



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

FLOOR SITUATION

H.Con.Res. 163 is being considered on the floor under suspension of the rules and will require a two-thirds majority vote for passage. This legislation was introduced by Representative Heather Wilson (R-NM) on May 24, 2007. The resolution was referred to the House Committee on Energy and Commerce, but was never considered.

H.Con.Res. 163 is expected to be considered on the floor of the House on June 24, 2008.

SUMMARY

H.Con.Res. 163 resolves that Congress commends the Director of the National Institutes of Health for working with leading scientists and researchers to organize the first National Institutes of Health conference on hydrocephalus in September 2005 and the Inaugural 'Cerebellar Development: Bench to Bedside International Conference' in November 2006.

H.Con.Res 163 also resolves that it is the sense of Congress that:

- The Director of the National Institutes of Health should continue the current collaboration, with respect to Dandy-Walker syndrome, among the National Human Genome Research Institute, the National Institute of Biomedical Imaging and Bioengineering, the National Institute of Child Health and Human Development, the National Institute of Neurological Disorders and Stroke, and the Office of Rare Diseases;
- Further research into the epidemiology, diagnosis, pathophysiology, disease burden, and improved treatment of Dandy-Walker syndrome should be conducted and supported;
- The National Institutes of Health should take the lead in sponsoring an annual workshop to increase awareness and set national research priorities for Dandy-Walker syndrome and hydrocephalus;
- The Centers for Disease Control and Prevention should form a coordinating committee for Dandy-Walker syndrome and hydrocephalus research, which would annually report to the public its findings on the progress in the epidemiology, pathophysiology, disease burden, treatment improvements, diagnoses, and awareness for Dandy-Walker syndrome and hydrocephalus; and
- Public awareness and professional education regarding Dandy-Walker research should increase through partnerships between the Federal Government and patient advocacy organizations, such as the Dandy-Walker Alliance and the Hydrocephalus Association.

BACKGROUND

Dandy-Walker syndrome is a congenital brain malformation involving the cerebellum and the fluid filled spaces surrounding it. It is estimated that between 10,000-40,000 Americans have Dandy-Walker Syndrome. Symptoms of Dandy-Walker syndrome include slow motor development and gradual enlargement of the skull. Dandy-Walker syndrome is also frequently associated with malformations of the heart, face, limbs, fingers and toes. The syndrome is named after researcher Walter Dandy and neurosurgeon Arthur Walker, who first described the condition. There are only two known researchers dedicated to the study of Dandy-Walker syndrome in the United States.

Hydrocephalus is the abnormal accumulation of cerebrospinal fluid in the cavities of the brain. This condition may cause increased pressure inside the skull and progressive enlargement of the head, convulsion, and mental disability. It is estimated that hydrocephalus affects approximately one in every 500 children in the United States.



LEGISLATIVE DIGEST

HOUSE REPUBLICAN CONFERENCE | CHAIRMAN ADAM PUTNAM

1420 LONGWORTH HOB, WASHINGTON, DC 20515

www.GOP.gov

PHONE 202.225.5107

FAX 202.226.0154

STAFF CONTACT

For questions or further information contact Adam Hepburn at (202) 226-2302.