

110<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

# H. CON. RES. 163

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IN THE SENATE OF THE UNITED STATES

JUNE 27, 2008

Received and referred to the Committee on Health, Education, Labor, and  
Pensions

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## CONCURRENT RESOLUTION

Expressing the sense of Congress in support of further research and activities to increase public awareness, professional education, diagnosis, and treatment of Dandy-Walker syndrome and hydrocephalus.

Whereas Dandy-Walker syndrome is the most common congenital malformation of the cerebellum and its causes are largely unknown;

Whereas between 10,000 and 40,000 people have Dandy-Walker syndrome in the United States;

Whereas the incidence of Dandy-Walker syndrome is at least 1 case per every 25,000 to 35,000 live births,

however this is likely a significant underestimate because of difficulties diagnosing the syndrome;

Whereas the Metropolitan Atlanta Congenital Defects Program, Centers for Disease Control and Prevention reports that Dandy-Walker syndrome may affect as many as 1 in 5000 live born infants;

Whereas approximately 70 to 90 percent of patients with Dandy-Walker syndrome have hydrocephalus;

Whereas Dandy-Walker syndrome accounts for approximately 1 to 4 percent of hydrocephalus cases;

Whereas patients with Dandy-Walker syndrome present with developmental delay, enlarged head circumference, or signs and symptoms of hydrocephalus;

Whereas Dandy-Walker syndrome affects males and females approximately equally;

Whereas seizures occur in 15 to 30 percent of patients with Dandy-Walker syndrome;

Whereas subnormal intelligence is manifested in 41 to 71 percent of patients with Dandy-Walker syndrome;

Whereas failure to diagnose Dandy-Walker syndrome with hydrocephalus in a Neonate or a child can cause serious neurologic complications;

Whereas Dandy-Walker syndrome is named after former University of New Mexico neurosurgeon and professor Arthur E. Walker (1907–1995) and Walter E. Dandy (1883–1941), who first described the disorder in 1914; and

Whereas there are 2 known researchers dedicated to Dandy-Walker Syndrome in the United States and additional investigators are needed: Now, therefore, be it

1       *Resolved by the House of Representatives (the Senate*  
2 *concurring), That—*

3           (1) Congress commends the Director of the Na-  
4       tional Institutes of Health for working with leading  
5       scientists and researchers to organize the first Na-  
6       tional Institutes of Health conference on hydro-  
7       cephalus in September 2005 and the Inaugural  
8       “Cerebellar Development: Bench to Bedside Inter-  
9       national Conference” in November 2006; and

10          (2) it is the sense of Congress that—

11           (A) the Director of the National Institutes  
12       of Health should continue the current collabora-  
13       tion, with respect to Dandy-Walker syndrome,  
14       among the National Human Genome Research  
15       Institute, the National Institute of Biomedical  
16       Imaging and Bioengineering, the National In-  
17       stitute of Child Health and Human Develop-  
18       ment, the National Institute of Neurological  
19       Disorders and Stroke, and the Office of Rare  
20       Diseases;

21           (B) further research into the epidemiology,  
22       diagnosis, pathophysiology, disease burden, and  
23       improved treatment of Dandy-Walker syndrome  
24       and hydrocephalus should be conducted and  
25       supported; and

