

North American Brain Tumor Coalition

**STATEMENT OF JOSEPH FAY
CHAIR, NORTH AMERICAN BRAIN TUMOR COALITION
Submitted to the Subcommittee on Labor, Health and Human Services,
Education and Related Agencies
Committee on Appropriations
United States Senate and United States House of Representatives**

It is my pleasure as Chair of the North American Brain Tumor Coalition to submit this statement in favor of a strong federal investment in biomedical research, an investment that is critically important to improving the treatments for brain tumors. For individuals with brain tumors, the possibility of surviving their diagnosis with a good quality of life depends on research and development of new treatments. Our recommendations to the subcommittee are intended to advance that research.

The North American Brain Tumor Coalition and Its Members

The North American Brain Tumor Coalition is a network of nine brain tumor organizations. Our members are the Brain Tumor Awareness Organization, Brain Tumour Foundation of Canada, Children's Brain Tumor Foundation, Florida Brain Tumor Association, Michael Quinlan Brain Tumor Foundation, National Brain Tumor Society, Preuss Foundation, Southeastern Brain Tumor Foundation, and Voices Against Brain Cancer.

Many of the members of the Coalition raise private funds to support brain tumor research, while also undertaking patient and family support initiatives. Almost all of our members disseminate educational materials about brain tumors, and many also have forums for collaboration and cooperation among brain tumor researchers. The diversity of our organizations reflects the serious and far-reaching impact of brain tumors on patients and their families. We are pleased to have a Canadian organization in the Coalition, an important sign of international collaboration among brain tumor organizations. The fact that the Coalition includes organizations outside the United States is also a recognition of the fact that brain tumors respect no borders.

The North American Brain Tumor Coalition brings these diverse organizations together to focus on advocacy on behalf of those with brain tumors. We are dedicated to improving the prognosis and quality of life for brain tumor patients. In order to achieve these goals, there must be an increased investment in research to understand the causes of brain tumors, improve brain tumor treatments, and strengthen neuro-rehabilitation services for those treated for brain tumors.

Brain Tumors and Their Impact

Brain tumors are not a single disease; there are approximately 126 types of primary brain tumors. The diversity of brain tumors contributes to the complexity of research in this field. Many of the 126 tumors classified as “brain tumors” are not in the brain but instead arise from structures that are associated with the brain. These include tumors of the membranes covering the brain (referred to as meningiomas) or adjacent cranial and paraspinal nerves (schwannomas). Brain tumors may be benign (most meningiomas are benign) to highly aggressive (glioblastomas). Both children and adults are diagnosed with brain tumors.

It is estimated that there will be more than 62,000 cases of primary malignant and non-malignant brain and central nervous system tumors in the United States in 2010.¹ There will be approximately 10,000 primary brain tumors in Canada in 2010. In 2010, it is estimated that 4,030 new primary brain tumors (malignant and non-malignant) will be diagnosed in children in the United States in 2010. Of the 4,030 new cases, an estimated 2,880 will be in children under the age of 15.²

Approximately 612,000 Americans are living with a primary brain tumor.³

The American Cancer Society estimates that almost 12,920 deaths in 2009 will be attributed to primary malignant brain tumors.⁴ This total does not include those who will die from primary non-malignant brain tumors.

Many tens of thousands – 140,000 or more – are diagnosed with metastatic brain tumors each year. Many tumor types can spread to the brain, but the most common are lung cancer, breast cancer, melanoma, kidney cancer, bladder cancer, and testicular cancer. It is estimated that metastatic brain tumors occur in 10 to 30% of adult cancers, and in one fourth of all cancers that metastasize.⁵

These statistics about incidence, prevalence, and mortality are important, but they do not fully convey the burden of brain tumors. For many brain tumor patients, treatments are inadequate. Those who receive treatments that do extend their lives may nonetheless experience serious side-effects from their brain tumors and treatment, side-effects that require intervention. In addition, a diagnosis with a brain tumor does not only affect the patient; it also has a profound effect on the patient’s family and friends.

¹ Central Brain Tumor Registry, 2004-2006.

² Central Brain Tumor Registry, 2004-2006.

³ Porter KR, McCarthy BJ, Freels S, et al., Prevalence estimates for primary brain tumors in the US by age, gender, behavior, and histology. *Neuro-Oncology*, In press.

⁴ American Cancer Society, *Cancer Facts & Figures 2009*, Atlanta, 2009.

⁵ Medline Plus, National Library of Medicine, accessed on April 7, 2010.

A study published in the *Annals of Internal Medicine* on April 6, 2010, describes the impact of a cancer diagnosis on children. The study notes that there have been significant improvements in treatments for some pediatric cancers. However, cancer treatments often cause serious health problems, including but not limited to second cancers and heart conditions. The researchers used computer models to estimate what happens to childhood cancer survivors and determined that survivors of brain cancer died about 18 years earlier than the general population. This study underscores the problems confronted by brain tumor patients who “survive” their diagnosis.

The Challenges of Brain Tumor Treatment and Research

In a report dated 2000, the Brain Tumor Progress Review Group, convened by the National Cancer Institute (NCI) and National Institute of Neurological Disorders and Stroke (NINDS), stated that the difficulty in treating brain tumors relates to the unique biology of the brain, including the fact the brain is enclosed in a bony canal that allows little room for tumor growth, brain tumors invade normal tissue and make surgical removal impossible, brain tumors are protected by the blood-brain barrier, the brain is rich in expressed genes and therefore is a fertile field for growth of brain tumors, and brain tumors appear to be less susceptible to attack by the immune system than tumors in other organs.

The complexity and diversity of brain tumors make the work of brain tumor researchers very difficult. For this reason, an aggressive and balanced approach to brain tumor research is necessary. The research effort must be strongly supported by the National Institutes of Health (NIH), as described below.

NABTC Recommendations for National Institutes of Health Funding

The North American Brain Tumor Coalition supports the recommendations of many other biomedical research and patient advocacy organizations that NIH funding be increased to \$35 billion in fiscal year 2011. This amount is necessary to sustain the commitment of the American Recovery and Reinvestment Act and prevent disruptions in the work of outstanding scientists committed to a wide range of research topics. The Coalition understands that this is a very aggressive recommendation in the current economic and budget climate, but this ambitious level of funding is necessary if additional advances in basic and applied science are to be achieved.

A recent accomplishment in brain tumor research underscores the need for additional resources and a sustained federal commitment in order to realize improvements in the quality of treatments for many diseases and quality of life for those who are diagnosed with those diseases. The Cancer Genome Atlas (TCGA) at NCI announced in January 2010 that researchers in TCGA Research Network had determined that glioblastoma multiforme (GBM) is not a single disease but four distinct molecular subtypes. In announcing the research findings, TCGA said that the research might lead to a more personalized approach to GBM, one of the deadliest of all brain tumors.

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The North American Brain Tumor Coalition applauds the important research finding of TCGA but also notes that the finding points to the need for additional research, including:

- Work to understand the molecular classification of other brain tumors, in addition to GBM;
- Research to translate basic research findings into treatment approaches;
- Identification of agents that might be evaluated in brain tumors, including those that are newly subject to a molecular classification scheme; and
- Clinical testing of possible new agents for brain tumor treatment.

In short, the findings of TCGA point the way to a new approach to brain tumor treatment, but we have only taken the first step in a long journey to effective, personalized brain tumor treatments.

This translates to the need for a balanced research program that includes the following elements:

- Support for investigator-initiated research so that new and promising ideas from the nation's leading brain tumor researchers can be tested;
- Funding for The Cancer Genome Atlas and other efforts that are advancing the molecular classification of disease;
- Resources for translational programs to translate basic findings into new treatments; for brain tumor research, this means the continuation of the Specialized Programs of Research Excellence (SPOREs) and the adult and pediatric brain tumor consortia;
- Support for clinical trials through the brain tumor consortia, cooperative groups, and cancer centers; and
- Aggressive and creative support for research on the late and long-term effects of brain tumor treatment, including research on interventions for these side effects.

We recommend that medulloblastoma be added to the list of cancers identified for further study through The Cancer Genome Atlas. We also encourage innovative strategies for data sharing in the SPORE program, including across SPORE sites. Research foundations and patient advocacy organizations are pioneering creative means for sharing clinical and research data, and we encourage NCI to consider some of these models for their applicability to SPORE sites and other research settings.

NABTC Recommends Strategies for Encouraging Collaboration

Brain tumor treatment is complex and multi-disciplinary, and research on these tumors must also have these characteristics. NCI and NINDS have established and supported a collaborative venture, the Neuro-Oncology Program, which takes a collaborative and cooperative approach to brain tumor research.

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This cooperative research approach is absolutely critical for brain tumors, but it will yield benefits for many other diseases as well. The Coalition applauds the leadership of the NIH Director in encouraging collaborative ventures that yield communication and collaboration among institutes. We also recommend that more funding mechanisms be created to facilitate this sort of cooperation among academic research institutions seeking NIH funding.

Urgency in the Brain Tumor Research Program

It is necessary to keep a long view in biomedical research, sustaining funding levels and preventing disruptions in research. However, it is also important to have a sense of urgency about the pace of research. The five-year relative survival rate for primary malignant brain tumors is 33.6% for males and 37% for females. For these individuals, time is precious and the research effort – literally their lifeline – must be accelerated as much as possible.

We appreciate the opportunity to describe the pressing need for improvements in brain tumor treatments and to recommend strategies that might accelerate this work.