III

110TH CONGRESS
2D SESSION

S. RES. 661

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

IN THE SENATE OF THE UNITED STATES

SEPTEMBER 15, 2008

Mr. DODD (for himself, Mr. WICKER, Mr. BROWN, Mr. LIEBERMAN, Mrs. MURRAY, Mr. BAYH, and Mr. CASEY) submitted the following resolution; which was referred to the Committee on Health, Education, Labor, and Pensions

SEPTEMBER 23 (legislative day, SEPTEMBER 17), 2008

Committee discharged; considered and agreed to

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 that 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 spina bifida affected pregnancy;

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, which is found in most over-the-counter multivitamins and foods rich in folate such as spinach, prior to becoming pregnant;

Whereas Hispanic women are at the highest risk, between 1.5 and 2 times higher than non-Hispanic whites, of delivering a baby with spina bifida or another neural tube defect, yet are the least likely to consume sufficient amounts of folic acid prior to becoming pregnant;

Whereas people with spina bifida face unprecedented medical complications associated with aging because people with spina bifida are living longer than people with spina bifida in previous generations lived and care for spina bifida is complex and involves myriad clinical specialists;

Whereas a 2005 nationwide survey of spina bifida clinics revealed 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 about spina bifida 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 numerous programmatic components, including 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, to reduce morbidity and mortality from spina bifida, and to increase the efficiency of, and decrease the cost of, care by supporting the collection of longitudinal treatment data, developing quality measures and treatment standards of care and best practices, identifying centers of excellence in spina bifida, evaluating the clinical and cost effectiveness of the treatment of spina bifida, and exchanging evidence-based information among health care providers across the country; and

Whereas October has been designated as ''National Spina Bifida Awareness Month'' to increase awareness of spina bifida, of ways to prevent spina bifida, and of the need for increased funding to support improving evidence-based research and enhancing the quality of life of those living with spina bifida: Now, therefore, be it

Resolved, That the Senate—

(1) supports the goals and ideals of National Spina Bifida Awareness Month and of national organizations working for people with spina bifida;

(2) recognizes the importance of—

(A) highlighting the occurrence of spina bifida;

(B) recognizing the struggles and successes of people who live with spina bifida; and

(C) advancing efforts to decrease the incidence of spina bifida;

(3) supports the ongoing development of the National Spina Bifida Patient Registry to improve lives through research and to improve the treatment of spina bifida in both children and adults;

(4) recognizes that there is a continued need for a commitment of resources for efforts to reduce and prevent disabling birth defects like spina bifida; and

(5) commends the work of national organizations that educate, support, and provide hope for individuals who are affected by spina bifida and their families.

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