



bHS QUARTERLY NEWSLETTER

MAY IS BRAIN TUMOR AWARENESS MONTH!

Volume 1, Issue 1

Spring 2011

Our mission is to support brain tumor patients and caregivers in the Kansas City Community through public awareness, education, and to aid local organizations working to research and cure brain tumors.

For more information, call 913.314.2255 or visit us online at www.beheadstrong.org

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Successful Annual Fundraiser

On Sunday, March 6th, 2011, beHeadStrong held our annual fundraiser at the Boulevard Brewery. It was well attended and was a very successful event. Thank you to our sponsors and everyone that came out to support us. Thanks to you we will be able to continue to help brain tumor patients and their families in the Kansas City area.

A special thanks to our volunteers for all of their hard work. We couldn't do it without you.

Next year's event will again be at the Boulevard Brewery. More information will be sent in the near future.

We look forward to seeing everyone there!!



*photography courtesy of Scott Boyd

38th Annual Hospital Hill Run

The 2011 Hospital Hill Run is quickly approaching and beHeadStrong will again participate. This year's event will take place on Saturday, June 4th.

If you are interested in running, contact Terri Risinger (terri_risinger@yahoo.com)

We are also looking for volunteers to help at the aide station and finish line. If you would like to volunteer, contact Pete Gaumer (pete@beheadstrong.org).

For more details on the event and ways you can help, please visit our website (www.beheadstrong.org).

We look forward to seeing everyone there! Thanks for your support!

A Few Words From The Doctor — Michael Salacz, MD

Friends,

I have been very privileged to work in a community with such a pro-patient organization as beHeadStrong. The number of positive patient comments I have received over the years in regards to your activity and advocacy is just amazing. So I was very honored to be asked to write a piece about brain cancer for the bHS quarterly newsletter. While I had thought to talk a bit about our program in specific and brain cancer therapy in general, I would also welcome your comments and suggestions in regards to content for this section in upcoming issues.

I continue to be amazed at both the rapid pace and the many different directions our understanding of and treatment for brain cancer is advancing. From the sequencing of the Glioblastoma genome, to the development of targeted therapies, vaccine approaches and unique drug delivery approaches, the world of brain cancer treatment is changing, I hope in a meaningful way for our patients. Although not (yet) one of the "old boys", we at Saint Luke's have quietly been doing our part as well and are able to offer our patients here in Kansas City "the best". Over the past 18 months, we have completed Phase I testing of a novel autologous tumor vaccine (TVAX) and are headed into Phase II testing soon for Glioblastoma. We have been treating patients with intra-arterial chemotherapy with and without blood brain barrier disruption; therapies which increase chemotherapy passage across the blood brain barrier and so get higher doses to the tumor cells without increasing systemic side effects. I have been working with a team from India to bring a homeopathic therapy here to the Kansas City area and, finally, we have been participating with several larger consortia to be able to offer advanced therapies including Cilengitide and Cedirinin to our patients.

Although we have accomplished a lot in just a short time, we still have a long way to go. Therapies we are offering now in Kansas City are more effective and less toxic than even a few years ago, but we are still searching for the elusive cure for our patients with brain cancer. Though our efforts are far reaching, we have not lost sight of our motto: "Improving the outcome of brain cancer, one patient at a time."

Michael Salacz, MD
Neuro-Oncologist & Medical Director of the St. Luke's Brain Tumor Center

Please send comments/suggestions to Jeanne Cochrane — jeanne@beheadstrong.org

Did you know...

- ◇ Cancers which arise from brain or spinal cord structures are called primary central nervous system cancers. Because over 95% of these tumors arise from brain structures, compared with 4% arising from spine structures, as a group they are called primary brain cancers. These cancers can be malignant (invade, metastasize and/or grow aggressively) or non-malignant (don't invade, don't metastasize and/or grow slowly). There are approximately 19,000 people each year diagnosed with primary malignant brain cancer. This equates to 6.4 cases per 100,000 people living in the United States.
- ◇ The number of people living in the US with brain cancer (both malignant and non-malignant) is estimated at over 612,000.
- ◇ Secondary brain cancers are also called metastatic tumors and arise from the spread of tumors originating outside of brain, from organs such as the lung, breast and skin (melanoma) among others. These account for 170,000 to 200,000 diagnoses each year.
- ◇ Glioblastoma is the most common primary malignant brain cancer, with an annual number of around 12,000 in the US, and historically, had an average survival after diagnosis of around 12 months. Many of the other types of primary brain cancers have different (and better) survival rates.
- ◇ The median survival from the European/Canadian study of Temozolomide in the treatment of Glioblastoma (Stupp, NEJM, 2005) is about 14.5 months for the entire cohort.
- ◇ The risk of developing primary brain cancer increases with age. The incidence of a person being diagnosed with a primary brain tumor under the age of 65 is 4.5 in 100,000 people compared with 17.8 for patients 65 years or older.
- ◇ There are few known risk-factors for brain tumors, but people who have received radiation, including exposures such as atomic bombs or industrial accidents or a history of radiation to a head/neck area (which may have included parts of the brain) has been shown as an increased risk.
- ◇ Research continues in many areas such as: occupational exposures, family history or predisposition to cancer, cellular phone use, diet, allergies, radiation exposure, and hormone use.
- ◇ Research is ongoing to further identify causes/risk factors as well as developing new treatment strategies to fight these devastating diseases.

◇ Data is from the Central Brain Tumor Registry of the United States, <http://www.cbtrus.org/factsheet/factsheet.html>, <http://www.cbtrus.org/2011-NPCR-SEER/WEB-0407-Report-3-3-2011.pdf> and The National Cancer Institute, <http://www.cancer.gov/cancertopics/factsheet/Risk/brain-tumor-study/print>

Get Involved

Every day, Kansas City men, women and children are faced with the devastating reality of a brain tumor diagnosis. Patients and their families fight not only the brain tumor, but also the resulting financial difficulties. beHeadStrong is a 100% local, 100% volunteer, grassroots organization that provides the critical financial assistance to these patients and families - allowing them to focus on fighting the tumor and supporting one another, instead of worrying about how to pay the electric bill. Help us continue to help the brain tumor community. To volunteer or make a donation, go to:

www.beheadstrong.org

Thank You!

We want to thank all of our supporters and volunteers. We can't do it without your help!

In Her Own Words...A Survivor's Story Meet Terri Risinger, Vice Chair of bHS



My brain tumor story started about 6 ½ years ago when I went to the emergency room for what I thought was a serious case of the flu. At 27 years old I was busy living life to the fullest. The previous weekend I had been skydiving (one of my many hobbies) followed by spending Thanksgiving with my great family. My world was perfect! Within 5 hours of arriving at the ER, I had been ambulated to a different brain and stroke hospital, poked, prodded, drugged, spinal tapped, CTed, MRled and finally diagnosed with a primary brain tumor, Ependymoma. Within a week I had undergone high risk brain surgery to remove as much tumor as possible... and that was the easy part. Then the rehab began. My tumor did not affect my cognitive ability but my physical ability was challenged. At 27 I learned how to walk, maintain balance, swallow, eat and drink again. After many weeks of a feeding tube, radiation, and a lot of blood, sweat, and tears I'm back to maintaining a life that to the outside world closely resembles my life before my brain tumor. But inside this world of mine, life has forever changed. I still deal with a 'souvenir cough' due to nerve damage and some hearing loss from radiation but really I've come out ahead. Now I understand what life is about, and now if nothing else, I have THIS moment to decide what I'm going to do right now. That is why I am part of beHeadStrong. In the chaos that a brain tumor diagnosis brings, beHeadStrong provides assistance for those that need it the most.