

**LGMD-1D DNAJB6 Foundation**  
**and International Autosomal Dominant**  
**Muscular Dystrophy Registry**  
**and**  
**MYOSYND™**

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**The Newsletter 11/20/20**

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## Taking Stock of 2020

**Making Lemonade:** As we focused in our last newsletter, Covid has delayed research studies but creative minds have advanced virtual studies thanks to the explosion of video conferencing. In addition, the foundation leadership has participated in virtual international conferences not traditionally available to the budget constrained. ([Global Genes](#), [NORD](#), [Treat NMD](#), [World CRISPR Day](#) and [FDA Listening Session for LGMD](#))

**MYOSYND™** (our “myopathy syndicate”) was formed in 2020 as a subsidiary of the foundation to register all persons with autosomal dominant muscular dystrophies, their support persons and associated foundations with similar goals. To date we have 80 individuals and added a new group, the Myofibrillar Myopathy organization. We encourage not only affected individuals but their families and friends to join as one voice since our conditions are not experienced in isolation. Patients may register [HERE](#) and support persons [HERE](#) .

**MYOSYND™ and the LGMD1D Foundation are in collaboration with Treat NMD to be included in an international database to advance opportunities for research.**

**Finally, sponsored genetic testing has given us the opportunity to help multiple families around the US and Canada arrive at specific genetic diagnoses. We have found this very rewarding and have over 100 individuals of which 8 families have participated in the last 3 months. (more on sponsored testing below)**

# Sponsored Genetic Testing

As mentioned above we have access to free genetic testing for muscular dystrophy which has been a big hit. To apply please follow this link: [FREE MUSCULAR DYSTROPHY GENETIC TESTING HERE](#)

Many doctors are not comfortable ordering genetic tests however we have been able to do this with widespread patient and primary care doctor acceptance. The sponsored testing encompasses many other areas and diseases not specifically in our expertise but we would be willing to assist patients, families and primary care doctors in search for a genetic diagnosis. ([Please see this list](#)) Again, this would be a selective process with full consent of a patient and their primary care doctor. Contact us for follow up: [wslowery.57@lgmd1d.org](mailto:wslowery.57@lgmd1d.org)

## Gene Matchmakers?

Yes, you knew it would only be a matter of time before a “Match.com” site would be available for people and their specific gene variants. Now this isn’t a site to post your gene for “blue eyes” and see who else has blue eyes, this is a serious site to post a known gene variant or an uncertain gene variant causing or suspected to cause a certain disease, however rare in hopes of connecting. This has tremendous social and research possibilities but first a genetic test must be done. The research we have done suggests 3 sites for public use:

[MyGene2](#): ready now.

[GenomeConnect](#): ready now.

[Rare-X](#): rolling out in December or January.

All are very protective of your data and you do not have to reveal any identification. This could be helpful for those persons with one or several “variants of uncertain significance.” I have registered on all three.

# Gene Therapy Developments 2020

The LGMD1D Foundation has been a proponent of gene therapy but realizes there are many other avenues to a cure for genetic diseases. A deeper dive into the depths of gene therapy are found [HERE](#).

Having said that, the [list of gene therapy](#) for specific diseases has been impressive in 2020.

Finally, a cloud that hangs over CRISPR gene editing is “[off target editing](#)”, however, progress has been made in the specificity and precision of [CRISPR editors](#).

The future looks good.

# Giving Tuesday 12/1/2020

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 secure site)
4. [CREDIT CARD](#) (GuideStar charity secure portal)
5. [VENMO](#) (@William-Lowery-24)  
(This Venmo account is the Foundation account and not personal)
6. **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.**

See your RMD calculator [HERE](#).

See your medicare income bracket [HERE](#).

See your tax bracket for SS [HERE](#).



**Thank you for your enduring support, William Lowery MD**