



**Brain Tumour
Research**

Funding the fight

IF ONLY... BRAIN TUMOUR RESEARCH COULD BE FUNDED IN THE SAME WAY AS LEUKAEMIA AND OTHER CANCERS

Newsletter – March 2009

www.braintumourresearch.org

Heroes wanted to be in at the beginning of this vital initiative and make a life-changing difference

In the UK more children and people under the age of 40 die of a brain tumour than any other cancer – yet brain tumour research is woefully under-funded!

We aim to change that and bring better hope and care to thousands of brain tumour patients and their families. We are hoping that readers will champion our cause and help us to **raise at least £7 million per year** to fund world class brain tumour research programmes and projects at UK universities where brain tumour research has already been established.

When Gary Lineker got behind leukaemia research in the late 80s it changed the course of that charity and the funds that went into specific research. The charity Leukaemia Research now raises £23m per year and supports doctors and scientists in hospitals and academic institutions throughout the UK working on a wide range of projects from basic laboratory research through to clinical trials in patients. Thanks to the fundraising efforts of Leukaemia Research and other charities, five year survival for leukaemia is now 80% compared to 20% thirty years ago.

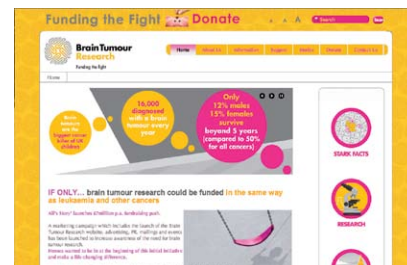
For brain tumour patients, five year survival remains at 12% for males and 15% for females. Please help us to change this shocking statistic.

Brain tumours are indiscriminate in the people they affect: young or old, male or female, with no regard to race. The prognosis is dependent on the type of tumour and its location in the brain; even a benign brain tumour can be life threatening. What's more, a benign tumour will become cancerous over time. Advances in surgery can delay the inevitable, but can leave debilitating side effects. Radiation therapy and some drugs can prolong life, but as yet there is no cure. To date, we don't fully understand the behaviour let alone the cause.

A significant investment into basic laboratory research could start to change this.

Brain Tumour Research website goes live

Key to the drive to raise £7 million per annum for brain tumour research is the website and we are delighted that it is now live. We have had some fantastic feedback already and are always pleased to receive more. If you would like your story published or a link to your website, please contact the team on 01296 733011.



OUR MISSION

- To raise at least **£7 million per annum**
- To **accelerate progress significantly in brain tumour research in the UK in order to make a clinical difference**
- To **improve the outcomes for brain tumour patients**

March 2009 – Early Day Motion calls on Government to ensure no barriers to research

"That this House, in recognition of International Childhood Cancer Day on 15th February 2009 and Brain Tumour Awareness Month in March, notes that 200,000 people each year develop a malignant form of primary brain tumour for which cure is unlikely; that in developed countries such as the USA, Canada and the UK, brain tumours have overtaken leukaemia as the most prominent cause of childhood cancer mortality, and calls on the Government to ensure that there are no unnecessary barriers to medical research or clinical trials on brain tumours amongst children"
John Bercow MP (Buckingham). Please ask your MP to add their signature and support to this motion.

Brain Tumour Research represents the united campaign voice of the Brain Tumour Research group of charities. Established in 2008, the charity Brain Tumour Research was launched specifically to raise substantial funds for brain tumour research and operates as a separate entity to the member charities.

Originally set up in 2004 as an informal partnership of a number of UK brain tumour charities under the banner of the United Brain Tumour Campaign, these charities committed themselves to working together to achieve a common goal, namely to **raise funds for research** into the prevention and treatment of brain tumours, as well as ultimately **finding a cure**.

Each of the members was galvanised into action as a result of personal involvement with brain tumours, having realised that there was relatively little being done to support brain tumour patients or carers, or towards funding research into finding a cure.

Today there are twelve UK brain tumour charities represented within the Brain Tumour Research group, giving the charity nationwide coverage. **In 2008 these charities jointly raised over £1 million.**

Funds raised will be allocated to existing UK centres where brain tumour research is already being carried out. Funds will be granted following an invitation for applications and will be subject to peer review.

OUR TRUSTEES... experienced brain tumour activists, working tirelessly to make a difference

Brain Tumour Research trustees represent group charities uniting as a common voice. Whilst maintaining their loyalties to the loved ones and charities that originally got them involved, they recognise the need to step up a level so that funding for brain tumour research is on a par with other cancers.



Chairman, Wendy Fulcher inspired by Neurosurgeon Kevin O'Neill, founded the Brain Tumour Research Campaign (BTRC) in 2003 to fund research at

Charing Cross Hospital. A founder member of the Brain Tumour Research Group of Charities, Wendy has represented the group on many forums, and is currently a representative of the National Cancer Research Institute brain tumour group. Wendy lost her husband John to a grade IV astrocytoma in June 2001.



Director, Sue Farrington Smith led the coming together of brain tumour charities in 2003 and, through her local MP John Bercow, established the

brain tumour All Party Parliamentary Group in July 2005 for which she provides the secretariat. She represents the group on the Cancer Campaigning Group and has co-ordinated the group's activities since its inception. Sue is a founding trustee of the charity Ali's Dream following the loss of Alison Phelan, her beloved seven year old niece to a brain stem glioma in June 2001.



Trustee, Nigel Boutwood has been at the forefront of brain tumour campaigning since 1993 when his son Charlie was diagnosed with a malignant medulloblastoma at the age of 20 months. Charlie's treatment was successful and he is now approaching adulthood. Nigel remains passionate about giving something back to the brain tumour community and finding a cure for this dreadful disease. He is also Chairman of the charity Charlie's Challenge.



Trustee, Tina Mitchell Skinner founder and Chief Executive of Hammerout is passionate about providing information and support for brain tumour patients

and their carers, particularly in the South West of England. In 2004 Tina initiated the March brain tumour awareness month which has been adopted by the majority of UK brain tumour charities. Her journey began in 2001 when her late husband Paul was diagnosed with a grade IV glioblastoma multiforme. He died in 2003 when their son John was just five years old.



Trustee, Sandy Saunders established The Diana Ford Trust in 2002 with other family members following the loss of his daughter Diana at the age of 42, to a grade

IV glioblastoma multiforme. Diana's three sons were just seven, five and two. Sandy campaigned tirelessly for the formation of an alliance of brain tumour charities recognising the power of working together. In 2008 The Diana Ford Trust, agreed to re-register as Brain Tumour Research and appoint new trustees from the membership. Two of the Diana Ford Trust's three family trustees resigned to facilitate the change. The move also allowed Brain Tumour Research to make use of the Diana Ford Trust's cash deposits to fund the first stage of the new awareness campaign.



Trustee, Carol Robertson witnessed the deterioration of her fiercely independent friend Andrea Key who lost her battle with a grade IV glioblastoma multiforme

in May 2002 at the age of 42, just five months after diagnosis. Andrea loved life and is sorely missed by her two children (then teenagers). Carol founded Andrea's Gift with other work colleagues and is now employed as fundraiser and charity development manager. Her enthusiasm for raising funds to develop long term research projects into adult and paediatric brain tumours, and to provide a level of support for Yorkshire based patients and carers in their very personal battles with the disease, knows no bounds.



Trustee, Dr Helen Bulbeck paves the way for brain tumour patients to receive pioneering surgery through her charity Brainstrust.

Galvanised into action in 2004 when her daughter Meg was diagnosed with a grade II mixed cell glioma at the age of 19, Helen was not going to roll over when told there was no treatment available in the UK. Brainstrust now explores brain tumour treatments worldwide and provides information and support to hundreds of brain tumour patients in the UK.

CAMPAIGNING...Brain Tumour All Party Parliamentary Group Meeting - 3rd March 2009

Dr Jane Cope, Director of the National Cancer Research Institute (NCRI) was invited to explain to the group the role of the Institute and the priority given to brain tumour research.

The Institute was set up in 2000 and has 21 partners which each fund at least £1 million per annum of cancer research in the UK. This includes both tumour specific and research specific charities. Tumour specific charity members are: Breakthrough Breast Cancer, Breast Cancer Campaign, Leukaemia Research, Children with Leukaemia and The Roy Castle Lung Foundation. Cancer Research UK is a member and funds both tumour specific and research specific projects, The Medical Research Council is also a member.

NCRI activities include maintaining a database of cancer research statistics populated by the members (this does not include projects funded by non NCRI partners), research initiatives and working closely with the cancer networks to coordinate phase 3 clinical trials and experimental cancer medicine.

In 2002 NCRI partners (15) funded £250m cancer research projects in 2007 with 20 partners this had increased to £420m, with the majority of funding coming from Cancer Research UK.

Over this period, spend on brain cancer research amongst the partners rose from just c.0.7m in 2002 to just £3million in 2007. This was largely on clinical trials rather than basic laboratory research to discover the causes and understand the behaviour. The charts also showed that when comparing the % mortality for brain tumours against % spend on research, brain tumours fared significantly worse than other cancers such as breast and leukaemia. Concerns were raised that unless the trend in brain tumour research funding is improved, as we get better at treating most cancers, the situation for brain cancer will deteriorate because some 25% of cancers spread to the brain.



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