

A milestone in brain tumour research: the UK's first national networked brain tumour tissue archive

A new collaboration announced recently gives unprecedented access to brain tumour tissue for research



Charities and hospitals have announced a new tissue banking initiative, called the Brain Tumour Archive Network that will unlock thousands of previously hard to access brain tumour samples for researchers throughout the UK.

Creation of the network was led by brainstrust and supported by a wider group of brain tumour charities including Charlie's Challenge, Brain Tumour Research and umbrella group Sophie's Wish. BRAIN UK, operating at the University of Southampton, will link existing archives of brain tumour tissue in a virtual network so that researchers can gain access to unprecedented levels of tissue to support their much needed research into better treatments and a cure for brain cancer.

BRAIN UK is run as a collaboration between representatives from the University of Southampton, Plymouth Hospitals NHS Trust and Bristol University and a network of 26 hospitals across the UK, without whose assistance the network couldn't operate. The British Neuropathology Society, British Neuro-oncology Society, Brain Tumour Network,

Medical Research Council and National Cancer Research Institute Brain Tumour Clinical Studies Group have provided input into and support for the project. There is a huge hitherto unmet scientific and clinical need for brain tumour tissue, and with the stratified medicine agenda growing, the demand for samples with better quality background information grows, making the timing of this project perfect.

James Nicoll, Director of Brain UK and Professor of Neuropathology at the University of Southampton, comments: "I am delighted that we are able to provide this new resource for brain tumour research. We need to understand brain tumours better – how they arise and how they grow – so that we can learn to treat them better. BRAIN UK can now provide researchers with access to unprecedented numbers of brain tumour samples. This can only be done with the collaboration of our colleagues in Neuropathology departments throughout the UK and thanks to funding from the charities brainstrust and Brain Tumour Research and the Medical Research Council."

Willie Stewart (pictured), Consultant Neuropathologist at Southern General, Glasgow, says: "One problem researchers in this field continually meet is a lack of tumour tissue for high quality research, yet there are vast resources of material in diagnostic laboratories throughout the country. This project paves the way for this invaluable material to be accessed to support high quality research projects."



Brain tumour tissue is currently incredibly difficult for researchers to access, as many types of tumour are rare. However, a review of current NHS archive holdings, dating back to the 1970s, revealed that a networked approach would make in excess of 400,000 stored samples potentially available to research. The Brain Tumour Archive Network will provide the interface that is needed between researchers and brain tumour tissue stored in NHS hospitals, giving easy access to the right tissue, in sufficiently large numbers with appropriate ethical approval already in place. It will support a diverse range of brain tumour research projects and change the face of neuro-oncology research.

Helen Bulbeck, co-founder and Director of Services at brainstrust says: "This is an exciting project. The Brain Tumour Archive Network is an initiative where tissue samples provided by patients from across the UK can be accessed through one central resource, then made available to scientists to study how and why brain cancer develops and spreads, and to devise the best possible treatments.

Sue Farrington Smith, Chief Executive of Brain Tumour Research says: "Brain tumours are the biggest cancer killer of children, and more children and young adults die from this disease than from any other cancer; in addition up to 40% of other cancers spread to the brain, yet research into brain tumours remains underfunded and under resourced. For years access to tissue has been the issue for researchers."

All involved in the project believe that the work will result in more research, better results, and better outcomes for brain tumour patients. ●

For further information please call Helen Bulbeck at brainstrust 01983 292405 or Katie Abbotts at Brain Tumour Research on 07810 504380, or Becky Attwood, University of Southampton, on 02380 592116. Case studies are available.

Brain Tumours – the facts

- 1 in 50 people who die under the age of 60 die from a brain tumour (2% of all deaths under 60)
- 71% of those that die of a brain tumour are under the age of 75 (compared to 47% for all cancers)
- More children and adults under 40 die of a brain tumour than from any other cancer
- Brain tumours receive just 1% of the national spend on cancer research
- 16,000 people each year are diagnosed with a brain tumour
- Only 18.8% of those diagnosed with a brain tumour survive beyond five years, compared with an average of 50% across all cancers
- Unlike most other cancers, incidences of diagnosis with and deaths from brain tumours are increasing (and are much more common now than in 1970)

(Source: Brain Tumour Research)

About brainstrust

There are at least 55,000 people living with and beyond a brain tumour diagnosis in the UK. brainstrust was founded in 2006. The Charity helps brain tumour patients and carers get back on top of things following a brain tumour diagnosis. It gives everyone diagnosed with a brain tumour access to the resources that will put them back in control. Its coaching based relationship with brain tumour patients and carers enables these people to develop their own resilience and to utilise brain tumour support resources to their full potential. www.brainstrust.org.uk

About Brain Tumour Research

Brain Tumour Research was launched in April 2009 to raise the awareness of and funding for scientific research into brain tumours and improve outcomes for brain tumour patients. www.braintumourresearch.org

About Sophie's Wish

Sheffield based Sophie's Wish was formed by family and friends of Sophie Burchill, to increase brain tumour awareness and research. www.sophieswish.org.uk

About Charlie's Challenge

Charlie's Challenge was established in 1993 shortly after 20-month-old Charlie Boutwood was diagnosed with a malignant brain tumour. He now lives life to the full and his remarkable recovery serves as an inspiration to find a cure. Over the last 20 years, the charity has been funding paediatric brain tumour research projects around the UK in its quest to improve treatments. www.charlieschallenge.com

About University of Southampton

Through world-leading research and enterprise activities, the University of Southampton connects with businesses to create real-world solutions to global issues. Through its educational offering, it works with partners around the world to offer relevant, flexible education, which trains students for jobs not even thought of. This connectivity is what sets Southampton apart from the rest; we make connections and change the world. <http://www.southampton.ac.uk/> <http://www.southampton.ac.uk/weareconnected> #weareconnected

About BRAIN UK

BRAIN UK is a virtual brain bank, in that it doesn't hold any tissue samples itself but holds the location of where they are held, i.e. it catalogues them. The tissue samples are physically located in the NHS archives of our 'Participating Centres', these are the Neuropathology Centres around the UK that have agreed to take part. We have ethical approval to grant projects access and use of central nervous system tissue, subject to scrutiny and approval by our committee. This can represent a large time saving compared to making individual ethics applications themselves and utilizes contacts that BRAIN UK have to locate tissue more easily.

Initially started five years ago, with post-mortem cases, in collaboration with David Hilton at Plymouth Hospitals NHS Trust, with 19 centres participating. In April 2014, in collaboration with Reena Kurian at Bristol University, we were granted 'favourable opinion' to extend the project to include details of living patient tissue. An additional 7 centres agreed to participate in the network, achieving a coverage of 25 of the 29 listed Neuropathology centres in the UK, in addition to the Corsellis Collection (an historic post-mortem archive).