



# 20 ANNUAL 25 REPORT

# Table of Contents

---

- 02 Table of Contents
- 03 Company Overview
- 04 Introduction
- 05 Objectives for the Year
- 06 2025 Recap
- 07 2025 Recap Continued
- 08 Research Highlights
- 09 Fundraising
- 10 Advocacy
- 11 Budget and Expenses
- 12 Summary
- 13 Acknowledgements

# Foundation Overview

---



## Lipodystrophy United

---

 22 Frances St, Los Lunas,  
NM 87031

 [www.lipodystrophyunited.org](http://www.lipodystrophyunited.org)

 [info@lipodystrophyunited.org](mailto:info@lipodystrophyunited.org)

### Key Detail Information

Legal Structure

**501(c)3**

Industry

**Patient Advocacy**

Year Founded

**2012**

Number of Staff

**4** (as of March 2025)

# Introduction

---

2025 marked a powerful chapter of growth, collaboration, and impact for Lipodystrophy United. Together with our community of patients, caregivers, clinicians, researchers, and stakeholders, we expanded access to education and support, elevated patient voices, and strengthened the foundation for future research and advocacy.

We've been able to advance infrastructure by expanding our Board of Directors with five (5) new members, who bring additional disease representation, regulation, and policy, and business expertise, and reimagined and expanded our Scientific Advisory Board. We also grew our capacity with new staff members and interns, and Community Programming advanced programs, such as Tea with LU, Lunch and Learn, and created even more!

From launching new resources and programs to deepening engagement with scientific and regulatory stakeholders, our 2025 accomplishments reflect what is possible when lived experience leads the way. We are proud of how far we've come and deeply grateful to everyone who helped make this progress.



# Objectives

---

Our mission is to support and educate those affected by lipodystrophy syndromes, raise awareness among the public and medical communities, and advance research, diagnosis, and treatment. At Lipodystrophy United, we envision a future where every individual with lipodystrophy has access to accurate diagnoses, quality care, and effective treatment, ensuring a better quality of life and, one day, a cure. Our objectives for 2025 aimed to keep our vision at the forefront of our organization while simultaneously expanding our fields of impact.



**Accurate  
Diagnoses**



**Quality  
Care**



**Effective  
Treatment**



**One day,  
a Cure**

## **These objectives included, but were not limited to....**

- Advancing scientific research and collaboration
- Further establishing diagnostic tools
- Maintain and form relationships with clinicians and researchers across the continental US
- Establishing and updating programming for new and existing patients and family/friends
- With the intended goal of increasing safe spaces, distributing diagnostic information, and fostering new relationships
- Host numerous patient-focused events across the continental US

**“When you start talking to other people with lipodystrophy, you **finally feel like yourself.**”**

**-Attendee with Lipodystrophy**

# 2025 Recap

## Research & Clinical Partnership

- Designed and advanced a patient-driven survey capturing disease burden and research priorities
- Presented a research poster: “Assessing the Burden of Lipodystrophy: Insights from a Patient-Driven Survey”
- Built momentum toward a patient-owned registry strategy
- Deepened collaboration with researchers and academic/clinical leaders to support better education, better data, and stronger patient participation in research



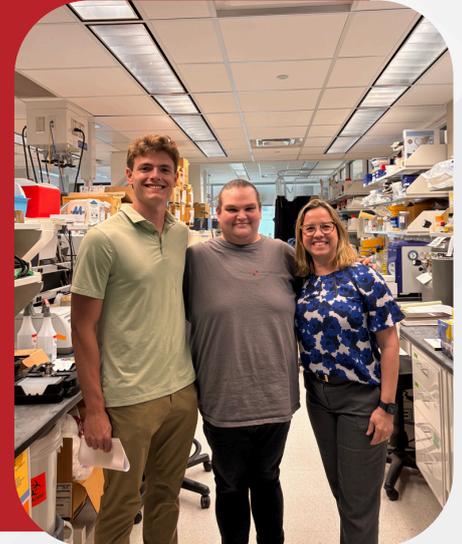
## Education & Resources

- Produced and published new educational content (including nutrition-related resources and video-based education)
- Created short-form educational content (TikTok/IG-style clips) translating scientific talks into patient-friendly learning
- Began development of glossary-style explanations of scientific terms to support non-medical audiences

# 2025 Recap Cont.

## Fundraising & Development

- Ran major year-end fundraising efforts (including Giving Tuesday momentum and match-based pushes)
- Strengthened sponsorship/funding strategy language and materials to support organizational sustainability and future programs



## Governance, Leadership and Org Development

- Launched our Scientific Advisory Board (SAB) and welcomed new BOD members
- Developed core governance tools supporting long-term scale (e.g., clearer committee structures and role clarity)
- Built internal strategy documents and operational planning to support growth into 2026 and beyond
- Begun updating all forward facing platforms for more user-friendly interactions



## Community Engagement/Support

- Continued to run and grow Tea with LU, providing consistent peer support and connection.
- Expanded community programming with structured discussion topics with organizations such as Give an Hour.
- Planned and launched/advanced Lunch & Learn-style educational programming to bring accessible, expert-led education to the community
- Strengthened community communications across channels (email + social), increasing regular touchpoints and engagement



# Research Highlights

---

**Global Registry Collaboration:** Successful collection of clinical data and Patient-Reported Outcomes (PROs). Data presented via abstracts and posters at major medical conferences, including ENDO (Global Endocrinology Conference) and the National Lipid Association Conference (NLA).

**Peer-Reviewed Publication:** Established a Scientific Advisory Board (SAB) comprised of top lipodystrophy experts from the US and internationally to guide LU's research priorities and strategy.

**Strategic Scientific Leadership:** Active Board Member of the ECLip Registry, ensuring the patient voice is integrated into data governance and research questions on a global scale.

**Generated Real-World Evidence (RWE):** Published a paper highlighting novel therapeutic approaches, specifically focusing on oral GLP-1 RAs in generalized lipodystrophy in the American Diabetes Association Journal.

**Data for Under-Represented Burdens:** Developed a mental health survey and collected responses from 50 people; data to be published soon. As well as developing a patient-driven survey on disease burden and research priorities.

**Conference Appearances:** Presented the poster: "Assessing the Burden of Lipodystrophy: Insights from a Patient-Driven Survey" at ENDO and NLA.

"I came to Lipodystrophy United thinking I could help them,  
but what I didn't know is that **I needed them.**"

-Researcher

# Fundraising

We had our best fundraising campaign to date in 2025! We saw an almost 150% uptick in donations from 2024, with over \$40k raised (image does not reflect a \$10k pledge made on December 2<sup>nd</sup>). From this analysis, we have learned that our audience responds better when a specific, tangible goal is attached to the donation ask. We also saw an increase in repeat donations when stewardship followed promptly after the initial donation and the second ask was of a smaller specified amount (i.e., our \$13 for 13 campaign). **Learn more in our fundraising report!**

## Giving Season Campaign Outline

Our campaign method entailed sharing multiple patients' stories, of varying lipodystrophy diagnoses, and explaining the Externally Led Patient-Focused Drug Development meeting, with all donations going towards travel/hotel support for the meeting in September 2026.

### Giving Tuesday

- Our giving season began on December 2<sup>nd</sup> with Giving Tuesday. A total of five (5) emails were sent, starting a week prior and ending on December 3<sup>rd</sup>. Corresponding patient quotes/images were shared via social media. A "Giving Tuesday Toolkit" was sent to our existing contact list to make easily shareable content available for distribution. We reached our campaign goal of \$30k in one day due to a generous match from Ormond MacDougald!

### \$13 for 13

- On December 13<sup>th</sup>, we launched the "\$13 for 13 years" campaign. We asked for a one-time donation of \$13 to help us reach our new goal of \$50k for travel/hotel support. This campaign consisted of a smaller-scale push for donations with one (1) email and two (2) social media posts shared.

### Other

- As 2026 approaches, we continue to share video content thanking our community for the donations and urging those who haven't to donate through the new year.

### Your support will provide:

- ♥ Travel and hotel support for patients and caregivers who otherwise could not attend
- 🗺 Essential accessibility accommodations so every individual regardless of mobility, health, or communication needs can fully participate

*Because of your incredible generosity, we have almost reached our original \$30,000 Giving Season goal. Thank you for showing up for our community in such a powerful way.*

Raised so far

**\$30,314 / \$50,000**

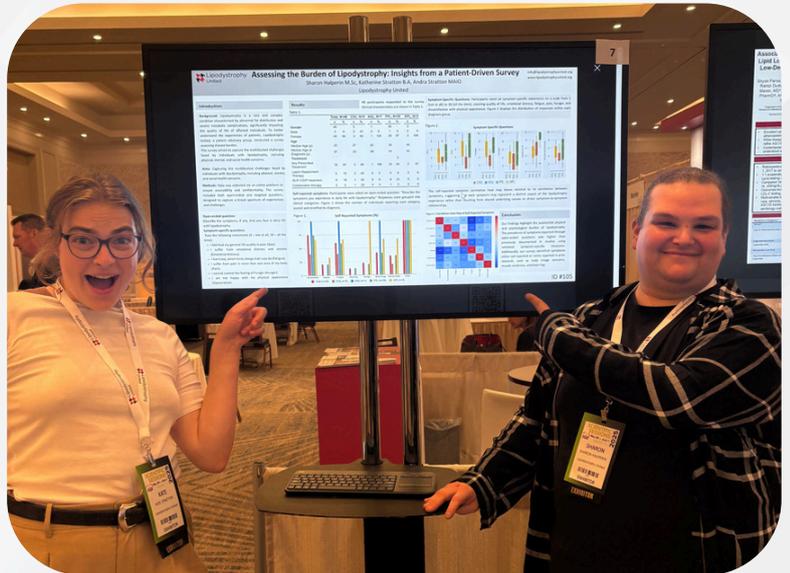
61% of our goal reached

59 donors

# Advocacy/Programming

## May 5 - 8: Professional Patient Advocates in Life Sciences (PPALS)

In May, two of our team members attended the Professional Patient Advocacy in Life Science's Patient Advocacy Certification Course. In this course, our members learned about topics such as industry partnerships, treatment development, and effectively representing the stories of our communities.



## May 28 - June 1: National Lipids Association (NLA)

In late May and early July, our team attended the 2025 National Lipid Association Scientific Sessions. We spoke with over 200 healthcare professionals, physicians, and industry representatives about lipodystrophy diagnosis, advocacy, and partnerships. We attended up-to-date informative talks about GLP1/GIP, which will have a direct impact on our community in the future!

## July 12 -15 : ENDO (Global Endocrinology Conference)

Our team also attended the 2025 Endocrine Society Annual Meeting. We had the opportunity to engage in over 200 meaningful, in-depth conversations with healthcare providers about lipodystrophy and our mission. We also saw strong interest from researchers eager to learn more about the condition. Over 20 healthcare providers expressed a desire for more direct support with specific patients, and we distributed hundreds of informational pamphlets.



# Programming Cont.

---

## July 17- 20: Ann Arbor Community Day

We had an incredible turnout of 30+ people for our one-day event at The University of Michigan. We marketed the event with flyers, reels, and Dr. Oral reached out to her patients with personal phone calls. Of those 30, 18 identified as patients or caregivers of those with lipodystrophy. That was an amazing turnout for our organization! During the event, Sharon Halperin, LU's Research Director, met with Dr. Elif Oral to strengthen our scientific collaborations and discuss clinical trial participation, an essential step in advancing treatment and deepening understanding of lipodystrophy. Sharon herself enrolled in two clinical trials during the visit, underscoring LU's commitment to patient-driven research.

## October 9: Global Lipodystrophy Leaders Forum

Lipodystrophy United is part of a global collaboration of numerous other non-profits spanning the world. We have monthly meetings to discuss ways to connect and advance our impacts. Such ways include the joint celebration of World Lipodystrophy Day, where we worked with Israel, Canada, and Italy, to name a few. We were able to translate the virtual symposium into over 20 languages! Another example is the current construction of a global cookbook for lipodystrophy-approved recipes. We're also participating in ECLip.



# Programming Continued

## October 24 - 27: Boston Community Day

Our 2025 Boston Community Day was an undeniable success. Created with the intentions of bringing clinicians and patients together, we exceeded our expectations thanks to Dr. Fourman and her team. We had a total attendance of 40 from over 5 states, and many of those attending were meeting people like them for the first time.



## Year Round Programming

### Tea with LU

As Tea with LU continues to grow, we adopted a new structure that strengthens the program's impact, accessibility, and sustainability—while maintaining its community-led heart. Our goal is to create a model that is welcoming, intentional, and responsive to the diverse needs of the lipodystrophy community. The new format allows for the growth of knowledge and genuine connection surrounding lipodystrophy.

### Lunch and Learn

Our Lunch and Learn program produced ten (10) extremely informative, permanent resources for our community. Spanning topics from nutrition, clinical trial structure, and GLP-1s. We received feedback that the program was more receptive once published, so in 2026, we will prerecord and upload lectures.

### Give an Hour

We hosted numerous sessions with Give an Hour this year. The sessions varied from caregiver mental health, facilitator training, and emotional resilience. We were beyond grateful to have this opportunity with Give an Hour, whose mission we admire greatly. Below is a quote from a parent of a lipodystrophy patient about her experience.

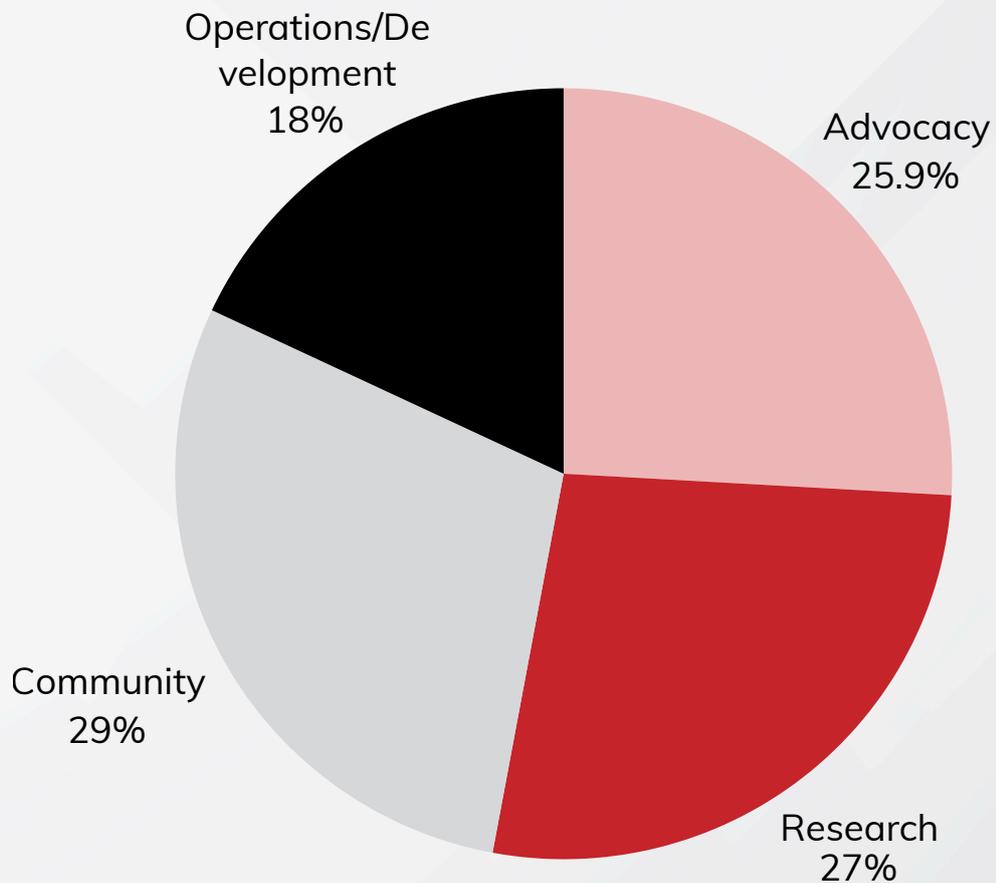
“Give an Hour has been incredibly informative and supportive for me as a mom of a son with a rare disease. Their resources offer meaningful insight that helps caregivers and families navigate the difficult moments that come with rare or any medical challenges. I've learned **practical strategies and coping tools that have truly helped me grow, both as a mom and as a person. I'm deeply grateful for the guidance they provide.**”

-Attendee with Lipodystrophy

# Budget/Expenses

---

## Distribution of Funds



**Total Income:**

Our total income for the 2025 calendar year prior to Giving Tuesday donations was **\$201,046.26**. Including...

**Foundation Donations:** 7,753.69

**Individual Donations** (all donations up to Dec 2nd): 11,090.83

**Giving Season Campaign Donations:** 40,314.00

**Interest Income:** 1,510.24

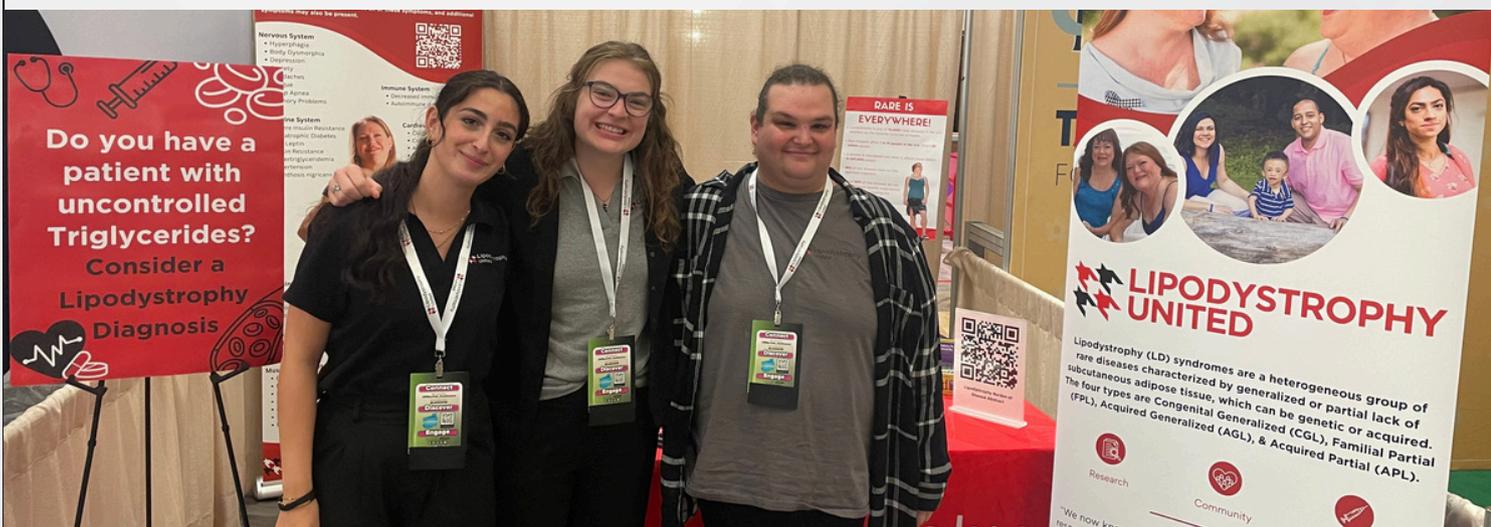
**Pharma Support:** 140,377.50

# Summary

In 2025, Lipodystrophy United strengthened our community support and expanded education through patient-centered programming and accessible resources. We advanced patient-driven research efforts, shared new insights on disease burden, and built stronger systems and partnerships to support long-term impact. With this momentum, we are entering the year ahead more connected, more prepared, and more committed than ever to elevating patient voices and accelerating progress for everyone living with lipodystrophy.

In 2026, Lipodystrophy United's primary focus is ensuring the strongest possible utilization and outcomes from our upcoming EL-PFDD meeting. The majority of our organizational effort will be dedicated to preparing our community to participate meaningfully and ensuring that patient and caregiver experiences are captured clearly, accurately, and in a way that drives real impact. To support this, we will align our programming around this goal, including an updated Tea with LU format and Voices of LU, designed to systematically gather patient-identified questions, concerns, and priorities regarding disease burden and treatment experiences. Our end goal is to produce a detailed, community-informed outline and guide that's primary job is to strengthen the meeting and provide future guidance for research and care discussion within the FDA and our organization/stakeholder relationships. We will continue to implement our community days, Lunch and Learns, global collaboration, stakeholder relationships, bolster the patient advisory committee, and start the care package initiative.

Please contact us at [info@lipodystrophyunited.org](mailto:info@lipodystrophyunited.org) with any follow-up questions or concerns.



# Acknowledgements

---

We'd like to acknowledge the following...

**Our lipodystrophy community** — patients, caregivers, and families who showed up, shared honestly, supported one another, and made every program meaningful. To everyone who contributed data, insights, and lived experience to strengthen the “voice of the patient.” And thank you to those who volunteered for facilitating connection, outreach, and day-to-day support that strengthen our community fabric.

**Our donors** — individuals, families, and community champions whose generosity sustained our programs and moved our mission forward. A very warm thank you to everyone who donated during Giving Tuesday, our largest community-based fundraising ever!

**Our Board of Directors** — We'd like to thank Larry Seida, Andra Stratton, Stephanie Fischer, Abbey Hauser, Dena Winchester, Mandy Pulliam, Ben Dickerson, and Sharon Halperin for their governance, stewardship, and the behind-the-scenes leadership required to grow responsibly.

**Our Scientific Advisory Board** — for helping ensure our work stays scientifically rigorous, patient-centered, and future-facing. We'd like to thank Dr. Elif Oral, Dr. Lindsay Fourman, Dr. Abhimanyu Garg, Dr. Nivedita Patni, Dr. Stephen Stone, Dr. Rebecca Brown, Dr. Yael Lebenthal, Dr. Ormond MacDougald, Dr. Baris Akinci, and Dr. Justin Rochford for their clinical leadership, partnership, and ongoing commitment to improving care and advancing patient-centered research.

**Clinicians, researchers, and speakers who contributed time and expertise** — thank you for making education more accessible and for listening to lived experience.

**Partner organizations and rare disease collaborators** — for sharing knowledge, resources, and solidarity as we work toward a stronger rare disease ecosystem.

**Our team** — for dedication, professionalism, and heart in every detail of the work.

Thank you to our sponsors

