



MYOTONIC
DYSTROPHY
FOUNDATION

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Contact: [Molly White](#)
Myotonic Dystrophy Foundation
Phone: 415-800-7777
E-mail: admin@myotonic.org

**Myotonic Dystrophy Foundation Recognizes Rare Disease Month
by Unveiling Hope and Inspiration Video**

SAN FRANCISCO, CA (February 19, 2014): In recognition of Rare Disease Month and [Rare Disease Day](#) The Myotonic Dystrophy Foundation (MDF) has released “[Hope and Inspiration](#)”—a short eight minute video that brings attention to myotonic dystrophy (DM), the community of people living with it and the compelling scientific advances that have made it the global poster child for neuromuscular disorders

Described as “the most variable of all diseases found in medicine,” DM is an inherited disorder that can appear at any age and manifests differently in each individual. The most common form of adult-onset muscular dystrophy, DM affects somewhere between 1:3,000 and 1:8,000 people worldwide. DM can cause muscle weakness, atrophy and myotonia, as well as problems in the heart, brain, GI tract, endocrine, skeletal and respiratory systems. There is currently no treatment or cure.

“Right now I feel the public doesn’t know much about myotonic dystrophy, but it’s getting there,” says Will Florence, age 14, whose brother Sam, 12, has DM and is featured with him in the video. “It effects his muscles mostly, and the heart, lungs and brain, and he’s not able to focus for very long.”

The video also includes Dr. John Day of Stanford University and Dr. Eric Wang of MIT, who describe the status of research and the tremendous advances in DM science that are bringing hope to people living with DM and their caretakers.

Dr. Day notes: “The implications of treatment of this condition are quite profound. DM has not only showed us that there is a new mechanism that can operate at the RNA level and cause disease; it has also allowed us to see that we can manipulate disease processes at the RNA level and treat any number of neurological and neurodegenerative diseases.”

MDF has released this video as part of the recognition of Rare Disease Day 2014, an annual global event held in February to focus attention on rare diseases as a public

health concern. Each year, Rare Disease Day is observed and celebrated on the last day of February (February 29 in leap years, and February 28 in other years).

About the Myotonic Dystrophy Foundation: The Myotonic Dystrophy Foundation (MDF) is the world's largest DM patient advocacy organization. Its mission is Care and a Cure: to enhance the lives of people living with myotonic dystrophy, and advance research efforts focused on finding treatment and a cure for this disorder through education, advocacy and outreach.

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