



Symposium 2024: Building Bridges and Solving the Puzzle

Introduction

The Symposium, *Lipodystrophy 2024: Building Bridges and Solving the Puzzle*, brought together **50+ patients and caregivers, 40+ clinicians and researchers, and key industry partners across 6 continents**. For many, this was the first time meeting others with the same condition, creating invaluable connections. Beyond building relationships, we collaborated to identify knowledge gaps, shape research priorities, and ensure the patient voice was central.

“The insights and dedication you brought to this event will undoubtedly continue to drive transformative change, making this community stronger and more united than ever before.”

- Feedback from a researcher

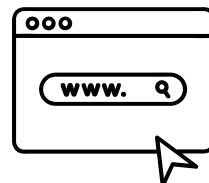


3 days of insightful content with expert keynotes, interactive sessions, and engaging activities

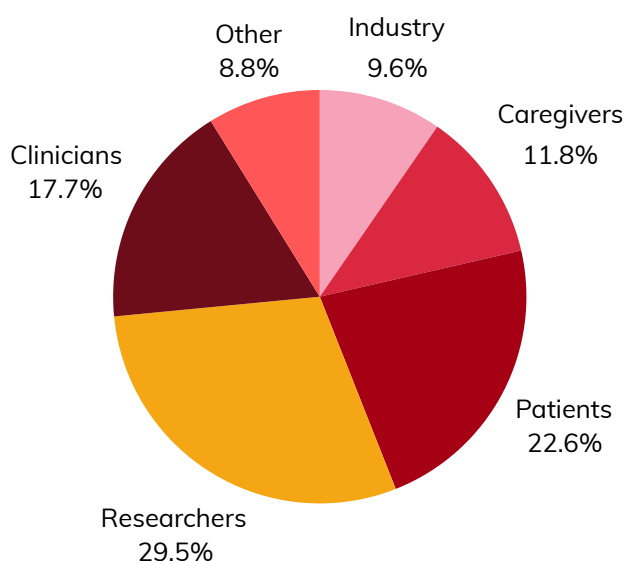
Multistakeholder engagement: patients, caregivers, researchers, clinicians, and industry partners in one room.

6/7 continents represented virtually, 4/7 in person

1100 new visitors as a direct result of the Symposium and advertising for it



In-person attendee breakdown by stakeholder



Researchers & Clinicians

Africa: Tunisia, Egypt

EU: UK, Scotland, Ireland, Germany, Spain, France

Far East: Japan, China, Taiwan,

LATAM: Brazil

Middle East: Oman, Saudi Arabia, Turkey

North America: US & Canada

Patient Organizations in Attendance

Lipodystrophy United

Lipodystrophy Canda

Lipodystrophy United - Israel

Lipodystrophy Germany

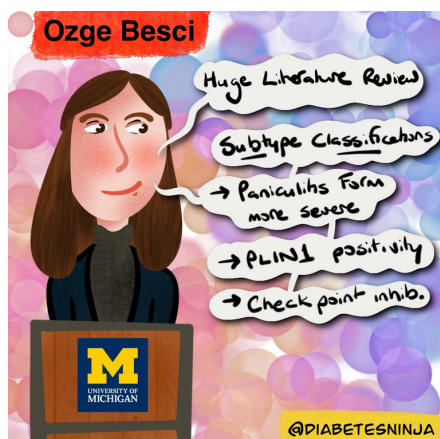
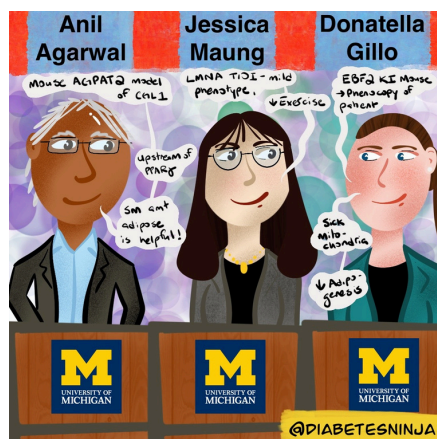
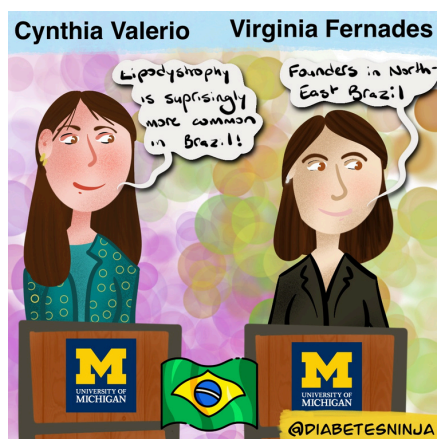
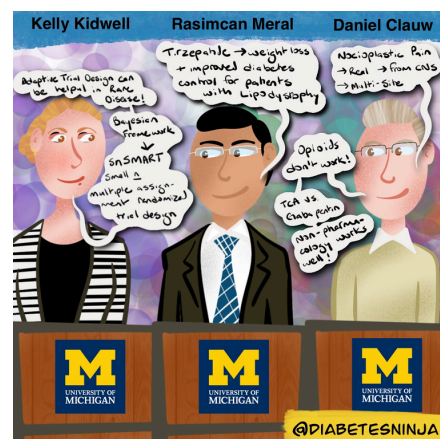
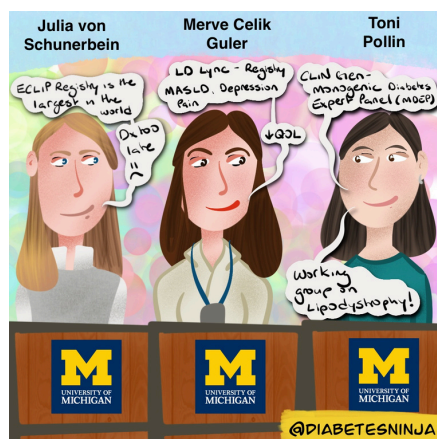
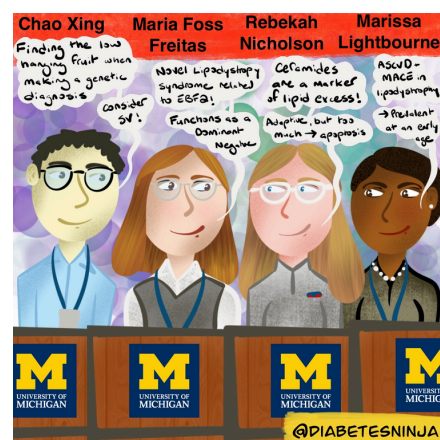
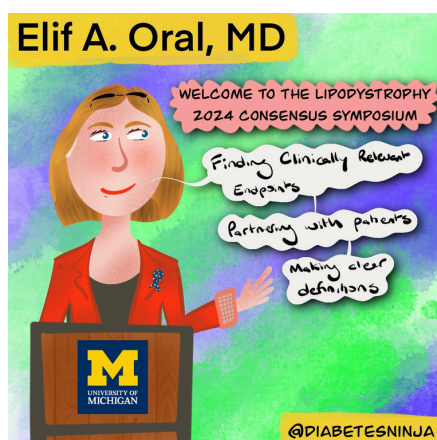
Association of Lipodystrophy - France

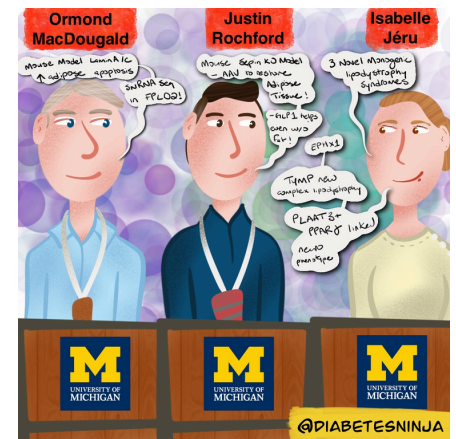
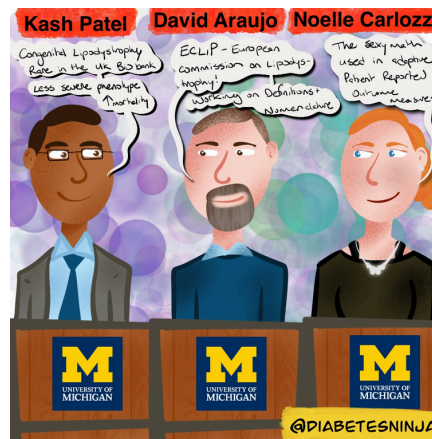
Lipodystrophy UK

Objectives

The patient voice was centered within each objective...

- ✓ To discuss the difficulties in the definition and classification of lipodystrophy syndromes to provide a better framework for therapeutic development.
- ✓ To determine the best outcome measures in clinical trials and solve problems for potential trial designs for very rare syndromes.
- ✓ To understand the ongoing efforts for determining the global prevalence of lipodystrophy syndromes and create collaborations for areas where data is missing.
- ✓ To create a path for efficient global collaborations (data, biorepository).
- ✓ To empower patient advocacy organizations and provide a path for a global network of patient advocacy.





The Highlights

✓ Pre-Meeting Community Engagement

- Peer Support Speed Networking
- Chair Yoga
- Patient Stories
- Panel with Researchers
- Importance of Patient Advocacy
- Lipodystrophy: The Basics - lecture/workshop/group conversation
- Lipodystrophy: Best Practices in Communications and Advocacy
- Emotional Support Dogs

“

“THIS WAS THE MOST COMFORTABLE I’VE EVER BEEN WITH MYSELF.”

“

“WHEN YOU START TALKING TO OTHER PEOPLE WITH LIPODYSTROPHY, YOU FINALLY FEEL LIKE YOURSELF.”

QUOTES FROM ATTENDEES WITH LIPODYSTROPHY

✓ A Few of Many Research Highlights

- Current investment involving transplanting fat cells that can replace the non-functioning fat cells in patients looks promising in the lab.

- Multistakeholder interest in identifying common endpoints for clinical studies including a burden of the disease endpoint, such as quality of life and treatment management.
 - Increased data sets that show generalized pain and muscle and joint pain is a common part of the lipodystrophy symptoms array. This notion didn't come easily. With the help of patient input researchers can now define invest in further research and provide treatment options for unique types of pain.
 - Collaborative, global effort to analyze and restructure current disease classification for the growing known types of lipodystrophy.
- ✓ Growing global recognition of the impact of patients experience with isolation and mental health and benefit from psychosocial support and connection to the community.

“

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IMPRESSED AND **INSPIRED** BY
THE WORK THAT YOU ALL
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“

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NEEDED THEM."

QUOTES FROM
RESEARCHERS

Speaker Line Up

Anil Agarwal, PhD (UT Southwestern, US)	Isabelle Jeru (France)
Baris Akinci, MD (Turkey)	Michelle Kahlenberg, MD, PhD (DOIM Vice Chair for Research, UM)
Saif Alyaarubi, MD (Oman)	Shokoufeh Khalatbari, MS and Matheos Yosseff (UM, US)
David Araujo, MD (Spain)	Ines Khochtali, MD (Tunisia)
Ozge Besci, MD (UM, US)	Kelly Kidwell, PhD (UM, US)
Rebecca Brown, MD (NIDDK, US)	Ni-Chung Lee, MD (Taiwan)
Noelle Carlozzi, PhD (UM, US)	Jilandre Linton (LD Parent)
Giovanni Cecarini, MD and Ferruccio Santini, MD (Pisa, Italy)	Marissa Lightbourne, MD (NIDDK, US)
Crystal Chavez (LD Warrior, US)	Yingying Luo, MD (China)
Taehwa Chun (UM, US)	Ormond MacDougald, PhD (UM)
Marianne Clancy, Cure HHT	Jessica Maung (UM, US)
Daniel Clauw, MD (UM, US)	Rasimcan Meral, MD (UM, US)
Greg Clines, MD, PhD (MEND Division Chief, UM, US)	Renan Montenegro, MD
Silvia Corvera, PhD (UMass, US)	Rebekah Nicholson (U Utah, US)
Christine Coppini (LD Warrior, US)	Elif Oral, MD, PhD (UM)
Ken Ebihara, MD, PhD (Japan)	Nivedita Patni, MD (UT Southwestern, US)
Virginia Fernandes, MD (Brazil)	Kashyap Patel (University of Cambridge, UK)
Lindsay Fourman, MD (MGH, US)	Toni Pollin, PhD (U Maryland, US)
Maria Foss Freitas, MD, PhD (UM, US)	Mandy Pulliam, MD (LD Warrior)
Abhimanyu Garg, MD (UTSW, US)	Sonia Rehal, PhD (LD Warrior, Canada)
Donatella Gilio, MD (UM and UPisa, US and Italy)	Justin Rochford, PhD (UK)
Leslie Gordon, PhD (Progeria Foundation, Founder and Medical Director)	Glenna Steele, Glut1 Deficiency Foundation
Brigid Gregg, MD and Durga Singer, MD, PhD	Stephen Stone, MD, PhD (WashU, US)
Natalia Guidorizzi, MD	Andra Stratton (Lipodystrophy United, Cofounder and President, LD Warrior, US)
	Simeon I. Taylor, MD, PhD (U Maryland, US)

Merve Celik Guler, MD (Turkey and UM, US)

Carol Haft (NIDDK, US)

Sharon Halperin (LD Warrior, Israel)

Cynthia Valerio, MD

Julia von Schunerbein, MD (Germany)

Chao Xing, PhD (UT Southwestern, US)



Summary

By combining lived experiences with scientific expertise, the symposium laid the groundwork for ongoing collaboration around patient priorities in research, patient reported outcomes, education, and progress in the lipodystrophy landscape.

LU Representatives



Andra Stratton, President and Co-Founder, and Kate Stratton, Program Manager, represented the lipodystrophy community alongside dedicated volunteers Larry Seida, Sharon Halperin, Crystal Chavez, Lori Seida, Christine Coppini, Jennifer Hepler, and many others (not all pictured here). Our work would not be possible without this incredible team, and we are deeply grateful to everyone who has contributed to our efforts.



*Resources: [Tools For Patients including informational brochures and Patient Journey Roadmaps](#)

www.lipodystrophyunited.org

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