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FOR IMMEDIATE RELEASE

Myotonic Dystrophy Announces Success With the Publication of the MDF 2014 Fund-a-Fellow Program Assessment

SAN FRANCISCO, CA (March 28, 2014): The Myotonic Dystrophy Foundation (MDF) has published the results of its first-ever Fund-a-Fellow Program Assessment measuring the impact of the first five years of its post-doctoral fellowship grant program. The assessment was designed to evaluate whether the program met its objectives, which include:

- Attracting new scientists to the field of myotonic dystrophy (DM) research;
- Increasing overall funding and activity in the field of DM research;
- Expanding knowledge and understanding of DM;
- Increasing the number of labs and academic programs engaged in or expanding their engagement in DM research

The assessment was based on the following participation:

- 8 of 11 Fellows responded: 73 percent response rate;
- 7 of 10 Principal Investigators (PI's) responded: 70 percent response rate

The Fund-a-Fellow program provides post-doctoral students within three years of receiving their doctorate a grant of \$100,000 over two years to conduct clinical, basic, or applied research in any of the following areas:

- Pathogenesis of myotonic dystrophy;
- Studies of disease progression that are necessary steps toward therapeutic trials;
- Best practices and management of myotonic dystrophy;
- Therapeutic and diagnostic development

“The assessment results show that we are indeed attracting interest and retaining researchers in myotonic dystrophy research with 71 percent of respondents reporting they’ve remained in the DM field, and 75 percent reporting that the fellowship was ‘very important’ or ‘important’ in their efforts to do so,” explains Eriko Nasser, research director at MDF. “MDF’s fellowships have proven to be an important program in MDF’s effort to fulfill its mission of Care and a Cure for DM patients by engaging postdoctoral research students early in their career and influencing the focus of their life’s work.”

A majority (60 percent) of MDF Fellows have gone on to secure additional research funding from organizations such as the National Institutes of Health (NIH) and have authored important research publications to help drive interest in DM at academic research institutions and pharmaceutical companies. “By providing funding for DM fellowships, MDF is helping influence participation in DM research. Once there is a

researcher established in a lab, then other connections to the disease and to funding are often created,” notes Nasser.

While overall the assessment results were very positive, opportunities were identified to enhance the program’s impact, including:

- Expanding FAF funding;
- Creating partnerships between participating labs, organizations and research institutions; and
- Further engagement opportunities with principal investigators and key research colleagues in the Fellow’s lab. Says Ms. Nasser, “The opportunities outlined in the assessment are all important issues that we plan to address. With confirmation provided by this successful program assessment, we can continue to make the case for growing support for DM research.”

For more information about the assessment and the findings call MDF at (415) 800-7777.

About Myotonic Dystrophy: Described as “the most variable of all diseases found in medicine,” myotonic dystrophy is an inherited disorder that can appear at any age and that manifests differently in each individual. The most common form of adult-onset muscular dystrophy, DM affects somewhere between 1:3000 and 1:8000 people in the US and worldwide, and 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 for DM.

About the Myotonic Dystrophy Foundation: The Myotonic Dystrophy Foundation is the world’s largest DM-only patient 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 treatments and a cure for this disorder.

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