Local Residents Testify For Dandy Walker Kids

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George Pugh testified before the Committee of Education, Health & Environmental Affairs on Friday about Dandy Walker Syndrome.

Thirteen year-old George Pugh has been getting a crash course in political advocacy, having toured the General Assembly in Annapolis and testified before a crowded committee co-chaired by Senator Roy Dyson. George testified on Friday for the Committee of Education, Health & Environmental Affairs to have a bill passed that would designate May as a national awareness month for Dandy Walker Syndrome (DWS).

By the look of him, it is hard to imagine that George was not expected to survive being born. "They told us that we'd have a vegetable, a very sick child, or a dead child," said his mother, Kia Pugh, who said that her specialist recommended that she abort her baby.

George was diagnosed with DWS when he was in the fetal stage of development, a rare neurological disorder characterized by the abnormal development of the brain that leads to the growth of a cyst on what is commonly known as the fourth ventricle of the brain cavity. This in turn can lead to hydrocephalus, a condition of fluid on the brain that increases pressure on the brain cavity, and, if left untreated, is fatal.

If passed, House Bill 895 and Senate Bill 477 would designate May as a statewide Dandy Walker Syndrome and Hydrocephalus Awareness month, the first step in Maryland getting more funding for research and treatment, which for parents and their children affected by the disease would be a welcome relief.

Kia described her problems finding out information on the syndrome when she was told that she should terminate her pregnancy. She said, "The book in my specialist's office only had one little paragraph."

Since Kia's pregnancy took place before the advent of the internet, Kia described having to track down information the old-fashioned way, and the frustration that came along with it. She described talking to other parents of Dandy Walker children and hearing similar horror stories about fears of giving birth to sick or dead children.

"If you live in a place where there aren't top-notch neurosurgeons, then you don't know," she said, adding that the bill should help to correct a lot of the ignorance that has surrounded her son's disease, and possibly bring about more effective treatments. A similar resolution is circulating Congress, asking for increased public awareness and funding. Kia explained that there are currently only two foundations conducting research on DWS, and she and George hope that public awareness will widen the pool of available research in years to come.

Kia was left going to the Department of Health and the National Institute of Health to conduct her own research, which for her was discouraging, to say the least. "They sent me eight to ten case files of just vile, sick, disgusting stiff," she said, adding that not much has changed since then. "All you saw was what could happen…no good news…"

But there has been a lot of good news for her son George, who has only had to have his shunt repaired four times in the last 13 years, and though he suffers from some learning disabilities, he is an honor roll student at Leonardtown Middle School who studies music and enjoys photography. He will be featured in a medical documentary called Dandy Kids, which is being peddled to networks like HBO and the Discovery Channel. "George is lucky," exclaimed Kia. "He has great things going on for him."

And George seems to be a very well adjusted boy. When asked about his experiences in Annapolis, testifying for Senator Dyson, he smiled as he described videotaping the tour, saying, "It wasn't really what I saw there, it's what I was taping…I realized how much I loved using the camera."

George also commented on the importance of his testimony. "If I wasn't there," he said, "then people wouldn't know what it's like."

As for his medical difficulties, George is optimistic. "Since I'm not in the ER very often," he said, "I don't really worry about my health…I imagine myself as a normal kid."

As Kia sat next to her son, proudly nodding as he spoke, she seemed happier than ever to have not taken her specialist's advice.