

Thank you Madam Chairwoman and Members of the Committee for this opportunity to testify on a brain defect called Dandy-Walker Syndrome and a commonly associated condition called hydrocephalus. The causes for both are largely unknown.

My name is Eric Cole and my two-year-old son, Ryan, is affected by both. I see it as my duty as a father and my social obligation to speak for thousands of Marylanders who are disabled and can not advocate for themselves.

I am not a doctor and am not here to present to you a bunch of medical terms or lengthy background information. I am here to share with you why greater Dandy-Walker Syndrome and hydrocephalus awareness is needed and submit to you why we need to see Senate Bill 477 enacted into law.

Dandy-Walker Syndrome is a birth defect where a part of the back of the brain called the vermis is underdeveloped or missing. Hydrocephalus, sometime called "water on the brain," is a condition in which there is an excessive accumulation of fluid in the brain. The "water" is actually cerebrospinal fluid that surrounds the brain and spinal cord.

While Dandy-Walker is present from birth, hydrocephalus can be acquired for no known cause or secondary to many conditions, illnesses or injury. The treatment for individuals with Dandy-Walker generally consists of treating the associated problems versus the syndrome itself. Hydrocephalus is treated today the same way that was developed in 1952, by inserting a special tube called a shunt into the brain to drain off excess fluid.

Many Maryland families routinely engage in activities to express gratitude to the dedicated medical professionals, researchers and others who work tirelessly to determine the causes of, find the cure for and to ameliorate the effects of Dandy-Walker and hydrocephalus. As we work together to fight this brain defect and often debilitating condition, we recognize that every person can take action to be a voice for someone in need.

Last year those of us before you today discovered that no other organization was advocating for the birth defect Dandy-Walker Syndrome. Instead of giving in to the diagnosis we began asking questions. In doing so, we met other families whose children were also living with Dandy-Walker Syndrome. We unified immediately and instead of passive acceptance of this brain defect we saw an opportunity to fill a worldwide void in Dandy-Walker advocacy. As a result, the Dandy-Walker Alliance was founded as a non-profit Maryland corporation representing a global constituency.

Throughout the month of May, which we hope will be designated as Dandy-Walker Syndrome and Hydrocephalus Awareness Month, the Dandy-Walker Alliance will organize events, conduct media outreach, release new educational materials and support local Dandy-Walker Syndrome and Hydrocephalus Awareness Month efforts to increase public understanding of ways to manage the environment to help individuals affected by this brain defect and condition. Already planned are poster contests, public service announcements and the official launch of a corporate social responsibility campaign. Every Marylander has a part to play in raising awareness and no part is too small. It can not be overstated how much this Awareness Month will help.

Madam Chair, My goal in being before you and by submitting testimony is to seek your help in raising the profile of Dandy-Walker Syndrome and the condition hydrocephalus in our great state of Maryland. I understand that balancing the policy needs of Maryland is a difficult job. I also believe that budget conscious initiatives like an Awareness Month will help to better educate the public at large and disseminate information about translational research.

With your leadership, guidance and support we have the opportunity to act on behalf of tens-of-thousands of disabled Marylanders who can not advocate for themselves and who presently rely on 56-year-old technology to treat their hydrocephalus. I simply want to give my son Ryan and other disabled individuals in Maryland the same full access, possibilities and experiences as any other person.

All we respectfully ask is 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.