LGMD-1D DNAJB6 Foundation

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SUMMER EDITION 2026

Community & Research Briefing

Practical tools, trusted links, and plain-language support for families affected by LGMD

AI TOOLS
Clinic finder, travel, insurance prep

CARE LINKS
Genetics, biopsy, mitochondrial resources

FOUNDATION
Programs, registry, videos, donations

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Platinum Transparency 2026
Candid.

Community Updates and Advocacy

New federal attention for LGMD, plus a simple way to walk together as a community.

LGMD Included in FY27 House Appropriations Report

In a historic milestone, **LGMD has been officially included in the FY27 House Appropriations Report**. Led by The Speak Foundation and patient advocates, this language brings federal attention to the 30+ forms of LGMD — calling for advances in biological research, cross-subtype therapies, natural history studies, and robust biomarkers.

The next advocacy focus is the **U.S. Senate**, where community voices can help keep this momentum moving toward better treatments and an ultimate cure.

Open House Report ■

Join the LGMD Community 5K Walk

The **LGMD-Info community** is sponsoring a 5K walk with registration through its website. Registration includes a partially sponsored t-shirt with a $10 fee. Participants may donate to the LGMD1D community, another LGMD community, or choose not to donate — a friendly way to show visible support across LGMD subtypes.

Register for the 5K ■

■ **Helpful Reminder:** Share the 5K link with family and friends who want a low-pressure way to participate. Personal stories continue to matter — especially as attention shifts to the Senate.

Gene-Targeted Therapy Watch

Research signals from autosomal dominant conditions — not LGMD-1D treatments, but relevant for families following gene-targeted medicine.

FSHD: del-brax Update

Delpacibart braxlosiran is designed to reduce DUX4 activity in FSHD. A Phase 1/2 biomarker cohort showed lower markers of abnormal protein production and muscle damage. A Phase 3 study is now recruiting.

Read FSHD Article ■

Huntington's: AMT-130

AMT-130 is a one-time investigational HD gene therapy. UCL reported high-dose participants showed **75% less disease progression** over 36 months vs. a matched natural-history group. More study and regulatory review are still needed.

Read UCL Update ■

Why This Matters for LGMD Research

The common theme is **precision**: identify the mechanism, measure it with biomarkers, and build clinical trials around meaningful change. That same path — mechanism, natural history, biomarkers, and trial readiness — is central for LGMD-1D research momentum.

At-a-Glance Resource Guide

Start with the question you have today. Each card links directly to the resource.

■ Find a Neuromuscular Clinic

Use MDA Connect to identify care centers and gather contact details by state or region.

Open MDA Connect ■

■ I Have a VUS or Uncertain Result

Review family testing, genetic counseling, and WES/WGS options with your clinician.

VUS Resources ■

■ Insurance or DME Help

Use the Navigator to organize codes, clinical documentation, and follow-up questions.

Insurance Navigator ■

❤■ Support the Foundation

Donate by website, PayPal, credit card, Venmo, Every.org crypto, or Square.

Foundation Website ■

■■ **ChatGPT Access Note:** Some QR codes open custom ChatGPT tools. A free ChatGPT account is sufficient for all AI features in this newsletter, including the Insurance Navigator.

Evergreen AI Tools for the LGMD Community

Custom ChatGPT tools — free version is sufficient. Use AI output as a preparation aid only.

LGMD Assistant 3.0

Helps locate neuromuscular clinics by state or country. Ask for addresses, phone numbers, and major academic centers.

Open Tool ■

Autosomal Dominant LGMD Therapy

Supports general therapy and research questions by genetic variant. Bring clinical questions to your care team.

Open Tool ■

Access Ally

Helps plan accessible travel. Enter the city, sites, mobility equipment needs, and vendor information requested.

Open Tool ■

LGMD Insurance Navigator

Helps prepare for insurance conversations about DME, authorizations, ICD-10 codes, and CPT/HCPCS codes.

Open Tool ■

■ **Suggested Prompt Style:** Be specific — include your country/state, variant if known, the task you need help with, and ask for phone numbers or source links when relevant.

Clinic-Finding and MDA Resources

Resources for finding care, summer camp, scholarship support, and MDA navigation.

MDA Connect

30-minute video calls with an MDA Specialist help families locate resources and navigate MDA programs.

Open MDA Connect ■

MDA Care Center Network

Search MDA Care Center locations and learn about multidisciplinary neuromuscular care near you.

Open Link ■

MDA Summer Camp

Information for campers and volunteers in the MDA Summer Camp program.

Open Link ■

MDA College Scholarship

Scholarship information for students in the neuromuscular community.

Open Link ■

■ **How to Use This Page:** For new symptoms or changing function, use these links to prepare for a neuromuscular-care discussion. Keep clinic phone numbers, addresses, and referral requirements in one folder for easier follow-up. For urgent symptoms, use local emergency services.

Diagnosis, VUS, and Testing Resources

A patient-friendly pathway for uncertain genetic results and related diagnostic questions.

1

Test Family Members

Discuss testing symptomatic and unaffected relatives with a genetic counselor.

2

Consider Deeper Sequencing

Ask whether whole exome (WES) or whole genome sequencing (WGS) is appropriate.

3

Register Your Variant

Gene-matching platforms connect families and researchers studying the same variant.

Click-Through Resource List

- **Foundation VUS Resolution**
  Articles on variants of uncertain significance
- **NIH Rare Genomes**
  Rare genome sequencing program for LGMD
- **Harvard Personal Genome Project**
  Open genome sequencing and data sharing
- **Stanford Undiagnosed Diseases**
  Stanford program for complex undiagnosed cases
- **Do I Really Have a Genetic Muscle Disorder?**
  Foundation newsletter on diagnostics
- **UMDF Genetic Testing**
  For suspected mitochondrial disease
- **Mitochondrial Disease Video 1**
  Educational video on mitochondrial disease
- **Mitochondrial Disease Video 2**
  Additional educational resource

Care Logistics and Rare-Disease Support

Practical links for biopsy planning, gene matching, travel assistance, and lodging.

Muscle Biopsy

- U. Iowa Muscle Biopsy Info
- Biopsy Requisition Form

Scan primary link

Gene Matching

- MyGene2
- GenomeConnect
- Rare-X

Scan primary link

Travel and Lodging

- Angel Flight
- Patient AirLift Services
- Joe's House

Scan primary link

■ **Editor Note:** For complex testing, biopsy decisions, travel support, or lodging programs, eligibility and referral requirements may vary. Use these links to prepare questions for the appropriate clinical, program, or support team.

Foundation Programs and Archives

Home base for the LGMD-1D DNAJB6 Foundation — programs, registry, educational videos, and more.

Foundation Website

Home base for the LGMD-1D DNAJB6 Foundation.

YouTube Archive

Recorded lectures and educational content.

Sponsored Genetic Testing

Foundation-assisted no-cost genetic testing information.

Autosomal Dominant Registry

Registry for autosomal dominant LGMD.

VUS Resolution Resources

Articles and resources on variants of uncertain significance.

Scan for Foundation Website

Insurance, DME, and Code Reference

LGMD Insurance Navigator

Requires free ChatGPT. Helps prepare for authorizations, DME requests, medication questions, and follow-up calls.

Open Tool ■

■■ **How to Use Codes Responsibly:** Codes are reference points for clinician and payer discussions. Coverage, coding, and documentation requirements can change — confirm any submission with your clinician, billing team, or plan representative.

ICD-10-CM Diagnostic Codes for LGMD

Effective for use beginning October 1, 2022, per CMS update. Confirm coding with the clinician, billing team, or plan.

ICD-10-CM	LGMD Subtype	Description
G71.031	LGMD1 (dominant)	Includes LMNA, MYOT, CAV3, etc. — covers LGMD-1D/DNAJB6
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 LGMD2I (FKRP), LGMD2J (TTN), etc.
G71.039	LGMD, unspecified	For cases without genetic confirmation

CPT / HCPCS Code Reference for DME and Services

Common procedure codes used in discussions with insurers, billing teams, and DME suppliers. Coverage, documentation requirements, and applicable codes can vary by plan and change over time. Always confirm codes with your clinician or billing team before submission.

■ Use the **LGMD Insurance Navigator** (previous page) to help prepare documentation, organize prior authorization requests, and formulate follow-up questions.

Service Type	CPT / HCPCS Examples	Notes
Walker / cane / platform	E0100–E0159	Basic ambulation aids
Seating / cushioning	E0181–E0199	Pressure-relief seating
Wheelchair accessories	E0992–E1002 etc.	Requires medical necessity documentation
Oxygen / respiratory support	E0424/E0431, E0468, E0470	Includes portable and stationary O■
Home ventilation	E0466	Non-invasive positive pressure
PT evaluation	97161–97164	Low / moderate / high complexity
PT/OT therapeutic exercises	97110, 97530, 97542	Therapeutic exercise, activity, wheelchair mgmt
Electrical stimulation	97032	Manual electrical stimulation
Caregiver training	G0539, G0542	Individual and group caregiver training
Psychosocial / genetic support	81404, 81405, 81406, 81408	Molecular pathology tier codes

■ **Reference examples only.** Coverage and documentation requirements can change. Confirm any code with your clinician, billing specialist, or insurance plan representative before use.

Ways to Support the Mission

Every donation directly supports research, registry maintenance, and family programs.

Website

Secure foundation website

Donate / Open ■

PayPal

Foundation secure PayPal

Donate / Open ■

Credit Card

Network for Good portal

Donate / Open ■

Venmo

@lgmd1d Foundation

Donate / Open ■

Every.org Crypto

Cryptocurrency donations

Donate / Open ■

Square

Square checkout page

Donate / Open ■

■ **Additional Giving Idea:** If you are over 72, consider asking your financial advisor about a **Qualified Charitable Distribution (QCD)** from a traditional IRA and how it may affect required minimum distributions and taxable income. QCD Overview • RMD Calculator • Medicare Income Brackets • Social Security Tax Brackets

Thank you for your support — enjoy your summer!

William Lowery, MD

Chairman of Medicine, Alameda Hospital • Founder/Chairman, LGMD-1D DNAJB6 Foundation