Global Leadership Forum, EL-PFDD, and upcoming events! View in browser

Lipodystrophy United

Sweater Weather 🍁 AND EXCITING ANNOUNCEMENTS

Fall Updates!

We would like to extend our heartfelt thanks to Chiesi Global Rare Diseases for hosting in Dublin and making it possible for us to come together once again for a very productive Lipodystrophy

Leaders Forum. What we achieved at this meeting was a coming closer to a genuine sense of unity across groups. This is not easy. We bring different cultures, languages, health systems, and perspectives. Through translation, shared purpose, and open dialogue, we made real progress on joint projects and strengthened our connections. What makes this gathering so special is knowing that there are people all over the world committed to the same fight. The most inspiring part is that we are no longer fighting alone; we are doing it together. And none of this would be possible without Chiesi's support, nor without the commitment of our international partners.

During the meeting, we discussed important topics, including mental health in our community, which aligned perfectly with the launch of our new mental health survey in partnership with Chiesi. Each time we gather, we are reminded that we are stronger together. ❤️

Members of the Leadership Forum

Lipodystrophy UK serves people affected by Lipodystrophy in the UK!

The organization

AiLIP serves people with lipodystrophy

Lipodystrophy UK

Acopel supports patients Lysosomal Storage Diseases (LSDs) and other Rare Diseases (RDs) in Colombia.

acopel

Lipodystrophy Canada

aims to identify and support individuals with lipodystrophies in France.

AFLIP

AELIP focuses on researching and providing hope to those globally affected by Lipodystrophy, residing in Spain.

AELIP

in Italy.

AiLIP

Lipodystrophy United
Israel increases awareness and understanding of lipodystrophy among the patient community, medical professionals and stakeholders in Israel.

Lipodystrophy United Israel

Exciting Announcement!!!!

Dear community,

We are thrilled to share an exciting milestone: Lipodystrophy United will host an Externally-Led Patient-Focused Drug Development (EL-PFDD) meeting, with the FDA in attendance, in the fall of 2026 (exact date to be determined).

This meeting will bring together patients, clinicians, researchers, industry partners, and advocacy organizations to elevate the patient voice and ensure that the true burden of lipodystrophy is clearly understood across all stakeholders. It will also provide a unique opportunity to strengthen global collaboration, connect with our international partners, and work collectively to communicate the lived experience and unmet needs of our community.

What does this mean?

Patient-Focused Drug Development (PFDD) is a process created by FDA to ensure that the voices, experiences, and priorities of patients and caregivers are meaningfully incorporated into drug development and regulatory decision-making. An EL-PFDD meeting is organized by the patient community—in this case, by Lipodystrophy United—with FDA staff and all stakeholders attending in a listening capacity.

At this meeting, patients and caregivers will have the chance to speak directly about the daily impact of lipodystrophy, the symptoms that matter most, and what an ideal treatment would look like. The majority of the meeting will follow a town-hall style discussion led by patients, so that the broadest range of lived experiences are captured.

Why is this important?

- It elevates the patient and stakeholders voices directly to regulators, researchers, and drug developers.
- It ensures the realities of living with lipodystrophy are central in drug development and evaluation.
- It creates a historic opportunity for our community to influence research priorities, future clinical trials, and treatment options.

What comes next for our community?

This meeting is being conducted as a parallel effort to FDA's PFDD initiative to more systematically gather patients' perspectives on their conditions and available therapies to treat their conditions.

There will be many opportunities for patients, caregivers, and families to share their perspectives—through panels, open discussion, and written comments.

Following the meeting, A Voice of the Patient report will be developed by Lipodystrophy United to capture perspectives shared during the EL-PFDD meeting.

We will share more details including participation opportunities, and how you can get involved—in the coming months. However, we would love to jump on a call with your team about how we can collaborate on this effort.

This is a tremendous step forward for the lipodystrophy community, and it is only possible because of the dedication, openness, and advocacy of each of you

---

Community Day

Join Us in Boston!

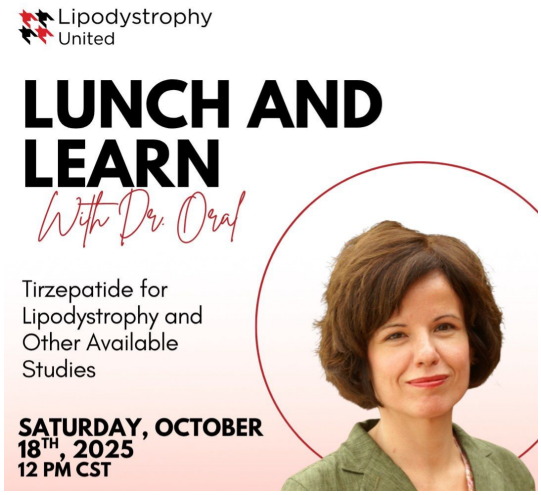
Join us this fall for a special **Community Day** featuring **Dr. Lindsay Fourman** and her team! Together, we'll delve into important topics such as **cardiovascular disease (CVD)** and **metabolic dysfunction-associated steatotic liver disease**

(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!



Lunch and Learn

Join Us for Lunch and Learn this Weekend!

When? Saturday, Oct. 18th at 12PM CST

Where? On zoom

Join us this fall for a special **Lunch and Learn** featuring **Dr. Oral** and learn about tirzepatide and Lipodystrophy!

RSVP!

Exciting Opportunity to Participate in a Meaningful Data Collection

In collaboration with Chiesi, Lipodystrophy United is putting on a mental health survey to collect insights Help shine a light on mental health in the lipodystrophy community. Takes ~15 minutes. Completely anonymous. Your experience can drive change.

Your voice matters. The insights you share will help identify unmet needs, inform new support resources, and bring greater attention to the real-life experiences of our community. Whether you're living with lipodystrophy, a caregiver, or a family member, your voice is essential to helping improve support and resources.

Here's how your input will contribute directly to meaningful action:

1. Global lipodystrophy leaders will review and discuss the

results to identify key findings and next steps.

2. The survey will be expanded to reach participants in non-English-speaking countries, ensuring broad global representation.
3. A public report will be shared to make the findings available to the whole community.
4. The results will guide conversations with the community to explore new ways to support individuals and families living with lipodystrophy.

Link for US/Canada Community Members

Lipodystrophy United
22 Frances Road, Los Lunas
United States of America

Thank you to our sponsors...


SENT BY
mailer lite