



LLN January 2018 Newsletter

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LLN: 24 years of serving the lymphedema community

www.lighthouselymphedema.org

Mark Your Calendar for the Next LLN-sponsored Educational Event:

LLN Patient Open Forum at Piedmont Henry Hospital **Date: February 15, 2018 Time: 6:00-8:00 PM**

Location: Piedmont Henry Hospital
Foundation Education Center (Meeting held in the Foundation Board Room)
1133 Eagles Landing Parkway
Stockbridge, GA 30281

Program: Therapist Shavonna Warthen, MA, OTR/L, CLT, will present “**The Challenges of Successful Management of Lymphedema.**” She will highlight lifestyle modifications, diet, exercises, weight management, and supportive resources for successful lymphedema management.

Shavonna is certified in lymphedema therapy and oncological management, and is also a certified Pink Ribbon Recuperative Yoga Specialist. Her rehabilitation career spans diverse settings including acute care, inpatient and outpatient, stroke rehab and geriatrics. In 2014, Shavonna implemented Piedmont Henry's Outpatient Lymphedema Program and offers breast cancer rehabilitation to the Southern Crescent area. Shavonna conducts weekly yoga classes via Cancer Wellness and presents at health seminars and workshops.

Driving Directions:

From I-75 South: Go to Exit 224 (Hudson Bridge Rd/Eagles Landing) and make a left turn off exit. Go to 3rd traffic light and make a left turn on to Hospital Drive. At Stop Sign, make a left. The Foundation Education Center and parking lot are on your right.

From I-75 North: Go to Exit 224 (Hudson Bridge Rd/Eagles Landing) and make a right turn off exit. Go to 3rd traffic light and make a left turn on to Hospital Drive. At Stop Sign, make a left. The Foundation Education Center and parking lot are on your right.

Also, Victor Luciano with BSN Medical will highlight his company's lymphedema-related products.

PICTURES FROM THE JOINT NLN-LLN CONVENTION OCTOBER 2017



Lymph Science Advocacy Programs members with Joan White



All LSAPS who were present at the convention



Dr. Margarita Correa spoke on lipedema and other fat disorders.



Dr. Stanley Rockson was the keynote speaker for the convention



Guenter Klose spoke on treatment and the history of the discovery of the lymphatic system



Rebecca Hammad described the benefits of doing lymphedema therapy on her brain and spinal injury patients at Shepherd Spinal Ctr.



Dr. Mike Weiler of GA Tech discusses their research on the lymphatic system



Nurse Ophelia (a Disney employee) provides comic relief before lunch on Thursday



Dr. Shelley DiCecco discussed sexuality & lymphedema



Therapists Molly Nettles & Shelley DiCecco



Walkers for "Stomp Out Lymphedema"



Sarah Bramlette presented on her personal history of dealing with lipedema/lymphedema

Highlights of the 2017 1st Joint NLN and LLN National Conference on Lymphedema Orlando, FL

Our thanks to these excellent speakers:

- Stanley Rockson, M.D. - "Research Breakthroughs in Lymphology"
- Margarita Correa, M.D. - "Lipedema - A Fatty Deposition Syndrome"
- Mike Weiler, PhD - "Research at Georgia Tech/Lymph Tech"
- Rebecca Hammad, MHS, OTR/L, CLT - "Managing Post-Neurological Injury with Lymphedema Therapy Techniques"
- Guenter Klose, MLD/CLT certified instructor, CLT-LANA - "Treatment of Lymphedema," including some of the history of the discovery of lymphatics.
- Shelley Smith DiCecco, PT, PhD, CLT-LANA, CI-CS - "Sexuality & Lymphedema: Pelvic Floor Health & Lymphedema"

And to these Patient Summit Speakers on October 11, 2017: (Many were from GA; all did an exceptional job, and had put lots of time into planning their presentations.)

- Wade Farrow, M.D., CWSP - "Anatomy & Physiology of the Lymphatic System"
- Julie Mills-Watson, LMT, CLT - "The Importance of Eating Healthy"
- Robyn "Redd" Smith, Med, COTA, CLWT, CLT - "Six Savvy Skin Secrets"
- Sarah Bramlette, MSHL, LSAP - "Building & Leading your Healthy Support Network"
- Joseph Feldman, M.D., CLT-LANA - "Pediatrics"
- Molly Nettles, OTR/L, CLT-LANA, STAR/C - "Heads Up: Head and Neck Lymphedema"
- Catherine Holley, RN - "Patient Care from a Professional Perspective"
- Hope Knosher, C-IAYT, E-RYT500 - "How Yoga Heals"

The Stomp Out Lymphedema Walk was held on Wednesday, October 11, 2017 immediately following the close of the Patient Summit. The special guest appearance was Nurse Ophelia, a Disney World employee who was extremely funny and brought lots of laughs from the audience.

2018 Lighthouse Lymphedema Network Calendar Dates to Remember:

- LLN Board meeting, January 27, 2018 at the Country Club of Roswell.
- Bellmere Gardens fundraiser/luncheon for LLN, May 5, 2018 (more details to follow in the April newsletter!)
- LLN Medical Professionals training course, October 19th, 2018 to be held at the ROAM facility at 1151 Hammond Drive, NE, Suite 240, Atlanta, GA 30346 (near Perimeter Mall).
- LLN annual all-day Fall Medical Conference October 20, 2018; also to be held at the ROAM facility (see next page for more details)

The ILF 2018 conference takes place on 6 – 9 June 2018 in Rotterdam, the Netherlands on board the SS Rotterdam, and will be co-hosted by the Nederlands Netwerk voor Lymfoedeem en Lipoedeem (NLNet). The IFL 2018 Conference will gather practitioners, researchers, affiliates and stakeholders from all over the world. (The ILF is also pleased to announce that the 9th International Lymphoedema Framework Conference in 2019 will be held in the USA and co-hosted by the American Lymphedema Framework Project (ALFP).) Also, see this ILF website for free publications to download: <https://www.lympho.org/publications/>

**First Notice: Mark Your Calendars Now For the
All-day LLN-Sponsored Fall Medical Conference
Saturday, October 20th 2018**

Brad Smith, MS, CCC-SLP, CLT will speak on Head and Neck Lymphedema at the Lighthouse Lymphedema Network-sponsored all-day medical conference on Saturday, October 20, 2018.

Location: The 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. (Note: This is NOT the Sandy Springs ROAM location we used previously – This ROAM facility is located on the upper level of the strip mall area *across from Perimeter Mall.*)

Topics: Head and neck lymphedema, obesity and lymphedema, patient speakers, discussions of the latest surgical & drug treatment options, updates on the National Lymphedema Treatment bill & insurance coverage changes (More information to come!)

Registration: Beginning March 1: Patients, family members and caregivers may register on-line securely using the LLN website: www.lighthouseymphedema.org. The conference registration fee is \$50.

IMPORTANT NOTE TO MEDICAL PROFESSIONALS (Therapists, Physicians, Physician's Assistants, Nurses, NPs): This all-day forum will be preceded by a half-day Short Course for Head & Neck Lymphedema Management - 4 hours - on Friday, October 19, 2018, 1-5 PM, also at the ROAM Perimeter Center. The course, taught by noted lymphedema therapist Brad Smith, will include measurement for head & neck lymphedema, treatment pathways, compression and kinesiotape for head & neck lymphedema, troubleshooting and Q&A time. The course will include CEU credits. The cost is only \$120.00 for the course and includes your attendance at the all day conference on Saturday. Register starting March 1 at the LLN website, www.lighthouseymphedema.org. Sign up ASAP – space is limited to 44 seats!

Special deal on registration fees for medical professionals: Short course on 10/19 only - \$120, conference on 10/20 only \$90; both events \$120 (a \$90 savings!)

Our hotel of choice will be the **Atlanta Marriott Perimeter Center**, 246 Perimeter Center Parkway, Dunwoody, GA 30346. (Toll-free reservation center: 1-888-858-2451) The hotel is under complete renovation which to be completed this spring. The cost per room is \$119.00, and the hotel will provide shuttle service to/from the hotel to the ROAM or the MARTA rapid transit system. A Continental breakfast and lunch will be provided at the Saturday program.



On Saturday, November 11, LLN Board members held a **Cheering Station for the 2-day walk sponsored by It's The Journey**. They met at Emory @ Peachtree Hills, wearing the LLN t-shirts & visors, and used their noise makers and strong voices to cheer on participants in this annual run/walk fundraising event.



LLN BANDAGES & GARMENTS FUND 2017 WRAP-UP

Once again, 2017 broke records for the past year by continuing to offer financial assistance to lymphedema patients across Georgia. Patients from all over Georgia applied for assistance from the Fund and services were provided to record numbers of lymphedema patients. This would not be possible without the generous partnerships with garment manufacturers, garment providers and certified lymphedema therapists. We thank all of you for your support of the LLN and the Bandages and Garments Fund.

Greatest successes for 2017:

- In March we received a grant from It's The Journey, Inc. for the fifth year in a row. Grant funding purchased garment solutions for 19 breast cancer survivors in 2017, and additional funding is available for the first quarter of 2018.
- In April we received a grant from Komen Greater Atlanta for the second year in a row. Grant funding purchased garment solutions for 17 breast cancer survivors from the 13-county metro Atlanta area.
- We provided 84 lymphedema patients with a garment solution specific to their needs.
- Over \$40,000 from a variety of sources funded the support for these 84 patients.
- An assistant administrator has volunteered to help oversee the Bandages and Garments Fund so that we can continue to serve the growing needs of lymphedema patients.

Greatest need for 2018:

- Funding - Every year more and more individuals are referred to the LLN for financial assistance. We need everyone's help to find new sources of revenue to continue providing service to Georgia residents through the Bandages and Garments fund and education programs. Do you have experience in this area? Do you enjoy organizing events that could raise funds for us? Please contact Deb Cozzone or Joan White to share ideas and get involved.
- Join the effort to pass the Lymphedema Treatment Act. If the LTA is passed, many patients will have insurance coverage for their garments. Please support this worthy cause and join the GA State LTA Team. For more information, check out <http://lymphedematreatmentact.org/>

In addition to our grantors, It's The Journey, Inc., and Komen Greater Atlanta, we heartily thank all of the garment manufacturers, garment providers, Certified Lymphedema Therapists and other organizations and individuals who have supported the Fund. The LLN and the Bandages and Garments Committee are grateful to all of you—without your help, we could never serve as many people as we do. Thank you!

LLN Outreach Activities: The LLN shipped 3 boxes of new and slightly used lymphedema treatment supplies to Washington state, and James and Donna Chavez will hand-carry them to Peru to give them to our therapist contact Carolina Aguirre. We appreciate these generous donations – they are put to very good use by Carolina's patients who could not afford compression garments otherwise.

LLN-sponsored Open Forum Meeting, November 16th, 2017 was held at Northside Forsyth Hospital, 1400 Northside Forsyth Drive, Cumming, GA 30041. Our thanks to therapist Samantha Cannon Martin, MSOT/L, CLT, who organized this meeting. She provided an update on the latest information and research from the joint LLN & National Lymphedema Conference held in October in Orlando, FL. Troy Bridle, representative with Lohmann & Rauscher, presented a demonstration of their newest compression garment choices. Samantha also discussed reducing scars and fibrosis using the Rian low level laser after surgery or radiation therapy.

News for our lipedema and fat disorder patients:

Felicite Daftuar <felicite.smith@gmail.com> the Fat Disorders Research Society tells us that FDRS has created a series of videos for treatments that fat disorder patients can do for themselves at home if they do not have sufficient medical care. The video playlist can be found on the FDRS YouTube Channel, under Playlist, then [Self-care: MLD, Pump, Breathe, Brush, Yoga](#). You can start with this link:

<https://www.youtube.com/watch?v=O7GwEIobx8k&list=PL1UXN1MUyFzXTK3PesPG3cT413XYRvMSz>

FDRS will continue to enhance this playlist over time. A Facebook post on FDRS and on LF can be found at the top of each page. Please also note the 2018 FDRS conference will be held the last weekend in April in Dallas, TX, USA (See the website www.fatdisorders.org.)

Other information for lymphedema patients:

JoAnn Rovig is a lymphedema therapist and patient educator who founded Jovipak and was the first lymphedema therapist in the Northwest, opening her clinic in Seattle, WA in 1993. She has created a new lymphedema management DVD. Since the NLN is no longer going to have a "store" to sell merchandise, books, etc., LLN will post the information for her DVD on our website and have a link to go to her website to purchase the DVD. The cost of the DVD is \$50.



The Lymphedema Treatment Act is an active bill in the current, 115th Congress, which runs from the beginning of 2017 to the end of 2018. The Lymphedema Treatment Act (LTA) will improve coverage for the treatment of lymphedema from any cause by amending Medicare statute to allow for coverage of compression supplies. Although this legislation relates specifically to a change in Medicare law, it would set a precedent for Medicaid and private insurers to follow. Specific goals of the LTA are as follows:

- to provide comprehensive lymphedema treatment coverage, according to current medical treatment standards;
- to enable patient self-treatment plan adherence by providing necessary medical supplies for use at home, as prescribed for each patient (including gradient compression garments, bandages, and other compression devices);
- to reduce the total healthcare costs associated with this disease by decreasing the incidence of complications, co-morbidities and disabilities resulting from this medical condition.

The HHS Secretary has confirmed that a change in statute is necessary to allow for coverage of compression supplies. (See section above for details.) The Lymphedema Treatment Act will amend Sec. 1861 of the Social Security Act to enable coverage of these items under Durable Medical Equipment.

As of January 2, 2018, the bill now has 304 House and 50 Senate supporters. See this link for information about contacting your Senator or Representative if they have not signed on yet: <http://lymphedematreatmentact.org/about-the-bill/current-status/>

2017 Donations:

Honoring:

The LLN Board of Directors
Deb Cozzone
Joy Vee Davis
Courtney Day
Peyton Day
Heather Ferguson
Rebecca Hammad
Max & Lola
Jean Miller
Molly Nettles
Stacy Saraydar
Carson Sollenberger
Beverly Thompson
Doug White
Joan White
Rebecca Wight

In Memory of:

Marge Duncan
Linda Harman
Larry Hart
Bill Morgan
Myrtle Petersen
Daniel Tinkler
Dorothy White

Donations:

Anonymous
Sally & Frank Anderson
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Sherilyn Bell
Michael Bernas
Laird Bloom
Blue Sky Restoration
Becky Bosselman
Sarah Bramblette
Gwen Brent
John Cherry
John Cherry III
Krista & Byron Cherry
Louis Cherry
Jill Cook
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Rebecca Sharp
Brian & Barbara Sherman
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Barbara Snyder
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Southern Loss Association
Stavres Family
Kristen Stein
Lauren Swenson
Beverly Thompson
Susan Tinkler
Unified Investigations & Sciences,
Inc.
YourCause

Shavonna Warthen
Emily Wendell
Joan & Doug White
Jolene & Philip White
Rene & Ronald White

Grants:

Susan G. Komen Greater Atlanta
Affiliate
It's The Journey, Inc.

Our sincere thanks to the following businesses for your financial support:

BiaCare by SIGVARIS
Body of Health and Life, LLC
BSNmedical Inc.
EZ Medical Wraps
Gloria Watts, Cox Foundation
Impedimed, Inc.
JUZO USA
Lymphedivas
Lohmann & Rauscher
MEDI USA
Xpandasox

Thanks to our volunteers and LLN board members:

Larry Ashmore
Billie Barron
Samantha Cannon Martin
Deb Cozzone
Vicky Day
Shelley Smith DiCecco
Melissa Driggers
Jackie Echols
Jade Gross
Elaine Gunter
Gary Gunter
Rebecca Hammad
Laura Hoffman
Gwen Forbes-Kirby
Stephanie Kirkpatrick
Debbie Labarthe
Bret Martin
Natalie McKay
Peggy Meyer
Charlotte Murphy
Molly Nettles
Vera Newman
Stacy Saraydar
Janie Smith
Jane Thiery
Beverly Thompson
Joan White



LymphEd's 2018 Courses for Medical Professionals

Complex Lymphatic Therapy (CLT) Certification Course

135 hour LANA-approved certification course for RNs, OTs, COTAs, PTs, PTAs, MDs, LMTs, DOs, and DCs. Incorporates the latest evidence-based research on the lymphatic system and effective treatment techniques in a 45 hour interactive home program and 9 days of in person instruction.

Dates: March 3, 2018-March 11, 2018 in Atlanta, Georgia
July 14, 2018-July 29, 2018 in Atlanta Georgia

Advanced Concepts in Lymphedema Treatment

20 hour course for certified therapists with focus on upper and lower extremity involvement. Discover advanced treatment techniques based on new evidence-based research in the 4 hour interactive home program and 2 days of in person instruction. Topics included: new pathways for clearance, patient involved MLD, adjuncts to treatment (cupping, taping), and compression problem-solving.

Dates: March 24, 2018-March 25, 2018 in Atlanta, Georgia

Advanced Treatment of Genital Lymphedema

20 hour course on advanced treatment techniques for certified therapists on male and female genital lymphedema. This course consists of a 4 hour interactive home program and 2 days of in person instruction covering the topics of: in-depth review of anatomy of pelvis/genitals, pathways for MLD, compression problem-solving, and involvement of the pelvic floor.

Dates: April 28, 2018-April 29, 2018 in Atlanta, Georgia

Advanced Treatment of Head and Neck Lymphedema

20 hour course on advanced treatment techniques for certified therapists on head and neck lymphedema. This course consists of a 4 hour interactive home program and 2 days of in person instruction covering the topics of: in-depth review of anatomy of head and neck, pathways for MLD, and compression problem-solving.

Dates: August 18, 2018-August 19, 2018 in Atlanta, Georgia

If you are interested in attending a LymphEd course or think your facility might be interested in hosting a LymphEd course, or just 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.

Stay Connected: Join the Facebook page for updates on upcoming course dates, discounts, events, and other important information pertaining to lymphedema.

Discounts!

Hosting sites receive a free slot and \$250 off Certification Course and \$75 off Advanced Courses for all additional attendees. Therapists qualify for discounts for attending more than one course. More discounts described on the website and all discounts can be combined

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.

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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