

Senate Bill 477  
2008 Regular Session - Witness Appearance  
Maryland Senate Committee on Education, Health and Environmental Affairs  
February 29, 2008 @ 1:00 PM

Good afternoon. My name is George. I am a thirteen year-old eighth grader at Leonardtown Middle School in St. Mary's County. I have Dandy-Walker Syndrome and Hydrocephalus. My parents tell me that I have had this disease since before I was born.

Because of how the doctors and nurses have taken care of me, most of the time I feel normal like other kids and I really don't notice I have a shunt or this condition. But sometimes my head gets intense headaches and this tells me that I have to go to the hospital. My parents take me to the emergency room where the doctors talk to me and make me take a lot of tests like cat scans and x-rays. Then they decide with my parents what needs to be done. I have had to get surgery four times.

The last time I felt really bad was in January 2006. My family and I went to the hospital where I had many tests and had to stay for three days. But this time I did not have to have surgery, which made me very happy and relieved. When I was younger, I used to always go to Children's Hospital in Washington, DC. Now that I'm older, I go to Johns Hopkins Hospital in Baltimore, Maryland. It's a good hospital. My doctor is Ben Carson. He's an amazing doctor and my parents tell me he is very famous. Most people know him for operating on Siamese twin babies. I have seen him on television and in magazines explaining his operations.

Most of the time, I don't worry about my health because I'm usually not at the emergency room. When I have to go, I know what to do when I need help.

Dandy-Walker Syndrome and Hydrocephalus has made me have some learning disabilities. I realize this now because I get impatient with people and want to get things done too fast. I also have trouble learning my subjects. Math, reading comprehension and writing are hard to do. I have to pay close attention and sometimes repeat what I'm doing in order to understand it better. My teachers also work with me to stay focused and to not get distracted by others. My parents, especially my mom, work with me at home as well. She even meets all of my teachers so that they understand my difficulties.

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To help me deal everyday with my learning disabilities I imagine myself as everyone else. This helps me to make many friends and to be interested in many things.

I love sports, singing and playing my guitars. The sports I can play are basketball, soccer, baseball, swimming, boating and skiing with my dad and brothers. I want to try snowboarding very much but this will have to wait until next year. I am taking a night class with my grandfather to receive this spring my boater's license. My doctors will not let me to play any kind of football or wrestle. My favorite music is rock, blues, and jazz. I play the acoustic and electric guitars, piano, and the bass guitar. I also sing in our school's choir and this year I qualified for Tri-County.

Recently, I went with my family to meet other kids with Dandy-Walker Syndrome and to see a new film about our lives called Dandy Kids. I got to fly for the first time on an airplane to Denver, Colorado. From this trip, I learned that this disease affects other people from all over the world, and that some kids are not as lucky as I am.

I think it would be a good thing if the Maryland government makes the month of May Dandy-Walker Syndrome and Hydrocephalus Awareness Month. Because it could make people wonder what it is I have to deal with and they could learn about it. Maybe they would feel the same emotions kids like me with Dandy-Walker and Hydrocephalus have. This could one day help us find a cure.

Thank you very much for listening to me about the conditions I have and the way I deal with them everyday.