Senate Resolution No. 461

**BY:** Senator RIVERA

**MEMORIALIZING** Governor Kathy Hochul to proclaim March 2025, 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 2025, 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 four genetic types: X-linked Alport syndrome (XLAS); autosomal recessive Alport syndrome (ARAS); autosomal dominant Alport syndrome (ADAS); and digenic Alport syndrome (a combination of Alport mutations); disease progression can vary based on genetic type; 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); there is currently no FDA-approved treatment to delay or stop renal function decline as a result of Alport syndrome; 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 less than 200,000 people in the general population in the United States making it a rare disease; while no exact prevalence data is available, increased access to genetic testing allows more patients to receive a confirmed diagnosis; 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 2025, 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.