



Welcome to the 1st edition of the Lipodystrophy United Newsletter

This newsletter is a step forward in our mission to raise awareness, share valuable knowledge, and build a strong sense of community and connection among those impacted by lipodystrophy. We hope the content inspires, informs, and supports you as we grow and strengthen our bonds together. Thank you for being an essential part of this journey!



Tea with LU
Tuesdays at 6PM CDT



Lunch and Learn
Dr. Justin Rochford
February 15th, 12pm CDT



Rare Disease Day
February 28th

A Month Full of Events!

- **Tea with LU** - Join us for an open conversation with your favorite cup of tea every Tuesday at 6pm central time. [Click here to register!](#)
- **Lunch and Learn webinar** with [Dr. Justin Rochford](#), a lipodystrophy researcher. Justin will explain all things related to lipodystrophy basic

science and will answer all your questions, [Click here to register!](#) Professor Justin Rochford leads a research team at the Rowett Institute focused on understanding how fat tissue dysfunction contributes to diseases like lipodystrophy, type 2 diabetes, and liver disease. His expertise in studying the biological mechanisms of lipodystrophy and developing potential treatments makes him a valuable resource for the community.

- **Rare Disease Day** - February 28th. Stay tuned for exciting events!

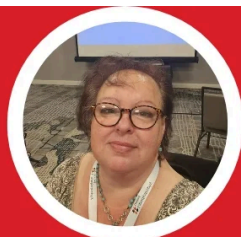
[Link to Event Page on our Website](#)



Caregiver Corner - Lori Seida

Meet Lori, mom to Julian, a resilient 24-year-old living with Congenital Generalized lipodystrophy. Julian's journey with lipodystrophy has been anything but easy—it took 21 years to get a diagnosis. Along the way, Lori faced countless challenges: doctors who were puzzled, misunderstandings from others, and the emotional toll of navigating the unknown.

[Read Lori's Journey Here](#)



Community Corner - Christine Choppini

2024 was a fantastic year, filled with the joy of connecting with wonderful friends through Lipodystrophy United. The emotional support and compassion I've received from everyone I've had the pleasure of meeting—both online and in person at the Lipodystrophy Symposium—has been

unparalleled. Thanks to my incredible medical team, I've made significant strides this past year, lowering my cholesterol and keeping my blood sugars in check.

As I look ahead to 2025, I'm excited for a year of changes, starting with a big move in February after living in my home for 22 years. While I'll continue working full time, I'm eager to embrace a slower-paced lifestyle, trading city life for the tranquility of the countryside. I'm also looking forward to diving back into my passions for photography and painting. Remember, always embrace your uniqueness and live a life that brings you happiness!



Lipodystrophy United continues to amplify our community's voice at the largest endocrine conference in the U.S., ENDO 2025 with an abstract highlighting results from our latest patient survey on the burden of lipodystrophy

[Click Here to Read Full Abstract](#)

 Lipodystrophy
United



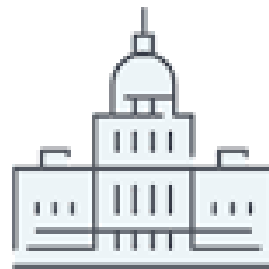
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RARE
DISEASE WEEK
ON CAPITOL HILL



Advocating for Change: Lipodystrophy United at Rare Disease Week on Capitol Hill!

Lipodystrophy United is proud to represent the lipodystrophy community at Rare Disease Week on Capitol Hill from February 24 to February 28, 2025!

We will be joining advocates from across the country to raise awareness, share personal stories, and push for meaningful policy changes to support those living with rare diseases. The first three days, February 24-26, are hosted by the EveryLife Foundation for Rare Diseases and focus on legislative advocacy. During this time, we will participate in training sessions, policy briefings, and in-person meetings with members of Congress, ensuring that the needs of the rare disease community are heard by decision-makers in Washington, D.C.

Following our advocacy on Capitol Hill, we will be attending the FDA-NIH Rare Disease Day on February 27-28, which shifts the focus to scientific and regulatory advancements in rare disease research and treatment development. This two-day event, held on the NIH campus in Bethesda, Maryland, will feature presentations from the FDA and NIH on efforts to accelerate rare disease research, networking opportunities, and exhibits from researchers and patient organizations.

By participating in both policy advocacy and research-focused discussions, we are ensuring that the voices of those living with lipodystrophy are heard in both legislative and scientific spaces.

Stay tuned for updates as we share our journey and highlight the voices of our incredible community!

Stay Connected!

Thank you for your continued support and participation! We're grateful to have such a dedicated community. We hope this newsletter helps keep you informed and engaged.

If you found this newsletter helpful, please share it with others in the community. Let's continue spreading awareness and support for those affected by lipodystrophy!

This newsletter was written by Crystal Chavez & Lori Seida, Community Newsletter Team at Lipodystrophy United.

World Lipodystrophy Day - March 31st 2025
#WLD2025

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Days

00

Hours

00

Minutes

00

Seconds



Lipodystrophy United

22 Frances Road, Los Lunas
United States of America

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