"Celebrating strength, raising awareness, and uniting voices from around the world

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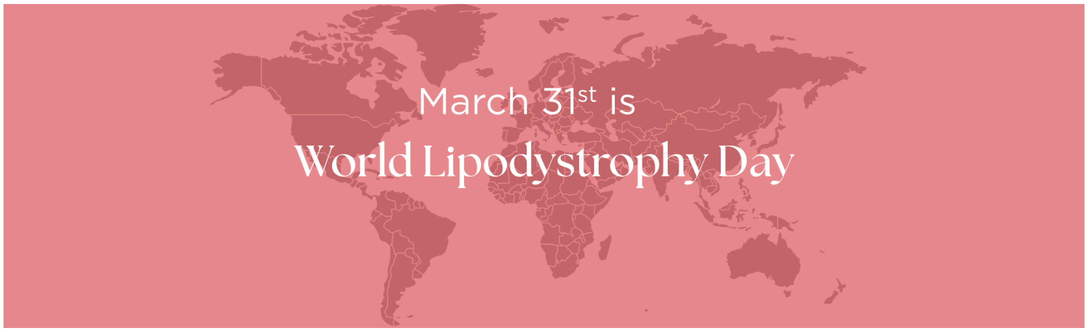
Lipodystrophy United

Happy World Lipodystrophy Day
March 31st, 2025



What Does World Lipodystrophy Day Mean to Us?

World Lipodystrophy Day (WLD) is observed annually on **March 31st** to bring awareness to the burden of Lipodystrophy. On this day, patient organizations from countries and regions all over the world hold awareness-raising activities. The first WLD was celebrated in 2013. It was started by AELIP (Asociación Internacional de Familiares y Afectados de Lipodistrofias) in Spain. The global goals of World Lipodystrophy Day are to raise awareness about the public health challenges posed by lipodystrophy, launch actions to help prevent the social isolation often experienced by individuals and families affected by lipodystrophy, conduct outreach activities to share the characteristics and unique aspects of lipodystrophy, and coordinate efforts with all involved parties—patients, public administrators, healthcare professionals, etc.—to secure resources and improve care for those affected.

So, for us World Lipodystrophy Day is a powerful reminder of why we do what we do. It's more than just a date on the calendar—it's a global moment of recognition, connection, and purpose. A day that our shared goals are united to create a larger scale of change. It’s a day to raise awareness, fight stigma, and honor the resilience of individuals and families living with lipodystrophy. It’s an opportunity to share our stories, raise awareness, and amplify the urgent need for better research, diagnosis, and care. Most importantly, it's a celebration of our global community—strong, united, and determined to create a better future for everyone impacted by this rare and often misunderstood condition. We are proud to collaborate with so many other lipodystrophy advocacy groups, listed below (scan QR codes to see their websites).

Exciting Announcements this World Lipodystrophy Day! Click the Red boxes!

Launch of Patient Stories on Youtube! More to come!

Patient Stories from the Symposium!

Bonfire Store Launch!

Bonfire Store

Launch of the Guide to Lipodystrophy, a collaboration with Lipodystrophy Leaders Forum

Guide to Lipodystrophy

Lunch and Learn this past Saturday, March 29th

On Saturday, we celebrated World Lipodystrophy Day in community, hearing from global leaders in research, advocacy, and lived experience. Dr. Elif Oral and Dr. Baris Akinci shared key insights into the science and treatment of lipodystrophy, while Zainab Alzoubi offered her personal story of living with lipodystrophy and important dietary tips through the lens of her expertise as a diabetic intern. Finally, Sonia Rehal told her advocacy story and honored our wonderful global collaboration. It was a meaningful way to honor the day—uniting science, patient voices, and international collaboration to raise awareness and drive progress. Full transcript and the recording of this event will come later this week!

World Lipodystrophy Day Virtual Symposium

JOIN US!

Panelists Include:

Dr. Elif Oral	11:30 AM - 12:00 PM
Dr. Baris Akinci	12:00 AM - 12:30 PM
Zainab Alzoubi	1:15 PM - 1:45 PM
Global Collabs w/Sonia	1:45 PM - 2:00 PM

Audience Q&A with Experts!

SATURDAY
29TH MARCH 2025

11:00 AM - 2:00 PM
CENTRAL STANARD TIME

LIPODYSTROPHYUNITED.ORG

Honoring Our Past, Inspiring Our Future

This World Lipodystrophy Day, we want to take a moment to reflect on the trailblazer lipodystrophy advocates and give a heartfelt thank you.

They were the ones who spoke up before it was easy. Before, there were Zoom calls, community pages, and more scientific papers to lean on. They were the ones who asked the hard questions, shared their stories, and made sure no one else would have to walk this road alone.

We owe so much to their courage and grit.

Even though March is ending, our appreciation isn't. Their efforts laid the foundation we're all building on today, and honestly, that's something worth celebrating way beyond one month.

Here's to the ones who started it all and to each of you continuing your work in your own way.

Stay tuned for the April newsletter, where we will tell stories from our youngest members of Lipodystrophy United to reflect our future.

Navigating Life with Lipodystrophy without a Roadmap

Co-Founder, Andra Stratton

If you're new to the world of lipodystrophy—whether as a patient or a caregiver—I want you to know, first and foremost: you are not alone.
I remember what it felt like when I first heard the word *lipodystrophy*—which didn't happen until I was 37 years old. It was shocking, to say the least, but it explained the years of constant medical challenges I had experienced and, indeed, verified that I was not crazy, weak, lazy, or a hypochondriac, as some had implied over the years.

More than 10 years later, I've learned that while this journey can be challenging, it is one that is easier to navigate **together**.

Here are a few things I've learned along the way that I hope will help guide you as you begin:

1. Find Your Community

Lipodystrophy is rare, but you don't have to walk this path alone. Connecting with others who understand what you're facing can be a lifeline. Whether it's through Lipodystrophy United, support groups, or social media communities, finding others who “get it” is invaluable. Ask questions, share your story, and lean on the people who truly understand.

2. Become Your Best Advocate

No one knows your body better than you do. In rare diseases, it’s common to encounter healthcare providers who aren’t familiar with lipodystrophy. Don’t be afraid to speak up, ask questions, and push for answers. Sometimes, the best doctors are those who admit they don't have all the answers but are willing to partner with you to learn and improve your care. Keep copies of your medical records, learn the science, and connect with lipodystrophy experts when possible. You are your best advocate—and your voice matters. Take up space and know that you deserve excellent care. This disease is not your fault.

3. Give Yourself Grace

This condition is complex. Managing it—whether it’s medications, dietary needs, or the emotional toll—takes a lot. There will be days when you feel like you have it all under control, and others when you don’t (my personal goal is more good days than bad). That’s okay. Give yourself grace, and ask your family and friends to do the same. This is a marathon, not a sprint.

4. Rest, Movement, and Finding Balance

Lipodystrophy is a progressive disease, but we now have tools to slow its progression.

Rest is not a luxury—it’s an essential part of managing the disease, especially when fatigue or pain creeps in. At the same time, movement and exercise—even gentle activities like walking or stretching—can help with metabolic complications, strength, energy, and mental health.

Some days, you may need more rest than movement—and that’s okay. Balance doesn’t mean doing everything all the time; it means knowing when to pause and when to move, without guilt. Part of finding that balance is learning to listen to your body.

5. Stay Hopeful—Research is Moving Forward

One of the most inspiring things I’ve seen over the past decade is how much more attention lipodystrophy is getting. Our community is partnering with researchers, clinicians, and pharmaceutical companies who are working hard to better understand this condition and develop new treatments.

Stay connected to organizations like ours—we'll keep you updated on progress, clinical trials, and ways to get involved.

If you're reading this, you're already taking a huge step toward building a network, learning, and finding your way.

Remember: we are here for you.
Reach out, ask for help, and know that you have a lipodystrophy family here to support you on your journey.

With strength and hope,
Andra Stratton
Co-Founder, Lipodystrophy United

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