

110TH CONGRESS
1ST SESSION

H. CON. RES. 163

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.

IN THE HOUSE OF REPRESENTATIVES

MAY 24, 2007

Mrs. WILSON of New Mexico (for herself, Mr. VAN HOLLEN, Mr. ADERHOLT, Mr. BONNER, Mr. BACHUS, and Mr. RYAN of Ohio) submitted the following concurrent resolution; which was referred to the Committee on Energy and Commerce

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—*

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

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

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

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

23 (C) the National Institutes of Health
24 should take the lead in sponsoring an annual
25 workshop to increase awareness and set na-

1 tional research priorities for Dandy-Walker syn-
2 drome and hydrocephalus;

3 (D) the Centers for Disease Control and
4 Prevention should form a coordinating com-
5 mittee for Dandy-Walker syndrome and hydro-
6 cephalus research, which would annually report
7 to the public its findings on the progress in the
8 epidemiology, pathophysiology, disease burden,
9 treatment improvements, diagnoses, and aware-
10 ness for Dandy-Walker syndrome and hydro-
11 cephalus; and

12 (E) public awareness and professional edu-
13 cation regarding Dandy-Walker research should
14 increase through partnerships between the Fed-
15 eral Government and patient advocacy organi-
16 zations, such as the Dandy-Walker Alliance and
17 the Hydrocephalus Association.

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