

The Lighthouse

Lymphedema Network Newsletter



Shining a Light on Lymphedema

www.lighthouselymphedema.org

November 2024

The LLN's 26th Annual Lymphedema Education and Awareness Conference

Speakers, therapists, providers, and patients gathered in Atlanta on October 18-19, 2024, for an informative series of lectures about lymphatic disorders, treatments, and coping skills.



Therapists enjoyed a lively continuing education session with Karen Ashforth on October 18, 2024.

Fibrosis Techniques for Breast Cancer, Lymphedema, and Lipedema

Keynote Speaker Karen Ashforth, MS, OTR/L, CLT-LANA, came from California to share her 40 years of experience. She worked with therapists during the pre-conference and also opened the main conference.

A significant goal of lymphedema therapy is the prevention and treatment of fibrosis. Fibrosis is caused by chronic inflammation and the buildup of hard collagen deposits and dense fat. This thick tissue blocks lymph flow, creating a lymphedema cycle of worsening stages.

Karen provided hands-on experience with fibrosis-reducing techniques during the pre-conference course for clinicians. The clinicians could interact with several tools, and even take some home to use with their patients.

To prevent fibrosis tissue from being able to lay down initially, one must reduce inflammation in the area. Wholistic lymphedema treatment includes treatment of inflammation through mechanical means and stress reduction to quiet the autonomic nervous system.

Karen Ashforth recommends exercise, yoga, massage, acupuncture, aromatherapy, and Reiki energy healing to reduce stress and inflammation and improve mood. She also discussed nutrition guidelines and supplements that reduce inflammation. She concluded her session by leading conference attendees through guided relaxation and breath control exercises, leaving everyone smiling and relaxed as our stress and inflammation melted away.

Lymphedema and Lipedema Surgical Options, Requirements, and Post-Care

Stefanos Boukovalas, MD, is a surgeon with the University of Tennessee Medical Center in Knoxville, Tennessee, and received medical training in Athens, Greece, and Houston, Texas. Upon completing his residency, he moved to Knoxville to set up a comprehensive new department for lymphedema treatment with other physicians and therapists. This new center incorporates advanced lymphatic diagnostics, including lymphoscintigraphy, bioimpedance spectroscopy, and ICG lymphography. He formed the Tennessee LE&RN Chapter and provides presentations worldwide for clinicians and patients.

Dr. Boukovalas described the various kinds of surgeries he performs for lymphedema at UT Knoxville. Using VLNT or venous lymph node transfer, he has successfully transplanted lymph nodes from the digestive system to reduce lymphedema in the limbs.

LVA or lymphaticovenous anastomosis is most successful with early-stage lymphedema, particularly after breast cancer surgery. This procedure has also been done during breast cancer surgery to reduce lymphedema risk.



Morning speakers, Stefanos Boukovalas, Denise Jones, Karen Ashforth, and Roberth Erkstam

The SAPL, suction-assisted protein lipectomy, or a liposuction technique is utilized to reduce the abnormal tissue that develops with chronic lymphedema. The procedure can improve the quality of life and minimize individual infection risks. He discussed the criteria required, or the signs/symptoms a person exhibits, for each of the surgeries and post-operative care guidelines.

A Patient's Story of Successful Lipedema Treatment

Denise Jones now realizes her lipedema began during puberty. No amount of diet or exercise would reduce the size of her legs, and the problem got worse after pregnancy. Lipedema runs in her family and leads to self-criticism. Denise didn't want her daughters to feel bad about their bodies.

Even after knee replacements, Denise did not hear about the disease of lipedema until another lady referred to it. Denise underwent lipedema surgery three times, and she feels 100% better medically.

She is now more active and able to play with her granddaughter, which makes her happy.

Healthy Lifestyle Practices - the Third Phase of Lymphedema Therapy

Robert Erkstam, OTR, CLT-LANA, is a lymphedema therapist and health & wellness coach. He and his wife, Lou, are co-owners of [Self Care Therapy](#) in Wilmington, NC.

The first phase of lymphedema therapy is **Treatment** - Complete Decongestive Therapy with a Certified Lymphedema Therapist. Next comes the **Maintenance** phase, where the patient takes on self-care. Robert calls **Healthy Lifestyle Practices** the third phase, which supports and maintains the first two.

Healthy Lifestyle Practices include four pillars: **nutrition, exercise, sleep, and stress**. When any of these gets out of balance or improves, it impacts the other three. He stressed that these topics need to be discussed during treatment by clinicians to help patients individualize each to their lifestyle. There is no one method for everyone.

Clinicians and patients cannot avoid difficult topics like obesity. Instead, they should be addressed with compassion to develop healthy practices the patient can incorporate. He spoke about diets low in carbohydrates and high in proteins and fats.

Exercise is imperative for a healthy lifestyle and can be modified to meet the person's needs, such as simple walking short distances, aquatics, or gym-type programs.

Sleep and stress management are essential when managing injury, inflammation, and co-morbidities, like heart disease. They allow the body to heal and recharge.

The four pillars of Healthy Lifestyle Practices support our goal of feeling better more often. They can improve the quality of life for lymphedema and lipedema patients by supporting lymphatic flow and the immune system and decreasing pain, tissue fibrosis, and inflammation.

~Reviewed by Deb Cozzone, LLN Communications Chair

PATIENT STORY: Amiya Shah and Intestinal Lymphangiectasia or WILD Syndrome

Amiya Shah is a 12-year-old lymphedema patient who lives in Canada with her mom, Dr. Priya Sood. Amiya's goal is to become a famous clothing designer. In the summer of 2024, Amiya attended the



Camp Watchme program in Colorado for children with lymphedema. There, she met Dr. Shelley DiCecco, CLT, a board member of the LLN.

After an uneventful pregnancy, Dr. Sood gave birth to Amiya, the second of three daughters. At birth, Amiya showed right labial swelling. In her first few weeks, Amiya vomited breast milk and had poor weight gain, followed by fever and a diagnosis of Citrobacter sepsis. She was diagnosed with Intestinal Lymphangiectasia and right-sided Hemi-Lymphedema.

Dr. Sood found limited support and understanding of lymphedema and Amiya's particular condition. Amiya has tried several treatment techniques, undergone different diagnostic procedures, and even consulted international consultants to finally be diagnosed recently with **WILD Syndrome** (Warts Immunodeficiency, Lymphedema, and Anogenital Dysplasia), for which there is currently no genetic test.

Today, Amiya uses a pump to break down her fibrosis, as well as multilayer bandaging and garments. Mother and daughter perform nightly manual lymphatic drainage, and Amiya is on a strict low-fat diet, using only 100% pure MCT oil, which helps nutrients bypass any impact on the lymphatics. This intense regimen works well to help maintain Amiya's swelling. Internet research and social media have been great sources of information on Amiya's rare condition. And their experience working with Dr. Shelley DiCecco at Camp Watchme was life-changing.

~Reviewed by Debbie Labarthe, LLN Secretary



Lymphedema Treatment Act advocates and lobbyists had a mini-reunion at the LLN Conference.
Back Row (left to right)
Debbie Labarthe, Kathy Weatherly, Yolonda Martin, Sherilyn Bell, Joan White, Kimberly Glover, Lindsay Ryback, and Rebecca Hammad
Front Row (left to right)
Andi Heinemann, Cindy Cronick, Becky Sharp, Naydza Muhammad, Angeline Gallow

Dermatology Concerns with Lymphedema & Lipedema

Dr. Jodi Ganz is a dermatologist in private practice in Atlanta. She also serves on the volunteer faculty at Emory University, where she teaches medical students about genital dermatology.

Doctors and patients may hesitate to examine genital skin, but Dr. Ganz does find skin cancers and lymphedema in the genital regions. Concerned patients should ask for this exam if their dermatologist, urologist, or gynecologist doesn't offer it.

While doing skin surveys, a dermatologist is in a good position to diagnose lymphedema, even for patients who don't realize they have it. When Dr. Ganz notices swelling or cellulitis, particularly on one side of the body, she asks about the history of the swelling and looks for patterns of lymphedema. She tests to eliminate other skin or medical conditions that mimic lymphedema. Then, she refers patients to lymphedema therapists when appropriate.



Lymphedema patients are more prone to developing skin conditions like cellulitis, fungal and bacterial infections, hyperkeratosis, and skin cancers. This is due to the buildup of unfiltered fluid under the skin. Skin wounds are more challenging to heal with lymphedema and may require special treatment.

Dr. Ganz recommends regular visits with a dermatologist who knows about lymphedema. Patients also need to take meticulous care of their skin and nails to avoid serious dermatological complications of lymphedema. She recommended Happy Feet of Atlanta for medical pedicures.

~Reviewed by Sharon Shepard, Newsletter Editor

Dr. Jodi Ganz meets LLN Founder, Joan White

Signs, Symptoms, and Treatment Options for Central Lymphatic Dysfunctions

Dr. Shelley DiCecco, PT, PhD, CLT-LANA, CI-CS, is a lymphedema therapist and Associate Professor at the Philadelphia College of Osteopathic Medicine, Georgia Campus. She spoke about the relatively new field of researchers studying the **central lymphatic system**.

The lymphatic system begins to develop after the sixth week of gestation, and early lymph sacs eventually turn into lymph nodes. However, variations are found in many humans' central lymphatic systems. These variations can contribute to lymphatic dysfunction or the worsening of lymphedema in other areas. There are medical tests to diagnose central lymphatic disorders, such as an MRL (magnetic resonance lymphangiography). Most central lymphatic dysfunctions need to be addressed surgically, and several will require multiple surgeries throughout the patient's life.

Therapists might suspect central lymphatic dysfunction if a patient has some combination of edema, chyle leakage, loss of appetite, tension in the abdomen, cyanosis, SOB, wheezing, cognition issues, and bowel or bladder issues. Therapists should reach out to colleagues for more information and referrals to specialists. Patients need therapists to serve as champions for finding care and insurance coverage for this rare disorder.



2024 Conference Presenters: Dr. Stefanos Boukovalas, Robert Erkstam, Dr. Shelley DiCecco, Dr. Jodi Ganz, and Karen Ashforth

Your Contributions help the Lighthouse Lymphedema Network bring internationally-recognized researchers and medical providers to Atlanta for our yearly conferences. Thank you for helping patients and therapists learn more about cutting-edge research and treatments that can improve quality of life for every person.

We now know that every case of inflammation, every illness, every good night’s sleep, and the digestion of every meal is supported by our lymphatic system. Our invisible lymphatics enhance our lives in ways we are only beginning to understand.

Thank you for helping us make the invisible visible!

~The Lighthouse Lymphedema Network Board

Thank you, Lighthouse Lymphedema Network:

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