Seattle Agenda - LAM Sessions
Saturday, Oct 21, 2023
The Charter Hotel Seattle
1610 2nd Avenue, Seattle, Washington, 98101

8:30 – 9:30 a.m.   **Check-in/Registration – Lobby**

9:30 – 10:45 a.m.   **Welcome and Opening General Session: Research Updates and Upcoming Clinical Trials**
This conference opener will provide a preview of the day, updates from The LAM Foundation and TSC Alliance plus an overview of promising research activities in both LAM and TSC.
Welcome Remarks:
- o Sue Sherman, MHA, CEO, The LAM Foundation
- o Kari Rosbeck, President & CEO, TSC Alliance
- Speakers:
  - o Brenda E. Porter, MD, PhD, Professor of Neurology, Stanford University School of Medicine; Director of Pediatric Epilepsy, Co-Director, Tuberous Sclerosis Complex Clinic, Lucile Packard Children's Hospital
  - o George Pappas, MD, MPH, LAM Clinic Director, Swedish Medical Center

10:45 – 11 a.m.   **BREAK – Lobby**

11 a.m. – 12 p.m.   **Session 2: Lymphangioleiomyomatosis 2023: Diagnosis, Treatment and Questions**
Speaker: George Pappas, MD, MPH, LAM Clinic Director, Swedish Medical Center
Dr. Pappas will lead an interactive presentation about advancements in our understanding of LAM, including how LAM is diagnosed and managed to optimize quality of life.

12 – 1 p.m.   **LUNCH**

1 – 2 p.m.	**Session 2: Benefits of Home-Based Exercise and LAMFit** *Speakers:* • Mary Beth Brown, PT, PhD, University of Washington • Claire Child, DPT, MPH, University of Washington *We all know exercise is good for us. But what do we know specifically about exercise benefits for individuals living with LAM? Join Dr. Mary Beth Brown and Claire Child, as they present their recently published findings from the LAM Exercise & Fatigue study. Hear what they learned about exercise training effects in LAM, blood oxygen levels during exercise and the use of health monitoring devices to guide home-based exercise LAM patients. Most importantly, hear what's coming next!*
2 – 2:15 p.m.	**BREAK - Lobby**
2:15 – 3:15 p.m.	**Session 2: LAM Patient Research Priorities Focus Group** *Moderator:* Marina Holz, PhD, Scientific Advisory Board, The LAM Foundation, Dean, Graduate School of Biomedical Sciences, New York Medical College. *The LAM Foundation seeks to better understand LAM patients' health needs and research priorities. The LAM Patient Needs Assessment, and Research Priorities Survey (LAM-PREP) will allow The LAM Foundation (TLF) to support scientific projects that can maximally benefit LAM patients and compare them to the scientific and research priorities of LAM professionals. Join this focus group and contribute YOUR VOICE to LAM research priorities. All participants will be required to sign a consent form and all answers will be confidential.*
3:15 – 3:30 p.m.	**BREAK – Lobby**
3:30 – 4:30 p.m.	**General Session: Understanding the Genetics of TSC and LAM and Potential for Gene Therapy** *This session will provide the foundation on what gene therapy is, the science behind it and the potential for gene therapy in TSC and LAM.* Speaker: Kiana Siefkas, MS, CGC, Genetic Counselor, Seattle Children's Hospital