WILL POWER RESEARCH FUND

Driven by the dedication to cure brain cancer. **April 2009, VOL I**

Thank you for your interest in fighting brain cancer!

The Tarantino family welcomes you to Will Power Research Fund! This is our first official newsletter. As many of you know, we are a 100% volunteer driven charity organization set up to help raise awareness of and find a cure for brain cancer. We formed Will Power because our son was diagnosed with a malignant glioma on January 5, 2007. We have since been joined by Patti Long and Mike Guardino, whose 26 year old son David died of a glioma three years ago. We dedicate our site to his memory. David and his twin brother Chris are shown on the right; David was an outdoor enthusiast like Will. For more detailed information please go to http://www.willpowerresearchfund.com/

FLORA LONDON MARATHON FUNDRASIER

Will Power Research Fund is happy to kick off our first official fundraiser. Will is going to run the Flora London Marathon on April 26th. For each $25 donation, you can guess his time! The winner will receive an autographed 16X20 photo that Will took on one of his hikes or a photo of Will running—the winner gets to choose from a selection of photos. To help you with your guess, here is a list of his last three marathons, when he ran them, and how fast he ran them.

1. Big Sur International Marathon April 29, 2007, time: 2:45:04; 7th place
2. Boston Marathon April 21, 2008, time: 2:29:30; 49th place
3. California International Marathon December 7, 2008, time: 2:26:08; 13th place

Also bear in mind when you submit your guess that the London Marathon has a reputation for being a fast race and Will has been training at altitude in Mammoth Lakes. We aren't sure whether this will speed him up or slow him down. Your donations will power research efforts to find a cure for Brain Cancer. Please help us in Will's race for a cure.

IN THIS NEWS LETTER

We hope you enjoy our first newsletter. We include:

1. The fundraiser information and sign-up sheet
2. Will's Trail – a journal entry on Will's latest running or outdoor trail event
3. In Brain Cancer News – a selection of current events in brain cancer research

GUESS WILL'S LONDON MARATHON TIME!

Will is running the London Marathon on April 26, 2009. Below is a history of his previous marathon results. Use these to help you predict his next finish time!

Will's Marathon Results		
Marathon	**Time**	**Place**
Big Sur (3 months after surgery)	2:45:04	7
Boston	2:29:30	49
Sacramento	2:26:08	13
London	Your guess?	Your guess?

Please make your guess in the following table. An example is provided. The cost for each guess is $25. Make as many guesses as you would like!!

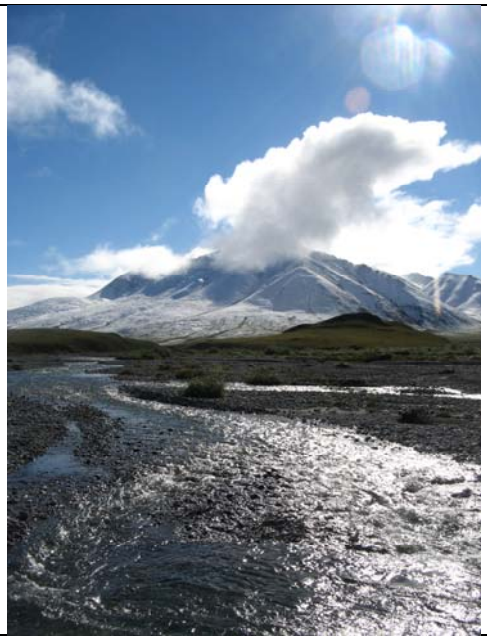
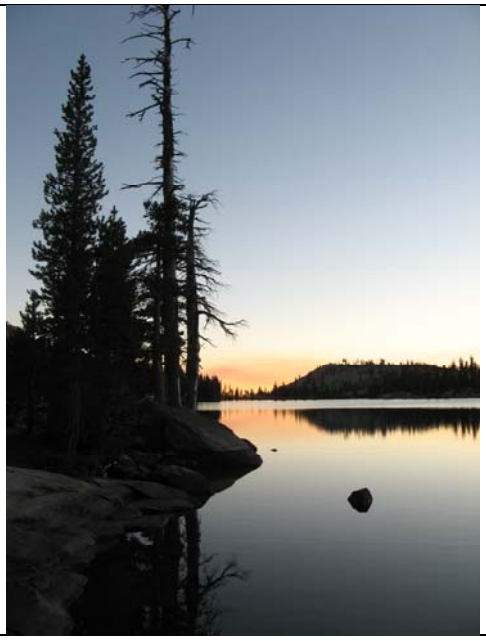
What is Your Guess?			
#	**Time**	**Place**	**Donation**
Example	2:25:30	35	$25
1			$25
2			$50
3			$75
4			$100
5			$125
6			$150
7			$175
8			$200
9			$225
10			$250

The person with the closest guess receives a print of one of Will's outdoor pictures. If there is a "time" tie we will break the tie with the "place" guess. Go here to see past London marathon results: http://results-2008.london-marathon.co.uk/

Email to: contact@willpowerresearchfund.com and donate via PayPal
OR
Mail to: Willpower Research Fund, 99 Pacific St. Suite 555F, Monterey, CA 93940. Postmark by April 25th and please enclose your check.

Thank you! Your donation will power brain cancer research!

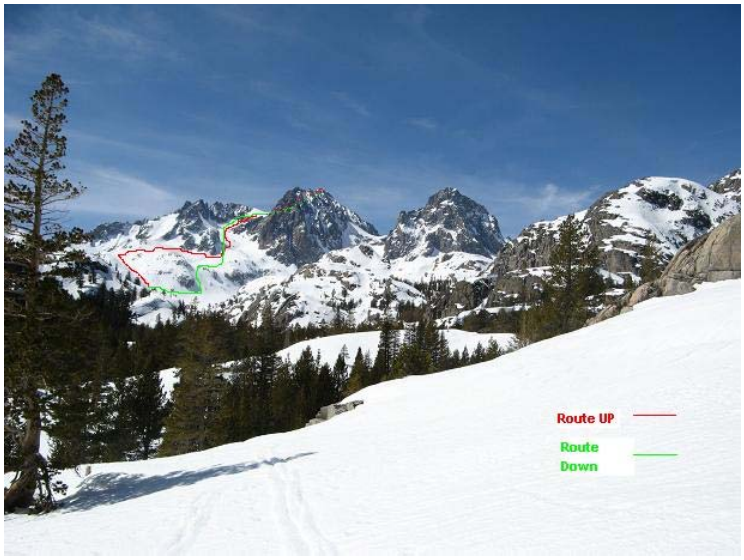
After the marathon, we will email the winner and allow them to select one of the pictures below or a picture of Will at the marathon (or Donate it to WPRF). The picture will be enlarged and framed on canvas as a high quality print and sent to you from Will Power Research Fund. Will's Pictures:

	
"Gates of the Arctic", Brooks Range	Sunset Over Lake in the Sierras
	
Denali	Caribou at Denali National Pa

WILL'S TRAIL

Will finished his Masters degree in Marine Ecology this fall and began working at Mammoth Lakes as a ski patrol. He is training in the area for the London Marathon. He plans on staying with us (his parents in Monterey) for a couple of weeks before the marathon to finish up his training. After the race, Will plans on attending a National Outdoor Leadership Instructor's Course in Wyoming, so that he can become certified to teach mountaineering courses. He recently went on a ski trip to climb Mount Ritter with his friend Ryan. Here are a couple of photos and a statement from Will.

Our trip to Mount Ritter (Will narrates): I had been looking at Mount Ritter all winter with the desire to ski it. The mountain dominates the skyline from Mammoth and the entire Sierra crest for miles. Recent weather and predictions suggested that the next two days should provide us with optimal conditions, though we were warned that the snow at 13,000 feet was likely to be crusty, breakable, and generally difficult to traverse. Regardless of the snow condition warnings, my friend Ryan Copenhagen and I set off from Mammoth's Main Lodge on the morning of the 18th at about 8:30. The route began with an easy skin up the road to Minaret Vista. The completely buried entrance station and toilets at the top suggested that there would be no shortage of snow.



After a short decent to Agnew Meadows, we began a gentle skin up along the San Joaquin toward Shadow Creek. By the time we got to the Shadow Creek drainage, the snow on the south slopes had already begun to turn to soft spring corn, making the skin up above the cascading creek fairly easy. After proceeding across Shadow Lake, we continued up the now gently sloping drainage to Lake

Ediza, a gorgeous Alpine Lake surrounded by the Minarets and the Ritter Range. We set up camp just below the tree line, melted snow to cook dinner and make some tea, and watched as the stars emerged.

The next morning, after a quick breakfast of tea and Pop Tarts, we set off just after 7:00, beginning our climb up a small u-shaped slope with a view of the sunrise which brought a sublime beauty to the moment. At the top of the slope, we traversed from the top under a few cliffs and rock outcroppings to the Ritter Glacier, while a few wayward birds and monarch butterflies danced around us. Above the glacier, we climbed up a narrow chute to the snowfield on Ritter's southeast face. It was too steep for me to ski up, even with crampons, so I was forced to boot-pack up to the snowfield. A half-hour later we were on top of Ritter, by far the highest mountain in the vicinity. Ryan and I celebrated on top with a bottle of Jameson that I bought on St. Patrick's day. We were able to ski directly off the summit, the snow during the climb had been consistently hard, requiring either ski-crampons or boot-packing. However, after summiting and taking about half an hour to celebrate, the snow had softened enough a few turns below the summit to make the descent fun, instead of nerve-racking. It was by far the best backcountry skiing I've had.

We skied down to camp, packed, and dropped back down along Shadow Creek to the San Joaquin. The climb back up to the Main Lodge was a chore, including bad, thin snow, and the long, tedious climb up the road. The sunset behind the Ritter range made the climb a bit more tolerable, but I had some blisters forming on my heels, which were diminishing the experience somewhat. We reached the lodge at 7:30, just as it was getting dark.

IN BRAIN CANCER NEWS

Disclaimer: The information, services, products, messages, and other materials contained on our website or in this newsletter are provided for educational and informational purposes only and are not a substitute for medical advice and treatment.

1) **Mapping brain cancer genes leads to further understanding of the disease as well as 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 multiforme (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 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 multiforme (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 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 incapacitated 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 http://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 financial hardship to be common 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 drugs to mitigate these changes and often face 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 refused to 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 his family are grateful for such programs.

While it may be convenient to assume that Will's insurance problems are his "fault" because he chose 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 parent's 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 are focusing on finishing degrees and beginning careers and are understandably 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 can lead to difficult times and serious health consequences. 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, and 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

FUTURE NEWSLETTERS

We are continuing to follow research in different types of brain tumor vaccines designed to "teach" the immune system how to fight brain tumors. Our next newsletter will focus on several different studies involving these vaccines, the various types of vaccines, and their potential for curing brain cancer.

We will also write about the London Marathon and keep you up to date on Will's future races and hiking adventures.

If you wish to receive future newsletters, please let us know! Be sure to enter your preferred email at: http://www.willpowerresearchfund.com/contact.htm

From all of us at Will Power Research Fund,

All our best!