112TH CONGRESS 1ST SESSION

S. CON. RES. 30

Supporting the goals and ideals of Spina Bifida Awareness Month.

IN THE SENATE OF THE UNITED STATES

OCTOBER 13, 2011

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

CONCURRENT RESOLUTION

Supporting the goals and ideals of Spina Bifida Awareness Month.

- Whereas, according to the Centers for Disease Control and Prevention, there are approximately 166,000 individuals living in the United States with a form of spina bifida, the United States most common permanent birth defect;
- Whereas the risk of spina bifida can be reduced by up to 70 percent if women consume 400 micrograms of folic acid daily, before and during pregnancy;
- Whereas there are 65,000,000 women of childbearing age in the United States, all of whom are potentially at risk of having a child with spina bifida;
- Whereas 1,500 children are born each year with spina bifida;
- Whereas, according to the Spina Bifida Association, spina bifida is a complicated condition, adversely impacting vir-

tually every organ system and requiring multiple clinical specialists to provide lifelong comprehensive, quality medical and psychosocial care;

Whereas the National Spina Bifida Program, administered by the Centers for Disease Control and Prevention, exists to improve the health, well-being, and 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, reduce morbidity and mortality from spina bifida, and increase the efficiency 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 both the clinical and cost-effectiveness of treatment of spina bifida, and exchanging evidence-based information among 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 the prevention of spina bifida, as well as enhancing the quality of life of persons living with spina bifida: Now, therefore, be it

- 1 Resolved by the Senate (the House of Representatives
- 2 concurring), That Congress—

- (1) supports the goals and ideals of National
 Spina Bifida Awareness Month;
 - (2) recognizes the importance of highlighting the occurrence of spina bifida, bringing to light the struggles and successes of those who live with spina bifida, and 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 treatments for 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 excellent work of the Spina Bifida Association to educate, support, and provide hope for people with spina bifida and their families.

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