

The Brain Tumour Charity shining a light on

The GREY MATTERS

The **BRAIN
TUMOUR
CHARITY**

Research | Awareness | Support

Issue 12 Summer 2016

Our new research

Welcome to the Citizens
Advice Service

#WalkWithUs sign up now!

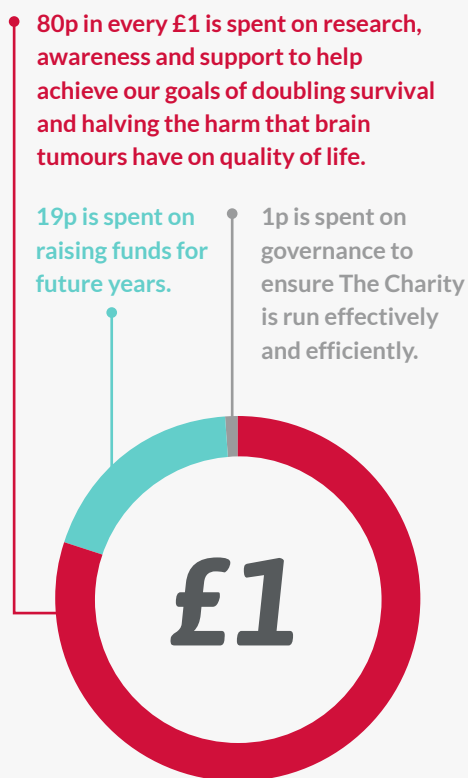
thebraintumourcharity.org



"Our wedding day was full of laughter and tears. Having The Brain Tumour Charity's favours, in memory of my daughter, completed the jigsaw."

Alan, whose daughter Charlotte lost her life to a brain tumour at the age of nine.

If you, like Alan, are looking for a different way to show your support for us, why not take a look at our online shop. Visit shop.thebraintumourcharity.org



Pictured on the front: One of our funded researchers from Newcastle University at work in the lab.

Hello

Welcome to the latest edition of *The Grey Matters*.

In April, I was honoured to run the Virgin Money London Marathon for The Brain Tumour Charity. Having read about the new research being funded in this edition of the newsletter, it's great to know all of the money raised by me and the other amazing fundraisers I met along the way is being invested so wisely.

Heartbreakingly, I had to pull out of the marathon at the 23 mile mark due to injury. I had an awake craniotomy to remove my oligodendroglioma brain tumour in 2015 and knowing I've got through that has spurred me on to keep trying – I've already accepted a place to run again next year.

I know however that everyone's motivation is different and I particularly enjoyed reading the story of Sarah Lambkin, one of my fellow runners, on page 20. Sarah tragically lost her mum to a brain tumour in 2007 and completed the marathon in her mum's memory. Sarah's story really brought home to me how urgent the need is, for everyone's sake, to find a cure.

If, like me, you're determined to make a difference, why not take a look at page 32 where you can find out about The Charity's next big event, The Twilight Walk 2016. I hope to be standing shoulder to shoulder with you there.

Mark Grimes



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Our new research



We're delighted to announce that we've just awarded £4.3 million to new and exciting research initiatives.

We received applications for funding from leading researchers across the globe but it's these forward-thinking, patient-focussed initiatives we've awarded that are the ones that will drive forward progress and help us achieve our goals of doubling survival and halving the harm of those affected.

We're proud that all of our applications go through a rigorous peer review process, which is approved by the Association of Medical Research Charities, and are excited to be funding some of the world's most promising research to date. In our next issue we'll be sharing the initiatives that we're funding to address quality of life issues.

It's thanks to the dedication of our amazing supporters that this funding has been made possible. Thank you!

Further information on this research can be found at thebraintumourcharity.org/new-research

New Ideas awards

Out of the initiatives we're funding, four are part of our 'New Ideas' scheme; designed to encourage innovative thinking and bring about pioneering breakthroughs. We hope this research can fundamentally change our understanding of brain tumours and the way we diagnose and manage them.



A donation of

£50

could go towards specialist equipment to help a researcher test potential brain tumour treatments in the lab.



3D printing of brain tumour cells

Dr Nicholas Leslie,
Heriot Watt University, Edinburgh

Up until now, researchers have struggled to get a true view of how brain tumour cells behave because of the difficulties in recreating the human brain environment in the lab. Dr Leslie has, for the first time, found an innovative way of using 3D printing to print and mix glioblastoma stem cells with other cell types common within brain tumours.

Dr Leslie's work will now create a more realistic model for testing treatments, meaning they can get to patients faster.



Exploring how networks are formed

Mr Michael Hart,
Addenbrooke's Hospital, Cambridge

Mr Hart's research aims to explore how networks are formed to the remote areas of the brain that are responsible for complex cognitive functions such as problem solving. By doing so, he hopes to define exactly how much of a low grade glioma can be removed while retaining as much brain function as possible.

This research could have an immediate impact by decreasing the after effects of surgery including lowering the chance of seizures.



Understanding left-over tumour cells

Mr Stuart Smith,
The University of Nottingham

Mr Smith will be using the 5ALA drink which is taken by patients ahead of surgery to make tumorous cells glow pink (and why it's also known as 'the pink drink') to analyse the residual cancer cells left in a patient's brain after surgery.

By removing these cells - which will also glow pink - and identifying the precise mutations within them, he hopes to develop targeted treatments which could lead to fewer tumour recurrences.



Uncovering tumour transition

Dr Paul Brennan,
The Cancer Research UK Centre, Edinburgh

Dr Brennan is looking at how and why some low grade gliomas change into high grade gliomas. By undertaking tests on low grade cells, he hopes to define the biomarkers (indicators, such as genes, molecules or other biological substances found in blood or cells, which can be used to measure or diagnose a tumour) that are changing the cells.

Dr Brennan's work could facilitate earlier detection of when tumours become aggressive and could allow for drugs to be tested to slow or stop this transition.



A donation of
£ 250

could cover a day of research
for one of our leading brain
tumour researchers to further
the understanding of a particular
type of brain tumour.

Quests for Cures awards

Two initiatives we're funding are part of our 'Quest for Cures - Collaborative Discovery Teams' scheme. This scheme has been established to acknowledge the growing importance of international and interdisciplinary team approaches to accelerating discoveries and bringing benefits to patients faster.



New drug development for medulloblastoma

Professor Louis Chesler,
Institute of Cancer Research, Sutton

Professor Chesler is working with a team from Germany and the USA to study Group 3 medulloblastoma - the most common malignant brain tumour in children. The team will be analysing the genome in medulloblastoma tumour cells while also working on new ways to test drugs for this tumour type.

If successful, the research could, for the first time, reveal how these tumours are wired. This could mean that new drugs to treat this tumour type are delivered to the clinic within five years.



"I'm honoured to hear about the new research that has been awarded. I lost my mum to a brain tumour when I was 16. By the time her symptoms had finally been diagnosed, it was too late. But there is hope for others."

"I look forward to a future where a brain tumour diagnosis is something that can be overcome, in all instances. It's ground-breaking research like this that could make that day come sooner."

**Laura, one of our
Young Ambassadors.**



Linking glioblastomas to DNA-protein parcels

Dr Steve Pollard,
The University of Edinburgh

Dr Steve Pollard is working with scientists from Canada and Denmark to look at parcels within cells that contain both DNA and protein, to see how they could be linked to causing glioblastomas. They will be using the very latest scientific editing tools to further their understanding of the parcels.

Very little is currently understood about the different proteins within the parcels and which ones should be prioritised for drug development. By undertaking this research the team hope to identify existing drugs that could be used to stop them developing into cancer.

This research also features a collaboration with the Structural Genomics Consortium who we have recently partnered with. You can read more about this on page 9.



Thank you for being part of the Research Involvement Network

We'd like to thank our Research Involvement Network (RIN) members for representing those affected by brain tumours and our researchers for choosing the RIN as a patient perspective group for their research.

Our RIN has been involved in many opportunities to work with researchers.

If you've been affected by a brain tumour and want to use your personal experience to shape the future of brain tumour research, you can join the RIN here thebraintumourcharity.org/RIN

Q & A with Wen Hwa Lee

Programme Director at the Structural Genomics Consortium

We're excited to be partnering with the Structural Genomics Consortium (SGC). This pioneering partnership, in which only a handful of charities are involved, will help us pave the way for the future of research into brain tumours. We caught up with Wen Hwa Lee ("Lee") from the SGC to learn more about the project.

What is the SGC?

We're an international group of researchers using cutting-edge science to accelerate the discovery of potential treatments for incurable diseases. What makes us different from other projects is that we share all of our findings, regardless of the result, and we never file patents on our discoveries. Any information we uncover is available free of charge, meaning that others never have to repeat the research we've undertaken. It's important to us that research always takes a step forward, never a step back.

What does your work involve?

We're working to unlock information about the structure and function of different proteins within the human body. By discovering the shape of the proteins which play a part in causing particular diseases - such as brain tumours - we can hope to develop drugs that 'lock on' to them and change their behaviour.



What does the partnership mean for us?

Being one of just a few charities who have entered this type of agreement, The Brain Tumour Charity is driving the next generation of discoveries forward. As part of the partnership, The Charity will be funding two research posts within the SGC focussing specifically on the proteins and biology that play a part in brain tumour development.

What is the potential impact of your work?

Our work has the potential to fundamentally change the way research for incurable diseases is approached, and that's why we're so pleased to have The Charity involved. We're accelerating progress and encouraging global collaboration on all fronts - several global pharmaceutical companies and researchers from around the world have already signed up to our model of sharing scientific discoveries, and this can only be of benefit to the future.

To find out more about our partnership with the SGC, visit thebraintumourcharity.org/SGC

Pioneering funding round launched

Paediatric low grade brain tumours

We've been talking to the world's most prestigious scientists about how to combat paediatric low grade brain tumours. Based on their input, we've opened a new funding call for this.

Funds for this research were generated by the fundraising efforts of Rob Ritchie whose son Toby was diagnosed with a brain tumour in 2013, aged five. In 2015, Rob and a team of 13 others ascended 8,848 metres on skis, as part of their Everest in the Alps challenge - raising £3 million for paediatric brain tumour research along the way.

"Everest in the Alps proved to be a much bigger challenge than we thought and that is commensurate with the amount of money we made and the goals of The Brain Tumour Charity to really push forward research in this area."

Rob Ritchie



A gift in your Will of
£5,000

could fund an incubator to grow cells in a controlled environment, which would then be used for research.

For further information on our new rounds of funding visit thebraintumourcharity.org/funding-opportunities



Thank you to ICAP



On 9 December 2015 we were honoured to be part of the ICAP Charity Day, which raised an incredible £7.5 million for their charities throughout the world.

Leading financial services company ICAP hold a global charity day every year, during which a huge number of charities and celebrity supporters are invited to make deals on the trading floor with 100% of the profit going straight to the charities involved.

Our patron Earl Spencer, former England rugby captain Lewis Moody and TV presenter and journalist Matt Allwright attended the day, closing deals on the trading floor and being great all-round ambassadors for The Brain Tumour Charity.

They were amongst several other celebrities who attended the event including the Duke and Duchess of Cambridge, Carey Mulligan and Paula Radcliffe.

We received an incredible £100,000 from the day which will help to fund our campaign for the earlier diagnosis of adults

so that brain tumours are treated earlier. CEO, Sarah Lindsell and Lewis Moody went to Number 10 to receive the donation on 17 March, which was presented by ICAP CEO Michael Spencer.

"ICAP Charity Day is the only place you can be savaged by Pacman, bump into Supermario and help raise money for The Brain Tumour Charity. It was huge fun for everyone involved and brought in a huge amount for The Charity. I couldn't have enjoyed it more."

Earl Spencer

A massive thank you to ICAP in the UK for selecting us as one of their charities last year. It's fundraising efforts like these that enable us to invest money in groundbreaking research projects that will enable us to get closer to doubling survival, halving the harm and ultimately defeating brain tumours for good.

Clinical trials for children

We're excited to be co-funding a new clinical trial into DIPG (Diffuse Intrinsic Pontine Glioma) tumours found in children.

Clinical trials are research studies that involve patients in a new way of managing a condition. They can include investigating a new treatment, a new way of giving an existing treatment, a new approach to diagnosing an illness or assessing an outcome after treatment.

3%

of brain tumour patients compared to 7.5% of all cancer patients are currently enrolled in clinical trials.

This latest clinical trial, called BIOMEDE, should open at the end of the year. It aims to recruit 150 children who have been diagnosed with a DIPG over a four year period.

BIOMEDE is designed so that if a drug does not have good results, it can be dropped from the testing. However, if a new drug for DIPG tumours becomes available, it can be added in and it won't have to wait for a whole new trial to begin. This flexible design will speed up the process of trialling new drugs, with the aim of finding new effective treatments for each tumour subtype.

To find out more about clinical trials, take a look at our database: thebraintumourcharity.org/clinical-trials-database or contact our Support and Information Team on 0808 800 0004.



A donation of

£10

could enable us to distribute our HeadSmart tools to a GP's surgery so that they know when to refer a child for a scan.



“We would’ve welcomed this trial for our little boy”

Zoe and Danny Thomas’ six year old son Alfie passed away from a DIPG in 2014.

Zoe said: “The BIOMEDE trial is essential to try and find effective treatments for children diagnosed with DIPG.

“When Alfie was diagnosed with DIPG, the only treatment available to him was sadly palliative and he was not eligible for any trials. No parent should be told that ‘nothing can be done for your child’ and we would have welcomed this urgently needed trial for our little boy.

“Children with DIPG do not have time to wait for the drawn out trial applications when new drugs come to the market, which is why the innovative aspect of this trial stood out to me. I believe that this new trial will not only drive forward research but it could potentially make a desperately needed change for the children of our future.”

The trial is being co-funded with Cancer Research UK and will be led in the UK by Dr Darren Hargrave from Great Ormond Street Hospital.

With prognosis rates for children with a DIPG being particularly poor - 70% of children not likely to survive more than a year - we are hopeful that this trial will give those affected by DIPGs access to better treatments and drugs, and will continue our drive to make every patient a research patient.

Could you share your brain tumour experience on camera? We want to make a short film showing how the disease affects patients and their families every day. To find out more visit thebraintumourcharity.org/share-your-experience



Young Ambassadors take it to Europe

This February, eight of our Young Ambassadors travelled to Brussels to press for more effective regulation to incentivise the development of paediatric cancer drugs and for better support services for those living with a brain tumour.

Our Young Ambassadors met Emma McClarkin, Member of the European Parliament (MEP) for the East Midlands to discuss their experiences and visited the office of the European Cancer Patient Coalition (ECPC).

Emma pledged to facilitate the translation of HeadSmart cards to be distributed throughout Europe. This is great news for the HeadSmart campaign, as it means our message could be spread further and young lives could be saved throughout Europe.

Hannah, one of our Young Ambassadors who attended said: “We discussed our personal stories with Emma McClarkin, and raised the issue that brain tumours

remain the biggest cancer killer amongst the under 40s, yet research is still lagging behind many other cancers.

“We also made progress with the European Cancer Patient Coalition. UK brain tumour patients alone cannot promote change although it is down to us to encourage individuals across Europe who have been affected by brain tumours to lobby their MEPs.

“The government needs to realise the importance and benefits of research into brain tumours and early diagnosis.”

The trip also coincided with Tasha Floyd’s birthday who sadly passed away last Christmas, aged 24, eight years after her first diagnosis of a brain tumour. Tasha was a popular Young Ambassador and the group were able to mark the occasion and remember their special moments with her.

Where we've been

It's been a busy few months for our HeadSmart campaign.

The team have been out and about engaging with leading healthcare professionals across the UK, helping us raise further awareness of the signs and symptoms of childhood brain tumours. By doing so, we can hope to further reduce diagnosis times.



Optometry Tomorrow 12 - 14 March

Along with 700 other delegates, we attended the annual Optometry Tomorrow conference and exhibition in Birmingham.

Future of Primary Care 17 March

The HeadSmart campaign got healthcare professionals talking at the Future of Primary Care conference in Salford.

Optrafair 9 - 11 April

HeadSmart was showcased at the UK's leading optical exhibition, Optrafair, which took place in Birmingham.

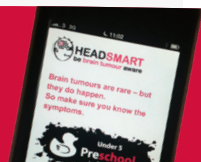
RCPCH Conference 26 - 28 April

Along with HeadSmart's lead clinician Professor David Walker, we attended the Royal College of Paediatrics and Child Health Conference in Liverpool.



Know the symptoms on-the-go

Text SMART to 81400 for your free mobile symptoms guide.



Driving change in the devolved nations

Ahead of the devolved nations' elections earlier this month, we launched tailored manifestos in Scotland, Wales and Northern Ireland outlining key measures that, if implemented, could transform survival and quality of life for everyone affected by a brain tumour.

The launch of each manifesto took place at dedicated events in Scotland, Wales and Northern Ireland during March – Brain Tumour Awareness Month.

The manifestos outline measures to improve the experience of diagnosis, treatment and care for people affected. Through working in partnership with politicians and policy makers on these issues, we can make the changes needed to double survival and halve the harm for those affected by 2020.



Scotland

Our manifesto for Scotland focuses on driving earlier diagnosis, equal access to treatment and care, care planning and accelerating research.

The manifesto was unveiled to Members of the Scottish Parliament (MSPs), supporters, researchers and clinicians during a launch event, sponsored by Cameron Buchanan MSP, at the Scottish Parliament on 2 March. The event included talks from Dr Paul Brennan, Senior Clinical Lecturer in Neurosurgery at the University of Edinburgh who spoke about his research into the diagnosis pathway for adults and how the manifesto, if implemented, could help to underpin this. Supporter Heather Dearie, who has been living with a brain tumour since 2010, also spoke about her experiences.



Wales

Our manifesto for Wales focuses on driving earlier diagnosis, equal access to treatment and care and the promotion and facilitation of research.

On 3 March a launch event, sponsored by David Rees AM, took place at the Welsh Parliament, where the manifesto was presented to Assembly Members (AMs). David Rees spoke about the current state of cancer care in Wales, while talks were also given by Pablo Goetz, a Consultant Neurosurgeon from the University Hospital of Wales and James Powell, Consultant Oncologist at Velinder Cancer centre. Other guest speakers included David Payne and Debbie Bryn, who are both living with a brain tumour, and Debbie's sister and carer Christine.



Northern Ireland

Our manifesto for Northern Ireland focuses on driving earlier diagnosis, equal access to treatment and care and care planning.

The manifesto was launched to Members of the Legislative Assembly (MLAs) during an event at the Northern Irish Parliament on 15 March. The event included talks from Kerrie MacKerracher, whose son Ewan lived with a brain tumour from the age of five to seven, and Danielle McGriskin, Christine O'Carroll and Gideon Burrows who are all currently living with a brain tumour. During the event, MLAs also had the opportunity to attend a drop-in session where they could speak directly with other people affected by a brain tumour, to hear first-hand how the measures set out in our manifestos could improve life today for those affected.

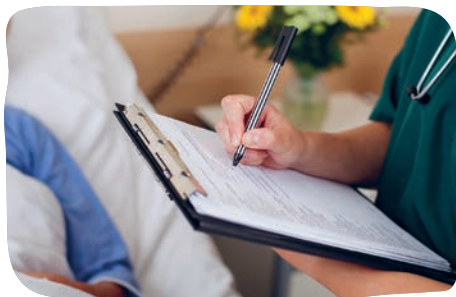
To view our manifestos for Scotland, Wales and Northern Ireland, visit thebraintumourcharity.org/manifestos

Where we're going

Nurse and AHP Study Day

20 May

We're hosting a study day in London for nurses and Allied Health Professionals (AHPs) working in neuro-oncology. The event allows us to support healthcare professionals, facilitate the sharing of best practice and get closer to halving the harm for those affected.



National Paediatric Information Day

11 June

When Ann's daughter, Iona (pictured on page opposite), was diagnosed with a brain tumour, aged five, she didn't know where to turn. Now she's urging other parents to attend our National Paediatric Information Day in Liverpool, to hear from and question leading doctors, nurses and researchers from across the world.

International Symposium on Pediatric Neuro-Oncology

12 - 15 June

We're proud to be platinum sponsors of ISPNO (the International Symposium on Pediatric Neuro-Oncology). Research and healthcare professionals from across the world will meet in Liverpool to discuss new research into, and treatments of, childhood brain tumours. As part of this, we'll also be hosting a Nurses Networking Event to explore improving life today for those affected. For further information visit thebraintumourcharity.org/ISPNO-nurses

British Neuro-Oncology Society meeting

19 June - 1 July

We'll be attending the British Neuro-Oncology Society (BNOS) meeting in Leeds, where we'll be talking to attendees about the results of our childrens and families survey. We'll also get to hear about research and treatment developments in neuro-oncology over the past year.



*“The future can be daunting,
but I feel better prepared”*

After two years of symptoms including headaches and vomiting, Lona was finally diagnosed with a brain tumour when undergoing tests for an ear condition. After an initial successful operation to remove most of the tumour, it started growing back in 2008. Now, at the age of 14, Lona's tumour is stable.

Ann attended our Paediatric Information Day in Birmingham last February where she had the opportunity to hear from leading healthcare professionals including neuro-oncology nurses, neurosurgeons and education psychologists. She's encouraging parents to attend our National Paediatric Information Day on 11 June where they'll have the one-off opportunity to hear, for free, from some of the global leaders in research with speakers travelling from the USA and Canada to speak at the event.

“When Lona was diagnosed, it was hard to know where to turn. There was just so much to take in.

“Birmingham Paediatric Information Day provided a one-stop shop for everything I needed to know. From chemotherapy and late effects to returning to school, I was able to hear talks from some of the UK's most prominent healthcare professionals and begin to make sense of Lona's journey so far. The future can be daunting, but I feel better prepared for what could be around the corner.”

Our National Paediatric Information Day is being organised as part of ISPNO (the International Symposium on Pediatric Neuro-Oncology) in partnership with Alder Hey Children's Hospital. Topics covered will include targeted therapy, radiotherapy, quality of life, end of life care and clinical trials, helping improve life today for those affected.

Limited spaces are available for this event. For further information and to sign up, visit thebraintumourcharity.org/NPID

My personal Everest

Having lost her mum to a brain tumour in 2007 Sarah Lambkin embarked on an extreme challenge to raise funds towards finding a cure.

Keen to do something completely outside of her comfort zone, Sarah pledged to run an incredible 1,000 miles in a year. She recently completed her final mile at the end of the Virgin Money London Marathon on 24 April, while at the same time raising over £3,500 for us.

"After my mum was diagnosed I think we were all in shock as she was never ill, she was the rock of our family and she held us all together, you didn't mess with my mum. Then, within two months she was gone. We all still miss her dearly.

"I was determined to raise awareness of brain tumours which have such a devastating effect on too many families including my own. Running was the best way I could make a difference, not only did it push me to focus on a challenge but it allowed me time to think and reflect. After a training run, I was always fully motivated to raise even more for research into brain tumours."

Despite Sarah's amazing achievement, she has not always been a keen runner.

"I never used to run. In fact, Lambkins don't run! I couldn't imagine running to the end of the street let alone 1,000 miles.

"However, about three years ago I decided that I needed to get fit and lose some weight, so I signed myself up to some charity runs and my fitness and determination grew from there."

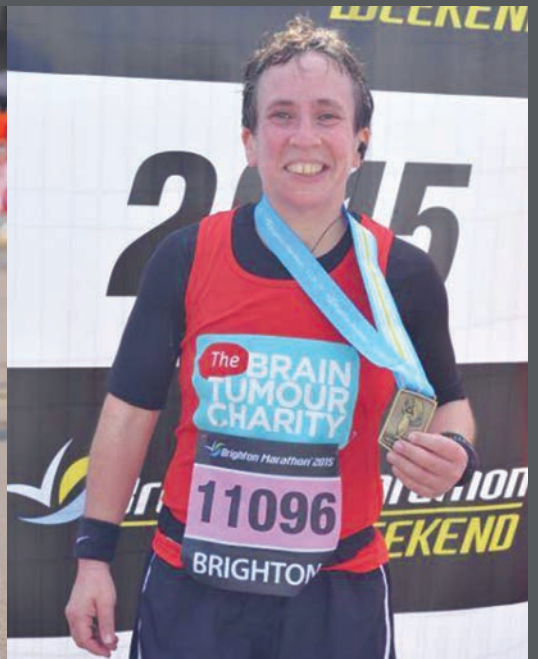
To ensure Sarah hit her 1,000 mile target, she ran up to 19 miles a week and completed various running events for us before her finale at the marathon.

"Being part of The Brainy Bunch Running Group on Facebook really made me realise how there are like-minded people who have gone through similar experiences. But in the end, we're all coming together so we can hopefully find a cure. They were all a real motivation to me."

"I'm thrilled that the money raised will go into research for new treatments to help improve the lives of those living with a brain tumour and eventually defeat this horrible disease."

Sarah and our runners are a real inspiration to us all and it's thanks to them we can fund this pioneering research. Read more on page 4.

For more information on our running events please visit thebraintumourcharity.org/events



Sarah pictured at the Brighton Marathon in 2015 as part of her 1,000 mile challenge. To watch a video about Sarah's challenge, visit thebraintumourcharity.org/sarahs-challenge



Classifying brain tumours

We've been pleased to hear that the World Health Organisation (WHO) are publishing major changes to the classification of tumours of the central nervous system this June.

The publication will emphasise the importance of molecular biomarker tests, which are crucial to understanding the biology of individual tumour types. Biomarker tests will allow doctors to give a more accurate diagnosis and prognosis, but could also potentially open up treatment options for patients.

The availability of biomarker tests is something we're championing as part of our drive for equal access to the best treatment and care.

Biomarkers are indicators such as genes, molecules or other biological substances found in blood or cells that can be measured and used to diagnose a tumour.

An example of a biomarker is the 1p/19q co-deletion, which is when two specific parts of chromosomes 1 and 19 are co-deleted in the tumour.

Patients that have this particular genetic change have been shown to respond better to certain treatments and have a higher chance of survival than others with similar brain tumours who do not have the 1p/19q changes.



A donation of
£ 100

could help fund equipment used to analyse genetic makeup, study protein structure or manipulate cells to behave in different ways.

Sandra McAuley was first diagnosed with a grade two glioma in December 2013 following a visit to A&E.

"When I found out I burst into tears. I thought I was going to die. I was finally sent home on Christmas Eve, my worst Christmas ever.

"In January I saw a neurosurgeon who said that the tumour was benign, but that I would have to watch and wait through regular scans. However after 14 months I couldn't wait any longer not knowing when the ticking time bomb in my head was going to go off, so I went for a second opinion.



"The new neuro surgeon recommended surgery and in September 2015 I underwent an awake craniotomy. Following this operation I discovered I was carrying the 1p/19q co-deletion.

"At the time I didn't really realise the significance of undergoing a biomarker test but it has significantly opened up my treatment options. I was able to have radiotherapy and PCV chemotherapy following surgery because they knew I would respond well due to the 1p/19q co-deletion chromosome that I carry.

"I would recommend a biomarker test to anyone who has the opportunity to have one. It now means that I can look further into the future than I originally thought and live my life to the fullest extent."

To find out more about biomarkers, view our factsheet. Visit thebraintumourcharity.org/biomarkers

Welcome to the Citizens Advice Service

We know from our *Losing Myself* report that one in two people with a brain tumour are experiencing financial difficulty. With 28% also giving up work entirely this can put huge pressure on families who are already trying to deal with issues surrounding diagnosis.



1 in 2 people affected by a brain tumour experience financial difficulties.

To help improve life today for people living with a brain tumour, we've partnered with Citizens Advice Rushmoor.

As part of this three year partnership we're pleased to have welcomed a specialist Benefits Advisor to our Support and Information Team. Our new advisor is on hand to guide people through the system, offer advice on benefits, money related issues and offer practical assistance with making benefit applications and dealing with benefit decisions.

This is a significant step forward in helping us achieve our goal of halving the harm of those affected by a brain tumour by 2020.

Alex Hughes, Chief Officer, Citizens Advice Rushmoor said: "We're delighted to be partnering with The Charity. We've been working closely with their team to ensure our services are tailored to the needs of the people they support so that we can help everyone, no matter where they're located in the UK, to find a realistic and achievable way forward.

"We hope the free, confidential and impartial advice we offer on more practical matters will reduce the suffering of those living with this devastating disease."

You can access the services being offered by Citizens Advice Rushmoor via our Support & Info Line (0808 800 0004) every Tuesday from 12.30 – 4.00pm.

For further information, visit thebraintumourcharity.org/get-support

My brother

We're proud to share our latest animation, *My Brother has a Brain Tumour*. The animation has been designed to help children come to terms with the diagnosis of a sibling and aims to improve life today for families affected.

Lily, the main character, is a seven year old girl whose big brother Noah has been diagnosed with a brain tumour. Lily helps children understand what is happening to a sibling or friend by talking about her brother's diagnosis and her own experiences.

"If I had seen a video like this when my brother was first diagnosed it would have helped me understand why he acts the way he does sometimes and why he can't do certain things. It helped me understand what he feels like – dizzy, sick, sore and sometimes angry. The video shows me that I am not alone – there are other kids who have brothers and sisters with brain tumours and sometimes we get treated differently to them."

A child whose brother has a brain tumour

My Brother has a Brain Tumour was created following the success of **Mummy has a Brain Tumour** and our **Jake** series. All of these animations can be watched at thebraintumourcharity.org/animations



A donation of

£10

could enable us to give a Brainy Bag to a child who's been diagnosed with a brain tumour.

You help us fund it all

We are the largest dedicated funder of research into brain tumours in the UK. For every £1 you donate, 80p is spent directly on our charitable objectives of doubling survival and halving the harm that brain tumours have on quality of life.

We work with thousands of people affected by brain tumours every year and know how vital it is to find a cure. Laboratory-based research is essential, but on its own is not enough. That's why we fund every aspect of research. We're funding researchers to find the cause of brain tumours and understand delays to early and accurate diagnosis. We're investigating new treatments to find a cure and clinical trials to improve care and quality of life.

We collaborate with global leaders across the world, including Cancer Research UK, Cure Brain Cancer (Australia) and the National Brain Tumor Society (USA) to ensure we maximise all opportunities.

Alongside our research, your donations help us make a difference for people affected every day through our support and information services. Our early diagnosis campaign for children, HeadSmart, has halved the average diagnosis time in the UK.

Thank you for helping us to defeat brain tumours.

Welcome to our new **Supporter Groups**:

The Peter Jordan Fund

The Jane Fuller Fund

The Emma Sim Fund

The Tasha Floyd Fund

The AJ Prowse Fund

The Carrie Masheter Fund

The Ali Ling Fund

The June Powell Fund

The Brain Tumour Warrior Fund

The John Lote Memorial Fund

The Tracy Vindel Fund

To find out more about setting up a Supporter Group, visit thebraintumourcharity.org/get-involved



Supporter Groups

Why become a Supporter Group?

“Setting up a Supporter Group helps to give you a focus. Since Reece passed away, his legacy has lived on.”

Debbie and Steve Nelson lost their son Reece, aged eight, to a brain tumour in 2012. During the short time they had with him after diagnosis, the family, including Reece’s older brother Charlie, were supported by our Children and Families Workers.

Following Reece’s death, Debbie and Steve set up The Reecie Nelson’s Superstars Fund.

“Reece’s story inspired us, we wanted a positive outcome for him. Knowing the extreme lack of funding that goes into brain tumour research, we knew we needed to do all we could to help.

“Setting up a Supporter Group has helped us come to terms with everything. We were

initially intimidated by the amount other groups had raised, but decided to go ahead with the mind-set that every penny counts. Whatever we were going to raise would be a bonus.

“Since setting up the fund in 2014, we’ve raised over £40,000 – a figure we can’t get our heads around. We’ve run marathons, hosted ladies nights, Charlie’s just undertaken a 316 mile bike ride starting and ending at the hospital Reece was treated at and we’ve had incredible support from friends and family – it’s brought everyone together.

“Setting up a Supporter Group has allowed us to give something back to those who helped us during hard times. The thought of being able to stop other families going through what we went through drives us on every day.”

How did you wear yours?

Thank you so much for helping us make Bandanas for Brain Tumours Day 2016 the biggest one yet!

On Friday 4 March and throughout the rest of Brain Tumour Awareness Month, thousands of you came together to #WearItOut with style, strength, attitude and love.

With over £80,000 being raised and money still coming in, hundreds of bandana selfies being sent our way and over 200 fundraising events taking place across the country, we'd like to extend our huge thanks to everyone who got involved.

This money can be used to help fund our pioneering research at the University of Cambridge, the University of Edinburgh and the University of Nottingham into early diagnosis for children and adults.

Thank you for being part of our united community!

See if you can spot your bandana selfie in our thank you video: thebraintumourcharity.org/wearitout-thankyou

**BANDANAS
FOR BRAIN
TUMOURS**

Next years
Bandanas for
Brain Tumours Day
will take place on
Friday 3 March
2017.





WearItOut

"In March alone, over 800 people would have been diagnosed with a brain tumour and that's too many. I was honoured to #WearItOut. The Brain Tumour Charity is a charity that's close to my heart and your efforts would have been much appreciated by many families across the country."

Tom Daley



The impact you can have is huge

Last summer one of our supporters, Mark Woolcott, took a collection box to his colleagues at RP Martin, a wholesale broking firm, to help with his son Leon's fundraising.

Ten-year-old Leon has been living with a brain tumour for three years and is one of our dedicated fundraisers.

Mark said: "Within the hour the box was full of notes. There was around £250 in cash – a huge amount for such a small cardboard box!"

RP Martin, inspired by Leon and Mark, subsequently nominated us as one of their chosen charities to represent the firm at the annual BGC Charity Day 2015.

The day raises a staggering \$12 million globally to support charities around the world through celebrities closing deals

on the trading floors of global financial services company BGC Partners.

Mark said: "I was so grateful to RP Martin and my fellow colleagues for choosing to support The Brain Tumour Charity. My son really wants to help raise money for vital research that might help other children through earlier diagnosis and better treatments in the future."

No matter how big or small, a partnership with your company could help us take a step closer to defeating brain tumours.

If you would like to nominate The Brain Tumour Charity at your workplace, please contact our Corporate Team: corporate@thebraintumourcharity.org or 01252 237804.



Looking for a fundraising challenge with a twist?

Between 10 - 14 July 2017, we'll be hosting our first ever bespoke trek abroad, amongst the mossy lava plains, hot springs, mountains and geysers of Iceland.

Join a small group of The Brain Tumour Charity supporters as we travel for five days through Iceland's classic highland landscapes. This tough and challenging trek journeys across black sand deserts, through glacial rivers and streams, over the colourful hills of Landmannalaugar and down into deep gorges.

The trip ends with an evening of celebrations in Reykjavik.

To take part or to find out more, visit thebraintumourcharity.org/challenges

Registration costs £199 per person and a minimum fundraising target of £2,100 (excluding Gift Aid) is required. All profits will go towards doubling survival and halving the harm of brain tumours.

#WalkWithUs

We're excited to announce that The Twilight Walk is back for another series in 2016. Following the success of last year, we'll be bringing back three of your favourite locations - Warwick, Chester and Windsor.

Last October, over 1,400 of the brain tumour community, from supporters and volunteers to clinical nurse specialists and researchers, came together across a month of sunny weekends to walk together and raise over an incredible £220,000 for vital research.

Along with your friends, family and work colleagues, please join us once again as the sun goes down over these three beautiful locations to walk, united as one, to stamp out brain tumours for good.

Together, we can have a bigger and better impact than ever before.



The
**TWILIGHT
WALK**



Warwick

Date: Sunday 2 October
Start point: St Nicholas Leisure Centre

Unite with us as we walk through Warwick taking in the sites of the river and historic castle.



Chester

Date: Sunday 9 October
Start point: Chester Race Course

Starting at Chester racecourse, walk with us along the river and the old city walls as dusk falls.



Windsor

Date: Sunday 16 October
Start point: Windsor Leisure Centre

Walk through Eton, see where the Princes' studied and take in the magnificent, regal sites of the castle.

*Sign up now
and #WalkWithUs*

Sign up and start your fundraising at
[thebraintumourcharity.org/
thetwilightwalk](http://thebraintumourcharity.org/thetwilightwalk)

Don't fancy walking?
By volunteering you can help ensure that The Twilight Walk is an incredible evening from start to finish. Register now at thebraintumourcharity.org/thetwilightwalk-volunteers

Thank you to The Brainy Bunch

We're forever inspired by your dedication, effort and passion to raise funds and awareness for us. Here are just some of your fundraising highlights over the last few months:

Join The Brainy Bunch today: 01252 749043 / fundraising@thebraintumourcharity.org



The Travis Moore Fund took part in the Nottingham Ikano marathon on 27 September – a year to the day since Travis passed away. Even the youngest fund members took part in the mini marathon. The Fund has raised over £17,000 to date.

The Andy Sherwood Fund took part in a 12 hour continuous spin bike relay in an attempt to raise funds and beat the current Guinness World Record. They raised over £2,000 and beat the world record by 99.6km.



Jennie Wilkinson from Hertfordshire has been diagnosed with an inoperable low grade brain tumour. She took part in the 10k London Winter Run in January and has currently raised £2,230 with more runs planned later in the year.



Rob Hughes from Anglesey Cookery School raised over £300 by holding a charity cookathon and there is more to come. 2016 will see a curry evening, bake off and another cookathon.



Grace and Alex sadly lost their mum to a brain tumour last year, so to finish what she started they got the whole school involved in a fundraising day. These amazing children and all their fellow pupils and parents at Belmont Primary raised an incredible £3,000 to help us defeat brain tumours.



The Simon Seivwright Fund held a golf day in memory of Simon on 16 September. Lots of businesses supported by providing raffle prizes, sponsored bottled water and snacks for the golfers. The golf day raised over £2,000.



The Monika Newsum Smith Fund took part in The Thames Path Challenge in memory of Monika. The relay team worked incredibly hard and raised over £2,500 for the Fund.



LANSCA (Leicestershire and Northamptonshire Society of Chartered Accountants) held a black tie fundraising dinner with guests including Bill Morrow, BBC Radio Northampton's John Griff, the Lord Lieutenant and the Lord Mayor of Northampton. They raised £725 on the night.



Matt, Jean and Nathan took on the Laguna Phuket Triathlon at the end of last year, which involved a unique 1.8k swim, 55k bike ride and 12k run. The team have raised over £1,500.



Rob took on the Jurassic Coast Challenge, raising more than £1,965. It was in memory of one of his best friends, Russ Clark, who sadly lost his battle to a brain tumour this January.



Elizabeth Wright along with her friends all took part in The Riverside 10k on 20 March raising just over £1,000 for The Peter Wright Fund.



Young Gloves Karate in Stourport raised over £765 at their annual BBQ and charity karate competition.



After a tough year, with both of Freddie Dare's parents being diagnosed with life threatening illnesses, he decided to take on a 12 hour cycling challenge to help make a difference to The Brain Tumour Charity and The British Heart Foundation. He has raised an incredible £6,497 for our work.

Young Aberdeenshire boys Mac (age 11) and Findlay (age 10) are cousins. They gave up all sweets, chocolate, crisps, cakes, ice-cream and fizzy drinks for two months to raise money in memory of their gran. The boys raised an incredible £2,562.

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 return your donations to:
The Brain Tumour Charity
Hartshead House
61-65 Victoria Road
Farnborough
Hampshire GU14 7PA



Become a regular giver today

Please complete this form and return to:
The Brain Tumour Charity, Hartshead House,
61-65 Victoria Road, Farnborough GU14 7PA

Name: _____

Address: _____

Postcode: _____

Email: _____

Phone: _____

Please pay The Brain Tumour Charity the sum of:

☐ £25 ☐ £10 ☐ £5 ☐ Other £ _____ (Min £2)

☐ per month ☐ per quarter ☐ per year

Start date: ____ / ____ / ____ (1 or 15 of each month)

We record your details on our secure database to keep you up-to-date with our work. We never sell or swap your details with any third parties for commercial purposes. You can opt out at any time: thebraintumourcharity.org/privacy-policy

giftaid it Make your donation worth 25% more!

☐ I confirm that I'm a UK tax payer and want to Gift Aid my donation and any other donations I have made in the past four years or make in the future to The Brain Tumour Charity. I'm aware that The Charity will reclaim 25p of tax on every £1 that I give and understand that I must pay more Income tax and/or Capital Gains Tax for that tax year than the amount of Gift Aid claimed on all my donations, I know it's my responsibility to pay any difference. If my circumstances change, I will notify The Brain Tumour Charity.

If you would like to make a one-off donation or find out how to leave a gift in your Will, visit thebraintumourcharity.org/wastodonate

The **BRAIN
TUMOUR
CHARITY**

Instruction to your Bank or Building Society to pay by Direct Debit



Name and full postal address of your Bank or Building Society

To: The Manager

Bank/building society

Address

Postcode

Name(s) of Account Holder(s)

Branch Sort Code

Bank/Building Society account number

Service user number

6 9 1 2 1 3

Reference

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Instruction to your Bank or Building Society

Please pay the Charities Aid Foundation Direct Debits from the account detailed in this Instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this Instruction may remain with the Charities Aid Foundation and, if so, details will be passed electronically to my Bank/Building Society.

Signature(s):

Date: