



CONGRESSMAN ROBERT ADERHOLT

FOURTH DISTRICT OF ALABAMA

NEWS RELEASE

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DANDY-WALKER SYNDROME FIGHT HAS LAMAR COUNTY ROOTS *Congressman Aderholt Joins Effort to Promote Awareness, Research*

WASHINGTON, D.C. – In 2005 while awaiting the birth of their first child Ryan, Andrea and Eric Cole of Kensington, Maryland (with roots in Lamar County) learned that he would be born with a rare birth defect called Dandy-Walker Syndrome and a condition called hydrocephalus. Today the family leads the fight against Dandy-Walker Syndrome and is the inspiration behind Congressman Robert Aderholt's (R-Haleyville) effort against this terrible birth defect.

"I had the opportunity to meet Ryan earlier this year and while talking with his parents we discussed how we could help this young man. However, when you talk to Andrea and Eric they'll be quick to tell you that this is a much larger problem and that Congress can play a valuable role in raising awareness about this birth defect and promote efforts to help end it," said Congressman Aderholt.

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 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.

Ryan Cole, was born on May 3, 2005, 3 months premature weighing 1 pound 15 ounces at George Washington University Hospital in Washington, DC. He would spend a total of 156 days in the hospital his first year of life.

His father, Eric Cole stated, "Not only has Rep. Aderholt connected with our family but he's also engaged at the national level to help increase public awareness of Dandy-Walker Syndrome and hydrocephalus. What he and his office have done to give guidance and support on behalf of disabled members in society who can't advocate for themselves are something that his constituents can be thankful for."

On May 24, 2007, Congressman Aderholt partnered with Democrat Congressman Chris Van Hollen (MD-8) to co-sponsor House Congressional Resolution 163 introduced by

Republican Congresswoman Heather Wilson (NM-1) 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. As of today there are 27 co-sponsors and the resolution enjoys wide bi-partisan support.

Inspired by Congressman Aderholt and other Members, Eric and Andrea took the steps to found the only national non-profit for Dandy-Walker Syndrome. Today, the Dandy-Walker Alliance (www.Dandy-Walker.org) is the only non-profit corporation 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, find the cure for and to ameliorate the effects of Dandy-Walker Syndrome.

The Coles credit Congressman Aderholt and his congressional colleagues in helping to create momentum that has inspired others across the country. A filmmaker from Colorado with a nephew affected by Dandy-Walker is completing the first ever documentary on Dandy-Walker Syndrome (<http://www.dandykidsdocumentary.com/>) which will premier on January 16, 2008 in Denver, Colorado. A couple in Florida also filmed a commercial with their three-year-old son affected by Dandy-Walker and hydrocephalus to help promote the need for blood donations since these surgeries often require transfusions.

Concluded Eric Cole, "Congressman Aderholt and his colleagues engaged when they did not have to and did so by providing bold leadership, guidance and support to act on behalf of millions of disabled members in society who can not advocate for themselves. This is something all residents of Alabama can be proud of and three people in Kensington, Maryland are forever grateful for."

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