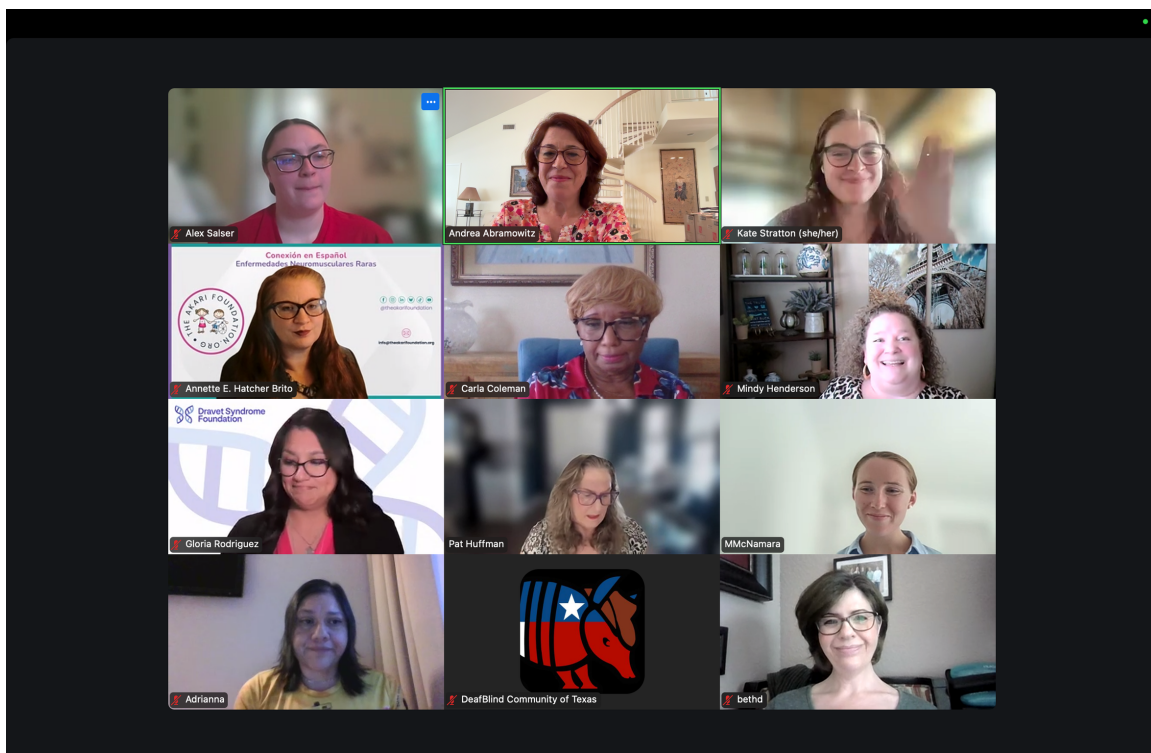


Learn about our August accomplishments and upcoming events!

[View in browser](#)



August: A Recap of our Work



August was an incredible month for our organization!

We proudly celebrated National Patient Advocacy Day on August 19th by participating in *Rare Across America* with the EveryLife Foundation. Our Executive Director, Kate Stratton, and community member, Crystal Chavez, met with state representatives from Texas, Michigan, and New Mexico to discuss bipartisan rare disease policy.

In this issue, we're excited to share highlights from Rare Across America, our Community Day in Ann Arbor, insights from our collaboration with Give an Hour, a community corner—and a special feature on the amazing work of our summer intern, Rowan.

Read on to see what we've been up to!

Don't miss tonight's Tea with LU!

A graphic for a 'Tea with LU' event. It features a red line-art illustration of a teacup and saucer with floral patterns. The text 'This coming' is written in a cursive script above the words 'Tea with LU', which are in a large, bold, sans-serif font. Below the illustration are three red rounded rectangular buttons with white text and icons. The first button says 'An Open Conversation for Our Community'. The second button has a clock icon and says 'Tuesday, September 2, 2025 6 - 7 PM CST'. The third button has an envelope icon and says 'Email info@lipodystrophyunited with any questions'. At the bottom left is the Lipodystrophy United logo, and at the bottom right is a globe icon followed by the URL 'https://lipodystrophyunited.org'. There are also faint background sketches of a tea bag and a book.



[Register Here!](#)



Rare Across America Highlights

This month, our Executive Director, **Kate Stratton**, and community member **Crystal Chavez** proudly represented our community during *Rare Across America* with the EveryLife Foundation. They met with state representatives from Texas, Michigan, and New Mexico to advocate for policies that could change many lives in the lipodystrophy community—including the [Give Kids a Chance Act](#), [Accelerating Kids' Access to Care Act](#), and [Protect and Restore Federal Funding for Medical Research](#)

They also highlighted the critical importance of [Medicaid for our community](#), and brought forward the **collective stories of our community**, stories we've gathered from speaking with hundreds of individuals over the past year. These personal experiences gave so much power to conversations about patient-driven research, equitable access to treatment, and the urgent needs of people living with lipodystrophy and other rare diseases.

Crystal shared, "Meeting with state representatives during Rare Across America was powerful. I was able to share my story of living with lipodystrophy and connect it to the urgent need for protecting NIH funding and expanding access to care. It was an incredible feeling to know our voices are being heard at the policy level."

Through these meetings, we strengthened partnerships with the EveryLife Foundation and fellow rare disease advocates, ensuring our voices continue to be heard on a national level.



Community Day

Join Us in Boston!

Join us this fall for a special



Community Day featuring **Dr. Lindsay Fourman** and her team! Together, we'll delve into important topics such as **cardiovascular disease (CVD)** and **metabolic dysfunction-associated steatotic liver disease (MASLD)**.

After the sessions, we'll take time to **explore the city** and **share a meal with friends and family**—a perfect mix of learning, connection, and fun.

Stay tuned for full details and registration information!

RSVP!



Empowering Our Community Through Training

In August, we hosted two impactful trainings to strengthen support within our community. We partnered with **Give an Hour** for a peer

support training and held a **facilitation training** for those interested in leading groups for our community.

It was inspiring to gain official training, and we're excited to see these new skills come to life in future **Tea with LU** sessions. If you're interested in accessing the **facilitation training recording**, please email **kate@lipodystrophyunited.org**.

Explore the valuable tools and resources available on the **Give an Hour** website below!

[Click here to Learn about Give an Hour Rare Community](#)

Join Us for our next Give an Hour Caregiver Support Session!

You are not alone: Connection, Boundaries, and Caregiver Community

Join us for a conversation with Julie Wells focused on the emotional and psychological toll of caregiving within the rare disease community. We will explore what it means to



practice compassionate boundary-setting by exploring respectful communication strategies that protect both the caregiver's well-being and the relationship with the person receiving care. We will also explore realistic approaches to connection that help caregivers engage with peer and community support, even when every and time are limited due to caregiving demands.

[Register Here!](#)

Community Corner: Athena

Athena, a vibrant 15-year-old, lives with **Familial Partial Lipodystrophy Type 4 (FPLD4)**. Her road to diagnosis was far from easy. After years of uncertainty, the **PLIN1 variant** was finally identified through genetic testing at **The Children's Hospital of Philadelphia (CHOP)**.

Recently, Athena underwent surgery to remove the right lobe of

her liver—a challenging moment in her young life. Yet, she remains determined and optimistic. She's eager to return to the dance floor and dreams of one day becoming a pediatric medical professional, inspired by her own experiences.

Athena's strength and resilience embody the spirit of our community, facing challenges head-on and continuing to reach for the future.





Thank You,
Rowan!

You cared deeply for our community, brought joy to our team, & made a lasting impact through your work.

We wish you all the best & can't wait to see where your journey leads. You'll be missed!

**Watch Rowan's Burden of
Disease Presentation
Linked Below!**



<https://lipodystrophyunited.org>

Watch Rowan's Presentation

Watch
Here!



Community Day Success!

Community Day in Ann Arbor was a wonderful success! With over 30 attendees, we shared a relaxing and inspiring afternoon filled with meaningful connection, great food, and even massages. Dr. Oral and her team provided invaluable insight into Radiant and other ongoing clinical trials, helping our community feel more informed and empowered. Cookie the horse stole the show with the kids, adding an extra touch of joy to the day. We can't wait to bring events like this across the U.S. so everyone in our incredible community has the chance to take part.

Lipodystrophy United

22 Frances Road, Los Lunas
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