brainstrust
the Meg Jones tumour charity

About brain tumours

- Brain tumours (primary and secondary) account for one death in every hundred.
- Brain cancer is the greatest cause of death amongst children after accidents.
- It accounts for one quarter of childhood cancer. Tumours of the central nervous system are the second most common form of cancer in children aged birth to 15 years.
- In the UK, there are 6,000 new cases of primary brain tumour every year.
- Today, forty nine people will be diagnosed with a brain tumour (secondary or primary). That's the same number that was diagnosed yesterday and the same number that will be diagnosed tomorrow.
- Secondary brain tumours (where the cancer spreads to the brain from other parts of the body) will occur in about 25% of cancer sufferers, so this is a significant health problem.
- If cancer metastasises to the brain, the prognosis worsens accordingly.
- Survival rates from brain cancer are low and have improved little in the last 40 years. One year relative survival is about 32%; at five years it is about 14%.
- Brain tumour patients, including those with benign tumours, have poorer survival rates than breast cancer sufferers. Yet most funding goes to the four big ones – breast, lung, prostate and bowel. Open any women's magazine and these are the cancers you will see featured. Never brain.
- The average number of years life lost to brain cancer is 20.1; to breast it is 13.5 yet breast cancer attracts 18% of National Cancer Research Institute spending: brain cancer a mere 1.5%.
- It is the fastest fatal disease in the over 65s. The incidence is increasing significantly in this age group.
- No structured research base exists for brain tumours, therefore treatment options are limited. It is not known why people get brain cancer.
- There is no UK wide strategy for the treatment of, or research into, brain cancer.

Sources

Notes from Andrew McEvoy, consultant neurosurgeon at the NHNN and from Professor Geoff Pilkington, Professor of Cellular and Molecular Neuro-oncology, Univeristy of Portsmouth.

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Silcocks P, Steward J, Wood H. Brain (Chapter 4). In: Quinn M, Wood H, Cooper N and Rowan S (Eds), Cancer Atlas of the United Kingdom and Ireland 1991-2000; Studies on Medical and Population Subjects No. 68. Office for National Statistics, London, Palgrave MacMillan, 2005.

About Meg – *brainstrust*'s icon

- Meg was diagnosed with a brain tumour when she was just 19, the same week she was leaving home to begin university. She still went! She is beautiful, engaging and charismatic – and is our icon.
- Meg's tumour was quietly malignant and in tiger country. If left to develop, which is what would have happened had treatment not been sought outside the UK, it would have become highly aggressive within a very few years. Meg would have had a short life.
- In June 2007, Meg had her tumour successfully resected in Boston, USA, using intraoperative MRI technology. Both Children's and the Brigham and Women's Hospital in Boston have this technology. This type of surgery has been available for twenty years in the USA. Three of these operations are done every week by Professor Peter Black and his team.
- Meg's symptoms included epilepsy, memory loss, hallucinations, visual disturbances, extreme fatigue, disorientation, nausea and headaches. All of these symptoms, except short term memory loss and disorientation, have disappeared since the day of her surgery. **The prognosis for Meg is excellent.**

Contact details

If you would like any more information about *brainstrust*, would like to organise an event or have suggestions for the Trustees please contact HQ. You can donate online or send donations by post to our address. Don't forget to make a Gift Aid declaration – download a form online.

Address: ***brainstrust***
3 Furzedown House
King's Somborne, Stockbridge
Hampshire SO20 6QL

Email: **hq@brainstrust.org.uk**
Telephone: **01794 388960**
Web: **www.brainstrust.org.uk**

Registered Charity No. 1114634

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About *brainstrust*

brainstrust builds solutions for brain tumour patients by:

- updating treatment
- improving care
- saving lives.

brainstrust aims to save future lives by establishing a pioneering brain tumour research and treatment centre in the UK – The *brainstrust* Centre of Excellence. It is working in partnership with the National Hospital for Neurology and Neurosurgery, London, to sustain clinical work supported by genetic and pathology research, and with the University of Portsmouth, to support laboratory-based research and translational medicine. The charitable trust is dedicated to improving proactive care for brain tumour sufferers and providing co-ordinated support in their search for treatment, through addressing the lack of coordinated support and lack of UK wide strategy for the treatment of, and research in, brain cancer. We explore the availability of treatment – worldwide, raise awareness and are proactive, not reactive.

brainstrust is funding:

- a brain tumour bank
- genetic profiling
- further development of functional imaging
- the *brainstrust* professor of functional brain tumour surgery
- Senior research fellows
- PhD research studentships
- a UK-wide network of neuro-oncology nurse specialists
- beds which are purely for the management of brain tumour patients
- state of the art surgical technology.

brainstrust was founded in 2006 after the charitable trust's icon, Meg Jones, was diagnosed with a brain tumour at the age of 19. Meg subsequently underwent successful neurosurgery for the removal of the tumour in Boston, USA, during the summer of 2007.

brainstrust has one mission – to make things happen for people who, like Meg, have brain cancer. Whether that is through making life easier or supporting brain cancer sufferers in their search for treatment – we will be there.

About our difference

brainstrust is here for the long term. We have a success story – our icon.

Some brain tumour charities have been established in memory of someone who has died of a brain tumour, and so the money raised goes into research. *brainstrust* is proactive and supports people when they need it, not after the event when it is too late. We support both clinical **and** research programmes.

And we have the people to do this. *brainstrust* has the active support of some of the world's leading practitioners in neuro-oncology:

- **Mr Andrew McEvoy** (Patron of *brainstrust*) – leading consultant neurosurgeon at the National Hospital for Neurology and Neurosurgery, Queens Square, London
- **Professor Geoff Pilkington** (scientific advisor to *brainstrust*) – Professor of Cellular and Molecular Neuro-oncology, Director of Research, School of Pharmacy and Biomedical Sciences, University of Portsmouth
- **Professor Peter Black** (Patron of *brainstrust*) – chair of the Departments of Neurosurgery at the Brigham and Women's Hospital and Children's Hospital, Boston; Neurosurgeon -in-chief at Brigham and Women's Hospital; Chief of Neurosurgical Oncology at the Dana Farber Cancer Institute; and Franc D. Ingraham Professor of Neurosurgery at Harvard Medical School.

brainstrust has the support of the Telsecure Group Ltd., a global provider of technological solutions. Rashid Qajar, CEO of Telsecure, and Sally Oakley, director, are both Patrons of *brainstrust*.

brainstrust – good for brains, bad for brain tumours

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