www.lighthouselymphedema.org

LLN May 2019 Newsletter

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LLN: Serving the lymphedema community for 26 years

L-R Laurel Sybilrud (Chairman of the It's the Journey Board Grants Chair), LLN BAG Fund Coordinators (and therapists) Janie Smith and Rebecca Hammad, and Stephanie Tucker (Executive Director of ITJ)

LLN BANDAGES & GARMENTS FUND 2019 UPDATE

We are excited to report we attended the It's The Journey Gala at the Atlanta Aquarium on March 25, and **our grant application for $20,000 was approved**. **In addition, we were presented with the Honorary Vanguard Award of $2,500 for our mission to fulfill all compression needs for our qualifying patients who do not have insurance coverage for their garments!** We thank the ITJ, who sponsor the Georgia 2-Day Walk, for their gracious gift which helps us meet the mission set for our providing compression garments for the cause. The night was special as we could meet all the grantors who work so hard to raise the monies that we receive as grantees. Last year's grant broke records for the LLN, and a total of 44 patients were served, with 6 new counties being served, bringing our total count to 72 GA counties.

Thank you to all the therapists and providers who give us the opportunity to be part of their patients' care. Rebecca Hammad continues to work with the non-breast cancer patients and provides many products by working with our compression garment companies who generously donate products to the patients in need. Shelley DiCecco helps by writing our grant applications. We look forward to next year working with all of you. Please contact Janie Smith with any questions or concerns at darnofell@aol.com .

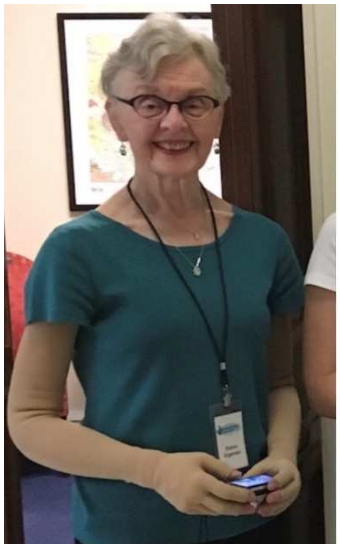
2019 Southern Loss Association Larry Hart Memorial Golf and Tennis Outing
Thursday, April 25, 2019 – Chateau Elan Golf Club, Braselton, GA

Southern Loss Association is a philanthropic organization which has served the Property Insurance Industry in the Atlanta area for over 50 years. The Lighthouse Lymphedema Network was the beneficiary from the sale of mulligans and the ball toss game - and instead of cash prizes for the winners of the golf outing, the SLA made a donation to the LLN in the amount of $2,000, making the total raised $4,037!

Thanks to Joshua Campbell with FRSTeam (Fabric Restoration Service Team), which sponsored the 50-50 ball toss game, and thanks to Candace Hight and Sherrie Boylan with Belfor Property Restoration, sponsor of the mulligans sale.

And a very big thank you to Southern Loss Association for selecting the Lighthouse Lymphedema Network again 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 sincere thank Susan Freeman, event coordinator & her team, Jennifer, Crystal, Brooke, and Kristy for their hours of labor to make this event extra special for 260 golfers & 320 dinner guests. Applause to each of you for your hard work!

IN MEMORIAM FOR A TRUE CHAMPION FOR LYMPHEDEMA – ELAINE EIGEMAN



Recently, one of our strongest advocates for the Lymphedema Treatment Act passed away. She will be greatly missed. Here is background information about Elaine from the LTA website: **http://lymphedematreatmentact.org**

Elaine Eigeman (Seattle, WA) was a lymphedema patient advocate who, in addition to serving as the Board Chair for the Lymphedema Advocacy Group, volunteers with the NW Lymphedema Center to enhance patient education, create community and encourage self-advocacy. She knew know firsthand, from 13 years with bilateral arm/hand LE, the demands of complete decongestive therapy (CDT) needed to compensate for permanent damage to her lymph transport system from bilateral breast cancer treatments in 1999. Elaine's husband Daniel provided daily manual lymph drainage (MLD) and she wore prescription gradient compression garments every day. Elaine was a Team Survivor NW hike leader where she encouraged cancer survivors at risk for lymphedema to be active and to use trekking poles to keep lymph fluid moving. When she reached Medicare age, her insurance coverage for compression garments ended. After learning the hardships and disability faced by many thousands of Medicare seniors in the Pacific NW who are denied medically essential compression garments, Elaine led a team from WA to the 2011 Lymphedema Lobby Days. When Elaine returned from that life-changing experience, she continued to expand her team of WA state advocates and deepen her involvement with the Lymphedema Advocacy Group. *(*Board Chair, *Lymphedema Advocacy Group)*

2019 Lighthouse Lymphedema Network Calendar Dates to Remember:

- May 5th-7th – Lymphedema Lobby Days in Congress for this year
- **October 18-19 – LLN Fall Educational Conference to be held again at the excellent ROAM facility at I-285 and Perimeter Mall in Atlanta. On Friday the 18th from 12:00-6:00 PM, a genital lymphedema treatment class for lymphedema therapists will be held in Suite 240. (The $200 cost for this course will include admission to the rest of the conference.) On Saturday the 19th we will hold our all-day educational classes for patients, families & caregivers ($50), and medical professionals ($90). Much more information to follow shortly!!**
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Fat Disorders Resource Society Conference: FDRS 2019 - An Overview

Molly Sleigh, OTR/L, CLT-LANA

The Fat Disorders Resource Society Conference was held April 12- 14, 2019 in Baltimore, Maryland. Prior to the conference, the first United States Standard of Care meeting for lipedema was held on April 11-12, 2019 in association with the FDRS conference. The standard of care meeting was supported by a grant from the NIH and NHLBI, and consisted of a team of twenty-one U.S. based members with expertise in lipedema. A welcome reception and fashion show was held the evening of April 12. The FDRS conference presentations focused on clinical examination; imaging techniques; co-morbidities including chronic venous disease and obesity with lipedema; lipedema manifestation and hormonal alterations; genetics and physiology; self care strategies including the use of deep breathing, therapy intervention, and nutrition; treatment of pain; defining Dercum's Disease and Ehlers-Danlos syndromes; current research; surgical intervention of lipedema; and patient stories. The group of twenty-nine presenters included surgeons, vascular specialists, researchers, physicians, patients, therapists, nutritionists, and scientists.

Molly Sleigh (in pink) with conference organizers & speakers

The keynote address entitled "Why Doesn't My Treatment Work for My Fat?" was given by Karen Herbst, MD, PhD. Dr. Herbst discussed the differences between "normal fat" and "sick fat". Her presentation included the following:

- Dismobility/immobility can lead to progression.
- Some of the consequences of "sick fat" include elevated blood glucose and blood pressure, metabolic diseases, fat deposition in other body organs (fatty liver) and other depots, extracellular matrix abnormalities.
- Inflammation is a major contributing factor to tissue fibrosis.
- Hypertrophic fat and fibrosis reduce the ability to lose weight.
- Lipedema fat infiltrates muscle and aging induces fibrosis to accumulate in muscle. Loss of muscle quality in lipedema is attributed to deposition of ectopic fat, depletion of a viable stem cell pool within the skeletal muscle niche.
- Healthy food plans are not effective against lipedema or lipoma fat, but healthy food is critical to reduce sick fat.
- Healthy eating includes the following:
  - Low carbohydrate (low sugar/starch)
    - Anti-inflammatory low carb
    - Ketogenic
    - Bright line eating
    - Intermittent fasting
  - Eating whole foods
  - Avoid liquid diets and those causing yoyo effect

- Lymphedema can be present with lipedema.
- Physical treatment of fibrosis may include CDT. Deep tissue therapy may help reduce fibrotic tissue and the use of instrument assisted soft tissue therapy (IAST) may be warranted. IAST may include astym, graston techniques, gua sha, and ba guan.
- If tissue fibrosis and blood flow can be improved, tissue can heal more effectively.
- Compression can be helpful in reducing or controlling tissue fluid overload in Stage 2-3 lipedema.
- The conclusions:
    - Fibrosis may be a main reason why lipedema and lipoma fat is resistant to loss by diet, exercise, and bariatric surgery.
    - Leaky microvessels may result in fibrosis, increased interstitial fluid/proteins/cell waste lead to lymph stasis and increased SAT growth.
    - Fibrosis can be reduced by anti-inflammatory agents, physical reduction, and use of sequential pneumatic pumps with use of Pit Paks.
    - Supplements NAC, natokinase, and melatonin may improve fat and fibrosis.

Vendors were present throughout the duration of the conference. Most of the presentations will be available online on the FDRS website at www.fatdisorders.org

STRIKE A POSE! How to safely exercise with lymphedema!

Saturday, April 27, 2019 – The Sports Rehabilitation Center, 2669 Osborne Road, Atlanta, GA

Thank you, Dr. Shelley DiCecco, for organizing a fun time to learn how to participate in Yoga, Pilates and Tai Chi, standing or sitting. The exercises focused on breathing, stretching, balance and strengthening.

Christine Ogle was the winner of registration for the fall conference, a $50.00 value. Arleen Wood was the winner of the soft silhouette leggings compression with benefits donated by SIGVARIS.

The happy participants at our inaugural Fun Day, a terrific event!

How to Select a Qualified Lymphedema Therapist

By Tiana Allen, LMT MEd CLT

What is Manual Lymphatic Drainage?

The Lymphatic System is a complex network of capillaries, vessels, valves, ducts, and nodes that help protect and maintain the internal fluid environment of the entire body by producing, filtering, and conveying lymph by using various blood cells. The lymph network transports fats, proteins, and other substances to the blood system and restores 60% of the fluid filtered out of the blood capillaries back into the interstitial spaces.

Lymph nodes are lymphatic structures that filter fluid and are responsible for immune system response by trapping, identifying and destroying pathogens (i.e., the "garbage disposal" of the body). Due to the complexities of the lymphatic system, much education is required behind understanding the overall system, its functionality and the disease processes which arise when it malfunctions.

Manual Lymphatic Drainage (MLD) is a systematic treatment involving specialized forms of manual techniques to direct fluid along normal anatomical pathways. In lymphatic diseases, excess lymphatic fluid is created, leading to swelling of affected body parts. **Lymphedema** is a chronic condition which requires life-long treatment after diagnosis. The term "Manual Lymphatic Drainage" comes from Dr. Vodder of the Vodder School of Lymphatic Therapies, which started in Germany in the 1960s and then expanded to Austria. The Vodder School was the original school for teaching manual lymphatic drainage (MLD) and later for combined decongestive physical therapy (CDT) as well. CDT is used to treat the disease processes of the lymphatic system as well as aid in the decongestion of the interstitial tissues, to "rev" up the immune system and to aid as a natural diuretic. Manual Lymphatic Drainage is primarily used to treat those with Lymphatic Diseases such as Lymphedema, Lipedema and Lipoedema.

Lymphedema treatment should be handled by a specialist trained in lymphedema management. Manual Lymphatic Drainage is not classified as a "massage" technique, but is a specialized treatment, and should be learned in a clinical setting, taught by certified and experienced practitioners of this technique (also called certified lymphedema therapists, CLT) who are recognized by the Lymphology Association of North America as CLT-LANA.

In recent years, performing the MLD technique properly by trained therapists (whether PTs, OTs, LMTs, RNs) has been overshadowed due to its "trendy" detoxification properties, and rapid growth of need in post-operative patients. This increase in demand for MLD has lead to altering the scope of practice of a therapist, and changes in the boundaries and ethics of promoting such a technique without having the therapist having had proper training or knowledge of MLD – and the patients with lymphatic problems suffer from inadequate treatment..

In an article in the Massage Therapy Journal entitled "Don't Overstep Scope of Practice (Your Career Depends on it), author Stephen A. Kreger, LMT states:

> *"Scope of practice could likely be the most important aspect of your career. Your clients might have no idea what you are fully trained to do, and what you are not trained in. This is why it is up to you to maintain the highest level of professionalism and work only within your legal scope of practice."*
>
> Kreger also writes: *"There is an almost immediate level of trust that most clients place in us, and a relinquishing of their power that comes with that trust.*
>
> 1. *Ensure that the public is protected from unscrupulous, incompetent and unethical practitioners;*
> 2. *Offer some assurance to the public that the regulated individual is competent to provide a certain service in a safe and effective manner;*
> 3. *Provide a means by which individuals who fail to comply with the profession's standards can be disciplined, including the revocation of their licenses."*

Thus, it is imperative that families, caregivers and those seeking a qualified lymphedema therapist should not look into simple "massage therapy," but rather into the LANA standards of training as well as other institutions and businesses, lymphedema clinics, nonprofit organizations, lymphedema community boards, and other educational spaces that specifically focus on the treatment and education of lymphedema before making a decision for a therapist. This is not an easy task, but in order to have proper treatment potentially for life, this effort must be made.

Helpful Tips:

Here is a list of things which are *NOT* MLD treatments:

- Cupping Therapies
- Simple Massage Therapy (anyone stating that they are "massaging" the lymph nodes, light massage, kneading, effleurage or any massage or "body rub" in general)
- Pushing or milking fluids out of any open incisions
- Using Infrared lights or radiofrequency machines
- Spa saunas or body wraps
- Wood therapy (a technique that uses specially shaped wood pieces claiming to sculpt the body in desired areas by forcing the removal of excess fluids)
- Ultrasound machines (ultrasonic cultivation/cavitation)
- Using any needles or syringes to draw fluids from extremities

Unfortunately, there is currently a huge lack of ability to "police" untrained individuals purporting to use these techniques (instead of proper training for MLD and CDT). What is needed are lymphedema treatment certification boards, who are able to monitor licenses and certifications of therapists and other professionals, in addition to providing and monitoring participation in continuing education courses to be able to track proper training of therapists.

Manual Lymphatic Drainage is a very specialized technique and its primary reasons for usage (lymphedema/lymphatic disease) are very important. If a Massage Therapist or any other health/wellness/beauty professional is not properly trained but leans on their limited hour CE course to treat these lymphedema patients, it should be considered as violating their scopes of practice.

The National Lymphedema Network (www.lighthouselymphedema.org) is an excellent resource for names of current certified lymphedema therapists in GA and the Southeastern US, as well as providing valuable information to help patients, their families, and caregivers better understand lymphedema and its treatment.

(A note for lymphedema therapists from Kathy Weatherly)

An important message for lymphedema therapists who wish to be LANA-certified:

The Lymphology Association of North America (LANA) is celebrating its 20th anniversary by offering qualified therapists* half-off the certification exam fee. This is a great year to take the next step as a Lymphedema Specialist by acquiring your CLT-LANA credentials. Remember, once you register online, you have a full year to take the exam--giving you plenty of time to pull out the books and refresh your memory. LANA provides a Candidate Information Booklet (CIB) on the LANA website with an outline for you to use as an exam study guide. Talk with you your therapist friends and form a study group. Becoming LANA-certified is a visible way of uniting our profession, building credibility and promoting the field of lymphedema treatment in the next 20 years. To learn more, visit: http://www.clt-lana.org

*must meet LANA eligibility requirements including 135 hours of Lymphedema training.

March was Lymphedema Awareness Month. And World Lymphedema Day was March 6th. LLN's Board Member Molly Sleigh, OTR/L, CLT-LANA, was recently interviewed on TV in Macon about lymphedema:

MACON, GA (WMGT/41NBC) – According to the Lymphatic Education and Research Network, up to 10 million Americans and hundreds of millions worldwide, suffer from lymphedema and lymphatic diseases.

Molly Sleigh, an occupational therapist at Coliseum Northside Hospital, visited "Daybreak" to talk about lymphedema, its signs and symptoms, and treatment.

Up to 10 million Americans and hundreds of millions of people worldwide suffer from lymphedema or lymphatic disease. Lymphedema is a chronic swelling condition caused by swelling of the lymphatic vessels. It is most often (in the US) seen in cancer survivors following treatment. Often lymphedema is not properly diagnosed, which can lead to delays in treatment and more serious development of the disease.

Lymphedema can affect anyone and everyone. There are two types of this disease: **primary or genetically inherited** malformations of the lymphatic system, and **secondary or acquired** due to cancer treatment, surgery, injury, or immune system insult. Internationally, the most common cause of lymphedema is infection by a parasite called filaria, which can reproduce and build up in the legs, blocking the lymphatic ducts so lymphatic fluid builds up, which leads in severe cases to the condition "elephantiasis."

The most common signs and symptoms are:

1. Excess swelling anywhere in the body due to the causes mentioned above
2. Sensation of heaviness in the limbs, affecting the ability to walk or to do everyday tasks

While there is no cure yet for lymphedema, it can be effectively treated by trained professional therapists. March was Lymphedema Awareness Month – our readers may have seen actress Kathy Bates (who developed lymphedema after having mastectomy surgery for breast cancer) promoting awareness in national media.

If you would like more information, Google-search "Lymphedema Network", which will take you to several excellent resources (including LERN and LLN).

News from our international clinic reporter, Caroline Aguerra, in Peru:

Hello everyone, I hope you are all doing well. Several of my patients want to thank you for your kind donations of compression garments & bandages!

Marcelina Torres, is a very dynamic woman, unfortunately this did not play in her favor as in 2013 she started going to the gym and that was the trigger for a primary lymphedema on both her legs. She unfortunately received poor medical advice and took diuretics that worsened her condition. At least now she has an idea on the "do and don'ts" and is very grateful for the Medi thigh long she received from you.

Rossana Rodriguez’s hand and forearm recently started swelling after a mastectomy done in 2008 (the trigger was too much computer time at work). She is a lawyer and had to wrap-up many cases before a deadline. For her to be able to go on with her typing and have her arm protected, she received a sleeve and a glove, both from Medi. Unfortunately, she came only once, and when I contacted her, I learned that even if she has access to much better medical care than Marcelina, the results were exactly same, because she was treated with electrotherapy which worsened her condition. This depresses me so much. I had given her all the information on what she should be aware of, and one physician in a fancy clinic provided the wrong treatment…

Elizabeth Castro had come to see me in 2012 as arm lymphedema had started to manifest after an oncologic treatment in 2008. With the advice I gave her then and the decompressive exercise routine, she was able to maintain the volume of her arm until now. Her lymphedema is still very slight, but some fibrosis had started to build up in the forearm and was very painful. She thanks you very much for a Medi sleeve with a gauntlet.

Patricia Gonzales del Valle had to travel soon after coming to see me. I did not find her exact size amongst the donation garments, but found a Juzo sleeve that could do for sleeping and for her to have some kind of protection for her upcoming plane flight. She has written these words for you:

Thank you for donating the sleeve that was given to me through Caroline Aguirre. It was given as a means to contain my right arm after a surgery in which I had nodes removed because of breast cancer. My most deep thankfulness for this kindness towards me. I know that you are helping many people like me.
Best Regards,
Patricia Gonzales del Valle Ganoza

It is my turn to wish you all the very best, and send you my very personal regards from Lima!

Caroline Aguirre


Marcelina


Rossana


Elizabeth


Patricia

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 3007*6. 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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