



beHeadStrong Quarterly Newsletter



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SUMMER 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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38th Annual Hospital Hill Run

beHeadStrong participants again took part in the Hospital Hill Run held on June 4, 2011. This included walkers, runners, an aide station, a charity booth with representation from St Luke's Brain Tumor Center, and many cheering fans. Over 25 runners and 75 volunteers from beHeadStrong were involved in the event. If you are interested in participating in next year's event on June 2, 2012 please visit beHeadStrong on Facebook or beHeadStrong.org and submit an email. A very big thank you to all of those who participated and assisted in making this a successful event. Special thanks to our sponsor, Mid America Foot and Ankle Specialists!



beHeadStrong Attends St. Luke's Brain Tumor Support Group Meeting

Ever heard the old saying, "Two heads are better than one?" beHeadStrong used that philosophy as we joined the St. Luke's brain tumor support group, and found that a GROUP of MANY heads, including those with brain tumors, are much, much better than one! beHeadStrong board members Jeanne Cochrane, Carol Murphy and Gail Mullin had the opportunity to talk with Martha Maccracken who is the brain tumor support group leader at St. Luke's Hospital. We shared laughs as we listened to each others' brain tumor stories. We "brainstormed" ideas regarding how to overcome typical brain tumor issues like: physical disabilities, cognitive deficits, family dynamics and tackling difficult insurance hurdles.

beHeadStrong is excited to be a part of this outreach program, and we feel this support group can help us bridge the gap between our organization and the brain tumor community needs in the Kansas City area. If you'd like to attend a support group meeting, they meet the second Tuesday of every month from 7:00 p.m.—8:30 p.m. at the Specialist in Cancer Care Office, Medical Plaza III, 4321 Washington, Suite 4000, Kansas City, Missouri 64111. For more information, please contact Martha Maccracken at 816-932-2386 or email her at mmaccracken@saint-lukes.org.

Raising Funds In A Tough Economy — Pete Gaumer

beHeadStrong, like other charities, has been impacted by the tough economic times the country has been going through. We are seeing more patients who need financial assistance and support in order to be able to pay their bills or pay for medications. We are working even harder to collect donations to help the brain tumor patients in need.

Having to work harder to get donations is compounded by the fact that we are an all volunteer organization, with no national backing. We do not have a marketing department securing corporate sponsors and putting on elaborate fundraising events. What we do have is a dedicated group of people who have, in some way, been affected by brain tumors and want to make a difference for those who are dealing with a brain tumor diagnosis.

beHeadStrong raises funds through two major avenues; fundraising events and online donations. This year our first fundraiser was an event held at Boulevard Brewery. Guests were treated to a dinner from 23rd St. out of Lawrence, a silent auction, raffle, and all the finest that Boulevard has to offer. Our most recent event was being part of the Hospital Hill Run. This was our 3rd year of having a running team and an aid station on the course. While these two events helped raise much needed money, we still need donations throughout the year and are always accepting donations via our website (www.beheadstrong.org).

When a donation is made to beHeadStrong, that money goes to help local brain tumor patients in need or for research at the St. Luke's Brain Tumor Center here in Kansas City. In an effort to be good stewards with donations, we try to keep it all right here in the metro area. So if you would like to make a donation to honor a loved one or friend who has been affected by a brain tumor, or just want to help a local organization helping others, you can feel confident that beHeadStrong will squeeze every last ounce of help out of your donation.

Pete Gaumer Resigns as Chairman

Pete Gaumer has resigned his position as Chairman, effective August 30th. Pete and his wife, Terry, are relocating outside of the Kansas City area so Pete can pursue a career opportunity. We want to thank both of them for all of their dedication and hard work over the years to help make beHeadStrong a success. We will miss them! In the interim, Terri Risinger, Vice Chair, will take over the Chairman responsibilities.

A Few Words From The Doctor — Michael Salacz, MD

Recently I saw a long-time patient of mine with brain cancer back in the clinic. It was a fairly uneventful visit; things were going well off of treatment. Towards the end of the visit, the patient's significant other asked me if I remembered telling them that "life will never be the same after a cancer diagnosis. However, that doesn't mean that it will be worse, in fact, for many people it is more full and meaningful than ever before." When I indicated that I did remember, both told me that they didn't believe me at the time, but that they have since come to realize that it was true – for them. In fact, they, individually and as a couple, had lived more life in the past few years since the cancer diagnosis than they had in the decades before diagnosis. In short, they had learned to smell the proverbial roses on the path of life instead of speeding past them.

I understood a long time ago that telling patients and families, "I know what you are going through", when I haven't walked their journey myself, is wrong. I have not personally had brain cancer and so can't say that I know exactly what my patients and families experience. However, I have had a personal history of cancer – this October I will be a 5-year survivor of melanoma. Fortunately, the cancer was still localized, but melanoma is an odd player and can sometimes come back after remaining hidden for years, even decades. This crosses my mind every time I have a headache or when I get an odd ache or pain. So I can say that I know what it is like to have a cancer diagnosis and that with certainty it changes one's life forever. But I can also say that it isn't always for the worse. It isn't easy to always "smell the roses" or live each day to the fullest. There are many demands from work, family and friends that keep us busy, but I have found that more often in the past few years, I am able to mentally step back and appreciate what I am doing and the people in my life. So if there is any message I can share it is to not take every day things for granted, rather enjoy the moment, the experience and the people around you.

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

Cancer-Related Fatigue - Carolyn M. Cook, BSN, OCN, CHPN

The concept of fatigue experienced by the oncology patient is a subjective phenomenon that is difficult to communicate, describe, or fully comprehend by patients, their families, friends, and caregivers. Cancer-Related Fatigue (CRF) may be present at the time of diagnosis, exacerbate during treatment, loom many years after treatment is completed and remain even though a remission or a cure has been achieved (Saarik, J & Hartley, J 2010). Breitbart W. & Yesne A. (2008), state CRF is "underreported, under diagnosed, and undertreated." Fatigue is a very common and distressing symptom associated with their cancer diagnosis. CRF has the potential to severely affect quality of life, as well as, emotional and physical performance.

According to Saarik, J & Hartley, J (2010) the prevalence of CRF continues to grow due to more effective cancer treatments with improved cure and remission rates. In 2008, it was estimated that there were 2 million people affected with CRF. CRF is the most universally reported symptom which prevents 91% of patients from leading productive and satisfying lives. It's interesting to note that 61% of patients also stated pain and nausea contributed significantly to a decreased quality of life, but pain and nausea were actively treated. According to The Allied Health Professions Palliative Care Project Team (2004), 80% of patients who reported fatigue were not treated.

Fatigue is described by Jorgenson R. (2008) as a mental and/or physical exhaustion that affects the whole body and prevents a person from carrying out any type of physical activity. According to Saarik, J & Hartley J (2010) CRF is described as a subjective, overwhelming, persistent feeling of tiredness that is totally out of proportion to the amount of activity that has been performed and routinely hinders daily activities. CRF affects the patients in all aspects of their lives including their physical endurance, cognitive function, and psychological well-being. According to Breitbart, W, & Yesne, A (2008) this fatigue is a personal and persistent feeling that is characterized by physical, mental, motivational and emotional symptoms that are more relentless than the fatigue experienced by well individuals.

Cancer-Related Fatigue - Continued

Rosman, S. (2008) writes that healthy people define fatigue as a natural occurrence after physical activity, while the cancer patient describes fatigue as a physical and psychological suffering that affects their daily life. Hauser K, Walsh D, Rybicki L, & Seyidova-Khoshknabi D, (2008) also define CRF as a universal, subjective awareness with physical, mental, and psychological features which diminish a patient's quality of life. CRF is underreported by patients and underestimated by many medical professionals; therefore, the condition is under treated or not treated at all. Patients are given the impression that they have to learn to live with it. Potter, J (2004) states that CRF is a very aggressive fatigue that affects every area of a person's life as they labor to cope with their disease and treatment. CRF is a very difficult and major symptom for patients and presents many obstacles for healthcare professionals as they try to balance treatment and treatment side effects.

In defining CRF three recurring attributes presented themselves in the literature. Those three attributes included: physical endurance, psychological well being, and cognitive function. All the literature agrees that this phenomenon is subjective and CRF is what the patient says it is. The most disturbing widespread attribute was the inability of the medical profession to define, quantify and then treat this fatigue with any success (Breitbart & Alici, 2008). To fully understand these attributes and how they affect the patient in their daily lives we must explore them individually. According to a phenomenological study done by Potter, J (2008) these three attributes have many far reaching affects on a patients quality of life as described below:

Physical Attributes: Unable to complete ADL's without assistance, unable to ambulate without assist or only for short distances, the need for frequent rest periods or sleeping for long periods of the day, spending more time in bed or on the couch, poor fluid and food intake, required assistance to complete household tasks, and being unable to cook or shop. Some patients even stated they were too tired to chew their food. They described the frustration of not being able to make plans ahead of time as they never knew how much energy they were going to have each day. It was very apparent that CRF had a profound effect on every activity of their daily lives and most profoundly on their quality of life.

Psychological Attributes: Feelings of uncertainty and unpredictability in their lives due to their vacillating energy levels, increased levels of stress and worry, loss of independence and the increase in dependence on others, the feeling of being a burden to loved ones, feeling isolated and lonely, depression, turning inward, feelings of hopelessness, and inability to accept their limitations.

Cognitive Attributes: Poor memory and concentration, decreased motivation, inability to process several thoughts at a time, lacks the ability to actively participate in conversations or their world around them.

CRF is defined when the patient experiences some or all of the symptoms described by the physical, psychological, and cognitive attributes.

CRF plays a very significant role in how a patient is viewed socially in our culture. According to Rosman S, (2008) fatigue isn't considered out of the ordinary for approximately six months to a year, but this timeline may depend on which treatment the patient is undergoing and how families, friends and caregivers perceive the fatigue and what burdens the patients fatigue is placing on them. Once a patient's fatigue lasts for more than a year and treatment is completed, the expectation quickly changes. Family, friends, and employers expect the patient to abandon the sick role and resume his previous life after the appropriate length of time. Our culture is very understanding at the beginning of a cancer diagnosis, but after the initial treatment is completed and a person is considered in remission or cured the expectation is that life will return to normal. Normal being whatever the patient's life was like before his cancer diagnosis. Rosman goes on to point out that once fatigue controls every aspect of a patient's life, and prevents them from returning to work or resuming their old life, then everyone in the patient's life must make adjustments. This type of adjustment only adds to the feelings of social isolation and rejection that the patient must experience due to his fatigue, which only adds to his decreased quality of life.

The consequences of CRF are all encompassing and affect every aspect of a person's quality of life. The patient perceives CRF as a paralyzing side effect that has permanently changed every aspect of their life. Fatigue is related to poor physical performance status and interferes with the accomplishment of a person's daily activities. It can also play an integral part in a person's personal, social and professional relationships and their ability to cope on a daily basis (Rosman S., 2008). Patients experiencing CRF also have difficulty when they apply for temporary or permanent disability. Often time's insurance carriers don't recognize CRL as a legitimate disability (Mock V, Atkinson A, Barsevick, A, Berger A et al., 2007).

It is imperative that we be aware that CRF exists and realize this is a debilitating side affect of diagnosis and treatment. As more oncology patients are living longer and are receiving more fatigue causing treatments, we must be aware of this side effect and provide interventions that increase the quality of life for this patient population.

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 Kyra Fenton, bHS Board Member



My story began 3 years ago when I was a traveling nurse in San Diego. I became extremely sick and ended up going to see several different doctors and specialists. After numerous tests, they still had no idea what was wrong. It wasn't until I came back home to KC that I finally had an answer. I was supposed to come back for my grandmother's 90th b-day party and ended up missing several flights. (I have no memory from Aug 2008 until after my surgery in April 2009, so some of this is from my family's account) Somehow, I finally made it home and my family knew that something was seriously wrong. I ended up going to see my old PCP who ordered a STAT MRI due to the fact I was in such pain and had no reflexes whatsoever. Good Friday 2009 I found out all my problems were due to a brain tumor. He sent me to KU and the whirlwind ensued. Since my tumor ended up being the size of a grapefruit, my family was prepared by my neurosurgeon that I probably wouldn't make it thru my surgery. She said if I did, then I would no longer be the daughter/sister that they all knew-but I would be alive. So no pressure on me, whatsoever, to prove them wrong! I came thru only to have to endure months of extremely hard therapy and rehab. It hit my cognitive abilities the most-not something you want to hear being a nurse! Thanks to my family's help and strength I'm still here today-my dad even helped me relearn math! beHeadStrong came into my life just at the right time. Not only did they help with gift cards, but with the emotional support as well. Thank you Gail Mullin! My best friend was also diagnosed around the same time. Unfortunately hers was a GBM. Even though she lost the fight, she helped me with mine. I have a type II meningioma, with a piece still left-otherwise I would have had an irreversible stroke. So, I get scanned every 6 months and if any growth is noted I will have to have radiation. I'm back to full-time OR nursing at KU and even work with my own neurosurgeon from time to time. I'm so honored to also be on the bHS board and to be able to help/give back to others. I am very blessed to have so many wonderful people in my life!