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Senate Bill 57
Sponsor testimony
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House Health Committee

Chairman Huffman, Vice Chair Gavarone, Ranking Member Antonio and members of the Ohio House Health 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. Additionally, Representative Pelanda introduced similar legislation to designate this awareness day during the 131st Ohio General Assembly. It was reported from the Ohio House of Representatives but did not make it through the Ohio Senate before the end of the general assembly. She and I have spoken about Senate Bill 57 and she supports this legislation.

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, the drooping of 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

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

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

impacts 200-400 children in the U.S. alone each year, and the median survival from diagnosis is 9 months.

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.

This disease has recently been in the spotlight nationally as it has tragically claimed the lives of two brave young people: Lauren Hill of Cincinnati and former Michigan University Football Coach Lloyd Carr's five year old grandson, Chad. Lauren Hill was a freshman college basketball player at Mount St. Joseph when she passed away in April 2015 at the age of 19 following her battle with DIPG. In an interview that was published in USA Today that was reporting on her final college basketball game in November 2014, Lauren said: "When I was diagnosed I remember kind of feeling lonely because nobody understood. And now that more people know about this story and the awareness of DIPG. I'm so happy that people know about it now and that we can get some research going and hopefully find that home run cure for cancer..."³

Senate Bill 57 was reported from the Ohio Senate Health, Human Services & Medicaid committee 12-0 receiving no opposition testimony. It received proponent testimony from: The Cure Starts Now Foundation; Nationwide Children's Hospital; Defeat DIPG Foundation; Cincinnati Children's Hospital and the American Cancer Society. Senate Bill 57 received unanimous, bipartisan support on the floor of the Ohio Senate as it received a vote of 33-0. You will note that 30 members of the Ohio Senate have signed onto this measure of co-sponsors joining me to establish this day designation in Ohio to bring awareness to this devastating childhood cancer.

Chairman Huffman and members of the Ohio House Health 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.

³ <https://www.usatoday.com/story/sports/ncaaw/2015/04/10/lauren-hill-obit-cancer-brain-tumor/21393079/>