

The Brain Tumour Charity shining a light on

The GREY MATTERS

The **BRAIN
TUMOUR
CHARITY**

Research | Awareness | Support

Issue 7 Autumn 2014

Launch of Leeds research programme

Receiving treatment: your first steps

Martin Kemp shows his support for HeadSmart

thebraintumourcharity.org



A little about us

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours and is the only national charity making a difference every day to the lives of people with a brain tumour and their families. We fund pioneering research to increase survival, raise awareness of the symptoms and effects of brain tumours and provide support for everyone affected to improve quality of life.

Meet the team at
thebraintumourcharity.org/theteam

Pictured on front:

Martin Kemp with Tasha Floyd, one of our Young Ambassadors, who lost her sight to a brain tumour. Read more about the Young Ambassadors on page 9 and about Martin Kemp's support on page 25.

Over 9,300 people are diagnosed every year with a primary brain tumour. We remember all those who have lost their life to a brain tumour and those who have lost family and friends.

Stay in touch



Sign up for our monthly e-newsletter and help us save on postage. Read the latest issues and sign up at thebraintumourcharity.org/enews



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Hello!

Welcome to the seventh issue of *The Grey Matters*. We hope you are as inspired by reading it as much as we were when writing and designing it.

With so much going on, one of the most challenging parts of creating *The Grey Matters* is just trying to fit everything in! These pages are only a snapshot of The Charity's work and your amazing support across the country.

One of our personal highlights from this issue is the interview with Jenny on page 26. Having tragically lost her mum to a brain tumour, she was diagnosed herself in 2006, and now volunteers at HQ to help make sure all our fundraisers have the materials they need. It's brilliant to have her on board and great to see her smiling face in the office.

Our Chair of Trustees, Andy Foote, has asked us to pay tribute to Peter McDermott and Maryanne Roach, whose tenure as Trustees has ended. Read more about their important contribution: thebraintumourcharity.org/trustees. Our thanks go to all our Trustees for the time they give, their guidance and support.

We're really excited about our Christmas pages – we can't believe it's nearly that time of year again! Do go and take a look at our range of cards and gifts, as well as ideas of festive ways to fundraise.

Thank you so much to you all for making our newsletter such a pleasure to create. Together we are stepping up the fight against brain tumours.

Richard and Kat

The Grey Matters Writer and Designer

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The Research news

Searching
for a cure

Driving global collaboration

Image (right): Researchers at the Brilliant Minds International Symposium with Vice Chair Neil Dickson and CEO Sarah Lindsell.



International Symposium, May

Over two days we brought together the world's leading brain tumour researchers for our Brilliant Minds International Symposium in London.

The event challenged top experts to find ways we can speed up the time it takes to turn discoveries into treatments and gave us a better understanding of the barriers to improving survival.

We know that we can only defeat brain tumours through global collaboration so we will be using the findings from the symposium to help develop our new research strategy, which will be published later this year.

Alongside the symposium, we held a reception in Parliament sponsored by Dominic Raab MP to celebrate the recent unprecedented £13million investment in research. Read more: thebraintumourcharity.org/celebratingthefuture

ISPNO, June

Along with over 700 delegates from around the globe, we took part in the International Symposium of Paediatric Neuro-Oncology (ISPNO), which takes place every two years.

We heard a number of the researchers we fund sharing their work with the international community and two of our Founding Trustees, Neil and Angela Dickson, met with brain tumour charities

and researchers from several countries to explore opportunities for collaboration.

BNOS, July

We were at the British Neuro-Oncology Society (BNOS) meeting in Liverpool to connect with researchers and clinicians. This year's Stephen Baker memorial lecture sponsored by The Brain Tumour Charity was given by Professor Stefan Pfister, Head of Paediatric Neuro-Oncology at the German Cancer Research Centre in Heidelberg.

We aim to double survival within ten years and reduce the harm caused by treatments.

Launch of Leeds research programme

Friends, supporters and researchers joined together for the official launch of our pioneering new £3million brain tumour research programme at the University of Leeds on 1 July.

Our Leeds programme is one of the three we announced earlier this year with a landmark joint £10million investment, and aims to target brain tumours with 'cancer-killing' viruses.

The launch, which was covered by ITV regional news, included a talk by programme lead Professor Susan Short, as well as a tour of the lab where some of the research is taking place.

Find out more about the Leeds research and watch the ITV coverage:
thebraintumourcharity.org/leedslaunch

Clinical Research Training Fellowship awarded

We are delighted to announce that Dr Jason Adhikaree has been awarded the first of a number of Clinical Research Training Fellowships jointly funded by The Brain Tumour Charity and the government's Medical Research Council.

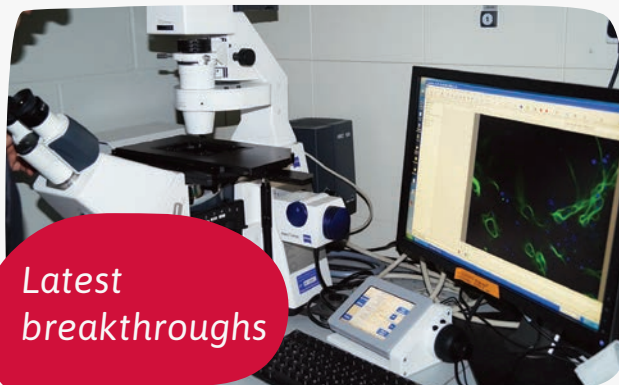
The fellowships, designed to attract talented clinicians to the brain tumour field, provide three or four years of support to allow doctors such as neurosurgeons to undertake specialised research training in neuro-oncology.

Dr Adhikaree will be based at The University of Nottingham for his fellowship, investigating how the body's immune system could be used to fight glioblastoma. Read more:
thebraintumourcharity.org/clinicalfellowship

Image: Andy Foote, The Brain Tumour Charity Chair, presents a plaque to researchers at the launch of our Leeds research programme, led by Professor Susan Short.



The research we fund thanks to your amazing support is making ground-breaking discoveries all the time, bringing us closer to new treatments and diagnostic techniques. Keep up to date with all the latest breakthroughs: thebraintumourcharity.org/researchnews



Latest breakthroughs

Accelerating new treatments through imaging

A team at the Institute for Cancer Research has found that a scanning technique called nuclear magnetic resonance spectroscopy (MRS) could be used to monitor the effectiveness of a new generation of drugs for children with a glioblastoma.

Using the technique would spare young brain tumour patients the trauma of repeated surgery as they undergo treatment, potentially speeding up clinical trials and accelerating progress towards better survival.



Potential new anti-cancer agent

At The University of Nottingham, Professor Richard Grundy and his team have identified a potential anti-cancer agent called RHPS4. It works by acting against an enzyme called telomerase, which has been shown to play a part in maintaining cancer cells.

The team found that RHPS4 could affect some brain tumour types more than others, with particular glioblastoma and medulloblastoma cells appearing to be more vulnerable to the agent when compared with certain ependymoma cells.

Further investigation is now needed to understand if RHPS4 can be taken forward as a possible new treatment.

Improving quality of life for children

Professor Colin Kennedy and his team have shown how, in combination with early monitoring following treatment, an alternative radiotherapy technique could help improve quality of life for children with a brain tumour.

The research found that hyperfractionated radiotherapy, which involves giving radiation treatment more than once a day in smaller doses, had a lesser impact on children's memory, planning and organisational skills compared with conventional radiotherapy.



Image: Dr Michod with (left to right) George, Olivia and Emily.

Inspiring the next generation

Dr David Michod, who we are funding to investigate childhood glioblastomas at the UCL Institute of Child Health, has been working with us to inspire the next generation of brain tumour researchers. In 2013, following an open invitation in *The Grey Matters*, he gave six young people a tour of his laboratory in London and the opportunity to carry out an experiment.

This year, Dr Michod asked us to offer a week's work experience for anyone interested in research aged either 16 or 17.

George, Olivia and Emily were chosen to take part and they spent their week in Dr Michod's laboratory in July.

We caught up with Emily at the end of her work experience:

Why did you apply for the work experience?

I applied because I am passionate about biological sciences, particularly the areas of genetics and oncology. Also, it is my ambition to do a biomedical sciences degree at university and possibly become a research scientist myself.

What did you enjoy doing most?

Honestly, I enjoyed every aspect of the work experience but the bit that really stood out was that the experience was so hands-on. It was really enjoyable to carry out the experiments in the lab with more advanced equipment than I have used before.

What did you learn about?

As well as telling us what his research involved, David told us about the process of his research – what happens between forming his hypothesis and then drawing a conclusion. I found this very beneficial.

How will the experience inspire you?

The placement has definitely given me an idea of what it is like to work in a real research lab, and I am so excited to go to university and hopefully continue my education to have a career like this one day!

What would you say to our supporters who fund the work of Dr Michod and other brain tumour researchers?

After speaking to David and watching him carry out his research, it is clear that the research he and others are doing is essential to the battle against brain tumours.



Q&A with Dr Sylvia Kocialkowski

University of Cambridge

Dr Kocialkowski is part of a team we are funding at the University of Cambridge to uncover the role of the BRAF fusion gene in pilocytic astrocytoma brain tumours. The project is being led by Professor Peter Collins and builds on his previous findings around the importance of the gene. It is hoped that the work could help diagnose and treat pilocytic astrocytomas in future.

Read more:
[**thebraintumourcharity.org/fusiongenes**](http://thebraintumourcharity.org/fusiongenes)

What inspired you to become a researcher?

I never cease to be amazed how science can explain the natural world. At university I discovered how science can also cure diseases and I decided to do research into cancer.

What excites you about your job?

Everything! It is very exciting to get an original idea that might lead to a solution and to design and optimise an experiment that gets a result. It is exciting too to read about the latest discoveries, have discussions with colleagues and attend talks on related projects. Being a researcher is an interesting and worthwhile job.

Can you give us an idea of your typical day?

A typical day is split between work at the lab bench, doing the actual experiments, writing protocols and processing and analysing data. The day is planned around the experiments which usually involve several steps stretching over a few days.

What is the potential of the work you're doing with Professor Collins?

Professor Collins's lab was the first to discover a fusion gene in a paediatric brain tumour. The gene, called BRAF, is now being studied to try to reveal its contribution to the tumour process. Knowing precisely what this 'cancer' gene does could potentially allow us to disable it and therefore control the evolution of the tumour.

Why is more money needed for research?

Because the cure for brain tumours will come from research. Recently, there has been a surge of new discoveries into the genetics of the different types of brain tumours and this progress must be sustained with more funding.

How would you help us raise money for research?

I would like to take part in The Twilight Walk Windsor in October!



Meet the Young Ambassadors

We are proud to introduce The Brain Tumour Charity's first Young Ambassadors. The Young Ambassadors, who have all been affected by a brain tumour, are volunteering to spread the word and make an impact for other young people all over the UK.

Already they've taken part in media interviews, spoken to decision makers in parliament and approached their local hospitals to check on the distribution of our Newly Diagnosed Packs for everyone diagnosed with a brain tumour. Keep an eye on our website and social media profiles for updates on how the Young Ambassadors are helping us to lead the way across all our work.

Some of the Young Ambassadors told us in their own words why they signed up:

"I'm passionate about the charity and helping people who've had a brain tumour."

Tom

"I have a voice to share my experience and help make changes for those affected by a brain tumour."

Danielle

"If we all make one small change, together we will make a big difference."

Emma N

"I want to create awareness."

Cameron

"I want to spread the word so that people are aware of the brain, the best part of you."

April

"I want to support people affected by a brain tumour to make a link with other people and families."

Emma B

"I want to be an ambassador so that other people know that they are not alone."

Rebecca

Meet all the Young Ambassadors:
thebraintumourcharity.org/youngambassadors

Image (top): The Young Ambassadors pictured with our CEO Sarah and members of The Brain Tumour Charity team.

The Supporter Groups

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 shared goal of defeating brain tumours as fast as possible. All of the money the groups raise directly funds an area of work they have selected. If you would like to find out more please get in touch.

supportergroups@thebraintumourcharity.org
thebraintumourcharity.org/supportergroups
01252 749043

"When I first introduced our Supporter Group model, I could not have imagined how many families it would unite. I am honoured that we now have over 190 groups raising funds and awareness in communities across the UK, as together we are stronger in our battle to defeat brain tumours."

Angela Dickson, Founding Trustee



Welcome to our new groups

The Kate Fenney Memorial Fund

The Alan Powell Fund

The Keith Millington Fund

The Linzi Geddes Fund

The Riccardo Bozzini Fund

The Graham Coulling Fund

The Parr's Beating Brain Tumours Fund

The Delme Bowen Fund

The David Hardie Fund

The Ben Lear Fund

The Dan Knight Fund

The Angela Forster Fund

The Lucie's Little Smiles Fund

The Jonathan Bristow Fund

The Simon Ellison Fund

The Mr Feast Fund

The Frolics Fund

The Nia Lane Fund



Image (left): Beth the dog and her team at Beth's Fun Dog Show held in Greenways, Kent. Raising money for The Sarah Kitchener Perrow Fund.

Focus on The Kate Fenney Memorial Fund

The Kate Fenney Memorial Fund was set up after Kate lost her life to a glioblastoma in April 2014. Along with her husband, Craig, Kate was co-founder of The Music Shipping Company.

Craig says that Kate spent her life helping others in any way she could, but especially as a wife, mother, Guide Leader and friend to her company's staff.

Soon after Kate died, friends at Marshall Amplification approached Craig and his family with an idea for a fitting tribute – a world record attempt for ensemble drumming! The attempt, called drumBEAT, will take place in Manchester on 21 November and will see 1,001 drummers taking part.



An interview with Craig, Kate's husband

What first influenced you to fundraise in Kate's memory?

During Kate's illness, the support for us all from our customers, colleagues and many drummers was inspiring. Kate always helped anyone wherever she could – it is fitting that we continue to do this on her behalf.

Why did you start The Kate Fenney Memorial Fund rather than setting up your own charity?

I wanted to work with The Brain Tumour Charity on drumBEAT. The amount of drummers, individual supporters and sponsors means that awareness of brain tumours can be raised amongst a large audience. This is very important to us, as well as raising money. We found the Supporter Group simple to set up and we received great help in integrating this with our event registration process.

Why The Brain Tumour Charity?

I am very impressed with the way The Charity is run. As a Supporter Group, all money raised is used for charitable objectives rather than operational costs.

Which area of The Charity's work did you select to fund?

Through The Charity we recently visited St James's Hospital in Leeds to see the dedicated research they are doing. I would love to feel that we could contribute to this or other cutting edge research.

What would you say to people who are thinking of setting up a Supporter Group?

Do it now!

Read Kate's story:
thebraintumourcharity.org/katefenney



The Grand Sleepover

In the last issue we introduced you to The Silas Pullen Fund. Silas's mum, Sarah, told us about The Grand Sleepover, an afternoon and evening of live music and messing about for families. The aim was simple – “to have the best time ever, playing, dancing, giggling and possibly sleeping!”

Committee member Natasha explains the idea for The Grand Sleepover, which took place in July: “My inspiration came from the memorial of my darling godson, Silas. There was a live band, and the children were having a blast, dancing and singing. I wanted to recreate that moment and raise money for The Brain Tumour Charity at the same time. Silas also loved camping so it seemed like a good idea to throw that in the mix too, a proper family event!”

To get started, Natasha gathered together a group of 12 friends and they were soon making plans - they even got Orlando Bloom, Jo Whiley and The Hoosiers to come along on the night. Natasha says: “If you have a good idea and you work hard, people will believe in you and support you, and then you can achieve your goal. It's a team effort.”

In future Natasha would love to see other families getting together to hold their own version of The Grand Sleepover. She is keen to point out that, although the first event had 130 families attending, “it can be any number as long as it involves camping, music, fun and raises some money!”

Thank you so much to Natasha and all the committee.

Read more about The Silas Pullen Fund:

thebraintumourcharity.org/silaspullen



**Save
the date!**

Supporter Group Day
Farnborough
18 November 2014



Leave a donation in your Will

Every day, members of The Brainy Bunch do legendary things to raise funds for us, from runs and skydives to headshaves and sponsored silences.

Leaving a donation in your Will is less well known but equally legendary. As part of the Remember a Charity consortium, we are asking you to become a living legend by including The Brain Tumour Charity when writing or updating your Will.

Alongside taking care of loved ones, a gift in your Will to support our work can make a big impact for families in future generations who will be affected by a brain tumour.

Our vision is a world where brain tumours are defeated – with a donation in your Will you can be part of making this a reality.

thebraintumourcharity.org/legacy

“When recently rewriting my Will I contacted The Brain Tumour Charity as I have seen the devastating effect of brain tumours first-hand. After asking The Charity some questions, I felt confident that my money will be put to excellent use so I have decided to include a gift to them.”

Helen Raphael

— THE — **LEWIS MOODY FOUNDATION**

Tackling illness, fulfilling dreams

Launch of The Lewis Moody Foundation

On Saturday 31 May we launched The Lewis Moody Foundation at Twickenham Stadium.

The Foundation has been set up by Lewis Moody, the former England rugby captain, and his wife Annie to help young families affected by serious illness. It will offer days out and one-off experiences as well as funding research through The Brain Tumour Charity aimed at saving young lives.

Lewis and Annie decided to create The Foundation after being inspired by Joss Rowley Stark, a promising young rugby player who sadly lost his fight with cancer at the age of 16.

Supporters are already raising money for The Lewis Moody Foundation. Lewis says: “We are really hoping that as many people as possible get behind us – individuals, sports clubs, schools, companies – to help us make a real difference.”

Find out more: thelewismoodysfoundation.org

BRAIN TUMOUR CHARITY

Brilliant Minds International Symposium

Putting patients at the heart of research

We are dedicated to putting patients at the heart of research. Part of the way we do this is to drive Patient and Public Involvement (PPI), which is about connecting patients and researchers to maximise the impact of research.

The unique insight of people affected by a brain tumour can help with the design and evaluation of research studies, ensure that research is focussed where it is most needed and break down barriers to joining clinical trials.

Our aim is for patients to be involved in the brain tumour research process wherever possible. At the Brilliant Minds International Symposium in May, part of the development of our new research strategy, leading researchers heard first-hand the views of patients about increasing the relevance and effectiveness of new projects.

We also ensure that patients and carers are involved in reviewing applications for research funding. Our Grant Review and Monitoring committee (GRAM) is made up of thirteen academic experts and two people with personal experience of a brain tumour diagnosis. The two 'lay members' give patients and carers a voice in deciding which research projects should be prioritised for funding.

Peter Moreton, one of the lay members, says: "It's great to be part of GRAM, working on the committee to make sure that research funded by The Brain Tumour Charity will lead to the best outcomes for patients."

"The view of the patient can be integral to our work as researchers. Understanding what they and their families deal with day to day ensures that we undertake our research with a strong awareness of the issues that impact on people's lives. I would encourage other researchers to make use of this perspective as often as possible during their projects."

Steven Clifford,
Professor of Molecular
Paediatric Oncology



Play your part

Patients, carers and loved ones

There are many ways that you can take part, including:

- Helping to identify research priorities.
- Joining a research steering group.
- Developing or reviewing The Brain Tumour Charity's information fact sheets or 'lay' information about research.
- Interviewing research participants.
- Talking to local community groups to share findings from research.

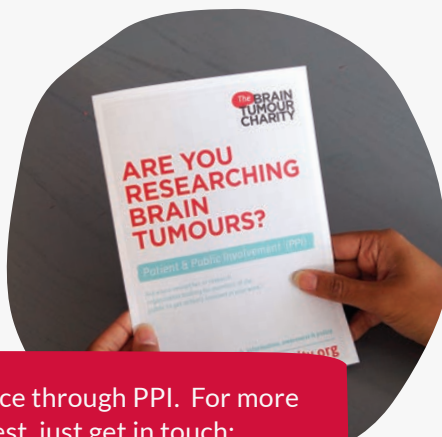
Whenever we have a PPI opportunity, we will let you know via our website, newsletters, e-newsletters and Facebook support group which you can join at bit.ly/supportonfacebook. Keep checking back for new announcements.

Researchers

We are keen to hear from you and will happily promote a call for PPI wherever we can as well as working in partnership with you to maximise the success of your project.

Previous calls for patient involvement include:

- Over 300 responses for a quality of life survey.
- Over 100 responses for an impact survey.
- Over 20 patient responses for a study into glioblastoma.



Together, we can make a real difference through PPI. For more information, or to register your interest, just get in touch: 01252 749999 / support@thebraintumourcharity.org

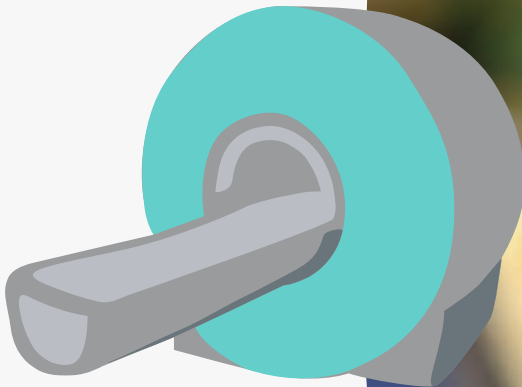
Expert information on treatments

Our Support and Information Service offers both emotional and practical support to anyone affected by a brain tumour diagnosis and handles around 5,000 enquiries a year.

This can range from talking through people's experiences to providing detailed information on a clinical trial that they might be eligible to join. The majority of what we do is emotional support, and this can be vitally important for those who feel they need to talk to someone without overburdening their friends and family.

We also help regularly with information about treatments. People are becoming increasingly engaged in the healthcare process and can look up more information than ever on what their treatment is likely to involve.

The dissemination of healthcare information to the public is a good thing, but it can be difficult to find resources that you can trust. We are dedicated to producing and providing only information that we know to be accurate and up to date.



Receiving treatment: your first steps

1

CLARIFY YOUR TREATMENT PLAN

Remember that it's you who is going to be having the treatment and nobody else. You have a right to know exactly what is being planned and a reasonable time frame for it to occur. Your healthcare team deal with many patients every day and it is easy for them to forget that you might not know exactly what they are talking about. Before giving your consent it's important to understand what they are suggesting so don't be afraid to ask.

2

GET A SECOND OPINION

Under the NHS Constitution you have the right to ask for a second opinion. Though this does not automatically guarantee that you will get one, most healthcare professionals are willing to oblige and understand the sensitivity around this subject. Getting a second opinion won't necessarily change the outcome but it can often help you to accept that you have explored every avenue and that the treatment being offered really is the best option.

3

FIND OUT IF YOU CAN JOIN A CLINICAL TRIAL

Clinical trials might not be mentioned for various reasons, for example, not knowing of a trial that is suitable for you. By using reputable sources like our online clinical trials database and Research & Clinical Trials Info Line, you can try and find if there are any trials out there for you and then take the information to your doctor to discuss in more detail.

Don't forget that a clinical trial will mean you getting the current 'gold standard' of treatment, even if you don't receive the new therapy being trialled.

Online clinical trials database



[thebraintumourcharity.org/
clinicaltrials](http://thebraintumourcharity.org/clinicaltrials)

Research & Clinical Trials Info Line



01252 749999

4

CONTACT OUR SUPPORT AND INFORMATION TEAM

Our Support and Information Team is here for you. If you have a question then we will find you an answer, even if it is a more appropriate person to contact. When we don't know something immediately, we will always get back to you with the information you need as soon as possible.

You can also ask the team to send you a Newly Diagnosed Pack, which provides simple and reliable information for every brain tumour patient, including a booklet about treatments.



support@thebraintumourcharity.org



0808 800 0004

Free from landlines and most mobiles.
Mon – Fri 9am – 5pm.

Start Christmas with us

The countdown has begun but don't worry – we're here to help make your Christmas fun, festive and stress-free.

Christmas cards and gifts available now

There's something for everyone in our brand new Christmas catalogue 2014. Take your pick and order all the cards you'll need in one go!



How to order

Choose from our full range of cards, gifts and essentials using the form in the enclosed catalogue or buy online:

thebraintumourcharity.org/shop

This year we've got more Christmas gifts and essentials on offer than ever before. From puzzles to test all the family to an innovative set of shopping bags that will transform your trips to the supermarket, we've got a selection that we're sure you're going to love.



In 2013 we raised over £40,000 from card sales alone, enough to fund a new pioneering research project for a year.

Thank you for supporting The Brain Tumour Charity at Christmas. Every penny goes directly to our work.





Festive ways to fundraise

Here are some ideas for how you can raise some cash while getting festive in the months to come. Have fun!

Mince pie and mulled wine party

Make sure the Christmas tree is sparkling, put on some carols and serve mince pies and mulled wine for friends and family in exchange for a donation.

Christmas fair

If you're creative or you know someone who is, take out a stall at your local Christmas fair and sell handmade gifts, decorations, clothes or treats.

Last hour's pay

Ask your colleagues to donate their last hour's pay before Christmas so that everyone leaves for the holidays knowing they are making a difference.

Secret Santa

Instead of spending £5 on Secret Santa presents, get your friends or colleagues to set the limit at £4 and have everyone put the extra £1 in a collection box.

January sale

Sell your unwanted presents at a post-Christmas car boot sale to make sure they go to a good home and donate the proceeds to us.

Join the Santa Run phenomenon!

Victoria Park's annual Santa Run is incredibly popular so make sure you sign up quick if you want to be involved in the fun on Sunday 7 December. The idea is simple – over 2,000 participants dressed up in free Santa suits take on a 5k or 10k course. It's a real spectacle and an experience you'll never forget! Book your place: thebraintumourcharity.org/santarun



Stine Giles

*“Fulfilling
her promise”*

Stine Giles, wife of former England cricket star Ashley Giles, was diagnosed with a brain tumour just before Christmas in 2006. The tumour was removed but has since returned and Stine is being monitored with regular scans following treatment. She and Ashley are currently enjoying life with their family and have chosen to raise money and awareness for The Brain Tumour Charity.

The initial symptoms of Stine's brain tumour were night-time headaches during the first part of 2006. One headache made her physically sick but when she called out the local GP she was told there was nothing wrong with her.

Stine dismissed the headaches as stress but just before she was about to fly out to Australia to see Ashley represent England, things took a turn for the worse.

“I was writing Christmas cards with dreadful handwriting that looked like a five year old's,” says Stine.

“At the gym I was falling off the exercise ball and I couldn't do my normal weights because I wasn't able to balance.”

After she started to drag her right leg, Stine went to see a different doctor who thought she might have had a minor stroke. Instead, a CT scan revealed a large benign brain tumour that was putting pressure on her brain.

An operation to remove Stine's tumour took place five days after her diagnosis and she spent Christmas in hospital.

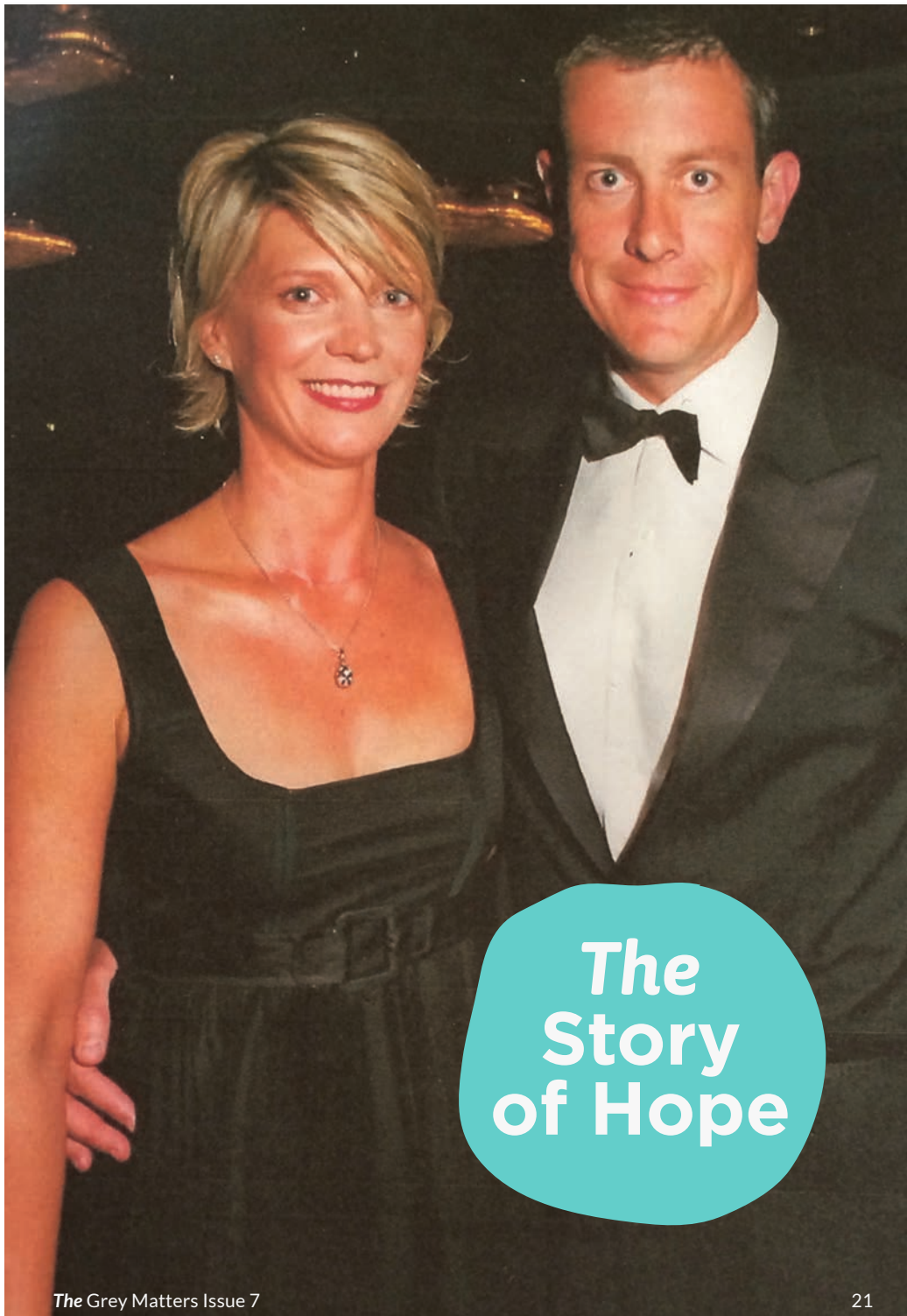
Despite the tumour returning in 2012, Stine is now throwing herself into fundraising for The Brain Tumour Charity. Ashley's JustGiving page explains: “Following on from Stine's brain tumours and subsequent treatments to eradicate them she promised herself that if the treatments went well and her prognosis was good she would endeavour to raise some much needed funds.”

“I am pleased to say that Stine's last couple of scans (one of which was crucial as to how effective the last intensive treatment had been) were incredibly positive and so we are back enjoying life as a family and Stine is fulfilling her promise.”

Stine's flagship fundraiser is an Indian Summer Night's Party to be held at Edgbaston Cricket Ground in October, featuring an Indian three course meal and entertainment.

Ashley has also been busy fundraising this summer after agreeing to play for Nuneaton Cricket Club in return for a donation.

We are very grateful to Stine and Ashley for their support. Find out more about the Indian Summer Night's Party at thebraintumourcharity.org/summernight



The Story of Hope

Image:
Blindfolded orienteering
activity at the Brecon
Beacons Family Day.

Brecon Beacons Family Day

5 July 2014



In July, we held our latest family day for children with a brain tumour, their siblings and parents in the Brecon Beacons. Children and adults alike had a great time building rockets, climbing trees, shooting targets and orienteering.

Family days have become a major part of The Charity's calendar, so that families affected by a brain tumour can have fun together away from the hospital and out of the house.

We already have a variety of other activities being planned for our future family days all over the UK. Register your interest now if you'd like to join us:

0808 800 0004

support@thebraintumourcharity.org

*"It's all about the
kids, but the adults
loved it too."*

*"A lovely day.
Had a great time.
Won't forget it."*

Brecon Beacons Family Day attendees



A day in the life of Elissa Coster

Children and Families Worker

I start the day at my desk in the Support and Information Team and begin to get in touch with families I support.

One call to a parent reveals that their son, who is living with a brain tumour, suffered a seizure in the night and left the family very shaken. The son is on watch and wait – which means that doctors are closely monitoring his tumour without giving any treatment until it is needed. It is an anxious time waiting for the next scan. I am able to listen, send a fact sheet, arrange a home visit and speak with the boy's school to offer them information about managing seizures. The family, who we met at a family day, are grateful to have our support.

Following this, I meet with our PR Manager to make a shortlist of the parents we know who are happy to talk to the press about the late diagnosis of their children. Stories in the media really help to raise awareness of the signs and symptoms of brain tumours.

In the afternoon I visit a London hospital for a meeting with a healthcare professional. Here I discuss the support I offer and introduce The Brainy Bag, which is designed for children with a brain tumour and includes games, toys, puzzles, pyjama vouchers and age-appropriate information. To make sure that as many people as possible know about us and our services, these meetings are vital. The healthcare professional is impressed and asks us to provide The Brainy Bag for her patients. I hope that this will be the start of a very productive relationship.

Then it's time for an early night, as I have to set off early in the morning to meet with some of our Young Ambassadors whose tireless efforts help promote The Charity throughout the country.

Get hold of The Brainy Bag

The Brainy Bag gives children with a brain tumour something that truly belongs to them at a confusing time in their lives whilst providing parents, carers and healthcare professionals with information to help explain difficult subjects. Email support@thebraintumourcharity.org to get hold of your bag.



Our HeadSmart campaign raises awareness of the symptoms of childhood brain tumours to drive down unacceptable diagnosis times.

headsmart.org.uk

Thank you for a brilliant three years

In June we celebrated HeadSmart's third birthday. Since the launch of the campaign, we have brought down the average time it takes to diagnose a childhood brain tumour from 14 to 6.7 weeks, saving lives and reducing long-term disabilities.

We'd like to say a huge thank you to all our supporters and HeadSmart Community Champions over the last three years, not least for helping to distribute over 1million symptoms cards.

Together we continue working every day to achieve our target – an average diagnosis time of five weeks or less. Visit thebraintumourcharity.org/teamheadsmart to join us.



HeadSmart in action: Luke's story

After Fay and Steve's six-year-old son, Luke, started being sick and having frequent headaches, they took him to the GP.

"She did all of the neurological tests and they didn't flag up anything obvious," says Fay. "She asked if he might be worried about school."

The GP advised Fay to bring Luke back if things didn't improve and when Luke was sick again, Fay began searching online.

"I very quickly came across the HeadSmart website, which lists all the main signs and symptoms of children's brain tumours."

Fay then remembered all of Luke's other niggles over the previous few weeks, such as mood

swings and problems with co-ordination.

"The HeadSmart information crystallised everything. It gave me what I needed to go back to the GP and say: 'I'm really worried.'"

This time Luke, now seven, was sent for a scan which confirmed that he had a brain tumour. Neurosurgeons were able to remove the tumour completely and Luke will be monitored closely for the next 20 years.

"Luke is a real inspiration," says Fay. "He takes everything in his stride and is well on the road to recovery."





Second place in the National Lottery Awards

We were delighted to announce at the end of June that HeadSmart had been nominated to win the Health category of the National Lottery Awards 2014, competing against six other projects.

Public voting was open for around a month, and we had a tremendous response from our social media community, with more people liking and sharing the stories, videos and graphics we posted than ever before. Our post on Facebook highlighting that 10 children and young people would be diagnosed with a brain tumour during one week in the summer holidays was seen by nearly 300,000 people.

Whilst we sadly didn't win, we came a close second and the National Lottery Awards campaign has meant that thousands more families are now brain tumour aware.

Thank you to the thousands of you who voted and spread the word to your friends and family, whether online or by word of mouth.

Martin Kemp visits HQ

In support of our bid to win the National Lottery Awards 2014, actor, film director and musician Martin Kemp visited HQ to meet families affected by a brain tumour and our new Young Ambassadors (read more on page 9).

Martin, who has had two brain tumours himself, said: "Today was one of the most inspirational days I've had for a long time. Let's hope HeadSmart wins the National Lottery Award. I want to say thank you to all the amazing children and adults that I met today."

Watch a video of Martin's visit:

bit.ly/MartinKempvisit

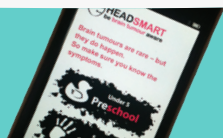


HeadSmart on social media

facebook.com/headsmartcampaign

twitter.com/HeadSmartUK

**Know the symptoms
on-the-go**



**Text SMART to 81400
for your free mobile
symptoms guide.**



Meet Jenny, Office Volunteer

Jenny has been volunteering at our Farnborough office for one afternoon a week since the start of 2013. Her main roles have been packing shop and Christmas card orders, despatching fundraising materials and filing.

Why did you choose to volunteer here?

I lost my mum to a brain tumour when I was 19 and had a meningioma removed myself in 2006. Thankfully I have generally recovered well. When I saw The Charity's sign when I went past the office I did a double take. I thought signing up to volunteer seemed a good way to do my bit and use the skills I've built up after 25 years as an infant school Admin Officer.

What do you enjoy most about volunteering?

It's great to see the requests for fundraising materials coming in and to find out what fundraisers are doing all over the country. Orders can be anything from just a few badges or stickers to a whole Supporter Group toolkit like I've been preparing today.



What's it like in the office?

Everyone's very friendly and there's a real sense of common purpose. The Charity has grown hugely in the time I've been here which has truly been an eye-opener.

Have you got any memories which stand out from your time with us?

The Volunteer Lunch in March this year was a complete surprise and a nice thank you in recognition. It's good to be appreciated. The Charity is close to my heart and I find it very rewarding.

We rely on the skills and commitment of our volunteers every day, and we are so grateful for the time they give.

If you think you could join The Brainy Bunch as a volunteer, we'd love to hear from you. There's something for everyone and we'll be there every step of the way with guidance and training if necessary.

Have a look at some of our opportunities, then drop us a line if you think you've got what it takes!

volunteering@thebraintumourcharity.org

01252 413162



Christmas Card Angel

Be an angel this Christmas and promote our range of cards and gifts to everyone you know. We'll send you a sales pack to get you started.

Collection Tin Co-ordinator

This role is about getting our collection tins into shops, pubs, gyms and garages and being responsible for sending in the money. Some volunteers also organise street or supermarket collections.

Cheer Squad

Our runners and challengers always say how our cheer points give them that vital boost to see them home. Come and be part of the occasion.

Office Volunteer

From packing up fundraising materials and HeadSmart symptoms cards to office admin, data entry and video editing, there's sure to be a way to use your skills.

HeadSmart

Community Champion

Could you drive our HeadSmart early diagnosis campaign for childhood brain tumours in your area? You'll distribute our symptoms cards far and wide, spread the word in the local press and give talks to clubs and schools.



Share your story or raise awareness

Whether you're living with a brain tumour or you've been affected by the diagnosis or loss of a loved one, you can raise awareness of the disease and The Charity. This could be as a Volunteer Ambassador for our support services (email **volunteering@thebraintumourcharity.org**) or, if you'd be happy to feature in the media and online, visit **thebraintumourcharity.org/yourstory**

Fundraising at work

Thank you
for all your
hard work

Wherever you work, fundraising is an easy way to bring colleagues together and make a real impact on the fight against brain tumours.

The benefits

- Builds better working relationships across teams.
- Boosts team morale.
- Involves staff at all levels.
- Raises social responsibility profile.

Find out more at thebraintumourcharity.org/corporate

Ready, steady, fundraise!

You can get involved whatever the size of your company:

The Brainy Bake Off

Get everyone to bake cakes, brownies, biscuits or bread and bring the treats into the office to sell to hungry colleagues.

Dress down day

Give your dress down day a theme and ask everyone to make a small donation to come in fancy dress.

Events with a twist

Add a fundraising angle to your Christmas party, social function, conference or team day. Raffles and auctions are great fun and can raise a lot of money.

Team challenge

Sign up for a sponsored run, cycle, skydive or trek with your team and get ready for the challenge of a lifetime.

A quick look at Payroll Giving

Payroll Giving (also known as Give As You Earn or Workplace Giving) is a tax free way for you to donate regularly straight from your salary, helping us to plan for the future and give our work the sustainable funding it needs.

WHY SIGN UP?

- You have complete flexibility to choose the amount and frequency of your donations.
- All Payroll Giving donations are deducted from your salary before tax so every £1 you give will only cost you 80p.
- Your company can win a prestigious Payroll Giving Quality Mark Award by getting just 1% of employees to join the scheme.

Visit thebraintumourcharity.org/payrollgiving to get started with Payroll Giving.



Q&A with Simon Hay CEO, dunnhumby

Image (above): dunnhumby employees preparing to take on a skydive.

The leading customer science company, dunnhumby, selected us as their Charity of the Year in 2013 and set a fundraising target of £60,000.

Why is it important for companies to support a charity?

It is the right thing to do. We have passionate people who like to make things happen and we learn about ourselves, the challenges others face and gain some perspective on life too.

Why did dunnhumby choose to support The Brain Tumour Charity?

Our “Helping Hands” programme lets all our colleagues nominate charities and everyone has a vote.

It was impossible not to be moved by the stories of a couple of colleagues who have devastatingly lost loved ones to a brain tumour. The Brain Tumour Charity has impressed us and it is a gift to be a small part of its work.

How have your employees raised money?

We have had people running the London Marathon, jumping out of planes and our main events, the Charity Show and the Christmas Auction, raised over £30,000 alone. Auction

items donated by employees have included dinner with the leadership team and graduates cleaning your house!

How else have employees got involved?

We use our business skills and experience. Our research team helped to assess the impact of The Charity’s support and information services, our word-of-mouth marketing team (BzzAgent) ran a Bandanas for Brain Tumours Day campaign and people have donated items for The Brainy Bag, which is being given to children with a brain tumour.

What does The Brain Tumour Charity bring to the partnership?

It is valuable to share thinking on our similar challenges. The Charity is also really good at telling us how we can help, which inspires employees to do more!

Talk to your colleagues, HR team or manager to find out how your company can support The Brain Tumour Charity.

Coast to coast challengers

In June, Sadie McNaughton and Will Bush set off to cycle The Way of The Roses, a route covering 170 miles of stunning landscapes between Morecambe on the Irish Sea coast and Bridlington on the North Sea coast.

The pair decided to raise funds after both Sadie herself and Will's dad, Graham, were diagnosed with brain tumours within six months of each other.

Despite Graham sadly passing away in the days before the ride, the pair continued with their training and fundraising, and Will touchingly rode the entire route on his father's bike.

Sadie and Will, who have raised over £5,500, wrote:

"After a lot of rain, some lovely sun, some steep uphill and wonderful downhill we made it all the way! We want to say thank you so much to everybody for your generous donations, we have raised far more than we ever expected to!"



*Discover the cycle of a lifetime
at home or abroad*



Land's End to
John O'Groats



Venice to Rome



Ho Chi Minh to
Angkor Wat

Get your place or find more routes: thebraintumourcharity.org/cycles

Do
something
incredible

Whether you're looking for a fundraising challenge that will push you to the limit, transform the way you see the world or give you an excuse to let your hair down, we'd love to help find your perfect fit.

Take a look at some of the adventures of The Brainy Bunch for inspiration, then see what's on offer at thebraintumourcharity.org/challenges



Arctic husky trail

A 250km Arctic husky trail saw Laura Millington and Helen Sherwen raise £9,327. Laura says: "We camped alongside our fluffy companions in -35°C temperatures. Every morning we cooked breakfast, packed up and began sledding. It was completely out of our comfort zone!"



Three Peaks

James and Kris successfully completed the Three Peaks Challenge with four friends in memory of Matthew Chadwick, raising nearly £4,000. Kris said: "We had a great team, two fantastic drivers and rain and snow only on Ben Nevis."



Tough Mudder

The Tough Mudder challenge was no match for Steven Craven and his team, who raised over £690 for The Steve Harris (SHY) Memorial Fund. Steven said the ice bath was "very painful" and he even got his head shaved for the event.



The Color Run

In July, Annie and friends raised over £1,500 by taking part in The Color Run. "It was such an amazing day! The atmosphere was incredible, everyone was so happy and getting covered in paint was a lot of fun."

Put the **FUN** into **FUNdraising**

Resell and recycle

Most of us love an opportunity to declutter with minimum hassle. Set up a table at work or a garden sale at home and ask people to bring and buy.

Bag pack

See if your local supermarket will let you bag pack in exchange for donations. We'll send you a t-shirt and a bucket and you'll soon find that your hard work helps to raise awareness as well as funds.

We dare you

Have your head shaved, have your legs waxed, give up alcohol, give up sugar, stay silent for a day. You'll easily get sponsorship for a personal challenge.

Car wash

Recruit some willing friends and family, wrap up warm and get drivers to donate £5 for a wash and wax. Good clean fun!

Talent show

From rollerblading to singing, juggling and dancing, you'll be surprised at how many people want to show off what they can do! Charge £5 to enter and £10 to watch.

Get quizzical

We love a quiz at lunch, in the pub or round the kitchen table. Half the fun is thinking of the questions! Charge a small fee to enter.

Baby photos

A fantastic party game. Everyone brings a baby photo and guests match as many pictures as they can to their friends in return for a few pounds. Give a prize to the winner.



Our runners, cyclists and challengers are incredible but if marathons and extreme obstacle courses aren't for you, there are so many other ways you can join The Brainy Bunch. Whether you're a first time fundraiser or a seasoned supporter, we hope these easy ideas for raising money in your community inspire you to go out and have some fun.

Remember, we're here to help you make plans, spread the word and smash your target!

fundraising@thebraintumourcharity.org

01252 749043

Dates for your diary

SEPT

- 20 Wiltshire Family Day
- 21 The Twilight Walk Warwick
- 28 The Twilight Walk Chester

Walk with us



Save the date!

Bandanas for Brain Tumours Day
6 March 2015

OCT

- 5 Great Scottish Run Glasgow
- 11 Indian Summer Night's Party hosted by Stine and Ashley Giles
- 12 The Twilight Walk Windsor
- 12 Royal Parks Half Marathon London
- 19 Great Birmingham Run
- 26 Great South Run Portsmouth

NOV

- 14 Wentworth Golf Day and Gala Dinner
- 18 Supporter Group Day
Farnborough
thebraintumourcharity.org/supportergroupday

With Darren Gough!

DEC

- 7 Santa Run
London

All month festive fundraising!
See page 19.

*Don't miss out
on the Brighton
Marathon on Sunday
12 April 2015. Places
are going fast.*



For more information about fundraising events,
visit thebraintumourcharity.org/events

Thank you to our fundraising heroes

Every day you inspire us with your dedication, effort and passion to change the odds and make a difference. Here are just a few highlights from your fundraising over the last few months.

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



A 1,000 mile coast to coast caravan trip in memory of their son, Jon, allowed Roy and Jacky Fredrickson to share their story with people they met along the way. They raised over £300 in donations for The Jon Fredrickson Fund.



A bungee jump at Salford Quays in May saw James raise almost £700 in memory of his uncle and charity ambassador, Tim Frost. James says: "I was humbled by my uncle, for the life he led and his dignity and strength in his final battle. That is true bravery."



Along with her sons, Beverley Reekes held a coffee and cake afternoon to mark the first Father's Day since her husband died of a brain tumour last year. The event, held in a local church, was attended by over 300 people and raised £3,000.



Love the Life you Live, a netball tournament in memory of Aoife O'Connor at Lode Heath School, raised £1,550. The event was held for the second time in two years and was organised by Liz Bodfish.



Chris Lal lost her son Robin to a brain tumour. He was known for 'striking a pose' in photos so, to mark his birthday this year, Chris and friends launched a social media campaign to get as many people striking a pose as possible in exchange for a text donation. They had photos submitted from over 21 countries and have now raised over £9,500 in Robin's memory.



Inspired by brother-in-law, Carlos, who is currently receiving treatment for a brain tumour, Lee Bell from Washington raised £3,152 by having his head shaved.



By eating chocolate and singing Barry Manilow songs to keep going, Helen Butler walked 79 miles over six days to complete the Yorkshire Wolds Way! The walk raised £700.



In June, Melissa Holian ran the St Albans Half Marathon in support of Orla and her family, raising over £2,348. She says:

"Two years ago, some very dear friends of ours were given the devastating news that their beautiful 10 month old daughter, Orla, was suffering from a grade four malignant glioblastoma. Since then Orla has been through 18 months of gruelling chemotherapy and undergone multiple life-threatening operations. In spite of all this, she is still smiling and still learning new things every day. I really wanted to complete the race for all the people who sponsored me and for Orla. She is such an amazing, brave little girl. At the moment she is having physio with a walking frame and her mum sent me a video of her taking 20 steps. It is the best video I've ever seen."



Led by mum-to-be Helen Neale, a team took to the waters at Lake Windermere as part of the Great Swim series, raising £1,461 so far.

Along with friends and family, Carol Rutherford tackled The Greensands Ridge Rovers Walk in Bedfordshire for the second year running. The group has raised nearly £11,000 to date.

Lynne Lyon hosted a barbeque attended by over 60 guests in her garden. She raised £752 by charging £5 for food and holding a raffle and a 'guess how many sweets in the jar' competition.

Seventeen year old Caitlin Powell and her team braved extreme weather to scale Ben Nevis, Scafell Pike and Snowdon in the Three Peaks Challenge. The team was driven through the night by Caitlin's father, Steven, and has raised over £3,800 so far.

A sponsored walk, a pub quiz and donations made by a local florist saw Kelly Bailey from Shropshire raise £3,144.



After seeing the care Stuart Woodcock received after being diagnosed with a brain tumour, the Woodcock family ran the Manchester 10k and raised over £2,400. Stuart was on hand at the race to cheer on his team!



Members of The Brainy Bunch have been taking on skydives all over the country. Dee and Claire jumped together to raise £2,000, Natalie (in the photo) raised £1,190, Anna raised £1,100 and Hannah played her part in a successful world record attempt for the number of tandem skydives in a day, raising £1,601. Hannah's mum Maria says: "It was a lovely atmosphere and everyone looked really happy! Hannah absolutely loved the skydive and was so pleased to have been involved."

The Ferrar family (below), friends and supporters raised £5,300 at their family fun day, held in Willaston village in memory of Lynn's husband, Bill.

Thank you for all you do.

Together we can defeat brain tumours.

If you wish to make a donation to support our vital work, please complete the form overleaf and return to the address below. You can also donate online: [**thebraintumourcharity.org/donate**](http://thebraintumourcharity.org/donate)

If you know someone who would like to support our work why not detach this form so they can make a donation?

You could also give them your copy of this newsletter so that they can see the impact of our work.

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



We rely 100% on voluntary donations

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

Name: _____

Address: _____

Postcode: _____

Email: _____

Phone: _____

Signature: _____ Date: _____

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.

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

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

Please pay The Brain Tumour Charity the sum of:

☐ £25 ☐ £10 ☐ £5 ☐ Other £ _____

☐ per month ☐ per quarter ☐ per year

Account name: _____

Account no. _____ Sort Code: _____

Bank name: _____

Bank address: _____

Postcode: _____

Start date for payments: ____ / ____ / ____

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

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

☐ I wish to donate by cheque

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

☐ I wish to donate by credit/debit card

Card type: ☐ Visa ☐ Mastercard ☐ Maestro

☐ Visa Debit ☐ CAF

Card number: _____

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

Issue no: _____

Signature _____ Date _____

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

Complete this form and post it to:
The Brain Tumour Charity, Hartshead House, 61-65
Victoria Road, Farnborough, Hampshire GU14 7PA

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

You can also donate online at thebraintumourcharity.org or text HOPE to 70555 to donate £5*

*see terms and conditions at thebraintumourcharity.org/waystodonate

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