

The Brain Tumour Charity shining a light on

The GREY MATTERS

The **BRAIN
TUMOUR
CHARITY**

Research | Awareness | Support

Issue 14 Spring 2017

Our patient guide

Children and Families Service

Brain Tumour Awareness Month #WearItOut

thebraintumourcharity.org



Shop our clothing range

If you've made a New Year's resolution to get active, then why not do it in style whilst supporting The Brain Tumour Charity?

Our active wear range of clothes, designed in The Charity's red and teal colours, features a light-weight running vest and a breathable cycling jersey with full front zip and ergonomic rear pockets.

Visit thebraintumourcharity.org/shop to get your resolution kick started.

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Hello

In this latest edition of *The Grey Matters* I'm proud to announce that HeadSmart has helped reduce childhood brain tumour diagnosis times from over 13 weeks to 6.5.

I've been working with The Brain Tumour Charity on the HeadSmart campaign ever since the development of the guideline for healthcare professionals which led to the launch of the public facing campaign as we know it today.

The idea behind HeadSmart grew from the concerns of families about how long it was taking for children and teenagers with a brain tumour to be diagnosed. One of those families was Neil and Angela Dickson, founders of The Brain Tumour Charity, who lost their daughter Samantha to a brain tumour when she was just 16.

It's fitting that to tie in with the relaunch of the guideline, the campaign is rebranding and at the heart of the new look is 'Sam'. Sam visually shows what the signs and symptoms of a brain tumour are to help make them easier to remember.

Thank you to everyone who has helped raise awareness of HeadSmart. The campaign has been incredibly successful in reducing diagnosis times, but more needs to be done. Turn to pages 18 and 19 to find out more about the new look and how you can get involved.

David Walker

Professor of Paediatric Oncology



Help us drive down diagnosis times

HeadSmart, our award-winning early diagnosis campaign, is relaunching and we need your help!

We've included two HeadSmart postcards with this edition of *The Grey Matters*. Please keep one and pass the other to a friend, family member or colleague to help raise awareness of the signs and symptoms of childhood brain tumours.

Our research investment

We are committed to doubling survival and halving the harm that brain tumours have on quality of life.

To achieve our ambitious goals we're investing in ground-breaking research which will help accelerate progress, increase our understanding of brain tumours and speed up the development of discoveries in the lab to effective treatments in clinic. On top of this, the research we fund will enhance quality of life for those living with a brain tumour and reduce the time it takes to get diagnosed.

Last year we announced that we have invested £18.3m into pioneering research into brain tumours. We are now delighted

that including further awards made recently, our total commitment to research into brain tumours to date stands at over £25.3m. This investment contributes to the significant impact that medical research charities have on research in the UK – a recent report from the Association of Medical Research Charities (AMRC) highlighted that in 2015, over 40% of publicly-funded research was funded by charities.

This has only been possible thanks to the dedication of our incredible supporters. Thank you.

To read more about our research visit thebraintumourcharity.org/our-research

A snapshot
of our
research
to date



48
Grants



12
Nations

Scientific Advisory Boards

Our Scientific Advisory Boards (SABs) are responsible for the assessment and rating of applications for research funding and making recommendations to our board of Trustees. The two boards, Biomedical SAB and Quality of Life SAB, are made up of internationally renowned scientific and medical experts that work in different areas of cancer research and social science.

Listening to the brain tumour community is extremely important to our work, so we have five lay representatives who sit on the SABs. They provide their perspective as experts by experience on whether the applications that we receive for funding are important and/or feasible for patients.

To find out more visit
thebraintumourcharity.org/SAB

Did you know

There are over 150 different types of brain and CNS tumours which is why it's so important that we fund research to find out what makes tumours different and how best to treat them.



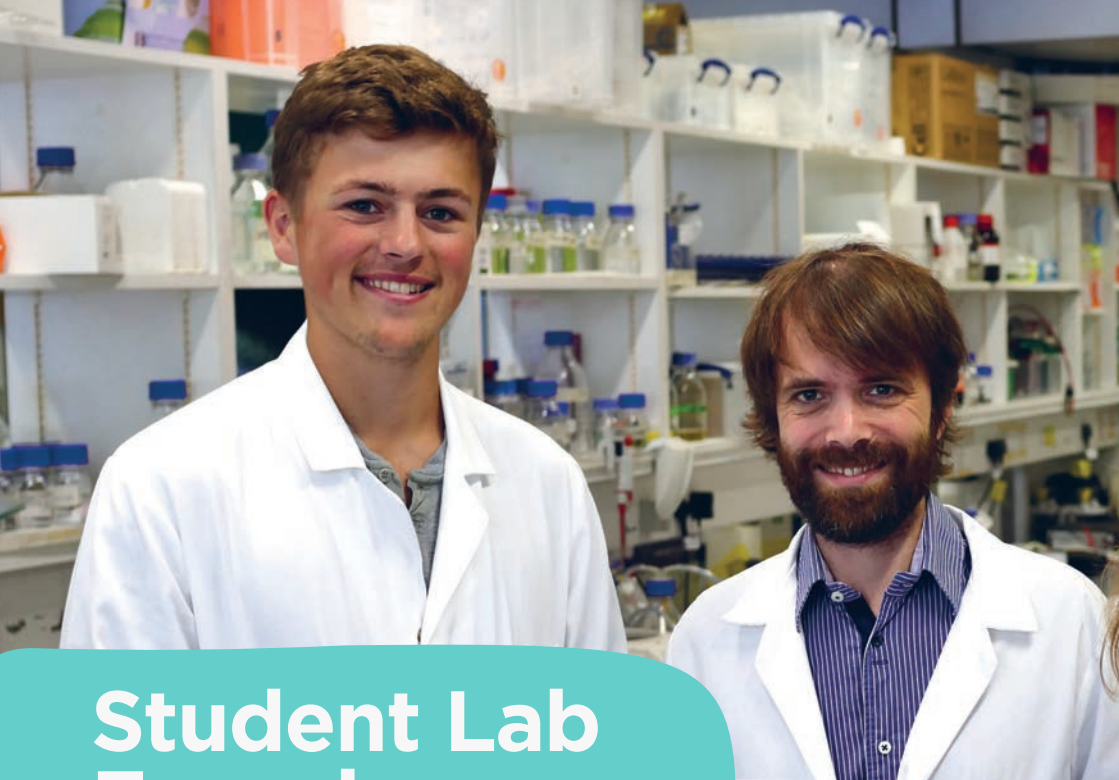
48

Institutions



255

Researchers



Student Lab Experience

Last August, we were delighted to offer students the opportunity to spend a week working alongside Dr David Michod and his research team at the UCL Institute of Child Health, London.

For the fourth year running, Dr Michod invited students to gain unique experience of working in a laboratory and become part of the team conducting vital research into brain tumours. The budding researchers were able to take part in practical experiments and get up close to the research that is taking place thanks to funding from The Brain Tumour Charity.

George lost his brother Alex in 2011 and since then has helped fundraise for The Alex Bolt Fund which specifically supports our research. George is studying molecular and cellular biology and was one of the students who got the chance to experience a week in the life of a researcher. He said: "One of the highlights of being in the lab for me was cloning DNA for the first time.



Image left: Dr David Michod with students George and Anna.

Image right: George during his lab experience.

"It was great to work with scientists who were clearly so passionate about what they do. It's really helped turn what I read in a textbook into reality, and put my knowledge into practice. The experience has motivated me and helped confirm that this is what I want to do as a career."

We're thrilled to offer young people such a valuable and rewarding opportunity, and inspire them to pursue a career in research. Dr Michod said: "It's really important to motivate young people because we need the next generation of researchers to find a cure to treat brain tumours."

To hear the students talk about their week as researchers, visit bit.ly/LabExperienceMichod

New research projects – watch this space!

In the May issue of *The Grey Matters* we will be announcing the new research projects we're funding as part of our New Ideas, Quality of Life, Quest for Cures and Everest Innovation Fund initiatives. These exciting research projects are in addition to the £4.3 million commitment we made last year to help us achieve our goals of doubling survival and halving the harm for those affected.

Read more about the research projects we currently fund at thebraintumourcharity.org/what-were-funding

Spotlight on The Glioma Conference

Collaboration across the brain tumour community is key to finding a cure – and finding it faster. The Glioma Conference is helping to do just that by bringing together scientists and clinical researchers working on various aspects of the origin, genetics, neuropathy, diagnosis, imaging and treatment of gliomas. The annual one-day meeting, which we have supported for the last six years, aims to foster new ideas and collaboration, and promote the development of junior researchers.

Why gliomas?

Gliomas are the most common type of brain tumour yet treatment has not progressed substantially in the last few decades. This is partly down to how difficult it is to diagnose these tumours.

Did you know

A glioma is a tumour that grows from a type of cell in the brain called a glial cell. Glial cells provide support and protection to neurons (cells that transmit information).

Bringing experts in their fields together will help to ensure that significant progress is made in developing new ways to detect gliomas and treat them.

Who attended?

The 2016 Glioma Conference, organised by Professor Paolo Salomoni (Samantha Dickson Brain Cancer Unit, University College London) and Professor Silvia Marino (Blizard Institute, Queen Mary University London), was the largest to date with over 250 global researchers, clinicians, physicists and PhD students attending.

We will continue to fund scientific conferences and workshops that inspire innovative research and drive progress to bring us closer to understanding brain tumours.



Image: (left to right) Silvia Marino, Paolo Salomoni, David Jenkinson, Riccardo Soffietti, Marcel Kool at the 2016 Glioma Conference.

A united voice

Following the Parliamentary debate on funding into brain tumours, we were invited to join the newly formed Task and Finish Group to look at ways to accelerate research into brain tumours.

The Task and Finish Group brings together experts in the field of brain tumour research, representatives from brain tumour charities and executives from various government departments – this collaborative approach will help to drive change in research policy.

The current barriers to research into brain tumours were discussed at the meeting in October including the need to establish research centres which specialise in brain tumours, limited collaboration between different types of researchers, and the

lack of good quality tissue samples and associated data. We're proud to be leading on this last issue and will be developing a biobanking infrastructure for brain tumours – we're currently working with the community on this so keep an eye on our website for more information over the next few months.

The group will now, having set some priorities around the above themes, work collaboratively towards addressing these important issues.

If you'd like to find out more about our policy work, contact us at [***thebraintumourcharity.org/policy-get-involved***](https://thebraintumourcharity.org/policy-get-involved)

The Society of British Neurological Surgeons

The autumn meeting of The Society of British Neurological Surgeons, held in Stoke, was an opportunity for us to build relationships with eminent neurosurgeons and improve the ways that we can support them, their teams and the children and adults they see who are living with a brain tumour.

The meeting also gave us the opportunity to hear from many inspiring speakers including Stephen Price, neurosurgeon at Addenbrooke's Hospital in Cambridge, who delivered The Hunterian Lecture – a prestigious accolade named after pioneering surgeon John Hunter.

Genomics England

People living with a high grade brain tumour are being offered a unique opportunity to help scientists 'decode' the disease and unlock potential treatments for those affected in the future.



Researchers have begun to gather samples from people with cancerous brain tumours as part of the groundbreaking Genomics England programme. Genomics England was created by the Government in 2012 to explore the way our genetic make-up influences the development and progress of certain diseases. Its aim is to scrutinise 100,000 genomes from people living with certain cancer types and those with other rare diseases.

Brain tumours were initially excluded from the project but following a campaign by leading neurosurgeons and neuroscientists, led by Professor Keyoumars Ashkan (pictured right), Genomics England announced a change of heart.

A drive has now begun to recruit at least 500 NHS adult patients, in England, who are about to undergo surgery for any type of glioma or other selected brain tumours

and who will allow a sample of their tumour, and a sample of blood, to be used for the project.

For more information, please visit thebraintumourcharity.org/genomics-england-recruiting



"Analysing these 1,000 matched tumour and blood samples will be a giant step towards understanding and evaluating the genetics of brain tumours and this holds the key to developing novel therapies which are essential for such a diverse disease."

Professor Keyoumars Ashkan



Become a Young Ambassador

We're excited to be expanding our Young Ambassador programme this April, bringing together young adults aged 18–25 who have been affected by brain tumours. Our Young Ambassadors play a vital role in being a voice for The Charity, representing us at local and national events and advocating on behalf of young people affected by brain tumours.

Laura, a Young Ambassador, who lost her mum to a brain tumour in 2009 said, "Being able to volunteer for The Charity has been the best platform for me to honour my mum's memory. As a Young Ambassador I've met incredible people that have inspired me with their immeasurable strength and determination.

"I know that the work we're doing by raising awareness is making a difference and I'm sure that the new Young Ambassadors will find their role as fulfilling and as exciting as we all have."

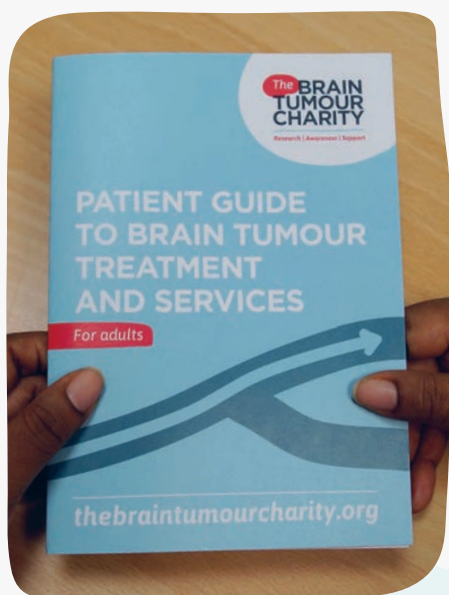
The role will also give individuals an opportunity to work on personal goals with support given by the team at The Charity, as well as from a Young Ambassador Mentor.

If you're interested in meeting others, developing your skills and are passionate about improving outcomes for people affected by brain tumours, we'd love to hear from you. To find out more visit thebraintumourcharity.org/young-ambassadors



Patient guide: an unexpected journey

We understand that being diagnosed with a brain tumour can be frightening and overwhelming, and it can be difficult to ask questions about treatment and care. To help patients navigate this difficult time, we've developed a guide which explains what patients should expect at every stage of their journey.



In our strategy, *Defeating Brain Tumours*, we set clear priorities to help us achieve our goals of doubling survival and halving the harm that brain tumours have on quality of life. One of those priorities was equal access to the best treatment and care which our new *Patient Guide to Brain Tumour Treatment and Services* helps to ensure by making all adult patients aware of the standard of care they should expect to receive from the NHS.

The guide, which was developed with people affected by a brain tumour, healthcare professionals and carers, also includes information on clinical trials and research opportunities that are not currently routinely offered to all patients. We hope that the guide will help families feel empowered to ask about these opportunities.

An introduction to the guide



When you're diagnosed

The first part of the guide outlines what information should be given to help ensure patients and their families are prepared for the next stages of treatment and care.

In a recent survey we commissioned, we found that 79% of people weren't given an individual care plan – as every patient and every journey is unique it's important that a care plan tailored to the individual's needs is developed.



During your treatment

Following a diagnosis, patients may face complex decisions – this part of the guide outlines what patients should expect to be told, including opportunities to participate in clinical trials.

We found that four in ten people were not given information about treatment options and just 5% were offered and/or had biomarker testing. We want to change this because biomarker testing can help ensure an accurate diagnosis is given and treatment plans are tailored to the tumour type.



After your treatment

It's often when treatment finishes that patients can feel most alone or overwhelmed, but the end of treatment shouldn't mean that care should end too. However, nearly two thirds of people living with a brain tumour told us that they were not signposted to suitable support.

In this section of the guide we outline the support a patient can expect to receive, for instance if they're affected by epilepsy, struggling to communicate or having mobility issues.

5-ALA – equal access

If a patient has been diagnosed with a glioblastoma and surgery to remove the tumour has been recommended, a drug called 5-ALA, also known as ‘the pink drink’, can be given which makes the brain tumour cells ‘glow’ during surgery under a special microscope and light. This enables the surgeon to see the tumour tissue more clearly making removal more accurate.

Unfortunately this isn’t routinely offered everywhere, but it should be. By raising awareness of this treatment method we can help ensure that it’s available to everyone who needs it.

You can read the full guide at thebraintumourcharity.org/patient-guide

Patient experience

Gideon Burrows was diagnosed with a brain tumour in 2012 and has since written a book about the uncertainty of a low grade brain tumour diagnosis. He offers not only his own experiences but that of others, as they navigate a new and complex world of ‘living low grade’. Download his book from Amazon: bit.ly/LivingLowGradeBT

“I think this guide is fantastic. I just wish it was available five years ago when my late father was diagnosed with a grade four glioblastoma. I’ve learned more from this leaflet in the time it took to read it than in the six months he was getting treatment for this awful disease. Thank you The Brain Tumour Charity for all the hard work you do!”

Carolyn Sloan

If you’ve been affected by a brain tumour, share your experience

Did your doctor talk to you about ‘the pink drink’?

Have you been made aware of biomarker testing?

Has your doctor talked to you about the 100,000 Genome Project?

Join the conversation around these topics and much more on our closed Facebook group.



<http://bit.ly/SupportGroupFB>



Our Children and Families Service

A brain tumour diagnosis can turn a family's world upside down, we're here to help turn it back around again.

Our dedicated Children and Families Service works to reduce isolation and anxiety for children, young people and their families by giving them the help, understanding and support they need.

We work with the whole family following a child's diagnosis. This support, which includes one-to-one support and private Facebook Groups, ensures no one has to face a brain tumour diagnosis alone.

Families can also attend one of our Family Days giving them an opportunity to enjoy a day out and spend quality time together away from hospital appointments and

treatment. These fun and relaxing days mean parents and children alike can meet others going through a similar experience.

As part of our Children and Families Service we also developed the Jake series of animations which explain a variety of subjects relating to brain tumours in a child-friendly way, as well as The Brainy Bag which is given to all children diagnosed with a brain tumour and provides a welcome distraction for children during hospital visits.

Find out more about the ways we can help by visiting thebraintumourcharity.org/children-and-families

Supported
by



Inspired by
Alex Bolt

Helping to reduce isolation

In 2001, Sarah's husband, Tony, was diagnosed with an oligodendroglioma. Following treatment it sadly returned more aggressively. Tony has struggled with depression and lives with side-effects from treatment, including tiredness and difficulties with speech.

Sarah said: "Despite everything, we remain positive and have as many holidays and fun times together as we can."

One memorable moment for all the family was attending their first Family Day for parents living with a brain tumour, run by The Brain Tumour Charity in partnership with The Lewis Moody Foundation.

Sarah first heard about the Family Day at a support group: "I wasn't sure what to expect from the day, but it was very relaxed and you could take part in as much or as a little as you liked. It was great to spend time with people in similar situations and I met some lovely people. I didn't expect to build a friendship from it, but I keep in touch with one family that we met on the day, which is really special.

"Our daughter was apprehensive about going and thought it would be 'all medical', but she had a great time and said she would like to go to more Family Days.

"We were able to take part in lots of activities on the day, including canoeing, archery, rugby and building a campfire.



"If a family is thinking about attending and is unsure about whether to go or not, I would highly recommend it. Everyone is very supportive and you can talk about your situation if you want to, but there isn't any pressure. The activities are brilliant and we all had a great time. We made some great memories."

Our next Family Day for parents living with a brain tumour will be on 25 March in Derbyshire, run in partnership with The Lewis Moody Foundation. To sign up for the day, or to find future Family Days for children living with a brain tumour, visit thebraintumourcharity.org/family-days

A big thank you to The Lewis Moody Foundation, for raising £500,000 for The Brain Tumour Charity to date. The money raised goes towards HeadSmart, research and our jointly run Family Days which help to ensure that families like Sarah's feel less isolated. To read more about Lewis and Annie's commitment to making a difference visit thelewismoodyfoundation.org



MEET SAM

Sam plays an important role in helping parents and teenagers understand the signs and symptoms of a childhood brain tumour. Each of the 10 symptoms is represented by a different, easily recognisable, version of Sam.

Do you know
the signs and
symptoms?

headsmart.org.uk

DRIVING EARLY DIAGNOSIS

Thanks to your incredible support, HeadSmart has helped reduce average diagnosis times for childhood brain tumours from over 13 weeks to 6.5.

We now want to see this reduced to four weeks. To do this, we need to continue to ensure that HeadSmart is seen as an important resource for GPs and other healthcare professionals. This means that the evidence on which HeadSmart is based must be reviewed, every five years, to ensure the signs and symptoms have not changed.

Over the last few months the Children's Brain Tumour Research Centre at The University of Nottingham, one of the partners involved in HeadSmart, has been reviewing the evidence and whilst many symptoms remain the same, one or two have been added or revised.

In the under five age category 'increasing head circumference' has been added and across all age categories, given the number of children being diagnosed via their optician, 'suspected loss of vision' has been added to one of the existing visual symptoms.

You may have also noticed that HeadSmart has a new look. This is to ensure that the campaign reaches all of its target audiences and in particular stands out to teenagers who on average take longer to be diagnosed than babies and children.

If, like us, you're passionate about raising awareness of the signs and symptoms of childhood brain tumours, visit headsmart.org.uk. You can also find us on Facebook and Twitter.

 **@HeadSmartCampaign**

 **@HeadSmartUK**

Find out more about Sam and all the signs and symptoms at headsmart.org.uk

Education resources



For children and young people diagnosed with a brain tumour, going back to nursery, school or college can come with its own set of challenges – our education resources can help.

Our report *Losing My Place: The Reality of Childhood with a Brain Tumour* found that nearly two thirds of those whose education has been affected needed extra help and support.

Our new set of education resources will help in the process of settling the child or young person back into nursery, school or college. The resources are designed to help parents and education professionals work together and better understand how side-effects and treatments of brain tumours can impact on education and school life.

The resources, which range from pupil support strategies to staff training documents, will help to reassure the child or young person that they will be understood when they return to the classroom, and will equip schools and colleges with the information they need to better support them.

To download the education resources visit thebraintumourcharity.org/education-resources



We're delighted to announce we've been awarded a grant of £114,224 over three years to fund our vital Children and Families Service.

Thanks to the support of BBC Children in Need we will be able to offer more Family Days, giving families the opportunity to connect with others and enjoy a fun day out together away from the hospital. Sadly, 84% of children and young people feel lonely because of their brain tumour [*Losing My Place: The Reality of Childhood with a Brain Tumour*]. These days are essential – it's where important friendships are made and for many, this is their first opportunity to share their experience with others and the strength they draw from this is invaluable.

BBC Children in Need's support will also be used to fund our Children and Families Workers who provide one-to-one emotional support to families, give information about treatments to children and young people in a way they can understand, and support our brilliant and passionate Young Ambassadors who are an integral part of The Charity.

Our Children and Families Services is also generously funded by St James's Place Foundation.



ST. JAMES'S PLACE
FOUNDATION

Inspired by
Alex Bolt

The role of a paediatric clinical nurse specialist

Sarah Holloway is a Senior Clinical Nurse Specialist (Neuro-oncology) working with children living with a brain tumour, and their families, at Birmingham Children's Hospital. Clinical nurse specialists work with families at all points in their brain tumour journey, from diagnosis onwards.

"My role is extremely varied – I have a large caseload of families so I react to their needs which change rapidly. I offer support over the phone, visit their homes, help families with applications for grants or benefits and explain diagnosis and treatment plans.

"Visiting patients' schools is also a big part of my role. I feel strongly that children should have access to the full range of educational opportunities available to them and not be held back by their diagnosis. I advise teachers about the effects of the tumour and treatment on learning, and ensure that all appropriate services – specialist teachers, physio etc. – are available. Hearing from patients who have done really well in their exams makes all the school visits so worthwhile.

"I often signpost families to organisations like The Brain Tumour Charity for information and additional support. When a child is diagnosed with a brain tumour we contact The Charity to get a Brainy Bag – the children really enjoy receiving the gifts and parents appreciate being made aware of support services like the Benefits Clinic.



"I love getting to know families; it's really rewarding and inspiring to see children and families find their way through their diagnosis and the challenges that brings. Often it's the small things that can make all the difference to them. I remember a young boy who was very poorly and all he wanted was to see his dog again. Sorting this for him and watching him cuddle his dog was such a special moment and one I'll never forget."

Our Support and Information Team can put you in touch with your local clinical nurse specialists:



0808 800 0004



support@
[thebraintumourcharity.org](mailto:support@thebraintumourcharity.org)

Training for nurses

Our annual event for nurses and allied health professionals working with adults living with a brain tumour is on Friday 19 May. Registration will open in January and attendance can contribute towards your CPD. For more information visit thebraintumourcharity.org/healthcare-professionals

Supporter Groups

Supporter Groups are a wonderful way to bring together friends, family and colleagues to fundraise in memory of, or inspired by, a loved one. Each group is committed to fundraising on an ongoing basis and is supported by a dedicated team every step of the way.

Welcome to our new Supporter Groups:

The Dawn Wardlow Fund
The Bethany Alders Fund
The Ed Jones Fund
The Shaun Knapton Fund



Supporter Group focus: The Michael Barry Fund

Michael lived in Newcastle-under-Lyme, Staffordshire with his wife Lucy. He had a wide and eclectic taste in music which he loved to share.

Michael and Lucy were a week away from buying their first house together when, in January 2014, he was rushed to hospital after having a seizure. Following a scan they were given the devastating news that Michael had a brain tumour.

Despite undergoing several treatments, in January 2016 Michael was told that the brain tumour had returned and he was given weeks to live. He died at home shortly after his 35th birthday.



Lucy said: “Michael faced each new treatment with a spring in his step, refusing to let his illness define him or to believe any reality other than he would get better and live out our dreams together. To watch Michael face each day with such positivity and strength of character and then be told there was nothing more we could do to save him was simply devastating.”

Following Michael’s death, Lucy began to read more about brain tumours and survival statistics and was horrified to see how underfunded research into brain tumours is.

“I read so many stories of other families devastated by the loss of their loved ones who had set up supporter groups to keep their memory alive and to keep fighting, and suddenly I felt less alone.”

Lucy set up The Michael Barry Fund and has raised over £16,000 in just under a year. Fundraising activities have included

gigs, open garden days and Lucy has also developed a range of crafty products inspired by Michael’s positive outlook.

Most recently The Michael Barry fund has been nominated by Lucy’s previous employer as their charity of the year.

“I was absolutely thrilled to find out we had been chosen. This is a fantastic opportunity to work in partnership with Macfarlanes law firm and it means a lot to me.

“I want there to be a future where no more lives are lost to this cruel disease and I am committed to fundraising in the hope that there might one day be a cure.”

Thank you to all of our supporter groups and amazing fundraisers, it’s through your efforts that we can continue to improve the lives of those affected.

For information on how you can set up a Supporter Group, visit thebraintumourcharity.org/supportergroups

Partnerships



As our Charity of the Year partnership with Lockton Companies LLP draws to an end, we would like to say a big thank you to everyone for taking on a variety of challenges and fundraising events to help defeat brain tumours.

With an ambitious target of £100,000, Lockton Associates across 12 branches held bake sales and quizzes, abseiled down buildings, jumped out of planes and cycled from London to Brighton. Thank you Lockton!

MACFARLANES

A big thank you to Macfarlanes LLP who are supporting one of our amazing Supporter Groups, The Michael Barry Fund, as its Charity of the Year 2016/17. A team from the law firm have already taken part in the Royal Parks Half Marathon and there are comedy nights, raffles and much more planned.

LONDON[®] & PARTNERS

Following a staff vote, we were delighted to be chosen as London & Partners inaugural charity partner alongside Pancreatic Cancer UK. The promotional company have already held a Halloween themed event and we can't wait to see what's next!

JAMES GRIFFIN SALES & LETTINGS

We're thrilled to announce James Griffin Sales and Lettings as a local business partner. The James Griffin Sales and Lettings team have supported us at The Twilight Walk in Windsor last October, and their directors, James and Ron, have signed up to our Iceland Trek in 2017 – thank you and good luck.

To find out more about how your company can support us, visit thebraintumourcharity.org/how-your-company-can-help

Having a lasting impact

Leaving a gift in your Will is an amazing opportunity to remember a loved one and give to an area of work which really matters to you.

If the time comes when you are writing or updating your Will, please remember The Brain Tumour Charity. Just 1% of your Will, after loved ones have been looked after, can have an impact for generations to come. To write your Will you can request an obligation-free home visit from The Goodwill Partnership by visiting thegoodwillpartnership.co.uk/thebraintumourcharity;

contacting The Law Society at solicitors.lawsociety.org.uk or calling us on 01252 237804 to find a local solicitor.

Including a gift in your Will is simple and can make the world of difference to those affected by a brain tumour.

Did you know

You can also leave a gift in your Will to one of our Supporter Groups. To find out more go to thebraintumourcharity.org/dedicating-your-gift

"When someone you care about dies, I think one of the hardest things to get your head around is the fact they no longer have any kind of impression in the world. Dave's brain tumour deprived him of many years of life, laughter and achievement, and so it's very important to me that some good had to come out of the situation.

"In my view, leaving a legacy in your Will in that person's name, after your family have been looked after, is a small act of kindness that shows we care. It has enabled me to feel that somehow Dave's life continues to have an impact and a purpose."

Gill lost her husband Dave to a GBM in March 2012.



Stamping out brain tumours

In October, over 1,800 of the brain tumour community united at The Twilight Walk to make the walks in Warwick, Chester and Windsor, the largest to date.

The three walks, which have raised an incredible £275k so far, saw the entire community – people who have been affected by a brain tumour, their loved ones, supporters, volunteers, healthcare professionals and researchers – walk shoulder to shoulder, united in their battle to stamp out brain tumours for good.

Thank you to everyone who took part and helped to raise awareness of brain tumours.

Already can't wait for The Twilight Walk 2017? Keep an eye out for the next *The Grey Matters* for more details.

The
**TWILIGHT
WALK**





Deb's story

When Deb's son, Chris, completed The Twilight Walk in Warwick in 2014 despite being in a wheelchair, she knew that her family would return each year to help stamp out brain tumours.

Sadly, just two months later, Chris passed away. Chris was initially diagnosed with a benign brain tumour when he was nine. After two operations and a six-week course of chemotherapy, he was told the tumour

had shrunk. 19 years later Chris was again diagnosed with a brain tumour, but this time it was a malignant glioma.

Last year Deb and her family walked The Twilight Walk in Warwick as part of their fundraising efforts for The Chris Thomson Fund. She said: "If Chris was still here he'd be doing it, so we're taking over for him."

This year, Deb decided to not only walk in Warwick, but to join the walks in Chester and Windsor too!

Although the highlight for Deb was walking through the castle at Warwick, she loved all three walks: "Taking part in Warwick, Chester and Windsor really was inspiring. It felt like Chris was with me, which at times was tough, but everyone talks to you and helps to get you through.

"It's a lovely atmosphere – if I could do The Twilight Walk each week I would! I'm already planning on getting a group together next year."

The Twilight Walk series made a big stamp on social media...



**212,000
PEOPLE
REACHED ON
FACEBOOK**



**138,000
APPEARANCES
ON TWITTER
FEEDS**



**1,700
LIKES ON
INSTAGRAM
POSTS**



Sara's story

Dr Sara Saigol joined us at The Twilight Walk in Chester and gave a moving and inspiring speech ahead of the walkers setting off: "Everyone today is walking with us, if you are not here with us, you are walking in our hearts. We will find a cure!"

Sara has vowed to do the walk each year to honour her brother who passed away from a brain tumour last January.

"He was really pleased that I went on the walk in 2015 and I would like to try to keep this up as a family tradition.

"Last year I walked with hope, this year I walked in memory. For all of us, we are not walking alone."



The Twilight Walk has been an amazing event to be a part of. Tonight's atmosphere is simply magical and the fantastic vibe has blown me away. Whether you are a volunteer, a member of staff, or you turned up to walk, it is truly an all-encompassing and inspiring experience which I would recommend to anyone.

Mark joined us as a volunteer at The Twilight Walk in Warwick

Regular gifts make an ongoing difference

As we start the new year, we want to thank everyone who supports us through a regular donation.

Regular donations are extremely important to us, helping to make a big difference every day and to plan ahead with confidence. You can support us in this way from just £2 a month, visit thebraintumourcharity.org/donate

Together, as part of **#TheBrainyBunch**, we will defeat brain tumours.

"I lost a loved one to a brain tumour last year and wanted to make a difference. I know that one of the best ways for charities to plan ahead and be effective is through regular giving from individuals like you and me. Setting up a direct debit takes two minutes but its impact will be felt for generations to come."

Anne Biggs, regular giver

Put a spring in your step...

...at the Virgin Money London Marathon 2017. Did you or someone you know get a ballot place? Fundraise for us and help double survival and halve the harm that brain tumours have on quality of life.



Brain Tumour Awareness Month

On 3 March, help us kick start Brain Tumour Awareness Month by joining thousands of people who will #WearItOut to defeat brain tumours. Our united community will come together to raise awareness and funds for research into brain tumours – all whilst wearing a bandana!

Whether you get your friends, family, colleagues or school involved, there are lots of ways you can raise money and have fun doing it. To order your Bandana Pack for ideas on how to #WearItOut and host the perfect bandana fundraising event, visit thebraintumourcharity.org/wearitout

Raising £150,000 this Brain Tumour Awareness Month could fund 600 days of vital research into brain tumours, so get creative with your bandana fundraising ideas and however you wear yours on 3 March, #WearItOut! Together we can make a difference to the lives of those affected by a brain tumour.

#WearItOut



Make it

Unlock your creative talent and design your own bandana masterpiece! We've included a stencil in your Bandana Pack to get creative and design your own bandana masterpiece!

Wear It Out



Use it

Look in the back of your wardrobe and wear a bandana that you already have!

or



Buy it

Buy one of our charity bandanas
thebraintumourcharity.org/shop

or

To find out more visit...

Text **Wear03 £5** to
70070 to donate £5

thebraintumourcharity.org/wearitout



300 mile cycle

A big thank you to dad of five, Rob Ward, and his 31-strong team, who took on the 300-mile London to Paris cycle challenge in September raising over £138,000.

Rob was joined on his cycle challenge by members of his family including his wife, brother and two brothers-in-law. Rob's friend Bod Buckby, who has undergone three surgeries for a brain tumour, took part along with Ian Pudney, whose son Charlie was diagnosed in 2015 aged seven with a grade three anaplastic ependymoma.

Rob said: "Back in January 2014, I received the devastating diagnosis of a brain tumour. Successful surgery followed, but the impact is far reaching for me and my family – as it is for countless others.

"The cycle challenge united so many people personally affected by this terrible disease and gave a huge awareness boost to the work The Brain Tumour Charity are doing towards finding a cure."

Congratulations to Rob and a big thank you to all of our fantastic fundraisers who are an inspiration. It's through your efforts that we can continue to improve life today for everyone affected.





A time for giving

The lead up to Christmas is always a busy time for The Charity and this year was no different. Thousands of orders for cards, decorations, gifts and wrapping paper flooded in raising an incredible amount of money which will help to double survival and halve the harm that brain tumours have on quality of life.

To ensure orders were picked, packed and posted in time for Christmas, volunteers from our corporate supporters gave up their time to help alongside our fantastic office volunteers. James Griffin, Barclays, AON, Cisco and Specsavers gave a combined total of over 65 hours' worth of donated time all whilst wearing their festive jumpers! Thank you – we couldn't have done it without you all.



"It has been a great pleasure to assist such a worthwhile charity. We all had such a good time getting into the Christmas spirit – thank you!"

AON volunteers

Thank you to The Brainy Bunch

We're forever inspired by your dedication, effort and passion to raise funds and awareness for us. Every event you hold and challenge you take part in is making a huge difference – thank you.

Join #TheBrainyBunch today: 01252 749043 / fundraising@thebraintumourcharity.org or visit thebraintumourcharity.org/get-involved



Inspired by Alan Igglesden, former England cricketer who is living with a brain tumour, his brother Kevin and girlfriend Jenny organised a fantastic golf day. The amazing event has raised £184,000 over the last 12 years! Pictured above is Kevin Igglesden (left) with Neil Dickson (middle) and brother, Alan Igglesden (right).



Abigail Piper cut her hair in support of Dad, Stuart, who has a brain tumour, raising a fantastic £5,750.



Sam Batchelor raised £25,000 at her ball in Sutton Coldfield in memory of her husband Jason, who passed away in Oct 2015.



Major Family Law in Newcastle held their second #brainyrounders tournament. The law firm, led by Joanne Major, have now raised £13,650.



Natasha Randall and Anna Stickland cycled from London to Paris raising £1,470 for The Travis Moore Fund. Anna and Natasha cycled without support, using their own planned route in memory of their brother Travis.



The Lappage family tragically lost Daren just two days before their charity golf day. Despite this, they found the strength to go ahead with the day raising over £17,000 and walked The Twilight Walk just a few days later.



Kathy and Nick Allso raised £3,000 on a 22 mile night hike from Derriford to Widecombe. The route was one they often took to visit their father, Michael, whilst he was in hospital.



Geoff Burgess and team undertook a gruelling 320 mile bike ride raising more than £3,000 in memory of Tom and Harry.



Charlotte Stanton held a golf day to remember her husband Charles, on what would have been his 38th birthday. They played 38 holes to mark the occasion bringing the total raised for us to £14,000.



James Harwood, who had surgery to remove a brain tumour, walked the Inca Trail as well as doing a 210 mile cycle challenge along with colleagues from Parker Design. Their combined efforts have raised £13,000 so far!



Donna Sanderson and her brother Scott ran The Yorkshire Half Marathon raising over £11,000 for The Ali's Angels Fund.



The Ann Jackson Fund held a plant sale in memory of Ann who always loved gardening and raised £350.

Thank you for all you do.

Together we can defeat brain tumours.

We rely 100% on voluntary donations, including gifts in Wills. If you know someone who would like to support our work why not give them your copy of this newsletter so that they can see the difference we make.

Or they can make a donation online:
thebraintumourcharity.org/donate

If you would like more copies please contact us:

enquiries@thebraintumourcharity.org
01252 749990

For queries about making a donation:

donations@thebraintumourcharity.org
01252 749043

Please return your donations to:

The Brain Tumour Charity
Hartshead House
61-65 Victoria Road
Farnborough
Hampshire GU14 7PA



Research | Awareness | Support

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Find us here too



We rely 100% on voluntary donations

Please complete your details for any donation you'd like to make

Name: _____

Address: _____

Postcode: _____

Email: _____

Phone: _____

Signature: _____ Date: _____

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Make your donation worth 25% more!

☐ I confirm that I'm a UK tax payer and want to Gift Aid my donation and any other donations I have made in the past four years or make in the future to The Brain Tumour Charity. I'm aware that The Charity will reclaim 25p of tax on every £1 that I give and understand that I must pay more Income tax and/or Capital Gains Tax for that tax year than the amount of Gift Aid claimed on all my donations, I know it's my responsibility to pay any difference. If my circumstances change, I will notify The Brain Tumour Charity.

☐ **I am interested in leaving a gift in my Will - please get in touch with me**

Yes, I pledge to help change lives by becoming a regular giver

Please pay The Brain Tumour Charity the sum of:

☐ £25 ☐ £10 ☐ £5 ☐ Other £ _____

☐ per month ☐ per quarter ☐ per year

Account name: _____

Account no. _____ Sort Code: _____

Bank name: _____

Bank address: _____

Postcode: _____

Start date for payments: ____/____/____

Signature: _____ Date: _____

For bank use only to The Brain Tumour Charity, Lloyd's Bank. Account No: 50290568, Sort Code 30-93-74

Complete this form and post it to:

The Brain Tumour Charity, Hartshead House, 61-65 Victoria Road, Farnborough, Hampshire GU14 7PA

Yes, I pledge to help change lives by making a single donation

☐ £250 ☐ £100 ☐ £50 ☐ £25 ☐ Other £ _____

☐ I wish to donate by cheque

(made payable to **The Brain Tumour Charity**)

☐ I wish to donate by credit/debit card

Card type: ☐ Visa ☐ Mastercard ☐ Maestro

☐ Visa Debit ☐ CAF

Card number: _____

Start date: ____/____ Exp date: ____/____

Issue no: _____

We record your details on our secure database to keep you up-to-date with our work. We never sell or swap your details with any third parties for commercial purposes. You can opt out at any time: thebraintumourcharity.org/privacy-policy.

*see terms and conditions at thebraintumourcharity.org/waystodonate

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