

A taste of
The Brain
Tumour
Charity
2016/17

CONTENTS

To ensure we reach the goals set out in our five year strategy (2015-2020), and to make the changes needed for everyone affected by a brain tumour, we're working on six priorities:



A Cure Can't Wait



Every Patient is a Research Patient



Early and Accurate Diagnosis



Equal Access to the Best Treatment



Improving Life Today



United in Our Battle to Defeat Brain Tumours

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FOREWORDS



It is a privilege to chair The Brain Tumour Charity and, in particular, to work alongside so many staff and fellow trustees who have been affected by this terrible disease – either personally or, most tragically, through the death of a child – and whose response has been to ensure that the devastating impact of brain tumours is reduced.

In 2016/2017, The Charity invested in several landmark initiatives to speed up the search for new treatments. These included The Everest Centre, to improve life for children living with low grade tumours, and the Brain Tumour

Fund, a first-of-its-kind, brain-tumour-focused venture philanthropy fund, for the development of new therapies. We committed £6.8 million towards research and formed two Scientific Advisory Boards to ensure that all projects funded were the best available globally.

An exceptional achievement for The Charity during the year included our role in further reducing the average childhood brain tumour diagnosis time to 6.5 weeks.

The challenges facing us remain immense. The astonishing and most welcome improvements in the recovery rates for almost all cancers have not been seen with brain cancer, and the nature of living with a brain tumour is frequently exceptionally challenging. We will continue to seek a cure and to support those affected by the disease.

Sir Martin Narey Chair of Trustees, The Brain Tumour Charity



At The Brain Tumour Charity, we know there's no time to waste in our search for a cure. To get results we need to act and we need to act quickly.

However, we also know that in order to achieve our vision – a world where brain tumours are defeated – we must put solid foundations in place.

That's why, like coffee farmers who handpick and plant the best seeds to produce the highest quality coffee, we've spent the year carefully selecting the research, projects and initiatives that will bring us the highest quality results.

We know that for The Charity to have the biggest impact we must embrace new ideas and invest in beginnings that will create a better future. Our work must be bold and inspiring. It must set us apart.

To reflect this, we've included our own unique brand of coffee, generously provided by expert coffee roasters 200 Degrees, with your annual report.

We hope that, as you enjoy a cup whilst reading the report, you'll get a taste of how we are bringing about global collaboration to speed up discoveries. We hope that you'll drink in a little of how our support work is improving the day-to-day quality of life for everyone impacted by the disease.

But above all, we hope that you'll take away a taste of the passion, energy and inspirational nature of our incredible community, and that a part of this stays with you forever.

Sarah Lindsell CEO, The Brain Tumour Charity



SCALING NEW HEIGHTS

As part of our strategy, Defeating Brain Tumours, we're committed to halving the harm that brain tumours have on quality of life. To do this, we know that we must act innovatively and not be afraid to invest in pioneering research in order to scale new heights.

This is why we're proud to have awarded £5 million to Dr David Jones to set up The Everest Centre for Research into Paediatric Low Grade Brain Tumours.

The centre, to be led from Heidelberg, Germany, will bring together the field's



ENCOURAGING INNOVATION

Last autumn, as part of our Quality of Life Awards, we announced that we would be funding three exciting research initiatives which would focus on reducing the burden and harm to those diagnosed with a brain tumour.

More recently, we've also awarded over £700k to eight cutting-edge research projects across the globe, including in Canada, Australia and the UK, as part of our New Ideas Awards.

These initiatives, alongside the others we've funded, reflect the pioneering

and bold nature of our research which we believe will help propel us more quickly towards our vision: a world where brain tumours are defeated.

thebraintumourcharity.org/new-ideas





As we work to speed up the time it takes to turn discoveries into treatments and cures, it's crucial that The Charity still funds only the highest quality research.



To ensure this, we have formed two Scientific Advisory Boards (SABs) which are made up of internationally renowned scientific and medical experts that work in different areas of cancer research and social science.

The Biomedical SAB, chaired by Professor Richard Gilbertson, and Quality of Life SAB, chaired by Dr Antony Michalski, are responsible for the assessment and rating of applications for research funding and making recommendations to our Board of Trustees. They also include five lay representatives who are an integral part of the SABs and provide a valuable perspective as experts of experience.

We know that exceptional results can only come from exceptional research.

Our SABs are vital to shaping this journey.

INVESTING IN A BETTER FUTURE FOR PATIENTS

While survival has doubled across all cancers, survival rates for adults with brain tumours have improved little in over 40 years.

In order to change this, we know that we must not be afraid to take calculated risks, and to embrace bold new beginnings.

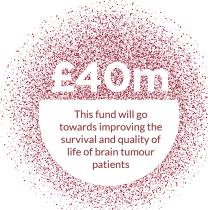
We've therefore taken the ground-breaking decision to establish The Brain Tumour Fund, a first of its kind, brain-tumour-focused venture philanthropy fund.

The Brain Tumour Fund, which is targeting £40 million in capital commitments, will invest in companies with products or platform technologies that have the potential to improve the survival of brain tumour patients or to reduce the debilitating effects of the disease.

As a cornerstone investor, we've pledged £10 million to kick-start the fund and believe that by attracting major investors

into the field of neuro-oncology research to also invest, we can drive forward the development of new therapies and speed up progress towards a cure.

thebraintumourcharity.org/ brain-tumour-fund



£34.1 million The amount we've committed to pioneering research into brain tumours to date.

11

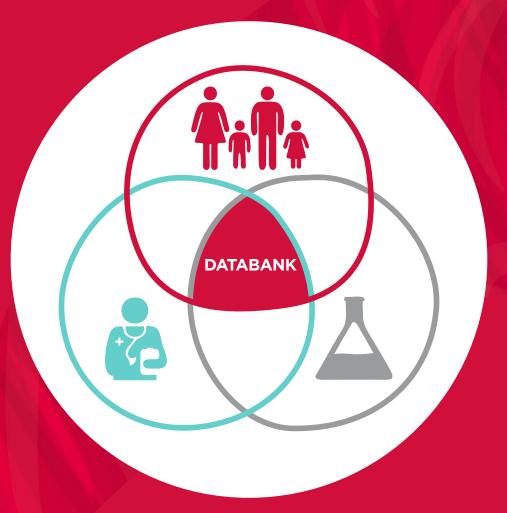


PROVIDING A DIGITAL PLATFORM FOR PATIENTS

Improving life for our community and accelerating our quest to find a cure is at the heart of everything that we do.

This is why, over the year, we began developing one of our most exciting, revolutionary initiatives to date – a global, patient-led data bank.

The data bank will provide a digital platform where medical and quality of life information can be shared openly with both patients and researchers. This innovative resource will enable patients



to share their data to help accelerate the progress of vital research and new treatments, as well as empowering them to make better informed decisions about their own treatment plans.

Our aim is for the data bank to help patients, clinicians and scientists collaborate for better health outcomes. This will be a crucial step in our quest to ensure that every patient who wants to contribute to research is able to and, going forward, could radically change the current research landscape.



The views of those affected by brain tumours are vital to researchers when shaping programmes of research. This ensures that their work remains relevant and reflects the needs of our community.

Since we launched our Research Involvement Network (RIN), to drive collaboration between researchers and patients, it has gained 85 members who, last year alone, were involved in an incredible 34 research projects.

By sharing their experiences, those living with a brain tumour, those who've lost someone to a brain tumour or those who are currently caring for a loved one with a brain tumour, have brought a wealth of information to the network. This insight has been invaluable in helping researchers to gain new perspectives on their work.

"It was great to be involved in this group, for our experiences to be useful and to feel like we were giving something back."

Deborah, whose daughter was diagnosed with a brain tumour aged three.

Only 3% of brain tumour patients are currently enrolled in clinical trials, despite many more wanting the opportunity.



Since we launched our award-winning HeadSmart campaign, we've helped drive down average childhood brain tumour diagnosis times from 13 weeks to 6.5.

Determined to get this reduced to four, over the last year we've relaunched the campaign. Following a clinical evidence review, led by the Children's Brain Tumour Research Centre at The University of Nottingham, one of the partners involved in HeadSmart, we updated the common signs and symptoms of a brain tumour in children and teenagers so that HeadSmart

HEAD | EARLY DIAGNOSIS OF BRAIN TUMOURS



HeadSmart is funded and promoted by The Brain Tumour Charity and run in partnership with the Children's Brain Tumour Research Centre (CBTRC) and the Royal College of Paediatrics and Child Health (RCPCH).

Do you know the signs and symptoms?

headsmart.org.uk/sam-animation

remains a respected resource for GPs and other healthcare professionals.

We also refreshed the brand identity, created a new website and developed an animation for the campaign to better engage key audiences and, in particular, stand out to teenagers who on average take longer to be diagnosed than babies and children.

Finally, as part of the exciting refocus we introduced an eye-catching campaign icon called Sam – named after Samantha Dickson, who sadly passed away from a brain tumour when she was just 16. Samantha's parents, Neil and Angela Dickson, are one of our founders and were instrumental in establishing our HeadSmart campaign. The awareness raised by relaunching the campaign will be crucial in making sure that brain tumours are diagnosed and treated much earlier.

IMPROVING THE ACCURACY OF DIAGNOSES

Improving the accuracy of brain tumour diagnoses means those affected could receive more effective treatments.

This is why, last December, we launched a funding call for our Clinical Biomarkers Awards.

Biomarkers are biological markers, or indicators, such as a molecule or gene, that can be used to help diagnose the type of brain tumour a patient has and how best to treat it.

By providing grants to researchers to focus on the discovery of these biomarkers, our hope is that their findings will bring us closer to earlier and more accurate diagnoses of brain tumours, drastically improving outcomes for patients.



2.7 million
The number
of HeadSmart
symptoms cards
we've distributed
to date.



From our report, Finding Myself in Your Hands: The Reality of Brain Tumour Treatment and Care, we found that nearly three out of 10 patients currently receiving treatment were not given a choice of relevant treatment options. In a recent survey, we also discovered that two thirds of people living with a brain tumour were not signposted to suitable support.

"If the Patient Guide had been around when Dad was diagnosed, I believe that we'd have been able to get more information from health professionals, more support and ultimately more precious time to spend with him."

Jayne Wilson, who lost her father to a brain tumour.

In order to take a vital step towards changing this, last November we were proud to launch our new *Patient Guide* to *Brain Tumour Treatment and Services* for Adults.

The guide, which has already been accessed by over 2,000 patients, includes our patient pathway which outlines the standard of care that we believe all adults living with a brain tumour should expect to receive from the NHS. It also offers information on clinical trials and research opportunities that are not routinely offered to all patients at this time.

We believe that this powerful resource will play a crucial role in empowering patients to confidently navigate the system and in ensuring that every person with a brain tumour has equal access to the best treatment and care.

thebraintumourcharity.org/patient-guide

USING OUR VOICE AS A CATALYST FOR CHANGE

Over the last year our Policy and Public Affairs Team have successfully influenced decision makers and organisations on a range of important issues that directly affect our community.

Highlights include lobbying NHS England to include brain tumours in their research around patient access to a clinical nurse specialist (CNS), getting a motion tabled in the Scottish Parliament on the relaunch of the HeadSmart campaign, which was signed by 46 MSPs and briefing the DVLA leading to the agency making the process by which they make decisions about an individual's ability to drive more transparent.

Evidence from The Brain Tumour Charity was cited on a number of occasions in the House of Lords Select Committee on Charities report, "Stronger Charities for a Stronger Society," published in March 2017. The Committee commented on our remarks regarding the impact of Brexit, volunteering, charity mergers, the Lobbying Act and the use of digital technology.

We have also played a key role in advising the Department of Health and other members of the Government's Task and Finish Group on what the current barriers to research into brain tumours are and have continued to lead on the discussions for change.

Currently only 1.9% of national cancer research funding is allocated to research into brain tumours



PUTTING THE RIGHT SUPPORT IN PLACE

In February, we were thrilled to award funding for our first low grade tumour clinical nurse specialist at King's College Hospital.

Having access to a clinical nurse specialist (CNS) makes a significant difference to an individual's experience of symptom burden, access to information and, emotional and mental health.

By funding this vital post, we can improve life today for patients and help to manage the impact that their brain tumour has on their health and wellbeing.



RAISING VITAL AWARENESS

Last June, following our survey of the experiences of 300 young people and parents on what life is like after a brain tumour diagnosis, we published our report, 'Losing My Place: The Reality of Childhood with a Brain Tumour'.

This research, which is the most comprehensive study of its kind, found that brain tumours interrupt the natural process of growing capacity and independence from parental care in ways no one involved can prepare for.

The report received national media coverage and will be used to help us ensure policy makers, healthcare professionals and the public understand the realities for a young person living with a brain tumour.

"Loss of vision meant she often felt lonely at first as she couldn't find her friends in the playground."

Parent, daughter aged seven with a high grade tumour.



Throughout the year we held a series of Family Days across the UK, some of which were generously funded by The Lewis Moody Foundation and BBC Children in Need.

In total, we were delighted to welcome over 100 families who took part in a range of exciting activities.

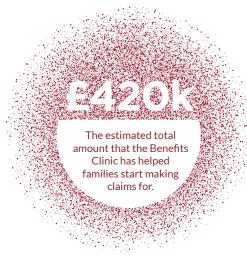
These events provided an invaluable opportunity for children or parents diagnosed with a brain tumour, and their families, to have some respite from their worries and some much-needed time and fun together. Most importantly, the days allowed parents and children alike to meet others in a similar situation and make real, long-lasting connections. The comfort and strength families draw from experiences like these is immeasurable.

OFFERING FINANCIAL GUIDANCE

Last April, we partnered with Citizens Advice Rushmoor to launch our very own Benefits Clinic to ensure that families affected by a brain tumour diagnosis were not having to face further worry and stress during an already difficult time.

Since setting up the clinic, on average, each person that the service has helped is nearly £5,000 better off, with some families set to be as much as £10,000 better off over a 12 month period.

The service has helped a large number of families across the UK on a wide range of money issues. It has empowered our community to ask for what they're entitled to and, in one case, helped an individual to avoid homelessness.





We've always recognised that in order to best support those living with a brain tumour, we must also support the professionals involved in their care.

This is why, last May, we decided to hold our first ever Nurse and AHP Study Day for nurses and allied health professionals working with adults with a brain tumour.

The event, which was attended by over 160 delegates, provided a unique

opportunity for individuals to network, hear from knowledgeable speakers and share best practice across the sector. Following the day, over 99% of the attendees rated the quality of the education they'd received as good or excellent.



OFFERING PARENTS NEW PROMISE

We were the leading sponsors of the International Symposium on Pediatric Neuro-Oncology (ISPNO) in Liverpool last June.

As part of this huge global event, which brought over 1,100 international academics and clinicians together, we were thrilled to host our third Paediatric Brain Tumour Information Day for families.

Speakers included world-leading experts, Dr Mark W. Kieran (Boston, USA) and Dr Roger J. Packer (Washington, USA) who, alongside other internationally renowned researchers and individuals personally affected by a brain tumour, delivered highly inspiring and informative talks.

In total, more than 90 people attended the day and, thanks to all our excellent speakers, families left the event feeling better informed, less isolated and more in control of the complex issues that they face on a daily basis.

bit.ly/NPIDVideos



During 2016/2017, we were delighted to be awarded grants by BBC Children in Need and St. James's Place Foundation.

Together, these combined donations, amounting to over £200,000, will help to fund our crucial Children and Families Service which provides families with support and information when they need it most.

These incredibly generous contributions will be instrumental in enabling us to provide a Children and Families Worker

who can offer vital one-to-one support for families, Paediatric Information Days, Family Days, Brainy Bags and our education packs for teachers – for the next three years.

The funding from St. James's Place was inspired by Alex Bolt, who died from a brain tumour at the age of just 16.





Inspired by The Alex Bolt Fund



A UNITED SEA OF RED

Last October, The Twilight Walk brought together over 1,800 passionate people, including volunteers, as they united to stamp out brain tumours for good. This was a 50% increase on the previous year, making the walks in Warwick, Chester and Windsor the largest to date.

The huge event saw walkers of all ages, whose lives have been touched by a brain tumour, completing the 10k routes in order to raise crucial funds for the 102,000 people currently living with a brain tumour in the UK.



THE STRENGTH **OF OUR SUPPORTERS**

Our Supporter Groups are devoted groups of friends, families and colleagues who come together to fundraise in memory of, or inspired by, a loved one in order to raise money and awareness for The Brain Tumour Charity.

In 2016/2017 they generated an astounding income of over £930,000*, which will be invaluable for our work.

Over the year we were honoured to welcome another 25 Supporter Groups, growing this inspiring community to 277 groups in total now.

*This figure includes all money raised directly by Supporter Groups excluding that generated by individuals associated with Supporter Groups in events such as the Virgin Money London Marathon.

"I am completely lost without Michael, but I know he wouldn't want me to give up. Setting up a Supporter Group fund to try and help others facing the same fight is a huge part of that, and something I know Michael would have completely supported."

Lucy Barry, who lost her husband Michael to a brain tumour.



Once again #TheBrainyBunch left us in awe of their incredible efforts, energy and drive as they continued to fundraise tirelessly for us throughout the year.

Thousands of our dedicated community got involved in a wide range of events and challenges, including runs, cycles, swims, rows, skydives, bake sales, car boot sales, raffles and balls.

In April, 101 runners took part in the Virgin Money London Marathon 2016 on our behalf. They raised over £248,000 for The Charity and gained excellent local and national media coverage, enhancing vital awareness of our cause.

A BURST OF BANDANA ENERGY

On 3 March, thousands of our community united with passion and energy to #WearltOut for Brain Tumour Awareness Month.

Across the country our wonderful supporters came together to hold a range of exciting events including bake sales, sponsored swims, dress down days and cycles, in order to fund 400 days of vital research into brain tumours.

BAFTA-award winning actress, Olivia Colman got in on the act too, enthusiastically donning a bandana to show her support. We're really grateful to all involved. Your fantastic efforts enabled us to generate a 34% increase on the total we raised the previous year. All the vital money and awareness raised will continue to move us closer towards our twin goals of doubling brain tumour survival and halving the harm caused by the disease.

The amount we raised towards our research.

CLOSING REMARKS



As a neurosurgeon, I'm reminded daily of the vital need for ground-breaking, new treatments for brain tumours.

I'm therefore proud to support The Brain Tumour Charity and the inspiring progress that it has made throughout 2016/2017.

The Charity's commitment to funding the most effective, outcomes-orientated research is unfaltering and every page of this report reflects its determination and pioneering vision in doing so. Major milestones during the year that have stood out to me include The Charity's work on the global, patient-led data bank, which could revolutionise the development of new treatments and diagnostics, and its investment into the venture philanthropy fund, an important move to stimulate further research into this cruel disease.

To accelerate the time it takes to turn lab discoveries into treatments, it's imperative that investments are made in a wide range of innovative projects. It's great to see that The Charity has awarded funding to several new research initiatives over the last year.

It's vital work like this that continues to move The Charity closer to unlocking potential treatments and closer to finding a cure.

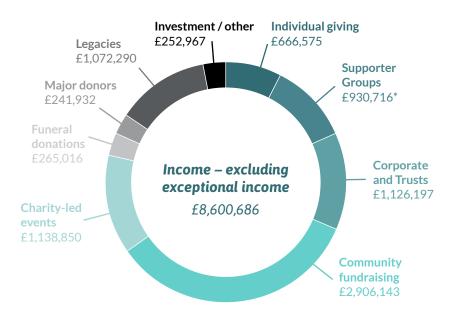
Professor Keyoumars Ashkan Professor of Neurosurgery, Kings College, London

OUR FINANCES

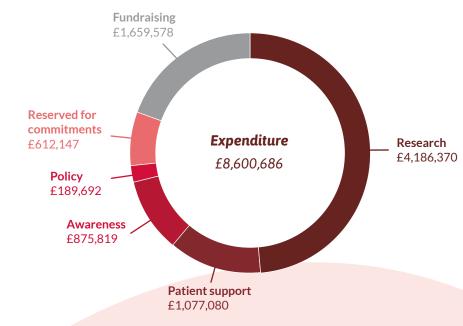
Last year, The Charity's underlying ordinary income, which excludes exceptional income, was £7,382,114, so we're delighted to see this figure rise to £8,600,686 for 2016/2017 – an increase of 17%.

We're also pleased to see that the income from individual giving has significantly increased from the previous year, jumping 32% to £666,575 from £505,179. All of our services are free of charge for anyone whose life has

been affected by a brain tumour. This, coupled with our research and awareness work, is only possible thanks to our dedicated supporters, as we receive no Government or statutory funding and rely 100% on voluntary funding.



*This figure is the amount raised directly by Supporter Groups. It excludes money generated by individuals associated with Supporter Groups in events such as the Virgin Money London Marathon.



HIGHLIGHTS K

Thanks to all you've done for us we've been able to achieve a lot this year. Here are some of our highlights.

Apr '16

Launched our own Benefits Clinic, making those we helped

£5,000

better off on average

May '16

Nurse and AHP Study Day

for 160 delegates

Jun '16

Published our report Losing My Place: The Reality of Childhood with a Brain Tumour

Sep '16

Quality of Life Awards

funding announced to help improve life for those affected



Oct '16

>1,800

people united through The Twilight Walk to raise

>£280,000

Nov '16

Launched the
Patient Guide to Brain
Tumour Treatment and
Services for Adults



Dec '16

Formed two
Scientific
Advisory
Boards

(SABs)

Dec '16

Awarded funding to **8 global**

research initiatives as part of our New Ideas Awards Jan '17

Relaunched our

HeadSmart campaign

Feb '17

Awarded funding for our first low grade tumour

clinical nurse specialist



Mar '17

#WearItOut raised over

£100,000

to fund 400 days of vital research into brain tumours

(Mar '17

Awarded

£5 million

for 'The Everest Centre for Research into Paediatric Low Grade Brain Tumours'



Last year The Charity continued to fund the highest quality research, and support thousands of people affected by a brain tumour. This work is only possible due to our dedicated supporters and the companies, charitable trusts and foundations, both in the UK and internationally, which continue to work with us. To everyone involved, we cannot thank you enough.

Trusts

BBC Children in Need
The Colin Oliphant
Charitable Trust
F J Wallis Charitable
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for Northern Ireland
The Hugh Fraser Foundation
Souter Charitable Trust
Stay Strong Stu
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Katy Holmes Trust
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Sarah and Ben Pullen

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FMedSci, FBPhS

Steve Backshall
Dr Steve Pollard

Tcheky Karyo

Tim Burgess and The Charlatans

Tom Daley

Our volunteers

We'd like to say a huge thank Governance you to all of our wonderful volunteers. Each one of you plays a key role in helping us to defeat brain tumours and we couldn't do what we're doing without you.

Trustees and

Trustees

Sir Martin Narey (Chair)

Neil Dickson MBE (Vice Chair)

Graham Lindsay (Vice Chair)

Tim Burchell

Angela Deacon

Angela Dickson MBE

Andy Foote

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Robert Posner

Simon Hay

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(from July 2016)

Dr Justine McIlroy (from January 2017)

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Professor Sir Colin Blakemore

Scientific and Medical Advisor to the Trustees

Professor Richard Gilbertson

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Sarah Lindsell

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Governance

Biomedical Scientific Advisory Board (Biomed SAB)

	,
Name	Institution
Professor Richard Gilbertson MBBS, PhD (Chair)	The Cambridge Cancer Centre
Dr Mark Gilbert MD (Vice Chair)	The Centre for Cancer Research at the National Cancer Institute, USA
Dr David Adams PhD	The Wellcome Trust Sanger Institute
Dr Kenneth Aldape MD	The University of Toronto, Canada
Professor Robert Brown PhD	Imperial College London and The Institute of Cancer Research
Dr Susan Chang MD	The University of California, San Francisco, USA
Dr Eyal Gottlieb PhD	The Technion Institute of Technology, Israe
Dr Paul Northcott PhD	St. Jude Children's Research Hospital, USA
Professor Nicola Sibson PhD	The CRUK/MRC Oxford Institute for Radiation Oncology
Professor Martin van den Bent MD, PhD	Erasmus University, The Netherlands
Dr Ian Waddell PhD	The Cancer Research UK Manchester Institute

Quality of Life Scientific Advisory Board (QoL SAB)

Name	Institution
Dr Antony Michalski MB ChB, MRCP, PhD, FRCPCH (Chair)	Great Ormond Street Hospital
Professor Martin Taphoorn MD, PhD (Vice Chair)	The VU University Medical Center, Amsterdam
Professor Terri Armstrong PhD, ANP-BC, FAANP	The National Institute of Health, USA
Dr Paul Brennan MB, BChir MRCS (Ed), PhD	The University of Edinburgh

Name

Dr Rachel Cox MB, ChB, MRCP MA MD Professor Filomena Maggino PhD Dr Diane Puccetti MD Professor Maggie Watson PhD, Dip.C.Psych., AFBPS

Institution

University Hospitals Bristol
Sapienza University of Rome, Italy
The University of Wisconsin
The Royal Marsden Hospital
and University College London

Lay Advisors

Deborah Crossan Christina Brincat Professor Celine Boehm Louise Edwards Rachel Rathbone

Last but not least...

We'd like to say a huge thank you to Tom Vincent, Rob Darby, Matt Shelton, Tim Moss and everyone at 200 Degrees Coffee for all their support over the year and for creating and donating this delicious blend, developed exclusively for The Brain Tumour Charity, to help us provide you with a taste of our work.











Get in touch:

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Thank you for all your support in 2016/17

thebraintumourcharity.org

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