Lighthouse Lymphedema Network

www.lighthouselymphedema.org

LLN October 2019 Newsletter

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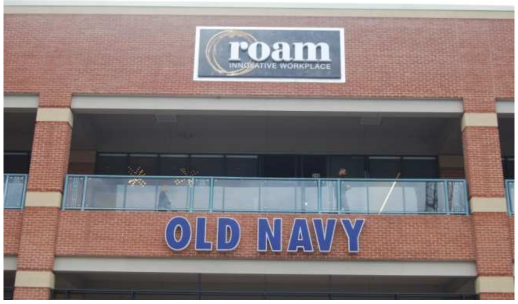
LLN: Serving the lymphedema community for 26 years

SPECIAL 2019 POST-CONFERENCE EDITION!

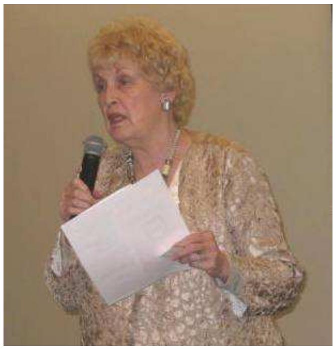
From our all-day LLN-Sponsored Fall Medical Conference
Saturday, October 19th 2019
And our genital lymphedema training session for therapists, Friday, October 18th

Our 2019 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, especially those who could not attend to see what they missed. Our presentation room was full for our Saturday conference, which covered a wide variety of relevant topics for lymphedema patients, their families & caregivers, and medical professionals. Our excellent vendors demonstrated their latest innovative products for lymphedema & lipedema management, and they answered many questions.

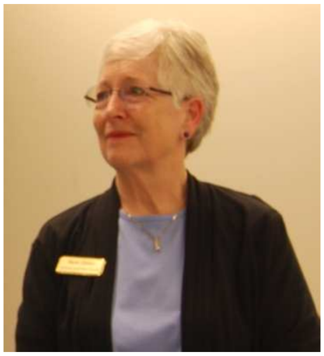
Once again, we offer our sincere thanks to Peyton and Vicky Day for opening the excellent ROAM facility for us to use, and for the incredible support staff. We received many nice accolades; the ROAM seemed so comfortable and the attendees appreciated the program with very positive comments about the speakers and the presentations. *("Excellent presenters! Dynamic speakers! Most interesting! Overall program was awesome, thanks! Conference was exceptional! Really enjoyed the patient stories!")*



The Roam facility



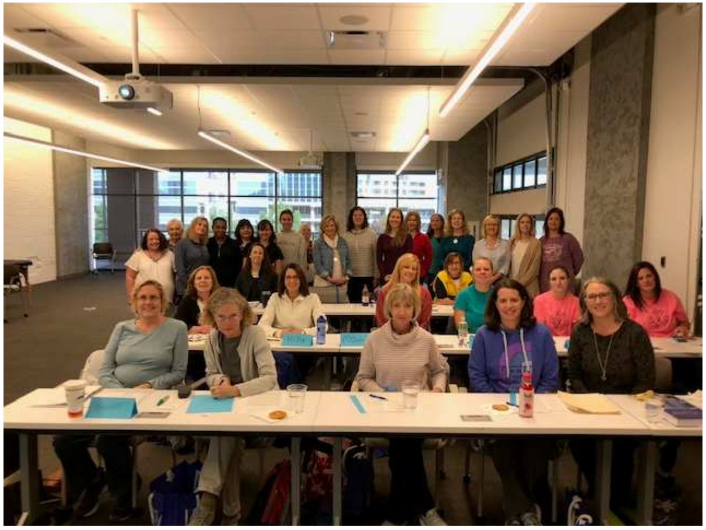
Joan White, LLN Director



Elaine Gunter, moderator

Lymphedema Therapists Genital Lymphedema Treatment Training Course

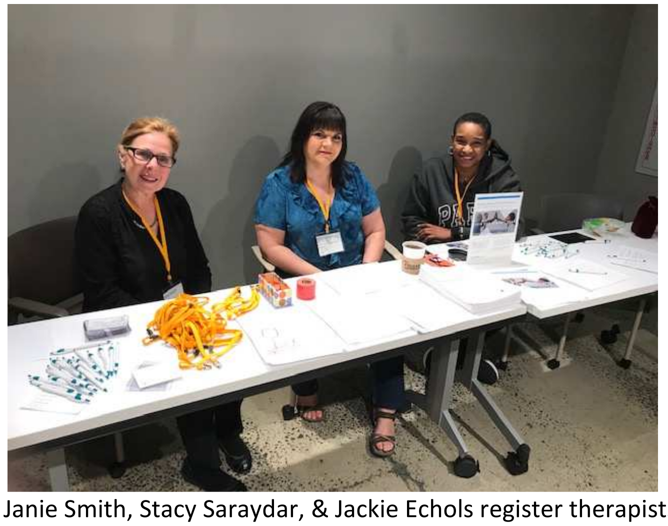
We had 29 therapists for this half-day session by led by Dr. Shelley DiCecco and Rhian Noble-Jones on Friday.



Other Conference Activities and Speakers

LSAP attendees: Blanche Pepitone, Joan White, Christy Smith, Becky Sharp, Pat Egan

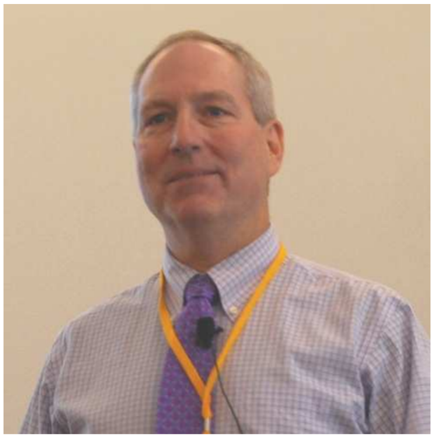
Attendees at our Friday night speakers' dinner



Janie Smith, Stacy Saraydar, & Jackie Echols register therapists for continuing education credits

Doug White & Billie Barron handling registration

Our Speakers

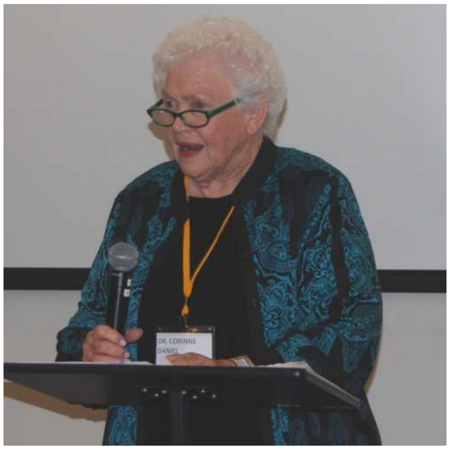


Michael Bernas

Catherine Baty

Judith Nudelman

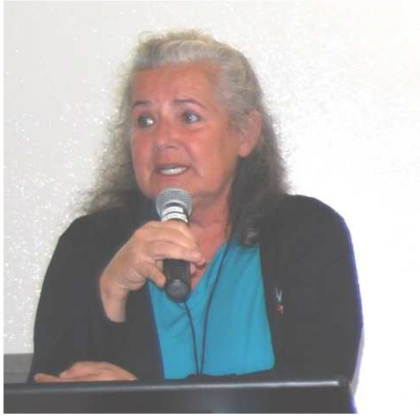
Brandon Dixon



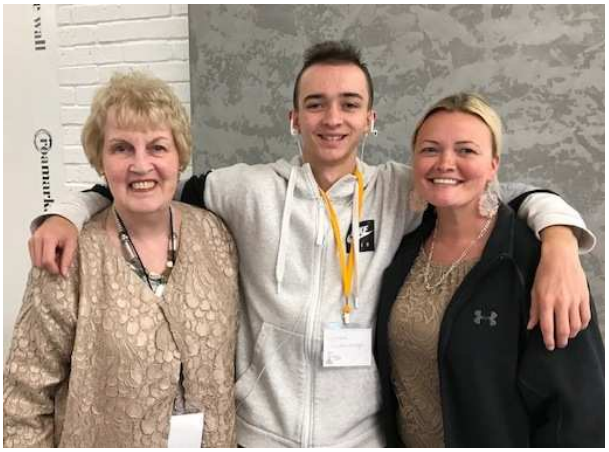
Corinne Daniel

Karen Herbst

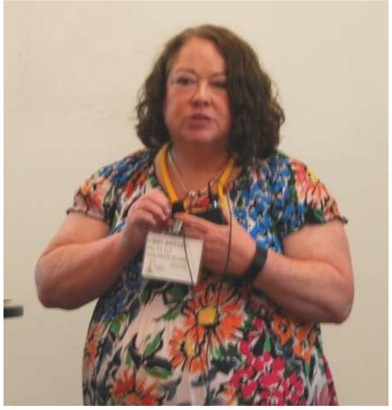
Shelley DiCecco



Kathy Weatherly



Joan White, Carson & Lisa Sollenberger



Libby Barnes

Koda Harris, Libby's patient

PRESENTATION SUMMARIES

PATIENT STORY: Corinne Daniel, PhD: ATTITUDE - My diagnosis of lipedema!

During her late 30's, Dr. Daniel's body began changing in weight and size of her upper arms and legs. She wondered what was happening because a healthy diet and exercise were a part of her life. As a teacher standing and walking are normal. She used over the counter support hose, shoes with good support. Her legs became very painful. While in her 40s, Dr. Daniel completed a master's study at the University of GA and her leg problems worsened, she fell while boarding a bus, rupturing a blood vessel in her right leg. That was a setback, and both legs hurt and continued to swell.

After noticing the continuous swelling, she was referred to a vascular specialist. He requested additional testing and referred her to an OT at University Hospital in Augusta. An isotopic tracer solution was in a vein in her toes and it should travel to her waist in about 30-50 minutes, while she lay in an imaging machine. After 3 hours, the isotopes were finally detected at her waist. Have you ever had to lie on a board with half of your body hanging over the edge? Not comfortable! Outcome: her lymphatic system worked only 30% - and she was ultimately diagnosed with lipedema.

Dr. Daniel's treatment was MLD and compression bandage wrapping from hip to toe for several weeks, and then she wore Reid Sleeve compression garments during sleep and compression hose during the day. She found the Reid Sleeve felt like sleeping in a ski boot, so she alternated legs, wearing only one Reid Sleeve at night.

She had a knee replacement and then gall bladder surgery. Always a health situation! In her 50s she realized that she could not out run her three-year old twin granddaughters. In her 60s she realized that she could not travel extensively, but she could study and learn so she got her doctorate in education.

Her husband assisted her in wrapping her legs. He came in one day with his electric drill with a pencil or dowel inserted where you would normally put a bit and showed Corinne his invention on a speedy way to wind bandages after washing and drying them. A clever & handy idea and a great time-saver!

Dr. Daniel's mother had large legs but small wrists and feet. She had difficulty with her legs being painful, and did not stand for long periods of time, but she lived to be 99 years old.

Her challenges:

- Cost of support and compression garments
- Clothing - She purchases 2 sizes too large and shortens length.
- Fatigue from extra weight. She feels like she is carrying 50 or 100 pounds of dog food. Hard to keep balance and walk without huffing and puffing.
- Deformity of thighs and hips of the weight causing stress on knees and hips
- Pain and tenderness of adipose tissue, bruising easily
- Unable to fly long distances, unable to drive long distances in 1 day without frequent breaks. At distant conferences, she goes a day early if a long flight is needed, or stays over a day if conference was stressful.
- Unable to sit for hours at computer
- Caring for self and family members.

What she does now to maintain herself at 81 years of age:

- Eats healthy use herbs as seasonings. Eats anti-inflammatory foods, Limit salt, carbohydrates, and sweets.
- Keeps all systems of the body working well together, digestive, circulatory, & respiratory, especially, and good skin care, plus she drinks water 1 ½ to 2 quarts a day
- Wears compression garments and stable shoes, and does self MLD
- Does water exercises and deep breathing
- Her therapist does dry brushing
- Stays active with family and friends, plans for joy in her life, worships, meditates and maintain a good attitude

She recommends these two works for inspiration: “Attitude” by Charles Swindoll, and “My Younger Days” by Maya Angelou.

Brandon Dixon, PhD: “Bringing Technology to the Diagnosis, Monitoring &Treatment of Lymphedema”

Dr. Dixon is a Bioengineer and Associate Professor at Georgia Tech; he has given several presentations at LLN conferences. His lab studies the lymphatics by working to understand how the lymphatics function, how they transport fluid, and how disease impacts the lymphatics. Dr. Dixon’s work is with the use of tissue-engineered model systems, and with animal models. The results cannot necessarily be assumed in humans, but their results are promising and are important to understand how the lymphatics work, what causes dysfunction, & how they repair and regrow. In the future, we can begin to surmise how to treat the lymphatic diseases and how to apply this information to humans. His lab has learned the following:

- A lymphatic cell can sense force from its surrounding area. Lymphatic pumping pressure changes along the length of the limb as compared to an artery, the more lymphatic vessels you have (increased lymphangiogenesis) the more likely there is a correlation to lymphedema- the body is making vessels, but they may not be working well.
- Pumping may be enhanced by targeting lymphatic calcium channel agonists with BayK-NPs, which is a current mouse model project.
- Looking at which type of environment will enhance lymphatic collecting vessel sprouting through use of various hydrogels.
- Looking at whether transferred lymphatic vessels actually integrate into the transferred location. Currently being conducted between mice using a GFP positive vessel (lights up under imaging). So far, this transfer is showing to be working.
- More recent work in the lab has been on larger animal models, such as sheep leg vs a rat tail. This research has shown that when a collecting lymphatic vessel is removed in a normal lymphatic system of a sheep leg, it does show regrowth. However, when looking at the pumping pressure of the lymphatic vessel that was not removed, it shows evidence of remodeling in which it is pumping harder but moving less fluid, prior to the removal of the other vessel.

Kathy Weatherly, BA, BS, OT, CLT-LANA: “Why Certified Lymphedema Therapists Should Get Their LANA Certification”

The Lymphology Association of North America (LANA) was founded 20 years ago as a non-profit organization 501 (c) 6. The mission statement: “The objectives and purposes of the organization shall be to promote standards for the certifications of healthcare professionals who help individuals with lymphedema and/or related disorders manage their lymphedema and to promote lymphedema awareness and the science of lymphology.”

LANA is now recognized by the American National Standards Institute (ANSI) which was founded in 1918 to facilitate the development of standards conformity assessment systems in the United States. A LANA designation assures patients that the therapist has at least 135 hours of training through a qualified school that has honed their lymphedema therapy skills. The LANA certified therapist has passed a voluntary North American certification exam that tests the therapist’s knowledge of lymphedema management.

Future of LANA: Lymphedema therapy is a key medical practice area. Therapists in Europe, Asia, Israel, Japan and the Middle East are now requesting that they be allowed to set for the LANA exam. Over 2,500 therapists have now passed the exam.

Kathy, who founded Solaris, says to all patients and medical professionals: If you are currently being treated by a certified lymphedema therapist without his or her LANA certification, you can still be assured this therapist is qualified to treat you. Verify that the therapist has at least 135 hours of education to become certified. The Lighthouse Lymphedema Network has a list of qualified lymphedema therapists on their website, and many do not have LANA certification. LANA gives a therapist the highest designation currently available to all certified lymphedema therapists.

Catherine Baty, DVM - “Lymphatic Function & Dysfunction Seen Through the Eyes of an Imager”

Dr. Baty is a veterinarian and a Research Assistant Professor at the University of Pittsburgh (where Dr. David Finegold researches the genetics of lymphedema) in the Dept. of Cell Biology. Her own research focuses at the microscopic level of cells and tissues.

She took us through the history of the study of lymphatics since the 1600s with the tiny handheld van Leeuwenhoek microscope to today’s advanced imaging technology which provides a much better way to see lymphatic vasculature. The development of the confocal microscope allows live cell imaging for 3-D projection of lymphatic cells. She shared imaging of cellular movement in the lymphatics, comparing normal cell function to impaired cell function with abnormal lymphatics. Fluorescent antibodies specific to lymphatics have provided advanced imaging combined with advances in microscopes.

Dr. Baty agreed that medical students and doctors do not get enough training in the lymphatic system (and improving that training is a high priority for her and Dr. Finegold), and are therefore not trained to look for abnormalities. However, advances in microscopy, cameras, light sources, and antibodies have made it possible to have better images of lymphatic vessels, and their structures & functions. Doctors must become more aware of these advances from recent literature, and learn to look for these answers to improve their diagnoses and treatment of patients with lymphedema!

Michael Bernas, MS – “Diagnostic Options: What Would I Choose?”

Michael Bernas is an Associate Professor of Education & Director of Scholarly Pursuit & Thesis at UNTHSC School of Medicine in Ft. Worth, TX. He has been actively engaged in lymphology research for many years as a member of the International Society for Lymphology Research.

Michael challenged the audience with “What is the definition of lymphedema?” Techniques that have been used to measure the degree of lymphedema present include (1) measuring the fluid content of the interstitium by water displacement (long considered the gold standard and still used in many countries without access to higher technology); (2) using a measuring tape repeatedly over time at the same spots (and by the same person doing the measurements) on a limb, e.g., 4 locations on an arm, and recording this data over time; (3) using a perometer (these work with parallel-acting light “curtains” made of photosensors and LEDs, with which the limb (affected or control) is scanned. The limb is inserted inside the open frame, which is then pushed over the limb, and the collected dataset is independent of the limb position. Protein content in the interstitial fluid can also be measured to help confirm the diagnosis of lymphedema (by using a refractometer).

Symptom assessments are also relevant: swelling, tightness, heaviness, and skin changes. Imaging techniques such as MRI, lymphoscintigraphy, and ultrasound help to rule out other problems. Indocyanine Green (ICG, a dye) imaging is not yet FDA-approved in the US but is widely used elsewhere, and has advantages to diagnosis. Finally, there is always genetic testing, especially if there is a family history. A number of genes (e.g., VEGF3) have now been identified as related to lymphedema. IN Michael’s opinion, the best diagnostic tools today are volume measurement, fluid protein assessment, surveys, and imaging.

PATIENT STORY: Lisa Sollenberger – “My Son Carson’s Story of Living with Lymphedema”

Lisa Sollenberger is a teacher at Cherokee Academy in Canton, GA, and her son Carson (now 16) has primary lymphedema. She presented a video about Carson, and her family’s struggle to get a proper diagnosis for him, when it was apparent several months after birth that he had swelling issues. Lisa and her mother, Debbie Labarthe (a member of the LLN Board) researched on the Internet and sought medical opinions literally from coast to coast in the US before ultimately getting a correct diagnosis.

Lymphedema has not kept Carson from flourishing – he is an active teenager involved in many sports. He is also an advocate for lymphedema education, and with his family, he has met with Georgia’s U.S. Senators and Representatives to urge passage of the National Lymphedema Treatment Act, to make coverage of diagnosis and long-term treatment mandatory by medical insurance companies. Carson also interacts as a role model for other young people with lymphedema. Lisa thanked his therapist, Dr. Shelley DiCecco, and the Lighthouse Lymphedema Network Board for their support as Carson has grown up.

Karen Herbst, MD – “Lipedema & Other Fat Disorders Update”

Dr. Karen Herbst’s lecture focused on description of adipofascia (literally: fatty connective tissue), adipofascial disorders, and potential treatment. Connective tissue supports, ensheathes, and binds tissues together. The connective tissue is made up of cells, fibers, and ground substance, and can be categorized into loose, dense, and specialized. Loose connective tissues include areolar, adipose, and reticular. An example of dense connective tissue is the tissue located in the lower back and feet. Specialized connective tissue examples include those within the lymphatics and blood.

Researchers do not agree on one comprehensive definition of fascia. It is described as a continuum of connective tissue structure with cellular diversity. Lipedema and lymphedema patients have connective tissue disorders. Specifically, lipedema is a loose connective tissue disorder. Subcutaneous adipofascia comprises 80% of total body fat. Hormones may become affected negatively if there is a problem within the adipofascia. Adipofascial disorders include lipedema, lymphedema, Dercum’s disease, familial multiple lipomatosis (FML) or angiolipomatosis, and multiple symmetric lipomatosis. Dercum’s Disease is now described by types and history instead of by size and location. The healing disorder type of Dercum’s Disease was outlined and lipedema types I-V were described. The pathophysiology of lipedema was outlined including the vascular component. Ehler’s Danlos disease was also discussed (13 types). Microangiopathy (small vessel disease) is a potential cause for adipofascial disease.

Higher body fat increases the risk for chronic venous disease. Chronic venous insufficiency and obesity are the leading causes for secondary lymphedema. Lipedema fat is unhealthy fat. Fibrosis develops not only in the adipose tissues, but also the larger vessels which may place those suffering with lipedema at higher risk of cardiovascular disease. Fibrosis worsens with time. An individual with lipedema can develop lymphedema.

Treatment should include manual therapy which breaks down the abnormal adipofascial structure to improve lymph flow through the tissues. Food plans should focus on whole (not processed) foods & low carbohydrates. Diet does not affect fibrotic fat, but is critical to reduce obesity. Intermittent fasting may be helpful. Compounds such as diosmin, pycnogenol, quercetin, and L-arginine may be helpful. Selenium (found in Brazil nuts, 3 per day) has been proven to decrease edema.

Conclusions include the following: a) loose connective tissue and adipofascia are additional terms for “fat”, b) those with lymphedema are at risk for developing an adipofascial disorder, c) new types of Dercum’s may aid in understanding this disease and its risk for lymphedema, d) fibrosis may be the main reason adipofascia is resistant to loss by diet, exercise, and bariatric surgery.

Shelley Smith, PT, PhD, CLT-LANA, CICS – “Lymphedema Down Under”

Genital lymphedema can involve a portion or the entire genitals, and can have internal involvement in females. A person may develop genital lymphedema from primary (one is born with a lymphatic dysfunction) or secondary (damage occurred post birth- most common in the US is cancer) causes. There are over 46 muscles attached to the bones of the pelvis, including the pelvic floor muscles, and these muscles need to be involved with treatment to assist with the muscle pumping to remove the lymphatic fluid from the genitals, trunk, and/or lower extremities. A person with genital lymphedema may experience some type of pain or pressure sensations, bowel and/or bladder dysfunctions, sexual dysfunctions, and/or infections in the genital region (urinary, vaginal, or prostate). In order to fully evaluate and provide appropriate treatment, the medical professionals do need to assess the appearance of the area, palpate for pitting and/or fibrosis, test skin mobility, and may need to document with photos (especially for insurances).

Treatment for genital lymphedema includes compression 23 hours a day, manual lymphatic drainage, exercises, and skin care in both the treatment and home program phases. The compression must support and compress the area and often a person will need multiple different types of garments during the day/night. The compression also must cover all involved areas, including the trunk. Manual lymphatic drainage, skin care, and exercises also need to be done daily to assist with movement of the fluid, improve one's ability to fully participate in activities of daily living, health of the tissue/skin, and to reduce risk of infections. Incontinence, or the leakage of bowel and/or urine, is not normal and should be addressed by the medical team with the patient. If left untreated, it can lead to skin breakdown, infection risks, and is a fall hazard. Sexuality with genital lymphedema is also an area that needs to be discussed and addressed with the medical team. Genitals with lymphedema are just like any other area with lymphedema involvement and need to be fully assessed and addressed. Do not let fear or embarrassment prevent you from receiving or providing the necessary treatment!

Judith Nudelman, MD – “In Support of Lymphedema Risk Reduction Behaviors”

Dr. Nudelman’s presentation focused on:

(1) a review of the lymphedema risk reduction behaviors such as medical interventions and patient behaviors;
(2) the relevance of evidence, history, and clinical experience;
(3) the essential factors when diagnosing early breast cancer-related lymphedema (BCRL) or expanding beyond BCRL;
(4) debunking myths in order to propose better decision making;
(5) risks associated with certain treatments and procedures, such as neoadjuvant chemotherapy and lymphadenectomy;
(6) why lymphedema is under-recognized and under-treated

Explaining that lymphedema is a clinical diagnosis, she clarified that any definition based on measurement of volume/swelling alone is inherently arbitrary. Risk factors for BCRL can be host-related or therapy-related.

The specific lymphedema risk factors discussed were: obesity (which can raise the risk factor by 30%), infection/cellulitis, surgery or other trauma, radiation, chemotherapy, vigor of lymphatic system, genetic predisposition, seroma, and metastasis in lymph nodes.

Reference was made to specific studies, which produced the following findings:

1. Arm volume is of little value in early BCRL; clinical exam and history are essential.
2. In March 2016, a study published in the *Journal of Clinical Oncology* suggested that although cellulitis increases the risk of lymphedema, blood draws/injections/blood pressure readings on the same side of the body as the affected arm and air travel may not be associated with arm volume increases. These results may help to educate clinicians and patients on post-treatment risk, prevention, and management of lymphedema.

Patient Story by Libby Barnes, BS, OT, CLT-LANA – “My patient, Koda Harris”

Koda was born in 2005. He was premature with puffy eyes, swelling on the dorsum of his feet, and a larger than normal scrotum. His family consulted doctors from where they lived in Alabama to California to get a medical diagnosis. When he was 3, primary lymphedema was finally diagnosed. In 2018, his family met Libby Barnes, a certified lymphedema therapist with the University of Alabama Spain Rehab center, and Koda’s journey of healing began right in his own home state.

By using MLD and constantly modifying and adapting compression garments, Libby was successful in reducing Koda’s scrotum from basketball size to baseball size. She used a MEDI reduction kit for knees for the scrotum. His grandmother made clothes that would fit his changing body.

Koda loves to play sports particularly baseball and basketball. After the successful therapy, he is now back to playing his beloved sports thanks to his therapist who became creative for his treatment.

Our sincere thanks to the following businesses for their financial support of this conference:

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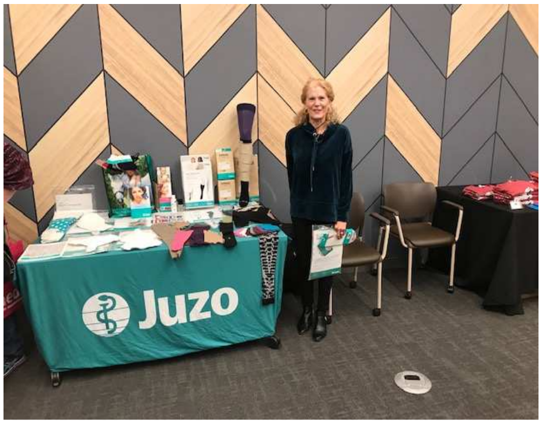
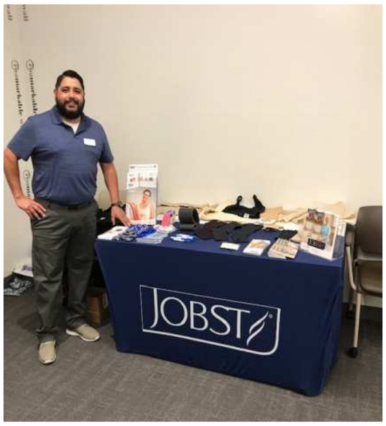
Thanks for these donations:

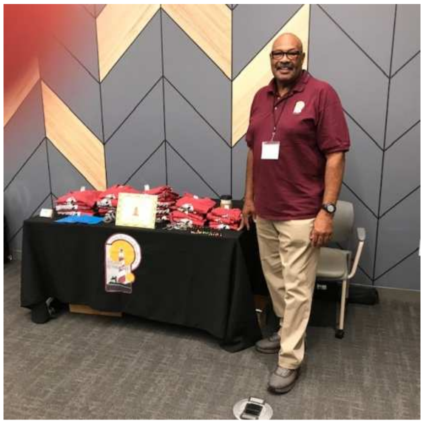
Essity, formerly BSNmedical, donated the blue JOBST bags for each of our attendees.
Gloria Watts-Cox Foundation gave us $500 for our Bandages and Garment Fund.
JUZO USA donated compression socks and laundry bags.
LANA donated a gift basket.
Sallie B's Skin Yummies donated a gift bag of skin care products.
L&R USA sponsored the cocktail hour prior to our dinner on Friday night for speakers and guests.
Vicky and Peyton Day very generously opened up the ROAM for us to host our 21st annual all day medical conference.
Billie Barron donated two baskets filled with Tupperware products.



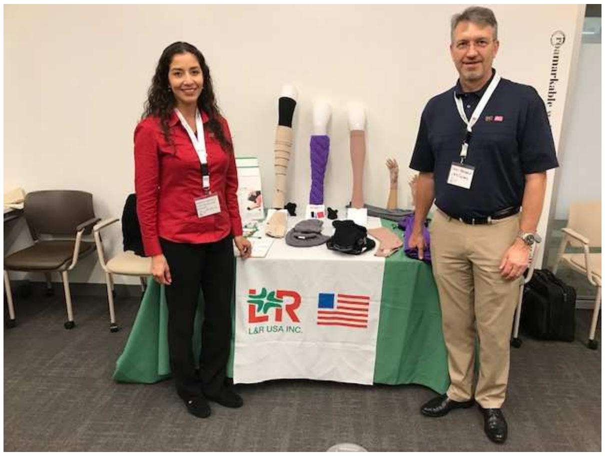
Eve Panek for Juzo



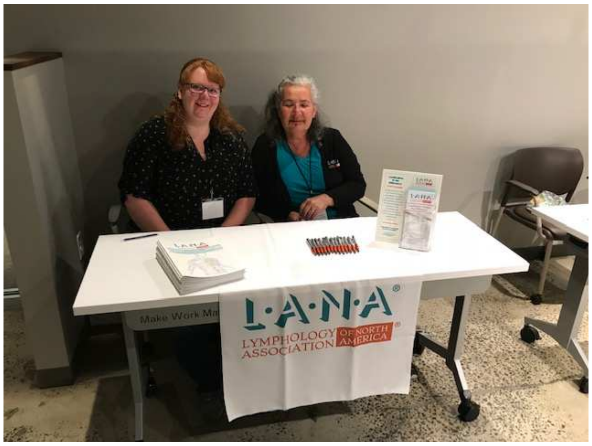
Victor Luciano for Essity



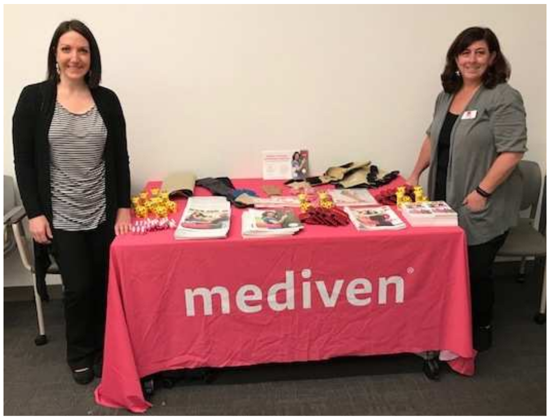
Lee Cox for Gloria Watts-Cox Foundation



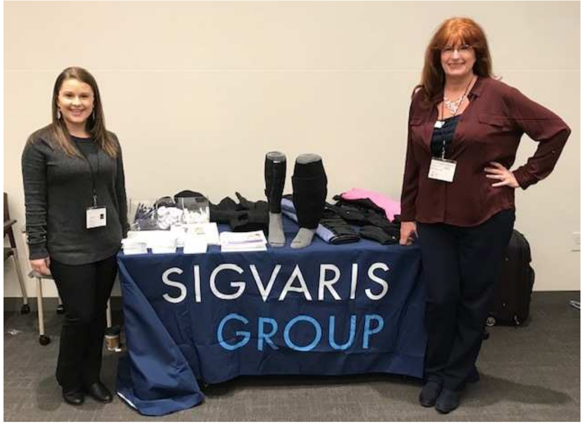
Araceli Badillo & Tony Briddle for L&R USA



Kathy Weatherly (R) & her daughter-in-law for LANA



Mical Frazier & Erin Sokalsky for MEDI USA/MEDIVEN



Lindsay Morris & Jill Ponder-Hobson for Sigvaris

Tammy Caraway for Lipedema Products

Thank you, Lighthouse Lymphedema Network:

Support LLN on Georgia Gives Day, Tuesday December 3rd!

Every day, the Lighthouse Lymphedema Network works to educate and create awareness about lymphedema and related disorders. Please support the LLN for GAgives on #GivingTuesday on Dec. 3. By giving any amount, even $5 or $10, you can be part of our mission. While the official date of Georgia Gives Day is December, 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 through efforts such as our annual conference & newsletters!

**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.

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