

LGMD Resources



On-line LGMD Support Groups on Facebook:

Social media has profoundly changed the way people with LGMD connect to others – around the corner and around the world. Thankfully, LGMD patients and their family members are now able to access peer support via the internet. No longer do individuals diagnosed with LGMD, family members and/or caregivers have to feel alone in dealing with this rare disease. Through [Facebook](#), a number of on-line LGMD related peer support groups have been established. ** An active Facebook account is required **

Some of the LGMD related support groups accessed through Facebook include:

Forums for sharing support, experiences, and thoughts about living with LGMD. (*Most are “Closed” Facebook Groups for privacy...individuals must “Request to Join”*)

- [LGMD: Beyond Labels & Limitations](#) – for ALL forms of LGMD
- **For LGMD1B:**
 - [LGMD1B](#) – for LGMD1B
 - [Limb Girdle Muscular Dystrophy Type 1b](#) – for LGMD1B
 - [Limb Girdle Muscular Dystrophy Type 1b](#) – for LGMD1B (*a “Public” Facebook group*)

- **For LGMD1D:**
 - [Limb Girdle Muscular Dystrophy Type 1D and Dnajb6 subgroup](#) – for LGMD1D
- **For LGMD1F:**
 - [Distrofia Muscular de Cinturas \(LGMD1F\)](#) – Portuguese group for LGMD1F
 - [LGMD1F](#) – Hungary Page For LGMD1F
- **For LGMD2A:**
 - [C3 Community](#) – for LGMD2A / Calpainopathy
 - [LGMD 2A – Die Muskeldystrophie vom Gliedergürteltyp](#) – German group for LGMD2A / Calpainopathy
 - [Limb Girdle Muscular Dystrophy 2A \(CALPAINOPATHY\)](#) – for LGMD2A
- **For LGMD2B:**
 - [Discovering Dysferlinopathy](#) – for LGMD2B / Dysferlinopathy
 - [Lgmd2B – Dysferlinopathy](#) – German group for LGMD2B / Dysferlinopathy
 - [LGMD 2B Muskeldystrophie des Gliedergelenkgürtels](#) – German group for LGMD2B / Dysferlinopathy
 - [Limb-Girdle Muscular Dystrophy 2b – for LGMD2B / Dysferlinopathy](#)
- **For LGMD2D:**
 - [LGMD2D](#) – for LGMD2D
 - [LGMD2D Patients, Parents, and Caregivers](#) – for LGMD2D
- **For LGMD2E:**
 - [LGMD2E](#) – for LGMD2E (a “Public” Facebook group)
- **For LGMD2G:**
 - [Limb-girdle muscular dystrophy type 2G](#) – for LGMD2G (a “Public” Facebook group)
- **For LGMD2I:**
 - [For LGMD2G:LGMD2I](#) – for LGMD2I
 - [LGMD2i \(Sverige\)](#) – Swedish group for LGMD2i
 - [Limb Girdle Muscular Dystrophy 2i \(LGMD2i\)](#)

- [Community Page](#) – for LGMD2i
- [Parents and Family of LGMD2I](#) – for LGMD2I
- **LGMD2I** – German “*Secret Group*” for individuals with LGMD2I – must contact [group admin](#) to request to join
- [LGMD2I / Limb Girdle 2I Dansk Gruppe](#) – Danish group for LGMD2I
- **For LGMD2J:**
 - [LGMD2J](#) – for LGMD2J
 - [Titin Related Muscle and Heart Disorders Discussion Group](#) – for LGMD2J
- **For LGMD2L:**
 - [LGMD2L](#) – for LGMD2L
- **For LGMD2S:**
 - [Limb Girdle Muscular Dystrophy Type 2S](#) – for LGMD2S
- **Other general LGMD groups:**
 - [Limb Girdle Muscular Dystrophy group](#) – *or all forms of LGMD (a “Public” group)*
 - [Limb Girdle Muscular Dystrophy Support Group](#) – for all forms of LGMD (*a “Public” group*)
 - [Limb-Girdle Muscular Dystrophy](#) – for all forms of LGMD (*a “Public” group*)
 - [Limb-Girdle Muscular Dystrophy](#) – for all forms of LGMD (*a “Public” group*)
 - [Living with Limb Girdle Muscular Dystrophy](#) – for all forms of LGMD
- **LGMD Groups by region, language or country:**
 - [Limb-Girdle Muskeldystrofi Norway](#) – Norwegian group for LGMD (*a “Public” group*)
 - [LGMD Norge](#) – Norwegian support group for LGMD
 - [Limb Girdle Muscular Dystrophy Andhrapradesh](#) – India group for LGMD (*a “Public” group*)
 - [Limb Girdle Muscular Dystrophy India](#) – India group for LGMD
 - [LGMD India](#) – India group for LGMD (*a “Public” group*)

- [LGMD Skandinavia](#) – Scandinavian group for LGMD
- [LGMD Support Group South Africa](#) – South Africa support group for LGMD
- [My Mio Life](#) – Russian & Eastern Europe support group for LGMD (*a “Public” group*)
- [Limb Girdle Muscular Dystorfi Türkiye](#) – Turkish group for LGMD
- [LGMD Gliedergürteldystrophie](#) – German group for LGMD
- [LGMD Southern New England](#) – group for residents in southern New England state (USA)
- [Limb-Girdle Muscular Dystrophy Victoria Australia](#) – Australian group for LGMD
- [Unknown Muscular Dystrophy Pakistan](#) – Pakistan group for LGMD
- **Other LGMD related groups:**
 - [Friends Who Like Limb Girdle Muscular Dystrophy Awareness Day](#)
 - [Friends Who Like Limb Girdle Muscular Dystrophy Awareness Day](#)
- Forum specifically for those who have limb-girdle weakness and an undiagnosed subtype of Muscular Dystrophy to share history, symptoms and other information with the goal of getting a confirmed genetic diagnosis. (*This is a “Closed” Facebook Groups for privacy...individuals must “Request to Join”*)
 - [LGMD Subtype Unknown](#)
- Forum specifically for spouses and/or caregivers. (*This is a “Closed” Facebook Groups for privacy...individuals must “Request to Join”*)
 - [Spouses Fighting Against MD](#)
- Forum for discussing gender-specific topics as they relate to LGMD. (*These are “Closed” Facebook Groups for privacy...individuals must “Request to Join”*)
 - [FeMD](#) – for women only
 - [Guys MD](#) – for men only
 - [Women with Neuromuscular Disabilities](#) – for women

only

- **Forum for teens living with Muscular Dystrophy.** *(This is a “Closed” Facebook Groups for privacy...individuals must “Request to Join”)*
 - [Teens with Muscular Dystrophy](#) – for teens only (ages 13-19)
- **Forum for moms, stepmoms, adoptive moms, and expecting moms living with Muscular Dystrophy** – or even ladies with MD who would like to have children one day and would benefit from asking questions. *(This is a “Closed” Facebook Groups for privacy...individuals must “Request to Join”)*
 - [Moms with MD](#)
- **Forum for mothers who have children diagnosed with Muscular Dystrophy.** *(This is a “Closed” Facebook Groups for privacy...individuals must “Request to Join”)*
 - [MD Moms](#)
 - [Mothers of Children with Limb Girdle Muscular Dystrophy](#) – specific to LGMD
- **Forum, where individuals with Muscular Dystrophy can ask questions and share experiences about obtaining Disability Benefits including Social Security Disability Insurance (SSDI,), Supplemental Security Income (SSI), and Private Disability Insurance (LTD).**
 - [Muscular Dystrophy Disability Benefit Workshop](#)
- **Forum for discussing advocacy and other issues & concerns regarding living with muscular dystrophy.**
 - [The Speak Foundation](#) – *This is a “Closed” Facebook Groups for privacy...individuals must “Request to Join”*
 - [Living with M.D.](#) – *This is a “Closed” Facebook Groups for privacy...individuals must “Request to Join”*
 - [Muscular Dystrophy Awareness of Kenya \(MUDAK\)](#) – This is a public group
- **Forum for discussing weight loss for individuals who**

have muscular dystrophy such as LGMD

- [Muscular Dystrophy Weight Loss](#) – *This is a “Closed” Facebook Groups for privacy...individuals must “Request to Join”*
- **Forum for discussing pulmonary issues and other breathing concerns regarding living with muscular dystrophy** *This is a “Closed” Facebook Groups for privacy...individuals must “Request to Join”*
 - [Breathe with MD](#) – A support group for MD patients, parents and/or caregivers to discuss topics related to pulmonary function decline and for those on non-invasive and invasive ventilation to share tips and insights.
- **The following Facebook page offers a “private” – member only/invitation based support group for the muscular dystrophy community.** You can learn more at
 - [Neuromuscular Disease MD Patient Group](#) (sponsored by The Speak Foundation) – This private or secret group is for individuals with muscular dystrophy to share. This group is only for the person dealing with the disease as some topics are so personal. Contact the Speak Foundation for entry into their private peer support group.

ALDA – Free Automated LGMD Diagnostic Assistant:

The Jain Foundation developed [ALDA \(Automated LGMD Diagnostic Assistant\)](#), a free online tool to help guide physicians toward the most probable diagnosis. This tool predicts the most likely type(s) of LGMD a patient may have based on clinical presentation and laboratory findings. (If you are a patient interested in taking advantage of the LGMD subtyping diagnostic tool, please contact either your physician or the Jain Foundation to help guide you through the process.) Learn more by visiting:

ALEX LANDIS EMERGENCY FUND (ALEF)

NMD United is a non-profit organization composed of adults living with neuromuscular disabilities. This organization generously offers a variety of small grants to help offset some of the few of the hidden costs of disability that individuals living on a fixed income or low wages are forced to pay in order to maintain their independence.

- Any adult living with a neuromuscular disability* is eligible to apply for and receive an [ALEF Grant](#). (*Membership in the Facebook group "[Living with M.D.](#)" or a stamped letter from a medical professional with a stated neuromuscular diagnosis for the applicant will be considered proof of eligible disability.)
- Individuals are eligible to apply for and receive all grants in a single calendar year. Former grant recipients of past years are eligible to re-apply.
- Grants are awarded on an as-needed basis as long as funds remain available. Individuals experiencing an immediate financial hardship, such that their health, safety and/or ability to independently live in the community is impacted, are strongly encouraged to apply.
- Grant requests are subject to approval by NMD United's ALEF Committee.
- For further information on this program, contact the ALEF Committee at alef@nmdunited.org
- Full details regarding the current ALEF grants available can be found on the [NMD United Website](#)

LGMD Genetic Testing:

Do you think you have a form of Limb Girdle Muscular Dystrophy?

It is very important for you to get a genetically confirmed LGMD diagnosis. If your doctor tells you that you have an LGMD but doesn't genetically confirm it, your diagnosis is incomplete. Knowing the exact form of LGMD or sub-type is important as there are health benefits for confirming a LGMD sub-type through genetic testing. As an example, some treatments like steroids will help patients with one type of LGMD and hurt patients with another type of LGMD, some sub-types can experience complications with the heart, breathing, and/or with anesthesia... so knowing what type of LGMD that you suffer from will help you manage your health. Further, if you want to help researchers and physicians trying to find a cure for your disease by participating in clinical studies and trials, you will need genetic confirmation in order to participate.

- **In the US, the [Muscular Dystrophy Association \(MDA\)](#) offers free genetic testing for LGMD.** Individuals must be registered with MDA to receive MDA's LGMD genetic testing service. To register, contact the MDA National Resource Center at 800-572-1717 or send an e-mail to resourcecenter@mdausa.org.
 - Learn more about the [MDA Genetic Testing Program](#)
 - To find an MDA Care Center near you, visit mda.org and type your state or ZIP code in the box and select "[Find MDA in Your Community.](#)"
- Unfortunately, the free Genetic Testing program offered by the consortium of LGMD Foundations at LGMD-Diagnosis.org is not accepting new applications at this time.
- **If you have an undetermined form of Muscular Dystrophy but not a confirmed genetic diagnosis, [In Depth Genomics](#)**

wants to test you for free! They hope to perform Whole Genome Sequencing, FREE on ANY patient, in ANY country who has been frustrated by an inability to get a genetically confirmed diagnosis.

- Phase I (registration) is open now...for any patient in any country.
- Phase II (sample collection) will begin in Spring 2018. Again, this is FREE. Initially, sample collection will begin in the US and then expand worldwide.
- ANYONE with a mystery illness or undetermined Neuro-Muscular Disease will be accepted into the program. And patients from ANY country may register.
- * * * Please note: if you already know your genetically confirmed LGMD Subtype such as LGMD1A, LGMD2B, etc. you need not apply.
- If you have any questions about the new program please email info@indepthgenomics.org.
- Learn more about Indepth Genomics and genetic testing at www.indepthgenomics.com/raring-to-go
- **[Invitae](#) also offers genetic analysis to identify the cause of a disease affecting an individual or a family.** This may be of interest to people who have not been able to get genetic testing through their insurance or sources such as MDA's LGMD testing program, or the genetic testing that had been offered through the consortium of LGMD Foundations.
 - [Invitae](#) offers a reduced [direct pay price](#) (if the patient just pays up front and doesn't involve insurance). They offer a neuromuscular panel consisting of about 120 different genes and this includes things like testing for duplication/deletion of exons, which traditional testing doesn't pick up.

International LGMD Patient Registries:

Have you received confirmation of your LGMD sub-type diagnosis? Please consider having your name entered into a diagnosis-specific LGMD Patient Registry.

When you register, you may have access to the following services, depending on the registry:

- General information about your disease
- Help to find appropriate experts (both scientific and clinical) in your country or area
- Information about ongoing or upcoming clinical trials relevant to your disease
- A source of knowledge about treatment options that are under development

To access a list of international LGMD Patient Registries, visit:

<http://lgmd-info.org/international-lgmd-patient-registries/>

LGMD Clinical Trials & Natural History Studies:

To explore what clinical trials & natural history studies may be available for LGMD and determine whether they are recruiting, the eligibility requirements, location, etc., please visit ClinicalTrials.gov

This is a searchable registry and results database of federally and privately supported clinical trials conducted in the United States and around the world. ClinicalTrials.gov gives you information about a trial's purpose, who may participate, locations, and phone numbers for more details. This information should be used in conjunction with advice

from your healthcare professionals.

Checklist for Assessing Legitimacy of Any Proposed LGMD Treatments:

Advocacy groups, research sponsors, and community leaders are frequently contacted by LGMD patients &/or family members asking whether or not they should participate in different “treatments” that are either being offered somewhere that they heard about over the internet, that a friend recommended or that they heard may “possibly” be available in the future...such as a form of stem cell therapy, gene therapy, snake oil treatments, green tomatoes, vitamins, medication, etc.

So, how does a patient who feels desperate and willing to try anything that may help them make informed decisions?

Patients can empower themselves by investigating whether or not a treatment has been published and proven to be safe and effective. For the health & safety of the LGMD patient, it is extremely important to determine whether a treatment is legitimate!

To assist you in assessing the legitimacy of any “Proposed Treatment for LGMD”, please consider using our [5 Question “Checklist”](#) (PDF Document).

LGMD Awareness Day on Social Media

Follow us on [Facebook](#) for educational posts and updates on current topics of interest.

You can also find us on [Twitter @Lgmd.Day](#)

“Mobility Map” – A Step-by-Step

Guide for obtaining a wheelchair:

Are you or a family member at a point of needing a wheelchair for mobility...but don't really know where or how to begin the process?

User's First, an advocacy organization, has created a "[Mobility Map](#)" which is an online step by step guide on how to get "The Right Wheelchair" for *your* specific needs! Every step is covered, from how to get started, getting a prescription, how to get fit through a wheelchair assessment, your home assessment, letters of medical necessity, funding & how to fight for your funding, dealing with denials, ordering your wheelchair, delivery of your wheelchair, etc.

Getting a proper wheelchair is so important for enhancing your function, maintaining comfort and improving your independence. It is a big decision...so you want to be well-informed throughout the entire process.

(Although written for the spinal cord injured patient, the material is still very applicable to those who have LGMD).

The [Mobility Map](#) was created to empower the consumer because it guides and educates them through the entire service delivery process of seating and wheeled mobility—so that you can take charge in choosing the best equipment to meet your personal needs.

Guidelines for LGMD Diagnosis and Care:

The American Academy of Neurology (AAN) published recommendations for the care of people with limb-girdle muscular dystrophy and related disorders.

- [Summary of Evidence-based Guideline for PATIENTS and](#)

their FAMILIES

- [Summary of Evidence-based Guideline for CLINICIANS](#)
- [AAN Practice Guidelines](#)
- Mobile Apps are also available “**Muscle Disease Guidelines**”: The American Academy of Neurology (AAN), representing more than 28,000 neurologists and neuroscientists worldwide, is the trusted name in evidence-based guidelines for diseases of the brain and central nervous system. The AAN Muscle Disease Guidelines app includes “Diagnosis and Treatment of Limb-Girdle and Distal Dystrophies,” published in the AAN’s leading scientific journal Neurology®.
 - Features
 - Clinical Practice Guideline for Physicians
 - Summary of Guideline for Clinicians
 - Summary of Guideline for Patients
 - Find Local Neurologists tool with interactive map
- Download the **AAN Muscular Disease Guidelines “app”** for [iOS](#) through the [iTunes Store](#) or for [Android](#) through the [Google Play Store](#).

Applying for Social Security Benefits:

Individuals with Muscular Dystrophy (MD), often face daily challenges in performing essential tasks, including activities in your personal life as well as job functions. If your MD prevents you from earning a living through gainful employment, then you can potentially qualify for disability benefits from the Social Security Administration (SSA).

For those who qualify, the SSA’s disability programs provide a source of steady, consistent income. This means you can count on receiving monthly benefits to cover your everyday living expenses and help you meet your ongoing healthcare needs.

For more details, please see our guide: [Social Security Guide for MD](#)

Resources for disease-specific medical information:

- [Facts About LGMD](#) – a publication from Muscular Dystrophy Association (MDA)

Websites:

- [LGMD Organizations/Foundations](#)
- [National Center for Biotechnology Information \(NCBI\)](#)
- [National Institute of Health \(NIH\)](#)
- [Muscular Dystrophy Association \(MDA\)](#)
- [Muscular Dystrophy Foundation Australia](#)
- [Muscular Dystrophy Canada](#)
- [Muscular Dystrophy New Zealand](#)
- [Muscular Dystrophy South Africa](#)
- [Muscular Dystrophy UK](#)
- [Treat-NMD](#): Neuromuscular Network
- [Team Titan](#) – LGMD2J and Titin Myopathy

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