



National Commission on Lymphatic Diseases

Town Hall Forum II
December 2, 2024
9:00 a.m. – 12:00 p.m. EST

VIRTUAL MEETING

AGENDA

9:00 – 9:05 a.m.

Welcome and Housekeeping Information

Selen Catania, Ph.D., NHLBI, NCLD Executive Secretary

9:05 – 9:10 a.m.

Welcome

Stephanie Dreyer, M.B.A. and Stanley Rockson, M.D., Co-chairs, NCLD

9:10 – 11:10 a.m.

Perspectives on Rare Lymphatic Diseases – Stakeholder Introductions

Stephanie Dreyer, M.B.A. and Stanley Rockson, M.D., Co-chairs, NCLD

The presentations will offer an overview of the different organizations in attendance, outline the major challenges faced by the individuals they serve, address the resource difficulties they encounter, and identify the top three factors that could most significantly improve the lives of those they support.

- Denise Adams, MD, Member of the Medical Advisory Board, Dana Wolinsky, Executive Director, Balin Weintraub and Charlie (Cat) Pinkerton, Patient Representatives – Project FAVA (Fibro-Adipose Vascular Anomaly)
- Karen Ball, Founder and Chief Executive Officer – Sturge-Weber Foundation
- Lauren Beauregard, Executive Director, and Lindsey Edwards, Patient Representative – CLOVES Syndrome Community
- Jen Boyce and Kevin Boyce, Founders – Will's Power
- Christy Collins, President – M-CM Foundation (Macrocephaly-Capillary Malformation)
- Michael Dellinger, PhD, Director of Research – Lymphatic Malformation Institute (LMI), Michael Kelly, MD, PhD, Executive Director, and Liz Bovee, Patient Representative – Lymphangiomatosis & Gorham's Disease Alliance (LGDA). *Joint presentation.*
- Mellennee Finger, Director, and Sinead Zalitach, Patient Representative and Coordinator for Parkes Weber Syndrome – K-T Support Group (Klippel-Trenaunay Syndrome)
- Anil Hingorani, MD, Member, AVF DEI Committee, and Mary Mendez, Patient Representative – American Venous Forum (AVF)
- Lindsay Hoy, MD, Chief Mission Officer and Vice Chair, Francis McCormack, MD, Emeritus Scientific Director – The Lymphangiomyomatosis (LAM) Foundation
- Leo Schultze-Kooland, MD, PhD, President – International Society for the Study of Vascular Anomalies (ISSVA)
- Beth Stronach, PhD, President, Ashley Genelin and Gretchen Spiess, Patient Representatives – Rasopathies Network



National Commission on Lymphatic Diseases

Town Hall Forum II
December 2, 2024
9:00 a.m. – 12:00 p.m. EST

(cont.)

- Brittany Williams, Founder and Executive Director, and Betty Westbrook, PTA, CLT, co-Director, Camp Watchme – Brylan’s Feat Foundation

11:10 – 11:50 a.m.

Closing Discussion

Stephanie Dreyer, M.B.A. and Stanley Rockson, M.D., Co-chairs, NCLD

Stakeholders from the rare lymphatic diseases community will discuss with NCLD members their perspective and provide input on how to enhance progress for lymphatic health, diseases, and research.

11:50 a.m. – 12:00 p.m.

Closing

Stephanie Dreyer, M.B.A. and Stanley Rockson, M.D., Co-chairs, NCLD

12:00 p.m.

Meeting Adjourns