Lipodystrophy United

April Showers Bring May Flowers!

Join us for our April Newsletter! In this newsletter, we will close out this month's major milestones for Lipodystrophy United, and we welcome May for many more exciting opportunities.

Upcoming Events

Sharing Our Mission at NLA Miami 2025 & ENDO 2025

We're excited to announce that Lipodystrophy United will be showcased at two major events in 2025: the National Lipid Association's Annual Meeting in Miami and ENDO 2025, one of the largest endocrine-focused conferences in the world.

This is a *tremendous* opportunity to bring our rare disease community into bigger rooms, where more providers, researchers, and organizations can hear our stories and better understand what it means to live with lipodystrophy.

Why it Matters
These events aren't just conferences; they're platforms. They're places where decisions are made, collaborations begin, and awareness takes root. By showing up, speaking up, and making ourselves visible, we're doing more than spreading information; we're changing the narrative.

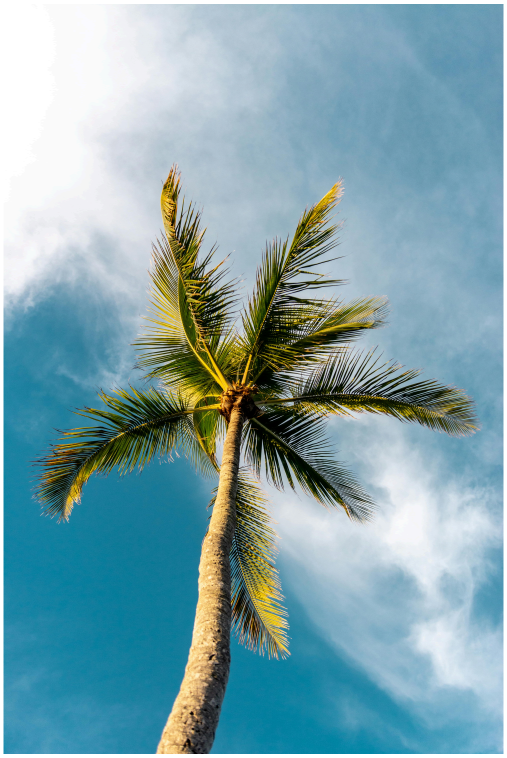
What We’ll Be Doing

We’ll share educational materials, patient perspectives, and our nonprofit’s mission. We’ll also talk to healthcare providers who may have never met someone with lipodystrophy before and help them connect the dots between symptoms and diagnosis. This is advocacy in action, and it’s a significant step in growing recognition and support for our community.

A Moment to Celebrate

We’re celebrating our voices being heard in bigger spaces with bigger impact—and we’re just getting started.

Thank you for being part of this journey. Whether you’re a patient, a caregiver, a supporter, or just learning about lipodystrophy, you matter, and your presence in this community helps move us all forward.



Family Dinner

All South Florida Community Members!

Will you be in or around North Miami from May 29 to June 1? If so, join us for a community dinner! Email us at **info@lipodystrophyunited.org** to find out more information (with the subject "NLA Community Dinner"). Please provide any dietary restrictions (such as vegetarianism) and allergies, so that we can plan accordingly. We cannot wait to see you there!

Science Spotlight

The Evolution of Lipodystrophy Awareness

This year, we're incredibly proud to shine a light on something that sets our community apart: giving our community members direct access to world-renowned lipodystrophy specialists. This kind of access is rare and powerful for community members.

Lipodystrophy awareness has come a long way. Our ability to continually bring in new research and experts proves just how far we've come. We are no longer invisible. We are part of the discussion. Together with patients, caregivers, advocates, and experts, we are shaping the future of care one conversation at a time.

One of these opportunities was our most recent lunch and learn with Dr. Stephen Stone. Dr. Stone shared an equally educating and entertaining talk on insulin resistance, diabetes, and lipodystrophy. This presentation is now available for viewing on our website or at the link below!

We've also attached the RADIANT study that Dr. Stone referenced in his talk. This study is a network for those who do not have a known mutation to connect and find answers for those outside of atypical diabetes diagnosis. Just like us, RADIANT aims to advance research in order to advance quality of life for their community.

Lunch and Learn!

RADIANT!

Spotlight Section

Behind the Movement: Meet the Next Generation.

We are taking a moment to shine the spotlight on not just where we've been but also where we're going.

Our movement was built by powerful voices who came before us. It will be carried forward by the next generations. Young lipodystrophy patients are already out here making waves, dreaming big, and showing up with so much strength and honesty.

First, A Note from Crystal
Reading Mallory and Julian's stories, I couldn't help but feel a deep mix of pride and hope. They're doing such powerful work. Not just in how they are dealing with learning to manage their disease. But in how they live and thrive while at college. They remind us that you can manage the hard stuff and move forward.

If I can offer *just a tiny bit of "slightly older adult" wisdom* (yes, I said it with a wink), it's this: your diagnosis doesn't get to decide your whole story. What matters most is what you *do* with the hand you've been dealt.

Mallory is chasing dreams behind a camera lens. Julian is owning his story while managing college life. Both of them are proof that it's not about having a perfect body or health. It's about having the courage to keep going anyway.

Let's keep cheering each other on. Let's keep showing up for each other just like this. We are honored to introduce Mallory Mattison and Julian Seida.

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Meeting the Next Generation: Mallory Mattison

Hi, my name is Mallory Mattison and I have been living with lipodystrophy for 12 years. Although this disease affects every single part of my life, I don't let it control how I live. One of my life goals is to become a medical documentary filmmaker and spread awareness through storytelling. I am currently in film school and I hope to work with a rare disease organization in the future. Lipodystrophy has created challenges for me as well. Most days I struggle with symptoms of this disease. I think it is important to remind yourself that it is okay to not feel good. Living with a chronic illness is not easy and taking care of yourself should be top priority.

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Meeting the Next Generation: Julian Seida

My goal is to live a normal, healthy life. I enjoy staying active and playing sports like baseball and basketball. However, one challenge I face is that people assume I'm perfectly healthy just by looking at me—they don't see that I have a fatty liver, high triglycerides, and diabetes. Because of these conditions, I have to be mindful of everything I eat and drink, while my friends can indulge without worry.

As a college student, my breaks aren't spent relaxing like most of my peers. Instead, I travel to Dallas or the Mayo Clinic for doctor appointments. The uncertainty before each visit makes me anxious—I never know what the doctors will say. My parents have been incredibly supportive, researching my symptoms and connecting them to lipodystrophy. It's frustrating, and at times, it gets me down, but I know this is something beyond my control.

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