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**THE SENATE**

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**ADJOURNMENT**

**International Brain Trauma Awareness Week**

**SPEECH**

**Thursday, 19 November 2009**

BY AUTHORITY OF THE SENATE

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## SPEECH

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**Page** 108  
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**Senator BILYK** (Tasmania) (7.16 pm)—I rise today to draw to the attention of the Senate the fact that this week is International Brain Tumour Awareness Week. The third Brain Tumour Awareness Week was held between Sunday, 1 November and Saturday, 7 November 2009 in Australia but this week is the International Brain Tumour Awareness Week. I would also like to mention the forthcoming 125th anniversary, on 25 November, of the first documented, modern-day surgery for a glioma.

Without complicating the issue too much, and bearing in mind I am not a doctor, I will just explain that gliomas are brain tumours associated with the three types of glial cells in the brain and they can cause quite a lot of illness and in some cases even be fatal. Glial cells make up the supportive tissue of the brain and, unlike neurons, do not conduct electrical impulses.

If left untreated, any type of glioma may grow and press on other structures within the brain. Pressure on the brain, of course, can be very harmful because it forces the brain against the skull, causing damage to the brain and hampering its ability to function properly. This reduced function can lead to long-lasting brain damage or, as I said, if left untreated can lead to death.

One of the organisations behind the development of International Brain Tumour Awareness Week was the International Brain Tumour Alliance, IBTA, which was established in 2005 and is an organisation that provides support, information and advocacy as well as conducting research into this significant illness. On its website, the IBTA promotes ‘greater collaboration, greater knowledge, greater hope’. That is a slogan that could be used to sum up medical treatment for many illnesses but is especially true in the case of brain tumours. More collaboration is needed to find new and better ways to treat and cure brain tumours, increased knowledge is needed to make the general public aware of the symptoms to look for, and hope is needed for both sufferers and their families.

I have established a parliamentary brain tumour awareness group within parliament. That held its first meeting in August. I established that group because I feel it is an area that needs more publicity and support and also because it is an area that I have personal experience with. In March of 2008, I suddenly became very ill. This was about 12 weeks before I was due to take up my position officially in the Senate following

my election in November 2007. I had no real warnings or symptoms that made me worried that I might be ill but it turned out I had two brain tumours in the back section of my head.

Without going into all the gory details, one was the size of a golf ball and it was pressing against my brain stem, blocking the brain fluid from going around in my skull. Without an exit, it was pooling on top of my brain—a circumstance known as hydrocephalus—forcing my brain to expand. I am sure some people could make the comment that that could be quite helpful! It was also increasing the pressure in my skull, which was obviously very dangerous. This caused me, quite out of the blue, to start having quite severe headaches. The other one was on the other side of the skull. It was smaller but still had the same damaging potential as its larger roommate.

I underwent two lots of surgery, five days apart. The first surgery was to have a drain put into my skull to drain the excess fluid, which enabled the second round of surgery to take place. The second surgery was to remove the tumours. When I came round, after what my surgeon described to me as text book surgery, I was told the good news—both of the tumours were benign, and both had been successfully taken out. Within 10 to 12 weeks of surgery I was able to take up my Senate position representing the people of Tasmania.

Here, I would like to reiterate my sincere thanks and admiration for all the staff at the Royal Hobart Hospital for their excellent care and attention to me throughout this ordeal. I still undergo frequent checks to make sure that nothing awful is happening in my head and I get wonderful care and attention every time I am there. But unfortunately not everyone is as lucky as I was. There are more than 120 different types of brain tumours. The three main categories are: primary; benign; and brain metastases, which arise from a cancer elsewhere in the body.

George Harrison had a brain tumour, as did Bob Marley and Ethel Merman. George Gershwin, William Casey and Mary Shelley, the author of *Frankenstein*, died from brain tumours. The former Premier of Queensland, Wayne Goss, was diagnosed with a brain tumour, and it was subsequently removed without any problems. The highly regarded and respected Professor Chris O’Brien, who was one of Australia’s top cancer surgeons and was diagnosed with an aggressive brain

tumour in 2006, died earlier this year. And the list goes on.

The cause of brain tumours is unknown. They strike randomly. They cannot be prevented by lifestyle choices and are impossible to screen and detect early. There is no cure—although you can recover if you manage to undergo successful surgery—and very little in the way of effective treatments. While the treatment for malignant tumours is often surgery, radiation or chemotherapy, depending on the type, location and degree of malignancy, the truth is that you simply cannot treat brain cancer the same way you treat leukaemia or most other forms of cancer. Even benign tumours can be inoperable or can cause death or brain injury as a result of surgery or excess pressure on the brain.

Brain tumours are the only cancer that affects a person's capacity both physically and mentally. Children with brain tumours—unfortunately, a lot of them do suffer from brain tumours—may suffer from neurological illness, with behavioural and cognitive problems, even if treatment has been effective. According to the Brain Tumour Alliance, paediatric brain tumours are the second most common cause of death in children for all cancers after leukaemia. In countries such as the United States, Canada and the United Kingdom, they are now the greatest cause of childhood cancer mortality in the age group zero to 14. This does not represent a growing incidence of brain tumours in children; it shows that the research and advances made in leukaemia treatment have, comparatively, left the insignificant improvements in brain tumour research behind.

Brain tumours are significantly difficult to treat well, even in high-income countries. The last major international breakthrough came in 2000, when researchers identified the usefulness of a certain chemotherapy drug when administered conjointly with radiation therapy and for a period afterwards. Apparently it works really well. That was hailed as the first breakthrough in 30 years. In 2004, 1,609 people in Australia were diagnosed with a malignant primary brain tumour. Sadly, about 300 Australian children are diagnosed with a brain tumour every year. Worldwide, 200,000 people develop a primary malignant brain tumour each year. Many of these people die within 12 months.

Brain Tumour Awareness Week strives to bring light to this silent killer. Compared with other cancers, a relatively high proportion of brain tumour research in Australia is dependent on private charity funding, although \$1.13 million out of the National Health and Medical Research Council program of \$357 million went towards brain cancer research. People are slowly gaining awareness of brain cancer as the serious illness

it is, but its coverage is still poor at best. There is a real need to promote further understanding and acceptance of brain cancer worldwide. Because it cannot be detected early, often the first signs are the symptoms that I explained earlier. By then, for many, it may already be too late. Many people live with knowledge of their inoperable brain tumours for only a few months. For those who have them removed, there is the chance they may grow back malignant. The incidence of brain tumours increased by approximately 10 per cent over the decade 1991 to 2000.

Because brain tumours are usually located at the control centre for thought, emotion and movement, their effects—especially in children—on physical and cognitive abilities can be devastating. Research for paediatric brain tumours cannot simply be taken from research done on adult brain tumours. Paediatric tumours and adult tumours differ in several important ways. Some tumours commonly found in adults do not commonly appear in children, and vice versa. With that in mind, adult brain tumours tend to occur in the cerebral hemispheres, the largest parts of the brain. (*Extension of time granted*).

There are a number of events taking place through November in Australia in regard to brain tumour awareness. In Brain Tumour Awareness Week, which, as I said, was from 1 to 7 November, lots of newspaper articles on brain tumours were written. Such articles help to bring the issue to the forefront of the layperson's mind. Patients, caregivers, health professionals and advocates shared stories and helped to raise awareness in a multitude of ways. The Walk 4 Life in Sydney's Centennial Park, where 335 people walked a total of 1,336 kilometres, raised about \$60,000. Nurses held a fundraising barbecue at Westmead Hospital. The Royal Melbourne Hospital held lunchtime lectures for staff. Those are just a few of the events that took place.

I encourage everyone listening to or reading this speech to educate themselves more about brain tumours so that they know the signs to watch out for to protect their own health and also the health of loved ones. Furthermore, I want them to realise that brain tumours can change their lives and the lives of those around them. Together we can promote brain tumour awareness and work towards giving both current and future generations a better chance at beating the challenge that brain tumours present. Thank you again, Senator Parry, for allowing me to speak a bit longer.