

Exciting opportunity for Titin families and affected individuals!

Muscle imaging, either in the form of muscle MRI, cardiac MRI, and muscle ultrasound, is an exciting area of clinical research -- not only for the purpose of diagnosis but also for use as an indicator of disease progression over time. To date, no one has described and documented a significant number of Titin myopathy patients according to their muscle imaging appearance. At the world-renowned National Institutes of Health (NIH) in Washington DC, near the capital of the United States of America, they are offering free MRI and ultrasound imaging to characterize what muscle looks in neuromuscular disorders.

Incentives for Titin families and individuals to take advantage of this opportunity are great, and include:

1. Reimbursement of all expenses to travel to the NIH (the visit will span over 2-3 days)
2. Patients/families stay at the Children's Inn, which is comfortable for all, and specifically set-up for families with medically fragile children

For more information and to arrange for your visit to the NIH, please contact Dr. Naz Dastgir at jahannaz.dastgir@nih.gov or PHONE 301-435-1507 or Sandra Donkervoort at sandra.donkervoort@nih.gov or PHONE 301-496-0272.