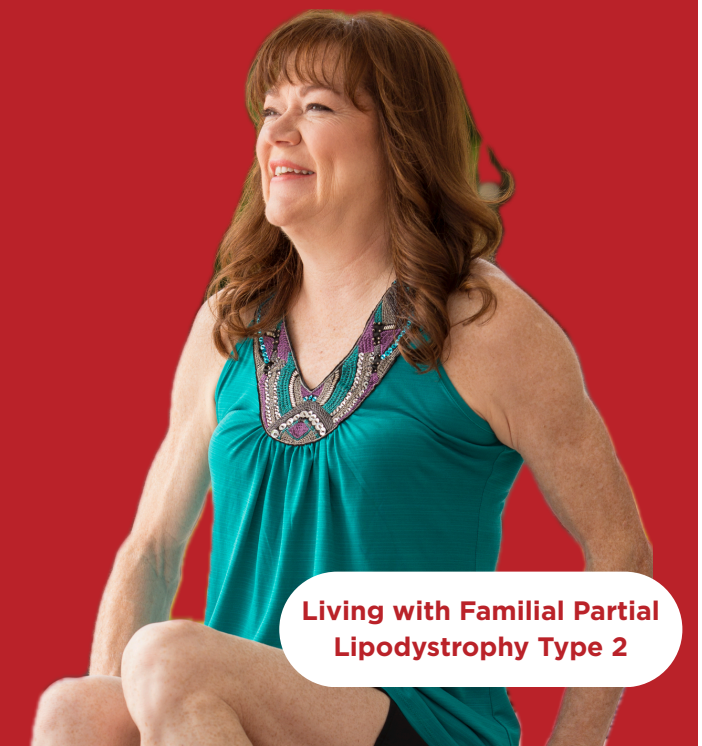
MANAGING LIPODYSTROPHY

Managing lipodystrophy often involves a combination of medications, lifestyle adjustments, and emotional support—and it requires patients to be strong advocates for their own care. For those with generalized lipodystrophy in the U.S., metreleptin is FDA-approved and can help manage hunger, diabetes, high triglycerides, and fatty liver. GLP-1 therapies, such as semaglutide or tirzepatide, may also be helpful for managing diabetes and weight. While this is not medical advice, understanding these options can help you feel more informed and empowered in conversations with your healthcare team. Always consult with your medical provider to find the approach that's best for you.

*New therapies are being researched to expand future treatment options.



CONTACT US!

Info@lipodystrophyunited.org
LipodystrophyUnited
LipodystrophyLU
Lipodystrophy United
Lipodystrophy United
lipodystrophyunite.bsky.social
22 Frances Rd, Los Lunas NM 87031

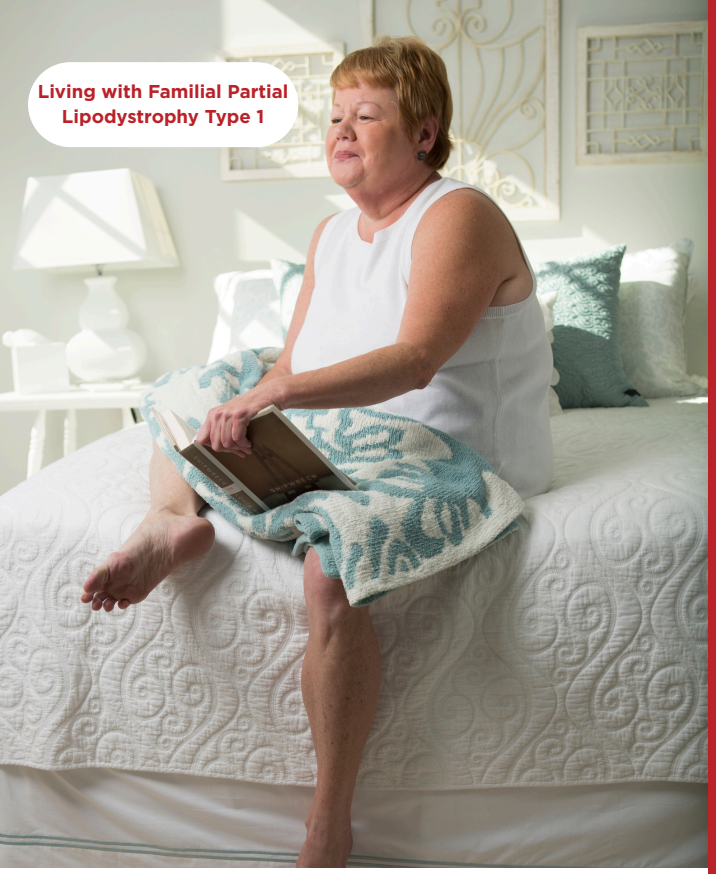
Website

Donate

Lipodystrophy United

A PATIENT'S GUIDE TO LIPODYSTROPHY

Lipodystrophy United



What is Lipodystrophy?

Lipodystrophy is a progressive, multi-system rare disease in which people do not have enough fat in some or all of their body. Lipodystrophy can lead to serious and life-threatening multi-system complications. New lifestyle and treatment options can slow the progression and improve quality of life.

THE FOUR TYPES OF LIPODYSTROPHY:

Genetic:
Familial Partial (FPLD)
Congenital Generalized (CGL)

Acquired:
Acquired Generalized (AGL)
Acquired Partial (APL)

Why seek diagnosis?

Without proper fat distribution, the body can have difficulty storing fats and sugars from food. The fat (triglycerides) and sugar (glucose) remain in the blood and can store in the organs leading to problems with organ function such as liver, kidney and heart disease. Early diagnosis can change treatment options and potentially slow the progression of the disease.

How do you diagnose lipodystrophy?

Diagnosis typically involves:

- A body composition test
- Blood tests for triglycerides, glucose levels, insulin resistance markers, and sometimes leptin levels

While most forms of lipodystrophy are genetic, some forms can be acquired. Genetic testing can confirm certain types of lipodystrophy, but:

- Not all mutations have been identified
- A negative genetic test does not rule out lipodystrophy
- The primary clinical sign to look for is abnormal fat distribution

SYMPTOMS

Visual symptoms can include some or all of the following:

- Very little fat in some or all parts of the body
- More fat in some or all parts of the body
- Very muscular appearance where fat lacks
- Very visible or large appearance of veins under the skin
- Itchy and painful bumps in the hands, feet, arms, legs, and bottom (xanthomas)
- Dark patches of skin around the creases of the neck, armpits, groin, or other areas (acanthosis nigricans)

Non-visual symptoms can include some or all of the following:

- Cardiovascular complications, cardiomyopathy or abnormal heart rhythm
- Polycystic ovarian syndrome or absence of menses, depending on subtype of lipodystrophy
- Metabolic dysfunction-associated steatotic liver disease (fatty liver)
- High triglycerides
- Difficulty in treating diabetes
- Severe insulin resistance
- High blood pressure
- Extreme hunger
- Pancreatitis
- Kidney disease
- Pain in muscle or joints
- Anxiety and/or depression
- Body dysmorphia
- Fatigue
- Leptin deficiency
- Sleep issues

Patients also report**

- Brain fog
- Digestive issues and/or gastroparesis (bloating, discomfort)
- Frequent infections or slow wound healing
- Esophageal problems

*Individuals with lipodystrophy may not experience all of the symptoms described

**"Patients also report" is not yet published

Lipodystrophy United