A decade of raising awareness, increasing national funding for vital brain tumour research and funding the fight to find a cure.
Brain tumours are indiscriminate; they can affect anyone at any age. What’s more, they kill more children and adults under the age of 40 than any other cancer... yet historically just 1% of the national spend on cancer research has been allocated to this devastating disease.

**Brain Tumour Research is determined to change this.**

We are building a network of experts in sustainable research at dedicated Centres of Excellence whilst influencing the Government and larger cancer charities to invest more nationally.

We are the only national charity in the UK that is dedicated to raising funds for continuous and sustainable scientific research into brain tumours and we are a leading voice calling for greater support and action for research into what scientists are calling the ‘last battleground against cancer’.

On 28th April 2009, 14 brain tumour charities put their ‘heads together’ to launch umbrella charity Brain Tumour Research with a mission to raise awareness and increase funding for vital research.

The charities highlighted that despite brain tumours being the leading cause of cancer deaths in children, brain tumour research was ‘woefully underfunded’ and a ‘poor relation to other cancers’ receiving less than 1% of the national spend on cancer research in the UK.

Actor and author **Sheila Hancock CBE**, whose grandson survived a brain tumour, backed the campaign sharing: “how terrible it had been to watch my own grandchild go through the diagnosis of a brain tumour and see both my child and my child’s child suffering.”
I was personally shocked by the statistics and found it tragic that research had not moved forward since my own niece Alison Phelan had been taken from us in June 2001, three weeks before her eighth birthday. Having formed Ali’s Dream with family and friends, we knew we couldn’t do it alone and were delighted to unite with other brain tumour charities to do something about it.

Professor Geoff Pilkington, then Professor of Cellular and Molecular Neuro-oncology at the University of Portsmouth, campaigned tirelessly about the urgent need to increase funding into brain tumours in order to put the building blocks in place and save lives. Having worked in the area for over 35 years, Geoff had seen little progress in research into brain tumours declaring it “the poor relation to other cancers”, despite one in four cancers ending up in the brain having started in other organs.

Mr Kevin O’Neill, Consultant Neurosurgeon at Charing Cross Hospital, part of Imperial College Healthcare NHS Trust, spoke of the increasing numbers of brain tumour cases and how they cause the biggest reduction in expected lifespan of any other cancer. He talked of his own frustrations that malignant brain tumours had very few treatment options and nothing approaching a cure. He praised the drive and determination of charities trying to make a difference, saying that by joining forces and working together there may now be a brighter future for all.

Move forward 10 years and we have much to be proud of and a decade of achievements to celebrate:

• Through collaboration with our Members and other charities, the patient voice is being heard, more patients and their families have access to support and information, and funding for research is increasing

• Our campaigning successes have shone a spotlight on the historic underfunding and have led to increased national investment in research into brain tumours

• Awareness is at an all-time high in the media, on social media and amongst parliamentarians, and with thanks to this and all of our supporters and celebrity ambassadors, our own fundraising has reached circa £4 million a year

• We are transforming research into brain tumours in the UK through our Centre of Excellence strategy, and building capacity in pioneering research having established four dedicated Centres enabling them to attract other funding as a result of our own investment

We have also met so many astonishing, powerful, helpful, angry, devastated yet determined people. Determined to make a difference. Determined to join us in helping to fund the fight and find a cure for this devastating disease.

Thank you to each and every one of you, and all of those we are yet to meet who will help us further. We are inspired by all of you. We wouldn’t be here without you. And we are here for you.

The next decade is set to see huge advances in our quest to improve outcomes for patients and their families – please stay with us as we seek to grow capacity, build infrastructure, accelerate treatments and increase national investment in brain tumour research to £35 million a year by 2025.

Together we will find a cure.

Sue Farrington Smith MBE
Co-Founder & Chief Executive
At the beginning of the 1990s Government funding for research was reduced and researchers had to resort to other means in order to receive the funding that they needed to pursue their research passions and improve outcomes for patients and their families.

Professors Geoff Pilkington and John Darling were two such eminent researchers with a particular passion to discover cures for brain tumours.

During the 1990s they galvanised families to back their cause with some forming charities that are still in existence today including two of our founding Member Charities, Charlie’s Challenge and Brainwaves NI, both of which have just celebrated their 25th anniversaries.

These and our other founding charities have gone on to achieve great things.

Ali’s Dream:
Is now in its 18th year and has raised over £1 million. The charity was instrumental in establishing both the Brain Tumour All-Party Parliamentary Group and the first Brain Tumour Research Centre of Excellence within the University of Portsmouth in 2010.

Anna’s Hope:
Was founded in 2006, the charity funds a pioneering specialist paediatric neuro oncology rehabilitation service called Brainbow which it co-founded in 2013 at Addenbrookes Hospital. As part of the service the Anna’s Hope Therapy Team provide rehabilitation therapy through a team of specialists to help children reach their full potential. The Anna’s Hope specialist nurse also provides support throughout the child’s treatment.

Brain and Spine Foundation:
Was founded in 1992 and provides information and support for over 350 neurological disorders. The charity also offers a helpline run by nurses and a signposting service for health professionals. In addition, it facilitates online support groups and produces information booklets and fact sheets, publishing a specific booklet on brain tumours in 2017.

Brain Tumour Action:
Is based in Scotland. Founded in 1993, it has just celebrated its 25th anniversary and continues to be run entirely by volunteers. The charity provides support and counselling for brain tumour patients, their relatives and friends as well as supplying hospitals throughout the UK with information booklets. Brain Tumour Action gives grants to research in collaboration with other charities and supports specialist nurse training in neuro-oncology. It helps inform policy in the Scottish Parliament and runs its own support groups.

Brain Tumour Research and Support across Yorkshire – BTRS (formerly Andrea’s Gift):
Established the Leeds brain tumour research centre in 2010. The charity also provides grants and financial assistance to brain tumour patients and their carers, as well as arranging for hospital wards, patients and research centres to be provided with the equipment they need. In Spring 2017 BTRS took over the day-to-day running of Ellie’s Fund Brain Tumour Trust.

Brain Tumour Research Campaign:
Has just celebrated its 15th anniversary and has raised over £3 million, being run entirely by volunteers. BTRC founded the brain tumour research
centre at Imperial College in 2008, to deliver a comprehensive brain tumour research programme looking at every possibility to improve the outlook for brain tumour patients by producing research that translates into treatments as quickly as possible.

**Brain Tumour Support (formerly Hammer Out):**
Was founded as a pioneering support service in 2003, and is uniquely dedicated to providing individualised support for patients and families affected by any type of brain tumour for as long as it is needed. Working in partnership with Macmillan the charity has developed a team of regional Brain Tumour Support Workers who offer ongoing one-to-one and group support, alongside telephone and online support and information, and a specialist counselling service.

**brainstrust:**
Is now a leading charity. It supports people with a brain tumour and their families so that they are less afraid, less alone and more in control. Founded in 2006, it provides coaching via a 24/7 helpline and accredited online information and support to over 30,000 people. With its knowledge of clinicians across the country the charity is able to offer treatment options to patients looking for second opinions. It co-founded the BRAIN UK national tissue bank registry at the University of Southampton in 2011, and has worked with Public Health England to make cancer records available to the public so that people can make more informed choices about their care.

**Brainwaves NI:**
Is a successful charity that supports over 350 patients and families as well as funding brain tumour research at Queens Medical Centre Belfast. The charity has just celebrated its 25th anniversary.

**Charlie’s Challenge:**
Celebrated its 25th anniversary in 2018 having raised over £1 million. The charity supported the launch of our first Centre at the University of Portsmouth and the establishment of the BRAIN UK national tissue bank registry at the University of Southampton.

**Children’s Brain Tumour Research Centre:**
Was established in 1997 at the University of Nottingham and to date has received over £10 million in grant funding. It brings together a multidisciplinary team of healthcare professionals and researchers who are working to improve the understanding, treatment and outcomes of children and young adults with brain tumours. The Centre initiated the HeadSmart campaign which was launched in 2011 with funding from The Brain Tumour Charity.

**Ellie Savage Memorial Trust:**
In partnership with Clic Sargent it has supported over 100 families living in East Anglia who have a child with cancer, including those with a brain tumour. The trust provides financial support and information, in its earlier days, it also funded research into brain tumours.

**Levi’s Star:**
Works across Yorkshire to provide a brain tumour educational outreach support service for children and young people living with the effects of brain tumours. Levi’s Star provides specialist educational intervention to paediatric brain tumour survivors and advises schools about best practice in supporting children with brain tumours. It has an honorary contract with Leeds General Infirmary, attending the weekly brain tumour clinic. Levi’s Star is also carrying out doctoral research at Leeds University, focusing on how children who have survived a brain tumour are supported within education. In addition, Levi’s Star provides grants to children with brain tumours across Yorkshire.

**The Diana Ford Trust:**
Joined an informal partnership of UK brain tumour charities known as The United Brain Tumour Campaign in 2005. In 2008, the Charity formalised this relationship and amended its name, to better demonstrate its objectives, to Brain Tumour Research. With the exception of our President Sandy Saunders, the trustees stepped down whilst representatives of founding charities put themselves forward to be Brain Tumour Research trustees.

There are now 22 brain tumour charities working together under the umbrella of Brain Tumour Research and between us our income has grown from £1.5 million a year in 2009 to £7 million a year to fund research and / or support, according to each individual charity’s objectives.
Brain Tumour Research has been fundamental in shining a spotlight on why more funding is needed for research into brain tumours and driving the overall push for change.

We first drew the public’s attention to how little was being spent on research into brain tumours at our launch with our 2009 *Inequality of Funding* report, highlighting how for decades brain tumours had been largely ignored by key decision-makers. This was followed by two further reports on National Research Funding in 2013 and 2014.

Working tirelessly to hold the Government and larger charities to account, Brain Tumour Research published its *Invest In A Cure* manifesto in 2015 and went on to lead the campaign behind the 2015 e-petition, launched by the Realf family calling for the Government to fund more research into brain tumours. Galvanising more than 120,000 signatures, the petition led to a Westminster Hall debate and the formation of a Department of Health and Social Care Task and Finish Working Group on Brain Tumour Research.

The publication of the Task and Finish Group’s report in February 2018 heralded a significant shift in focus and led to a £20 million Government funding announcement and a pledge of £25 million from Cancer Research UK (CRUK). The tragic death of Dame Tessa Jowell from a brain tumour, following her moving personal testimonies and calls for change, proved a catalyst for the establishment of the Tessa Jowell Brain Cancer Mission (TJBCM). A further £20 million Government funding pledge followed, bringing the total pledge to £65 million (including CRUK’s funding), over the next five years (£13 million per year), to facilitate a cure for brain tumours.

This is all moving in the right direction but there is still so much more to be done if we are to achieve parity with other cancers such as breast and leukaemia. Through our role as Secretariat of the All-Party Parliamentary Group on Brain Tumours and our position on the Steering Group of the TJBCM, Brain Tumour Research will continue to hold decision-makers to account and...
call for increased funding to address infrastructure inadequacies and the longstanding lack of treatments available for brain tumour patients.

In 2015 we called on the Government and larger cancer charities to Invest in a Cure. Progress has been made and it is now time for the Government, larger cancer charities, and the brain tumour community to work together to Find a Cure and give hope to the thousands of people diagnosed with a brain tumour every year in the UK and their families.

We will continue to call on the Government to work with the brain tumour community to stimulate further increases in the national investment for research into brain tumours to £35 million per year by 2025 in order to grow research capacity, build research infrastructure, accelerate treatments and improve outcomes for patients and their families.

John Bercow: I was shocked at how little attention had been paid to brain tumours and in April 2004 led the first ever debate on brain tumours in the House of Commons. I highlighted in particular that the issue of children with brain tumours had been under-debated, under-reported and underfunded. It had attracted minimal – dare I say it, derisory – attention. There had been not one adjournment debate until that debate, not one oral parliamentary question, and only two written parliamentary questions.

Helen Jones MP, Chair of the Petitions Committee: This is a real chance to save lives, so I say to the Minister: read the report and champion its recommendations in government. That way we can have world-class scientists in this country and save the lives of many people, including young people, who will have the chance to make an enormous contribution to this country. It is as simple as that. This cancer has been neglected for far too long. That now has to change.

Extract from Westminster Hall Debate 16th April 2016

Cancer site-specific Research as a % of national Cancer Research Spend

<table>
<thead>
<tr>
<th>Year</th>
<th>Cancer Total £</th>
<th>Brain Tumours £</th>
<th>%</th>
<th>Breast £</th>
<th>%</th>
<th>Leukaemia £</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>2002/03</td>
<td>297,872,437</td>
<td>967,718</td>
<td>0.3%</td>
<td>22,457,672</td>
<td>7.5%</td>
<td>17,690,579</td>
<td>5.9%</td>
</tr>
<tr>
<td>2008/09</td>
<td>502,573,570</td>
<td>4,149,415</td>
<td>0.8%</td>
<td>43,584,446</td>
<td>8.7%</td>
<td>29,135,148</td>
<td>5.8%</td>
</tr>
<tr>
<td>2013/14</td>
<td>540,459,570</td>
<td>5,970,298</td>
<td>1.1%</td>
<td>42,790,424</td>
<td>7.9%</td>
<td>32,239,796</td>
<td>6.0%</td>
</tr>
<tr>
<td>2016/17</td>
<td>589,869,718</td>
<td>8,615,902</td>
<td>1.5%</td>
<td>46,087,203</td>
<td>7.8%</td>
<td>35,081,014</td>
<td>5.9%</td>
</tr>
</tbody>
</table>
Our mission is to build a network of experts in sustainable research at dedicated Centres of Excellence whilst influencing the Government and larger cancer charities to invest more nationally and we were delighted to launch our first Centre at the University of Portsmouth in 2010. After a stringent peer review process, we selected three further Centres which were launched in 2014 and 2015.

With secure long-term funding covering the key salaried positions within these Centres, the researchers are able to pursue the sustainable and continuous research so desperately needed by the scientists and clinicians working in this historically underfunded field.

The scientists at our four UK Centres of Excellence are working together to gain a greater understanding of brain tumours and to identify ways in which they can be treated effectively. Our funding strategy means that we are investing in long-term research, building the ‘critical mass’ of expertise needed to accelerate the journey to find a cure. In turn, this facilitates increased research investment from other sources to grow the overall capacity for brain tumour research within the UK.

It is essential that we fund long-term research into this devastating disease. Despite advancements for many other types of cancer, treatment options for brain tumours are still very limited, largely due to the historic underfunding for research into neuro-oncology.

We have partnered with world-leading experts to establish game-changing partnerships at key universities in the UK.
Led by Professor Silvia Marino, the first female President of the British Neuro-Oncology Society, researchers at our Queen Mary University of London Centre have developed new ways of analysing brain tumours using artificial intelligence alongside neuropathology techniques, in which samples from the tumours and healthy brains of patients can be directly compared. This highlights differences that are most important to target with new personalised drug treatments. Experiments to validate these findings at pre-clinical level are now required to then move the most promising targets into clinical trials for adult glioblastoma multiforme (GBM) brain tumours. The Centre is also expanding its research into paediatric medulloblastoma.

Professor Oliver Hanemann’s team at the University of Plymouth has established one of Europe’s leading low-grade brain tumour research centres where it is identifying new ways to categorise meningioma, including using a blood test that could avoid the need for biopsies. The new data is informing the testing of personalised drug treatments. Its work in schwannoma and glioma brain tumours is following similar paths, with an emphasis on targeting the role of the immune system and tumour microenvironment, whilst also looking at tumour initiation. The team has already completed early stage clinical trials, with more to follow.

Pioneering consultant neurosurgeon, Mr Kevin O’Neill, alongside Senior Research Fellow, Dr Nelofer Syed, lead our Centre at Imperial College London. Their focus is on a metabolic approach to cancer treatment and they have moved research on arginine depletion out of the lab and into early stage clinical trials with encouraging results. The teams continue to develop surgical techniques including Raman spectroscopy, whilst artificial intelligence is enabling them to study long-term survivors and identify patterns to inform future research.

Established by world-renowned Professor Geoff Pilkington, the team at our Centre at the University of Portsmouth has developed all-human 3D models of the blood-brain barrier and the vasculature of the brain that not only enhance research, but also reduce the need for animal models to be used. Its work on drug repurposing has identified a number of potentially effective compounds, with clinical trials in children and adults already at the planning stages.

Initiated by brainstrust in 2011, the University of Southampton houses BRAIN UK, a virtual tissue bank which we are proud to fund. Its database catalogues a wealth of data about brain tumour samples held within the UK’s network of NHS and Academic Pathology Centres. It now achieves almost 100% coverage of the national population and therefore represents a globally unique population-wide resource. BRAIN UK also offers a ‘fast track’ ethics approval service, enabling research to begin more quickly than would otherwise be possible.
From a standing start of no income when we launched in 2009, we have seen a staggering rise in income to £4 million a year by our 10th year and a total raised of over £18 million. We set out to raise awareness through our campaigning and our amazing supporters came on board in their thousands, including our first patrons the Rt Hon John Bercow MP and actor Ian Reddington. Known to millions of TV viewers, Ian was the first to take on major roles in two of the most popular soaps: Tricky Dicky, Albert Square’s lothario market manager in Eastenders and Vernon the hapless drummer in Coronation Street. Having read the stories of so many children, young adults and mums and dads who have been affected as well as the families that lost them, Ian couldn’t help but get involved and has been supporting us ever since.

Alongside our Member Charities, we had nationwide media coverage and were soon joined by Fundraising Groups dedicated to raising funds for Brain Tumour Research. Our first two groups were Head 1st and Taylan’s Project.

Head 1st was set up by the inspirational Nicole Phillips (then Nicole Witts), a long-term survivor who, despite setbacks, has continued to help raise awareness and funds for our cause ever since. Looking amazing, she bravely posed in nothing but a pink hat to launch our 2011 Wear A Hat Day achieving fantastic coverage in national and regional media.

Taylan’s Project was established by Figen and Andy Rawlinson following the tragic loss of their seven-year-old son, Taylan, on 19th August 2009. They have loyally supported our campaigning ever since as well as contributing over £200,000 to research with the support of friends and family. Kelly Jo Hearsey was one such friend who on 26th September 2010 reached the summit of Kilimanjaro raising over £6,000. At the top Kelly looked up to heaven and told Taylan that his family loved him and missed him so much.

Our first amazing supporters to help us fund the fight, included Henry Brydon who, in 2010, at the age of 25 set off with his friend Jamie King (then 26) on a 25,000-mile cycle ride from our founding office in Padbury, north Buckinghamshire to Sydney.
Australia, raising over £25,000. Henry had been inspired by his
cousin Jack who, in 2003 aged just 17, was diagnosed with a
brain tumour. We are pleased to report that Jack continues to do
well, is working in insurance in London, has got married and is
about to become a dad.

Brave Josie Philips was 27 when she and her husband, Roger,
sailed round Britain to raise awareness of this awful disease. Their
epic event raised over £15,000 for our work. Having been first
diagnosed in 2004, she then discovered in 2008 that her tumour
had become malignant. Josie and Roger left Ipswich on 15th
May 2010 and sailed over 2,000 miles before returning on the
1st September having met up with representatives of seven of our
Member Charities en-route. Her endeavours saw her recognised
as one of 10 sailors around the world on a list of tributes by the
international website sail-world.com in January 2011. In March
2011, another of her dreams came true when she gave birth to
Edie. Josie and Roger went on to have two more children, Harriet
and Francesca.

Ellie Othick-Bowmaker, diagnosed with a brain tumour aged
11 in 2007, touched our hearts when she recorded Butterfly’s
Wings with her songwriter uncle, which she devoted to founding
Member Charity Ali's Dream, contributing £9,200 to childhood
brain tumour research. Her mother, Heather, founded Ellie’s Fund
after Ellie died aged 14 in February 2010, becoming a Member
Charity of Brain Tumour Research. Ellie’s Fund is now supporting
the work of the regional charity Brain Tumour Research and
Support across Yorkshire.

We will always be grateful for the support of Daryl and Louise
Wilkinson of Clearthinking Creative who designed our logo and
early materials pro-bono, and have been helping develop our
brand and marketing collateral ever since at very generous rates.

The launch of Brain Tumour Research could not have been as
successful without the dedication and help of Vanessa Dury,
who galvanised support from a number of MPs and Peers in
Westminster for the launch and, three months later, drafted our
first statistics report gaining national coverage. Her daughter
Maisie received treatment for a brain tumour in June 2007
at the age of two and is now a delightful 14-year-old. The
family has continued to support us with awareness raising and
fundraising ever since. Vanessa’s sister, Sally Gross, a teacher
at Beachborough School near Brackley, Northamptonshire, has
organised an annual Wear A Hat Day at the school every year.

We were their Charity of the Year in 2010 and 2011, and the
school has contributed over £20,000 to our work over the years.

Our Community PR Manager, Liz Fussell, has helped many of
our Member Charities and early supporters to share their stories
and raise awareness, having worked for us since our launch. Her
brother, Andrew, was diagnosed with a low-grade brain tumour in
2002 and sadly lives with life-changing consequences of surgery
and radiotherapy.

Bill Tarmey, Coronation’s Street’s Jack Duckworth, threw himself
into supporting our vital work as a patron following the brain
tumour diagnosis of his son, Carl Piddington, in 2009. Sadly,
Bill passed away in November 2012. Carl lived for nearly 10
years after his diagnosis – his prognosis at the time was one year
without surgery, five years with surgery, which he had. Carl passed
away in March 2019. His wife, Sandra, and family stood by him
throughout his treatment and continue to be stalwart supporters –
we salute the family.

Wear A Hat Day moved into a different league with the
support of the millinery industry, with high-profile, couture milliner
Philip Treacy OBE. Philip became patron in 2011 and designed
our first ever Wear A Hat Day brooch. Wear A Hat Day is our
most successful fundraising campaign and has raised some
£1.5 million since it began in 2010.

The launch of our first Centre at the University of Portsmouth
saw our celebrity supporter Sheila Hancock CBE invite local
businesses, organisations and Portsmouth residents to help
raise £1 million to fund brain tumour research at the Centre.
She unveiled our first Wall of Hope, on which supporters place
tiles for each £2,740 they raise, to recognise their fundraising
contribution and commemorate loved ones.

We have been overwhelmed by the dedication of so many
wonderful supporters over our first decade; too many to
mention in this brochure. As each year goes by our loyal band
of supporters continues to grow and with it the number of
researchers we fund. The first decade has been about laying
foundations, building and growth. The next decade will be all
about bringing our work to fruition.

Together we will find a cure.