

The Brain Tumour Charity shining a light on

The GREY MATTERS

**THE
BRAIN
TUMOUR
CHARITY**

A CURE CAN'T WAIT

Issue 20 Spring 2019



Bake it 'til you make it

Fired up for change

Spotlight on - Hal Cruttenden

thebraintumourcharity.org

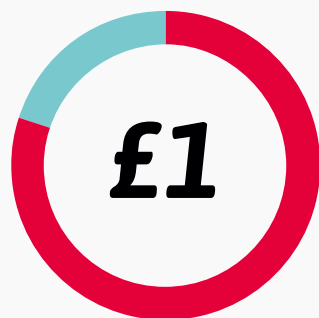


You raised a fantastic £76,507!
Enough to fund over nine months
of world-class research.

We'd like to say thank you
to everyone who bought and
sold our Christmas gifts, cards
and decorations. And to the keen
quizzers, festive fashionistas
and speedy Santas who helped
us raise money to accelerate
a cure. Huge thanks also to the
hard-working volunteers who sent
out fundraising packs and shop
items, ensuring it all got there
safely and in time for Christmas -
you're all stars!

To everyone who has
supported us this season:
a heartfelt thank you!

How we spend your money



We aim to spend at least 80p of every
pound spent on our charitable objectives.

**Third
Sector
Awards** Winner
2018



Our Charity of the Year award



Sarah Lindsell

Hello

Welcome to issue 20 of *The Grey Matters*.
Reflecting on our first issue in 2012, it's
so encouraging to see how far we've come.

From the success of our HeadSmart
campaign - reducing diagnosis times
- to our triumphant campaign for the
uptake of 5-ALA, we're making headway.
But what has particularly stood out
for me is our research commitment.

Brain tumour survival rates have seen
little progress in over 40 years, so a cure
really can't wait. That's why, in 2012,
we wanted to put £3 million towards
research into brain tumours each year.

Now, since that time, we're thrilled
to have committed £30.3 million. Less
than 2% of cancer research funding goes
towards brain tumours. We're helping
ensure brain tumours are not left
behind and survival rates improve.

So this continually-growing investment
is astounding and so promising for our
progress towards doubling survival
and halving the harm of brain tumours.
Find out more about the progress we're
making on the next page.

And it's because of you, our supporters,
that this has been possible. Thank you. We
couldn't do it without you. Now, together,
we must keep up the momentum to make
this year even bigger than the last and
accelerate change for everyone affected
by a brain tumour. **A cure can't wait!**

Sarah Lindsell, CEO

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Committed to change

Thanks to your ongoing support and generosity, we've made promising progress towards our goals of doubling survival and halving the harm of brain tumours. Now, we'd like to reflect on how far we've come, with your help, and what we plan for this year.

Last year, we planned to:

Reduce the number of neurosurgical centres without access to 5-ALA



Thanks to the late Baroness Tessa Jowell and neurosurgeons Stephen Price, Colin Watts and Pablo Goetz, the Government agreed to the national roll out of 5-ALA (the 'pink drink'). The NHS Long Term Plan supports this and NICE (National Institute for Health and Care Excellence) guidelines have been published on its use.

Commit a further £11.7 million to ground-breaking research



We're selective about the research we fund to ensure your money makes a difference. So, occasionally we don't invest as much as we'd like. But in 2018, we committed £9.7 million to research, surpassing our five year target of £20 million by 2020 two years early!

Get ready to launch BRIAN, our global, patient-led data platform



We've made great progress with BRIAN, and are ready to launch later this year. So far, over 580 people have signed up, giving consent to share their hospital records. And we've been granted access by NHS Digital to anonymised data from 140,000 patients, which stretches over 10 years.

Reach those affected earlier so they have trusted info and support from the start



Last year we reached double the number of people recently diagnosed with a brain tumour compared to the year before. We're still working hard to engage with more of those newly diagnosed by the end of 2019 to ensure everyone has access to the right support.

Fund our first Future Leader research programme



In the last issue of *The Grey Matters* we were proud to introduce Dr Laure Bihannic, our first Future Leader. Laure is exploring medulloblastoma, a childhood brain tumour.

Help more patients contribute to research



With the help of BRIAN (read more on page 15) and our Research Involvement Network (RIN), 12.2% of people newly diagnosed with a brain tumour are now involved with research through us.

Fund five more CNSs to improve patient experience and quality of life



Following the appointment of Charlotte, our Clinical Nurse Specialist at King's College Hospital, we recently recruited Kelly in Nottingham and Julie in Edinburgh. Find out more on pages 10-11.

Just a few of our priorities in the coming year...



Commit a further £8.5 million to research before the end of our strategy in 2020.



Launch the initial version of BRIAN now we have data access.



Grow our service further to meet the needs of at least double the number of people that we support.



Drive the roll out of the patient-centred model of care to all neuroscience centres. This will improve outcomes for all.

Adapting the future

The Tessa Jowell BRAIN-MATRIX is a first-of-its-kind clinical trial helping advance a cure for glioma brain tumours by treating them with drugs that are more targeted than ever before. We're excited to be investing £2.8 million to get it off the ground.

The trial is named in honour of the late Baroness Tessa Jowell. Tessa was a strong advocate for adaptive trials and enabling people to share their data to improve understanding of brain tumours. These are both core foundations of the trial.

What makes this adaptive?

Everyone in this trial will get a molecular diagnosis of their tumour, so researchers can tailor treatments to an individual's diagnosis. Researchers will test new potential treatments as they become available. The adaptive design means that as these new treatments become available, they can be added as new 'arms' of the study, accelerating progress towards a cure.



Professor Colin Watts

What impact could the trial have?

BRAIN-MATRIX is helping improve the future of brain tumour care. It will:

- Set up a system in the UK that enables people with a glioma to have molecular testing and get treatments specific to their tumour.
- Help reduce side-effects and increase survival.
- Pave the way for treatments to be tested faster, providing more people with a therapy that could work better than the current standard of care.
- Collect quality data from people on these new treatments, to find patterns in treatment response and identify new areas for research.

But it won't stop there, we expect the trial to impact those affected by a brain tumour globally too, helping drive much-needed improvements and propel our understanding worldwide.



Where's the trial being run?

This groundbreaking, five-year trial is led by Professor Colin Watts (left) at the Queen Elizabeth Hospital Birmingham. Initially, 10 centres will be able to recruit people onto the trial: Birmingham, Cambridge, Edinburgh, Glasgow, King's College London, Leeds, Liverpool, Manchester, Nottingham and Oxford.

These are major centres for people with a glioma, so the majority of people with a brain tumour in Scotland and England will come under their care.

How can I join?

The trial is now being set up. We'll let you know when it's open for patient recruitment. Once open, the criteria are wide so the neurocentres taking part can

offer the trial to adults and children who have a grade 2, 3 or 4 glioma and are able to undergo a surgical procedure, including biopsy. Please speak to your consultant to find out more.

Unfortunately The Charity is unable to sign up anyone for the trial.

To learn more about the trial, visit thebraintumourcharity.org/brain-matrix

Did you know?

If you're not being treated at one of the recruitment centres, you could still get involved in BRAIN-MATRIX. If you can travel regularly to one of the ten centres, then you may be suitable for the trial. Speak to your consultant to find out more.

Join our movement!

Help us do more for a cure by volunteering at one of our challenge events across the UK.

Choose your role

There are a number of roles you can choose from to support our fundraisers at an event, and each one is invaluable. So whether you can spare a day or a few hours, please get involved. All we ask is that you bring your energy, enthusiasm and enjoy yourself!

Our opportunities:

Cheer Champion

Help us create an exciting atmosphere, while raising awareness of The Charity, as you cheer, shout and clap on the sidelines to support our team.

Meet and Greet Volunteer

As a Meet and Greet volunteer, you'll be helping us in the marquee on the day, setting up and providing refreshments for our fantastic fundraisers.

Volunteer Photographer

Capture magical moments from the day and take photos of all our participants in action.

Learn more about these and other event day volunteer roles at thebraintumourcharity.org/event-volunteering



"I decided to volunteer at the Edinburgh Marathon after a friend was diagnosed with a brain tumour. I was keen to help in any way that I could, and cheering The Charity's runners on at the side of the road seemed a valuable way to show my support.

"But I hadn't appreciated how people shouting words of encouragement could be such a big help. It felt wonderful to see our cheers giving the runners a massive boost.

"By the end of the day, I had no voice and was freezing cold, but I was elated. Getting to meet so many incredible people with so many inspiring stories was honestly one of the best experiences of my life. If anyone was considering volunteering at an event, I would definitely tell them to do it!"

Laura Miller, Cheer Champion

We have events up and down the country that need lots of wonderful volunteers.

Bath Half Marathon
Virgin Money London Marathon
Vitality London 10,000
Edinburgh Marathon Festival
Peak District Challenge
Prudential Ride London
London to Brighton Cycle
Marathon Walk London
Royal Parks Half Marathon
Tough Mudder events across the UK





Supporting patients all the way

People with low grade brain tumours urgently need better access to clinical nurse specialists. That's why we're committed to funding low grade CNS roles across the UK.

In the last issue of *The Grey Matters*, you may have seen the interview with Charlotte Robinson (above), our first funded clinical nurse specialist (CNS) for people with low grade brain tumours in the UK.

Access to a named key worker, often a CNS like Charlotte, can have a highly positive impact on people's experiences of diagnosis and treatment for a brain tumour.

But we know access varies. Not only are CNSs at risk of underfunding and overwork, they're a scarce point of contact for people with a low grade brain tumour.

"Charlotte was the go-to person for all our queries. Just knowing that we had the constant presence of someone like her was very reassuring. It's difficult to put into words the importance of having that reassurance in such circumstances."

Relative of one of Charlotte's patients

In our report *Finding Myself in Your Hands*, almost half (47%) of people with a low grade tumour said they don't have access to a CNS or other single point of contact. This is compared to just 34% of people with a high grade brain tumour.



Our progress – an update

We're determined to improve this. So, in addition to Charlotte at King's College Hospital, we're delighted to be funding two new CNS posts.

Kelly Dawson (above) is our new CNS at Nottingham University Hospitals NHS Trust. Kelly qualified from The University of Nottingham in 2011 and then worked as a staff nurse in the Neurosciences Department at Nottingham University Hospitals. She was appointed to the Neuro-Oncology Clinical Nurse Specialist service in 2013, and now, with five years' experience, she will take up the funded low grade CNS role.



A donation of
£25

could pay for one hour with a specialist nurse, like Charlotte and Kelly, so all patients can access the best care possible.

"People with a low grade brain tumour need practical, emotional and psychological support. Developing this new role and service will give them access to vital CNS support, advice and guidance. We're all very excited about the service and look forward to collaborating with The Brain Tumour Charity."

Kelly Dawson

We're also thrilled to be funding Julie Collins at the Edinburgh Centre for Neuro-Oncology, Western General Hospital.

But we won't stop there. We think this vital source of support should be there for everyone who needs it, so we're committed to funding more specialist nurses. Watch this space for more updates on our progress!

Cannabis – an update

We've been following the latest developments on the availability of cannabis-based medicinal products, and taking action to support our community to pursue the best treatment and care possible. Read on for an update on what's been happening and what we think.

You may have seen the high-profile cases in the news involving children with epilepsy and access to cannabis oil to control their seizures. Billy Caldwell and Alfie Dingley saw marked improvements in their conditions after using the oil.

As part of our drive to ensure everyone affected by a brain tumour has equal access to the best treatment and care, we campaign on a range of topics that affect our community. So we've consistently campaigned, along with other charities, to ensure that people with a brain tumour have access to cannabis-based medicinal products.

We know our community values the right to explore alternative treatment options, and the Chief Medical Officer for England, Sally Davies, has made it clear that cannabis-based products can treat chronic pain, as well as chemotherapy-induced nausea. These are side-effects that may affect people living with a brain tumour.

In June, the Government announced the legalisation of medicinal cannabis for people with an unmet need, and

on 1 November NHS England released guidance for clinicians on prescribing it.

But unfortunately this guidance is still highly restrictive, and very few people with a brain tumour, multiple sclerosis (MS) or epilepsy will be able to access the medicine.

While we welcome the change in the law, we don't think the proposed guidance is in the best interests of everyone who could benefit from medicinal cannabis.

We've now co-signed a letter with other health charities calling on the Government to urgently review this guidance. We'll also be feeding into an upcoming consultation by the National Institute for Health and Care Excellence (NICE), where we'll press home the guidance's restrictive nature.

As always, we'll continue to consult with our community and with clinicians to identify how these developments will affect people with a brain tumour.

To find out more please visit thebraintumourcharity.org/limited-access-to-medicinal-cannabis

In the UK,
76%

would be open to consuming cannabis-based medicinal products if prescribed by a doctor.



We're dedicated to supporting everyone affected by a brain tumour. In 2018, we were able to help over 13,000 people through our support services.

Support for everyone at every stage

The Brain Tumour Charity knows that everyone affected by a brain tumour is different and each journey is unique. So our support services aim to help everyone, no matter who they are, at every step.

Our expert and attentive team provides trusted guidance and impartial information to the person diagnosed, their friends and family, carers, teachers, colleagues and so many others.

Our experience has shown that different people get in touch in different ways. So, whether you prefer to talk to us, write to us, or send a message, there's something for everyone, and all free of charge.

The team is available over the phone and on email. They also run a free benefits clinic over the phone every Tuesday. However, if you're looking for information, but not ready to get in touch, our free factsheets and resources are available online and to order. Just visit thebraintumourcharity.org/understanding-brain-tumours

Alternatively, you can join one of our Facebook communities, where you can receive peer-to-peer support in a safe space.

To find out more and request to join a group visit thebraintumourcharity.org/facebook-support-groups

The new opening times for The Brain Tumour Charity's support services are:

Mon, Tue, Thurs, Fri: 9.00am-5.00pm Wed: 9.00am-9.00pm

Get in touch by calling us on 0808 800 0004 or emailing support@thebraintumourcharity.org

Your needs can't wait

Looking after your emotional, physical and psychological needs is important for everyone affected by a brain tumour.

Consider exercise

"If possible, taking part in exercise such as running or walking is a great way to manage stress and keep a positive focus."

Adam Carroll



Listen to your cravings

"Listen to your body. When I was taking steroids and managing my weight, I researched what my food cravings meant and then gave my body the nutrition it really wanted through better food choices. That way I was satisfied and my weight was better controlled."

Jen McCrear



Try mindfulness

"I find listening to a mindfulness meditation app before bed a really effective way to relax and switch my mind off."

Kate Bowen

Keep things calm

"Our family found using classical music, massage and Reiki all really helpful when trying to reduce anxiety around Mum's diagnosis."

Heather Gillies

Join support groups

"Joining a support group can be really useful for your emotional wellbeing. When you're diagnosed you can feel completely on your own, and it's important to know that you're not."

Pip Whitmore

Read more tips at thebraintumourcharity.org/boost-your-wellbeing



The power of people

The true heroes of any project are its people. And our data project, BRIAN (Brain tumouR Information and Analysis Network), is no exception.

With over 200 people affected helping us design BRIAN and over 750 patients, carers and those who have lost someone registered, our databank is being led by you, for you. Jess and Mark (pictured above) are just two examples of the people behind the project, making a difference and ensuring BRIAN is built with you at the centre.

Qualified Business Analyst, Jess, was diagnosed with a brain tumour in 2013 and works on the project full-time. With our community and developers, Jess is helping ensure those affected are at the forefront of everything we do.

Jess said, "Data is useless without the collective power of people to make change. By combining clinical and patient-reported data, we'll propel BRIAN forward and drive a data revolution!"

Mark runs the team developing BRIAN. He is a Chartered Mathematician and

experienced Quantitative Analyst who developed his career at the Bank of England and as Head of Research within an agency of HM Treasury. Mark also has a personal connection, having cared for his wife Sarah who sadly died as a result of her brain tumour in 2016. Now, he wants to accelerate treatments through our databank and help us ensure the views of carers are included.

Mark said, "I'm excited about the data BRIAN can provide around treatments people are on, and the impact this could have. If Sarah was here, she wouldn't rest until BRIAN was built, so I'm doing this for her and our community."

Through BRIAN, we're uniting with our community to accelerate change and ensure nobody is left in the dark about their health, options and outcomes.

Find out more and sign up at thebraintumourcharity.org/brian

Taking research further

We're delighted to announce that we're committing over £1 million to five exciting new initiatives, three of which are featured here.

We know that earlier diagnosis, better treatments and improvements to quality of life can't wait. In order for us to accelerate our goals of doubling survival and halving the harm of brain tumours, progress needs to be made. And it needs to be made quickly.

That's why we're proud to be funding the Expanding Theories and Clinical Biomarkers research initiatives. The Clinical Biomarkers award will focus on generating new knowledge around clinical biomarkers, or indicators, to bring us closer to more accurate diagnosis and targeted treatments. Meanwhile, the Expanding Theories award will support innovative and novel research projects which could fundamentally change our understanding of brain tumours.

Find out more about these research projects and other initiatives we're funding at thebraintumourcharity.org/what-we-are-funding

Clinical Biomarkers



Understanding the effects of abnormal genes on treatment outcomes

Professor Martin J. van den Bent
The Erasmus University
Medical Center, Netherlands

Anaplastic gliomas are a group of primary brain tumours which are currently treated with surgery and radiotherapy. However, a clinical trial in Europe, North America and Australia has found that if a certain DNA mutation occurs within this type of glioma, it could affect the type and intensity of treatments needed, as well as the outcome.

The aim of Professor van den Bent's research is to analyse tumour samples collected from people on this trial to gain a better understanding of how this DNA defect affects treatment outcomes. This research will help provide a clearer prognosis for those with anaplastic gliomas and identify which patients would benefit from more or less intense treatments.

Expanding Theories



Better targeting and disrupting of glioblastoma cells

Dr Vincenzo D'Angiolella,
Group Leader, Oxford Institute
for Radiation Oncology

Glioblastomas are the most aggressive, and one of the most common types of brain tumour found in adults.

The aim of Dr D'Angiolella's research is to understand what drives these aggressive tumours and to identify ways in which we can disrupt the process.

We know that one particular set of glioblastomas loses a gene that should stop them growing, but they've managed to find an alternative pathway enabling them to survive. Dr D'Angiolella will therefore be testing various drugs that block this new pathway, in the hope of killing the tumour cells, while leaving the normal cells intact.

Expanding Theories



Classifying brain tumours using artificial intelligence

Dr Phedias Diamandis,
University of Toronto,
Canada

There are over 140 types of brain tumour, and the most effective treatments can differ for each. Therefore, it's vital that diagnoses are made as accurately and quickly as possible. To help address this, we're committing £120,000 to a research project led by Dr Diamandis who, together with his team, has developed a brain tumour classification tool, using an emerging form of artificial intelligence.

The aim of this research project is to 'train' the classification tool to differentiate brain tumour types. This could improve accuracy and speed of diagnosis and allow patients to receive treatments tailored to their specific tumour type.

Bake it 'til you make it!

Big Bandana Bake is back this March, and we need you to help us make a stir. We want to raise hundreds and thousands (get it?) – £200,000 to be precise – for research into brain tumours.

Last year, you got your bake on to raise £185,000 over 445 bake sales, helping to drive us towards our goals of doubling survival and halving the harm of brain tumours. This year, the money you raise could help fund a researcher and their work into new treatments for three years!

Brain tumours are still the biggest cancer killer of children and adults under 40. Yet less than 2% of the hundreds of millions invested in cancer research funding is spent on them. This has to change. Every cake you bake and every pound you raise will help us find a cure faster.

So join us and hold a Big Bandana Bake on any date in March. Wherever you hold yours – at work, at home or in your local community – you'll be one of hundreds of bakers across the UK getting messy in the kitchen to raise dough for research.

It's also a great way to get together with colleagues, friends, family and your community to raise awareness of brain tumours – March is Brain Tumour Awareness Month, after all!

We know that with your help, raising £200,000 will be a piece of cake!



Sign up for your **FREE** fundraising pack

Just visit thebraintumourcharity.org/bigbandanabake It's got everything you need to hit the ground running:

- a handy guide
- recipe cards
- cake flags
- a sweepstake
- posters and a banner
- balloons
- your very own bandana, while stocks last!

Please take note of the estimated delivery time of 7–10 working days when registering, so you receive your pack in plenty of time to plan your flan-tastic event.

Want more bandanas? You can order them on our online shop (shop.thebraintumourcharity.org) while stocks last. But hurry, they're limited! You could always get creative and whip up your own bandana, too.

How businesses can help

Independent workplace catering specialists, Blue Apple, fittingly supported our Big Bandana Bake in 2018 and raised an incredible £2,500 through bake sales.

Ruston Toms, Founding Director at Blue Apple, first got involved with us in 2015 after his son, Jordan, was diagnosed with a brain tumour while at university. Since then, Blue Apple has become a corporate partner and helped raise money and awareness at every opportunity, including our annual baking bonanza.

Ruston said, "The teams at Blue Apple really got behind Big Bandana Bake and enjoyed getting involved. As the cause is so close to our hearts, we wanted to help bake a difference. We're so pleased and proud to have also become corporate partners so we can raise more funds and awareness."

Scott Northway, part of the Marketing team at Blue Apple, added, "It was a fantastic event for us as a catering company, with our teams putting on an amazing show of baking. It was a great success that touched the hearts of our staff and customers. We heartily recommend getting involved and can't wait to raise (and eat) even more in 2019."

Thank you to everyone at Blue Apple – your support is invaluable to us.



Find out how your company can bake a difference this year on page 18.

Our corporate partners are stepping up to take brain tumours down and we're so grateful for their support. We're proud to announce our new partners are:



A fair chance of survival

The good:

Think pink: A reiteration that 5-ALA (the 'pink drink') will be made available. This is something that, alongside healthcare professionals, we've campaigned for.

Future forward: The NHS will work with the voluntary sector on disease specific apps and will ensure technical barriers don't stop innovation. This is great for the brain tumour community, especially around our BRIAN project (find out more on page 15).

Don't go it alone: All people with cancer, including secondary brain tumours, to get access to a clinical nurse specialist. Find out how we're improving access to CNSs on pages 10-11.



Steven and Katheryn White presenting our petition to Number 10.

On Monday 7 January, the eagerly awaited NHS Long Term Plan (for England) was published after delays due to Brexit negotiations and debates.

For people diagnosed with one of the six less survivable cancers, survival rates are much starker than for many other cancers. As part of our work with the Less Survivable Cancers Taskforce, we've been campaigning for the addition of a survival target in this new plan and improvements for those affected by the less survivable cancers. However, the plan has been met with mixed feelings. Here we give you a run-down of the good and bad.

The bad:

The Less Survivable: We worked with the Less Survivable Cancers Taskforce and members of our community to ask for a survival target. Sadly, this failed to get the dedicated attention so desperately needed to address the stark variation in survival rates.

The dedicated workforce: There's currently no full workforce plan. Without dedicated NHS staff, the NHS Long Term Plan and its commitments can't be implemented.

However, in reply to the NHS Long Term Plan, we make one commitment: to keep fighting for those with a brain tumour to access the NHS's best treatment and care.

Find out more about our involvement with the Less Survivable Cancers Taskforce thebraintumourcharity.org/downing-street and learn more about the NHS Long Term Plan at thebraintumourcharity.org/nhs-long-term-plan



Spotlight on – Hal Cruttenden

Earlier this year, our Young Ambassador, Grace Latter, spoke to celebrity supporter, comedian Hal Cruttenden. Hal shared his experience of his mum's brain tumour diagnosis and why he got involved with us.

"My mum had a glioblastoma and she knew from the word go it was only a matter of time. It's horrendous that this sort of diagnosis can hit anyone out of the blue and at any age. And I now know there are so many symptoms that can affect people.

"My mum never had those symptoms that other people have, such as personality changes. For my mum, it was her speech.

"She increasingly lost her speech as the disease progressed.

"In 2013, while travelling with her friend in India they thought she had a stroke, she couldn't talk. She was stabilised so my older sister and I flew out to get her from the hospital. She was transferred from Jaipur to Delhi, where we met her.

"The doctors in Delhi were brilliant. One doctor said 'I think this is bad and you need to see a specialist when you get back' and he prepared us to face the worst.

"We had time with my mum. She knew she had maybe 12 months, so we managed to do little trips and make the most of being together as a family. She was extraordinary. The only thing we didn't do was see the Northern Lights; you can't guarantee they'll come out. But it was the little things, such as Andy Murray winning Wimbledon (she was a massive tennis fan) that were equally important.

"My mum was very aware of what the diagnosis was and she concentrated on enjoying the time we had together. I'm a very bad example of a mature person and I find that when things happen to me, I panic about the tiniest thing. If the cat brings in a mouse, I fall apart.

"With my mum I felt weirdly positive because she was so strong and so loving. We luckily had that extra time, through the treatment she had, to create some special memories before she died.

"But watching my mum decline and battle so bravely through two operations, radiation and chemotherapy treatments, was obviously tough. For her, on receiving the diagnosis she just said, 'Well, I've had a wonderful life'. It is unimaginable to me how people cope with such news, especially when it's delivered to them when they're a young adult or when it's about their little child.

"That's why The Brain Tumour Charity is so important and inspiring, and why I wholeheartedly support them. Because, together, we have to find a cure for this devastating disease.

"Next year, I'm continuing to tour throughout the UK and will hopefully be starting a podcast – if I can work out the technology behind it. And, fingers crossed, we'll have another Comedy Night in support of The Charity too."

We'd like to say a big thank you to Hal, and all of our celebrity supporters, who raise awareness and funds to help those affected by a brain tumour. We're so grateful! To find out more about Hal and what he's up to visit halcruttenden.com



Pictured: Grace with Hal

A united sea of red

Last autumn a record-breaking number of you across the UK joined The Twilight Walk 2018, our biggest, most inspiring walk ever.

We were overwhelmed and so thankful to see over 5,600 people join us up and down the UK, in Warwick, Edinburgh, Windsor or at their own walk, somewhere special. And we're thrilled to announce that you've raised a phenomenal £500,000, enough to fund over seven-and-a-half years of research.

Thank you to everyone who took part, including our wonderful volunteers. Together, we're moving further, faster, and we couldn't do it without you.



"Holding your own walk with your friends and family brings you together for a common cause. We had so much fun, catching up with old friends and getting to know new ones."

Lynsey Ward, Walker



"Graham and I feel it is so important to be there every year... It is such an important event to so many people."

Berrie Norton, Trustee and Walker

The
**TWILIGHT
WALK**

Where are they now?

Read the promising progress being made by researchers that you've helped us fund.



Revisiting viruses

Professor Susan Short
Leeds Centre for Translational
Neuro-Oncology

Last year we announced Professor Susan Short's research on Reovirus. Now, as part of the five-year research programme, she's also exploring the HSV1716 virus. Like Reovirus, HSV1716 has also been shown to cross the blood-brain barrier to target the tumour, as well as stimulate the immune system to attack it.

Perhaps more remarkably, HSV1716 makes glioblastoma cells more sensitive to radiotherapy, meaning this could be used in combination with standard treatment. We've proudly invested £1.5 million into this novel study.



Inhibiting DIPG

Dr Alex Bullock
University of Oxford

With our £200,000 funding, Dr Alex Bullock's two-year research project aimed to develop a drug to slow down one of the key genetic drivers of diffuse midline glioma (previously DIPG). The driver, a protein called ALK2, encourages the tumour's growth.

Over the last two years, alongside M4K Pharma, Dr Bullock's team have developed and tested over 170 drugs to try and hinder ALK2. The project has found several highly-promising drug molecules and will now collaborate with other labs to test these in pre-clinical models.

SOMETHING'S CHANGING

THE
BRAIN
TUMOUR
CHARITY

We know when someone's diagnosed with a brain tumour, a cure can't wait. We want to accelerate a change in everything we do and engage an even wider community. That's why you'll start to see changes in the way we present and talk about ourselves. Here, we explain why we've refreshed and what it means for our future.

We're picking up the pace

As a charity, we've expanded rapidly in the past few years. Since our merger in 2013, we've doubled our income – this has allowed us to commit more than £20 million to research since 2015, drive down childhood diagnosis times and improve the basic standard of care for those affected. But we want to kick things up a gear. We want to do more and do it faster.

What's changed?

In 2017, we consulted with our community and discovered the way we communicated about ourselves and our impact needed to be clearer and stronger. So we've updated our logo and tagline to stress the pace at which we need to work to achieve our ambitious goals.

You'll see a change in the way we talk and a different look and feel, including in the next *The Grey Matters!* A cure simply can't wait, and we know that the only way to reach one is to accelerate a change in everything we do.

And what hasn't?

What hasn't changed is who we are. We're still the same charity and we still have the same values and goals. We're still committed to doubling survival and halving the harm brain tumours have on quality of life. We're still committed to investing in research, and still aim to spend 80p of every £1 spent on our charitable objectives.

Visit thebraintumourcharity.org/somethings-changing to read more about our refresh and how we went about it.



Fired up for change

On 5 December, we hosted a **Parliamentary reception at the House of Commons to celebrate the progress and accomplishments that have been made in this disease area since the launch of our strategy in 2015.**

The event, kindly hosted by Lord Andrew Adonis and supported by Built Environment Communications Group (BECG), was attended by almost 200 members of our community. The occasion highlighted our united commitment to find a cure and the urgent need for us to keep up the momentum for change to ensure that more people do not suffer unnecessarily.

Lord Adonis opened the proceedings, speaking passionately about his friend, the late Baroness Tessa Jowell. We were also privileged to hear from our Chair of Trustees, Jack Morris CBE, who reiterated our commitment to defeating

brain tumours, and from Dr Colin Watts who emphasised how the Tessa Jowell BRAIN-MATRIX has the opportunity to change the brain cancer landscape. See more on page 6.

There were also fantastic speeches from Sarah Jones MP, our corporate partner, BECG and Jess Mills, who paid an emotional tribute to her mum, Tessa Jowell.

Sharing just how proud she was to be helping to drive her mum's legacy forward, Jess ended her speech with the powerful words "we will continue with fire in our hearts" until we find a cure for this. It is a sentiment reflected throughout our community.

We all know that despite the progress made, there is still so much more to be done to defeat this devastating disease.

And none of us will stop until we have.
A cure can't wait.

Challenges change lives



Could you do more for a cure?

Zoom along the SkyWire zipline

Calling all superheroes! If you've ever wondered how it would feel to fly, now's your chance to find out.

This June, we're offering our supporters a brand new challenge in SkyWire, England's longest and fastest zipline.

Get ready to soar through the air at speeds of up to 60mph, as you enjoy breathtaking views of the Cornish coast and the Eden Project Biomes, 100 metres above the ground.

Whether you're naturally an adrenaline junkie, or just want to do something outside your comfort zone, this thrilling challenge is definitely one that you'll never forget.

Find out more at
[thebraintumourcharity.org/
eden-project-zipline](https://thebraintumourcharity.org/eden-project-zipline)

Trekking for new treatments

"When my husband Matthew was diagnosed with a grade 4 glioblastoma, our world was thrown into turmoil. Yet despite everything, Matthew remained positive. Even through surgery, radiotherapy and chemotherapy, he never complained once. In fact, only hours after his surgery he was joking from his hospital bed.

"But for me it was different. When the person you love most in the world has a brain tumour you feel totally helpless. Watching him go through everything was really hard and I was desperate to help in any way that I could.



"I'd never considered doing a big challenge event before, but Matthew's positive attitude inspired me. I thought if he can go through everything he has without



Hayley and Matthew Smith

moaning, I could do something testing too! So I signed up to take part in The Charity's Sahara Trek 2019.

"Now I'm in training and already feel incredibly daunted by the thought of the sand and the heat. But my hope is that by pushing myself in this way, I'll be able to raise a lot in sponsorship as everyone will know how tough I'll find it.

"Matthew is so mentally strong. If he can go through everything with a smile on his face, I can definitely take on this challenge to help find a cure!"

Find out more about how you can
take on your own challenge at
thebraintumourcharity.org/challenges

Q&A with Lucy Stead

We recently caught up with one of our funded researchers at the University of Leeds, Dr Lucy Stead. She told us about her research into glioblastoma in adults and her walk in Cleckheaton, Yorkshire for The Twilight Walk 2018.

Q. Why did you choose a career researching brain tumours?

I wanted to do something that can have an impact on human health, and most of all I wanted to work on a disease where a difference is sorely needed. When I was younger I watched an episode of ER where a character was diagnosed with incurable brain cancer, and it struck me that no cancer diagnosis should be without hope.

Q. Tell us a bit about your research

I work on adult glioblastomas, which often recur after treatment. We know there must be something about specific cells in these tumours that allows them to survive treatment and regrow. I'm comparing these regrowths with the original tumours – we hope to identify and characterise those treatment-resistant cells so we can find better ways to kill them.



Q. Why is this research so important?

We really need a better understanding of progression following treatment – it's a vital unmet need. The average survival time for someone with a glioblastoma is 15 months, and so many recur after treatment. Our approach could also be used in more advanced models of glioblastoma, for different types of brain tumour and to find out more about why brain tumours form and progress. It could pave the way for new avenues of research.

Q. Tell us about your own walk for The Twilight Walk 2018

I held the walk because I strongly believe research funding will improve patient outcomes for this disease. There's been an historic shortage of funding in this area and, of course, this type of cancer is complex. The walk went really well! What was particularly special was that it united patients, loved ones, researchers and members of the public who were simply willing to give up their Friday evening to raise much-needed funds.

Lucy is also a co-applicant for the Tessa Jowell BRAIN-MATRIX – see pages 6-7 to find out more.



Supporter Groups

Our Supporter Groups are brave and dedicated groups of people who raise money and awareness of brain tumours in the name of a loved one. Their efforts are helping us accelerate a cure.

Welcome to our new Supporter Groups:

Emily Oliver's Fighting Fund

The Addie Brady Foundation

The Catherine Roberts Fund

The Christy Jordan Fund

The Damien Hughes Fund

The Darin Kibria Fund

The Luke Fallon Fund

Find out how you can set up a Supporter Group by visiting thebraintumourcharity.org/supporter-groups



The Khushil Pandya Fund

Namrata and Bhavesh Pandya's son Khushil was diagnosed with a diffuse midline glioma (formerly DIPG) in 2015. They were told his tumour was incurable and that he probably had 6-9 months to live. But Khushil lived for two and a half years, and he lived them to the full, leaving a legacy of positivity that's inspired everyone around him.

Namrata said, "Khushil had a saying for life's surprises: 'So what?' He didn't let things faze him or knock him back. We set up The Khushil Pandya Fund to raise funds for research, make a difference and give some hope to parents. Everyone's helping us raise funds: friends, family, colleagues and Khushil's school."

Last autumn, the Fund united 77 walkers on a memorial walk past Khushil's favourite London sights. In total they raised £3,837. This included a generous donation and matched funding from Namrata's employer, HSBC. Namrata has also written a book about her son – *Perception: Experiencing the Wonders of Life* – which was published on 8 December 2018.

Your letters

We care about what matters to you. Here, we share a selection of your stories and views on how The Charity has impacted your life recently.



"I wanted to say thank you to every single person involved in The Twilight Walk Edinburgh.

The walk itself was tough but I came away feeling empowered and proud. I did the walk on my own, but met a lady also on her own, who had the same tumour type as my daughter.

We ended up walking together and talking through our experiences. The whole day was an amazing experience and it was a beautiful, beautiful event to be part of.

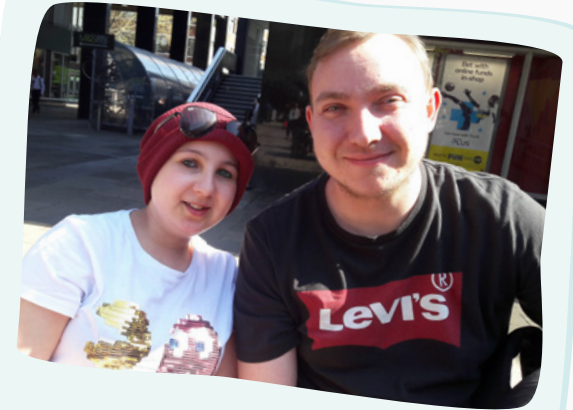
I was so inspired. Thank you!"

Julie Wilkerson

"When I get together with the other Young Ambassadors it feels like a big sigh of relief, everyone gets it and I don't have to explain myself"

Cam Aspery

Cam (right) with fellow Young Ambassador Abigail (left)



"Since my daughter Abbie's diagnosis, our family has made a promise to make amazing memories and to really enjoy each day. The Charity's Christmas Family Day enabled us to do just that. I loved watching my children all playing together in a winter wonderland, sliding around in the snow, throwing snowballs and getting into the Christmas spirit.

We'd have never had an experience like this if it wasn't for The Charity.

Every family in our position deserves to have magical days like this. I can't tell you how much we appreciated ours. Thank you."

Nicola Hodson

Pictured is Abbie with her mum (Nicola), dad, sister Hannah and cousin. This is Abbie's favourite picture from the Family Day.



Thank you to #TheBrainyBunch

A heartfelt thank you to all our inspirational fundraisers across the UK. Here are just a handful of some of the incredible ways you're helping to raise much needed funds and awareness in your local community.

Thank you for
all that you do.

Join #TheBrainyBunch
today: 01252 749043
/ fundraising@
thebraintumourcharity.org



Pete's Little Pink Bike

Pete Williams, 46, completed an epic ride on his daughter Ellie's bicycle in her memory. Ellie lost her life to a rare brain tumour at the age of seven. Inspired by her love of cycling, six-foot Pete rode her little pink bike to raise money for vital research.

Pete started his challenge at Bristol Children's Hospital, where Ellie was treated, and rode through Avon, Somerset, Devon and Cornwall. To date, Pete has raised £57,000!



Daisy's ExPLODition

Daisy Sadler, from Banbury, is finally back home after her mammoth five-month challenge! Her horses, Olive and Arthur, pulled her, Tad the dog and her wagon all the way to the Kelpies in Scotland and then back, raising over £25,000 in support of The Imogen Whitby Fund, a Supporter Group of The Charity.



Paul's Pedal Power

Paul Pegrum, from Gloucester, decided to take on the 1,000-mile cycling challenge from Land's End to John O'Groats in memory of his friend Cai Davies (Welsh Guards, ret'd). Paul cycled through rain, wind and occasional sunshine, raising a fantastic £8,000 while doing so!



Grandma inspires Douglas to shed his locks

The brave Douglas Barr from St Cyrus, Scotland shaved his long locks off in memory of his grandmother, raising £350 for The Charity!



North East Golf Day raises £10,000

In memory of their son Michael, Paul and Mary Almond held the inaugural Michael Almond Golf Day at Bellingham Golf Club in Northumberland. The event was a great success, raising more than £10,000.



Raj Rana Fund smashes £50,000 target

The Berkshire-based Fund celebrated reaching this amazing milestone in October, having started the Fund just six years ago. Their next target... £100,000. There's no stopping the Raj Rana Fund!



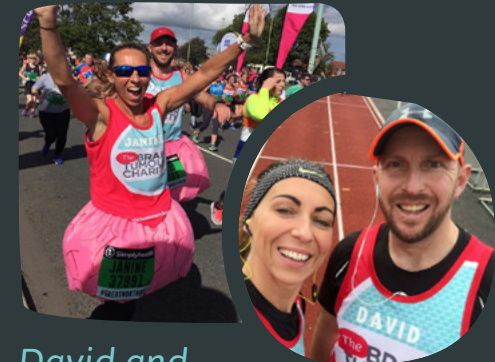
True Scottish team spirit helped raise over £7,000

The team at 1825 Financial Planning in Ayr and Glasgow held a sponsored cycle between Edinburgh and Glasgow in September. They raised an incredible £7,141 thanks to their fundraising and matched funding support of Standard Life.



Sennen voted Spirit FM Young Fundraiser of the Year

Sussex youngster and fundraising superstar, Sennen Calver, aged five, received this fab accolade for the idea of a community Fun Run which raised over £5,000 – and rising!



David and Janine go the extra mile

David and Janine Stewart from Bathgate, Scotland set a 2018 challenge to run a marathon and two half marathons dressed in brain outfits. To date they have raised over £10,000 in memory of a close friend.

How your regular gift can make a lasting difference

Our regular givers Joyce and Dave explain why they donate on a monthly basis to The Charity:

"We lost our lovely son, Steven, to a very difficult-to-treat brain tumour. We met many wonderful young people in a similar situation and realised more focused research into this dreadful condition was needed, as statistics show brain tumours are one of the least-researched of the major, life-threatening cancers.

"After our daughter, Sarah, found The Brain Tumour Charity online, we felt a regular donation would help develop the research structure needed to provide the best chance of achieving results. Every donation, big and small, is important – but regular giving really adds up over time and can help The Charity plan and develop vital long-term research projects to develop successful new treatments for brain tumour patients."



A gift of

£8

per month could pay for a test to help identify personalised treatments for patients.



If you chose to donate

£20

per month, this could pay for a whole day of world-class research every year.

You can set up a Direct Debit today at thebraintumourcharity.org/donate for as little as £2 per month. We rely 100% on voluntary donations, including regular gifts – and these can be made in memory of, or inspired by, a loved one or dedicated to one of our Supporter Groups. Thank you for helping to fund vital, life-saving research.

Thank you!

Thank you.

**A cure can't wait.
Together we can
move further, faster.**

We rely 100% on voluntary donations, including gifts in Wills. If you know someone who would like to support our work, why not give them your copy of this newsletter so that they can see the difference we make.

**Or they can make a donation online:
thebraintumourcharity.org/donate**

If you would like more copies please contact us:
enquiries@thebraintumourcharity.org
01252 749990

For queries about making a donation:
donations@thebraintumourcharity.org
01252 749043

Please send your donations to:
The Brain Tumour Charity
Hartshead House
61-65 Victoria Road
Farnborough
Hampshire GU14 7PA

**THE
BRAIN
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A CURE CAN'T WAIT

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