

# The Lighthouse



## Conference Edition Newsletter

November 2022

*Shining a Light on Lymphedema*  
[www.lighthouselymphedema.org](http://www.lighthouselymphedema.org)

### 2022 STATE OF GEORGIA LYMPHEDEMA MEDICAL CONFERENCE

The Lighthouse Lymphedema Network was excited to meet in person for their 24th Annual conference on October 22, 2022. Attendance was also available on Zoom. Therapists and nurses received continuing education credits for this valuable conference. Reviews by select attendees and important information from our speakers follow.



### SPEAKERS

#### Imaging and Interventions for Lymphatic Flow Disorders in Children



**Erin Pinto, MSN, RN, CCRN, FNP-BC**, is a Nurse Practitioner in the Jill and Mark Fishman Center for Lymphatic Disorders at Children's Hospital of Philadelphia.

Erin began her presentation with a review of the function of the central lymphatic system and the history of imaging techniques. She described improved imaging techniques being applied at Children's Hospital of Philadelphia (CHOP). This is one of the foremost

hospitals in the world developing techniques to diagnose and treat lymphedema disorders in children.

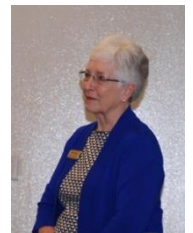
She explained DCMRL - Dynamic Contrast Magnetic Resonance Lymphangiography that can be used to diagnose lymphatic flow disorders. The imaging focuses on four major areas - hepatic, mesenteric, heart, and lung to provide doctors with a clearer picture of the lymphatic system to diagnose central lymphatic flow disorders and chronic lymphatic disorders. Depending on the diagnosis, treatment may be offered with hybrid approach including surgery like the lymphaticovenous anastomosis (LVA), stents, catheters, and/or thoracic duct repair. Some disorders can be treated with medication.

Pediatric and adult primary lymphedema patients are benefiting from new research and treatments. Ms. Pinto concluded with pictures and stories about children diagnosed and treated successfully at CHOP.

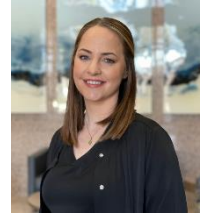
~Reviewed by Janie Smith, LLN Board Member

**Our Conference Moderator, Elaine Gunter** has served as the LLN's newsletter editor, database manager, and conference moderator for many years.

She announced that 2022 would be her last conference, as she is retiring from the LLN Board. She will be sorely missed, and her contributions are much appreciated.



## Treatment for All Children with Lymphedema and A Team Approach to Camp Watchme Campers



**Betty Westbrook, PTA, CLT-ALM**, is the Founder/Director of Camp Watchme, Medical Advisor for Brylan’s Feat Foundation, Co-Founder of the Pediatric Lymphedema Alliance, and Creator and Host of Lymphedema Podcast.

Westbrook gave a mini course on treatment of lymphedema in pediatric patients. Citing case studies, she showed that great progress can be made in short amounts of time. She stressed that imaging is a very important part of more complex cases but with straightforward cases, therapists can treat with the typical sequences of MLD. She cautioned that the midline must never be crossed without imaging.

Children can be affected by primary or secondary lymphedema and primary lymphedema occurs at a rate of 1 in 100,000 under the age of 20. It is possible for primary lymphedema to be seen in utero via ultrasound. She questions whether the genetic testing, often done around gestational age of 10-11 weeks, could include testing for known lymphatic abnormalities. This might give parents time to learn about lymphedema and prepare for the birth and treatment of a child at risk for the condition.

Westbrook believes that communication throughout treatment is key. She recommends involving both parents and children in treatment. She touched on each of the elements of CDT. Compression is a must and pediatric bandaging kit guides can be found at [www.brylansfeat.org](http://www.brylansfeat.org). Compression needs to be guided by a certified lymphedema therapist. Skin care requires good hygiene, lotion and checking for any trouble spots. For nail care, she highly recommends Little Martin’s Baby Electric Nail Trimmer because it files nails rather than clip them. Westbrook likes exercises to be fun and engaging. She stressed the importance of allowing children to try new things. Westbrook encourages parents not to say “no” to experiences, but to know what to do in case of injury. While no additional coursework or training is required to treat pediatric lymphedema, advanced training is available. Many resources can be found at [BrylansFeat.org](http://BrylansFeat.org), including a Parents’ Lymphedema Road Map for pediatric lymphedema.

After the discussion of pediatric lymphedema, Westbrook spoke about Camp Watchme, the only camp in the United States dedicated to children with lymphedema. “Watch Me” is a reminder that parents and children can advocate for themselves—“Just watch me!” At the camp, children, parents, and therapists come together to learn.

The Mussman family, attendees at Camp Watchme in 2021 and 2022, joined Westbrook to discuss their experiences. While camp was educational and fun, it also offered networking opportunities with other families. The children met other children with lymphedema, often for the first time. Because of camp, Bryce (11) has taken more responsibility for his own self-care, has become more aware of nutrition, and has made friends for life.



Westbrook also spoke with Sandra Dupree, PT, CLT, Camp Watchme Mom and Camp Watchme Therapist. Through the camp experience, Dupree formed deep connections with other therapists, family members and children with lymphedema. This experience has enhanced her work with her own child and other pediatric patients. Dupree consults with therapists in other countries who treat pediatric patients, and many have seen significant improvement due to her work.

~Reviewed by Deb Cozzone, LLN Board Member



## Looking through the Skin with Near-infrared Fluorescence (NIRF) to Assess Lymphatic Health

**Melissa B. Aldrich, MBA, PhD** is an Associate Professor in the Center for Molecular Imaging at the University of Texas at Houston. Dr. Aldrich conducts research using Near Infrared Fluorescence to see the internal development of lymphedema in breast cancer survivors. You can read a recent article on her work at: <https://doi.org/10.1007/s10549-022-06667-4>

Researchers use Indocyanine Green (ICG), a safe internal dye that binds to lymphatic proteins, to highlight the lymphatic system and lymphatic flow. They have modified infrared cameras to see through the skin and video the lymphatics. This imaging system provides better imaging than lymphoscintigraphy in regard to the actual lymphatic flow in the particular tissue, not simply a global flow of the deep lymphatics to the nodes. Currently, it is being used for research and microsurgery in the US but has potential to revolutionize clinical treatment of lymphedema.

UT Houston researchers are already making discoveries about lymphedema. Results have shown that “dermal backflow” can be detected using NIRF lymphatic imaging 8-23 months before arm swelling develops in Breast Cancer related lymphedema. Her research reaffirms the updated Starling’s Theory where all interstitial fluid is removed by the lymphatic system, not the venous system. So, all edema is due to lymphatic dysfunction. The NIRF imaging also shows that inflammation appears to reduce lymphatic pumping, and exercise or deep breathing increases it. NIRF lymphography is a valuable new tool for researchers.

~ Reviewed by Sharon Shepard, Editor



## Importance of all aspects of CDT and a Mentally Healthy Me

**Brigit Anderson, OTR, CLT**, works with HonorHealth in Scottsdale, AZ. She talked about the emotional aspects of having lymphedema and the five pillars of a Win-Win Therapy for patients. These are: Compression, Skin Care, Therapeutic Exercise, Manual Lymphatic Drainage, and Compassion. The therapist must address the patient’s emotional needs as well as physical condition.

Therapeutic exercises should be individualized based on the patient’s interests and experience. Physical activities should make the patient feel good, creating feelings of peace, emotional balance, creativity, and joy. Depression is often associated with lymphedema and can be counteracted by scheduling activities that “spark joy” and make the patient feel cared-for. Lymphedema therapists provide some of this feeling through their care but should also encourage patients to find additional supports for their positive mental health.

Brigit also discussed the importance of therapists or healthcare practitioners taking care of their own mental health to avoid burnout. A healthcare provider who practices intentional self-care will be at their best when sharing these win-win therapies with their patients.

~Reviewed by Sharon Shepard, Editor



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## Gadgets and Gizmos for Lymphedema Treatment

**Shelley DiCecco, PT, PhD, CLT-LANA, CI-CS** is the Owner/Instructor of LymphEd, LLC, a Casley-Smith International Lymphedema Instructor & President, Assistant Professor at the Georgia campus for Philadelphia College of Osteopathic Medicine in PT Department, and a Pelvic Floor and Certified Lymphedema Therapist. She encourages everyone (patients and healthcare providers) to keep researching lymphedema as new treatments are being developed. Everyone needs to know the techniques for new treatments as well as precautions or contraindications. Google Scholar is a good resource for research.

Know your anatomy when treating lymphedema, and what lies below the skin besides the lymphatics. Your lymphatics, arteries, veins, and nerves typically all travel together in the body and are connected via fascia to other tissues or structures. Due to this fascia, when one addresses the lymphatics, the arteries/veins/nerves in that area are also impacted to some degree. This is especially important with superficial large vessels or nerves, like in the neck or groin, and for nerves at the elbow and knee. Other health conditions impacting the large vessels can be made worse when one addresses the lymphatics in the area, including dislodging clots, increasing blood pressure, and/ or damage to the vessel walls.

**Elastic Tape** can be used to stimulate lymphatic pumping as it lifts and massages skin. Because it is also used by athletes, it is preferred over compression garments by some patients. But it is not appropriate if the skin has any unhealed wound, infection, active cancer, allergy, etc. Skin should be clean, healthy, and hair-free. Tape should never be applied over large blood vessels, especially in the neck and groin areas. Edges should be rounded, and the tape should not be over-stretched.

**Cupping** uses a negative-pressure device to lift skin so fluid can move. This can also block pain for patients. Cupping should be only applied strong enough to attach the cup and lift the upper layers of the dermis, not deep enough to lift muscle and the direction should be in the direction of desired fluid movement. Cupping should not be performed over superficial large vessels or nerves.



**Steel Blading** uses various instruments to mobilize soft tissue to disrupt fibrosclerotic or hardened tissue often seen with lymphedema. The pressure should be light to moderate, at most, and should not be performed over superficial large vessels or nerves.

**Dry Brushing** has no actual research to support benefits with lymphedema. It could possibly help with exfoliating dry skin and desensitizing skin with hypersensitivity. Dry brushing should only be used 2-3 times a week max and should not leave the skin discolored. Dry brushing should be performed in the same direction/pattern as MLD to help move fluid from the areas. It is not indicated for skin that is injured, or around sensitive areas like the face and especially eyes.

“Gadgets and gizmos” combined appropriately with lymphedema treatment can enhance the patient experience and encourage compliance. Dr. DiCecco demonstrated several gadgets with the help of a young patient who especially likes the elastic tape.

~Reviewed by Sharon Shepard and Shelley DiCecco



## Sponsors Support the LLN's Bandages and Garments Fund



The Lighthouse Lymphedema Network's Bandages and Garments (BAG) Fund is one of our most active programs. The BAG Fund assists underserved patients with lymphedema by providing financial assistance for bandages and garments necessary for an individual's successful self-care. Patients without insurance or with insurance which excludes coverage for lymphedema supplies must be under the care of a certified therapist, who can recommend them for assistance. The LLN receives a generous grant from **It's The Journey's Georgia 2-day Walk for Breast Cancer** to aid patients with breast cancer-related lymphedema. Fundraising by the LLN supports patients who have lymphedema from any source other than breast cancer. These include lower extremity lymphedema, primary lymphedema and other types of cancer.

**Therapists** with patients who are not insured for compression supplies, please contact Janie Smith at [darnofell@aol.com](mailto:darnofell@aol.com) for further information or for an application. The application process is easy to follow and complete. The therapist and patient fill out a short form and funds may be awarded based on financial need. There is, at times, a small co-charge required from the patient.

The LLN wants to help therapists help patients get the products they need.

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## Thank You All to our Lighthouse Lymphedema Network Sponsors from Joan White and the LLN Board



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