

# National Commission on Lymphatic Diseases

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 Lymphedema and Lipedema – 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 – Project FAVA (Fibro-Adipose Vascular Anomaly)
- Karen Ball, Founder and Chief Executive Officer – Sturge-Weber Foundation
- Jen Boyce and Kevin Boyce, Founders – Will's Power
- Christy Collins – M-CM Foundation (Macrocephaly-Capillary Malformation)
- Michael Dellinger, PhD, Director of Research – Lymphatic Malformation Institute (LMI) and Michael Kelly, MD, PhD, Executive Director– Lymphangiomas & Gorham's Disease Alliance (LGDA). Joint presentation.
- Mellennee Finger, Director, and Sinead Zalitch, Patient Representative and Coordinator for Parkes Weber Syndrome – K-T Support Group (Klippel-Trenaunay Syndrome)
- Anil Hingorani, MD, Member, AVF DEI Committee, and Emily Donovan, Patient Representative – American Venous Forum (AVF)
- Lindsay Hoy, Chief Mission Officer, Frank McCormack, Emeritus, Scientific Director, and Kristen Duncan, Patient Representative – The Lymphangiomyomatosis (LAM) Foundation
- Leo Schultze-Kooland, MD, PhD President – International Society for the Study of Vascular Anomalies (ISSVA)
- Beth Stronach, PhD, President – Rasopathies Network
- Brittany Williams, Founder and Executive Director, and Betty Westbrook, PTA, CLT, co-Director, Camp Watchme – Brylan's Feat Foundation



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(cont.)

11:10 – 11:50 a.m.

## **Closing Discussion**

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

Stakeholders from the lymphatic 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**