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S. RES. 204

Designating March 31, 2010, as 'National Congenital Diaphragmatic Hernia Awareness Day'.

IN THE SENATE OF THE UNITED STATES

June 24, 2009

Mr. VITTER submitted the following resolution; which was referred to the Committee on the Judiciary

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RESOLUTION

Designating March 31, 2010, as 'National Congenital Diaphragmatic Hernia Awareness Day'.

Whereas the congenital diaphragmatic hernia birth defect is one of the most prevalent, life-threatening birth defects in the United States;

Whereas the congenital diaphragmatic hernia birth defect is a severe, often deadly birth defect that has a devastating impact, in both human and economic terms, affecting equally people of all races, sexes, nationalities, geographic locations, and income levels;

Whereas the congenital diaphragmatic hernia birth defect occurs in 1 in every 2,000 live births in the United States and accounts for 8 percent of all major congenital anomalies;

Whereas, in 2004, there were approximately 4,115,590 live births in the United States, and in approximately 1,800 of those live births, the congenital diaphragmatic hernia birth defect occurred, causing countless additional friends, loved ones, spouses, and caregivers to shoulder the physical, emotional, and financial burdens the congenital diaphragmatic hernia birth defect causes;

Whereas there is no genetic indicator or any other indicator available to predict the occurrence of the congenital diaphragmatic hernia birth defect, other than through the performance of an ultrasound during pregnancy;

Whereas there is no consistent treatment or cure for the congenital diaphragmatic hernia birth defect;
Whereas the congenital diaphragmatic hernia birth defect is a leading cause of neonatal death in the United States;

Whereas 50 percent of the patients who do survive the congenital diaphragmatic hernia birth defect have residual health issues, resulting in a severe strain on pediatric medical resources and on the delivery of health care services in the United States;

Whereas proactive diagnosis and the appropriate management and care of fetuses afflicted with the congenital diaphragmatic hernia birth defect minimize the incidence of emergency situations resulting from the birth defect and dramatically improve survival rates among people with the birth defect;
Whereas neonatal medical care is one of the most expensive types of medical care provided in the United States and patients with the congenital diaphragmatic hernia birth defect stay in intensive care for approximately 60 to 90 days, costing millions of dollars, utilizing blood from local blood banks, and requiring the most technically advanced medical care;

Whereas the congenital diaphragmatic hernia birth defect is a birth defect that causes damage to the lungs and the cardiovascular system;

Whereas patients with the congenital diaphragmatic hernia birth defect may have long-term health issues such as respiratory insufficiency, gastroesophageal reflux, poor growth, neurodevelopmental delay, behavior problems, hearing loss, hernia recurrence, and orthopedic deformities;

Whereas the severity of the symptoms and outcomes of the congenital diaphragmatic hernia birth defect and the limited public awareness of the birth defect cause many patients to receive substandard care, to forego regular visits to physicians, and not to receive good health or therapeutic management that would help avoid serious complications in the future, compromising the quality of life of those patients;

Whereas people suffering from chronic, life-threatening diseases and birth defects, similar to the congenital diaphragmatic hernia birth defect, and family members of those people are predisposed to depression and the resulting consequences of depression because of anxiety over the possible pain, suffering, and premature death that people with such diseases and birth defects may face;

Whereas the Senate and taxpayers of the United States want treatments and cures for disease and hope to see results from investments in research conducted by the National Institutes of Health and from initiatives such as the National Institutes of Health Roadmap to the Future;

Whereas the congenital diaphragmatic hernia birth defect is an example of how collaboration, technological innovation, scientific momentum, and public-private partnerships can generate therapeutic interventions that directly benefit the people and families suffering from the congenital diaphragmatic hernia birth defect;

Whereas collaboration, technological innovation, scientific momentum, and public-private partnerships can save billions of Federal dollars under Medicare, Medicaid, and other programs for therapies, and early intervention will increase survival rates among people suffering from the congenital diaphragmatic hernia birth defect;

Whereas improvements in diagnostic technology, the expansion of scientific knowledge, and better management of care for patients with the congenital diaphragmatic hernia birth defect already have increased survival rates in some cases;

Whereas there is still a need for more research and increased awareness of the congenital diaphragmatic hernia birth defect and for an increase in funding for that research in order to provide a better quality of life to survivors of the congenital diaphragmatic hernia birth defect, and more optimism for the families and health care professionals who work with children with the birth defect;

Whereas there are thousands of volunteers nationwide dedicated to expanding research, fostering public awareness and understanding, educating patients and their families about the congenital diaphragmatic hernia birth defect to improve their treatment and care, providing appropriate moral support, and encouraging people to become organ donors; and

Whereas volunteers engage in an annual national awareness event held on March 31, making that day an appropriate time to recognize National Congenital Diaphragmatic Hernia Awareness Day: Now, therefore, be it

Resolved, That the Senate—

(1) designates March 31, 2010, as ‘National Congenital Diaphragmatic Hernia Awareness Day’;

(2) supports the goals and ideals of a national day to raise public awareness and understanding of the congenital diaphragmatic hernia birth defect;

(3) recognizes the need for additional research into a cure for the congenital diaphragmatic hernia birth defect; and

(4) encourages the people of the United States and interested groups to support National Congenital Diaphragmatic Hernia Awareness Day through appropriate ceremonies and activities, to promote public awareness of the congenital diaphragmatic hernia birth defect, and to foster understanding of the impact of the disease on patients and their families.