

Thank you Madam Chair and members of the Committee for also allowing me the opportunity to testify on the brain disorder called Dandy-Walker Syndrome and a commonly associated condition called Hydrocephalus. As previously stated by Mr. Cole, the causes for both of these disorders are largely unknown.

My name is Brian Blackwell and I have been blessed with five wonderful children. My youngest son, Samuel, is four years old and was diagnosed with Dandy-Walker Syndrome at eighteen weeks gestation. As the father of a child with Dandy-Walker, I feel responsible to advocate on his behalf, the residents of Maryland, as well as citizens of the United States, who may not be able to advocate for themselves.

Although I am not a resident of the great state of Maryland, I am the co-founder of the Dandy-Walker Alliance, a Maryland based 501(c)(3) public charity that is dedicated to raising awareness and providing support to individuals who are living with or have recently received the diagnosis of Dandy-Walker and/or Hydrocephalus. I am grateful for the opportunity to share with you my experiences and offer an explanation as to the need to raise awareness, while asking for your support to enact Senate Bill 477 into law.

After we received our son's diagnosis of Dandy-Walker Syndrome, we felt completely alone and helpless. Our research turned up very little information on this "rare" brain disorder. Our doctors painted a very grim picture and strongly encouraged us to "consider" our options. After five very long, hopeless months, our son was born. He came out kicking and screaming into an operating room filled with shocked doctors and nurses. Although the diagnosis was correct, the physicians were completely wrong about the outcome.

Less than twenty four hours after our son was born, he returned to the operating room to have a shunt inserted into the cyst, which is attached to the fourth ventricle of his brain, in order to drain the excess cerebral spinal fluid from his brain, to his abdomen. As Mr. Cole previously stated, the shunt technology was introduced in 1952 and there has been no major technological advances since its introduction. Over the past four years, my son has had to endure seven shunt revisions because this outdated technology has close to a forty percent failure rate. He has also endured

five other surgeries, however if you were to meet him on the stret, you would never think that this little boy has been through twelve surgeries in his short little life.

The helplessness that we felt after receiving the diagnosis of Dandy-Walker, along with the frustration of not having any choice but to use a piece of equipment that is out dated, in order to keep my son alive, led us to the decision that we must start informing the world about this disorder. Once we began networking and sharing our experiences, we were overwhelmed by the responses that we have received. Everywhere we turned, we found more and more individuals who had been through a very similar experience when they received their diagnosis, yet their children were actually thriving. We quickly learned that this “rare” brain disorder, was not so “rare” after all. Instead of the 1 in 25,000 to 35,000 occurrence rate that we were told upon receiving the diagnosis, the CDC is now stating that this is occurring in as many as 1 in 5,000 live births and possibly even more.

We are hopeful that by the state of Maryland being the inaugural state to set aside a month dedicated to raising awareness for Dandy-Walker and Hydrocephalus, the bar will have been set, and that other states will soon follow. As Mr. Cole stated, the Dandy-Walker Alliance has developed an out reach campaign to be launched during the month of May. We are confident that this campaign backed by the acknowledgement of the state of Maryland is sure to enlighten others about Dandy-Walker and Hydrocephalus.

On behalf of all the citizens of this great state, as well as their fellow Americans, we respectfully ask that you partner with those of us who are here today and deliver to Governor O’Malley a bill that designates the month of May as Dandy-Walker Syndrome and Hydrocephalus Awareness Month.

Thank you again for your time and the opportunity to participate in this hearing. I will be happy to answer any questions you may have.