

The Brain Tumour Charity shining a light on

# The GREY MATTERS

The **BRAIN  
TUMOUR  
CHARITY**

Research | Awareness | Support

Issue 19 Winter 2018



Your treatment. Your choice.

Come together for Christmas

Top tips for PIP

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



## Jack Morris appointed Chair of Trustees

We're delighted to welcome businessman Jack Morris CBE as our new Chair of Trustees. Jack became involved with The Charity after his daughter, Emily, was diagnosed with a glioblastoma in 2015. She sadly passed away last year.

"Emily's diagnosis was a devastating time in our lives. The Charity's support for those affected, its investment in high-quality research and its work to raise awareness are bringing about real change. I'm honoured and privileged to be able to help drive that forward as their new Chair."

## How we spend your money



We aim to spend at least 80p of every pound spent on our charitable objectives.



In our 2015 strategy, we pledged to commit £20 million to research by 2020. To date, we've committed £21.6 million, surpassing our goal two years ahead of schedule. Thank you for your ongoing support, helping make this possible.



Liam with Baroness Tessa Jowell

# Hello

I became aware of The Charity when Baroness Tessa Jowell made her diagnosis public in September 2017. Though only 12 months ago, we've achieved so much since then and you've been so important to that.

Many of you fed into the research that helped Tessa during her incredible speech in the House of Lords. You also shared your stories in Parliament and showed your support. Your dedication helped drive us forward – so thank you.

But we must keep up this progress. Following Tessa's death, the Government made a big announcement on extra funding. It's great, something to be celebrated, but there are still a number of important changes which remain, for instance, data sharing (find out more on page 6).

You can also help hold the Government to account – write to your MPs, tell them your story and encourage them to keep moving towards a better world for those affected by brain tumours.

The time for change is now, so we must be bold, brave and resilient. If Tessa was here, I think she would say 'it's not about me, it's about the patients'. It's about giving hope to those diagnosed and their families – now and in the future.

**Liam Conlon,**  
Friend and former colleague of Baroness Tessa Jowell and ambassador for us

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# Your treatment. Your choice.

*We believe our community should have the right to try experimental treatments with the potential to improve their diagnosis.*

**Following our Patient Choice Survey this year, an overwhelming majority of you told us you want the right to choose treatments, take risks and propel change.**

The survey had almost 400 responses from people affected by a brain tumour and the majority were overwhelmingly in favour of patient choice in treatment.

We want you to feel empowered to take control over your own care and decide what's best for you.

Currently our community don't feel this is possible and are being denied access to potentially life-saving treatments – it's time that changed!

Surely everyone has the right to live their life in the way they choose. Over 98% of respondents believe they should have the right to consider trying an experimental treatment, even if it may not have a better outcome than standard treatment.

One respondent echoed many others saying: "Everyone should have the choice of every treatment possible. Clinical trials should always be available to patients should they wish to try it."

It's important that patients are well informed about what options are out there. We want to help make this possible. Working alongside politicians and healthcare professionals, we aim to improve knowledge of, and access to, off-label drugs (medication used outside its licenced disease), complementary and alternative treatments and clinical trials.

If you have any questions regarding treatment options and the right to choose, please don't hesitate to contact our Information and Support team on 0808 800 0004, email us at [support@thebraintumourcharity.org](mailto:support@thebraintumourcharity.org) or contact us on live chat [thebraintumourcharity.org/live-chat](https://thebraintumourcharity.org/live-chat)

## Over 98%

of supporters believe they should have the right to consider trying an experimental treatment.

Comments from  
the survey

*"My husband has a terminal diagnosis and I've researched treatments not available on the NHS, but it is difficult to know who to trust. Give us the facts and let us make the choice of treatment."*

*"With a terminal diagnosis, I think it should be the patient's right to try any experimental treatment which has achieved positive indicators."*





# Understand your data

A lot of our day-to-day decisions are based on data. Facebook suggests new friends for you, Netflix recommends TV shows you may enjoy and Amazon advertises items based on previous purchases. But, have you thought about using your medical data to influence decisions about your clinical care?

Each time you visit a healthcare professional, that encounter is recorded. This makes up your medical records, which contain data that can help you understand, manage and monitor your treatment and care.

Every piece of information provides a learning opportunity, and we believe our community should be able to seize this. Having access to your medical records can empower you to take more control of your own health, perhaps even improving outcomes.

Everyone has the right to a copy of this information from the NHS, free of charge. However, from our own experiences, we know these files contain illegible codes and jargon. This presents a huge obstacle to empowering patients to use their data to manage their own care and make more informed decisions.

That's why, in January 2018, we launched our patient-led databank, BRIAN (Brain tumouR Information and Analysis Network).

Through BRIAN, and with your consent, we aim to access medical records and change the way they're presented. We want to make them clearer, improving the accessibility and legibility of data and empowering patients to make more informed decisions.

But, alone we can only get so far. The only way BRIAN can make a difference is with your help. Please sign up to BRIAN today and consent for us to access your data. Together, we can pick up the pace and move closer to a cure. Thank you!

Find out more by visiting [thebraintumourcharity.org/BRIAN](http://thebraintumourcharity.org/BRIAN)



# Grab a slice of the action this March!

*It's back! March is Brain Tumour Awareness Month and we'll be kicking it off with the return of Big Bandana Bake.*

Earlier this year, we held our first ever Big Bandana Bake and you brilliant bakers raised £185,000 – enough to fund over two years of research into brain tumours.

We're excited to rise to the challenge again next year and raise even more! But we need your help – every egg cracked, every spoon licked and every penny donated will help us get closer to a cure.

So save the date and join us in March 2019 as we don a bandana, get messy in the kitchen and help bake a difference for everyone affected by brain tumours. We'll share more on how to get involved soon.

Over  
**445**  
bake sales held  
and  
**£185,000**  
raised



## Meet the researcher: Dr Laure Bihannic

Post-doctoral Research Associate  
St. Jude Children's Research Hospital, USA

We're delighted to be awarding post-doctoral researcher, Dr Laure Bihannic, a Future Leader grant of £180,000 to investigate medulloblastoma, a childhood brain tumour. We caught up with her to find out about her background, her project and share her words of wisdom to fellow young researchers.

### What motivated you to want to research brain tumours?

I've always been interested in cancer research, particularly how researchers can make an impact in the lab that can be translated to patients at the bedside with novel diagnostics and therapeutics. I was introduced to paediatric brain tumour research during my Masters, when I did an internship here at St. Jude, in Memphis, Tennessee.

### Tell us about your research

I'm working on a childhood brain tumour called medulloblastoma, which can be divided into four overarching subgroups. The cell origins of two of these (WNT and SHH) are pretty well characterised, but for the other two – Groups 3 and 4 – this knowledge is missing. The aim of my research is to gain a deeper understanding of the origins of Groups 3 and 4 medulloblastoma, and ultimately use this to develop better targeted treatments.

### Why is this research so important?

Unfortunately, around a third of medulloblastoma patients do not survive, and those that do can suffer dramatic side effects, such as neurological disorders. We need to find treatments that are more accurate and less harmful in order to improve survival and quality of life for patients.

### What would you say to other young researchers out there?

Find a project you're passionate about. Research is an intense field, so you need to be really motivated by what you're doing. And find a lab that's dynamic and collaborative – science is about collaboration. I think it's so important to have an interactive, friendly environment to work in.

Take a look at page 20 to find out about the work of Dr Paul Northcott, Laure's colleague at St. Jude.



## New SAB members

We're pleased to welcome two new members to our Biomedical Scientific Advisory Board.



**Professor Steve Clifford,  
Newcastle University**

Funded by us, Professor Clifford has categorised childhood medulloblastoma into several different subtypes, allowing healthcare professionals to tailor treatments. He's currently researching which biomarkers could be used to identify these subgroups.



**Professor Colin Watts,  
University of Birmingham**

Professor Watts' research aims to improve treatments and survival rates for people with gliomas by understanding the differences between tumours. His team have also used the dye 5-ALA (the 'pink drink') to reveal different parts of glioblastoma during surgery, helping surgeons remove more of the tumour.

## Join our RIN

We know that collaboration is key in the fight against brain tumours. That's why we founded our Research Involvement Network (RIN) in 2015, to give patients, carers and family members a voice and presence within the research community.

Since then, we've fostered closer co-operation between researchers and those affected, to ensure research into this disease remains as relevant as possible.

### What to expect

By signing up to the RIN, you'll be joining over 150 people affected by brain tumours who've been involved in more than 80 different research projects. You don't need scientific or clinical knowledge to contribute – your experience will be valuable whatever your background.

You can expect to:

- review research proposals
- join steering groups or advisory boards
- attend lab tours
- receive research updates

Visit [thebraintumourcharity.org/rin](http://thebraintumourcharity.org/rin) to find out about more ways you can get involved and fill out an application form.

# Clinical trials

Clinical trials can be a mystery, from understanding how to access them to knowing what to expect. To help unravel the mystery, Vicky, whose daughter Amelia recently joined a clinical investigation, shares their experience.

**The Paediatric EVICEL® Neuro Study, a multi-centre study, is looking into the use of surgical intervention, EVICEL® for children.**

EVICEL® can help surgical wounds heal and prevent bleeding and occurrences of cerebrospinal fluid (CSF) leak, which can cause seizures, sickness and tinnitus. It's currently licensed for adults, but not children; the study aims to change this.

"We were under the care of Mr Sivakumar, Consultant Neurosurgeon at Leeds General Infirmary, one of the centres involved in the study, when he asked if we'd consider being part of the research. We were given information to read and spoke to the research nurse, then it was just a matter of signing a release form.

"Our neurosurgeon talked about it so well. He eased our worries and it sounded really good. There were risks obviously, there is with everything, but we knew it worked really well for adults, and we knew she was in the best place, so we wanted to go for it.

"The trial was randomised, so it wasn't until after surgery that we knew Amelia had received EVICEL®. The wound healed really well and the neurosurgeon didn't have to shave her hair, so just a small line is visible.

"It's been a few weeks now and it's not even noticeable and she didn't have any problems with infection! We have follow-ups for EVICEL® so they can monitor Amelia's progress but they're at the same time as our normal appointments, so we don't have any extra visits.

"I would recommend clinical trials. Just speak to your medical team and make sure you understand the risks - our team were brilliant - and don't be scared to ask questions. You need to be informed, so ask them everything and anything."

**Learn more about clinical trials at [thebraintumourcharity.org/clinical-trials](http://thebraintumourcharity.org/clinical-trials) and read more about Vicky and Amelia's journey at [ameliasplayroom.wordpress.com](http://ameliasplayroom.wordpress.com)**



Vicky and her daughter Amelia



## Here when you need us

**We believe everyone affected by a brain tumour should get the help and guidance they need, when they need it. So, we're expanding and improving our support services; starting last year with the introduction of Live Chat (our online chat service).**

During the summer we trialled extended opening hours, so we could be there when you needed us most. Now, we're pleased to announce we'll be continuing these extended hours for our free telephone helpline, Live Chat, email and Facebook support services through September and October. Our specialist support for children, families and young adults is also included.

We're also trialling new, modern technologies, such as Artificial Intelligence (AI), to expand and improve our services. We're currently exploring the idea of a 'chatbot'. A chatbot is a computer program that uses AI to simulate conversation with you online. The benefit of using a chatbot is that you can get an immediate answer to your questions any time of day.

In the beginning, a chatbot will be fairly basic and will only be able to answer simple questions, but it will grow as it interacts with you. We hope that, one day, this could be a viable new service so that you can get support whenever you need it. We'll keep you updated on our progress in this area.

We'll also continue to expand and improve our support services throughout this year based on what we hear from you, so watch this space for more!

**The new opening times for The Brain Tumour Charity's support services are**

Mon, Tue, Fri: 9.00am-5.00pm  
Wed and Thu: 9.00am-9.00pm

Get in touch by calling us on 0808 800 0004, emailing [support@thebraintumourcharity.org](mailto:support@thebraintumourcharity.org) or visiting [thebraintumourcharity.org/live-chat](http://thebraintumourcharity.org/live-chat)



## BACK TO SCHOOL

It's September and back to school for pupils and teachers across the UK. After their home, school is often where young people spend most of their time, so it's an important place to raise awareness of brain tumour symptoms.

### Eva's story

Eva MacDonald, 22 and one of our Young Ambassadors, was diagnosed with a low grade astrocytoma after a teacher at her primary school noticed her handwriting had deteriorated over the summer holiday. Before this, Eva had seen her GP several times with symptoms including headaches, nausea, stiff neck and loss of balance.

"One of the teachers knew that there was a neurological problem. A consultant later said the tumour had most likely been growing since I was born. I want to use my story to raise awareness of brain tumours and their impact. They are truly devastating and living with the consequences can be a struggle. I hope my experience will inform others about the possible signs and symptoms before it's too late."



## HOW YOU CAN HELP

HeadSmart has helped halve average childhood brain tumour diagnosis times from 13 to 6.5 weeks. We want to see this reduced to four weeks for children and teenagers, but we can only do this with your help – the time for action is now.

We need everyone – parents, teens, teachers – to raise awareness of the symptoms of brain tumours in schools.

Visit [headsmart.org.uk](http://headsmart.org.uk) to order:

- symptoms cards
- posters to display on noticeboards
- an education pack, with template letters for parents and head teachers, 25 symptoms cards and card holder for your local school.

For more information please email [info@headsmart.org.uk](mailto:info@headsmart.org.uk)

### Please share the signs and symptoms.



Persistent/recurrent headache



Persistent/recurrent vomiting



Balance/co-ordination/walking problems



Abnormal eye movements



Blurred or double vision



Behaviour change



Fits or seizures



Abnormal head position, such as wry neck, head tilt or stiff neck



Increasing head circumference (crossing centiles)



Delayed or arrested puberty



@HeadSmartCampaign



@HeadSmartUK

# Tyler's royal honours

*Our Young Ambassador, Tyler Murphy, was honoured by none other than the Queen in her recent Birthday Honours list.*

**Tyler was honoured with a British Empire Medal for his tireless work, helping to support children with a brain tumour and other life-threatening diseases.**

Aged just 12, Tyler was diagnosed with a brain tumour and has since undergone 27 operations, leaving him with severe disabilities, such as vision problems and numbness on his left side. And in 2016 a stroke left Tyler with speech problems too. But despite all this, Tyler brightens the lives of other young people living with life-threatening illnesses. In 2014, whilst lying in hospital, Tyler had an idea; sending gift boxes to children in a similar situation.

With that selfless thought, Tyler's Trust was born and has since donated hundreds of gift boxes to sick and hospitalised children across the south east. We're so proud of Tyler and thrilled that he's been honoured in this way.



## Be a Young Ambassador

**If you're aged 18-25, affected by a brain tumour (whether you or a loved one has been diagnosed) and passionate about improving outcomes, then we need you!**

We're looking for new members of our Young Ambassadors Programme. Acting as a voice for The Charity, our Young Ambassadors share their story to help others, lobby for change and speak and volunteer at events.

You'll also connect with other young adults affected and develop your skills and confidence.

Applications open November 2018 and close 11 January 2019. For more information on the role and how to apply please visit: [thebraintumourcharity.org/young-ambassadors](http://thebraintumourcharity.org/young-ambassadors)



Lloyd, lost his wife Rachida to a brain tumour in 2014.

# LEAVE NOTHING UNSAID.

We all put things off. They can be as simple as saying 'I love you', or as difficult as saying 'goodbye'.

Writing a Will is a simple thing that often gets overlooked. But making one is easy and with our free Will writing service, cost needn't be an issue. Your Will is a positive statement about what matters to you. And by leaving a gift to us in yours, you'll help find a cure for brain tumours faster.

Don't wait. Leave nothing unsaid.

Find out more at:  
[thebraintumourcharity.org/gift-in-will](http://thebraintumourcharity.org/gift-in-will)



# My personal Everest

"Losing a parent to a brain tumour is a devastating event. One of our supporters, 23-year-old Esme Tuttiett, has been through this ordeal twice, having lost both her mum and dad to the most aggressive form of brain cancer, glioblastoma. She's now taking on the Virgin Money London Marathon 2019 for us, raising awareness and funds to help combat this truly awful disease.

"I was six when we lost my mum to a brain tumour. I was tiny when she died, so my memories of her are a bit blurry. I do remember her playing with me in the garden and singing nursery rhymes with me in the car.

"Last year, when I was writing my Masters dissertation at Loughborough University, my dad, who was a head teacher, had noticed he was getting a few of his words muddled up. We all thought he was overtired and put it down to stress caused by his work. But eventually it got worse. He went to the GP and was sent for further tests. That's when he called me and said, 'something's been found and it doesn't look good.'

"I rushed home and we were given the diagnosis – he had two tumours, both quite large. It was very sudden. He was given a prognosis of three months, and initially he was still pretty much himself. But before he could start treatment he deteriorated rapidly. He got worse day by day.

"That was a horrible week. I was still trying to finish my dissertation by the deadline. I wanted to be able to tell my dad I'd finished it, which I was so glad I managed to do before he died in September 2017.

"I've watched the London Marathon coverage over the years and the buzz is incredible. I love a challenge, so when I decided to do something to raise awareness and money to combat brain tumours, I thought 'why not go all out and do the Marathon?' I enjoy running, but I've never run a marathon before! The training is going to be tough. I'm preparing by doing cardio, HIIT and spinning, and I plan to start upping the duration and distance of my runs.

"Any time I have a doubt or wobble, or think 'can I actually do this?', I just think about the potential good I can do. That's my biggest driver. And I've got my mum and dad in my memories, too – I want to do it for them."

**It's very rare for two members of the same family to get a brain tumour. If you have any concerns or would like further information about the risk factors for brain tumours, visit [thebraintumourcharity.org/risks-and-causes](http://thebraintumourcharity.org/risks-and-causes)**



Esme with her dad and brothers.



# Come together for Christmas

*By making us part of your festive celebrations and reflections, you can help us stop brain tumours in their tracks.*

## Christmas shop

Ordering your Christmas cards and gifts from us is a simple and effective way to support our mission to defeat brain tumours. Browse through our beautiful selection in the enclosed Christmas brochure and order yours today. Every card and gift sold will help us reach a cure faster.



## Christmas quiz

Our Christmas quiz is back for 2018! So, brush up on your trivia knowledge and help us take on brain tumours this Christmas. Get together with your friends, family and colleagues and find out who's really the brainiest of the bunch. By raising as much as possible at your quiz, you can help us move forward faster, funding vital research and support.



## Festive Fashion

This Christmas, we're inviting everyone to don something seasonal, be it a Christmas jumper or reindeer earrings, and get fundraising! Get everyone involved in this fun fundraiser – from your office to your school or social club, dress in your best festive wear and raise more for a cure!

## Santa Run

If you're looking for a festive fun run this Christmas, then why not sign up to a Santa Run near you? Join us as we pick up the pace and accelerate a cure this festive season. Find out more on our website.



## Christmas Angels

Become one of our Christmas Angels and help us sell our range of beautifully designed Christmas cards and gifts to friends, family and colleagues.

Last year, you raised £56,000 by buying our seasonal cards and gifts, helping us fund over seven months of research! This year, we hope to raise even more towards a cure!

**Find out how you can get involved with us this festive season at [thebraintumourcharity.org/christmas](http://thebraintumourcharity.org/christmas)**





# New Quest for Cures

*Thanks to your support, we're funding two new Quest for Cures research initiatives.*



## New therapies for children with ACP

Dr Todd Hankinson,  
University of Colorado

Adamantinomatous craniopharyngioma (ACP) is a rare childhood brain tumour that has a devastating effect on a child's quality of life. The majority of children with ACP suffer life-altering disabilities, such as blindness, permanent hormone imbalances and morbid obesity.

ACP tumours are heterogeneous, which means they're made of different types of cells. We're awarding over £1 million to Dr Todd Hankinson's research programme, which aims to understand the behaviour of the different types of cells, identify targets for treatment and develop new therapies. This could dramatically improve quality of life for children with ACP and revolutionise treatment for this disease.



## Novel approaches to treating medulloblastoma

Dr Paul Northcott,  
St. Jude Children's Research Hospital

Previous research has helped identify four overarching subgroups of medulloblastoma, the most common high grade childhood brain tumour. Children diagnosed with Group 3 and 4 medulloblastomas have the worst outcomes due to frequent tumour recurrence. This suggests that changes in the tumour during treatment may be driving resistance, leading to progression.

With our £1.5 million funding, Dr Paul Northcott and the MERIT team (Medulloblastoma Epigenome Regulation in Treatment) will research the changes in the tumour and how they contribute to treatment failure.

They then hope to identify novel approaches to reverse this resistance and accelerate a cure.

## Guiding the way

**We're thrilled to have worked with our community to feed into new NICE (National Institute for Health and Care Excellence) guidelines, published in July.**

This is the first time in over a decade the guidelines have been updated for brain tumour patients and we're proud to have been part of it. We involved our community, asking their thoughts on the guidelines and feeding their views into the process.

The new guidelines include guidance on 5-ALA (the 'pink drink'), a surgical intervention for high grade gliomas that makes brain tumour cells glow pink and helps surgeons remove more of the tumour.

This is something we've been asking for with Baroness Tessa Jowell and top neurosurgeons. Particular thanks to Stephen Price, Colin Watts and Pablo Goetz, who have long advocated for its universal use. They've been invaluable in helping us understand this issue and barriers to its use.

It's now our role to ensure healthcare professionals can implement these guidelines and ensure this becomes the pathway for all patients. Thank you to members of our community, Research Involvement Network and Policy Involvement Group, who helped on this and to everyone who campaigned for 5-ALA.

## The TWILIGHT WALK

**Last year, over 3,200 of you joined The Twilight Walk and took strides towards a cure, raising a record-breaking £350,000. This year, it's set to be even bigger and better, so don't miss out!**

With not long until The Twilight Walk begins, there's still time to sign up and #WalkWithUs this year. You can hold your own walk, of any length, somewhere special to you, on any date in October.

## #WalkWithUs

Our community fundraisers can help you set up your own walk and we have great resources to guide you on the path to success. Alternatively, you could join our 10km routes in Warwick (30 Sept), Edinburgh (7 Oct) or Windsor (14 Oct). No matter where you walk, please join us as we unite to celebrate loved ones, raise money and give brain tumours the boot. Find out more at [thebraintumourcharity.org/thetwilightwalk](http://thebraintumourcharity.org/thetwilightwalk)





## Q&A with our Clinical Nurse Superstar

Charlotte Robinson of King's College London is our first funded Clinical Nurse Specialist (CNS) and the first funded low grade glioma CNS in the UK.

### Can you tell us what your normal working day looks like?

I have clinics, visit patients on the wards and email and call patients and hospitals, making referrals, chasing medication and checking how they're doing.

### How can a CNS help people affected by a brain tumour?

If they have questions, worries or new symptoms, we can bring their appointment forward, offer reassurance or organise another MRI.

We escalate anything of concern to different teams, such as the neurosurgeons, neuro-oncologists or community palliative care team. We're their support network.

### What are some of the ups and downs of being a CNS?

I really look forward to chatting with patients and seeing them in clinic,

getting to know them professionally and on a deeper level. Recently, I received an amazing letter from a patient's sister, thanking me for helping the family. It made me realise how important my role is in making the best out of a terrible situation, helping those affected and their relatives on this horrible journey they've been made to go on. But there's definitely a psychological burden to this cruel disease.

### How important is it to fund more clinical nurse specialists, like you?

So important. Research shows that those diagnosed with a low grade tumour don't have access to a CNS and could face this journey alone. We need more clinical nurse specialists to change this, but the funding just isn't there yet.

### Tell us a surprising fact about you?

I'm half Australian and I've run a marathon!

*"Recently, I received an amazing letter from a patient's sister, thanking me for helping the family. It made me realise how important my role is... helping those affected and their relatives on this horrible journey they've been made to go on."*

Charlotte Robinson  
Clinical Nurse Specialist



A donation of

**£25**

could pay for one hour with a specialist nurse, like Charlotte, so all patients can access the best care possible.



## No one should face a brain tumour alone

Living with a brain tumour can cause feelings of isolation for those affected. Yet not even half of those diagnosed with a low grade tumour have access to a named key worker.

This means too many people are lacking the proper emotional and practical support to help them cope with this devastating diagnosis. It's time this changed! But we need your help.

Our first Clinical Nurse Specialist (CNS), Charlotte, has been a huge help to patients so far, but the field is still underfunded and clinical nurse specialists are being stretched too thin. That's why, this year, we need your help to fund our next low grade CNS.

Only with your help can we ensure the needs of brain tumour patients and their carers are not forgotten; giving them equal access to emotional support and the care and treatment they're entitled to.

No one should face a brain tumour alone. Please support our campaign by donating today at: [thebraintumourcharity.org/fund-a-CNS](https://thebraintumourcharity.org/fund-a-CNS)



# Top tips for PIP

As a Benefits Advisor for Citizens Advice, helping our community, Denise knows first-hand how many people struggle when applying for Personal Independence Payment (PIP). PIP is one of the most common benefits for those affected by a brain tumour, yet understanding this benefit, whether you're eligible and navigating the process, can be difficult. So now, Denise is sharing her top tips.

## 1. A points-based system

One of the big questions I'm asked is, how do I know whether I'm entitled to PIP? The application covers a range of different activities, such as eating or cooking food, communicating and mixing with others, and bathing. For each activity you need help with, you'll be awarded a 'point'. The more help you need, the higher your points. Once you get to eight points, in either the daily living or mobility activities, the PIP award is triggered.

## 2. Begin your application as soon as possible

The standard PIP process has three stages and can take a few months to complete. That's why it's important to begin the application as soon as you think you may be entitled. If your claim is successful, your payments will be backdated from the moment you start the first stage (a phone call to log the claim).

## 3. Fast track for those with a terminal diagnosis

If you've been given a terminal diagnosis with a life expectancy of six months or less, you can apply for PIP under the special rules. If you're in this position you'll be given a form, DS1500, from your medical team, hospital, GP or specialist nurse. You can send this to the assessors so you'll receive the highest rate of PIP, normally within a couple of weeks.

## 4. Don't let the form put you off

Under normal rules, your next step is to complete an assessment form. This is something we often get enquiries about as many people find this stage of the process daunting. However, the form isn't as long as it seems because many sections may not apply to you. This doesn't mean you won't be eligible, as it's possible to get the points you need in one activity, so do persevere.

## 5. Success is in the detail

You must have had a condition for three months before applying for PIP. During this time you may learn to cope and feel you don't have difficulties, but this might not be true. For each activity you need help with, you'll be awarded points towards your application. So, for instance, if you can't cook without sitting down, or you need help from someone else, this means you need an aid.

Many people also mention having difficulty but don't explain why. The more information you can give, the more the person making the decision can understand. For example, rather than just saying 'I have difficulty showering' add, 'because I can't stand for long periods of time'.


## 6. Don't do it alone

Your assessor can't and won't make any assumptions, so if you have fatigue or memory problems – common symptoms for those diagnosed – you need to say so. That's why detailed information, supported by examples is crucial. One way to ensure your form's as informative as possible is to get advice from someone, like a friend or family member, or you can book an appointment with me.

## 7. The final step

Your last step will be a face-to-face appointment. Be prepared to talk about how your condition affects you – and you may need to repeat what you put on your form. However, if you're uncomfortable with something do say. And if you need someone with you, for moral support or to join discussions and take notes, let them know. As long as the person is over 16, this should be fine.

You can also ask for adjustments if the centre doesn't have something you need, or you can change your venue if it's over 90 minutes away and you have difficulty travelling long distances.



If you need help with the benefits system, Denise is here every Tuesday from 9.30am-4.30pm. Call 0808 800 0004 any day to book your telephone appointment. Read more about PIP at [thebraintumourcharity.org/understanding-pip](http://thebraintumourcharity.org/understanding-pip)



# How your business can help

Wondering how to help? Like our partners, Underbelly, just be yourself!



In June, our comedy night returned, as comedian Hal Cruttenden was back to stand-up to brain tumours. So, when our corporate partners, Underbelly, heard the news, they decided to lend a hand!

Underbelly did what they do best to make a difference. They kindly donated their Southbank venue, and promoted the event on the walls of the 'Summer at Southbank' festival, free of charge, raising awareness to thousands of people. They also promoted Hal's Comedy Collective through their social media channels and donated four tickets to their headline circus show 'Circa's Peepshow' to our raffle.

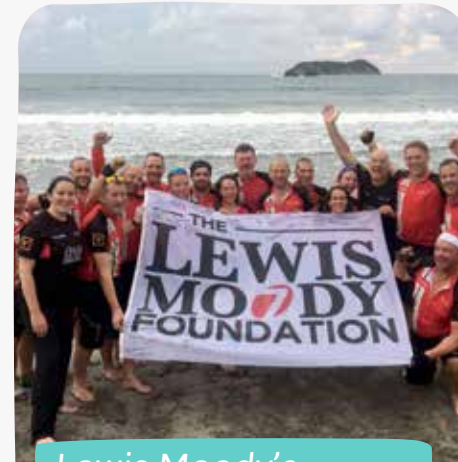
Their contribution meant Hal's Comedy Collective was not only in a great venue, but was well attended and raised more towards a cure! Thank you to Underbelly, Hal and everyone who came along and helped make the night a big success!

**We're proud to welcome our new partnerships:**



## Citation

Find out how we can work together - email [corporate@thebraintumourcharity.org](mailto:corporate@thebraintumourcharity.org)



## Lewis Moody's £1 million milestone!

The Lewis Moody Foundation was set up in 2014 by ex-England Rugby Captain, Lewis Moody, and his wife, Annie. Now, four years on, The Foundation has reached the £1 million milestone!

Through challenges such as a 1,000km bike ride and crossing Costa Rica by bike, foot and kayak – as well as marathons, swims and hosting balls – The Foundation has been dedicated to defeating brain tumours.

Lewis and Annie said, "We're so grateful to everyone who's helped us reach the £1 million mark. It's incredible and means we can support more families affected by brain tumours now and in the future."

We're so thankful to The Foundation for helping us fund research, our HeadSmart campaign and our Family Days.



## The Big Match

On 26 May, The Big Match kicked-off at Millwall FC for a day of fundraising, football and fun for all the family, marking the event's fifth anniversary.

The Big Match is organised by Neil Humphries to raise money for us and Action for Children, inspired by his dad, who sadly passed away from a brain tumour in 2012.

The main event was the much-anticipated charity football match, where celebrities and guests battled it out. This was followed by The Big Match Kidz training and the 'Extra Time' gala dinner, which included an auction and entertainment.

To date, Neil has raised over £260,000 with The Big Match, an incredible sum helping us get closer to defeating brain tumours. Thank you to all the players and supporters who help make this a success.



# Viv's Legacy

*Viv McBeth was a Community Fundraiser here at The Charity, who many of you may have met.*

But Viv also raised money for The Charity in her spare time. Sadly, she lost her fight against a brain tumour last year, and her friend Sheona is continuing Viv's legacy, through one of her biggest fundraisers - The Silver Ribbon Ball.

"Viv and I have been friends for over 20 years and when she was first diagnosed it was a shock. But through her fabulous spirit, inspiration and determination we made some unforgettable memories.

"The Silver Ribbon Ball started in 2012 and has brought a lot of people together who have suffered from a brain tumour and remembers those we've lost. It's a beautiful night with a meal, entertainment and games.

"Both The Charity and The Ball are very important to me. I've made a lot of new friends over the last seven years because of it; and because of Viv. So I feel it's important The Ball continues, in her memory.

"This year was especially emotional, as it was the first since her passing. But with the support of the other girls on the committee, Julie, Elaine, Heather and Claire, The Ball was a success and seeing so many people come together was amazing."

Through ticket sales and auctions, The Silver Ribbon Ball raised over £10,000 this year, an amazing achievement and one Viv would be proud of! Thank you to everyone who made this possible and who donated to this touching event. The Ball will be back again for 2019, so watch The Charity's website for more information soon!

(From left to right) Sheona Swan, Claire McCallum, Elaine Mair, Heather Dearie, Julie Leslie



# Supporter Groups

Our Supporter Groups are dedicated and courageous groups of people who raise awareness and funds for us in the name of a loved one. Their tireless efforts are helping us defeat brain tumours faster.

*Welcome to our new Supporter Groups:*

Lizzie's Fund

The Chris Squance Memorial Fund

The Frank Riding Memorial Fund

The Jon Moss Fund

The Khushil Pandya Fund

The Paul Crichton Charitable Fund

The Tiya Gandhi Fund

Find out how you can set up a Supporter Group by visiting the [thebraintumourcharity.org/supporter-groups](http://thebraintumourcharity.org/supporter-groups)



## Making strides together

In May, two of our Scotland-based Supporter Groups ran together to raise funds at the BHGE 10km in Aberdeen. The Repper Brothers Fund united 100 runners, or 'Ali's Athletes', in memory of Ali Repper, who passed away from an astrocytoma last year. The Paul Young Fund ran in support of Paul Young, who had a glioblastoma and sadly died since the event took place.

Ali's brother Graham said, "We had the support of so many people cheering us on. The whole day was entirely reflective of Ali's positivity, determination and desire never to give up when the going gets tough."

Kirsten, a family member of Paul, said, "When Paul was diagnosed, we knew we had to run for him. Ali's team couldn't have been more supportive – we joined in with them on the day. It was amazing to see loads of The Charity's red t-shirts."

# Your letters

*We care about what matters to you. Here, we share a selection of your stories and views on how The Charity has impacted your life recently.*

Thank you for your support, which is always there when needed, your tact, enthusiasm and positivity. I know I have a trusted source of help and reassurance in The Brain Tumour Charity.

Thank you!  
**Brian x**



Lauren and I would like to thank The Charity for your support and generosity in order for us to attend the Big Meet. We found the event very worthwhile and enjoyable; it was great meeting new people, sharing our experiences and making new friends. We felt very supported and everyone was so friendly.

Going to these events is invaluable to us as Lauren is very isolated and no one else understands how challenging it is to live day-to-day with the complications of her brain tumour. Thank you again for having us at the Big Meet.

Love and best wishes,  
**Yvonne and Lauren Monaghan x**

**Find out more about our events on pages 32 and 33**

The Family Day was a fantastic day. All the staff were brilliant and made us feel instantly at ease. It gave me and my family an opportunity to have some much needed fun. Also time for me to speak with other people who are going through something similar, which was helpful for me. Hopefully see you all again and I'm sure we'll talk soon."

Many thanks,  
**Carmen Brady-James xx**



I really enjoyed the Family Day. I feel like the activities that were chosen were well balanced for all ages. All staff members were very approachable and made the day as enjoyable as possible.

**Oisin, age 15**



The kids and adults had a FAB day at the Family Day. Great activities and something for everyone. Thank you so much.

**The O'Hares**





# Upcoming events

*We have lots of great events and activities throughout the year. Find out what we're up to and how you can get involved.*



6 October 2018

## Edinburgh Family Day

Join us at the Edinburgh Academy for our Edinburgh Family Day, where we'll be hosting a day of fun activities for children and adults living with a brain tumour and their families.

24 November 2018

## Christmas Family Day

Would you like to meet other families in a similar situation? Find a safe space where your child can be just that – a child? Where your family can enjoy precious time together? Then our free Christmas themed Family Day can provide the perfect festive day out for you and your family.

1 December 2018

## Leeds Young Adult Meet Up

Young adults with a brain tumour diagnosis, aged 16-30, are invited to join us for some festive fun. The day will be filled with games and quizzes that everyone can enjoy whilst getting to know each other and will end with a meal.



February 2019

## Sahara trek (Sign up by end Oct)

If you've ever wanted to do something amazing, push yourself to the limit, experience bucket-list worthy views, and help change the lives of those affected by brain tumours, then join the Sahara Trek in 2019! This charity trek is an event you'll never forget, making memories and lifelong friends along the way.

10 March 2019

## Barcelona Marathon

One of the most attractive marathons in Europe, the Barcelona Marathon 2018 – or Zurich Marató de Barcelona – is a flat, 26 mile, circular route through beautiful Barcelona. The fascinating route passes many tourist attractions and the very popular Gothic District.



17 March 2019

## Bath Half Marathon

This is a fast and flat half marathon around the river Avon, finishing in the heart of historic Bath. You'll start and end at the same point in Great Pulteney Street; one of the widest Georgian boulevards in Europe.



14 April 2019

## Brighton Marathon

The Brighton Marathon is one of the UK's best loved 26.2-milers. Running alongside the stunning backdrop of the sea, this challenge on the south coast gets bigger and better each year.

To sign up or discover more fantastic events visit [thebraintumourcharity.org/events](http://thebraintumourcharity.org/events)



# Thank you to #TheBrainyBunch

A heartfelt thank you to all our inspirational fundraisers across the UK. Here are just a handful of some of the incredible ways you're helping to raise much needed funds and awareness in your local community.

Thank you for  
all that you do.

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



Nine-year-old Ollie Shear from Reading wanted to hold an event to support his mum who's living with a brain tumour. He organised a kids' duathlon and raised £4,612!



Anne-Marie Woodcock's annual Prosecco Tea was full of cakes and cheers as England beat Sweden. This Preston based bubbly event raised £1,400 for The Lee Woodcock Memorial Fund.



Jane Parks from Shrewsbury, raised a whopping £9,229 by pledging her birthday to The Charity, in support of her daughter who's living with a brain tumour.



Steve Garrett from Newcastle raised an amazing £1,600 by having his legs waxed, in memory of his friend Michael Almond.



Claire Smith and family from Chester-le-Street, held a collection at Marks and Spencer in the Metro Centre in Newcastle raising £1,300 on the day. Their continued support has already led to more than £3,000 being raised for The Charity.



17-year-old Rhudi Baume Kennedy, from Glasgow, held his second 'five-a-side' Football Tournament at the Allander Leisure Centre in East Dunbartonshire and raised an incredible £2,138, pushing his total to £5,416 raised to date.



Andy Downes from Diss, organised a massive motor bike ride for the second year running, in memory of his friend Ted who sadly passed away from a brain tumour. Over 140 bikers took part and raised £1,391!



Coventry based running club Sphinx AC decided to ditch the trainers and hold a fantastic quiz in memory of their friend Lee Timms. Lots of fun was had and the night raised an incredible £1,256 for The Charity.



Jacqueline held a Tea Garden party in memory of her son, Jon, which raised £785, bringing The Jon Fredrickson Fund total to over £10,000!



Stuart Blackburn from Aylesbury, along with friends Rob, Trev and Wayne, all employees of Mitsubishi Electric, completed The Three Peaks Challenge over three days in memory of their friend Alan, raising a fantastic £5,125! Stuart said, "It was the most humbling experience ever".



Georgie and Jo Linscott from Farnham gathered a group of friends and walked 45km through the South Downs to raise funds for their dad who is living with a glioblastoma. The group raised an amazing £11,285.



Lionel Spittle from Wolverhampton, raised over £5,000 by completing his 65 Challenge. This saw Lionel not only swim 65 lengths and cycle 65 miles but also run 65 laps, all to mark his 65th birthday and the five-year anniversary since he lost his wife, Linda, to a brain tumour.

# 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](https://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 send 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





How your regular gift can make a lasting difference

*Our regular givers Joyce and Dave explain why they donate on a monthly basis to The Charity:*

"We lost our lovely son, Steven, to a very difficult to treat brain tumour. We met many wonderful young people in a similar situation and realised more focused research into this dreadful condition was needed, as statistics show brain tumours are one of the least researched of the major, life-threatening cancers.

"After our daughter, Sarah, found The Brain Tumour Charity online, we felt a regular donation would help develop the research structure needed to provide the best chance of achieving results. Every donation, big and small, is important – but regular giving really adds up over time and can help The Charity plan and develop vital long-term research projects to develop successful new treatments for brain tumour patients."



A gift of

**£8**

per month could pay for a test to help identify personalised treatments for patients.



If you chose to donate

**£20**

per month, this could pay for a whole day of world-class research every year.

You can set up a Direct Debit today at [thebraintumourcharity.org/donate](https://thebraintumourcharity.org/donate) for as little as £2 per month. We rely 100% on voluntary donations, including regular gifts – and these can be made in memory of, or inspired by, a loved one or dedicated to one of our Supporter Groups. Thank you for helping to fund vital, life-saving research.

***Thank you!***