Senate Resolution No. 1649

BY: Senator MURRAY

MEMORIALIZING Governor Kathy Hochul to proclaim June 30, 2026, as Arthrogryposis Awareness Day in the State of New York

WHEREAS, It is the custom of this Legislative Body to recognize official days that are set aside to increase awareness of serious health conditions 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 is justly proud to memorialize Governor Kathy Hochul to proclaim June 30, 2026, as Arthrogryposis Awareness Day in the State of New York; and

WHEREAS, Arthrogryposis Multiplex Congenita (AMC) is a rare condition that occurs in utero where there are multiple congenital (from birth) joint contractures, or multiple joints that are stuck in one position and have very little flexibility, resulting in low muscle tone; and

WHEREAS, Translated, arthro means joint, gryposis means crooked, multiplex means multiple, and congenita means existing at birth or present at birth; and

WHEREAS, Arthrogryposis is an umbrella diagnosis with many syndromes and subtypes and occurs 1 in 3,000 live births; AMC is non-progressive but the contractures can recur after treatment; furthermore, all joints, including the spine and the jaw, can be affected; and

WHEREAS, Currently, there are 400 identified types of Arthrogryposis such as Amyoplasia and Distal; some individuals never have their type of Arthrogryposis identified; and

WHEREAS, Most distal Arthrogryposis types and most syndromes (like Escobar, Sheldon-Hall) are genetic in origin; 20-30% of babies born with AMC will die in the newborn period because they have a lethal genetic type or they have severe central nervous system dysfunction; and

WHEREAS, Approximately 1/3 of cases of AMC are amyoplasia type which is non-genetic and sporadic in the population; and

WHEREAS, The cause of Arthrogryposis is not fully known at this time but may be due to an unborn baby not moving properly during fetal development; movement is vital to proper joint development; and

WHEREAS, Common joint contractures include: clubbed feet or vertical talus, extended or flexed knees, dislocated and/or externally rotated hips, internally rotated shoulders, extended or flexed elbows, flexed wrists, adducted thumbs (stuck-in-palm), and fingers are fisted or extended; and

WHEREAS, While there is no cure for AMC, stretching the joints multiple times per day, serial casting, various therapies (physical, occupational, and speech), splinting, bracing, tendon releases and lengthening, osteotomies (bone cuts), and external fixators can help improve a person's independence level and quality of life; and

WHEREAS, Despite the fact there is no cure for AMC, most children with Arthrogryposis grow up to be independent and successful adults; and

WHEREAS, On June 30, 2026, families across the State of New York and the Nation will be wearing the color blue to honor those affected by Arthrogryposis; and

WHEREAS, Increased awareness and expanded knowledge of Arthrogryposis, as well as its impact on the quality of life of those affected, will allow the community-at-large to better support people who struggle with the challenges of this disorder; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Kathy Hochul to proclaim June 30, 2026, as Arthrogryposis Awareness Day 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.