

BY: M. of A. Lemondes

MEMORIALIZING Governor Kathy Hochul to proclaim April 29, 2023, as Undiagnosed Rare Disease Day in the State of New York

WHEREAS, It is the custom of this Legislative Body to recognize official months that are set aside to increase awareness of serious health 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, this Legislative Body hereby memorializes Governor Kathy Hochul to proclaim April 29, 2023, as Undiagnosed Rare Disease Day in the State of New York, in conjunction with the observance of National Undiagnosed Rare Disease Day; and

WHEREAS, In 2016, the Rare and Undiagnosed Network started the awareness campaign for an annual Undiagnosed Rare Disease Day to be held on April 29th of each year; and

WHEREAS, The main objective of this day is to raise awareness for the undiagnosed rare-disease community among the general public about the emotional, physical and financial impact on the lives of patients and their families; and

WHEREAS, Undiagnosed Rare Disease Day also celebrates those living with an undiagnosed disease and their families, as well as to remember the ones we have lost; and

WHEREAS, As many as 25 million Americans, about 1 in 13 people, suffer from a rare, undiagnosed condition; since 80% of undiagnosed diseases have identified genetic origins, it is imperative to raise awareness about the importance of genomics for undiagnosed disease patients; and

WHEREAS, Undiagnosed diseases are particularly troubling from the perspective that they leave patients, parents, family and caregivers bewildered in answering simple questions like why and how did this happen and what can we do about it; and

WHEREAS, This prognosis creates the additional challenge of what to do with no precedent to fall back on as well as those impacted having limited or no advocacy simply because of the lack of definition and prevalence; and

WHEREAS, In the case of a young girl, her medical fragility was so stark from multiple unrelated congenital problems that her medical team had no real sense of what to do other than treat each condition individually; and

WHEREAS, Undiagnosed disease can place a tremendous burden and uncertainty on primary caregivers, usually parents, and the direct

impacts on other young children, which may be extremely high at times but ultimately engenders seeds of empathy that the communities of these children, when they become adults, will benefit from greatly; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Kathy Hochul to proclaim April 29, 2023, as Undiagnosed Rare Disease Day in the State of New York; and be it further

RESOLVED, That copies of this Resolution, suitably engrossed, be transmitted to The Honorable Kathy Hochul, Governor of the State of New York, and to the Rare and Undiagnosed Network.