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LLN January 2020 Newsletter

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LLN: Serving the lymphedema community for 27 years

LLN

and



Parker H. Petit Institute for Bioengineering and
Bioscience

Present

Lymphatic Research at Georgia Tech: A Behind the Scenes Tour Saturday, February 8, 10 AM – 12 PM

**Parker H. Petit Institute for Bioengineering and Bioscience
Georgia Institute of Technology
315 Ferst Dr.
Atlanta, GA 30332-0405**

Attendees will tour the research facility with Brandon Dixon, PhD, Associate Professor and Woodruff Faculty Fellow, and graduate students and staff engaged in lymphatic research. There will be a question and answer period after the tour, and light refreshments.

Free of Charge to Attend, but RSVP required!

Important Notes:

Attendees will meet in the Atrium area of the Parker H. Petit Institute for Bioengineering and Bioscience (drop off area in front of building if needed).

Attendees must be 18 years or older.

Attendees must wear close-toed shoes, have their long hair tied up and wear safety glasses (provided by GT).

**** (RSVP to <http://lighthouselymphedema.org/home2/index.php/news-events/all-events/ga-tech-research-facility-tour>)**

Parking instructions and directions at: <https://petitstitute.gatech.edu/directions>

Status Report from the Lymphedema Treatment Act (LTA) website (<https://lymphedematreatmentact.org/>):



“The Lymphedema Treatment Act (LTA) is a federal bill that aims to improve insurance coverage for the medically necessary, doctor-prescribed compression supplies that are the cornerstone of lymphedema treatment. **UPDATE: On 12/12/2019 the Lymphedema Treatment Act was passed in the House of Representatives as part of H.R.3, the House Drug Pricing Bill!**”

LTA will need your advocacy more than ever to get our bill through the Senate. Although H.R.3 as passed by the House is not expected to be taken up in the Senate, there may be a compromise drug pricing bill that combines provisions from both chambers. Or the Senate may choose to put the LTA into another Senate package. All options are currently on the table. **Make Your Voice Heard** by contacting your Senators and asking them to support this important bill. Our advocacy tools under the “How You Can Help” menu on the website to make it easy to take action. Just enter your zip code, and all necessary information is provided.”



LLN BANDAGES & GARMENTS FUND 2020 UPDATE

Now that the Holidays are over, we are coming to the end of the 2019-2020 It's The Journey Grant cycle for our breast cancer patients. We have served 33 patients, spending \$18,363.85 of the ITJ Grant money, and we are waiting for the invoices of the promised money to be used for fitting the patients with compression garments. We are excited to announce the ITJ Grant 2020-2021 has been granted to the Lighthouse Lymphedema Network and will be presented in March 2020. We want to thank board member Shelley DiCecco for her continuous help in writing our grant application.

As always, Rebecca Hammad is taking care of all applicants that are non-breast cancer, and she works diligently with the compression garment companies who graciously give their compression products to the needy patients. We thank all of the companies for their gifts of monies and compression products that go toward fitting the patients with day- and night-wear compression to manage the swelling that occurs with lymphedema. We look forward in working with all the therapists, providers, and compression companies next year to provide the compression products to each approved patient in need.

Please contact me at darnofell@aol.com with any questions or concerns you may have about the BAG FUND assisting a patient with compression garments.

Janie Smith, PT/CLT BAG FUND Coordinator

2020 Lighthouse Lymphedema Network Calendar Dates to Remember:

- LLN Board Meeting, Country Club of Roswell, Saturday January 25th, 9:30 AM
We welcome two new board members who are LLN patients, Sharon Shepard and Ellen Frank
- LLN Fall Lymphedema Education & Awareness medical conference, on Saturday, Oct. 24th, at the same Roam Facility at Perimeter Mall, Atlanta GA as the past 2 years. There will be a training course for therapists on Friday, Oct. 23rd.

From Jobst: A Toledo Tale: The Story Behind Compression Stockings

by Technology team September 25, 2014

BSN-JOBST, Inc.

Twentieth century inventor Conrad Jobst's most important legacy is the development of the compression stocking. Great inventions are often discovered out of necessity, and compression socks are no exception. Jobst Vascular Institute at ProMedica Toledo Hospital tells us more about how Conrad Jobst initially found relief—in a swimming pool, of all places—leading to the design and implementation of today's compression stockings.

How did Conrad Jobst begin to discover the concept of compression stockings?

Jobst suffered from chronic venous disease throughout his life, causing him to have swollen, painful legs and skin breakdown, also known as venous ulcers. He was a tall, elegant gentleman and when he was in a swimming pool, the water pressure on his legs made him feel better. Since he was an astute engineer, he concluded the pressure applied to his legs reduced his discomfort. He developed a mechanism to apply this same pressure outside of the pool, and the result is known today as compression stockings.

How did he make this concept a reality?

Conrad collaborated with a physiologist, Dr. Otto Gauer, to ensure the physiologic principles were correct. They designed compression to be the greatest at the ankle with a gradual decrease in pressure up to the knee. The reason for this specific design is that when a person is standing, the highest venous pressure is at the ankle. Therefore, he wanted to properly counter the internal venous pressure with appropriate external pressure. This design has remained the principle for compression stockings since the time of Conrad.

How do compression stockings help patients?

Since the development of compression stockings, it has been shown that patients with chronic venous disease who wear these garments have reduced swelling, reduced risk of skin breakdown (venous ulcers), with an improved healing when ulcers do exist. Other patients who have lower extremity swelling but who are not classified as having chronic venous disease can also benefit from elastic compression stockings. The stockings apply pressure to the outside of the legs, which prevents fluid accumulation in the tissues, thereby decreasing swelling. People benefit the most from compression stockings when they put them on first thing in the morning, wear them throughout the day and take them off before going to bed. Studies have shown that compression stockings improve venous return of the lower extremity. As a result of that, many patients see improvements.

What conditions can compression stockings alleviate?

The conditions that the stockings are particularly helpful with are chronic venous disease, sedentary or inactive patients who spend the majority of time with their legs hanging down, patients with congestive heart failure sufferers which results in failure who have lower extremity swelling, and other medical conditions that result in swelling of the legs. Individuals who are taking long, multi-hour flights, over five hours, where they are sitting still with very little movement can have an increased risk of blood clots and will experience swelling in their lower legs. Compression stockings will help reduce swelling and reduce the risk of blood clots in these individuals taking long flights.

Prior to Conrad Jobst's invention, what was the alternative?

Conrad suffered with severe venous insufficiency and developed advanced ulceration of his legs. Some physicians recommended amputation since "there is little we can do." So before Conrad, there were no commonly available alternatives. As mentioned earlier, Conrad Jobst recognized that he experienced great relief when in his swimming pool, and reasoned it was due to the external pressure of the water. He thought that suitable external compression was an excellent argument in favor of combating the congestion in his legs. He reasoned that the essential characteristics of an effective stocking would be:

1. Perfect fit.
2. Made exactly for the leg involved.

3. Provide elastic counter pressure, which cancelled the pressure produced by the diseased veins.
4. Required a fabric with proper elastic properties
5. Ultimately developed a pattern to properly construct the stocking.

What was Conrad Jobst's reputation in the medical community?

His biomedical contributions were becoming recognized in the field of medicine, papers were appearing in medical journals, and compression treatment was gradually being accepted by the medical profession. Unfortunately, Conrad Jobst died before the custom-made Jobst venous pressure gradient stocking gained general acceptance. We are indebted to Caroline Jobst for carrying the work of Conrad forward. Caroline grew the Jobst company into one which was nationally and internationally recognized for its excellence in quality and service.

LLN BOARD MEMBERS AT OUR CHEERING STATION TO SUPPORT PARTICIPANTS IN THE ANNUAL **IT'S THE JOURNEY** 2-DAY WALK



L-R: Deb Cozzone, Laurel Sybilrud of ITJ, Peggy Meyer (rear), Laura Hoffman, Jackie Echols

LLN International Activities Update - We have sent a box of gently used compression garments and bandages to Ghana, where they will be gratefully accepted and used!

From our colleague Caroline Aguirre in Peru:

Dear Lighthouse Network, hello from Lima Peru!

I am not a "Facebook person"... but I must admit that after opening an informative-only page on lymphedema on that social media, where I just translated and present information, I have received quite a number of likes even without advertising the page, and I get to answer to many questions via messenger through that page. So if you have a Spanish speaking person in need of information you can direct them to: <https://www.facebook.com/LINFEDEMAinformacion> .

I am pleased to send you a glimpse of some of the people you have helped this year. They all thank me, and I thank all of you at LLN and the vendors who made this possible.

Maya Saéñz had a mastectomy in 2007 and never really thought about her arm, until it started swelling noticeably this year after the beginning of an oral chemo treatment. She is still in treatment and it is almost impossible to have the necessary time for continuity in order to do an intensive course with her, but she is so positive, enthusiastic and looking forward to it that it is a pleasure to work with her, and as soon as the frequency of her medication diminishes, she is committed to working seriously on her arm! She did go to other therapists and was starting to get desperate, as she did

not notice any improvement. So when she met me and immediately felt relief with the use of a correct technique (my eternal thanks to DeCourcy Squire!!!) and your help with providing the correct garments, she was ecstatic.

"Dear Mrs. Aguirre

I want to thank you very much for the manual lymphatic drainage. I feel very much relieved! At the same time, I also want to thank you for all the information that you provided to me regarding the compression therapy, which I am pretty sure will be of great importance for the success of the treatment. I appreciate that you gave me the Mediven arm sleeve and the glove with fingers. They are very comfortable and allow me to do my daily household chores.

With my best regards, Maya Sáenz"

Elisa Sarmiento is a ceramist, artist and renovator who has primary leg lymphedema. It is not very pronounced but is starting to cause greater discomfort as she has to lift heavy weights, as she is the only caretaker of her elderly mother who is now bedridden. There was no way to consider in this case any kind of regular treatment as she is 24/7 at the disposal of her mother and has no time left for herself. So she just received all the information she needed, one manual drainage, and the basic garments (a thigh-high Medi and Juzo panties) she requires to protect herself the best as possible in these conditions.

"Dear Caroline,

Thank you for the help I have received treating my legs. From the first day after the treatment, I felt a great improvement. The donated panties and stockings are helping to ease the pain in my limbs, and I trust that progressively these will benefit my health. Thank you very much for your help and count on me for anything useful I can do in return.

Regards, Elisa Sarmiento Pastrana"

As you know, you have given me several knee-high Jobst garments that I cannot use for lymphedema patients, but one of the beneficiaries of those is Carmen Rodriguez, an active woman who has venous swelling of the lower leg, combined with a thrombosis in 2018, and permanent tingling and burning sensations on the skin. (She had to have some veins removed as they were so wide they did not function properly.)

"Dear Caroline,

With this letter, I would like to express my thankfulness for the anti-thrombus garments that you so kindly gave me the day I went to your practice for a lymphatic drainage session. Some months ago, I underwent surgery to remove varicose veins in both my legs; the recommendation and the treatment given by my surgeon-cardiologist Dr. Akira Tsuha, was that I had to use continuously these kinds of products. I thank you once again for the kind gesture you had for me.

Regards, Carmen Rodríguez de Flores"



Carmen

Maya

Elisa

With kind personal regards to all of you,

Caroline Aguirre

IMPORTANT NEWS ABOUT LYMPHEDEMA SURGEON DR. WEI CHEN:

Dr. Chen, who has given presentations on microsurgery and lymphedema reconstructive surgery at LLN's Fall Conferences (and has performed this surgery on several LLN patients), has relocated from the University of Iowa to the Cleveland Clinic in Cleveland, OH. He is taking the position of regional head of reconstructive micro- and super-microsurgery and co-director of the Center for Super-microsurgery and Lymphedema Reconstruction.



Wei Chen, MD, plastic surgeon who treats lymphedema

In a May 2019 interview with LE&RN (<https://lymphaticnetwork.org/news-events/wei-chen>), Dr. Chen was asked: **What does the future look like for lymphatic surgery?**

“Some of us are now harvesting just lymph vessels and sparing the lymph nodes. It seems counterintuitive that you’re going to treat someone’s LE by harvesting more lymph nodes. Instead, the premise and the goal of lymph vessel transfer means we no longer need to take the lymph nodes. We’ve been doing lymph vessel transfer for four years now. In January 2018 we presented our results for the first time and people were shocked. They were finally accepting the lymph node transfer and now we were telling them they didn’t need nodes to treat LE. We don’t know the precise mechanism of how the vessel transfer works. We have seen the efficacy of these procedures (they work well) and now we need to go back and find out why. But that’s why micro surgery is required. And what we could do 20 years ago compared to what we’re doing now is amazing.”

How has breast cancer affected you? You can help researchers learn about the impact of breast cancer treatment.

The Dr. Susan Love Foundation is now enlarging the ongoing the LOVE Army of Women Study to include all women with any stage of breast cancer, with or without breast reconstruction. The study is open to all women anywhere in the US diagnosed with any stage of breast cancer (stage 0 – stage IV) who underwent any treatment for breast cancer. Participants simply fill out an on-line questionnaire. The BREAST-Q is a questionnaire used around the world in patient care and research, and it measures quality of life and breast satisfaction. In this study, researchers are testing 5 new scales relevant to all breast cancer patients and 7 new scales for women who develop arm lymphedema. These new scales will make it possible for researchers and health care providers to better understand the impact of breast cancer and lymphedema on quality of life.

Use this website to join the study:

<https://redcap.partners.org/redcap/surveys/?s=P4E4THL3AC>



Saving Our Arms: Bilateral Lymphedema Myths and Prevention

By Sharon S. Shepard, LLN Board Member

Since my diagnosis of bilateral early stage breast cancer in 2017, I have encountered a series of myths concerning lymphedema prevention. These myths prevail in a medical community where lymphedema is barely covered in medical and nursing schools. As a patient, the myths have affected my care. As an advocate for other patients, I am disturbed by medical providers' lack of knowledge and concern about lymphedema.

The obesity myth was the first and most destructive idea that affected my treatment. My surgeon had just read about a scientific study that appeared to link lymphedema to obesity. Because I am not obese, she said I needn't worry about lymphedema. My surgical nurse repeated this myth as she was blowing veins in my left arm trying to start an IV before surgery. My surgeon removed the standard three sentinel lymph nodes from each armpit, though there were no signs my tiny breast cancers had spread to any lymph nodes. Feeling good after my surgery, I drove myself to yoga class the next day, to prevent obesity. I skipped the arm exercises.

I thought I had immunity from lymphedema. I used both arms carefully to take care of myself and my family. We were preparing to move to Georgia from North Carolina, and there was much physical work to do. I felt guilty asking for help from friends and family. I developed seromas (a pocket of clear serous fluid that may develop in the body after surgery) under both arms and treated them with ice and heat until a physical therapist relative told me not to use heat. My surgeon drained the seromas, but still did not warn me about lymphedema. She did advise me not to lift or exercise until I healed.

When I finally received training from a Certified Lymphedema Therapist three weeks post-surgery, the truth about this condition swept away other myths about lymphedema. It is not:

- Rare - It affects more than 10 million Americans, at least 30% of cancer patients.
 - Unpreventable – Reducing stress on the lymphatic system does help.
 - Caused by obesity, though adipose tissue makes it harder to diagnose and treat.
 - Psychosomatic – Patients do not get lymphedema from worrying about it.
 - Temporary – This is a life-long concern, especially as my tissues age.
 - No Big Deal – At best, lymphedema prevention affects quality of life for every cancer survivor.
- Lymphedema can be debilitating and life-threatening without treatment.

I am grateful for the training which helped me identify my lymphedema in early stages and seek treatment. Unfortunately, the CLT did not have a protocol for bilateral prevention of medical procedures, like blood-pressure checks, blood-draws, injections and IVs. The advice for bilateral patients was to take turns with the arms on these procedures – “playing Russian Roulette” and hoping not to get lymphedema. Instead, I made a “Sophie’s Choice,” sacrificing my non-dominant left arm. I also realized instinctively that a previous fracture of my right arm would be a risk factor for lymphedema.

Gradually, I discovered alternatives to the use of arms for medical procedures. An oncology nurse remembered patients asking for blood pressure checks on the leg, though this isn't standard procedure. I looked up the method online and have taught many nurses how to take an ankle blood pressure. This creates an awkward beginning to every healthcare visit, but I am learning to handle the situation without getting upset.

Nurses have attempted to draw blood from my feet, with painful and humiliating results, especially as they do not understand my concerns about lymphedema. The same study that suggested lymphedema is caused by obesity also eliminated needle sticks and bilateral breast cancer as risk factors. I explain to nurses that a blown vein or infection could stimulate my lymphatic system. Some seem to think I am over-reacting, hyper-vigilant, or unnecessarily anxious about a rare condition they cannot see.

Standard laboratories do not allow blood draws from anywhere but the arms, but hospital labs have phlebotomists who are skilled at drawing from other places. With my fragile veins, I have learned to ask for a phlebotomist who draws from babies and fragile patients in the hospital. But I fear an accident where I wake up in an emergency room with IVs creating lymphedema in both arms. And I know any future surgery will require complicated explanations and IVs.

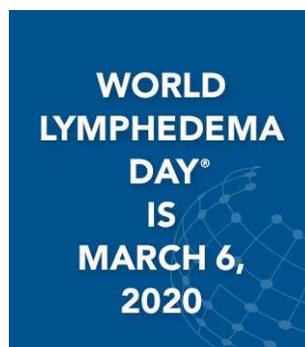
In the current climate, the burden is on patients to prevent lymphedema, though many are less educated than their medical providers about risks and prevention methods, especially in the crucial first weeks after surgery. Patients also might be too shy, embarrassed, forgetful, or sick to tell nurses about their risks for lymphedema. And when a patient does advocate for lymphedema prevention, medical providers are likely to push back with lymphedema myths - fat-shaming the patient, prescribing a diuretic, or suspecting an anxiety disorder. Both the burden and the blame can be placed on the patient, for a condition created by medical procedures.

Bilateral breast cancer should be abbreviated BC² instead of BCx2, because the lymphedema consequences are exponential, not merely doubled. Every lymphotomy survivor, but especially someone with additional risk factors like BC² or obesity, needs early lymphedema prevention training and a written protocol to share with medical providers. And our surgeons and nurses need accurate information about lymphedema and its consequences, not myths based on flawed interpretations of a scientific study. As more early stage BC² patients are discovered through MRI and improved mammography, lymphedema prevention needs a higher priority.

Illustrating a problem is often the first step to solving it, so I tell my story to explain, not complain. I have been lucky in many ways – to discover my cancers early, have an excellent prognosis, and have the education and resources to manage my chronic lymphedema. My doctors relied on decades of research and the experiences of millions of cancer patients to give me modern care. As we look to the future, I hope greater understanding of lymphedema and its prevention will result in an even better quality of life for all survivors. Women need healthy arms to take care of ourselves and our families, do our jobs and serve our communities. For all we do, healthy arms are vital.

Question for our therapists: "Does a bilateral breast cancer patient have to play "Russian Roulette", taking turns having medical procedures such as blood pressure and blood drawn on each arm, while hoping to not develop lymphedema?"

Therapist Shelley DiCecco, PT-LANA, PhD responded: "Unfortunately, when the patient's breast cancer is bilateral, medical personnel typically will use the least involved side (unless they are doing a procedure that is side-specific). Yes, they technically could use the legs or other body parts- but realistically, most facilities are not equipped or personnel knowledgeable enough to know how to use an alternative site. This is where the therapist needs to educate the patient on which side should be used, how to care for the arm post-procedure, and how to watch for adverse signs so they can be addressed immediately."



LE&RN reminds us: "From its beginnings in 2016 when it was officially established in the New York State legislature and in the U.S. Senate, World Lymphedema Day, March 6, has developed into a truly global movement. As in past years, advocates around the world are planning events to recognize the day. You can join them!" See <https://lymphaticnetwork.org/wld>

2019 Donations to LLN

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Laura Hoffman
Trinity and Jonathan Maiden
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Carson Sollenberger
Beverly Thompson
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Grant:

It's The Journey Inc. (Georgia 2-
Day Walk for Breast Cancer)

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

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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 _____

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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

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