

Senate Bill 57
Proponent testimony
March 7, 2017
Senate Health, Human Services and Medicaid Committee

Chairman Burke, Vice Chair Beagle, Ranking Member Tavares and members of the Ohio Senate Health, Human Services and Medicaid Committee. Thank you for allowing me to submit proponent testimony on Senate Bill 57, legislation that if enacted into law would designate May 17th as “Diffuse Intrinsic Pontine Glioma (DIPG) Awareness Day.

In September 2014, one week after his sixth birthday and first week of kindergarten, my son, Michael Mosier, was diagnosed with DIPG. Michael was an active and energetic little boy who loved learning, playing baseball, playing in the mud, and being the kindest big brother to his little sister, Lila. The diagnosis was devastating for us – “terminal upon diagnosis,” “zero survival,” “no effective treatments,” and “no cure.” Within weeks, our son went from running the bases at baseball practice and bouncing across trampolines at his birthday party to being unable to walk and confined to a wheelchair, losing functioning of the left side of his body, having double vision, and suffering speech limitations.

Michael however, proved inspirational to us, and rather than feeling sorry for himself, or complaining, he soldiered on, even in the face of worsening symptoms and side effects from 30 rounds of radiation, chemotherapy, and the growing tumor. He set about to accomplish a variety of goals every day on a “to do list,” including continuing to go to school, building Legos, or just getting a milkshake. He insisted that whatever was on his list that day be completed before he went to sleep at night.

Michael passed away on May 17, 2015, after a heroic battle, and he is remembered and missed greatly each and every day. Michael is one of the thousands of children who have been impacted by this disease.

DIPG is the second most common malignant brain tumor found in children and is the leading cause of childhood death due to brain tumors. DIPG essentially has a zero percent survival rate. This brainstem tumor impacts 200-400 children in the U.S. alone each year, and the median survival from diagnosis is 9 months.

Our children deserve increased awareness and attention on this deadly and devastating pediatric cancer. By declaring an awareness day in Ohio for DIPG – the deadliest pediatric cancer – we will take the concrete steps of raising the profile of this disease and supporting families who have had to battle this grave illness, demonstrating that they are not alone in their fight. We hope you will help to lead this effort, alongside other states such as Maryland and Wisconsin that have already established May 17 as DIPG Awareness Day.

Chairman Burke and members of the Ohio Senate Health, Human Services and Medicaid Committee. Thank you for allowing me to submit proponent testimony on Senate Bill 57. My family would appreciate the committee's favorable passage of this legislation.

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