

110TH CONGRESS
2^D SESSION

H. CON. RES. 163

CONCURRENT RESOLUTION

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

1 (C) public awareness and professional edu-
2 cation regarding Dandy-Walker research should
3 increase through partnerships between the Fed-
4 eral Government and patient advocacy organi-
5 zations, such as the Dandy-Walker Alliance and
6 the Hydrocephalus Association.

Passed the House of Representatives June 26, 2008.

Attest:

Clerk.

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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.