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Advocate Spotlight 2017

Why did you get involved in the NBTS advocacy program? What are you hoping to achieve?

I got involved with the NBTS advocacy program after losing my dad to a GBM in 2014 after a four and a half year battle. When he was diagnosed we knew nothing about the disease or what treatment options were out there. We were lucky enough to qualify for two clinical trials after two separate surgeries that I believe helped prolong my dad's life and provided a good quality of life during his battle.

Shortly after graduating college I went to work for a small grass roots foundation in Kansas City where I learned more about clinical trials that are providing promising research and the importance of funding them so patients can have affordable access to these new therapies. I hope to help take the necessary steps needed to get closer to finding a cure and to be a part of this movement that allows cancer patients access to the treatments they need to survive. My ultimate goal is for brain cancer to not be a death sentence.

If you don't directly know anyone who has been affected by brain cancer, it can be hard to truly understand what it is like. The survival rate is low and progression of the disease is fast. The National Brain Tumor Society's Advocacy Program provided the opportunity to educate elected officials about the needs of the brain cancer community.

How can advocacy and public policy help the brain tumor community? How can advocates make a difference?

In most cases, patient's odds are at best when participating in a clinical trial. Advocacy helps the brain cancer community by providing the important information regarding all possible treatment options out to the public and ensuring these options are easy to access.

It is so important that we educate ourselves, use our voices to make a difference, and make sure that funding for these treatments are included in pieces of legislation moving forward. Decisions on public policy are constantly being made and have a huge impact on patients and their families with issues ranging from affordability to accessibility.

This funding is the only way to ensure we are finding new therapies and improving the quality of life for patients out there. It is important that patients and caregivers don't have worry about how they are going to pay for this on top of my mortgage and kids college tuition and other expenses, as well as treatment.

What did you think about the NBTS 2017 Head to the Hill and why should others in your state attend next year?

Attending Head to the Hill was one of the most rewarding experiences I have had since losing my dad. Not only did I meet a number of patients and family members that have experienced receiving the same devastating news that my family did, but we were able to hear from the head of the Neuro-Oncology Branch at the NIH and learn about the latest findings in research, the progress being made, and how this funding will be used in future treatments.

If you have any interest in advocacy work or have a connection to brain cancer, you should definitely attend Head to the Hill in 2018. It was one of the most empowering events that I have ever been a part of. It's a great way to carry on the legacy of a loved one, get inspired by current survivors and patients, and deepen your connection with the brain cancer community in general.

How can Members of Congress help brain tumor patients and their families in their states/regions?

Members of congress want to hear your story. I was very surprised by the response and level of engagement I received from the elected officials and their staff when meeting and in my follow-ups. We elected these officials to speak on our behalf. When we connect with them by sharing our concerns and pointing out issues they might be missing, we allow them to bring up these points when considering different pieces of legislation.

What are your perceptions and thoughts about the National Brain Tumor Society?

The National Brain Tumor Society is an incredible tool for the brain cancer community. Their prodigious efforts are truly community based, and range from academic researchers, to doctors, pharmaceutical companies, to patients, caregivers, and policy makers, who allow for rapid progress towards a cure. This organization understands that it will take the collaboration of multiple entities to conquer this disease. Their efforts are unmatched.

How can others in your state, or across the country, get involved?

Others can get involved by doing the following:

Educating themselves on current brain cancer statistics, and why this research is so important for groundbreaking discoveries.

Exploring what treatment options are available and the impact these collaborations on cutting-edge medical information are having on the progress we are making in cancer research.

And grasping a good understanding of how public policy affects how much is invested in bio-medical research and what health care policies will cover.

We always think 'it won't happen to me', but when it does it is nice to know someone is committed to finding a cure.