

Petitions Committee enquiry on Brain Tumour Research Funding

What is the Petitions Committee?

Any member of the public can start an e-petition on the Government Petitions Website <https://petition.parliament.uk/>. Historically the government has provided a written response to any petition gaining 10,000 or more signatures. In July 2015 the government set up a new committee to recommend for debate any petitions with in- excess of 100,000 signatures. This Petitions Committee officially launched in October 2015.

The Petitions Committee is set up by the House of Commons to look at e-petitions submitted on petition.parliament.uk and public (paper) petitions presented to the House of Commons.

The Petitions Committee can:

- ask for more information in writing—from petitioners, the Government, or other relevant people or organisations
- ask for more information in person—from petitioners, the Government, or other relevant people or organisations. This might be in Parliament or somewhere else in the UK
- write to the Government or another public body to press for action on a petition
- ask another parliamentary committee to look into the topic raised by a petition
- put forward petitions for debate in the House of Commons

The Committee is made up of 11 backbench Members of Parliament from Government and Opposition parties. The number of seats each party is calculated to reflect the membership of the House as a whole. The Chair of the Committee was elected on 17 June 2015.

The Petition calling for more funding for Brain Tumour Research

On 3rd August 2015 Maria Lester set up a petition in honour of her brother Stephen Realf which called on the government and larger cancer charities to raise investment to 30-35 million per year.

The full wording of the petition can be found in the [Petitions Committee Report –Funding for Research into Brain Tumours](#).

The Brain Tumour Charity's involvement in this petition and Petitions Committee Enquiry.

Many people approach us to promote their e-petitions and campaigns. Whilst we try to support as many of these as we can, we are also mindful of ensuring that what is being asked for reflects our strategic aims.

On the face of it, greater funding seems like an obvious fix for a disease area where there has been historic under-investment. However, the Government e-petitions site has seen hundreds of petitions calling on the government to fund more research into brain tumours - none of which has resulted in any meaningful response from the government. The lack of research into brain tumours is a highly complex issue. We felt that calling for more funding alone did not reflect this complexity and our research strategy, '[A Cure Can't Wait](#)'.

Additionally, we currently co-fund research projects with some of the 'larger' cancer charities - for example, CRUK and Children with Cancer UK. We therefore chose at that stage not to actively promote this e-petition.

In September 2015 the Petitions Committee decided to hold an inquiry into the issue raised by the petition.

The Petitions Committee called on members of the public who are personally affected and charities in the field including Cancer Research UK, Children with Cancer UK, Brain Tumour Research and us (The Brain Tumour Charity) to give evidence to the committee about the issues surrounding research into brain tumours.

We gave evidence to the committee outlining our views on the barriers to research. Amongst our points were the following:

National Cancer Research Institute (NCRI) partners' spend

Brain tumour research funding as a proportion of site-specific spend in 2014 was 3.3% (1). In addition to site-specific spend, there is a certain amount of fundamental research that may underpin understanding of cancer across a number of sites. Including this type of research, 1.5% of cancer research spend by Government and the largest cancer charities such as CRUK was used for research into brain tumours (£7,679,072 of a total of £497,982,061)(1).

Over the past forty years, the proportion of people who survived for ten years after a leukaemia diagnosis has increased more than sixfold (2). This success desperately needs to be emulated for brain tumours, and will depend on a co-ordinated research effort. It is telling that the proportion of site-specific spend on leukaemia has ranged from 14.4% - 17.5% since 2002, second only to breast cancer in terms of the proportion of dedicated site specific research spend (1).

The Brain Tumour Charity's research programme

We have invested over £13million and have committed to investing £5.2million in our current research portfolio over the next four years. [A Cure Can't Wait: Our Research Strategy](#) commits to a further investment of £20 million over the next five years, funding research into five priority areas:

- **Biobanking:** We want to accelerate progress in research by increasing the collection of, and access to, brain tumour tissue.
- **Early diagnosis:** We want to improve patient outcomes by ensuring early and accurate diagnosis.
- **Understanding brain biology:** Improving our understanding of the biology behind brain tumours is essential to the development of new treatments.

- Catalysing new treatment: We want to catalyse the translation of discoveries made in the lab to clinical benefits for patients.
- Enhancing quality of life: We want to improve quality of life for all affected by brain tumours and ensure high quality care.

The need for diverse funders

Although our own research commitment is an important part of the combined effort to improve survival and quality of life for people with a brain tumour, it should not be left to charities to step in where Government involvement is insufficient. There are a number of reasons why continued Government commitment is essential to maximise the return on our investment for people with a brain tumour.

Firstly, we have a duty to our donors to ensure that as much as possible of the money that they give goes towards the activities that they want us to invest in. This means that, like most charities, we are not able to pay for the full economic cost (FEC) of the grants that we award. Although top-up support to provide parity with Research Councils grants is available to institutions in the form of the Charity Research Support Fund (CRSF), the value of this fund has been falling in real terms over the last few years. There is a risk that this may make charity grants less attractive.

We often seek to co-fund projects alongside other charity and Government funders. For example, we fund a number of Clinical Research Training Fellowships with the [Medical Research Council](#) (MRC), which is a non-departmental public body funded through the government's science and research budget; and along with Children with Cancer UK and Great Ormond Street Hospital Children's Charity we fund the INSTINCT strategic research network, which brings together leading clinical and research programmes in high-risk paediatric brain tumours. The benefits of co-funding arrangements are not only financial. They also allow funders to share risk, contribute to complementary elements of a research programme and share skills and expertise. Clearly this sort of funding model can only happen in an environment with a diverse network of different funders.

The research workforce

The perception of a commitment to funding and the creation of a positive research environment in a particular field can help to attract the best international researchers to the UK. This may in turn result in an increase in high quality, successful applications to open funding calls and the reputation of UK centres as being internationally competitive.

Whilst it is true that grants from the National Institute for Health Research (NIHR) and the Research Councils are open to applications from researchers working on any condition and judged in open competition, the priorities of institutions and individual researchers also will be influenced by perceptions of Government priorities. Success breeds success, with grants awarded in a theme attracting researchers to work in that area. Actions such as the designation of centres as NIHR Biomedical Research Centres (BRCs) may help to contribute to the positive perception of the UK as a desirable place to conduct brain tumour research.

There is clearly a need for research-led improvements in our understanding of, and treatments for, brain tumours. We are not suggesting that lower quality applications should be prioritised, but the Government should support the recruitment and retention of outstanding scientists working in neuro-oncology.

Summary

There is a clear unmet need for improved outcomes for people with brain tumours, with improvements in survival lagging far behind that of other cancers. This can only happen through a sustained investment in excellent research. Government should support the recruitment and retention of outstanding scientists, and funders should work with the UK brain tumour research community to address the shortfall in applications that are successful in open competitions. This presents an opportunity for the UK to gain a reputation as an excellent place to conduct brain tumour research, with benefits for institutions and patients alike.

The Petitions Committee Enquiry Report - Funding for Research into Brain Tumours

On Monday 14th March 2015 the Petitions Committee Launched a Report outlining its findings. We were particular pleased to see the following recommendations included in the report:

- Consider the evidence in this report about the differences between the HeadSmart guidance for GPs and the recently updated National Institute for Health and Care Excellence (NICE) guidelines for the recognition of and referral for suspected cancer in children, young people and adults, and ensure that NICE reconsiders its guidelines.
- Work with professional bodies and Clinical Commissioning Groups to ensure that GPs and other health care professionals receive appropriate training, perhaps as part of their Continuing Professional Development, on the symptoms of brain tumours.
- Take urgent steps to raise general awareness of brain tumours.
- Ensure that there is adequate support for young scientists who wish to pursue a career in brain tumour research, so that they can stay and progress in their areas of specialism.
- Ensure that there is effective coordination of bio-banking and tissue collection, to facilitate brain tumour research.
- Provide a full explanation, with expected timescales, of the steps it is taking to ensure that off-patent drugs in new indications are being made available to patients consistently across the country, providing appropriate safeguards are maintained.

Funding for Research into Brain Tumours Westminster Hall debate

On Monday 18th March 2015 over 50 MPs attended a debate in Westminster Hall to speak on behalf of constituents affected by a brain tumour and debate the findings of the report. Minister for Life Sciences George Freeman MP acknowledged that not enough progress had been made on the issues highlighted in the report and replied on behalf of the government with a series of recommendations for action.

These include:

- Asking the National Institute for Health Research (NIHR) to look at publishing a national register on how public funds are spent across research of different disease areas and different organs by therapeutic area.
- Convening a 'task and finish' working group in the Department of Health to touch on other issues that have been raised, including data collection, trials, off-label drugs, research barriers and skills.
- Including brain cancer in the Genomics England programme.
- Talking to NICE about guidance procedures for the referral of suspected cancer.

You can read a full transcript of the debate at <https://hansard.parliament.uk/commons/2016-04-18/debates/16041811000001/BrainTumours>

What are the next steps?

We will push the government to provide more details on the timing and scope of the recommendations made in the Westminster Hall Debate.

We will continue to work with multiple stakeholders in order to ensure that our strategic goals as outlined in '[Defeating Brain Tumours](#)' are met. We will continue to seek opportunities to work with larger cancer charities in funding high quality research. We will work with policy makers at all levels to ensure that we set the agenda on all issues pertaining to brain tumour research, treatment and care. We do this through a number of channels; we jointly run the All Party Parliamentary group on Brain Tumours with another charity and we lobby governments directly.

For example, we recently launched manifestos in each of the devolved nations, which contained key recommendations around early diagnosis, treatment and research and we are involved in a number of key stakeholder groups and work jointly with them to bring about the changes needed. If you would like to understand more please contact policy@thebraintumourcharity.org.

Dated 28/03/16

References

1. National Cancer Research Institute. NCRI Cancer Research Database [Internet]. Available from: <http://www.ncri.org.uk/what-we-do/research-database>

2. Cancer Research UK. Leukaemia survival statistics [Internet]. 2015 [cited 2015 May 19]. Available from: <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/leukaemia/survival/>