



Kyla Miller Foundation
P.O. Box 712
Dillsburg, Pennsylvania 17019
www.kylamillerfoundation.org

Spring 2010



Kyla Miller Foundation

KMF Brain Matters

KMF Community Calendar – Spring 2010

April 23, 2010

1st Annual GRAPES OF WRATH: Stomping Out Pediatric Brain Cancer! A wine, cheese and chocolate tasting event with silent and Chinese auctions! Hershey's Chocolate World, Hershey, PA. Cost is \$40.00 per person. Must be 21 years or older! Sample seven different wines paired with a complimenting cheese and Hershey's chocolate. Sponsorships available. Silent auction items include autographed Donovan McNabb Eagles jersey, autographed Melissa Gilbert memorabilia, autographed Greg Biffle NASCAR memorabilia, original paintings, Team Edward and Team Jacob memorabilia and more!! Guest speaker: Matt Kretz, a current pediatric brain cancer child fighting this disease. More information available at www.kylamillerfoundation.org/wine.html.

May 1, 2010

Carly's Crusaders 1st Annual Walk-A-Thon and Family Fun Day. Boiling Springs High School, 11:00 AM to 4:00 PM. Come out to join Carly's Crusaders for a day-long walk-a-thon and family fun day to raise money for pediatric brain cancer research. No registration fee. Pledge forms available at <http://carlyscrusaders.ning.com>. \$50 in pledges gets you a free tshirt!

May 6 / 7, 2010

Kyla Miller Foundation Night with the Harrisburg Senators! Ticket vouchers are \$9.00 each and good for any 2010 regular season home game. May 6th we'll be at the ballpark to toss out the first pitch, have an information stand on the concourse and give an interview during one of the innings! May 7th is our official game night! Come out to the Friday night game at 7:00 PM against the Richmond Flying Squirrels. The team is giving away 9 flat screen TV's throughout the game, and the game concludes with a spectacular fireworks display!

May 22, 2010

KMF 5K and Fun Mile – Bermudian Springs High School, 8:00 AM. Sponsored by Rita's of Hanover and RoadID. Get the details at www.Active.com or www.kylamillerfoundation.org/5k.html. \$20 for the 5K and \$15 for the fun mile!

August 20, 2010

3rd Annual KMF Golf Classic – The Golf Club at Felicita Spa and Resort, Harrisburg, PA. New Price - \$75.00 per player! Sponsorships available. Entrance Fee includes driving range warm-up, round of golf, cart, food, participation gift, entertainment. Cash prizes awarded for top three placements! Other prizes available. Register at www.kylamillerfoundation.org/golf.html.



Help us help other children. Send a dollar (or more) to KMF and support our "Buck Pediatric Brain Cancer" initiative. 100% of your donation will go to fund scientific pediatric brain cancer research. Send your donation today to:

Kyla Miller Foundation - BPBC
P.O. Box 712
Dillsburg, PA 17019

In this issue:

Vaccine Studies at Duke and UC (Page 2) Brain Tumor's 'Grow-or-Go' Switch Found (Page 3)
ABTA Palliative Care Guide (Page 2) Funds for Pediatric Cancer Still Low (Page 3)
CBTRUS Estimates 62,930 New Cases this Year (Page 2) KMF Community Calendar (Page 4)

Why we fight for a cure...

News is getting out about Kyla Miller Foundation and our fight to end pediatric brain cancer. Since the Winter 2009 issue of KMF Brain Matters was posted I was contacted by two families affected by pediatric brain cancer.

The first is close to home. A young lady by the name of Carly, from a nearby community, is dying from brain cancer. She would be in Kindergarten this year had she not been diagnosed with DIPG – Diffuse Intrinsic Pontine Glioma. This is an inoperable brain stem tumor, and like Kyla's tumor it has no cure.

Carly is at home with her family. While I have not met with the family, I was able to get on a website started by a group of supporters that have taken Carly's fight to heart. Pictures of this precious little girl remind me so much of Kyla... a very healthy, active little girl whose body has just changed dramatically because of steroids to keep the pain and swelling away. And no matter how much I or you or anyone else wishes

for a medical cure, the reality is that there just isn't one.

Carly's supporters got wind of Kyla Miller Foundation and contacted us to help their cause. We will be at their Carly's Crusaders 1st Annual Walk-A-Thon and Family Fun Day on May 1st at Boiling Springs High School to help them spread awareness about pediatric brain cancer and to help raise money for pediatric brain cancer research.

The second family I came in contact with is from New York. They had just lost a 13 month old boy, whom I will refer to as "Grandson", to PNET – Primitive Neuroectodermal Tumor. Grandson was diagnosed with PNET at six months of age! I cannot fathom what is worse... losing a child at ten years of age or losing a baby before he's even had the chance to live!

Grandson's grandmother knew that she wanted to do something for him so that his very short life with them was not in vain. She began surfing the net with keywords such as "foundation" and "PNET", and that

Stephanie Miller

led her to Kyla Miller Foundation. We had a wonderful talk on the phone, not just about things to consider when starting up a foundation but about the tragedy and heartbreak of losing our children to this devastating disease.

Grandmother asked me when will it get better... when will the pain of loss go away? The truth is, it doesn't. We lose our loved ones... our grandparents and parents, aunts and uncles. We never expect to lose our children, and the pain cuts deeper than a knife to the heart. The wound will never quite heal, but scar tissue eventually covers it so that we can move on with our lives and do the work that is meant to be done to bring awareness to the public about pediatric brain cancer.

I am reminded, just so, that stories like the ones I have just shared with you are why we continue to fight for a cure... for Kyla, for Carly, for Grandson, for so many other children that cannot fight this disease without our help.



Vaccine may shift odds against deadly brain cancer

March 4, 2010 – Caleb Hellerman, CNN

Doctors at Duke University's Preston Robert Tisch Brain Tumor Center, in collaboration with Johns Hopkins and Pfizer, have been working with a trial vaccine called CDX-110 – a vaccine that triggers the immune system to attack cancer cells. Patients with glioblastoma multiforme [GBM] in the study have been responding to this aggressive form of treatment against a cancer this is traditionally incurable.

CDX-110 targets a specific protein found in brain cancer cells called EGFRviii. The protein acts as a homing beacon for the disease fighting cells stirred up by the vaccine. 40% of tumor cells produce this protein, so the vaccine is showing promise in at least extending the lifespan of one with GBM with fewer side effects and very low toxicity.

The University of California, San Francisco, is also working on another type of vaccine for brain tumors – one that is custom-made from the patient's own tumor cells. This vaccine works by targeting a heat-shock protein, which is produced in high quantities by tumor cells. While CDX-110 is funded by Pfizer, this program in San Francisco is funded by National Cancer Institute and a handful of non-profits. American Brain Tumor Association is one of those non-profits. They are hopeful that this study brings about a useable vaccine. So far, this custom-made vaccine has been working for 13 out of 14 patients, while the study at Duke has one patient six years without a recurrence.

American Brain Tumor Association Offers Palliative Care Guide

Palliative care is often associated with hospice, or end-of-life, care. Since first emerging in the 1970's it has evolved to include much more than end-of-life issues. American Brain Tumor Association has put together a new family resource document explaining the differences between palliative and hospice care and the different services offered under palliative care.

Palliative care doesn't start with a terminal diagnosis. It starts with the first diagnosis of a serious illness, and how you and your family can make decisions facing this illness. The approach is holistic or "whole person", taking quality of life into account as well as treating the disease. Each palliative care program is individualized rather than one-size-fits-all.

To enlist palliative care services, talk to your doctor, nurse or social worker. They can get you information on what services are available in your particular geographic area. If your local area does not offer palliative care services, there are online organizations that can get you pointed in the right direction.

To print off ABTA's Palliative Care Guide, go to www.Abta.org/sitefiles/pdflibrary/FactResource-PalliativeCare-FINAL.pdf.

CBTRUS Estimates 62,930 New Cases in 2010

Central Brain Tumor Registry of the United States – The Central Brain Tumor Registry of the United States estimates that 62,930 new cases of primary non-malignant and malignant brain and spinal cord tumors will be diagnosed in the United States in 2010.

Between 2004 and 2006, 33.8 percent of all primary brain tumors were meningioma tumors. Glioma, including glioblastoma, accounted for 32 percent of all reported tumors, and 80 percent of all malignant tumors.

According to the statistical data that CBTRUS has been collecting, an estimated 4,030 new cases of pediatric primary brain and spinal cord tumors will be diagnosed in 2010. That's eleven new cases every day! Of those, 8 will be under the age of 15.

The current relative five year survival rates based on age group of primary malignant brain and spinal cord tumors is:

Age 0-19 years: 72.1%	Age 55-64 years: 16.7%
Age 20-44 years: 55.9%	Age 65-74 years: 9.6%
Age 45-54 years: 30.7%	Age 75 or older: 5.2%

For more information, visit www.cbtrus.org.

Brain Tumor's 'Grow-or-Go' Switch Found

Syfy News – March 12, 2010. Research supported by American Brain Tumor Association has uncovered the switch that tells brain tumors to grow or migrate. Cancer cells in brain tumors adjust to periods of low energy or they die. When energy levels are high, tumor cells grow and multiply. When energy levels are low, cells grow less and migrate more.

Scientists at the Ohio State University Comprehensive Cancer Center – Arthur G. James Cancer Hospital and Richard J. Solove Research Institute discovered that a molecule called miR-451 directs the change, which is accompanied by slower cell proliferation and increases in migration. Associating this behavior to the cancer's ability to invade and spread indicates that the molecule may be used as a biomarker to predict how long patients with glioblastoma multiforme will survive, and whether the marker may serve as a target to develop drugs to fight this type of brain cancer.

Researchers have found that glioblastoma cells shift from their typical means of metabolizing glucose, a sugar brought by the bloodstream and usually used for energy, to an alternate means that consumes resources within the cell. Glioblastoma tumors adapt to their surroundings and survive conditions that might fatally starve them of energy, using miR-451 to sense the availability of glucose.

Principal investigator, Sean Lawler, assistant professor of neurological surgery, said, "The change in miR-451 expression enabled the cells to survive periods of stress caused by low glucose, and it causes them to move, perhaps enabling them to find a better glucose supply. The migration of cancer cells from the primary tumor, either as single cells or as chains of cells, into the surrounding brain is a real problem with these tumors. By targeting miR-451, we might limit the tumor's spread and extend a patient's life."

Experiments with living cells demonstrated that high levels of glucose correlated with high levels of the molecule, which promotes a high rate of tumor-cell proliferation. Low glucose levels, on the other hand, demonstrated cell proliferation and increased cell migration. When scientists boosted levels of the molecule in migrating cells, it slowed migration 60 percent, and, after 72 hours, almost doubled the rate of cell proliferation compared with controls. Interestingly, when they forced an increase in the molecule miR-451, the cells quickly died, suggesting a possible role in therapy.

Analyses of patient tumors demonstrated that patients with high levels of miR-451 had an average survival of about 280 days, while those with lower levels of miR-451 lived about 480 days.

The findings of this study have been published in the March 12 issue of the journal *Molecular Cell*.

Funding for Pediatric Cancer Still at All-Time Low

From an article published on www.curesearch.org – Children's Oncology Group. In 2007, National Cancer Institute gave \$172 million to pediatric cancer research. This is the most recent expenditure reported, and while this may seem like a great deal of money, we need to keep two things in mind. First, this \$172 million has to be spread across all areas of pediatric cancer research. Second, we need to compare that with funding that was given towards other types of adult cancers: \$572 million to breast cancer, \$296 to prostate cancer, and \$258 to colon cancer.

And despite landmark legislation that was passed in 2008 promising an additional \$150 million over five years to pediatric cancer research, only \$5 million has been given to date. This is a fraction of the money going to adult cancer research. CureSearch's President and CEO John Lehr attributes the reason in their not being a national movement to spread awareness the way Susan G. Komen Foundation raised awareness for breast cancer. He hopes to change that when he speaks to Congress this Spring.