

113TH CONGRESS
1ST SESSION

S. RES. 152

Designating November 28, 2013, as “National Holoprosencephaly Awareness Day” to increase awareness and education of the disorder.

IN THE SENATE OF THE UNITED STATES

MAY 22, 2013

Mr. COWAN submitted the following resolution; which was referred to the
Committee on Health, Education, Labor, and Pensions

RESOLUTION

Designating November 28, 2013, as “National Holoprosencephaly Awareness Day” to increase awareness and education of the disorder.

Whereas Holoprosencephaly (commonly known as “HPE”) is a birth defect of the brain in which the prosencephalon (also known as the “embryonic forebrain”) does not sufficiently develop into 2 hemispheres resulting in a single-lobed brain structure and severe skull and facial defects;

Whereas in most cases of HPE, the malformations are so severe that babies die before birth;

Whereas in less severe cases of HPE, babies are born with normal or near-normal brain development and facial deformities that may affect the eyes, nose, and upper lip;

Whereas the 3 classifications of HPE that vary in severity and impairment to cognitive abilities are Alobar (in which the brain has not divided at all), Semilobar (in which the hemispheres of the brain have somewhat divided), and Lobar (in which there is considerable evidence of separate brain hemispheres);

Whereas HPE affects approximately 1 out of every 250 pregnancies during early embryo development, with many of those pregnancies ending in miscarriage;

Whereas HPE affects 1 in 10,000–20,000 live births;

Whereas the prognosis for a child diagnosed with HPE depends on the severity of the brain and facial malformations and associated clinical complications, with the most severely affected children living several months or years and the least affected children living a normal life span;

Whereas there is no standard course of treatment for HPE because treatment must be individualized to the unique degree of malformations of each child;

Whereas the Federal Government, acting through the National Institutes of Health and the National Institute of Neurological Disorders and Strokes, supports and conducts a wide range of research on normal brain development and recent research has identified specific genes that cause HPE; and

Whereas November 28, 2013, would be an appropriate day to designate as “National Holoprosencephaly Awareness Day”: Now, therefore, be it

1 *Resolved*, That the Senate—

1 (1) supports the designation of November 28,
2 2013, as “National Holoprosencephaly Awareness
3 Day”;

4 (2) urges Federal agencies—

5 (A) to continue supporting research to bet-
6 ter understand the causes of HPE;

7 (B) to provide better counseling to families
8 with the genetic forms of HPE; and

9 (C) to develop new ways to treat, and po-
10 tentially prevent, HPE; and

11 (3) calls on the people of the United States, in-
12 terested groups, and affected persons—

13 (A) to promote awareness of HPE;

14 (B) to take an active role in the fight to
15 end the devastating effects of HPE; and

16 (C) to observe “National Holoprosen-
17 cephaly Awareness Day” with appropriate cere-
18 monies and activities.

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