

The Brain Tumour Charity shining a light on

The GREY MATTERS

The **BRAIN
TUMOUR
CHARITY**

Research | Awareness | Support

Issue 11 Spring 2016



#WearItOut for Bandanas
for Brain Tumours Day 2016

Peer review process explained

Thank you for walking with us!

thebraintumourcharity.org

Visit our new website

We're excited to announce the launch of our new website, developed with insights from our supporters.

Our pages on understanding brain tumours, symptoms and treatments have all been made easier to read, print and share via social media. We've also developed the jargon buster that featured on our previous site into a fully interactive tool, offering extra details on longer medical terms so that everything is easier to understand.

Our aim is to ensure that everyone using our website can find what they need – whether you're looking for support and information after diagnosis or want to get involved with campaigning and fundraising.

thebraintumourcharity.org

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*Over 9,600 people are
diagnosed with a primary
brain tumour every year.
We remember all those
who have lost their life
to a brain tumour and
those who have lost
family and friends.*

Pictured on the front: Louis (aged eight on the far left) and his family will #WearItOut with strength following his diagnosis of a brain tumour in 2015.



Image: Jose with members of the Romford Support Group at The Twilight Walk 2015 in Windsor. Tricia is fifth from the left and Kim fourth from the right.

Hello

Welcome to *The Grey Matters*, packed full of news from The Charity, updates on research developments, and your inspirational stories and accomplishments.

We're both neuro-oncologist nurses at Queens Hospital Romford and have been working with people with brain tumours for over 14 years between us. Because of our strong ties with the brain tumour community, we joined The Twilight Walk in Windsor last autumn which we walked alongside our families and one of our patients, Jose (centre in picture above). Jose chose to push, rather than sit in, his wheelchair the whole 10km and we were particularly proud to re-live his story when reading it on page 16.

The Twilight Walk was one of the most humbling things we've done. To meet so many courageous people wanting

to share a common unity when facing adversity made us feel really proud to do the job we do. We were pleased to read of all the research updates (page 4) and to hear about the support and information provided to those who are affected (pages 18 and 20) in this issue, and to know that all the money raised by those who joined us on The Twilight Walk is in safe hands.

We can't wait to be united with the brain tumour community once again for Bandanas for Brain Tumours Day on 4 March (page 28). This is an event we take part in every year, along with many of our patients, and we'll #WearItOut with love for all those who we support this year.

We look forward to standing shoulder to shoulder with you once again.

Kim and Tricia
Neuro-Oncologist Nurses,
Queens Hospital Romford

Research updates

Thanks to your support, we can invest in forward-thinking, patient-focused research. Here are some of the latest developments from our labs:

Newcastle University

Professor Steve Clifford's lab has been investigating the genetic defects that are present in group three medulloblastoma. It has been found that a gene called VAV1 is overactive in 70% of people in this group but when it is switched off there is a reduction in tumour growth. This discovery provides a new target for drugs that may be able to reduce activity of the gene.



University of Leeds Centre for Translational Neuro-oncology

Professor Susan Short and her team have started investigating whether a harmless virus can be used to target and destroy cancer cells. In initial studies, nine glioma patients were injected with the virus and in eight of these patients, the virus was shown to have successfully reached the brain tumour. This is an important discovery, as many drugs can't pass through the protective barrier that surrounds the brain.





University of Glasgow

Professor Anthony Chalmers' lab has begun to investigate the invasive properties of glioblastoma cells and develop new methods to detect and treat the disease. They are working in collaboration with the Beatson Drug Discovery Unit to test a new drug that blocks the activity of a protein found in glioblastoma cells. If successful it would mean that the tumour cells couldn't invade the surrounding healthy brain tissue.



University of Cambridge

Dr Colin Watts and his team have been studying glioblastoma samples and have proposed that tumours are comprised of three different regions. The team have utilised fluorescent dyes which 'light up' the different regions of the tumour and have collected samples from each, allowing them to determine their genetic make-up and response to drugs.



UCL Institute of Child Health, London

Dr David Michod has been investigating the role of the protein DAXX in childhood glioma. The lab at UCL has studied three different types of glioma and discovered that abnormally high levels of modified DAXX occur in glioma samples. These changes to DAXX could give researchers a better understanding of the disease, resulting in a more accurate tumour diagnosis and the development of drugs to target DAXX.

Where we've been...

Glioma Conference

Every year we sponsor the Glioma Conference in London which brings together leading researchers and clinicians to discuss the progress being made in understanding the causes of glioma and the development of treatments available.

At the latest meeting, talks were given on choroid plexus carcinoma – a rare but aggressive type of childhood brain tumour – and a new research project helping improve our understanding of brain development. Glioma Conference is co-hosted by Professor Paolo Salomoni from the Samantha Dickson Brain Cancer Unit, UCL.

The NCRI Cancer Conference

Last November, during the National Cancer Research Institute (NCRI) Cancer Conference in Liverpool, we had the opportunity to meet researchers, hear about the latest research developments, share ideas and develop alliances with others in the cancer community.

We hosted an event for neuro-oncologists, neuro surgeons and scientists working in the field of brain tumour research, allowing us to promote our funding calls and further encourage collaboration across the field.

The Society for Neuro-Oncology Conference

At the Society for Neuro-Oncology (SNO) Conference in the USA last November, we heard about the industry's newest research findings and hosted a discussion on low grade gliomas. With those in attendance working in the brain tumour research field, we were able to delve, in depth, into the problems they face and what is needed to accelerate research in the area. We will be using this feedback when further implementing our *A Cure Can't Wait* research strategy, which can be read at thebraintumourcharity.org/a-cure-cant-wait

Where we're going...

Keep an eye out in the next *The Grey Matters* to hear about our upcoming conferences in Liverpool; the International Symposium of Paediatric Neuro-oncology (ISPNO) from 12 – 15 June and the National Paediatric Information Day (NPID) on Saturday 11 June. To register for the Information Day, visit thebraintumourcharity.org/NPID

Q&A with Richard Gilbertson

We caught up with Professor Richard Gilbertson, our new Chair of GRAM (Grant Review and Monitoring committee), who recently joined the Cancer Centre at the University of Cambridge from St Jude Children's Research Hospital in the US.



What attracted you to the Cambridge Cancer Centre?

Having worked for 15 years in the US and served on many external advisory boards, Cambridge is the most impressive scientific environment I have encountered. I really feel that anything is possible here and we will make a difference for patients.

What was the highlight of your career at St Jude's Children's Research Hospital?

I served as the Director of the National Cancer Institute (NCI) Comprehensive Cancer Centre at St. Jude. In 2013 we were re-designated as an NCI Comprehensive Cancer Centre with a score of 'Exceptional' - the highest score awarded by the NCI.

Please could you tell us about your role at the Cambridge Centre.

I serve as Li Ka Shing Chair of Oncology, Head of the Department of Oncology and Director of the Cancer Centre. I'm working with the faculty to develop a new strategy that leverages all the great science and clinical care ongoing in Cambridge. My own lab studies the origins of cancer, particularly children's brain tumours, and is seeking to develop new treatments.

What plans do you have for shaping the Cambridge Cancer Centre?

We have generated a new 12 program structure that engages over 600 doctors and scientists and spans all the hospitals, institutes and departments in Cambridge. The structure also engages our new research partners in the pharmaceutical industry, and in physics, chemistry, engineering, maths and astrophysics. These great minds are now working together to defeat cancer and are defining a roadmap for cancer science in Cambridge for the next five years.

How does the next five to ten years of brain tumour research look to you?

There are four key areas where we should see developments; repurposing (where we take drugs used for other cancers or diseases and use them to treat brain tumours), developing targeted treatments, immunotherapy (which uses the body's immune system to fight cancer), and targeting the healthy cells and tissues that surround and support the tumour.

To read more about what Professor Richard Gilbertson had to say, visit thebraintumourcharity.org/richardgilbertson

Peer review process

We fund research through a fair, open and transparent process called peer review, recognised as best practice in awarding research grants. We're proud members of the Association of Medical Research Charities (AMRC), which governs this process. We're confident we fund only the best research that has the greatest chance of success to improve diagnosis and treatments of brain tumours.

We're delighted to have passed our peer review audit for 2015. Of our submission, the AMRC commented: "This was a very clear and well written audit response. The committee agreed that the information and links were very helpful and that the peer review process was robust."

amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

- 1 This is an invitation to all researchers to apply for funding. It outlines the type of research required and specifies the amount of funding available over a specific time frame.

THE CALL

- 4 Following external peer review, all applications, review forms and responses are sent to the GRAM committee who make a recommendation on whether to fund the project or not. The GRAM panel is an international team of independent scientific and medical experts and patient representatives who see applications, giving them a comprehensive view of all proposals. They make recommendations on who to fund.

GRAM

- 5 The Research Sub-Committee meet to discuss the GRAM committee's recommendations. The Research Sub-Committee is made up of members of The Board of Trustees – both lay members and those with a scientific background.

RESEARCH SUB-COMMITTEE

- 2 The applicants have several months to complete their application which includes in-depth scientific details of the proposal, the applicants' CVs, the rationale behind their ideas, what they hope to achieve, how it will benefit those affected by a brain tumour and any ethical issues that need to be addressed.

APPLICATIONS RECEIVED

- 3 All applications that have been submitted are peer reviewed by external experts in the same field. Our Research Team source these peer reviewers by looking for research scientists who work in a similar field, but do not have a conflict of interest. Applicants are then given the opportunity to respond to any comments.

PEER REVIEWED

- 6 The full Board of Trustees have the final say and decide whether or not to award the grant.

BOARD OF TRUSTEES

Our current GRAM committee members:

Chair: Professor Richard Gilbertson

Dr Antony Michalski,
Great Ormond Street
Hospital for Children

Dr Simone Niclou, Public
Research Centre for
Health, Luxembourg

Professor Susan Short,
University of Leeds

Professor Martin
Taphoorn, VU University
Medical Center
Amsterdam,
The Netherlands

Professor Chris Twelves,
St James's Hospital, Leeds

Professor Martin van den
Bent, Erasmus University
Hospital, Rotterdam,
The Netherlands

Dr Ian Waddell,
University of Manchester

Mr Peter Moreton,
Lay representative

Mrs Karen Ackling,
Lay representative

#WearItOut

for Bandanas for Brain Tumours Day every March, it's always great fun. I'll #WearItOut with style this year!

What are your top tips for those looking to raise more funds for research?

Aside from the usual fundraising efforts, a great way to make a long-term commitment is to remember The Charity in your Will. A lot of people think you have to leave a large amount but this isn't true. As little as 1% of your Will, after your loved ones have been looked after, could make a world of difference to people like me who rely on research breakthroughs as it's the little things in life that can mean the most!

What are the little things in life that mean the most to you?

Experiencing the seasons changing
and treasuring moments such as laughing
so much it hurts!

**For more information on leaving
a gift in your Will, visit
thebraintumourcharity.org/gift-in-will**

Off-patent Drugs Bill blocked at House of Commons

The Off-patent Drugs Bill was blocked at its second reading in the House of Commons in November despite support from MPs of both parties, health organisations and a number of charities including us.

The intention behind the Bill was to improve access to off-patent drugs. This is a problem across many disease areas – by the time a secondary use for a drug has been found (it has been ‘repurposed’), its patent has often expired meaning that there is no financial incentive for a pharmaceutical company to seek a new licence for it. Patients aren’t therefore able to get easy access to drugs that have been proven to treat their illness.

As part of our strategy to double survival and halve the harm that brain tumours have on the quality of life, we are working to ensure everyone has the same access to high quality treatment. The Bill would have helped address a barrier to treatment, putting the responsibility on the Government to seek licences for off-patent drugs. Supporting access to cost-effective and readily available treatments in this way would impact across many other disease areas too, including breast cancer, Parkinson’s disease and Alzheimer’s.

Following the blocking of the Bill, the Government has committed to meet with organisations and see if there are non-legislative means of achieving the aims of this Bill. We will continue to advocate for better access to repurposed drugs for people with a brain tumour and to build on the momentum and awareness of this campaign.

We’d like to thank all of our supporters and their MPs who backed the Bill.



Utilising existing drugs for treatment of brain tumours

We fund Professor Salomoni at UCL, who has found that hydroxychloroquine, a drug licensed to treat malaria, could have the potential to control the migration and invasion of cancer stem cells. If it is proved successful in the treatment of brain tumours, we will be relying on the Government’s support to seek a licence for this use, so that the people who need it most can have access to it.

Children and families survey

We've heard that those affected by a brain tumour, regardless of the grade, can have poor experiences of healthcare and often live with far reaching and life altering side effects of both the tumour and the treatment. Because national surveys, such as the National Cancer Patient Experience Survey, only consider adults with a high grade tumour however, we don't have the qualitative evidence we need to back this up and act upon it.

It's for this reason that last year we launched our *Losing Myself: The Reality of Life with a Brain Tumour* report, the most comprehensive study of its kind globally, focusing on what life is really like for adults living with a brain tumour in the UK.

We're now working to widen our understanding of what life is like for children and young people living with this disease. We also want to find out how a brain tumour diagnosis and its long-term effects can impact on their families.

To gather this information, we launched a comprehensive survey last November which was completed by children, young adults and family members who provided us with an in-depth insight into how living with a brain tumour or with someone who has a brain tumour has affected their day-to-day life.

A full report of our findings will be available from June 2016. As we have done with the *Losing Myself* report, we will use the findings from the children, young people and families report to educate healthcare professionals, influence policy makers and to tailor our services to improve the lives of those affected every day.



***Losing Myself* and its companion report for policy makers *Finding Myself in your Hands*, can both be viewed at thebraintumourcharity.org/losing-myself**

Driving change through policy

The interim report of the Accelerated Access Review, a UK Government review looking at ways to speed up patient access to new drugs, was published last October.

Along with other charities and industry groups, we have been contributing to the review by providing feedback about the barriers that exist to accessing new medicines.

The interim report outlines five themes that have arisen from the initial consultation process and how they may work in practice. Of these, we particularly welcome the report's intent to move towards a system of 'managed access' for promising new medicines, meaning that drugs lacking the evidence base to be funded by the NHS would be made available to patients for a fixed period of time, whilst more evidence is collected. Additionally, the review commits to building on existing initiatives like the Adaptive Pathways Pilot, which explores how to improve access to medicines for disease areas where there is unmet need and a lack of available treatment options.

Ahead of the final report this April, we will continue to engage with the Accelerated Access Review as it develops its proposals for speeding up access to new medicines and technologies.

Getting our voices heard

On 9 December we hosted the All Party Parliamentary Group (APPG) on brain tumours at the Houses of Parliament. Supporters, their MPs and clinicians attended to hear a talk from Emma Greenwood, a member of the secretariat of the Independent Cancer Taskforce, on the new five year English cancer strategy. We also heard from Dr Ahmadur Rahman, a clinical oncologist, who spoke about the importance of capturing patient experience and the challenges of setting up research. Ambassadors April Watkins and Gala Rowley reflected on their own experiences and hopes for what the strategy might achieve.

The APPG meetings are a great opportunity for us and our supporters to get their voices heard by key decision makers in Government and the NHS. If you'd like to register to attend our next APPG, visit thebraintumourcharity.org/campaign-with-us

HeadSmart news



Maisy's story

Optometrist Martin Baker recognised the signs of a brain tumour when Maisy, aged nine, came in for a routine eye test with her mother Dawn in April last year. He sent Maisy straight to the emergency eye clinic and within 48 hours, she'd had an operation to remove a very large tumour. Doctors think it could have been growing for over two years.



HeadSmart cards in Welsh

Thanks to your support in helping us spread the word about HeadSmart, we've now been able to translate the symptom cards into Welsh. If you would like Welsh HeadSmart materials for your school, please contact: info@headsmart.org.uk

Maisy had been experiencing headaches and had vomited occasionally, she had been referred to her local ophthalmology department for further tests. If Dawn or her GP had seen a HeadSmart card, her symptoms may have been linked sooner.

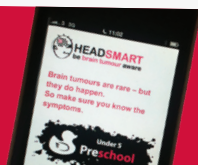
Dawn said, "I didn't know what the symptoms meant. If someone had told me about the implications of them, perhaps it could have been caught earlier. We are just very lucky and can't thank Martin enough."

Sarah Mee, our Head of Policy and Campaigns said, "Maisy's story demonstrates the important role opticians can play in the diagnosis of brain tumours. Early diagnosis can make a significant difference to the type of treatment a child needs and the lasting impact it can have on his or her quality of life."

Maisy is doing well and is back at school and both Martin and Dawn are now championing HeadSmart.

Know the symptoms on-the-go

Text SMART to 81400 for your free mobile symptoms guide.





Amelia, Pride of Britain

"Amelia, we think you are probably the bravest person we have ever met."

Simon Cowell spoke for all of The X Factor judges when he presented our 10-year-old supporter Amelia with a Pride of Britain Award for her fundraising achievements.

Amelia lost her dad Peter to a brain tumour in February 2015. He was diagnosed with the disease in January 2014, shortly after her younger brother Josh was told he had a life-threatening condition called Arteriovenous Malformation – a tangle of blood vessels in his brain which puts him at risk of having a stroke.

Since then, Amelia has raised over £25,000 for charities including us.

Her incredible efforts earned her the award of Lidl Young Fundraiser of the Year at The Mirror's Pride of Britain Awards last October.

Congratulations Amelia – and huge thanks to you and all of our amazing fundraisers.

The next step for HeadSmart

HeadSmart's leading clinician, Professor David Walker, has published an academic paper in *Neuro-Oncology* which details the success of the campaign in its first two years. *Neuro-Oncology* is the leading journal in the brain tumour research field and this will help generate greater awareness of HeadSmart amongst healthcare professionals across the world.

Professor David Walker said, "This strategy, to speed up the diagnosis of brain tumours, by the NHS using an awareness campaign to educate both the public and healthcare professionals is a world-first in paediatric cancer.

"As a result, the campaign is now being emulated internationally and has been acknowledged by a number of NHS and charity awards of excellence."

54% of paediatricians now say they feel more confident about diagnosing brain tumours compared to a previous 32%.

Following the success of HeadSmart, a campaign to reduce diagnosis times for adults is planned. We're funding the research behind this, which will take place at the University of Edinburgh and the University of Cambridge.

My personal Everest

Jose has a grade two brain tumour. Along with his friends, family, nurses and Support Group, he joined us for The Twilight Walk in Windsor where he made the momentous decision to push, rather than sit in, a wheelchair. He completed the whole 10km.

Jose was diagnosed with a brain tumour in February 2009 after an emergency trip to A&E.

“Overnight, mine and my family’s lives were turned upside down. I was told that a tumour was situated on the main artery of the brain but it would be too risky to try and remove it, all that could be done was to monitor the tumour.”

In 2011 the tumour began growing. A biopsy confirmed that Jose had a grade two astrocytoma and he endured six weeks of radiotherapy from which he suffered severe side effects. He is still on medication today to prevent seizures and cluster headaches and finds it hard to walk anything but a short distance.

Jose and his wife, Bridgette, had never attempted The Twilight Walk before but when they found out that his nurses were walking, they made the decision to join them too.

“My wonderful Oncologist nurses Kim and Tricia from Queens Hospital said they were doing the walk with their team and families, so Bridgette and I, along with friends from our Romford Support Group joined them. A wheelchair was arranged for me to sit in and my friend Eddie kindly volunteered to push me. The Romford Support Group is mine and Bridgette’s deepest passion, we have made the greatest friendships there but also recently lost some of them to brain tumours.”

Once at the walk, Jose made the decision to push his wheelchair in memory of the friends that he has lost, and the friends who are still with him on the journey.

“Although there were many times throughout that long night that I thought about giving up, I knew if I did so then it will be easy to give up in the future when the road ahead gets tough. The amazing support, clapping and cheering from the entire team at The Twilight Walk as we stepped over the finish line with the wheelchair was incredible, the spirit and atmosphere was utterly overwhelming and a moment that will stay with me and my group for the rest of our lives.”

Image (bottom right): Jose (on the far right) raising funds for The Brain Tumour Charity.

27

Every day 27 people are diagnosed with a brain tumour in the UK



"People are now asking me what's next. I'm happy to steer clear of any more 10km walks, but Bridgette and I will both #WearItOut with strength this Bandanas for Brain Tumours Day. One step at a time, we are fighting this disease together."



Carers' Facebook Support Group



Our Carers' Facebook Support Group provides a safe online space where people who are supporting and caring for those diagnosed with a brain tumour, and their friends and family, can connect with each other, share experiences and find and give support.



Neil Wilkie is a member of the Carer's Facebook Support Group:

"I've been married to Debbie for two years, 18 months ago she was diagnosed with Percy - a grade four glioblastoma (GBM). Hearing the doctor say the words 'incurable' and '14 months' was a surreal experience.

"Debbie had 'successful' surgery and waved goodbye to Percy. Radiotherapy and chemotherapy followed with difficult side effects.

"Throughout all of this family and friends were great, pulling together, being supportive and fundraising for The Charity. They're already planning to #WearItOut for this year's Bandanas for Brain Tumours Day! Debbie is also a member of The Charity's Facebook Support Group and finds it helpful to have the support of others with a brain tumour.

"I found the postings on the group from those with brain tumours interesting, but I wasn't one of them. I needed somewhere that I could offload my pain and worries, confidentially, in a way that Debbie couldn't see. I needed somewhere I could get help, support and ideas from people that were in a similar position to me.

"The Carers' Facebook Support Group provides me with this and I hope many more benefit from it."

Find out about Facebook Support Groups:
thebraintumourcharity.org/facebookgroups

The Research Involvement Network

The Research Involvement Network offers researchers and people affected by brain tumours the opportunity to collaborate in shaping the future of brain tumour research. Since we launched the Research Involvement Network earlier this year, we have helped bring together

those affected by brain tumours such as Amy McLaughlan, with researchers Stuart Smith and Ruman Rahman. By involving people throughout this research journey we know we can help make research as relevant and effective as possible.

Stuart Smith and Ruman Rahman

Stuart Smith and Ruman Rahman work together at The University of Nottingham. Their latest research proposal to study the genetic characteristics of the most infiltrative glioblastoma cells was put to our Research Involvement Network.

“For such a devastating disease, bringing together a network is a difficult task. The feedback we have received is extremely useful. There is much opportunity for us to refine and focus our research question and description of work on this feedback.”

Stuart and Ruman plan to submit their proposal in January.

“We will continue engagement with this network pre and post future grant awards, the feedback is invaluable.”

Amy McLaughlan

Amy joined the Research Involvement Network in September 2015 after her father sadly passed away from a brain tumour earlier in the year.

“Being involved in the network I feel like I’m able to make some sort of positive contribution – I’m quite good at working out how things may come across to other people so being able to check the lay summaries is a valuable contribution I can make. I also run a Supporter Group called The Small but Mighty Fund and although fundraising is massively rewarding, being able to get a ‘behind the scenes’ look at research is hugely interesting to me. I feel like surely one day, one of these studies that I have made a tiny contribution to, will be the breakthrough we’re all waiting on.”

For further information and to get involved, visit thebraintumourcharity.org/researchinvolvementnetwork

Our information services

Our aim is to produce relevant, useful information that helps improve life today for those affected by a brain tumour, a key part of halving the harm caused by this disease.

Underpinning all of our support services is the information that The Charity provides, which is made possible thanks to your donations. Our Support and Information Team have over 40 fact sheets on offer in addition to a wide range of information on various subjects relating to brain tumours, with more in the pipeline. Last year, our online fact sheets were viewed over 86,000 times.

Nancy Jenkins is a member of our lay panel: "I'm keen to support The Charity, but don't

have abundant free time. Checking fact sheets is something I can do on my lunch break and fit around other things. It also makes use of my nit-picking skills! I'm pretty literate and have an eye for detail so will pick up on grammar aspects or typos, but most importantly I can read the fact sheets from a lay person's point of view. They aim to convey often quite complex information in a comprehensible way without dumbing it down.

"Reading fact sheets has enabled me to learn about many aspects of brain tumours and the work of The Charity which I find really interesting. It's my way of contributing to a cause I believe in, and help improve the lives of those living with this disease."



To make sure that the information we produce is clear, accurate, balanced, evidence-based and up-to-date, all of the material produced by the team is certified by The Information Standard. Our Information Standard process ensures that each piece of information bearing the Information Standard quality mark has undergone a rigorous production process and careful assessment.



The steps to providing information:

1

We identify the need for information on topics such as specific tumour types or getting your affairs in order, from our community of users and research like our *Losing Myself* report.

2

Our Support and Information Team undertake rigorous research, using reliable and credible sources such as academic journals, government websites and expert advice.

3

A draft is written, checked by The Charity Team and then sent out for review by an expert panel. The panel varies depending on the topic but is made up of professionals from a particular field who can confirm that the information provided is accurate, relevant and reliable.

4

A lay panel will then check that the information is clear, easy to understand and accessible to the general public.

5

Once feedback has been collected from both panels and final changes have been made, the information will be critiqued and proof-read once again, before being made available for use.

6

All fact sheets and information can be viewed on our website at thebraintumourcharity.org/understanding-brain-tumours

Information Days with Dr Catherine McBain



Dr Catherine McBain, a consultant clinical oncologist at The Christie in Manchester, joined our Manchester Information Day with her team last year. Information Days allow attendees to hear in-depth presentations from leading experts including neurosurgeons and specialist nurses, and to meet others affected by a brain tumour.

“We’ve had links with The Brain Tumour Charity’s Support and Information Team for many years. Our team are always keen to attend events to inform patients and carers, to share developments in our services and hopefully improvements which will benefit patients, and that’s why we came along to the Manchester Information Day. It was a really great day for all involved, both for healthcare professionals and patients. We find it incredibly worthwhile and it is an initiative we are keen to support.

“My talk on the day centred around clinical trials of potential new brain tumour treatments. My colleagues’ talks focused on both the holistic and medical aspects of brain tumour care. They talked about neurosurgery, coping with treatments and we also had panel discussions with patients about the reality of being in a clinical trial.

“For us, it was very interesting to be able to meet The Brain Tumour Charity Team as well as chat to people who have been affected in an informal setting. It’s always helpful for people not only to be able to chat to us, but also to others who are in a similar situation. Being able to share stories and experiences is hugely important for anyone affected by a brain tumour.

“Patients’ feedback is vital to the successful running of events like this but I hope that these Information Days serve several purposes; to provide factual information about treatment and clinical trials; to introduce patients to information and support services and to meet other patients and staff away from a hospital setting”.

To watch Dr Catherine McBain’s full talk, visit: bit.ly/drcatherinemcbain

For more details on upcoming Information Days visit: thebraintumourcharity.org/infodays

Getting Involved

Charity of the year

Many thanks to Lockton Companies LLP and Avaya who have both recently selected us as their charity of the year partner.



"The partnership means so much to me as I lost my brother to a brain tumour in 2009. A number of my colleagues have also been directly affected by the disease and we are all looking forward to helping defeat brain tumours."

Henry Dyson,
Lockton Companies LLP associate



Engage **The Power of We™**

"I am delighted to hear that Avaya will be supporting The Brain Tumour Charity as they have supported my family so much. We will be holding a netball tournament for Bandanas for Brain Tumours Day – it will be fantastic to get all the staff playing for a great cause"

Steve Wright, Avaya, whose son Luke was diagnosed with a brain tumour after his mum spotted our HeadSmart campaign.

BGC Charity Day

We were also chosen by staff at Martin Brokers to be one of the charities supported by the BGC Charity Day in September 2015, where all the revenue for one day is shared between dozens of charities worldwide. Celebrity ambassadors including Jimmy Carr, Lewis Moody, Samuel L Jackson and John Terry took to the London trading floor to answer calls and did their bit to raise \$12 million globally.

We would like to say a huge thank you to all of our corporate partners for their fantastic support. To get your company involved, please contact our Corporate Team on: 01252 749049



Image: The Ali's Angels Fund at The Twilight Walk in York

Supporter Groups

"The only way to get through grief of losing Ali was to put my mind to fundraising and The Ali's Angels Fund was born. Ali has left behind the most amazing bunch of friends a person could wish to have in their life and whilst I am running the fund, I couldn't do it without their help and support. It is so important that we do this in Ali's memory – to keep his spirit alive by helping others."

The Ali's Angels Fund

Supporter Groups are set up by families and friends in memory of a loved one or inspired by someone living with a brain tumour. We then work together to achieve our goal of doubling survival within 10 years and halving the harm that brain tumours have on quality of life within five years. All of the money the groups raise funds areas of work they have each selected.

Welcome to our new groups:

The Alan Sansom Fund

The Sue Robson Fund

The Ali's Angels Fund

The James Willetts Fund

The Laura Fischer-Beards Fund

The B-Hive Fund

The Alex Bolt Golf Day and Gala Dinner

In its final year the Alex Bolt Golf Day and Gala Dinner at Wentworth in November 2015 was a huge success, raising over £150,000 on the night, bringing the total for all five years to almost £500,000 to be invested into finding new treatments for paediatric brain tumours.

The Wentworth Gala Dinner began as a partnership between The Alex Bolt Fund, ex-England cricket player, Darren Gough and Alex's PE teacher Gareth. The Alex Bolt Fund was set up by Jeannette in memory of her son Alex who sadly passed away from a high grade glioma, age 16 in 2011.

Jeannette said: "Alex was incredibly sporty, fun-loving, kind and generous. He was a good son, we were very proud to be his parents."

Alex and Darren had met after he had been diagnosed, Darren said: "When I spoke to him on the phone, sometimes he was well, sometimes he wasn't so good, but what amazed me about the whole situation was that he was always so positive about it. I don't think there was a negative bone in his body.

"I went from talking to him, to seeing him, to suddenly going to his funeral, that's how quick it was."

It was at Alex's funeral that Darren Gough, Alex's PE teacher Gareth and Alex's Uncle decided that they wanted to do something to help and the first Alex Bolt Golf Day and Gala Dinner at Wentworth took place six months later. In addition to the

Gala Dinner, The Alex Bolt Fund has also conquered Mount Kilimanjaro, held an annual run 'Bolt4Bolt', hosted a number of coffee mornings and pampering evenings, as well as a celebrity cricket match and a 'Bare All for Bolt' calendar.

"To find a cure would be the most amazing thing. For any family to go through what we went through, what our parents went through, if no one else had to suffer it's worth climbing mountains and running distances."

Alex's sister Susie



Image: Jeannette and Peter Bolt at The Alex Bolt Gala Dinner in 2013.



Thank you for walking with us

Last autumn, over 1,400 of the brain tumour community united at The Twilight Walk series, covering an incredible 10,000km in total and raising over £220,000 to date for vital research. From supporters and volunteers to clinical nurse specialists and researchers, we were joined by all of those who have been affected, in one way or another, by this devastating disease.

The walks took place across four different weekends in the beautiful locations of Windsor, Chester, Warwick and York. Along with the walkers' friends and families who came out in support, the weather was also on our side with a record four sunny Sundays in a row!

Walkers set off as the sun went down and took in the sights during their 10km

loop. On returning back to base, they were greeted with medals, refreshments and music from live bands – a true hero's welcome.

Thank you to everyone who walked with us to stamp out brain tumours. If you'd like to do the same and take part in this year's events, keep your eye out for further details in the next edition of *The Grey Matters*.

"We had a great evening - all the volunteers were brilliant. We hope to have raised about £1,500 between us all."

**Debbie joined us for
The Twilight Walk in Windsor.**



The TWILIGHT WALK



"For a group of people to get together like this to raise money is amazing. We're all doing it in memory or for someone we know. There's nothing more inspiring than that."

Heather and Phoebe joined us for The Twilight Walk in York.



"Words cannot express how emotional but inspirational the entire event was and how lifted I felt by everyone else who was there, particularly all the young guys and girls who were there supporting their friends. Everybody was totally committed to doing their bit and to supporting each other."

Alan lost his daughter to a brain tumour in 2003 and joined us for The Twilight Walk in Warwick.



"It was a really special day for me and my family on Sunday. The past year since my surgery has been a real struggle and so to finish the walk was a big achievement. I felt very humbled by reading the bibs of all those who had lost loved ones through the effects of brain tumours."

Kim joined us for The Twilight Walk in Chester.

#WearItOut



**BANDANAS
FOR BRAIN
TUMOURS**

By getting involved in Bandanas for Brain Tumours Day on **Friday 4 March**, part of Brain Tumour Awareness Month, you will be part of our united community and help raise awareness of brain tumours and vital funds for research into early diagnosis.

Together, we raised over £86,000 last year. This year let's make it even bigger and better!





Wear it

Whatever your plans for Friday 4 March, make sure your bandana goes with you. Help raise awareness of brain tumours and **#WearItOut** with style, strength, attitude or love.

Share it



Help us spread the word far and wide by taking a selfie in your bandana and sharing it using the hashtag **#WearItOut** or on our pages: [facebook.com/thebraintumourcharity](https://www.facebook.com/thebraintumourcharity) and [@BrainTumourOrg](https://twitter.com/BrainTumourOrg) on Twitter.

Selfie it



Raise it

It doesn't have to end once you **#WearItOut**. Why not join thousands of other supporters helping us raise even more funds for early diagnosis? **Bake it, swap it, give it up** or look up other ways to fundraise at thebraintumourcharity.org/wearitout



Bake it

Buy your 2016 bandanas for £3.50 each (including postage and packaging) from thebraintumourcharity.org/wearitout or call 01252 749043

Thank you to The Brainy Bunch

We're forever inspired by your dedication, effort and passion to raise funds and awareness for us. Here are just some of your fundraising highlights over the last few months:

Join The Brainy Bunch today: 01252 749043 / fundraising@thebraintumourcharity.org



Co-op employee Jackie Taylor and over 100 of her colleagues ascended the equivalent height of Everest (29,009ft) using their headquarters' 14 floors of stairs. The six hour relay-style ascent involved 158 consecutive climbs of the buildings 336 steps and raised £2,000 for us.

Jackie was inspired by the tragic loss of her husband Ian, "I'm passionate that even the slightest contribution might stop other families dealing with the loss we have had to endure so I'm going balls out to raise awareness in my own way. Even if it means climbing Everest!"



We had some amazing runners join us for the Great Scottish Run including Watson Jones who is 75 years old and ran the 10k in just 47 minutes, and Kali, our youngest runner at just five years old! She raised £461 on her own in support of her Auntie, who is living with a brain tumour.



Sally lost her dad to a brain tumour in May this year. She shaved her head in his memory and to support those who have to lose their hair to treatment.



Scape Group, based in Nottingham, have raised over £24,000 after choosing The Brain Tumour Charity as their charity of the year partner for 2015. They have held a golf day, Bond themed quiz night and Steve Elkin, their Chief Strategy Officer, took part in a 1,000 mile cycle challenge.



250 staff and friends from Newcastle-upon-Tyne law firm Major Family Law, hosted a huge rounders match at The Falcons rugby ground. Inspired by the devastating diagnosis of a brain tumour affecting close family and friends, the firm has now raised £9,000 for vital research, awareness and support.



The Rouleurs Cycle club undertook a gruelling three-day, 500km cycling trip around Ulster in October to raise funds and awareness for us and two other charities. The challenge was inspired by fellow cyclist, Gideon Burrows, who was diagnosed with a low grade inoperable brain tumour in May 2012.



Chris is living with a visual impairment following treatment of his brain tumour. In September 2015, a 12 strong team of friends helped him cycle the Way of The Roses, coast to coast from Morecambe to Bridlington. The group have raised £11,187 to date.



Sarah and her family and friends have been raising funds following the diagnosis of her brother-in-law Wayne. The group have so far taken part in events such as Wolf Run, a Row For It! Relay, Run or Dye, The Twilight Walk series, climbed Kilimanjaro and held a community tea party. They have raised over £6,500 to date.

A total of 48 runners took part in the Ipswich Half Marathon in memory of Ruth Mehmed. They have raised £13,000 for The Brain Tumour Charity.



Independent First in Paisley recently held their Annual Golf Day, raising £5,100 for us. The two Directors Eddie Rainey and Scott Abraham have both lost loved ones to a brain tumour in recent years.



Jamie started fundraising for The Charity last year to mark what would have been his Mum's 50th birthday, he raised an incredible £13,000. Determined to equal if not exceed last year's total, Jamie this year held a charity football tournament and did a 160ft bungee jump and has raised a further £14,223 to date.

During August 2015, Colin cycled solo from Amsterdam to Budapest following the Rhine and Danube rivers, in memory of Cydara Verrier. He has raised over £1,000 to date.

Thank you for all you do.

Together we can defeat brain tumours.

We rely 100% on voluntary donations.
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



Become a regular giver today

Please complete this form and return to:
The Brain Tumour Charity, Hartshead House,
61-65 Victoria Road, Farnborough GU14 7PA

Name: _____

Address: _____

Postcode: _____

Email: _____

Phone: _____

Please pay The Brain Tumour Charity the sum of:

☐ £25 ☐ £10 ☐ £5 ☐ Other £ _____

☐ per month ☐ per quarter ☐ per year

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

giftaid it 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.

If you would like to make a one-off donation or find out how to leave a gift in your Will, visit thebraintumourcharity.org/waystodonate

The **BRAIN
TUMOUR
CHARITY**

Instruction to your Bank or Building Society to pay by Direct Debit



Name and full postal address of your Bank or Building Society

To: The Manager

Bank/building society

Address

Postcode

Name(s) of Account Holder(s)

Branch Sort Code

Bank/Building Society account number

Service user number

6 9 1 2 1 3

Reference

Instruction to your Bank or Building Society

Please pay the Charities Aid Foundation Direct Debits from the account detailed in this Instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this Instruction may remain with the Charities Aid Foundation and, if so, details will be passed electronically to my Bank/Building Society.

Signature(s):

Date: