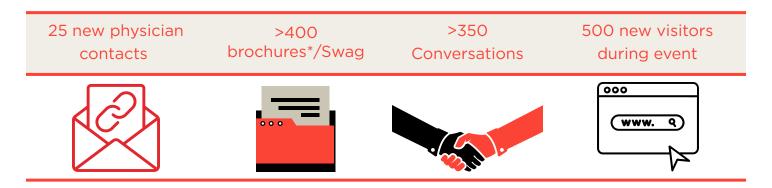


# **ENDO 2025 BOOTH INSIGHT REPORT**



## Introduction

The ENDO Society Conference 2025 provided an exceptional platform for Lipodystrophy United (LU) to engage with the global endocrinology community. This prestigious event, held annually, brings together leading experts, researchers, clinicians, and patient advocates to discuss the latest advancements in endocrinology and related fields. At the conference to raise awareness and increase education about lipodystrophy, foster connections with researchers, clinicians and other stakeholders, and promote the mission of Lipodystrophy United.

LU's booth was a busy hub for information, interaction, and advocacy. LU representatives showcased educational materials about lipodystrophy, highlighted stories and images of people living with lipodystrophy, shared information about treatment and clinical trial options, presented a poster on the burden of the disease of lipodystrophy, and hosted a fundraising walk. By engaging with these crucial lipodystrophy stakeholders, LU enhanced the understanding of the challenges faced by individuals living with lipodystrophy and advocated for improved diagnosis, treatment, and support.



Page 1

### The Highlights

- ✓ Almost all conference booth visitors recognized lipodystrophy as a rare disease.
- ✓ Over 50 clinicians stated that they have or think they have a patient with lipodystrophy in their care.
- ✓ Over 10 clinicians have patients with lipodystrophy, but did not know how to treat them, and we were able to connect them with experts.
- ✓ Five providers shared that they had encountered lipodystrophy in the past but didn't recognize it at the time—and now feel equipped to identify it in the future.
- ✓ Multiple endocrinologists stated how isolated their patients are and how much they will benefit from psychosocial support and connection to the community.



#### Summary

Lipodystrophy United's participation in <u>ENDO 2025</u> was a resounding success. The organization networked with endocrinologists and researchers, raised awareness about lipodystrophy, and distributed educational materials to attendees worldwide. Our impact extends into the future as clinicians apply their newfound knowledge of lipodystrophy to diagnose and better treat patients.

LU's Research Director, Sharon Halperin, presented the <u>poster and abstract</u>, "Assessing the Burden of Lipodystrophy: Insights from a Patient-Driven Survey," during two scheduled presentation times, providing insight and education about the disease beyond the conference booth.

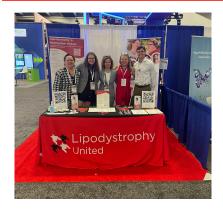
Additionally, traffic to the booth was very steady throughout all days during convention floor hours. Engaging in thought-provoking conversations with over 350 individuals, demonstrating need for continued diagnosis and treatment education. The LU team fielded questions across many body systems and received requests for resources. These discussions with medical professionals continue to reflect the need for a deeper understanding of lipodystrophy's impact on the whole individual. The team also collected contact information from 25 esteemed endocrinologists and researchers who expressed interest in hearing more, expanding LU's research and clinician network in the field.

In addition to these interactions, the distribution of 400 copies of educational materials served as a tangible reminder of the organization's mission and presence. These materials acted as conversation starters, prompting follow-up email inquiries from many clinicians seeking to learn more. Additionally, the website welcomed 500 new visitors, demonstrating a growing interest in lipodystrophy and the resources provided by the organization.

The team also participated in relevant educational and networking opportunities by attending lectures, engaging with other medical and advocacy groups and meeting with lipodystrophy stakeholders. Insights will guide future research priorities and advocacy efforts as we continue provide accurate and comprehensive information to individuals affected by lipodystrophy.



#### **Booth Representatives**



Andra Stratton (Co-Founder), Kate Stratton (Executive Director), Sharon Halperin (Research Director), along with intern Rowan McDonnell and community member Laura Barrett and Christine Coppini, proudly represented the lipodystrophy community at the booth.



\*Booth Materials: Physicians Guide to Lipodystrophy; Patients Guide to Lipodystrophy

www.lipodystrophyunited.org