

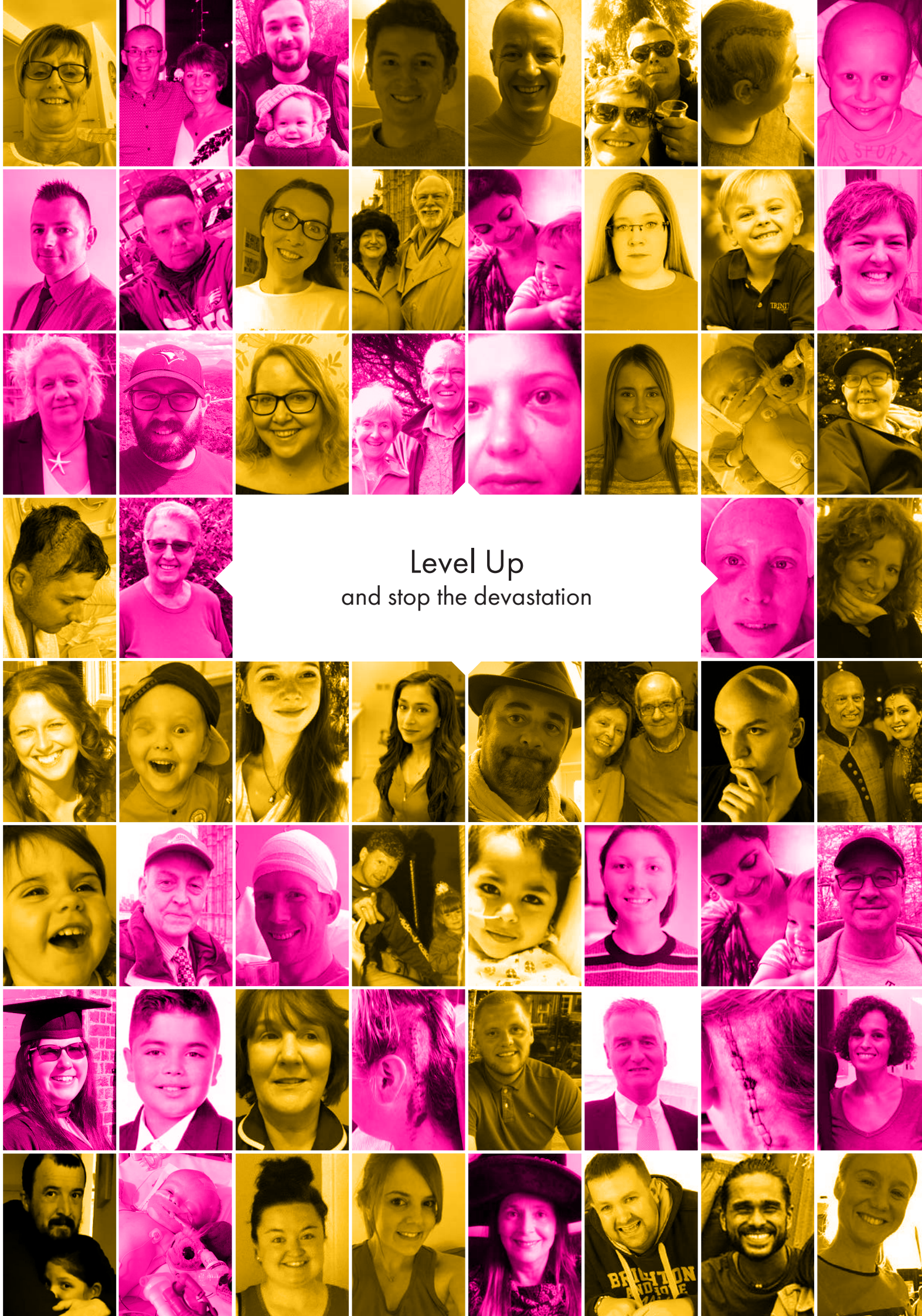


More than 100,000
people are demanding action
It's time for a cure



**Brain Tumour
Research**

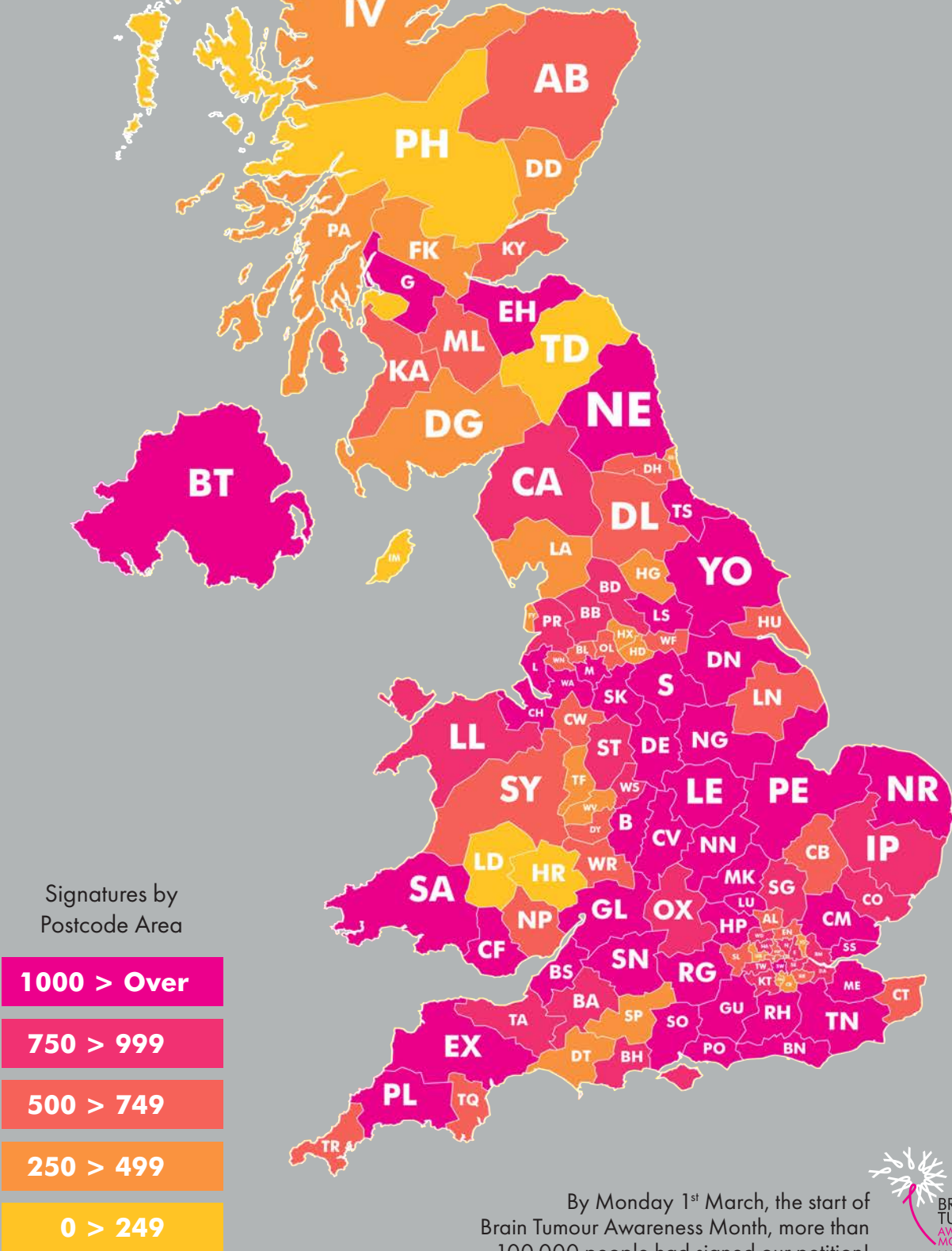
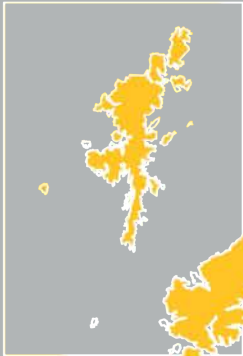
Together we will
find a cure



Level Up
and stop the devastation

PETITION TO INCREASE
NATIONAL INVESTMENT INTO
BRAIN TUMOUR RESEARCH
TO £35 MILLION A YEAR

UK SIGNATURE LOCATIONS



By Monday 1st March, the start of Brain Tumour Awareness Month, more than 100,000 people had signed our petition!





Edward's Story

Edward Ruggiero took this self-portrait after surgery and treatment for a grade 3 anaplastic astrocytoma.

Diagnosed in 2017 at the age of 29, Edward was given a prognosis of three to five years and now feels he is living on borrowed time.

A life-threatening infection following an awake craniotomy meant further surgery to remove part of his skull, leaving his head misshapen.

Edward also has permanent hair loss as a result of treatment.

He chose not to continue with a punishing chemotherapy regime.

Brain tumours kill more children and adults under the age of 40 than any other cancer

Just 12% of those diagnosed with a brain tumour survive beyond five years

Level Up – give hope to brain tumour families



“It seems so brutal that, in a world in which we have achieved so many things, the only treatment for brain cancer is to cut it out by surgery, burn it with radiation and poison it with chemotherapy. With such a limited life expectancy, why would I waste any of that precious time putting myself through more horrific treatment for the sake of a few more months?”

“Some days it’s as much as I can do to get out of bed and that seems pitiful for a 33-year-old man at what should be the prime of my life. My brain tumour has robbed me of my career, my prospects and, ultimately, it will rob me of my life.”

Edward Ruggiero

Brain tumours kill more children and adults under the age of 40 than any other cancer, yet since national cancer spend records began in 2002, £680 million has been invested in breast cancer, but only £96 million spent on brain tumours¹ – that’s a difference of £35 million a year over 17 years. This disparity continues with brain tumour research spend continuing to receive £35 million a year less over the last three years¹.

We call on the Government to:

- Introduce a new levelling up brain tumour research fund of £105 million
- Increase the national investment into brain tumour research to £35 million a year
- Demonstrate joined-up thinking for investment across the brain tumour research pipeline

Five-year survival for breast and prostate cancer is greater than 70%, leukaemia more than 40% yet, for brain tumours, it is just 12%.

The only way we can improve outcomes and reduce deaths from brain tumours is to invest in research which will help find a cure. At the current rate of spend, it could take up to 100 years for brain cancer to catch up with developments in other diseases and for a cure to be found.

Research into brain tumours must not be left behind – the nation needs to Level Up and invest at least £35 million a year if we are to find a cure for brain tumours in the next 20 years.

Just 1% of the national spend on cancer research has been allocated to brain tumours. Historic underfunding means that successive Governments have failed brain tumour patients. Improvements in both treatment options and outcomes for patients with this disease have not kept pace with those experienced following a diagnosis of breast cancer or leukaemia.

The correlation of better research funding and improved patient outcomes is as stark as it is obvious.

We want the UK to become a world leader in finding therapies for brain tumours. It is time for the UK Governments, larger cancer charities, and the brain tumour community to focus on finding a cure and give hope to the thousands of people diagnosed with a brain tumour every year in the UK.

Brain tumours are indiscriminate; they can affect anyone at any age. It is only by investing in a new Levelling Up Brain Tumour Research Fund that we can grow capacity in the brain tumour research community, build infrastructure and accelerate treatments. We believe this new Fund would be a worthy legacy so that we can find a cure for brain tumours and stop the devastation.

The brain tumour research pipeline needs adequate funding throughout – not to do so at the discovery end risks evidencing the quality of research that is needed for the allocation of clinical research funding. We want to see joined-up thinking and a greater investment in discovery science which would facilitate better access to monies promised in 2018, namely £40 million to be allocated through the National Institute for Health Research (NIHR), and which is more relevant to the later, clinical trial stage, of the translational research pipeline that takes innovation from the scientist’s bench to the patient’s bedside.

Only by levelling up can we usher in the game-changing research promise of hope so desperately needed for brain tumour patients and all those impacted by this devastating disease – the biggest cancer killer of children and adults under the age of 40.



Since 2002
**£35 MILLION MORE
A YEAR HAS BEEN SPENT
ON BREAST CANCER
RESEARCH THAN ON
BRAIN TUMOURS**



The journey to this petition



“My sister’s little girl Alison Phelan was diagnosed with a brain stem glioma (DIPG) brain tumour in August 2000. Ten months later we lost her, in June 2001, three weeks before her eighth birthday...”

...“Unbeknown to me in that same time frame the Chairman of our charity, Wendy Fulcher was dealing with similar devastating news as her husband John was diagnosed with a glioblastoma multiforme (GBM) brain tumour in August 2000 and died just 10 months later, in June 2001, age 52.

“Twenty years on and the fate of children and adults diagnosed with these tumours has not improved – in fact, the five-year survival rate has fallen to just 12%.

“What’s more, people diagnosed with low-grade brain tumours that become aggressive over time live with a ticking time bomb, not knowing if or when their tumour might become a lethal grade 4. In the meantime, they endure sometimes multiple surgeries, chemotherapy, and radiation therapy. They can suffer changes in personality and more and more disabling impacts, and their loved ones’ lives and livelihoods are changed forever as they become carers.



Wendy Fulcher

“These families do not have time on their hands – do we really need to continue the existing rhetoric that has failed them for a generation and wait another twenty years before a cure is found?”

“These families need a cure now, they don’t want to be told by their clinician to go and make memories, they deserve to be told what the treatment options are, treatments that will extend their loved ones’ lives by more than mere months.

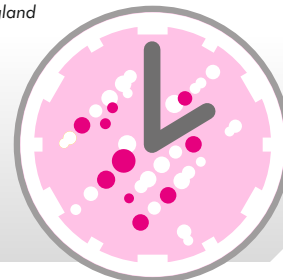
“Now is the time to give hope to the thousands of families impacted by a brain tumour every year.

“Along with more than 100,000 people, I am calling on the Government to make this the time to level up and stop the devastation!”

Sue Farrington Smith MBE
Chief Executive, Brain Tumour Research

THE DATA IS SHOCKING

EVERY TWO HOURS
in England



...someone is diagnosed with a
BRAIN TUMOUR



Since Brain Tumour Research was established in 2009, the charity has been a driving force for change, shining a spotlight on the urgent need for more funding for research into brain tumours.

In 2015, the charity launched what would become a hugely successful campaign in support of an e-petition, initiated by the Realf family, calling on the Government to fund more research into brain tumours.

The petition was started by Maria Lester in August 2015 to mark the first anniversary of the death of her brother, Stephen Realf, a Royal Air Force pilot from Rugby, who was diagnosed with a brain tumour at just 19 and died at 26. The petition called for funding for research into brain tumours to be increased to £30-35 million a year in order to bring it into line with funding for other cancers.

With our support and that of the wider brain tumour community, the Realf family's petition quickly gained more than 120,000 signatures, becoming the first to prompt an inquiry by the new House of Commons Petitions Committee and leading to the publication of a landmark report. This was followed by the April 2016 Westminster Hall debate attended by more than 70 MPs, all of whom were in agreement that more needed to be done.

The House of Commons Petitions Committee declared that "successive Governments have failed brain tumour patients and their families for decades." Its March 2016 report Funding for research into brain tumours quoted the most recently reported investment in brain tumour research (2014) as 1.5% (£7.7 million) of the £498 million national spend on research into cancer.

The establishment of a dedicated Task and Finish Working Group on Brain Tumour Research, run by the Department of Health and Social Care (DHSC), was a milestone in our campaigning.

Two years later, in May 2018, when the report of the DHSC Task and Finish Working Group on Brain Tumour Research was published, the Government committed to a £40 million funding boost, with Cancer Research UK (CRUK) committing to a further £25 million, over five years.

The tragic death of Baroness Tessa Jowell from a brain tumour in May 2018, following a standing ovation in the House of Lords in January for her speech on the devastating disease, also proved to be a catalyst for change and, with the establishment of the Tessa Jowell Brain Cancer Mission, there is an even greater call now to invest in both increased research and greater support for those affected by brain tumours.

These were steps in the right direction, but three years after these positive actions were announced we learn that only £9 million of the promised Government money has been spent and the COVID-19 pandemic has seen CRUK warning of a £150 million downturn in its research spending.

Where does this leave brain tumour research?

Progress has been made, but there is still so much more to be done.

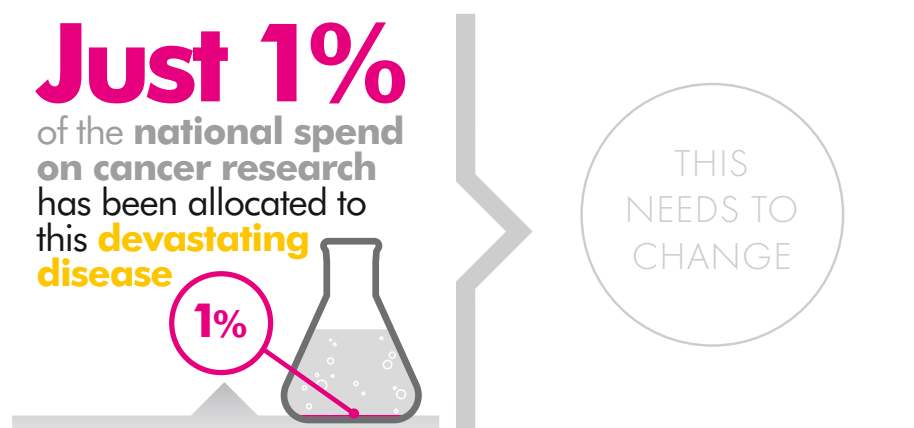
It is time for the Government to create a legacy for the brain tumour community and make the UK a world leader in finding curative therapies for brain tumours. It is time for the Government, larger cancer charities, and the brain tumour community to focus on finding a cure and give hope to the thousands of UK citizens diagnosed with a brain tumour every year.

It is time for the Government to introduce a dedicated Levelling Up Brain Tumour Research Fund of £105 million and to increase the ongoing national investment in brain tumour research to £35 million a year so that we can stop the devastation of this awful disease.

"Research gave my son hope. The campaigning we have done since Stephen died in August 2014 at the age of 26 and the impact we have had since, has given me the belief that he didn't die in vain. But the bold words and optimism of 2018 need to be matched by actions and those making such announcements need to know they will be held to account."

"When my son was diagnosed in 2008, his oncologist said: 'who knows what we will know about brain tumours in 10 years' time?' This gave him hope; research gave him hope; he hoped things would change, improve, and save him. My hope for other families lives on through research."

Peter Realf, petitioner



Signatures and memorials,

sampled from the 100,000 petition signatories.



Shay Patel

Shay Patel was just 11 years old when he was diagnosed with a glioblastoma multiforme (GBM) in November 2018.

The diffuse nature of

the tumour meant that it could not be removed by surgery and his devastated parents, Nicola and Deenu, were told that any treatment would be palliative; there was no chance of a cure.

Despite undergoing experimental treatment in the United States and starting an experimental personalised vaccine treatment in Germany in 2020 before everything was halted due to COVID-19, by early May a scan showed that the tumour was growing again and very aggressively.

Shay lost the use of his left side. He stopped speaking, lost the ability to swallow and had to be fed via a feeding tube.

Shay died on 1st September 2020, aged 13.

His mother, Nicola, said: "One of the hardest parts of Shay's journey, was that we knew from the outset that we would lose him. Whilst we had hope of a miracle, there is no cure for such a tumour and there have been no breakthroughs in treatment for over 30 years.

"The only way that this will change is by increasing funding for research."

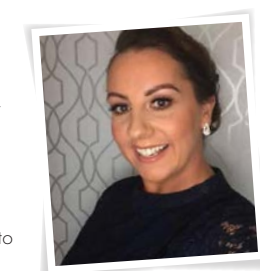
Ria Melvin

I was diagnosed with a glioblastoma grade 4 brain tumour aged 23. I have been forced to fundraise and travel abroad to access treatment that the NHS cannot offer. Time for change is now.



Lauren Loan

In October 2020, my 38-year-old sister Katie got diagnosed with a rare, inoperable brain tumour: diffuse midline glioma in the thalamus. She was given two to three short years to live. She was supposed to start treatment on 24th November, but she had eight shunt surgeries as it kept malfunctioning which kept delaying the treatment starting. On Tuesday 5th January, we got the most devastating news that the cancer had spread to other parts of the brain which meant it was no longer treatable and Katie only had weeks to live. She came home and died eight days later on Friday 15th January, only three months after diagnosis. She has two beautiful boys aged four and 13 years old who have to grow up without their mam; her husband is only 40.



I promised her I would never stop raising awareness of this awful disease and as long as I am on this earth that is exactly what I will do. I pray one day no-one will have to endure the pain she did and no family will have to go through the nightmare my family have and will continue to go through.

Amanda Dalgleish

My daughter has been diagnosed with a brain tumour. She had surgery in December to remove 85% of it, she is now having radiotherapy and chemotherapy. She is only 29 and has two babies, one 18 months, the other five months. More money is needed. We are hoping for a positive outcome.

Margaret Lenton

My 61-year-old son was diagnosed with inoperable brain tumours, GBM grade 4, just over a year ago. With marvellous treatment from Southampton Hospital, he is one of the 25% living for a year after diagnosis. He feels well, but very tired, and keeps positive and hopeful. We pray to have him with us for much longer and are so grateful to the NHS. God bless all of the researchers, specialists, nurses and all those who head the battle against all cancers.

Hayley Burgess

I signed the petition as I sadly lost my beloved mother to this horrible disease in 2019. She did everything she could to fight this, enduring a craniotomy operation and gruelling radiotherapy sessions, but sadly the tumour was too aggressive and after a short six months we had to say goodbye to our amazing inspirational mum. Mum was taken way before her time and still had so much to live for and grandchildren to enjoy.





**Brain Tumour
Research**



Dominique Nicholson



Pippa Simpson

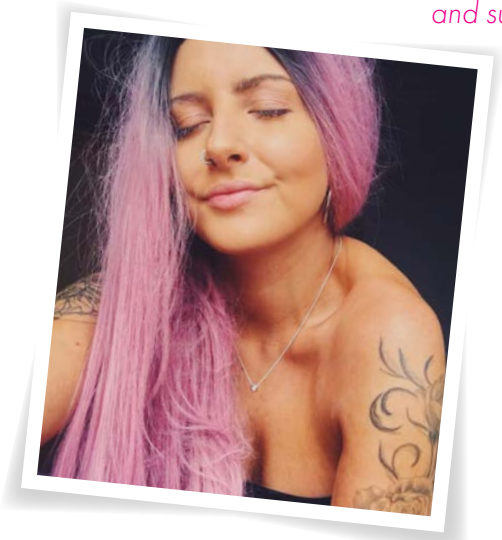
Pippa Simpson was just 19 when she was diagnosed in December 2018 with a grade 3 anaplastic pleomorphic xanthoastrocytoma (APXA), an

aggressive and hard-to-treat brain tumour.

She was forced to drop out of university and move home. She went on to endure six weeks of radiotherapy and numerous IVF injections to freeze her eggs due to the effects that treatment may have on her fertility. She completed the radiotherapy in April 2019, but by July was told her tumour had begun growing again. Pippa was given targeted chemotherapy, which she continues to take to this day, and has now been in remission for more than a year.

She said: *"Since my diagnosis two people I know have also been diagnosed with brain tumours. This shocked me as I never realised how common brain tumours are in young people. I was shocked to learn that only 1% of the national spend on cancer research has been allocated to the disease, in spite of it being the biggest cancer killer in children and young adults. The only way we can beat this disease is through continuous and sustainable scientific*

research. I know only too well how important this is."



Nadia Majid

Our four-year-old son Rayhan deserved a chance at life. He died, four months from diagnosis. He might have had a chance if it hadn't taken so long for the medics to diagnose him due to lack of awareness and in doing so allowed the cancer to spread. He might have had a chance if his strain of brain cancer was more researched and the medics had the options of using different treatments/drugs to offer him, rather than the 'one size fits all' protocol and a 'fingers crossed' approach. This beautiful boy had everything to live for. He just wasn't given the armour he needed to stand a chance of winning his battle.

We need to stop sending brain tumour warriors to battle without the adequate armour. More needs to be done.

Dominique Nicholson

In June 2019 I gave birth to my second daughter. In July, just over three weeks later, I was diagnosed with a meningioma and within a week of the diagnosis I was in surgery having it removed.

I was one of the lucky ones but I know many aren't so lucky.

Janina Jenkins

I signed the petition in memory of my husband Nigel who died at the end of 2019, aged 55.

He was first diagnosed in 2007. When his brain tumour returned for the third time in 2019, there was no hope and no different treatment to what he received in 2007, which is not good enough. It shows how underfunded brain tumour research is when there are no new treatments after 12 years. The brain tumour stole him from me, his family and friends.

I want to stop others going through this heartbreak.

Nicola Wharton

My son, Aaron Wharton was diagnosed with an anaplastic ependymoma in April 2020.

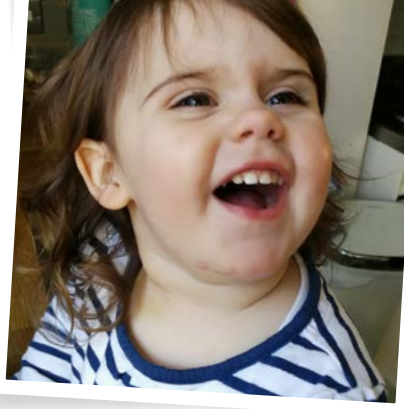
Currently, Aaron is one of the fortunate warriors, with clear scans to date following radiotherapy treatment. Unfortunately, we now know all too well that it is not the same outcome for everyone else. We signed this petition not just for Aaron, but for all the brain tumour warriors, past and present, in the hope that a cure can be found.

Francesca Johnson

My husband Brian had so much more living to look forward to until the tumour was diagnosed when he was 68 in 2017. The doctors misdiagnosed him several times at first, but the treatment enabled him to live for another two years and seven months. The last few months of his life were terrible.

Lily Deans

I have signed this petition in memory of my darling father Michael Deans, who we lost at the age of 49. He left behind a wife, a daughter and a son, brothers, parents and friends who all miss him and love him desperately. Brain tumours are the cruellest of diseases. Seeing my dad deteriorate in front of me and ultimately having to bury him at such a young age is something I wish on nobody. Please increase the national funding. Nobody should have to go through the pain of losing a parent.



Nina Sullivan

Blaise Nelson

Blaise Nelson was just six when he was diagnosed with a large, low-grade glioma in his brain and coating on his spine in February 2018. The satsuma-sized growth was near his brainstem, causing pressure to his cerebellum.

Despite undergoing major surgery and extensive treatment, including a clinical trial to try to prolong his life, Blaise's treatment options ran out. He died at home in October 2019, leaving his devastated parents, Rachel and Chris, and three siblings.

Chris said: "Much more research into brain tumours needs to be done. There's an urgency for better treatments and for better diagnoses. We were never able to find out exactly what cancer Blaise had – maybe if we'd been able to, it would have helped him."

Penny Wilson

My daughter Eve Wilson was diagnosed with a brain tumour aged 10, after months of being poorly and fighting with doctors and hospitals to be taken seriously.

It shouldn't take this long; better research needs to be done to find faster ways of diagnosing this terrible and underfunded disease.

She got approved for proton therapy, but we had to wait for treatment. More needs to be done for better and faster treatment options to give a better chance of survival and that's why I signed the petition.

Joanne Moore

My beautiful husband sadly passed away from a glioblastoma stage 4, nine months from diagnosis. He was my soulmate, the love of my life and my everything. To see him suddenly going from a fit and healthy man to fighting for his life was utterly devastating and I will never come to terms with losing him. He was a fantastic dad to our son and still had so much to live for.

We need money NOW to find a cure. So many lives are needlessly being lost to brain tumours.

Freya Nobbs

I signed the petition because my father died of a brain tumour (medulloblastoma) four months ago. He left behind his three children and wife, who all miss him dearly.

Angela Robson

I signed the petition because I was diagnosed with a grade 4 glioblastoma multiforme in December 2019. Prior to my diagnosis, I knew nothing about brain tumours. Following three weeks of severe headaches, and admission through A&E, I naively thought once I had surgery, I would make a full recovery. More awareness is needed.

Vikki Sullivan

My reason for signing the petition is because of my daughter, Nina (pictured above). She was diagnosed with a brain tumour in the summer of last year, aged one.

Nina started with seizures when she was six months old, but was otherwise well. An MRI scan a few months later showed a tumour, and although surgery was possible it could only remove part of the tumour. Whilst her tumour is low grade it has regrown unexpectedly rapidly, and as a result Nina will start chemotherapy this week, just before she turns two.

I am signing this petition for Nina, and for all those affected by a brain tumour in some way. With research comes hope.

Clare Gooddy

In August 2014 my mum, Joan Gooddy, was diagnosed with a grade 4 glioblastoma multiforme brain tumour. She was 54 years old.

We were told from the outset that there was no cure for this type of tumour and even with a successful surgery the tumour would grow back and would eventually kill her. Our world was shattered.

Mum had two debulking surgeries plus radiotherapy and chemotherapy, the latter of which proved too harsh for her to handle and she had to come off it. There was no alternative chemotherapy for her to try.

Eighteen months later my incredibly brave mum passed away at home.

Throughout the course of her treatment, we knew that we were fighting a losing battle due to the lack of progress in brain tumour research because of an appalling lack of funding. To watch someone you love fight like hell in a battle you know they can't win was devastating and has left a permanent scar on myself, my sister and my dad.





Kelly Ann Alexander

Kelly Ann Alexander was turned away from A&E when her brain tumour symptoms were dismissed as the effects of too much drink. She was eventually diagnosed with a

low-grade oligodendroglioma brain tumour in October 2015 after she began to suffer 14-15 seizures a day.

Kelly Ann underwent an awake craniotomy, but later contracted a serious infection, which required replacing part of her skull. In August 2017, she was given the devastating news that the tumour had grown back and underwent radiotherapy and chemotherapy.

She said: "I'm determined to make the most of whatever the future holds for me, my husband and my beloved horse. The uncertainty makes it very difficult for my mental health though, and I'm having to take things very slowly."

Holly Roberts

My son Larsen (pictured above) died from a brain tumour so rare that there were only about seven researched cases in the world – medullopithelioma of the optic nerve. I signed this petition because if more money was spent on brain tumour research then perhaps his consultant would have heard about it, perhaps they would have diagnosed him accurately earlier, and perhaps the treatment would have been kinder than the chemotherapy which ultimately killed him.

Susan Elms

Until January 2020, this had never affected me and I knew very little about it. I was a very fit and healthy 44-year-old with a gorgeous eight-year-old daughter and a very loved husband. I worked full time in marketing in London and I lived life to the full.

However, in January last year I suffered a night time seizure, out of the blue, and it was discovered I had a brain tumour that they now estimate had been there 10 years. I have had a difficult year resulting in a big operation in November 2020 to remove the tumour from my frontal lobe. I'm still waiting for full results. Due to the pressure on the NHS I sense they have been delayed, however they believe it's been a success and I won't need further treatment only monitoring.



Larsen Roberts

It's been terrifying for me and my family, particularly my daughter who was just seven at the time and really struggled to make sense of it. I can possibly never return to the full life I led before due to the medication I now have to take. The thought of families going through this with children is absolutely heart breaking so we MUST get more funding into this terrible disease.

Melanie Rowley

I signed the petition calling for increased national investment into brain tumour research because my husband and father of our three children is fighting a glioblastoma multiforme. Since his diagnosis in July 2019, I have done so much desperate googling looking for hope and while I haven't found the miracle cure, I have found so much support from family, friends and strangers. Most of all I have found strength in our facing of this battle together and we are still fighting nearly 20 months on.



Jo Crossey

We signed this petition in honour of our son Sean. He was diagnosed in August 2016 with a grade 4 glioblastoma multiforme, had three rounds of surgery, endured radiotherapy and chemotherapy but sadly died in September 2019. He was 29 years old and had been married for just three months. Such a tragic waste of a life, the heartbreak doesn't ease; so if this petition gets the attention of the Government and secures future funding into brain tumour research then that's great. It's too late for our Sean but hopefully it can reduce the number of families that will be affected by this cruel disease.

Anna Cowan

I have signed the petition because I have seen the rapid devastating destruction that brain tumours cause. We lost our wonderful Mum, wife and nanny on 4th July 2020, around four months after diagnosis. There were no treatment options and we came together with care and love for Mum's last few months with us.

I'm desperate for the day when we can fight brain tumours with the latest science and with the new treatments just waiting to be discovered.





Sam Suriakumar

Doting husband and father Sam Suriakumar was diagnosed with a brain tumour after being taken ill on his commute home from work. He has been told his tumour, a glioma, is growing 'like a cobweb', making surgery difficult without affecting other parts of his brain which control speech, memory, emotions and mobility

He said: "When I first heard the words 'brain tumour' it felt like life had stopped and I was in a dark tunnel with no light. I couldn't speak, hear or understand what was going on. To be honest, I am still trying to digest it and, as terrifying as things are, it will not defeat me."

Amy Owen

At four weeks old, our baby boy Roux (pictured above) was diagnosed with an immature teratoma which covered 10cm of his brain. He has spent more than six months of his life in hospital and has battled through 10 major brain surgeries at Leeds General Infirmary to help remove the tumour. After his fifth surgery, we were asked to consider stopping his treatment and begin end of life care as his consultants felt Roux was too weak to continue with surgery and his tumour was continuing to grow at a rapid pace. The only road they had to go down for Roux was surgery and it was explained that Roux's tumour was so rare there was little to no other research into other ways of treating it. We weren't ready to give up on our little warrior and eventually it was agreed that Roux could continue his treatment plan.

Almost six months on from his last operation and Roux is doing extremely well. He's been left blind in his left eye and has to have intensive physio, occupational therapy and play therapy. He is at continued risk of tumour regrowth and seizures, has a VP shunt and has obvious development delays, but overall he is a happy little character who we feel incredibly lucky to have in our lives.

We are unsure how Roux's life will be impacted in the future as a result of the tumour, however we do know that we owe that life to the incredible professionals who care for him. We wholeheartedly believe that more should be done to help with the research of brain tumours so that in the future other people don't have to suffer like Roux did.



Roux Owen

Katy Clayton

On 16th March 2020, we lost Ewan James Smith, aged just 36. Ewan was a loving father of twins aged just one at the time of his death and an older son aged five. He leaves behind his wife, parents and three sisters, all heartbroken.

Ewan had been experiencing headaches and had been prescribed migraine tablets. He had visited the doctor several times. He had also visited the optician to try to get an answer why he was having such regular headaches and sickness amongst dizziness and other symptoms. Ewan was an extremely physically fit and healthy man. He collapsed on Friday 13th March after a seizure and was rushed to hospital. He was in ICU with us all until Monday 16th when he died. Ewan had an undetected brain tumour on his brain stem.

Ewan was a Police Officer for Essex Police. He was the most unique, loving and genuine man who we miss so very much every minute of every day.

Simonetta Stonehouse

It is just over four years since we lost my lovely brother Adrian Vitoria. It doesn't get any easier, you just learn to live with the pain.

Victoria Neill

Losing my dad at 20 has been excruciating. We couldn't afford to stay in our family home, so we had to sell belongings and, eventually after a year, move into a flat. My mum had to get a job, after more than 20 years of not working, to make sure we had a parent at home whilst my dad worked away. We struggle with money and my brother and I support ourselves and Mum to get by. My family were the closest family. My dad was our rock. Losing him was losing a pillar in our family. Since then, everything has changed but out of it all it has brought us even closer together.





Shirley Clements

Finlay Church

Finlay Church was an active youngster with a black belt in karate when he was diagnosed in 2014 with glioblastoma multiforme.

In the 17 months after his diagnosis, Finlay endured neurosurgery, chemotherapy and radiotherapy, taking part in trials including testing the efficacy of re-purposed drugs. In his final days, he dictated a letter in which he talked of his love for his family, his fondness of chocolate and curry, and his fear of losing the fight. He died on 25th November 2015.

His mother, Penny, said: *"I am ashamed to admit that there came a stage when I wished Fin had leukaemia. Surely that would be better, there were treatments and things would be OK wouldn't they? Investment in research and increased public awareness meant leukaemia was no longer a death sentence. But where is the investment and subsequent improvement in outcomes for patients with brain tumours? As we fought as hard as we could for Fin, we were sickened to learn that the treatment for brain cancer is antiquated and barbaric, as cruel as the disease itself."*

Kathryn Clements

One morning in July 2020 without warning, my mum, Shirley Clements (pictured above), became disorientated, was vomiting and had lost her short-term memory. She was sent to hospital as her symptoms carried on for a few days.

MRI results showed a huge inoperable tumour which was already in various areas of her brain. A biopsy did not determine exact information about the tumour other than it was gliomatosis cerebri. The tumour was suspected to have been growing for years with symptoms that were not typical of a brain tumour.

In November 2020, Mum embarked on 33 rounds of radiotherapy. Initially we saw slight improvement however MRI results showed the tumour had continued to grow.

Mum had one round of chemotherapy and was due another, but on the 13th February 2021, she woke in excruciating pain, begging my dad to help her. An ambulance

was called and she was taken to hospital. A CT scan showed that there had been a break in the tumour and another had started to grow. There was nothing they could do for her.

From that evening her care became palliative. She was transferred to a hospice where at 5:15pm on 23rd February aged 59 years, she took her last breath and was finally free of this awful disease.

Lorraine Robinson

My gorgeous, brave boy who sadly died aged six in 2006. He had battled three brain tumours since a few days after his fifth birthday. He had three brain surgeries, radiotherapy and high dose chemotherapy. He had a supratentorial primitive neuroectodermal tumour (SPNET) in the front left of his head where an adult usually gets a tumour. Doctors at Birmingham Children's Hospital had never dealt with an SPNET in that position before so they had to go to a New York Hospital for ideas on how to treat it.

From what I can see nothing has changed in all that time in terms of how brain tumours are treated and that saddens me so much. It's like my child died in vain.

I'm thankful my family and I had 22 months with my son from diagnosis, but it doesn't make up for a lifetime without him.

Annabel Jeens

I signed the petition as my dad was diagnosed with a benign brain tumour in 2015. His uncle, my great uncle, died on Christmas Day 2020 from a stage 4 malignant brain tumour.

Anita Ferguson

I lost my husband of five months to grade 4 glioblastoma multiforme IDH1 Wildfire on 27th April 2019. Iain passed away exactly six months after his diagnosis, having undergone a craniotomy, chemotherapy and radiotherapy.

Three months after I buried my husband, I was diagnosed with a brain tumour. It took two years, numerous GP visits and eventually, me collapsing and an ambulance ride to finally get a diagnosis.

Brain tumours need substantial funding, and awareness among medical staff needs to be heightened so diagnosis can be made earlier. All too frequently brain tumour symptoms are missed by GPs or dismissed – this needs to change.

I am one of the lucky ones. My tumour, so far, is benign. Sadly, my husband was one of the thousands whose diagnosis was terminal.

Claire Middleton

We signed the petition in honour of our superhero son, Arthur (age six), who was diagnosed with brain tumours when he was two. He has undergone two surgeries, chemotherapy and a clinical trial. He, and all the other brain tumour warriors out there, deserve better!





"I watched my grandson Jack go through the frightening diagnosis and treatment of a brain tumour. At the time we felt so helpless; unlike many other cancers, there is still so much complexity to unravel about brain tumours and their causes. We were lucky and my grandson was one of the few to make a full recovery. But many do not..."

Dame Sheila Hancock DBE
Actor and Author

Member Charities



Fundraising Groups



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For more information, email us at:
campaigning@braintumourresearch.org

Brain Tumour Research, Suite 37, Shenley Pavilions, Chalkdell Drive
Shenley Wood, Milton Keynes MK5 6LB

www.braintumourresearch.org
Tel: 01908 867200



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¹NCRI Data Package 2019 - Table 3: NCRI spend by cancer site (apportioned value)

