

# International Myotonic Dystrophy Awareness Day

## Sample Language – Local Monument Lighting Request

**Name of Event:** International Myotonic Dystrophy Awareness Day

**Description of Event:** September 15th will mark the first ever [International Myotonic Dystrophy Awareness Day](#) across the globe! A Global Alliance of over 40 nonprofits/NGOs, health care providers, academic and private research labs, biotech and pharmaceutical companies, and other entities from over 15 countries have joined together to raise awareness of myotonic dystrophy. Myotonic dystrophy is a genetic neuromuscular disease often considered the most variable disease in medicine due to the significant range of symptoms experienced at all stages of life, as well as the multiple body systems it affects. Every person can experience the disease differently, even within the same family, and symptoms usually increase in severity with each new generation. There is currently no treatment and no cure.

Along with the Global Alliance, families, friends, and communities in dozens of countries worldwide are mobilizing to hold activities leading up to and on September 15th. These awareness raising activities include: social media campaigns estimated to reach up to two million people; a United States Senate Resolution declaring September 15th as International Myotonic Dystrophy Awareness Day in the United States - with similar proclamations being planned in other jurisdictions; extensive efforts to educate healthcare providers and policy makers across the globe; lighting of landmarks and monuments; sports field jumbotron; fundraisers for programs and services; and much more.

Raising awareness of myotonic dystrophy, a rare disease estimated to affect approximately 1 in 2,100 people, will help lead to improved medical care, increased funding for research, diagnostic screening, drug development, and stronger policymaking. Increased awareness amongst families, healthcare providers, law-makers and regulators, and our greater international community will serve to improve health outcomes, reduce disability, and increase life expectancy for individuals living with the disease. It will also serve to increase collaborative efforts to accelerate advances in research on myotonic dystrophy.

**We want to light up our local monument/landmark in green to symbolize the day and help others learn about this disease! Learn more about the Global Alliance and International Myotonic Dystrophy Awareness Day here: <https://www.myotonic.org/international-dm-day>**