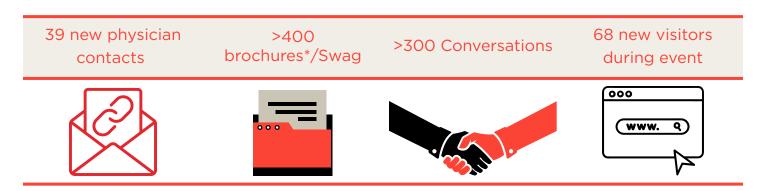


ENDO 2024 BOOTH INSIGHT REPORT



Introduction

The ENDO Society Conference 2024 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. Participation in this conference was aimed at raising awareness and increasing education about lipodystrophy, fostering connections with researchers and clinicians, and promoting 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, and shared information about treatment and clinical trial options. 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.

- ✓ Most conference booth visitors recognized lipodystrophy as a rare disease a notable improvement from 5 years ago.
- ✓ Over 200 clinicians stated that they have or think they have a patient with lipodystrophy in their care.
- ✓ A young endocrinologist shared, "I remember a question about lipodystrophy on the medical board exam, 'If it is not Cushing's, think lipodystrophy.'"
- ✓ 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 2024</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 their patients. During the weekend, the organization garnered an impressive 448 views of the real-time social media content posted. We aim to amplify our impact and inspire greater support among the lipodystrophy community by holding a Facebook Live discussion about the event experience in late June.

The booth rarely had a moment of quiet during convention floor hours. This networking success was a remarkable testament to the organization's dedication and efforts in raising awareness about lipodystrophy to all who passed the booth. Engaging in thought-provoking conversations with over 300 individuals allowed for a deeper understanding of lipodystrophy's impact and the need for continued research. The team collected contact information from 39 esteemed endocrinologists and researchers, expanding LU's research and clinician network in the field.

The distribution of 300 brochures and nearly 500 branded pens and tissue packets serves as a tangible reminder of the organization's mission and presence. These materials acted as conversation starters, prompting follow-up email inquiries from four clinicians seeking to learn more. Additionally, the website welcomed 68 new visitors, demonstrating a growing interest in lipodystrophy and the resources provided by the organization.

The organization's efforts also extended to educating individuals previously unaware of lipodystrophy. Over 70 individuals gained valuable insights into the condition, enabling them to make informed decisions about their health. Discussions with approximately 50 attendees

Page 2

regarding clinical trials further emphasized the importance of research and potential treatment options. LU's attendance also allowed for connection with global lipodystrophy experts and

strengthened already established relationships and commitment to collaboration and knowledge sharing.

Finally, reviewing 15 lipodystrophy-related abstracts ensured that the organization remained upto-date with the latest research findings. This review process informed the organization's advocacy efforts and enabled them to provide accurate and comprehensive information to individuals affected by lipodystrophy.



Booth Representatives



Andra Stratton, President and Co-Founder, and Kate Stratton, Program Coordinator, represented the lipodystrophy community at the booth for the first three days and were joined by a parent of an 8-year-old living with congenital generalized lipodystrophy on the final half day.



*Brochures: Physicians Guide to Lipodystrophy; Patients Guide to Lipodystrophy; Voices of Lipodystrophy

www.lipodystrophyunited.org