



www.lighthouselymphedema.org

LLN October 2018 Newsletter

Find us (& great info) on Facebook: 
([@LighthouseLymphedema@LLymphedema](https://www.facebook.com/LighthouseLymphedema))



Follow us on Twitter: [@LLymphedema](https://twitter.com/LLymphedema)

LLN: Serving the lymphedema community for 25 years

SPECIAL POST-CONFERENCE EDITION!

**From our all-day LLN-Sponsored Fall Medical Conference
Saturday, October 20th 2018
And our head & neck lymphedema training session for therapists, Friday,
October 19th**

Our 2018 Lymphedema Education & Awareness conference was a great success for all attendees. We have created this special edition of our newsletter to provide highlights of the conference for everyone. We had 24 therapists for Brad Smith's training session on Friday, and our room was full for our Saturday conference, which covered a wide variety of relevant topics for lymphedema patients, their families & caregivers, and medical professionals. And our excellent vendors demonstrated their latest new products for lymphedema management. We offer our sincere thanks to Peyton and Vicky Day for opening the ROAM facility for us to use. We received many nice accolades. The food was delicious! The staff at the ROAM was unbelievable! The ROAM seemed so comfortable and the attendees appreciated the program, and some of them stated that this was the best LLN conference EVER!

We also celebrated a special milestone, the 25th anniversary of LLN!



LLN Director Joan White was surprised with flowers and a cake in honor of her 25 years of leadership and the creation of LLN (which is now the largest patient-centered lymphedema support group in America). Thanks to Molly Nettles-Sleigh and Samantha Cannon Martin for creating this worthy celebration for Joan!



L-R: Gwen Forbes Kirby, Dr. Shelley Smith DiCecco, Veronica Seneriz, Debbie Labarthe, Dr. Wei Chen, Joan White & Dr. Kevin McGill



Dr. Wei Chen



Robyn "Redd" Smith



Gwen Forbes Kirby



Dr. Shelley Smith DiCecco



Dr. Kevin McGill



Khadija Loh



Daniel Joao



Veronica "Vern" Seneriz



Brad Smith



Debbie Labarthe



The Roam facility where the conference was held



Attendees signing in on Saturday morning



Another group shot of attendees



Molly Nettles, OTR/L, CLT-LANA, our GA Gives Day Coordinator



Our speakers during the afternoon question & answer session

Pictures from our Head & Neck Lymphedema Treatment Training Course



Our 24 attending therapists, Dr. Wei Chen, and teacher Brad Smith at the very back-middle!



Brad Smith demonstrating head & neck treatment techniques on Molly Nettles-Sleigh



Course attendees practicing measuring techniques for patients with head and neck lymphedema

Evaluation and Management of Head and Neck Lymphedema – Brad Smith, MS, CCC-SLP, CLT

Brad Smith is a renowned speech-language pathologist who also became a lymphedema therapist to better serve his patients. He held a workshop for our therapists, providing basic instruction for treatment of head and neck lymphedema (HNL). Starting with measuring the face and neck to obtain facial and neck composite scores, which provide objective data when reporting changes in edema in the head/neck. He discussed the invaluable role of taking accurate photos to document change as well as tissue/skin assessment. Problem solving for use of anterior vs. posterior pathways for MLD was discussed as well as practicing that technique. Special care must be taken when working on eyelids and intra-orally. Considerations for home treatment vs outpatient treatment need to be taken into account when looking at patient's severity of disease, travel distance, financial and familial support. Instructions for construction of chip pads, Schneider packs, and homemade compression were provided, as well as descriptions of various off-the-shelf and custom compression garments. Kinesiotaping was described as a beneficial element to success. Finally, HNL troubleshooting was provided using the POPCICLE acronym (*Postural issues, Obstructions, Pathway, Compression, Infection, Compliance, Look for other issues, Evaluate every method you are utilizing*).

Patient Khadija Loh's Story

Ms. Loh works as an IT program Manager. She was born and raised in Morocco and moved to the US for her MBA. Khadija has suffered from lymphedema, lipedema and venous insufficiency for over 23 years. She says that finding the right doctors for these conditions was not an easy task back then; it took 19 years before she was finally diagnosed with lipedema by Dr. Karen Herbst in Tucson, AZ.

In October 2017, she traveled to France and had a vascularized lymph node transplant (VLNT) procedure performed by Dr. Corrine Becker. She admits the surgery was “no walk in the park,” and was very painful. In June 2018, her MRI showed good progress, and she went back for the 2nd phase of the treatment, which consisted of a liposuction procedure.

Khadija is very compliant and wears her compression garments daily. She's very determined to win the battle against lymphedema and has promised to spread the word when she finally becomes lymphedema-free. We sincerely thank Khadija for presenting her story and giving hope for lipedema patients.

Patient Daniel Joao's Journey

Mr. Joao's dentist noticed something under his tongue in April 2016. This was not the first time he experienced prolonged canker sores, which had all eventually healed in the past.

- August 2016 – Daniel had a biopsy after seeing multiple doctors, including his GP, dermatologist and allergist.
- September 9 – He received the results of the biopsy; it was positive for poorly-differentiated squamous cell cancer of the floor of the mouth.
- September 17 – He told his mother, which was very difficult for him to do. She did not take the news well because she had recently lost Daniel's dad to prostate cancer.
- November 6 – Day of surgery, lasting 15 hours. He had to have a complete jaw reconstruction with removal of the lower half of his mouth, including a large portion of his tongue, all his lower teeth, & all the lymph nodes in that area. He had great family support; his wife stayed at the hospital 24/7. His memories from that time were less about surgery and more about family. He remembered saying goodnight to his daughter the night before surgery, and of his son's coming to visit him after surgery but initially having a difficult time looking directly at Daniel.
- February 14, 2017 – He finished the toughest part of his journey - radiation treatment - which has had the most lasting effect so far.
- October 6, 2017 – After his lower jaw reconstruction, he received new lower teeth. Restoring his appearance was the most important thing to him. Most people would probably think eating once he received the teeth, but he just wanted to look the same as before.
- September 2018 – Daniel was always an active person (a runner). He is back to running and finally reached 5 miles.
- November 7, 2018 – His 2 year check-up appointment. He has a head and neck scan scheduled, and if all comes back cancer-free, then his appointments will change from twice a year to annually. The chance of reoccurrence for this cancer drops drastically after 2 years.

Daniel began his presentation showing a picture of him with his wife and 3 children. All of us were amazed after all his surgeries, radiation, and treatment, he looks exactly as he did in the picture with his family taken prior to his illness. He did develop lymphedema in his face and neck, and it was worse on his right side. Daniel was very concerned about his jaw line reappearing; his therapists treated that area of his neck with a low-intensity laser to decrease the swelling and fibrosis, and create improved lymph drainage. Daniel, we so admire you and your determination. Thank you for sharing your journey!

Patient Veronica Seneriz's Story: Lymphedema Distichiasis Syndrome (Primary)

People with lymphedema-distichiasis syndrome develop puffiness or swelling of the limbs, typically the legs and feet. Another characteristic of this syndrome is the growth of extra eyelashes (distichiasis) ranging from a few extra eyelashes to a full extra set on both the upper and lower lids. Actress Elizabeth Taylor was born with a double set of eyelashes. Veronica wears contact lenses to prevent progression of astigmatism and scarring of her corneas.

Veronica noticed her legs were swelling when she was 20. Her father had always had one swollen leg and had experienced over 100 cases of cellulitis. His family didn't know what he had, but they always had a suitcase packed & ready to leave for the hospital. One day in 1998, Veronica was driving and noticed a billboard sign, "If you have swelling like this, you may have lymphedema". She wrote down the number and immediately made contact with the 1-800-number listed on the billboard.

Both Veronica and her father were then diagnosed with hereditary lymphedema. Family history: Her grandfather, father, uncle, two first cousins all had/have lower extremity lymphedema. She is a 3rd generation primary patient with lymphedema distichiasis. To lose weight, she walked an incline on a treadmill while her legs were wrapped with compression garments.

Ms. Seneriz is the founder and creator of the **Lymphie Strong** Site. She has attended lobby days for the passage of the Lymphedema Treatment Act, and is a member of the Texas Chapter of LERN. She is a graduate of the Lymph Science Advocacy Program (LSAP) in 2017. Veronica, we so admire your determination and dedication to educate others about lymphatic disease!

"The Current State of the Art in Surgical Lymphedema Treatment" - Wei Chen, MD, FACS

Dr. Chen is a plastic surgeon with expertise in micro- and supermicro-surgery at University of Iowa Hospitals and Clinics, performing lymphedema surgeries for the past 12 years. He stressed the importance of therapists and surgeons working together to establish a plan and never starting treatment with surgery, but with CDT. Intervene early! He discussed the spectrum of surgeries that are available for patients with lymphedema differentiating between options for "fluid-predominant state" lymphedema vs "solid-predominant state" lymphedema. He acknowledged the limitations in diagnosing lymphedema with clinical signs only and feels that imaging of the lymphatics should be a standard of care for proper diagnosis and treatment planning. Fluorescent indocyanine green (ICG) lymphography is his preferred choice in most cases for both diagnostic imaging for lymphedema and tracking changes in the lymphatics over time. He also uses fluorescent ICG lymphography for a detailed lymphatic mapping during pre-operation planning, intra-operative navigation, and post-surgical monitoring. Results from ICG imaging are used to determine severity staging of the lymphedema as follows: ICG lymphography pattern change from normal linear pattern to abnormal dermal backflow (DB) patterns (splash, stardust, and diffuse patterns). Splash represents mild DB; whereas, stardust/diffuse represents moderate/severe DB.

The physiologic procedures offered at U-Iowa are as follows:

Lymphaticovenular Anastomosis (LVA) is an advanced, minimally-invasive procedure. Using an ultra high-power microscope and super-microsurgical technique, lymphatic channels in the range of 0.2- to 0.5-mm are connected to nearby veins. The sutures used in the LVA are nearly invisible to the naked eye. Successfully constructed LVAs allow lymphatic fluid to flow into the bloodstream, reducing symptoms in the affected limb. LVA is most effective in patients with early "fluid state" disease who ideally demonstrate linear patterns on ICG lymphography. It can be offered selectively in those with more advanced disease.

Vascularized Lymph Node Transfer (VLNT) is a microsurgical modality in which healthy, functioning lymph nodes are transferred from another part of the body to the affected limb to treat lymphedema. Using

sophisticated microsurgery techniques, the lymph nodes are transplanted while preserving their blood supply, thereby preserving the function of the lymph nodes. It has proven effective in late-stage lymphedema. There is, however; a risk of donor site lymphedema and they are not aesthetically pleasant as it leaves a hump where transferred to, typically over wrist or ankle.

Vascularized Lymphatic Vessel Transfer (VLVT) is a procedure Dr Chen developed in which a thin layer of skin with vascularized lymph vessels - but not the nodes as described in VLNT - is transferred. It is a safer, more aesthetically pleasing, and equally effective lymphedema treatment.

“Fat Tissue is a Real Issue with Lymphedema” - Shelley Smith DiCecco, PT, PhD, CLT, LANA, CI-CS

Dr. DiCecco addressed the connection between fat and lymphedema. She pointed out that a Basal Metabolic Index (BMI) of 25 or more significantly increases the risk of lymphedema development. Lymphedema is an issue of swelling and inflammation which will be further agitated by obesity. She pointed out that fat adipose produces hormones called adipokines that have a significant role within the immune system for regulating inflammatory responses. Adipokines are a key factor for obesity, type II diabetes with regulatory insulin sensitivity, and tissue inflammations. The endothelial glycocalyx lines the capillaries and its function is to limit clots, platelets, and inflammatory cells that adhere to vascular lining, which helps reduce heart disease. However, high level of blood glucose and LDL- cholesterol damage the endothelial glycocalyx, which leads to the capillaries being damaged from clots, inflammation, and plaque buildup. Inflammation is a significant factor with lymphedema as well as obesity. Thus, weight loss should be seriously considered with lymphedema patients. As clinicians, we can help with discussing resources for weight loss and exercise.

“Updates in Metabolic Surgery” – Kevin McGill, MD, FACS, FASMBS

Dr. McGill is director of Bariatric Surgery at Piedmont Hospital. He discussed this surgical technique, which he called metabolic surgery, to focus on the physiological problems obesity incurs such as type II diabetes, heart disease, arthritis, etc. which can be reversed with weight loss. He described surgical weight loss procedures such as gastric sleeve and Roux-en Y surgeries. Dr. McGill also recommended that his patients follow up with bariatric nutritionists to address their specific needs. Dr. McGill talked about the obesity medicine having been dismissed years ago, but now it is seen as a disease, and there is an American Board of Obesity Medicine that has been established.

A New Perspective on Lymphedema - Robyn “Redd” Smith, MEd, COTA/L, CLT, CLWT, LASH-FKT

Use a semicolon ; that means “My story isn’t over.”

Robyn “Redd” Smith, MEd, COTA/L, CLT, CLWT is an Occupational Therapy Practitioner, Lymphedema and Wound Therapist and owner of a private lymphedema and wound care practice in Salt Lake City, Utah. She is the Clinical Education Liaison for SIGVARIS, NA traveling the country teaching about lymphedema and wound care. Redd is the Executive Director of Life Rehab International, a humanitarian group that takes medical practitioners to resource-poor areas of the world treating lymphedema and teaching local medical staff how to continue the treatment patients.

In her presentation, she informed us of exciting changes in physicians’ understanding of lymphedema due to new research, which is leading them to want to know more about treating it. Now that the doctors are listening, we need to raise our level of involvement at whatever level a person with lymphedema can. Redd was very upbeat and talked about “Living with Lymphedema, Keep Dancing, Spread your Influence, Create your ‘Lymphatic Village!’” She urged us to get kids to organize a car wash, or garage sale to help support patients you know. Become a buddy to someone – “call me if you need to talk.” Have a club adopt a disease or sponsor a silent auction. In other words, get your community involved in helping to raise funds and create awareness about lymphatic disease. Rather than living with lymphedema as the center of your life, concentrate on living!

A Pharmacological Approach to Treatment - Gwen Forbes-Kirby, PT, CLT-LANA, STAR/C

Ms. Forbes-Kirby discussed the various drug therapies for the treatment of lymphatic disease.

- Ketoprofen – an anti-inflammatory drug – goal to help break down fibrosis tissue – Has side effects of gastric, neuro and cardiac with long term use.
- Lymfactin – from Finland. Injection of VEGF-C to stimulate lymph vessels, used with secondary breast cancer related lymphedema
- Ubenimex – studies out of Stanford University, CA sponsored by BioPharmaceuticals. This drug is used to treat leukemia of adults in Japan. Although a few patients had success in reduction of their lymphedema, the company is not going to pursue the study. Dr. Rockson has since stated he and his team will continue to look at the patients who were successful.

Ms. Forbes-Kirby then discussed the Lymph Tech imaging system developed by Dr. Brandon Dixon's team of bioengineering research students at Georgia Tech. The Lymph Tech is a 3D volume scanner. The goal of the Lymph Tech is simple but highly accurate technology to be used in home or clinic. Dr. Dixon's research focuses on elucidating and quantifying the molecular aspects that control lymphatic function as they respond to the dynamically changing mechanical environment scanner they encounter in the body. Through the use of tissue-engineered model systems and animal models, the research is shedding light on key functions of lymphatic transport, and the consequence of disease on these functions.



Attendees who went to DC to push passage of the National Lymphedema Treatment Act

Update on Lymphedema Treatment Act - Debbie Labarthe

This legislation (HR.930/S.497) will amend the Medicare law by adding the *Allowable Benefit Code* to insure coverage of doctor-prescribed compression supplies under the Durable Medical Equipment category. At the Fall Medical Conference, the LLN recognized the attendees who have met with Congressional Offices in Washington DC, as well as those who have advocated for the LTA thru local town hall meetings, emails, phone calls, faxes, and tweets. Our voices are making a difference! The LTA was first introduced into Congress in 2010, and it has been re-introduced in each subsequent session. It is **currently the most supported healthcare bill in Congress!** It has earned the Super Majority status in both House and Senate, with a total of 445 cosponsors (House: 381; Senate: 64). We continue our efforts to gain more Senate cosponsors. To view a list of the Senators who have **not** yet cosponsored the LTA, go to: www.lymphedematreatmentact.org. If your Senator is on the list, please contact him/her and urge their support. This website also provides easy-to-use email templates and scripts for phone calls, faxes, and tweets. We remain very hopeful that leadership committees will take action to move the bill to the floor for a vote in November! Let's get the LTA passed in 2018!

Our Excellent Supporting Vendors!

Body of Health and Life

BSNmedical Inc., an Essity Company/Jobst

Gloria Watts-Cox Foundation

JUZO USA

L&R USA Inc.

LymphEd, LLC

MEDI USA

SIGVARIS INC.

Wear Ease



Thank you, Lighthouse Lymphedema Network:



**Support the Lighthouse Lymphedema Network
on Georgia Gives Day, November 27th!**

While the official date of Georgia Gives Day is November 27th, the website is open to donations year round and you can donate to the LLN any time and at your convenience! Simply go to www.GAgivesday.org and search for “Lighthouse Lymphedema Network”. Use the DONATE NOW button to make your donation in support of one of our fundraisers and the LLN. Because we have no paid staff, ALL funds raised by the LLN directly serve the lymphedema community!

**Georgia Gives Day is a collaboration of the Georgia Center for Nonprofits (GCN) in partnership with participating nonprofits, state agencies, corporations and businesses, associations, foundations and public relations and advertising firms.

Donations may also be mailed to: LLN, 10240 Crescent Ridge Drive, Roswell, GA 30076

Return service requested to:

***LLN Newsletter Editor
1625 Sprucewood Court
Decatur GA 30033 USA***

