

**DEFEATING
BRAIN TUMOURS
2015-2020**

**HAVE WE MADE
A DIFFERENCE?**

Brain tumours are the biggest cancer killer of children and adults under 40.³ Over **88,000** children and adults are estimated to be living with a brain tumour in the UK and most are coping with a reduced quality of life;⁴ over **5,000** will lose this battle each year.⁵

In 2015, The Brain Tumour Charity outlined a five-year strategy '**Defeating Brain Tumours**'. This strategy set the unapologetically ambitious goals of doubling survival and halving the harm caused by brain tumours in the UK.

Here, we summarise some of our proudest achievements from the past five years, as well as the difficult challenges we have faced in striving towards these goals.

A full report detailing the impact our five-year strategy, across our six key initiatives, is available at www.thebraintumourcharity.org/impactreport

*Based on data for three years prior, due to the collection lag. High grade tumours only; low grade data are unavailable. ¹Calculated from Global Burden of Disease (2017). Accessed September 2019. ²Calculated from Office of National Statistics. Cancer survival in England - adults diagnosed, 2019. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/cancersurvivalratescancersurvivalinenglandadultsdiagnosed>, Accessed June 2020. ³Cancer Research UK. <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/brain-other-cns-and-intracranial-tumours/survival>, (Data: England and Wales, 2010-2011, ICD-10 C71-malignant tumours). Accessed June 2018. ⁴Estimated for malignant and non-malignant brain and CNS tumours using the latest data on UK cancer registries for England, Scotland, Wales and Northern Ireland in 2020. Enquiries on the estimate to be directed to The Brain Tumour Charity. ⁵Cancer Research UK. <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/brain-other-cns-and-intracranial-tumours#heading-zero>, (Data: 2015-2017, UK). Accessed October 2020.

OUR GOALS

Double survival

Halve the Average Years of Life Lost (AYLL) to a brain tumour by 2025

5 months¹

longer life, on average, from 2015-2020*



One-year survival has improved significantly in recent years which gives us hope that **progress is being made**

For example, in England, one-year survival improved

14.7%²

from 2008-2012 to 2013-2017

Halve the harm

Halve the harm that brain tumours have on quality of life by 2020

In 2015, a baseline measure of

36%

of perfect quality of life was estimated from '**Life with a Brain Tumour**' research⁵

Unfortunately, COVID-19 has delayed the ability to gather 2020 data to measure further improvements

KEY ACHIEVEMENTS

JULY 2015

Our '**Defeating Brain Tumours**' strategy was released, aiming to double survival and halve the harm that brain tumours have on quality of life.

HeadSmart, our early diagnosis campaign for children, was included in the '**Achieving World Class Cancer Outcomes: A Strategy for England 2015-2020**'.



Increased parental awareness of HeadSmart has helped to reduce the childhood diagnosis time to 6.5 weeks in 2016, improving the lives of children like Luke Wright.

'**Losing Myself: The Reality of Life with a Brain Tumour**' research was completed and published. As the largest, most comprehensive study to date into day-to-day life with a brain tumour, this research has guided much of our support services strategy.

MARCH 2016

The first **Quest for Cures** (Q4C) research grants were awarded. These are our largest grants of up to £1.5m each, funding global, collaborative research into pioneering treatments for brain tumours.

We entered a partnership with the **Structural Genomics Consortium** (SGC) to fund two research posts focusing on accelerating the discovery of potential treatments for brain tumours with this open science programme.

MAY 2016

Research we funded led to a revision of the **World Health Organisation** (WHO) classification of brain tumours. For the first time, there was consensus on four subgroups of medulloblastoma – the most common brain tumour in children – enabling more tailored treatment.

OCTOBER 2016

Childhood brain tumour diagnosis times were **reduced from 13 to 6.5 weeks** following the success of **HeadSmart**, our UK-wide campaign.

NOVEMBER 2016

A **Patient Guide to Brain Tumour Treatment and Services** was published, which empowers our community to feel confident when talking to their medical team.

DECEMBER 2016

The Grant Review and Monitoring Committee (GRAM) was replaced with two **scientific advisory boards** (SABs), to bring together internationally renowned scientific and medical experts, who work in different areas of cancer research and social science.

JUNE 2017

The **Everest Centre**, a groundbreaking international research initiative was awarded a £5 million grant, our biggest to date.



The Everest Centre works to propel understanding and improve treatment of paediatric low grade brain tumours.

The first patient steering group meeting took place for **BRIAN**, our revolutionary app and research databank to help transform outcomes for people with brain tumours.



BRIAN is an app to help people cope with a brain tumour and power a cure.

FEBRUARY 2018

Research we funded on the **signs and symptoms** of adult brain tumours was published.

We helped set up a roundtable meeting, initiating the **Tessa Jowell Brain Cancer Mission**, which aims to improve brain tumour survival for everyone affected by the disease.



In January 2018, Dame Tessa Jowell delivered a parliamentary speech in which she said that all patients should benefit from *"the latest and greatest science"* and called on us to focus on *"living well with cancer, not just dying from it"*.

MARCH 2018

Our research contributed to the development of a **classification system** for brain tumours based on molecular profiling, improving diagnostic accuracy and speed, and enabling treatments to be tailored to patients' tumour type.

Our first **Future Leaders** grant was awarded, to fund the future leaders of scientific research into brain tumours.

SEPTEMBER 2018

5-ALA, the 'Pink Drink' which helps neurosurgeons see and successfully remove more of a tumour during surgery, became available across the UK, improving surgical outcomes.

OCTOBER 2018

The first data were released from the NHS and Public Health England (PHE) into **BRIAN**.

NOVEMBER 2018

We announced a £2.8m founding investment for the **Tessa Jowell BRAIN MATRIX** platform trial, an **adaptive research environment** providing infrastructure for future clinical trials.

JANUARY 2019

Following the success of our funded programme for children, molecular testing for brain tumours was incorporated into the NHS long-term plan, giving everyone a more accurate diagnosis.

MARCH 2019

Our yearly income grew to £11 million, more than doubling from £5.1 million in 2015.

OCTOBER 2019

The **BRIAN** app was launched for those affected by a brain tumour.

FEBRUARY 2020

We contributed to, and are authors on, a **Response Assessment in Neuro-Oncology Patient-Reported Outcomes** (RANO-PRO) publication, reporting data on a quality of life assessment for gliomas.

MARCH 2020

Invested £38m over 5 years in pioneering research into brain tumours, attracting £89m of additional funding.

1.15m people accessed our online support pages during 2019/20.

MAY 2020

The **Tessa Jowell Centres of Excellence** initiative was launched, based on our 'National Brain Tumour Standard of Care' to recognise UK centres that offer excellence in brain tumour treatment.

OCTOBER 2020

Our **BRIAN** app attracted over 2,000 users within a year of launch, and this number is rising.

“

The Charity offers something precious to everyone affected by a brain tumour: hope.

”

Tasha, who was at the heart of our strategy

LOOKING TO THE FUTURE

As we renew our strategy '**Defeating Brain Tumours**', we will learn from the past and build on the progress we have made together.

We hold ourselves to account for our strategic goals – to double survival and halve the harm – that represent **hope** for our community and remain **urgent, relevant and ambitious**.



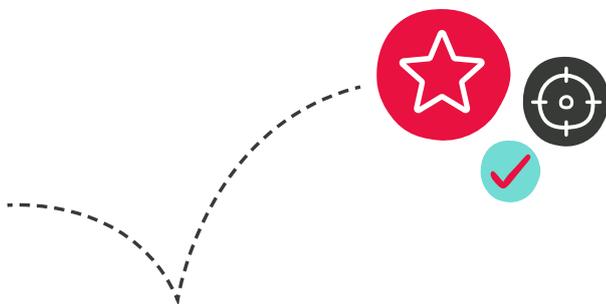
**TOGETHER
WE WILL DEFEAT
BRAIN TUMOURS!**

“

Our son Alec made us promise to stop this brutal disease from taking other lives, just as he realised that his own was ending, aged just nine. Several years on and the foundations are laid for bringing hope to others and fulfilling that promise to our son. Together, we know that real change is possible – that we do make a difference.

”

Clare Normand, mother of Alec (pictured)



We will continue to **build on our strong foundations** and **pursue our goals** relentlessly, despite challenges such as COVID-19. We will use our progress over the past five years as a springboard to **drive forward change**, through existing projects and explore even more pioneering options, towards our vision of a world where **brain tumours are defeated**.