Type Hype

Know your type. Find your people.

If you have limb-girdle muscular dystrophy (LGMD)—or think you might—this brochure will teach you about the importance of subtype identification, how to access genetic testing, and why finding the right care team can make a difference for you.





EMILY,
AN INDIVIDUAL
LIVING WITH
LGMD2I/R9

Table of Contents

01 Intro to LGMD — PG 4

02 Signs & Symptoms — PGS 5-7

03 Genetic Clarity — PGS 8-9

04 Testing Access — PGS 10-13

05 LGMD Subtypes — PG 14

06 LGMD2I/R9 — PG 15

07 Specialized Care — PGS 16-17

08 Ongoing Monitoring — PGS 18-19

09 Answers & Support — PG 20

What is LGMD?

Limb-girdle muscular dystrophy (LGMD) is a set of rare, progressive muscle disorders that can change how your body moves over time in the limbs (arms, legs) and girdle (shoulders).

Because LGMD can affect each person differently, understanding how it shows up in your body is an important step toward getting the right care.

If you're experiencing symptoms, you deserve answers.

01 / Know the signs

Learn to recognize the signs of LGMD.

02 / Get tested

Understand how genetic testing can help confirm a diagnosis and identify subtype.

03 / Find clarity

See how getting clear answers can help you and your care team move forward with more confidence.

LGMD usually begins with small changes in strength, balance, or endurance.

Progressive muscle weakness, often beginning in the hips and shoulders, can be a sign of LGMD.

Changes in strength, balance, or endurance may develop gradually and can be easy to overlook.

Recognizing the signs and sharing them with your healthcare provider can help pave the path to a correct diagnosis.



Discussing your symptoms with your healthcare provider can help bring clarity sooner.



KRISTEN,
AN INDIVIDUAL
LIVING WITH
LGMD2I/R9

LGMD symptoms can look and feel like other conditions.

The signs and symptoms of LGMD can overlap with other conditions, which can make it difficult to reach a clear diagnosis.

For many people, the journey to understanding what's happening can take years.



LGMD is genetic, so it may run in families.

Gene changes that cause LGMD can be passed down, even by people who don't have symptoms. This means others in your family may also be affected or could be carriers.

Understanding this can help you take the next step in learning how it could impact your family.

Genetic testing can offer clarity—and that clarity may be closer than you think.

Testing your DNA is the only accurate way to confirm an LGMD diagnosis and identify your specific subtype.

By looking at your unique genetic makeup, results can help rule out other conditions and may provide clearer answers about what's causing your symptoms.



STEWART, HUSBAND & CARE PARTNER TO AN INDIVIDUAL LIVING WITH LGMD2I/R9



DAN,
HUSBAND &
CARE PARTNER
TO AN INDIVIDUAL
LIVING WITH
LGMD2I/R9

A convenient test can provide real answers.

Genetic testing can often be done using a saliva sample, cheek swab, or blood test.

Your healthcare provider can help guide you through the process and connect you with the appropriate resources to get started.



Genetic testing may be available at a reduced price or at no cost to you.

Some programs sponsor testing for eligible patients, which may reduce or cover the cost.

Your healthcare provider can order the test and explain what it looks for, along with how your information is kept private and protected.



Ask your healthcare provider about reduced- or no-cost testing.

Or, you can scan this QR code using the camera app on your phone to learn more about organizations like Invitae and The Lantern Project.

INVITAE

the lantern project



LACEY,
AN INDIVIDUAL
LIVING WITH
LGMD2I/R9

Not all LGMD is the same. One specific subtype is 2I/R9.

There are more than 30 types of LGMD—and each subtype can affect the body differently.

Knowing your LGMD subtype can help explain what you're experiencing, support more informed conversations with your care team, and help you plan next steps with greater confidence.

LGMD2I/R9 is associated with FKRP.

LGMD2I/R9 is linked to a change in a gene called fukutin-related protein *(FKRP)*. This gene helps support the stability of your muscles during everyday movement.

When the FKRP protein doesn't work as it should, muscles can become more vulnerable to damage over time, **which may help explain certain symptoms you're experiencing.**



JAMESON,
AN INDIVIDUAL
LIVING WITH
LGMD2I/R9

A subtype diagnosis can lead you to specialists.

LGMD symptoms are sometimes mistaken for muscle injury or conditions like rhabdomyolysis.

Confirming your diagnosis and subtype can help shift your care to a more specialized approach.

Once your results are available, a genetic counselor can explain what they mean, and your neuromuscular specialist can help guide next steps and care over time based on your subtype.



The right team can help coordinate your care.

Your neuromuscular specialist can help bring together a care team based on your specific needs. This may include physical or occupational therapists, as well as specialists like cardiologists or pulmonologists who can help monitor how LGMD may affect your heart and lungs.

Advocacy groups can also offer support, information, and connection along the way.

When your care team works together, it can feel more coordinated, more personalized, and more focused on what matters most to you.

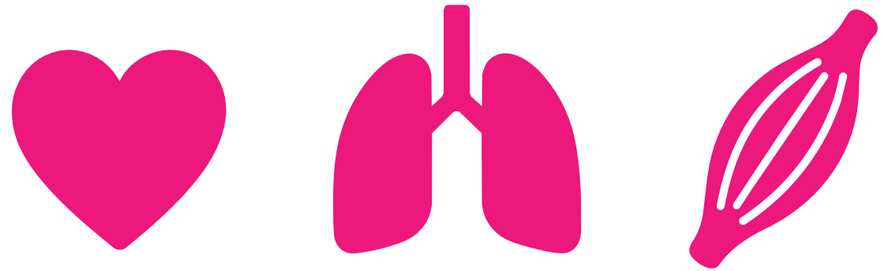
Need help finding a healthcare provider in your area?
Use our helpful tool by scanning the QR code with the camera app on your phone.



MELISSA,
AN INDIVIDUAL
LIVING WITH
LGMD2I/R9

Ongoing monitoring helps you stay ahead of your future.

Because some forms of LGMD like 2I/R9 can affect the heart and the muscles used for breathing, regular monitoring is an important part of ongoing care. Even if symptoms feel stable, changes can happen over time. Working with your care team to **track heart, lung, and muscle function** can help catch changes earlier and guide more informed care decisions.



Type Hype

Don’t wait to confirm your diagnosis or subtype.

Ask about genetic testing today.

If you have LGMD—or think you might—genetic testing can help bring clarity.

It’s important to know: Many people go for years without knowing their exact subtype.

Don’t wait to confirm your diagnosis or subtype. Learn more about how you can request genetic testing today by scanning the QR code below with the camera app on your phone.

Knowing your subtype can help guide your care

BRIDGEBIO

© 2026 BridgeBio Pharma, Inc. All rights reserved. BridgeBio is a trademark of BridgeBio Pharma, Inc.
All other trademarks are the property of their respective owners. MAT-US-BBP418-0219 V1