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LRB099 12545 GRL 36017 r

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SENATE RESOLUTION

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WHEREAS, X-Linked Myotubular Myopathy is a genetic neuromuscular disorder characterized by muscle weakness; most affected individuals have a severe form of the disease that can cause diminished muscle tone, feeding difficulties, and severe breathing complications; and

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WHEREAS, X-Linked Myotubular Myopathy symptoms are often present at birth and almost exclusively in males; it is estimated that 1 out of every 50,000 male babies born will have X-Linked Myotubular Myopathy; and

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WHEREAS, Respiratory distress may cause affected infants to require constant and prolonged mechanical ventilation, which carries many risks such as recurrent infection, inadequate shallow breathing, and lack of oxygen in the blood; individuals with X-Linked Myotubular Myopathy usually survive only into early childhood; and

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WHEREAS, Poor muscle development can cause delays in motor skill milestones; most individuals are unable to walk and require assistance for normal daily activities; for affected individuals who live into adulthood, additional symptoms include bone fractures, malformation of the hip, and scoliosis; and

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1 WHEREAS, X-Linked Myotubular Myopathy is caused by
2 mutations in the MTM1 gene; molecular genetic testing can
3 detect a mutation in 60 to 98 percent of affected individuals;
4 and

5 WHEREAS, Treatment of X-Linked Myotubular Myopathy is
6 focused on the specific symptoms experienced by each affected
7 individual and usually requires intensive medical
8 intervention; there are ongoing studies to identify more
9 effective treatment therapies; therefore, be it

10 RESOLVED, BY THE SENATE OF THE NINETY-NINTH GENERAL
11 ASSEMBLY OF THE STATE OF ILLINOIS, that we designate June 17,
12 2015 as X-Linked Myotubular Myopathy Awareness Day in the State
13 of Illinois in order to bring attention to those affected by
14 this disorder and the efforts of many to identify better
15 treatment for those individuals.