



Lipodystrophy
United

Lipodystrophy United 2025

BOARD RESOURCE

For Recruitment of Board Members and Volunteers

Kate Stratton
Executive Director

Francesca Amato
Operations Manager

Sharon Halperin
Research Director

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ABOUT

Lipodystrophy United



LU was founded in 2012 by a small group of individuals living with lipodystrophy who connected on social media and noted that their experience was not reflected in any accessible public information and growing research in the study of the disease was not accessible to the general public and didn't directly reflect the true burden of the disease. Recognizing the challenges patients face, Lipodystrophy United (LU) was founded with a clear mission: to serve as a bridge between the patient and research communities.

As is common in rare diseases, they had to learn from scratch how to develop a nonprofit from nuts to bolts, become experts in the disease, build the community, and create and execute a plan to improve diagnosis and disease awareness. They secured official 501(c)3 status.

They jumped headfirst into advocacy, driven by the fact that a treatment, a recombinant human leptin analog called metreleptin, was already in development, clinical trials had been ongoing for patients with generalized lipodystrophy for many years, and trials for partial lipodystrophy were in the early stages. The existing industry and regulatory involvement provided unique opportunities and additional learning challenges.

Lipodystrophy United (LU) was founded in September 2012. Non-profit status was given to the foundation in 2014 and revoked in 2015 due to paperwork complications. Nevertheless, LU regained nonprofit status through a 501(c)3

form and continues to hold official nonprofit status today (March 2024). The organization's mission became clear when former president Andra Stratton spoke in the open speaker section of the Open Public Hearing portion of the FDA Advisory Review Committee meeting for metreleptin in 2014. At the meeting, one of the physicians on the advisory board committee stated that he did not see the difference between patients with partial lipodystrophy and the general population with metabolic syndrome. **The founding board determined that it is crucial that all stakeholders of lipodystrophy should be educated to understand the unique burdens and needs of lipodystrophy patients.** The board requested a meeting with the FDA to help provide a better understanding of the unmet needs within the lipodystrophy patient community. From 2014 to 2018, Lipodystrophy United (LU) has made accomplishments that have helped to advance research, diagnose patients, and fight for metreleptin drug approval. During this four-year period, LU built a unified patient community and built trusted relationships with the medical community. It is now in the hands of our Lipodystrophy community to regrow for the effect of advocating for our patients through education of patients as well as medical professionals, and engagement with stakeholders.

Organization and Management



Larry Seida

Board President and
Chief Financial Officer



Kate Stratton

Executive Director



Sharon Halperin

Research Director and
Board Secretary



Francesca Amato

Operations Manager

MISSION AND VISION

For Lipodystrophy United, nothing is more important than remaining true to our initial goal: representing our community of people with lipodystrophy.



Mission

Our mission is to increase awareness and understanding of lipodystrophy among the patient community, medical professionals, and stakeholders. Lipodystrophy United aims to be the leading resource in the United States for patients and healthcare professionals dealing with lipodystrophy, providing clear, actionable information and support for managing the condition.

Our Vision



**Accurate
Diagnoses**



**Quality
Care**



**Effective
Treatment**



**One day,
a Cure**

Accomplishments

2015 marked the first World Lipodystrophy Day and the beginning of our quality of life study. In 2016, we held a patient-led FDA listening session to continue educating stakeholders on the burden of the disease. Since then, we have hosted an in-person 2018 symposium, published a natural history study, established a patient registry, and formed the Global Lipodystrophy Leaders Consortium in 2022. In 2024, Lipodystrophy United revitalized its community by advancing its mission through rebuilding its online presence, boosting social media engagement, and reconnecting patients and caregivers. This effort united over 100 community members and medical professionals, and secured \$150,000 in fundraising, further cementing the organization's leadership in patient education and support.

Advocacy

We have had the opportunity to represent Lipodystrophy United at multiple national conferences. These conferences were not rare disease-specific, which gave us a fantastic opportunity to advocate for ourselves. They included the National Lipid Association Scientific sessions and the Endocrine Society's 2025 ENDO sessions. We have also been selected to present our data at these conferences, introducing numerous pharmaceutical representatives and physicians to the struggles faced by our community. Before these, a few of our staff members completed patient advocacy courses through Stamford Research Center with Professional Patient Advocates in Life Sciences. Our organization learned how to better communicate with pharmaceutical partners, engage with policymakers, and amplify community voices in a responsible and impactful way.



Officers

Two-year, virtual commitment.

Board Chair/President

- Presides at meetings
 - Appoints committee chairs with the approval of the majority of the Executive Committee
 - Works closely with Executive Director (when time comes) to guide organization, or in the absence of an Executive Director, assumes/shares the day-to-day operation of the organization (identify funding sources, public relations, legal oversight)
 - Public spokesperson for the organization (along with the ED when the time comes)
 - To speak effectively about LD, it is this individual's responsibility to understand standard medical terms, genetics, treatment options, and the patient's perspective for all types of LD. In such cases, the Board may need to determine another individual who can speak capably about their experience with LD.
 - Stays current with all LD research and social media groups. Digest updated information and disseminates it to the Board and the community at large on a bi-weekly basis, at a minimum.
 - Co-signs checks with the Treasurer.
 - Shall be an ex officio member of all committees
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Vice Chair/President

- Presides at meetings when the Chair is absent
- Keep up with current lipodystrophy news and research
 - Have a good basic knowledge of different mutations
- Serves as a Committee Chairperson when appointed
- Can be assigned predetermined day-to-day duties to ensure the smooth operation of the organization if no paid staff is available. (e.g., scientific liaison, publicity, assist with identifying funding sources)
- Be in a position to speak publicly about LU
- Can assume the duties of a vacant officer's position temporarily

Secretary

- Keeps the organization's records
- Takes BoD meeting minutes; distributes them to the BoD
- Disseminates announcements regarding the BoD and the organization
- Keeps the current list of the BoD, Medical Advisory Board/Committee, and general supporters
- May be assigned to work with the Communications Committee or other appropriate committee
- Can be assigned predetermined day-to-day duties to ensure the smooth operation of the organization if no paid staff is available. (e.g., website, newsletter, constituent database,

general correspondence)

- Has access to the mailing list and generates communication to that mailing list
- Assists with the nominating and voting process for Board members

Treasurer

- Oversees organization's general and daily finances; should a staff person be hired to oversee daily finances, the treasurer's role will be that of advisor
- Creates financial reports for BoD meetings
- Serves as Chair of the BoD Finance Committee
- Co-signs checks with Board Chair
- Prepares IRS 990

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Every board member has common responsibilities, including...

- Hire and set the compensation for a CEO and other potential LU employees
- Obtaining a basic biological understanding of each type of lipodystrophy
- Engage their own community about the importance of lipodystrophy education
- Encourage their personal and professional connections to donate or volunteer for LU
- Communicate with the rest of the board regularly about one's own time constraints and capacity

# Committees

There are standing (also known as permanent) committees, as well as ad hoc committees. Committees are usually chaired by a Board Member with non-Board members as committee members. All committee members should be willing to commit to taking on the responsibilities. To minimize the strain on the executive committee, it is essential to establish a minimum of three committees: research, fundraising, and patient engagement.

### **Standing Committees:**

#### Research Committee

- a. A team of experts that works to continue to discover the causes and treatment of lipodystrophy
  - i. Stay up to date with lipodystrophy developments
  - ii. Educates doctors about lipodystrophy
  - iii. Act as a consultant to executive board members if questions about lipodystrophy arise
  - iv. Advocate for patient needs in medical and/or research settings

#### Development Committee

- a. Assigns annual fundraising goals
- b. Outlines annual plan of activities; it is understood that the board participates in some capacity for special events and/or fundraisers.

- c. Works with all committees to identify a variety of revenue streams
- d. Identifies appropriate services provided by LU

#### Patient Engagement Committee

- a. A group of volunteers that
  - i. Seek to hold LU events in their own community
  - ii. Interact with lipodystrophy patients about their experiences and needs
  - iii. Share patient stories to raise awareness (with consent of the patient)

#### **Other Examples of Standing Committees:**

##### Finance: chaired by the Treasurer

- a. Assists the Treasurer in overseeing the organization's finances
- b. Sets annual budget; ensuring that no funds are spent unless it's in an approved budget is very important, especially to a young group
- c. Provides timely reports to the BoD on the state of the organization

##### Nominating:

- a. Ideally, founding members should be the bulk of this committee. They know the mission statement and will ensure that the coming BoD will maintain the mission.
  - i. Recruitment of Board Committee
  - ii. Identifies individuals as BoD prospects
  - iii. Provides a slate of BoD nominee officers
  - iv. Oversees the election process
  - v. The initial role should be to establish a nomination process that can be implemented when the time is right.

##### Communication:

- a. Handles all communication, including press releases
- b. Oversees the management of the website
- c. Guides the programs and activities of the organization
- d. Identifies volunteers to assist with the mission of the organization

##### Pediatric Committee:

- a. Identifies pediatric-specific needs of the patient community
- b. Works with pediatric endocrinologists and other pediatric specialists to serve as a liaison for LU in activities approved by the Executive Committee
- c. Partners with other committees to help achieve pediatric-specific goals





# Operational Plan

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Our primary objective is to strengthen internal systems, processes, and leadership capacity. This will be done by rebuilding the Board of Directors, establishing expectations, restructuring the Patient Advisory Board, and sending commitment letters to all board/advisory members. We also want to standardize our process by creating onboarding packets, training documents, and knowledge guides. Additionally, by defining internal roles and project timelines using tools such as Trello, Slack, and calendars. Improving website design, accessibility, and content structure is crucial to our mission.

## Advocacy

**Primary Objective:** Amplify the voices of patients and caregivers to drive systemic change.

- **FDA Engagement:**
  - Host a Listening Session by June 2025 focused on partial lipodystrophy.
- **Medical Conferences:**
  - Attend ENDO 2025 and NLA 2025 to increase clinician awareness.
  - Host pre-conference patient engagement events.
- **Global Policy & Collaboration:**
  - Participate in Rare Disease Week & Global Lipodystrophy initiatives.
  - Draft policy alignment summaries for public use.

## Community

**Primary Objective:** Strengthen peer support, education, and storytelling within the lipodystrophy community.

- **Tea with LU:**
  - Run consistent sessions, including open chats and expert-led topics.
- **Lunch & Learn + Podcast:**
  - Monthly educational sessions with researchers, dietitians, etc.
  - Launch a podcast that merges science with patient stories.
- **Storytelling Initiative:**
  - Record and share patient stories (YouTube, events).
  - Launch an ambassador program to foster leadership.
- **Resource Development:**
  - Develop brochures, care packages, and peer support tools.
  - Launch a new Facebook forum for peer-to-peer support.

## Research

**Primary Objective:** Establish and formalize a patient-driven research infrastructure.

- **Registry Development:**
  - Complete and finalize a lipodystrophy registry questionnaire by June 2025.
  - Include validated patient-reported outcome measures (QoL, pain, fatigue).
  - Involve at least 5 patients, 3 clinicians, and 2 researchers in the development.
- **Scientific Advisory Board:**
  - Establish a formal research network with monthly meetings.
  - Ensure patient engagement through Lunch and Learn and podcast integration.
- **Research Dissemination:**
  - Publish a burden of disease paper and updated clinical guidelines.
  - Submit an abstract and attend ENDO 2025.
- **Resource Creation:**
  - Develop and distribute educational materials for both physicians and patients/caregivers.

- Ensure multilingual access (Spanish, Hebrew).

## Development

**Primary Objective:** Ensure financial sustainability and expand organizational capacity.

- **Fundraising & Sponsorships:**
  - Strengthen partnerships with Chiesi, Regeneron, and other sponsors.
  - Launch new fundraising campaigns and merchandise.
- **Grant Strategy:**
  - Write a unified grant language document.
  - Explore funding for research seed grants.
- **Future Planning:**
  - Begin planning to hire an Executive Director.
  - Explore formalizing a Global Alliance.



## For inquiries, contact us.

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