

The Brain Tumour Charity shining a light on

# The GREY MATTERS

The **BRAIN TUMOUR CHARITY**

Research | Awareness | Support

Issue 18 Summer 2018



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



## Our Research Impact

A cure can't wait. That's why, alongside our support services, we fund pioneering research in the UK and around the world.

In 2015, we set an ambitious goal: commit £20 million to research by 2020. We're proud that, to date, we've now committed £20.2 million. But, we believe the sky's the limit of what can be achieved. So, we can't stop now. Thank you to all our supporters – you have been instrumental in this – but let's keep going and keep getting closer to a cure.

Discover our research revolution  
[thebraintumourcharity.org/  
 the-research-impact-report](http://thebraintumourcharity.org/the-research-impact-report)

## Research we fund



Since 2015, we've funded 13 international research projects and 26 right here in the UK.

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Steve Pollard, Professor of Stem Cell and Cancer Biology

# Hello

Recently, I've heard my colleagues claim we're 'on the edge of a breakthrough', so to kick off issue 18 of *The Grey Matters*, I'd like to share what this means to me.

Over the last five to 10 years, we've seen real and tangible progress. We can now grow cells in the lab more easily, enabling us to continually test new theories and search for new treatments.

As our understanding, funding and tools to improve science develop, it's becoming easier to undertake research that would have been unachievable even five years ago. For me, as a scientist, this is so exciting, because it means we can carry out research that applies to real-life patients and do so faster and more easily.

One of the things I'm interested in is how the brain keeps many tumour cells 'sleeping', preventing the tumour from growing too rapidly and how we could use this to effectively 'put to sleep' the entire tumour, indefinitely.

All this progress is driving a real 'sky's the limit' approach, with real opportunities to make discoveries, and so much to be optimistic about, but we still need to put in more time and money. That's why your donations make a difference; to The Charity, to researchers like me, and most importantly, to those affected by a brain tumour. So let's not stop now, please help push us over the edge.

**Steve Pollard**  
 Professor of Stem Cell and Cancer Biology,  
 University of Edinburgh.

# Actions not words

The first half of 2018 has seen major developments in the battle to defeat brain tumours.

**Inspired by Baroness Tessa Jowell – who began lobbying for change after her own diagnosis – the brain tumour community has come together in force to do even more to help end this terrible disease.**

In February, a landmark summit on brain tumours promised to focus on innovations and clinical trials; paediatric brain tumours; and patient care and experience (the area which we are leading on with NHS England).

This was followed by a debate in the House of Commons in April, calling for greater sharing of health data and more adaptive clinical trials to improve outcomes for brain tumour patients.

We have also seen the launch of the Universal Cancer Databank (UCD) project by the Eliminate Cancer Initiative, with whom we have been working closely on a variety of initiatives.

We're also delighted that our own databank – BRIAN (the **B**rain tumou**R** **I**nformation and **A**nalysis **N**etwork) – which we're building with the help of our own community (page 18), will play a key role in the development of the UCD.

Baroness Jowell said: "It is my hope that through my cancer journey and sharing of my data, we will be able to develop better treatments for cancer and speed up the discovery of new ones."

Tessa Jowell with Sarah Lindsell and MP, Sarah Jones



## What's been agreed so far?

As a result, Public Health England has agreed to work alongside us to make progress in the following areas:

### Early diagnosis:

The Brain Tumour Charity will launch a national campaign, which will help deliver faster diagnosis times in both adults and children, targeting healthcare professionals and the public.

### Patient experience:

The Brain Tumour Charity will work with all neurosurgical centres in the UK to share best practice in brain tumour treatment and care, prioritising the 'Integrated Sub-specialist Multi-disciplinary Neuro-oncology Service' – commonly known as the Cambridge Model – by December 2019.

### Accelerating research:

Public Health England will work with all brain tumour charities to improve access to data for the purposes of research.

NHS England will explore the opportunity for patients with brain tumours to participate in novel trial methodologies.

They will also promote methods which ensure research tissue is managed to the highest standards; this includes snap freezing samples.

### Precision treatment:

NHS England will roll out 5-ALA (or 'the pink drink') nationally to improve precision surgery for high grade glioma patients, making it universally available for all eligible patients by end of July 2018. We've been lobbying for equal access to 5-ALA for many years, so are proud to see this is now a main priority for NHS England.

### Quality of life:

NHS England will include those who have been treated for a brain tumour in the roll out of the 'Cancer Quality of Life Metric', currently being developed, to improve our understanding of their quality of life outcomes.

We'll continue to work with key influencers, with whom we've built strong relationships, to ensure this momentum's maintained. #CloserToACure

Find out more about all the outcomes and developments [thebraintumourcharity.org/global-cancer-databank](http://thebraintumourcharity.org/global-cancer-databank)

Tessa Jowell with her daughter Jess and granddaughter



## Asking the right questions

A brain tumour diagnosis is overwhelming and sparks many questions – but knowing how to ask them and whether you've covered everything can be difficult. Neuro-Oncology Nurse at Addenbrooke's, Ingela Oberg, shares the top questions you could ask.

### *If my child has a brain tumour when should I inform their school?*

The earlier the better when it comes to informing your child's school, but should you need guidance on how to tell them, your GP or neuro-oncologist can help you with this.

### *Can I go on an airplane after surgery?*

No, not for six weeks. The change in pressure and oxygen levels pose a risk to your health and can cause a seizure. Speak to your medical team to find out when you could be allowed to fly again.

### *Is a special diet advised?*

Whilst there is no proof and limited benefits highlighted for undertaking a special diet when you have a brain tumour, if this is something you want to try, speak to your GP first, as you would with any diet.

### *How can I get on to a clinical trial?*

I'd advise patients to ask their medical team about clinical trials, as they're best placed to know what trials are available and which are best for them. Find out more about getting on to a clinical trial on page 27.

### *I've heard about steroids. Should I be on them?*

Steroids can help lessen symptoms, but speak to your GP about this for more information.

**These are a range of questions you could ask. But, for a more comprehensive list, please visit [thebraintumourcharity.org/your-mdt](http://thebraintumourcharity.org/your-mdt)**



Ingela Oberg



## Preparing for the future

If you have a brain tumour, whatever your circumstances, you may want to consider planning a phased return to work or school. You may also want to consider updating or writing your Will. But, we understand this can feel overwhelming and difficult. So, we're here to guide you.

### *Getting back to it*

#### **Returning to work or school:**

Organising your return to work or education can be confusing, so we've designed online resources to guide you. They provide tools to help others understand the effects of a brain tumour and suggestions for 'reasonable adjustments' your employer can make.

#### **Ending your benefits:**

If you're on benefits but are returning to work, you'll need to tell the government of changes in your situation. If you have any questions, our benefits clinic (run in conjunction with Rushmoor Citizens Advice Bureau) is available every Tuesday from 9.30am to 4.00pm. Call 0808 800 0004 any time to book an appointment.

**Turn the page for more help preparing for the future.**



### Online resources



Employment resources  
[thebraintumourcharity.org/employment-resources](http://thebraintumourcharity.org/employment-resources)



Educational resources  
[thebraintumourcharity.org/education-resources](http://thebraintumourcharity.org/education-resources)

## “There is no better time than now”

### Writing a Will:

Having an up-to-date Will is the only way to ensure the people and causes you care about are looked after in the way you intend. Yet, many of us put it off. Sharon Highway did too, until she and her husband, Oliver, faced a situation no one should – writing their Wills in the hospital.

“When the seriousness of Oliver’s diagnosis hit home, we quickly needed to organise a Will before his surgery in just six days. Luckily, a friend suggested a Will writer, who we met three days later in the hospital café. We then had to ask complete strangers to witness our signatures. This was not what we wanted to be doing or thinking about when our whole world had been rocked. We learned the hard way there’s no better time than now to write or update a Will.”



## Will writing made easy

Many people avoid writing their Will believing it to be difficult, time-consuming or expensive. Alex Broughton, 36, felt the same, but now wants to help us end these misconceptions.

### 1 You can write a Will for free!

Even the simplest of Wills must comply with complex legal guidelines, but this doesn’t need to cost anything. All supporters of The Brain Tumour Charity can access the National Free Wills Network, which is quick and easy to use.

Alex said, “We got a gift in Will information pack from The Charity and called the nearest solicitor to us. There was no pressure to leave anything to The Charity, and writing our Wills didn’t cost a penny”.

### 2 You can remember a loved one in your Will

You can dedicate a gift to a chosen charity to honour the life of a loved one – or you could dedicate a gift to one of our Supporter Groups.

Alex said, “Leaving a gift to The Sue Robson Fund, the Supporter Group that honours my mum, was my way of cementing my support before passing it over to others”.

### 3 If your estate is liable to Inheritance Tax, you could reduce what you have to pay by leaving a gift to charity

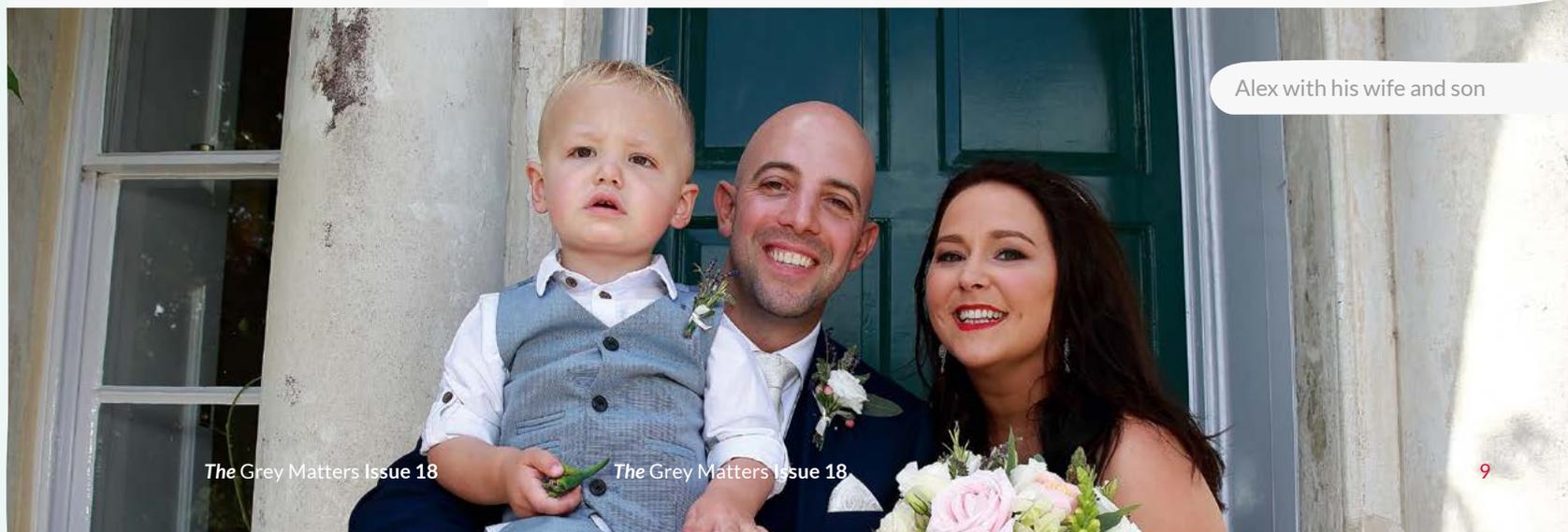
Depending on your circumstances, you may be able to reduce the amount of Inheritance Tax you pay by leaving a gift to a charity. Your chosen professional can give you more guidance on this.

### 4 There are three main types of gift you can include

You can leave a percentage share, fixed amount or specific item. But a percentage share is the most valuable, as it won’t lose value over time.

Alex said, “My solicitor gave me a document of what I needed to think about before the initial meeting. It was really useful, particularly when deciding what type of gift to leave”.

To find out more about how to write your Will for free, or how to leave a gift in your Will, please visit [thebraintumourcharity.org/littlethings](http://thebraintumourcharity.org/littlethings)



Alex with his wife and son

# CELEBRATING YOU AWARDS 2018

*"So blessed to have been part of an amazing evening at the first ever Celebrating You Awards. Surrounded and seated with inspirational individuals who together all have just one goal. Such an incredible charity and evening."*

Sam Jenkins

**We'd like to say thank you to everyone who attended our first ever Celebrating You Awards. We hope you had a lovely time celebrating some fantastic achievements with us.**

Created by a chemical reaction, a firework is bold and bright, impossible to ignore, and changes the dark landscape into something remarkable. This is exactly what we are doing together, proving that the sky's the limit.

But, unlike a firework, we cannot fizzle out. There's still so much to do, as we pick up the pace to find a cure and defeat brain tumours for good.

Congratulations to all the nominees and winners from the night – we're so proud of your accomplishments and are grateful for everything you do to support us.



# Volunteers Week

*This year alone, we've seen major achievements in the field of research into brain tumours, treatment and awareness. But none of this would be possible without our amazing volunteers.*

**Our volunteers are exceptional, and we want to say thank you this Volunteers Week (1-7 June).**

They are the people who help us influence politicians and bring about much-needed change. They packed and sent hundreds of Big Bandana Bake fundraising packs so our dedicated fundraisers could bake a difference.

They are the people who shape our great research, who ensure our factsheets are as informative and clear as possible, and who tirelessly give up their time to help others.

Our volunteers continue to go above and beyond, helping us improve life today for those affected by a brain tumour.

So, we want to shine a light on these individuals this Volunteers Week and say a massive thank you, because without you all, we simply couldn't do what we do.

If you would like to get involved but don't know how, then please get in touch. Whether you'd like to volunteer on a routine basis, or you're looking for a more ad-hoc opportunity, we have something for everyone.

Visit [thebraintumourcharity.org/volunteering](http://thebraintumourcharity.org/volunteering) or call us on 01252 237818.



*"I joined The Brainy Bunch as a Collection Tin Co-ordinator because I wanted to support The Brain Tumour Charity to help beat this dreadful disease. The Charity is very close to my heart so this is one way I can help."*

Yvonne, Collection Tin Co-ordinator



## Be aware, be HeadSmart

17-year-old Jade couldn't wait to start driving, but when she noticed problems with her vision while practising, her whole world was turned upside-down. Now, Jade and her family are supporting HeadSmart to help improve diagnosis time and awareness of brain tumours.

"I realised I needed to go to the optician after I drove over the kerb. But within minutes of the appointment it became clear something was wrong. It didn't matter which lenses I tried, I was still struggling to read anything. The optician immediately referred me to hospital, and that's when they discovered three germinoma tumours pushing on my optic nerve, pituitary gland and the frontal part of my brain.



"I was in shock. But, slowly, a lot of other things made sense. As well as poor vision, my periods had stopped, I'd lost my appetite and I was always tired. Doctors had originally diagnosed me with an eating disorder.

"Thankfully, after 25 sessions of radiotherapy, a recent scan revealed no visible sign of the tumours. But it shows how important it is for all healthcare professionals and individuals to recognise the signs and symptoms of a brain tumour. That's why we're supporting HeadSmart."



## Repurposing the reovirus

**Proudly funded by us, Professor Susan Short is using a natural virus to develop new therapies to treat glioblastomas.**

Professor Short and her team have identified that the reovirus, a naturally occurring virus, has the potential to be a new therapy for glioblastoma.

The reovirus is toxic to the tumour cells. Once the virus is inside the cell, it replicates, causing the cell to burst and releasing the virus, enabling it to enter and destroy surrounding tumour cells. The presence of the reovirus also stimulates the immune system to attack the tumour too.

Professor Short's research has proved that the reovirus can cross the blood-brain barrier, meaning the treatment could be injected into a blood vessel. This is significantly less invasive and lower risk for patients. It is currently being tested in clinical trials.



Find out more [thebraintumourcharity.org/cancer-killing-viruses](http://thebraintumourcharity.org/cancer-killing-viruses)



A monthly donation of

**£20**

would purchase the specialist liquid nutrients that are used to grow glioblastoma cells in the lab, so researchers can assess responses to different drugs

**HEAD SMART**

Please share the signs and symptoms!



[headsmart.org.uk](http://headsmart.org.uk)

# You've baked a difference

*Thank you for uniting to bake a difference for Brain Tumour Awareness Month 2018.*

We want to say a heartfelt thank you to everyone who grabbed a slice of the action this Brain Tumour Awareness Month and joined our first ever Big Bandana Bake.

Literally battling wind, rain and snow, nothing stopped our dedicated community from holding their Big Bandana Bake events. Many of our amazing Supporter Groups and corporate partners also joined in the fun all over the UK, and we are so grateful.

This year, through more than 445 bake sales, 3,217 bandanas bought and #BuyASlice virtual bake sales, you've raised £172,000. This jaw-dropping amount can help us fund over two years of desperately needed research.

So, however you contributed, we want to thank you. Because of you, we're picking up the pace to find a cure and defeat brain tumours – for good.



**445  
bake  
sales**



**3,217  
bandanas  
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**£172,000  
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## A little boy's big legacy

On 3 March, the 19th Joseph Foote Ball was held at the Hilton Metropole, Birmingham, in honour of Joseph Foote, who died from a brain tumour, aged just nine.

Thank you to the 613 people and 25 volunteers who attended the ball and helped raise an incredible £320,000. Our thanks also go to the West End Singers, Paul Zerdin, Lemar and Madhen Band for their brilliant performances.



## A marathon challenge

This year, almost 100 people picked up the pace to get closer to a cure by running the Virgin Money London Marathon.

Two examples of the exceptional athletes involved were Eagle Radio's Morning Matt, who, after a public vote, vowed to raise money in our name and help stamp out brain tumours. While Simon Kindleysides has become the first man to complete the Virgin Money London Marathon in an exo-skeleton suit. Read more about Simon on the next page.

So far, all our fast-moving fundraisers have raised over £204,000! We are so grateful for your support.



# My personal Everest

In April 2013, 33-year-old accomplished singer, and guest judge on BBC1's *All Together Now*, Simon Kindleysides, had his world turned upside-down when he became paralysed due to a low grade brain tumour. Now, five years on, Simon has become the first paralysed man to walk the London Marathon, aided by an exo-skeleton suit.

"I'd suffered from headaches for many years but thought nothing of it, I just put it down to being busy and stressed, until I woke up one morning in April 2013 and could no longer feel my legs.

"I spent five months in hospital having tests and scans, trying to figure out the cause of my paralysis. Eventually, a scan revealed a small mark in the core of my brain; a tumour, about 12mm big. They explained the low grade tumour was causing my paralysis, but that due to its size and position, surgery was not an option, and so I was sent home.

"Paralysed and without a wheelchair, I came home to discover I could no longer access my flat. With no lift to get up to the flat, and the council unable to rehome me, I found myself homeless. With three children this hit me hard and I struggled to accept my situation.

"But seeing my children, I decided I could either stay in bed, feeling sorry for myself, or I could be a role model to them, and to others who are disabled, and show them the sky's the limit, no matter what your situation!

"Before becoming paralysed, I'd always dreamt of doing the Virgin Money London Marathon so, when the ReWalk exo-skeleton came into the picture, I knew what I had to do.

"Training was tough, it was the first time I'd stood for five years, and although the suit isn't tricky to use, it requires a great deal of concentration to move and core strength to power. But, I'm so glad I did power through.

"Now, I can say, after a ton of training, and the gruelling 26.5 hours to reach the finish line, I have become the first paralysed man to walk the Virgin Money London Marathon, all thanks to the suit and the amazing support of my team, family and friends. Crossing that finish line is a moment I will never forget and I hope it shows my children, and everyone else, that no matter how bleak your situation may feel, you cannot take it lying down."

Find out more about Simon's marathon challenge at [thebraintumourcharity.org/simons-marathon](http://thebraintumourcharity.org/simons-marathon)



Simon and his team joined by friend and Gogglebox star, Sandi Bogle (front left).



# Be a part of BRIAN

Looking to make a difference through your diagnosis? BRIAN can help!



Yanni Tsamplakos

For those with a brain tumour, sharing information shouldn't be done in hindsight. 67-year-old Yanni Tsamplakos is one of 300 people (so far!) helping us change this by joining BRIAN (the Brain tumour Information and Analysis Network).

"I've played in a band for most of my life, currently The Merseyside Legends. So when I lost hearing in my right ear it made an impact.

"After visiting an ear specialist, I was sent for an urgent MRI, which revealed the cause of my hearing loss – a low grade – acoustic neuroma. I was in shock but had to decide – Gamma Knife Therapy or surgery. I thought of what might happen if surgery went wrong, and opted for Gamma Knife.

"But it didn't work. Surgery was my last option. My wife spent days looking for the right surgeon until she found Professor Wright, who operates on acoustic neuromas. He agreed to help and in January 2011, I underwent surgery.

"It was a success! I have a few issues; some numbness on the right side of my face and I lost hearing in my right ear but I consider myself lucky. With a few adaptations, I continue to perform with my band.

"Years later, I met a lady diagnosed with the same tumour as me, but her experience was so different. She'd been left with life-altering disabilities, and I kept thinking, what if she'd known about my surgeon?

"That's why I signed up to BRIAN. If I can help others by sharing information and my experience, maybe I can help limit the damage, ease worries and give hope."

Whether you're a patient, parent or carer, or if you've lost a loved one, BRIAN can help you find and share information. Learn more at [thebraintumourcharity.org/BRIAN](http://thebraintumourcharity.org/BRIAN)

*"I had no problem signing up, and a member of The Charity was there if I got stuck. But for me, if I can help someone through this, I'd do anything."*

# Ask the Researcher: Panel Edition

On 6 March we invited over 150 people to discover new research and ask their questions to our panel of research experts.

Jordan, a young ambassador, attended and, as someone personally affected by a brain tumour, shares his lessons from the night.

## 1 Tailoring treatments

Professor Richard Gilbertson has been involved in understanding the language brain tumours speak and tailoring treatment plans for individual patients.

## 2 Trojan horse

Professor Martin van den Bent's team have developed a 'Trojan Horse' method, using proteins to 'sneak' a drug into the tumour. The drug then attacks the tumour from the inside out.

## 3 Drink pink

Professor Colin Watts discussed the postcode lottery of the 'pink drink'. The pink drink lights up brain tumour cells so it can be seen and removed more easily. It's only available at some neurocentres, but everyone agreed this must change and are helping make this a reality! Find out more about Professor Watts and the pink drink on page 22.

## 4 Identifying tumours

Dr Paul Northcott and his team are identifying tumour types and sub-types, helping doctors diagnose more accurately, tailor treatments, and improve information given to patients.

If you missed the night then don't worry. You can now catch it on our website [thebraintumourcharity.org/ask-the-researcher](http://thebraintumourcharity.org/ask-the-researcher)



# Everest One Year On

In June 2017, we were proud to open a brand new research centre called **The Everest Centre for Research into Paediatric Low Grade Brain Tumours**. This was only made possible because of our remarkable trustee, **Rob Ritchie**, who, with 13 of his friends, family and colleagues, travelled to Verbier to take on the very first Everest in the Alps challenge.

The team of intrepid adventurers skied a gruelling 8,848 metres uphill, the height of Everest, in support of Rob's now 10-year-old son, Toby, who was diagnosed with a low grade brain tumour, and to help kick-start this incredible research centre, raising over £3 million.

One year since opening, The Everest Centre has gone from strength-to-strength. Led by Dr David Jones, the team is now 15 strong, and have recently taken on their first PhD student, Katy.

As the team grows, so does their influence and the countries they reach. Over the last year, they have been spreading the word about their vital work, discussing new findings with the scientific community and helping us propel brain tumours to the top of the agenda. Most recently, Dr David Jones presented a lecture at the Hospital for Sick Children in Toronto, whilst the team published an article in highly-respected journal, *Nature*, showing just how well-regarded The Everest Centre is becoming within their field.

But, a major achievement of The Everest Centre is their work with the European Society for Paediatric Oncology to launch a new clinical trial: Low Grade Glioma in Children (LOGGIC). This will be the first trial to assess the quality of life for children diagnosed with low grade gliomas. It's an amazing trial and one we're sure will lead to revolutionary outcomes.

**Find out more about The Everest Centre**  
[thebraintumourcharity.org/everestcentre](http://thebraintumourcharity.org/everestcentre)



## Everest in the Alps: the second ascent

To mark one year since the launch of **The Everest Centre**, **Rob Ritchie** decided to take on **Everest in the Alps: the second ascent**.

Joined by wife, Tanya, and 30 adventurers, Everest in Alps: the second ascent aimed to raise £350,000 for The Everest Centre.

The group split into seven teams; Toby's Team, Team Barclays, Team Smith and Williamson, Team BMS, Team JP Morgan, Team Goldman Sachs and Team USA. Together, they climbed for over ten hours, every day, for four days. Battling temperatures that plummeted below -30 degrees, they proved that even 8,848 metres won't stop their mission to defeat brain tumours.

*"Everest in the Alps will make a difference for The Everest Centre, helping fund research that wasn't there before."*

**Phil Spencer**, TV presenter, journalist and intrepid skier of Everest in the Alps

The team have smashed their original target, and have so far raised a staggering £900,000. We are so thankful and proud of them for completing this challenge once again and raising a phenomenal amount for research in to low grade paediatric brain tumours.

# The Gift of Research

Professor Karen Kirkby and her husband, Norman, were inspired to leave gifts in their Wills after learning how underfunded research into brain tumours is.

We funded Professor Colin Watts as he explored the clinical applications of a fluorescent dye, which helps identify different regions of a tumour. Using this dye, Professor Watts and his team investigated the theory that tumours are made of distinct types of cells, each with different properties which determines their response to treatment.

Professor Neil Burnet worked with Professor Watts during this project, helping us to double survival and halve the harm. But, when Professor Burnet's path crossed with Professor Karen Kirkby's husband, Norman, working together at Addenbrookes, he had no idea the impact this ground-breaking research would have.

Karen said, "A vast amount of innovative research came out of that year and Norman was struck by the need to improve outcomes for those diagnosed with a brain tumour. It's clear that research into brain tumours is an area of unmet need.

## Did you know

1/4 of our research is funded by gifts in Wills.

"As an academic researcher, I passionately believe research will make a huge difference to outcomes and quality of life. But if I don't commit, by leaving a gift in my Will, how can I expect others to?"

"Norman and I both believe that The Brain Tumour Charity is an excellent way to make this happen as soon as possible."

Professor Watts is now exploring the use of hydrogels, which are in a liquid state until injected, to administer brain tumour treatments. Professor Watts has theorised that using hydrogels could allow a higher concentration of a drug to reach the tumour than current drug delivery methods.

This is just one example of research aiming to make a dramatic difference to brain tumour treatments. Gifts in Wills, such as those from Karen and Norman, help make this possible. If you'd like to find out more about leaving a gift in your Will, please visit [thebraintumourcharity.org/littlethings](http://thebraintumourcharity.org/littlethings)

*"I passionately believe research will make a huge difference to outcomes and quality of life. But, if I don't commit to this myself, by leaving a gift in my Will, how can I expect others to?"*

Karen Kirkby,  
Researcher and Supporter



Karen and Norman Kirkby

## The Price You Pay

Our *Life with a Brain Tumour* publications detail the physical, mental and emotional impact of a brain tumour. Now, we've launched a new report in the series – *The Price You Pay*.

Highlighting the financial impact of a diagnosis, and the inadequate levels of information and support available, we're calling for changes to the system.

Thank you to the 300 people who helped us create this report, your stories and experiences will help us drive change so that one day, the cost of a brain tumour won't be so high. In the meantime, if you're struggling with finances or the benefits system, you can call our benefits clinic every Tuesday 9.30am-4.00pm on 0808 800 0004. Call us any time to book your appointment.

To read our report please visit [thebraintumourcharity.org/price-you-pay](http://thebraintumourcharity.org/price-you-pay)



# A day for all the family

Would you like to meet other families in a similar situation? Or perhaps you're searching for a safe space where your child can be just that – a child. If so, then our family days are the perfect getaway.

These get-togethers are the ideal place to meet others who understand, to share stories and experiences and to do so in a safe space. With no pressure to get involved in activities, and refreshments provided throughout the day, they really are a relaxing getaway for all the family.

But don't take our word for it, the Cooks explain why they come along with their son, Matthew, who's living with a brain tumour.



"Before we came to our first day we were really anxious and nervous, we weren't sure whether it was for us or what to expect. But, once we were there it was really nice to relax and be around people that understood."

"We come to a day like this because we can relax and have fun, but most importantly so can he. It gives our son the chance to be who he is, in a comfortable environment where there's no pressure, no need for him to do anything. If he needs some quiet time, he can."

*"Matthew can just be a little boy – and that's why we like coming."*

Faye and Andy Cook,  
family day attendees

We run two types of family days, one for children with a brain tumour and the other for parents who have a brain tumour. Find out more and book a day at [thebraintumourcharity.org/family-days](http://thebraintumourcharity.org/family-days)

## Did you know

96% of families feel better supported after attending our family days.

## Don't desert us – join the Sahara Trek

**When:**  
23 February – 2 March 2019

**Where:**  
Sahara Desert, Morocco

**How much:**  
£195 registration fee, £2,700 minimum fundraising target

Join us as we traverse undulating desert, rainbow rock gorges and sandy dunes to change the lives of those affected by brain tumours.

Don't get us wrong, this will be a gruelling challenge. But it will also provide breath-taking views, bucket-list worthy experiences, and unforgettable memories with new friends. Sound like a challenge right up your desert road?

Sign up now  
[thebraintumourcharity.org/sahara-trek-2019](http://thebraintumourcharity.org/sahara-trek-2019)

# PNET5: biomarking a better future

*We're excited to be investing nearly £1 million into the PNET5 clinical trial, which is on the verge of transforming childhood medulloblastoma treatments.*

Medulloblastoma is the most common high grade brain tumour type in children, but current treatments are aggressive and can leave them with life-altering disabilities. But, PNET5, a major European-wide clinical trial, aims to change this.

Previous research we funded identified seven sub-types of medulloblastoma, some of which can be classified as 'standard' or 'lower' risk. PNET5 wants to show that, as a result of this discovery, some children could safely receive less aggressive therapy.

This could increase their quality of survival; reducing the time spent in a hospital and suffering from side-effects and, critically, the risk of long-term disabilities for these vulnerable children.

In order to establish whether a child has a lower or standard risk medulloblastoma – and therefore can take part in this pioneering trial – we've committed to paying for all children diagnosed with a medulloblastoma in the UK to receive a biomarker test.

The first child, Alex Hobbs, has now signed up, kicking off this revolutionary trial to make safer and kinder treatments a reality.

We're excited by the potential of PNET5, but need your help to make it happen. Only together can we transform treatments for children like Alex, and improve life for so many families.

Please help us end the devastation. Donate to this amazing research today [thebraintumourcharity.org/PNET5-trial](http://thebraintumourcharity.org/PNET5-trial)



Alex (right) with his dad

## Clinical trials and tribulations

Clinical trials help researchers test new approaches and treatments to help improve diagnosis and assess outcomes. However, many of you tell us finding a clinical trial can feel difficult and confusing. So, we're here to help.

### *What's the difference between a standard trial and an adaptive trial?*

A standard clinical trial sees one drug or treatment tested on a patient to assess outcomes. An adaptive clinical trial allows researchers to add in new drugs or a combination of therapies, during the trial, in response to the patient's condition.

### *Why should I join a clinical trial?*

Clinical trials are crucial for advancing science and understanding, and improve outcomes for those affected. You'll also be able to access other treatments which could be beneficial to you.

### *Who can join a clinical trial?*

The eligibility criteria can be very specific, and many factors have a bearing. You should always speak to your medical team about trials you're interested in, as they can offer advice based on your circumstances.

### *How can I find a clinical trial?*

Your clinician should be able to talk to you about available trials. Alternatively, if you would like to receive more information, please call us on 0808 800 0004.

### *How else can I help with research?*

Our Research Involvement Network (RIN) is a great way to get involved. You won't need an in-depth understanding of research, your experience can provide researchers with a vital perspective helping shape or evaluate research.

If you have any questions about clinical trials or our Research Involvement Network, please contact our Information and Support team on the number above. Or use our live chat service by visiting [thebraintumourcharity.org/live-chat](http://thebraintumourcharity.org/live-chat)

Last year, we came together for the biggest (and we think best) The Twilight Walk yet. Over 3,200 of you came to #WalkWithUs and raise a record-breaking £350,000, taking those vital steps closer to a cure.

This year, we know it's going to be bigger, better, and more beautiful as we unite to defeat brain tumours, share stories and celebrate how far we've come, moving closer to achieving the goals we set in our research strategy, *A Cure Can't Wait*.

So, along with your family, friends, neighbours and colleagues, join us as we look to the sky and reach further than ever before for our most memorable walk yet.

You can choose one (or more!) of our three locations, or hold your own walk. Simply choose a place that's special to you, invite your family and friends and, together, raise money to stamp out brain tumours.

Please join us this autumn, because wherever you walk, or whether you volunteer, you will help us make strides towards a cure.

# The TWILIGHT WALK



# UNITE. SHARE. CELEBRATE.

#WalkWithUs

WARWICK  
30 September

EDINBURGH  
7 October

WINDSOR  
14 October

Sign up and #WalkWithUs  
[thebraintumourcharity.org/](http://thebraintumourcharity.org/)  
[thetwilightwalk](http://thetwilightwalk)



# Supporter Groups

Our Supporter Groups are dedicated ambassadors, fundraisers, awareness raisers, and volunteers who come together in memory of, or inspired by, a loved one, helping defeat brain tumours faster. We're proud to have 298 Supporter Groups, to date, helping us defeat brain tumours faster.

Welcome to our new Supporter Groups:

- Amelia's Research Fund
- The Gina Rose Going Strong Fund
- The Fifi Fund
- Ben's Brain Battle Fund
- The Matthew Smith Fund
- The Richard Smart Fund
- The Paul Young Fund
- The Christine O'Carroll Fund
- The Lee Woodcock Memorial Fund
- The Neil Hamilton Fund
- The Peter Moreton Fund
- The Jas Badhesha Memorial Fund
- Cariss's Cure Crusade

Find out how you can set up a Supporter Group at [thebraintumourcharity.org/supportergroups](http://thebraintumourcharity.org/supportergroups)

## The Brain Tumour Warrior Fund

Natalie Sweeney and Angela Conway first met at a brain tumour support group and soon discovered not only were they both living with a brain tumour, and the same age, but lived in neighbouring towns and even had mutual friends!

A friendship soon blossomed and The Brain Tumour Warrior Fund was born. We're so grateful to these inspirational women for their support.

"We started The Fund as a way to give back to The Charity and raise awareness of HeadSmart. We've had a lot of fun so far, from fashion shows and pub quizzes, to afternoon teas and a horse racing family fun day. It's given us a real sense of community, and working together means we've always got someone to lean on or celebrate with."



The Grey Matters Issue 18

# How your business can help

There are so many ways companies big and small can help us defeat brain tumours faster.

## Challenge

Take on a team challenge with your colleagues to raise funds, awareness and staff morale. We have plenty of unique UK or overseas challenges that can help you get involved and defeat brain tumours faster.

## Teach

Could you and your colleagues offer your talent to help make a difference to people affected by a brain tumour? We welcome pro-bono training and skill-sharing with us, our volunteers and inspiring Young Ambassadors, to help us reach our goals.

## Choose

Choosing us as your charity partner will make a vital difference to everyone affected by brain tumours, and your staff. You'll help us to raise awareness and vital funds and, ultimately, defeat brain tumours.

To find out how to get involved and discover more of our amazing opportunities, email [corporate@thebraintumourcharity.org](mailto:corporate@thebraintumourcharity.org) or call us on 01252 749043.

We're proud to announce our new partnerships:



"Lockton's partnership with The Charity has brought out the best in everyone here."

Simon Coleman,  
COO of Lockton LLP Companies

# 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'll never forget the support we received"

**"When my brother was diagnosed with a brain tumour last year, the only information we had was the name of the tumour and his prognosis: 12-18 months. We felt lost, so I looked online, but it only made things worse and information seemed to conflict.**

I stumbled across The Charity by chance. They provided a safe space to ask questions and gave much-needed information, supported by factsheets, which I could discuss confidently with my brother and mum.

I'll never forget how lost we felt in those first few hours after diagnosis and I'll never forget the support we received from The Charity."

**Nicola Bolton, Information Reviewer**

## Walking in her shoes

"I am looking at raising money for The Brain Tumour Charity after my sister, Helen, was diagnosed with a grade 3 Oligodendroglioma at the age of 28.

"Helen turns 31 next week and has been through a hell of a lot. She has had a craniotomy, completed radiotherapy and chemotherapy; in fact, she has just passed the one-year anniversary since she finished chemo. She has had scans since, and everything looks stable.

"I've recently turned 29 and, being around the same age as she was when she was first diagnosed, it made me think how I would have felt, if it was me in her shoes, and I cannot believe what she went through.

"After attending your Ask the Researcher event, it really made me think of what I could do to help. Hence, I went home and instantly signed up to walk the Thames Path, which will be a real feat for me."

**Claire Magorrian, Fundraiser**

## Community fundraiser bakes a difference

"We would like to let you know how amazing Steph, one of your community fundraisers, is. Our Supporter Group - The Imogen Whitby Fund - recently held a Bandana Bake sale in memory of our daughter, who passed away last year.

"Kathryn met with Steph several times to plan the event and, when she wavered in confidence, she gave Kathryn so much support to do this. Steph wasn't pushy and gave Kathryn belief in herself.

"On the day of our sale, she turned up early to help set up, rolled up her sleeves and just got stuck in. She helped us make the event more than a bake sale but an information event too, which was important to us. We wanted to give people the information we wish we'd had to detect the signs as soon as possible in our family members. She helped with the sale, she helped with the raffle, she even helped with the clean-up afterwards and was a huge support to us all!

"We don't quite know how to say thank you, it doesn't seem enough, but we'd like you to know she is greatly appreciated and goes over and above for us all."

**Kathryn and Lester Whitby, Fundraisers**

# 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.

Thank you for all that you do.

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



BN5 Magazine and the community in Henfield arranged a Christmas Extravaganza raising funds inspired by their friend Olivia Pugh. They raised an astounding £6,371!



Layla Mackinnon pledged her 10th birthday in memory of her father, Billy, raising £810! If that's not enough, Layla's also planned fundraising ideas for the entire year. Her second event has raised over £1,000 already!



Frances Rose Singleton spent the whole of November without sugar or carbs in support of her sister who was going through radiotherapy. Frances has raised a fantastic £1,030.



Cade Nicholson shaved his head in memory of his mum and raised a wonderful £227.



Rishii Chowdhury took part in a 10 hour, non-stop tabla jam with his friends and members of his family, raising a fantastic £1,796 for The Charity in the process! A really unique event.



2017 Captains of Chevin Golf Club, Neil and Janet, have chosen to support The Brain Tumour Charity throughout the year with various events, which includes Alan playing 100 holes in 24 hours. To date they have raised an amazing £9,619.



Gas Company SGN held a Casino Night in support of their colleague, Richard Smart, who's currently living with a high grade tumour and recently set up a Supporter Group. The night raised an incredible £8,915. The entire Smart family are also doing a year-long sponsored weight loss.



The Alistair Good Fund held a West End Musical and Opera Concert to mark the 10th Anniversary of losing their much loved son Alistair. The two evenings raised a tremendous £10,000 and were also an opportunity for Caroline to celebrate her 80th birthday, and mark Tony and Caroline's 60th wedding anniversary.



Nicole Proffitt promised her father, Richard, before he passed away, that she'd organise and run a half marathon to raise funds for research into brain tumours. Nicole's mum, Mandy, brother, Jack, and several friends also ran with her. So far they have raised nearly £2,000.



Annie Watson was diagnosed with a low grade brain tumour in 2014 and recently held a charity night in January where the Benidorm Rovers played for her guests on their tour of Scotland! The evening was a great success and she presented The Charity with a cheque for £2,000!

# 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](https://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



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Find us here too





## 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](http://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!