



Lipodystrophy United

Welcome to the 2nd edition of the Lipodystrophy United Newsletter

February was a time to amplify our voices for Rare Disease Awareness Day (February 28th). This month, we focus on advocacy, education, and building connections. Join us in making a difference!

Upcoming 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: Special World Lipodystrophy Day Event - On March 29 we will host a special live Lunch and Learn event with talks from lipodystrophy experts patients and caregivers and amazing activities. [Click here for more details and registration.](#)

World Lipodystrophy Day:

Global Awareness Video

A **global video featuring patients, caregivers, and advocates** introducing themselves in their native languages to showcase the **diversity and unity** of the lipodystrophy community.

✓ The video will go live on **social media and our website** as a key advocacy tool.

♥ Throughout the day, we will be **sharing personal stories** from people living with **all types of lipodystrophy**—highlighting **their journeys**,

challenges, and hopes for the future.



Caregivers Corner - Lori Sieda

Caring for a Loved One with Rare Disease: Strength & Support

Caring for a loved one with lipodystrophy is both challenging and rewarding. The road to diagnosis can be long, and even after answers come, navigating treatment and support is no easy task. Caregivers often take on multiple roles—advocate, educator, and emotional anchor—while trying to maintain their own well-being. In this blog, I'll share insights on managing these challenges, finding the right support, and prioritizing self-care along the way.

[Read Lori's Journey Here](#)

1495 UNIVERSITY OF ABERDEEN
The Rowett Institute

Justin Rochford

Lunch and Learn with LU:
*What is Basic Science, and
How Can It Help
Lipodystrophy Patients?*

Justin Rochford
*Professor of Metabolic Health
University of Aberdeen, UK*

ABERDEEN 2040

COURTESY OF HANLIDA ARCHITECTS
CHARTERED ARCHITECTS & PLANNERS

Scientific research is essential for advancing care and treatment for rare diseases like lipodystrophy. In our first session since relaunching Lunch and Learn, over 25 community members joined—many engaging for the first time! Dr. Justin Rochford from the University of Aberdeen discussed basic science’s role in understanding lipodystrophy, highlighting how research on adipose tissue can lead to better treatments. His talk emphasized the power of science in shaping future care. Staying informed helps drive progress for all—patients, caregivers, and advocates alike.

[Watch the Full Lunch and Learn Here](#)

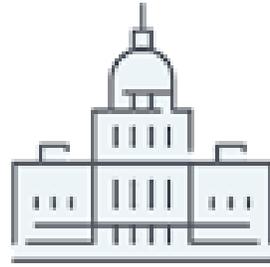


Community Corner - Karen Pinkham

I stumbled upon Lipodystrophy United while researching lipodystrophy after school on a Friday evening as I had time to spare before escorting my students with special needs to the prom. When I discovered a community of individuals that looked like me that weren’t my relatives, I felt an instant connection that brought me to tears. I believe that was in May 2012.

I think of myself as one of the old timers in this wonderful group of warriors. I have been blessed to attend the first symposium held in the U.S. in 2014. My dad and I were fortunate to attend the 2018 symposium as well. I like to think my dad was with me in spirit at the 2024 symposium. I’ve mourned the passing of many and prayed for healing for countless others. I’m excited to see rejuvenation occurring in the foundation. The fight for research, treatments and general awareness is a marathon, not a sprint, and it takes a team to keep the momentum going. With the knowledge of the “old timers” and the energy of “newcomers”, I’m convinced we are on the precipice of major breakthroughs for our community.

RARE DISEASE WEEK ON CAPITOL HILL



Last week, our executive director Kate Stratton attended Rare Disease week in Capitol Hill and Michigan Medicine Rare Disease Day Symposium together with community representatives Laura and Crystal.

"Last week was one of the most intense weeks of my life. Attending **DC** during a time when **rare disease research is under threat**—when science is being deprioritized—felt unprecedented.

Yet, amidst the challenges, I felt **empowered**. Hundreds of people in the **rare disease community** stood together to **push for change, highlight the urgency of these issues, and remind policymakers that health is not political—it's human**.

At our core, we all share **common values**—the well-being of our loved ones and community. This priority transcends **politics, geography, and culture**. When we recognize that, the conversation is no longer about **whether** we should act—it's about **how** we are going to solve this together. Telling stories of our community brings the conversation back to this basic human experience.

What if the next step? Simply to lean into our community. Join **Tea with LU** or **Lunch and Learns**, connect with others who understand, and find support in shared experiences. **Now more than ever, we need each other.** Taking action doesn't have to feel overwhelming—it can be as simple as **volunteering, engaging, and finding empowerment in the ways that feel right for you.**

I am honored and thrilled to continue these conversations as we continue to work towards a better future for our community."



Ask the Advocates: Wisdom from the Trailblazers

To honor this month, we're launching "Ask the Advocates", a special initiative where our longtime community leaders, those who paved the way for lipodystrophy awareness, will answer your questions! Whether you're newly diagnosed or have been on this journey for years, this is your chance to hear firsthand experiences, gain insights, and learn from the voices who helped build this movement. Have a question for our OG advocates? Submit it today, and we'll feature their answers in next month's newsletter!

[Ask your question here](#)

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World Lipodystrophy Day - March 31st 2025
#WLD2025

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