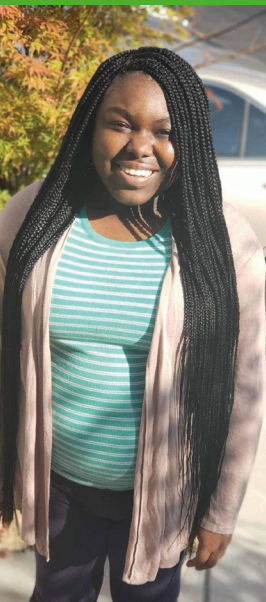




## TOGETHER WE ARE STRONGER



**Whether you are a long-time community member, or newly diagnosed, you are not alone on your limb-girdle muscular dystrophy (LGMD) journey.**

Contained in this brochure are numerous resources to help you along the course, including ways to connect with others who are living with LGMD. The LGMD Awareness Foundation (LAF) is the informational hub for the LGMD community and we truly believe that Together We Are Stronger.



[LGMD-info.org](http://LGMD-info.org)

## Quick Facts About LGMD

- ➔ A term used for a group of rare neuromuscular conditions which are inherited and known to cause muscle weakness and wasting.
- ➔ The muscles most commonly affected are those closest to the body (proximal muscles), specifically the muscles of the shoulders, upper arms, pelvic area, and thighs.
- ➔ More than 30 forms of LGMD exist; with new forms (sub-types) being discovered each year.
- ➔ Some LGMD sub-types have a 'dominant' inheritance and some have a 'recessive' inheritance pattern.
- ➔ In some cases, a family history exists.
- ➔ The onset of symptoms can occur in childhood, adolescence, or adulthood.
- ➔ LGMD occurs in all parts of the world and among all ethnic groups.
- ➔ Males and females can inherit LGMD.
- ➔ No cure or treatment exists for these progressive conditions.
- ➔ Promising research continues and clinical trials are being conducted which gives hope to many individuals.

# Living with LGMD

Being diagnosed with LGMD can be an overwhelming and confusing time. For many, the path to a formal diagnosis is long and difficult. The LAF resources and online support may help ease this transition by providing knowledge, community, and helpful advice. Although living with LGMD offers unique challenges, individuals live full and rewarding lives—leading successful careers, traveling the world, or starting a family. Patient-developed resources addressing common concerns can help answer questions about navigating the world post diagnosis.

## Importance of Joining an LGMD Patient Registry:

1. Find opportunities for scientific advancement in the fields that matter most to you.
2. Help speed up discovery and cultivate a trial-ready community.
3. Work with researchers and clinicians to collect important patient data in clinical trials and studies.
4. Expand your knowledge of LGMD and build connections with patients worldwide.
5. Empower yourself through education and advocacy while playing an important role in emerging innovations.

**View a list of registries at [lgmd-info.org](http://lgmd-info.org)** ▶



## Genetic Confirmation

Have you and/or a family member received genetic confirmation of your limb-girdle muscular dystrophy (LGMD) sub-type? If you have, visit International LGMD Patient Registries - LGMD Awareness Foundation (lgmd-info.org) to find out more about your sub-type.

### Genetic Testing Resources



**If you have not received a genetic confirmation of your LGMD sub-type, please visit this page.**

It is very important for you to get a genetically confirmed LGMD diagnosis! If your doctor tells you that you have 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 an LGMD sub-type through genetic testing. As an example, some treatments such as steroids will help patients with one type of LGMD and be contradicted in other forms of LGMD. Some sub-types can experience complications with the heart, breathing, and/or with anesthesia. Having a genetically confirmed diagnosis will help you manage your health. If you want to help researchers and physicians trying to find a cure for your condition by participating in clinical studies and trials, you will need genetic confirmation in order to participate.

# About the LGMD Awareness Foundation

## Raising awareness and advocating for individuals with LGMD

Whether you are a long-time community member, or new to the scene, you are not alone on your LGMD journey. We are the informational hub for the LGMD community and we truly believe that ***Together We Are Stronger.***

The LGMD Awareness Foundation, Inc. is a patient-led 501(c)(3) non-profit advocacy organization dedicated to globally raising awareness of the rare neuromuscular conditions known as limb-girdle muscular dystrophy (LGMD). In collaboration with other LGMD foundations, our focus is to provide curated educational information and resources for the LGMD community and public.

By increasing awareness of and advocating for individuals living with limb-girdle muscular dystrophy, we hope individuals living with these progressive conditions will have an easier time accessing diagnosis, care, and treatment.



# LGMD Awareness Foundation Initiatives

All of our initiatives are focused on providing educational information and resources to the LGMD community. There is great strength in awareness, understanding, and unity. Join us as we advocate, educate, and celebrate!

## ADVOCATE

Advocate for yourself and the LGMD community by genetically confirming your subtype, joining a registry, and actively seeking the best treatment. Raising awareness leads to better healthcare, encourages research, and gives the public a clearer view of the challenges living with LGMD.



“Getting a confirmed diagnosis is the most important thing one can do to help improve medical care and speed clinical development of new therapies.”

— **Dr. Jean-Pierre Laurent**  
*LGMD2i Research Fund, Director*

- ✓ LGMD Awareness Day – celebrated annually on September 30
- ✓ Girdie, the LGMD Ambassador
- ✓ Lime Green for LGMD Awareness
- ✓ New patient advocacy that starts at the time of diagnosis
- ✓ Government relations initiatives to shine a light on LGMD

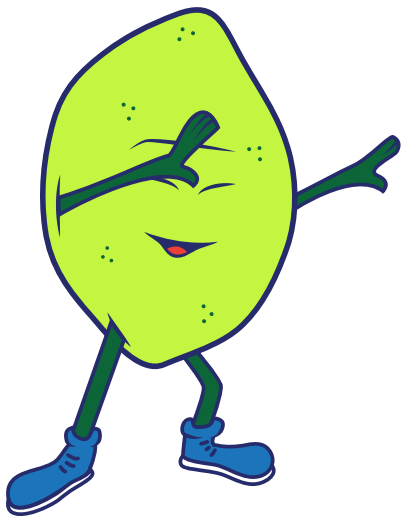
## EDUCATE

It's important to know and understand the facts about LGMD and your subtype. Learning from others living with LGMD, the researchers studying LGMD, the clinicians working with patients living with LGMD, and LGMD organizations equips you with the tools to navigate your future. On our website you will discover the many resources that are available to support you throughout your journey: [lgmd-info.org](http://lgmd-info.org)

## CELEBRATE

We acknowledge one another and celebrate our strengths individually, and as a community through building awareness, finding support, sharing experiences, and living our best lives. LGMD Awareness Day is celebrated worldwide on September 30. The LGMD community comes together to celebrate each other and breakthrough research. We acknowledge that together we are stronger.

- ✓ Protect your mental and physical health through self-care and finding support
- ✓ LGMD Awareness Day is celebrated annually on September 30
- ✓ Wear lime green - visit our LGMD swag shop
- ✓ Post photos on social media using #LGMDawareness @LGMDawareness





## LGMD Resources

The LGMD Awareness Foundation takes pride in sharing resources that are available to the LGMD community.

- ✓ Clinical Trials & Natural History Studies
- ✓ 65+ LGMD Related Online Support Groups
- ✓ Upcoming LGMD Events
- ✓ LGMD Patient Registries
- ✓ LGMD Genetic Testing Resources
- ✓ Financial/Grant Opportunities
- ✓ LGMD Organizations & Foundations
- ✓ Plus, Much More



[info@LGMD-info.org](mailto:info@LGMD-info.org)  
[LGMD-Info.org](http://LGMD-Info.org)

Find us on Social Media @LGMDawareness: [f](#) [📷](#) [🐦](#) [🎵](#) [in](#)