



## LLN September 2019 Newsletter

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LLN: Serving the lymphedema community for 26 years

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[www.lighthouselymphedema.org](http://www.lighthouselymphedema.org)

### **Register NOW for the LLN-Sponsored Fall Medical Conference Saturday, October 19<sup>th</sup> 2019, 8:15 AM – 4 PM**

**Location:** as in 2018, the all-day conference will be held at the **ROAM Perimeter Center, 1151 Hammond Drive, NE, Suite 240, Atlanta, GA 30346**, located less than one-tenth of a mile off I-285 at the Ashford-Dunwoody Rd exit and within 100 yards of the Dunwoody MARTA station, ROAM Perimeter Center is easily accessible for Metro Atlanta commuters. (This ROAM facility is located on the upper level of the strip mall area on Hammond Drive *across from Perimeter Mall and close to I-285.*) A Continental breakfast and lunch will be provided at the Saturday program. On-site registration starts at 7:30 AM.

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#### **Presentation Topics:**

1. Judy Nudelman, MD - Do no harm: Lymphedema risk reduction behaviors
2. Katherine Herbst, MD - Lipdema & other fat disorders updates
3. Catherine Baty, MD - Lymphatic function and dysfunction seen through the eyes of an imager
4. Michael Bernas, MS - Diagnostic options- what would I choose?
5. Brandon Dixon, PhD - Bringing technology to the diagnosis, monitoring & treatment of lymphedema
6. Shelley Smith DiCecco, PT, PhD, CLT-LANA, CI-CS – Genital lymphedema
7. Kathy Weatherly, BS, OT, CLT - Historical & future role of the Lymphology Association of North America (LANA)
8. And two patient stories

**Registration:** Patients, family members and caregivers may register on-line securely using the LLN website: [www.lighthouselymphedema.org](http://www.lighthouselymphedema.org). The conference fee is **\$50**.

Our hotel of choice will be the **Crown Plaza Atlanta Perimeter at Ravinia, 4355 Ashford Dunwoody Rd, Atlanta GA 30346, Dunwoody, GA 30346**. (Toll-free reservation center: 1-800-554-0055, or go to the Ravinia website: [www.cpravinia.com](http://www.cpravinia.com) ) Enter the code **LLN2019** to receive our conference rate of \$119 for a king/single room or \$149 for a double room with 2 queen beds. A shuttle will be provided from the hotel to the Roam facility Saturday morning.

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## FOR LYMPHEDEMA THERAPISTS:

### 21<sup>st</sup> State of Georgia Lymphedema Education and Awareness Program



Pre-Conference Mini Course on

#### ***Treatment of Genital Lymphedema***

Sponsored by the Lighthouse Lymphedema Network and LymphEd, LLC

This 6 hour course will be presented by:

***Shelley Smith DiCecco, PT, PhD, CLT-LANA, CI-CS with LymphEd, LLC &  
Rhian Noble-Jones, PhD, PgD (PT) with University of Glasgow in Scotland***

The course is open to all lymphedema certified medical professionals. CEUs will be provided.  
**The course will cover treatment topics for males and females with genital lymphedema, including evaluation and compression options.**

As part of the mini course, there will also be a round table discussion on the quality of life outcome tool, The Lower Limb and Genital Lymphedema Questionnaire for Men (LLGLQ).

\*\*All attendees are **required** to download The Lower Limb and Genital Lymphedema Questionnaire for Men (LLGLQ) from the following website [www.lymphed.com/maleedematool](http://www.lymphed.com/maleedematool) at least 4 weeks prior to the conference.

Only light refreshments will be provided.

***Date: Friday, October 18, 2019***

***Time: 12:00pm until 6:00pm***

***Location: Roam Perimeter***

***1151 Hammond Drive, NE Suite 240***

***Atlanta, GA 30345***

***Note: The registration fee for the course also includes the 21<sup>st</sup> State of Georgia Lymphedema Education and Awareness Program full day conference on Saturday, October 19, 2019***

**Class size is limited to 24 therapists, so do not miss your chance to attend this mini course!**

To register, please visit the Lighthouse Lymphedema Network [www.LighthouseLymphedema.org](http://www.LighthouseLymphedema.org)

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## 2019 Lighthouse Lymphedema Network Calendar Dates to Remember:

September 28, 2019 – LLN Board meeting at Roswell Country Club

October 5-6, 2019 - Georgia 2-Day Walk for Breast Cancer

October 18, 2019 - LLN and LymphED will co-sponsor a mini-course on genital lymphedema

October 19, 2019 - State of Georgia Lymphedema Education & Awareness Conference, ROAM Perimeter, 1151 Hammond Drive, NE, Atlanta, GA



## LLN BANDAGES & GARMENTS FUND 2019 UPDATE

Here at the LLN, we are looking forward to autumn as many of you may be. Cooler weather, football, and for the LLN, a six-month report for our grant from It's The Journey. We appreciate all the applications from the therapists that allows us to be a part of their patients' care. Keep those applications coming and the DME's for the chance to work with all of you. And as always, the compression garment companies. We have increased our base of distribution adding new DME businesses and counties as we grow throughout Georgia. We hope to continue expanding and reaching more areas as the need for compression garments is so important to the patients who have lymphedema. We have served 17 patients as of March 2019 with a total of \$9,000 distributed.

On May 21, 2019, Deb Cozzone and I attended ITJ the Lunch and Learn program. The presentations were informative and the speakers helped us to feel empowered to speak on breast cancer while engaging and educating patients. Please feel free to go on the Georgia 2-Day Walk for Breast Cancer web site and help this organization in any way possible to pay it forward and help all the future patients in need of services that ITJ provides with their grants: [www.2daywalk.org](http://www.2daywalk.org). (Or participate in the 2-Day Walk, see next article!)

Please contact me at [darnofell@aol.com](mailto:darnofell@aol.com) with any questions or concerns you may have about the BAG FUND assisting with compression garments.

Janie Smith, PT, CLT, BAG Fund Coordinator



The **Georgia 2-Day Walk for Breast Cancer**, sponsored by It's the Journey, is an annual fundraising endurance **walk** that takes place on **October 5-6, 2019**, and takes participants through 30 miles of Atlanta over the course of **2** days. Last year, nearly 1,000 walkers committed to fundraising and training for this event. Register at

<https://itsthejourney.org/event/2019-georgia-2-day-walk-for-breast-cancer/>

**LLN will have a cheering station on the 29th – stay tuned for its location!**



Lymphatic Education  
& Research Network

Held in 5 cities in the US; find information & register at <https://lymphaticnetwork.org/lymph-walk>. Thank you for supporting lymphedema and lymphatic disease education, research and advocacy!

## **Review of the International Lymphedema Framework Conference**

Co-hosted by the American Lymphedema Framework Project

June 13-15, 2019, Hyatt Regency Hotel, Chicago, IL, USA

**(The 2020 International Conference will be held in Copenhagen, Denmark.)**

The 9<sup>th</sup> International Lymphedema Framework Conference was the first to be held in the USA. What a perfect setting on Lake Michigan and the Chicago River that meanders through downtown Chicago! 406 participants from 28 countries within North America, Asia, Africa and Europe met at the Hyatt Regency Hotel in downtown Chicago to gain and share new perspectives with clinicians, researchers, industry/healthcare providers, advocacy groups and patients in attendance.

Describing the conference in one sentence is difficult. It was stimulating, motivating, and simply an honor to be in the presence of so many dedicated physicians and other medical professionals. My appreciation for these individuals is beyond description. How do you say thank you as a patient to these professionals who devote their time and talent to research, treatment standards and to all the vendors who continue to improve products necessary for a better quality of life for us patients. Special thanks to the CAP Partner, Louise Maagaard and Mille Skovbjerg Denmark, Anna Kennedy Canada, Professor Neil Pillar Australia, Professor Christine Moffatt, UK, and to the other coordinators of the conference.

The **Lymphoedema Impact and Prevalence INTernational Lymphedema Framework (LIMPRINT)** is an international study aimed at capturing the size and impact of chronic edema in different countries and health services across the world. Focus is to provide evidence to support the development and reimbursement of lymphedema services. The project is coordinated by the International Lymphoedema Framework (ILF) through its participating national frameworks. This challenging project has demonstrated the possibility of global research within a charitable framework and the power of strong academic partnerships to ensure delivery of robust evidence from each country. From 2014 to 2017, 9 countries with 40 sites have contributed to an international data set of over 13,000 patients. The preliminary analysis has begun to illuminate the burden on acute and community health services across the world and to identify the patient populations most at risk. Jane Armer, RN, PhD, FAAN, showcased the American Lymphedema Framework Project (ALFP) projects.

Professor Christine Moffatt with the ILF of the United Kingdom, Dr. Joseph Feldman and Jane Armer, RN, PhD, ALFP, USA welcomed the delegates to the congress and presented various awards and honored several attendees. Sophia Hanson, patient, Lymph Science Advocacy Program (LSAP) member, and keynote speaker discussed how she has “Thrived with her Lymphedema”. Dr. Stanley Rockson then presented on “The Changing Field of Lymphatics”. Dr. Feldman was honored for his professionalism and his caring heart for his patients. Dr. Feldman has guided LANA with an ever-steady hand from its inception to its current status. He is co-director of the ALFP, served at the NLN medical advisory board and countless other organizations.

Various topics that were discussed included “Support of Lymphedema Risk-reduction Behaviors; Precautionary measures: the need for evidence-based guidelines; Lymphatic in Health and Disease; Advances in Diagnostics; Chronic Wounds and Lymphedema, Compression Challenges; Obesity and Its Impact; Lymphedema: Newer Treatment Options Through Research; Standard of Care; Lower Limb Assessment; Lymphedema and Infection; Lymphedema Surgery: What Works and What Doesn’t; Managing Lipedema & Nighttime Compression. There was a Pediatric workshop where Dr. Julie Hanson, mother of Sophia Hanson spoke.

The Patient Summit was held Friday afternoon and all-day Saturday. Professor Neil Piller opened the program “Lymphedema 101; Dr. Kathleen Francis discussed Treatment Protocol; Bonnie Lasinski, PT, CLT-LANA, CI-CS, Compression 101 and Maureen McBeth, MPT, CLT-LANA discussed Exercise. Saturday, Self-Management & Risk Reduction Tips were discussed by Julia Rodrick, OTR/L, CLT-LANA; Stephanie Ross, DPT discussed Psychosocial Aspect; Dr. Jay Granzow spoke on Surgical Interventions; and Melanie Thormos, MSN, APPN, FNP-C, spoke on Technology and Lymphedema; Obesity and Lymphedema was discussed by Dr. Tobias Bertsch, PhD.

## 9<sup>th</sup> International Lymphoedema Framework Conference, Chicago, June 13-15



Professor Christine Moffatt, Dr. Paula Stewart, Kathryn Thrift, B.S., CLT-LANA, Jane Armer, RN, PhD, Marcia Beck, ACNS-BC, CLT-LANA, Bonnie Lasinski, PT, CLT-LANA, CI-CS, Dr. Kathleen Francis, Electra Paskett, PhD, Julia Rodrick, OTR/L, CLT-LANA, LLN Director Joan White



Shelley DiCecco, PT, PhD, CLT-LANA, Gwen Forbes-Kirby, PT, CLT-LANA, Joan White, Becky Sharp, Dr. Judith Nudelman – all enjoyed the Friday night cruise on Lake Michigan.



**Attendees of the 2019 Lymphedema Lobby Days in Washington, DC**

The Lymphedema Advocacy Group held its annual Lymphedema Lobby Days in Washington DC May 5-7, 2019. LLN Board Member Debbie Labarthe and her husband Clint attended and represented Georgia. They joined 40 other advocates from across the country, representing 46 states. The group held meetings with 226 Congressional offices to encourage support for bill HR.1948/S.518, the Lymphedema Treatment Act (LTA). The objective of the LTA is to amend the current Medicare law by adding the Allowable Benefit Code to ensure coverage for doctor-prescribed compression supplies for lymphedema patients. As of August 1, the LTA has 363 cosponsors (311 House; 62 Senate), and the numbers are climbing steadily.

This Congress, the House adopted many new rules, one of which is the '290 Rule' which is designed to expedite House bills with broad, bipartisan support by guaranteeing a floor vote once they have reached 290 or more cosponsors. The LTA has now met these criteria and will hopefully be presented to the House floor soon for debate and voting! After the LTA is passed in the House, it will move to the Senate for consideration. When passed by both House and Senate, and signed by the President, the LTA will finally close the coverage gap on doctor-prescribed compression supplies for the millions of lymphedema patients currently on Medicare across the U.S.

For more information, go to [www.lymphedematreatmentact.org](http://www.lymphedematreatmentact.org) where you can view the Cosponsors List for both the House Bill and Senate Bill. If your Representative or Senator is not on the Cosponsors List, please take a few moments to call his/her office, using the phone number and script provided. You will also see the name of one or more staff members to ask for. Calling is the most effective approach, or you can send an email as well. Just follow the link to the email template provided, and add your personal comments where indicated. Every phone call and email makes a difference! Thank you for your support on this important legislation!



**LLN Members Clint & Debbie Labarthe at the Capitol**

## Question from a patient for our therapists to answer:

**Patient:** *I recently had to have a colonoscopy. To help prepare for the procedure on the day prior to the procedure, I drank the required bowel-cleaning liquid. The next morning, when I woke up, I noticed that my lymphedema arm was a lot more swollen. I assume that the increased swelling must have been triggered by the contents in the bowel-cleaning liquid. Is this likely? Have you had any other patients report this same experience? From K.H., Jasper, GA.*

**Response from therapist Shelley Smith DiCecco, PhD, PT, CLT-LANA, CI-CS:** The bowel prep for a colonoscopy requires you to completely flush your gastrointestinal system. This allows the MD to see the lining of your GI system more clearly so s/he can see tissue changes and/or polyps. Unfortunately, the flushing process also dehydrates the patient. Whenever anyone becomes dehydrated, your body responds by pushing fluid from your vessels to the tissues for safe storage. You may notice this after a long day at the beach or after doing hours of yard work- your rings are tight on your fingers. With a normal functioning lymphatic system, your body will be able to reclaim the fluid from the tissues once your hydration levels have improved. With an altered or damaged lymphatic system your body is not able to reclaim this fluid from the involved areas, like your arm or leg. So, this is why it is so important for anyone with a compromised lymphatic system, like with lymphedema, to drink plenty of water and stay hydrated. So, the next time you have to perform a bowel prep, make sure you are drinking plenty of water to prevent the increase in edema in your arm.

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Donate now to support the Lighthouse Lymphedema Network on (or before!) through the Georgia Gives Day

December 3, 2019

[www.gagivesday.org](http://www.gagivesday.org)

The Lighthouse Lymphedema Network (LLN) was founded in 1993 with the mission to increase awareness and general knowledge of the condition known as lymphedema and to ...

LLN secure direct donation link:

<https://www.gagivesday.org/c/GGD/a/lighthouselymphedema/>

Help us help others by donating to support LLN's mission to educate lymphedema patients, their families, caregivers, and therapists! LLN's mission is unique in this role.

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***Thank you, Lighthouse Lymphedema Network:***

Please accept my gift/donation in appreciation for your efforts to support, educate, and create awareness about a serious medical condition called lymphedema.

Donor's Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: (Home) \_\_\_\_\_ (Work) \_\_\_\_\_ (Cell) \_\_\_\_\_

E-mail: \_\_\_\_\_

Enclosed is my tax deductible donation of \$ \_\_\_\_\_, to be used for the General Fund \_\_\_\_\_, or the B.A.G. Fund \_\_\_\_\_

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. Call 770-442-1317 for information. You can also make a donation on-line by credit card: The donation page is: <http://lighthouselymphedema.org/get-involved/donate.htm>.

**Change of Address Request:** We try to keep our mailing list updated constantly; if you have any changes that should be made to your mailing or e-mail addresses, please send this information to the LLN address above, or by e-mail to [elaine.gunter@comcast.net](mailto:elaine.gunter@comcast.net).

**Remember: Don't forget to give us your e-mail address if you want to be reminded about meetings, to receive the LLN newsletter as a PDF file (in color!), and to help us save mailing costs! [elaine.gunter@comcast.net](mailto:elaine.gunter@comcast.net)**

**LLN's website is <http://www.lighthouselymphedema.org>**

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