

The Brain Tumour Charity shining a light on

The GREY MATTERS

The **BRAIN
TUMOUR
CHARITY**

Research | Awareness | Support

Issue 15 Summer 2017



thebraintumourcharity.org

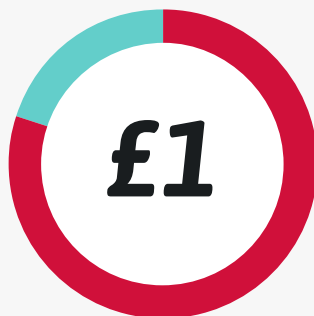


United in style

Sometimes it's the small, subtle gestures that matter most. Wearing our grey cord bracelet, complete with unity charm, is a lovely way to express solidarity or show someone that you're there for them. The bracelets could also make thoughtful gifts or wedding favours.

To take a closer look or to order yours, visit our online shop at thebraintumourcharity.org/shop

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

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Cariss with her partner Stuart

Hello

Recently I realised something special and I thought it would be nice to share it with you, here, in the 15th edition of *The Grey Matters*.

Last autumn, I volunteered at The Twilight Walk. Previously when I'd taken part in the walk myself, I'd felt incredibly proud knowing that the money I was raising would help further The Charity's pioneering research.

Yet what struck me this time, as a volunteer, was how I was still able to make such a huge impact.

Standing in my red t-shirt, I was approached by countless people who wanted to talk and swap advice, and it dawned on me that it didn't matter what any of us could contribute – whether

we walked, volunteered or stood cheering on the sidelines – in our united battle against brain tumours, we all had something to give.

When I was diagnosed with an oligoastrocytoma back in 2014, the life I'd imagined – to become a mum and have a family – disappeared.

But when I look around at events like The Twilight Walk, I am reminded that I do have a family – #TheBrainyBunch family – and now my purpose is to help them in any way that I can.

I hope that you'll continue to join me.

Cariss Evans

Fundraiser and volunteer
for The Brain Tumour Charity

Our research progress so far

In 2015, we launched our ambitious strategy, *Defeating Brain Tumours*, with the bold goals of doubling survival and halving the harm that brain tumours have on quality of life. Now we're delighted to share some highlights of our progress with you.

We're proud that our research sets us apart. It's subject to rigorous peer review and assessment, so we know that it's the best scientific and clinical research available globally. We also don't limit our funding to one type of research. Instead we invest in a wide variety of projects, people, grants and centres, and encourage our scientists to share their results openly, accelerating us towards our goals faster.

We know there's much more to do, but thanks to your support, we're moving closer towards our vision. With your continued passion and commitment, we will get there.

Since the strategy launched we've...

Helped to reduce average diagnosis times for childhood brain tumours down to 6.5 weeks with our HeadSmart campaign.



Committed a staggering £11.4m million to pioneering research.



Launched our Research Involvement Network, to drive collaboration between researchers and patients.



Been able to support the most prestigious researchers and are currently funding 259 globally.

Had our research published in esteemed scientific journals. It has appeared in 57 over the past five years highlighting the significant advances that we're making.



Increased the percentage of patients involved in research from 15.7% to 21.6%, based on an estimated 10,600 people being newly diagnosed each year.



Formed a pioneering partnership with the Structural Genomics Consortium (SGC) to conduct collaborative research under an open access policy.



A donation of

£100

could pay for a test to understand the genetic changes associated with the development of a brain tumour to help identify personalised treatments.

Some of the initiatives we'll be focusing on next are:

1

Funding the potential discovery of clinical biomarkers (or indicators such as genes or molecules) to bring us closer to earlier and more accurate diagnoses of brain tumours.

2

Initiating The Brain Tumour Charity's global, patient-led data bank, where patients can unite to share their data and make a vital contribution towards accelerating research that will bring us closer to finding a cure.

3

Commissioning research into how long it takes adults to be diagnosed with a brain tumour, with the aim to halve this.

Introducing The Everest Centre

After a thorough application and assessment process, we're delighted to announce that we have awarded £5 million to Dr David Jones to set up **The Everest Centre for Research into Paediatric Low Grade Brain Tumours.**

The centre, to be based in Heidelberg, Germany, will bring together the field's most prestigious scientists. This dynamic team will work to address critical problems in low grade childhood brain tumours, increasing our understanding of the disease biology and enabling us to positively impact children's lives.

Research suggests that 62% of children who survive a brain tumour are left with a life-altering, long-term disability with many experiencing a significant decrease in their quality of life. Yet so far there has been little financial investment into crucial research to change this.

In order to make vital progress within this neglected area, Dr Jones and his team will be focusing on four key areas of research.

They will be looking at what causes a tumour's growth to slow in the hope that by understanding this, tumour growth could be halted earlier.

"We originally funded Dr David Jones as a PhD student at Cambridge from 2005 to 2009, and it soon became obvious that he was an extremely talented scientist. I'm delighted that we have come full circle and are once again funding him in the new Low Grade Centre. With his great track record, we can expect some exciting results from The Everest Centre in the next few years."

Neil Dickson,
Vice-Chair of Trustees and Founder



Dr David Jones



The German Cancer Research Center
where The Everest Centre will be based

Researchers will also be creating more realistic laboratory models to identify and test new treatments, and will study different tumour samples to determine where in the brain these tumours started.

Finally, the funds will allow a clinical trial, where children with low grade gliomas can be given targeted treatments, to be open for recruitment much quicker. If successful, this first-of-its-kind trial has the potential to completely alter the gold standard treatment protocol for many low grade glioma patients.

We will initially be investing in this research for five years, and while the centre will be based in Germany, it will have strong ties to the UK with each of the four work streams having co-leaders in Germany and England. We will be monitoring developments avidly and if everything is progressing well, we intend to keep funding these researchers for as long as they need, beyond the initial five years. This should mean that they can make a real difference to the everyday lives of children and young people living with low grade tumours.

None of this would have been possible without the incredible efforts and funds generated by Rob Ritchie. Rob, whose son Toby was diagnosed with a brain tumour aged five, skied up 8,848 metres in the Swiss Alps (the same height as Everest) with a team of 13 others. Their grit, hard work and determination raised £3 million, specifically for research into low grade childhood brain tumours.

It is thanks to Rob, and fundraising efforts like these, that we're able to invest in such pioneering research, bringing us closer in our quest of halving the harm that brain tumours have on quality of life and defeating them for good.

"I'm thrilled that the money raised through Everest in the Alps is being used to establish The Everest Centre. This pioneering research will allow scientists to accelerate progress towards finding more effective treatments for the disease and could be revolutionary in improving the lives of children living with low grade tumours."

Rob Ritchie, Trustee

Our innovative research

We're thrilled to announce that, thanks to your loyal support, we've been able to award over £700,000 to eight exciting new global research initiatives in Canada, Australia and the UK.



Focusing immunotherapy treatments on glioblastoma

Dr Roberta Mazzieri,
The University of Queensland, Australia

Immunotherapy treatments harness the body's natural defence system and use it to recognise and destroy tumour cells. However, glioblastoma brain tumours still remain resistant to these treatments.

Dr Mazzieri and her team will be investigating two pioneering ways to overcome this and will be looking at techniques to reverse the tumour's suppression of the immune system.

This research could identify new treatments for glioblastoma patients with the potential to substantially prolong quality of life and improve survival rates.

Overcoming the blood-brain barrier

Dr Jason Gill,
Durham University

Dr Gill is looking to overcome the challenge of getting chemotherapy drugs across the blood-brain barrier by developing a new drug that can be injected into the cavity left after surgery, using a chemical called a thermogel.

This project is particularly novel in that the drug is being specifically designed so that it is activated by enzymes normally released by glioblastoma tumours in response to tumour growth.

This research project could lead to a viable new approach for the treatment of brain tumours.





Targeting glioblastoma cells

Dr James Dixon,
The University of Nottingham

Research has shown that some cells within glioblastoma tumours respond to treatments, whereas others are able to avoid them.

Dr Dixon and his team have developed a new drug delivery method, based on small molecular compounds, called peptides, that target unique sugars found on the surface of tumour cells. The team will identify peptides that target particular cell types within the tumour so that, in the future, specific drugs can be engineered, attached to the peptide and delivered to susceptible cells.

This cell-specific drug delivery would be revolutionary in targeting the whole tumour.



New drug development for glioblastoma

Dr Arezu Jahani-Asl,
Jewish General Hospital, Canada

Dr Jahani-Asl and her team are the first to show that a cancerous protein called OSMR drives the growth of glioblastoma tumours.

In this research project, the team aims to design and create two different types of drugs to target and inhibit OSMR activity, opening up new potential therapeutic options that have not been explored before.

They will also be looking at how OSMR interacts with another tumour causing protein called EGFRvIII, so that this interaction can be disrupted to halt tumour growth.



A donation of

£250

could cover one week of research time for a PhD student looking at drugs to inhibit OSMR and stop cancer growth.

New drug delivery method

Dr Colin Watts,
University of Cambridge

The blood-brain barrier stops harmful substances from reaching our brains, but it can also hinder the delivery of drugs to the brain.

To overcome this, Dr Colin Watts and his team are testing hydrogels as a new drug delivery method for the treatment of high grade tumours. The gels will be loaded with the most effective drug combinations and injected into cavities left after surgery.

If successful, this treatment method will be tested in a clinical trial, with the potential of moving rapidly into clinical practice.



Exploring DNA Mutations

Dr Ruman Rahman,
The University of Nottingham

Dr Rahman's research aims to understand what happens when specific genes within an ependymoma, the second most common high-grade brain tumour in children, fuse together causing tumour growth.

He and his team will be looking at how these genes behave and whether they can be targeted by drugs.

If successful, this exciting research could lead to the discovery of treatment options for childhood ependymoma.

To find out more about this incredible work visit thebraintumourcharity.org/new-ideas

Running for research

This April, Harjyot Hayer joined 86 runners from our wonderful community as they supported The Charity at The Virgin Money London Marathon 2017 to raise funds to support vital research initiatives like these.

Whether you ran, walked or waved a banner – we can't thank you enough. Every contribution, every cheer and every step will help us save lives sooner.

Understanding tumour progression

Dr Paulo Ribeiro,
Queen Mary University London

Dr Ribeiro and his team aim to develop a genetic tool whereby they can study tumour heterogeneity (when tumours are made up of many different cell types each with genetic mutations) and how it influences tumour progression and response to therapy.

This research will allow the team to determine how heterogeneity can be targeted to improve outcomes for glioblastoma patients.



Cutting out cancer-causing genes

Dr Khuloud Al-Jamal,
King's College London

Dr Al-Jamal will be looking at whether she can deliver a gene-editing tool, which can cut out cancer-causing genes, to glioblastoma cells.

Dr Al-Jamal and her team aim to test the delivery of this ground-breaking tool, by using small needle-shaped structures called 'nanotubes'.

This drug-delivery technique could provide a new treatment option for brain tumour patients and increase survival rates.

"Sadly I lost my dear father to a brain tumour. I ran in his memory to help fund The Charity's invaluable research because I don't want other families to experience such heartache."

Harjyot Hayer

The Grey Matters Issue 15



THANK YOU HEADSMART

**HEAD
SMART**

EARLY
DIAGNOSIS
OF BRAIN
TUMOURS



Claire Lloyd says: "When my nine-year-old son Jack was first sick, he seemed fine in himself and still had lots of energy.

"However when he continued to be ill and the anti-sickness medication prescribed by the GP had no effect, I grew more and more concerned.

"One evening I typed 'child with persistent vomiting' into Google. My search led me to the HeadSmart website which lists the most common signs and symptoms of childhood brain tumours. So later that night when Jack started complaining that he had a headache and sore neck, I didn't take any chances and rushed him straight to A&E.

Thanks to your unwavering commitment and support, our HeadSmart campaign is helping to ensure children and teenagers with brain tumours are diagnosed faster.

Since HeadSmart launched, it has helped reduce average diagnosis times for childhood brain tumours from over 13 weeks to 6.5. Now our goal is to further reduce this to four.

“ I explained to the doctors what I'd seen on the HeadSmart website and within an hour Jack was given a CT scan.”



"I explained to the doctors what I'd seen on the HeadSmart website and within an hour Jack was given a CT scan.

"As we sat waiting for the results, I could hear the doctors talking. I could hear them saying that they had found something on a scan and I remember thinking: *Please don't be Jack. Please don't be Jack.* But when the doctor came in and sat on the end of the bed, I just knew.

"He said: 'I'm really sorry but we've found a tumour.'"

"I felt numb, but the doctors were amazing. Jack was transferred to King's College Hospital, London and by 1pm the following day he was having surgery.

"Now he has had part of the tumour removed and is awaiting stereotactic radiosurgery.

"It's a very difficult time but Jack is doing great and to look at him, you wouldn't know that there's anything wrong.

"We're just so thankful that we found the HeadSmart website that day. Having that information was vital in getting Jack the care he needed quickly. I believe it has made the difference between him being here or not."

To watch Claire's poignant story visit
headsmart.org.uk/jacks-story

Watch and share our animation on your social feeds and with friends and family to ensure as many people as possible know the signs and symptoms of a brain tumour.

headsmart.org.uk/sam-animation

Do you know the signs and symptoms?



The Patient Guide

Since the launch of our new *Patient Guide to Brain Tumour Treatment and Services for Adults*, it has been read by over 2,000 people, improving lives across the country and ensuring more patients are aware of the standard of care they should expect to receive from the NHS.

However, we know that for the guide to have the vital impact that it urgently requires, it needs to reach a lot more patients. Over 10,000 people are diagnosed with a brain tumour each year and receiving this guide at diagnosis would make a huge difference in helping them to navigate their journey.

Therefore if you, or somebody you know, has been diagnosed, please do download this valuable resource from our website. We believe that everyone should have equal access to the best treatment and care. The more people we can reach, the sooner we can make this happen.

"When my dad, Hayden, was diagnosed with a brain tumour our lives fell apart. Yet our family wasn't provided with any information about Dad's tumour, the effects it could have or any form of support. We weren't so much as handed a leaflet.

"In Dad's final weeks, instead of getting to spend treasured time with him, our family was left rushing around trying to get answers and desperately doing our own research online.

"If the Patient Guide had been available back then I believe our family would have had a totally different experience. I have since learnt from it's checklist that there were so many things that we were never told.

"If we'd had the guide to use, I believe that we'd have been given more information, more support and ultimately more precious time to spend with Dad."

Jayne Wilson



Jayne and Hayden

Checklist

Have you been given:

- ✓ The name and contact details of a key worker (usually a clinical nurse specialist).
- ✓ The opportunity to discuss treatments.
- ✓ Information about local support.
- ✓ Information on clinical trials available to you.

To download the guide and read the checklist in full visit thebraintumourcharity.org/patient-guide

Pushing for equal access

The 5-ALA drug, also known as the pink drink, which patients can be given ahead of surgery to make tumourous cells glow pink under UV light, still isn't being routinely offered everywhere. We want this to change but we need your help.

If you, or somebody you know with a high grade glioma did not have access to 5-ALA please get in touch with us and share your story.

Contact us at policy@thebraintumourcharity.org



"5-ALA represents a simple and yet robust way to help surgeons visualise abnormal tumour tissue without the need for elaborate equipment or untoward side effects. However, as yet, 5-ALA does not attract national funding, which is why, as a community we need to do as much as we can to promote awareness of it and research into its use."

Mr Surash Surash, Consultant Neurosurgeon at Royal Victoria Infirmary, Newcastle upon Tyne

Protecting your rights

Last year, as part of our commitment to improving life today for those affected by brain tumours, we welcomed a specialist benefits advisor to our team. 12 months on, the impact has been huge.

From our *Losing Myself* report we discovered that one in two people living with a brain tumour were experiencing financial difficulty, while 28% had to give up work entirely.

To help families overcome this additional stress and vulnerability at such a difficult time, last year we partnered with Citizens Advice Rushmoor to offer email support and a weekly telephone Benefits Clinic every Tuesday through our Support & Info Line.

We're delighted to announce that, so far, the service has helped a large number of families on a range of money related issues, from claiming a new benefit or tax credit they should be receiving to, in extreme cases, avoiding homelessness.

In total, over a 12 month period, the predicted financial difference that this service will make for the families helped is estimated at nearly £420,000, with some set to be more than £10,000 better off.

Some have gone from struggling to know if they can afford the most basic of human rights, like a bed, to being able to comfortably afford things that many of us take for granted such as a bus fare or a weekly food shop.

This much needed service has clearly made a tremendous impact and as we continue to ensure that more people living with a brain tumour have access to it, we're incredibly grateful for your continued support.

It's your commitment and funding that continues to help us improve life today for those affected by brain tumours. We can't thank you enough.

For advice on money related issues, benefit applications or navigating the system, contact our Benefits Clinic (0808 800 0004) open every Tuesday from 9.30am - 4.00pm, or email support@thebraintumourcharity.org to book an appointment.

The logo for Citizens Advice, featuring the words "citizens advice" in white lowercase letters inside a dark blue speech bubble shape.

**citizens
advice**

Since setting up
the Benefits Clinic...

£5,000

On average, each person we've
helped is nearly £5,000 better off.

£420,000

Is the estimated financial difference
the service will make to families
over 12 months.

The Goodwill Partnership

Time, inconvenience and cost are often given as reasons why people have not written their Will, but it's the only way of ensuring that the people and causes you care about are looked after in the way you intend.

We know that this peace of mind is invaluable, which is why The Brain Tumour Charity is working with The Goodwill Partnership, an independent, discounted Will-writing service.

A trained counsellor from The Goodwill Partnership can visit your home at a convenient time and take your Will instructions for free.

If you decide to go ahead, a single Will costs just £95-£98 (+VAT), but there is no obligation to proceed or to leave a gift to The Charity.

To find out more go to
thegoodwillpartnership.co.uk/
thebraintumourcharity



My personal Everest

When Jennifer Amy set her sights on an extreme challenge to help raise funds towards finding a cure for brain tumours, she refused to let anything – including her own diagnosis – hold her back.

Jennifer explains: “When my consultant first told me that I had a brain tumour, I laughed. It was only after I’d stepped outside his office that I sunk to the floor in shock.

“Aged 15, my life had changed in an instant. I’d gone from having a budding future ahead of me to believing that my goals of travel, attending university and living a normal life were over.

“I was so worried that my friends would treat me differently, I even kept my diagnosis a secret.

“To help me through difficult days, I’d often contact The Brain Tumour Charity. The team spent hours talking to me on the phone, offering me support, advice and strength.

“I decided that I had two choices: to hide away or use my situation to help to make a difference to other people’s lives. So I set up The Jennifer Amy Fund Supporter Group and started fundraising to help the brain tumour community.

“One day I came across an advert in *The Grey Matters* looking for volunteers to take part in a challenging five-day trek across Iceland encountering black sand deserts, glacial rivers, steep hills and deep gorges. I was desperate to take part, yet I knew training wouldn’t be easy. Due to my oligodendroglioma grade II tumour, I suffered with severe fatigue and struggled being active.

“While other people might do moderate training, I knew I needed to force myself on a big trek every weekend to try and help my body adjust.

“Now I’m regularly climbing the hills near my home and trying to cut down on my naps. It’s exhausting, but knowing I’ve overcome bigger challenges before keeps me going.

“So far I’ve raised over £7,000 for The Charity and I can’t wait to complete the trek. It’s going to be incredibly tough but knowing the huge impact the money I’m raising will have on the lives of people with brain tumours and their families continues to spur me on.

“I used to hide my condition, but now I can’t tell you how proud I feel to be flying the flag for #TheBrainyBunch on this trek. Step by step I will get there.”



To support Jennifer's fundraising
go to thebraintumourcharity.org/
the-jennifer-amy-fund



New Teenage and Young Adult Service

The Brain Tumour Charity is excited to be developing our new Teenage and Young Adult Service.

This new, dedicated service will offer emotional and practical support from a dedicated Teenage and Young Adult (TYA) worker, as well as the opportunity to connect with others through our new Young Adults Facebook Group and at events alongside our wonderful Young Ambassadors.



"It's really important to us that teenagers and young adults know that they aren't alone on their journey. Whether they want to meet others, access support or find the right information, we're here to help."

Emma Wood, Teenage and Young Adult Worker (TYA)

If you are interested in meeting others, developing skills or finding out more about the services available, please visit thebraintumourcharity.org/TYA to register your interest.

Our exciting new CNS role

Following our report *Finding Myself in your Hands*, which found that only 53% of people diagnosed with a low grade tumour said they had access to a single point of contact, we're proud to announce that we will be funding a clinical nurse specialist (CNS) in King's College Hospital, London, to support patients living with low grade tumours.

We know that the impact of not having a CNS is significant, with more people likely to report higher symptom burden, less access to information on managing their symptoms and their emotional or mental health being more severely affected.

By recruiting a low grade tumour clinical nurse specialist, we can improve life today for patients and ensure that there is always someone protecting their right for equal access to the best treatment and care. We know that for those managing the symptoms of a brain tumour day in and day out, the impact will be huge.



A donation of

£200

allows a clinical nurse specialist to spend a day personally supporting patients through their brain tumour diagnosis and treatment.

Q&A with Jen Watson

Director of Nursing,
King's College Hospital, London



By 2020 our goal is to be funding 25 low grade tumour clinical nurse specialists. Now, as we support our first one at King's College Hospital, we catch up with Jen Watson to find out more about what this exciting new post will mean for patients.

What difference will the appointment of this low grade tumour CNS at King's make to patients?

Low grade tumours pose a particular type of anxiety for patients and support must be provided to help manage the unique challenges individuals with these tumours face. A CNS recruited specifically to look after these patients will mean that there is a consistent and knowledgeable point of contact who will be able to support and assist those affected throughout.

You're the pilot site for this project. Why is it exciting to be involved at this early stage?

This project is a fantastic opportunity for us here at King's to work collaboratively with the third sector, pooling skills and resources to help deliver excellent care to our patients with low grade tumours. We feel extremely excited to be working with The Brain Tumour Charity on this service and are delighted to be the pilot site for it, enabling us to evaluate its impact, so that we can help influence future funding decisions made by The Charity.

What challenges currently face the CNS team and how will this post help alleviate them?

The CNS team are extremely busy, so this new role will be invaluable in allowing us to continue to deliver excellent patient care. This post will ensure that there is a knowledgeable and skilled nurse, with the expertise and experience required to manage the unique needs of low grade tumour patients.

What valuable contribution will this person make to the team?

The new CNS will be dedicated to offering the best care and support to patients and families affected by low grade brain tumours and will ensure that they're at the forefront of the medical team's care and decision making.

What would you like other hospitals to learn from this model?

We will monitor the impact of this role on patients and their families to gauge where they would like greater or different support from the service we currently provide. We hope to then share our findings with other organisations to help them recognise the benefit of this type of investment.

Join our united voice



Politics plays a vital role in our fight to find a cure. With a snap general election set for 8 June, it's now more important than ever to speak up about our battle to defeat brain tumours.

The election should be a catalyst for us all to influence candidates and for the next Government to take action on four key issues over the next five years:

- 1 **Guaranteeing access to EU research funding after Brexit;**
- 2 **Improving awareness to drive early diagnosis;**

- 3 **Delivering fair access to benefits for those in need;**
- 4 **Ensuring equal access to the best treatments like 5-ALA.**

We're therefore asking those of you whose lives have been affected by a brain tumour to join our exciting new advocacy programme and use your personal experience and passion to help us drive real change for brain tumour patients. We must speak up for change – together, our voice is louder.

To find out how you can get involved go to thebraintumourcharity.org/get-involved-in-policy

Breaking down barriers

In January, we attended a meeting of the Task and Finish Group which brings together experts in the field of brain tumour research to develop recommendations to drive forward change in research policy.

We discussed barriers to research including the lack of patients participating in clinical trials.

The Charity first highlighted this issue in our research strategy, *A Cure Can't Wait*, back in 2015. We're making good progress, but there's still more to do.

Dr Paul Mulholland, a consultant medical oncologist at The National Hospital for Neurology and Neurosurgery, London, says: "A medical oncologist sub-specialising in brain tumours can enhance the team to provide patients with the best care and treatment. If there were more, it could increase the number of opportunities for patients to enter clinical trials, accelerating the development of new treatments and our search for a cure."

The General Election may delay the group's final report. We will ask the new Government to make publishing this report and implementing its recommendations a priority.

Joseph's legacy of hope

On 4 March, the 18th annual Joseph Foote Ball was held at the Hilton Metropole, Birmingham, in honour of Joseph Foote, who sadly died aged nine, from a brain tumour.

The inspiring event, which was attended by over 700 people and raised an incredible £265,000, is known for being a very special occasion.

However, this year it held extra significance, as this August will mark 10 years since Joseph passed away.

Joseph's father, one of our Founders and Trustee, Andy Foote says: "Joseph was an incredibly caring boy who brought a lot of joy to a lot of lives. He always used humour to cope with his illness and not a moment goes by when I don't miss him. Recently I was watching a rugby match with one of his best friends, now 19, and I just kept thinking, Joseph should still be here too. He had so much left to enjoy."

In 2001, inspired by Joseph, Andy established The Joseph Foote Trust, which has since merged with Brain Tumour UK and Samantha Dickson Brain Tumour Trust to subsequently become The Brain Tumour Charity. There has been a significant step change in the brain tumour sector following the merger and Andy played a leading role to make this happen.

Andy says: "I'm proud of what we've achieved but my focus isn't on what we've done, it's on what there is still to do."



"While survival has doubled across all cancers, this is not the case for brain tumours. Yet I passionately believe that this is our time."

"Every day we're making vital progress, getting closer to our vision, and I am certain that with relentless hard work, unity and continued investment in our pioneering research, we will raise survival rates in line with other cancers."

"I'm proud of what we've achieved but my focus isn't on what we've done, it's on what there is still to do."

Andy Foote, Founder and Trustee



Thank you to The Lewis Moody Foundation

Heroes head east for HeadSmart

A huge thank you to Lewis Moody MBE and the 12 cyclists who embarked on the epic headeast cycle challenge in partnership with luxury superyacht company Y.CO in December. The 1,000km ride, from Vietnam to Cambodia, saw the challengers tackle steep mountains, dense jungles and temperatures of over 35 degrees to raise £75,000 for The Lewis Moody Foundation and the HeadSmart campaign.

We're incredibly grateful to the headeast team, Y.CO, Viper 10 and everyone who sponsored the team and donated to the challenge.

To follow The Foundation on Facebook and hear more about their activities and how you can join Lewis on his next epic adventure, headwest, visit facebook.com/thelewismoodysfoundation/



"This was such a team effort, everyone did so well and I'm incredibly proud of what we've achieved."

Lewis Moody

Running in memory

On 12 March, Lewis Moody and a team of 30 fantastic runners took on the 2017 Vitality Bath Half Marathon to raise £20,000 for the work of The Foundation and The Charity.

The day was a great success and was made the more inspirational by 10 of the group, who formed 'Team George', running in memory of their good friend Steve George.

"As a close friend of Steve's, I was proud and honoured to run for him and be part of such an amazing team. His family have received so much kindness from The Foundation and being able to take part in an event like this with Lewis and the team was a great way to show my own support."

Kay Davis



If you wish to fundraise for The Charity through The Foundation or for more on the story behind The Lewis Moody Foundation, visit thelewismoodysfoundation.org

Inside the lab

This March, we were thrilled to offer OSCAR's Paediatric Brain Tumour Charity, #StayStrongStu and The Brain Tumour Warrior Fund, the opportunity to meet Professor Simon Bailey and Dr Dan Williamson for a lab tour at the The Wolfson Childhood Cancer Research Centre, Newcastle University.

These charities, alongside, The Katy Holmes Trust, and many other organisations, are united through us and play a vital role in funding pioneering world-class research that is making excellent progress towards doubling survival rates for those affected by brain tumours. We were delighted to be able to show them a glimpse into the crucial impact of their work.

During the tour, the team were educated on Professor Steve Clifford's INSTINCT project, which is specifically looking at advancements in childhood medulloblastoma research, and were able to preview how this work is bringing us yet another step closer to finding a cure.

"A lab tour like this is really important for a charity like ours to keep wanting to perform. We came away with a renewed sense of wanting to do even better."

Marie Hughes, Chief Executive of OSCAR's Paediatric Brain Tumour Charity

How did you

#WearItOut?

*Thank you to
everyone who
wore a bandana
this March!*

On Friday 3 March, bandanas united thousands of our passionate community as you joined together to #WearItOut for Brain Tumour Awareness Month.

Up and down the country you came together to hold bake sales, sponsored cycles, swims and even roller discos, in order to raise awareness and vital funds for research into brain tumours.

Many of our wonderful Supporter Groups and corporate supporters also joined in the fun. Inspired by Super Sam's Fund, over 300 Edinburgh Woollen Mill branches joined us to #WearItOut and raised over £10,000 to support The Charity.

In addition, 30 Tesco Express stores swapped their shopping baskets for bandanas, raising nearly £2,000 and bringing us another step closer to defeating brain tumours.

With more than 240 events held and hundreds of bandana photos taken, so far we've raised over £100,000, and there is still more coming in. Your donations will be used to fund an incredible 400 days of vital research into brain tumours.

So whether you planned a huge party, or quickly snapped a bandana selfie, we can't thank you enough. Every bandana worn and contribution made has made a huge impact. One day, that impact will mean that brain tumours are defeated for good.





"Brain tumours are the biggest cancer killer of children and adults under 40 in the UK. This is a shocking statistic and has to change."

"I was delighted to #WearItOut this March to show my support to the thousands of families affected."

"We can only beat things like this together. I am honoured to play my part."

Olivia Colman
BAFTA-award winning actress



Supporter Groups

Our incredible Supporter Groups are dedicated volunteers who bravely come together in memory of, or inspired by, a loved one to raise funds and awareness for The Brain Tumour Charity.

Welcome to our new Supporter Groups:

The Trevor Atkins Fund
 The Freddie Tully Fund
 The Pamela Price Fund
 The Gary Clements Fund
 The Susan Shaw Fund
 The Great Minds Fund
 The Karyn Bent Fund
 The Imogen Whitby Fund
 The Richard Mannering Fund
 The Charlie Todd Fund

To find out more about our Supporter Groups or how you can set one up, visit thebraintumourcharity.org/supportergroups

"When my son Gordon died from an inoperable brain tumour, our family wanted to do something to honour his memory, so we set up The Gordon King Memorial Fund.

"As part of our efforts, I organised an annual golf competition. Friends were invited and instead of a trophy, one of Gordon's clubs was engraved and presented to the winner each year.

"Now we've raised over £52,000 for The Brain Tumour Charity. Knowing that we're playing an essential role in supporting vital research and getting to nominate the area of research that we wished to see Gordon's Fund support has been deeply comforting.

"Through our commitment to helping others, we will ensure that Gordon's legacy continues to live on."

John King
 The Gordon King Memorial Fund

A gift of a lifetime

"I'm looking at our engagement rings,
do you remember buying them?"

We married in September 1956. We were
so happy, a wonderful future before us.
We didn't know then about the brain
tumour which would take you from me.

Sixteen months together was all we had.
I never forgot you.

I'm in my eighties now and I'm giving our
rings to The Brain Tumour Charity, they
will use them to raise funds for research
for a cure – perhaps give another couple
longer together.

I think you will like that."



As soon as we read this beautiful
note, enclosed alongside two vintage
engagement rings, we knew we had
to celebrate this love story. The rings
felt too precious to be sold at auction,
so we made it our mission to find
them a new home where they would
be cherished.

Over the course of a national Valentine's
campaign on social media, promoted
by Geoffrey Munn, jewellery specialist
from the Antiques Roadshow, we were
inundated with expressions of solidarity
before a generous offer was made.

The inspiring lady behind this story
describes the journey of donating
these rings in memory as "a roller-
coaster of emotions all the way from
sad memories to quiet contentment
that I had done something which felt
so right. I am so very happy that the
rings have found a home."

Giving a gift to The Brain Tumour
Charity in memory of someone you love
is a truly special way of celebrating their
life. You can do this by dedicating a gift
in your Will to a loved one or making
a donation in their memory.

For more information contact:
inmemory@thebraintumourcharity.org
or visit [thebraintumourcharity.org/give-
in-memory](http://thebraintumourcharity.org/give-in-memory)

Runway fashion helps fund research

We would like to say a huge thank you to St Andrews Fashion Show who chose us as their charity partner this year and put on a sensational show to help us fund some very exciting research.

Despite adverse weather conditions unfortunately forcing the original event to be cancelled, the team at St Andrews worked incredibly hard, and on the 14 February the show did indeed go on as dedicated students hit the catwalks, raising £28,000 for The Charity.

The glamorous and dazzling event was a great success and we're thrilled that all the funds raised from the 2017 launch party – Starfields – and the show will be going towards an innovative research project at Heriot-Watt University in Edinburgh, where scientists are printing 3D brain tumours for the first time to help develop drug treatments.

We're incredibly grateful to everyone at St Andrews, and to The Silas Pullen Fund, which inspired The Charity's application.

The Fund was set up in memory of Silas who sadly died of a brain tumour aged 11.



"When Silas was diagnosed, he was put on the same drugs that people were being offered 40 years ago. Right now, there is little else to offer these children – but the pioneering work undertaken by The Brain Tumour Charity gives families like ours who are facing the disease more hope."

Ben and Sarah Pullen

Partnerships

We're thrilled to announce that 2017 is proving to be a very exciting year for The Charity with a number of new corporate partnerships including Audit Scotland, Carbon Clear, Edinburgh Woollen Mill, Floor & Wall Ltd, Michelmores, moneycorp (Gatwick) and Resolute.

With the year already packed with fundraising events and activities, we're all very much looking forward to working alongside our new partners.

To find out more about getting your company involved visit thebraintumourcharity.org/how-your-company-can-help



We have lots of exciting events taking place this year and we'd love to see as many of you taking part as possible.

The Charity needs to keep making progress in our mission to double survival and halve the harm that brain tumours have on quality of life, but we can't do it without you.

So whether you fancy walking, running, biking, skydiving or even volunteering, please join us – as long as you're passionate we know that we'll make a great 'pear'!

Find out more at thebraintumourcharity.org/events



Last year over 1,800 of you came together for The Twilight Walk, united in our quest to defeat brain tumours. This year we are asking even more of you to **#WalkWithUs** as we take further vital steps towards finding a cure.



Last year, The Twilight Walk raised an astonishing £280k, as hundreds of you joined us on our journey to double survival and halve the harm of brain tumours.

Now, along with your family, friends and colleagues, we're asking you to please join us once again.

We know that every small step you take will have a huge impact in helping the 102,000 people currently living with a brain tumour in the UK.

You can choose from one of our three locations, or if you can't reach one of those you can still **#WalkWithUs** by holding your own 10k walk in your village, city or town.

Whether you take part or volunteer, your contribution will make a huge difference. Our journey to defeat brain tumours is an ambitious one, but with you walking beside us, we know we'll get there.





UNITE. SHARE. CELEBRATE.

#WalkWithUs

CHESTER
1 October

WARWICK
8 October

WINDSOR
15 October

Sign up and #WalkWithUs:
thebraintumourcharity.org/thetwilightwalk

Thank you to #TheBrainyBunch

We're forever inspired by your dedication, effort and passion to raise funds and awareness for us. Every event you hold – however big or small – makes a huge difference to those affected by a brain tumour.

**Thank you
very much.**

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



Anthony Morgan and nine friends took on the Invincible Challenge in support of Anthony's brother, Daniel, who is living with a brain tumour, and raised £1,200.



Palletforce has raised a fantastic £8,737 through their members' meeting last year and hope to raise even more in 2017!



Following her diagnosis of a brain tumour in June 2016, instructor Alexis Strong held a Line Dancing event in Brierley Hill, Dudley and raised £1,500.



Matthew and Hayley Smith raised £5,100 from their Burns' Night Ball.



Joe Cosgrove and his friends celebrated his birthday by taking part in a spinathon and raised £612 in memory of Joe's friend, Iestyn.



Mat Bayfield (pictured above) and Kelly Pritchard organised a walk every day throughout the month of January. Their penultimate walk brought together a phenomenal 540 walkers and, to date, they have raised over £20,000.



Mark Pritchard-Jeffs signed up to do the £1,000 Challenge at the JFT Ball in 2016. He rallied the Stratford-on-Avon Tennis Club members and they held a 24 hour non-stop tennis-a-thon raising a total of £7,854.



Karly Murray, 11, from Liverpool kept a promise she'd made to her grandad, Dave, before he passed away, that she would cut her very long hair. She also ran in the Liverpool Santa Dash and overall raised a total of £325.



Brain tumour survivor, Jonathan Edwards, 13, and his family raised £3,000 for The Charity.



Sainsbury's in Prestwick have raised more than £7,500 this year with more in the pipeline.



Hannah from Southampton worked incredibly hard to get fit and has taken on two extremely tough obstacle courses raising £2,365.



Angela Howarth and her Tai Chi class in Liverpool held a bring-and-buy sale and raised £1,184 – the most they've ever raised at this annual event.



Lisa Greenaway and the NI Pigeon Racing Fraternity at Dromore County Down raised £8,000 in total over the year.



Louise Hogg, together with her family and many friends, organised a wonderful charity ball in memory of her beloved father, Colin Venner, who passed away in December 2015 and raised £16,411 towards our work.

The little gifts that make a massive difference...

Every donation we receive helps us to get closer to our vision of a world where brain tumours are defeated. Our work is funded solely by voluntary donations, so whatever you can give makes a huge difference.



A donation of

£2

a month for one year could pay for a specialist nurse for an hour to help people with a low grade tumour, and their families, receive essential information and support.



A donation of

£20

a month could pay for a day's world-class research every year.

Set up a regular donation today at: thebraintumourcharity.org/donate

Find out more about leaving a Gift in your Will: thebraintumourcharity.org/my-gift

Did you know

You can set up a Direct Debit for as little as £2 per month. It's up to you how much and how often you donate.

Every donation or regular gift can be made in memory of, or inspired by, a loved one or dedicated to one of our Supporter Groups.

Regular donations and gifts in Wills help us to commit to long-term funding, for example our five year investment into our new Everest Centre.

Just 1% of your Will, after loved ones have been looked after, can have an impact for generations to come.

Thank you!

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

If you would like more copies please contact us:

enquiries@thebraintumourcharity.org
01252 749990

For queries about making a donation:

donations@thebraintumourcharity.org
01252 749043

Please send your donations to:

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



Research | Awareness | Support