

Lipodystrophy Symposium 2024

Thursday, November 7th - Sunday, November 10th

Comprehensive Agenda: Lipodystrophy United Pre-Meeting Sessions and University of Michigan Symposium Schedule

Lipodystrophy 2024 Consensus Symposium: Patient/Caregiver Pre-Meeting

Thursday, November 7th, 2024

Hilton Garden Inn: 1401 Briarwood Circle Ann Arbor, MI 48108

Time (Eastern Time)	Session
10:00 AM - 1:00 PM	Welcome Booths & networking Event (Storytelling Cafe) Location: Library (Booth) & Conference Space (Networking Event)
1:00 PM - 2:00 PM	Light Lunch & Networking Activity Location: Conference Space
2:00 PM - 2:30 PM	Break
2:30 PM - 3:15 PM	Peer Support Speed Networking <ul style="list-style-type: none"> • Kate • Crystal Location: Conference Space
3:15 PM - 4:15 PM	Chair Yoga <ul style="list-style-type: none"> • Instructor: JT. Location: Conference Space
4:30 PM - 5:00 PM	Break <ul style="list-style-type: none"> • Note: Everyone breaks, except available volunteers to set up for dinner. Chiesi and Regeneron booths stay set up, available to talk to patients.

	Location: Conference Space
5:00 PM - 6:00 PM	Soup, Salad and Social Hour Location: Conference Space
6:00 PM - 7:00 PM	Symposium Introduction & Keynotes <ul style="list-style-type: none"> • Full Dinner Served • Speakers: Kate introduces the symposium • Keynotes: <ul style="list-style-type: none"> ○ Christine Coppini - a personal journey of resilience and advocacy. ○ Andra Stratton - on being a global rare disease advocate. ○ Samantha Pulliam - on being a medical professional with lipodystrophy • Regeneron Introduction to the community, 5 minutes Location: Conference Space
7:00 PM - 8:00 PM	Panel with Researchers <ul style="list-style-type: none"> • Dr. Elif Oral • Maria Foss Freitas • Cynthia Valerio • Additional medical professionals TBD Location: Conference Space
8:00 PM - 8:10 PM	Closing Remarks <ul style="list-style-type: none"> • Kate: Quick presentation of logistics for the following day. Location: Conference Space

Friday, November 8, 2024	
Kensington Hotel: 3500 S State St Ann Arbor, MI 48108	
Time (Eastern)	Session
9:00 AM - 9:45 AM	Breakfast
9:45 AM - 10:15 AM	Importance of Patient Advocacy <ul style="list-style-type: none"> • Andra Stratton: patient advocacy and rare disease in current times
10:15 AM - 10:45 AM	Lipodystrophy United - Shaping the Future of the Foundation <ul style="list-style-type: none"> • Kate Stratton
10:45 AM - 11:00	Break

AM	
11:00 AM - 12:00 PM	Lipodystrophy: The Basics - lecture/workshop/group conversation <ul style="list-style-type: none"> • Crystal • Sharon
12:00 PM - 1:00 PM	Lunch and Networking
1:00PM - 2:00 PM	Lipodystrophy: Best Practices in Communications and Advocacy <ul style="list-style-type: none"> • Crystal • Sharon
2:10	CONCLUSION OF PRE-MEETING
	Break - Eight minute walk back to respective hotel OR stay to hang with service dogs
	<p>Thank you</p>  <p>global rare diseases </p>  <p>For sponsoring Lipodystrophy United Activities and Pre Meeting</p>
4:30 & 5:00 PM	Shuttle to University of Michigan

Lipodystrophy 2024 Consensus Symposium: Building Bridges and Solving the Puzzle

University of Michigan North Campus Research Complex
2800 Plymouth Rd, Building 18 Dining Hall
Ann Arbor, MI 48105

Friday, November 8th, 2024

Time (Eastern)	Session
5:30 PM - 5:45 PM	Opening Remarks Leadership from Caswell Diabetes Institute and Department of Internal Medicine, UM <ul style="list-style-type: none">• Michelle Kahlenberg, MD, PhD (DOIM Vice Chair for Research, UM)• Martin Myers, MD, PhD (CDI, UM)• Greg Clines, MD, PhD (MEND Division Chief, UM, US)
5:45 PM - 6:30 PM	Keynote 1 Chaired by Elif A.Oral (UM, US) and Andra Stratton (LU, US) The Promise of Cell Replacement Therapies for Lipodystrophy: How Close Are We? <ul style="list-style-type: none">• Silvia Corvera, PhD (UMass, US)
6:45 PM - 7:05 PM	Patient/Caregiver Stories <ul style="list-style-type: none">• Sonia Rehal, PhD• Jilandre Linton
7:15 PM	Dinner and Poster Reception
8:00 PM & 9:00 PM	Shuttles back to hotels

Saturday, November 9th, 2024

University of Michigan: 2800 Plymouth Rd - Ann Arbor, MI 48105

Time (Eastern)	Session
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7:00 AM & 7:45 AM	Shuttles
7:15 AM	Breakfast
8:00 AM - 8:40 AM	Review of Key Data, Ongoing Accomplishments and Processes Chaired by: <ul style="list-style-type: none"> ● Rebecca Brown, MD (NIDDK, US) <ul style="list-style-type: none"> ○ 8:00 AM - 8:15 AM Estimating Prevalence of Congenital Generalized Lipodystrophy, methodology and data availability. <ul style="list-style-type: none"> ■ Kashyap Patel (University of Cambridge, UK), <i>virtual participant</i> ○ 8:15 AM - 8:30 AM Definition, Classification, Nomenclature: ECLIP work plans <ul style="list-style-type: none"> ■ David Araujo, MD (Spain), <i>virtual participant</i> ○ 8:30 AM - 8:40 AM PRO development process <ul style="list-style-type: none"> ■ Noelle Carlozzi, PhD (UM, US)
8:40 AM - 10:10 AM	Panel on Mechanism of Disease Chaired by Ormond MacDougald (UM, US) <ul style="list-style-type: none"> ● Ormond MacDougald, PhD ● Justin Rochford, PhD (UK) ● Isabelle Jeru (France) - <i>virtual participant</i>
10:10 AM - 10:20 AM	Break
10:20 AM - 11:20 AM	Panel 1: Rising Stars in the Field Chaired by Carol Haft (NIDDK, US) - <i>virtual participant</i> <ul style="list-style-type: none"> ● Stephen Stone, MD, PhD (WashU, US). Two stories of Lipodystrophy: deep clinical phenotyping of Widemann-Rautenstrauch Syndrome/ <i>In vitro</i> profiling of LMNA p.R482 hotspot in FPLD2 ● Lindsay Fourman, MD (MGH, US) Exploring the lipodystrophy like continuum in the general population: insights from the UK Biobank ● Nivedita Patni, MD (UT Southwestern, US): Challenges in Diagnosing Lipodystrophy Syndromes in Children
11:20 AM - 11:55 AM	Keynote 2 Chaired by Simeon I. Taylor, MD, PhD (U Maryland, US) - <i>virtual participant</i> New Insights into Pathogenesis and Classification of AGL <ul style="list-style-type: none"> ● Abhimanyu Garg, MD (UTSW, US)
11:55 AM - 12:10 PM	Data Compilation and Schema for Classification of AGL <ul style="list-style-type: none"> ● Short presentation by Ozge Besci, MD (UM, US) ● Reaction and discussion by Giovanni Cecarini, MD and Ferruccio Santini,

	MD (Pisa, Italy) - virtual participants
12:10 PM - 1:00 PM	Lunch and Work Group Interactions Activities for patients
1:00 PM - 3:00 PM	Parallel special workshop (virtual and in person) led by Baris Akinci, MD (Turkey) <ul style="list-style-type: none"> FPLD definition and differentiation from FPLD-like phenotype and Truncal Obesity Breakout Sessions (3 Tracks) <ul style="list-style-type: none"> Track 1: Disease Definition and Overall Classification: Leads - David Araujo, MD - virtually & TBD in person Track 2: Patient-Reported Outcomes and Clinical Trial Outcome Measures: Leads - Andra Stratton & Elif Oral, MD Track 3: Prevalence Estimates: Leads: Rebecca Brown, MD, Abhimanyu Garg, MD, Chao Xing, PhD, Kashyap Patel, PhD
3:00 PM - 3:30 PM	Reports from Breakout Sessions and Special Workshop
3:30 PM - 3:50 PM	Break
3:50 PM - 5:00 PM	Mechanisms of Disease or Complications Panel: translational conversations Chaired by Taehwa Chun (UM, US) <ul style="list-style-type: none"> Chao Xing, PhD (UT Southwestern, US) Analysis Pipeline for Whole Exome and Genome Data for Rare Diseases Maria Foss Freitas, MD, PhD (UM, US): <i>Opening a door through WGS: A Novel Gene for Lipodystrophy</i> Rebekah Nicholson (U Utah, US) Of ceramides and inflammation: link to lipodystrophy and cardiovascular disease Marissa Lightbourne, MD (NIDDK, US) Major adverse cardiac events in lipodystrophy.
5:00 PM - 6:00 PM	Recent Advances Through Animal Models Chaired by Anil Agarwal, PhD (UT Southwestern, US) <ul style="list-style-type: none"> Anil Agarwal, PhD (UT Southwestern, US) Reversal of Lipodystrophy in CGL1 mouse model Jessica Maung (UM, US) Modeling human LMNA variants in mice Donatella Gilio, MD (UM and UPisa, US and Italy) A new animal model of lipodystrophy
6:00 PM - 6:35 PM	Keynote 3 Chaired by Brigid Gregg, MD and Durga Singer, MD, PhD Clinical Trial Data: New Leptin Receptor Agonist <ul style="list-style-type: none"> Rebecca Brown, MD (NIDDK, US)

6:45 PM - 7:15 PM	Concert by Angela Hench (Soprano) and Reception featuring local artist Lidia Kaku
7:15 PM - 8:00 PM	Dinner Patient stories: On Being a Healthcare Professional with Lipodystrophy <ul style="list-style-type: none"> Sharon Halperin <ul style="list-style-type: none"> Present LU research Crystal Chavez
	Shuttles back to hotels

Sunday, November 10th, 2024	
University of Michigan: 2800 Plymouth Rd - Ann Arbor, MI 48105	
Time (Eastern)	Session
7:00 AM & 7:45 AM & 8:30 AM	Shuttles
7:15 AM	Breakfast
8:00 AM - 9:00 AM	Regional Priorities in Lipodystrophy Across the Globe: Improving Data availability Where Data are Sparse Chaired by Renan Montenegro, MD <i>virtual participant</i> and Cynthia Valerio, MD <ul style="list-style-type: none"> Middle East: Saif Alyaarubi, MD (Oman) - <i>virtual participant</i> Far East: Ken Ebihara, MD, PhD (Japan), Yingying Luo, MD (China) - <i>virtual participant</i>, Ni-Chung Lee, MD (Taiwan), <i>virtual participant</i> Africa: Inas Khoctali, MD (Tunisia), Solaf M.El-Sayed, MD (Egypt) - <i>both virtual participants</i> LATAM: Cynthia Valerio, MD, Natalia Guidorizzi, MD, Virginia Fernandes, MD
9:00 AM - 10:00 AM	Andra Stratton's Panel: Impact of Patient-Driven Research How Patient Foundations Can Drive Scientific Discovery and New Drug Development as well as Equity Across the Globe <ul style="list-style-type: none"> Glenna Steele, Glut1 Deficiency Foundation Marianne Clancy, Cure HHT Andra Stratton, Chan Zuckerberg Initiative, Rare as One Network
10:00 AM - 11:00 AM	Elif Oral's Panel: Clinical Trial Topics <ul style="list-style-type: none"> Kelly Kidwell, PhD (UM, US): Very Small Clinical Trial Design Rasimcan Meral, MD (UM, US): Tirzepatide Retrospective Data: Is It Too Good to Be True?

	<ul style="list-style-type: none"> • Daniel Clauw , MD (UM, US) Treating chronic pain based on underlying mechanisms, <i>virtual participant</i>
11:00 AM - 12:00 PM	Registry Panel Chaired by Shokoufeh Khalatbari, MS and Matheos Yosseff (UM, US) <ul style="list-style-type: none"> • Julia von Schunerbein, MD (Germany) ECLIP Registry and Its Potential, <i>virtual participant</i> • Merve Celik Guler, MD (Turkey and UM, US) and Baris Akinci, MD (Turkey) LD Lync Update • Toni Pollin, PhD (U Maryland, US) Clin Gen MDEP panel and its progress, <i>virtual participant</i>
12:00 PM - 12:15 PM	Conclusions and Next Steps
1:00 PM	Shuttle to the Airport

The University of Michigan Medical School thanks Chiesi for an investigator-initiated grant to Dr. Oral to support this meeting and post meeting work.