



Target

Welcome



Brain Tumour Awareness Month in March is a month of celebration, as well as awareness, fundraising and action.

We raised £1.25 million pounds in tough economic times last year. So many of you feel strongly about improving life for people affected by this illness. Thank you for your support.

We're celebrating our 15th anniversary this year. Looking back at how much we've grown, we can honestly say that you have been our biggest inspiration.

Without your drive and vision, we could not imagine Brain Tumour UK forging ahead as we are today. You inspire us and who knows – maybe together we will find the cure for brain tumours we all hope to see.

The research funding you have made possible has increased almost five-fold since 2009. Top scientists say the next 10 years will see exciting new developments.

Meanwhile, we will continue to embrace more people through our support services. We want every person affected by a brain tumour to know that they are not alone.

Together we'll tackle any obstacles in our way. Whether the challenge is to ensure that brain tumour care does not suffer under a reformed NHS or to secure fair government funding for brain tumour research, we know that, with you, we can succeed.

With you beside us – we know the next 15 years will be even better.

Jenny

Jenny Baker OBE
Chief Executive

Patients to have a say in future brain tumour care, says Health Secretary



In the House: Andrew Lansley MP talks about brain tumours

‘No decision without me about me’ will form the basis of brain tumour care under a reformed NHS, says Health Secretary Andrew Lansley MP.

Mr Lansley addressed a packed meeting of the All Party Parliamentary Brain Tumour Group, attended by Brain Tumour UK, at Westminster in January.

Brain Tumour UK supporters, clinicians, patients and carers sought reassurances from Mr Lansley that the proposed new Health Bill will not set back brain tumour care.

Mr Lansley set out his vision for the future of the NHS in relation to brain tumour care and outlined the three pillars of his reforms starting with ‘no decision about me, without me’.

He said shared decision-making processes were already starting to help, for example in prostate cancer.

Pillar two will focus on decisions being made by health professionals, not politicians and will be achieved through new quality guidelines and stronger cancer networks, he said.

Pillar three will focus on how best to deliver improved outcomes.

“It is unacceptable that the UK lags behind comparable nations when it comes to brain tumour outcomes,” said Mr Lansley, adding that a new focus on early diagnosis should lead to improvements.

Brain Tumour UK Chief Executive Jenny Baker said: “We welcome the Health Secretary’s reassurances, in particular the emphasis on shared decision-making and a focus on early diagnosis. We will work closely with Government to ensure the patient’s voice is heard!”

For more information visit
www.braintumourconsortium.org.uk

The Brain Tumour Awareness Month Summit

Save the date – Wednesday 29th February 2012.

Around 200 campaigners, clinicians, researchers, media, interested politicians and patients are set to converge on the Abbey Centre near Westminster for a summit to mark the eve of Brain Tumour Awareness Month and you're invited!

The summit will celebrate the Brain Tumour Consortium's successes over the past year and once again take our key messages to an influential audience. Brain Tumour UK is a member of the Consortium.



The afternoon is designed around sessions to celebrate success, learn lessons and highlight the impact our work is having on front line care. The first session - 'the fight against Brain Tumours: an assessment of progress' will take stock of where the campaign against brain tumours is and whether there is anything we can learn from other campaigns in the sector.

The rest of the day will focus on our success in working towards the three 'asks' in our **Manifesto For Everyone Affected By A Brain Tumour** published in October 2010. Its three areas were 'improving early diagnosis, implementing best practice and increasing research funding' so, 18 months on, Brain Tumour Awareness Month 2012 is a good time to take stock and learn what impact the Manifesto is having by hearing from front line professionals:

Professor David Walker will examine the impact early diagnosis can make to outcomes and provide examples and transferable lessons from the Headsmart Campaign to increase awareness of brain tumour symptoms in young people.

Professor Garth Cruickshank will consider progress and practice towards fully implementing NICE's Improving Outcomes Guidance 2006: what difference it can make and what the impact of the Government's new Health Bill might be. Prof Roy Rampling will present the findings of his much-anticipated review of brain tumour research funding by charities, including progress made towards 7.5% of brain tumour patients being enrolled in randomised trials and the barriers to more research being carried out.

The FREE event runs from 14.30-17.30, followed by a drinks reception.

For further information please visit www.braintumourconsortium.org.uk

Medicine and Me: Brain Tumours

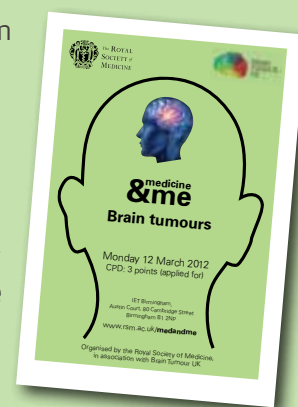
Put your questions about brain tumours to leading experts in a friendly environment at the *Medicine and Me: Brain Tumours* conference.

The meeting on 12 March 2012 in Birmingham is organised by the Royal Society of Medicine in association with Brain Tumour UK.

The role of imaging in brain tumours, epilepsy and brain tumours, the patient's experience, depression and where you can find support, are some of the topics on this year's agenda.

Moira Dennison, Brain Tumour UK's Head of Support Services, says: *Medicine and Me* meetings are designed to bring together specialist healthcare professionals and patients with chronic conditions and to give a direct voice to patients and carers to air their concerns on the impact of diagnosis, treatment and care, in addition to hearing up-to-date developments about brain tumours."

To book your place or for more information visit: <http://www.rsm.ac.uk/academ/mmc07.php> or contact Nevena Marjanovic Tel: +44 (0) 20 7290 2980



Decoding brain tumours



Professor John Darling, Co-director of Brain Tumour UK's Neuro-Oncology Research Centre at the University of Wolverhampton, has spent the last 35 years trying to understand brain tumours.

He believes the next decade will see major breakthroughs in treatments, as patients reap the benefit of years of research.

The professor, one of the UK's leading brain tumour experts, stumbled into the field by accident.

"I started out looking at bugs and viruses and wanted to study infectious diseases after my 'masters', but my professor thought it would be a 'dead end' as many of the problems in this area had already been solved."

Although initially disappointed, the young microbiologist considered cancer as an alternative career path.

He spotted a job ad in 1978 for someone to grow cells for a brain tumour project run by David Thomas at the National Hospital in London. David was setting up one of the first integrated programmes of brain tumour research involving scientists and clinicians in the UK. "I have never looked back," he says.

"Stumbling into brain tumours was a very lucky accident."

I was given free rein to set up a small lab in London and develop my interest in neuro-oncology. I could not have asked for a better career opportunity," he says.

After many years as a self-confessed 'lab rat', Professor Darling's role changed as he moved into overseeing other scientists and securing more funds for research. Fast-forward to today, where apart from co-directing Brain Tumour UK's Neuro-Oncology Research Centre, he has a complex matrix of roles as the University's Director of Research, Dean of School of Applied Sciences and Director of the Research Institute in Healthcare Science.

More removed from the lab bench now, he has never lost his passion for cultivating cells to make the type of discovery that could change the lives of people threatened with a devastating diagnosis.

"I am most proud of my contribution to the discovery of cell-based technology to predict how patients will respond to chemotherapy," he says.

It has taken years of fine-tuning for this to make its way into practice and patients are only starting to see the real benefits now.

"I am in the last decade of my career and the next 10 years will see the biggest benefit for people with brain tumours."

This will include the development of new, more targeted and more effective treatments, he says.

For example, the work of Professor Darling and his team is likely to make possible the identification of the 20% of glioblastoma patients who respond to chemotherapy, so their treatment can be intensified. It could also mean new ways of treating patients who are traditionally resistant to chemotherapy

"I would like to think that I played a small part in making this happen," he says.

Compared to other types of cancer, brain tumour research has made little progress as survival rates have not improved over the past 40 years.

However, if it were not for the painstaking efforts of dedicated scientists like Professor Darling – who despite the challenges have persevered to keep adding to the bank of knowledge about brain tumours over many years – the UK would not be at this exciting jumping-off period for new treatments.

"I am an optimist. I believed things would get better from when I first started out."

One of the biggest frustrations of his career has been the "side-lining" of neuro-oncology compared to more

The Brain Tumour UK Neuro-Oncology Research Centre

Our brain tumour research lab in the University of Wolverhampton brings together some of the UK's leading researchers to accelerate the search for knowledge in the field of neuro-oncology.

prevalent cancers such as breast and lung cancer. Brain tumour research funding has suffered disproportionately, receiving much less in relative terms than it deserves. A lesser interest in brain tumours by the medical and scientific community has been the result.

A personal challenge has been to entice more young scientists to tackle brain tumours by choice, as opposed to stumbling into the field the way he did.

"I would like to think that I was one of the torch-bearers who kept neuro-oncology alive in this country."

The fact that the British Neuro-Oncology Society's annual meeting now boasts 200/300 attendants compared to 10/15 when he started out, shows that the tide is turning and that interest in the field is growing.

"We will reap the benefits in years to come."

His rich and rewarding career leaves Professor Darling little time for hobbies, although he does confess to a passion for archaeology, a love for the Shropshire countryside and an impressive collection of fountain pens!

MEET PROFESSOR DARLING AND HIS TEAM

OPEN DAY: Brain Tumour UK Neuro-Oncology Research Centre

When: 17 March

Time: 11am – 2pm

see page 4 for details

Brain Tumour Awareness Month -

What's on and how you can get involved

Take part in the Brain Tumour UK Cupcake Challenge:

When: 1-31 March

Make and bake cupcakes and sell them to raise funds and awareness for Brain Tumour UK (see page 7 for more information).

Visit our cupcake website: www.braintumouruk.org.uk/cupcakes



Cuban Cycle challenge:

When: 9 March

Linda Dare, 50, (right) and her friend Mary Pike, 51, are undertaking a self-funded Cuban Cycle challenge, cycling 350km over seven days to raise funds for Brain Tumour UK. Linda from Taunton, Somerset, lost her husband, Richard, to a brain tumour in October 2010. "I felt I needed a challenge to raise money for this wonderful cause. If it helps just one person beat this cruel disease it will be worth it."

To donate visit: <http://original.justgiving.com/lindacoombes1> or <http://original.justgiving.com/marypike2>



Adidas Silverstone Half Marathon

When: 11 March (10am-3pm)

A team of 20 Brain Tumour UK runners will take part in this exciting annual event, which starts and finishes at the historic Silverstone Racing Circuit.

Before the run, our team will be drilled army-style by Shaun Casey of Regiment Fitness, who will ensure they are warmed up and in good spirits for the race.

Join us at our cheering parties along the route or at our marquee in the charity village.

For more information or to donate to our runners, contact us on 0845 4500 386.

Thinking about running for Brain Tumour UK in the future?

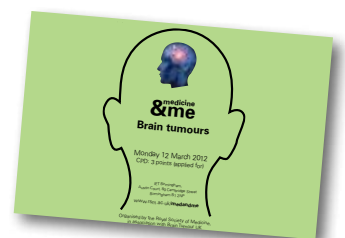
Visit our running page to find out more about other running events: www.braintumouruk.org.uk/running



Medicine and Me Conference: Brain Tumours

When: 12 March (From 10am-5pm)

Join us at a conference about brain tumours where the patient's voice is paramount. Brain Tumour UK and The Royal Society for Medicine co-host this annual conference, which takes place in Birmingham this year. (see page 2 for more information)



OPEN Day: Brain Tumour UK Neuro-Oncology Research Centre

University of Wolverhampton

When: 17 March: (11am-2pm)

Meet our team of top researchers and find out more about the groundbreaking work they do.

(To find out more about the open day and read our interview with Professor John Darling, who co-directs Brain Tumour UK's Neuro-Oncology Research Centre, see page 3)



- March 2012

Tea for 80

When: 24 March

Sisters Laura Bailey, 24, and Nicola Naisbett, 28, are hosting an afternoon tea party for 80 people in Durham to raise funds for Brain Tumour UK.

Tickets to this event are sold out, but to support the sisters, visit:

www.justgiving.com/AfternoonTeaForBrainTumourUK

The sisters lost both their parents to brain tumours.

Laura says: "When I was 10 years old and my sister 13, mum Diane was diagnosed with a malignant melanoma on her back. This was removed and she was in remission for a number of years. During this time, in 2000, my dad Trevor was diagnosed with an aggressive brain tumour - (I was 12 and my sister 15).

He sadly lost his life in 2001."

"Four years later, mum was diagnosed with secondary cancer in her brain, which had spread too far for radiotherapy. She became ill soon after her chemotherapy began and my sister and I were her primary carers during her six-month fight against the disease. Whilst caring for mum, my sister was working part-time and studying for her degree and I was working part-time and preparing for my A-levels. We have both now graduated and my sister is a teacher and I am a trainee lawyer."

"We feel very strongly about Brain Tumour UK which provides support to carers and sufferers and which funds research into treatments and hopefully one day a cure for brain tumours."



National Brain Tumour UK Skydive Day

When: 25 March 2012 (8am-6pm)

Challenge yourself by jumping out of a plane at 10,000ft for Brain Tumour UK on our annual skydiving day at **Brackley and Salisbury airfields**.

All you need is guts, and a minimum sponsorship of £395. This is a truly amazing day and one you will never forget. You can jump in tandem or alone. Go on give it a go!

(If you can't join us on our national skydiving day in March, you can have this experience of a lifetime on any other day of the year.

Contact us on 0845 4500 386 Or email us at: fundraising@braintumouruk.org.uk



Brain Tumour UK displays

When: 1-31 March

Find out more about about Brain Tumour UK and the work we do by visiting our displays at various neuroscience centres throughout the country during Brain Tumour Awareness Month:

- Walton Centre Liverpool, main foyer
- Cancer Centre, Leicester Royal
- QEH in Cancer Centre (Patrick Centre) – North and Midlands
- Christies Cancer Centre (North and Midlands)
- Neuro Support Centre, Liverpool – during the last week of March



**BRAIN
TUMOUR
UK**

*Providing support
Funding research
Raising awareness*

Going bald for Brain Tumour UK

When: 1-31 March

Heather Taylor Nicholson, 51, from Penzance is going bald for the entire month of March to raise funds for Brain Tumour UK.

The former nurse is living with a brain tumour.

"I would like to show solidarity for my fellow tumour sufferers, to emphasize our vulnerability and to raise awareness about brain tumours".

"It is also a tribute to my dear friend Veronica, who died of a brain tumour that was not diagnosed until too late. She was 48 years old.

To donate: visit: <http://www.justgiving.com/Heather-Ann-Taylor-Nicholson>
Read Heather's blog at meningiomaheadstart.blogspot.com/



Start your own Fundraising Group

Mason's Magic touches thousands



Mason's Magic

Mason Fountain can't stop smiling.

The seven-year-old brain tumour patient from Ipswich in Suffolk has set up Mason's Magic: the first official fundraising group set up under the umbrella of Brain Tumour UK - to put a smile on the faces of other children with brain tumours.

Mason is thrilled to bits.

Since setting up Mason's Magic, his life has been turned upside down - he has attracted thousands of followers on social media network Twitter, including Gordon Ramsay, Amanda Holden, ex-Ipswich Town goalkeeper Craig Forrester and ITFC midfielder Jimmy Bullard.

He has been interviewed on TV and radio and raised thousands of pounds within weeks.

"He's loving it - we can't believe the response," says proud mum Shelley Fountain, 29.

Mason is selling wristbands and jewellery through his website to boost his fundraising efforts (www.masonsmagic.co.uk)

Mason was diagnosed in 2010 with a tumour on his pituitary gland and has undergone 20 months of gruelling chemotherapy.

In spite of his own problems, Mason wanted to help other children because he's had wishes granted in the past.

Mason was given a £500 grant from the Brain Tumour UK Denny Care & Relief Fund, to move his bedroom downstairs, when he was too ill to climb stairs.

He also went on a trip to Disneyland Paris and met his pop idols N-Dubz and he wanted other children to have the same opportunities.

"Mason knows that when he was feeling down and poorly, these treats made a big difference."

"The most difficult time was when Mason had to undergo the chemo. He hated it and I had to make him do it. It was awful," says Shelley.

The results of his latest MRI scan show that the chemotherapy has only reduced the tumour by 20%.

"Mason realises that he will have to live with this tumour for the rest of his life. It is hard for anyone to come to terms with that, let alone a child," says Shelley.

Meanwhile, Mason can't wait to meet other children with brain tumours through Mason's Magic.

He loves his Ipad and PS3 and playing football. He is also a keen Ipswich town supporter and has been a mascot for the team.

To help Mason achieve his goal, follow him on Twitter
[@masonsmagic](https://twitter.com/masonsmagic),



like him on Facebook:
<http://www.facebook.com/Masonsmagic07>



To donate visit
www.justgiving.com/masonsmagic

Find out more on his own website:
www.masonsmagic.co.uk



Mason with siblings Jack and Kloie

How to start your own fundraising group

You too can set up your very own Fundraising Group under the umbrella of Brain Tumour UK.

This way you can help raise funds for Brain Tumour UK, but manage your own group, in your own name, with your own events and marketing.

We will guide you through the requirements to get you started and you will be asked to sign an agreement to make sure things are being done correctly. We will offer you all the support you need along the way.

For more information contact Claire Glazebrook on 01494 549 180 or email Claire on: fundraising@braintumouruk.org.uk.

BE A PART OF IT

Join in the Cupcake Challenge in aid of Brain Tumour UK



CUPCAKE CHALLENGE

Everyone loves cupcakes - join in the fun

You can make and bake your own cupcakes and raise vital funds and awareness for brain tumours during Brain Tumour Awareness Month – March 2012

What is the Cupcake Challenge?

The Brain Tumour UK Cupcake Challenge is a new event, which we hope will 'bake' into something really big.

We need your help. Every penny raised will go towards vital support services for patients and families, funding research into diagnosis and treatments and campaigning to make life better for everyone affected by a brain tumour.

You can take up the cupcake challenge in whatever way suits you – whether it's taking cupcakes to work to sell to colleagues, holding a traditional cake and coffee morning at home for friends or something a little more daring.

We want you to have fun whilst raising vital funds for our work during Brain Tumour Awareness Month in March.

Whatever you do, we'll support you all the way. Take up the Cupcake Challenge today.

Make and Bake your own event: Be inspired

Get some ideas for your own cupcake event and find out how we can help you. Visit our website:

www.braintumouruk.org/cupcakes to see top cupcake recipes, download a poster for your event and a fundraising pack, including the A-Z of cupcake ideas.

Our Cupcake Wall of Fame – features weird and wonderful cupcakes and the crazy things supporters are doing with cupcakes.

See who has baked the biggest, healthiest, funkiest, furthest-travelled cupcake and find out the most unusual places to eat a cupcake.

Submit your own ideas, photographs and recipes, challenge each other... have a bake-off!

Follow us and join the conversation on twitter - #cupcakechallenge



Who inspired the Cupcake Challenge?

The idea came from Brain Tumour UK fundraiser and supporter Ann Atkins, mum of Iona Atkins, living with a brain tumour. Iona, nine, was diagnosed with a rare brain tumour when she was five.

Ann, of Solihull, says: "I thought a Cupcake Challenge would be a good way of marketing the charity – which could grow year by year. Raising the profile of Brain Tumour UK is something I am proud to promote and it's a nice thing to have your idea associated with a charity which means so much to you and your family. AND EVERYONE LOVES CUPCAKES!"



Boost for Brain Tumour UK in Wales

Our new Welsh patron



Welsh singer Jamie Pugh, who lost his wife to a brain tumour, is our first patron in Wales.

Jamie has decided to talk openly about his loss to raise awareness of plans to give more patients, families and carers access to services they need.

Former Britain's Got Talent semi-finalist Jamie Pugh has spoken openly about the pain of losing his first wife Tracey to a brain tumour.

The 40-year-old Welsh singer, who appeared on the TV show in 2009 has become Brain Tumour UK's first patron in Wales because he wants to help others in the same situation.

"I did not want to talk about Tracey on Britain's Got Talent, because I did not want the sympathy vote, nor would it have been respectful."

However, he feels the time is right now. "I want to share our story with people who will understand and interpret it in the way it is meant," he says.

Jamie and Tracey, who had met at school, had been married for six years and had a three-year-old son, Callum, when she was diagnosed.

"Tracey had been experiencing headaches, visual problems and disorientation for many months. GPs told her she was suffering from migraines, one going as far as to say she needed to 'get off her backside and get a job'."

It was only when she went to see an optician that she was referred for an urgent MRI and the tumour spotted.

Jamie believes that the tumour should have been detected earlier. "It's disgusting

Our plans in Wales:

Brain Tumour UK has consulted widely with patients, carers, families, other charities, the NHS and medical professionals to identify the support services most needed by people affected by the condition in Wales.

The charity is raising funds to deliver these services in partnership with other charities and organisations. This will include vital support projects in local communities and increasing people's awareness of treatments, options and care.

Contact:
Moira.dennison@braintumouruk.org.uk

Tracey was not referred for an MRI despite showing what I now know are typical brain tumour symptoms."

Jamie was the first one to be told the results of the scan.

"My first thought was – how do I tell her? I was also angry – that this was happening to her," he says. When he told his wife, she said simply: "I knew."

Tracey underwent two operations over a period of 12 months along with radiotherapy followed by chemotherapy

She lived with her condition for 14 months before sadly passing away on November 5th 1999 when only 27.

Jamie looked after her for most of the time with constant support from family. "Right up until her passing all around her kept up communication and in touch with her to reassure her that we were there even though we didn't know if she could see, hear or understand us," he says.

"For me the hardest thing was watching what the brain tumour was doing to her. This disease takes away your dignity. It destroys everything that makes us human.

As a Brain Tumour UK patron Jamie wants other people affected by the condition to know that there is help out there.

"I spent many a night on the hospital's out-of-hours line, asking: 'What do I do now?' It felt like I was banging my head against a wall. It should not be like that."

"It's been 12 years but I only have to look at Callum and I see her, he's the image of his mother. I am lucky now that I have a new partner Donna and that in life I have found love again.

"You don't think you will ever move on, because the pain of loss is so great, but you do, in time the pain eases, and the memory of the life that was lived takes over."

Contact Jamie via:
fundraising@braintumouruk.org.uk

Fundraising for Wales

Jamie Pugh is planning a Celebrity Kilimanjaro trek in January 2013 to raise funds towards the charity's £150,000 target for the Welsh project. He has exciting plans and would love to hear from anyone wishing to help or join the challenge.

At 5,895m, Mount Kilimanjaro is one of the largest volcanoes ever to break through the Earth's crust. It remains one of the most stunning challenges in the world.

Contact:
fundraising@braintumouruk.org.uk
to find out how you can take part.



**BRAIN
TUMOUR
UK**

**Providing support
Funding research
Raising awareness**

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fundraising@braintumouruk.org.uk
braintumouruk.org.uk/fundraising

Brain Tumour UK is the leading, caring charity committed to fighting brain tumours. Our personalised support is available online, on the phone, by email and through support groups. Our scientific research improves the quality of life for brain tumour patients and identifies better treatments. We raise awareness to change things for the better, for everyone affected by a brain tumour.

Registered charity 1117538 (England & Wales) and SC042096 (Scotland)

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Registered office: Cawley Priory, South Pallant, Chichester, PO19 1SY

The views expressed in this magazine are not necessarily those of Brain Tumour UK.



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