

113TH CONGRESS
1ST SESSION

S. RES. 142

Designating May 15, 2013, as “National MPS Awareness Day”.

IN THE SENATE OF THE UNITED STATES

MAY 15, 2013

Mr. GRAHAM (for himself, Mr. HOEVEN, Mr. WHITEHOUSE, Mr. BEGICH, Ms. HEITKAMP, Ms. MURKOWSKI, and Mrs. BOXER) submitted the following resolution; which was considered and agreed to

RESOLUTION

Designating May 15, 2013, as “National MPS Awareness Day”.

Whereas mucopolysaccharidosis (referred to in this resolution as “MPS”) are a group of genetically determined lysosomal storage diseases that render the human body incapable of producing certain enzymes needed to break down complex carbohydrates;

Whereas MPS diseases cause complex carbohydrates to be stored in almost every cell in the body and progressively cause cellular damage;

Whereas the cellular damage caused by MPS—

(1) adversely affects the human body by damaging the heart, respiratory system, bones, internal organs, and central nervous system; and

(2) often results in intellectual disabilities, short stature, corneal damage, joint stiffness, loss of mobility, speech and hearing impairment, heart disease, hyperactivity, chronic respiratory problems, and, most importantly, a drastically shortened life span;

Whereas symptoms of MPS are usually not apparent at birth;

Whereas, without treatment, the life expectancy of an individual afflicted with MPS begins to decrease at a very early stage in the life of the individual;

Whereas research has resulted in the development of limited treatments for some MPS diseases;

Whereas promising advancements in the pursuit of treatments for additional MPS diseases are underway as of the date of agreement to this resolution;

Whereas, despite the creation of new remedies, the blood-brain barrier continues to be a significant impediment to effectively treating the brain, which prevents the treatment of many of the symptoms of MPS;

Whereas the quality of life of the individuals afflicted with MPS, and the treatments available to those individuals, will be enhanced through the development of early detection techniques and early intervention;

Whereas treatments and research advancements for MPS are limited by a lack of awareness about MPS diseases;

Whereas the lack of awareness about MPS diseases extends to individuals within the medical community;

Whereas the cellular damage that is caused by MPS makes MPS a model for the study of many other degenerative genetic diseases; and

Whereas the development of effective therapies and a potential cure for MPS diseases can be accomplished by increased awareness, research, data collection, and information distribution: Now, therefore, be it

1 *Resolved*, That the Senate—

2 (1) designates May 15, 2013, as “National
3 MPS Awareness Day”; and

4 (2) supports the goals and ideals of “National
5 MPS Awareness Day”.

○