

LGMD CLINIC STAFF Quick Reference Guide

How can LGMD patients connect with others?

1. The LGMD Awareness Foundation website posts about happenings and shares upcoming events on social media.
2. Join a subtype specific registry. A list of registries can be found on the LGMD Awareness Foundation website.
3. Join an LGMD peer support group on social media.

Where can LGMD patients learn more about LGMD or their specific subtype?

1. LGMD patients can search on the LGMD Awareness Foundation website for a list of subtype specific research organizations. Individual research organizations or subtype specific foundations may have data from natural history studies and other subtype specific educational materials.
2. Search for publications online listing their specific subtype in the search.
3. Find an LGMD subtype specific social media group.

Where can LGMD patients find out about up-and-coming therapeutic research and clinical trial opportunities?

1. LGMD patients can search clinicaltrials.gov
2. Follow LGMD Awareness Foundation on social media where announcements are posted.
3. The SPEAK Foundation hosts conferences, summits and webinars to share information, specifically from drug developers and clinical experts. Subscribe to *LGMD News Magazine*.

What are some ways LGMD patients can get involved in LGMD advocacy?

1. Participate in awareness campaigns (LGMD Awareness Day, wear lime green).
2. Sign up to be featured in an upcoming LGMD "Spotlight Interview" through the LGMD Awareness Foundation website.
3. Build awareness on social media or in their immediate communities. Copy LGMD facts from the LGMD Awareness Foundation website and social media outlets and then re-purpose them within their own community.

QUICK LINKS

List of LGMD Organizations:



LGMD Patient Registries:



LGMD Peer Support Groups on Social Media:



Subscribe to the free quarterly LGMD News magazine:



LGMD Family Guide:



Questions or need more LGMD Advocacy Bundles (LAB)?

Contact Carol Abraham
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LGMD-Info.org

LGMD Foundations

Subtype	Foundation Name	Website
LGMD 1D/D1 DNAJB6-related	LGMD-1D DNAJB6 Foundation	lgmd1d.org
LGMD 1F/D2 TNPO3-related	“Conquistando Escalones” Association	conquistandoescalones.org/en
LGMD 2A/R1 Calpain3-related	Coalition to Cure Calpain 3	curecalpain3.org
LGMD 2B/R2 Dysferlin-related and Miyoshi Myopathy	Jain Foundation	jain-foundation.org
LGMD 2C/R5 Gamma Sarcoglycan-related	Kurt + Peter Foundation	kurtpeterfoundation.org
	Proyecto Alpha	proyectoalpha.org
	Dion Foundation	thedionfund.org
	CureSCG Foundation	www.curescg.org
LGMD 2D/R3 Alpha Sarcoglycan-related	LGMD2D Foundation	lgmd2d.org
	Proyecto Alpha	proyectoalpha.org
	Stichting Spierkracht	stichtingspierkrac.wixsite.com/spierkracht
	CureSCG Foundation	www.curescg.org
LGMD 2E/R4 Beta Sarcoglycan-related	Family Group of Beta-sarcoglycanopathy (GFB ONLUS)	beta-sarcoglycanopathy.org
	Projecto Alpha	proyectoalpha.org
	CureSCG Foundation	www.curescg.org
LGMD 2F/R6 Delta Sarcoglycan-related	Projecto Alpha	proyectoalpha.org
	CureSCG Foundation	www.curescg.org
LGMD 2I/R9 Dystroglycan-related	CureLGMD2i Foundation	curelgmd2i.com
	LGMD2i Research Fund	lgmd2ifund.org
	McColl-Lockwood Laboratory for Muscular Dystrophy Research	atriumhealth.org/research-clinical-trials/mccoll-lockwood-laboratory-for-muscular-dystrophy-research
LGMD 2J/R10 Titin-related	Team Titin	titinmyopathy.com
LGMD 2L/R12 Anoctamin5-related	LGMD2L Foundation	lgmd2l-foundation.org
LGMD 2S/R18 TRAPPC11-related	Camron’s Cure Foundation	camronscure.com
LGMD 2T/R19 GMPPB-related	Cure LGMD 2T Foundation	curelgmd2t.org
Non Subtype Specific	LGMD Awareness Foundation	lgmd-info.org
	Muscular Dystrophy Association	mda.org
	The Speak Foundation	thespeakfoundation.com



Together We Are Stronger