

The Brain Tumour Charity shining a light on

# The GREY MATTERS

The **BRAIN  
TUMOUR  
CHARITY**

Research | Awareness | Support

Issue 17 Winter 2018

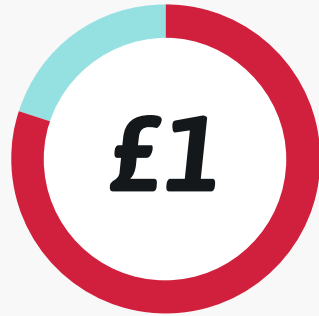
We celebrate YOU in our new exciting awards

Join us for the Big Bandana Bake!



[thebraintumourcharity.org](http://thebraintumourcharity.org)

## How we spend your money



80p of every  
£1 you raise goes  
on our **charitable  
objectives**

20p is spent on  
raising funds for  
**future work** and  
governance



## Thank you!

To everyone who bought or sold our Christmas cards, gifts and decorations, to every volunteer who helped to pick, pack and post them, and all who took part in our Christmas quiz, we would like to say a huge and heartfelt thank you. We couldn't do everything we do without you.

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# Hello

I'm pleased to bring you the first edition of *The Grey Matters* for 2018. I hope you've had a restful Christmas and enjoyed time with your family and friends.

Moving in to the new year, and building on success from 2017, The Charity has some exciting and bold new plans for 2018, including a new programme of free family days, which are a real safe-space for families affected by a brain tumour.

When Ross, my husband and father of our two girls, Brooke and Texas, received his diagnosis, our whole world changed forever. Being diagnosed with a brain tumour is scary, especially when you then hear how little funding goes towards research. But to see first-hand everything The Charity is doing to change this, and the way every supporter is making a difference in their own way, is heart-warming.

In fact, the difference our community makes every day is why The Charity are launching an awards event to recognise outstanding people and celebrate these achievements. The Charity are excited to launch this event later in 2018.

A brain tumour diagnosis has a devastating and lasting impact for those diagnosed, and their family and friends. Everything from health to ability to drive, finances and even relationships are affected by this devastating disease. This just has to change.



Research is hope and the only way to defeat brain tumours. So, I'm excited to don a bandana in March for Brain Tumour Awareness Month and the Big Bandana Bake (pages 18-19). This is one way, together, we can make a difference. If we reach The Charity's goal of raising £150,000, we can fund over two years' of desperately needed research. I know Brooke and Texas will relish getting messy in the kitchen, and for such a worthy cause – and I know I'll relish eating their creations (having made my donation, of course).

I'm eager to see what this year holds, and I am proud to be a part of it.

**Holly Matthews,**  
Actress and Supporter  
of The Brain Tumour Charity

# Our Exciting Year Ahead

Thanks to your overwhelming generosity and support, we've made excellent progress towards our goals of doubling survival and halving the harm that brain tumours have on quality of life. We're determined that 2018 will bring us even closer to a world where brain tumours are defeated.

In 2015, we launched our bold five-year strategy, *Defeating Brain Tumours*. We're thrilled, as we pass the half-way point, to have reached a number of exciting milestones. We've committed almost £16 million towards pioneering research, including the launch of The Everest Centre, and helped drive down the average childhood brain tumour diagnosis time from 13 weeks to 6.5.

However, there's still a lot to do. These are just some of our exciting, ambitious plans for 2018. With your continued support we know we can achieve them.

**Thank you.**

*This year  
we plan to:*



Commit a further **£11.7m**  
into ground-breaking research



Fund our first future  
leader of research  
looking into the causes  
and treatment  
of brain tumours



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



Reduce the number  
of neurosurgical centres  
without access to the  
drug **5-ALA (The pink drink)**



**Develop an adult, early-diagnosis campaign** to reduce the delay in diagnosis



**Launch The Brain Tumour Fund**; the first venture capital fund in the world to focus exclusively on finding new treatments for the disease



**Fund five more CNS** (clinical nurse specialist) posts to improve patient experience and quality of life



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



**More patients** contributing to research

## Our Strategy:



**A cure can't wait:** investing in high quality, forward-thinking, patient-focused research to speed up the time it takes to turn discoveries into treatments.



**Every patient is a research patient:** ensuring every patient can contribute to research and clinical trials, as this gives them faster access to treatments, better care and the opportunity to help defeat this disease.



**Early and accurate diagnosis:** reducing diagnosis times and improving accuracy of diagnoses, so brain tumours are treated earlier, with the best treatment, at the right time.



**Equal access to the best treatment and care:** ensuring every person with a brain tumour has access to high quality treatment, care and information.



**Improving life today for everyone affected by a brain tumour:** providing information and support to help navigate the system and improve quality of life.



**United in our battle to defeat brain tumours:** working as one to make change happen.

**Download a copy of our strategy** [thebraintumourcharity.org/defeatingbraintumours](http://thebraintumourcharity.org/defeatingbraintumours). To find out about ways you can support us, please visit [thebraintumourcharity.org/get-involved](http://thebraintumourcharity.org/get-involved)

# BRIAN: sign up now

*Together, we can transform lives!*

**Anyone with a brain tumour wanting to share their medical records to help make better-informed decisions about their own treatment and care, and help clinicians and scientists accelerate research, will soon be able to. We need to act together to make this happen and we need to act now.**

## What is BRIAN?

We've been working hand-in-hand with people affected by brain tumours to create the 'Brain tumouR Information and Analysis Network', or **BRIAN**, a secure, collaborative, free app designed to help defeat brain tumours. BRIAN will allow those affected to share their medical records, upload information about their quality of life and access information on others' experiences. It will also enable those affected to contribute to vital research, which could help improve survival and quality of life for others.

## Why is BRIAN so important?

Creating BRIAN is a crucial step in our quest to ensure every patient who wants to be able to contribute to research is able to.

By sharing your information with BRIAN, you can help make a difference not only to yours, or your loved one's experience, but to thousands of others.

One of our founders, Neil Dickson, who lost his daughter Samantha to a brain tumour, poignantly described being affected by a brain tumour as: 'being in an exclusive club that nobody wants to be part of'. But, if every single person in that club united and signed up to the platform today, the difference we could make for everyone affected would be huge.

For those with a brain tumour, there is, at present, no way of learning from what others have experienced in terms of their treatment and care. Decisions are often being made without the benefit of balancing potential risks and the impact on quality of life and outcomes. Individuals are also missing out on accessing potentially beneficial clinical trials simply because they're unaware.

Similarly, clinicians are not as equipped to guide patients to make better-informed decisions on their treatment and care due to limited data being available, a difficulty also faced by scientists conducting research. Currently scientists' access to a comprehensive volume of data is challenging and can take years, meaning some research projects don't even get started, delaying vital progress.

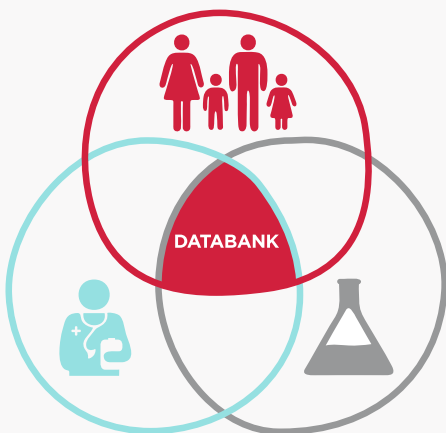
But there is one simple way we can all change this - by telling BRIAN.

## Where will BRIAN store my information?

BRIAN is based around a highly secure database housed in the UK which provides data security in line with industry best practice. Once you've given us your consent, BRIAN will receive a copy of your medical records from the NHS and store them securely alongside your own reported quality of life information.

*"The answers and insights generated by this project will hopefully propel forward our search for new and effective treatments. I believe that it's going to be game-changing."*

**Dr Paul Brennan, senior clinical lecturer in neurosurgery at the University of Edinburgh**



# 97%

of those with a brain tumour said they'd be happy to share their medical data to help accelerate research.

## How do I use BRIAN?

Sharing information with BRIAN will be simple. You'll be able to do it from your phone via an interactive app or on your computer – anywhere, any time.

You'll be able to log in and tell BRIAN about your symptoms and quality of life. This will then contribute to an anonymous report, which can help you and others with a brain tumour make better-informed decisions about treatment plans and also aid future research and clinicians.

We are working hard to develop our databank and aim to launch it in autumn 2018. If you would like to give your consent for BRIAN to access your medical records, and be among the first to join, please fill in our online form (hard copies are also available).

We will then keep you updated on BRIAN's progress.

**Thank you.**

Please sign up online: [bit.ly/joinBRIAN](https://bit.ly/joinBRIAN)



# Exciting new insights from INSTINCT

**In 2014, alongside Children with Cancer UK and Great Ormond Street Hospital, we co-funded INSTINCT, a £4 million research programme, aiming to develop tailored and targeted new treatments for childhood brain tumours, including medulloblastoma and high grade gliomas.**

Nearly three years on, we're delighted to report this prestigious team of talented and dedicated researchers, including Professor Steven Clifford, Professor Chris Jones and Dr Darren Hargrave, are making crucial progress, aiming to treat some of the most lethal childhood brain tumours.

Recently, Professor Clifford has distinguished seven subtypes of medulloblastoma, the most common high grade tumour in children. This type of classification can predict and explain the tumour's response to different treatments. It could be invaluable when planning the best treatments for those diagnosed and help spare children from unnecessary adverse effects of over-treatment.

Meanwhile, researchers at The Institute of Cancer Research, led by Professor Chris Jones, have identified 10 different sub-groups for high grade gliomas in children. These are based on various characteristics such as tumour type, age of diagnosis, location of tumour, and the number of mutations found within the tumour. These findings could not only improve the accuracy of diagnosis, but also identify new treatments.



A donation of  
**£250**  
could fund a day  
of top quality research to  
further the understanding  
of a particular type of  
brain tumour, for more  
targeted treatments.



# Meet the Researcher: Professor Steve Clifford

Principle Investigator of INSTINCT  
Newcastle University



Professor Steve Clifford is a Professor of Molecular Paediatric Oncology and Principal Investigator of INSTINCT - a collaborative, multi-centre research programme, investigating high-risk brain tumours.

Steve explains: "When I first started investigating paediatric brain tumours in 2000, there was no biological understanding of brain tumours. Treatments for medulloblastoma were aggressive and impacted quality of life greatly, and my team consisted of just two researchers. The field was in desperate need of clinical improvements.

Now, almost 20 years on, there are 24 researchers working with me at the Newcastle centre, the molecular study of brain tumours is becoming routine and our new understanding is influencing trials and treatments. Most recently through INSTINCT, we've identified seven sub-types of medulloblastoma, which will help us develop better, kinder treatments for paediatric brain tumours.

In fact, this potential is already being explored in one sub-type - WNT. The identification and understanding of WNT, which we now know is a less aggressive form of medulloblastoma, is enabling us to

test a less aggressive treatment for this tumour type. It means we're a step closer to reducing the damaging after-effects of treatment, improving quality of life.

With the collaboration of three UK research centres - Newcastle University, the Institute of Cancer Research and the University College London Institute of Child Health, INSTINCT is pioneering in its approach to create better, faster results, standing out as a new way of doing things. We're leading the world in molecular diagnostics and, with the support of The Brain Tumour Charity, we want to see every child, no matter what their tumour type, have access to more personalised, less aggressive treatments.

INSTINCT's research on high-risk tumour types, like medulloblastoma, can provide the blueprints for the future and I'm excited to see what that future looks like."

## Gaining a global perspective on research

To accelerate our understanding of brain tumours, collaboration is key. So, we're uniting with medical research charity, Worldwide Cancer Research (WCR), co-funding two global research initiatives to find and develop more effective treatments for brain tumours.



### Paving the way for clinical trials to treat Diffuse Midline Glioma

Professor Adrian Bracken,  
Trinity College, Dublin

Recent pre-clinical research has shown there's potential to treat Diffuse Midline Glioma\* by using drugs to block the activity of a protein called EZH2. However, mutations within EZH2 have led to drug resistance, therefore, Professor Bracken and his team are aiming to find alternative methods to block EZH2's activity. If successful, this exciting work could lay the foundations for clinical trials to treat Diffuse Midline Glioma.



### Developing effective and targeted therapies

Dr Lee Wong,  
Monash University, Australia

This research will explore how mutations in H3.3 (a type of protein) drives a cell to become cancerous in many types of cancers, including brain cancer (gliomas).

Dr Wong and her team are aiming to understand the role of H3.3 and how mutations within it drive tumour growth. They will use stem cells to determine the function of H3.3 and what happens to the stem cells once H3.3 is mutated. This study could help provide a basis to develop effective and targeted therapies for H3.3 in the future.

\*formerly known as Diffuse Intrinsic Pontine Glioma (DIPG)



# Harnessing technology for breakthroughs

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## Creating a drug database

Over 50% of brain tumour patients are diagnosed with a glioblastoma, and sadly these aggressive tumours can be difficult to treat.

So, we've awarded the Dutch/British WINDOW Consortium £1.5 million to explore more effective combination therapies against this tumour type.

Using a computer programme, researchers will predict dual and triple drug combinations, tailoring treatments based on the molecular profile of an individual's tumour. A clinical trial can then be developed to identify if drug combinations are safe, and how much of each drug can be given. Then, this information can be used to develop future clinical trials, with the hope of improving survival rates of people with glioblastoma.

To learn more please visit [thebraintumourcharity.org/awarding-window-consortium](http://thebraintumourcharity.org/awarding-window-consortium) and to find out more about new research please visit [thebraintumourcharity.org/our-research](http://thebraintumourcharity.org/our-research)

## 3D printing progress

In October, we were thrilled to offer Supporter Groups the opportunity to meet Professor Nick Leslie and his team for a lab tour at Heriot-Watt University, Edinburgh.

The team has developed a novel 3D printing technique to print brain tumour cells. Using this impressive technology, the team are able keep cells alive and observe how the cells behave in an environment similar to real-life.

He explained that the speed and scale they can print the 3D tumour cells in should allow faster, more representative ways of testing new drugs to treat brain tumours, speeding up the process by which new drugs become available to patients.

*"Going on a tour like this, seeing the technology first hand and learning from the scientists about this incredible research, left us all feeling incredibly proud that the £50,000 we've raised is helping to fund a project of this calibre. We came away filled with hope and a renewed enthusiasm for our fundraising."*

Amy McLaughlan, Founder  
of The Small but Mighty Fund

# The Graeme Turner Fund

*In 2006, Rachel Cole's brother, Graeme, sadly passed away as a result of his brain tumour. Wanting to make a positive difference, Rachel and her family and friends started The Graeme Turner Fund to raise money for vital research into brain tumours. However, a few years on, the Fund's taken on a whole new meaning for Rachel.*

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**Below, Rachel writes about her experience, from setting up the fund to where she is today.**

"My brother Graeme passed away on 27th October 2006. We were left feeling helpless, wanting to do something to make a positive difference. We wanted to help others going through what we'd gone through, and help create a world where brain tumours are defeated. So, we began thinking about fundraising for The Charity in Graeme's name; and setting up The Graeme Turner Fund was the perfect way to do it.



Me and Graeme in March 2002

After setting up the fund as a memorial to Graeme, we began to plan our first major fundraising event.

In 2004, just six months before his diagnosis, Graeme had climbed Kilimanjaro, which was an amazing feat, but he'd had to turn back before reaching the very top. It was something he'd really wanted to do, so when our friend suggested we climb it and plant the Team Graeme flag at the summit, it was clear what our first fundraising venture would be. I decided to scatter some of his ashes at the summit too, so that Graeme really did make it to the top.

*"Anyone who's seen someone close to them die from a brain tumour would never want anyone else to go through the same. It was important for us all to feel like we were doing something positive, raising money specifically for research into brain tumours and as a memorial to my brother, Graeme. That's why we set up The Graeme Turner Fund."*

**Rachel Cole**

Alongside my Dad and friends, including some who travelled from Australia and Norway, we climbed Kili together, for Graeme and The Charity. The whole trip was unforgettable and incredibly moving. It was a great personal achievement but to do it in Graeme's name, raising money for his fund, made it truly exceptional.

To date, we've raised almost £33,000 through Graeme's fund. It gives us hope that the money raised in his memory is funding research that could find a cure or improve quality of life for those affected by a brain tumour.

Now, I find myself further invested in this hope and The Charity, not only in Graeme's memory, but because of my own brain tumour diagnosis. It feels strange, to say the least, but I think it's reminded everyone why we set up the Fund – to make a difference and help stop this devastating disease.

Graeme's last birthday party in July 2006



Me and my Dad on our way up Kili

Since my diagnosis, the love and support I've received from every area of my life has been overwhelming. I felt helpless during my brother's illness and channelled a lot of that into raising money. I feel humbled that others are doing the same for me by donating to the fund. I am pleased to be here to thank them. But Graeme will always be the team captain.

Their ongoing support and fundraising means we can get a step closer to a cure. It gives me so much hope for the future."

**Rachel writes a blog of her life, from illness-driven posts to bits of trivia, current activities and cherished moments with her friends and family. To read more from Rachel visit [rachelcole226.wordpress.com](http://rachelcole226.wordpress.com)**

# Working out work, together.

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*We know that a brain tumour diagnosis not only affects health, but can impact every aspect of yours and your loved one's life, including employment.*

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From our *Losing Myself* research, we discovered that three in four people with a brain tumour have had their, or their partner's, working life affected. Many people change jobs, reduce their hours or duties, and 28% stop work entirely. As a result, financial difficulties are common, and some people feel a loss of identity and purpose. Having to look into your employment rights and options, during an already difficult time, can feel stressful and overwhelming.

That's why we've developed easy to understand employment resources for you. These can be used with your prospective or current employer to help develop the support you need so you can remain in, return to, or find new work.

Our resources include information on how to tell your employer, should you choose to, about your, or your loved one's, diagnosis, a list of reasonable adjustments you could ask your employer to make, a 'charter' of employment rights for people with, or caring for someone with, a brain tumour and advice for employers themselves.

We believe everyone affected by a brain tumour should have access to resources they need, when they need them, and we're determined to make this happen.

To view or download the resources, please visit [thebraintumourcharity.org/employment-support](http://thebraintumourcharity.org/employment-support)

## Let us support you

A brain tumour diagnosis poses many questions, but it can be difficult to know exactly what to ask and what support you need.

With us, you don't have to know what you're looking for to get in touch. Whether you need a listening ear, or reliable information and advice, together, we can explore various options to help you. We offer free, specialised services which includes our information pack, benefits clinic, Information Days, Family Days and online communities.

Whatever you're going through, whatever you need – we're here to ensure everyone can access the right support.

*"It's easier to talk to you than other people sometimes, I feel safe coming to you, not embarrassed. During difficult times, knowing I can ring up and speak to someone has been a lifeline. It's provided my children with reassurance also, knowing I have somewhere I can turn instead of trying to cope alone. The Charity has truly been a rock for me."*

**Fiona, Information and Support Line user**



### Information and Support

0808 800 0004 (Mon-Fri, 9.00am - 5.00pm)  
[support@thebraintumourcharity.org](mailto:support@thebraintumourcharity.org)



### Online chat service

To start a chat go to  
[thebraintumourcharity.org/live-chat](https://thebraintumourcharity.org/live-chat)  
and click on the 'Can we help?' button  
in the bottom right of the page  
between Monday to Friday.



### Research and clinical trials

01252 749 999 (Mon-Fri, 9.00am - 5.00pm)  
[clinicaltrials@thebraintumourcharity.org](mailto:clinicaltrials@thebraintumourcharity.org)



### Benefits clinic

0808 800 0004 (Tues 9.30am - 4.00pm)



### Online communities

[thebraintumourcharity.org/facebookgroups](https://thebraintumourcharity.org/facebookgroups)

Download our information pack at:  
[thebraintumourcharity.org/information-pack](https://thebraintumourcharity.org/information-pack)

For more information on the wide range of support services that we offer, including Information and Family Days, our Children and Families Service, Young Adults Service and clinical trials, please visit  
[thebraintumourcharity.org/get-support](https://thebraintumourcharity.org/get-support)





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On Friday 1 September, there was great excitement and celebration at The Charity as The Saturdays' singer, Rochelle Humes, visited our offices to surprise us with the wonderful news that our HeadSmart campaign had won the National Lottery Good Causes Best Health Project award.

Beating 1,300 entries to win the award, HeadSmart was voted the UK's favourite National Lottery funded health project. We won £5,000 and an iconic National Lottery trophy, which was presented to two of our founders, Neil and Angela Dickson, during a special awards ceremony, aired on BBC One.

Backing the campaign, Luke (10), and his family, told Rochelle how HeadSmart's website had helped him get an early diagnosis and saved his life. His mother Fay said: "We can't thank HeadSmart enough – without it our son may not have been here today."

Since it launched, HeadSmart has helped reduce childhood brain tumour diagnosis times from over 13 weeks to 6.5, but more needs to be done.

We're determined to continue increasing vital awareness of the signs and symptoms of childhood brain tumours and this recognition greatly helps. To everyone who voted – thank you!



## *"That tiny card saved my boy's life!"*

**Rosalind explains: "My son, Daniel, was a mischievous, happy three-year-old, so when he became grumpy, throwing tantrums, at first I put it down to the toddler phase. But I noticed Daniel was increasingly lethargic and started falling over a lot. He was also being sick and when he woke up with a headache one morning, alarm bells started to ring.**

A few months earlier, I'd been on Facebook and came across a HeadSmart card a friend posted, which listed the symptoms of childhood brain tumours including vomiting, lethargy and losing balance. Suddenly the symptoms flashed into my mind - they matched Daniel's exactly.

I took Daniel to see a GP. At first he was diagnosed with hayfever, but when the antihistamines didn't work and he started getting worse, I trusted my instincts and took him to A&E. That afternoon, he had an MRI scan and the consultant confirmed our worst fears - Daniel had a brain tumour, the size of an adult fist.

The next morning, Daniel had a nine-hour operation to remove the low grade tumour. It seemed like an eternity. We veered between fear he wouldn't make it and that, if he did, the Daniel who woke up wouldn't be the Daniel we knew.

At last, we got the call to say he was in recovery. As we walked into the room, he was yelling at the top of his voice: "Get off me!" and relief flooded through me. That's my cheeky, bossy boy! Daniel was in intensive care for four days and back home just 10 days after his diagnosis.

Daniel is now doing well and has scans every six months. I'm so grateful to HeadSmart, without the signs and symptoms card, I wouldn't have recognised his symptoms as they can be easily confused with other things. I want to see physical versions of the HeadSmart symptoms card distributed to every school to help make others aware. I truly believe that tiny card helped save Daniel's life, and I know it will save others."

To share the HeadSmart symptoms, please go to [headsmart.org.uk](https://headsmart.org.uk)



Daniel after getting the all clear from Alder Hay Hospital

# Big BANDANA BAKE

*Take cover... this could get messy!*

*This March, we'll be kicking off Brain Tumour Awareness Month by baking a difference for everyone affected by brain tumours - with our first ever Big Bandana Bake. And we want you, and your friends, family and colleagues, to join us!*

By donning a bandana, getting messy in the kitchen and holding bake sales, you'll be joining hundreds of bakers across the country to raise vital funds so, together, we can defeat brain tumours.



We know the only way to defeat this devastating disease is to go big. And when we say big, we mean BIG! This March, we want to raise £150,000. Why? Because less than 2% research funding for cancer in the UK is spent on research into brain tumours. Because we know that for the 11,000 people diagnosed each year, and their family and friends, this isn't good enough. Because £150,000 will fund a life-saving research project for over two years, and only by investing in world-class research, can we discover better diagnostic techniques, develop new treatments and, ultimately, find a cure.

It's a big goal, but we know, together, we can rise to the challenge and reach this target. So, whether you're a bona fide baking champion or a complete bake-o-phobe, we need you to bandana up and bake, because with every cake you bake, and every penny you raise, you help us get closer to a cure.



Yum!

Sign up today by visiting [thebraintumourcharity.org/bigbandanabake](http://thebraintumourcharity.org/bigbandanabake) and receive your free fundraising pack. It's filled with everything you need to make your Big Bandana Bake a big success - from a handy guide and recipes, to cake flags and a banner for your event. And don't forget to order your bandana from [thebraintumourcharity.org/bandana2018](http://thebraintumourcharity.org/bandana2018) too!

So join us this March, and get a slice of the action!

# CELEBRATING YOU



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*We're proud of everything we've achieved in the past few years. We've helped halve the time taken, on average, to diagnose children with brain tumours, funded a new £5 million centre for research into paediatric brain tumours, and launched services to support families at every step.*

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However, all this would not have been possible without you. Much like a chemical reaction, every element of what we all do comes together to create something even more amazing than our separate parts. Without even one of these elements, no matter how big or small, this reaction simply does not work.

And that is exactly why we've created The Brain Tumour Charity Awards: Celebrating You. We want to celebrate you and your involvement in all the work we do, because we need each and every one of you; all kinds of people, who do all kinds of things, in all kinds of places, united for one cause. And we'd like to thank you for that, your contribution really does make an impact.



Thank you to everyone who nominated someone for an award, we received over 100 nominations, which is wonderful, and it was truly humbling to read all the stories of people who have gone above and beyond to help defeat brain tumours.

Everyone shortlisted will be invited to our celebratory event in April 2018, which is sure to be a particularly memorable night, filled with great chemistry. We'll also be celebrating everyone who was nominated with a special thanks – whether you win or not, you're still vital to what we do.

We'll be sharing some of the incredible stories soon, so keep your eyes peeled and get ready to vote for your winners.

Coming up, is the tricky part – choosing the winners! We'd like you to help by voting for your winner in the following categories:

*The Viv McBeth  
Award for Fundraiser  
of the Year*

*The Award for  
Special Recognition*

*The Volunteer  
of the Year Award*

*The Influencer  
of the Year Award*

We'll be telling you how you can vote soon. But, for the meantime, find out more about the awards here [thebraintumourcharity.org/celebrating-you-awards/](http://thebraintumourcharity.org/celebrating-you-awards/)



# Our passionate fight for 5-ALA!


Time and again we see access to the best treatments being determined by where a person lives, not by what's right for them; and we're committed to changing that.

One clear example is 5-ALA. Also known as 'the pink drink', 5-ALA is a drug given to high grade glioma patients, which makes their tumour cells glow pink during surgery. This means the surgeon can see the tumour more clearly and remove it more accurately, reducing risks to healthy brain tissue.

Removal of as much of the tumour as possible is the only factor surgeons can influence for better survival. Studies show that 5-ALA allows increased removal of tumour tissue, lengthening the time the disease does not get worse.

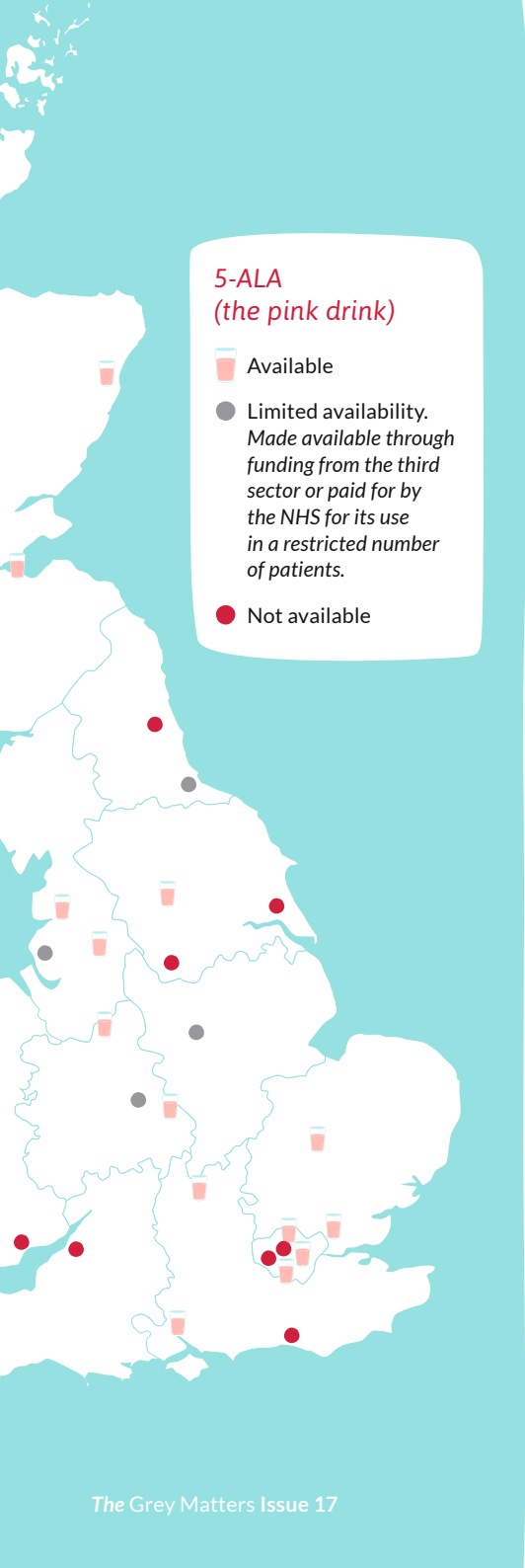
Currently, almost half of UK neurosurgery centres have either limited or no access to 5-ALA and we want this changed.

By delivering and implementing a targeted campaign, raising awareness of the inequality, and providing Trusts with the evidence for its use, we want to reduce the number of neurosurgical centres without access by 30% by March 2018.



Just under half of neurosurgical centres have limited or no access to 5-ALA.





## To achieve this, we've:

- 1** Been speaking with neurosurgeons to understand barriers to accessing 5-ALA, and liaising with health charities to find ways we can overcome these.
- 2** Sent every neurosurgical centre in the UK a Freedom of Information (FOI) request regarding access for their patients.
- 3** Written to the Secretary of State for Health, with endorsement from the neurosurgical community, to ask for solutions.
- 4** Begun to engage with the drug's developers to facilitate its entry onto schemes aimed at improving NHS access to innovative technologies.
- 5** Been working with NHS authorities in Wales to build evidence for 5-ALA and highlighted the inequality at a national level (Scotland and Northern Ireland have full access. Patients in North Wales can access the drug as part of their treatment in England).
- 6** Launched a petition asking you to back this campaign so we can bring this vital issue to the attention of the UK Government.

To read more, please go to  
[thebraintumourcharity.org/  
equal-access/](https://thebraintumourcharity.org/equal-access/)

# Getting back on the road

**Three in four people affected by a brain tumour will lose their driving license at some point. It can leave you feeling like you've lost your independence. However, for many this is not a life-long restriction and there are things you can do to speed up the process so you aren't off the road for longer than necessary.**

One problem we often hear of is the long waiting times to get a license reissued once your medical team have declared you fit to drive again. The DVLA have a duty to protect the driver and other roads users, however having to wait to get your licence back can feel incredibly frustrating and confusing. To help, we have created a step-by-step guide to help you speed up the process and gain some control over your situation.

## *Step 1. Surrender your license voluntarily*

It may be the case, after being diagnosed with a brain tumour, that you'll have a 'no drive period' put in place. This can come as a shock, however, if you choose to voluntarily surrender your license when you are first diagnosed, you will know exactly when you'll be unable to drive, can make arrangements before surrendering, and, further down the line, it will be easier for you to get back on the road once your medical team has deemed you fit to drive again.

## *Step 2. Reapply eight weeks early*

The DVLA deal with over 700,000 medical notifications and renewals each year, which involves a number of steps to ensure safety for all involved. As a result, it can take some time to get your license back. However, as long as your medical team have declared you fit to drive, you can reapply for your license eight weeks before your original 'no drive period' is due to end. This will help you get the ball rolling sooner and get you back on the road as quickly as possible once your 'no drive period' is over.



### Step 3. Section 88

By voluntarily surrendering your license, being certified fit to drive and sending your application eight weeks early, you may now be able to get back on the road under Section 88 of the Road Traffic Act 1988. As you voluntarily surrendered your license, if your medical team supports you are fit to drive and the DVLA has notified you that they've received your application, you may well be able to drive legally\*, while the DVLA process your application, without a physical license, weeks or even months before you would have, if you hadn't followed these steps.

*\*To check you qualify for Section 88 please read the full terms and conditions.*

**If you need any more guidance surrounding the DVLA and reapplying for your licence, please contact our helpful Information and Support team on 0808 800 0004 - or by using our free Live Chat service on our website [thebraintumourcharity.org/get-support](https://thebraintumourcharity.org/get-support).**



## Supporting you both

**When our recent report, *Losing Myself*, highlighted that two in three people experience relationship problems as a result of their brain tumour diagnosis, we were compelled to do something about it.**

We commissioned a report aiming to discover why this is the case and ways to improve this isolating issue, with real-life couples and experts helping shape the report.

From this, we discovered there is a clear gap in information available to support those affected by a brain tumour and their partner during this difficult time. So, as part of our strategy this year, we want to build on this report and help close this gap.

We'd love to hear your thoughts on how you'd like this service to look, including suggestions of support or resources you'd like to see. You can get in touch via our Information and Support line - 0808 800 0004 - or by using our free Live Chat service on our website [thebraintumourcharity.org/get-support](https://thebraintumourcharity.org/get-support).

In the meantime, if you need to chat, or have a question, our friendly Information and Support team are here to help, so please get in touch.

## Going above and beyond!

### *In training for the second ascent!*

Once again, our amazing trustee, Rob Ritchie, is preparing to ascend 8,484 metres (the height of Everest) in the Swiss Alps, on skis, to raise funds for pioneering research into paediatric brain tumours.

Rob and his wife, Tanya, whose son Toby was diagnosed with a brain tumour aged five, will be joined by 30 others covering four days of gruelling terrain. This extraordinary challenge, 'Everest in the Alps: the second ascent' is looking to raise £350,000 for The Everest Centre for Research into Paediatric Low Grade Brain Tumours.

The six teams involved recently attended a training session at the Lomax Gym in the City, where top endurance trainer, Becky Scott, put them through their paces to help prepare them for this inspiring challenge, which will test their fitness and endurance to the max.

We are incredibly proud of them and wish everyone the best of luck.



*"Like many children with a brain tumour, my son, Toby, faces his personal 'Everest' every day; getting dressed, moving around school, fighting fatigue and trying to live the life of a normal school boy. If he can do all that with a smile on his face, I am determined to do this for him."*

**Tanya Ritchie, Toby's mum and part of the all-female Everest team, Toby's Team.**

**If you'd like to help the 'Everest in the Alps: the second ascent' teams reach their target by donating to their JustGiving pages, please go to [thebraintumourcharity.org/everestinthelaps](https://thebraintumourcharity.org/everestinthelaps)**



## Headwest

**Former England Rugby Captain and founder of The Lewis Moody Foundation, Lewis Moody, adventurer Alan Chambers MBE and superyacht challenger brand Y.CO are back for part three of their global trek.**

Aiming to raise vital funds for our HeadSmart campaign, raising awareness of the signs and symptoms of a brain tumour in children and teenagers, the group is traversing the most challenging terrains across the globe.

The team has already raised over £275,000 tackling arduous journeys to the North Pole for Headnorth in 2015, and through Vietnam and Cambodia for Headeast in 2016. Now, for this year, the team have travelled west for, you guessed it, Headwest.

The team are now home after an emotional and challenging journey, but are proud to announce that they have smashed their original target, and have raised over £100,000 so far.



## Looking for a life-saving adventure?

**Join us in July 2018 as we trek up Mount Snowden, the highest peak in Wales (1085m), at dusk, to see breath-taking views over Snowdonia. Then, watch the sun set on the summit, before heading down with us into the picturesque village of Llanberis to enjoy a celebratory breakfast.**

Led and accompanied by fully qualified and experienced mountain guides, this challenge is ideal for beginners with a good level of fitness and walkers looking to experience their first night-time mountain walk. Every £1 raised on this incredible challenge will help us fund life-saving research.

**To take part or to find out more, please visit [thebraintumourcharity.org/snowdonbynight](http://thebraintumourcharity.org/snowdonbynight)**

# Uniting for a fairer future

## Q&A with Ed Bartlam

Co-Founder and Director of Underbelly



Our partners are so important to us – every day their dedicated support helps us get closer to a world where brain tumours are defeated. We're immensely grateful to them all.

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### **How did you first become involved with The Charity?**

My son, Alfie, was diagnosed with an anaplastic ependymoma, aged four. It was a terrifying time and I was shocked to discover how crippling underfunded research into brain tumours is. Following Alfie's treatment, I wanted to help change this, so I did some research and, following a recommendation from Dr Antony Michalski, a paediatric oncologist at GOSH, I got in touch with The Brain Tumour Charity.

### **Why did you choose us?**

I was really impressed with the scope of research The Charity invests in, and their collaborative approach to achieve results more quickly. They allowed us to choose which area of research we wanted to support and knowing they donate 80p of every £1 raised towards charitable objectives was so reassuring.

### **What has it meant to your organisation to be involved with us?**

My team and I work closely, so when Alfie was diagnosed, everyone was affected. So, when we organised The Big Brain Benefit everyone pulled together. Having such an important cause linked with our work has got the whole team enthused, everyone wants to help and do more.

### **What would you say to other companies considering a partnership with The Charity?**

The Charity's been dedicated, engaging and efficient to work with. Any company considering getting involved, should do so and ask for a meeting. I've been so impressed with how they work with us so closely, enabling us to make a positive difference and I'm looking forward to continuing to work with them.

Find out more about getting your company involved here [thebraintumourcharity.org/how-your-company-can-help](https://thebraintumourcharity.org/how-your-company-can-help)

## Susannah's shining legacy

Since setting up The Susannah Lees Fund, Carrie and her family have raised over £16,000 to help fund vital research to find a cure for brain tumours. The family were very grateful to receive a generous gift in a Will from their neighbour, Mick, recently, supporting their fund's meaningful work.

Often, it's the little things that mean the most. In fact, leaving just 1% of your Will to us, or a supporter group, could make a world of difference. By including a gift of any size, your generosity can offer hope for the future and have an impact for generations to come. Thank you.



Carrie Lees, who lost her daughter, Susannah, to a brain tumour in 2006.

Carrie said, "Being the first Supporter Group to receive a gift in a Will feels very special and touching. My daughter, Kate, and I both shed tears. Mick was our neighbour for many years and was moved by Susannah's illness. I believe gifts in Wills are incredibly important, helping ensure The Charity's vital work can continue in the future. When I remade my Will after Susannah died, I made sure I named The Charity to receive a gift. Susannah had an open, joyous personality that embraced all people and experiences. She was the sort of person who could light up a room. I hope, by leaving a gift, her legacy will shine on."

If you would like to dedicate a gift in your Will as a tribute to a loved one or to one of our Supporter Groups, please request a free information pack, [at thebraintumourcharity.org/littlethings](http://thebraintumourcharity.org/littlethings)

Over 1/4 of all our research is funded through gifts in Wills.





## Our biggest, most beautiful walk yet

In October, over 3,200 of our passionate community united at Chester, Warwick, Windsor, and their own walks, to make The Twilight Walk 2017 our biggest, most inspiring yet. It saw thousands affected by a brain tumour unite to make a lasting difference, share stories and celebrate the lives of loved ones.

The atmosphere was brimming with hope and determination and, together, you've raised a fantastic £300,000. Thank you to every person who took part including our amazing volunteers; every step you took and penny you raised brings us closer to a cure.

*"Living with a brain tumour is life-changing. Yet, with support from friends, family and The Brain Tumour Charity, I feel determined, strong and loved. The Twilight Walk is the perfect opportunity to take these feelings and do something positive and I believe life can and will be better for people with brain tumours thanks to The Charity's work; as the song goes, 'walk on with hope in your heart'."*

**Louise Smith, supporter of The Charity, who was diagnosed with a brain tumour last year.**



**Already looking forward to The Twilight Walk 2018? you can express early interest here: [thebraintumourcharity.org/thetwilightwalk](http://thebraintumourcharity.org/thetwilightwalk)**



# MAKE YOUR NEXT BIRTHDAY

## life-changing

Make your next birthday life-changing for people affected by a brain tumour. Join the #TheBrainyBunch Birthday Pledge.

### It's a piece of cake

In a world filled with material things, why not do something life-changing this birthday instead? Ask friends, family and colleagues to donate to The Brain Tumour Charity rather than buy cards and gifts. And you could even host a party to fundraise too!

Every penny you raise will help change the lives of people living with a brain tumour, and their families - whether that's through vital support, ground-breaking research, or by raising awareness.

Did you know, £250 could pay for one day of top quality research exploring kinder and more targeted treatments to improve survival and quality of life for someone diagnosed with a brain tumour.

It's super simple to sign up – complete #TheBrainyBunch pledge form and we'll be in touch to help you spread the word about your extra special day.



*"I pledged my birthday because, since joining as a Young Ambassador, I've seen the impact every pound makes. Making a birthday pledge is a creative and amazing way to remember those fighting brain tumours or no longer with us. Please pledge your birthday and together we can defeat brain tumours!"*

Chandos, a Young  
Ambassador Mentor.

### Sign up today

Visit [thebraintumourcharity.org/birthdaypledge](https://thebraintumourcharity.org/birthdaypledge)

# 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.*



## Touching lives at The Twilight Walk

What a day! This was my fourth The Twilight Walk experience; my husband Graham and I have walked it, registered it and now route stewarded it, and every experience has been special for different reasons.

You thought of every detail, for example, the big sign saying, 'Want to walk in a group? Meet here!' If I had turned up on my own, I would immediately have felt cared for and included. Nobody is neglected and nobody is overlooked. Those small things become the big things, and sum up why The Brain Tumour Charity does things better than a lot of other, similar charities. I loved meeting the researchers, the carers and all the incredible people in our community, hearing their stories and sharing ours.

Graham and I come not because we are Trustees (although we are inordinately proud of that role), we come for the same reason as the other walkers, because our son died and we're honouring our promise to him - to go on helping him to make a difference, in death as in life. We come because we are still hurting, wanting to know someone's out there, fighting our son's corner for all the others just like him. I think today your team proved that you are. Thank you.

**Berendina and Graham Norton, Trustees.**

## *"We finally spoke about the dark days after six years"*

Thank you to the whole team for putting on such a valuable and interesting Paediatric Information Day on 1 October. The day was eye-opening and afterwards, for the first time in six years since my daughter, Ava, was diagnosed and treated for her brain tumour, my husband and I were able to talk about those dark days together.

The event forced us to think about it all and that was a really positive thing. To be able to voice words and feelings that have been locked up for so long was a massive step and I think that was all down to the day. I'm so glad we attended.

**The Vacalopoulos family**



## *"I met people who really understood my experience"*

In 2016, I was diagnosed with an ependymoma and flew to Florida for proton beam therapy, and had to take time out of education, which was quite isolating.

Last September, I signed up to attend The Charity's first Young Adult Big Meet. A month before, a Young Adults' Facebook group had been set up with messages going around which made me feel less alone, but when the day arrived I was still nervous. I didn't think I'd know anyone and was worried about getting tired, but those feelings disappeared quickly.

I soon realised I recognised people from the Facebook group and as we started doing activities like archery, climbing and a massive crate stack challenge we all got talking, sharing our experiences and getting to know each other. It was really nice meeting others in the same position and talking about what we'd experienced, with everyone understanding. I even met a girl who'd received proton beam therapy too!

I got so much out of the day and will definitely be going again in future. To anyone reading this, thinking about going, I hope to see you there!

**Molly Howarth, Young Adults Big Meet Attendee**



# 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 are helping to raise much needed funds and awareness in your local community.*

*As always,  
thank you for  
all that you do.*

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



Captain Tom Roach and his team of 15 soldiers from 221 Field Squadron, EOD (Explosive Ordnance Disposal) took on the gruelling challenge of completing 24 marathons in 24 hours raising a staggering £5,258.



With the help of friends and local artists, the extremely talented singer/songwriter Dee Hepburn held an afternoon of music at the beautiful Friern Manor raising over £3,000.



Staff at St George's C of E Infant School, completed a sponsored 10 mile walk in support of a colleague who is currently undergoing treatment. The pupils also participated in a fun run raising a fantastic £3,380!



Alasdair decided to pledge his birthday this year, asking friends and family for donations rather than presents. He also took on a 10k walk with his family and raised over £400!



Rhos United under-11's football team have raised £2,861 by holding a bag pack and climbing Snowdon, in support of Leo's Mum, Jo, who died from a brain tumour in September 2017.



Not many people can say they've had a huge party to celebrate their birthday attended by hundreds of people with Princesses, Magician, Face painter, Balloon modeller, DJ, Glitter tattoos, Bouncy castle, BBQ, Hog roast, Cake, Sweets, Games...but Jessica had two! Jessica's family held the incredible events to celebrate what would have been her 10th birthday and have to date, raised over £78,000.



Nico, Monty, Will and Jacob took on a huge bike ride from London to Land's End, covering hundreds of miles in memory of Nico's father, Julian, and inspired by Monty's Dad, Chris, who's living with a brain tumour. The bike ride has raised almost £60,000.



Keepmoat Homes in East Midlands raised an amazing £5,500 from their summer ball in memory of their dear colleague, Louise Thompson, who sadly lost her life to a brain tumour in April.



Louis's mum (Susan), dad (John) and sister (Charlotte), held their annual garden party and have raised an amazing £20,000 for The Louis Dighton Fund.



Rachel and John Waters organised a dinner with sports personalities such as Neil Back and Martin Johnson, after John was diagnosed with a brain tumour. Rachel and family raised over £11,000 in 2017.



Supporter Group Warriors from the North East, Angela Conway and Natalie Sweeney, held various events, including a fantastic race day and a tea party, raising over £3,750.



Juliette Denny and team, challenged themselves to run 100 miles in three days along The South Downs Way as well as hosting a five-a-side football tournament. They have raised an amazing £11,000 for The Charity.



# Thank you for all you do.

## Together we can defeat brain tumours.

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](http://thebraintumourcharity.org/donate)***

*If you would like more copies please contact us:*

[enquiries@thebraintumourcharity.org](mailto:enquiries@thebraintumourcharity.org)  
01252 749990

*For queries about making a donation:*

[donations@thebraintumourcharity.org](mailto:donations@thebraintumourcharity.org)  
01252 749043

*Please send your donations to:*

The Brain Tumour Charity  
Hartshead House  
61-65 Victoria Road  
Farnborough  
Hampshire GU14 7PA



**Research | Awareness | Support**



## 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 focussed 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](https://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!