



## NEWS RELEASE

### Lottery gives BIG boost to brain tumour support service

Almost £250,000 has been awarded by the BIG Lottery Fund to create the UK's largest 'one-stop shop' for brain tumour support.

The money will go to the Hampshire-based Samantha Dickson Brian Tumour Trust (SDBTT) – the UK's largest brain cancer charity – and will be used to provide enhanced patient support services for the 6,500 people diagnosed with the disease in the UK each year and their families and carers.

Paul Carbury, Chief Executive of the trust, said: 'We are delighted with the award from the Big Lottery Fund. The funding will enable us to significantly expand our services for the benefit of children and adults who have been diagnosed with a brain tumour. The project will enable thousands more people to get access to our services so we can improve outcomes for patients.'

Carly Hornbuckle, whose daughter Bella aged 5 has been diagnosed with a brain tumour, was equally enthusiastic: 'The support provided to me by the Trust has been fantastic – I got a lot out of speaking to them while I was waiting for Bella's scan results during a very traumatic time. It's great news that this grant will enable the Trust to support many more families who are going through the same experiences as we are.'

The £236,977 will pay for additional staff, information, educational roadshows, website development, volunteers, training and evaluation to provide a co-ordinated approach and to significantly expand existing patient support services. Brain tumour patients and their families, parent representative groups and health professionals will all benefit from the revised programme.

Many advantages of the new, co-ordinated SDBTT service include:

- Working with health professionals to improve support for families
- Improved quality of life for patients and their families
- Support for schools, teachers and groups where a child in attendance has a brain tumour
- A central resource for clinical trials information
- The provision of comprehensive information on different tumour types and treatments
- Up to date information on the latest research breakthroughs

- Plans to extend the opening hours of the existing helpline and email service.

The project will be delivered from the charity's headquarters in Hampshire and through 60 umbrella groups across the country.

-ENDS-

## **NOTES TO EDITORS**

### **About The Samantha Dickson Brain Tumour Trust (SDBTT)**

Samantha Dickson Brain Tumour Trust SDBTT is the leading adult and childhood brain tumour charity dedicated to research and support in the UK. The charity's aim is to raise awareness, support and funds for brain tumour research to help fight this devastating disease and give hope to brain tumour patients in the future. It also offers support and information to patients and their carers.

The charity has been working to find a cure for brain tumours since it was set up in 1996 by Samantha's parents, Neil and Angela Dickson. Since then millions of pounds have been raised for brain tumour research and support services for patients and carers, and the charity has become the largest funder of brain tumour research in the UK.

More information on Samantha Dickson Brain Tumour Trust is available by calling 0845 130 9733 or visiting [www.braintumourtrust.co.uk](http://www.braintumourtrust.co.uk).

### **General Statistics**

Out of the £420million spent on cancer research in the UK, less than 1% is spent on brain tumour research.

6,500 people are diagnosed each year with a primary brain tumour.

3,400 people lose their lives to a brain tumour each year.

Despite being the biggest childhood cancer killer and causing more deaths among the under 40s than any other cancer statistics show that brain cancer has received a fraction of the funding of higher profile cancers. Statistics also show that high profile cancers have received up to 20 times the investment of brain cancer and have seen survival rates almost double in 30 years.

Often dubbed the 'forgotten cancer', the UK's brain cancer survival rates have barely changed in 30 years whereas other cancer types have seen clear improvements.

The average years of life lost (calculated from the shortening of life attributable to brain cancer, compared to life expectancy) to brain tumours is the highest of any cancer at over 20 years and is the biggest killer of adults under 40.

## **SDBTT Statistics**

Record year from 1<sup>st</sup> April 2009 – 31<sup>st</sup> March 2010

Record income of £1.4m for the year

Record research expenditure of £1m

Three major research breakthroughs:

University of Newcastle – our research team have pinpointed characteristics of medulloblastoma tumours that could help to determine the severity of an individual child's cancer. A new project is now trialling a UK-wide system for testing tumour samples and will assess whether this could be used routinely to improve diagnosis and tailor treatment for individual patients.

Queen Mary University, London – our research team has made a major breakthrough with regard to the childhood brain tumour pilocytic astrocytoma. Research has identified certain genetic changes that are frequently found in these tumours, and which relate to a pathway that could be involved in the development of the tumour.

National Hospital University College London – for the first time in the UK adult high grade brain tumour patients are having a chromosome test on their tumour samples. The test identifies approximately one in three patients whose tumour is far more reactive to chemotherapy

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