK for individuals looking to access it privately.

The list price of the treatment is not currently publicly available and anybody who has questions about accessing the treatment should first speak to their healthcare team.

Anybody due to have surgery for their glioblastoma may wish to ask their healthcare team to make sure their tumour tissue can be frozen without preservatives and without being embedded in paraffin blocks, in case they wish to consider DCVax-L in the future.



# DRIVING PROGRESS IN RESEARCH

## SIMPLE LANGUAGE TEST COULD HELP SPOT BRAIN TUMOURS SOONER

Lead researcher: Dr Paul Brennan,  
University of Edinburgh

A new study suggests that a simple language test – dubbed the ‘Noah’s Ark’ test because it asks people to name as many animals as they can in one minute – could help GPs identify whether patients displaying common brain tumour symptoms urgently need further tests.

The study investigated how people who’d been referred with a suspected brain tumour scored on the test, with those who went on to be diagnosed with a brain tumour scoring significantly lower than those who suffered with headaches but had a brain tumour ruled out after an MRI.

The findings, published in *BMC Neurology*, suggest the test could help GPs identify which patients need an urgent brain scan, while reassuring patients who just need to be observed further.

More research is needed, but experts at the University of Edinburgh hope the test could help reduce the time it takes to diagnose brain tumours in the future – enabling prompt access to treatment and maximising their quality of life.

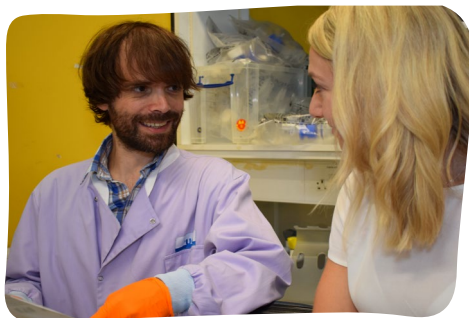
## ALCOHOL ABUSE DRUG MAY HOLD THE KEY TO TREATING CHILDHOOD BRAIN TUMOURS

Lead researcher: Dr David Michod,  
University College London

Researchers at the Samantha Dickson Brain Cancer Unit at University College London (UCL) have found that disulfiram, an alcohol abuse drug also known as Antabuse, could effectively kill high grade glioma cells without harming healthy cells.

The new study led by Dr David Michod involved treating different types of paediatric cancer cells with disulfiram, which efficiently killed the cancer cells within 48 hours at doses that could be safely given to humans.

In addition to the promising effects seen in aggressive cancer cells, the team found that low grade brain tumour cells exhibited even greater sensitivity to the treatment. This suggests that disulfiram could offer a new and kinder approach to treatment for children with slow-growing, low grade tumours.



While further studies are needed, experts hope the findings could be advanced into clinical trials within five years to assess whether disulfiram may offer a new and well-tolerated treatment option for children diagnosed with a glioma.

## IMMUNOTHERAPY RESEARCH ADVANCES AHEAD OF SCHEDULE

Lead researcher: Dr Tyler Miller,  
Massachusetts General Hospital.

Turning the body’s natural defence system into a brain-tumour-beating weapon isn’t a new idea. In fact, certain immunotherapies have shown huge success in other cancers, but have unfortunately failed to provoke the desired response in those diagnosed with a brain tumour.

Until now, scientists have been baffled by brain tumours’ ability to suppress the immune system and prevent it from attacking – step forward Dr Tyler Miller!

In just the first year of his three-year project, Dr Miller has been able to identify differences between immune cells that are helping to attack the brain tumour and those working to suppress the immune system.

The speed of this discovery has empowered Dr Miller to accelerate ahead with the project. Two years ahead of schedule, he’s been able to build a working model of the tumour microenvironment that includes tumour cells, immune cells and blood vessels.

This new knowledge will help his team understand which immunotherapies can turn the whole immune system against the tumour and test their theories.

## THIS IS HOW WE ACCELERATE A CURE

Thanks to the support of our generous and dedicated community, we’ve achieved some incredible things since 2015, when we launched our first research strategy – *A Cure Can’t Wait*.

The research you’ve funded has helped make significant advances in our understanding of brain tumours and led to the development of new tools to more effectively diagnose, study and treat this terrible disease.

To help us build on this progress and move us further, faster towards a world where brain tumours are defeated, last year we launched our new research strategy, *Accelerating a Cure*.

*Accelerating a Cure* outlines our commitment over the next five years to fund at least a further £40m towards pioneering research that continues improving our knowledge of brain tumours and ensures this new knowledge is translated into new treatments that help extend life expectancy and clinical interventions that improve quality of life.

Read our new research strategy and find out how your donations are making a truly life-changing impact by visiting [thebraintumourcharity.org/accelerating-a-cure](https://thebraintumourcharity.org/accelerating-a-cure)





# MEET FUTURE LEADER DR VERÓNICA RENDO



Launched in 2017, our Future Leaders scheme supports exceptional researchers who are just starting their careers – so they can establish themselves as leading experts in brain tumour research.

Dr Verónica Rendo is a biologist with a PhD in Medical Science, based at the Dana-Farber Cancer Institute in Boston, USA.

## ABOUT DR RENDO'S RESEARCH PROJECT

Dr Rendo is now using her extensive expertise to help us understand why drugs called MDM2 inhibitors aren't as effective at fighting glioblastomas (GBM) as they should theoretically be.

Researchers have found that GBM cells grown in the lab can be highly sensitive to MDM2 inhibitors but often relapse quickly.

The first aim of Dr Rendo's project is to understand how GBMs learn to grow despite being treated with MDM2 inhibitors. As well as understanding the cause of this resistance, she hopes to learn why some GBM cells are more vulnerable to MDM2 inhibitors.

The second aim of Dr Rendo's project is to identify how MDM2 inhibitors can be combined with other treatments and therapies to increase the overall effectiveness of treatment.

## WHAT ARE MDM2 INHIBITORS?

p53 is a protein that senses when a cell is under stress, for example when a healthy cell is damaged or cancer cells divide uncontrollably. When p53 senses this stress it can stop cells from dividing and try to repair the cell or, if the cell is too damaged, it can send a signal to let the cell die. Tumour cells want to divide, so they find ways to stop p53 from doing its job and in many types of cancer p53 is shut down entirely. Interestingly, in people diagnosed with a GBM, p53 is rarely entirely shut down, instead it remains functional but suppressed – often by a different protein called MDM2. MDM2 inhibitors are relatively newly developed drugs that can be used to separate MDM2 from p53, allowing p53 to do its job again.

## THE RESULTS SO FAR

GBM cells are heterogenous, which means even cells from the same tumour can be subtly or dramatically different. Dr Rendo has found that even when these different types of GBM cells have p53 repressed by MDM2, they react differently to MDM2 inhibitors.

In some types of GBM cells, p53 does become active again but in others it remains suppressed and means the treatment is less effective. The next stage of the project is for Dr Rendo to explore how these differences occur.

An ongoing clinical trial investigating the effects of MDM2 inhibitors in people diagnosed with a GBM has confirmed the therapy circumvents the blood-brain barrier – a huge obstacle in research into brain tumours.

By working closely with the team running this study, Dr Rendo has been able to replicate these conditions in her lab-grown tumour samples – presenting a unique opportunity to evaluate how p53 is being activated by the MDM2 inhibitors.

By setting up a regular donation, no matter the size, you help us fund research projects like our Future Leaders grant that make sure the brightest minds in the field are committed to defeating brain tumours.

Donate today by visiting:  
[thebraintumourcharity.org/donate/](https://thebraintumourcharity.org/donate/)



## LAUNCHING OUR

# BETTER SAFE THAN TUMOUR.

## CAMPAIGN

In July 2022 we launched our huge new campaign to help raise awareness of the common signs and symptoms of a brain tumour – *Better Safe Than Tumour*.

Knowing the signs and symptoms could lead to faster diagnosis times which could reduce the impact a brain tumour has on someone.

*Better Safe Than Tumour* builds on the legacy of our award-winning *HeadSmart* campaign by also including the signs and symptoms that adults need to be aware of.

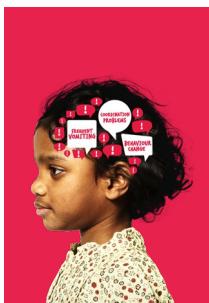
The new campaign has a brand new, attention-grabbing look and feel that demands to be noticed. We hope you've spotted it out there on major news websites, heard it being discussed on the radio or seen it shared by superstar celebrity supporters like Hal Cruttenden, Nicki Chapman, Dominic Matteo and Alastair Stewart!

We've also got a new website for the campaign which includes a symptom checker that can help people understand what their next steps should be if they or a loved one displays symptoms.

"Brain tumours are not as rare as people may think so it's so important to raise awareness of them. If it wasn't for the HeadSmart campaign, maybe we would have put up with Noah's headaches and sickness for longer which could have had an impact on the success of his treatment."

**Lucy**, whose son Noah was diagnosed with an ependymoma when he was seven.

Find out more at:  
[headsmart.org.uk](https://headsmart.org.uk)



## BETTER SAFE THAN TUMOUR.



### THE LEGACY OF OUR HEADSMART CAMPAIGN

Since the launch of our *HeadSmart* campaign in 2011, the average time it takes for children to be diagnosed with a brain tumour has drastically decreased.

Before the launch of *HeadSmart*, average diagnosis times for children with brain tumours in the UK was 13 weeks – this has been reduced to 6.5 weeks!

We hope our new *Better Safe Than Tumour* campaign will play a part in further reducing diagnosis times to four weeks or less, as well as helping to cut the time it takes for adults to be diagnosed.

"It's important for me to share my experience and help raise awareness that a simple headache can sometimes be much more serious... it's important to be aware of the signs and symptoms of a brain tumour."

**Elena**, who was diagnosed with a meningioma.

### HELP US SPREAD THE WORD!

Knowing the signs and symptoms of a brain tumour can lead to a faster diagnosis, which could lead to someone receiving treatment quicker and reduce the impact of a brain tumour.

That's why we need your help to spread our campaign far and wide, so everyone knows they're better safe than tumour!

Share our campaign on social media using the hashtag **#BetterSafeThanTumour**.

You can also phone us on **01252 749990** or email us at [info@headsmart.org.uk](mailto:info@headsmart.org.uk) to get digital and print packs that are personalised to the space you want to distribute them.

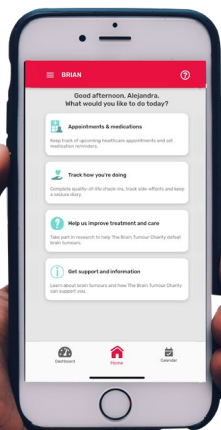
# TAKING BRIAN\* TO THE NEXT LEVEL



BRIAN is the game-changing app that can help you manage and cope after a brain tumour diagnosis, while also helping researchers accelerate the search for a cure. We're determined that the development of BRIAN will always be led by the needs of those it was made for, so we regularly meet with BRIAN users and Young Ambassadors to get their thoughts, as well as running feedback surveys so every user can have a voice.

In response to feedback about the BRIAN user experience, we've recently updated the mobile app's interface to make it really simple and intuitive to use – ensuring everybody has the best possible experience while using it!

The new home screen means it's easier than ever for users to find what they're looking for in BRIAN, with all the different features now split into four distinct categories. Users can still customise their dashboard with the features they use most often and this is always easily accessible by tapping the icon at the bottom of the screen.



This year we've also built, tested and released two new features that help better support our community and make it easier for researchers to collect the data they need for studies – the Seizure Tracker and Clinical Trial Link.

The Seizure Tracker allows users to record the type, time and duration of their seizures, which can then be shared with their clinicians.

The Clinical Trial Link allows researchers to collect data from consenting clinical trial participants through BRIAN. This makes it easier for researchers to securely collect data, which is ring-fenced from the general data analysis in BRIAN until the trial has been completed and the results have been reported.

This is an amazing resource for brain tumour patients, families, and care providers. The BRIAN app has a lot of potential as it continues to improve. There are not enough words as to how much you have helped thousands of people with this application.

**Paolo Jose De Luna** – Clinical Research Nurse – St. Bartholomew's Hospital

BRIAN is a very useful tool and we are already using it at King's in a variety of ways. BRIAN brings together data from a whole spectrum of different databases and registries, and pushes the right information through to patients.

**Prof Keyoumars Ashkan** – King's College Hospital

With this project, researchers will for the first time have access to large amounts of data from lots of patients. This is game-changing for research into brain tumours!

**Dr Paul Brennan** – Senior Clinical Lecturer in neurosurgery at the University of Edinburgh

Using BRIAN was a good way to keep track of things, as I've suffered with memory issues since starting treatment. I've entered medication, symptoms, side-effects and mood tracking information.

**Molly** – diagnosed with a grade 1 pilocytic astrocytoma

I use BRIAN daily to keep track of all my medications and complete the quality-of-life surveys. The recently added Seizure Tracker empowers me to track the type of seizure I have, when they happen, how long they last and whether there were any triggers – then share it with my healthcare team to inform my treatment.

**Hayley** – diagnosed with suspected grade 2 glioma

Find out more about BRIAN by visiting:

**[askbrian.org.uk](http://askbrian.org.uk)**





# SPILLING THE BEANS ON BRITAIN'S BEST BREAKFAST

After losing both his parents within a year of each other, his father to a glioblastoma and his mother to Motor Neurone Disease, Jeremy Daubeney felt like he needed to do something.

He decided to tackle the Tour de Full English.

The Tour de Full English was a challenge of Jeremy's own design. He would cycle across the country in search of Britain's best cooked breakfast, spreading awareness and raising money for charity.

Jeremy spent 57 days cycling across England, Scotland and Wales, with nothing more than Barney (his bike), a tent and a few supplies. He covered a whopping 2552 miles and got stuck into 24 different breakfasts.

And the competition was much closer than you'd think! Each breakfast was given a score out of 100 and there were only 20 points separating the winner and last place.

With a whopping 81 points, just a single point ahead of second place, the winning breakfast was cooked up by Caffi Y Ragna on the Pembrokeshire coast!

“A really tasty breakfast with a bit of chef's flair as well – crispy onions in the beans was an absolute game changer! Stunning scenery and lovely staff too. If you're in Pembrokeshire, check it out!”

As well as putting the country's cafes to the test, Jeremy also managed to raise an egg-cellent amount of cash for The Brain Tumour Charity and The Motor Neurone Disease Association – over **£37,500!**

The Tour de Full English may have ended, but Jeremy certainly hasn't slowed down his efforts to take research up a gear and help us defeat brain tumours. After joining The Charity as one of our Young Ambassadors, he's written for our website, spoken to nearly 50 MPs at our drop-in event at Parliament, and played a starring role in an award-winning marketing campaign – proving that not all heroes wear crepes!

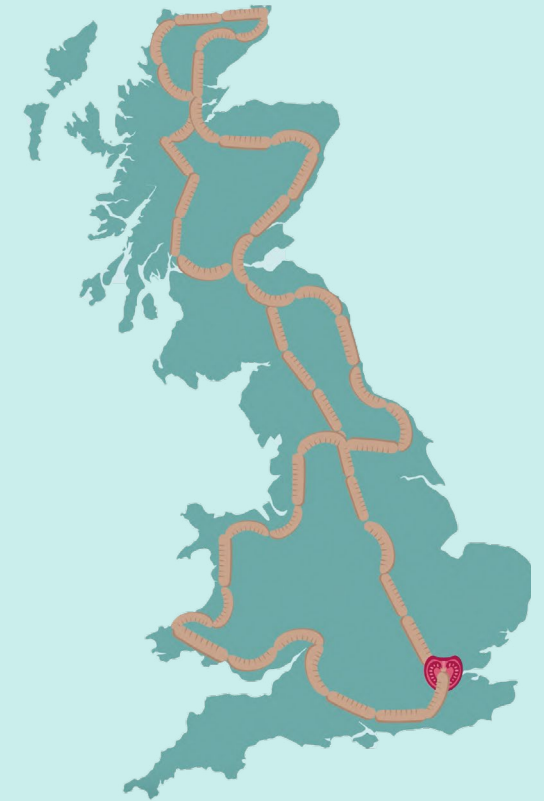
You'd be forgiven for thinking that Jeremy might be tired out from helping us move further, faster! But this summer he headed back out on his bike, accompanied by his friend Lottie, to cycle from the UK to Greece to raise more vital funding for research.

Thanks a brunch Jeremy!

## WANT TO HELP US MOVE FURTHER, FASTER TOWARDS A CURE?

There are so many ways you can get involved and help us defeat brain tumours – from making a donation or taking on a fundraising challenge to sharing your story or volunteering your time.

Find out more by visiting: [thebraintumourcharity.org/get-involved](https://thebraintumourcharity.org/get-involved)



[illegible]

As well as raising money from ticket sales, we'll also be hosting a silent auction for those who want to purchase some of the artwork on display.

To find out more visit  
**[thebraintumour  
charity.org/time](http://thebraintumourcharity.org/time)**



## 2023

Visit [thebraintumourcharity.org/celebrating-you/](http://thebraintumourcharity.org/celebrating-you/) to find out more.

# BEYOND BRAIN TUMOURS OUR NEW CO-CREATED STRATEGY

We strongly believe that when it comes to defeating brain tumours, we can't do it alone. We need the community to guide us to make sure we're moving in the right direction.

Because who knows more about what needs to change than families who've been personally affected, researchers who've dedicated their career to finding treatments and healthcare professionals who support those with brain tumours?

In order to create a clear way forward for the next five years, we're dedicated to hearing from everybody affected by a brain tumour and committed to working together to co-create our new organisational strategy – *Beyond Brain Tumours*.

## WHAT IS CO-CREATION?

Listening to the voice of the brain tumour community has always been important to The Charity.

At its core, co-creation is about making sure we do more than just listen and that we do this from the very first steps of developing our new strategy – rather than asking for input deep into the process.

It's committing to the idea that your voice has equal weight when we're making decisions about the future of The Charity and giving everybody who wants to be involved a platform to be heard.

It's about bringing together everyone who shares our aim to move further, faster towards a world where brain tumours are defeated – even if we don't necessarily all share the same ideas about the best way to get there.



## JOINING IN TO CREATE CHANGE

The first step on this journey was reaching out to the community to see who wanted to join in with the co-creation.

And we were absolutely blown away by the response!

Over 1,000 people answered our call and volunteered their time to get involved. A diverse mix of people from the community have taken part so far – including leading researchers, dedicated healthcare professionals and people personally affected by a brain tumour.

In the spirit of true collaboration, we've also been joined by the CEOs of Brain Tumour Research, brainstrust, Brain Tumour Support, The International Brain Tumour Alliance, The American Brain Tumor Association and The National Brain Tumor Society.

Once we knew who wanted to join us in the co-creation process, it was time to get to work!

**1,000+** members of the community got involved with the co-creation so far

**500+** people living with a brain tumour

**400+** people whose loved one has been diagnosed with a brain tumour

**8** representatives from other charities who share our aim to defeat brain tumours

**75+** healthcare professionals

**50+** researchers





## MAPPING THE NEED

We started by running a survey so we could understand what the community felt needed to change to improve the lives of everyone affected by a brain tumour.

We then ran a series of workshops in which we invited a diverse mix of people from the community to tell us more about the issues they've faced and what they feel are the barriers to change.

Next, we entered a period of intense analysis, looking at every shred of information we could find about the landscape we're operating in.

Finally, we combined everything we'd learned so far into a new strategy factbase that collects all the data and insights that will shape *Beyond Brain Tumours*.



## WHAT MUST CHANGE?

- 1 Research into brain tumours is under-funded despite the severe impact they have on quality of life and life expectancy.
- 2 Research that generates new knowledge about brain tumours isn't being translated into kinder, more effective treatments.
- 3 There are significant differences in treatment and care when 70% of people diagnosed with a brain tumour are left with an unmet need – whether that's physical, emotional or financial.
- 4 The community wants to see more collaboration between charities that want to see brain tumours defeated!
- 5 Health data isn't being used to its full potential for improving outcomes for those affected by a brain tumour.

## GETTING RADICAL

Once we knew what needed to change, it was time to get radical and imagine what the world would need to look like if we're truly going to achieve our goal of moving beyond brain tumours. This involved a truly radical "What if..." workshop in London with 74 members of the community taking part.

## WHAT COMES NEXT?

A successful strategy needs to be realistic and part of that is accepting that we can't change everything we'd like to. That's why the next step in our strategy is deciding what we have the power to change and how we can do that. If there are things that we know need to change but can't do it alone, this is when we'll decide who we need to join forces with to make it happen. If you'd like to join in and help us co-create our new strategy, you can sign up on our website.

[thebraintumourcharity.org/beyond-brain-tumours](https://thebraintumourcharity.org/beyond-brain-tumours)



This has the potential to be a very powerful process creating a strategy which the whole brain tumour community has contributed to, is aligned with and invested in.

**Neil** - diagnosed with a meningioma



Being part of co-creating *Beyond Brain Tumours* is so important because it not only gives us an insight into what The Charity is doing and the plans for the future, but also the opportunity to share our experiences and what areas we believe could be improved.

**Heather** - diagnosed with an acoustic neuroma



# GETTING THE BEST TREATMENT AND CARE

## TOP TIPS FOR GETTING THE BEST TREATMENT AND CARE

### 1. Ask about a Clinical Nurse Specialist (CNS)

A CNS can help you with everything from information about your treatment and care to questions about what financial support is available. Having a CNS can significantly improve your experience, so make sure you ask who your CNS is and how you can contact them – don't be afraid to push for this information. And, if a CNS isn't available to you, make sure you find out who you should contact with your questions and concerns.

### 2. Make sure you have a care plan

Going through your care plan or holistic needs assessment with your healthcare team can make it easier to play an active part in your care. This can also help you understand what you should expect and give you a better idea of the support that is available to you.

### 3. Talk to your healthcare team

If you're concerned about your treatment or care, the best thing to do is to talk directly to your medical team about how you're feeling. This can be daunting, but often it's the best way to resolve your concerns. It won't affect your treatment and your healthcare team won't think you're a nuisance!

### 4. Speak to PALS

The Patient Advice and Liaison Service (PALS) is a service within hospitals that can provide confidential advice, support and information. The PALS team will talk to hospital staff on your behalf, deal with your problems in confidence and listen to your suggestions for improving services.

## GETTING A SECOND OPINION

Although you don't have a legal right to a second opinion, you do have the right to ask for one without it affecting the standard of care you receive. You might consider asking for a second opinion if:

- ♥ You want to check other experts agree with your treatment plan
- ♥ Your treatment plan has been changed and you're unsure about it
- ♥ You disagree with your treatment plan
- ♥ You've been told that the only treatment available to you is palliative care and you want to know every possible option has been explored.



## CHOOSING WHERE TO GET TREATED

The NHS Constitution gives most people living in England and Scotland the right to choose where to receive treatment. When making this kind of decision, you might want to think about the following questions:

- ♥ How far away is the centre?
- ♥ What support will I get?
- ♥ What treatment do they offer?
- ♥ Do they specialise in my tumour type?
- ♥ What research opportunities do they have?
- ♥ Are they a Tessa Jowell Centre of Excellence?

## FINANCIAL ASSISTANCE FOR TRAVEL COSTS

Under the Healthcare Travel Costs Scheme (HTCS), you may be able to claim back money spent travelling to and from the hospital, as well as parking charges. You can find out more at [thebraintumourcharity.org/help-with-travel-costs](https://thebraintumourcharity.org/help-with-travel-costs)

## HAVE YOUR VOICE HEARD

Share your experience of treatment and care so we can better understand what's working well and what can be improved. Your responses help us work with healthcare centres across the UK to raise standards and improve outcomes for everybody affected by a brain tumour. To get involved visit [thebraintumourcharity.org/care-surveys](https://thebraintumourcharity.org/care-surveys)

## TESSA JOWELL CENTRES OF EXCELLENCE

Tessa Jowell Centres of Excellence (TJCoE) are neuroscience centres that achieve excellence in treatment, research and care. To become a TJCoE, centres go through a rigorous assessment process which includes peer review and patient feedback from our Improving Brain Tumour Care surveys.

There are 17 Centres of Excellence in the UK, but you shouldn't be concerned about your level of care if you're not being treated at a TJCoE. Not all centres applied to the programme and those that weren't successful often missed out by a small margin.

We also expect standards of care to improve as both the Tessa Jowell Brain Cancer Mission and The Brain Tumour Charity work to share best practice with centres who haven't yet achieved TJCoE accreditation.



# ENGAGING WITH CHANGE MAKERS IN PARLIAMENT

To mark Brain Tumour Awareness Month, we held a drop-in session for MPs in Parliament in March to share the key issues that came out of our Improving Brain Tumour Care surveys. This event was also an opportunity for MPs to meet some of our community and speak to them about their experiences.

We were pleased that 51 MPs – or their offices – attended the event, including Derek Thomas MP, the Chair of the All Party Parliamentary Group on Brain Tumours, and Jeremy Hunt MP, the Chair of the Health and Social Care Select Committee. We asked them to take action on three key issues:

1. Ensuring that all brain tumour patients have access to a Clinical Nurse Specialist or key worker to help coordinate their care.
2. Offering all brain tumour patients a Holistic Needs Assessment to help identify their support and care needs.
3. Ensuring brain tumour patients are informed about research, and are given the opportunity to participate in research.



Our two Young Ambassadors Jeremy Daubeny and Victoria Neill and our Involvement Champion Kaz Melvin were fantastic advocates, sharing their experiences and desires for change, and made a brilliant impression on the politicians in attendance.

Since the event, we've continued to engage with the MPs who attended the drop-in and worked with our community to empower them to effectively speak up for those affected by brain tumours.

## HELPING SHAPE THE FUTURE OF BRAIN TUMOUR CARE

Our Policy & Campaigns team have been busy providing evidence to help the Government develop its strategy for cancer treatment and care. In 2022, they responded to two important consultations, helping shape the future of the 10-year Cancer Plan for England and the new Scottish Cancer Strategy.

We submitted detailed responses to both consultations, highlighting the key issues affecting the brain tumour community, including: research funding, awareness campaigns, early diagnosis, disparities in treatment and care, investment in the cancer workforce, access to a Clinical Nurse Specialist, Holistic Needs Assessment provision, and research participation.

It's vital that the voice of the community plays a key part in developing these strategies, so we published guidance to help individuals respond to both consultations.

Our amazing Young Ambassador Madelaine Powell created a brilliant video to encourage more people to respond and our Scottish Steering Committee helped us finalise our response to the Scottish Cancer Strategy consultation.

We look forward to seeing the strategies when they are published. When they are, we will continue to keep the Government and NHS accountable in order to drive improvements in treatment and care for everyone affected by a brain tumour

## WANT TO GET INVOLVED?

We have an amazing group of campaigners who get involved in our Policy & Campaigns work. If you'd like to join us, please fill out this form on our website: [thebraintumourcharity.org/campaign-with-us](https://thebraintumourcharity.org/campaign-with-us)





# THE TWILIGHT WALK IS BACK!

We've taken the tough decision to postpone The Twilight Walk 2022 until March 2023.



We are so incredibly grateful to everyone who registered their support to take part in The Twilight Walk 2022 – and we are really sorry for any inconvenience that rescheduling has caused. Unfortunately our overall sign-ups for the event simply hadn't yet reached the level we would normally expect to help make the event a success – and so we have needed to take the tough decision to push it back.

While we're really disappointed to need to move the event, it does enable us the exciting opportunity to hold The Twilight Walk in Brain Tumour Awareness Month in March. We hope this will provide a perfect time to come together for The Twilight Walk and make as much noise, and raise as much money, as we possibly can in such an important month for brain tumours.

Get involved by visiting [thebraintumourcharity.org/thetwilightwalk/](https://thebraintumourcharity.org/thetwilightwalk/)

“

It is truly a special privilege to lead The Twilight Walk for The Brain Tumour Charity. I'm motivated by The Charity's outstanding work in funding research into treatments for brain tumours, the support they offered to me in my own journey after being diagnosed with a brain tumour – as well as others suffering from this disease. My journey was, in many ways, long and difficult, but I was one of the lucky ones who benefited from research supported by The Charity. I received a new treatment and after 20 years I am now tumour free. So, The Twilight Walk each autumn gives me the opportunity to give back, to thank The Charity and the community and to share my story of hope.”

## THE TWILIGHT WALK LONDON

**When: March 2023**

**Time: To be confirmed**

**Where: To be confirmed**

# THE TWILIGHT WALK

Enjoy a brand-new location for The Twilight Walk and join us for our first Charity-led walk in four years!

Tackle our traditional 10k with us and help us pick up the pace of research as we stomp through the iconic, historical city of London together.

## THE TWILIGHT WALK OWN WALKS

**When: Anytime throughout March**

**Where: Somewhere important to you!**

If you can't make it to London or would prefer to walk somewhere more meaningful to you, we're on-hand to support you in holding your The Twilight Walk Own Walk! Even if we're walking apart, together we can help move further, faster towards a cure.

Choose from our **10km**, **40km** or **130km** options, or set your own distance. You may choose to do it in a day, across multiple days or even split the distance up across a team and do it as a relay throughout March.

Our Community Fundraising Team will be here to support you every step of the way and if you raise £100 or more in sponsorship, we'll send you a commemorative medal to mark your amazing achievement.



# THE LEWIS MOODY FOUNDATION REACHES AN AMAZING GOAL

Since 2014, ex-England Rugby Captain Lewis Moody has gone to some extreme lengths to tackle brain tumours – including cycling through rainforests and trekking to both the North and South Poles.

Now the World Cup winner is celebrating yet another historic milestone as The Lewis Moody Foundation has raised an amazing total of £2 million to help defeat brain tumours!

Lewis and his wife, Annie, were inspired to launch the Lewis Moody Foundation after they met the incredible Joss Rowley Stark in 2012. Sadly, Joss passed away in 2013 after a battle with a rare form of cancer and The Foundation was created in 2014 in his memory. Administered by The Brain Tumour Charity, The Foundation raises funds for pioneering research and vital support services facilitated by The Charity.

We're so proud of what Lewis, Annie and their amazing supporters have been able to achieve and we can't wait to celebrate their next £2 million – and beyond!

Find out more about The Lewis Moody Foundation at [thelewismoodyfoundation.org](http://thelewismoodyfoundation.org)

THE  
LEWIS MOODY  
FOUNDATION  
TOGETHER WE CAN TACKLE BRAIN TUMOURS



## THANK YOU!

We really appreciate all your support and here are just some of the ways you've helped us move further, faster towards a cure!

### OUR COMMUNITY TRULY WENT THE DISTANCE AT THE VIRGIN MONEY LONDON MARATHON!

In October 2021, we had our most successful Virgin Money London Marathon ever. We had 100 people running for The Charity, raising an astonishing £435,199!

### GIVING THE GREATEST GIFT AT CHRISTMAS

We were blown away by the response to our 2021 Christmas Appeal, as you helped us raise over £225,000.

### YOU HELPED CREATE A BRIGHTER FUTURE

Thanks to the generosity of our inspiring community, our bright minds vs brain tumours campaign smashed its fundraising target – raising more than £140,583 in total!

### THANK YOU FOR HELPING US STOMP OUT BRAIN TUMOURS

Throughout March, our supporters stepped up to help us stomp out brain tumours by taking on walking challenges every single day of the month and raised an incredible £45,000.

### FANCY TAKING ON A CHALLENGE TO HELP DEFEAT BRAIN TUMOURS?

Learn more about the different ways you can fundraise to help us move further, faster towards a cure at [thebraintumourcharity.org/fundraise-for-us/](http://thebraintumourcharity.org/fundraise-for-us/)





# WIN BIG

## WEEKLY LOTTERY

Big prizes, even bigger impact for our community!

Supporting The Brain Tumour Charity has always meant being a part of creating big wins for families affected by a brain tumour.

Now, there's a fun, new way to support the cause that could mean a big win for you too – The Win Big Weekly Lottery!

For as little as £1 a week, you can continue to make a big difference to our community and be in with a shot of winning up to **£25,000**.

Every Friday a winning number is drawn at random and all you need to do is match your digits to win. All profits we receive will help transform the future for those affected by brain tumours.

You can play today for your chance to win big cash prizes every week, while helping us take an even bigger step towards a world where brain tumours are finally defeated.

Play today by visiting  
[lottery.thebraintumourcharity.org](http://lottery.thebraintumourcharity.org)



# BRAINTEASERS

## Emoji Quiz!

1



2



3



4



5



6



7



8



9



10



## Wordsearch

O	Y	M	I	I	E	S	H	T
L	J	S	E	M	U	N	C	R
W	A	R	E	P	R	O	R	E
O	U	T	P	H	W	I	A	A
C	M	O	I	D	E	T	E	T
I	R	O	B	P	R	A	S	M
T	L	O	U	E	S	N	E	E
F	P	A	B	U	A	O	R	N
N	I	A	R	B	F	D	H	T

Brain, Hospital, Cure, Research, Treatment, Donation, Support

Can you decode these 10 emoji clues?

Here's an extra hint – all of the answers are featured somewhere in this issue of *The Grey Matters*.



**Answers**  
1. The Twilight walk 2. Celebrating You Awards 3. London Marathon 4. Gift in Wills 5. BRAIN databank 6. Lewis Moody Foundation 7. The Grey Matters 8. Tour de Full English 9. Best Care Everywhere 10. TIME Art Fair



# CHRISTMAS SHOP

Discover our entire range and place your Christmas order at:  
[shop.thebraintumourcharity.org/christmas](http://shop.thebraintumourcharity.org/christmas)



**Yappy Christmas**  
 [uncoated board]  
 Inside: Yappy Christmas



**12 Days of Christmas**  
 [uncoated board]  
 Inside: Season's Greetings



**Gathering Around the Tree**  
 [red foil on textured board]  
 Inside: Season's Greetings



**Night Delivery**  
 [gloss board]  
 Inside: Happy Christmas



**Heading to Church**  
 [uncoated board]  
 Inside: Merry Christmas and Happy New Year



**Postman Cat**  
 [uncoated board]  
 Inside: Blank



**Penguin Friends**  
 [red foil on gloss board]  
 Inside: Merry Christmas



**Fluffy Sheep**  
 [silver foil on uncoated board]  
 Inside: Blank



**Christmas Reindeer**  
 [silver foil on uncoated board]  
 Inside: Blank



**Peace to the World**  
 [silver foil on gloss board]  
 Inside: With Best Wishes for Christmas and the New Year



**Decorating the Tree**  
 [gloss board]  
 Inside: Blank



**Holy Night Choir**  
 [gloss board]  
 Inside: Merry Christmas and Happy New Year



**By The Light of the Moon**  
 [silver foil on uncoated board]  
 Inside: Season's Greetings



**Golden Partridge**  
 [gold foil on uncoated board]  
 Inside: Merry Christmas



**Colourful Robin**  
 [red foil on uncoated board]  
 Inside: Happy Christmas



**Money Wallets**

## GIFT WRAP & TAGS



**Fluffy Robin set**



**Santa and Rudolph set**




**Colourful Christmas set**



**Woodland set**

## PUZZLES, GAMES & STOCKING FILLERS





# MAKE BEATING BRAIN TUMOURS YOUR LEGACY

By leaving The Brain Tumour Charity a gift in your Will, your legacy can help us continue funding ground-breaking research into the future until we find a cure for brain tumours.

Find out how you can make a lasting impact.

**[thebraintumourcharity.org/gift-in-will](https://thebraintumourcharity.org/gift-in-will)**

**thebraintumourcharity.org 01252 749990**

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