



# Target

## Welcome



**At Brain Tumour UK we believe that if all of us who are passionate about brain tumour issues speak as one, then we will have a more powerful voice.**

We recently joined forces with The Joseph Foote Trust. Its founder, Andy Foote, is our new chairman and wants to collaborate with others to improve the lives of everyone affected by a brain tumour.

Research is one area where our stronger impact will soon be felt. We're working now with the University of Nottingham (see story right).

By sharing resources and experience, we hope to make an even bigger difference to the lives of people affected by the condition, and this includes support. Our outgoing chairman Jeremy Payne, who lost two brothers to brain tumours, looks at the development of support services during his term (page 2).

As always we are hugely indebted to our supporters, who amaze us with their energy and dedication.

Their passion was visible every step of the way during RelayGB, organised by Brain Tumour UK supporter John Stanford and which many of you joined, raising a massive £100,000. (Page 7)

Inside you can read about our mass lobby of Parliament, and some of you even carried the Olympic Flame in tribute to loved ones affected by brain tumours.

Thank you all for helping us to strive for a world free of the fear of brain tumours.

**Jenny Baker OBE**  
Chief Executive

## Bigger Brain Tumour UK massive boost for research



Photo: Children's Brain Tumour Research Centre

Brain Tumour UK boosts research into children's brain tumours

**An exciting result of the coming together of Brain Tumour UK and The Joseph Foote Trust is the boost in the charity's determination to fund groundbreaking scientific research.**

Since the two charities joined forces in April this year, Brain Tumour UK has made further major commitments to quality research projects aimed at improving the lives of patients and identifying new and better treatments.

The biggest of these is the charity's agreement to raise £750,000 over the next five years to fund the Children's Brain Tumour Research Centre at the University of Nottingham, which has been supported by The Joseph Foote Trust in the past.

Brain tumours now kill more children than leukemia in this country and are the biggest child cancer killer.

Jenny Baker, Brain Tumour UK's Chief Executive and Andy Foote, who took over as chairman on July 1, have both lost sons to the condition.

Jenny said: "The Joseph Foote Trust have been hugely successful in raising and investing vital funds in groundbreaking brain tumour research. By

consolidating our resources and experience, we will be able to have a greater impact on more people affected by brain tumours and become an even bigger force in the sector."

Supported by thousands of fundraisers and donors, Brain Tumour UK will also continue to fund the Brain Tumour UK Neuro-Oncology Research Unit at The University of Wolverhampton.

The two research centres are likely to remain the charity's main focus of research-related investment over the next few years.

The charity is also funding two specialist posts – a three-year clinical trials nurse at the Queen Elizabeth Hospital in Birmingham and a three-year part-time clinical trials project officer at the National Cancer Research Institute.

"We are delighted to be funding these two posts as we believe this will enable Brain Tumour UK to influence the growth of UK clinical trials which will ensure more access to the latest therapies for brain tumour patients," says Jenny.

**Read more about the Children's Brain Tumour Research Centre on Page 5.**



# 'I want everyone to know what I know now - you're not alone'

Outgoing chairman **Jeremy Payne**, who lost two brothers to brain tumours, looks back at how the charity has been supporting patients and families during his term.

I joined Brain Tumour UK because of what my family went through.

We were not used to looking outside ourselves for help. We tried to rely on ourselves and that made everything more difficult.

I want everyone to know what I know now: Brain Tumour UK can help you come to terms with what is happening to you.

Growing support services has been one of my key areas of focus and I am very proud of what we have achieved.

In 2009, we had four support groups, a helpline with limited hours and our social media outreach was in its embryonic stages.

Fast forward to today and thanks to a more strategic approach, Brain Tumour UK now boasts a comprehensive support and information service, both locally and centrally, and a firm commitment to roll out the services we offer UK-wide.

We have consolidated the existing services and added new services by asking you - the patients and carers - what you needed.

New services introduced as a result of your feedback, include more online support, more support groups (we now have 21), social media, a pilot counseling service in Thames Valley, regional newsletters and support by text for the under 25s.

And now that we have joined forces with the Joseph Foote Trust, we want to develop more services for younger patients.

By working with other organisations, we are able to ensure you get the information and services you need.

Our development co-ordinators liaise with other organisations and healthcare professionals and in Scotland, at parliamentary level, to influence debate and decisions about the allocation of funds for brain tumour patients. (See Page 3)

We are increasingly being recommended by hospitals, doctors and other charities, who want to work with us.

We have made significant inroads in Scotland by offering support groups with other charities and helping to put brain tumours on the political agenda.

Looking forward, we plan to roll out our services to Wales and Northern Ireland. We are on a roll and with Brain Tumour UK's new chairman Andy Foote at the helm, we will grow even stronger to be there for you when you need us, wherever you are.

## HOW CAN WE HELP YOU?

Tell us what you think we should be doing to help people affected by brain tumours. Are we getting it right? Can we do more? Get in touch. [support@braintumouruk.org.uk](mailto:support@braintumouruk.org.uk)

## Jeremy's story

Jeremy Payne lost two brothers to brain tumours.

Robert, was 58 when he started getting severe headaches in 2001. He was diagnosed with a high grade glioblastoma.

"His family and friends were totally devastated. It was completely unexpected and there was no explanation," says Jeremy.

Robert, a former captain in the Royal Navy, had just retired and was looking forward to spending time with his wife and two daughters. He died within a year of diagnosis without seeing his three grandchildren.

While the family was still trying to come to terms with this, Jeremy's brother, Richard, started having problems with his legs and doctors suspected he might have motor neurone disease.

"I went with Richard and his wife to a specialist, expecting to have the diagnosis of motor neurone disease confirmed. We very much expected him to live."

The news that Richard had the same condition as his brother came as a total shock.

"We were thinking 'How could this happen? How can we have another brain tumour in the family?'"

Richard started losing his eyesight and movement in the left side of his body. He died aged 66, 15 months after being diagnosed, leaving his wife and four children.

"Both of them died just as they stopped grinding away at work, getting to where they wanted to be in life and looking forward to the rest of their lives. That had been taken away from them."

*Jeremy stepped down as chairman on July 1, but stays on as trustee.*

## SUPPORT IN NUMBERS

In 2011 we:

- spent £300,000 on extending our support services
- supported 3,436 individual patients and family members
- increased and facilitated 21 patient support groups
- awarded 230 patient grants totalling £106,000
- launched our text support service
- further strengthened links with neuroscience centres and partners

# 'Joining a support group gave me back my confidence'

Brain Tumour UK offers 21 support groups across the UK – in collaboration with other charities.

**Tommy Kirkland** explains why the Glasgow Brain Tumour Support Group has become his lifeline.



Tommy Kirkland with his fiancé Gillian Williams

Tommy, 42, was diagnosed with a brain tumour the size of a baseball five years ago and has beaten four tumours since.

He is a regular member of the Glasgow Brain Tumour Support Group, since it started in June last year.

The group, jointly run by Brain Tumour UK and Maggie's Cancer Caring Centres, have 12 members with more spaces available.

Tommy, from Coatbridge, was diagnosed with a tumour after he started being sick and having headaches. Tommy said: "I was a typical high flying male, I worked hard, played hard and kept myself pretty fit.

When I had these symptoms so often, I booked myself in for an MRI scan and was whisked off to Southern General Hospital where I was diagnosed with a large brain tumour. I was operated on immediately

and recovered in about two months."

Since then, the tumour grew back and was removed again. A year later, Tommy had another tumour in a different part of the brain that was removed, followed by a fourth tumour in 2011.

"Until I found out about Brain Tumour UK, I was rather lost.

For a while I looked and spoke slightly differently and was treated with kid gloves. Through the support group, I regained my confidence and found a new way of dealing with my illness. To find out I was not the only person in Scotland to go through this, made me feel more normal."

To find out more about our support groups contact:

**support@braintumouruk.org.uk or visit [www.braintumouruk.org.uk](http://www.braintumouruk.org.uk)**

## Brain Tumour UK's latest secret weapon

When it comes to ensuring brain tumour patients get the support they need, Gina Rutterford is like a dog with a bone.



The latest addition to Brain Tumour UK's team of development co-ordinators is described as our secret weapon.

Armed only with a phone and a friendly smile, Gina has been rattling cages on behalf of people with brain tumours in Central, Eastern UK and Greater London, with amazing effect.

"I think it is dreadful that people with brain tumours sometimes don't even get the support they're legally entitled to. It is my mission to make sure they get what they need," says Gina.

"I team up with partners in organisations which have commonality with brain tumours such as specialist nurses in neurology hospitals, cancer centres, hospices, other neurological organisations and cancer networks."

Not only do they share resources and workloads, but together these partners have a much louder voice when it comes to persuading the NHS to spend more money to improve life for people with neurological conditions.

Gina believes a certain amount of 'pig-headed' determination is vital in her role - as a local nurse discovered when Gina left 20 messages on her phone.

As a result of Gina's efforts, the number of support groups on her patch has grown from two to nine and three more are in the pipeline.

Gina listens to what people with brain tumours are saying and ensures their voice is heard.

She recently used support group testimonials to complain to the Chief Executive of a neurological hospital about the lack of a brain tumour nurse specialist at his hospital.

"I've not had a response yet," says Gina, but she won't give up until she does. And it had better be good...

## HELP US SAVE COSTS BY READING TARGET ONLINE

As you may know, the Royal Mail increased their costs for postage substantially this year. This has had a dramatic effect on the costs of bringing you Target by post in print form.

Recently we've improved the way we present Target on our website by introducing 'turning pages', as well as, providing it as a PDF download.

As a result of the Royal Mail increases, and to make the best use of our resources, from 2013 we will be providing Target **by email only** (with links to the full interactive version online) to everyone for whom we have a valid email address.

If we have your email address, and you wish to continue to receive Target in print form, please tell us by using the online form at [www.braintumouruk.org.uk/target-by-post](http://www.braintumouruk.org.uk/target-by-post), or by calling us on 0845 4500 386.

**We don't have your email address?** Help us save costs and make the most of your generous support. Provide us with your email address by using the online form at [www.braintumouruk.org.uk/register-my-email](http://www.braintumouruk.org.uk/register-my-email)

# Debbie's magic touch transforms lives



Debbie Edwards

From her home in Buckinghamshire, Debbie transforms the lives of people for whom the loss of their hair through treatment also means a loss of identity.

"For many women – and men – hair is an integral part of who they are and losing it can be deeply traumatic. We give them their confidence back enabling them to continue a normal way of life," says Debbie.

As the owner of HairInXS, Debbie is one of only a few experts in the UK specialising in cosmetic hair replacement for people who've had radiotherapy, which in some cases makes hair regrowth difficult.

They arrive at her salon sporting bandanas, wigs or caps. They don't look at themselves in the mirror – simply not believing anyone will be able to patch the growing gaps in their hair and self-esteem.

Next, Debbie shares albums with before and after photographs of smiling men and women to show what she can do.

To her clients, many of whom have brain tumours, Debbie Edwards is a modern day fairy godmother.

Denise Bentley is featured in one of the albums. She refused to have radiotherapy to save her life because she was too traumatised by the idea of losing her hair.

"Denise asked if I would be able to help her and I said: 'Yes, just have the treatment,' but when she showed up on my doorstep after the therapy, she had almost no hair left. I had no idea how I was going to do it, but I knew I couldn't let her down," says Debbie.

Debbie persevered and 15 hours later Denise walked out with a smile and a full head of hair.

**"They rely on you totally to change their lives," says Debbie.**

Debbie's method, perfected over 15 years, involves attaching a fine mesh to the client's existing hair and weaving hair made from mono fibres and colour-matched to the client's hair into the empty patches, giving the illusion of a full head of hair.

The hair has to be tightened every six weeks and Debbie and her team become part of their clients' lives.

"Being compassionate and caring is everything", says Debbie. "You have to be able to listen and be a shoulder to cry on."

And sometimes you cry with them. Like when 19-year-old Billy, who lost most of his hair and who reminded Debbie of her own two boys, said, "Girls look at me now, but for all the wrong reasons."

"I felt so sad for him, I cried and cried," says Debbie.

Today Billy is one of hundreds of people who have been given their lives back by a fairy godmother whose heart is clearly in her job.

To find out more visit [www.hairinxs.com](http://www.hairinxs.com) or call Debbie on 01753 859777/445.

**"She gave me back not only my hair, but my life" says Jess Taylor**



"At the end of July 2007 at the age of 13 I was diagnosed with a medulloblastoma. Unfortunately my surgeon could not remove everything and a month later, I began a four-month course of chemotherapy followed by six and a half weeks of radiotherapy to my brain and spine.

I was told that I would lose my hair, and that it would grow back very thin, patchy and bald around the bottom half of my head.

I found that so depressing, I didn't want to go anywhere with my friends.

Debbie and her team gave me back not only my confidence, but my life. I feel so happy being able to go out with my mum and family now without people looking at me as if I am not normal."



# Leading the way in child brain tumour research

Brain tumours are the biggest child cancer killer in the UK. As part of our commitment to funding groundbreaking research, Brain Tumour UK supports the Children's Brain Tumour Research Centre (CBTRC) at the University of Nottingham to help improve the lives of young brain tumour sufferers and their families.

## What does the centre do?

The CBTRC is dedicated to improving the lives of young brain tumour sufferers and their families worldwide. They research and develop new treatments and improve survival rates of children with brain tumours.

The CBTRC aims to establish links between paediatrics, neurosciences, oncology, imaging, pharmaceutical sciences, human development, stem-cell technology, cellular genetics and physiology.

The centre also works with children's cancer research organisations around the world to make sure they're improving their knowledge of the disease every day.

A huge range of research is carried out at the centre, looking into as many aspects of child brain tumours as possible, including:

- Understanding the biological factors that cause brain tumours as children grow.
- Improving existing treatments and developing new targeted drugs to treat brain tumours in children and new ways of delivering them.
- Developing and promoting guidelines for health services and encouraging professional training to encourage early diagnosis of brain tumours.
- Providing training to clinicians and researchers internationally

## When was the centre founded and who are its leaders?

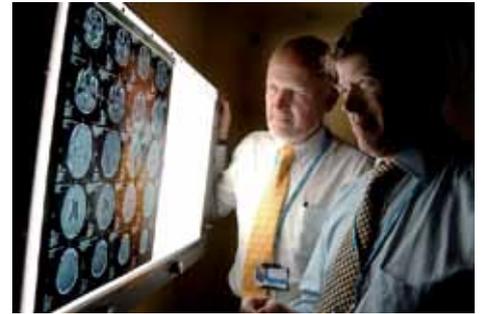
Established in 1997, the CBTRC brings together a multi-disciplinary team of leading healthcare professionals and researchers committed to improving our understanding of childhood brain tumours.

The centre is under the leadership of Professors Richard Grundy and David Walker, internationally renowned experts in the field of neuro-oncology.

What will money raised by Brain Tumour UK be spent on?

The funds will be used to buy the latest, cutting-edge equipment, as well as, investing in the best possible people to help achieve the research priorities identified by the centre for the next five years:

- Identifying the biomarkers and biological pathways that cause ependymoma – the third most common malignant brain tumour in children and to ensure this information is applied in clinical trials.
- Improving our basic understanding of why treatments fail and developing better ways of testing drugs and their side-effects.
- Measuring the true financial cost of childhood brain tumours to families and the wider economy to influence how much money is spent on research of the disease.



Professors David Walker and Richard Grundy

## RYAN LEE



**'The clues were there that he had a brain tumour'**

Ryan Lee was diagnosed with an aggressive brain tumour in 2009, which ultimately left him unable to walk, talk, eat and drink or do the things he'd been able to do for 14 years of his life.

The previously fit and healthy teenage boy died in May 2012, after 10 months of a hard fought battle against cancer, aged 15.

His mum, Deb Lee, says: "We thought Ryan had a lifetime of experiences ahead of him. What we hadn't realised was that for quite some time the tumours were growing in his brain.

We had no idea that the clues were there for at least six months, such as headaches and body pain in the morning, tiredness and a noticeable change in attitude and behaviour.

If the signs had been spotted earlier, Ryan would have begun treatment sooner although the severity of his tumours would not have changed the eventual outcome.

We are grateful for the support we received from Professor David Walker and his team."

CREDIT:  
All information supplied by CBTRC

## Facts about childhood brain tumours

450 children are diagnosed with brain tumours every year in the UK.

Five-year survival rates for children with brain tumours in the UK have risen from 50% to 70% over the last decade.

Many brain tumours remain incurable, and 60% of those who do survive often have significant disability following diagnosis and treatment.

Childhood brain tumours are linked to the process of growth and development of the brain, while those in adults are usually linked to ageing or environmental factors.

For more information about the CBTRC visit [www.http://www.cbtrc.org/cbtrc/index.aspx](http://www.cbtrc.org/cbtrc/index.aspx)

What can you do to help: To find out how you can support the CBTRC through Brain Tumour UK, visit our website at <http://www.braintumouruk.org.uk/childrens-brain-tumour-research-centre>

# Keeping good company

A fast-growing number of businesses are partnering with Brain Tumour UK to inspire staff and customers.



John Shepherd and Andy Foote

## Jenny Baker, Brain Tumour UK Chief Executive, says:

"Our corporate partnerships are a win-win situation. Their support provides vital help to people with brain tumours, while benefits for the company include team building, press and marketing opportunities and the morale boost that comes from staff knowing they're helping a great cause."

Moore Stephens LLP, chartered accountants and business advisers, is one of our latest partners, having voted Brain Tumour UK as their Charity of the Year for 2012/2013.

The partnership came about through David Fryer, a long-standing Moore Stephens employee, who has a brain tumour.

Gordon Vallance, Brain Tumour UK's Head of Fundraising, says: "Moore Stephens staff are hugely enthusiastic and are organising events ranging from skydiving to golf days to office cupcake days, a pub quiz and running races."

Employees are helping to fund research at the Brain Tumour UK Neuro-Oncology Unit at Wolverhampton University and researchers share updates of their work with staff, giving them an ongoing focus. Moore Stephens has generously agreed to match fund every penny raised by their staff for Brain Tumour UK.

Brain Tumour UK's fundraising team provides tailored support to every partner and this has been so successful with Moore Stephens that their staff has easily exceeded the fundraising target they set initially.

Andrew Potts, chair of the corporate social responsibility committee at Moore Stephens, is keen for as many staff and partners as possible to join in the fundraising activities.

"Teaming up with Brain Tumour UK is a great way to raise awareness within the firm about the support available to people affected by the disease. I am delighted by the amount the firm has managed to raise just six months into the partnership, as well as the number of people who have got involved."

Another corporate partner is leading Midlands' residential property specialists John Shepherd, who have pledged to support Brain Tumour UK for the next 12 months.

The decision follows the company's long association with the Joseph Foote Trust, which joined forces with Brain Tumour UK in April 2012.

Andy Foote, Brain Tumour UK chairman, said: "John Shepherd is one of the most respected names in the property industry and I am confident their support will make a huge difference to our fundraising efforts."

John Shepherd, who founded the company over 20 years ago, said: "We have been inspired by the work the charity is doing to help those in need and we are proud to partner this great cause throughout 2012."

**To find out how your company could get involved talk to our Fundraising Team on 0845 4500 386 or email [fundraising@braintumouruk.org.uk](mailto:fundraising@braintumouruk.org.uk)**

## More than shaking a tin



Kiki Connor

**Our Umbrella Fundraising Groups led by volunteers are not just about shaking tins for a few spare coins, but provide a real financial boost to Brain Tumour UK.**

Kiki Connor who co-founded the Brain Tumour UK Chiltern Fundraisers with Anne Parsons, explains how a small committee with 20 'foot soldiers' raised £10,000 for the charity last year.

"Bric-a-brac sales and street collections are our bread and butter, but we raise most funds through special events such as the annual Chiltern Hills Walk, which we hope will raise over £4,000 this year," says Kiki.

The 5-mile circular walk in Hawridge, which takes place on Sunday, 7 October, has become a popular event on the local calendar since first organised by Kiki and her husband, Andy, five years ago.

"It is a great day out, with lunch in the pub beforehand, and drinks and socialising afterwards."

The Chiltern Fundraisers recently raised £940 by hosting a musical extravaganza. Other plans for the year include a quiz night, Santa Float collections, cake sales and street collections.

Kiki started fundraising because she is a friend of Brain Tumour UK's Chief Executive, Jenny and her husband Richard who lost their eldest son Stephen to the condition in 2004.

"Having witnessed what Jenny and her family went through and how she put her own grief to one side to support other families, inspires me," says Kiki.

Being a fundraiser has meant new experiences and opportunities to meet inspiring people for Kiki and her team.

"If we didn't enjoy it, we would not be doing it," she says.

**Contact Kiki at [kiki.connor@braintumouruk.org.uk](mailto:kiki.connor@braintumouruk.org.uk)**

**Want to start your own fundraising group? Visit [braintumouruk.org.uk/umbrella-groups](http://braintumouruk.org.uk/umbrella-groups) or contact us on 0845 4500 386 or [fundraising@braintumouruk.org.uk](mailto:fundraising@braintumouruk.org.uk)**

## SEARCHING CHRISTMAS CARD ANGELS

If you are positive and outgoing, want to work from home, in your own time and raise funds for people affected by brain tumours, why not be one of our volunteer Christmas card angels.

We would love your help to promote the sale of our 2012 Christmas Cards through personal contacts and networks. We will send you a comprehensive sales pack and our volunteer angels co-ordinator will be on hand to answer any queries.

If you would like to find to more, contact Kiki Connor at [kiki.connor@braintumouruk.org.uk](mailto:kiki.connor@braintumouruk.org.uk)



# RelayGB

## World record smashed for brain tumour research



**They ran in pouring rain, blistering heat, on deserted mountain paths and busy highways, but in the end it was all worth it for 465 RelayGB runners who smashed the world record in long distance relay running.**

The charity fundraising challenge, organised by Brain Tumour UK supporter and Moore Stephens director, John Stanford, has raised over £100,000 for brain tumour research and helped spread the word about brain tumours in every city, town and village en route.

The runners, many of whose lives had been affected by brain tumours, covered 2,680 miles across the UK in 100 back-to-back marathons in 18 days. This was 757 miles further than the previous record set in Romania at 1,923 miles.

John, who ran 20 marathons for Brain Tumour UK in 2010, came up with the idea in tribute of his friend, David Fryer, who has a brain tumour.

He says: "This has been an amazing journey. The support crew has been

absolutely fantastic. Thank you to everyone who has taken part, who has run and helped to make this world record a success."

The final leg runners who crossed the finish line at Wandsworth Park in London on May 18, included former Scottish women's rugby international and brain tumour survivor, Vicky Galbraith.

Vicky said: "I feel fortunate to be here at the end of this amazing event. I feel fortunate to be alive, to be able to run, talk and walk. As a patient and cancer drug researcher I know how important it is that we continue to work together to fund and develop new and better treatments."

Jenny Baker, Chief Executive at Brain Tumour UK, said: "I warmly salute John Stanford's infectious leadership, his support team's commitment and the enthusiasm of hundreds of runners joining up to achieve exhilarating success and raise vital funds for our charity's world-class research programme at Wolverhampton University."

### 'We were like one big, happy family'

**Tireless fundraiser Carolyn Pierpont, who ran two legs of RelayGB in Scotland, explains what it felt like to be part of the event.**



The mum of Aiden, 2, has raised thousands of pounds for brain tumour research since her partner Mark Toshney was diagnosed in 2009

"RelayGB was like a big gang that you really wanted to be part of. During the race, and even now, the runners are in contact on Twitter. We are like one big, happy Brain Tumour UK and RelayGB family," she says.

Carolyn shared her first marathon leg from Castletown to Wick with two friends, with her stretch amounting to 12 miles. Throughout her run, Carolyn was battered by strong winds and rain. "It was like getting a free dermabrasion treatment," she says.

Carolyn, Mark and two friends shared the leg from Inverbervie to Arbroath, where Mark handed over the baton to legendary runner and medal winner Liz McColgan.

During the race Carolyn's mum Wilma and stepdad Drew made sure the runners had enough energy to keep them going with homemade soup, cake and sandwiches

Carolyn says: "I loved being part of RelayGB. I am inspired by Mark and other brain tumour patients. If they can face hours of chemo- or radiotherapy, I can force myself to run a few miles."

## Gordon shares his fundraising to-do list



**With over 17 years in the not-for-profit sector, Brain Tumour UK's new Head of Fundraising, Gordon Vallance, plans to strengthen the charity's voice on the national stage.**

His experience in large charities such as World Vision and Hearing Dogs for Deaf People, where income doubled from £3-6million during his tenure, will bring a new dimension to Brain Tumour UK's fundraising efforts.

"I am inspired by the charity's unique challenges and needs. I believe my extensive fundraising experience of developing charities and the people who work for them, will make a real difference," says Gordon.

"My aim is to raise awareness of our work at a local and national level, building on the success of events such as the annual ball and London Marathon, which capture the essence of the charity - It's fun but with a serious message."

Developing the charity's network of volunteer fundraisers is another item on Gordon's to-do-list. (see article on Chiltern Fundraisers on page 6)

With the challenge of continuing the impressive growth in fundraising income that the charity has achieved in recent years uppermost in his mind, Gordon also plans to build relationships with a wider audience through social media and the website.

# Carrying the torch for Brain Tumour UK



Brain Tumour UK chairman Andy Foote with the Olympic Flame

**Brain Tumour UK trustees and fundraisers who carried the 2012 Olympic Torch, have helped to shine an ongoing light on the people affected by the disease.**

All the torchbearers have a personal connection to brain tumours.

Andy Foote, Brain Tumour UK Chairman carried the torch through Solihull on Sunday, July 1.

Andy set up The Joseph Foote Trust after his son Joseph was diagnosed with the condition. Joseph died in 2007, aged nine. The Trust joined forces with Brain Tumour UK earlier this year.

Andy said: "I was blown away by the support and emotion of the occasion. It was such a fantastic experience to be able to recognise the work of so many friends and family who have supported my immediate family and the charity over the past 12 years."

Trustee, Graham Lindsay, carried the Flame in Lowestoft, Suffolk on Thursday 5 July. Graham was nominated by his employers for his long service, fundraising and work as a Brain Tumour UK trustee.

Both Graham's wife, Judy, and her sister, Margaret, are living with rare, low grade brain tumours.

Fellow trustee Richard Eaton carried the torch in Kelham, near Newark on 28 June. Richard also chairs a local childhood cancer charity and is a local Justice of the Peace.

Richard's younger brother, Edward, was diagnosed with a brain tumour aged 10, and

has been living for nine years with the after effects of the surgery ever since

Fundraiser Carolyn Pierpont carried the torch through Forfar in Angus, Scotland, on 12 June for her partner Mark Toshney and Andrew Willett, from London, carried the torch on 22 July through Barking and Dagenham in memory of his youngest son Georgie, who died of a brain tumour last year.

Jenny Baker, Brain Tumour UK Chief Executive, said: "I am really proud that so many members of the Brain Tumour UK community were chosen as torchbearers. The legacy of their involvement is that their stories will continue to inspire others in the future"



**Providing support  
Funding research  
Raising awareness**

**0845 4500 386**

[braintumouruk.org.uk](http://braintumouruk.org.uk)

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**0845 4500 386 x1**

[support@braintumouruk.org.uk](mailto:support@braintumouruk.org.uk)

[braintumouruk.org.uk/support](http://braintumouruk.org.uk/support)

For fundraising:

**0845 4500 386 x2**

[fundraising@braintumouruk.org.uk](mailto:fundraising@braintumouruk.org.uk)

[braintumouruk.org.uk/fundraising](http://braintumouruk.org.uk/fundraising)

Brain Tumour UK gives help today and provides hope for tomorrow. We do this by delivering breakthrough support, information and research on the path to the cure. We campaign at all levels to raise awareness, and we collaborate with others to improve the lives of everyone affected by brain tumours.

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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.



**FRSB**  
give with confidence

## Brain tumour lobby a great success

A mass lobby to Parliament by hundreds of brain tumour patients and carers from across Britain has been a great success.

The lobby, held on Wednesday, June 13, was organised by the Brain Tumour Consortium, of which Brain Tumour UK is a founding member. The aim of the event was to tell MPs that brain tumour issues are not getting the attention they deserve and to ask for their support in raising the profile of the disease.

As a first step, MPs were asked to improve awareness about brain tumours by pledging to sign an Early Day Motion, to do more to promote awareness of brain tumours in their constituencies and to participate in meetings of the All Party Parliamentary Group on Brain Tumours.

A month after the event 45 MPs had signed the Early Day Motion and three parliamentary questions had been tabled about brain tumours.

Jenny Baker, Brain Tumour UK Chief Executive, said: "We are encouraged by this positive result. We desperately need to get MPs and Government to understand the severity and incidence rate of brain tumours so that hopefully existing resources will eventually be allocated more fairly and effectively."

### How you can still get involved:

If you were unable to join the lobby, you can still help by asking your MP to back the early day motion:  
<http://www.parliament.uk/edm/2012-13/186>

Your MP's contact details can be found here:  
<http://www.parliament.uk/mps-lords-and-offices/mps/>

The Brain Tumour Consortium: <http://www.braintumourconsortium.org.uk>

# Extra Copy

## Page 5

May want to mention in footer that Deb Lee is living with a brain tumour – meningioma and has been a personal user of BTUK. She raised c £6k to enable set up of Nottingham support group)

## Page 6

Start your own group  
To find out more about the support available to start your own Brain Tumour UK official fundraising umbrella group, contact us on 0845 4500 386, email us at fundraising@braintumouruk.org.uk, or visit our website: [www.braintumouruk.org.uk/umbrella-groups](http://www.braintumouruk.org.uk/umbrella-groups).

## Page 7

'We had to keep the baton moving'  
Throughout the 18 days John and his eight support crew members were on the road in their motor homes doing day and night shifts to cycle next to the runners, keep them safe, and sometimes even run alongside them.

Team member Steve Baxter, 50, from Hampshire, says:

"We met one another for the first time the day the race started, but we instantly gelled. It was an amazing experience. We had to keep the baton moving, whatever the weather.

The runners showed tremendous enthusiasm with some starting a marathon at 3am in cold, wet weather. If someone was feeling a bit low, our job was to encourage them- cycling or running with them, talking to them and making sure they were hydrated and fed. I lost 10 pounds because of a lack of sleep and the running. I feel privileged and proud to have been involved in RelayGB"

## Page 7

### Getting Gordon

Favourite pastime - Meeting interesting people and having meaningful discussions

Favourite music – various types for various moods. Current collection Adele, Eva Cassidy, Damien Rice

Last Book read: The Wanted by Lee Child  
What his partner says about him: Helpful, dependable and good company

How he got into fundraising: A friend asked me to help him on a charity project helping children in Romania, I saw my efforts really made a difference and wanted to do more.