

The Brain Tumour Charity shining a light on

# The GREY MATTERS

The **BRAIN  
TUMOUR  
CHARITY**

Research | Awareness | Support

Issue 8 Spring 2015



A Cure Can't Wait: Our Research Strategy

Bandanas for Brain Tumours Day

Launch of Jake animations

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



Image: Neil Dickson MBE and Angela Dickson MBE (right) pictured with some of our amazing volunteers at HQ in December.

## Founders awarded MBEs

Neil and Angela Dickson, Founders of The Brain Tumour Charity, are to receive MBEs for their services to the brain tumour community. They were recognised by the Queen in the New Year Honours List eighteen years after they founded the Samantha Dickson Research Trust following the death of their 16-year-old daughter from a brain tumour.

Our Chief Executive, Sarah Lindsell, said: “Neil and Angela have transformed the brain tumour research landscape and brought hope to people who for many years had none.

“And thanks to them, people affected by brain tumours have a voice and a support network, through The Brain Tumour Charity.”

Over 9,300 people are diagnosed every year with a primary brain tumour. We remember all those who have lost their life to a brain tumour and those who have lost family and friends.

**Pictured on front:** Bhavna Emery-Jones wearing our 2015 bandana. She says her attitude since being diagnosed with a brain tumour has been ‘bring it on!’

## Stay in touch



Sign up for our monthly e-newsletter and help us save on postage. Read the latest issues and sign up at [thebraintumourcharity.org/news](http://thebraintumourcharity.org/news)



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# Hello



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Welcome to *The Grey Matters*, packed full of our latest news as well as your inspirational achievements and stories.

I am particularly proud that this issue covers the launch of *A Cure Can't Wait: Our Research Strategy*, which we have developed with patients, carers and leading global experts to define our priorities over the next five years.

The strategy, which we have already begun to implement, represents a minimum £20million investment in the highest quality research across initiatives including biobanking, early diagnosis, quality of life and the development of new treatments. Turn the page to read more about the work we will be doing to help defeat brain tumours as fast as possible.

It is thanks to you, our supporters, that we can commit to funding pioneering research with the potential to transform the lives of people affected by a brain tumour. This issue shows some of the incredible commitment and imagination of people all over the country who are on track to raise an unprecedented £6million for us this financial year.

Now we need your support more than ever to increase our fundraising even further and secure the future of the plans we have set out in our research strategy. Together, we can make sure we deliver on our ambitious goals.

Thank you for standing shoulder to shoulder with us as we fight brain tumours on all fronts.

**Dr Alison Evans**  
*Head of Research*

# A Cure Can't Wait: Our Research Strategy 2015-2020

Following consultation over the last year with the very best experts in brain tumour research globally, including at our Brilliant Minds International Symposium, we have developed a new research strategy for the next five years.

*A Cure Can't Wait: Our Research Strategy* focuses on two of our strategic goals – doubling survival and halving the harm.

The strategy is underpinned by our values and global collaboration to ensure the best outcomes for everyone affected by a brain tumour in the UK.

We know that brain tumours are different to other cancers – they affect the part of you that makes you, you. This is why our research strategy does not simply focus on survival but also on quality of life.

Now is the time to focus our efforts on key priority areas to revolutionise research and accelerate progress towards the cure we are all desperately seeking. Critically, we need to ensure that our research, policy and advocacy activities are integrated so that we can optimise the environment in which research is conducted and facilitate the rapid translation of fundamental discoveries to benefit patients.

This strategy will represent a significant multi-million pound increase in our research investment, which is only possible due to the ongoing support of each and every donor, fundraiser and partner. Thank you – we can only do this together.

Read the strategy in full at:  
[thebraintumourcharity.org/researchstrategy](http://thebraintumourcharity.org/researchstrategy)

Over the last 18 years, our researchers have made discoveries that give hope every day to people diagnosed with a brain tumour. See our timeline of research breakthroughs: [thebraintumourcharity.org/research-timeline](http://thebraintumourcharity.org/research-timeline)

With your amazing support, we are now ready to step up the search for a cure and create a world where brain tumours are defeated.

# DOUBLE SURVIVAL HALVE THE HARM

## ACCELERATE

Biobanking to accelerate research progress through centralised collection of, and access to, brain tumour tissue samples

## DIAGNOSE

Diagnosing brain tumours earlier and more accurately for both children and adults

## UNDERSTAND

Increasing understanding of the genetics and biology of tumour development to identify effective new treatments

## CATALYSE

Translating laboratory discoveries into new and effective treatments that increase survival and quality of life

## ENHANCE

Enhancing care and quality of life for everyone affected by a brain tumour, including patients and carers

## AN INTERNATIONAL APPROACH

PIONEERING

PASSIONATE

COLLABORATIVE

SMART

# The Research News

Searching for a cure

## At the cutting edge of new research

By playing our part in conferences all over the world, we make sure we are always at the forefront of research into brain tumours. The meetings allow researchers to share progress and improve knowledge across the field.

### Glioma Conference

October



Every year, we sponsor the Glioma Conference in London to bring together top researchers working on high and low grade glioma brain tumours. At the latest conference, we heard about research into the origins of brain tumours, as well as developments in diagnosis, surgery and radiotherapy. Professor Denise Sheer, who we fund, spoke about her work at Queen Mary University of London on genetic changes in low grade childhood brain tumours, before junior researchers presented their recent findings.

The Glioma Conference is co-organised by Professor Paolo Salomoni (pictured above), who leads our UCL research programme exploring new ways of treating brain tumours.

### National Cancer Research Institute Conference

November

During the National Cancer Research Institute Conference in Liverpool, we met hundreds of researchers and healthcare professionals, helping us to build connections with the wider cancer community. Two of the talks at the conference were given by researchers we fund, Professor Steve Clifford and Professor Anthony Chalmers, while Dianne Jones from The Hannah Louise Jones Fund explained her views on the importance of tissue banking as a parent whose daughter was diagnosed with a brain tumour.

### Society for Neuro-Oncology Annual Meeting

November

At the Society for Neuro-Oncology Annual Meeting in the USA, we joined international colleagues to share the latest developments in brain tumour research. In particular, we welcomed trial results showing that use of the electromagnetic NovoTTF device could lead to improved survival for glioblastoma patients. Read more: [thebraintumourcharity.org/NovoTTF](http://thebraintumourcharity.org/NovoTTF)





## Celebrating a new era of research

Image: INSTINCT researchers with our Founding Trustees Neil Dickson MBE and Angela Dickson MBE (left), as well as our CEO Sarah Lindsell (right) at the programme's launch.

At Newcastle University, in September, we held the launch of our £4million jointly-funded INSTINCT research programme to drive forward new treatments for some of the deadliest childhood brain tumours.

Supporters and friends saw our research in action with a laboratory tour and heard a talk by Professor Steve Clifford, who is leading the programme.

Paula Holmes from The Katy Holmes Trust also spoke at the event. The Trust, which was set up in memory of ten-year-old Katy who lost her life to a DIPG brain tumour, is now working with us to help fund the DIPG element of the new research.

Children with Cancer UK and Great Ormond Street Hospital Children's Charity are the other funders of the programme.

Tracey, one of our supporters, said: "The launch event was very informative and showed the amazing work that's been made possible by people who raise funds for The Charity. It was also great to hear from families who have been through the same suffering."

## Tailoring treatments for children

The INSTINCT programme is being conducted at Newcastle University, the University College London Institute of Child Health and the Institute of Cancer Research.

Researchers will be using cutting-edge screening techniques to identify critical genetic and biochemical features of aggressive tumours.

Their findings will be used to develop tailored treatments so that therapies which target specific tumour characteristics can be offered to children with the most dangerous tumours.

The aim of the research is to find ways to save lives as well as spare children with less deadly forms of tumour the trauma of unnecessary and potentially damaging treatments.

Read more at [thebraintumourcharity.org/INSTINCT](http://thebraintumourcharity.org/INSTINCT)

## Q&A with Dr Jason Adhikaree

### The University of Nottingham



Last year Dr Jason Adhikaree was awarded our first Clinical Research Training Fellowship. The fellowships are jointly funded by The Brain Tumour Charity and the Medical Research Council and are designed to attract talented doctors to the brain tumour research field. Dr Adhikaree is investigating how the body's immune system could be used to fight glioblastoma brain tumours.

Read more:  
[thebraintumourcharity.org/clinicalfellowship](http://thebraintumourcharity.org/clinicalfellowship)

### **Why did you apply for the Clinical Research Training Fellowship?**

The fellowship gives doctors like myself an opportunity to dedicate three or four years to research. It allows excellent quality research to be combined with clinical experience to push forward advances in the doctor's speciality.

### **Why is getting more clinicians involved in brain tumour research important?**

Improvements in survival will require research in a range of areas to increase understanding of the causes of brain tumours, detection, imaging and treatments. To achieve this, clinicians and scientists from all backgrounds must unite.

### **What motivates you in your job?**

As a researcher and an oncologist my main goal is to improve cancer treatment through my research and ultimately patient outcomes. Nothing would give me more pleasure than to see my projects improving survival.

### **What is the potential impact of your research?**

Immunotherapy, manipulating a patient's immune system to attack their own cancer, is an exciting emerging treatment option. One type of this therapy is a vaccine using white blood cells which is showing promise in early trials. I am aiming to enhance these vaccines and I will also be looking at combining them with additional immunotherapies which allow a greater immune attack on cancer cells, potentially paving the way for clinical trials.

### **Why is more money needed for research?**

Research into multiple areas is essential to improving survival. The more money we can invest in these areas, the better the outcomes we will achieve.

### **How would you help us raise funds?**

It would probably be a long distance assault course. I have run the London Marathon, three half marathons and a 10k Santa Run in the last 18 months so I am planning the next challenge!



# Making your voice heard

In our strategic plan for the next five years, we have committed to significantly improving the NHS experience that brain tumour patients receive and halving the negative impact that brain tumours and treatment have on quality of life.

Part of the way we are working to achieve these goals is to influence policy makers to deliver better care.

## APPG on brain tumours

In 2014/15 we are driving the agenda of the All-Party Parliamentary Group (APPG) on Brain Tumours to focus on quality of life issues. The latest meeting of the group, which connects MPs and peers with the brain tumour community, took place in the autumn.

Speakers at the meeting included our Young Ambassador Rebecca Reed and Mr Paul Grundy, Chair of the Brain Tumour Clinical Reference Group, who explained an NHS initiative to improve the patient experience.

A key issue raised by patients and family members was poor communication by doctors breaking bad news, while there were also repeated calls for better rehabilitation services and respite care.

To attend future APPG meetings, email [policy@thebraintumourcharity.org](mailto:policy@thebraintumourcharity.org)

## General election manifesto

Ahead of the general election in May, we are publishing a manifesto calling on all political parties to make key commitments to accelerate brain tumour research, drive early diagnosis, ensure equal access to treatment and enhance quality of life.

Read our full manifesto: [thebraintumourcharity.org/manifesto](http://thebraintumourcharity.org/manifesto)

## National Cancer Patient Experience Survey

The results of the National Cancer Patient Experience Survey 2014 were released in September and show continued poorer standards of care for brain tumour patients. Our position on this is clear – it is unacceptable.

The annual survey asks cancer patients 70 questions about their diagnosis, treatment and care. In the latest survey, brain tumour patients reported the worst experience of all cancer patients in several areas including being treated like a set of symptoms, not being given a clear explanation of test results and seeing hospital and community staff work well together.

Read our full response to the results and find out what we are doing to make vital changes: [thebraintumourcharity.org/patient-experience](http://thebraintumourcharity.org/patient-experience)

# The Supporter Groups

We now have an incredible 200 Supporter Groups, all dedicated to raising funds and awareness on a long-term basis.

Groups are set up in memory of a loved one or inspired by someone living with a brain tumour. They are a great way to bring friends, family and colleagues together, strengthening our community and helping to defeat brain tumours faster.

If you would like more information please get in touch.

**[supportergroups@thebraintumourcharity.org](mailto:supportergroups@thebraintumourcharity.org)**  
**[thebraintumourcharity.org/supportergroups](http://thebraintumourcharity.org/supportergroups)**  
**01252 749043**

*Image (below):* A team from The Sarah Kitchener Perrow Fund took on the 300 mile London to Paris cycle, raising nearly £7,000.



## Welcome to our new groups

**The Andrea Fiandaca Fund**

**Charlie's Journey Fund**

**Jessica Green's Fund**

**The Mandy and David McGowan Fund**

**The Heads Up For Henry Fund**

**The Chris Murphy Fund**

**The Martin Vizzard Memorial Fund**

**The Alan Morris Memorial Fund**

**The Monika Newsam-Smith Fund**

**The Alistair Hare Fund**

**The Travis Moore Fund**

**The Repper Brothers Fund**

**The Think Pink Fund**

**The BW Fund**



**Focus on...**

## The Alfie's Journey Fund

The Alfie's Journey Fund was set up in February 2014, inspired by six-year-old Alfie who was living with a DIPG brain tumour.

Sadly Alfie passed away in June after a very brave fight. His family are determined to continue supporting our work in memory of their 'Alfie Bear'.

So far The Alfie's Journey Fund has raised over £24,000.

Read more: [thebraintumourcharity.org/alfies-journey](http://thebraintumourcharity.org/alfies-journey)



## An interview with Zoe and Danny, Alfie's mum and dad

### What first influenced you to fundraise?

Following Alfie's diagnosis we wanted to help fund research so that children and their families have a better prognosis in the future. With our Supporter Group we have a platform to raise awareness and funds with expert help to guide us through.

### Why The Brain Tumour Charity?

We first heard of The Charity after Alfie's diagnosis while we were looking for support and advice. It was credited in quite a few research reports and we found they fund a lot of cutting-edge research, while raising vital awareness as well. Setting up a group was very simple and the team helped us all the way through.

### Which area of The Charity's work did you select to fund?

Our group is funding paediatric research to help children affected by a DIPG tumour. We feel very passionate about making a difference to DIPG research in our Alfie's memory.

### Tell us a little about your fundraising so far?

Friends have run marathons, competed in Tough Mudder and taken part in the Snowdon Challenge. There have also been mufti days in local schools, coffee mornings, fêtes and our first Charity Dinner and Auction was held in September. Currently there is a hair growing and beard growing challenge taking place!



Image (above): Grant (right) with his dad, John

## Race against the tube

Inspired by John Mills, who is living with a brain tumour, The John Mills Fund has currently raised a total of over £18,000.

John's son, Grant, decided to take on the tube in a head-to-head race in September to see if he could beat the time taken for passengers to travel through 23 stations. Titled Trainers4Brains, Grant's fundraiser involved a nine mile race starting at Hainault and finishing at Hornchurch.

Cheered on by friends and family members including John, it was a nail biting finish with Grant finishing just seconds after the tube pulled in! Not to be defeated by a tube train, he says he's "definitely interested in a re-match soon." The race raised almost £2,000 and attracted fantastic local media coverage.

Read more about The John Mills Fund: [thebraintumourcharity.org/johnmills](http://thebraintumourcharity.org/johnmills)





## The power of conversation

Recently we heard how a simple conversation made a life-changing impact.

Beth's Dog Show is an annual series of nationwide dog shows that raises money for The Brain Tumour Charity through The Sarah Kitchener Perrow Fund, a Supporter Group set up after Sarah tragically lost her life to a brain tumour.

One of the organisers of Beth's Dog Show, David, had a chance conversation with a lady about why the events started. A few days later, he received an interesting phone call:

"We were overwhelmed when we took a phone call from the lady we had been speaking to at the show to say that, as an executor of a Will, she had selected The Brain Tumour Charity to receive a gift of £75,000. We couldn't believe that Sarah's story could inspire such generosity from someone who had never met her. It is a gift that we know will make a huge difference to the pioneering research that can be funded."

*"It is a gift that we know will make a huge difference to the pioneering research that can be funded."*

Compared to other charities, we currently receive very little income from gifts in Wills. If you are writing or amending your Will, please consider leaving a small percentage or set amount to The Brain Tumour Charity. Your support today will help us save lives tomorrow. Visit [thebraintumourcharity.org/legacy](http://thebraintumourcharity.org/legacy) to find out more or call 01252 749043





# Support on Facebook



In May 2013 we launched our online community for patients, carers, family and friends in the form of a Facebook support group.

The group is a way for people affected by a brain tumour to meet each other online, share experiences and feel less isolated. Members use the group as a safe space where they feel comfortable talking about anything they want whilst knowing that others will understand.

Over the past year and a half we have been overwhelmed by the warmth and sense of community shown on Facebook. People are welcoming, hugely supportive and are happy to share their experiences in the hope that they can make someone else's journey a little less frightening.



*This group has helped me so much I do not know what I would have done without it! I felt really isolated and terrified when I was told I had a brain tumour but the people in the group have been so supportive and kind that it has kept me going recently when others couldn't."*

Clare, 15-year-old living with a brain tumour



## Join the community

Our Facebook group currently has over 1,600 members which means that you can talk to people being treated in different places throughout the UK and usually meet someone with a similar tumour or experience to you.

You can access the group whenever you want and are very likely to find someone else online at 2am who is also unable to sleep! The community is moderated by members of our Support and Information Team, has a code of conduct and anything you post will not be seen by your Facebook friends unless they are members too.

Join The Brain Tumour Charity Facebook support group now:  
[bit.ly/supportonfacebook](http://bit.ly/supportonfacebook)

## Cara Chapman, Facebook support group member



"My mother, Janet Chapman, was diagnosed with a glioblastoma in February 2013. I have a wonderful partner and my brother and I are close, but this was such a new and terrifying experience that there were times of incredible loneliness. Somehow, a brain tumour felt different to any other kind of cancer and I was left with the feeling that other people didn't really understand.

"When I attended one of The Brain Tumour Charity's information days the Facebook group was mentioned. I have used Facebook a lot over the years so it felt natural and I signed up straight away. I was greeted with a group of people who just got it. I could vent when I was angry, share when I was sad and tearful, and this group was always there. It didn't seem to matter what time of day or night, there was almost always someone online happy to chat. It definitely helped me to feel less alone and joining the group pointed me in the direction of The Charity's fact sheets which I found very helpful and reassuring.

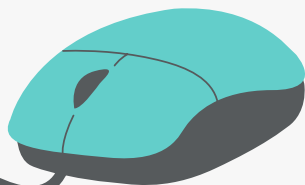
"My mum sadly passed away in January 2014 and I now feel like I can give back in the Facebook group by supporting people on the journey having been through it myself.

"Since losing mum we've also held a collection for The Brain Tumour Charity at mum's funeral, run a World Cup sweepstake and some of my family took part in The Twilight Walk Warwick. It feels important to be able to support this brilliant organisation."

“

*I was greeted with a group of people who just got it. I could vent when I was angry, share when I was sad and tearful, and this group was always there.*”

Cara Chapman



# Marc Silk

*“Surround yourself with happiness”*

Marc Silk was diagnosed with a brain tumour in 1990 at the age of 18. His passion for film helped him through his recovery and he achieved his boyhood dream nine years later when he featured in Star Wars Episode I: The Phantom Menace. Marc is now a leading voice actor and a Patron of The Brain Tumour Charity.

Recording with Star Wars creator George Lucas in the legendary Abbey Road Studios was the realisation of a lifetime ambition for Marc Silk.

“As a kid, I watched my VHS video of The Making of Star Wars over and over again until it was nearly worn out,” he says. “I’ve always been fascinated by the magic of what goes on behind the scenes.”

Little did he know that he would one day feature as the voice of Jedi Council senator Ahsoka in Star Wars Episode I. “Just meeting George Lucas was enough of a thrill, never mind being in the actual film,” says Marc.

Currently, as well as playing roles including Scooby-Doo and the US Bob the Builder, Marc also does voiceovers for commercials and shows like the Royal Variety Performance.

Yet back in 1990 when he was diagnosed with a brain tumour, Marc had only just started work experience at BRMB radio station in Birmingham.

He found that seizing happy moments helped him to think positive during his radiotherapy and recovery.

“My mantra was: ‘I am going to get through this and I am going to have an incredible life.’ When you can’t control what is happening to you, the only control you do have is how you react to it.

“I coped by surrounding myself with happiness. I immersed myself in music, books and documentaries that made me happy and inspired me.”

Marc says that the support and opportunities offered by The Brain Tumour Charity for young people diagnosed with a brain tumour today, such as the Young Ambassadors programme, would have “really helped me connect and share with others going through the same journey”.

Last year Marc helped launch our animated character, Jake, who we have developed to give children a way of understanding more about their diagnosis and treatment (read more on page 22). Marc is impressed by Jake: “He’s loveable! The intention behind him is brilliant and I’m sure he’ll help The Charity’s fantastic work.”

Visit [marcsilk.com](http://marcsilk.com) or follow Marc on Twitter: @marcsilk



***The  
Story  
of Hope***

# The £2,015 CHALLENGE

The fun starts now  
- good luck!

Do something amazing in 2015 and raise £2,015 for life-changing research, awareness and support.

Follow our pathway to beat the target or swap in your own fundraising ideas to make the challenge perfect for you, your family, colleagues and friends.

£50

## Collection tin

Put out a collection tin at your workplace, local shop, gym or restaurant = £50

£1,300

## Summer Social party

30 guests @ £15 each = £450  
Sell 30 raffle tickets @ £5 = £150

£1,600

## The Twilight Walk

Bring a friend  
2 @ £150 sponsorship  
= £300

£1,725

## Tea and Bake Off

Sell 25 cakes @ £3 = £75  
10 Bake Off competition entries @ £5 each = £50



## Need help with your fundraising?

We're here for you every step of the way.  
[fundraising@thebraintumourcharity.org](mailto:fundraising@thebraintumourcharity.org)  
01252 749043



### Sale

£200

Hold a sale on eBay or at a nearby school or church. Buy, make or donate items = £150

### Bandanas for Brain Tumours Day

£400

20 guests @ £10 each = £200

### 10k run

Sponsorship = £250

£700

### Grand National sweepstake

25 bets @ £2 = £50

£450



£2,015

### Matched funding

Secure matched funding from your work = £290

## YOU DID IT!

Well done and thank you!

Your money can help find new treatments and save lives.



# A day in the life of Ingela Oberg

Clinical nurse specialist

Ingela Oberg is a clinical nurse specialist working with brain tumour patients and their families at Addenbrooke's Hospital in Cambridge. Clinical nurse specialists offer support from the time of diagnosis, act as a point of contact with other healthcare professionals and can refer patients to other services.



My day starts by checking the answer machine. I deal with queries ranging from pre- and post-operative complications, medicines and end of life advice to long-term concerns about outcomes, driving and returning to work.

I once had a phone call first thing in the morning saying that a patient had become hard to rouse and was constantly vomiting. I got back to his wife to tell her I was calling an ambulance.

The patient had bled into his tumour requiring an emergency operation. Thankfully he made a remarkable recovery and is now back home receiving further treatment. So even in dire situations we are often the first ones families turn to.

Then I undertake my weekly telephone clinic. I call patients to discuss their most recent scan results and go through their medication, disease management and any questions they may have.

My day continues by prioritising urgent cases requiring review and preparing the multi-disciplinary team meeting where doctors, surgeons, clinical nurse specialists and other

healthcare professionals work together to develop a tailored plan for every patient.

When patients come back for results, I see them with a consultant. We jointly explain their diagnosis and give them The Brain Tumour Charity's Newly Diagnosed Pack. The packs are very effective and complement our work by linking people to The Charity's guidance, information and support.

The job we do is not easy and most of us struggle with the unfairness of its reality. But having been on the other side of the fence when I lost my younger brother to a brain tumour, I know the difference we make. I couldn't think of a more rewarding job.

Our Support and Information Team can find details of your local clinical nurse specialist, send you a Newly Diagnosed Pack and help with any aspect of living with a brain tumour:

0808 800 0004  
[support@thebraintumourcharity.org](mailto:support@thebraintumourcharity.org)

# Proton beam therapy

The story of five-year-old Ashya King has brought proton beam therapy to the public eye but the issues around the treatment are not always fully understood. Our Support and Information Team has provided a summary to help you find out more.

## What is proton beam therapy?

Proton beam therapy is a specialised form of radiotherapy using positively charged subatomic particles (protons). It is highly targeted and does less damage to healthy cells than conventional radiotherapy.

The treatment is not suitable for all types of tumour and works best when there are clearly defined margins and the tumours are smaller.

## Proton beam therapy in the UK

Currently proton beam therapy is not available in the UK, but it is still accessible on the NHS through the NHS Overseas Programme. Over the last five years 517 patients have been referred through this programme, with 394 of them being accepted and treated. This has cost, on average, around £80,000 per patient though this varies depending on their specific diagnosis.

In 2012 the UK government announced that they would be commissioning two proton beam therapy treatment centres at University College London Hospital NHS Foundation Trust and the Christie NHS Foundation Trust in Manchester. The latest information says that patients will start to be treated in 2018. It is hoped that this £250million investment

will save lives as the centres will be able to treat up to 1,500 people a year and at a considerably reduced cost compared to the amount spent to send patients abroad.

In addition to this, the current system only pays for flights and accommodation. The availability of proton beam therapy in the UK will hopefully help eliminate the unforeseen costs that some families we support have experienced as they pursue the most effective treatment.

Read our proton beam therapy fact sheet to learn more:

[thebraintumourcharity.org/proton-beam-therapy](http://thebraintumourcharity.org/proton-beam-therapy)



Visit [thebraintumourcharity.org/factsheets](http://thebraintumourcharity.org/factsheets) to find our full selection of fact sheets on topics including treatments, fatigue, memory problems, depression and scans. Every fact sheet we produce has Information Standard accreditation, meaning that you can rely on them to be thoroughly researched, accurate and up to date.

The Information Standard



Certified Member

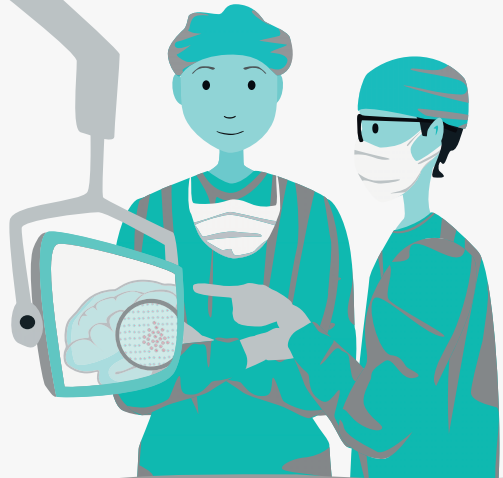
# Meet Jake

On 2 October we were delighted to be joined by families, healthcare professionals and other charities at Birmingham Children's Hospital to launch our Jake animations for children with a brain tumour.

Jake is an animated eight-year-old boy who takes other children through his experiences of living with a brain tumour to help them understand more about their diagnosis and the treatments they may face.

*"The Jake initiative fills a very important gap in information that is available for primary school children who are old enough to understand explanations, but who do not have the background knowledge and insight of our teenage patients. I have already started recommending Jake to newly diagnosed young patients and I think it will make explaining brain tumour scans and treatments much easier."*

Dr Martin English,  
Consultant Paediatric Oncologist,  
Birmingham Children's Hospital



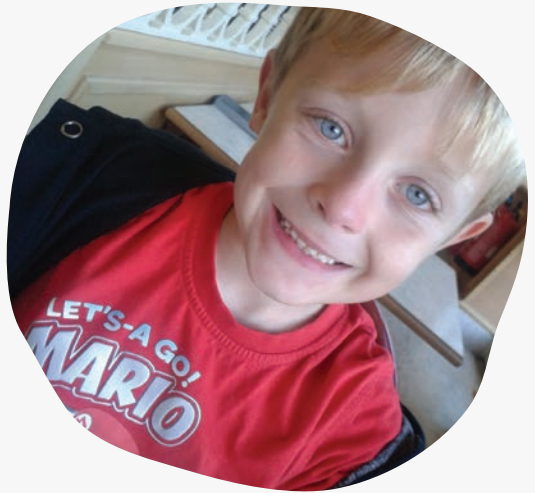
You can join Jake to learn more about brain tumours, scans, steroids, neurosurgery, radiotherapy and chemotherapy. Watch all six animations now at [thebraintumourcharity.org/jake](http://thebraintumourcharity.org/jake)

## Jake in action

Six-year-old Finn was diagnosed with a brain tumour in December 2013 and was rushed into life-saving surgery. This caused him to develop posterior fossa syndrome, which leaves children with temporary and complete loss of speech. As such, Finn has found it very difficult to talk about his surgery and side effects.

*“Finn has watched the neurosurgery animation over and over again. After brain tumour surgery he has only just started to refer to the lump in his head as a tumour. The animation has reopened conversations that have given us opportunities again to reassure him.”*

Finn's mum



Since his surgery Finn has been recovering well. His mum says he is the funniest guy she knows and the family's heart and inspiration every day.

*“I just wanted to say a huge thank you for Jake. My little boy, age three, had his first follow-up MRI today and was so excited to go to the hospital thanks to the scans animation. He'd been so terrified of hospitals and procedures following his diagnosis and surgeries, we were worried how he would react. He was actually excited to go and be like Jake in the 'doughnut machine'. A huge thank you.”*

Mother of a three-year-old child with a brain tumour

Adults are finding the Jake animations helpful too, not only in understanding their own treatment but also to explain to their children what mum or dad are going through.

*“I watched them all with my kids this afternoon. It prompted loads of discussion and questions, and them doing surgery on me on our sofa!”*

Gideon Burrows,  
low grade brain tumour patient

Thank you so much for giving Jake such a warm welcome! Please keep spreading the word so as many people know about him as possible and look out for our final two animations coming in 2015 - Mummy Has A Brain Tumour and My Brother Has A Brain Tumour.



# The HeadSmart news

Saving children's lives

## HeadSmart heroes

Since we launched the HeadSmart early diagnosis campaign for childhood brain tumours, we have reduced average diagnosis times from 14 to 6.7 weeks.

The campaign's Community Champions and volunteers have played a vital role in its success. Here are just a few of our HeadSmart heroes.

Thank you to everyone who has helped to spread the word and raise funds – together we are saving children's lives.

Visit [thebraintumourcharity.org/teamheadsmart](http://thebraintumourcharity.org/teamheadsmart) to get involved.



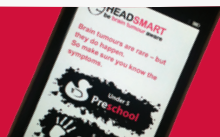
### David Kershaw

HeadSmart has received tireless support in the Blackpool area from Community Champion David Kershaw. Most recently, he organised a month of awareness raising activities concluding with Jake's Seaside Scamper in memory of his son, Jake.

During the awareness month, the HeadSmart colours were displayed on the Blackpool Tower and symptom information was shown on video screens on the pier. The Seaside Scamper, a 5.2 mile seafront walk, raised £630.



Know the symptoms  
**on-the-go**



Text SMART to 81400  
for your free mobile  
symptoms guide.

## Sacha Langton-Gilks

In September, Sacha Langton-Gilks was named Volunteer of the Year at the prestigious Third Sector Awards. She was recognised for her outstanding contribution as a HeadSmart Community Champion following the brain tumour diagnosis of her son David, who tragically lost his life in 2012.

Sacha has been paramount to the distribution of HeadSmart symptoms cards in Devon, Poole, North Dorset, Hampshire and Wiltshire. In addition, she inspired MP, Dominic Raab, to call a Westminster Hall debate on childhood brain tumours and has met with several other MPs, ministers, public health experts and teachers in her quest to get symptoms cards to every parent nationwide.

## Paula Green

Paula Green's work in Lincolnshire has led to primary schools, the University of Lincoln, Lincoln City Football Club and local businesses displaying symptoms cards and raising awareness. She has additionally secured the support of The Co-operative Pharmacy, meaning that all 48 of its Lincolnshire branches are displaying the cards.

## Julia, Marie and Emma

Three York mothers, Julia Holding, Marie Hughes and Emma Taylor, have worked together to get 24,000 symptoms cards into York schools. Both Julia and Emma have daughters living with the effects of a brain tumour diagnosis, while Marie sadly lost her son Oscar last year. The team has also taken on other activities including running an awareness stall in St Helen's Square in York.

## Amy Bennett

Amy introduced HeadSmart to Bounty, the UK's largest parenting club, who will be distributing symptoms cards in their Newborn Packs that are given to 820,000 parents each year. Our partnership with Bounty also means that cards will be sent to 36,000 healthcare professionals a year. Amy's daughter was diagnosed with a brain tumour at three weeks old and is now doing well.

## Emma Bassett

Community Champion Emma Bassett found out she had a brain tumour in 2004 at the age of 12. She believes that she could have been diagnosed earlier and saved numerous operations if her parents or teachers had received symptoms cards.

Emma has supported HeadSmart in many ways, from making a speech to MPs in parliament about the importance of the campaign to running the British 10k and Great North Run to raise funds. Recently Emma became one of The Brain Tumour Charity's first Young Ambassadors.

## General Optical Council

The General Optical Council, the UK's regulator for optical professionals, is showing its support for HeadSmart. The council ran a feature in its e-newsletter in September which generated requests for more than 4,000 symptoms cards from 54 different opticians.

# Fundraising at work

Thank you  
for all your  
hard work

We believe that being pioneering, passionate, collaborative and smart will help us win the fight against brain tumours faster. If these sound like values that matter to the business or organisation where you work, we'd be a perfect partner.

## Stand out from the crowd

One way for your company to work with The Brain Tumour Charity is cause related marketing. It's simple – you link your product or service to us to increase sales and donate a percentage of the profits.

Cause related marketing is proven to help you stand out in the market place, build brand awareness and gain new customer interest. Research from Business in the Community shows that 86% of consumers are more likely to buy a product that is associated with a cause or issue and 73% agree that they would switch brands for the same reason.

Last year Waitrose showed their support through cause related marketing, choosing us to benefit from the sale of their 2014 charity Christmas cards along with three other charities.



*“Our internal charities department put forward a list of charities and we looked at each website to find out some more information. As brain tumours seemed to be a cause that is so underrepresented, we wanted to choose you.”*

Nicola Manners, Buying Manager at Waitrose



### Can your workplace help?

If you think your business could help us change the lives of people diagnosed with a brain tumour, our *Getting Your Company Involved* booklet is packed full of information on our work, the ways you can support us and how the money you raise will make a difference. We also have step-by-step guides on how you can beat your fundraising target. Visit [thebraintumourcharity.org/corporate](http://thebraintumourcharity.org/corporate) or email [corporate@thebraintumourcharity.org](mailto:corporate@thebraintumourcharity.org) to get hold of a booklet and a guide today.

# Q&A with Inderjit Ghali

Senior HR Advisor,  
Dennis Publishing



Dennis Publishing selected us as their Charity of the Year for 2014 and staff have raised over £11,000. Inderjit has played a key role as part of the company's Corporate Social Responsibility Team.

## **Why is it important for companies to support a charity?**

It's a way to give something back. Our employees are passionate about what we do and it's great to see this enthusiasm transferred into helping such a good cause.

## **Why did Dennis Publishing choose to support The Brain Tumour Charity?**

We ask our employees to nominate charities each year. Sara Clayton, who works on one of our magazines, lost her brother to a brain tumour and to help commemorate his life she set herself an amazing challenge to take on a fundraising event each month of his 30th birthday year. Impressed by her determination, we felt it would be a brilliant opportunity to get involved.

## **How have your employees raised money?**

We have hosted events including pub quizzes, pool tournaments, ice cream giveaways and an egg decorating contest. The big Charity Day we held included a cake sale, jaffa cake challenge, silent auction and a BBQ lunch. Our HR Director and I also took part in The Twilight Walk Windsor.

## **How else have employees got involved?**

Our film team and photographers have undertaken various pro bono projects to help The Charity promote its work. We've also donated items for event goody bags, advertising space in many of our magazines and toys for The Brainy Bag, which is given to children with a brain tumour.

## **What does The Brain Tumour Charity bring to the partnership?**

We are given real insight so we can see exactly what our activities are supporting. The Charity is also great at asking for help when they need it, giving us a chance to share our expertise.

# What's in your diary for Friday 6 March?

**Wherever you are and whatever you're doing, make sure you're helping to make it the biggest Bandanas for Brain Tumours Day ever.**

Buy your bandanas for £3.50 each (including postage) and order your free fundraising kit at [thebraintumourcharity.org/bandanas](http://thebraintumourcharity.org/bandanas) or call 01252 749043



To show your support, simply buy our latest exclusively designed bandana and **Wear it out!** By wearing your bandana, you'll be joining a team of thousands of people playing their part in Brain Tumour Awareness Month.

Even better, why not hold a Bandana Day in your school, office, gym, pub or club? We've got everything you'll need to organise an amazing day, including fundraising ideas to guarantee a good time.

## **Wear and share**

Share your #Wearitout photos with us via [facebook.com/thebraintumourcharity](https://www.facebook.com/thebraintumourcharity) or on Twitter @BrainTumourOrg



**#Wearitout**



Wear it out!

The design of our 2015 bandana is inspired by energy and movement. It is a statement of our incredible potential to make change happen by causing a chain reaction of awareness. Wearing the bandana is a symbol of your commitment to spreading the word and getting everyone you know to do the same.







## Meet Ella, regional volunteer

Ella began volunteering for us in 2014. She has cheered on runners in the Great North Run, shown walkers the way at The Twilight Walk and will be supporting a fundraising Casino Night in February.

Last autumn, Ella also chose to take on the Spartan Race in Yorkshire to raise money.

### **Why did you choose to volunteer?**

My student nursing course includes a volunteering module. I chose The Brain Tumour Charity because my mum had a brain tumour 13 years ago and survived. I wanted to join The Charity to see the support that it offers and the research that helps so many families.

### **What's been your highlight so far?**

The whole experience has been amazing. Being part of the Great North Run and The Twilight Walk was inspirational and the atmosphere was like nothing I have experienced before. The Charity is close to my heart and everything I have been involved in has been so rewarding.

### **How do you work with other volunteers?**

As part of a team of volunteers based in York, I have regular meetings with other volunteers and our Community Fundraiser, Francesca. This allows us to find out the latest news from The Charity and new opportunities to get involved.

### **What would you say to someone thinking about volunteering for us?**

There is a role for everyone at The Brain Tumour Charity. Big or small, it's all appreciated. Also everyone is very friendly and there's a real sense of common purpose.

### **Tell us about the Spartan Race**

The Spartan Race was very hard. I didn't expect to be swimming through mud and sliding down hills, but the sense of achievement at the end made all the aches and pains worth it.

Volunteer with us today:  
[volunteering@thebraintumourcharity.org](mailto:volunteering@thebraintumourcharity.org)

# Thank you for walking with us



We'd like to say a huge thank you to every single walker, volunteer and corporate partner who made The Twilight Walk in 2014 such an unforgettable experience from start to finish. In total we brought together over 1,200 people of all ages in Warwick, Chester and Windsor to take a stand against brain tumours and show that we are united in the fight.

The spirit, strength and passion of supporters at each 10k walk made our team feel so proud to be part of the brain tumour community and we were humbled and honoured to hear why everyone was inspired to take part.

In total we raised over £210,000, enough to fund four pioneering research projects for a year.

Keep your eyes peeled over the next few months for details of The Twilight Walk in 2015.

See more stunning photos from our walks at [thebraintumourcharity.org/twilightphotos](http://thebraintumourcharity.org/twilightphotos)



*"I had no idea what to expect on the day, but the whole experience was truly inspirational and magical! Seeing so many other people who had experienced brain tumours in one form or another was amazing because at the time you think you are alone going through such a tragedy. I was overcome with emotion at the start of the walk and elated by the end of it and came home feeling as though I had really achieved something in honour of my mum."*

Claire Higgins, The Twilight Walk Warwick



The  
**TWILIGHT  
WALK**



## A fitting tribute to a family man

**Howard Kirkham lost his battle with a brain tumour in April 2014. His family and friends decided to pay tribute by setting themselves a series of challenges over 12 months to raise money for three charities including The Brain Tumour Charity.**

The Kirkhams were able to share their plans with Howard during the last few days they spent with him. Sara, Howard's daughter, spoke about their experience:

"Dad was a real family man, a highly respected friend and well-known member of the community. He loved the outdoors, walking, gardening and sailing. Most of us children had never seen dad cry but he did when we told him about our challenges.

"He was very proud of what we were all planning to do. Dad would have loved cheering us on at our challenges and would have even taken part in some himself.

"There have been many tough moments, both emotionally and physically. We have laughed lots and cried lots! Hearing that all nine cyclists had reached Abersoch after cycling 120 miles in a day was amazing. Taking part in The Twilight Walk Chester with 32 of our family and friends, watching Rhona running in the Great North Run, hearing all eight walkers had completed the Three Peaks in under 24 hours and watching Richard finish his 53 mile Lakes in a Day Ultra Run were massive highlights. Knowing we are helping to fund such valuable work has kept us focused and we have really supported each other, especially mum, through this very difficult time.

"We have raised over £15,000, which is a fitting tribute to a very special husband, dad, grandpa, son and friend."

If you are inspired by the Kirkhams and would like to take on a challenge of your own, visit [thebraintumourcharity.org/challenges](http://thebraintumourcharity.org/challenges)



## Perfect runs for everyone

In 2014 hundreds of runners raised an incredible £832,000 to help fund our vital work. If you're thinking that the new year is your chance to get fit and do something amazing for charity, or if you're looking to step up to your next challenge, then we've got you covered. From a 5k run in Brighton to a full-blown marathon in New York, there's something out there that's perfect for you.

Here are just a few ideas to get you started.



### Rookie runner

#### Run or Dye

The world's most colourful 5k.  
*Events across the UK*

#### Electric Run

A high-energy 5k through an electric wonderland with music and lights to keep you moving to the beat.  
*Events across the UK*

#### Spartan Sprint

Fifteen obstacles over 3 miles designed to push your limits, test your strength and challenge your endurance.  
*Events across the UK*



### Seasoned strider

#### Bupa 10,000

A 10k passing some of London's most famous sights.  
*London, 25 May*

#### Great North Run

Tackle an iconic half marathon shown live on the BBC.  
*Newcastle, 13 September*

#### Wolf Run

A unique combination of three kinds of off-road running – mud runs, trail runs and obstacle runs.  
*Warwickshire and Leicestershire, April, June, September and November*



### Hardcore harrier

#### Brecon to Cardiff Ultra

A 42 mile, one way race that winds its way from Brecon following the River Taff.  
*24 May*

#### New York City Marathon

The New York City Marathon has grown from a race in Central Park with 55 finishers to the world's biggest marathon.  
*1 November*

#### Thames Path Challenge

Beautiful and varied scenery along 100km, 50km or 25km of the Thames Path Trail.  
*London, 12-13 September*

Sign up  
now!

Find out more and sign up:  
[thebraintumourcharity.org/runs](http://thebraintumourcharity.org/runs)



# Thank you to The Brainy Bunch

Every day you inspire us with your dedication, effort and passion to change the odds and make a difference. Here are just a few highlights from your fundraising over the last few months.

Join The Brainy Bunch today:  
[fundraising@thebraintumourcharity.org](mailto:fundraising@thebraintumourcharity.org)  
01252 749043

Three Learndirect offices held a dress down week, with staff paying £1 to wear their own clothes. The week raised £100.

Angus Owen rode from Land's End to John O'Groats for The Silas Pullen Fund, raising over £1,500.



Lee Johnson and a team of his friends walked The Twilight Walk Chester dressed as characters from The Wizard of Oz, raising over £1,000. Lee (dressed as Dorothy) has two brain tumours which he has named Horace and Boris, and wanted to take part in the walk with the support of his friends to "get back to normality and do something positive".



By making loom band bracelets and selling them at her local Hampshire garden centre, Chloe raised £45 for The Peter Blunt Fund.



The eleventh annual Alan Igglesden Charity Golf Day brought together sporting friends including the family of Alan 'Iggy' Igglesden, ex-Kent and England cricketer, and our Patron Phil Tufnell. This year was extra special as Iggy was celebrating his 50th birthday and the 1st birthday of his daughter, Beth.



Our congratulations go to Paula Holmes from The Katy Holmes Trust who recently won an Inspirational Woman of the Year Award. This followed her epic journey climbing Mount Kilimanjaro in August. She said: "Katy and I always wanted to climb Kilimanjaro together so completing it in her memory was an emotional as well as physical challenge". The Katy Holmes Trust has committed over £710,000 towards research into high-risk paediatric brain tumours as part of our new INSTINCT programme – read more on page 7.



A large group of farmers, families and friends from Cumbria got together to celebrate the life of Craig Bell, who lost his life to a brain tumour in March 2014. The group pulled Craig's own seven tonne tractor through the local area, raising £16,000.



Debra Johns, a neuro-oncology nurse specialist, raised over £1,100 by running 10km at the Loch Ness Marathon Festival with her husband Ian. She said: "I know for sure that any funds raised for The Brain Tumour Charity will make a difference. It's a fantastic charity".



Organised by former England cricketer Darren Gough for the fourth year running, The Alex Bolt Golf Day and Gala Dinner at Wentworth Golf Club raised £116,000. The dinner featured a performance by Jack Pack and welcomed celebrities and sports stars including Kevin Pietersen, Lewis Moody and Nicky Clarke.

**Gemma Farmer's cousin Tommy is living with a brain tumour. To show their support, family and friends held a fancy dress car wash at Tommy's family home in Milton Keynes. They have raised £300 so far with more on its way.**



Pioneering members of The Brainy Bunch have been finding ways to make mountain climbing even tougher. Friends Beth, Katie and Emily led a three-legged mass climb of over 50 people up Snowdon, raising over £4,600 to date. Meanwhile, Adele and friends not only completed the Three Peaks Challenge but carried a fridge the whole way round! They have raised £1,370.

Independent First Limited's annual Golf Day in Milngavie near Glasgow raised £4,200 in memory of Eddie Rainey's sister Maureen, who lost her life to a brain tumour, and in support of Scott Abraham's young cousin who is living with the disease.



Twenty employees from UPS volunteered at The Twilight Walk Warwick. One of the volunteers, Daniella, said: "A group of us decided to volunteer as we personally know the impact that brain tumours can have on families. We had a great evening stewarding the walk, selling merchandise and manning the registration desk. It was fantastic to join hundreds of people coming together in support of such a great cause."

In 2013 Hattie ran the gruelling 50k Royal Parks Ultra Marathon in support of her sister's husband Charles who was fighting a brain tumour. After Charles sadly lost his battle, the sisters decided to take part in the Ultra Marathon together in 2014 on what would have been Charles's 36th birthday. So far Hattie and Charlotte have raised £6,700.



Twenty two young children aged five and under took part in their own Daylight Walk on the day of The Twilight Walk Windsor. Organiser Zoe Bourn, who recently lost her mum Julie Fisher to a brain tumour, said: "I thought the 10k route would've been a bit much for their little legs. A Daylight Walk for them and their friends was a great way of raising awareness and funds". In total the Daylight Walk has raised £1,100.

# Thank you for all you do.

## Together we can defeat brain tumours.

If you wish to make a donation to support our vital work, please complete the form overleaf and return to the address below. You can also donate online: [thebraintumourcharity.org/donate](http://thebraintumourcharity.org/donate)

If you know someone who would like to support our work why not detach this form so they can make a donation?

You could also give them your copy of this newsletter so that they can see the impact of our work.

**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 return your donations to:**

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



# We rely 100% on voluntary donations

Please complete your details for any donation you'd like to make

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

Postcode: \_\_\_\_\_

Email: \_\_\_\_\_

Phone: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

*giftaid it* Make your donation worth 25% more!

I agree that The Brain Tumour Charity can claim Gift Aid on this and all the donations I have paid in the last four years and all donations I make from the date of this declaration until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for the current tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities and Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for the current tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 25p of tax on every £1 that I have given.

I am interested in leaving a gift in my Will - please get in touch with me

Yes, I pledge to help change lives by becoming a regular giver

Please pay The Brain Tumour Charity the sum of:

£25  £10  £5  Other £ \_\_\_\_\_

per month  per quarter  per year

Account name: \_\_\_\_\_

Account no. \_\_\_\_\_ Sort Code: \_\_\_\_\_

Bank name: \_\_\_\_\_

Bank address: \_\_\_\_\_  
\_\_\_\_\_

Postcode: \_\_\_\_\_

Start date for payments: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Yes, I pledge to help change lives by making a single donation

£250  £100  £50  £25  Other £ \_\_\_\_\_

I wish to donate by cheque

(made payable to **The Brain Tumour Charity**)

I wish to donate by credit/debit card

Card type:  Visa  Mastercard  Maestro

Visa Debit  CAF

Card number: \_\_\_\_\_

Start date: \_\_\_\_ / \_\_\_\_ Exp date: \_\_\_\_ / \_\_\_\_

Issue no: \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_

For bank use only to The Brain Tumour Charity, Lloyds Bank. Account No: 50290568, Sort Code 30-93-74

Complete this form and post it to:  
**The Brain Tumour Charity, Hartshead House, 61-65  
Victoria Road, Farnborough, Hampshire GU14 7PA**

The personal information you provide will be held securely in accordance with our internal data protection policy and the Data Protection Act 1998. We do not share your details with third parties apart from professional subcontractors. Please tick if you prefer not to receive mailings and updates from The Brain Tumour Charity

You can also donate online at [thebraintumourcharity.org](http://thebraintumourcharity.org) or text HOPE to 70555 to donate £5\*

\*see terms and conditions at [thebraintumourcharity.org/waystodonate](http://thebraintumourcharity.org/waystodonate)

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