

# Community Day Insight Report



**You still have to live life. Disease can't define your life. As I told my son [with lipodystrophy], your blood sugar has been good all day, you've been selfless all day, you can treat yourself to a second cookie. We have insulin in the car and know how to manage. This disease can't define your life everyday all the time.**

**-Community Member Present at the Event**

# Introduction

The weekend trip to Ann Arbor on July 19th proved to be a powerful and meaningful experience for patients and caregivers in our lipodystrophy community. We had the opportunity to strengthen connections within our community and collect valuable data that will guide our work in the months ahead.

During the event Sharon Halperin, LU's Research Director, met with Dr. Elif Oral to strengthen our scientific collaborations and discuss clinical trial participation—an essential step in advancing treatment and deepening understanding of lipodystrophy. Sharon herself enrolled in two clinical trials during the visit, underscoring LU's commitment to patient-driven research. This theme was reflected throughout the day, especially in the insightful presentations led by Dr. Oral and her team. After a lively Q&A session, the event transitioned to community-building activities, including a “speed dating” round that fostered meaningful connections among caregivers, physicians, and patients.

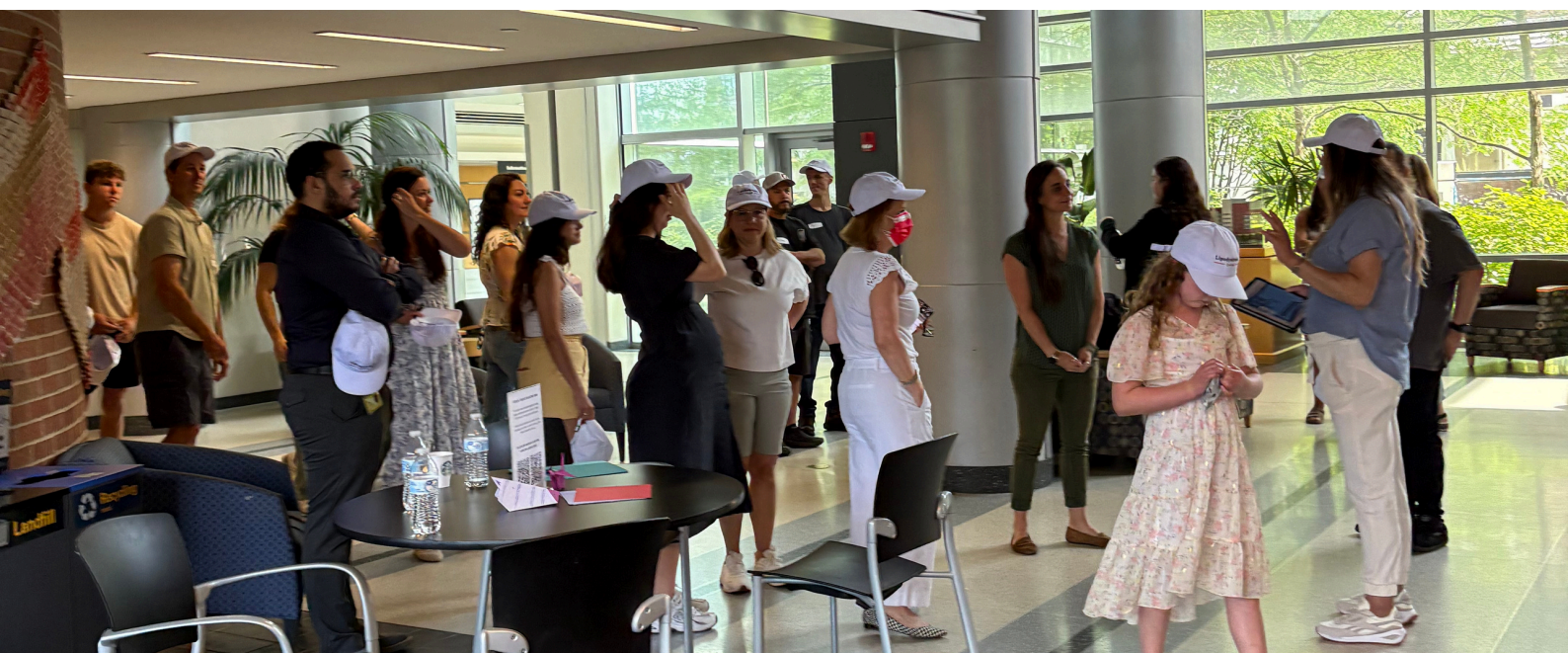
In the afternoon, the group gathered outside for a BBQ lunch, followed by time to unwind together. The event was a great success, and we're excited to continue hosting similar gatherings in the future!



**I told my doctors I was active; they want me to eat more carbs. Another doctor sees my stats and tells me to have less carbs. The doctors only know the parts of you that you share; you know all of you.**

**-Community Member Present at the Event**





**I'm confident with my body now, but I wasn't always there. It takes time, and you're not there all the time.**

**-Community Member Present at the Event**

## Highlights

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- ✓ We had over 30 attendees present for the event!
- ✓ Patients shared that it was a fantastic opportunity for young individuals to bond over shared experiences.
- ✓ Patients expressed that the talks covered important and pertinent materials on lipodystrophy and their experiences.
- ✓ Our biopharma partners expressed gratitude for the opportunity to meet people in our community.



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# Summary

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Lipodystrophy United's community day in Ann Arbor was a resounding success! We had an incredible turnout of 30 plus people. We marketed the event with flyers, reels, and Dr. Oral reached out to her patients with personal phone calls. Of those 30, 18 identified as patients or caregivers of those with lipodystrophy. That was an amazing turnout for our organization!

The first half of the day went fantastically. Members of our team, Francesca Amato and Rowan McDonnell, shared presentations about upcoming changes to LU infrastructure and the Burden of Disease Research Project. Both of which were widely praised by the community and created excitement for future involvement within the organization. We had customized hats, LU merchandise, and snacks available to all attendees.

Furthermore, Dr. Oral and her team shared very important information with our community about the ongoing LD Lync registry and other clinical trials and their impact on the lipodystrophy community. Dr. Oral and her team's energy was unmatched, drawing in a lot of engagement prior to and during the event. We continue to hear that patients are being heard and seen by her and her team.

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Moreover, the BBQ received much praise, as patients noted they haven't had many opportunities to meet in person. One parent shared, "I really wanted my son to meet others who have Lipodystrophy to hear what they have gone through.... It was a bonus for him to meet other people with lipodystrophy. Thank you for planning and setting up this



enjoyable event!” Additionally, attendees could relax with massages and enjoy petting and holding the farm animals. Throughout the day, patients shared experiences and messages of strength (quoted in this report).

Overall, the event was a great success. Due to the amazing turnout and feedback we’ve gotten, we have decided to host more community days around the country. We will happily share that information with anyone interested in attending or who would like to know more!



**You have to view yourself as able to care for yourself and as important enough to be cared for.**

**-Community Member Present at the Event**

## Representatives



Sharon Halperin, Research Director, Francesca Amato, Operations Manager, and Rowan McDonnell, intern, represented the lipodystrophy staff.

[www.lipodystrophyunited.org](http://www.lipodystrophyunited.org)

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