

The Brain Tumour Charity shining a light on

The GREY MATTERS

The **BRAIN
TUMOUR
CHARITY**

Research | Awareness | Support

Issue 16 Autumn 2017

Driving Breakthroughs

"I can't thank the HeadSmart campaign enough"

20th Anniversary Celebrations

thebraintumourcharity.org



HeadSmart crowned winner!

We're very excited to announce that our HeadSmart campaign has won the National Lottery Good Causes Health Award!

On 1 September, TV presenter and singer, Rochelle Humes visited our offices to surprise us with the announcement that we had won £5,000 to go towards the campaign and presented us with an iconic trophy.

This award means so much to us as we continue to drive down diagnosis times and save lives.

We're incredibly grateful to each and every one of you who took the time to vote.

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

On the cover

Driving Breakthroughs.....4

"I can't thank the HeadSmart campaign enough".....10

20th Anniversary Celebrations.....20

Don't miss...

Q&A with Dr David Jones.....8

Meet the Researcher.....11

My personal Everest.....16

Coming together for Christmas.....18

BBC One Lifeline Appeal.....33

Hello

**Welcome to the 16th issue
of *The Grey Matters*.**

As one of the founders of The Charity, this year holds particular significance to us as it marks the 20th anniversary of the launch of the Samantha Dickson Brain Tumour Trust – set up in memory of our daughter Samantha, who sadly died from a brain tumour aged 16.

Samantha was the hub of our family. She kept everyone in order and made sure our life and our household was always filled with laughter.

When she eventually lost her brave fight it would have been so easy to have dropped into doom and gloom, but we took on her courage and decided to do something positive in her memory to help fight the disease that tore our family apart.

In 1997, we set up the Samantha Dickson Brain Tumour Trust and later merged with The Joseph Foote Trust and Brain Tumour UK to become The Brain Tumour Charity, the largest brain tumour charity in the world.

Over the last two decades we've felt incredibly proud of how much The Charity has gone on to accomplish.



Particular highlights for us include helping to cut the average childhood brain tumour diagnosis time in half thanks to our HeadSmart campaign, the opening of the Samantha Dickson Brain Cancer Unit at University College London and the funding of PhD student David Jones, who has gone on to become one of the most talented brain tumour scientists in the world.

Samantha was always helping others, and we think she would have been proud of everything that The Charity has achieved.

To us, she is, and always will be, “the wind beneath our wings”.

Neil and Angela Dickson MBE,
Founders

Driving Breakthroughs

As we continue to pave the way for a transformation in the treatments and quality of life available for those affected by a brain tumour, we're thrilled to have awarded over £3.8 million to five forward-thinking, patient-focused initiatives across the globe.



Quest for Cures awards

In order for us to accelerate more quickly towards our twin goals, of doubling survival and halving the harm that brain tumours have on quality of life, it's imperative that we build strong networks and work collaboratively with global experts.

That's why we're proud to be supporting world-class researchers in the Netherlands, and Canada, as well as in the UK for our Quest for Cures – Collaborative Discovery Teams initiative.

By building global collaboration between multi-national and multi-disciplinary teams, we're able to fund the very best scientific and clinical research available and speed up the time it takes to turn discoveries into treatments and cures.

The impact this could have for those affected by a brain tumour could be pivotal.





Developing therapeutic options for clinical trials

Dr Gelareh Zadeh,
University of Toronto, Canada

Meningiomas are one of the most common primary brain tumours, yet treatment options for those with clinically aggressive meningiomas (CAM) are severely limited. In fact, little research whatsoever has been carried out to understand the makeup of these tumours. With a team of experts based around the world, including in Cambridge and Liverpool in the UK, Dr Zadeh will look at the genetic characteristics of these tumours. The researchers will study tumour samples from patients who suffered a recurrence despite radiation and surgery. They will then link this scientific data to clinical data, enabling them to see the effect of these tumour-driven molecules on the whole person and their quality of life, not just the tumour itself.

This information could be used to develop vital new treatments for future clinical trials.



Accelerating the development of new treatments

Professor Thomas Würdinger,
VU University Medical Center,
Netherlands

Over 50% of brain cancer patients are diagnosed with a glioblastoma. Working with Dr Colin Watts, who is based at The University of Cambridge, Professor Würdinger's team aims to find new combinations of drugs that kill the different types of abnormal cells found in this tumour type. The team will create models to test new and existing drugs to see how they work alone and in combination. This research will build on the work of GLASS – a global network studying glioblastoma progression – creating a follow up network that focuses on finding cures for glioblastomas.

If successful, Professor Würdinger, Dr Watts and the team hope that this project will accelerate the development of new drugs and the testing of these drugs within the UK.

Quality of Life awards

Following on from the launch of our research strategy, *A Cure Can't Wait*, and the findings from several of our landmark surveys, we're delighted to have awarded funding to three exciting initiatives as part of our

second Quality of Life awards. These projects will address key quality of life issues affecting those living with a brain tumour, including fatigue and emotional well-being, and will work towards drastically improving these.



Improving life for children with medulloblastoma

Professor Colin Kennedy,
The University of Southampton

The clinical trial, SIOP-PNET5-MB, is designed to improve treatments for children who've recently been diagnosed with 'standard risk' medulloblastoma. Professor Kennedy's team will study the effects of these treatments on participants' quality of life. Children and parents will answer questions before and after treatments via a web-based platform. Health professionals will then analyse this data and implement it into the clinical trial to make improvements. The study hopes to reduce behavioural and hearing defects, as well as learning difficulties and to improve quality of survival for children with 'standard risk' medulloblastoma.



Developing a self-management programme

Professor Linda Sharp,
The University of Newcastle

Professor Sharp and her team will develop a supported self-management programme to help improve the quality of life for adult primary brain tumour survivors. The team will work with health professionals, survivors and carers to design a self-management programme specifically for people with brain tumours. By encouraging active participation from those living with the tumours in their own rehabilitation, Professor Sharp hopes to minimise the adverse effects of their illness and promote their well-being.



Reducing the effects of fatigue

Dr Alasdair Rooney,
The University of Edinburgh

Many studies show that fatigue is the most common problem experienced following treatment for a brain tumour. Dr Rooney and his team will look at whether lifestyle changes can help combat the effects of fatigue. Patients taking part will be split into three groups. The first group will have an interview to boost their motivation and then be advised by a specialist personal trainer on their diet, eating, resting, stress and exercise habits. The second group won't have the interview but will receive advice, while the third group won't receive any extra measures.

Dr Rooney hopes to see whether making lifestyle changes could reduce the effects of fatigue and improve the day-to-day quality of life for those experiencing it.

To find out more about these extraordinary projects, visit thebraintumourcharity.org/new-research-initiatives

Together, let's
put a spring
in our step!



Every event you take part in for The Charity, whether it's a run, bike ride, swim or skydive means that we can fund vital research initiatives like these.

So if you're lucky enough to get a sporting place, be it for a marathon or any other event, we'd be honoured if you'd consider taking part on behalf of The Brain Tumour Charity.

Every challenge you tackle, no matter how big or small, puts a spring in our step, moving us closer towards defeating brain tumours. Thank you!

Find out more at
thebraintumourcharity.org/events



Q & A with Dr David Jones

Lead Researcher for The Everest Centre
for Research into Paediatric Low Grade
Brain Tumours.

Can you tell us a little bit about the research you will be leading on at The Everest Centre?


The team behind The Everest Centre comes from a wide range of scientific and clinical backgrounds, with complementary experience and expertise. Together, we want to learn about the precise origins of paediatric low grade (slower growing) brain tumours. We want to know from which of the normal cell types in the brain they arise, and why distinct groups of tumours share similar underlying features. Part of our research is to then identify factors that slow tumour growth and to create more realistic laboratory models of these tumours, in order to identify and test new treatments.

Why is this research so important?

Low grade tumours have been understudied (and underfunded) for a long time. These tumours are the most common brain tumour type in children, and often impose a life-long burden on those affected and their families. Through our work at The Everest Centre, we want to improve not just the quantity but also the quality of survival.

What do you hope to achieve within the first five years?

There are two main things that we aim to achieve which will have the most immediate impact on clinical practice. The first is to come up with a more precise, molecular-based diagnostic system for low grade brain tumours. By making sure that every child receives a more precise diagnosis, we can ensure that they are receiving the right treatments and the best possible care.



Climbing for a cure

Following the huge success of the Everest in the Alps Challenge 2015, we're delighted to announce that Rob Ritchie has committed to taking on this phenomenal challenge again in 2018.

Next February, Rob and his wife Tanya, whose son Toby was diagnosed with a brain tumour aged five, will ascend 8,848 metres in the Swiss Alps (the same height as Everest), alongside seven teams, in an attempt to raise an incredible £350,000 towards funding for The Everest Centre for Research into Paediatric Low Grade Brain Tumours.

The centre, which was launched this June, aims to improve the understanding and treatment of low grade (slower growing) paediatric brain tumours, and was only possible thanks to the efforts of Rob and his team who raised £3 million during the 2015 trek.

We're incredibly grateful to Rob and all the teams involved and will be supporting them every step of the way.

To find out more about this inspiring challenge and to support the teams in this extraordinary feat, please visit thebraintumourcharity.org/everestinthelaps

The second is to bring a new type of targeted treatment into a clinical trial for low grade brain tumours. The hope is that this new class of medication can provide as good or better control of the tumour, while reducing the longer-term side effects caused by current chemo- or radiotherapies.

What sets this research apart?

The establishment of such an internationally collaborative project for low grade brain tumours is unique in Europe, and arguably world-wide. The expertise of the team, in combination with the world-leading technologies and methods that will be used for the work, could make this initiative truly transformative.

To learn more about the Everest Centre please visit thebraintumourcharity.org/everest-centre

"I can't thank the HeadSmart campaign enough"

**HEAD
SMART**

EARLY
DIAGNOSIS
OF BRAIN
TUMOURS

On Mother's Day 2015, Emre told his mother, Tiffani, that he had a bad headache.

Tiffani says: "Within minutes he was in a drowsy state and screaming in pain every time he vomited. We took him to A&E but doctors thought it was just a migraine."

When Emre's early morning headaches persisted for several weeks, Tiffani did an online search and came across the HeadSmart campaign.

She explains: "Emre was displaying the red flag symptoms listed on the HeadSmart website, so I went to the doctors several times."

Unfortunately doctors kept dismissing Tiffani's concerns, but the HeadSmart information stayed with her. So when Emre drew a picture on his etch-a-sketch showing a black dot on his forehead, which he described as "the headache that never went away," Tiffani demanded an immediate referral.

After an MRI and further tests, the family were told that Emre had an inoperable cystic tumour and were advised on the best ways to manage his condition.

Tiffani says: "It took three months of me pleading to get a diagnosis but he's here, stable and getting on with life! I can't thank the HeadSmart campaign enough."



A donation of

£50

could ensure 50 families receive a HeadSmart symptoms card making them aware of the signs and symptoms of brain tumours in children and teenagers.

To learn more about the signs and symptoms of brain tumours in children and teenagers, and to make sure others do too, please share our website link on your social media feeds with family and friends: headsmart.org.uk

Meet the Researcher Dr Darren Hargrave

Dr Darren Hargrave is a consultant paediatric neuro-oncologist at Great Ormond Street Hospital and the Chief Investigator of several completed, on-going and planned clinical trials in paediatric cancer. He is involved with some of the most pioneering and patient-focused research in the world, including projects such as INSTINCT, BIOMEDE and LOGGIC, and his work is already beginning to show incredible promise for better outcomes for patients.



Darren explains: “Early in my oncology career I was inspired to work with children with brain tumours. These children did not have the outcomes that children with other types of cancer had and desperately needed better and kinder treatments. I strongly believed that if we could understand the biology of brain tumours, however long it took, then inevitably we could start to develop better treatment options.

“At the start of my career, very little was known about the biology of childhood brain tumours, but over the past few years there has been an explosion in the understanding of what leads to paediatric brain tumours and these discoveries are ready to be translated into clinical trials. It’s a very exciting time and I’m delighted that a lot of the work I’m leading on is contributing to this.

“Ultimately, the key aim of my research is to improve survival rates amongst children with brain tumours. However, it’s also hugely important to me to look at how I can improve their quality of life too. Irrespective of how tough things are for these children, they just get on with life and I really want to reduce their burden. As a doctor who looks after children every day, my focus is and always will be to directly try and improve their care and that’s why research programmes and trials like INSTINCT, BIOMEDE and LOGGIC are so important.

“I passionately believe that the research being carried out now is just about to translate into better outcomes for these children. We won’t stop until it does.”

To read more on this interview and INSTINCT, BIOMEDE and LOGGIC, please visit thebraintumourcharity.org/darren-hargrave-research



Q & A with Jasmin Patel

**Optical Engagement Manager,
The Brain Tumour Charity**

Can you tell us a little about your role?

My role is to lead on our In-Sight project, which aims to improve life today for those affected by a brain tumour and reduce diagnosis times. By engaging with the optical community and developing resources for them, I'm able to increase awareness of brain tumours and the signs and symptoms someone with a brain tumour might experience.

What is the potential impact of your post for those affected by brain tumours?

By supporting optometrists and raising awareness of the importance of eye examinations, I can help to reduce the time it takes for someone first experiencing symptoms to receive a diagnosis. This means that their prognosis can be drastically improved.

My role will also benefit those living with a brain tumour. Approximately 28% of people with a brain tumour report visual difficulties. By providing guidance to healthcare professionals, I can help ensure those affected have access to the right information that can immensely improve their quality of life.

What have you achieved so far?

Within my first month, I have already engaged six eye clinics, providing them with our Patient Guide and information on the support services we offer. I have liaised with many professionals in the optical network, as well as patients affected by a brain tumour to understand their needs and have been able to help raise vital awareness of our HeadSmart campaign, promoting it both in person to opticians and through interviews in optical magazines.

How do you expect to raise awareness going forward?

We plan to provide a specific guideline for optometrists, which will include the visual signs and symptoms of brain tumours and techniques to detect these.

We currently have over 35 opticians supporting the HeadSmart campaign and one of the key goals of the In-Sight project is to increase this dramatically over the next year.

"I'm delighted that Jasmin has taken up the challenge of leading the In-Sight project, which aims to engage the optical industry in The Charity's goals of reducing diagnosis times and improving life today for those living with a brain tumour. Whereas an eye care professional presented with the signs and symptoms of a brain tumour would generally know what to do and refer on, raising further awareness of the disease with optometrists and their patients will I'm sure, lead to a significant increase in earlier diagnoses and better patient outcomes. Too many brain tumours are diagnosed in an advanced state after a medical trauma when the tumour has grown large and is difficult to treat effectively. This must change. I welcome Jasmin's appointment and wish her every success in her new and vital role."

John Maynard, Co-founder and former Finance Director, Sauflon Pharmaceuticals Ltd

Jasmin's appointment was only made possible thanks to optical industry advisor, John Maynard who has committed to providing half of the funding for our In-Sight project. This contribution will have a crucial impact on our progress in reducing diagnosis times. We can't thank John enough for his generosity.



Nurse and AHP Study Day

This May, we were proud to hold our second Nurse and AHP Study Day. The CPD accredited event was attended by 160 delegates and provided attendees with the opportunity to hear from a range of renowned experts on topics including developments in neurosurgery, biobanking and sub-specialisation.

Speakers included Professor Keyoumars Ashkan, Dr Alasdair Rooney and Dr Olaf Ansorge.

We also had the privilege to hear from two of our inspirational supporters, Jennifer McCrea and Cariss Evans, on what life is like living with a brain tumour.

By providing this platform for professionals to network, share knowledge and best practice, we hope that we can progress further towards improving life today for patients and providing them with equal access to the best possible treatment and care.

Uniting to find answers

Awareness

Campaign

Early
diagnosis

Equal access

Research

United



J M G U B I S G O U G N S C
M S V T L J S F T G S C H T
O F S X U D E T I N U A C J
M H F E M X N T U H N X A N
T R D J C Q E W C G I Z M K
T C F F G C R R E C B K P R
S I S O N G A I D Y L R A E
I F Q F F E W L I L R M I X
W F Q H S K A Q A L Y H G P
B E N E F I T S W U Z V N M
Y U R F B K H K Y A Q I Z I
R J Z F Y D H Q L F J E R B
Q P Z L A E C Q Q W V J A F
O C K W J N A J V N A U Q Z

Unlike this word search, the puzzle of how to defeat brain tumours is not so easily solvable.

However by sparing just a few minutes to join our community of e-campaigners, your contribution can make a valuable and vital difference.

As one of our e-campaigners, you'll act as a voice for The Charity on the issues that matter most to our community – issues such as those listed in the word search above.

You could use platforms such as Facebook and Twitter to lobby for our cause, share your story to help us raise awareness or give us your invaluable input to help us shape campaigns. Every voice makes a big difference in our drive for change. Together, we can make it happen sooner.

To become one of our e-campaigners, please visit thebraintumourcharity.org/e-campaigner

Keep this card and see that we hold those in power to account.

We will work with those affected by brain tumours, healthcare professionals, policy makers and politicians to deliver:

- 1 A thriving environment for research into brain tumours.**
We want to ensure that the voice of our research community is heard in the Brexit debate.
- 2 Early and accurate diagnosis.**
We want to drive childhood diagnosis times down to four weeks in line with NHS targets.
- 3 Equal access to the best treatment and care.**
We want 5-ALA (the pink drink) to be available for all patients where clinically appropriate.
- 4 Fair access to benefits for those in need.**
We want Bereavement Support Payments to be available for up to 10 years.

The Policy Team

A digital revolution for research

We're excited to report that we're making excellent progress in developing our global, patient-led brain tumour databank.

This ground-breaking project will enable those affected by a brain tumour to upload real-time information about their own diagnosis, the treatment they receive and the impact it has on their quality of life. It will also allow them to access information on others' experiences, so that they can make better-informed decisions about their own treatment and care.

At the same time, the databank will collect clinical and medical data from patients' NHS trusts, with the appropriate consent, and store it securely with patient-reported

quality of life data. This data will then be made available to clinicians and scientists around the world in order to drive forward global research into brain tumours.

We believe that the databank will radically transform the landscape of research into brain tumours and we'd love for you or your loved one to benefit from it.

To find out more and to express your interest in registering for the databank, please visit thebraintumourcharity.org/brain-tumour-databank

My personal Everest

When Jordan Toms was diagnosed with a brain tumour, instead of feeling defeated, he became resolute in his quest to get better so that he could help others.

Jordan explains: "I'd always been a really fit and healthy person, but when I was 22 I was diagnosed with an oligodendroglioma brain tumour. I still remember staring at the peach-sized white blob on my MRI scan picture in disbelief. I'd just handed my dissertation in and was meant to be out partying with my university friends and making plans for the future. Yet in a single moment my whole life had turned upside down.

"I had surgery to remove 80 percent of the tumour, and afterwards I couldn't talk, walk or lift my left arm. I'd gone from being an active guy who visited the gym four times a week, to not being able to even hold my own toothbrush or spray my own deodorant.

"At times it was tempting to just lie in bed, feeling defeated. But I was inspired by a man I met in hospital, who despite being paralysed from the waist down, was always laughing and joking, and so I refused to sulk and instead got to work.

"I began having speech therapy and practised walking down the hospital corridors every day. It was a huge mountain to climb, but I kept going and, with a lot

of hard work, slowly I was able to talk, walk and move my left arm again. Eventually, I even returned to the gym. Going back, bald from radiotherapy and with a big scar, made me feel understandably self-conscious though, and suddenly I saw everything in a whole new light.

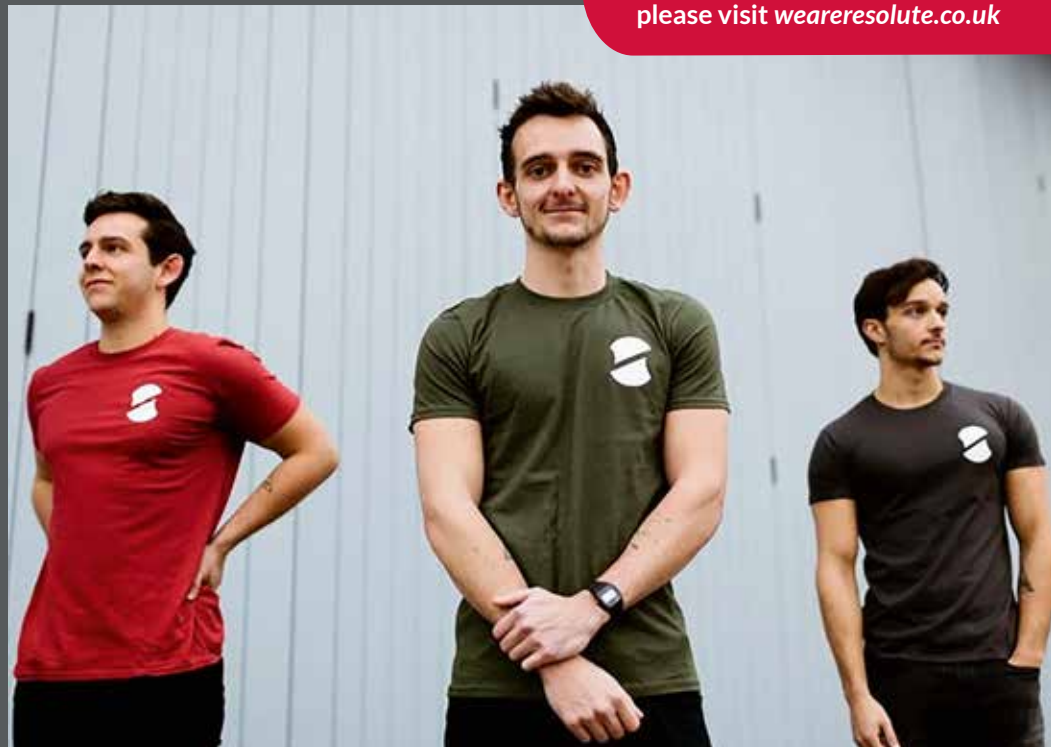
"I realised that no matter what any of us looked like or where we were in our journey, we should only be measured by our hard work, focus and determination. It gave me an idea, and with my brothers, Callum and Adam, I set up Resolute, an activewear brand to inspire everyone to have the courage to exercise, look after their health and reach their goals, whilst also helping to beat cancer.

"I'm now proud to say that 20 percent of our profits go towards supporting The Brain Tumour Charity and Macmillan Cancer Support, who have both helped me through my journey.

"It's been difficult launching the brand whilst still having treatment, but I feel really passionate about turning my experience into something positive. Resolute has helped change my life. Now I want it to make a valuable difference to the lives of others."



To learn more about Resolute,
please visit weareresolute.co.uk



Coming together for Christmas

Christmas is often a time for celebrations but it's also a time for reflecting and remembering. However you'll be spending yours this year, we hope you'll spend it together with us, as part of our united community.

Christmas cards and gifts

A simple, yet very effective, way to support The Charity over the festive season is by ordering your Christmas cards or gifts from us. Our online shop offers a beautiful selection and every item sold helps us to make a big difference for the 102,000 people currently living with a brain tumour in the UK.



#TheBrainyBunch Christmas quiz

This Christmas we're inviting everyone to take the opportunity to bring their friends, loved ones, colleagues and community together by holding a festive Christmas quiz. Every quiz held will help us raise vital funds for our research and support services, and we will provide you with everything that you need. To find out more, keep your eyes peeled for the launch of #TheBrainyBunch Christmas quiz on our website.



Santa fun runs

If you're looking for some festive fun this Christmas, why not unite with us and raise funds by taking part in a Santa fun run. To sign up to the run in Victoria Park, London go to thebraintumourcharity.org/santa-run

Become a Christmas Angel

Spread some Christmas cheer and help fund life-saving research at the same time by becoming one of our Christmas Angels and selling our cards and gifts to family, friends and colleagues.

Last Christmas our dedicated supporters, volunteers, researchers, corporate partners and healthcare professionals raised an extraordinary £70,000 through the seasonal sales of our cards and gifts. That's enough to fund an early-phase clinical trial to test new treatments.

Through the research that we fund, we're committed to ensuring that more families can enjoy their Christmases together. Thank you for helping us to achieve this.

To find out more about what we're doing for Christmas, visit thebraintumourcharity.org/christmas

20th Anniversary Celebrations

Beautiful and memorable events took place this June as one of The Charity's founders, Neil and Angela Dickson MBE, invited a host of special guests to join them to take part in The Samantha Dickson 20th Anniversary Celebrations.



On 23 June, The Samantha Dickson 20th Anniversary Dinner Dance took place in Dogmersfield, bringing over 240 people together and raising over £65,000 in Samantha's honour.

It was a moving occasion for all and, two days later, the celebrations continued as the couple welcomed supporters, trustees, families, Young Ambassadors, volunteers and researchers for a summer party and barbecue.

Guests enjoyed a delicious hog roast, sports day style races, and, as a fitting finish to the afternoon, Neil and Angela took the time to present all the winners with chocolate medals.

"The ball was very special to us as a large number of people who attended had known Sam and had supported us for 20 years. The barbecue on Sunday was special for different reasons. We were very moved to see a number of teenagers and young adults there on the day, many of whom were children we'd supported in the early days of The Charity. To see them as Young Ambassadors, continuing to help other brain tumour patients and their families is what The Charity is all about."

Neil and Angela Dickson MBE, Founders

A Mighty Boy

When Silas Pullen was 10 years old, his parents, Sarah and Ben, were told that their son had a terminal brain tumour and only had months to live.

Now, in her profoundly moving and inspiring book, *A Mighty Boy*, Silas' mother, Sarah, shares her family's journey upon hearing Silas' diagnosis, to his death and beyond.

Sarah says: 'At its heart, *A Mighty Boy* is a story of the love between a mother and a son. It is a book about seizing the moment and somehow managing to survive the death of a child, but most of all it is a book about a small, smiling boy.'

A Mighty Boy: A Mother's Journey Through Grief by Sarah Pullen, is available from a range of stockists priced £14.99 for a hardback copy, with Sarah's share of profit from every book sold going to The Silas Pullen Fund in support of The Brain Tumour Charity.



The right support for you

Receiving the news that you or a loved one has been diagnosed with a brain tumour can be incredibly difficult. Whether you're looking for reliable information or need someone to talk to, we're here to help.

With a range of specialised services available including our Information & Support Line, Patient Guide, Benefits Clinic, Information Days, Family Days, New Teenage and Young Adult service and online communities, we have a service tailored to meet the needs of everyone affected by a brain tumour.

Furthermore, we're pleased to be expanding our online services to include Live Chat, which will enable people to receive real-time support from one of our experienced team.

To try Live Chat or find out more about our support services visit thebraintumourcharity.org/get-support



The superstars shaping the future

A big thank you

Our Young Ambassadors are an integral part of The Brain Tumour Charity. Having all been affected by a brain tumour, either directly or through the diagnosis of a loved one, they work tirelessly to help us raise awareness of the disease and move closer towards our twin goals: to double survival and halve the harm that brain tumours have on quality of life.

Dedicated and passionate, these inspirational young adults are determined to change the future for other young people affected and, by sharing their stories and giving their time, they've made an important difference to the support that we've been able to offer our community this year.

Examples of just some of the vital contributions our Young Ambassadors have made over the last 12 months include speaking for us at key events, helping us to build petitions, taking part in fundraising events, sending out Brainy Bags, being part of patient mandate groups, contributing ideas to help us develop our services and speaking out to local press.

Without them we simply could not reach as many young people as we do, or engage as effectively with the young audiences that we support. We can't thank them enough.

A big welcome

We're delighted to introduce our new team of Young Ambassadors.



We know that these 22 inspirational young adults will use their first-hand experience to play a crucial role in helping other young people affected by a brain tumour diagnosis. We're incredibly grateful for their support.

To find out more about each one of our new Young Ambassadors or if you have any questions about our Young Ambassadors Programme, please visit thebraintumourcharity.org/Young-Ambassadors

New Teenage and Young Adult Service

Our Young Ambassadors have played a vital role in helping us to shape and develop our new Teenage and Young Adult Service (TYA).

The service offers dedicated support to young adults aged 16-30 who have been diagnosed with a brain tumour, enabling them to connect with others, feel better supported and less isolated.

The support available includes:

- Emotional and practical support from a dedicated Teenage and Young Adult Worker.
- A closed Facebook group to connect young adults with others in a similar situation, no matter where they live.
- Opportunities to be put in touch with one of our Young Ambassadors who understand what it's like to live with a brain tumour diagnosis.
- Events where young adults can meet people, learn new skills and get helpful information and support.

To find out more about the service and see how we can help you or your friend or family member, please visit thebraintumourcharity.org/TYA



Celebrating our community

Every challenge, activity and event you take part in makes a huge difference to the impact we can have for those affected by a brain tumour. Our deepest thanks to everyone involved.



LMF Ball

The Lewis Moody Foundation annual charity ball took place at The Grand Connaught Rooms on 25 May, raising over £85,000.

Hosted by David Flatman, over 140 people joined Lewis and his wife Annie at their masquerade themed ball. Special guests included Radio 1 DJ Greg James, TV presenter Steve Backshall and British rower Helen Glover MBE.

The money raised will help to fund Family Days, as well as the HeadSmart campaign and research into brain tumours. Thank you to everyone who supported the evening.



Ride for Emily

In May, Charles and Judith Barnett embarked on an epic 500 mile tandem bike ride from San Francisco to Los Angeles in memory of Emily Morris, who sadly died of a brain tumour aged 31.

Inspired by Emily, the daughter of Charles and Judith's dear friends Susan and Jack Morris, and her courage, the couple were honoured to take part in this incredible challenge in her memory. Cycling one of the most diverse routes in the world, featuring rugged coastlines and towering forests, the pair completed this amazing feat in just seven days, raising over £32,000 for The Charity. We are extremely grateful.



The Big Match

On 20 May, the fifth annual The Big Match took place, raising an astounding £58,000 for The Charity and Action for Children.

Held at Millwall FC and The Hilton Tower Bridge, the event was organised by Neil Humphries who lost his dad to a brain tumour in 2012 and was supported by a host of ex-pro players and famous faces including Razor Ruddock, former X Factor finalist Jake Quickenden and Debbie McGee.

After an exciting match, The Brain Tumour Charity triumphed to claim the title of The Big Match Champions 2017, with Neil himself scoring a hat trick.

A big thank you to everyone who attended and special thanks to Neil for his unwavering support.

The Brain Tumour Charity Awards: Celebrating You

We're excited to announce that in April 2018, we will be hosting our first ever The Brain Tumour Charity Awards.

Since we launched our strategy, *Defeating Brain Tumours*, back in 2015, we've made excellent progress against our strategic goals and these awards will recognise some of the volunteers, researchers, fundraisers, healthcare professionals and other members of our community who have made this possible.

So keep your eyes peeled because in the coming months we'll be asking you to nominate and vote for your winner in several different award categories.

To find out more go to thebraintumourcharity.org/celebrating-you





My Promise to Luke

My beautiful son, Luke, was really excited about his school trip to Iceland in January 2015, aged 15. He was so excited that his bag was packed weeks before he was due to go. But a week before his trip, Luke was diagnosed with a brain tumour and needed immediate surgery, meaning he couldn't go. As was his character, Luke took the news with a smile and a solution, and said he would go the year after as he already had a sweatshirt printed by his school. Luke even joked: "This is the most expensive sweatshirt I own, it cost £800" – the price of the trip.

Luke had a big heart and sunny smile, he could chat to everyone and loved to help at his local Beavers group. He was a triplet and had a special bond with his two sisters. After his diagnosis, we decided to make Luke's future as much of an adventure as we could – we did lots of camping and holidays in the UK. I always promised to get Luke to Iceland but with his chemotherapy, radiotherapy and our fear of Luke flying with a brain tumour, Luke never got to Iceland.

So I vowed to go in his memory. When I discovered The Brain Tumour Charity was arranging a trek to Iceland I had no hesitation, I had to go.

The trek was emotionally challenging for me. Day two was the hardest as we trekked for 11.5 hours but it was truly beautiful; I doubt I'll see sights like that again! I also met some incredible people. We now have an Icelandic #TheBrainyBunch WhatsApp chat going, which is funny but also very supportive. I am so grateful to The Charity for organising such a brilliant trek. To date, we have raised over £80,000.

I wore Luke's sweatshirt. My beautiful boy was with me the whole journey and I know he would have loved seeing and experiencing all that I did. I did it for Luke – it was a promise I made to him.

Lynne Fallon
In memory of Luke
7 April 1999 – 2 March 2016



Partnerships

We're delighted to announce that The Charity continues to establish new corporate partnerships with a number of fantastic organisations including: BMS Group, The Collective, Gateley PLC, Seymour PR and Underbelly.

With lots of impressive fundraising events already being planned, we're very much looking forward to working alongside our new partners.

"We decided to work with The Brain Tumour Charity as, for many of us at BMS, this devastating disease is a subject close to our hearts. With 30 people in the UK diagnosed with a brain tumour every day, the statistics are truly astonishing. We're delighted to support such an important cause and look forward to helping increase the profile of this great charity and raising as much money as possible."

Nick Cook, CEO of BMS Group

bms.



THE COLLECTIVE

SEYMOUR PR
EST 2012



♦ Gateley Plc

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

Supporter Groups

Our wonderful 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 LoveUKaira Fund
The Harriet Downing Fund
The Cy Lapwood Fund
The Andrew 'Pud' Leigh Fund
The Judy D'cruz Fund
The Jackie Sutherland Fund
The SGB Charity Fund
The Lee Hastings Fund
Saving Amy's Brain Fund
The Kim Smith Fund
The Remembering Sarah Fund

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



The Sarah Kitchener Perrow Fund

When Sarah Kitchener Perrow was diagnosed with a brain tumour she was committed to making a difference. Even during treatment, she devised ways to raise funds and awareness. Sadly, aged 27, Sarah passed away. Following her death, her family set up The Sarah Kitchener Perrow Fund to continue Sarah's ambition to change outcomes for others.

Now this inspiring group has raised over £250,000 to fund research into high grade brain tumours. We're incredibly grateful to all of Sarah's family and friends for their continued support.

"People who met Sarah were amazed at how she stayed focused on living life to the full. We set up this Supporter Group in Sarah's memory to keep her positive attitude and spirit alive. With exceptional support from family and friends, we strive to make Sarah proud by raising funds to improve treatments and survival rates so that others may beat this devastating disease."

Sarah Kitchener Perrow's family

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



The little things that mean the most



Ellie Edlmann (Neurosurgery Registrar and Research Fellow for Addenbrookes Hospital and the University of Cambridge) who lost her mum Sue to a brain tumour in 2014, pictured here with her husband Richard.

"It had never crossed my mind to leave a gift in my Will to a charity before, but following the death of my mum Sue from a brain tumour I started to look at the world differently. I realised that if I had any money left after my family had been taken care of, I'd want it to go to something meaningful so that it could make a real difference. Having witnessed first-hand some of the incredible research projects that The Brain Tumour Charity are working on during a recent lab tour, I felt inspired to include them when I updated my Will. I like the idea that my money could help contribute towards pioneering new research that could help save and improve so many lives. Mum was always passionate about making a difference to those in need. I hope by leaving a gift to The Charity in her honour, my money is able to do just that."

Ellie and her brother Alex fundraise tirelessly for The Charity through The Sue Robson Fund.

It's the little things in life that can mean the most. Leaving just 1% of your Will to us can make a world of difference. Including a gift is simple but has an impact for generations to come.

If you would like to dedicate a gift in your Will as a tribute to a loved one or to one of our Supporter Groups, please do register for a free information pack.

Simply go to thebraintumourcharity.org/littlethings to find out more.

Giving the gift of time

Our volunteers are an inspirational group of people who give their time and energy to help move us closer to our vision of a world where brain tumours are defeated. We simply couldn't do all that we do without them.

If you're interested in joining this fantastic team, we're expanding our volunteer programme and would love to welcome you. There's a wide range of roles available, and you can give as much or as little time as you'd like – whether you can spare an hour, a day or more, your contribution will make a vital difference. Here are just some of the roles we're recruiting for:

Uniting through laughter

On 12 July, comedians Hal Cruttenden, Dara Ó Briain, Tony Law and Bennett Aron treated guests to an evening of great entertainment and laughter as The Charity held our first ever comedy night at the Backyard Comedy Club in Bethnal Green.

It was wonderful to see so many of our inspirational supporters on the night, including Grace Latter, and Shona and Graham Floyd, the parents of Tasha, one of our first ever Young Ambassadors who sadly died from a brain tumour aged 24. The evening raised over £5,000 and we're incredibly grateful to everyone involved.

Community Ambassador

Our Community Ambassadors play an important role in representing The Brain Tumour Charity at local events. They speak about what we do and the importance of the funds our supporters raise, as well as sharing their own stories.

Collection Tin Co-ordinator

Our Collection Tin Co-ordinators help us distribute and monitor charity collection tins in the local community. They help us to raise funds and awareness in a number of different locations and are an essential part of our fundraising team.



"I volunteer because it's important to me to make a difference. By sharing my experience and representing The Charity at different events, I'm able to do this."

Peter Buckle, a Community Ambassador, who sadly lost his wife Wendy to a glioblastoma.



Volunteer for The Twilight Walk

Our volunteers at The Twilight Walk are a key part of the event's success. There are a variety of roles available at the walks such as route stewards, merchandise volunteers and greet and cheer volunteers. All you need is lots of enthusiasm and a willingness to get involved.

To volunteer for us or to find out more about our roles, please visit thebraintumourcharity.org/volunteering

Wherever you walk, **#WalkWithUs**

If you want to take part in The Twilight Walk this year but can't make the dates or reach one of our locations, don't worry – you can still unite with us to make a lasting difference, share your stories and celebrate the lives of loved ones, by holding your own walk.

Simply choose a date in October, plan a 10k route locally and ask your family, friends and colleagues to join you. You could take in scenes from your city, enjoy a countryside ramble or walk along the coast – the possibilities are endless!

So why not get a date in your diary today? Wherever you walk, every step you take and penny you raise will have a significant impact in helping the 102,000 people currently living with a brain tumour in the UK.

To sign up, please visit thebraintumourcharity.org/own-walk

**The
TWILIGHT
WALK**

Get ready to #WearItOut

On 2 March

Next March, we're asking you to help us kick-start Brain Tumour Awareness Month by uniting with our wonderful community to #WearItOut to defeat brain tumours. By holding an event, whilst you #WearItOut, you can help us raise crucial funds for life-saving research and make a lasting difference to the lives of those affected by a brain tumour.

There are lots of ways to take part. You could hold a bake sale, coffee morning or organise a fun school event – anything that you wish. All that matters is that you get involved, get inspired and have fun.

Last year, thanks to you, we raised £130,000 – enough to fund an incredible 520 days of vital research into brain tumours.

So whatever you plan for Friday 2 March, make sure that you #WearItOut.

United, we will defeat brain tumours. Your event could help lead to a breakthrough.

To register your interest, visit
[thebraintumourcharity.org/
WearItOut](http://thebraintumourcharity.org/WearItOut)





A big thank you

A special thank you to all of our high profile supporters who've gone that extra mile to help us raise awareness of The Charity and funds over the year. Everything you do is greatly appreciated.

BBC One Lifeline Appeal

This July, we were thrilled to have Tom Daley represent The Charity as the face of our BBC One Lifeline Appeal.

Sadly, Tom lost his father, Rob, to the disease in 2011, and he and his family have supported The Charity since.

In the appeal, Tom highlighted the success of the HeadSmart campaign, which has helped reduce average diagnosis times for childhood brain tumours from 13 weeks to 6.5, and asked for support that will allow The Charity to fund a new project to help drive down adult diagnosis times.

Tom said: "Losing a parent at any age is absolutely devastating. You can feel like you've nowhere to turn, but The Brain Tumour Charity were an incredible support for me and my family during one of the toughest times of our lives."

The appeal helped The Charity raise vital awareness and over £20,000. We're incredibly grateful to Tom and his family for their unwavering support.

"A huge thank you to everyone who's donated to the appeal. Together, we can defeat brain tumours."

Tom Daley

Thank you to #TheBrainyBunch

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

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

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



The Dave Booth Memorial cycle team from Lincolnshire cycled 300 miles in 24 hours, raising over £46,892 – a fantastic achievement!



Bailey-Jane Bull from Cambridgeshire had her luscious locks shaved in aid of The Charity, raising £825 in total.



Annalise Parisi from Bridgend was diagnosed with a brain tumour aged 17 and has now raised £852 by climbing Pen-Y-Fan.



Andy Cheetham, who is living with a brain tumour, his wife Bronwen and children, Eva, Lucy and Nell, took on the South Downs Way walk over two weeks, raising £5,765.



Alfie Bear's Journey Fund reached an incredible £100,000 this year. The fund has been chosen as the Mayor of Northampton's charity of the year and preparations are under way for their annual charity dinner in September, which will mark what would be Alfie's 10th birthday.



Louise Smith from Northwich, who is living with a brain tumour, challenged herself to climb the dizzy heights of the Eiffel Tower. She achieved her goal and made it to the top with the support of husband, Mike and daughter, Amelie raising £7,000.



Mike Riley from Liverpool walked 117km from Camino to Santiago de Compostela, in Spain, and raised £3,694. Each day Mike wore a bespoke t-shirt with the name of a different loved one on, in whose memory he walked.



The former Mayor of Bridgnorth, Vanessa Voysey, raised £3,500 in memory of her son, Mewen. Vanessa held a whole range of events including curry nights, a quiz, a rock gig and much more!



Caversham Rock Choir sang their way around a number of locations, raising awareness for The Karyn Bent Fund. This amazing group raised over £700.



Holland and Green, in Oxfordshire, raised over £3,000 by taking part in Rough Runner.



Now in its fifth year, with the incredible support of Ann Atkins and the Row for it Rowers, this year's Row For It! challenge in Solihull raised £26,000. A big thank you to everyone involved.



The Bobby Cox Fund has raised over £50,000 in memory of Bobby, with 150 people taking part in a 1000m swim, 40km bike and a 10km run.



Colin Dorrance and The Cycle for Sam (C4S) team cycled 480 miles from Carlisle to Stonehaven and back, raising funds in memory of Sam, Colin's nephew, in support of Super Sam's Fund. The C4S team have raised over £40,000.

Thank you for all you do.

Together we can defeat brain tumours.

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

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

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

The little gifts that make a big 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 one
hour to help people affected
by a brain tumour.



A donation of

£20

a month can pay for a day's
work for a world class
researcher to explore new
treatments each year.

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

Find out more about leaving a gift in your Will: thebraintumourcharity.org/littlethings

Did you know

You can set up a Direct Debit for
as little as £2 per month.

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 fund vital life-saving research

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

Thank you!