

# Help us go head-to-head with brain tumours

## Become a trustee for the UK's leading brain tumour charity

Unremunerated but expenses paid

The Samantha Dickson Brain Tumour Trust is the largest brain tumour charity in the UK – and the biggest dedicated funder of laboratory-based brain cancer research in Europe.

Brain tumours kill more children, and more adults under 40, than any other cancer.

Since 1996, we have funded research that has led to significant advances in the search for better treatment, diagnosis and understanding of the disease. We have also provided emotional support and information to brain tumour patients, their families and carers. In short, we are making a real difference.

We have had a record-breaking year for fundraising, so we are keen to recruit new trustees who can help us seize the momentum while ensuring our future growth and sustainability. We would particularly like to hear from people with experience in any of the following:

- Major donor and/or senior-level fundraising
- Charity governance and law
- Marketing
- Business or finance in a large institution

We would also welcome applications from senior health professionals, ideally with a background in oncology.

Trustees are required to attend a Board meeting four times a year (on average) and encouraged to join one of the Trust's sub-committees (Finance & Audit, Research, Patient Support or Fundraising). Meetings are usually held in Central London. Trustees will be appointed for an initial period of three years after which the commitment can be renewed. For further details and an application pack please visit:

[www.braintumourtrust.co.uk/trusteerecruitment.htm](http://www.braintumourtrust.co.uk/trusteerecruitment.htm)

For an informal discussion about the role please contact our Chair, Neil Dickson, or our CEO, Paul Carbury, on 0845 130 9733.

Applications should be emailed enclosing a CV and a cover letter marked private and confidential to [paul@sdbtt.co.uk](mailto:paul@sdbtt.co.uk) by 5pm on Friday 4 September. Interviews are likely to be held week commencing 21 September.



SAMANTHA DICKSON  
BRAIN TUMOUR TRUST

Head to head with brain tumours

July 2009

Dear Applicant

Thank you for your enquiry, we are delighted you are interested in becoming a trustee of the Samantha Dickson Brain Tumour Trust. Please find enclosed further information about us and our work and the role you would be expected to play as a trustee.

You will also be able to look at our annual report and accounts which are publicly available on the Charity Commission website [www.charity-commission.gov.uk/registeredcharities/ScannedAccounts/Ends27/0001060627\\_a\\_c\\_20080331\\_e\\_c.pdf](http://www.charity-commission.gov.uk/registeredcharities/ScannedAccounts/Ends27/0001060627_a_c_20080331_e_c.pdf)

Please visit our website at [www.braintumourtrust.co.uk](http://www.braintumourtrust.co.uk) for further information. We are a registered charity and company limited by guarantee.

If successful, you would be joining us at an exciting time as we continue to grow and develop. Our objectives are to achieve the best possible outcomes for people with brain tumours through our world class research programme and patient support work.

On the 2 August we will be featured on national television with our BBC1 Lifeline Appeal and if you are able to tune in, this would give you a good overview of our work. The appeal will be broadcast on BBC1 at 5.20pm on the 2 August and repeated at 1.20pm on BBC2 on Weds 5 August. The appeal will also be available on BBC iPlayer and YouTube if you miss it first time.

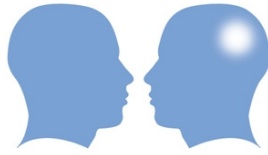
If you would like an informal discussion about the role with either myself or our Chair, Neil Dickson, please contact us on 0845 130 9733.

Please email a CV and cover letter to [paul@sdbtt.co.uk](mailto:paul@sdbtt.co.uk) by 5pm on Friday 4 September. Interviews are likely to be held week commencing the 21 September.

I look forward to hearing from you.

Yours sincerely

Paul Carbury  
Chief Executive



**SAMANTHA DICKSON  
BRAIN TUMOUR TRUST**

Head to head with brain tumours

## **Trustee Recruitment Pack and Information**

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## **1 Why Brain Cancer Research, why now?**

Brain tumours kill more children, and more adults under 40, than any other cancer. Yet often dubbed the 'forgotten cancer' the UK's brain survival rates have barely changed over the last 30 years, with understanding and treatment of the disease falling way short of standards across the rest of Europe and North America.

Research from the University of Cambridge names brain tumours as a 'Cinderella' cancer, with high individual cancer burden but low research spending. This research shows that brain tumour patients have their life expectancy reduced by on average 20 years – the greatest reduction of any cancer. Other cancers such as breast cancer and leukaemia have seen significant research investment in previous decades, and improvements in survival rates have been achieved.

Now is the time for investment to overcome the inequities that people with brain cancer face.

## **2 About Us**

Samantha Dickson Brain Tumour Trust is the UK's leading brain tumour charity and has been leading the fight against this terrible disease for 12 years; our vision is to find a cure for brain cancer. Our main aims are:

- To fund brain cancer research developing new treatments and identifying the causes of brain tumours so we can improve survival rates and the quality of life for children and adults;
- To provide advice, education and support to brain cancer patients and their families/carers;
- To promote early diagnosis of brain cancer to improve quality of life and survival rates

We are the biggest brain tumour charity by income and are the largest single funder of laboratory based brain cancer research in Europe. To date, we have invested £5 million in 45 research projects throughout the UK.

Every year we provide support and care to hundreds of brain cancer patients and their families. Through information we have empowered parents to spot the signals and signs of a potential brain tumour so they can quickly get a diagnosis. We receive no government funding and rely on people affected by brain cancer to fund the research and support.

### **3 Achievements**

Amongst our many achievements since our creation in 1996, the key milestones are:

- Establishment of the UK's first dedicated Brain Cancer Research Unit at the University College London (UCL) Cancer Institute;
- Helping to improve the survival rates of children with brain tumours from 55% to 65% over the past 10 years through our portfolio of research projects;
- Development of new nationally approved guidelines for GPs across the country to help with early identification of childhood brain tumours;
- Breakthroughs in understanding the causes of brain tumours in a number of projects
- Development of a specialised patient support service for families and children

All our research programmes and projects are peer reviewed by eminent professionals in the brain cancer field and we are members of the Association of Medical Research Charities (AMRC). Our research projects are carefully selected with the advice of our Scientific and Medical Advisory Board and leading specialists in the field of neuro-oncology from around the world.

But our vision to find a cure for brain cancer is in its infancy.

### **4 Brain Tumours: the facts**

The facts regarding brain tumours are stark:

- Brain cancer is one of the most lethal of all cancers.
- There is no cure and limited understanding of the cause.
- Brain cancer accounts for more deaths among children under 15 and adults under 40 than any other cancer - 3,400 people lose their lives to a brain tumour each year.
- Only 65% of children survive for five years after diagnosis - much lower than the leukaemia survival rate of 85%.
- Adult brain cancer patients have an even worse prognosis – only 14% live for longer than five years.
- Evidence suggests that it can take three times longer to diagnose a child with a brain tumour in the UK when compared with the USA, Poland and even Mexico.
- Brain tumours receive only £2 million of the UK's annual £400 million cancer research spend

A quarter of all childhood cancer occurs in the brain affecting one in 2500 which puts nearly 32,000 life years at risk. More children die of brain tumours than any other cancer accounting for the loss of 10,000 life years each year.

Long term survivors of childhood brain tumours experience ten times the disability of well children and often require state or family support in adulthood. This accounts for 20,000 additional disabled life years for all the children who are diagnosed each year.

Though there are huge challenges to overcome we have some exciting plans to achieve our strategic objectives:

- Launch of world class research project at the Samantha Dickson Brain Cancer Unit at UCL
- Ongoing childhood and adult brain cancer research programmes – current spend £1 million per year
- Launch of a new telephone helpline and patient support service
- Development of a significant major donor programme and capital appeal
- Development of Early Diagnosis Campaign to enable health professionals to spot the early warning signs of childhood brain tumours

## **5 Our History – Samantha’s Story**

Samantha was a bright, lively, happy fun-loving girl who enjoyed school, music, drama, sports, swimming, modern and tap dancing, travel and skiing. She played the flute and piano and was a dedicated scholar, working for distinction in all her exams. Sam had an incredible zest for life and always wanted to be where the action was.

At the age of 14, Samantha's life and that of her parents, Neil and Angela and brothers James and William were turned upside down when she was diagnosed with a brain tumour. She had been having unusual headaches and minor blackouts for many months, and despite seeking medical advice both through the NHS and privately, it took ten months before it was discovered she had a brain tumour. Sam lost her struggle for life in October 1996, just six days short of her 17<sup>th</sup> birthday.

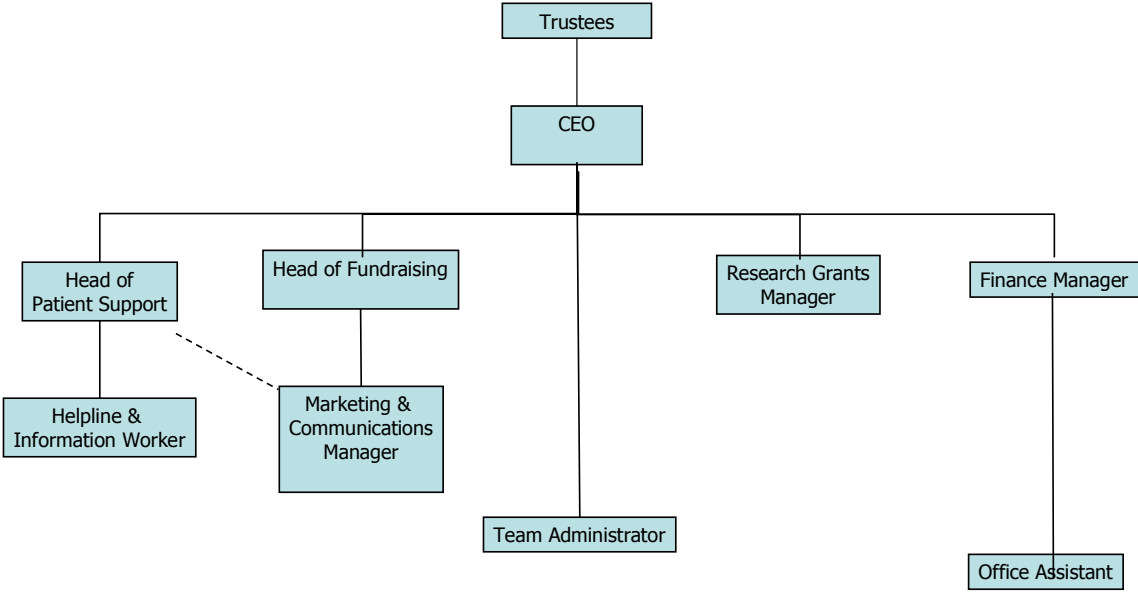
Neil and Angela wanted to help other children in Samantha’s position and went on to set up the Samantha Dickson Brain Tumour Trust to lead the fight against brain cancer. In the past 12 years we have grown to be the biggest brain tumour charity in the UK. We are working, not only in memory of Samantha, but for thousands of other children and adults like her.

## **6 Our Structure**

Trustees meet as a full Board four times a year and there are 3 sub-committees that will meet 2-3 times a year. These are Finance and Audit, Research and Patient Support. We are also developing a Fundraising Committee which will help oversee a major donor/capital appeal.

We have a small staff team of nine which is led by our Chief Executive who reports to the Chair of Trustees and the full Board.

# SDBTT Organisation Structure



June 2009

## **7 Terms of Reference for the Trustee Board**

### **Objectives:**

- to take overall responsibility for everything that Samantha Dickson Brain Tumour Trust does
- to act collectively and effectively in the interests of Samantha Dickson Brain Tumour Trust
- to give strategic direction, determining and safeguarding the mission and vision of Samantha Dickson Brain Tumour Trust
- to take the decisions required for the proper control and management of Samantha Dickson Brain Tumour Trust including final decisions on research grants applications
- to ensure that there is a clear structure for governing the organisation, including defining the role of any sub-committees or working groups
- to ensure that Samantha Dickson Brain Tumour Trust has adequate financial resources for its activities
- to act prudently to protect the assets and property of Samantha Dickson Brain Tumour Trust
- to ensure that Samantha Dickson Brain Tumour Trust complies with its own governing document, relevant laws and the requirements placed upon it by its funders and/or other bodies
- to review the risks to which Samantha Dickson Brain Tumour Trust is subject, take action to mitigate these risks and to ensure sound risk management
- to act as a responsible employer
- to ensure that the principles of equality and diversity are upheld and that Samantha Dickson Brain Tumour Trust is fair and open to all sections of the community in all of its activities
- to seek assistance from experts in areas where the trustees lack the necessary skills
- to induct every new trustee

### **Meetings:**

- meetings to be held as often as board business requires but a minimum of 4 times a year
- a formal record to be kept
- the day and time of meetings to be arranged to suit most trustees, but ensuring that no one member is continually prevented from attending meetings
- business to be conducted efficiently
- comments on agenda items and/or board papers from trustees unable to attend a meeting to be given, where applicable, to the Chief Executive and/or Chair in advance of the meeting for inclusion during board discussions
- All trustees are required to comply with the Trust's policy on conflicts of interest including disclosing all relevant interests annually and at the start of any meeting where they are relevant to the agenda

## **8 Trustee Role Description and Person Specification**

On appointment trustees will be asked to complete a declaration of interests form and be CRB checked.

### **The statutory duties of a trustee**

- To ensure that the organisation complies with its governing document, charity law, company law and any other relevant legislation or regulations
- To ensure that the organisation pursues its objects as defined in its governing document
- To ensure the organisation uses its resources exclusively in pursuance of its objects: the charity must not spend money on activities which are not included in its own objects, no matter how worthwhile or charitable those activities are
- To contribute actively to the board of trustees' role in giving firm strategic direction to the organisation, setting overall policy, defining goals and setting targets and evaluating performance against agreed targets
- To safeguard the good name and values of the organisation.
- To ensure the effective and efficient administration of the organisation
- To ensure the financial stability of the organisation
- To protect and manage the property of the charity and to ensure the proper investment of the charity's funds
- If the charity employs staff, to appoint the chief executive officer and monitor his/her performance

### **Other duties**

In addition to the above statutory duties, each trustee should use any specific skills, knowledge or experience they have to help the board of trustees reach sound decisions. This may involve:

- Scrutinising board papers
- Leading discussions
- Focusing on key issues
- Providing guidance on new initiatives
- Other issues in which the trustee has special expertise as a 'trustee champion'

### **Person specification**

- Commitment to the organisation
- Willingness to devote the necessary time and effort
- Strategic vision
- Good, independent judgement
- Ability to think creatively
- Willingness to speak their mind
- Understanding and acceptance of the legal duties, responsibilities and liabilities of trusteeship
- Ability to work effectively as a member of a team
- Nolan's seven principles of public life: selflessness, integrity, objectivity, accountability, openness, honesty and leadership.