



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

Autumn 2010



Kyla Miller Foundation

KMF Brain Matters

KMF Community Calendar – Autumn 2010

HALLOWEEN at HOSS'S – Sunday, October 31, 2010

FACT: Childhood cancers account for the majority of deaths in children.

FACT: In 2010, over 4,000 children in the United States will be diagnosed with primary brain or spinal cord tumors.

FACT: About 2,900 of them will be under the age of 15.

FACT: About 35% of them will die from this disease within 18 months of diagnosis.

Help us help them on Halloween by participating in our HOSS'S Community Night event, and HOSS'S will donate 20% of your entire bill to Kyla Miller Foundation in support of our mission to end pediatric brain cancer.

GET YOUR VOUCHER by going to kylamillerfoundation.org/hosss.html. Your HOSS'S server has cards with information about our website.

PRINT YOUR VOUCHER and bring it with you and your family on Halloween to the MECHANICSBURG HOSS'S.

GIVE THE VOUCHER to your server to be attached to your bill.

As a special treat for parents uncomfortable with their children Trick-Or-Treating on Halloween Sunday, Kyla Miller Foundation will be onsite in the Creepy Crawly Craft (Small Banquet) Room between the hours of 3PM and 7PM entertaining children of all ages with crafts, games and prizes in a safe and friendly environment.

Obtain your voucher today by visiting our website or by calling (717) 259-9742! Required for participation. Voucher distribution is prohibited on HOSS'S property.



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:

HR 971 (Page 1)

Ride Across Iowa Inspires Support (Page 2)

Clinical Trial at Duke University (Page 2)

Vaccine at Duke Offers Hope to GMB Patients (Page 2)

Doctors Recognize Difficulty in Research Dollars (Page 3)

KMF Community Calendar (Page 4)

Why we fight for a cure...

Stephanie Miller

Autumn... a season of change. For some it brings to mind cooler weather, football games, camp fires, back to school and Halloween. For others autumn brings changes in the scenery... browner grass, rotton tomatoes in the garden, corn that can't be harvested, leaves falling off the trees. In other words, death. Nature all around us is dying, in preparation for the winter months to come before new life in Spring awakens us once again.

of nature reminds us of the death of our children and knowing that we will never see them again in this life. Only those that have walked in our shoes can relate, and it's a journey that too many are walking.

The tragedy is that while malignant brain tumors are the second leading cause of death in children with solid tumors, the numbers of children with solid malignant brain tumors are statistically lower than many other forms of pediatric cancer. Monetary funding for pediatric brain tumor research is primarily

lumped into adult brain tumor research. Tissue samples are low in volume, and so actually finding new therapies and doing genetic research is a long and pain-staking process.

So why bother? Why should it matter if only a few hundred of them die throughout one year? Because children are dying, and unless we do something about it they will continue to die. One life lost to this disease is one life too many. Help us help these children.



HR 971 Proclaims 10-10-10 Pediatric Brain Tumor Awareness Day

Harrisburg, PA – A chance meeting at a popcorn fundraiser for Cub Scout Pack 88 at a York Springs Rutters between KMF President and co-founder Stephanie Miller with Pennsylvania State Representative Will Tallman resulted in Rep. Tallman introducing House Resolution 971 proclaiming 10-10-10 as **Pediatric Brain Tumor Awareness Day** in Pennsylvania. The resolution was sponsored by Rep. Tallman from Adams County, and co-sponsored by Rep. Kerry Benninghoff from Centre County.

man solicited his colleagues for co-sponsors to the resolution, Rep. Benninghoff asked to be the number two assemblyman on the resolution.

In the coming weeks, KMF will be presented with a ceremonial copy of the House resolution on the floor of the General Assembly in Harrisburg. To view the House resolution, go to:

<http://www.kylamillerfoundation.org/HR971.PDF>

Rep. Benninghoff is no stranger to this disease; one of his children is fighting a brain tumor. When Rep. Tall-

man solicited his colleagues for co-sponsors to the resolution, Rep. Benninghoff asked to be the number two assemblyman on the resolution. In the coming weeks, KMF will be presented with a ceremonial copy of the House resolution on the floor of the General Assembly in Harrisburg. To view the House resolution, go to:

Rep. Tallman's site: <http://repwilltallman.com>

Rep. Benninghoff's site: <http://kerrybenninghoff.com>

Ride Across Iowa Inspires Support

Hershey, PA – In July 2010, Dr. Melanie Comito, pediatric hemotologist-oncologist from Penn State Children’s Hospital in Hershey, Pennsylvania, embarked on a 450 mile bicycle ride across the state of Iowa, raising awareness about pediatric brain cancer and the need for research opportunities to fight back against this disease. Along the way she spoke to many of the 9,999 other riders in the ride, and in the end she raised over \$1,100 for Kyla Miller Foundation and their mission to end pediatric brain cancer.

During the journey, Dr. Comito blogged about the trip, taking many pictures along the way of the Iowa backdrop. The overwhelming lesson learned on this first-time tour across Iowa on a bike was that, “*You can never train your backside to sit on a bike for that long.*”

But that won’t deter her for riding again next summer. In fact, she may have company. Some of her colleagues at Penn State Children’s Hospital may throw their own backsides into the ride, with KMF riding along as bike support.

Clinical Trial Opens for Medulloblastoma or PNET

Source: *Pediatric Brain Tumor Foundation*

Duke University – Doctors at Duke University’s Preston Robert Tisch Brain Tumor Center announced a new clinical trial open for pediatric patients who have been diagnosed with a recurrence of medulloblastoma or PNET brain cancer. Pediatric brain tumor research at Duke University is heavily funded by the Pediatric Brain Tumor Foundation, based in North Carolina.

Patient eligibility includes:

- Age 21 or younger
- Histiopathic diagnosis of local recurrent or progressive medulloblastoma or PNET
- Ability to undergo debulking of recurrent disease
- Failed standard radiotherapy (craniospinal + focal boost)
- Suitable candidate for high-dose chemotherapy with autologous peripheral blood stem cell rescue

The treatment is conducted in four parts: surgery, induction, consolidation and post-transplant immunotherapy, which could last up to one year.

Potential candidates should discuss with their primary pediatric oncologist. To learn more, visit Duke University’s Brain Tumor Center at:

<http://www.cancer.duke.edu/btc/modules/ClinicalTrials4/index.php?id=98>

Vaccine at Duke Offers Hope to GBM Patients

Source: *Eurekalert.org*

Duke University – On October 4, 2010, Duke University announced that a new vaccine administered with standard therapy in patients with newly diagnosed glioblastoma multiforme has extended the life expectancy in patients compared to patients that did not receive the vaccine. The study, published in the *Journal of Clinical Oncology*, notes

notes that in 17 out of 18 patients, life expectancy increased from 15 months to 26 months, and the patients lived disease progression free an extended eight months.

The vaccine targets a very aggressive cancer gene called EGFRvIII – the “worst of the worst” of cancer genes according to John

Sampson, M.D., Ph.D., at Duke. The vaccine being used is known as CDX-110 by Celldex Therapeutics or Rindopepimut by Pfizer. The EGFRvIII marker also appears in other types of cancer, which makes further research paramount.

For information, go to

http://www.eurekalert.org/pub_releases/2010-10/dumc-dve100110.php

Doctors Across US Recognize Difficulty in Getting Research Dollars

Source: *Cincinnati.com*

Cincinnati, OH – A 16 year old Florida girl diagnosed with Glioblastoma Multiforme journeyed to Cincinnati Children’s Medical Center to undergo a clinical trial to fight against this disease, only to be crushed that the therapy was not working. Returning home, the young girl hopes that a standard treatment will slow down the growth of her disease until another trial opens up that might help save her life.

This is the story of so many children diagnosed with GBM – the killer brain cancer. A GBM diagnosis is a death sentence.

Advocates for this type of brain cancer all agree on one thing – “they need dollars for research to find effective treatments against it.”

The problem continues to be an unwillingness on the part of companies to invest millions of dollars in research for such a small population of patients. Instead, they look for drugs that will help millions across the population for things like heart disease or the more common breast and colon cancers – which then result in millions of dollars in profits. Maryam Fouladi, director of the neuro-oncology program at Cincinnati Children’s Medical Center, takes it a step further to say that “It’s not just a lack of funding; it’s a lack of interest.” In 25 years, only two new drug therapies have been put on the market to fight brain tumors. While more are in the pipeline, experts say they’re a long time coming.

In addition to a lack of funding for research, there is also the lack of numbers – the quantity of people diagnosed with brain tumors. In 2010, only 2900 children under the age of 15 will be diagnosed with a primary brain tumor. Sources, like the National Institutes of Health, will only pay for research that will show positive results. This is often difficult

regarding brain tumors for two reasons: the biology of brain tumors makes finding sources to fight them difficult, as does the blood-brain barrier – the body’s natural defence which prevents toxins from traveling through the blood to the brain.

Brain tumors are made up of multiple cell types, making it difficult to target specific genetics in order to use therapies for cures. Types of cells act differently, so a one-size-fits-all strategy does not work in brain tumors.

Equally, the blood-brain barrier makes it difficult for many types of drugs to pass through to the brain in order to battle the cancer cells. Scientists have to find ways around this, and are turning towards molecular research on brain tumors. It’s working for some forms of cancer, but not for brain cancer.

Even more disheartening is the general lumping of brain tumor research money all together, instead of separating pediatric brain tumor research from adult brain tumor research. Again, it all comes down to numbers, with such a small population of children being diagnosed with malignant brain tumors.

Regarding GBM, it’s not called the deadliest brain tumor for nothing. Christopher McPherson, a neurosurgeon at UC Neuroscience Institute at University Hospital in Cincinnati, says, “It’s a smart tumor. It’s an aggressive tumor. It finds ways to get around the drugs. It’s nearly universally fatal.”

Folks like Fouladi and McPherson want to see a change in trends, but donors want to see survivors who can talk about their triumphs. Until money is available for desperately needed research, donors are going to be waiting a long time, and children will still be waiting for a cure.