



Where Can Brain Tumor Patients Turn for Support and Information?

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In December 2004, Olympic figure skater Scott Hamilton was diagnosed with a brain tumor. While Hamilton's diagnosis made the newspaper headlines, he was just one of the over 180,000 people who are diagnosed with a primary or metastatic brain tumor each year. More specifically, 40,000 people are diagnosed with a primary brain tumor and 20% to 40% of all cancer patients (primarily breast, lung, melanoma, and colorectal cancer patients) are diagnosed with brain metastases each year.

In addition, the incidence of brain tumors has increased by 25% since 1975 and some estimates suggest that the number of people who develop and die from a brain tumor has increased by as much as 300% worldwide. The Central Brain Tumor Registry of the United States reports annual brain tumor incidence rates to be 14.0 per 100,000 person-years. African-Americans have an incidence rate of 9.9 per 100,000 person-years and men have a higher incidence rate than women.

In addition to these alarming statistics, brain tumors still remain a hidden disease and patients are often at a loss when looking for support and information. Once a brain tumor is diagnosed, many patients undergo brain surgery almost immediately, leaving the family little time to process what is happening and gather helpful information. The role of the oncology health professional is crucial in supporting the patient as well as providing them with outside resources such as the National Brain Tumor Foundation (NBTF).

The NBTF, founded in 1981, raises funds for research and provides various resources to patients and family members, such as printed information and articles, a quarterly newsletter, support groups, a monthly e-mail newsletter, a treatment center database, contact with patients and caregivers, a medical information nurse, caregiver trainings, and regional and local conferences. In fact, NBTF sponsored the first-ever patient-professional conference in 1990 and is planning a conference in New York for 2005. NBTF has also partnered with



professional organizations including the American Association of Neurological Surgeons, the American Association of Neuroscience Nurses, and the Association of Oncology Social Workers, to name but a few. At NBTF, we believe that by collaborating with organizations such as ASCO we can all achieve our goal of supporting physicians, patients, and caregivers.

Each month, NBTF receives over 1,000 inquiries from patients and caregivers through our Web site and Patient Information Line. Questions range from treatment issues, financial needs, neuropsychological changes, psychosocial issues, insurance concerns, and questions regarding medical centers. The NBTF Patient Information Specialist helps explain complicated procedures and offers information about treatment options.

For more information, please call the NBTF Patient Information Line at 800-934-CURE or visit our Web site at www.braintumor.org to find out more about the types of programs NBTF offers to patients and family members. We are also happy to provide brochures to distribute at your hospital and a representative to conduct a training session for your staff. The NBTF works to assist health professionals in the important work they do by providing support and information to patients and families.