



THE
KELLY HEINZ-GRUNDNER
BRAIN TUMOR FOUNDATION

A subsidiary of
National Brain Tumor Society

WINTER 2011

Vol V Issue IV
FINAL ISSUE

The Dragonfly

Quarterly Newsletter for Foundation Supporters



Upcoming Events!



The Third Annual Beef & Beer Winter Fundraiser will be held on Friday, January 21, 2011 at the Hockessin Memorial Hall from 7:00pm – 11:00pm. This has been a sold out event its first two years, so you are encouraged to purchase tickets as soon as possible at www.KHGfoundation.org/beefandbeer. If you have questions about the event or would like to donate an auction item, please call Kirsten Costango at 302.540.6949.

The Fourth Annual GET YOUR HEAD IN THE GAME® Brain Tumor Awareness Walk will be held on Saturday, April 30, 2011 at Dravo Plaza at Riverfront Wilmington. Registration is now open for both individual walkers and teams at www.GetYourHeadInTheGame-Walk.org If you are interested in joining a committee, volunteering for the event, or becoming an event sponsor, please email Karen Backner at kbackner@braintumor.org.

Tulips Across America!

With another successful campaign this year, The Kelly Heinz-Grundner Brain Tumor Foundation (KHG) continued to spread beauty across the country, and more importantly, raise brain tumor awareness through its Tulips Against Tumors™ Tribute. Thanks to the support of its new parent organization, the National Brain Tumor Society (NBTS), KHG was able to expand the reach of the Tribute to thousands more this year.

Tulips Against Tumors was established as a way to raise awareness of brain tumors, to raise money for KHG, and to pay tribute to the Foundation's namesake, Kelly, whose favorite flower was a tulip. Supporters purchase high quality tulip bulbs imported from Holland, then plant them on a designated day to honor those who are struggling with brain tumors, valiant brain tumor survivors, and those who have been lost.

This year's National Planting Day, where people across the country come together as a community to plant bulbs, took place on Saturday, November 6. As part of this special day, a "Garden of Hope" was planted at the University of Delaware. Chris Grundner, KHG Executive Director, and Chris Stein, musician, songwriter, and two-time brain tumor survivor, led approximately 50 KHG supporters in the garden dedication ceremony and blessing of the tulip bulbs. Families and individuals were then given the opportunity to select a tulip bulb and plant it in honor or in memory of their loved ones. Approximately 500 tulip bulbs were planted. KHG supporters enjoyed fellowship and light refreshments following the ceremony. Chris Stein also

performed several of his original songs during the program. In addition, a second Garden of Hope was created at the NBTS headquarters in Watertown, Massachusetts. NBTS staff members planted tulip bulbs in front of the office building and a local community newspaper was on hand to cover the event.

"I want to first thank everyone who purchased bulbs this year and helped to make the Sixth Annual Tulips Against Tumors Tribute a success. I also want to thank everyone at the University of Delaware for donating a perfect location for our garden this year




photo by Ed Weirauch

Alek, 14, Arynne, 13, and Jacob, 13, of Camden, Delaware, helped plant tulip bulbs in the "Garden of Hope" at the University of Delaware in memory of their brother, Ethan Williams, who passed away from a brain tumor in January, 2010, at the age of eight.



photo by Lisa McEvoy

NBTS staff member Kristen Kesler helps plant tulip bulbs in front of the Watertown, Massachusetts office in November.

and helping to coordinate the event, especially David Singleton, Associate Vice President, Facilities, and Tom Taylor, Landscape Engineer, without whom we would have been lost," Grundner stated. "In addition, a special thank you goes to Kirsten Costango, from Team Elizabeth, and Sue Loeffler, from Team Christina's Crusaders, who helped organize the refreshments and the volunteers that day. I can't wait to see how things progress in 2011. I know it is going to be great!" 

Help Establish a Brain Tumor Postage Stamp

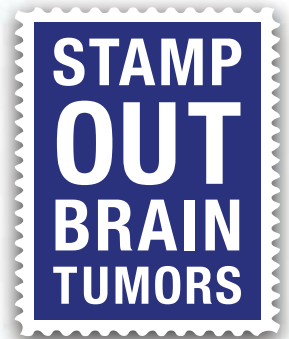
The National Brain Tumor Society (NBTS) has submitted an application to the Citizens Stamp Advisory Committee of the U.S. Postal Service requesting the production of a stamp to increase brain tumor awareness. To support this application, a petition has been started and supporters of the brain tumor community are being asked to sign their name in endorsement of the proposed new stamp. If you are interested in letting your voice be heard, you can participate in two ways: (1) sign the electronic petition that will be sent to the Citizens Stamp Advisory Committee, or (2) edit, print, and mail a letter to the Citizens Stamp Advisory Committee. Instructions for both options

can be found at www.braintumor.org/get-involved/brain-tumor-awareness-stamp.html.

There is no such thing as too many signatures or too many letters! The Citizens Stamp Advisory Committee considers only "events and themes of widespread national appeal and significance." Right now, 600,000 people are living with a primary brain tumor — that's more than the population of Seattle, Denver, or Washington, DC. Thousands more have metastatic tumors.

"In my new role as the Director of Awareness for NBTS, I am tasked with doing everything I can to bring attention to this disease," stated

Chris Grundner, Executive Director of The Kelly Heinz-Grundner Brain Tumor Foundation (KHG). "This project is just another example of the types of initiatives the Awareness group will be spearheading on behalf of the entire brain tumor community. I encourage all of KHG's supporters to join in the effort and help speak out for all those who are affected by this devastating disease," added Grundner.



Kick-Off Meeting Sets the Stage for an Exciting 2011 Walk



photo by Scott Coleman

Approximately 2,500 people and over 65 teams start their journey at the 2010 Walk.

On Tuesday, November 9, dozens of team captains and volunteers gathered together for an official kick-off meeting for the Fourth Annual GET YOUR HEAD IN THE GAME® Brain Tumor Awareness Walk. Event co-chairs Kevin Sullivan and John D'Agostino led the meeting that included an overview of the National Brain Tumor Society (NBTS) and some of the proposed changes for the 2011 event, as well as the formation of a new walk committee. Many openings still exist on most of the sub-committees, including the Volunteer, Marketing, Public Relations, and Sponsorships committees. Interested parties are encouraged to participate in the next Walk Committee meeting that will take place on Tuesday, February 8, 7:00pm at the Barclays Dry Rock building at 125 S. West Street. For more information, please contact John D'Agostino at jdag@santoracpa.com.

KHG Racing Around the Nation

The Kelly Heinz-Grundner Brain Tumor Foundation (KHG) received great exposure in states out west in 2010. Cyclists in two major races were spotted on the winning podiums sporting KHG's special commemorative cycling jersey created in conjunction with Deep Blue Racing Team.

Peter Piccolo claimed first place in the Firecracker 50 Mountain Bike Race in Breckenridge, Colorado. He competed in the Men's Sport Category (40-49 age bracket) and finished with a time of 4 hours, 55 minutes, and 41 seconds. The 50-mile race was held over the Fourth of July holiday and had a capacity 750 participants. Congratulations, Pete!

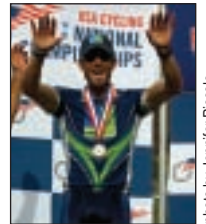


photo by Jennifer Piccolo

Peter Piccolo

Katrina Dowidchuk placed third in the Women's Master (40-44 age bracket) at the USA Cycling Cyclo-cross National Championships with a time of 38 minutes, 27 seconds. She also placed first in the individual time trial for her age bracket. The Cyclo-cross Nationals were held December 8-12 in Bend, Oregon, with over 1,600 participants of all ages and skill levels, and attracted over 8,000 spectators. Katrina powered through a tough course, overcoming various surfaces, hills, and obstacles. In addition, she was one of only a handful of competitors in her category from east of the Mississippi who even qualified for her race. Congratulations, Katrina!



photo by Jennifer Kraut

Katrina Dowidchuk

KHG is proud of all its participants across the country who wear its special racing kit. Although all of you can't be mentioned by name, know that your support is greatly appreciated and KHG wishes you lots of success in all your riding endeavors! If you would like to learn more about Deep Blue Racing, please visit www.teamdrt.org.

Area Races Raise Funds and Awareness



Brain tumor survivors of all ages gather for a post-race photo at the Fifth Annual Race for Hope in Philadelphia in November.

photo by Jennifer Luefky

Running to fight brain tumors was a popular pastime this fall as two local race events brought out participants in Wilmington and Philadelphia. On Saturday, October 30, the Union City Grille

restaurant hosted its Second Annual Union City Grille Halloween 5k Run/Walk, a community event benefiting The Kelly Heinz-Grundner Brain Tumor Foundation. Participants were treated to food, refreshments, live music, and a children's Halloween parade. The following weekend, over 6,000 people attended the National Brain Tumor Society's Fifth Annual Race for Hope in Philadelphia on Sunday, November 7. This event surpassed all expectations by generating over \$850,000 for research, patient support, advocacy, and awareness. For information on upcoming KHG and NBTS events, please visit www.BrainTumor.org/events.

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New, More Frequent Communication for KHG Supporters

Beginning in February, supporters of The Kelly Heinz-Grundner Brain Tumor Foundation (KHG) will begin receiving the National Brain Tumor Society's (NBTS) monthly eNews, which will officially replace The Dragonfly newsletter.

"Although it's always difficult to let go of something you value, it's rewarding for me to know that more news will be delivered on a much more timely basis than we were able to accomplish with The Dragonfly," stated Chris Grundner, KHG Executive Director. "In addition, KHG supporters will be exposed to a much broader spectrum of brain tumor developments in the areas of medical research, patient services, and advocacy," Grundner continued. All KHG supporters who receive The Dragonfly via email today will be automatically switched to eNews. To learn more and to view archived eNews issues, visit www.brainumor.org/news.

Davis Joins KHG

The Kelly Heinz-Grundner Brain Tumor Foundation (KHG) would like to welcome Kristin Davis to the team. On January 3, Kristin joined the Foundation as its Marketing Communications/Office Manager.



Kristin grew up in the small town of Tabernacle, New Jersey. She attended Rowan University in Glassboro, New Jersey and graduated Cum Laude with a degree in Communications. After graduation, Kristin moved to the Jersey Shore to work as a producer at News Channel 40, NBC – the local NBC affiliate serving southern New Jersey. After a few years, she took her communication skills to a real estate office to serve as Assistant to the Broker and Marketing & Office Coordinator. She also became involved with Big Brothers Big Sisters and found a love for volunteer work.

Kristin brings a wealth of communication and office management skills and a passion for making a difference to KHG. She is excited to be in Delaware and working with the KHG team!



Continuing Medical Education Online Course Launched

A free, web-based educational activity, "Latest Advances in the Diagnosis and Treatment of Malignant Gliomas," is now available online. Presented by the Abramson Cancer Center of the University of Pennsylvania and The Kelly Heinz-Grundner Brain Tumor Foundation, this CME is designed for all healthcare professionals interested in the treatment of gliomas.

When patients present with neurological or cognitive deficits indicating a possible brain tumor, crucial decisions must be made to produce an accurate diagnosis, effective treatment plan, and hopeful prognosis. This multidisciplinary educational activity outlines the latest innovative approaches to treat patients with newly diagnosed tumors. The course is CME-certified by the University of Pennsylvania School of Medicine. This activity has been approved for AMA PRA Category 1 Credits™. A non-credit version of the program is also available for members of the general public. The course is available 24 hours a day, seven days a week.

For more information, please visit www.KHGfoundation.org/support/cme.php.

2011 EVENTS CALENDAR

See website for more information

Third Annual Beef & Beer Winter Fundraiser	Jan. 21
GET YOUR HEAD IN THE GAME® Night with the Wilmington Blue Rocks	April TBD
Fourth Annual GET YOUR HEAD IN THE GAME® Brain Tumor Awareness Walk	April 30
Race for Hope - Washington DC	May 1
New York Brain Tumor Walk	June 18
GET YOUR HEAD IN THE GAME® Night with the Philadelphia Phillies	Sept. 21
NBTS Summit - Philadelphia	TBD
Race for Hope - Philadelphia	Nov. 6



Message from the Executive Director

As the wise Greek philosopher Heraclitus once said, "Change is the only constant." That statement is true for each of us in our individual lives, and also for every organization that has ever existed. The Kelly Heinz-Grundner Brain Tumor Foundation (KHG) is no exception to that rule. As we continue to merge

and become fully absorbed by the National Brain Tumor Society (NBTS), I feel this is the right time to reflect back on our achievements and look ahead to future advancements.

Together, in our brief existence as KHG, we have accomplished so much. As I stated in the previous issue, we have made a tremendous impact in raising awareness in the Delaware Valley through our annual events and marketing campaign. Just as importantly, I feel we have developed a strong, local brain tumor community that never existed prior to KHG. You, our supporters, have shared hope, comfort, and inspiration among thousands affected by this terrible disease. We have built a momentum that will only get stronger and will not stop until a cure for brain tumors is discovered.

It is so exciting to know that as we speak, we are on the doorstep of raising national brain tumor awareness. As we have always stated, our plan from the beginning was to take our movement around the country. We would not be at this critical point of opportunity without you.

With that said, I want to share with you some of the new, exciting changes you can expect in 2011. First, as you may already have read in this issue, this is the twentieth, and last edition, of The Dragonfly quarterly newsletter. We have put a lot of heart and soul into this publication over the years. We hope you have found value in the issues, and have learned a thing or two in the process. It has been our joy to communicate the incredible milestones we have reached time after time because of your efforts and commitment. This story, however, is not a sad one, as we are transitioning to bring you the monthly NBTS eNews that you will begin receiving automatically via email. You will still be kept up to speed on what is going on locally, but now, you will also learn about the new advancements happening across the country, as well as all of the amazing patient support and medical research programs NBTS

is helping to fund. A whole new world of brain tumor information and education will soon be at your fingertips.

Second, our 2011 event calendar will get even busier. We will kick off the year with our Third Annual Beef & Beer Winter Fundraiser on Friday, January 21, at the Hockessin Memorial Hall. If you are interested in attending, please purchase your tickets online as soon as possible as this event sells out every year. Next up, make sure you mark your calendar for our Fourth Annual GET YOUR HEAD IN THE GAME® Brain Tumor

Awareness Walk on Saturday, April 30 – please note the new date this year – at Dravo Plaza at Riverfront Wilmington. As always, summer brings baseball, which means we will be back hosting evenings with the Wilmington Blue Rocks at Frawley Stadium – April date to be determined – and with the Philadelphia Phillies at Citizens Bank Park on Wednesday, September 21. In October, plans are on again for the Third Annual Union City Grille Halloween 5k Race benefitting KHG. And added to our calendar this year, we hope you can join us at the Sixth Annual Race for Hope Philadelphia 5k at the steps of the Art Museum on Sunday, November 6. Last year's event boasted over 6,000 participants and raised over \$850,000. A couple of other upcoming nearby events to keep in mind are the Race for Hope in Washington, D.C. on Sunday, May 1, kicking off Brain Tumor Action Week in Washington, and the inaugural New York Brain Tumor Walk on Saturday, June 18. Come help us make history!

Lastly, as I have mentioned more than once (I am so excited to share the news),

we will be launching the GET YOUR HEAD IN THE GAME® Movement to a national audience to raise brain tumor awareness in 2011! We now have the opportunity to heighten public discussion and educate a broader spectrum of people, so brain tumors will no longer be in the dark. Again, without you, we would not be here today on the verge of shining a national spotlight on this dreaded disease. There is so much more to accomplish, but I know as part of NBTS, and with your continued support, we will make the difference we all want in conquering brain tumors!

Sincerely,

Chris



Governor Jack Markell (center) and KHG Director Chris Grundner (left) welcoming NBTS Executive Director Paul TonThat (right) to the State of Delaware this past fall.

Where to Contact Us

In addition to our Wilmington contact information at the bottom of each page of this newsletter, you can also reach NBTS and its resources via the following:

National Brain Tumor Society

617.924.9997 www.braintumor.org

Patient Services

800.934.2873 www.mybraintumorcommunity.org

If you are not already, sign up to receive our monthly eNewsletter at www.braintumor.org/news/newsletters.html