JAIN FOUNDATION INC

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Dear Clinician or Researcher:

You are receiving this letter because you have submitted sequence variants to the dysferlin database at the Leiden Muscular Dystrophy pages. I am writing to inform you about a new foundation relevant to patients with mutations in the dysferlin gene and/or have a diagnosis of LGMD2B or Miyoshi Myopathy. The Jain Foundation (www.jain-foundation.org) was established by an endowment from the Jain family on September 1, 2005. The Jain Foundation is fully funded by private donors and does NOT ask for financial contributions from patients or physicians.

Our goal is to hasten development of a cure or therapy for LGMD2B/Miyoshi. Our strategy is to:

1. Fund scientific research and the development of therapies/cures/drugs that target dysferlin deficiency (the cause of LGMD2B/Miyoshi)
2. Develop a patient registry for use in clinical trials relevant to LGMD2B/Miyoshi
3. Advocate for inclusion of LGMD2B/Miyoshi patients in clinical trials of existing therapies
4. Provide funding for clinical trials of new LGMD2B/Miyoshi drugs/therapies
5. Provide support and access to diagnostic resources and information about LGMD2B/Miyoshi

Because this is a rare disease, the symptoms, disease progression, and molecular analysis of each patient is very important to improving our understanding of the disease. In addition, through the registration of patients, we can determine the true incidence of LGMD2B/Miyoshi and highlight its importance to scientists, clinicians, and drug/pharmaceutical companies worldwide. Furthermore, patient recruitment has become a limiting step for many clinical trials, especially trials that require knowledge of each patient's genetic mutations. Such mutation-targeted therapies are becoming much more common, and it is more and more difficult for patients who have not been fully diagnosed to the point of identifying mutations in both copies of their dysferlin gene to enroll in trials. Patient recruitment for clinical trials is particularly difficult in the case of rare diseases like LGMD2B/Miyoshi.

The Jain Foundation is doing its best to address these issues for LGMD2B/Miyoshi patients, but cannot succeed without your help in reaching out to patients.

Please point all of your patients with LGMD2B/Miyoshi (with and without genetic confirmation) to the existence of the Jain Foundation: (www.jain-foundation.org/patients.php)

Patients who register will have access to the following services:

- Information about ongoing or upcoming clinical trials relevant to their disease
- A source of knowledge about treatment options that are under development
- Financial support for gene mutation analysis (a $2000USD value) in cases where this diagnostic step is warranted (for example: confirmed absence/reduction of the dysferlin protein)
- General information about LGMD2B/Miyoshi

For additional information about the Jain Foundation, please feel free to contact Dr. Laura Rufibach. Her contact information can be found at the top of this letter. Dr. Rufibach can be reached any time by phone or email. She will be very happy to hear from you and answer any questions you might have.

Thank you very much for your consideration and your efforts on behalf of these patients.