WILL POWER RESEARCH FUND

Driven by the dedication to cure brain cancer.

IN BRAIN CANCER NEWS (updated 8 April, 2009)

1) **Mapping brain cancer genes leads to further understanding of the disease and treatment strengths and limitations**.

The Cancer Genome Atlas (TCGA) Research Network, funded by the National Cancer Institute (NCI) and the National Human Genome Research Institute (NHGRI) of the National Institutes of Health (NIH), has reported the first results of its large-scale, comprehensive study of the most common form of brain cancer, glioblastoma multiform (GBM). In a paper published Sept. 4, 2008, in the journal Nature, the TCGA team discusses the discovery of new genetic mutations. This information has the potential to improve diagnosis and treatment of GBM.

TCGA identified of many gene mutations involved in GBM including three previously unrecognized, but fairly frequent, mutations; and the delineation of core pathways disrupted in this type of brain cancer. This research is useful for explaining why some brain tumors are more susceptible to chemotherapy than others and why tumors tend to become resistant to treatment over time. Such studies can provide much needed information that can potentially lead to more effective treatments. For example, it was found that patients with an efficient MGMT gene do not respond to well Temador, where as those without it tended to be more susceptible to Temador. This is because the MGMT gene repairs the cancer cells as fast as Temador destroys them. This is important to know, because Temador causes hypermutation, leading to very chemo-resistant tumors, which complicates future treatment. Therefore, treatment should be matched with the genetic components of brain tumors.

2) **Avastin gets FDA approval**.

Avastin (bevacizumab) has been approved by the FDA for use in treatment of brain tumors. Recent research suggests that Avastin increases survivability of patients with malignant gliomas for 3 months when used in conjunction with the drug CPT-11 (irinotecan), which is significant considering the poor prognosis for these tumors.

Avastin is also known to increase quality of life for these patients by decreasing disease symptoms and reducing reliance on medications with unpleasant side effects such as steroids. It can also buy the patient some time to try new experimental treatments that can potentially extend life even longer.

Brain tumors, especially the grade IV glioblastoma multiform (GBM), can develop blood vessels increasing their blood supply. This process, called angiogenesis, spurs the

tumor's ability to grow. Avastin is an anti-angiogenesis drug that restricts the tumors blood supply by counteracting the tumor's ability to grow blood vessels. Avastin does this by inhibiting the vascular endothelial growth factor (VEGF), which is considered the most important growth factor.

Unfortunately, many other factors have also been identified, such as the fibroblast growth factor, and platelet-derived growth factor. These various growth factors suggest that redundant processes stimulate blood vessel growth, indicating that targeting one factor will not lead to a cure. A multipronged approach that targets several growth factors at once will hopefully lead to a more thorough suppression of angiogenesis.

3**) Brain Tumors wreck havoc on patient and family finances**.

A recent study conducted by the American Cancer Society and the Kaiser Family Foundation demonstrated that even cancer patients with private health insurance face severe financial challenges. More insurance companies today require hefty out of pocket expenses, including percentages of co-pay, caps on yearly expenses, caps on specific benefits, and maximum lifetime caps. In addition, many people with cancer lose their insurance, when they become incapacitate by treatments or symptoms of the illness and can no longer work. These financial difficulties often lead to bankruptcy. Medical bills continue to be the leading cause of bankruptcy in America. For more information go to www.kff.org.

A study (http://www.tbts.org/upload/images/NBTF_no%20one%20report_correctedFINALa.pdf) released by the National Brain Tumor Association has shown this to be especially true of brain cancer patients. Brain tumor patients must cope with cognitive changes including mood swings, ability to focus, memory loss, mobility, and seizures. They also often need very expensive designer drug to mitigate these changes, and job loss due to these changes. Chemotherapy treatment for brain tumors is incredibly expensive. Temodar and Avastin can cost thousands of dollars a month. We have personally experienced these situations. Will's chemotherapy treatment was $6,000 a month and his insurance did not cover it, because his prescription plan only covers generic drugs. Many insurance plans do not cover brand name drugs even when there is no generic alternative. Will's insurance claimed to cover chemotherapy, but they decided to define Will's chemotherapy as a prescription drug, because it was taken at home in the form of a pill and not administered at the doctor's office. Fortunately, Commitment to Care donated the Temodar to Will; Will and family are grateful for such programs.

While it may be convenient to assume that Will's and other sufferer's insurance problems are their "fault" because he choose an inadequate insurance, the truth is that he was going to college at the time when he needed insurance so his only choices were the insurance through his school or an individual plan. The insurance through his school expected a 30% co-pay on all expenses, so had he chosen his school's plan he would have been

much worse off, not to mention once he left school he'd have no insurance at all and no ability to obtain insurance, because he now has a pre-existing condition. Individual plans are full of gaps especially pertaining to prescription drugs. I looked up his insurance and the most thorough coverage of prescription drugs they offered contained a $5,000 yearly cap. This is not helpful if the costs of your drug treatments run more than $50,000 a year.

Will Power focuses on young people with brain cancer. This group is particularly susceptible to insurance woes, because they have often recently lost coverage through their parents policies, are going to college, or in between jobs. Besides the fact that obtaining insurance is often not a priority for healthy young people who focusing on finishing degree and beginning careers and are understandable not anticipating to be waylaid by a catastrophic illness. David Spilfogel had just started a new job and was on a thirty day waiting period for his insurance to kick in when he was diagnosed, so he had no insurance at all, which is not unusual for young people. His parents had to conduct fundraisers so that he could be seen at certain clinics. Lack of adequate insurance is not simply a financial problem; it is a matter of life and death. Studies show that one of the leading indicators of prognosis for cancer patients is healthcare coverage. Link to http://www.cancer.org/downloads/accesstocare/CFF2008_Special_Section.pdf .

These studies underscore the need for health care reform. Not only do many people not have health insurance, many people have inadequate health insurance and do not realize it. When they discover that their insurance is inadequate, it is often too late. Also, it is important to understand that individual plans have all kinds of limitations, gaps and loopholes, because they are designed to be temporary. Even those with the best coverage often find themselves fighting with insurance companies over specific treatment plans, especially when they are dealing with medical situations that have no standard treatment protocols as is the case with recurrent GBMs.

4) **The NCI reduces funding for the Adult Brain Tumor Consortium**.

The National Cancer Institute has decided to reduce funding by almost 50% for the Adult Brain Tumor Consortium. The ABTC is supported through a U01 Cooperative Agreement from the NCI. The consortium performs innovative, multidisciplinary Phase 1 - 2 clinical trials that focus predominantly on adult patients with grade IV gliomas (glioblastoma multiforme).

ABTC's objectives are to:

1. perform multidisciplinary clinical trials using surgery, radiation and systemic therapies
2. combine targeted agents in appropriate combination regimens
3. incorporate pharmacokinetic and pharmacodynamic endpoints as appropriate into clinical trials testing novel agents
4. evaluate novel imaging endpoints in clinical trials

5. foster collaborations with other researchers in the field, including the NCI-funded brain tumor SPORES and Cooperative Groups

The ABTC consists of investigators at premier institutions across the United States. ABTC, and especially through its predecessors NABTT and NABTC, have demonstrated that clinical trials are not only possible in this challenging tumor type, but represent the best hope for making further progress against this devastating disease. (Information provided by the NCI.)

Current ABTC institutions include: Cleveland Clinic Foundation, Duke University, Emory University, Harvard Neuro-Oncology. Henry Ford Hospital, Johns Hopkins University, M.D. Anderson Cancer Center, Memorial Sloan-Kettering Cancer Center, Moffitt Cancer Center, University of Alabama at Birmingham, University of California, Los Angeles, University of California, San Francisco, University of Pennsylvania, University of Pittsburgh, University of Wisconsin, Wake Forest University.

The reduction in funding is unfortunate because this consortium directs provides much needed information sharing across the various brain tumor centers, including analysis, techniques, and data. Such sharing is vital for this type of cancer since it is less common, so adequate data is more difficult to obtain. For a detailed article on the importance of consortiums, here is a link to an article written by Will's nuero-oncologist at UCSF, Susan Chang. http://www.touchneurology.com/files/article_pdfs/chang.pdf

For more information on how this decision may affect brain tumor research and patients, see: http://www.nabraintumor.org.php5-2.websitetestlink.com/wp/?p=101