

National Commission on Lymphatic Diseases

November 18, 2024
9:00 a.m. – 11:30 a.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 – 10:40 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.

- Karen Bock, PT, MPT, PhD, Secretary, and David Doublestein, PT, PhD, Vice President – Lymphology Association of North America (LANA)
- Cheyenne Brinson, President – Fat Disorders Resource Society
- Heather Ferguson, Founder and Executive Director, Becky Sharp, and Franci Schwab, Patient Representatives – Lymphedema Advocacy Group
- Kimberly Karr, OTR/L, CPHQ, RAC-CT, Manager of Coding and Payment Policy, and Naydza Muhammad, LOTR, CLT, Patient Representative – American Occupational Therapy Association (AOTA)
- Jonathan Kartt, MA, Chief Executive Officer and Kasi Grosvenor, MBA, Project Manager and Patient Representative – Lipedema Foundation
- Guenter Klose, CLT-LANA, MLD/CDT Certified Instructor, Executive Director, Linda Hodgkins, MS, OTR/L, CLT-LANA, Lymphedema Team Leader at Hartford Healthcare, and Yolanda Martin, Patient Representative – Klose Training Lymphedema Certification.
- William (Bill) Repicci, MA, President and Chief Executive Officer, and Veronica Seneriz, Patient Services Director – Lymphatic Education & Research Network (LE&RN)
- Catherine Seo, PhD, Founder and Director and Lisa Duerre, Patient Representative – Lipedema Simplified
- Jennifer Williams, PT, DPT, CLT-LANA, Director of Clinical Education and Cindy Wessels, Patient Representative – National Lymphedema Network



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(cont.)

10:40 – 11:20 a.m.

Closing Discussion

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

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

11:20 a.m. – 11:30 a.m.

Closing

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

11:30 a.m.

Meeting Adjourns