Better Safe Than Tumour goes to Parliament

Taking strides to change lives

Our partnership with Wickes kicks off

Meet our Future Leaders
HELLO!

It’s my great privilege to have taken up the CEO role at The Charity this year and to have joined such a dedicated organisation, relentless in its search for a cure and tireless in its support for all those who’ve experienced this most difficult of diagnoses.

We’re incredibly grateful to trustees Graham Norton, Graham Lindsay and Beth Worrall for their invaluable contributions steering The Charity in 2022-3 during the search for a permanent CEO.

As we embark on delivering our new co-created strategy for change, Living Longer and Better, this issue is packed full of updates on the impact we’ve already made this year thanks to your support – as well as plenty of ways to get involved in the coming months!

You’ll find profiles of three more of our exceptional Future Leaders, whose game-changing research projects aim to discover new treatments, transform care and improve quality of life.

You’ll see how our Better Safe Than Tumour campaign is expanding further, faster – among MPs and MSPs from Holyrood to Westminster, and, with your help, in people’s local communities up and down the UK!

Finally, you’ll find our wonderful range of Christmas products at the back of this issue. Every card, gift and stocking filler you buy will help us propel progress towards our vision of longer, better lives for everyone diagnosed with a brain tumour.

Thank you,

Dr Michele Afif, CEO
We were truly saddened, earlier this year, to learn of the passing of Laura Nuttall on 22 May. Laura, one of our former Young Ambassadors, was diagnosed with a glioblastoma in 2018 and was resolute in her determination to share her story and raise vital awareness of brain tumours.

Laura was one-of-a-kind and loved by so many. As well as inspiring countless others affected by brain tumours, she embarked on an epic bucket list, ticking off wishes at a dizzying rate, from piloting a Royal Navy ship to reading the weather on the BBC! Her loss is a fierce reminder of why we must move further, faster every day to accelerate cures for brain tumours, so that other families don’t have to endure this kind of heartbreak in the future.

In 2021, we launched a fundraising appeal to raise money for our cutting-edge trial into cannabinoids and, thanks to your support, we raised the £450,000 needed to make it happen. Now, we’re excited to announce that the ARISTOCRAT trial has officially started recruiting participants! This groundbreaking trial will investigate whether combining nabiximols (also known as Sativex) with chemotherapy could help extend the lives of people diagnosed with recurrent glioblastoma.

The Big Bake is back and there’s still time for you to help us raise some dough to defeat brain tumours!

We’re calling on bakers across the UK to rise to the challenge and host their own Big Bake in September – whether you want to whip up funds at work or cause a stir in your community.

Visit thebraintumourcharity.org/get-involved/big-bake to find all the ingredients you need to make sure you’re ready to crumble.

Playing our Win Big Weekly Lottery for just £1 a week supports someone diagnosed with a brain tumour. Every time you play, it’s a big win for us in pursuit of our goals: doubling survival and halving the harm done by brain tumours.

To be in with a chance of winning big, visit lottery.thebraintumourcharity.org or scan the QR code below.

It was a pleasant surprise when I won £1,000 in the lottery. I decided to use the winnings to put towards a family holiday. Ben’s early death has shown me how important it is to spend more time creating memories with my family.

Alan – Win Big Lottery winner
March was Brain Tumour Awareness Month and saw members of the community raise their voices for change up and down the UK, from Holyrood to Westminster!

We began by hosting an event in Edinburgh to raise awareness of the signs and symptoms of brain tumours among Members of Scottish Parliament (MSPs), including then Minister for Public Health, Women’s Health and Sport, Maree Todd MSP.

Next, we headed to Westminster with volunteers Nicola, Katie and Gemma, all of whom have been affected by a personal or loved one’s brain tumour diagnosis. We met with MPs to campaign for faster diagnosis and to raise awareness of our Better Safe Than Tumour campaign.

This accompanied the launch of our urgent report, Brain Tumours: Fighting For a Faster Diagnosis, which you can find on our website.

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

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

We asked you to distribute envelopes containing signs and symptoms cards in your community, from your daily walk to community groups, schools – everywhere and anywhere.

And you certainly got stuck in, with 568 packs of envelopes already ordered! That’s a huge amount of awareness raised up and down the UK, with potentially 56,800 homes and 113,600 people reached if everyone passed on their cards. Thank you!

"It was incredibly rewarding to be able to speak to the many MSPs who attended about early diagnosis and explain to them just how big an impact a brain tumour can have."

- Heather, who has bravely supported and advocated for us since 2014

"It was great to share my sister’s story in the hope that it inspires change."

- Katie

To find out how you can get involved and keep up the momentum, visit headsmart.org.uk/help-us-spread-the-word.
MEET MORE OF OUR FUTURE LEADERS

DR MARA DE MARTINO

Weill Cornell Medicine, New York City, USA

Dr Mara De Martino is a highly accomplished scientist in the field of tumour immunology research, who has won several awards. She currently works as a postdoctoral fellow at Weill Cornell Medicine, where she’s investigating the immuno-metabolic properties of radiation therapy in glioblastoma.

ACTIVATING THE IMMUNE SYSTEM AGAINST GliOBLASTOMA

The immune system is the body’s natural defence system against infections and diseases, including cancer. But cancer cells can sometimes avoid detection and attack by the immune system. This is called ‘immune escape’.

Dr De Martino’s groundbreaking project aims to understand how lipids affect immune escape and treatment resistance in glioblastoma, the most aggressive form of brain tumour. Lipids are crucial molecules that shape cell structure, store energy and influence cell function.

Dr De Martino’s research employs advanced techniques to investigate how radiation therapy alters lipid metabolism in glioblastoma cells. This metabolic change leads to immune suppression, allowing cancer cells to evade the body’s natural defences.

This research could have significant implications for people diagnosed with glioblastoma and their families. Dr De Martino’s work could inform new treatment approaches, improve outcomes and extend survival rates. Additionally, her findings may benefit other cancer types, as lipid inhibitors are already being tested in clinical trials.

This work could lead to a new treatment strategy to cure brain tumours by targeting lipid metabolism.

- Dr Mara De Martino

DR ANGEL ALVAREZ-PRADO

University of Lausanne, Lausanne, Switzerland

Dr Alvarez-Prado has a remarkable publication track record and was awarded the prestigious EMBO (European Molecular Biology Organisation) Fellowship and Marie-Sklodowska-Curie Fellowship. He has the ambitious goal of re-programming the communication between cancer cells and their microenvironment to create an anti-tumour immune response.

FIGHTING GliOBLASTOMAS ON TWO FRONTS

Glioblastomas are extremely difficult to treat for a few key reasons: their location, their heterogeneity (this is where there are lots of different subgroups of cells within the same tumour that all behave differently), and their ability to re-educate cells in the nearby environment to suppress the immune system.

The current standard treatment largely targets cancer cells directly, while some newer strategies are instead focused on exploiting the immune system to fight the tumour. So far, neither of these approaches has significantly improved people’s survival. But Dr Alvarez-Prado’s innovative project will target both cancer cells and their supporting immune microenvironment at the same time.

Dr Alvarez-Prado will focus on exploiting a natural defence mechanism present in all cancer cells. One of the key players in this defence mechanism is a protein called ‘ADAR1’, which helps cells distinguish between molecules originating from viral infection and those produced during normal processes in the body, preventing unwanted immune reactions. When the former are detected, the cells stop growing and send a signal alerting the immune system to fight the infection.

Dr Alvarez-Prado hypothesises that removing or inhibiting ADAR1 will have a similar effect in glioblastoma cells and halt their growth. Importantly, research has shown that glioblastoma cells have certain characteristics that make them more vulnerable to ADAR1 inhibition. If successful, this project could lead to a better treatment for patients that is less harmful because it takes advantage of a weakness specific to glioblastoma cells.

The potential impact of this research on treatment for glioblastoma is significant, since the compound Dr Alvarez-Prado will use to inhibit ADAR1 is structurally very similar to that of a drug already being used to treat other cancers. We’re extremely excited for his findings!

- Dr Mara De Martino
MEET MORE OF OUR FUTURE LEADERS

DR CHRISTOPHER MOUNT
Harvard Medical School, Cambridge, MA, USA

Dr Christopher Mount is a doctor and scientist who’s passionate about discovering new treatments for brain tumours. At Massachusetts General Hospital, he’s working in a lab that specialises in studying the different cells in brain tumours and how they communicate with each other. He hopes to find new targets for immune therapy that could be used to treat brain tumours.

TARGETING CELLS IN ADULT AND CHILDHOOD GLIOMAS

High grade gliomas are complex and aggressive brain tumours that are challenging to treat.

Dr Mount’s game-changing project aims to bring the immunotherapy revolution to people diagnosed with gliomas, and focuses on a type of immunotherapy called CAR-T cell therapy. These engineered immune cells can recognise and bind to specific proteins on cancer cells. Traditionally, CAR-T cells can only identify a single target, but because gliomas contain a complex mixture of cells, their effectiveness is limited.

Dr Mount and his team have played a key role in mapping the complexity of gliomas and hope to use this knowledge to design CAR-T cells to target and eliminate multiple cell types found in gliomas, improving treatment effectiveness.

The modified CAR-T cells’ effectiveness will be evaluated through lab experiments using cell cultures and animal models carrying human gliomas.

Dr Mount’s work not only offers hope for people diagnosed with a glioma and their families, but also contributes to accurate diagnoses and predicting treatment responses, ultimately improving quality of life for more people. Advancements in CAR-T cell therapies may also have broader implications for treating other cancers.

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

Our Junior Fellowship awards are part of our Future Leaders programme. After three years, our postdoctoral fellows are invited to submit an application for a four-year Junior Fellowship, to support themselves and a research associate in a host laboratory.

During this time, fellows should develop as independent researchers and begin to build their own groups. In April 2023, we were thrilled to award two £600,000 Junior Fellowship grants to Dr Spencer Watson and Dr Tyler Miller!

DR SPENCER WATSON
Swiss Federal Institute of Technology, Lausanne, Switzerland

Dr Watson’s project aims to use new high-dimensional imaging techniques coupled with machine learning to identify unique 3D regions within recurrent glioblastomas.

State-of-the-art spatial analysis tools and bioengineering will then be used to identify ways to target dormant and recurrent cancer cells.

Massachusetts General Hospital, USA

Gliomas contain a large number of cells that suppress the immune system. The immunosuppressive cells prevent the action arm of the immune system, T cells, from attacking the tumour.

This project seeks to deeply understand what causes these cells to become immunosuppressive and discover ways to target them so that brain tumours become sensitive to breakthrough immunotherapies.
OUR SPECIALIST SUPPORT FOR YOUNG ADULTS

Did you know we provide specialist support for young adults aged 16-30 who’ve either received a brain tumour diagnosis or are affected by a loved one’s diagnosis?

We know that receiving a brain tumour diagnosis, or learning of a loved one’s diagnosis, is a life-changing event that can lead to lots of questions.

It’s not always easy to ask your friends and family these questions and it can be difficult to access your healthcare team at the exact moment a question comes to mind.

Our Young Adults Service helps young people connect with others and supports them with any information they might need.

We’re so grateful to the Elliott Simmons Charitable Trust and the Lewis Moody Foundation who kindly support our Young Adults Service.

You can find out more about our support for young adults at thebraintumourcharity.org/get-support.

Did you know we provide specialist support for young adults aged 16-30 who’ve either received a brain tumour diagnosis or are affected by a loved one’s diagnosis?

On Friday 26 May, we were delighted to welcome 76 young adults affected by a brain tumour diagnosis and their guests to our inaugural Young Adults Masquerade Ball!

This simply amazing evening, funded by Property For Kids, was held at the iconic Chatsworth House.

The attendees enjoyed a three-course meal, entertainment from a magician, a photo booth for making memories – and, of course, lots of dancing!

We’re incredibly grateful to Property For Kids for funding the event and to everyone involved in making it happen.

From Family Days to young adult events like these, we’re dedicated to providing opportunities for our community to come together in an inclusive, fun and relaxed way.

As always grateful to The Charity for providing opportunities to be able to unite young people who can be so easily forgotten through an extremely difficult experience whilst also having fun in such beautiful surroundings.

- Victoria Neill, an attendee at our Young Adults Ball

An Evening To Remember...

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- Victoria Neill, an attendee at our Young Adults Ball

Victoria Neill with fellow Young Ambassador, Amy Heald, and her partner, Drew Nagys
Mel, 22, a sports coach from New Ferry on the Wirral, found her way to our Young Adult Support Services following her brain tumour diagnosis in December last year.

In September 2022, Mel suddenly started suffering from daily headaches. Her GP diagnosed a sinus infection, prescribing Sudafed and antibiotics, but things didn’t improve. Mel said,

“Several days later I was back at the doctors, as now I couldn’t even lift my head off the pillow and was drowsy and shaking. I was told, ‘It’s nothing neurological, don’t worry’."

This meant that, though she went on to experience vomiting, some vision loss and blackouts, she “didn’t worry about anything, as I thought it would pass, and I was potentially experiencing a burnout!”

But then she was contacted about an e-consult she had filled in two weeks before and given an appointment at her local ophthalmologist within the hour.

There, she was told things “had been left too long” – and that she had to go for an immediate scan. Mel discovered her diagnosis just a few hours later.

“At first it was utter shock, I knew I wasn’t well, but to hear those words ‘you have a brain tumour’ – nothing comes close to describing that moment.”

Mel underwent a craniotomy on 23 December. “The day after surgery was horrible – not necessarily an ill feeling, but just sheer lack of strength made me think ‘what have I done’ and I partially took the blame for it!”

“I couldn’t even lift myself up in bed, or go to the toilet alone, so when nurses of a similar age were looking after me, I felt embarrassed and ashamed… even though they had my best interests at heart.”

Mel is now recovering well and has returned to work as a sports coach. Though sadly, one of her big loves, Karate, is off-limits for now. Family and friends have been fantastic – but Mel found she needed to speak to others her own age who fully understand what she is going through.

Joining the Young Adults Facebook Group and attending online meet ups has proved invaluable. Mel said:

“Joining the Young Adults Facebook Group and attending online meet ups has proved invaluable. Mel said:

“I didn’t know anyone else who had been through this at my age – but the support from the Young Adults Service has been incredible. From the online meet ups to messages in the groups, nothing has ever been too much of an ask for the staff and they always go above and beyond.”

Mel Kelly and her mum, Joanne, at the recent Young Adults Masquerade Ball

Mel was also excited to receive an invitation to our Young Adults’ Masquerade Ball. She said,

“The thing I enjoyed most was meeting people face-to-face rather than over a screen. Having the opportunity to talk to each other through the online meet ups before the Ball made it more comfortable to meet for the first time.”

And in the months since her diagnosis, Mel has thrown herself into fundraising for The Brain Tumour Charity. Her Twilight Walk in March saw family and friends come together to take on an impressive 12 miles together – marking 12 weeks of Mel’s recovery, and raising a fantastic £3,680!
Your Will is a very special personal document. It’s your way of ensuring your wishes for the people you care about are fulfilled after you’re gone.

As one of our supporters, you can write a simple single or mirror Will for free using one of our Will writing providers.

And once you’ve taken care of your loved ones, we’d really appreciate it if you’d consider leaving a gift in your Will to The Brain Tumour Charity.

Big or small, a percentage in our name could fill more labs with research into brain tumours that could give hope to thousands of people in years to come.

When you picture the future, what do you hope for?

At The Charity, we hope for a future full of kinder effective treatments. Labs full of groundbreaking brain tumour research. And survivors. Lots of survivors.

Yet while brain tumours are the biggest cancer killer of children and adults under 40, survival rates have improved little in a generation, research investment is low compared to other cancers and diagnosis is still taking far too long.

With a gift in your Will you can help change this. You’ll help to fund vital research and give hope to everyone who has to face a brain tumour in the future.

It’s extraordinary to me that a disease that kills more young people than anything else in this country just has very few treatments. Without research we won’t get new treatments and without new treatments we can’t give more hope to families in the future.

- Sarah, who lost her son Silas to a brain tumour.
Our partnership with home improvement retailer Wickes launched with a bang in April this year, with Wickes team members up and down the country getting stuck in to raise funds and awareness for us!

From 20-24 April, the Wickes team stood together with us against brain tumours by dressing in red to make a difference for everyone affected – joined in many stores by members of the brain tumour community.

Customers across Wickes’ stores were invited to donate 50p when making a purchase to help us take on brain tumours together.

And we’re delighted to report that an incredible £96,000 was raised! That’s enough to fund nearly a year of cutting-edge research into brain tumours.

What a start to this amazing partnership! A huge thank you to everyone at Wickes for making this event such a success, not to mention all those who were able to donate and everyone who volunteered their time to help out.

We’re especially grateful to the teams at Wickes for being so welcoming and making us feel so at home. Together we’ve got the tools to make a difference for everyone affected by a brain tumour diagnosis.

Gina Almond, Director of Fundraising & Marketing at The Brain Tumour Charity

I am so proud of what has already been achieved in such a short space of time. I’d like to thank all our colleagues and customers who have shown a real passion for the cause, embracing our new charity partner to raise such an incredible amount of money. We stand together in this fight against brain tumours.

- David Wood, CEO of Wickes
On 4 April, we were absolutely delighted to welcome members of the brain tumour community to our Celebrating You Awards 2023 at the Business Design Centre in London.

The ceremony celebrated and recognised all those who’ve gone above and beyond to create change over the last few years – and you can discover the very deserving winners below!

You can find out more about all of them at: thebraintumourcharity.org/news/celebrating-you

It was such a moving, inspiring evening and we’re so grateful to everyone who submitted a nomination. Our judges found it more difficult than ever to pick those shortlisted and the winners; everyone who was nominated has our deepest thanks for everything they do for those affected by a brain tumour.

**AND THE WINNERS WERE...**

Outstanding Contribution Award:
Sarah Lindsell

Award for Special Recognition:
Laura Nuttall

Young Fundraiser of the Year:
Will Alexander

The Viv McBeth Award for Fundraiser of the Year:
John Royden

Professional Excellence Awards:
Kings Neuro-oncology team
Jillian Sokratous

Influencer of the Year:
Sigourney Bonner

Change Maker of the Year:
Heather Dearie

Partner of the Year:
Underbelly

Research Rising Star:
Farshad Nassiri

Volunteer of the Year:
Andy Tudor

OUR TIME ART EXHIBITION

From 6 to 15 April, we were thrilled to hold our one-of-a-kind Time Art Exhibition at The Business Design Centre in London.

This special event featured photographs, illustrations, paintings, scans and sculptures submitted by people in the community, as well as artworks by upcoming and renowned artists from across the world.

If you got involved, whether by submitting art, coming along to the exhibition or placing a bid, we’re incredibly grateful. The exhibition raised invaluable awareness of brain tumours among the public.
We were thrilled to see so many people unite to take strides for The Twilight Walk throughout Brain Tumour Awareness Month in March.

For the first time, we took on The Twilight Walk London, with over 850 of you forming a sea of red walkers, passing iconic landmarks such as Big Ben, Buckingham Palace and Hyde Park.

And over 860 of you took part in 265 Own Walks up and down the country in March 2023 and October 2022, all determined to raise awareness and make a difference for everyone affected by brain tumours.

In total, your efforts raised an awe-inspiring £416,400. That’s enough to fund over three and a half years of world-class research into brain tumours.

Your footsteps really are the future – thank you!

Scan the QR code to be the first to hear about The Twilight Walk 2024!
TOP PICKS FROM OUR CHRISTMAS SHOP

Spread some Christmas cheer, treat your loved ones, and get the warm, fuzzy feeling that comes with doing some good this festive season. Every purchase you make from our online shop helps accelerate change for those affected by brain tumours.

Christmas Cards

Special Delivery Service – Merry Christmas (10 pack) £4.25
Robin and Holly – Season’s Greetings (10 pack) £4.25
Snowy Forest Friends – Happy Christmas (10 pack) £4.25
Let It Snow – Season’s Greetings (10 pack) £4.25

Woolly Christmas – Blank for your own message (10 pack) £4.25
Christmas on the Road – Happy Christmas (10 pack) £4.25
Tree Elf – Merry Christmas (10 pack) £4.25
Sacred Dove – Blank for your own message (10 pack) £4.25

So Many Chimneys, So Little Time – Happy Christmas (10 pack) £4.25
Decorated for Christmas – With best wishes (10 pack) £4.25

Virtual Gifts

Virtual gifts are donations sent on behalf of your loved ones. They will receive a beautiful e-card PDF and the donation goes towards changing the life of someone affected by a brain tumour.

Choose either the Gift of Knowledge (£5), the Gift of a Helping Hand (£10), or the Gift of a Hug in a Bag (£30). Plus, pick from some fantastic card designs and even add a personalised message!

Puzzles, Games, Stocking Fillers and Festive Favours

Money Wallets £1.25 EACH

To browse our entire range visit: shop.thebraintumourcharity.org or scan the QR code below!
The Oli Hilsdon Foundation was set up in 2019 to fund research in loving memory of Oli Hilsdon, who lost his battle with a glioblastoma in January 2019, just 10 days before his 27th birthday.

Oli was diagnosed with a glioblastoma at age 22 and given less than 12 months to live. He fought his diagnosis with optimism, courage and a wicked sense of humour.

We were excited to partner with The Foundation in 2019, when they pledged £1.5 million to fund a pioneering University College London (UCL) research programme to map glioblastoma cells. The project is led by Professor Simona Parrinello and is due to finish in March 2025.

We’re thrilled to say that The Oli Hilsdon Foundation has now raised the money needed to fully fund the pioneering research programme – a whole year earlier than anticipated!

The funding in full of this exceptional research project is game-changing for people diagnosed with a glioblastoma. It will accelerate the cures and improved quality of life they so desperately need.

We’re so proud to work alongside The Oli Hilsdon Foundation and are immensely grateful for their commitment to our world-class research.

You can find out more about The Oli Hilsdon Foundation at olihilsonfoundation.org.

In June, our fabulous corporate partner Underbelly once again held their family-friendly festival, Alfstock, to raise money for research into childhood brain tumours and celebrate the life of Alfie, son of Underbelly founder Ed Bartlam. Alfie died from an ependymoma brain tumour in 2019.

We’re thrilled to report that this year, Alfstock raised a magnificent amount of funding to help accelerate a cure, as well as raising much-needed awareness of this devastating disease. Thank you, Underbelly!

Thanks to the generosity of our inspiring community, our Bright Minds vs Brain Tumours campaign smashed its fundraising target – raising more than £148,300 in total! That could fund over a year of cutting-edge research into brain tumours.

A huge congratulations and well done to our amazing 138-strong team of runners who took to the streets in April for the TCS London Marathon 2023!

We’re so proud of our inspiring community, our Bright Minds vs Brain Tumours campaign smashed its fundraising target –
WIN UP TO £25,000!
while supporting The Brain Tumour Charity to help every single person affected by a brain tumour.

By playing the Win Big Weekly Lottery, I hope that researchers will one day find a cure for this terrible disease.

- ALAN, who won £1,000 in our Win Big Weekly Lottery

thebraintumourcharity.org 01252 749990

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