

The North American Brain Tumor Coalition: An Agenda for Improving Brain Tumor Treatments

The North American Brain Tumor Coalition (NABTC) seeks to enhance the access of individuals with brain tumors to quality brain tumor care. Achieving this goal means ensuring that all brain tumor patients have access to the best treatments currently available while at the same time fostering, encouraging, and demanding the development of better treatments.

Although there have been incremental improvements in brain tumor treatment, the survival rates for many brain tumors have not changed in the last 40 years. The five-year survival rate for all brain tumors is 35 percent, and for some types of brain tumors the rates are even lower. For those with brain tumors and their families and friends, there is a desperate need for more research into better treatments.

Ten years ago, the National Cancer Institute (NCI) and the National Institute of Neurological Disorders and Stroke (NINDS), the two institutes leading the federal brain tumor research program, convened a panel of brain tumor experts to develop a plan for brain tumor research. Unfortunately, the Brain Tumor Progress Review Group report that emerged from that planning process remains almost entirely relevant today, as the goals of that report have not yet been realized through research advances. The speed of research progress is much too slow for brain tumor patients, and the NABTC proposes a concrete and specific plan of action to improve brain tumor research and care.

The NABTC proposes the following agenda to advance brain tumor care and research:

- Congress should boost funding for the National Institutes of Health (NIH) by at least 10 percent in FY 2010. This funding increase, which builds on the infusion of funds through the economic stimulus package, will sustain ongoing research and permit initiation of innovative new projects.
- The National Cancer Institute should restore funding for the Adult Brain Tumor Consortium for the five-year period beginning in 2008.
- Congress should enact legislation to eliminate the Medicare waiting period (H.R. 1708/S. 700). This bill would terminate the unreasonable and unjustified two-year waiting period for Medicare benefits that faces brain tumor patients and others with serious illnesses from the time they are eligible for Social Security Disability payments.
- Congress should define a plan for revitalizing and reinvigorating the brain tumor research effort by enacting the Comprehensive Brain Tumor Care and Cures Act.