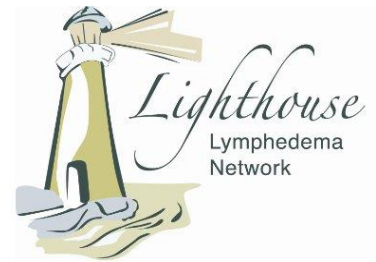


The Lighthouse

Lymphedema Network Newsletter

May/ June 2022



Shining a Light on Lymphedema

www.lighthouselymphedema.org

Lymphedema Heroes: Southern Loss Association and Mr. and Mrs. Orlando Ojeda with Full Circle Restoration



The Southern Loss Association is a network of insurance professionals that train and support each other. They also have a history of helping charities, especially the Lighthouse Lymphedema Network. Since 2012, they have given our network more than \$50,000 to support education conferences and patient compression therapy.



The Lighthouse Lymphedema Network was the charity supported by April's SLA Larry Hart Memorial Golf and Cornhole Tournament. Larry Hart was a partner in the White-Hart insurance adjusting company and dear friend of the LLN's Doug and Joan White. At the event, Susan Freeman of the SLA presented a donation for \$5000 to Doug and Joan, along with board members Francine Schwartz Schuler, Sharon Shepard and Beverly Thompson.

The SLA donation was matched twice by member Orlando Ojeda, founder and CEO of Full Circle Restoration in Duluth, GA. Full Circle Restoration is a 24-hour disaster response company. They have experts in fire, storm and water damage, and certified mold/fungus remediation. They serve commercial property managers, the insurance industry & property owners with repairs, restoration, and reconstruction.

We sincerely thank Orlando Ojeda, his wife Melissa, Full Circle Restoration, and the Southern Loss Association for a total of \$15,000.00 in donations. They will be well used.



Fun-raising with Joan

Our fearless and feisty leader, Joan White, gave board members quite a tour of the Chateau Elan Estates during the Southern Loss Association golf tournament. Despite more than 30 years of inflammation, pain, and annoyance from lymphedema, Joan at 80 remains positive and focused on helping others through the Lighthouse Lymphedema Network. We are grateful for her service and driving abilities.

Remembering Judith Casley-Smith, Lymphedema Pioneer



Dr. Judith Casley-Smith passed away peacefully in May at her home in Adelaide, Australia. She and her husband published the book, *Modern Treatment for Lymphoedema* in 1997.

On behalf of Casley-Smith International, President Jill Bracha stated that “Judith and her husband, Dr. John Casley-Smith, dedicated their lives to lymphedema treatment and research and had a major impact on patients, doctors, therapists and teachers all over the world. Working in a country with vast distances and scarce treatment resources, Judith was a forerunner in the concept of patient self-treatment” of lymphedema.

Judith emphasized techniques for self-bandaging, self-massage, and special exercises for lymphedema. These empower patients and improve their quality of life. She also used circumference measurement and volume calculation to estimate lymphedema stage, severity, and treatment progress. This tool is still used by therapists for patient education, clinical decision making and as support for treatment coverage by insurance providers.

Dr. Casley-Smith trained therapists in Australia, the UK, USA, Canada, Holland, and Israel, and some of these were certified as Casley-Smith Instructors. She retired in 2003 but continued to support the Casley-Smith International Foundation. Today, there are 18 teachers, 4 trainee teachers, and hundreds of therapists offering lymphedema treatment and information based on the Casley-Smith Method of Lymphedema Treatment. Their ranks include Lighthouse board member and presenter, Dr. Shelley DiCecco, who also serves as board Vice President of Casley-Smith International.

Lymphedema Education Conference Scheduled for Saturday, October 22, 2022

Roam Perimeter Center, 1151 Hammond Dr. NE, Atlanta. Online/Zoom attendance available.

Presentations are scheduled to start at 8:30 am and end at 4 pm. Please sign up using the enclosed registration page or on our website: <https://lighthouselymphedema.org/home/> CE credit is available for professionals.

Imaging and Interventions for Lymphatic Flow Disorders in Children

Yoav Dori, MD, PhD, Pediatric Cardiologist and Director of Jill and Mark Fishman Center for Lymphatic Disorders and Lymphatic Research at Children’s Hospital of Philadelphia, Associate Professor of Pediatrics, Perelman School of Medicine at the University of Pennsylvania.

Treatment for Children with Lymphedema

Betty Westbrook, PTA, CLT, Founder/Director of Camp WatchMe, Medical Advisor for Brylan’s Feet Foundation, Co-Founder of the Pediatric Lymphedema Alliance, Host of Lymphedema Podcast.

Looking through the Skin with Near-infrared Fluorescence to Assess Lymphatic Health

Melissa B. Aldrich, MBA, PhD, Associate Professor, Center of Molecular Imaging, University of Texas at Houston.

Importance of all aspects of CDT and a Mentally Healthy Me

Bridgit Anderson, OTR, CLT, Honor Health, Scottsdale, AZ.

Gadgets and Gizmos for Lymphedema Treatment

Shelley DiCecco, PT, PhD, CLT-LANA, CI-CS, Owner/Instructor LymphEd, LLC; Casley-Smith International Lymphedema Instructor & VP; Associate Professor at the Georgia campus for Philadelphia College of Osteopathic Medicine in PT Department; Pelvic Floor and Certified Lymphedema Therapist.

Patient Stories

Sponsor Tables - Demonstrating ‘gadgets and gizmos’ to help with lymphedema treatment.

Lymphatic Imaging Improvements Spur Research, Treatment

Historically, lymphedema was not well understood because the lymphatic vessels and nodes are nearly invisible to the naked eye. But new discoveries, treatments, and therapies for lymphedema are being developed thanks to scientific breakthroughs in **technology** and **tracer agents** that highlight the lymphatics. Our conference will feature two speakers discussing recent innovations in lymphatic imaging and its impacts on research and surgery for lymphedema.

The Progression of **Technology** and **Tracer Agents** for Imaging the Lymphatic System

X-rays – Beginning in the 1930's, **blue dye** or **oil soluble x-ray contrast agent** is injected into lymphatics.

CT scans - Advanced **x-rays** create **3D** images of internal structures and edema, sometimes using **radioactive tracers**.

Lymphoscintigraphy - **Gamma cameras** are used with **radioactive tracers** to locate lymph nodes and larger lymphatic collectors. Extensive use of radiation is a concern for patients and medical providers.

Magnetic Resonance Imaging (MRI) - Radiation not required. Often uses a **metal-based contrast agent**.

Infrared cameras - The **Indocyanine Green (ICG) tracer agent** was FDA approved and found safe for patient use in 1959, and recent research shows it binding strongly to HDL and LDL lipoproteins found in lymph. It is being used and improved to highlight lymphatics [1]. Cameras that pick up the fluorescence (**NIRF**) include **night-vision goggle** technology adapted at the University of Texas [2] and others developed in Asia.

Photoacoustic Lymphangiography (in development) combines **ultrasound** with the **ICG tracer** and may help “obtain clearer images of the lymphatic system and blood vessels when compared with NIRF” [3].

Research and Clinical Applications

MRI Lymphography can image the deep structures to exhibit typical lymphatic anatomy and locate abnormalities indicating primary lymphedema [4]. **Dr. Yoav Dori** has applied this technology in pediatric cases [5].

ICG Lymphography is currently approved for US research and surgical settings only, but its potential for use in clinical diagnosis and therapy is being explored. The ALERT system in Australia uses a near-infrared camera to give lymphedema patients a “personalized approach to their own conservative therapy” [6]. Once an individual’s lymphatics are mapped using ICG lymphography, massage and compression can direct fluid toward healthier lymphatic passageways. And a recent study in China used ICG lymphography to identify early-stage secondary lymphedema in cancer survivors. “Identifying subclinical lymphedema is helpful for early treatment and may reduce the chance that the disease will progress to a chronic late stage” [7].

Lymphatic Imaging is being developed to “image only cancer-positive lymph nodes. So instead of removing all the draining lymph nodes, surgeons could remove only those that are cancer-positive.” Eventually, “one could image whether malignant lymph nodes respond to systemic drug treatments simply by imaging their cancer status” instead of removing them [2].

In her *Letter Calling for a National Commission on Lymphatic Diseases*, **Dr. Melissa B. Aldrich** wrote, “Almost all extracellular fluid must transit back to the blood circulation via lymphatics, not venous capillaries, as was previously taught.... As such, all edema is basically lymphedema.” [8] We must conclude that advances in technology and tracer agents for more accurate imaging and study of the lymphatic system are essential and will improve medical care not only for patients with lymphedema, but for all people with inflammation.

References

[1] A. Polomska, S. Proulx, [Imaging technology of the lymphatic system](#). *Advanced Drug Delivery Reviews* 170, 2021 294-311.

[2] E. Sevick, [NIRF, Nodes and Night Vision](#), International Innovation 2017, 62-64.

[3] Y. Suzuki, H. Kajita, A. Oh, M. Urano, S. Watanabe, H. Sakuma, N. Imanishi, T. Tsuji, M. Jinzaki, K. Kishi, [Photoacoustic lymphangiography exhibits advantages over near-infrared fluorescence lymphangiography as a diagnostic tool in patients with lymphedema](#), Journal of Vascular Surgery: Venous and Lymphatic Disorders 10. 2, March 2022, 454-462.

[4] E. Lee, D. Biko, W. Sherk, W. Masch, M. Ladino-Torres, P. Agarwal, [Understanding Lymphatic Anatomy and Abnormalities at Imaging](#), RadioGraphics 42, 2022, 487-505.

[5] G. Chavhan , J. Amaral, M. Temple, M. Itkin, [MR Lymphangiography in Children: Technique and Potential Applications](#), RadioGraphics 37, 6, 2017, 1775-1790.

[6] H. Suami, L. Koelmeyer, [Mapping the Lymphatics and Monitoring the Progression of Lymphedema](#), guest blog post for the Lymphedema Research and Education Network, May 2020.

[7] Miao Liu, Siyao Liu, Quanping Zhao, Ying Cui, Jin Chen, Shu Wang, [Using the Indocyanine Green \(ICG\) Lymphography to Screen Breast Cancer Patients at High Risk for Lymphedema](#), Diagnostics 12, 2022, 983.

[8] M. Aldrich, [A letter calling for a National Commission on Lymphatic Diseases](#), Lymphedema Research and Education Network, August 2021.

Author: Sharon Shepard recently took over LLN newsletter duties from longtime editor, Elaine Gunter. Sharon is an English teacher, writer, and bilateral breast cancer survivor. Sharon.s.shepard@gmail.com.



Helping the Lighthouse Lymphedema Network



It's the Journey, Inc. raises millions of dollars to support breast cancer screening, research, early detection, diagnosis, and support services in Georgia. Their grants to the Lighthouse Lymphedema Network have provided compression garments to hundreds of lymphedema patients who don't have insurance coverage for these expensive items. The Lighthouse Lymphedema Network is grateful for their continuing support.

The *Amazon Smile* website features 'feel good shopping.' Amazon will donate 0.5% of your purchases on the website. If you would like to support the LLN in this way, you must go to www.smile.Amazon.com to make your Amazon purchases and select "Lighthouse Lymphedema Support Group" as your charity. You can bookmark this page on your computer or add it to your home screen on your computer or cell phone.



We need our congressional representatives to bring the **Lymphedema Treatment Act** up for a vote! Go to <https://lymphedematreatmentact.org/contact-congress/> for easy instructions to add your voice.

Dr. Shelley DiCecco provided a webinar for the LLN community on April 2, 2022. **The Fluid is Ours to Direct: Lymph Drainage and MLD Pathways** covered normal lymphatic drainage, the purpose of manual lymphatic drainage, and the different types of strokes. Dr. DiCecco also showed viewers multiple alternative pathways for draining the upper and lower extremities - for individuals not responding to the standard pathways.

Dr. DiCecco explained that to find the alternative pathways without imaging, healthcare providers must 1st use palpation skills, or their hands to assess tissue for viable pathways, 2nd compare this to their knowledge of anatomy to assess pathway/node options, and 3rd to always watch for proof of drainage and to not be afraid to change!

Videos demonstrated how healthcare providers and even patients could assess for these viable pathways. Dr. DiCecco walked everyone through the most common alternative pathways for both the upper and lower extremities and provided supporting research. Joan White said, "this was one of the best talks I have ever heard on lymphedema!" We look forward to Dr. DiCecco's talk about "Gadgets and Gizmos for Lymphedema Treatment" in our fall conference.

Tabouli for Summer – From Jean LaMantia

Tabouli (also spelled Tabouleh) is a refreshing summer salad on a hot day, with its fresh lemon juice, parsley and mint. This recipe originates from the mountains of Lebanon and Syria and is popular throughout the Mediterranean where all these ingredients are readily available. You can also find it in supermarket deli counters and restaurants around the world.

Ingredients

¼ cup fine bulgur wheat,
2-3 tomatoes, chopped (as much chopped tomato as chopped parsley)
2 green onions, finely diced (sprinkle with cinnamon and set aside)
1 cup flat leaf parsley, finely chopped
12-15 leaves of fresh mint, finely chopped
1 tsp lemon zest
3-4 tbsp freshly squeezed lemon juice /pomegranate molasses (see option below)
3-4 tbsp of extra virgin olive oil (or MCT oil)
Salt and pepper to taste
Optional – feta cheese
Option – Substitute 2 tbsp of Pomegranate molasses for 2 tbsp of the lemon juice. It gives a very authentic flavor to the tabouli. Pomegranate molasses is made by cooking pomegranate juice, sugar, and lemon juice. You get the health benefits of pomegranate in a tangy syrup.



Method

1. In a bowl, soak bulgur wheat in room temperature water while you prepare other ingredients - it should be al-dente, or to your personal preference. Hand-squeeze to remove excess water when done soaking
2. Mix chopped tomatoes, green onion, chopped parsley, mint and lemon zest in a bowl. Add bulgur when ready.
3. In a separate bowl, whisk olive oil, lemon juice, (pomegranate molasses), salt and pepper and pour over salad. Mix to combine and refrigerate before serving.

Health Benefits

Bulgur wheat is parboiled (partially boiled) whole grain wheat. It is available in fine, medium and course grind. Because it is whole grain, it has more **fiber** than couscous, which is refined. If you don't eat wheat, you can **substitute quinoa**.

Tomatoes are rich in the red pigment **lycopene**. Lycopene is best known for its protective action against prostate cancer and its healthy vitamin C content.

Bright green **parsley** is a source of important plant **antioxidants** – luteolin and apigenin, **pigments** -lycopene, alpha carotene, lutein and zeaxanthin, and **vitamins** K, C, and A, as well as the B vitamin, folate.

Fresh **mint** is known as a digestive aid and for soothing an upset stomach or irritable bowel. But the amount in this recipe is not likely to be therapeutic; it just adds a nice cooling mouth feel on a hot day.

Lemon juice is a good source of vitamin C and other important plant nutrients called **polyphenols**. One of those is **hesperidin**, which, at one time was known as vitamin P because it preserves capillary blood vessels by making them less leaky. That is why some herbal supplements for venous disease and lymphedema contain hesperidin.

Extra virgin olive oil is high in the fatty acid called oleic acid, otherwise known as omega-9 fatty acid. **Oleic acid is known to be anti-inflammatory**. While it is a long-chain fatty acid and would therefore require the lymphatic system for absorption it is none-the-less a heart healthy oil. If you are reducing the amount of long chain fatty acids in your diet, then you can **substitute MCT oil**.



Jean LaMantia, RD is a registered dietitian, cancer survivor and author of three books including *The Complete Lymphedema Management and Nutrition Guide*. Jean is also the creator of **Lymphedema Nutrition School**. You can find out more about Jean, her books and programs and read her blog at <https://jeanlamantia.com/>

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The 24th Annual - State of Georgia
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Program Location: **ROAM**, 1151 Hammond Drive, Suite 240, Atlanta, GA 30346. Upper level, above Old Navy, near Perimeter Mall.

Hotel: **Crown Plaza, Atlanta Perimeter at Ravinia**, 4355 Ashford Dunwoody Road. The conference room rate is \$129.00 per night. Self-parking is \$12.00 per night. Rooms are limited.

Many thanks to our Sponsors who support the LLN's mission!



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The Lighthouse Lymphedema Network is a 501(C) (3) non-profit organization. Please make all checks payable to the **Lighthouse Lymphedema Network** and mail to the *LLN, 10240 Crescent Ridge Drive, Roswell, GA 30076*. For information, e-mail joanwhite59@gmail.com.

You can also make a donation on-line by credit card at: <http://lighthouselymphedema.org/get-involved/donate.htm>.

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