

The **BRAIN
TUMOUR
CHARITY**

Research | Awareness | Support



14/ | ANNUAL
15 | REVIEW

The Brain Tumour Charity

Today

40

Brain tumours are the biggest cancer killer of children and adults under 40 in the UK.

27



Every day 27 people are diagnosed with a brain tumour, while every year over 5,000 people lose their battle with this devastating disease. For those who survive, most will have a reduced quality of life.

2%



With just 2% of the cancer research funding in the UK being spent on brain tumours, there is an urgent need for more research.

Tomorrow

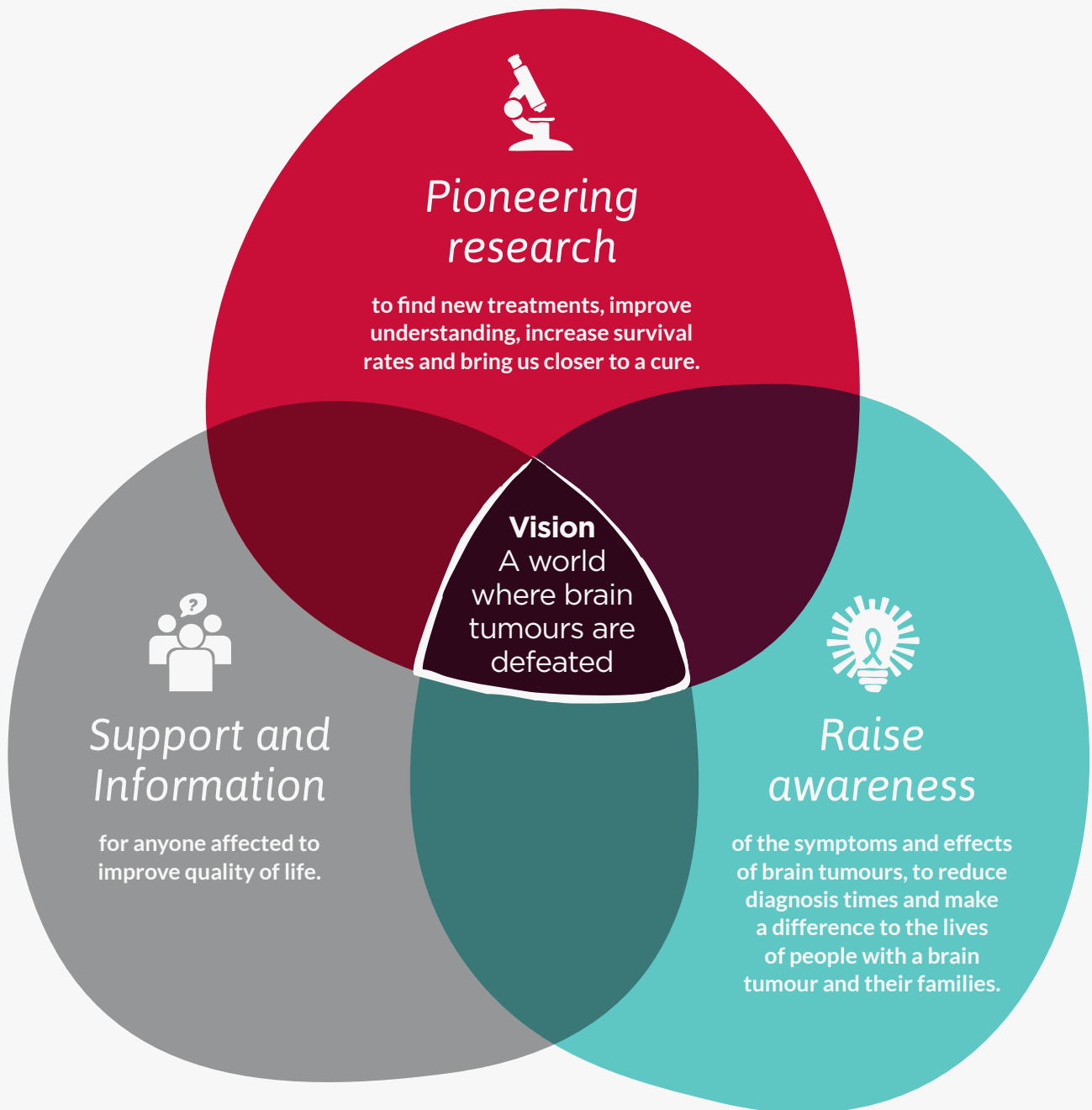
Double survival within 10 years



Halve the harm that brain tumours have on quality of life



We fight brain tumours on all fronts through research, awareness and support to save lives and improve quality of life.





Time to take action

Welcome to our 2014/15 Annual Review

Welcome to our 2014/15 Annual Review. Inside, you can read how 2014/15 became a landmark year for us – not only the year that we raised more than ever before – but also the year that we took stock and said enough is enough. We've lived with the fact that brain tumours are the biggest cancer killer of children and the under 40s for too long and it's something we can accept no more.

Whilst survival has doubled across all cancers, 10 year survival rates for brain tumours have improved little for adults in 40 years. In fact, they have stagnated. 30 years ago they were increasing at 3% per decade, now they don't seem to be increasing at all.

We knew that we could learn from the success rates seen in other diseases such as HIV or AIDS and that we could have a much bigger impact on the lives of those affected. Over the course of a year, we set to action this.

We have a passionate community of patients and specialists who are desperate to find a cure. We listened to those living with a brain tumour, the global research community, healthcare professionals, the biotech and pharmaceutical industry, donors, other charities, our Trustees, staff and volunteers to see what the priorities were that we needed to address. The overwhelming message was the poor survival rate and quality of life.

As a result of feedback from our community we developed our new five year strategy *Defeating Brain Tumours* (page 18) which sets out to double survival and halve the harm of those affected by a brain tumour. To outline the key areas that our funded research needs focus on to achieve these goals, we also developed *A Cure Can't Wait: Our Research Strategy* which you can read about on page 8.



These new strategies may be a decade overdue but they are necessary and unashamedly ambitious. We recognise that to make progress we need to work together relentlessly – we now have world-class researchers, healthcare professionals and other charities on board and this marks an essential step towards our vision of a world where brain tumours are defeated.

All of this would not be possible without the dedication of you – our wonderful supporters. It's thanks to our Supporter Groups, fundraisers, corporate partners, one-off donors, regular givers, people who remembered us in their Will and everyone in-between that we raised more than ever before in 2014/15. It's thanks to your support that we can be so confident the ambitious goals set out during the year can be achieved.

We still have a lot of work to do but we know that, by working together, we will get there.

Going above and beyond



Rob Ritchie's youngest son Toby was finally diagnosed with a brain tumour in 2013 at the age of five, after suffering with health problems for several months. Because of its position in his brain stem, the tumour couldn't be fully removed so the family opted for chemotherapy to slow its growth.

In March 2015, along with a team of 13 others, Rob undertook an extreme alpine challenge, ascending 8,848 metres – equivalent to the height of the world's largest mountain – on skis. Through the generosity of Rob's employer Goldman Sachs, and colleagues, friends and family, the four-day Everest in the Alps challenge became our biggest fundraiser yet, raising £3 million for paediatric brain tumour research.

” 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



**Pioneering
change**

**Gaining
recognition**

**Changing
lives**



Bringing together brilliant minds



Over two days in May 2014, for the first time globally, we brought together the world's leading brain tumour researchers, scientists and clinicians to challenge them to answer one question: "What are the biggest barriers to increasing survival and improving quality of life for people diagnosed with a brain tumour?"

Outcomes from our Brilliant Minds Symposium, alongside feedback from people affected by a brain tumour – our experts through experience – was used to shape our new, ambitious five year research strategy: *A Cure Can't Wait* (page 8).

” *The Brilliant Minds Symposium was a unique opportunity to take part in discussions that will shape the future of the research environment in neuro-oncology. It provided a great chance to hear views from leaders in the field on the barriers and opportunities that exist to increasing survival, whilst also improving quality of life in the shortest possible time.*

There was an extremely strong willingness from all in attendance to start to address these, which gives a very positive outlook for the future of research into brain tumours.

Professor Susan Short, Leeds Institute of Cancer and Pathology

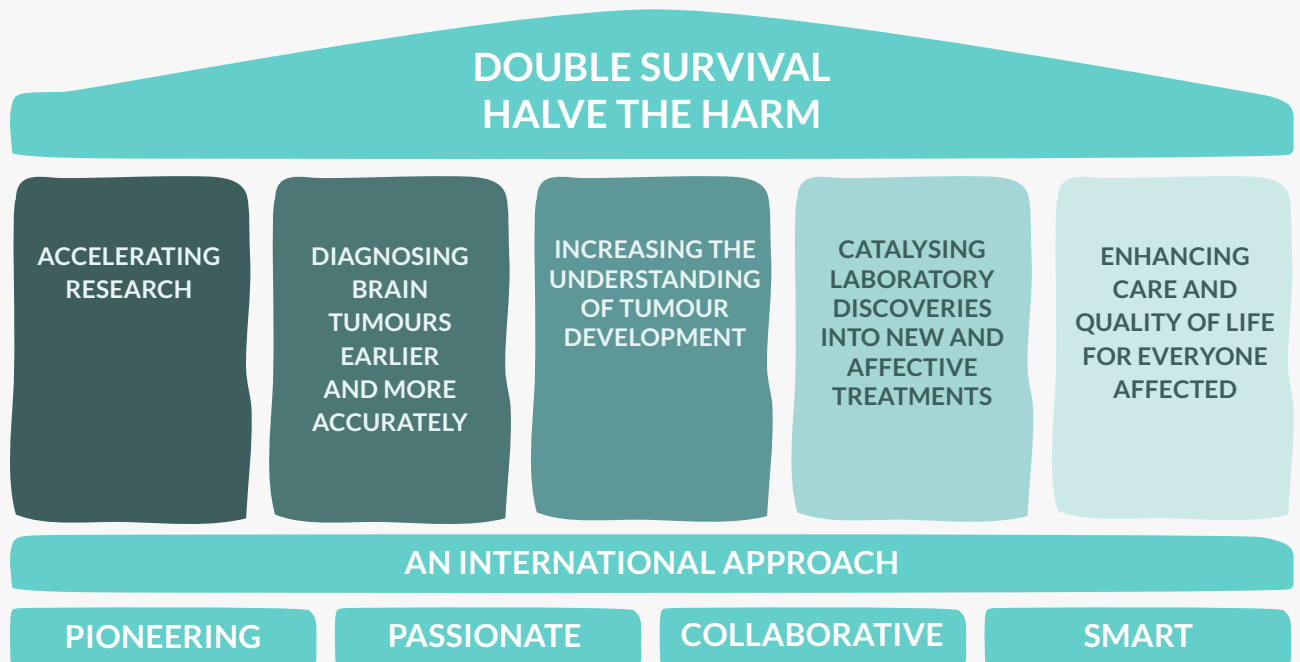


A Cure Can't Wait

Our Research Strategy 2015–2020

A Cure Can't Wait: Our Research Strategy was launched in December 2014 and focuses on two strategic goals – doubling survival and halving the harm that brain tumours have on quality of life.

To have the greatest impact for everyone diagnosed with this disease and to achieve our ambitious goals, our research strategy focuses on five priority areas.



For further information, visit
thebraintumourcharity.org/a-cure-cant-wait

Looking forward: *A Cure Can't Wait* promises to invest in pioneering, outcome-orientated and patient-focused research. It represents a significant multi-million pound increase in our research investment over the next five years – we are committed to investing at least £25 million into research from 2015 to 2020.



Our current research

As the UK's largest dedicated funder of research into brain tumours, we fund world-class cutting-edge research projects that are amongst the best in their field. We only fund projects that we are confident will have a lasting impact on the future of brain tumour research.

In 2014/15 our flagship research commitments included investment into three five-year research programmes:

UCL Centre of Excellence, the Samantha Dickson Brain Cancer Unit

The team are investigating how tumour cells produce energy and package up their DNA. High grade gliomas are very aggressive and have a poor prognosis, by investigating the biological mechanisms behind them the team hope to identify new treatment targets to be used in clinical trials.

The University of Leeds

The University of Leeds is studying non-toxic cancer killing viruses which 'invade' and kill tumour cells, whilst leaving healthy cells unharmed. These new methods to deliver drugs to the brain are urgently needed as many drugs cannot pass through the protective barrier that separates the brain from the bloodstream. A clinical trial is now in development as a result of this research.

The INSTINCT Programme

A collaboration between Newcastle University and the Institute of Cancer Research which is exploring new ways to treat some of the most aggressive childhood brain tumours by identifying links between tumour characteristics and prognosis. We are funding this programme alongside Children with Cancer UK and Great Ormond Street Hospital Childrens Charity.

We will invest £5 million in these programmes from 2014-19. For further information, visit thebraintumourcharity.org/our-research

During the year, we also funded research projects at:



24 peer-reviewed research articles were published in leading scientific journals such as Neuron. Publishing results means that other scientists are aware of the work being done in different laboratories and means that this work can be built on to advance the field and prevent accidental duplication.



Pioneering research

In 2014/15 we set to work on the promises made in *A Cure Can't Wait: Our Research Strategy*. Highlights included:

Launching new research funding calls.

Following the success of our **HeadSmart: Be Brain Tumour Aware** campaign, we announced a research funding call to investigate the diagnosis pathway for adults with a brain tumour. The findings will allow us to understand the impact an earlier diagnosis may have on outcomes, and we plan to use them to help us build a symptoms awareness campaign for adults.

Awarding funding for clinical fellowships.

In August 2014 our first Clinical Fellow, Dr Jason Adhikaree, was appointed at The University of Nottingham. He is investigating how the body's immune system could be used to fight glioblastoma brain tumours, the most aggressive brain tumour in adults. By encouraging more clinicians into the field, we can accelerate research and come closer to finding a cure.

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

Dr Jason Adhikaree

Looking ahead: In 2015 we will launch three significant funding rounds that will invite applications for novel ideas, global team collaboration and quality of life research.



£12 million

We have invested £12 million to date into research



More than one in five of our current research grants is supporting a clinical trial to test a new brain tumour treatment.



Every patient is a research patient



Less than 3% of brain tumour patients are on a clinical trial compared to an average of 7.5% across all cancers. Taking part in clinical trials can give patients faster access to treatments, better care and the opportunity to play a part in defeating this disease.

Ken had a glioblastoma removed in April 2014 and went on a clinical trial led by Professor Garth Cruickshank at Queen Elizabeth Hospital Birmingham. He first learnt about clinical trials at one of our Information Days, where he heard a talk by Professor Cruickshank on a new trial taking place which delivered chemotherapy straight to the brain.

Ken was contacted by a research nurse at Queen Elizabeth Hospital the day after hearing from Professor Cruickshank about taking part in the trial – he didn't hesitate to accept the offer.

” *Clinical trials are essential to giving brain tumour patients more of life's best moments because we cannot get better treatment without them. I've got my fingers crossed for my trial that the researchers will find some progress. The trial may not provide 100% of the solution but it might provide 1% – and that's worth doing.*

Ken, who had a glioblastoma removed in April 2014 and went on a clinical trial led by Professor Garth Cruickshank at Queen Elizabeth Hospital Birmingham.



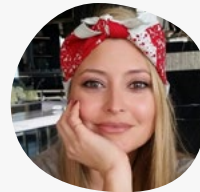
Raising awareness

Thanks to increased awareness of The Brain Tumour Charity and the dedication of our amazing fundraisers, 2014/15 was a record year for us in which we generated £7,158,964 – more than ever before.

We worked with a number of celebrities throughout the year to further increase awareness of brain tumours, their impact on quality of life and the need for earlier diagnosis. This included Tom Daley, Martin Kemp, Ronni Ancona and Suzanne Shaw.

In May 2014, former England rugby captain Lewis Moody MBE, and his wife Annie, launched The Lewis Moody Foundation which raises funds for research through The Brain Tumour Charity.

Bandana Day 2015, our annual awareness event each March, was our most successful yet and drew support from a number of celebrities, including Tom Daley, Clare Balding, Ronni Ancona and Holly Candy. The campaign raised over £86,000 for vital research, with sales of bandanas more than trebling from the previous year.



Increasing awareness online



55,430

Facebook likes across The Brain Tumour Charity and HeadSmart pages grew from 44,141 to 55,430 – these posts had a potential reach of 20.3 million.



↑ 4,774

Twitter followers increased by 4,774 across the two handles, with a potential reach of 24.1 million.



20,000

Surviving Terminal Cancer, a film directed by supporter Dominic Hill and sponsored by us, was shown at the British Film Institute in London and has since received over 20,000 views online.



Celebrity involvement



Actress and impressionist Ronni Ancona backed our Bandanas for Brain Tumours campaign 2015 with a video encouraging people to Wear it out!

Ronni witnessed first-hand the devastation caused by brain tumours after the nephew of a close friend, eleven-year-old Silas, was diagnosed with an incurable high-grade glioma and died 17 months later.

Ronni, who has two young daughters, met Silas in the summer before his death:

“Silas was an incredibly brave, strong and kind boy. It was almost impossible to believe when I watched him playing with my girls that day that he was fighting a brain tumour, and that there was nothing anyone could do”.

Ronni’s Bandanas for Brain Tumours video can be seen at [youtube.com/BrainTumourCharity](https://www.youtube.com/BrainTumourCharity)

” *When I was asked if I could help The Brain Tumour Charity raise awareness, I didn’t have to think about it. Wearing a bandana on 6 March is a simple way for anyone to show their support for such an important cause during Brain Tumour Awareness Month.*

Ronni Ancona

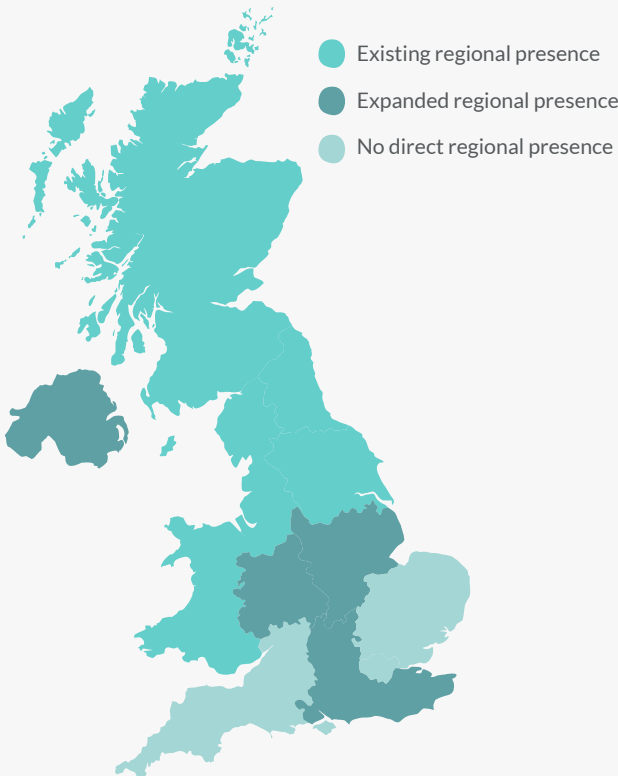


Expanding our support and information services

The diagnosis of a brain tumour is the start of a journey that is complex, difficult and isolating. People with a brain tumour, and their families, can face many choices and it is hard to get reliable information to help make those decisions. In 2014/15 our support and information service provided a vital lifeline for thousands of people affected by a brain tumour.

We unveiled a range of new fact sheets on **epilepsy and brain tumours, glioblastoma, Avastin®, symptoms of a brain tumour in adults** and **'watch and wait'**, bringing our total of Information Standard accredited fact sheets to over 40. In addition, we reviewed nine of our existing fact sheets.

We expanded our regional presence with Operations Managers in the Midlands, South East and Northern Ireland, who focus on healthcare professional engagement, NHS service improvement and supporting the set up and delivery of local services.



For further information on our support and information services, visit thebraintumourcharity.org/get-support

176,000

The support and information pages on our website were visited over 176,000 times



2,500

members of our Facebook Support Group were able to gain peer support in a safe environment.



2,800

people were provided with support through our Support & Info Line, on the phone, by email and online.



1,500

people came to one of our support and information events across the UK to hear from healthcare professionals, meet others in a similar situation and learn more about support available in their area.



Support for children and young people

Meet Jake

In October 2014 we launched our Jake animations that are designed for children with a brain tumour. Jake is an animated eight year old boy who takes other children through his experiences of living with a brain tumour to help them understand more about their diagnosis and the treatments they may face. The animations cover a range of topics including scans, steroids, radiotherapy, chemotherapy and neurosurgery, and provide much-needed support to children and parents alike coming to terms with a diagnosis.



4,700

The Jake animations were viewed over 4,700 times in the first six months post-launch

” *The Jake initiative fills a very important gap in information that is available for primary school children who are old enough to understand explanations, but who do not have the background knowledge and insight of our teenage patients. I have already started recommending Jake to newly diagnosed young patients.*

Dr Martin English,
Consultant Paediatric Oncologist,
Birmingham Children’s Hospital.

Meet our Young Ambassadors

Through our dedicated Children and Families Service, we launched our Young Ambassador programme, offering support to young people affected by a brain tumour diagnosis and introduced Brainy Bags for children who have been diagnosed with a brain tumour. Brainy Bags contain gifts such as pyjamas, puzzles and teddy bears, and help provide comfort at a time of uncertainty. They are also a useful resource for families, carers and healthcare professionals to help address some difficult emotions a child may be feeling.



” *I became a Young Ambassador for The Brain Tumour Charity essentially so I could use my experience of having a brain tumour to spread the word and raise awareness. Currently brain tumours are underfunded, under researched and under acknowledged, I seek to change this and being a Young Ambassador means I can.*

April Watkins, aged 24,
one of our Young Ambassadors.



Making a difference

Reducing diagnosis times

Thanks to celebrity support, an investment of £182,000 and the support of our dedicated volunteers across the UK during 2014/15, our HeadSmart: Be Brain Tumour Aware campaign gained further momentum and was shortlisted in the National Lottery Awards 2014.

HeadSmart has driven down unacceptable diagnosis times for childhood brain tumours from 9.1 weeks (2011) to 6.7 weeks. For further information, visit headsmart.org.uk

” *My son would be so proud his work continues to power ahead and that HeadSmart continues to win support and action from parents, opticians, health visitors, GPs and public health experts.*

Sacha, lead community champion for HeadSmart



Uniting the community

We're here to unite the brain tumour community. In 2014, we united over 1,100 walkers and over 100 volunteers who joined us in Chester, Warwick and Windsor for our annual The Twilight Walk.

” *We walked with friends and family as a thank you for all the care our son Richard, aged 35, has received this year whilst undergoing treatment for a grade IV glioblastoma.*

Pamela



Devoted to finding a cure

The Brain Tumour Charity makes a unique and significant contribution to the brain tumour community, which was recognised in January 2015 when two of our Founding Trustees, Neil and Angela Dickson were awarded MBEs in recognition of their dedication and service.



Working together

In 2014/15 we had 50 new Supporter Groups join The Charity, bringing the total number up to 211. Between them, the groups raised over £800k, an incredible 18% of our total income.

” *I set up a fund after I got diagnosed with a brain tumour in March 2014, I didn't know anything about brain tumours before then. I believe all cancer types should get an equal share of funding and this is why I am spreading the word about this cause.*

Daniel from The DJG Cancer Fund (wearing the cap in the picture).

Gifting their time

Our army of volunteers across the UK dedicated over 22,000 hours of their time during 2014/15 to help us raise funds, raise awareness of our services, speak up about the need for improvements in treatment and care and ensure the smooth running of the office. We are indebted to their support.

” *It's great to see the requests for fundraising materials coming in and to find out what fundraisers are doing all over the country. There's a real sense of common purpose.*

Jenny, office volunteer





Looking ahead

Defeating Brain Tumours: Our Strategy 2015 – 2020 defines our priorities over the next five years as we aim to create a world where brain tumours are defeated.

Over the course of 2014/15 we listened to people living with a brain tumour, the global research community, healthcare professionals, the biotech and pharmaceutical industry, donors, other charities, our Trustees, staff and volunteers. The overwhelming message was that there are two priorities to address – the poor survival rate and the impact of brain tumours on quality of life.

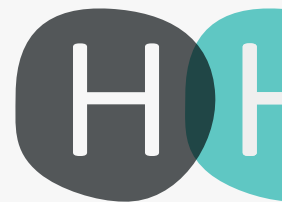
Our strategy therefore has two over-riding goals:

*Double survival within
10 years in the UK.*



Our goal is to halve the average years of life lost to a brain tumour from 20.1 to 10 years by 2025.

*Halve the harm that brain tumours
have on quality of life in the UK.*



Our goal is to halve the harm caused by brain tumours by 2020, from a baseline measure which we will agree with clinicians and patient groups by the end of 2015.



Looking ahead: priority areas

To reach our goals, we have established six key priorities over the next five years to direct our activities, engage the brain tumour community and make the changes vital for success:

1

A Cure Can't Wait

Our Research Strategy to invest in forward-thinking, outcome-orientated and patient-focused research.

2

Every patient is a research patient

Making sure every patient is able to contribute to research and clinical trials.

3

Early and accurate diagnosis

Working to reduce diagnosis times and improve accuracy of diagnosis.

4

Equal access to the best treatment and care

Ensuring every person with a brain tumour has the same access to high quality treatment and care.

5

Improving life today

Providing information and support to navigate the system and improve quality of life.

6

United in our battle to defeat brain tumours

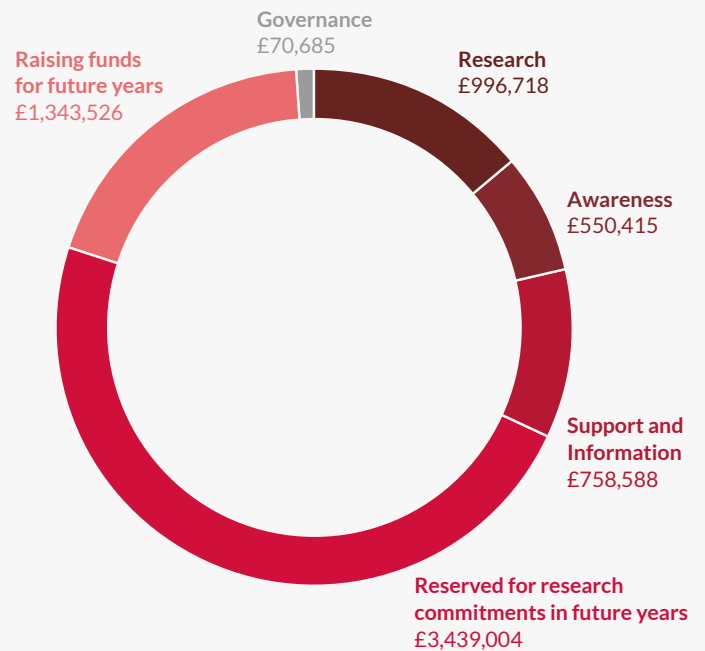
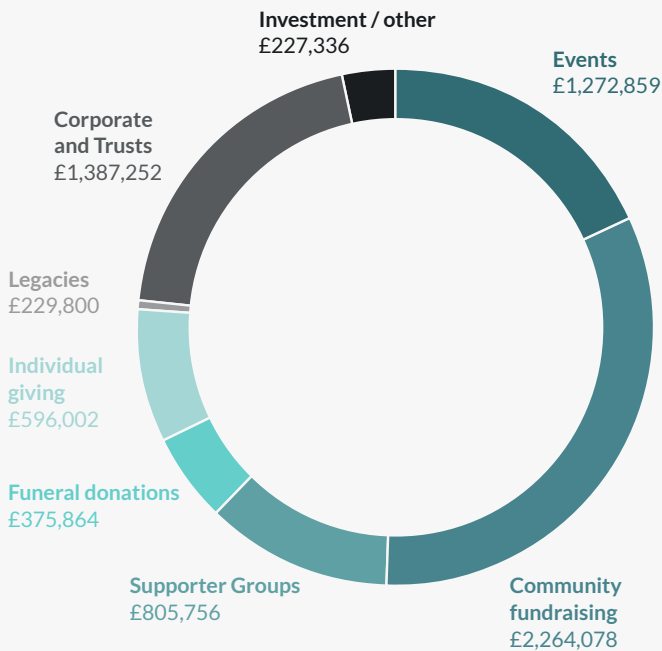
Leading and facilitating a community that works collaboratively to make change happen.



Our finances

The Charity's incoming resources increased by just over £2 million (39%) to £7,158,946.

All of our services are free of charge for anyone affected by a brain tumour. This, coupled with our research and awareness work, is only possible thanks to our supporters, as we receive no government or statutory funding and rely 100% on voluntary funding.



Income

Events	£1,272,859
Community fundraising	£2,264,078
Supporter Groups	£805,756
Funeral donations	£375,864
Individual giving	£596,002
Legacies	£229,800
Corporate and Trusts	£1,387,252
Investment / other	£227,336
Total	£7,158,946

Expenditure

Research	£996,718
Awareness	£550,415
Support and Information	£758,588
Reserved for research commitments in future years	£3,439,004
Raising funds for future years	£1,343,526
Governance	£70,685
Total	£7,158,936

* Our committed research expenditure at 31 March 2015 totalled £5,246,574. We will undertake significant new research investment over the next five years following the publication of our new research strategy in December 2014.



Thank you to our dedicated supporters

It's thanks to the dedication of thousands of our supporters throughout the year that we're where we are today. Thank you for all your incredible fundraising efforts – from the runners, trekkers and cyclists to our corporate partners and those who organise their own unique events, we appreciate each and every effort.

Together, we raised over £7 million in 2014/15. By working together, we can defeat brain tumours.



804

ran in marathons, half marathons and other events



The **TWILIGHT WALK**

1,100

walked together to stamp out brain tumours in The Twilight Walk



1,065

organised their own fundraising events across the UK



7,000

joined us to Wear it out for Bandanas for Brain Tumours Day



229

trekked up mountains, through deserts and across the UK



148

cycled across all terrains in the UK and around the world





Thanks

In addition to our thousands of dedicated supporters, we are grateful to many companies, charitable trusts and foundations, both in the UK and internationally, which are having a significant impact across all areas of our work. These investments are making it possible for us to fund the best research to help find a cure, support everybody affected by this devastating disease and raise awareness of brain tumours to save lives.

Trusts and foundations

The Adrian Swire Charitable Trust
BBC Children in Need
The Catherine Cookson Charitable Trust
Childwick Trust
Colin Oliphant Charitable Trust
The Freemasons' Grand Charity
Garfield Weston
Katy Holmes Trust
Masonic Samaritan Fund
McClay Foundation
OSCAR's Paediatric Brain Tumour Charity

Corporate partnerships

Aykroyd & Sons Ltd
Bluecube Technology Solutions
CGI Group
Chiltern Railways
CTN Communications
Dennis Publishing
dunnhumby
Goldman Sachs
Hays
Howard Kennedy F S I LLP
LexisNexis

M&C Saatchi
Mulberry
Rolls-Royce
Subsea 7
Thomson Airways Birmingham
Toys R Us
UPS
Venn Group
VoIP Unlimited
Waitrose

We also extend our huge thanks to our celebrity supporters who have worked with us and helped us generate greater awareness of The Charity.

A special thank you to:

Tom Daley
Lewis and Annie Moody
Darren Gough
Mel Giedroyc
Hal Cruttenden
Martin Kemp
Ronni Ancona
Suzanne Shaw



Trustees and Governance

Trustees

Sir Martin Narey (Chair)
(appointed as Chair 1 April 2015)
Neil Dickson MBE *(appointed as Chair 1 September 2014, resigned as Chair 31 March 2015, appointed as Vice Chair 1 April 2015)*
Graham Lindsay (Vice Chair)
Tim Burchell
Angela Deacon
Angela Dickson MBE
Ann Gales *(resigned 12 February 2015)*
Andy Foote *(resigned as Chair 1 September 2014)*
Nigel McGinnity
Philippa Murray
Berendina Norton
Graham Norton
Robert Posner
Dr Steven Powell *(appointed 1 April 2015)*
Simon Hay *(appointed 11 June 2015)*

President

Professor Colin Blakemore

Scientific and Medical Advisor to the Trustees

Professor Roy Rampling

Chief Executive Officer

Sarah Lindsell

Company Secretary

Angela Deacon

Governance

The Charity has an independent Grant Review and Monitoring Committee (GRAM) and is supported by over 300 international reviewers from around the world who undertake peer review assessments of research grant applications and make recommendations to the GRAM.

Name	Institution/lay member
Professor Roy Rampling (Chair)	Glasgow and Western Infirmary
Karen Ackling	Lay member
Professor Martin van den Bent	Erasmus University, The Netherlands
Professor Steven Clifford	University of Newcastle
Professor V Peter Collins	Cambridge University
Dr John Mason	University of Edinburgh
Dr Antony Michalski	Great Ormond Street Hospital for Children
Peter Moreton	Lay member
Dr Simone Niclou	Luxemburg Institute of Health, Luxembourg
Professor Martin Taphoorn	Medical Centre Haaglanden, The Hague, The Netherlands
Professor Susan Short	University of Leeds
Professor Chris Twelves	University of Leeds
Dr Ian Waddell	University of Manchester
Professor Richard Wise	Cardiff University

The **BRAIN
TUMOUR
CHARITY**

Research | Awareness | Support

Registered office:
Hartshead House
61-65 Victoria Road
Farnborough
Hampshire GU14 7PA

01252 749990
enquiries@thebraintumourcharity.org
thebraintumourcharity.org

© The Brain Tumour Charity 2016. Registered Charity
no. 1150054 (England and Wales) SC045081 (Scotland)

