



WILL POWER RESEARCH FUND

Driven by the dedication to cure brain cancer.

OCT 2009, VOL III

Thank you for your interest in fighting Brain Cancer!

Welcome to the Will Power Research Fund

This is our third 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 three 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 donated \$10,000 to vaccine research at the UCSF Helen Diller Family Cancer Research Center. Thank you for your interest and support!

In this Newsletter

1. WPRF trip to the UCSF Helen Diller Family Cancer Research Center
2. *CDX-110* vaccine being developed at Duke
3. Will's current adventure on the "*Hayduke Trail*"

For the full journal go to:

<http://www.trailjournals.com/entry.cfm?trailname=9738>

4. A journal entry from Will's *Sierra High Route* adventure.

For the full journal go to:

<http://www.willpowerresearchfund.com/articles/SHRAug09.pdf>



Arleen at the Cancer Center

Next Newsletter... *don't know yet...we will see where this journey takes us*

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



Kurt and Debbie Weaver
Won "Guess Will's Marathon Time"
Guess: 2:30:00; Race time: 2:30:25
Pictured with Will's Photo:
"Gates of the Arctic" at the Brooks Range

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

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WPRF trip to the UCSF Helen Diller Family Cancer Research Center

By Arleen Tarantino

Will Power Research Fund is happy to announce that we have donated \$10,000 to Dr. Andrew Parsa's research investigating the vaccine Oncophage as a possible new treatment for brain cancer. Here is a description of our trip to the new UCSF cancer research center.



Bill and I toured the impressive, shining with glass and metal, UCSF Helen Diller Family Cancer Research Building on June 9, 2009. It had just opened the week before at the Mission Bay Campus on June 2, 2009. The mission of the new research center is to accelerate and enhance cancer research through increased communication and collaboration between the many different branches of cancer research, including brain, prostate, and breast cancer research as well as supporting research such as

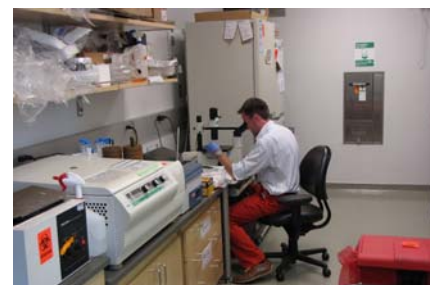
epidemiology, chemoprevention, screening, behavioral science, surveillance and survivorship research. It also houses scientists studying the basic biological causes of cancer in general to further investigation into new ways to treat all forms of the disease.

Jeff Hawk, the Director of development for Neurological Surgery at UCSF, showed us around the facility. He introduced us to boyish looking, jean wearing, Dr. Russ Pieper, a principal investigator at the center who researches the behavior of brain tumor at the cellular level. He examines methods of targeting pathways that are necessary for glioblastoma multiforme (GBM) formation in an attempt to disrupt these pathways and thwart these tumors' ability to resist treatments over time. He's very energetic and enthusiastic about his mission at UCSF.



Dr. Russ Pieper takes us on a tour of their lab facility

He was especially excited about the consolidation of so many different types of researchers under one roof. He believes that communication between the various researchers is imperative to improving the understanding and treatment of cancer. As Dr. Pieper explained it, a researcher might have an unorthodox idea that under normal circumstance they would reject. However, due to the proximity of researchers they might wander over to a neighboring researcher and casually suggest the idea to them.



A researcher at the Helen Diller Center in San Francisco

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That researcher might have explored an area that makes the idea seem more feasible so possible treatments that would have been automatically rejected might receive a second glance.



Touring the Lab with Jeff Hauk, the Director of development for Neurological Surgery at UCSF

We then explored the research labs teeming with young researchers and students busily working. We were impressed with how light, clean, and organized the lab was a far cry from the Dr. Frankenstein type lab in the movies. We saw the tissue bank where all the tumors removed from patients at UCSF are stored. They save tissue from every tumor, each labeled according to type and grade, so that they can use them for ongoing research. *We realized that Will's tumor must be stored there.*



Arleen talks with Dr. Parsa

Next we were introduced to Dr. Andrew Parsa, who explained his research to us. He is working on a vaccine called Oncophage, which is developed by Antigenics. If you're interested, we detailed how the vaccine works in our last Newsletter (download link: <http://www.willpowerresearchfund.com/articles/WPRN5-09.pfd>). During his discussion, he noted that he takes no money from Antigenics in order to avoid the possibility of having funding influence his objectivity. We were very impressed by this point, because we have done some research in the past concerning antidepressants and how funding of these drugs by the pharmaceutical industry is problematic.

Dr. Parsa also explained how Oncophage was potentially more hopeful than other cancer vaccines. One, the pathways of Oncophage, which are dependent on utilizing heat shock proteins, are specific whereas the dendritic vaccines are nonspecific. This is advantageous because it improves the ability to measure the efficacy of the vaccine and decreases the likelihood of side effects such as autoimmune reactions that have been noted in vaccines with less specific pathways. Two, Oncophage works on all gliomas, whereas vaccines like CDX-110 being researched at Duke can treat only a certain subtype of glioblastoma that is present in 25% to 40% of brain cancer cases.

This, of course, is not to suggest that dendritic vaccines and CDX-110 are not worth studying. We believe different research venues are necessary to finding cures to cancer. Below, we provide some information on CDX-110. The hope is that eventually there will be many different ways of treating gliomas because each one is different and has different strengths and

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weaknesses. Researchers eventually hope to be able to tailor treatments to specific tumors instead of forcing these very different tumors into a one-size-fits-all protocol.

IN BRAIN CANCER NEWS – CDX-110 (A new hope for many GBM patients)

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According to research conducted at Duke's Preston Robert Tisch Brain Tumor Center, the vaccine CDX-110 may significantly increase survival in patients with Glioblastoma Multiforms, the most common and deadly type of brain cancer.

The vaccine works by triggering an immune response to the tumor in patients who have a protein expressed on approximately half of patients with GBMs. This protein, known as epithelial growth factor receptor variant III (EGFRvIII), is not expressed in healthy tissues but is prevalent in GBMs, which makes it an attractive target for a vaccine.

The vaccine trains the immune to kill tumor cells that express the protein, helping to prevent the re-growth of brain tumors in patients who have already been diagnosed and treated with standard regimens including surgery, chemotherapy, and radiation.

"This vaccine represents a very promising therapy for a cancer that comes out of the blue and robs people of something most of us take for granted – time," said John Sampson, M.D., Ph.D., a neurosurgeon at Duke and lead investigator on this study. "The possibility of doubling expected survival – with few if any side effects – would represent a big step and a lot of hope for this group of patients."



The study was funded by the National Institutes of Health and Celldex Therapeutics, a subsidiary of Avant Immunotherapeutics, which has patent rights to the vaccine, has provided vaccine for use in the study. This study included 23 patients being treated at Duke and at M.D. Anderson Cancer Center. The patients all had GBMs and had already received standard treatment. Each patient received vaccine injections monthly and was given a chemotherapeutic agent called temozolomide (Temodar) in conjunction with the vaccine treatments. The temozolomide is believed to increase the immune response to the EGFRvIII, Sampson said.

"This reflected something of a surprising conclusion, because it stands to reason that



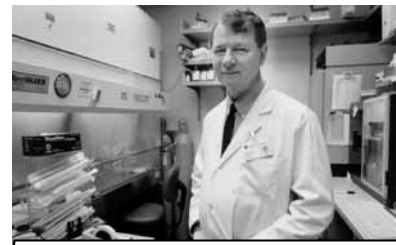
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chemotherapy, which suppresses the body's immune system, would make the vaccine less effective," Sampson said. "What we found was that the opposite is true. While the body is recovering from chemotherapy, immune response is actually stronger as the immune system overcompensates in order to right itself. It's the perfect time to introduce a vaccine."

Patients were typically progression free for 16.6 months rather than the expected 6.4 months. Furthermore, study patients lived for an average of 33.1 months. In contrast, GBM patients who are only treated with standard therapy live an average of 14.3 months. "We're more than doubling survival time in this group, and we have some patients who are four, five or six years out from diagnosis, which is virtually unheard of in these people," Sampson said. Moreover, the vaccine has few side effects other than swelling at the injection site. A Phase III trial is now open at more than 20 sites nationwide.



Darell D. Bigner, MD, PhD, Director

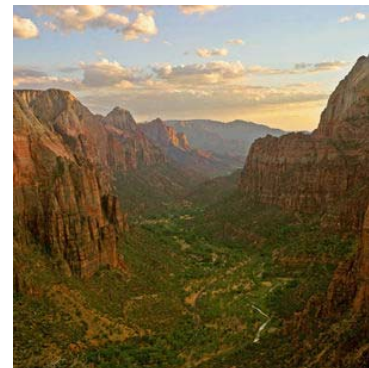
Researchers involved with this study include Gary Archer, Darell Bigner, Henry Friedman, Duane Mitchell and David Reardon of Duke; Amy Heimberger and Raymond Sawaya of M.D. Anderson Cancer Center; and Tom Davis and Tibor Keler of Celldex Therapeutics.

See more about Duke's program:

<http://www.cancer.duke.edu/btc/modules/clinicaltrialsmain22/index.php?id=1>

1000 mile hike to raise Brain Cancer research dollars

By Will --- This fall, I am attempting an approximately 1000 mile route across the Colorado Plateau known as "the *Hayduke Trail*" named for Edward Abbey's undomesticatable defender of the canyons in *The Monkey Wrench Gang*. The creators of the trail describe it this way: "This route is not intended to be the most direct way through this region, nor is it the easiest or even the most logical way through the area." While not a highly technical route, it is (with few exceptions) NOT a *trail* as much as it is a loose description of a way to wander through Southern Utah and Northern Arizona.



Why spend nearly two months in the desert wandering cross-country through canyons, across rivers, and over mountains in one of the most remote and "desolate" regions left in the lower 48 states? First of all, the *Hayduke Trail* traverses one of the most unique and beautiful places in the entire world, and one which, because it is in my own country, can be visited and experienced relatively simply and inexpensively. Second, I am going with Sharon Dziengel, a good friend of mine who hiked with me for approximately two-thirds of the Pacific Crest Trail, one of the seminal experiences of my life. Sharon and I have kept in close contact since, and we are both looking forward to the opportunity for a "reunion". Third, because it is not an "official" trail, Sharon and I are free to alter the route as we please to suit our needs.

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This adds a sense of ownership to the trip beyond what one gets on the Appalachian Trail (AT), Pacific Crest Trail (PCT), or even the unfinished Continental Divide Trail (CDT). The Mitchell-Coronella route is more a source of inspiration than a rigid designation. Finally, we would like to raise some funds for brain cancer research, and this hike seemed like a good way to attract some interest and support.



I spent about two months looking over maps and guidebooks, and I worked out a tentative route. We plan to begin in **Zion National Park** and head south to the **Grand Canyon**, resupplying in Colorado City along the way. The route drops down a side-canyon to the Colorado River before climbing out and following the North Rim to the North Rim village for resupply. From there, a circumnavigation of the Wahalla Plateau along Bright Angel Creek, the Colorado River, and up the Nankoweap drainage takes us back to the North Rim before we head up Marble Canyon to Lee's Ferry. Travel in the Marble Canyon would be exceptionally difficult, so we might opt to go across the Paria Plateau and drop into Buckskin Gulch (supposedly the longest slot canyon in the world), or even take the Arizona Trail to Kaibab Gulch (the upriver portion of Buckskin Gulch). Wherever we join the Paria/Deer Spring drainage we then follow it upstream to **Bryce Canyon National Park** and Tropic, Utah for resupply.

From Tropic we then take a wandering route through the **Grand Staircase Escalante National Monument**, resupplying in the town of Escalante before proceeding to the southern portion of **Capitol Reef National Park** and the Henry Mountains. After the Henry Mountains, we enter the Dirty Devil Drainage and work our way to Hite Marina on Lake Powell. From Hite our route goes East and then North through Dark Canyon and the Needles Region of **Canyonlands National Park** before joining a system of dirt roads leading into Moab, Utah. From Moab we continue another 2-3 days, finishing in **Arches National Park**.

We plan to arrive at a town every 3-7 days to resupply, i.e. stock up on food and other necessities. We plan on visiting the following towns for resupply: Springdale (Zion), Colorado City, Grand Canyon North Rim, North Rim, Lee's Ferry, Tropic, Escalante, Hite, Needles, and Moab.

We started on September 28th and will finish in mid-late November. I will take pictures and keep a journal along the way, posting regular updates on the internet, as I did on the AT (2004) and CDT (2005), (see www.trailjournals.com/entry.cfm?trailname=3118).

We will put a link to the *Hayduke* Journal on WPRF.com

Thank you in advance for your interest and support!

Will



An entry from Will's Sierra High Route (SHR) Journal

SHR Day 0: 8/15/09

At present, I'm bivouacked at road's end in King's Canyon National Park (KCNP). I had not planned to camp here, but I made a last minute decision to wait until morning so I can get a permit. Miniature mosquitoes buzz through the warm evening, hovering around me working up the courage to land. Once they do, they quickly perish and are consumed. Sleeping here isn't exactly endorsed by the park...but I don't see any "no camping" signs, besides, no one will ever know that I was here... unless they happen to read this.

This morning, I woke behind my friend Lindsey's cabin at 6:00, in some bushes next to the stream where they set up their experiments. Linds was kind enough to give me a ride to Onion Valley, bless her, and we stopped for a light bite along the way. There was a bit of confusion about which road went to the trailhead, but we soon found it. The drive up switch backed up a fairly steep slope, and the occasional sense of exposure made Linds so uncomfortable that she would move into the oncoming lane when it was on the inside. Luckily, despite the number of people and cars at the trailhead/campground, traffic was minimal, especially downhill.



One thing about the Eastern Sierra, it isn't coy; the climb up Kearsarge Pass was an abrupt insertion into the alpine environment. A climb up the east side hits you immediately in the gut/soul with the Sierra's brilliant beauty: glowing granite spires, luminous sapphire lakes, and crystal clear skies. Range of light indeed!

From the pass I dropped down to the blindingly blue lakes below. Not paying attention to where I was going, I accidentally wandered off on a minor side-trail. No matter, I just followed the drainage cross-country, playing connect the dots from lake to lake, revealing a truly spectacular landscape by the time I reached the PCT where the hanging valley dropped into Vidette Meadow. I followed the PCT briefly down to the meadow before joining the Bubb's creek trail and following it along the creek as it descended a glacial staircase to King's Canyon, among the most spectacular canyons in the Sierra. There were a large number of tourists at Road's End, playing in the S. Fork King's River and returning from day hikes. The permit station had closed at 3:00 and didn't open until 7:00am, so I quickly hitched down to the visitor center to see if I could grab one there. ... <http://www.willpowerresearchfund.com/articles/SHRAug09.pdf>

Next Newsletter...January 2010 if not before.