

110TH CONGRESS
2D SESSION

H. RES. 1480

Supporting the goals and ideals of National Spina Bifida Awareness Month.

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 23, 2008

Mr. SMITH of New Jersey (for himself, Mr. STUPAK, Mrs. SCHMIDT, and Mr. BURTON of Indiana) submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

Supporting the goals and ideals of National Spina Bifida
Awareness Month.

Whereas Spina Bifida is the most common, permanently disabling birth defect;

Whereas Spina Bifida occurs during the first month of pregnancy and leaves a permanent opening in the spinal column which subsequently impacts nearly every organ system;

Whereas an estimated 70,000 to 130,000 people in the United States currently live with Spina Bifida;

Whereas all women of childbearing age are at risk of having a pregnancy affected by Spina Bifida;

Whereas an estimated 70 percent of neural tube defects, such as Spina Bifida, can be prevented if a woman consumes

adequate amounts of folic acid, a supplement found in most over-the-counter multivitamins and foods rich in folate, such as spinach, prior to becoming pregnant;

Whereas Hispanic and Latina women are at the highest risk (1.5 to 2 times higher than the next highest risk population, non-Hispanic white women) for delivering a baby with Spina Bifida or another neural tube defect and are the least likely to consume sufficient amounts of folic acid prior to becoming pregnant;

Whereas there are unprecedented medical complications associated with aging that a person with Spina Bifida faces because they are living beyond previous generations and care is complex, involving a myriad of clinical specialists;

Whereas a 2005 nationwide survey of Spina Bifida clinics uncovered that the current system of care serving people with Spina Bifida does not fully meet current or anticipated needs and physicians have little evidence-based research on which to build neurological, orthopedic, or urologic treatment regimens and interventions;

Whereas the National Spina Bifida Program, administered by the Centers for Disease Control and Prevention, exists to improve the health, well-being, and overall quality of life for the individuals and families affected by Spina Bifida through the National Spina Bifida Patient Registry and critical quality of life research in Spina Bifida;

Whereas the National Spina Bifida Patient Registry helps to improve the quality of care, reduce morbidity and mortality, increase the efficiency of care, decrease the cost of care, develop quality measures, treatment standards, and best practices, identify centers of excellence in Spina Bifida, evaluate the cost-effectiveness of Spina Bifida

treatment, and exchange evidence-based information between health care providers across the United States;

Whereas the Spina Bifida Association is the only national voluntary health agency working for people with Spina Bifida and their families through education, advocacy, research, and service; and

Whereas October is designated as “National Spina Bifida Awareness Month” to help increase awareness and prevention of Spina Bifida and to emphasize the need for increased funding to support evidence-based research and to enhance the quality of life of those living with Spina Bifida: Now, therefore, be it

1 *Resolved*, That the House of Representatives—

2 (1) supports the goals and ideals of “National
3 Spina Bifida Awareness Month” as designated by
4 the Spina Bifida Association;

5 (2) recognizes the importance of highlighting
6 the occurrence of Spina Bifida, bringing to light the
7 struggles and successes of those who live with Spina
8 Bifida, and advancing efforts to decrease the inci-
9 dence of Spina Bifida;

10 (3) supports the ongoing development of the
11 National Spina Bifida Patient Registry to improve
12 lives through research and to improve treatment for
13 children and adults;

14 (4) recognizes that there is a continued need for
15 resources to reduce and prevent disabling birth de-
16 fects like Spina Bifida; and

1 (5) commends the work of the Spina Bifida As-
2 sociation for its excellent work to educate, support,
3 and provide hope for individuals and their families
4 who are affected by Spina Bifida.

