

NEWS RELEASE



**SAMANTHA DICKSON
BRAIN TUMOUR TRUST**

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BIGGEST CHILD CANCER KILLER STUCK IN FUNDING TRAP

The UK's leading brain cancer charity is calling for a review of cancer research investment following evidence of what it claims is a 'funding trap' within the UK's cancer programme.

Despite being the biggest childhood cancer killer, and causing more deaths among the under 40s than any other cancer, the Samantha Dickson Brain Tumour Trust¹ is unveiling statistics² which show that brain cancer has received a fraction of the funding of higher profile cancers and is killing more people than ever before. Every year in the UK, 6,500 people are now diagnosed with the disease.

The 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 over the same period, with understanding and treatment of the disease falling way short of standards across the rest of Europe and North America. Research, funded by the charity, indicates that the medical profession in the UK takes around three times longer to diagnose a paediatric brain tumour than countries such as Poland, Mexico and the US.

Paul Carbury, CEO of the charity, said: 'Humanitarian agencies often talk of the poverty trap. Brain cancer is the victim of a funding trap. There's a cycle of funding which sees much of the investment going to large, established research centres which represent the high profile cancers. In the absence of a nationally recognised facility on this scale, brain cancer has never been able to break this cycle and attract sufficient funding or academic talent. It's undoubtedly why we are still seeing such ignorance around the disease and its shocking mortality rates.'

The announcement coincides with the opening of a major new brain tumour research facility at University College London, funded by the charity, which it's hoped will go some way to addressing the current funding inequality and enable much greater understanding of the disease.

Bringing together top academics from across the international field of neuroscience, The Samantha Dickson Brain Cancer Unit³ will be the UK's first 'centre of excellence' dedicated to the disease and will be able to compete for funding at the highest level. It's envisaged that this partnership will provide

the blueprint for similar centres around the UK, with the charity hoping to raise funds for two or more over the next five years.

Paul Carbury added: 'Whilst this centre of excellence represents a big step forward, it is by no means a panacea. Government and the funding agencies need to wake up to the reality that more people than ever before are losing their lives to this devastating disease. If we are to reverse its appalling record in our society, we urgently need to see funds allocated on a more equitable basis.'

Professor Chris Boshoff, Director of the UCL Cancer Institute, said: 'Our new centre will offer a great boost to the field of research but, given the chronic lack of funding to date, we need to receive continuous and enhanced support if we are to achieve progress on a scale seen elsewhere in the cancer world.'

'The strategic partnership between UCL and the Samantha Dickson Brain Tumour Trust will establish a brain cancer programme which will contribute significantly to our understanding of the biology of the disease, have an international impact on brain cancer research and make laboratory discoveries which can be translated into clinical care.'

Morna Sinclair, whose daughter had a brain tumour and had to be seen several times by the GP before finally being diagnosed by the hospital, said: 'There is still so much ignorance around this disease and I had to really fight to be taken seriously. My daughter would wake every morning screaming from the pain of her headache and I was told she was attention seeking. I even had to resort to videoing her seizures in order to prove how bad they were. Although our story has a happy ending and our daughter is now fine, it's so clear to us that the medical profession still has a long way to go to understand this horrible disease.'

- Ends-

Notes to Editors

1. The Samantha Dickson Brain Tumour Trust (SDBTT) exists to find a cure for childhood and adult brain tumours through funding research, as well as offering support, hope and information to patients and their carers. SDBTT has become the largest single funder of laboratory based brain tumour research in the UK. They have been leading the fight against this terrible disease for 11 years; their vision is to find a cure for all brain tumours. Their aims, over the next three years are to establish a world class research programme to see a step change in the desperate lack of funding for new treatments, to tackle the inequalities that brain tumour patients face in accessing promising new therapies and to increase the number of specialists working in the brain cancer field.
2. Statistics table overleaf
3. The objective of the new Samantha Dickson Brain Cancer Unit will be to fund a group of clinicians and scientists to lead translational research into the understanding and treating of brain tumours. The unit will have a unique network with the clinical brain cancer activities at University College London Hospital (UCLH), with the research programmes at the UCL Cancer Institute and the UCL Institute of Neurology.
 - Case studies available on request

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