LGMD-1D DNAJB6 Foundation

and

MYOSYND™

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MDA Conference 2026

The MDA conference remains one of the highlights of the year each March. While the meeting is weighted more heavily toward ALS and SMA, many of the therapeutic advances presented have implications that extend well beyond those conditions and are relevant to the LGMD community. On our YouTube channel, I have selected four videos from the conference that I believe are especially valuable: exercise, trial preparation, gene therapy, and strategies for addressing insurance denials.

Outside the conference, several important developments are unfolding in the broader rare disease landscape. The FDA appears to be recalibrating its approach to help streamline therapy approval for rare diseases. At the same time, government proposals are being discussed that could improve access to treatment by helping cover costs, including outcome-based payment models in which therapies are reimbursed based on patient benefit.

For LGMD, three companies—Sarepta, Dyne, and Avidity—have reported early encouraging results with antisense oligonucleotide (ASO) therapies.

AI Is Here

AI has already shown remarkable progress: it has passed medical and legal-style exams, reached olympiad-level mathematics, contributed to Nobel-recognized protein structure research, and is beginning to perform impressively in diagnostic conversations. Taken together, these milestones show that AI is moving beyond novelty and becoming a practical tool for everyday professional life. At the foundation, we have continued to expand how we use it and now consider it indispensable. While there are several excellent large language models available—such as ChatGPT, Claude, and Gemini—we have found that one paid account, costing about $20 per month, can provide a highly effective cognitive companion for most intellectual work.

Please enjoy the story of the Australian dog Rosie and her owner Paul: When Rosie, a beloved dog in Australia, developed advanced cancer, her owner refused to give up hope. Using AI as a guide, he teamed up with scientists and doctors to help create a personalized cancer vaccine just for her. Rosie later began to improve, and her story became a touching example of what can happen when love, science, and new technology come together. It is not a miracle cure, but it is a hopeful glimpse of how compassion and innovation may open new doors for the future.

Our Evergreen AI Links

The foundation sponsors AI through Chat GPT and LLMs. We are providing QR access codes to our custom GPTs for the LGMD community which offer valuable assistance for our challenges. You will need a free Chat GPT account to use them, a paid account offers more utility.

LGMD ASSISTANT (find a clinic): Like most of us with LGMD, finding a neuromuscular doctor or clinic in your state or country can be problematic. With LGMD Assistant 3.0 you can type in your suspected variant, if known, and your state or country (be sure to ask for all addresses and phone numbers to be included) and the custom GPT will provide you with local MDA clinics and university hospital centers near you:

THERAPY: Autosomal dominant therapy questions for specific genetic variants answered here:

PLANNING A TRIP: LGMD person planning a trip to Atlanta, Paris, Rome or Riyadh? Check out Access Ally. Just type in the city and country, sites you want to visit and equipment you will need (ask for addresses and phone numbers of vendors to be included). The response will direct you to accessible facilities, rentals and all accommodations you will need. Do not forget to keep chatting with it to get all your questions answered:

LGMD INSURANCE NAVIGATOR: Having trouble getting authorizations for medications, DME or dreading the next insurance interaction, just type in your insurance and what you need and you will get answers. (again it may take several follow up chats but this will be very helpful, include available ICD 10 codes for LGMD subtypes and CPT codes below for what you need:

ICD-10-CM Diagnostic Codes for Limb Girdle Muscular Dystrophy (Effective for use beginning October 1, 2022–per CMS update)		
ICD-10-CM Code	**LGMD Subtype**	**Description**
G71.032	LGMD2A / R1	Calpain-3 dysfunction (calpainopathy)
G71.033	LGMD2B / R2	Dysferlin dysfunction
G71.0341	LGMD2D / R3	Alpha-sarcoglycanopathy
G71.0342	LGMD2C / R5 or LGMD2F / R6	Gamma or delta-sarcoglycanopathy
G71.035	LGMD2L / R12	Anoctamin-5 dysfunction
G71.038	Other genetically confirmed LGMD	Includes LGMD21 (FKRP), LGMD2 (TTN), etc.
G71.039	LGMD, unspescified	For cases wcithut confirmation
G71.031	LGMD1 (dominant)	Includes LMNA, MYOT, CAV3, etc.
G71.039	LGMB, unspesestified	Inlcudes LMNA, MYOT, C/

Common CPT codes for the LGMD community:

Service Type	CPT / HCPCS Codes
Walker / cane / platform	E0100–E0159
Seating / cushioning	E0181–E0199
Wheelchair accessories	E0992–E1002 etc.
Oxygen / respiratory support	E0424/E0431, E0468, E0470 etc.
Home ventilation	E0466
PT Evaluation	97161–97164
PT/OT Treatments	97110, 97530, 97542
Electrical stimulation	97032
Caregiver training	G0539, G0542
Psychosocial support	81404, 81405,81406, 81408

OUR WEBSITE:

Important MDA Links

MDA Connect: HERE and HERE

(Helps find a neuromuscular doctor near you!)

MDA camp for attendees and volunteers HERE

MDA college scholarship program HERE

An emergency preparedness plan is crucial for those with LGMD

Important Patient Care Links

1. **I have weakness but my genetic panel just shows "variants of uncertain significance" (VUS).**

   Step 1: Test other family members with and without symptoms and take results to a genetic counselor.

   Step 2 Consider sponsored whole exome sequencing (WES) and whole genome sequencing (WGS)

   Harvard, Stanford Center for Undiagnosed Diseases

2. **Do I really have a genetic muscle disorder? See HERE**

3. **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.

4. **Are you having a muscle biopsy?**

   Tissue referral to University of Iowa

   University of Iowa Muscle Biopsy Requisition

5. **Gene matching sites, you must register all your VUS variants to connect with others to help establish a genetic diagnosis: MyGene2, GenomeConnect, Rare-X**

6. **Sponsored flights for rare conditions HERE and HERE.**

7. **Joe's House (discount lodging for patients with cancer and rare conditions)**

Important Foundation Links

1. LGMD1D DNAJB6 Foundation
2. Foundation YouTube Archive
3. Foundation assisted sponsored genetic testing
4. Foundation Autosomal Dominant Registry
5. Foundation: Solving Your Variant of Uncertain Significance (VUS)
6. LGMD1D AI Assistance and LGMD Apps

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.

Thanks for your support and enjoy your summer!!

William Lowery MD