

Limb Girdle Muscular Dystrophy Awareness Day Sample Proclamation

Whereas, Limb Girdle Muscular Dystrophy (LGMD) is considered a rare disease that is known to cause muscle weakness and wasting;

Whereas, LGMD most commonly affects muscles closest to the body (proximal muscles), specifically the muscles of the shoulders, upper arms, pelvic area, and thighs.

Whereas, LGMD isn't really one disease but a group of hereditary, genetic, neuromuscular disorders with over 30 sub-types currently identified;

Whereas, LGMD occurs among all ethnic groups affecting both males and females;

Whereas, LGMD symptoms can begin in childhood, adolescence or adulthood;

Whereas, LGMD is a progressive, serious and debilitating condition that has a significant impact on the lives of those affected;

Whereas, individuals and families affected by LGMD often experience problems such as diagnosis delay, difficulty finding a medical expert, and lack of access to treatments or ancillary services;

Whereas, research is ongoing and important advances are being made everyday in understanding the genetic causes for the disease, there is still no known cure or treatment.

Whereas, while the public is familiar with some rare disease such as, ALS, and sympathetic to those affected, many patients and families affected by LGMD bear a large share of the burden of raising public awareness to support the search for treatments;

Whereas, a global collaborative of LGMD focused foundations and individuals living with LGMD have organized a global day of awareness on September 30, 2018;

Whereas, patients, caregivers, medical professionals, researchers and others in the state of (NAME OF STATE) will participate in that observance;

Therefore, be it resolved that September 30, 2018, will be observed as LGMD Awareness Day in (NAME OF STATE)