

## 2013-J833

LEGISLATIVE RESOLUTION recognizing February 28, 2013, as National Rare Disease Day

WHEREAS, It is the custom of this Legislative Body to recognize official days that are set aside to increase awareness of serious issues that affect the lives of citizens of New York State; and

WHEREAS, Attendant to such concern, and in full accord with its long-standing traditions, it is the sense of this Legislative Body to recognize February 28, 2013, as National Rare Disease Day; and

WHEREAS, National Rare Disease Day is an observance held on the last day of February every year to raise awareness of rare diseases and to improve access to treatment and medical representation for individuals with rare diseases and their families; and

WHEREAS, In 2008, Rare Disease Day was established for the reason, according to the European Organization for Rare Diseases (EURORDIS), treatment for many rare diseases is insufficient, as are the social networks to support individuals with rare diseases and their families; and

WHEREAS, One year later, Rare Disease Day went global as the National Organization for Rare Disorders (NORD) mobilized 200 rare disease patient advocacy organizations in the United States in an effort to coordinate activities and better promote the day; and

WHEREAS, There are nearly 7,000 diseases and conditions considered rare, each affecting fewer than 200,000 Americans; and

WHEREAS, Of these 7,000 rare diseases, more than 80 percent of them are considered ultra rare, affecting less than a few thousand Americans; and

WHEREAS, While each of these diseases may affect small numbers of people, rare diseases as a group affect almost 30 million Americans; and

WHEREAS, Since many rare diseases are genetic, tragically, approximately half the people affected by rare diseases in the United States are children; and

WHEREAS, Research on rare diseases, which are serious and often life-threatening, is important because it frequently adds significantly to

the general understanding of more common diseases; and  
WHEREAS, People suffering from rare diseases typically experience difficulty in obtaining a timely, accurate diagnosis, finding physicians or treatment centers and experience limited treatment options and those options are generally more expensive than those for common diseases; and  
WHEREAS, It is imperative that there be greater public awareness of rare diseases, and more must be done to increase activity at the State, local and national levels to support those afflicted as well as their families; now, therefore, be it  
RESOLVED, That this Legislative Body pause in its deliberations to recognize February 28, 2013, as National Rare Disease Day.