



LLN April 2018 Newsletter

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LLN: Serving the lymphedema community for 24 years

www.lighthouselymphedema.org

LLN Spring Fundraiser – Please Plan to Attend! Bellmere Luncheon & Garden Tour

*Please join us for a wonderful experience
at the private Bellmere Estate
Located at 10777 Bell Road in Johns Creek, GA*

Saturday, May 5, 12:00 - 3:00

Directions: Bellmere Gardens is located at 10777 Bell Rd., Johns Creek, GA 30097-1803. Johns Creek is slightly northeast of Atlanta. If you live in any other part of the Atlanta area, take I-285 N. Merge onto GA-141 N (Peachtree Industrial); at the split, veer left towards Cumming onto GA 141 which is now Medlock Bridge Road. Turn right onto Bell Rd. Bellmere will be on the left. Look for the balloons. Once on the driveway, you will see the Garden House sign.

*Bring friends & savor a delicious luncheon in the lovely Garden House
Enjoy a demonstration on succulent plants by Rita Boughrum with Gracious Gardens
Participate in the raffle for flower arrangements created by the Master Gardener
Stroll through the lush Bellmere gardens and grounds*

***Advance registration is required; seating is limited to 110
Tickets: \$45.00***

*All proceeds benefit the Lighthouse Lymphedema Network
Register online at our website www.lighthouselymphedema.org
Or for more information, contact Vicky Day: vicky@peyday.net*



Q&A from our Facebook Page – Answers by therapist Gwen Forbes-Kirby, PT, CLT-LANA

1. I am having so much swelling recently and in so much pain. The Lymphedema doctor I have seen in the past I do not care for. How can I find a good lymph doctor? I also have a Baker's cyst behind my knee that is killing me. Do you know what kind of doctor I would see for the cyst?
An orthopedist is the type of physician who would follow a Baker's cyst. They are usually a result from knee issues such as arthritis. Vascular surgeons have some idea of the lymphatic system, but to date have not embraced Lymphedema as a whole. Word of mouth from other patients or reputable patient-oriented organizations would be my recommendation.
2. I would love to hear what others use for insect repellent (both on the body and in outdoor living areas).
Most of my patients will try more natural products, but success is limited. Long sleeves and netted hats are an option, but many go with the more traditional products containing DEET when good protection is imperative.
3. A nurse suggested use of a whirlpool for the skin on my legs that is loose.
Not sure what the end goal is, but if you want your tissue to remodel, tightening compression on a consistent basis is your friend. Whirlpools as a form of treatment have become outdated in clinics because of the cleaning and monitoring requirements. I think warm water pools where one can walk and perform exercises are wonderful for lymphedema patients, and there is now evidence they are very beneficial.
4. My left shoulder is acting up real bad. Guess the arthritis in it is getting worse and I can't do the right side neck and shoulder parts of MLD self-treatment. It hurts too much, and I can't lay my hand flat against my neck to do that part. Any ideas on how I can do it a different way.
In addition to following up with a physician (rheumatologist) to address the arthritis, you could start with gentle neck stretches on the affected side, then do shoulder rolls to open the lower components on the other side.

The Lighthouse Lymphedema Network Board of Directors for 2018



(L-R Janie Smith, Peggy Myer, Billie Barron, Gary Gunter, Delores Brennan, Elaine Gunter, Joan White, Vicky Day, Laura Hoffman, Deb Cozzone, Shelley DiCecco, Rebecca Hammad, Bret Martin, Samantha Martin, Stacy Saraydar, Jackie Echols. Not present: Larry Ashmore, Melissa Driggers, Jade Gross, Gwen Forbes-Kirby, Stephanie Kirkpatrick, Debbie Labarthe, Natalie McKay, Charlotte Murphy, Molly Nettles, Vera Newman, Beverly Thompson)

Our Board is composed of patients, therapists, and others who volunteer their time and effort. Each member has a specific role in support of LLN and its activities to help lymphedema patients and their families, as well as educating medical professionals about the diagnosis and treatment of lymphedema.

LYMPHEDEMA LOBBY DAYS 2018 in Washington DC: March 4th thru 6th, 2018

Since 2012, the grass-roots organization, Lymphedema Advocacy Group, has hosted this annual event to advocate for the Lymphedema Treatment Act (LTA). The objective of the LTA is to amend the Medicare law by adding the necessary Allowable Benefit Code so that doctor-prescribed compression supplies are covered under the Durable Medical Equipment (DME) category. This year, 73 advocates participated, representing 30 states. The GA/AR/LA State Team consisted of two LLN Board members, Debbie Labarthe and Rebecca Hammad, along with Carson Sollenberger, Mickey Hammad, Julie Mills-Watson, and Amber and Kendall Gallman, all from GA; and Angie Gallow of LA. Their team included both primary and secondary lymphedema patients, family members, and therapists.

For two full days on Capitol Hill, the advocates met with House and Senate members, seeking their support of the LTA (bill HR.930/S.497). Within the following week, 17 additional House members and one Senator had cosponsored the LTA! Thirteen of the 14 GA House members have cosponsored the LTA! The total number of cosponsors is now: House -- 331; Senate – 55. However, since bills of this size seldom pass as a stand-alone bill, efforts are being made to identify a larger healthcare-related bill which the LTA can be attached to, and presented to the floor for a vote.

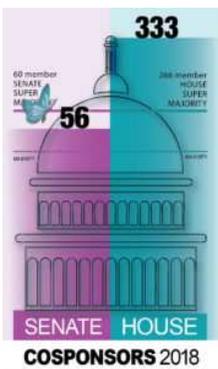
We need all lymphedema patients, family members, friends, and therapists to go to the LTA website, www.lymphedematreatmentact.org, and see if your Representative and Senators are on the Cosponsors List. If not, reach out to each of them via email, phone call, fax, or tweet and urge their support of this bipartisan legislation. On the website, you will find the suggested scripts for phone calls and tweets, as well as templates for emails. You will also find a list of the Senate and House Leadership Offices with their contact info. Your voice makes a difference! Together we can pass the LTA! Thank you!



LEFT: The GA/AR/LA Team: Debbie Labarthe, Carson Sollenberger, Angie Gallow, Amber Gallman, Kendall Gallman, Mickey Hammad, Rebecca Hammad, and Julie Mills-Watson



RIGHT: Advocates with Rep. Dave Reichert (R-WA), lead sponsor of the LTA (in middle of back row)



Go to the LTA website for more information and a handy script to use when contacting legislators:
<http://lymphedematreatmentact.org/>

It's the Journey Grant Presentation to LLN



LLN Treasurer Charlotte Murphy, ITJ Chairwoman of the Board and Grants Chair Laurel Sybilrud; LLN BAG Co-coordinator Janie Smith

On March 5th, It's The Journey, Inc. awarded grants totaling \$827,000 to 33 breast cancer programs across Georgia. It's The Journey (ITJ), producer of the Georgia 2-Day Walk for Breast Cancer (formerly Atlanta 2-Day Walk for Breast Cancer), provides grants annually for Georgia programs that focus on breast cancer screening, diagnostics, genetic counseling and testing, support services, and research. The funds for these grants were raised during the 2017 Atlanta 2-Day Walk for Breast Cancer by over 1,000 walkers and tens of thousands of donors. An additional \$75,000 from the 2017 2-Day Walk will be awarded among other funds for research grants in September at the 2018 Georgia 2-Day Walk for Breast Cancer.

The Lighthouse Lymphedema Network received a \$15,000 grant to help to fund LLN's outreach Bandages and Garments Fund to help provide compression garments for less fortunate breast cancer patients who have developed arm lymphedema. LLN Board members Charlotte Murphy and Janie Smith attended the dinner to accept our grant check. Charlotte had these comments about a special extra bonus that occurred:

*"This was a wonderful evening! We met a very nice lady named Jenn Nott from Cincinnati, OH. After dinner, ITJ made the grant check presentations to all the recipients. We received our check for the 1st half of the grant, and had our picture taken. Afterwards, there were a few more special presentations of additional grant money to recipients chosen by the top 2 Day Walk teams. So, remember the nice lady I told you about earlier? Well, she was the winner of the 2017 Randi Passoff Spirit Award, and was given the opportunity to award **an additional \$5,000.00 in grant funds**. I am proud and honored to say that she chose the LLN to receive these funds, so we received \$20,000 in all! As I said earlier, this was a wonderful evening!"*

LLN sincerely thanks Board members Shelley DiCecco for writing the grant and Deb Cozzone, Larry Ashmore, Janie Smith and Charlotte Murphy for their help.

The 2018 Georgia 2 Day Walk for Breast Cancer will be held on September 29-30, 2018. LLN will have a cheering station on those days – stay tuned for its location!



SOUTHERN LOSS ASSOCIATION GOLF AND TENNIS OUTING

Raised \$4,000 for the Lighthouse Lymphedema Network

Thursday, April 12, 2018 – Chateau Elan, Braselton, GA

Thank you, Southern Loss Association, for selecting the Lighthouse Lymphedema Network as your charity of choice for your spring Golf and Tennis Outing. Your LLN representatives at this event were Billie Barron, Peggy Meyer, Charlotte Murphy, Beverly Thompson and Joan White. We sincerely thank Susan Freeman, event coordinator, and her team, Jennifer, Candace, Kristy and Crystal for your hours of labor to make this event extra special (over 250 golfers). Applause to each of you for your hard work!



FRSTTEAM, Fabric Restoration Service Team, sponsored the 50-50 ball toss game. Thank you Joshua Campbell and Cheri Zorzoli with FRSTEAM. Special thanks to Kelley Brown with BluSky Restoration for donating his half of the ball toss game winnings to the LLN.



Belfor Property Restoration sponsored the sale of mulligans. Thank you Candace Hight, Sherrie Boylan and Jessica Keith with Belfor.

Unique AmazonSmile link to raise funds for LLN

When customers sign up for AmazonSmile, they're asked to select one of over a million charities to support. When customers click on your unique link (LLN), they skip this charity selection process. Instead, they're taken to smile.amazon.com and are automatically asked if they want to support Lighthouse Lymphedema Support Group. Amazon donates 0.5% of the price of eligible smile.amazon.com purchases to LLN. **Your unique charity link is:**

<https://smile.amazon.com/ch/58-2301746>

LLN SEPTEMBER 2018 OPEN FORUM MEETING

Topics: “Elements of Breast Cancer Rehabilitation: Lymphedema Management, Treatment of Axillary Cording, and Restoration of Physical Functioning through Exercise and Dry Needling.” There will also be a vendor to demonstrate bandaging supplies.

Date: Thursday September 13, 2018 from 6-8 pm; light refreshments will be served

Location: Emory Johns Creek Hospital Education Center, Classrooms A & B, 6325 Hospital Parkway, Johns Creek, GA 30097

Presenters: Certified lymphedema therapists Crystal Champion, PT, DPT, CLT and Terry Sylvester, PT, CEAS, CLT



LLN BANDAGES & GARMENTS FUND 2018 UPDATE

The Lymphedema Lighthouse Network would like to thank Deb Cozzone for her service the last eleven years as our administrator of the BAG Fund. Deb was not only the major distributor of the funds, but also a dedicated fundraiser. Deb will stay on the board and will be available to us with her talents and knowledge, and we all wish Deb the best in all of her endeavors.

My name is Janie Smith and I have been training with Deb for several months. Moving forward, all applications should be emailed to me at the email address below. I will be handling the process for all breast-cancer related lymphedema patients and will forward on any non-breast cancer related applications to Rebecca Hammad for processing.

Please note that we will be putting our applications for non-breast cancer related patients on hold secondary to exhausting our funds on recent applicants. We will need additional funding before we can start accepting applications again.

I have had the privilege of learning all the good works that the BAG Fund has done over the years by providing the necessary compression garments for the management of chronic swelling. If anyone has ideas, or the ability to raise money for such a good cause, we are always interested to hear those ideas. We depend on donations and grants and if anyone knows of a grant we could apply for, please let us know.

We at the LLN thank you all for the support. We could not reach so many people in need without the garment manufacturers, garment providers, and the certified lymphedema therapists as well as all of the organizations and individual donors who have supported the BAG Fund. I am looking forward to working with all of you. Please contact me with any questions or concerns at darnofell@aol.com.

2018 Lighthouse Lymphedema Network Calendar Dates to Remember:

- Bellmere Gardens Luncheon, Saturday May 5th, Johns Creek, GA
- LLN September 12th Open Forum meeting, Emory Johns Creek Hospital Education Ctr, 6-8 PM
- 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). (*Course for certified lymphedema therapists ONLY*)
- LLN annual all-day Fall Medical Conference October 20, 2018; also to be held at the ROAM facility (see next page for more details)

First Notice: Mark Your Calendars Now

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 on Hammond Drive *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: 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 for the course starting March 1 at the LLN website: www.lighthouseymphedema.org. Sign up ASAP – space is limited to **24** 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 to be completed this spring. The cost per room is \$119.00. A Continental breakfast and lunch will be provided at the Saturday program.

News from Carolina Aguirre, Who Runs Our International Project in Lima, Peru:

The end of the summer vacations has arrived and schools are resuming classes in these coming days. My practice has been unusually busy this summer (generally people leave Lima and my work calms). This season, with your donations I have helped two young ladies Alejandra and Janette. Alejandra has primary lymphedema on both legs, very well controlled and mostly focused on one foot, she purchased the correct garments but was still lacking compression on one foot, so I was able to help her with a to-the-calf Medi. She wrote you a letter (see hereunder). Janette is still in the process of finishing a breast cancer treatment, her arm lymphedema is not controlled yet, as Alessandra she had a garment but still lacked compression for her hand. She received a Medi glove from the donations. She has not been able to write to you but sends all of the Lighthouse team a heartfelt thank you.

As you can tell, I have left in my stock more short garments, gloves and to the knee or calf socks, rather than complete limb types. Therefore, as the above cases are not the majority, I am also donating short socks to people with venous issues. I send you the gratitude of Nicole and Rosa María. Nicole occupies most of her time growing fruit and vegetables, including heavy work such as clearing water canals by hand or tending to the trees, etc. Her legs were more or less under control until she had an emergency flight for family reasons and had no protection for them. Rosa María is undiagnosed as she has important financial issues and no health insurance, so we do not know if the swelling of her legs is a primary lymphedema triggered by an infection she had just before, or a venous type as both legs swelled at the same time and only to the knee. She is planning to travel to Spain in March where she will be able to see a doctor; in the meantime, she also received from you garments that will help her until then, especially for the long flight ahead of her.

I myself would like to thank once again your great support! I am thrilled to know that I will be receiving in mid-March a new donation from the Lighthouse Network, and would like to forward you in these few lines all my appreciation for your incredible help and a special thank you for Joan's unconditional support.

For your information, as social networks are shifting, I am trying to spread online information on lymphedema in Spanish. Even if it is a mirror of the data I have on my website (translations from the Australian LAA and from DeCourcy Squire's training in Atlanta) I know some people, especially the younger ones, search the web only in certain networks. The information has been since a while now on Facebook (although I just opened some months ago a new page just for lymphedema for it to be easier to find), and now I am in the process of uploading it on Steemit. <https://cuervoblanco.pe/tratamiento-de-linfedema> <https://www.facebook.com/cuervoblanco.pe> <https://www.facebook.com/LINFEDEMA.informacion> <https://steemit.com/@cuervoblanco-pe>

May springtime get to your hemisphere very soon!!
All the best for each one of you,
Caroline Aguirre



Rosa Maria



Nicole



Alessandra



Janette



Lucia

Caroline sent an update recently after receiving another shipment: "My client María Inés had a health incident, her arm swelled accordingly and her sleeve did not fit anymore, I was able, thanks to your donations, to visit her at the hospital and find a sleeve to see her through this episode. She thanks you very much!"

And the first item that was handed away with this new shipment was a LympheDiva sleeve. I remember so clearly in my training that DeCourcy Squire said to us that even if there are fun colored sleeves on the market, the lymphedema patients will usually pick a neutral colored one. Not in the case of Lucía! She is an "animal print lady" and by those coincidences that happen sometimes, the Animal Print LympheDiva sleeve was her size! So I didn't wait to offer it to her, and she was so delighted by it! On her other hand she wears "animal print elastic bracelets" on. You have made her day!

Review of the Open Forum Meeting Piedmont Henry Hospital

Thursday, February 15, 2018

Shavonna Sumlin Warthen, MA, OTR/L, CLT presented the “Challenges of Successful Management of Lymphedema.”

Shavonna stressed that the initial key to successful management of lymphedema is an early diagnosis along with intervention. Often our medical professionals have limited or no knowledge about lymphedema, thus resulting in improper and/or delayed treatment. Denial of coverage by some insurance providers, i.e. Medicaid, is said to be due to “chronic conditions.”

The goal of treatment is to reduce swelling and maintain the reduction to decrease risk of infection and maximize patient engagement in activities of daily living. Shavonna pointed out that some areas in Georgia have few or no certified lymphedema therapists, which causes patients to have to drive some distance to get therapy. Note: The Lighthouse Lymphedema Network lists certified lymphedema therapists in the SE on their website

www.lighthouselymphedema.org.

- Always be measured by an experienced compression fitter. Garments should be replaced every 6 months.
- Your certified lymphedema therapist will teach you self-management of your lymphedema.
- Skin is the largest organ in the body and protects the body against threats of injury and foreign invaders so keep clean. Soaps, cleansers and lotions should be free of perfumes and fragrances, hypo-allergenic, low pH lotion and possess good moisturizing qualities.
- Wear compression garments during movement/exercise. When playing tennis or aerobics, you may need to wear more compression. Beneficial exercises: yoga, swimming, and walking.
- Weight Management is extremely important and patients should strive towards proper nutrition.
- Common risk reduction practices: avoid skin injuries, avoid saunas or hot tubs, no blood pressures taken on the affected arm, use insect repellents and avoid areas that are mosquito infested.

Shavonna’s exceptional program was followed by a product presentation by **Victor Luciano from BSNmedical**. BSNmedical offers products by Jobst, Farrow Wrap, and JoviPak. Victor gave us a through overview of all the options available from each company.



Don't Forget to Register for the 16th Annual Gloria Watts-Cox Lymphedema Run/Walk, Saturday, June 2, 2018

The Run-Walk starts at 8:00 AM at Enon Church, 3550 Enon Rd, College Park, GA 30349. To get to the church, take I-20 West to I-285 South, turn right on Camp Creek Pkwy to Enon Road (4-5 mi). Turn left and drive to the end of the road. Enon Church will be on your left. Registration: 7:30-8:00 AM; Run/Walk starts at 8:00 AM; Health Fair: during & after Run/Walk. For more details, contact:

Gloria Watts-Cox Foundation

2734 Waleska Way, East Point, Georgia 30344.

Phone Number: (404) 349-3992

Website: <http://gloriawattscoxfoundation.org/>

LLN will have a team participating, as always, to support this worthy cause (which in turn supports LLN!)

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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