

## **PRESS RELEASE**

### **Brain tumour lobby demands of Government: "Don't forget brain tumour care!"**

Forthcoming NHS reforms risk further delays in plans to end the postcode lottery and drive up standards in brain tumour care according to a coalition of around 200 patients, carers, charities and healthcare professionals who are descending on the Houses of Parliament today.

NICE published its *Guidance on Improving Outcomes for People with Brain and Other CNS Tumours* in 2006 but a five year delay in national implementation has led to a postcode lottery of treatment, rehabilitation and care across the country. Today's lobby of Parliament will ask MPs to sign up in support of the Guidance and make sure the guidelines are not lost in the wider NHS reforms.

The Government has proposed a solution which will see neuroscience centres carrying out self-assessments from April 2011 and making recommendations for improvement. Full peer-reviewed, independent assessment of the neuroscience centres-will commence from 2012.

Moves to replace Primary Care Trusts with GP consortia, however, risk jeopardising this progress because the lessons learned from self-assessment could be lost during major NHS reforms in 2011 and it is not clear whether GP consortia will have any incentive to pay for ~~any~~ improvements suggested by the self assessment process once they have control of budgets.

80,000<sup>1</sup> people are diagnosed with a brain tumour each year. These figures may be as much as twice as large if secondary cancers in the brain are included. Campaigners say that many of these patients are at risk of suffering from a reduced quality of life and a worse survival outcome if NICE Guidance isn't fully implemented without further delay."

Professor Garth Cruickshank Consultant Neuro-surgeon at the Queen Elizabeth Hospital Birmingham said:

*"The fact we are so close to seeing real progress which will drive up standards of brain tumour care is very welcome but it is essential that the lessons we learn from the self assessment process are not lost in the wider NHS reforms expected this year.*

*"In the five lost years since NICE's Guidance on the care of brain tumour patients has been published but not uniformly implemented many patients and their families have suffered. This is totally unacceptable. We are asking MPs to sign up to sign up to the Guidance to ensure the principles behind it are not lost in the NHS reform agenda."*

Sheila Hancock, Actor, Author and Chancellor of the University of Portsmouth, whose grandson was diagnosed with a brain tumour at the age of four said:

*"It is terrible to watch a grandchild go through the diagnosis and treatment of a brain tumour, to see both your child and her child suffering. You feel so helpless. We were incredibly lucky – Jack now lives a normal healthy life. It is also tragic to learn that so many people with this disease may not have been receiving the care they deserve because*

*of delays in implementing the NICE Guidance. It would be unforgivable if, on the eve of some genuine steps forward which would guarantee uniform standards in brain cancer care, the progress was lost in the name of NHS reform."*

### **Notes to Editors**

1. The IOG was designed to be implemented over a three-year period starting in 2006 but so far there is little evidence that implementation has been uniformly put in place in England and Wales where the IOG applies. Equivalent standards have not yet been fully adopted in Northern Ireland and Scotland. Consequently, some patients struggle to get prompt access to essential chemotherapy and radiotherapy. Others find that no-one takes responsibility for their support and care when they leave hospital and that rehabilitation services are patchy or unavailable.
2. Brain Tumour Research, Brain Tumour UK, the International Brain Tumour Alliance and Samantha Dickson Brain Tumour Trust organised the Lobby at the Houses of Parliament in order to ensure the speedy implementation of the Guidance on *Improving Outcomes for People with Brain and Other CNS Tumours*.
3. The Government's self-assessment solution which starts in April 2011 is the first step in its National Cancer Peer Review Process before full independent assessment starts in 2012.
4. Around 200 people are expected to join the lobby, representing some 100 constituencies, including patients, carers, friends and family, charities, neuro-oncology professionals and scientists.
5. The event is taking place on Tuesday 29th March 2011 between 2.30 and 4pm. Participants will gather in Old Palace Yard outside the Palace of Westminster by 1.30pm.

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<sup>i</sup> Register my tumour, recognise me, Brain Tumour UK, March 2009.