

110TH CONGRESS
2^D SESSION

H. CON. RES. 163

IN THE SENATE OF THE UNITED STATES

JUNE 27, 2008

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

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

