



LLN September 2017 Newsletter

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LLN: 23 years of serving the lymphedema community

www.lighthouselymphedema.org

Plan to attend our 2017 joint conference with the National Lymphedema Network in October!



The National Lymphedema Network (NLN) Board of Directors and Scientific Conference Committee invite you to attend our 2017 International Conference, The Future of Lymphedema Care: Patient Engagement & Clinical Collaboration. **The Conference will be held Wednesday, October 11 through Saturday, October 14 at Disney's Coronado Springs Resort at Walt Disney World ® Lake Buena Vista, Florida.**

This year's NLN conference will be held in tandem with a very special Patient Summit, which has been organized in partnership with the Lighthouse Lymphedema Network and will be held October 11-12, 2017. This collaboration offers an opportunity to connect with both colleagues and patients while learning the latest research and therapeutic approaches to lymphedema and lymphatic diseases. **[See next page for Patient Summit Agenda!]**

Thursday will bring together patients, therapists, clinicians, and exhibitors for the commencement of the Medical Provider Conference. We welcome Dr. Stanley G. Rockson as the conference Keynote Speaker who will elaborate on Research Breakthroughs in Lymphology. Dr. Rockson is an Allan and Tina Neill Professor of Lymphatic Research and Medicine, Professor of Medicine, and Director at Center for Lymphatic and Venous Disorders, Stanford University School of Medicine, and Falk Cardiovascular Research Center, and we are honored to have him. A redesigned exhibit hall will offer attendees an enhanced experience in learning about the designs, tools, and technology. Particular exhibitors will offer focused workshops to provide an in-depth exploration and discussion of their products. Also on Thursday, the Exhibit Hall opening will be followed by the Marilyn Westbrook Garment Fund fashion show, an event that will honor all the vendors that have generously contributed to the fund over the years. This runway event is for all patients, medical providers, researchers, and exhibitors to enjoy together.

Register today at www.lymphnet.org!

2017 PATIENT SUMMIT AGENDA

Wednesday, October 11

- 7:00 AM Breakfast
- 8:30 AM Welcome
Joan White, LSAP
- 8:35 AM **Patient Story**
Melissa Driggers, BBA, LSAP
- Moderator: *Rebecca Hammad, MHS, OTR/L, CLT*
- 9:00 AM **“Anatomy and Physiology of the Lymphatic System”**
Wade Farrow, BS, M.D., CWSP, FACCWS
- 9:30 AM **“The Importance of Eating Healthy”**
Julie Mills-Watson, LMT, LLCC
- 10:00 AM **“Six Savvy Skin Secrets”**
Robyn Bjork, PT, CWS, WC, CLT-LANA
- 10:30 AM Short Break
- 10:50 AM **“Building and Leading Your Healthy Support Network”**
Sarah Bramblette, MSHL, LSAP
- 11:20 AM **Pediatric**
Joseph Feldman, M.D., CLT-LANA
- 12:00 PM **“Heads Up: Head and Neck Lymphedema”**
Molly Nettles, OTR/L, CLT-LANA, STAR/C
- 12:30 PM Lunch
- 1:30 PM **“Patient Care from Professional Perspective”**
Catherine Holley, RN
- 2:00 PM **“How Yoga Heals”**
Hope Knosher, C-IAYT, E-RYT500
- 2:30 PM **“Sexuality and Lymphedema/Pelvic Floor Health and Lymphedema”**
Shelley Smith DiCecco, PhD, PT, CLT-LANA, CI-CS
- 3:00 PM **“Treatment of Lymphedema”**
Guenter Klose, MLD/CLT, CLT-LANA, CI
- 3:45 PM Closing Remarks
Joan White, LSAP
- 4:30 PM Stomp for Lymphedema (Separate Registration – All Welcome)**
Elizabeth Blissett, LSAP
- 5:00 PM Exhibit Hall Opening Reception**
Exhibit Hall Hours: 5-7pm

Thursday, October 12

(General Assembly – Combined Patient Summit & Medical Professional Sessions)

- 7:00 AM Breakfast in Exhibit Hall
Parent to Parent Networking in Exhibit Hall
- 8:00 AM Welcome
Jeannette Zucker, PT, DPT, CLT-LANA
- 9:00 AM **Keynote Speech – “Research Breakthroughs in Lymphology”**
Stanley Rockson, MD
- 9:45 AM Break

- 10:00 AM **“Lipedema – A Fatty Deposition Syndrome”**
Margarita Correa, M.D., CLT
- 10:45 AM **“Research at Georgia Tech/Lymph Tech”**
Mike Weiler, PhD
- 11:15 AM **“Managing Edema Post-Neurological Injury with Lymphedema Therapy Techniques”**
Rebecca Hammad, MHS, OTR/L, CLT
- 11:45 AM Special Guest Appearance
- 12:15 PM Exhibit Hall Kickoff
 Lunch in the Exhibit Hall
- 1:45 PM **“Pushing the Limits: A Novel Approach to Balance and Lymphedema”**
Erica Demarch, PT
Tiffany Kendig, PT
- 2:45 PM **“Update on New Surgeries”**
Jay Granzow, MD, MPH, FACS
Sarah McLaughlin, M.D.,
- 3:45 PM Closing Remarks
- 4:30 PM Welcome Reception by Tactile Medical & Juzo**
- 6:00 PM Marilyn Westbrook Garment Fund Fashion Show**

Exhibit Hall Hours – 7:00 AM – 6:00 PM

**Be sure and register now for these excellent educational events
 at Sigvaris in the Atlanta area!**



LLN Event Co-sponsored with Sigvaris – Friday September 29, 2017 at the Sigvaris Manufacturing & Education Center, 1119 Highway 74 South, Peachtree City, GA

This will be a two-part event, so please register appropriately:

- (1) **Part 1, from 8:00 AM – 5:30 PM will be for medical professionals only**, 8.5 accredited CEs for licensed **therapists and fitters**, led by course instructor Robyn Bjork, MPT, CWS, CLT-LANA, CLWT – cost of the course will be \$44.50, a 50% discount if participants register for this course at www.sigvariseducation.com using the code **LLNHALFOFF** by September 1. This course is designed to certify attendees in the selection, measuring, & fitting of appropriate compression therapy for common and complex medical indications. The course will help attendees understand the pathophysiology of edemas of various etiologies, clinically differentiate between them, and make appropriate product recommendations.
 - (2) **Part 2, from 10 AM – 2 PM, a Patient Pampering and Education Session, free to patient participants only**. Register at www.lighthouseymphedema.org. Participants will get a tour of the Sigvaris plant, have lunch, learn tips to keep feeling great, nutrition and simple meal prep ideas, and see fashionable options for patients with lymphedema
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Update on the National Lymphedema Treatment Act for August:



Thank you for helping us reach this milestone of support in the House! Check to see if your Rep is among our 270 House cosponsors and 32 Senate cosponsors. We have reached our goal in the House, but we are only halfway to our Senate goal. There is no "magic" number needed in order to pass the bill, but our goal is to reach a super majority in both the House and Senate. That means 60% or greater of all members in each chamber, now 266 in the House and 60 in the Senate. **Some offices need little more than to be asked. Others need a lot of education and persuasion from their constituents. Every email and phone call makes a difference!**

Many thanks to our new LLN Board member volunteer!!

Welcome new board member **Charlotte Murphy**, who will become our new LLN Treasurer, replacing Larry Ashmore. All of LLN's work responsibilities to serve lymphedema patients are voluntary, so we very much appreciate the outstanding years of past service and willingness to serve in the future from our board members!

LLN Therapists answer a patient's question:

"A patient has just come to therapy for the first time, and she is experiencing terrible itching when wearing the compression bandages on her arm. Even when wearing a stockinette sleeve under the bandages, her skin was still quite itchy". What should she/her therapist do?

Stephanie Kirkpatrick, PT, DPT, CLT of the Emory Clinic Radiation Oncology Department asked: "Is she able to wash her arm after the bandages are removed? Are they applying lotion prior to bandaging?" She noted that she has had patients, especially in the hot summer, have a skin reaction. She has some other lotions and creams she uses to reduce the itching as much as possible.

Samantha Cannon, MSOT/L, CLT of Northside Forsyth Hospital in Cumming adds: "I agree with Stephanie on using different lotions as well. Sometimes, the patients may need to bring a cortisone cream to help with the red itchy areas. I will also suggest them to bring cornstarch or baking soda to use instead of lotions. Therapists can't provide items other than what the hospital provides us to use. Therefore, the patients will have to purchase something to bring with them so we can then use it. The arm has to be washed with a gentle cleanser and the wrong soap may be the issue as well. Patients can bring an unscented soap with them if they are not happy with what the therapist is using. Also, they may be using a scented detergent that can make them itch. Compression bandages and garments have to be washed with unscented detergent such as Tide Free™, All Free™, or others specifically labeled for sensitive skin. Unscented baby detergent is also available but it tends to be more expensive. Don't use any additives like Woolite™ or Downy™ fabric softener. Don't use the dryer preferably, but if you must, use gentle heat and don't use dryer sheets."

2017 Lighthouse Lymphedema Network Calendar Dates to Remember:

- **Saturday, September 23, 9:30 AM - LLN Board of Directors meeting**
 - **Tuesday-Wednesday, October 11-12 - LLN joint conference for patients & caregivers with NLN, Coronado Beach Resort, Disney World, Orlando, FL**
 - **Thursday-Saturday, October 12-14 (NLN Conference for medical professionals is Oct 12-15) same location**
-

LLN benefits again from the Southern Loss Association's annual golf & tennis outing Chateau Elan, April 20, 2017

The Southern Loss Association once again made the LLN a beneficiary of \$4,150 proceeds from the sale of mulligans, the ball toss game, and the generosity of the members at their annual golf & tennis outing. 280 golfers enjoyed a day in the sun. LLN is very grateful for this continued support, and we thank Susan Freeman, and her committee of Jennifer, Christy, Candace, and Crystal for once again pulling off a great event.



Belfor sponsored the mulligan table.



FRSTeam sponsored the Ball Toss game



Peggy Myers, Beverly Thompson, Billie Barron, and Joan White represented the LLN at the dinner where they were presented with the \$4,150 donation from the SLA.



LLN BANDAGES & GARMENTS FUND UPDATE for 2017

The Bandages and Garments Fund has had an exceptionally busy 6 months. So far in 2017, we have helped 54 individuals get the garments they need, an increase in over 20% from 2016. Thanks to grant funding received in March from It's The Journey, we have already served 9 patients who have breast cancer related lymphedema (BRCL). And thanks to the grant funding received from Komen Greater Atlanta in May, we have served an additional 7 BCRL patients. Many thanks to these wonderful organizations who continue to help us meet the needs of the BCRL population.

The high demand for non-BCRL bandages and garments during the first two quarters of 2017 has left the BAG Fund with very little funding. At this time, new applications for non-BCRL are being accepted on a limited basis. We need your donations and your commitment to raising funds for the Bandages and Garments Fund in order to help the large number of patients who continue to apply for assistance. Please consider the LLN as you are making donations to charitable organizations. We have no paid staff and all of us volunteer our time and talents to improve the life of those with lymphedema.

For Therapists: You should have received new, updated application and recommendation forms for your use. They were emailed to CLTs in Georgia on August 10. If you do not have the most recent revision of these documents, please contact Deb Cozzone at debcozzone@hotmail.com to receive your copy.

A Note from Caroline Aquirre, our Lymphedema Therapist in Peru to Whom We Donate Compression Supplies:

Hello Everyone!! I hope all is well for you on your side of the hemisphere. Here we are having a rather mild winter that is not good for crops, but I must confess I find it great because I hate being cold. I have helped a couple of persons with your donations. I did get a small note from Ms. Tuly Durante, a very active 64 year old who works in a customs agency. Her legs are quite big, and none of your compression garments fitted, but I was able to help her with your bandages.

Regarding the garments, I do have some great news: Finally, Medi products are being imported to Peru. This is a great relief to be able to find correct measures even if they do not have all the models. They are organizing a lymphology day (to present their products) on August 24th, I will be there! Lohmann & Rauscher is also now importing some of their compression bandages, mainly for arms, so now it is possible to work better on my patients after years of DIY and improvisation. So things move slowly but they move nonetheless. I send everyone all my best from Lima!!

Saturday, May 13 – Gloria Watts-Cox 15th Annual Walk/Run

In November 2002, Lee Cox of East Point, GA, established the Gloria Watts-Cox Foundation (GWCF) in loving memory of his wife, Gloria, who passed away at age 50 due to complications caused by lymphedema. Since that time, the GWCF has sponsored an Annual 8K Walk/Run to help raise funds and awareness to help support those suffering from lymphedema.

On Saturday, June 3rd, at the 15th Annual 8K Walk/Run, Lee Cox was presented with a Proclamation from the Atlanta City Council, recognizing him for his role as the Founder/Director of the GWCF and his ongoing efforts to raise funds and awareness to help support those suffering from lymphedema. The Atlanta City Council also saluted the GWCF for the light, support, and help that it gives to others in Gloria's memory.

In celebration of this year's 15th Annual Walk, the event also included a Health & Wellness Fair which featured vendors displaying compression wraps, sleeves, and garments for lymphedema patients; a blood mobile bank; booths offering free blood pressure and PSA screenings; as well as a formal program featuring wonderful speakers and presentations. LLN Board Member Stacy Saraydar, a Certified Lymphedema Therapist with Piedmont Hospital in Atlanta, spoke about the various causes of lymphedema, risk factors, and the standard treatment protocol to reduce/maintain swelling. The keynote speaker, Dr. John McKnight, Medical Oncology, Newnan, GA, gave a presentation entitled "The Cancer Journey", which addressed risk factors, and also shared myths and facts about chemo and diet. Other speakers included breast and prostate cancer survivors and individuals sharing heart-healthy and weight-healthy guidelines. To learn more about the Gloria Watts-Cox Foundation, visit their website at <http://www.gwcfoundation.com>

Saturday, May 13 – Gloria Watts-Cox 15th Annual Walk/Run



Row 1: Lee Cox is presented with a Proclamation from the Atlanta City Council, recognizing him for his efforts as the Founder/Director of the GWCF; Emil Hernandez, Carson Sollenberger, and Debbie Labarthe representing *Team Lighthouse Lymphedema*.

Row 2: LLN Board Member Stacy Saraydar facilitates the wheel for attendees to ‘spin and win’ a variety of prizes; Walk/Run attendees beginning the 8K journey; LLN Board Member Natalie McKay, certified fitter at Piedmont Hospital Compression Therapy Rehab Services.

Row 3: Speakers of Health & Wellness Program (left to right): **Dr. Hershel Robinson, Cindy Givens, Dr. Gregory Bolden, Stacy Saraydar, Dr. John McKnight, LaWanda Long, and Renata Demons**; Tammy Malone, compression supplies vendor, accompanied by her children, Ashley and Austin (who completed the Walk/Run in 1st place in Women’s and Men’s Categories, both at 36 minutes.)

Are you interested in attending a course on lymphedema treatment?

Do you think your facility might be interested in hosting a course on the treatment of lymphedema?

Do you like discounts on courses?

LymphEd is a company dedicated to providing education and resources on lymphedema for therapists and the community. **LymphEd** provides four excellent courses for therapists interested in beginning a career in the treatment of lymphedema or for certified therapists desiring advanced knowledge or skills in lymphedema. **LymphEd** offers great benefits for hosting sites, sites sending multiple attendees, and for therapists attending more than one **LymphEd** course.

For more information, please visit the website www.lymphed.com, or contact Shelley Smith DiCecco, PT, PhD, CLT-LANA, CI-CS at shelleydicecco@lymphed.com.

Overview of **LymphEd's** Current Course Offerings:

- **Complex Lymphatic Therapy (CLT) Certification Course-** *(135 hour LANA approved certification course for therapists)*
- **Advanced Concepts in Lymphedema Treatment-** *(20 hour course with focus on upper and lower extremity involvement)*
- **Advanced Treatment of Genital Lymphedema-** *(20 hour course on male and female genital lymphedema)*
- **Advanced Treatment of Head and Neck Lymphedema-** *(20 hour course)*



Congratulations to our outstanding nursing professor colleagues and lymphedema research specialists Drs. Jane Armer and Mei Fu!

(Those of you who attended our 2016 conference will remember these nurse educators and their excellent presentations!)

STTI Announces 2017 Nurse Researcher Hall of Fame Inductees

The Honor Society of Nursing, Sigma Theta Tau International (STTI) inducted 23 nurse researchers into the International Nurse Researcher Hall of Fame at STTI's 28th International Nursing Research Congress in Dublin, Ireland, 27-31 July 2017. On Saturday, 29 July 2017, these 23 individuals — representing Australia, Canada, Finland, Taiwan, the United Kingdom, and the United States — will be presented with the International Nurse Researcher Hall of Fame award and participate in a conversation with STTI President Cathy Catrambone, PhD, RN, FAAN. Created in 2010, the International Nurse Researcher Hall of Fame recognizes nurse researchers who have achieved significant and sustained national or international recognition and whose research has improved the profession and the people it serves. The honorees' research projects will be shared through STTI's [Virginia Henderson Global Nursing e-Repository](#), enabling nurses everywhere to benefit from their discoveries and insights. The award presentation is sponsored by Wiley.

“Congratulations to these 23 individuals for their incredible combined contribution to global health and the future of nursing,” said **STTI President Cathy Catrambone, PhD, RN, FAAN**. “I look forward to learning more about their personal stories and achievements, and to seeing how their work inspires other researchers.”

2017 International Nurse Researcher Hall of Fame Honorees Who Work with LLN:

Jane Armer, PhD, RN, FAAN, Professor, University of Missouri, Sinclair School of Nursing
Mei R. Fu, PhD, RN, FAAN, Tenured Associate Professor, NYU Rory Meyers College of Nursing

Dr. Armer adds: *“Of note, in addition to my induction, 2 colleagues in lymphedema research are being inducted, Dr Mei Fu, NYU professor and BSN, MSN, PHD alumnus of MUSSON, as well as ALFP steering committee member; and Dr Sheila Ridner, Vanderbilt University professor, who conducted pre- and post-doctoral research with our lab at MU SSON/EFCC. All 3 are long-time members of the National Lymphedema Network (NLN) Medical Advisory Board and active members of the Oncology Nursing Society (ONS) Lymphedema Interest Group. In addition, Jane and Mei are members of the Lymphology Association of North American (LANA) board of directors. Sheila is on the board of the Lymphatic Education & Research Network (LE&RN). This 2017 HOF induction is a great recognition of advances in the lymphedema field with significant multidisciplinary partnerships led by nurse researchers.”*

A Lymphedema Support Group Has Been Started in Tallahassee, Florida!

From Carin L. Butler, Social Work Intern at the Neurology Outpatient Rehab Center at Tallahassee Memorial Healthcare:

“We are pleased to announce that Tallahassee Memorial Healthcare Neurological Outpatient Rehabilitation Center has started a Lymphedema Wellness Group. We meet the first Wednesday of each month (2:00-3:00 pm) at 1609 Medical Drive Tallahassee, FL 32308 (2nd Floor Conference Room).

Discussion topics will include: lymphedema education, available treatments, certified lymphedema therapist visits, guest speakers, exercise and massage at home, equipment and compression garment information, healthy living, resilience, and supportive community.

Thank you, Lighthouse Lymphedema Network (a totally volunteer organization):

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.

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

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

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