



WILL POWER RESEARCH FUND

Driven by the dedication to cure brain cancer.

June 2010, VOL IV

Thank you for your interest in fighting Brain Cancer!

Welcome to the Will Power Research Fund

This is our fourth 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; 100% of all donations go to brain cancer research. 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 four years ago. We dedicate our work to his memory.

For more on our efforts, past newsletters, and information on brain cancer go to our website at: <http://www.willpowerresearchfund.com/>

Our Results: Will Power Research Fund recently gave **\$10,000** to a pilot study run by UCSF that attempts to quantify the cognitive and emotional effects of brain cancer treatment.

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Will finishing the Eugene Marathon
(See article on page 8)

Next Newsletter...*we will see where this journey takes us, but we expect in December.*

What you can do to help

Pass on the newsletter; let's get the word out to more people about our cause. Will Power Research Fund is now on Facebook where we provide updates on current research and associated links. If you are on Facebook, join our Will Power Research Fund page and encourage your friends to join. Anybody have a good idea for a fundraiser? If you do, we would enjoy hearing it. Send us an email and let us know your ideas to us at: contact@WillPowerResearchFund.com or email Will at Will@WillPowerRF.com

The Will Power Research volunteer Team, Bill, Arleen, Will, Eric, Patti, and Mike



An introduction to our NEW online photo shop

New – “Thank You” gifts for your support!

Will Power Research Fund now offers quality photographs, taken by Will on his backcountry hiking and running adventures, as gifts to thank you for your donation!

Choose from a wide variety of our favorite shots, ranging from depictions of wildlife (everything from grizzly bears to snails) and exotic landscapes (like Utah’s canyons or the Gates of the Arctic) to abstracts and even portraits. Print styles include everything from simple pictures to gallery-quality mounted canvas. We also offer an annual 12 month calendar, which includes 30-40 of the best photos that Will takes through the year. Visit the gallery at www.willpowerresearchfund.com/gallery



Will to run the California International Marathon Dec. 5

Will is going to take another stab at 2:20 this fall in Sacramento, the site of his 2008 P.R. (2:26:06). After two disappointing races due to poor race strategy (London) or poor training due to injury (Eugene), he has decided to give it at least one more shot. Training begins following a



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NOLS course he is teaching in Wyoming through the month of July. Will plans to incorporate a lot of long distance trail running into his training this year. Traveling throughout the country and running along the way since he will not be doing another lengthy backpacking trip.

Join Will and run to raise money for Brain Cancer Research! This fall's fundraiser is inspired by Courtney Monaco, the survivor of an Aunt with brain cancer who ran the Boston Marathon to raise money for Will Power! Join Will and run the California International Marathon (or the fall marathon of your choice) and raise money for Will Power. Simply direct them to our website and ask them to donate in your name. They are eligible for all the usual gifts (photos or calendars). If you raise over \$500 we will send you a Will Power Research Fund singlet (see photo) to run the race in (optional of course). Raise \$1,000 and we will also send you the 2011 photo calendar (signed personally by Will) and the singlet! In addition, feel free to contact Will (will@willpowerfund.com) for training advice or other questions. If you run CIM, we would love to join you for a large carbo-load Saturday night before the race! Let us know if you will be running CIM and we will coordinate the carbo-load for the group.



Follow Will's training on the WPRF Blog and Facebook page! Starting this August, Will plans to post weekly on his training and progress through the fall. Follow Will's training and see pictures of where he is running. He will keep you informed of his next destination(s). If you would like to get together with Will for a run, or maybe just a meal (he likes to eat), contact him (will@willpowerfund.com); if he is going to be in your area, he would enjoy running with you!

My first marathon...a marathon of love!

By Courtney Monaco

Courtney Monaco ran The Boston Marathon this year to raise funds for WPRF. We are delighted that she was inspired by Will and is determined to help us find a cure for brain cancer. Due to her effort we have an additional \$2800 to donate to promising research studies to fight this dreaded disease.

Since witnessing the battle that my wonderful aunt, Barbara Bemiss, ultimately lost with a tenacious glioblastoma in May 2009, my world has been rocked. I decided that in order to help me grieve I needed to do something for myself, but I wanted to do something that would help others dealing with brain tumors in the process. I set a goal to run this year's Boston Marathon, but I also wanted to raise funds for a cause with a sole focus on curing brain tumors. This is what led me to the Will Power Research Fund. I feel blessed to have found this amazing young man named Will, his wonderful support system of family and friends, and their drive to cure brain cancer.

Throughout my self-created marathon training, there were many times when I questioned if I would be able to do this. As such a newbie, I felt like I had a lot of nerve to even set this goal for



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myself. I read many training books, had many discussions with veteran marathoners and ultimately decided to put one foot in front of the other and just go for it. Long run after long run, week after week, the marathon drew closer, and I began to freak out. I had started to raise funds so I knew there was no turning back now! I did not want to let anyone down, especially the Tarantinos! After all, I went looking for them! I thought a lot about all of Will's amazing accomplishments, it really inspired me to never give up and just put one foot in front of the other, so that's what I did.

April 19, 2010: I boarded a bus filled with strangers for a 6:15 am departure off to Hopkinton, Massachusetts to face my fears and overcome one huge obstacle. Had I trained nearly enough? Probably not. Would my doctor even think I should be doing this right now? Probably not. Will I finish this? Still not sure of the answer. As the bus traveled further away from anywhere I truly recognized, I realized that the bus would not be taking anyone home. We were getting back only one way; one foot in front of the other.



Courtney Monaco and her uncle, Alan Bemiss.

Upon entering my assigned corral #26, I started to relax and try to take it all in, the start was about to happen. Was I dressed properly? Are my sneakers okay? Too late to worry about the small stuff now! Am I really running this with thousands of people, yet running it alone? It was time to put one foot in front of the other and go. The cause was keeping me steady.

I could not believe the crowds along the way, so supportive, positive and energizing! I thought about where Will would be at certain mile points, versus how slow I was! "Just keep going", I said to myself throughout the whole race. I thought a lot about the reasons behind my efforts. As I chugged and chugged along; I knew my aunt was proud of me. I knew the money raised, though meager, would go to a wonderful research cause. I had to keep going even though many tempting trains were off in the distance, and I pictured myself hopping on one for relief!

The halfway mark was pretty monumental for me. I had never done an official half marathon; I had covered the mileage during training runs but never entered an official half marathon race. The longest race I had entered previously was a 5-miler. What a big difference! I remember saying to myself as I passed through the time gates at the halfway point, "You mean I have to do that all again?" I think I even laughed a maniacal laugh! There were many times that I thought



about quitting but realized quitting was not an option. Will is not a quitter so who was I to think that I could quit now!

I realized during this training experience, and ultimately the Boston Marathon, that I want to continue on with my efforts. I want to run the Boston marathon again next year, improve my time and raise money for the Will Power Research Fund. I want to start earlier next year if possible and have an even loftier fundraising goal. I now know that I can do it. If I just put one foot in front of the other.

Thanks for reading, Courtney Monaco

Delta-24-RGD

By Arleen Tarantino

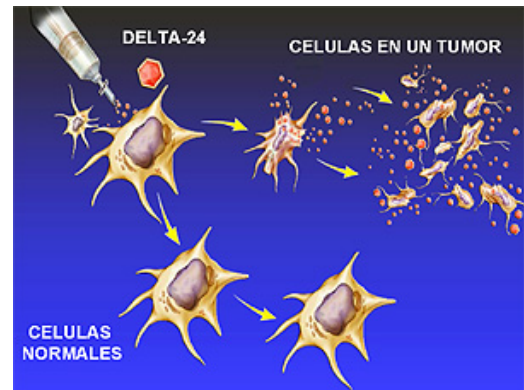
Disclaimer: The information, services, products, messages, and other materials contained on our website or in this newsletter are provided for educational and informational purposes only and are not a substitute for medical advice and treatment.

Will Power Research Fund is currently looking into the possibility of donating some funds to research involving a modified cold virus called Delta-24-RGD. Will's great uncle, Richard Stevens, drew our attention to this exciting new research, and we thank him.



Delta-24-RGD is being studied by Dr. Juan Fueyo and his wife, Dr. Candelaria Gomez-Manzano. It is an adenovirus, the kind that causes the common cold, which has been modified to attack glioma cells (brain cancer cells), but not healthy human cells. Like many cancer cells, glioma cells lack retinoblastoma protein (pRb), a protein that prevents unrestrained cell division. The absence of pRb is one of the reasons cancer cells develop into deadly tumors. Delta-24-RGD is designed to attack only cells that lack this protein, so unlike chemotherapy and radiation, it does not harm healthy cells. When the virus attacks a cancer cell, it takes control of the cell's replication machinery and forces the cell to produce more viruses. These newly generated viruses can then attack even more cancer cells.

Studies using mice infected with human glioblastoma tumors have been very promising. Survivability was significantly increased, with 60% of the mice apparently cured. While studies with mice are quite preliminary, this is an especially encouraging result because Delta-24-RGD managed to destroy the glioma's brain stem cells via autophagy (self-cannibalism). The virus forced both the "adult" glioma cells and the cancer's brain stem cells to self-cannibalize. The ability to eliminate the cancer's stem cells is crucial for curing brain cancer because these stem cells tend to be less susceptible to chemotherapy and radiation, which is theorized to be a primary cause for the recurrence of brain cancer.





Delta-24-RGD holds promise because it might make glioma cells more vulnerable to other treatments. For example, a study published in 2007 suggested that Delta-24-RGD may have a synergistic effect when combined with temodar (temozolomide). Temozolomide is the present gold standard chemotherapy treatment for gliomas. Temozolomide works by hindering the glioma cell's ability to replicate its DNA. Unfortunately, some of the cancer cells retain the ability to repair their genome, so they can renew replication of their DNA, allowing the tumor to eventually return.

This resistance limits temozolomide's efficacy in many patients. When the Delta-24-RGD virus infects a host cell it must mitigate the host cell's DNA repair mechanism in order to successfully take control of the cell's transcription machinery. Thus, when Delta-24-RGD attacks a glioma cell, it has the added effect of making the glioma cell more vulnerable to temozolomide, because it takes control of the mechanism that the cell uses to restore its ability to transcribe DNA. So the virus acts like a double-edged sword increasing temozolomide's efficacy with one slice while simultaneously destroying glioma cells with another slice.

In addition, because viruses force cells to express their genes, Drs. Fueyo and Gomez-Manzano are looking into using Delta-24-RGD to make gliomas more susceptible to vaccines like CDX-110, the vaccine in development at Duke University (see in Brain Cancer News Oct. 2009). These vaccines work by training the patient's immune system to attack cells expressing particular protein receptors predominant in glioma cells, epithelial growth factor receptor variant III (EGFRvIII) in CDX-110's case. Unfortunately, these types of receptors are not expressed by all gliomas, rendering the vaccines ineffective in these patients. Delta-24-RGD can, possibly, combat this by forcing the infected glioma cells to transcribe the requisite receptor proteins, making them susceptible to the vaccine.

At present, a phase I clinical trial is being conducted on humans. In this trial, Delta-24 will be injected into brain tumors through a surgically implanted catheter. After a couple of weeks, the tumors will be removed and examined. Later, however, researchers hope to use mesenchymal stem cells, as a Trojan horse to deliver the virus to the tumor. These stem cells are attracted to tumors, even when the tumor is garrisoned behind the blood-brain barrier. By hiding the virus inside the stem cells, it could be delivered directly to the tumor without detection by the patient's immune system and, once inside, destroy it.

While research on Delta-24-RGD is still in the preliminary stages, it is the kind of research we are interested in because it entails looking at a cure for brain cancer using a fresh approach and it encourages seeking multipronged treatments for gliomas. We believe this kind of innovative research is the most hopeful.

This is a report from MDACC that commented on this research:

<http://www2.mdanderson.org/depts/oncolog/articles/07/11-nov/11-07-1.html>

Article from the Journal of the National Cancer Institute:

<http://jnci.oxfordjournals.org/cgi/content/full/95/9/633>



UCSF Neurocognition Study

By Will Tarantino

*Will Power Research Fund recently gave **\$10,000** to a pilot study run by UCSF that attempts to quantify the cognitive and emotional effects of brain cancer treatment.*

I met with the lead researchers (Dr. Chang and Dr. Racine pictured below) of this study on the Thursday after my most recent MRI in order to learn more about their proposed goals and methods. I was impressed, and after discussing the merits of their pilot study with my family, we decided to make a donation to help support their work.

The main impetus for this study comes the improved prognosis for recurrence and survivability for brain cancer patients due to more effective treatments. This has made patient's quality of life more important. Traditional cancer treatments "Slash/Burn/Poison" (surgery/radiation/chemotherapy) are notorious for causing side effects that can, at times, seem worse than the disease. In fact, many of the symptoms usually associated with cancer (hair loss, nausea, fatigue) are actually side-effects from treatment. The added complications of using these treatments in the brain can lead to severe neurocognitive deficits, including memory loss, reduced fine motor skills, speech impediments, attention deficits, and other faculties. However, these long-term effects are only beginning to concern patients, because improvements in treatment are allowing them to live long enough for side-effects to become a concern. I have actually noticed a personal memory deficit in comparison with my pre-treatment self, particularly regarding my vocabulary and concentration ability.



According to the group at UCSF, cognitive effects of brain cancer treatment are currently measured and considered, but the measurements are much too coarse and rely on tests that are comically simple and heavily skewed towards the low end of the mental spectrum. In other words, a "high-functioning" individual may be noticeably duller (so to speak) post-treatment, but still be given a top score by the test because he/she is still a fully functioning adult. This is only a minor consolation to the individual since their personal quality of life is still significantly diminished. Unfortunately, more elaborate tests that would provide greater resolution of neurocognitive ability are impractically time consuming and costly to administer. As patients and physicians become increasingly concerned about the long-term quality of life consequences of brain cancer and its treatment, the need for an efficient mechanism for measuring cognitive changes in patients is emerging rapidly.

The main goal of the UCSF study is to use advanced cognitive tests and high-resolution MRI images to find correlations between the physical and mental effects of cancer treatment. Quite a bit of research is available regarding the effect of traumatic brain injuries on cognition, but radiation damage is different in a number of ways. Most significantly, brains show some



capacity to heal or adapt following a traumatic injury, but little to none following radiation damage. This may be a result of the extreme novelty of high dosage radiation applied to the brain in human evolution. The hope is that MRI images could replace the intense neurocognitive testing process. For (a rather coarse) example, indications of damage to the left temporal lobe would likely be an accurate indicator of a speech deficit. Mental side-effects of treatment options could be evaluated quantitatively using imaging studies, creating a reliable metric for monitoring neurocognitive side-effects and (hopefully) lead to treatment evaluations that more effectively consider quality of life. The MRI studies potentially also allow for the development of a “susceptibility map” of the brain, identifying the areas most vulnerable to radiation. This information would be invaluable for patients and doctors to more accurately evaluate the costs and benefits of treatment.

Eugene Marathon

By Will Tarantino

Training: I began training for Eugene in December after a few weeks of rewiring my body for running after a summer of backpacking that culminated with two months on the Hayduke Trail. The first month and a half went beautifully, I was feeling strong, and I was getting in plenty of miles. To top it off, I was running occasionally with the Mammoth Track Club, one of the premier training groups in the country. My excitement about the opportunity to run with Deena Kastor (2004 Olympic Marathon Bronze Medalist and American Record Holder); Meb Keflezghi (2004 Olympic Marathon Silver Medalist and 2009 NYC Marathon Winner); Ryan Hall (fastest American-born marathoner, 2:06, and 2008 trials winner); and the others in their group was immediately heightened by the kindness and generosity these premier runners were with their time and training tips (I never told them about my illness or Will Power, though I may when I go back to Mammoth next winter). They seemed genuinely happy to have my company. Of course my participation was limited to easy efforts or Deena’s long runs. It was a welcome change from running alone 7 days a week last winter, and I could only join them twice a week anyway due to my work schedule.

Unfortunately, just as I was starting the meat of the training cycle in the middle of February, my training went from exceptional to dead standstill in a little over a week. Despite a slight twinge in my right knee on Tuesday, Feb. 16, I ran a 46 min fartlek. I took the next day off, but jumped right back into it, ignoring the progressing signs in favor of denial. On the following Sunday I ran a 20 mile progressive effort with Deena. With five miles to go, when we were about to start some pick-up intervals, my knee practically blew up and I was actually “limping” beside her. She encouraged me to stop (her support car was nearby), but I didn’t want her to think I was dodging the hard part of the run, so I pushed through, eventually slowing to a hobble over the last mile or so.

The next day was agonizing, even walking was painful. I began an aggressive icing/stretching regimen, hoping for a miraculous recovery. Stupidly, I ran the next day (only about 20 mins), but my lack of success convinced me to take the rest of the week off.



A week after my blow-up I tried to run a long run with Meb, who was also having knee problems. I made it 20 minutes before I began to feel significant pain. However, I'd learned my lesson and stopped immediately. I didn't run again for ten days.

During this time, I continued my aggressive, daily icing and stretching, but that didn't seem to be helping much so I added a number of strengthening exercises and quite a bit of Ibuprofen to my treatment plan. I immediately noticed more rapid improvement. When walking to the bus and back finally stopped hurting, I started to run as long as I could without any pain (usually a 15 minute loop with 5-10 minutes added on if things were going well). About three weeks after my failed run with Meb, I made it through a 2 hour long run with minimal issues. I found that two things dramatically improved my knee's tolerance of running: running on uneven ground or with a variable stride; and minimalist shoes (i.e. thin soles). Using these tactics I made it through a previously scheduled half-marathon on March 20th, finishing third in 1:14. Running 1:12 (two minutes slower than my PR) would have gotten me the win.

The remainder of my training was delicately balanced between getting as much running in as I could and keeping everything under control. I began to run with the MTC guys again, and they seemed happy to have me back. After my MRI on April 7th I went for a run in Big Basin Redwoods State Park. Perfect temperatures, the redwood-needle trail surface, an undulating trail, evening light, and a series of waterfalls all combined for an effortless ten miles along steep, challenging trails. I virtually floated along the path, moving through the forest with as much effort as a lazy breeze. On the other hand, I did not compete in another half-marathon that I had signed up for that weekend because my knee hurt the next day.



Will at Mile 18

I got steadily better over my final three weeks before the marathon, and after half of the mountain shut down on the 18th I was finally back up to my training intensity and volume before my injury. I decided to just hold it there until the race, without a taper. I actually threw in a few extra long runs to test my knee out and try to force a few late adaptations.

The Race: On the Thursday before my race, I left Mammoth and drove north to Redwood National Park on California's North Coast. Eric (my brother) met me there with Krista Herr (his girlfriend). I went for another great run through old-growth Redwoods and along the cragged coastline before rejoining them for dinner involving a failed attempt to make the saturated wood in the area burn. I slept out under the stars, always a good night.

After arriving in Eugene the next afternoon I went for a short run to get the drive out of my legs. I felt



pretty good. Dad's sister Linda had arranged for a wine tasting and dinner at a local winery. The winery was an extravagant monster, though I thought it was cool that all of their vineyards on the grounds were organic. As luck would have it, I was the only one asked for ID, but I didn't have my wallet, so I missed the tasting. Turned out for the best, though, the wine was mediocre (I had some at dinner, which was actually quite excellent). The following day I made it my mission to relax, with the exception of an easy four miles, until I had to go to the expo, which was extremely packed with soon to be runners, family, and fans, to get my packet and attend the elite athlete meeting (I was running the race for free by virtue of a PR under 2:30). We all had an early dinner at the hotel, and I turned in just after 7:00.

A 5:00 wake-up call got me out of bed, and I had a quick breakfast of bread with peanut butter and water before meeting up with Liz (who I'd met at the elite meeting). We caught one of the school buses carting runners from our hotel to the race start. Our little group of about 50 "elites" had our own gathering area in the bleachers of Hayward Field and (this is key) our own bathrooms. It is not unusual for racers to need a last-minute run to the restroom, and lines are always long.

Finally, hearts pounding, all of the racers in the marathon and half-marathon were lined up,

SET! ... BANG!

The starter fired with minimal warning, startling the 7,000 runners into starting the race. Possibly the hardest part of a marathon start (assuming you're not stuck behind a flock of penguins, like I was in London) is avoiding the urge to run too fast. With how my training went this winter, I was hoping to maintain 5:50's and scrape by in the low 2:30's. I opened a little fast, about 5:42; I brought it briefly under control the next two until I was passed by Tim Harder. I went with him for a bit, hitting high '30s as we circled a loop around a narrow park where Eric and Krista met me with my homemade sports drink.

After passing by my support team, I asked Tim what his plan was. He was shooting for 5:35's and a 2:26. That happens to be my PR, but I knew I wasn't in that kind of shape, so I bid him adieu and dropped back a bit, 3 miles later I was still only 20 yards behind him and running mid-thirties, I guess psychologically I just couldn't let him go. The lack of training at a goal pace had clearly had an effect, I could not "feel" it and I never got into a consistent rhythm.

Tim pulled away just before the half marathoners left us at mile ten. Just passed the halfway mark I crossed the Willamette River and met with part 2 of my support



Will at Mile 23



team. Head Will Groupie Linda (my dad's older sister) and her stalwart, spunky sidekick Nancy (her friend from Connecticut) were there to cheer me on and provide me with some fuel.

My splits careened between low '40s and mid '50s until mile 16, when I had to stop to relieve myself (an unfortunately common issue that I've only managed to avoid at Boston and CIM). After leaving the "Honey Pot" I managed three consistent 5:50's before fatigue began to set in just as I was passing directly behind the hotel we were staying at, where my mom, her mom, and my groupies' spouses were enjoying breakfast while watching the suffering unfold, and grandma was disappointed that I didn't wave. Just after passing the hotel I had arranged for water stop 3 to be delivered by my dad and my mom's father. They were there, my drink was there, but due to a miscommunication they were not prepared to pass it to me. I continued on and drank more water to compensate. They did get me as I passed by on the other side of the river four miles later.

I bounced around between the low and high '50s over the last 10k. Speeding up as I caught two and passed three runners who'd hit the wall. The second was Tim Harder, who was in much distress and thinking about dropping out. I encouraged him, pointing out that he only had four miles left so he might as well finish.

Finally, I left the river and turned towards Hayward Field, the famous home track of the University of Oregon, Alma Mata of such greats as Steve Prefontaine, Kenny Moore, Alberto Salazar, and Joaquin Cruz. The course, now recombined with the half-marathon (the main pack of which was finishing as well) turned through the stadium's gates and onto the track with about 200m to go. Sprinting past the half-marathoners (in the inside lanes, and separated from the marathon course, actually a nice set-up) on one of the most storied tracks in the country was a finish that can compete favorably with even Boston or London. I finished 14th, with a time of 2:34.

Wrap up: Given my training for this race I am reasonably satisfied with the result. Despite my ridiculous sense of pace, lack of intelligence, and poor control of bodily functions during the race I still managed to maintain sub-6:00 pace on little more than a three months of base training split in half by five weeks of rest. I plan to take this as an encouraging indication of a high level of base fitness that I can carry into my training for Sacramento's California International Marathon in December.

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