



CONGRESSMAN CHRIS VAN HOLLEN EIGHTH DISTRICT OF MARYLAND

DANDY-WALKER SYNDROME AND HYDROCEPHALUS

(Extensions of Remarks - November 14, 2007)

SPEECH OF
HON. CHRIS VAN HOLLEN
OF MARYLAND
IN THE HOUSE OF REPRESENTATIVES
WEDNESDAY, NOVEMBER 14, 2007

Mr. VAN HOLLEN. Madam Speaker, I rise in support of H. Con. Res. 163, expressing the sense of the Congress in support of further research and activities to increase public awareness, professional education, diagnosis, and treatment of Dandy-Walker Syndrome and hydrocephalus.

In 2005 while awaiting the birth of their first child Ryan, Andrea and Eric Cole of Kensington, Maryland learned that he would be born with a rare birth defect called Dandy-Walker Syndrome and a condition called hydrocephalus. Ryan was born on May 3, 2005, 3 months premature and weighing 1 pound 15 ounces, at George Washington University Hospital in Washington, D.C. He would spend a total of 156 days in the hospital during his first year of life.

Today, the Cole family leads the fight against Dandy-Walker Syndrome and is the inspiration behind my efforts against this terrible birth defect. On learning that no national organization existed to advocate on behalf of individuals with Dandy-Walker Syndrome, Eric and Andrea took the necessary steps to found the only national non-profit organization for Dandy-Walker Syndrome, and located it in Maryland's Eighth Congressional District, which I represent. Today, the Dandy-Walker Alliance remains the only non-profit organization committed to educational and informational activities, programs and publications and supporting non-partisan research and events to increase public awareness of Dandy-Walker Syndrome. The Dandy-Walker Alliance supports all efforts to determine the cause(s) of, to find the cure for and to ameliorate the effects of Dandy-Walker Syndrome.

Dandy-Walker Syndrome is a congenital malformation of the cerebellum that can cause developmental delay, is frequently associated with hydrocephalus that can lead to an enlarged head circumference, and can cause neurological damage possibly leading to death. The Centers for Disease Control and Prevention reports that Dandy-Walker Syndrome may affect as many as 1 in 5,000 live born infants of which approximately 70 to 90 percent will develop hydrocephalus. Treatment for individuals with Dandy-Walker generally consists of treating the associated problems rather than the syndrome itself. Hydrocephalus is treated today the same way that it was in 1952, by inserting a shunt into

the brain to drain off excess fluid.

In addition to what the Coles are doing with the Dandy-Walker Alliance, a filmmaker from Colorado with a nephew affected by Dandy-Walker is completing the first-ever documentary on Dandy-Walker Syndrome called "Dandy Kids," which will premiere in January 2008. A couple in Florida was also inspired to film a commercial with their three-year-old son affected by Dandy-Walker and hydrocephalus to help promote the need for blood donations since the brain surgeries to treat his hydrocephalus often require transfusions.

Dandy-Walker Syndrome involves many complex issues. That is why the Director of the National Institutes of Health should continue the current collaboration, with respect to Dandy-Walker Syndrome, among the National Human Genome Research Institute, the National Institute of Biomedical Imaging and Bioengineering, the National Institute of Child Health and Human Development, the National Institute of Neurological Disorders and Stroke and the Office of Rare Diseases.

Further research into the epidemiology, diagnosis, pathophysiology, disease burden, and improved treatment of Dandy-Walker Syndrome should be conducted and supported. The National Institutes of Health should take the lead in sponsoring an annual workshop to increase awareness and set national research priorities for Dandy-Walker Syndrome and hydrocephalus.

The Centers for Disease Control and Prevention should also form a coordinating committee for Dandy-Walker Syndrome and hydrocephalus research, which would annually report to the public its findings on the progress in the epidemiology, pathophysiology, disease burden, treatment improvements, diagnoses, and awareness for Dandy-Walker Syndrome and hydrocephalus.

Finally, public awareness and professional education regarding Dandy-Walker research should increase through partnerships between the Federal Government and patient advocacy organizations, such as the Dandy-Walker Alliance and the Hydrocephalus Association.

Madam Speaker, let's tell families like the Coles that they are not alone in their fight against Dandy-Walker Syndrome. Certainly we can lend a hand in helping to further raise awareness of Dandy-Walker Syndrome and to act on behalf of disabled members in society who cannot advocate for themselves. I think we all agree that partnerships between the Federal Government and advocacy groups are important to the American people. That is why I urge my colleagues from both parties to join me in co-sponsoring House Concurrent Resolution 163 to raise awareness for Dandy-Walker Syndrome and hydrocephalus.

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