

BY: Senator RIVERA

MEMORIALIZING Governor Kathy Hochul to proclaim March 2022, as Alport Syndrome Awareness Month in the State of New York

WHEREAS, The State of New York takes great pride in recognizing serious genetic diseases by proclaiming official months to increase awareness of such concerns, which affect thousands of New Yorkers; and

WHEREAS, It is the sense of this Legislative Body to memorialize Governor Kathy Hochul to proclaim March 2022, as Alport Syndrome Month in the State of New York; and

WHEREAS, Since 2014, this month-long campaign has aimed to spotlight this rare, genetic kidney disease during National Kidney Awareness Month; and

WHEREAS, Alport Syndrome is a rare genetic disorder characterized by progressive kidney disease and abnormalities of the inner ear and the eye; and

WHEREAS, The disease we now know as Alport Syndrome was first described in the British medical literature in the early years of the 20th Century; in 1927, Dr. Cecil Alport published a paper describing the association of kidney disease and deafness in affected individuals, and in 1961, the disorder was named after Dr. Alport; and

WHEREAS, There are three genetic types: X-linked Alport syndrome (XLAS) is the most common, and affected males typically have more severe disease than affected females; autosomal recessive Alport syndrome (ARAS) the severity of disease in affected males and females is similar; and autosomal dominant form (ADAS) which affects males and females with equal severity; and

WHEREAS, The hallmark of the disease is the presence of blood in the urine (hematuria) early in life, with progressive decline in kidney function (kidney insufficiency) which ultimately results in kidney failure, especially in affected males; about 50% of untreated males with XLAS develop kidney failure by age 25, increasing to 90% by age 40 and nearly 100% by age 60; people with Alport Syndrome experience progressive loss of kidney function; and

WHEREAS, Alport Syndrome is often discussed with a related disorder known as thin basement membrane nephropathy (TBMN), in which the predominant pathologic abnormality is thinning of glomerular basement membranes; and

WHEREAS, Alport Syndrome is estimated to affect approximately 1 in 5,000-10,000 people in the general population in the United States, which means that approximately 30,000-60,000 people in the United States have the disorder; and

WHEREAS, It is imperative that there be greater awareness of this serious health condition, and more must be done to increase activity at local, State and National levels; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Kathy Hochul to proclaim March 2022, as Alport Syndrome Awareness Month in the State of New York, and to urge the citizens of this great Empire State to learn about the causes, symptoms, diagnoses and treatments for Alport Syndrome; and be it further

RESOLVED, That a copy of this Resolution, suitably engrossed, be transmitted to The Honorable Kathy Hochul, Governor of the State of New York.