Lighthouse
Lymphedema
Network

www.lighthouselymphedema.org

LLN January 2019 Newsletter

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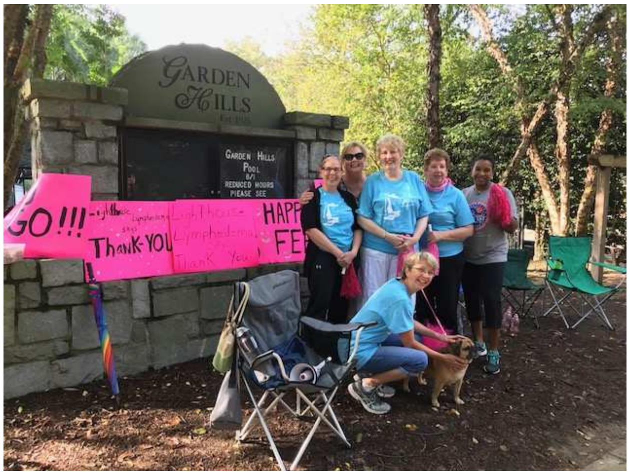
LLN: Serving the lymphedema community for 26 years

The 2018 Georgia 2-Day Walk for Breast Cancer was held on September 29-30, 2018. LLN had a cheering station for the walkers on the 29th!

GEORGIA
2-DAY WALK
FOR BREAST CANCER



LLN Board members who participated were (right photo) seated: Deb Cozzone: back: Janie Smith, Laura Hoffman, Joan White, Peggy Meyer, & Jackie Echols. In the left photo, the folks wearing the red & gray shirts work for Travelers Insurance and ITJ director Laurel Sibylrud is wearing a black shirt.

The Lighthouse Lymphedema Network members and friends from Travelers Insurance cheered on the walkers in the Georgia 2-Day Walk for Breast Cancer sponsored by It's The Journey. We were in the charming neighborhood of Garden Hills, supporting this outstanding organization dedicated to providing much-needed funds for breast cancer screening, research, early detection, diagnosis and supportive services in Georgia. With the generous and dedicated support of donors, participants, and volunteers, ITJ has raised over $14 million and awarded 335 grants for vital breast health services in over 100 counties. The Lighthouse Lymphedema Network is proud to be one of the grant recipients from the generosity of It's The Journey. *(See our Bandages & Garments Fund report for a description of how we have used our grant money.)*

LLN BANDAGES & GARMENTS FUND 2018 UPDATE

The Lighthouse Lymphedema Network's Bandages and Garments Fund, through the 2018-2019 grant from (ITJ) It's the Journey Inc., has provided assistance to thirty-four breast cancer patients. We have nine more patients who are in the queue to receive their garments after treatment. We have reached six new counties with this year's ITJ grant, and now have reached a total of 71 counties in the state of Georgia. This would not be possible without the certified fitters and the garment providers who have applied in the interest of their patients. We thank all of you for reaching out to the LLN and letting us be a part of your patients care through the gracious grant money provided by ITJ.

In addition to our grantors, It's The Journey, Inc., and Komen Greater Atlanta, we heartily thank all of the garment manufacturers, garment providers, Certified Lymphedema Therapists, and other organizations and individuals who have supported the Fund with products and money. We also sincerely thank Lohmann & Rauscher for their $3,500 donation in products for the BAG Fund, the Gloria Watts-Cox Foundation which donated $600, and our other vendors who have provided products throughout the year.

Rebecca Hammad continues to help the non-breast cancer patients with their garments. Through her diligent efforts to use donated products from our vendor sponsors, she has been able to fit many patients this year. We cannot adequately express the gratitude these patients have in their time of need to receive these vendor-donated garments.

We look forward to working with everyone next year with anticipation that the ITJ will grant our 2019-2010 funding application. To date in 2018, we used $14,721.07, and with nine applicants still in our queue, we have promised $4,800.00 more. We will always have an amount that will come back to us in the BAG Fund, so patients may continue to apply for the chance we will have monies left through the month of February with the current ITJ grant. If you have questions or concerns, please contact Janie Smith at darnofell@aol.com.

Actress Kathy Bates and Lymphologist Dr. Stanley Rockson on the "Dr. Phil TV" show

Thursday, January 3, 2019

You could see that Dr. Phil McGraw and award-winning actress Kathy Bates have a genuine friendship. Kathy won an Oscar for her role in "Misery," and she has appeared in many films including "Fried Green Tomatoes" and "Titanic." Her roles on TV include "The Big Bang Theory" and "Harry's Law." She was diagnosed with breast cancer just as "Harry's Law" was cancelled, and she was also diagnosed with ovarian cancer in 2003. She decided to have bilateral removal of both breasts because "breast cancer runs like a river in my family" (likely due to the BrCa gene). She was scared about developing lymphedema because her boyfriend at the time had it, and his arm felt like wood and at times would leak.

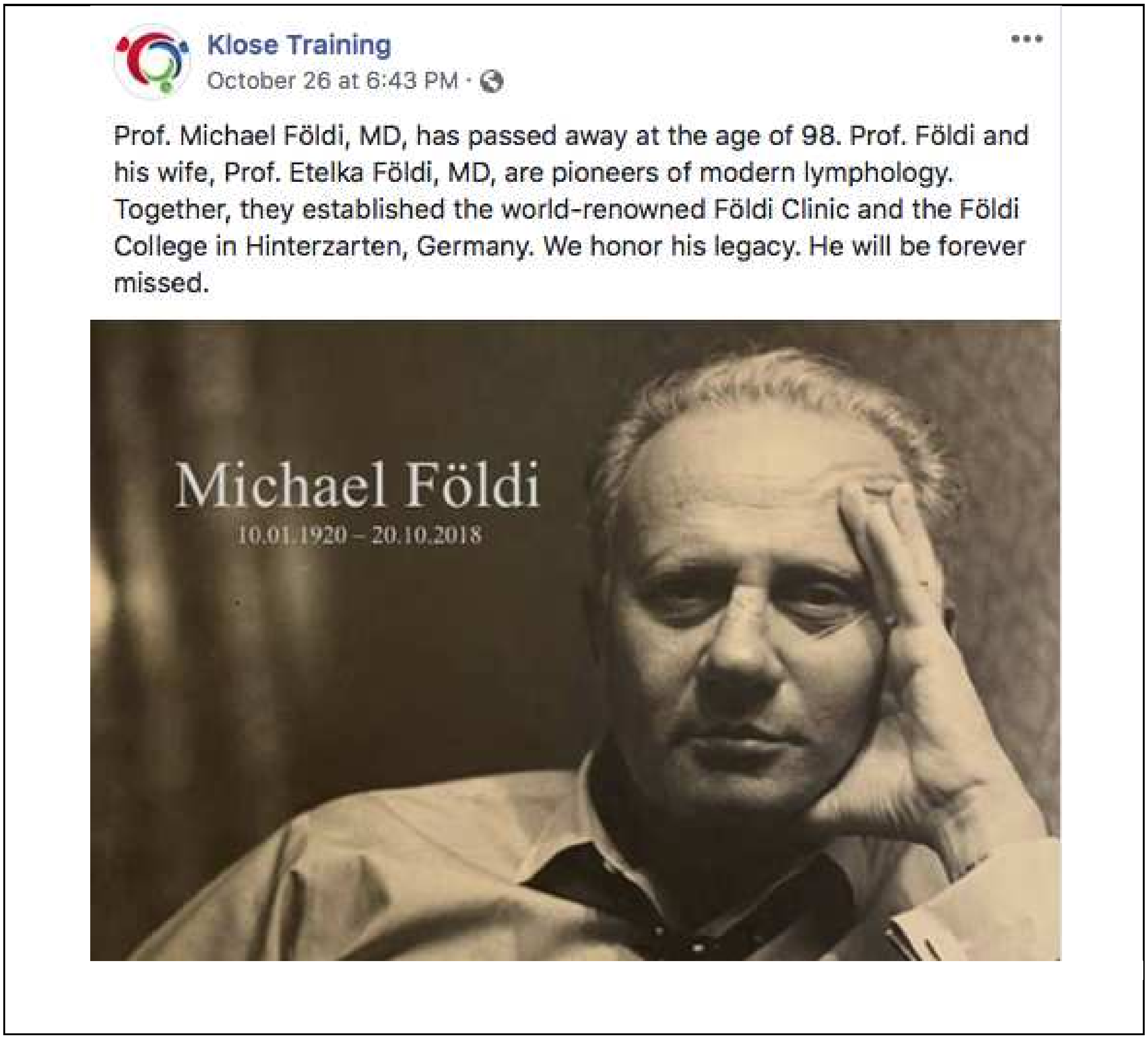
Kathy now serves as the national spokesperson for the LE&RN, and has talked to members of Congress as an advocate for the National Lymphedema Treatment Act and better medical awareness of lymphedema. She said "The last 5 years of my life have been the best 5 years of my life".

Did you know that there are more lymphedema patients than MS, ALS, Parkinson's, and AIDS combined? The average physician only receives approximately 15 minutes of study in school about lymphatic disease. Ms. Bates told of a patient going to his doctor, concerned about the swelling, but he was advised to go home and "do exercises." Dr. Phil explained how primary lymphedema (has a genetic component) and secondary lymphedema differ (usually acquired).

Dr. Stanley Rockson, Stanford University, co-founder of LE&RN, explained that lymphedema is not a well-recognized disease, and even patients who have coronary by-pass surgery can develop it. "Cure" is too strong a word at present. His group at Stanford is doing studies on lymphatic disease. He did give us red flags to determine if we have lymphedema, such as swelling, infection, or surgeries where lymph nodes were removed. (Cellulitis is a bacterial infection in the skin.)

Emma Detfleson, a 10 year-old primary lymphedema patient, was introduced. She and Kathy are working together to promote awareness of lymphatic disease and to raise funds for research.

Patient Veronica Senriz was also introduced, and has over 100 years of lymphedema in her family. Attendees of the LLN 2018 fall conference will remember "Vern," who told us her story and her diagnosis of lymphedema distichiasis.



Klose Training
October 26 at 6:43 PM ·

Prof. Michael Földi, MD, has passed away at the age of 98. Prof. Földi and his wife, Prof. Etelka Földi, MD, are pioneers of modern lymphology. Together, they established the world-renowned Földi Clinic and the Földi College in Hinterzarten, Germany. We honor his legacy. He will be forever missed.

Go to the LTA website for more information and a handy script to use when contacting legislators: http://lymphedematreatmentact.org/ As of 1/4/2019, there were 385 cosponsors in the House and 66 in the Senate.

An article about the most common cause of lymphedema outside the US

From The New York Times Sunday Magazine, September 12, 2018

Traveling in Vietnam, his leg swelled terribly. Had he caught something?

By Lisa Sanders, MD

It was almost dawn when the 19-year-old man was awakened by terrible leg pain. He had no idea how long he was asleep, but it had been a horrible night so far. He and his father arrived in Hanoi the day before. They'd spent the day seeing the sights, and the evening eating — then drinking. He'd come back to the hotel jet-lagged and hot and a little drunk. He made it to his bed and fell asleep fully clothed. A few hours later, he was woken by cramps in his stomach. Over the next couple of hours, everything he'd taken in that evening came out. It was awful. Only when there was nothing left could he go back to bed.

But now there was this strange, painful sensation of pressure on his lower right leg. The predawn light was enough to see that his right calf and foot were hugely swollen. His left leg was fine, but the pants covering his right calf were stretched tight. He peeled the denim down his leg. What he saw didn't even look like a leg — certainly not *his* leg. No bones were visible. Not his shin, not his ankle. His normal-size toes looked tiny and foreign at the end of this strange sausage.

When his father woke up, he looked at the boy's leg and called the front desk. A local doctor wasn't sure what the boy had but recommended that he see his doctor when he got home.

Could It Be a Parasite?

The young man felt fine for the rest of the trip, except that his sightseeing was limited by his swollen foot. Once he got back to his apartment in Boulder, Colo., he went to the urgent-care center. They ordered blood tests to look at his kidneys and liver, the most common culprits in leg swelling. They checked the young man's thyroid level — too little of that hormone can also lead to edema, an excess of fluid building up in the body. And he was sent for an ultrasound of his leg: He'd been on long transcontinental flights, which can cause clots to form. The blood tests were all completely normal and the ultrasound showed nothing but early signs of varicose veins. That was probably the cause of the swelling.

The young man tried using a compression stocking and elevating his leg as the doctors suggested. That helped, but after a few months, his leg was as big and painful as it had ever been. One afternoon his leg hurt so much that he went to the emergency room at Boulder Community Hospital. Once again blood was taken and an ultrasound done. The results were the same — normal. But the E.R. doctor was struck by the fact that the edema started while he was traveling in Southeast Asia. In some tropical regions, a mosquito-borne parasite can invade the system of delicate vessels that circulate the protein-rich fluid known as lymph throughout the body, a key part of our immune system. Those parasites can clog the system, causing swelling. He referred the patient to Dr. Todd D. Turner, an infectious-disease specialist in Boulder.

Other More Dangerous Possibilities

After hearing the young man's story, Turner dismissed the possibility that this was lymphatic filariasis, the formal name for this parasitic infection. The resulting swelling — sometimes so significant it's called elephantiasis — takes decades to manifest.

Turner pressed his thumb into the leg where he knew the shinbone must be. His digit sank a good half inch into the swollen flesh. The swelling, he reasoned, was probably caused by an obstruction. But where? The two ultrasounds showed that he had no clot in the vessels of the lower leg. Perhaps the obstruction was located higher up? Because so many of the possible causes of this swelling had been investigated, Turner was worried about cancer. He ordered a CT scan of the young man's abdomen and pelvis to look for a mass or enlarged lymph nodes compressing the vessel, and an M.R.I. of the thigh.

The young man came to Turner's office to get the results. The CT scan and M.R.I. were normal. Turner also thought the problem was in the patient's lymphatic system, causing a disorder known as lymphedema. As lymph flows through the body, it takes up excess fluid and detritus from the tissues — usually dead cells and sometimes invading bacteria. The fluid then passes through the lymph nodes, where it is filtered and returned to the bloodstream. It's a circulation that normally works so well we don't even think about it. But not in his case. Something was going awry. The young man could barely bring himself to listen. All he really heard was that it couldn't be fixed. He left feeling discouraged.

His Grandmother Steps In

The patient's grandmother, who lived in Denver, was very concerned about his leg and asked her grandson to call right after his appointment with Turner. When he didn't, she called him. "What kind of problem with your lymphatic system?" she pressed after hearing his brief summary. He couldn't remember, he told her. It started with the letter H. "You didn't write it down?" she scolded.

As soon as his grandmother got off the phone, she turned to the internet. She couldn't find a single lymphedema that started with an H. She called her grandson again. Could Turner have said he had an inherited, or "hereditary," lymphedema? Yes, that was it. Hereditary. That made sense to the grandmother. Her daughter-in-law, the young man's mother, had persistent leg swelling just after her pregnancy. Sadly, she died a few years earlier from lung cancer. Could he have inherited something from her?

The Key Is in the Eyelashes

Further searches revealed nearly a dozen different types of inherited diseases causing lymphedema. She scrolled through the description of each. Suddenly a detail caught her attention: There was one genetic disorder that results in leg swelling *and* a double row of eyelashes. Her daughter-in-law had thick, beautiful lashes and often complained about their tendency to poke into and irritate her eyes. Moreover, this inherited condition was also associated with a risk of a cleft palate, which her grandson had when he was born. Could this disorder, called lymphedema-distichiasis (from the Greek, meaning a double row of eyelashes) be the culprit?

She texted Turner, letting him know what she found. The doctor was amazed. He'd never heard of this disorder. Nor did he know much about the patient's mother — or the fact that the patient had been born with a cleft palate.

Now the doctor turned to the internet. The disorder was caused by a mutation in a gene called FOXC2. Although the gene was identified years ago, it still wasn't clear why these patients develop lymphedema, or have extra eyelashes. The only treatment was directed at managing the symptoms: mobilizing the fluids with massage, elevation and compression stockings and eating a low-sodium diet to reduce the fluid retained.

Born to Swell

A child of someone with lymphedema-distichiasis has a 50 percent chance of getting it, too. Affected males usually develop swelling at puberty. Females tend to develop it a little later in life — often, like this young man's mother, at the time of their first pregnancy. Why the swelling starts at all is still unclear.

A genetic test confirmed that the young man had the abnormal gene. Maybe, he told me, when he's older and thinking about children, he'll be interested in talking with a genetics counselor. Until then, though, he's tired of the whole subject and ready to do what it takes to manage this and move on. He wears his compression stocking and eats as low sodium a diet as he can manage as a non-cook. His right leg is never as thin as his left, but it mostly doesn't hurt and gets him around.

His grandmother, for her part, was delighted that Turner was open to what she found. "We needed each other to figure out what was going on," she told me. "He is the expert on medical information, and of course that's essential. But I was the expert on my family, and that was important, too. Not every doctor is as open as Dr. Turner to that kind of expertise."

Lisa Sanders, M.D., is a contributing writer for the magazine and the author of "Every Patient Tells a Story: Medical Mysteries and the Art of Diagnosis." If you have a solved case to share with Dr. Sanders, write her at Lisa.Sandersmd@gmail.com.

From Science News: The long-term financial toll of breast cancer

Date: August 22, 2018
Source: Johns Hopkins University Bloomberg School of Public Health

Summary: The financial fallout from breast cancer can last years after diagnosis, **particularly for those with lymphedema**, a common side effect from treatment, causing cumulative and cascading economic consequences for survivors, their families, and society, a new study suggests.

The financial fallout from breast cancer can last years after diagnosis, particularly for those with lymphedema, a common side effect from treatment, causing cumulative and cascading economic consequences for survivors, their families, and society, a study led by Johns Hopkins Bloomberg School of Public Health researchers suggests.

Excluding productivity costs, those with lymphedema were estimated to have an average of $2,306 in out-of-pocket costs per year, compared to $1,090 for those without lymphedema -- a difference of 112%, the study found. When factoring in productivity costs, those with lymphedema spent an average of $3,325 in out-of-pocket costs, compared to $2,792 for those without lymphedema.

"That extra $2,000 or so may not break the bank in one year," says study leader Lorraine T. Dean, ScD, assistant professor in the Department of Epidemiology at the Bloomberg School. "But it can take away discretionary spending, or whittle away retirement savings. If it's a recurring burden each year, how can you ever rebuild? That extra $2,000 in spending can cripple people over the long term."

The findings, published Aug. 18 in the *Journal of Supportive Care and Cancer*, are a call to action for policymakers to develop new ways to curb costs after cancer, the authors say.

A growing body of research highlights the "financial toxicity" of cancer, a term that pertains to the harmful personal economic burden caused by cancer treatment, explains co-author Kala Visvanathan, a professor in the Bloomberg School's Department of Epidemiology. The financial consequences of cancer have been shown to affect mental health and a variety of other health outcomes, including rates of death.

Although previous studies have attempted to tally how much breast cancer survivors spend on their care, this earlier research has largely focused on costs in the short term after diagnosis or used insurance claims to calculate costs -- measures that can miss much of what patients are actually spending, Dean says.

To get a handle on real expenditures and how this disease affects patients over the long term, she and her colleagues used several different methods to assess cancer-related costs in 129 breast cancer survivors from Pennsylvania and New Jersey, who were an average of 12 years out from diagnosis and had a mean age of 63. Just under half of them had lymphedema, an adverse effect of breast cancer treatment that affects an average of a third of breast-cancer survivors. All were insured by public or private providers.

These volunteers were asked to keep diaries for six months of all direct and indirect costs related to their overall health care, from doctor and emergency department visits to medications and gym memberships. For those who had lymphedema, they also included all lymphedema-specific health care needs, such as compression garments and bandages.

Additionally, participants recorded productivity losses at work and home. These were defined as times when they couldn't perform usual activities or needed help to carry out daily activities.

To help capture a full year of data, the researchers asked the volunteers to recall these types of expenses, using personal calendars, insurance statements and receipts as memory aids for the previous three months. They were also asked to project the next three months of health care-related expenses.

To better understand why participants spent what they did and how their financial situations evolved, the researchers interviewed a subset of 40 patients representing a range of socioeconomic statuses and ages and those with and without lymphedema.

The interviews provided insight into what these costs meant for these women's lives. Many reported the use of savings, loans, or debt to cover medical costs, which were often so large that they compromised patients' abilities to manage basic needs like utility bills. These costs had rippling effects on their future financial status, decreasing their ability to help family members, support their children's educational endeavors, and retire. For those with lymphedema, medical costs also affected their ability to effectively manage their condition.

Breast cancer and resulting lymphedema also had past ramifications on the participants' finances that had lasting impacts, Dean explains. For example, many of those interviewed had stories of lost jobs or educational opportunities that were directly or indirectly caused by their medical conditions, events that they never financially recovered from.

Together, Dean says, these results show that the economic burden of breast cancer and its complications can continue long after diagnosis, even among those who have insurance. While the annual costs may not seem extreme for a middle-class household, she adds, the amounts add up over time.

Measures often discussed to help patients cut costs, such as encouraging healthier behaviors, place the onus directly on patients to find ways to save, says Dean. Rather than further burden patients still dealing with the consequences of a serious disease, she and her colleagues suggest strategies that change the health care system and the division of financial responsibilities between patients and insurers. For example, most insurance companies don't fully cover lymphedema care needs, which can be substantial. Congress is considering legislation (HR930; SB497) that could amend Medicare to cover certain items, such as compression garments, as durable medical equipment.

"The U.S. is too resource-rich for people to have to make decisions between their health and their wealth," Dean says. "By making some important changes in coverage, we can help breast cancer survivors who continue to struggle with economic burdens long after their cancers are considered cured."

Journal Reference:

1. Lorraine T. Dean, Shadiya L. Moss, Yusuf Ransome, Livia Frasso-Jaramillo, Yuehan Zhang, Kala Visvanathan, Lauren Hersch Nicholas, Kathryn H. Schmitz. **“It still affects our economic situation”: long-term economic burden of breast cancer and lymphedema**. *Supportive Care in Cancer*, 2018; DOI: 10.1007/s00520-018-4418-4

   Cite This Page: Johns Hopkins University Bloomberg School of Public Health. "The long-term financial toll of breast cancer." ScienceDaily. ScienceDaily, 22 August 2018. <www.sciencedaily.com/releases/2018/08/180822114444.htm>.

2019 Lighthouse Lymphedema Network Calendar Dates to Remember:

- LLN Board Meeting, Country Club of Roswell, Saturday January 12th, 9:30 AM

LymphEd

LymphEd's 2019 and 2020 Courses

Still Scheduling Additional Dates!

Complex Lymphatic Therapy (CLT) Certification Course

135 hour LANA approved certification course for RNs, OTs, COTAs, PTs, PTAs, MDs, LMTs, DOs, and DCs. Incorporates the latest evidence-based research on the lymphatic system and effective treatment techniques in a 45 hour interactive home program and 90 hours of in person instruction.

Dates: Split Course: 1st Weekend 1/24/19-1/27/19; 2nd Weekend 2/22/19-2/24/19; and 3rd Weekend 3/22/19-3/24/19 in Atlanta, GA

Advanced Courses are all 20 hour and evidence-based for certified therapists with a 4 hour interactive home program and 2 days of in person instruction.

Current Advanced Courses:

Advanced Concepts in Lymphedema Treatment

Advanced treatment techniques for upper and lower extremity involvement, including new pathways for clearance, patient involved MLD, adjuncts to treatment (cupping, taping), and compression problem-solving.

Dates: February 9th- February 10th, 2019 in Atlanta, GA

Advanced Treatment of Genital Lymphedema

Advanced treatment techniques for male and female genital lymphedema with an in-depth review of anatomy of pelvis/genitals, alternative pathways for MLD, compression problem-solving, and importance of the pelvic floor with genital lymphedema.

Dates: May 4th - May 5th, 2019 in Atlanta, GA
May 2nd-May 3rd, 2020 in Calgary, Canada

Advanced Pediatric Lymphedema

Advanced evaluation and treatment options for the pediatric lymphedema population, including the causes and diagnosis of the pediatric lymphedema, MLD, compression, and other concepts in treatment.

Dates: September 28th - September 29th, 2019 in Calgary, Canada

Advanced Treatment of Head and Neck Lymphedema

Advanced evaluation and treatment options for head and neck lymphedema, with in-depth review of anatomy of head and neck, alternative pathways for MLD, and compression problem-solving.

Dates: To be scheduled

If you are interested in attending a LymphEd course please visit the website www.LymphEd.com, or contact Shelley Smith DiCecco, PT, PhD, CLT-LANA, CI-CS at shelleydicecco@LymphEd.com.

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

Course Discounts!!!
Check out the website for information on great course discounts! All discounts can be combined!

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Everyone living with lymphedema
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Annette Bymes
Deb Cozzone
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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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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**.

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