

The leadership story of Sue Farrington Smith MBE

Chief Executive, Brain Tumour Research



Sue at Westminster 2016

Brain tumours kill more children and adults under the age of 40 than any other cancer. Founded in 2009, **Brain Tumour Research** is the only UK national charity dedicated to raising funds for continuous and sustainable scientific research into brain tumours and, at the same time, campaigning for the Government and larger cancer charities to increase the national investment in brain tumour research.

A decade on, the charity's campaigning successes have shone a spotlight on the historic underfunding and have led to increased national investment in research into brain tumours. What's more they are transforming research into brain tumours in the UK through their dedicated brain tumour research centre strategy, building capacity in pioneering research having established four dedicated research centres at four UK universities; the goal is to build a network of experts in sustainable research – and ultimately to find a cure.

Brain Tumour Research's Chief Executive and co-founder, Sue Farrington Smith, tells of the personal tragedy which acted as inspiration to the charity's formation, the hard work and good fortune involved in its remarkable success story, and the evolving leadership challenges.

A fellow of the Chartered Institute of Management Accountants (CIMA), and an alumna of The Open University who started studying for her psychology degree aged 32, Sue was awarded an MBE in the 2017 New Year's Honours List for services to brain tumour research and awareness raising.

There is no doubting the end-game of the charity headed by Sue Farrington Smith MBE. Sue talks about the importance of having a clear vision, a clear goal and a clear message. To succeed, they are hugely reliant on the goodwill of volunteers, on the support of donors and on caring about people.

She says: "The overarching goal is to find a cure – and the route to that cure is a network of dedicated brain tumour research centres, collaborating nationally and internationally. The scientists believe we can find a cure, our supporters believe we can get there, I believe we can do it. When we established the charity, I set a clear fundraising target of £7 million annually for seven centres so people knew what we were aiming for.

"Whenever we put something out into the marketplace, I want it to be clear, and I want to be able to see that there's a deliverable and it's SMART (specific, measurable, achievable, relevant and time bound), not just woolly words. However, it is also important not to be closed, but to be open to new ideas that come up along the way and can help us with our goal; for example, we're now funding a brain tissue registry to help facilitate research at the centres – this was not in my original vision.

“We’re very much goal focused as an organisation but, more than anything, I want us to work together and really be caring about the people we are supporting. Sometimes I can be clumsy with the things I say and might unintentionally upset the families we strive to support, but I listen to my sister Julie, as she soon puts me right. I feel her pain. She’s the grieving mum, I’m an auntie. That caring message is at the core of everything we do.

“I personally sign every single thank you letter that goes out and always add a little handwritten note on it. I feel that if our supporters have spent their time fundraising for our cause, I can spend half a minute writing a personal thank you message to them. I’m always touched when people proudly post a copy of their letter and my handwritten message on their Facebook page.”

How it all began



Sue, her family with Rt Hon Ed Balls then State Secretary and Mr Speaker

The story begins with the loss of Ali, her sister’s little girl, who was seven when she was diagnosed with a brain tumour in August 2000, sadly passing away 10 months later. Sue was able to spend some valuable time with both Ali and her mum Julie while running her own marketing business having recently left her role as Head of Business Development at former UK supermarket chain Safeway.

Reflecting on how it all began for Ali’s Dream, moving on to the United Brain Tumour Campaign and ultimately Brain Tumour Research, Sue talks emotionally about the purpose, energy and passion that emerged from this personal tragedy and deep loss for the family. As she reflects on key events, we note the importance of timing, of utilising your own and your friends’ expertise, gaining the attention of influential politicians, and collaborating with influential stakeholders who can help implement your vision.

“We lost Ali on a Thursday (7 June 2001) in the very early hours, less than three weeks away from her eighth birthday. By 10am on the Friday morning, my sister announced we would start a charity called **Ali’s Dream**. I knew I could do the marketing and set up a website and through my connections was able to set up the charity’s bank account on the Monday so that we were able to announce Ali’s Dream at her funeral. Being able to tell people about the charity and give out the bank account details raised £10,000 in the first month and as a volunteer-led charity we raised £108,000 within the first year.

“As I was working from home, running my own business, I was able to take responsibility for the marketing aspects such as the website, and start talking to friends, family and connections to gather names for our database and other activities. To cut a long story short and having researched the brain tumour charity landscape at that time, I was invited to talk about Ali’s Dream as well as the other UK brain tumour charities at the second UK Brain Tumour Society conference in 2002. This went really well and meant I was now in touch with all other registered brain tumour charities in the UK.

“I helped facilitate the coming together of brain tumour charities, researchers and clinicians at a UK Brain Tumour Society workshop in Luton in March 2003 to develop a vision and action plan for the brain tumour community. Following initial attempts at bringing charities together in a controlled way, later that year, eight of us got together in a pub in Kettering to move things forward in a more collaborative way.

“Knowing that we couldn’t resolve the issues alone and that we would need to influence the Government, three of us decided to visit our MPs! I went to see my local MP, John Bercow, at one of his surgeries and he offered to help raise the issues in an adjournment debate. There had never been a debate in the House of Commons on the subject of brain tumours, and only ever one parliamentary question.

“John advised me not to be surprised if there was only him and the responding minister in the chamber but not one to be put off, I told him he could count on me to get more MPs there. With the support of fellow charities throughout the UK, I prepared a pack and drafted letters for them to send to MPs in their local areas. This resulted in there being 10 MPs in the chamber that night! As a result of this debate, which took place in April 2004, I was then contacted by Schering-Plough, who were marketing a drug for brain tumours called Temozolomide (TMZ for short), that they wanted licenced for use by the NHS for recurrent brain tumour patients. In parallel to this, those brain tumour charities who wanted to work together formed a loose coalition known as the United Brain Tumour Campaign (UBTC) which we launched in June 2004.



The DHSC Task and Finish Working Group

“In October 2004, Schering-Plough funded a reception at the House of Commons and with the support of fellow charities we engaged more than 20 MPs. Seeing such an interest in the subject, John offered to establish an All-Party Parliamentary Group of cross-party MPs following the 2005 General Election, asking me to provide the secretariat. Schering-Plough provided pro bono access to their lobbying consultant to guide me in this new role.

“In 2006, working with other brain tumour charities and supported by Schering-Plough, we turned around the decision by NICE (National Institute for Health and Care Excellence) not to fund Temozolomide for recurrent brain tumours, such that it would now be funded by the NHS.

“The following year, Sandy Saunders, who lost his 38-year-old daughter to a brain tumour in 2002 and founded The Diana Ford Trust, was determined that the UBTC charities should

formalise our relationship and come together as one charity. After several meetings with me and Wendy Fulcher, founder of the Brain Tumour Research Campaign (BTRC) charity, we agreed to put the proposal to fellow charities. In 2008, the Diana Ford Trust changed its name to Brain Tumour Research and its trustees stepped down, with the exception of Sandy, while representatives of some of the member charities of the UBTC became a trustee and we were able to utilise The Diana Ford Trust funds of roughly £20,000 to set up Brain Tumour Research.

“Basically, that £20,000 enabled me to get the website up and running, establish our branding and produce the first set of marketing materials. I asked favours from people from my own marketing business. I had an office with five desks and PCs, so the infrastructure was there and I persuaded my husband to let me spend 100% of my working time on the charity, with no pay, albeit that I was still able to service some of my clients using sub-contractors.

“I actually ended up working pro bono for two years; it was my mission and my passion. I utilised the people within my marketing company’s team to help me draft copy for the website and marketing materials, write press releases, undertake the bookkeeping, and answer the phones etc. We had various people and agencies helping with our design work and PR on a pro bono basis and in 2012 my husband and I chose to close my marketing business.

“We launched the charity at the House of Commons in April 2009. Brain Tumour Research is unique in our sector in that it has member charities who support the organisation without losing their own identity. We now have 22 member charities and more than 40 fundraising groups whose stories and experiences will never be lost and will always be recognised for their contribution. Togetherness / embracing is a strong value of Brain Tumour Research.



“It wasn’t easy at the start but with the support of a coach friend of mine I kept focusing on what I was trying to achieve. Originally as the United Brain Tumour Campaign, it was just me and the member charities, and I was using them as a sounding board. Then I had the trustees to add to that support while we developed Brain Tumour Research. Now, as I have been able to build a team, I have a Director of Finance and Operations, and a Director of Fundraising and

Brain Tumour Research Team 2017

Marketing to use as sounding boards. I also have Wendy Fulcher, who runs the Brain Tumour Research Campaign charity and is the Chairman of Brain Tumour Research, and of course my coach, friend and businessman husband!”

Growing an organisation

Brain Tumour Research's progress has been startling – raising 'just' £6,000 in the year ending 2009, compared to £3.4 million in fundraising in 2018. And from a handful of volunteers in 2009 to 34 staff at present, many of whom are involved because in some way their lives have been affected by this devastating disease. In setting up a charity, Sue talks about the importance of knowing who your audience is and having the right kind of 'shopfront' to attract them. She also talks about focusing on your vision, and 'punching above your weight', about paying attention to how you work together to achieve that vision and about what and how you need to change as the organisation grows. In terms of people management and caring for people, Sue highlights the importance of being honest and straightforward, about being willing to develop people yet also recognising when it's right for the organisation to let someone go.

"Right from day one, I knew that we would build the charity based on PR and the website. Because, if you're diagnosed with a brain tumour, the first thing you do is search online so, if you came to our website, you'd find out about us, and if we started being in the papers, you'd find out about us. Those two things were our shopfront.

"Because we had that vision of being a big organisation, we acted like we were a big organisation and developed the culture accordingly. I've always run the organisation in a structured way based on the experience I gained in my corporate roles. In the early days, we would try to bring out into the open, some of the things that weren't working quite well as an organisation, to help us move forward – teamwork, and time management, things that all organisations struggle with. When we launched, we also introduced an annual members' workshop to bring all the member charities together to explore issues, share concerns, share best practice, share ideas. It's a bond and we support each other.

"Back in 2009, I knew exactly what I wanted to do. But as you start to recruit people, things can go a bit haywire so then you have to bring it all back in. In the beginning, I was in control of everything. I knew every single supporter individually. I knew what everybody in the team was up to because there were only five or six of us. As we then started to grow, processes and guidelines began to get lost as people joined and added their own tweaks, which is fine. But, guided by a consultant, we found that we weren't as clear and as focused anymore. So then we needed to communicate about how we would behave as an organisation; what the processes are; what the rules are and basically start bringing in those various disciplines.

"We started having off-site away days to provide an opportunity to bond, build trust and get to know each other better. I've had help to design workshops which I've then facilitated myself as well as using external facilitators on occasions. It's been all thought through, with a clear agenda and purpose as to what we need to achieve, to help the organisation improve. A lot of people think they're busier than the next person. It's amazing to see that, even in a small organisation, silos can form. I'm always really aware that we must not allow those behaviours to happen. After these events, I can see the benefits and changes in team members' behaviour the very next day.

"I also make sure that we make time for activities like health and safety audits, as the governance aspects are a strong value of mine. We operate a continuous improvement log; we think about how we can change processes and move forward. We don't just pay lip service – we take continuous improvement and delighting our supporters very seriously.

“I try not to overstretch us but I’m always aware of what we need to do. I’m a driver; I like the team to have targets; I try and focus their minds. I’m also a hands-on leader. People have to earn my trust in the first few months. Once I think they’re going in the right direction, I leave them to it. If they’re not going in the right direction, then I confront the situation and try and coach them!

“I’ve made mistakes along the way, and I’m always aware of my own mistakes. We’ve kept some people for longer than we should have done. Some of that is because I feel guilty about letting them go. My way is more to support and develop people but actually that can end up not helping the organisation. It is our obligation as a manager to wean out people that are not being productive or don’t fit the culture.

“I am open, honest, and very straightforward and some people find that difficult. Over the years a lot of colleagues have said that I’m a great boss because I am straight with them and I want to help develop them. When you work with some people who actually don’t want to be developed, they’re the tough ones and, eventually, you have to make some difficult decisions.

“A strong value of mine is recognising others’ contributions. In all of our materials, we share the logos of our brain tumour charity members. In our *Believe* magazine, we promote and applaud the activities of our member charities. We aren’t territorial; if somebody comes to us that needs support or is looking for treatment options, we have no hesitation in signposting them to our relevant member charities who specialise in those aspects.”

Taking stock – and the next steps

With an organisation like Brain Tumour Research that continues to grow and succeed, the need to take stock and revisit its shape, development and next steps is essential. By refusing to rest on its laurels, the charity has developed clearer targets and more dynamic branding to increase its reach and influence, helped by further serendipitous interactions with journalists and politicians.

“In 2015, we had a ‘taking stock’ moment, working with PB Political Consulting who help us with our lobbying. We took a day out to work on a clear manifesto and what we wanted to do. I wanted to be clear – what are we actually going to be able to say in five years’ time (2020), that we actually achieved? What are the tangible things that we can be measured by?

“Maria Lester, a writer for *The Mail on Sunday’s You* magazine who had lost her brother Stephen to a brain tumour, then got involved. She wanted to start an e-petition and we seized that moment. We helped her shape the e-petition ‘Ask’ with our manifesto ‘Ask’ so that we had a clear call on the Government. She launched the e-petition in *You* magazine with a double page spread sharing the story of her brother and asking people to sign the petition.

“We galvanised our member charities and all of our supporters, behind this petition and with the support of the *You Magazine*, we got 10,000 signatories in the first month. This is one example of serendipity over the years – the new Petitions Committee was formed in the summer of 2015 and Maria had used their platform to set up the e-petition.

They organised an official launch of the Petitions Committee in September 2015 and seeing the interest that was gathering, they used Maria's e-petition as their launch case study!

"If an e-petition receives 100,000 signatories, it usually prompts a Westminster Hall debate. We were determined to achieve this. With this focus, we galvanised and supported brain tumour patients and bereaved families to promote the e-petition in their regional media around the UK and we used social media. I sent out emails to our member charities and other organisations and I was literally saying 'please, please, please get behind this'; this is our opportunity, we must seize the moment. We ultimately obtained more than 120,000 signatures by the six-month deadline!

"Working with Rebecca Harris, MP for Castle Point, who was the chair of the Brain Tumour All-Party Parliamentary Group at the time and patron of one of our member charities, the Danny Green Trust, every single MP was urged to be at the Westminster Hall debate. Supported by us, Rebecca's team sent a copy of *Danny's Journey*, a book written by his father Chris Green, co-founder of the Danny Green Trust, to every MP. MPs were targeted with emails from our office, Rebecca's letter (which we drafted) and enclosures. We also provided a template to our supporters to write to their MPs, and we ended up with more than 70 MPs and standing room only at that debate in April 2016.

"Speakers included an MP whose son has a brain tumour and another two MPs who have brain tumours. Every MP spoke with emotion about their own constituents. The responding Minister was George Freeman, then Minister for Life Sciences, who had attended a recent Speaker's House event that we had held to promote the e-petition. I had seized the opportunity to take him to one side at that event and explain the issues. Swept away by the emotion at Westminster Hall, George volunteered to establish a Task and Finish Group on the subject of brain tumour research. We had our first meeting in October 2016 and I kept the vision that the 120,000 plus petitioners were on my shoulder to give me the courage to say things at the working group meetings, which included civil servants, clinicians and researchers, to make things happen.



"This milestone and our continued success encouraged us to revisit our values to come up with five words that would describe the organisation as it had now evolved – these are now **goal focused; game-changing; influential; embracing; and intelligent** – although our founding archetype has not changed, these words were more dynamic and easily understood than the original five words."

Celebrities, scientists and supporters

The individual leader and leadership challenges

Sue describes herself as a 'natural born leader'. She suggests that being the eldest of five, with three sisters and one brother, taught her about politics at a very early age: 'if you're one of four girls, it's often about attention seeking'. She reflects on playing with her siblings and

how she carried out the leadership role that fell naturally to her, carefully manoeuvring and compromising so everyone could enjoy and take part when, for example, performing a play for their parents and other family members. She also reflects on ways in which she and her siblings were given different tasks while working together on a project – such as decorating a room – learning practical skills and the importance of teamwork and collaboration in the process.

As a child, she tested out her appetite for entrepreneurship: “I was a bit of an entrepreneur from an early age but actually not a very good one at that stage. I used to go to the shops and buy sweets to sell to family and friends. But the trouble is, I made a loss – I was trying to make more sales by selling them at less than you’d buy in the shop!”

Clearly Sue soon got the hang of entrepreneurship and this along with strong leadership, teamwork and collaboration with stakeholders beyond her immediate organisation are integral to the success of Brain Tumour Research.

While there have been many leadership challenges for Sue along the way, at present, the charity’s three-strong leadership team are joined by Heads of Departments for a weekly management team meeting. Sue explains: “I often don’t need to say anything anymore because the team works together, they know their roles and their objectives and come up with ideas to implement our various fundraising and awareness activities. As you get good people into the organisation, they all work together and motivate each other.

“As a leader in the third sector, the biggest lesson is having to deal with people who have not had corporate experience, and don’t think in a certain way and don’t have the experience to know what I am on about. I get quite frustrated when people don’t operate in a professional way. I get most enjoyment working with and talking to people that I feel are on my wavelength.

“You have to have a lot of patience and you have to have broad shoulders. And you have to have resilience because it’s often two steps forward and one step back. I know I get frustrated a lot but I have learned to deal with it. The poem ‘If’ by Rudyard Kipling often resonates – ‘if you can keep your head while all around are losing theirs’ – I often repeat that mantra in my head. I also remember a particular quote by the Dalai Lama – ‘if you think you’re too small to make a difference, try sleeping with a mosquito’. I often have conversations with myself and also with God – I ask him ‘*am I doing the right thing?*’. I often get signs and serendipitous opportunities come along. I believe that Ali is up there guiding me too!”

About collaboration beyond the organisation, Sue says: “As a member of the AMRC (Association of Medical Research Charities), I have often been asked by other CEOs how I’ve managed to get the member charities to work together and gain buy in and I am helping to advise some of them in this respect. As a relative newcomer to the charity sector, I have found it somewhat strange that some larger charities tend to think of smaller charities as an irritant that is getting in their way. In our sector, big is not always beautiful or best, a collaborative approach and joint working often meets the needs of numerous stakeholders and I believe that we should recognise different people’s perspectives, bring them along, and work at the pace of the slowest member if we are to achieve lasting change. That way people will trust you and come with you, after all, we all have the same end goal. Patience is

a virtue, as I'm always telling my husband and children. It's important to always have the end goal in mind, and sometimes you have to remind people of that.

"In my view you shouldn't try to force people to do something, or insist on people doing something. It's got to be from the heart, and it's got to be a belief. I don't feel that I am a very important person and I'm not an attention seeker but I understand that sometimes I have to perform, even though I might not feel comfortable about doing it. Some of it comes back to my religious beliefs that one should be humble so I have these inner conflicts going on all the time. And, at the end of the day, I believe I am on a journey and that I have a purpose and I trust in God that I am pursuing the purpose that he expects me to."

Brain Tumour Research – braintumourresearch.org

Ali's Dream – alisdream.co.uk