Lighthouse
Lymphedema
Network

www.lighthouselymphedema.org

LLN January 2021 Newsletter

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LLN: Serving the lymphedema community for 27 years

The Lighthouse Lymphedema Network Will Conduct Virtual Training Sessions for Lymphedema Therapists and Patients This Year!

Given the necessity of cancelling all in-person conferences until the population can become appropriately vaccinated for COVID-19, and following the success of our virtual Fall Medical Conference last October, we have decided to conduct training sessions as webinars by Zoom to help our lymphedema therapists everywhere earn their Continuing Competency Hours (CCHs) more easily in 2021 – and to help our patients more easily and frequently learn valuable new information about managing their lymphedema treatment. Dr. Shelley DiCecco, an LLN Board member, will conduct the training.

Our first virtual seminars for therapists and patients will be Saturday, Feb. 20th , and the topic will be "Let's Get Physical – Updated Manual Lymphedema Drainage (MLD) Techniques for Therapists & Patients." You must pre-register to participate.

The intensive presentation for Therapists will be held first on Zoom from 10:00-11:30 EST. Each class will cost $25, and participants will be given instructions for obtaining their CCHs. Register and pay securely by credit card at our website *www.lighthouselymphedema.org*.

On the same day, we will repeat this topic (in a less-intensive format) for patients, at no charge, from 12:00-1:00 EST. General questions will be handled at the end of the session. Patients should also register separately at our website *www.lighthouselymphedema.org*.

If you are not familiar with Zoom webinars, you will be sent information about how to download the free app to your PC, tablet, or phone from www.zoom.com. It's very easy! Then, we will send you the link to join the meeting at the start time for your webinar. You will participate with your microphone muted, and you will be able to send questions, which will be collected during the presentation and answered at the end. (Here is a very good and easy tutorial on using Zoom: https://www.aarp.org/home-family/personal-technology/info-2020/how-to-use-zoom.html).

If we have a good response with our first webinar, we plan to do others in May and August. Potential topics include "Compression Bandaging: Basics to Advanced" and "Down the Drain, A Refresher Course on Normal Drainage for the Whole Body to Help Guide Treatment."

Shelley Smith DiCecco, PhD, PT, CSLT, CI-CS

Our webinars this year will be presented by Dr. Shelley Smith DiCecco, a graduate of Clemson University with a BA in Special Education, with a Master of Physical Therapy from the University of St. Augustine, and a Doctorate in Physical Therapy (with her dissertation emphasis on female genital lymphedema) from Texas Woman's University. Dr. DiCecco became a Woman's Health Specialist for pelvic floor disorders in 2000 and a Certified Lymphedema Therapist in 2001. She completed her Lymphology Association of North America (LANA) Certification in 2013 and her Casley-Smith International Lymphoedema Instructor Certification in 2016. She started the lymphedema education company, LymphEd, LLC in 2017. Dr. DiCecco assisted with, or led several continuing education courses, conferences, and seminars, as well as presented at community events on lymphedema, pelvic floor disorders, and other orthopedic conditions over the years, both nationally and internationally. She has published articles on lymphedema and pelvic floor disorders. She is working on cadaveric research on the lymphatic system in Atlanta and is consulting on quality of life research for lymphedema internationally. She holds many different positions; she is the Director of lymphedema and pelvic floor services at The Sports Rehabilitation Center in Atlanta, GA; she is an Assistant Professor at the Georgia's Campus for the Philadelphia College of Osteopathic Medicine in the Physical Therapy Department; she is the Vice President for Casley-Smith International; and she is the LLN's lead grant writer and contributed a chapter in LLN's book on lymphedema, *The Puzzle: An Inside Glimpse of Lymphedema*. She is a member of the American Physical Therapy Association and its Oncology, Women's Health, and Education Sections, and is a member of LANA, the Lymphoedema Association of Australia, the Casley-Smith International Group, the lymphedema round table for therapists in Atlanta, and the pelvic floor therapist in Atlanta group.

Lymphatic Education
& Research Network

From LERN President & CEO William Repicci: An Update

We asked LE&RN supporters to send us stories about living with lymphatic diseases and this community came through. We shared these with Congress. LE&RN advocates then made calls and sent emails and letters to their Congressional representatives during LE&RN's Lobby Week. Many of you took part in stakeholder calls to Capitol Hill with Kathy Bates, Dr. Tim Padera, Kelly Bell, Dr. Stan Rockson, me, and others. On December 21, the US FY2021 Appropriations Bill passed and we succeeded in securing the strongest language calling for the establishment of a National Lymphatic Commission on Lymphatic Diseases. We also succeeded in our request for a $1.5 million competitive grant program for Chronic Disease Education and Awareness at the Centers for Disease Control (CDC), with lymphatic diseases the only disease specifically mentioned. (See below for the official bill language.)

BUT: The Lymphedema Treatment Act itself failed to be passed this year - January 3rd, 2021 will mark the start of the 117th Congress. We came so close to seeing the Lymphedema Treatment Act signed into law this month and will continue to persevere until the bill is across the finish line!

Persistence and Patience Really Do Pay Off

By LLN Board Member Debbie Labarthe

My personal connection to lymphedema began in 2004, when my grandson, Carson (then 13 months old), was finally diagnosed with primary congenital lymphedema in his leg, pelvis, and abdomen. Six months later, he and I joined a few LLN Board members at the GA Capitol as Governor Sonny Perdue signed a Proclamation declaring an annual statewide Lymphedema Awareness Day in Georgia. This was Carson's first appearance as a patient advocate. Then, in 2010, we met the fierce lymphedema warrior, Heather Ferguson, when she was a speaker at our annual LLN Conference and shared her vision for national legislation to amend the Medicare law by closing the coverage gap on doctor-prescribed compression supplies for lymphedema patients. She later founded the grass-roots organization, the Lymphedema Advocacy Group (LAG), and our paths would cross again.

In 2016, Carson and I made the first of three trips to Washington DC to participate in LAG's annual Lymphedema Lobby Days, and we met with our state Representatives and Senators to advocate for the Lymphedema Treatment Act (LTA). In 2017, the day after Lobby Days ended, Carson and I personally met Senator David Perdue at a constituent event at which time Carson shared the highlights of his lifelong journey with lymphedema and the effectiveness of compression supplies. He explained the purpose of the LTA and asked Senator Perdue for his support. Unfortunately, Senator Perdue did not cosponsor the LTA during that Congress, which was very frustrating and disappointing, but we were determined to keep trying. In 2018, we attended Lobby Days again. By October of that year, all 14 Georgia Representatives had cosponsored the LTA. We were pleased with that milestone, but disappointed that we were unsuccessful in gaining the support of either GA Senator. In late 2018, while viewing pics and news on a social media platform maintained by Senator Perdue's staff, I learned that GA Senator David Perdue and [former] GA Governor Sonny Perdue are cousins! I retrieved the 2004 photo of Carson and I posing with Governor Sonny Perdue and thought that Senator Perdue would enjoy knowing that we had met his cousin at the GA Capitol in 2004 when Carson was just a toddler advocating for lymphedema patients. The next time I emailed Senator Perdue's Health Legislative Aide (HLA), I included that photo and requested that she share it with the Senator. (This photo from 2004 would eventually be mentioned again.) In 2019, my husband joined me for Lobby Days. Once again, all 14 Georgia Representatives cosponsored the LTA, but neither of our two Senators cosponsored it. I was unable to attend Lobby Days in 2020, but I continued with emails and phone calls to the HLA to encourage the Senator's support. As a Georgia constituent, I was also able to participate in a telephone webinar with Senator Perdue this summer, which was coordinated by Heather Ferguson and Capitol Counsel. I reiterated the importance and rationale of the LTA, then followed up with a few more emails and phone calls.

Since 2016, there have been lots of emails, phone calls, feelings of confidence and success, and times of frustration. But we never gave up. We just became more driven and motivated each year. The payoff for our perseverance finally occurred on November 30th, when I received an email from Senator Perdue's HLA, stating that he would be cosponsoring the LTA. When I sent a 'thank you' email to the HLA, I stated how pleased we were to receive the news of the Senator's decision and how we had looked forward to that news since 2016. The HLA's email reply was "I would say it goes even further back with Carson's picture with Sonny (which I believe was in 2004?)! I have shown that photo and his with Carson to Senator Perdue many times to remind him of those back home struggling with lymphedema." This experience has made us feel that our persistence and patience truly paid off.

Shepherd Center

A Report by Rebecca Hammad, MHS, OTR/L, Therapy Manager in the Post-Acute Program at Shepherd Center, Atlanta, GA

Spinal Cord Injuries, Acquired Brain Injuries, Multiple Sclerosis, and other neurological conditions often have several factors in common: onset of impaired mobility (movement), impaired sensation (feeling), and impaired cognition. So why, you may ask, are we mentioning neurological impairments in a lymphedema newsletter? Well, paralysis (full or partial) impairs the body's ability to move fluid. This decreased ability to move fluid is largely due to the loss of muscle pump. This can lead to the accumulation of swelling in the arms and legs. A limb that has impaired movement is more difficult to move when it is weighed down with excess fluid, making rehabilitation after a brain or spinal injury even more difficult. Fluid that is not removed may damage the lymphatic system over time and this initial accumulation of fluid can lead to lymphedema.

When a certified lymphedema therapist (CLT) is managing lymphedema with complete decongestive therapy (CDT), the therapist relies on a patient's mobility and sensation for successful treatment. A patient needs to move around during a treatment session, perform exercises, and learn self-manual lymphatic drainage and self-wrapping. Additionally, sensation is necessary to give feedback to the therapist while being wrapped. For example, if a compression wrap is applied too firmly and circulation is impaired, the patient would experience numbness/tingling and could report these symptoms for the wrap to be modified or removed. But the absence of sensation makes applying this treatment an inherent risk, because the patient would be unaware of a wrap being applied too firm.

So, we are left with a conflict: paralysis may lead to accumulation of swelling, but lack of sensation in a limb is a risk factor for applying compression.

Therefore, in 2013 we set out to modify the traditional approach to CDT to manage swelling after paralysis, while reducing the risk of applying compression to a limb with absent sensation. In 2018 we published our results in the peer-reviewed journal *Spinal Cord*, the publication for the International Spinal Cord Society. Here is the link to the full article at no charge: https://works.bepress.com/rebecca-hammad/

Key points for the CLT's: Paralysis is NOT a contraindication for managing edema with complete decongestive therapy. However, there are important considerations and modifications that should be applied. Modifications include increased padding layers to protect the bony areas with application of fewer layers of short stretch compression.

Specifically related to padding, add the following items:

1. Longitudinal padding along tibia/top of foot
2. Built-up padding behind the ankle to reduce pressure on the heel by filling in this posterior space
3. Toe wraps applied outside of foot padding vs directly on the skin

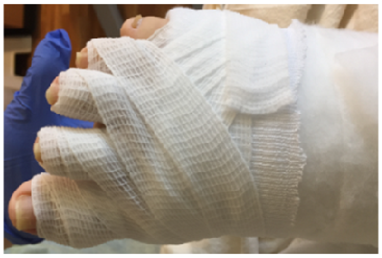
Specifically related to compression bandages:

1. Apply <u>fewer</u> layers of compression bandage. For a below-knee bandage application, recommend 3 layers on foot, 2 layers across ankle to calf, and 1 layer just below knee.
2. Do not use a herringbone (crisscross) pattern when applying the compression bandage across the ankle bend.

Wheelchair positioning modifications:

1. Open the angle of the wheelchair foot plate to decrease the bend of the ankle (decreased dorsiflexion). This will decrease pressure from the compression wrap at the ankle bend.
2. Perform brief "weight shifts" away from the bent ankle position periodically throughout the day by positioning the foot off the wheelchair footplate into plantar flexion to relieve the pressure at the bend of the ankle.

(See next page for more)


We had planned to share this information and more during the October 2020 LLN conference, but with the program being adjusted to a one-day virtual program, the LLN asked us to write a summary for the newsletter. This summary is really just a glimpse into what we are learning and we hope to be able to share our work in presentation format at a future conference. Until then, all our best in 2021!

Harley Smith was a patient at the Shepherd Center; we asked him to tell us his story:

“I grew up in Decatur, GA, and I was very athletic and competitive. I have three children and all of them are a big part of my life. I am married to my wife Christa who is a wonderful friend and life partner.

On July 5, 2012 I had a trampoline accident which left me quadriplegic, with basically no feeling or circulation in my body below my chest area. One of the complications that I began to have was swelling in both of my feet, ankles and calves. The swelling occurred during the day and became so extensive that I couldn’t even put my shoe on. I had to take the shoelaces out of my shoe so that I could get my foot in to wear it. When I went to my doctor about this problem, she asked me if I had a blood clot. I was sent for an ultrasound test but it came back negative for a blood clot. On one of my visits, my doctor looked at my foot and calf, and said ‘I’m concerned that this may be lymphedema.’ She put in a referral for me to get lymphedema therapy at Shepherd Center.

Shepherd Center‘s lymphedema management process taught me exactly what I needed to know to control and manage my lymphedema, and it truly changed my day-to-day life. I’m so thankful to have experienced Shepherd’s lymphedema therapy program.”

LLN BANDAGES & GARMENTS FUND UPDATE

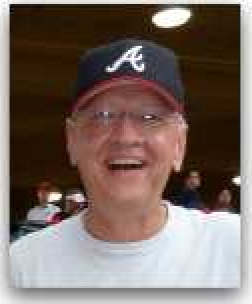
From Janie Smith, PT, CLT, our BAG Fund Co-coordinator:

Happy New Year! As we go into the New Year 2021, we are heading into our last quarter of our grant money from It’s The Journey. Because of the slow year we had in 2020 due to the COVID pandemic, the second half of our grant money was just recently awarded. We look forward to any and all qualifying grant applications so that we can fill the need for compression garments for indigent lymphedema patients. We have had a few successful fund raisers for the non-breast cancer patients and generous gifts from our garment providers. As always, we thank our DMEs for all the monetary and garment gifts that they provide to the needy patients. Rebecca Hammad, MHS, OTR/L continues to serve all non-breast cancer patients. We look forward to working with the therapists, DMEs, and garment companies this coming year to provide much-needed compression garments.

The BAG Fund also received generous donations from Angelo Rizzo of Therapeutic Solutions and DeCourcy Squire – these donations will be added to the BAG Fund to extend our capabilities this year.

Please refer all concerns or questions to darnofell@aol.com.

In Memoriam for our Long-time Board Member, Larry Ashmore, PhD



On Saturday, December 19, 2020, Dr. Larry E. Ashmore passed away at the age of 68 after a 12-year battle with cancer. After learning about LLN from his physical therapist, Larry joined our board and served as our treasurer for many years and also did LLN’s non-profit IRS filings.

Larry was our LLN Volunteer of the Year in 2015. We noted then: “"Every year at this time, we recognize one of our own who has shown exceptional service to the LLN. The person we recognize this year has served as the LLN treasurer for several years. After his cancer surgery, he developed lymphedema in his arm from an infected port for chemo delivery. His positive attitude and happy smile has seen him through two reoccurrences. You will see him at our conferences with his iPhone and credit card “Square”, which he will happily use if you purchase a basket or other item being sold today to help our patients through our Bandages and Garment Fund. We recognize Larry Ashmore for his service today as our 2015 Volunteer of the Year.”

Larry was born in 1952 in Atlanta, Georgia and was married with three daughters. He spent much of his working career at SunTrust Bank as an internal auditor. While working there, Larry attended Nova Southeastern University, where he earned a Doctorate in Business Administration. He was licensed in Georgia as a CPA, and as an accomplished business leader, he followed his dream to become a professor, and taught for the Masters of Accounting program at Georgia State University and was also a member of the Advisory Council of the University's School of Accountancy. During his career at GSU, Larry had the opportunity to lead a group of students to the Annual Georgia Internal Audit Case Competition, where his team went on to win the event. He additionally worked part-time with the public accounting firm, Kilpatrick, Rea and Associates in delivering assurance and tax services. Larry retired from SunTrust Banks, Inc. in 2012, after 25 years, serving the last several years as Senior Vice President and Managing Director of Audit Services. His earlier professional career included the firms Ernst & Young and KPMG.

Board member Deb Cozzone added this note: “Larry revolutionized the way we were banking, by separating funds into separate accounts that more closely aligned with our initiatives. He almost single-handedly managed the audit of our 2014 financials, which was very detailed and time-consuming. He was a professional, offering excellent advice for improvement in our financial practices and processes. He was forever patient with me as he provided me more responsibilities for the payment of BAG Fund invoices through the electronic banking system. He always had a smile on his face and he was an intelligent, compassionate, loving and kind man. He always found time for a kind word and thoughtful questions for our volunteers at the LLN conference. His lust for life (whether riding his motorcycle, loving his family or serving others), his faith and his strength in the face of adversity will leave a legacy for all who knew him.”

The LLN Board members will deeply miss Larry - he helped us make a difference helping others.

News from our long-time supporter, Southern Loss Association: The Southern Loss Association’s annual Golf Outing was held October 14. The LLN was the charity of choice for this outing, and we sincerely thank SLA for their generosity. The SLA board later voted to permanently name the spring golf outing “The Larry Hart Memorial Golf Outing," which will assure the LLN of continued support from the SLA.

Donations to LLN in 2020:

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Diana Cole
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Grant:

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

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Thank you, Lighthouse Lymphedema Network:

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Enclosed is my tax deductible donation of $_________, to be used for the General Fund _____, or the B.A.G. Fund ________

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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**.

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1625 Sprucewood Court
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