

# **LGMD-1D DNAJB6 Foundation**

**and**

**MYOSYND™**

**A 501 (C)(3)**

**A Holiday Newsletter**

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# **2021 Reflections**

**The Foundation saw green shoots appear in 2021 as research studies opened up for patient enrollment. This included virtual intakes to research studies as a necessary adaptation to the Covid epidemic. Thanks to your generosity the Foundation was able to donate 12,000 dollars toward supplementing travel expenses for financially strapped patients.**

**In addition, our registry of autosomal dominant forms of limb girdle muscular dystrophy (LGMD) continues to grow. We are approaching 100 participants in our registry and have collaborated with informal groups to be “research ready” for all members.**

**The proliferation of genetic testing techniques and sponsored genetic testing in 2021 has been a windfall for the Foundation. We were able to facilitate testing in over 200 people (including family members) and this resulted in 30% of those persons achieving an exact genetic diagnosis for their LGMD. In short, there are too few general physicians that can bridge the gap between a person’s primary symptom and a genetic diagnosis. To put that in perspective, there are 7 to 8,000 known monogenic disorders affecting persons who will have limited access to these genetic techniques.**

**The Foundation had a role in many virtual conferences this year including the International LGMD Conference, Rare Disease, Global Genes and International CRISPR day. We had a presence in the Rare Disease Legislation Conference and LGMD FDA Patient Listening Session.**

# 2022 Projections

**We anticipate many new diagnostic and therapeutic breakthroughs in 2022. Not only in the rare monogenic diseases but also advances in common conditions like diabetes, cholesterol and heart disease. Gene therapy can now turn dormant cells in the pancreas, liver and heart into cells that replenish these organs and thus the body. These leaps of science have occurred in animal studies thus far but the Foundation follows these developments and chronicles them as best we can in our quarterly newsletters.**

**Finally, the Foundation will continue our commitment to our core mission of fundraising for the LGMD community. We maintain a platinum status as an assurance of fidelity and transparency.**



# Giving

1. [OUR WEBSITE](#) (a secure site with all the listings below)
2. [AMAZON SMILE](#) (list the LGMD-1D DNAJB6 Foundation for donation with each purchase at no cost to you.)
3. [PAYPAL](#) (Our foundation's secure site)
4. [CREDIT CARD](#) (GuideStar charity's secure portal)
5. [VENMO](#) (@lgmd1d) Foundation Account
6. Accepting all crypto currencies [HERE EVERY.ORG](#)
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 for your holidays and 2022.**

**William Lowery MD**