

Chairwoman Manning, Vice Chair Bird, Ranking Member Robinson and members of the House Primary and Secondary Education Committee: I come before you to articulate my support for the passage of House Bill 606, a bill that will benefit those like my late daughter, Morgan Tackett, who faced challenges everyday as a young person with epilepsy.

Passage of this bill is critical since children typically spend many hours of the day in school throughout the year and the interference of epilepsy can come without warning at any time. Epilepsy has no conscience, no boundary and no timetable so it becomes an overwhelming shadow lurking in children's lives.

In 2002, at just 2 years old, my daughter Morgan Tackett was diagnosed with epilepsy. Early one morning, after my husband had gone to work, Morgan ran into the living room where we had been watching morning cartoons and dropped to the floor. I thought she had tripped over her ruffly white nightgown, but when she did not get up, I rushed to roll her over and shift her bouncy brown curls out of her face just to see something was not right in her behavior and reaction. I rushed to find the phone and call 911. As I secured her head, per instructions from dispatch, I had no idea what was happening or why.

Our lives changed forever from that point on. Thousands of seizures and related situations took away from her quality of life in seventeen years. Many trips to the nurse's office during school taught us that while some school nurses were kind others were not. In her journal, Morgan wrote of one particular nurse who told Morgan that she had seen seizures and that Morgan was faking. Morgan was so upset and scared that she went to the restroom and proceeded to prepare herself there for a seizure alone with no help or support. School was often not a safe and happy place for Morgan.

Some of Morgan's teachers convinced us that her condition was a behavioral issue and that we needed to send her to a behavioral home where she was put into a situation surrounded by troubled children, not children with epilepsy or a neurological disorder. At one school, Morgan was sent to an empty classroom to suffer through her seizures by herself rather than being cared for in an appropriate way by someone trained and knowledgeable about her condition. Despite missing significant school due to her condition, Morgan was a good

enough student that she was offered a full-ride scholarship to Columbus School of Art and Design with the most scholarship money in her class. Imagine all of the things she could have accomplished if she had received the educated support of the adults surrounding her in a school setting.

Morgan's mental health suffered every time she was left out of school and social situations because of the fear and lack of education of the people around her. In third grade, Morgan raised the most money in cookie sales for her Girl Scout troop to take a trip to the Columbus Zoo and yet, she was left behind because the troop leader, who was also a school teacher at the time, was afraid she would have a seizure. Imagine watching the light die in your 9-year old daughter's eyes when she finds out she can't go on the trip she had earned because the adult in charge was afraid and didn't know how to deal with the manifestation of this disease.

Morgan knew what it meant to deal with epilepsy through her elementary, adolescent and teen years. She knew how hard it was and in 2015, Morgan traveled to advocate on Capitol Hill in Washington DC for kids just like her who suffer from epilepsy. She cared enough about others to plead with Senator Portman on the steps of the Capitol to support research to help raise her quality of life, give her relief and save her life.

Our daughter's heartbreak is why I speak to you today. Morgan overdosed on her seizure medication days after she graduated from high school. She lived in fear of never being free like the other kids around her. She lived in fear that the outside world would never accept her. Morgan was an artist who longed to make the world more beautiful.

It is because of Morgan that I returned to college and will graduate this Saturday from Wittenberg University. I continue to advocate for others in Morgan's memory. My husband and I will return to Washington DC next month to continue Morgan's story in hopes that more support surrounds people like Morgan who live in the shadow of epilepsy. It is our hope that the stigma of epilepsy and other seizure disorders becomes nonexistent as we educate society and those surrounding these children so that they may lead more normal lives, without the constant uncertainty of when or where a seizure may occur.

5/10/2022

Tracey Tackett

HR606 Proponent

Epilepsy is a chronic physical illness that cannot be controlled without medical intervention. It is NOT a psychological or behavioral issue. The fear, suspicion, and lack of education, particularly from those in authority, had a profound effect on Morgan's mental health. Due to Morgan's situation, Nationwide Children's Hospital in Columbus has been working to change their protocols to shift focus to include not just the treatment of the physical manifestations of epilepsy but also the mental health aspects as they recognize the toll this disease takes not just physically but also mentally and emotionally.

I beg you to pass this bill so that other children like Morgan do not have to face the darkness associated with epilepsy. Educated and prepared teachers and school nurses have the opportunity to shape the school experiences of these children in a way that can have a lasting impact on not only their education but their long-term self-image and mental health. I don't want to see one more child lost to the lack of care and concern that took the light and promise of my Morgan from the world and from me. You have the opportunity to make that happen.

Thank you!