

Thank you Mr. Chairman 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.

Our names are Eric and Andrea Cole and our two-year-old son, Ryan, is affected by both. We see it as our duty as parents and our social obligation to speak for thousands of Marylanders who are disabled and can not advocate for themselves.

We are not doctors and are not here to present to you a bunch of medical terms or lengthy background information. We are here to share with you why greater Dandy-Walker Syndrome and Hydrocephalus Awareness is needed and submit to you why we need to see House Bill 895 enacted into law.

While Dandy-Walker Syndrome is present from birth, which is where a part of the back of the brain called the vermis is underdeveloped or missing, 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, sometime referred to as water on the brain, 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 cause(s) 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 we 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.

Even though Dandy-Walker Syndrome is the most common congenital malformation of the cerebellum and hydrocephalus affects over one million Americans their causes remain largely unknown. However, with your help we can raise the profile of both. It will come as little surprise to know that awareness campaigns such as this create scientific interest which leads to more research and what we hope will one day lead to a cure. It can not be overstated how much this will help.

Mr. Chairman, we understand that balancing the policy needs of Maryland is a difficult job and we thank you all for your service.

Our 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. We 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. We simply want to give our son Ryan and other disabled individuals in Maryland the same full access, possibilities and experiences as any other person.

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. This charge also includes being a voice for the premature, the disabled and our wounded warriors. While their disabilities may always be something that will affect them, they do not define who they are.

All we respectfully ask is that you partner with us 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. We will be happy to answer any questions you may have.