

# 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
  - [C3 Community](#) – for LGMD2A / Calpainopathy
  - [LGMD 2A – Die Muskeldystrophie vom Gliedergürteltyp](#) – German group for LGMD2A / Calpainopathy
  - [Discovering Dysferlinopathy](#) – for LGMD2B / Dysferlinopathy
  - [Lgmd2B – Dysferlinopathy](#) – German group for LGMD2B

/ Dysferlinopathy

- [LGMD 2B Muskeldystrophie des Gliedergelenkgürtels](#) – German group for LGMD2B / Dysferlinopathy
  - [LGMD2D](#) – for LGMD2D
  - [LGMD2D Patients, Parents, and Caregivers](#) – for LGMD2D
  - [LGMD2E](#) – for LGMD2E (*a “Public” Facebook group*)
  - [LGMD2I](#) – 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
  - [LGMD2J](#) – for LGMD2J
  - [LGMD2L](#) – for LGMD2L
  - [LGMD Subtype Unknown](#) – for individuals with an unconfirmed LGMD diagnosis
  - [Limb-Girdle Muskeldystrofi Norway](#) – Norwegian group for LGMD (*a “Public” group*)
  - [Limb-Girdle Muscular Dystrophy](#) – for all forms of LGMD (*a “Public” group*)
  - [Limb Girdle Muscular Dystrophy Andhrapradesh](#) – India group for LGMD (*a “Public” group*)
  - [LGMD Support Group South Africa](#) – South Africa support group for LGMD
  - [LGMD1B](#) – for LGMD1B
  - [My Mio Life](#) – Russian & Eastern Europe support group for LGMD (*a “Public” group*)
  - [Livng with Limb Girdle Muscular Dystrophy](#) – for all forms of LGMD
- **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, step moms, 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](#)
  
- **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"*
  - [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**
  - [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 pages offer "private" – member only/invitation based support groups 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:

[www.jain-foundation.org/lgmd-subtyping-diagnosis-tool](http://www.jain-foundation.org/lgmd-subtyping-diagnosis-tool)

# 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.

- Unfortunately, the free Genetic Testing program offered by the consortium of LGMD Foundations is not accepting new applications at this time. However the LGMD consortium will be launching a new program later this year that will test many more genes and identify a wider range of diseases. They are preparing to launch a new program that will provide free whole genome sequencing for patients (in the USA) with neurological and neuromuscular symptoms. The new program will be for anyone (residing in the USA) experiencing neuromuscular or neurological symptoms, including the LGMDs that were included in this program. Please submit your email address to receive updates and to be notified when the program launches and is accepting patients. If you have any questions about the new program please email [info@indepthdiagnostics.org](mailto:info@indepthdiagnostics.org).

# 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 finding 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](http://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](http://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 health care 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. [www.facebook.com/LGMDAwarenessDay](http://www.facebook.com/LGMDAwarenessDay)

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

## **LGMD Awareness Scholarships:**

The LGMD Awareness Scholarship was designed to reward students who teach others about Limb Girdle Muscular Dystrophies, often referred to as LGMDs. There are two scholarship categories, merit-based and social media based. A total of four \$3000 scholarships will be awarded in 2016. The scholarship money can be used for tuition, books, and equipment required for education courses. Students may apply for both scholarship categories but students will be awarded at most one scholarship.

This opportunity is open to students who are enrolled or will be enrolled in some form of higher education (including 2 year colleges, 4 year colleges/universities, graduate schools, law schools, medical schools and vocational schools) at an accredited US institution in 2016. GOOD LUCK!

For further details: [www.jain-foundation.org/scholarship](http://www.jain-foundation.org/scholarship)

## **“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 on-line 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.

Website: [www.unitedspinalmobilitymap.com](http://www.unitedspinalmobilitymap.com)

## **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-Diagnosis website](#) (click on the last question on the page “What do I do once I have a genetic diagnosis” to access their “resource page”)
- [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

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Towards LGMD Research & Support

