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Senate Bill 57
Sponsor testimony
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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 present sponsor testimony on Senate Bill 57, legislation that if enacted into law would designate May 17th as “Diffuse Intrinsic Pontine Glioma (DIPG) Awareness Day.

This issue was brought to my attention by a pharmacist constituent who resides in Worthington who asked me to introduce this legislation to help raise awareness of this devastating childhood cancer.

According to Boston Children’s Hospital, Diffuse intrinsic Pontine Glioma (DIPG) are highly aggressive and difficult to treat brain tumors found at the base of the brain. DIPG affects the pons portion of the brainstem, rendering nervous system function impossible. Symptoms include double vision, inability to close the eyelids completely, dropping one side of the face, and difficulty chewing and swallowing. Unfortunately these symptoms usually worsen rapidly because the tumor is rapidly growing. DIPG, for all its difficulties, presents an opportunity for all forms of cancer. It is one of the most resistant of all cancers to chemotherapy treatments; it affects primarily children.¹

In 2016, both Maryland and Pennsylvania established DIPG Awareness Day on May 17, and it is my hope that Ohio will join in this important effort. May is Brain Tumor Awareness Month across our country, and having this day of recognition for the deadliest pediatric brain tumor would be a meaningful step for Ohio to take to stand in solidarity with the families who have had to confront this disease.

In September 2016, the Centers for Disease Control announced that brain tumors have become the leading cause of childhood cancer death, surpassing leukemia.² 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.

¹ <https://thecurestartsnow.org/impact/cancer-facts/dipg-facts>

² <https://www.theguardian.com/society/2016/sep/16/brain-cancer-deadliest-us-children>

By declaring an awareness day in Ohio for DIPG – the deadliest pediatric cancer – we will take the concrete steps of both raising the profile of this disease and supporting the Ohio families who have had to battle this grave illness, demonstrating that they are not alone in their fight.

Chairman Burke and members of the Ohio Senate Health, Human Services and Medicaid Committee. Thank you for allowing me to present sponsor testimony on Senate Bill 57. I am happy to answer any questions that the committee might have.