



## July is Disability Pride Month and We're Honoring It Together

Disability Pride Month is a time to honor the strength, visibility, and advocacy of disabled people around the world. For many in the lipodystrophy community, disability is an everyday experience, one that comes with challenges, adaptations, and incredible resilience.

At Lipodystrophy United, we stand proudly with those in our community who identify as disabled. This month, we reflect on the power of visibility, accessibility, and inclusion, and we recommit ourselves to making sure everyone in our community feels seen and heard.



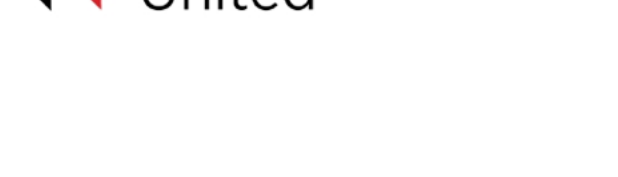
### Community Corner

Miranda Billington holds a Master of Public Health Education (MPH) and a Bachelor of Science in Workforce Education Training and Development (WED) from Southern Illinois University Carbondale (SIUC).

With 12 years of civil service experience, including roles at the Social Security Administration (SSA) and Veterans Health Administration (VHA). Additionally, she has 10 years of experience in employer group health insurance and has held an insurance license. Miranda's commitment to health goes beyond her professional duties. She successfully used her education and professional knowledge to investigate her own medical history, leading to a diagnosis of Familial Partial Lipodystrophy Type 2 (FPLD2) confirmed by genetic testing. This also led to the same diagnoses for her daughter and father in January 2021.

Miranda also volunteers with Lipodystrophy United (LU), sharing her expertise in health education to help create a comprehensive disability resource for the community. Outside of her professional life, she has been married for 28 years and enjoys time with her two adult children and one grandchild. Miranda's combined experience in public health and personal health challenges makes her a valuable contributor to the Lipodystrophy community.

90% of disabilities are invisible  
#ThinkOutsideTheChair



From chronic pain and fatigue to metabolic disorders like lipodystrophy, many disabilities can't be seen, but they deeply affect daily life. Disability Pride Month is a powerful reminder that you don't need to "look disabled" to deserve accessibility, understanding, and respect. At Lipodystrophy United, we recognize and honor every form of disability, visible or not.

[Click here to learn more](#)

### NAVIGATING OUR COMPLEX HEALTH SYSTEM WITH LIPODYSTROPHY



## Social Security and Disability Benefits: What You Need to Know

Navigating disability benefits can feel overwhelming, especially when living with a rare disease like lipodystrophy. Here's a simplified guide to understanding the key programs available through the U.S. Social Security Administration (SSA):

### Social Security Benefits Categories

#### Retirement Benefits

- Monthly payments to individuals who've worked and paid into the Social Security system.
- Eligibility typically begins at age 62, with full benefits available at your full retirement age (based on birth year).

#### Social Security Disability Insurance (SSDI)

- For individuals who've worked in the past but can no longer do so due to a disabling condition expected to last at least one year or result in death.
- Based on work history and disability severity.

#### Supplemental Security Income (SSI)

- Provides financial help to individuals with limited income and resources.
- Supports both disabled individuals (including children) and older adults (65+) regardless of work history.

### Applying for SSDI with Lipodystrophy

Lipodystrophy is not currently listed as a qualifying disability under SSA's official listings. You will need to apply using a **medical vocational allowance**. This means demonstrating—through thorough documentation—that your condition prevents you from sustaining employment.

Key steps:

- Work with your doctor to complete a **Residual Functional Capacity (RFC) form**, describing how symptoms limit your ability to work.
- Submit all medical records, labs, imaging, treatment notes, and your diagnosis.
- Include a detailed **work history** to show how your condition affects your ability to perform previous or similar jobs.

**Prep time:** Expect to spend **at least 2 hours** gathering:

- Medical records
- Doctor contacts
- Medication lists
- Lab results
- Work summaries
- W-2s or tax documents

#### Important Tips:

- Use only the official SSA site: [www.ssa.gov](http://www.ssa.gov)
- Don't skip the preparation—most application denials are due to insufficient medical evidence.
- You do *not* need a lawyer to submit the initial application or the first appeal.

#### Documents to gather:

- Social Security number/card
- Birth certificate
- Contact information for all healthcare providers from the past 12 months
- Medication names/doses
- Medical records (12 months)
- Test results (bloodwork, imaging, etc.)
- Work history and your latest W-2 or tax return

If you're unsure whether Social Security disability is the right fit for your lipodystrophy journey, consider whether your condition prevents you from working and whether you've worked in Social Security-covered jobs long enough to qualify.

**Remember:** Invisible conditions like lipodystrophy are real, and your experience matters. Don't hesitate to advocate for the benefits and support you need.

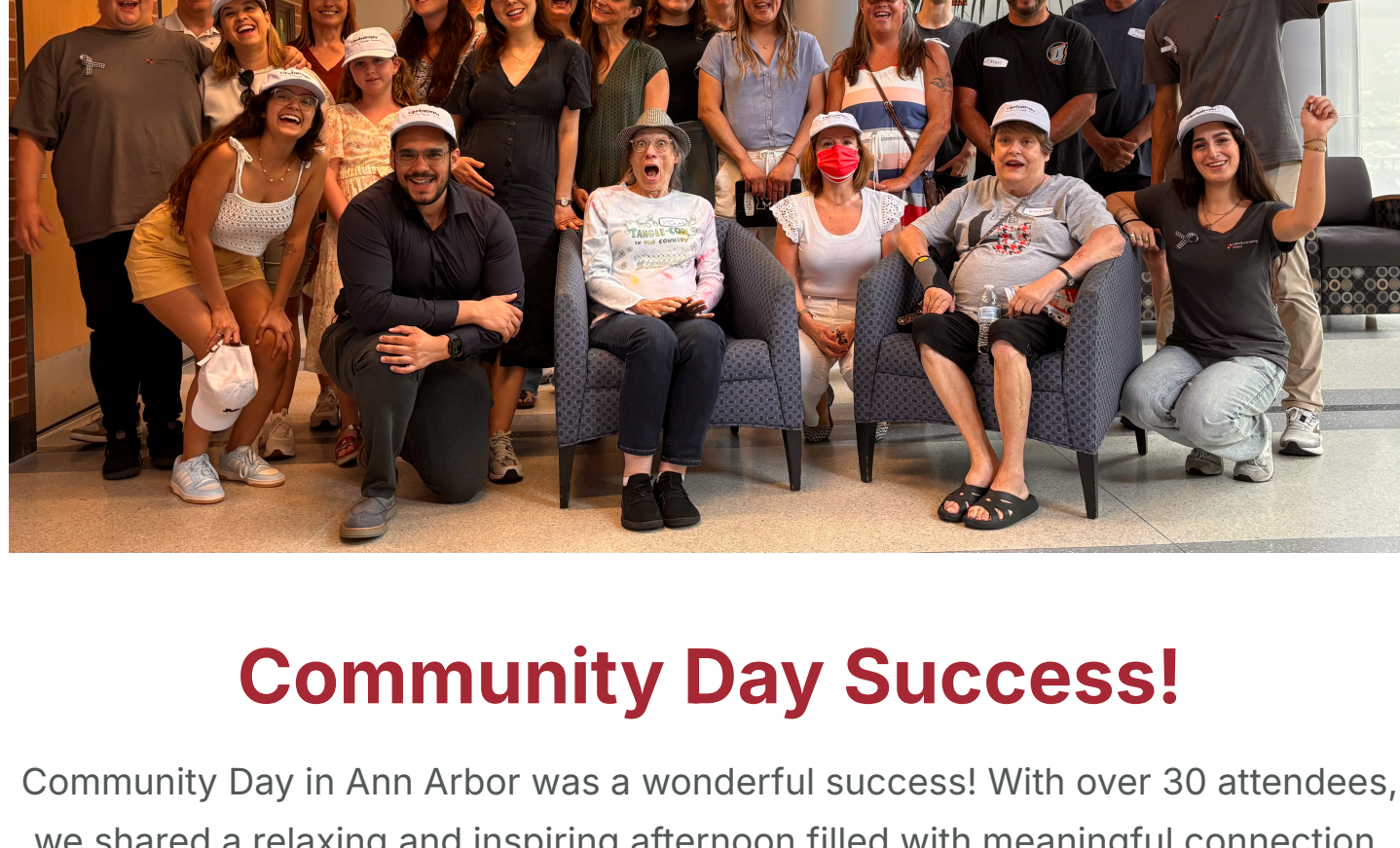
Ant that will help your readers understand your message.

*Need help starting your application or have questions? Reach out to us at [info@lipodystrophyunited.org](mailto:info@lipodystrophyunited.org).*



## Highlights from The Annual Meeting of Endocrinology

- ✓ Close to all conference booth visitors recognized lipodystrophy as a rare disease.
- ✓ Over 50 clinicians stated that they have or think they have a patient with lipodystrophy in their care.
- ✓ Over 10 clinicians have patients with lipodystrophy, but did not know how to treat them, and we were able to connect them with experts.
- ✓ Five providers shared that they had encountered lipodystrophy in the past but didn't recognize it at the time—and now feel equipped to identify it in the future.
- ✓ Multiple endocrinologists stated how isolated their patients are and how much they will benefit from psychosocial support and connection to the community.



## 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**  
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