

109TH CONGRESS
1ST SESSION

S. RES. 57

Designating February 25, 2005, as “National MPS Awareness Day”.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 16, 2005

Mr. GRAHAM (for himself, Mr. SPECTER, Mr. BROWNBACK, Mr. KOHL, Mr. HATCH, Mr. FEINGOLD, Ms. CANTWELL, Mr. CHAMBLISS, Mrs. MURRAY, Mrs. DOLE, Mr. SANTORUM, and Mr. JEFFORDS) submitted the following resolution; which was considered and agreed to

RESOLUTION

Designating February 25, 2005, as “National MPS Awareness Day”.

Whereas Mucopolysaccharidosis (“MPS”) and Mucolipidosis (“ML”) disorders are genetically determined lysosomal storage disorders that result in the body’s inability to produce certain enzymes needed to breakdown complex carbohydrates;

Whereas these complex carbohydrates are then stored in virtually every cell in the body and progressively cause damage to these cells, adversely affecting an individual’s body, including an individual’s heart, respiratory system, bones, internal organs, and central nervous system;

Whereas the cellular damage caused by MPS often results in mental retardation, 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 the nature of the disorder is usually not apparent at birth;

Whereas without treatment, life expectancy of an individual afflicted with MPS is usually very early in life;

Whereas recent research developments have resulted in limited treatments for some MPS disorders;

Whereas promising advancements are underway in pursuit of treatments for additional MPS disorders;

Whereas despite newly developed remedies, the blood brain barrier continues to be a significant impediment to effectively treating the brain, thereby preventing the treatment of many of the symptoms of MPS;

Whereas treatments for MPS will be greatly enhanced with continued public funding;

Whereas the quality of life for individuals afflicted with MPS and the treatments available to them 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 disorders;

Whereas the lack of awareness about MPS disorders extends to those within the medical community;

Whereas the damage that is caused by MPS makes it a model for many other degenerative genetic disorders;

Whereas the development of effective therapies and a potential cure for MPS disorders can be accomplished by in-

creased awareness, research, data collection, and information distribution;

Whereas the Senate is an institution than can raise public awareness about MPS; and

Whereas the Senate is also an institution that can assist in encouraging and facilitating increased public and private sector research for early diagnosis and treatments of MPS disorders: Now, therefore, be it

1 *Resolved*, That the Senate—

2 (1) designates February 25, 2005, as “National

3 MPS Awareness Day”; and

4 (2) supports the goals and ideals of “National

5 MPS Awareness Day”.

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