

The Brain Tumour Charity shining a light on

# The GREY MATTERS

The **BRAIN TUMOUR CHARITY**

Research | Awareness | Support

Issue 13 Autumn 2016

Investing in new research

A united approach to patient data

Defeating brain tumours: one year on

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



## Something for every occasion

We're excited to have expanded our online shop with a brand new range of beautiful greeting cards, canvas bag and a new occasion favour – perfect for any celebration or to simply let someone know that you're thinking of them.

Don't forget, every time you shop with us you're helping us to defeat brain tumours!

Happy shopping!  
[thebraintumourcharity.org/shop](http://thebraintumourcharity.org/shop)

## The TWILIGHT WALK

It's not too late to sign up to *The Twilight Walk*

#WalkWithUs this October!

If you're looking for a fun and easy-going fundraising challenge, then this is the event for you! Join us as we return to Warwick, Chester and Windsor – your three favourite locations – to walk 10k through the historic streets at sunset and stamp out brain tumours for good.

To join the thousands of others taking part, visit [thebraintumourcharity.org/thetwilightwalk](http://thebraintumourcharity.org/thetwilightwalk)



# Hello

I'm proud to bring you the latest issue of *The Grey Matters*, packed with developments that have taken place since I've been in Rio.

I've been involved with The Brain Tumour Charity since losing my dad, Rob, to a brain tumour in 2011. The Charity provided my family with incredible support and I'm honoured to give something back.

Whenever I speak to someone from our community, I'm always touched by an overwhelming sense of determination to unite together and defeat this devastating disease.

It's amazing how far we've come. When my dad was first diagnosed in 2006, things were very different. Support and information, funding, collaborative research and the chance to meet others going through the same experience were few and far between.

Competing in the Olympics always reminds me of how important teamwork is, and I'm so proud to be part of a united brain tumour community that is working together to reach our goal.

We still have a long way to go, but I hope the features in this issue inspire you to do all you can to continue our battle.

**Tom Daley**  
 Patron of The Brain Tumour Charity

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# Investing in new research

*We're delighted to have just awarded funding to three new research initiatives, focussing on quality of life.*

In the last issue of *The Grey Matters*, we announced that we'd just invested £4.3 million in new and exciting research. We're proud to now unveil the final three initiatives that make up part of this investment.

These new patient-focussed initiatives all address quality of life issues and we're looking forward to working with leading researchers across the country. This will help us get closer to achieving our goal of halving the harm of those affected, sooner.

As always, it's only thanks to the support and dedication of our amazing community that this investment has been made possible. By coming together, we can defeat brain tumours.

Further information on all of our new research initiatives can be found at [thebraintumourcharity.org/new-research](http://thebraintumourcharity.org/new-research)

## Did you know

Brain tumours are the biggest cancer killer of people under 40, yet less than 2% of all funding into cancer research in the UK is invested in brain tumours. Your donations, including Gifts in Wills, are helping to change this.



## Enhancing communication and quality of life

**Professor Colin Kennedy,  
The University of Southampton**

Professor Kennedy is working to improve the communication between children with brain tumours, parents and their doctors via an online reporting system.

He believes that quality of life and mental health suffer if children aren't monitored closely straight after diagnosis. He is championing the importance of discussing general well-being, as well as the side effects of the tumour, during routine follow-up appointments to reduce these issues.

## Combatting the side effects of cerebellar tumours

**Mr Conor Mallucci,  
Alder Hey Children's Hospital**

Mr Mallucci is using a surgical approach to investigate Cerebellar Mutism Syndrome (also known as CMS and Posterior Fossa Syndrome), a serious and poorly understood side effect seen in 25% of children who have tumours removed from the cerebellum – located at the very back of the skull.

Mr Mallucci hopes to develop a greater understanding of CMS so that children's treatment and quality of life can be improved.



## Improving treatment strategies for medulloblastoma

**Professor Chris Clark,  
Institute of Child Health, UCL**

Professor Clark is using DTI – Diffusion Tensor Imaging; a technology which measures the flow of water around the brain – to explore which areas of the brain can be affected during treatment for medulloblastoma, causing symptoms of CMS.

He hopes to define areas of the brain that should be avoided during treatment to minimise long-term effects and improve quality of life.



## 500 miles in memory

A huge thank you to our trustees Andy Foote and Tim Burchell, and their friends Mark Roberts and Steve Verrall, for raising over £52,000 by completing the world-renowned 500-mile Camino de Santiago walk across northern Spain.

Andy's son Joseph was diagnosed with a brain tumour at the age of two. Despite multiple operations and a worldwide search for effective treatments, he died in 2007 aged nine.



## Update from the Tennant lab

It's almost three years since we started funding Dr Daniel Tennant at the University of Birmingham. Dr Tennant and his team have been investigating a new approach to treating adult gliomas spanning low and high grade. We caught up with him to hear about their progress.

### **Please tell us a little about your research**

In some cases tumours can develop because the energy producers in cells (known as mitochondria) become dysfunctional. We've been investigating how and why mitochondria change in the first place, and hope to use this information to develop new therapies to target them.

### **What's unique about your research?**

Studying the role of mitochondria in brain tumour development is a really new area of investigation. There are very few brain

tumour labs across the world focussing on this – even now, three years after our work started. By questioning the basic processes by which things happen, we can hope to make fundamental changes in our understanding of brain tumours that will lead to a better chance of our findings eventually leading to a cure.

### **How has funding from The Brain Tumour Charity helped?**

This research would never have got off the ground without funding from The Charity. By taking a risk on a pioneering project such as ours, The Charity has enabled us to make vital discoveries which could lead to more successful treatments for those affected.

### **What progress has been made so far?**

We've made some very interesting discoveries over the last three years. We've found unusual ways in which mitochondria evolve and have linked this directly to a change in response to therapy. This means that it could be possible to tell whether or not a patient would respond to a particular therapy or treatment, depending on how their mitochondria have evolved.

### **You're nearing the end of our funding, what's next for you?**

We'll be fine-tuning the pathway between dysfunctional mitochondria and therapy resistance over the next couple of months, which will bring this stage of our project to an end. The next step is to ensure this is incorporated into clinical decision-making.



## See inside our labs

Wondering what day-to-day life looks like inside our labs? You can learn more about Dr Tennant's research and the other initiatives we're funding by watching our new series of lab videos. See behind the scenes and hear from the lead researchers on what their work is aiming to achieve at [bit.ly/InsideOurLabs](http://bit.ly/InsideOurLabs)

## SGC update

In the last issue of *The Grey Matters* we introduced you to Dr Wen Hwa Lee from from The Structural Genomics Consortium (SGC) at the University of Oxford. As part of this pioneering partnership, which will help us pave the way for the future of research into brain tumours, we're funding two research posts at the SGC to explore brain tumour development.

We're pleased to announce that we've now filled these posts and our new researchers will start work later this autumn.

To learn more about the partnership, which we're one of just a handful of charities to be involved in, watch our SGC animation at [thebraintumourcharity.org/SGC](http://thebraintumourcharity.org/SGC)

## Where we've been

### National Paediatric Information Day

11 June

We hosted a National Paediatric Information Day in Liverpool this June, organised as part of ISPNO.

As well as hearing from and speaking to doctors, nurses and world-leading international researchers, families met others going through a similar situation. They also heard about the new report from our Life with a Brain Tumour project, *Losing My Place: The Reality of Childhood with a Brain Tumour* (page 28) ahead of the launch at ISPNO. To watch videos of the fantastic talks from the day, including Mr Mike Taylor and Dr Roger Packer, visit [bit.ly/NPIDVideos](http://bit.ly/NPIDVideos)

By building global collaborations between researchers and involving those who've been personally affected – our 'experts by experience' – in their discussions, we can accelerate progress and get closer to finding a cure. Here's where we've been to help us achieve this:

### International Symposium on Pediatric Neuro-Oncology (ISPNO)

12 – 15 June

We were the leading sponsors of ISPNO in Liverpool this June where over 1,100 international academics and clinicians came together.

This was a great opportunity for us and our new Chief Scientific Officer David Jenkinson (page 10), to build relationships with world-class researchers, discuss our funding opportunities with new contacts from across the globe, promote our HeadSmart campaign and make valuable connections with paediatric healthcare professionals. We also launched our new report *Losing My Place: The Reality of Childhood with a Brain Tumour*.

### British Neuro-Oncology Society annual conference

29 June – 1 July

Every year, neuro-oncology researchers and healthcare professionals from across the UK head to the British Neuro-Oncology Society (BNOS) annual conference to hear about the latest research breakthroughs.

At this year's conference in Leeds, Professor Richard Gilbertson, Chair of our Scientific Advisory Board, presented alongside internationally renowned keynote speakers. We also attended scientific update sessions and promoted our Life with a Brain Tumour reports to the researchers attending.



Image: Our founders Neil and Angela Dickson on our charity stand at ISPNO.

## Where we're going

Here's where we're going over the next few months to help us to continue our collaborative work:

### European Association of Neuro-Oncology conference

12 – 16 October

We're attending the European Association of Neuro-Oncology (EANO) conference in Germany this October. The EANO conference spans all areas of neuro-oncology from diagnosis,

treatment and effects, to care and education. We're also looking forward to sponsoring the EANO Nurses Education Day as part of our continued drive to support healthcare professionals.

While the conference and Nurses Education Day will be invaluable to all areas of our work, it'll also allow us to strengthen our ties with our European colleagues and, following the Brexit referendum this June (page 15), ensure we remain united in the battle against brain tumours.

### Society of Neuro-Oncology conference

17 – 20 November

We'll be attending the Society of Neuro-Oncology (SNO) conference in the USA this November to hear about the industry's newest research developments and learn about the findings from the latest clinical trials. Experts from across all areas of the brain tumour research field and international brain tumour charities will come together to accelerate progress and move closer to finding a cure.



*Image:* Some of our Research Team meet with colleagues from CRUK to discuss ways to collaborate on future research initiatives.

## Thanks to our community

It's thanks to our wide network of supporters that we're where we are today. We'd like to give a special thank you to:

### OSCAR's Paediatric Brain Tumour Charity

OSCAR's Paediatric Brain Tumour Charity was set up in memory of Oscar who sadly lost his battle, aged nine, to a medulloblastoma in 2014. We were delighted to recently receive a commitment of £125,000 from them to go towards our new research initiative with Professor Louis Chesler at ICR, looking at new drug development for medulloblastoma.

### St Andrews FS2017

We're proud to have been named as the Charitable Partner for St Andrews Charity Fashion Show 2017. Our application for the partnership was inspired by Ben and Sarah Pullen, from The Silas Pullen Fund, and the funding will go towards our new 3D printing initiative at Heriot Watt University, Edinburgh.

### Stay Strong Stu

Thanks to the Stay Strong Stu campaign for donating £65,000 to us this May. The campaign was set up in memory of Stu Ridley from Northumberland who tragically lost his battle with a brain tumour in July 2015. The money will be funding research into high grade brain tumours.



## Welcome to our new CSO

This June, we were delighted to welcome our new Chief Scientific Officer (CSO), Dr David Jenkinson. David heads up our Research Team and will be responsible for implementing *A Cure Can't Wait: Our Research Strategy*.

"As Chief Scientific Officer, it's my responsibility to make sure we fund the world's best research.

"I lead a small team who regularly visit institutions across the country to tell them about The Charity and our funding opportunities. I believe it's vital we get the UK to the forefront of neuro-oncology research. By encouraging talented researchers, from a range of different fields, to get involved with research into brain tumours, we can hope to achieve this.

"A key part of my job is ensuring we implement The Charity's five year research strategy. Collaboration is a key focus of the strategy and is what attracted me to The Brain Tumour Charity in the first place.

"As a volleyball coach in my spare time, I know the value of working as a team to achieve a common goal. I am impressed with how The Charity is championing collaboration to ensure that every penny of funding has the biggest possible impact. I hope to expand our community with the contacts from my previous role at Cancer Research Technology, part of Cancer Research UK.

"Since starting, I've met with a number of international charities, Cancer Research UK, up-and-coming pharmaceutical and biotechnology companies, and have many other collaborations in the pipeline. By establishing groupings between academia and industry I hope to ensure that research into brain tumours is a priority for all, and that products are developed to improve life today for those affected.

"We're at a crucial point in research and rapid progress can only be made by coming together to tackle the big questions. It's a challenging but exciting time to be getting involved."

To find out more about our research strategy, visit [thebraintumourcharity.org/a-cure-cant-wait](http://thebraintumourcharity.org/a-cure-cant-wait) or to meet the rest of our senior leadership team, including our new Director of Services and Influencing, Emma Tingley, visit [thebraintumourcharity.org/slt](http://thebraintumourcharity.org/slt)

# A united approach to patient data

We're proud to be working with Cancer Research UK, Macmillan Cancer Support and a variety of other cancer charities to improve the use of patient data.



**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

As it stands, patients' cancer data is routinely collected during hospital visits and is included in the cancer registry. Data in the registry can be used to help improve diagnosis, treatment and care for specific cancer types.

We know however that some hospital trusts are better at recording data, and making patients aware that their data is being collected, than others.

By working with other cancer charities, we're making recommendations to the Government on how patients can be better informed about their data. We're also looking at how we can work with those personally affected and NHS trusts to ensure that this vital data is properly recorded.

We believe that everyone living with a brain tumour has the right to know how their data is being used, and that data collected should be recorded correctly to ensure it's of benefit to the future of research.

The cancer registry showed that 53% of adult high grade brain tumours were diagnosed as an emergency in 2013. Of those diagnosed, just 28% survived one year – the poorest survival across all diagnosis routes for adults with a high grade brain tumour.

This evidence has contributed to recommendations made in the *Achieving world-class cancer outcomes: a strategy for England 2015-2020* which look to prioritise and improve early diagnosis for people affected.

If you're interested in data collection or any other aspects of our policy work, contact us at [thebraintumourcharity.org/policy-get-involved](http://thebraintumourcharity.org/policy-get-involved)



53% of adult high grade brain tumours were diagnosed as an emergency in 2013.



*"Through working with The Brain Tumour Charity, I've met so many people affected by this dreadful disease. I know that many of the other Young Ambassadors had to wait a very long time to be diagnosed which had a big effect on their treatment and outcomes. I would want my data to be used to analyse routes to diagnosis so that in the future, no-one has to go through what my friends did."*

Chandos, one of our Young Ambassadors, was diagnosed with a brain tumour at the age of three.

*"Data in the cancer registry is important because it gives us an unbiased and accurate view of what is happening with brain tumour care on a national level. We know that there are variations in care across the country, but without this data it's difficult to understand and improve this."*

*"In terms of research, the data provides us with a list of who had what treatment and what the result was – which we can use as the basis for lab research. Most important of all, the data helps us make the argument for more research and funding, without which things are not going to improve".*

Dr Matthew Williams, Clinical Oncologist at Imperial College London, is currently using patient data to investigate glioblastoma.

If you've been affected by a brain tumour and want to use your personal experience to shape the future of brain tumour research, you can join our Research Involvement Network at [thebraintumourcharity.org/RIN](http://thebraintumourcharity.org/RIN)

## Defeating Brain Tumours: one year on

It's been a year since we launched our five-year *Defeating Brain Tumours* strategy and we're proud of all our community has achieved. To find out more about our strategy to double survival and halve the harm of those affected, visit [thebraintumourcharity.org/defeatingbraintumours](http://thebraintumourcharity.org/defeatingbraintumours)

Some of  
our strategic  
milestones  
to date  
2015/16



Committed a further  
£4.3m to 10  
research projects

Held Nurse &  
AHP Study Day



*Losing My Place*  
report published

£10m raised



## Launching our patient pathway

In our *Defeating Brain Tumours* strategy, we pledged to improve life today for people affected by helping them better navigate the healthcare system.

We're pleased to be launching our patient pathway which will help them do just that.

We know that following a brain tumour diagnosis, dealing with the NHS and other agencies can be a new and sometimes intimidating experience. We believe everyone affected, regardless of their age, postcode or tumour type should have access to the best treatment, care and information, but are aware this isn't always the case.

Through working with nurses, healthcare professionals and patients, we've developed our patient pathway which outlines the standards of care we believe all adults diagnosed with a brain tumour should expect from the NHS. It also includes information on investigations, clinical trials and research opportunities that are not currently routinely offered

to all patients, but we believe should be. We hope that by having this information patients and families will feel empowered to ask about these opportunities, influencing how services are improved.

People living with a brain tumour can use this guide to feel better informed during their treatment and care, know who and what to ask and feel confident when discussing options with their medical team.

Our patient pathway will help us reach our goal of halving the harm that brain tumours have on quality of life, sooner.

To find out more about the patient pathway, visit [thebraintumourcharity.org/patient-pathway](http://thebraintumourcharity.org/patient-pathway)

### Did you know

Less than 3% of brain tumour patients take part in a clinical trial, compared to an average of 7.5% of patients across all cancer types.

## Campaigning together to drive change

We're excited to be working in coalition with other charities that represent people affected by cancers of unmet need, such as oesophageal and pancreatic cancer, to identify common issues across diagnosis, treatment and care.

Our initial focus is on the *England Cancer Strategy* which was published last year. The strategy, which we're advocating for, aims to transform cancer services and improve the NHS experience for those affected. We're proud that it includes recommendations for the NHS to evaluate the findings of our HeadSmart campaign, as well as to encourage access to a clinical nurse specialist (CNS), develop a Cancer Patient Experience Survey for under 16s and improve digital communications.

We've also been invited to participate in the Cancer Patient Experience Advisory Group (CPEAG) as a representative of rarer cancers. This group, which involves a number of charities, will lobby NHS England to ensure the recommendations in the *England Cancer Strategy* are implemented.

Every day we hear stories from people affected by a brain tumour that highlight the issues that matter to them. By uniting with other charities, we can campaign with a louder voice and drive the vital change needed to improve life today for those affected.

### After Brexit: continuing to collaborate

On 23 June the UK voted to leave the EU. We don't yet know the full extent of the impact this decision will have on research, treatment and care in the long term; however we're working with other organisations, including the Association of Medical Research Charities, to establish how the medical research sector should respond to the vote.

For further information, visit [thebraintumourcharity.org/eu-decision](http://thebraintumourcharity.org/eu-decision)

# My personal Everest

After watching his nephew, Sam, go through gruelling radiotherapy and chemotherapy for his posterior fossa brain tumour, Colin Dorrance embarked on an extreme challenge to raise funds towards finding a cure.

“My nephew Sam, aged five, spent 10 months from August 2015 to June 2016 in hospital in Edinburgh, 100 miles from his home in Stonehaven, Aberdeenshire receiving treatment. Each day away from home was a personal Everest for him, his mum Tanya and his dad, my brother Graeme.

“Sam’s parents set up a Supporter Group called ‘Super Sam’s Fund’ for The Charity, which paved the way for a series of fundraising events. During the winter months of Sam’s treatment, I raised the idea of a sponsored bike ride of 200 miles in two days from Gretna Green to Stonehaven. I’d never attempted anything of this magnitude before, and never for something so close to home – a personal Everest. ‘Cycle for Sam’ was born.”

Months of training were required, planning the route and putting facilities in place to help achieve the ultimate goal. Colin and his family embarked on a social media campaign to involve as many people as possible, in both Gretna and Stonehaven.

This June, Colin and his team of cyclists completed ‘Cycle for Sam’ raising over

£27,000 for us. “It became a wonderful example of what can be achieved with the personal touch, online awareness, goodwill and collaboration. Hundreds of people helped in their own way – family, friends, colleagues, strangers, businesses, community groups, schools and the police. Everybody did so without wanting the recognition that they deserve.

“The cycle was a challenge, it pushed me harder than ever. Sam was discharged from hospital the week before the event and was well enough to lead us into Stonehaven in a mini-motorcade of reception vehicles, which he loved. Sadly, Sam passed away a couple of weeks after the event, making his presence on the day even more cherished.

“He has a legacy to be proud of – this event, along with the mini events it triggered, have raised over £27,000, five and a half times the target.”

Thank you to Colin and all our amazing fundraisers who are an inspiration. It’s through your efforts that we can continue to improve the lives of those affected.





It's beginning  
to look a lot  
like Christmas...

Whatever your plans for Christmas, there are many ways you can make #TheBrainyBunch part of your celebrations and reflections this year.



### Christmas cards and gifts

Spread Christmas cheer with our new range of cards, wrapping paper and gifts. Check out our Christmas catalogue and order all you need in one go from our online shop.



### Santa fun runs

Have some festive fun with #TheBrainyBunch and raise money for those affected by taking part in a santa fun run in December. Sign up today!

### Seasonal songs at Christmas

Join our community as we unite to reflect and rejoice at our annual Christmas Carol concert on 7 December at St Giles in the Fields, London and The Parish Church of St Helen Witton with St. Thomas Rudheath, Northwich (venue TBC). Tickets cost £10.00 per person (under 5s free). Book now!

To book tickets and find out more about what we're doing for Christmas, visit [thebraintumourcharity.org/christmas](http://thebraintumourcharity.org/christmas)

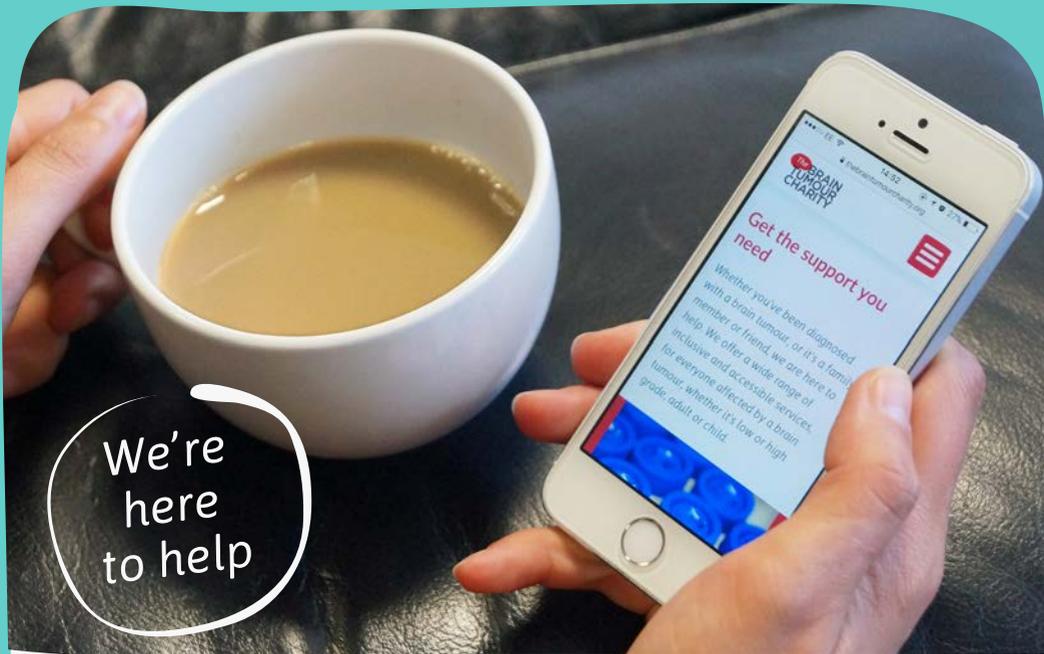
### Become a Christmas Angel

Give a little extra back this Christmas by becoming a Christmas Angel and selling our cards and gifts to family, friends and colleagues.

...everywhere  
you go



Last Christmas, our dedicated community of supporters, volunteers, researchers, corporate partners and healthcare professionals came together to help us raise over £57,000 through seasonal sales. That's enough to fund the work of one of our research fellows in Professor Salomoni's lab at the Samantha Dickson Brain Cancer Unit, UCL for one year. The team are hoping to discover new treatments for high grade gliomas through studying the relationship between a cell's metabolism and the way DNA is packaged.



We're here to help

**We know that a brain tumour diagnosis can be frightening and can lead to lots of questions. We're here to help.**

Our Support & Information Service can help you to understand every aspect of your journey from diagnosis, tumour types and treatment to clinical trials and helping you live your life – not your disease.

We know that one in two experience financial difficulty (*Losing Myself: The Reality of Life with a Brain Tumour*). As a result, we're pleased to now offer a weekly telephone Benefits Clinic every Tuesday afternoon through our Support & Info Line.

The report also found that 29% of people living with a brain tumour are severely isolated – as well as our Support & Info Line, we also run a variety of online support services including Facebook Support Groups, regular Twitter Q&A sessions and online live discussions.

For families, we work with the whole family following a child's diagnosis offering one to one support. We also run Family Days which allow you to meet others going through similar experiences.

If you simply need some information, we have a number of online factsheets covering various topics and we can also translate these for you.

-  **Support & Info Line**  
0808 800 0004  
*(free from landlines and mobiles)*
-  **support@thebraintumourcharity.org**
-  **Join our communities:**  
[thebraintumourcharity.org/](http://thebraintumourcharity.org/)  
[facebooksupportgroups](https://www.facebook.com/thebraintumourcharity)

## Our Benefits Clinic in action

We welcomed Denise, our Citizens Advice benefits advisor, to the team in April. Denise heads up our new Benefits Clinic and has been providing advice to people like Kay Dallimore:

“My son Connor was diagnosed with a grade 2 – 3 astrocytoma when he was five and has suffered with various disabilities as a result. He’s been on Disability Living Allowance (DLA) for nearly 12 years.

“This January, Connor was invited to claim Personal Independence Payment (PIP), but the claim got turned down and we were told that other allowances, including his DLA and my carers allowance were being stopped.

“We couldn’t understand why, as our circumstances hadn’t changed. We tried to appeal but were constantly given conflicting information.

“Luckily, our Macmillan worker told us about The Brain Tumour Charity’s Benefits Clinic.

“At such an anxious time, it was lovely to talk to someone who understood the system and procedures. Denise told us who we needed to speak to, and after asking for a mandatory reconsideration, the decision was overturned.

“Thanks to the Benefits Clinic, I was given hope and reassurance that I was doing the right thing and the confidence to keep fighting on.”



Enquiries made during the first two months of the Benefits Clinic (launched at the end of April 2016)

- Personal independence payment
- Employment support allowance
- Income support
- Housing benefit
- Disability living allowance
- Working and child tax credits
- Carers allowance
- Council tax reduction

For advice on navigating the system, money related issues or benefit applications, contact our Benefits Clinic (0808 800 0004) open every Tuesday from 12.30 – 4.00pm.



## Working with our community: Nurse & AHP Study Day

*This May, we were delighted to hold our first study day for nurses and allied health professionals (AHP) working with adults with a brain tumour in the UK.*

The event provided an opportunity for over 160 delegates to hear from experienced, knowledgeable speakers on topics that are crucial to the care of those affected.

The programme was developed through consultation with nurses and allied health professionals on the areas they felt their patients would benefit from the most, including sessions on clinical trials,

fatigue, vocational rehabilitation, a carer's experience, novel treatments, palliative care and best practice.

Speakers included Zoe Faulkner who spoke touchingly of her experience as her husband's carer and Dr Jonathan Martin who discussed the importance of advanced care planning in palliative care.

*Image: Kate Hayward a Clinical Specialist Occupational Therapist, giving a presentation on Vocational Rehabilitation.*

## Continuing to improve best practice

With over 99% of the delegates rating the quality of the education at our Nurse & AHP Study Day as good or excellent, we're pleased to announce we'll be hosting another one next year. Keep an eye out in future issues of *The Grey Matters* for more information.

*"I really enjoyed this very informative study day. I will be changing my practice because of this."*

*"The various sessions complemented one another in a useful way. I now feel far more informed and able to deal with my patients more effectively."*

*"A fantastic insight into how the journey impacts patient and carer quite differently. It highlighted how small changes to clinician protocol, in terms of flexibility, can make it easier for the patient and carer."*

# HeadSmart news

We're delighted to announce that the Royal College of General Practitioners (RCGP) has chosen HeadSmart as its new clinical spotlight project. The project, which will run until 2017, will help GPs to identify the signs and symptoms of childhood brain tumours.



Dr Rebecca Chellaswamy, who has been appointed by RCGP to lead the project, will be working closely with us and the Children's Brain Tumour Research Centre in Nottingham to ensure HeadSmart is brought to the attention of as many GPs as possible over the next year. By raising awareness of HeadSmart among healthcare professionals through workshops and an online toolkit, we hope that diagnosis times for childhood brain tumours can be reduced to under four weeks in line with NHS targets.

Dr Rebecca Chellaswamy said: "The UK has already made significant progress in diagnosing brain tumours at an earlier stage and this project aims to further this.

"We're thrilled to be working with the HeadSmart campaign to raise awareness of guidelines and resources that support not only GPs and other primary care professionals, but also the public, in order to improve clinical outcomes in this relatively rare but important area."

## Did you know

Over the last five years, HeadSmart has gained recognition from healthcare professionals around the country and has won a number of prestigious awards. Now, we're very excited to announce that it's getting a new look! Keep an eye on the website in the coming months: [headsmart.org.uk](http://headsmart.org.uk)

500

Over 500 children and young people are diagnosed with a brain tumour every year in the UK

58%

58% of children diagnosed with a high grade brain tumour are diagnosed as an emergency

↓ 6.7

To date diagnosis times have reduced from 9.1 to 6.7 weeks since the public launch of HeadSmart

# Supporter Groups

Our fantastic Supporter Groups are dedicated and courageous groups of volunteers who come together to raise funds and awareness for The Brain Tumour Charity.

Welcome to our new Supporter Groups:

- Super Sam's Fund
- The Andrea Barcroft Fund
- The David Whatley Fund
- The Michael Barry Fund
- The Nick Hart Fund
- The Ann Jackson Fund
- The George Grant Superman Fund
- The Duncan McLean Fund

To find out more about our Supporter Groups or how you can set one up, visit [thebraintumourcharity.org/supportergroups](http://thebraintumourcharity.org/supportergroups)

253

We currently have 253 Supporter Groups

£460k

Since April the Supporter Groups have raised £460,179 for research into brain tumours



Save the date!

Friday 3 March 2017

Look out for more details in the next issue of *The Grey Matters*

#WearItOut



# Together we can shape the future

1%

Leaving just 1% of your Will to us could have an impact for future generations



Making an appointment with a solicitor is cited as one of the main barriers to writing a Will

3%

Gifts in Wills make up just 3% of our annual income – this is less than many other charities

*“I decided to leave a gift in my Will to The Brain Tumour Charity after losing my partner to this disease. Enhancements in treatment and surgery enabled Simon to have a more fulfilling life and survive his tumour for 20 years.”*

Bridget Jeffery

**Writing a Will allows you to ensure that your loved ones and the causes that are important to you are looked after in the way you intend. For those who may have considered writing a Will in the past but have been put off by the time, inconvenience or cost, we're pleased to be launching The Goodwill Partnership – a no-obligation home visit Will writing service for our supporters.**

Will writing services usually cost between £250 and £450, but thanks to our collaboration with the Goodwill Partnership, a basic Will costs between £95 and £98 (+VAT). This is a great opportunity for our community of supporters to think ahead to how they can help our work live on far into the future.

Setting up an appointment with The Goodwill Partnership to go through your Will requirements is free. There's no obligation to go ahead or include us in the Will and no up-selling of other services.

It's the little things in life that can mean the most and leaving as little as 1% of your Will to The Brain Tumour Charity can have an impact for generations to come. Together, we can shape the future for those affected.

For more information visit [thebraintumourcharity.org/writing-will](http://thebraintumourcharity.org/writing-will) You can also find a local solicitor by visiting [solicitors.lawsociety.org.uk](http://solicitors.lawsociety.org.uk)

## Volunteer focus: Emma

Emma was one of 110 volunteers who helped make The Twilight Walk a success last year.

After being diagnosed with a grade 2 brainstem glioma in 2015, Emma wanted to make a positive contribution to the fight against brain tumours and meet other people who understood what she was going through.

“I volunteered because I really wanted to help The Charity in any way that I could. Due to the location of my tumour, I sometimes lose feeling in my limbs, so volunteering was the perfect way for me to be involved in the walk. Everyone was really accommodating and made sure that I was okay during the day. It was really nice to be surrounded by people who understood.

“I enjoyed every bit of the day. The other volunteers and staff were really kind and everyone taking part in the walk was so friendly and motivated! It was great to talk to them and hear their stories too. Knowing we were all there helping do something good for a cause that means so much to me was really special.”

Emma was so inspired by her experience that she'll be returning to volunteer at The Twilight Walk in Warwick again this year.

“I'm looking forward to volunteering again this year with my boyfriend so that I can show him what it's like to be a part of such a united community that are coming together to create something positive.



**#TheBrainyBunch**

“I'm not able to change my situation, but by working together there's hope that we can change the future.”

Join Emma and be a part of The Twilight Walk this October. You can find out more about volunteering here [thebraintumourcharity.org/thetwilightwalkvolunteers](http://thebraintumourcharity.org/thetwilightwalkvolunteers)

There are other volunteering opportunities too. Be a part of our cheer squad and make some noise to support our runners and cyclists at events throughout the year to find out more visit [thebraintumourcharity.org/volunteer](http://thebraintumourcharity.org/volunteer)

# Losing My Place: The Reality of Childhood with a Brain Tumour

*This June, we launched the final report from our Life with a Brain Tumour project – Losing My Place: The Reality of Childhood with a Brain Tumour.*

*Losing My Place is based on a survey of almost 300 young people and their parents following a childhood brain tumour diagnosis. It provides a unique insight into the suffering that childhood brain tumours cause for children, young people and their families.*

*“Our youngest son was only ten weeks old when Dylan was diagnosed so he knows no different. But my oldest son, who is six, has become more and more withdrawn because Dylan takes all of our attention. He is suffering at school.”*

Jessica Mitchell

The report tells stories of courage and perseverance against a disease that often forces children to miss out on so much. It will be used to help us ensure policy makers, healthcare professionals and the public understand the realities of living with a brain tumour for all ages.

The findings will also be used to help us shape our services for children and families in the future.



This vital report, which is the most comprehensive study of its kind, was only made possible thanks to the families who filled out our children and families survey last November. Thank you for helping us improve life today for those affected.

To see a copy of our *Losing My Place* report, visit [thebraintumourcharity.org/losing-my-place](http://thebraintumourcharity.org/losing-my-place)

## Iceland: be part of it!



*Looking for a once in a lifetime challenge for 2017? Then why not join The Brainy Bunch in Iceland.*

With limited spaces still available, you can be part of our united community on a five day trek through Iceland's spectacular classic highland landscapes.

By taking part in this incredible trek, you'll not only get to challenge yourself and spend quality time with other supporters of The Charity, you'll also be doing something remarkable in the fight against brain tumours, raising vital funds because a cure can't wait.

**When** 10 – 14 July 2017

**Where** Reykjavik, Iceland

**How much** £199 registration fee, £2,100 minimum fundraising target (to include flights and accommodation)

To find out more and register, visit [thebraintumourcharity.org/challenges](http://thebraintumourcharity.org/challenges)



# Updates from The Lewis Moody Foundation

## Charity ball

The Lewis Moody Foundation annual charity ball took place at The Grange in London on 5 May, raising over £105,000.

The star-studded event brought together celebrities including former England rugby captain Chris Robshaw, Radio 1 DJ Greg James, Olympic medallists Sharron Davies and James Cracknell and England cricketer Stuart Broad.

Former British Lions rugby player Martin Bayfield was host for the night with British comedian and freestyle rapper, Chris Turner, the Me and Mr Brown band from South Africa and our Young Ambassador and magician Harry, providing entertainment for all.

The ball promoted the incredible work being undertaken by The Foundation and raised much-needed awareness of the struggles faced by families when coming to terms with a brain tumour diagnosis.

The money raised from the night will go towards funding our Family Days for families of parents living with a brain tumour and research into early adult diagnosis, helping us unite families and improve life today for those affected.

For more on the story behind The Lewis Moody Foundation, visit [thelewismoodyfoundation.org](http://thelewismoodyfoundation.org)

*"We're so proud and honoured that Lewis Moody was so inspired by our son Joss, that the Lewis Moody Foundation was born. It not only keeps Joss's memory alive but also gives us a focus to help other families."*

Graeme and Tiffany Stark

## Bringing families together

We were excited to host our first joint Family Day with The Lewis Moody Foundation in Wiltshire this April.

The day was designed for families where parents have been diagnosed with a brain tumour. The impact of a parent's diagnosis can be wide reaching and the day allowed families to get away from daily worries, spend quality time together and meet others experiencing similar difficulties.

*"The day gave us precious time away from the reminders that I'm living with a brain tumour. It gave my children time to just be children. The funniest moment of the day was Lewis being rugby tackled to the floor by about 10 children!"*

Marie Wren who is currently living with a brain tumour.

The next Family Day for The Lewis Moody Foundation will be on Saturday 5 November. To find out more about our family days, visit [thebraintumourcharity.org/family-days](http://thebraintumourcharity.org/family-days)

## Heading East for HeadSmart

This December, Lewis and a small team of riders will cycle 1,000km from Vietnam to Cambodia, as part of the headeast challenge in partnership with The Yacht Company (Y.CO), with the aim of raising £75,000 for our HeadSmart campaign.

The headeast team, which includes rugby players Lee Mears and Josh Lewsey and polar adventurer Alan Chambers, are following on from Lewis' Head North expedition, in partnership with Y.CO, which saw him venture through to the Geographic North Pole last year, raising nearly £100,000 for The Foundation along the way.

To sponsor the team and follow their progress, visit [bit.ly/HeadEastChallenge](http://bit.ly/HeadEastChallenge)



# The Big Match

**On 18 June, over 800 guests united at the fifth annual The Big Match to raise an incredible £57,000 for us and Action for Children.**

Held at Newbury Town Football Club, the event was organised by supporter Neil Humphries who lost his dad to a brain tumour in 2012 following a series of misdiagnoses.

Highlights of the day included a children's training session, a charity football match and 'Extra Time' – a gala dinner which was hosted by Ampika Pickston from The Real Housewives' of Cheshire and featured performances from X Factor's Jay James and Britain's Got Talent's Twist and Pulse.

Two teams of fundraisers and celebrities battled it out on the pitch to claim the title of The Big Match Champions 2016. The Brain Tumour Charity team, which included footballers Francis Benali and Jimmy Carter, TOWIE's Charlie King, Ex on the Beach's Nancy-May Turner and Jay James, narrowly missed out on the title during penalties, losing to worthy winners Action for Children.

A huge thank you to Neil and everyone who attended – including Debbie McGee who sadly lost her husband Paul Daniels to a brain tumour in March – for raising vital funds and awareness for the two charities!



*"The Big Match started in 2012 after my dad passed away from a brain tumour. I'd previously supported Action for Children and wanted to create an event where I could continue to support them along with The Brain Tumour Charity. Dad loved football and children so we decided to organise a charity football match.*

*We raised £10,000 the first time around so went bigger and better the next year with celebs, ex pro footballers, a children's event and gala dinner, and it's snowballed from there. The Big Match has so far raised over £240k and we are all very proud."*

**Neil Humphries**

# Thank you to The Brainy Bunch

We're forever inspired by your dedication, effort and passion to raise funds and awareness for us. Thank you to each and every one of you – no matter how big or small, you're helping to make a big difference to those affected by a brain tumour.

Join #TheBrainyBunch today: 01252 749043 / fundraising@thebraintumourcharity.org



Grant Stephenson from Kilmarnock ran the 10k 'Roon the Toon' with a group of family and friends, he has raised £14,000 so far.



Stevie Gedge took part in an open water swim in The Solent, ran 10k and will be taking part in a skydive for The Ali Ling Fund. She has raised over £800 so far.



Lynne Broadbent, from Wetherby, completed the Cleveland Way raising £1,500. "My brother has had two pretty horrid brain tumour operations, so what I did was a doddle in comparison."



Joe and his team of Cardiff boys took on the Dragon Ride and raised over £2,800 in memory of Sarah Morfoot.



A team of Knaresborough ladies took part in the Great Knaresborough Bed Race in memory of two close friends, raising £1,900 and laughing all the way!



Kieran, aged nine, decided he wanted to help others and raise funds for our HeadSmart: be brain tumour aware campaign. He had his head shaved at school and raised over £500.



Anna, aged nine, from Aberdeen raised over £2,500 in support of a school friend who was recently diagnosed with a brain tumour. Anna ran the Aberdeen Colour Run and hosted a coffee morning with her Mum.



10 year old Jaye-Jaye chose to cut her hair and raised over £1,700 in support of family friend Sophie Morris. Sophie's friends and family in St Ives have raised an amazing £75,000 to date.



Angela White from Kendal lost her husband and several friends to brain tumours. She ran 190 miles and cycled 150 miles across the country for us, raising more than £6,000 so far.



A team of 12 from Measham Medical Unit took part in the London to Brighton 100km walk in support of colleagues diagnosed with brain tumours. They have raised over £13,000.



The Emma Sim Fund got busy baking and selling cakes in their Soup and Sweet fundraiser raising over £1,000.



Pete and friends cycled 143 miles across the Brecon Beacons in South Wales. Taking on the infamous climbs of Black Mountain, Rhigos and Devil's Elbow in memory of Pete's wife Eva, they raised £5,100.



Inspired by his son Oliver, who was diagnosed with a brain tumour at 18 months old, Ross cycled from London to Paris in just 24 hours. Oliver is now doing well and is helping fundraise with his brother Thomas.

# Thank you for all you do.

## Together we can defeat brain tumours.

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

Or they can make a donation online: [thebraintumourcharity.org/donate](http://thebraintumourcharity.org/donate)

If you would like more copies please contact us: [enquiries@thebraintumourcharity.org](mailto:enquiries@thebraintumourcharity.org)  
01252 749990

For queries about making a donation: [donations@thebraintumourcharity.org](mailto:donations@thebraintumourcharity.org)  
01252 749043

Please return your donations to:  
The Brain Tumour Charity  
Hartshead House  
61-65 Victoria Road  
Farnborough  
Hampshire GU14 7PA



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Find us here too



# We rely 100% on voluntary donations

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

*giftaid it* Make your donation worth 25% more!

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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

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

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: \_\_\_\_\_

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

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Card number: \_\_\_\_\_

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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](http://thebraintumourcharity.org/privacy-policy).

\*see terms and conditions at [thebraintumourcharity.org/waystodonate](http://thebraintumourcharity.org/waystodonate)

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