

# North American Brain Tumor Coalition

## NORTH AMERICAN BRAIN TUMOR COALITION BRAIN TUMOR ACTION WEEK ADVOCACY PRIORITIES

The North American Brain Tumor Coalition (NABTC) represents individuals with brain tumors and their friends and families. Approximately 612,000 Americans are living with a primary brain tumor, and tens of thousands more are experiencing the effects of metastatic brain tumors. For all of these individuals, the hope of a long life after a brain tumor diagnosis rests on research advances.

To accelerate research and development of new brain tumor treatments and improve the quality of life of those with brain tumors, the NABTC urges:

- ***Funding for the National Institutes of Health (NIH) at a level of \$35 billion in FY 2011.*** This aggressive recommendation would support ongoing research efforts, permit the initiation of promising new research, and facilitate the translation of basic research findings into new treatments.
- ***Funding for the Peer-Reviewed Cancer Research Program at the Department of Defense at a level of \$50 million.*** This small initiative funds research on pediatric brain tumors and other forms of cancer. The need for new treatments for pediatric brain tumors, including treatments with fewer serious side effects, is pressing, and the Peer-Reviewed Cancer Research Program supports innovative approaches to pediatric brain tumor research to respond to that need.
- ***Implementation of key provisions of health care reform according to the statute and without delay.*** Of critical importance to brain tumor patients are prompt implementation of the high risk program for those who are currently uninsured and the expansion of dependent coverage to individuals up to age 26.
- ***Introduction and co-sponsorship of the Brain Tumor Awareness Resolution.*** The diversity of brain tumors – more than 126 types of brain tumors – and their complexity leave the public and policymakers confused about the disease and its effects and treatment. NABTC urges action on a Brain Tumor Awareness Resolution to increase awareness of brain tumors and their effects.

**NORTH AMERICAN BRAIN TUMOR COALITION  
URGES STRONG FEDERAL COMMITMENT  
TO BRAIN TUMOR RESEARCH**

***The Burden of Brain Tumors***

When a person receives a diagnosis of a brain tumor, his or her life is dramatically changed, and a complicated journey of treatment and recuperation begins. Brain tumors affect the organ that is the essence of the “self,” and there are significant obstacles to research and treatment on brain tumors because of their location and complexity.

The burden of brain tumors is also conveyed by the numbers:

- In 2010, more than 62,000 Americans will be diagnosed with a primary malignant or non-malignant brain or central nervous system tumor.
- Approximately 612,000 Americans are living with brain tumors.
- There will be approximately 13,000 deaths from primary malignant brain tumors in 2009; this number does not include those who die from primary non-malignant brain tumors.
- At least 140,000 thousand Americans will be diagnosed with metastatic brain tumors each year. Many tumors or cancer types can spread to the brain; the most common are lung cancer, breast cancer, melanoma, kidney cancer, and bladder cancer. As many as 10-30% of those diagnosed with cancer develop metastatic brain tumors.
- The five-year relative survival rate for primary malignant brain tumors is 33.6% for males and 37% for females.

Even those who survive brain tumors may suffer serious side effects from treatment, including second cancers and heart conditions. A recent article in the *Annals of Internal Medicine* detailed this issue for survivors of childhood cancer; the authors estimated that survivors of pediatric brain tumors may have a life span 18 years shorter than the general population.

***The Promise of Research***

For those with a brain tumor diagnosis, research represents the key to extending life and improving the quality of life. Researchers have recently announced the molecular characterization of glioblastoma multiforme (GBM), one of the most aggressive forms of brain tumor. This is an important research development that hints at the potential for personalized approaches to brain tumor treatment.

The molecular characterization of GBM also helps identify the research that must still be undertaken, including molecular characterization and basic research on many other types of brain tumors in addition to GBM, translational research to translate basic research findings into new treatments, and clinical research to test possible new treatments.

## ***A Strong Federal Role in Brain Tumor Research***

The North American Brain Tumor Coalition, a network of brain tumor organizations representing brain tumor patients and their families and friends, recommends that Congress:

- ***Increase funding for the National Institutes of Health to \$35 billion.*** This is an aggressive increase in National Institutes of Health (NIH) funding that is necessary to prevent disruption in ongoing research projects and permit investment in groundbreaking new research initiatives. We recommend that the increase in funding be shared by all institutes to support the strongest possible research opportunities. With the funds available to NIH, we recommend special attention to several high priority items:
  - ***Expand The Cancer Genome Atlas*** – include medulloblastoma among the cancers that will be undergo molecular characterization
  - ***Continue the Neuro-Oncology Program*** – the joint research program of the National Cancer Institute and National Institute of Neurological Disorders and Stroke should be continued and its collaborative model should be replicated through NIH grants to extramural researchers
  - ***Focus Research Efforts on Late Effects of Treatment*** – improvements in cancer survival rates must be accompanied by improvements in quality of life and reduction in the late effects of treatment
- ***Increase funding for the Peer-Reviewed Cancer Research Program at the Department of Defense to \$50 million.*** This program has funded promising projects in pediatric brain tumor research, blood cancer, colorectal cancers, and melanoma. It should be continued in order to sustain research projects that complement research supported by NIH.

**NORTH AMERICAN BRAIN TUMOR COALITION  
URGES ATTENTION TO NEEDS OF  
THOSE WITH SERIOUS AND LIFE-THREATENING ILLNESSES**

***Health Care Access for Brain Tumor Patients***

Individuals with brain tumors often confront problems obtaining adequate and continuous access to quality health care.

- Brain tumor patients may lose health care coverage if they lose their jobs.
- Even if brain tumor patients are eligible for Social Security Disability payments, they will experience delays in access to Medicare.
- Those with brain tumors may reach their annual and life-time insurance spending caps.
- Children who survive brain tumors may find insurance out of their reach when they become adults.
- Brain tumor patients have a need for sophisticated care, and they need active monitoring and follow-up care even after active treatment ends.
- Brain tumor patients become expert in negotiating insurance rules and practices to obtain access to the highly specialized care they need, and still they may find that care denied because of limitations of their insurance plans.

***Provisions of Health Reform Affecting Brain Tumor Patients***

Key provisions of the new health care reform program address issues facing brain tumor patients. The North American Brain Tumor Coalition urges the earliest possible implementation of these provisions, consistent with standards outlined in the law. The Coalition also recommends that the needs of individuals facing serious and life-threatening illnesses be a key focus in making implementation decisions.

Key provisions of health reform that will assist brain tumor patients include:

- A temporary national high-risk pool to provide coverage to adults with pre-existing conditions, to be implemented by June 2010.
- Coverage of dependents up to age 26 through their parents' health insurance, in place by the end of September 2010.
- Regulations that would bar lifetime limits on coverage, limit rescissions of coverage except in cases of fraud, and prevent exclusions of children with pre-existing conditions, implemented by the end of September 2010.
- Limits on beneficiary responsibility for drug coverage through Medicare Part D.
- Health care quality initiatives to boost overall health care quality.
- Coverage of the routine patient care costs for those enrolling in clinical trials.

Individuals with brain tumors need specialized and complex care, with the necessity for this care sometimes lasting for many years. As the exchange program is implemented and health insurance coverage is offered through this structure, the special needs of brain tumors and others with serious and life-threatening illnesses must be fully evaluated and considered.

S. RES. XXXX/  
H. RES XXXX

Designating May 2010 as “National Brain Tumor Awareness Month:

IN THE UNITED STATES SENATE/  
UNITED STATES HOUSE OF REPRESENTATIVES

RESOLUTION

Designating May 2010 as “National Brain Tumor Awareness Month”

Whereas 62,000 Americans are diagnosed with primary brain tumors each year, and more than 140,000 are diagnosed with metastatic brain tumors that are the result of cancer spreading from another part of the body to the brain,

Whereas brain tumors are the leading cause of death from solid tumors in children under the age of 20, and are the third leading cause of death from cancer in young adults ages 20-39,

Whereas brain tumors may be either malignant or benign, but can be life-threatening in either case,

Whereas 612,000 Americans are living after a diagnosis of a brain tumor,

Whereas treatment of brain tumors is complicated by fact that there are more than 120 different types of tumors,

Whereas treatment of brain tumors presents significant challenges because of the location in an enclosed bony canal, the difficulty of delivering treatment across the blood-brain barrier, the obstacles to complete surgical removal of the tumors, and the serious edema that results when the blood-brain barrier is disrupted,

Whereas brain tumors have been described as a disease that affects the essence of “self,”

Whereas brain tumor research is supported by a number of private non-profit research foundations and by institutes at the National Institutes of Health, including the National Cancer Institute and National Institute for Neurological Disorders and Stroke,

Whereas important advances have been made in understanding brain tumors, including the genetic characterization of glioblastoma multiforme, one of the deadliest forms of brain tumor,

May 2010

Whereas basic research advances may fuel research and development of new treatments, including targeted therapies,

Whereas there still remain daunting obstacles to the development of new treatments and there are no strategies for screening or early detection of brain tumors,

Whereas there is a need for greater public awareness of brain tumors, including the difficulties associated with research on these tumors and the opportunities for advances in brain tumor research and treatment,

Whereas May, when brain tumor advocates nationwide unite in awareness, outreach, and advocacy activities, would be an appropriate month to recognize as National Brain Tumor Awareness Month,

Now, therefore, be it

*Resolved, That*

- (1) it is the sense of the Senate/House that May should be established as National Brain Tumor Awareness Month; and
- (2) continued strong public and private investment in brain tumor research will be necessary to advance research and improve those treatments available to Americans diagnosed with brain tumors.