

LGMD-1D DNAJB6 Foundation

and

MYOSYND™

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8/7/2023

Summer Edition

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Table of Contents:

LGMD Conference 2023	Page 2
Important Links	Pages 3-4
Ways to Donate	Page 5

Summertime

The Foundation is taking advantage of the lazy days of summer, like the famous song in the musical Porgy and Bess, to prepare for the exciting fall International LGMD conference in Washington, D.C. Please follow the links for information and registration below. Our vice president, Natasha Lowery, will be hosting our Foundation table on the Friday afternoon reception October 27th. I will make select lecture videos available in our video archive for those who cannot attend. We look forward to a good time.

2023 LGMD Conference

October 27-29, 2023

Register [HERE](#)

[LGMD NEWS](#)

(latest edition)

Important Links

Since our inception in 2018 we have collected links to help everyone's journey. Due to the onboarding of new members and new links I am adding this as an evergreen list to our newsletter.

MDA Connect: <https://www.mda.org/care/connect>



MDA Connect: Helps find a neuromuscular doctor near you!

[LGMD1D DNAJB6 Foundation](#)

[LGMD1D Foundation YouTube Archive](#)

[LGMD1D Foundation assisted sponsored genetic testing](#)

[LGMD1D Foundation Autosomal Dominant Registry](#)

[LGMD1D Foundation: Solving Your Variant of Uncertain Significance \(VUS\)](#)

Sponsored Whole Genome Sequencing: (next step for VUS resolution)

[NIH](#)

[Harvard](#)

[Stanford Center for Undiagnosed Diseases](#)

Do I really have a genetic muscle disorder? See [HERE](#)

Do I have a mitochondrial muscle condition? [Video1](#), [Video2](#)

United Mitochondrial Disease Foundation (UMDF) Genetic Testing For Suspected Mitochondrial Disease Program [HERE](#) . Sponsored testing that clinicians can order if a mitochondrial disease is strongly suspected.

Are You Having a Muscle Biopsy?

[Tissue referral to University of Iowa](#)

[University of Iowa Muscle Biopsy Requisition](#)

Gene matching sites, you must register all your VUS variants to connect with others to help establish a genetic diagnosis: [MyGene2](#), [GenomeConnect](#), [Rare-X](#)

Sponsored flights for rare conditions [HERE](#) and [HERE](#).

[Joe's House](#) (discount lodging for patients with cancer and rare conditions)

Ways to Donate

1. [OUR WEBSITE](#) (a secure site with all the listings below)
2. [PAYPAL](#) (Our foundation's secure site)
3. [CREDIT CARD](#) (Network For Good credit card portal)
4. [VENMO](#) (@lgmd1d) Foundation Account
5. [EVERY.ORG](#) (ALL CRYPTO CURRENCIES)
6. [SQUARE](#)
7. **If you are over 72 consider a Qualified Charitable Distribution (QCD) from a traditional IRA and lower that dreadful RMD and avoid that higher tax bracket. Also available to Roth IRA participants.**

RMD calculator [HERE](#), medicare income bracket [HERE](#).
tax bracket for SS [HERE](#).

Thank you for your support and all the best from us!

William Lowery MD

