Senate Resolution No. 945

BY: Senator MURRAY

MEMORIALIZING Governor Kathy Hochul to proclaim July 2025 as MECP2 Duplication Syndrome Awareness Month in the State of New York

WHEREAS, MECP2 duplication syndrome is usually caused by duplication of DNA on the Xq28 region of the chromosomes; and

WHEREAS, Despite MECP2 duplication syndrome's being a neurodevelopmental disorder, it causes multisystemic health problems, such as severe gastrointestinal symptoms, frequent respiratory infections, and treatment-resistant seizures; and

WHEREAS, Some individuals have large duplications which include many other genes, and the full extent of phenotypes, due to duplication of other genes, is not completely understood at this time; and

WHEREAS, Recent studies have shown a link between MECP2 duplication syndrome and autism, and many with this syndrome do have distinct features of autism; and

WHEREAS, Patients with MECP2 duplication syndrome are highly responsive to proper stimulation such as education, exercise, music, age-appropriate social interactions, and related activities; and

WHEREAS, MECP2 duplication syndrome can cause significant anxiety, depression, and emotional exhaustion for caregivers; and

WHEREAS, MECP2 duplication syndrome was not formally recognized until 2005; and

WHEREAS, MECP2 duplication syndrome research, which has shown that symptoms of the disorder can be reversed in mice, using a small anti-sense oligonucleotide, gives hope for the future development of effective treatments for humans with this disorder; and

WHEREAS, Clinical readiness studies have been done to identify ways to monitor response to therapy and ensure safety as a preparation for future clinical trials; and

WHEREAS, Natural history studies are ongoing to define the natural course of MECP2 duplication syndrome over the span of 12-18 months to prepare for the start of clinical trials; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Kathy Hochul to proclaim July 2025 as MECP2 Duplication Syndrome Awareness Month in the State of New York; 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.