March 4th: LLN Lymphedema Education Program
Specifically for RNs, LPNs, PAs, & NPs

Registration is $25 to cover CNE credits application for attendance

As part of our continuing educational efforts, the Lighthouse Lymphedema Network is sponsoring a Nurses and Other Medical Professionals Intensive Program on Saturday, March 4, 2017, 8:00 AM to 1:00 PM, at the Richard H. Rich Auditorium (77 Bldg, 1st floor) at Piedmont Atlanta Hospital, 1968 Peachtree Rd, NW, 30309

(campus map: http://interactive.medmaps.com/site/piedmont_atlanta)

These lectures are designed to help nurses and other medical professionals recognize lymphedema, and learn how to interact effectively with lymphedema therapists for improved patient treatment. See the next page for registration details!

SAME DAY/SAME LOCATION: 1:30-3:00 PM

LLN-sponsored first 2017 Open Forum for Lymphedema Patients & Therapists:

Following the Medical Professionals Intensive program, we will hold an Open Forum for patients & caregivers to meet with our speakers and lymphedema therapists from 1:30-3:00pm at the same location, the Rich Auditorium. The Open Forums are a great opportunity to have one-on-one discussions with our speakers and therapists and ask lots of questions!
Our 2016 LLN Volunteers of the Year, Billie Barron & Vicki Day

We are excited to recognize two outstanding volunteers as our 2016 Volunteers of the Year. Although Billie Barron does not have lymphedema, she has a heart full of compassion to help others. After joining the board, she immediately became our designated person for registrations for all conferences and events. Billie also serves as the assistant to our website administrator and lends her expertise to designing our flyers. We thank her for her generosity and kind spirit that she shares with the LLN. Thank you, Billie, for always saying yes to anything that is requested! We appreciate you and recognize you as one of our 2016 Volunteers of the Year.

Vicky Day serves on our conference committee and in fundraising. Who can ever forget the luncheons and tours of her families beautiful Bellmere Gardens. In 2015, she and her husband, Peyton, hosted a Nurses Intensive program at their business in Sandy Springs called the ROAM. After her daughter was diagnosed with lymphedema, it became her mission to find the best care for Courtney. Being a parent is always a challenge, but when your child has special needs, it becomes necessary to look outside the box, so to speak, to find and provide the best quality of life. Courtney and her therapist wrote a book entitled "A Leg Up." We thank Vicky for her service to the LLN and recognize her as one of our 2016 Volunteers of the Year.

LLN also gave a special LLN Youth of the Year award to our long-time special assistants, Justin & Kyle Cozzone, sons of Deb Cozzone, manager of our BAG Fund. Thanks for being our A-Team to help our vendors!
19th State of Georgia Lymphedema Education & Awareness Conference a Big Success!

Our Speakers

L-R: Guenter Klose, PT CLT-LANA, Hope Knosher (yoga therapist), Melanie Driggers (patient), Keith Delman MD, Gwen Forbes-Kirby PT, CLT-LANA, Nadiv Shapira MD, LLN Director Joan White, moderator Elaine Gunter

Our 19th annual conference was indeed a resounding success, with high marks from our attendees on the informative presentations. Summaries of our speakers’ presentations can be found at our website – www.lighthouselymphedema.org

Kathleen Westbrook, a therapist from Knoxville, TN, was our lucky winner of a really big gift basket in our drawing of visit-the-vendors game cards.

Comments from conference participants:

- (from a therapist) I don’t mind giving up my Saturday for a conference as good as this, thanks!
- Re: Melissa Drigger’s moving presentation as a lymphedema patient: “Thank you so much for presenting at Lighthouse! You have inspired me to keep working a lymphedema support group here.”

We also thank Bob Hartel of Solaris for once again sponsoring the speakers dinner on Friday night, October 21 at the Brio Tuscan Grille!
Many thanks to everyone who donated to LLN on this year’s Georgia Gives Day – We raised $3,355 to support LLN ($2,000 for our BAG Fund, $1,355 for LLN’s General Fund)! Other BAG Fund contributions: Solaris generously donated $3500 in compression garment products, the Gloria Watts-Cox Foundation gave a $350 donation, and we sold $215 worth of LLN books. We also raised $762 from the sale of gift baskets & other items to support our conference fund. (A special thanks to therapists Samantha Cannon & Shelley Smith-DiCecco for creating our really creative gift baskets!)

LLN BANDAGES & GARMENTS FUND UPDATE for 2016

2016 presented the largest demand ever for the services provided by the LLN’s Bandages and Garments Fund. Patients from all over Georgia applied for assistance from the Fund and services were provided to record numbers of lymphedema patients. This would not be possible without the generous partnerships with garment manufacturers, garment providers and certified lymphedema therapists. We thank all of you for your support of the LLN and Bandages and Garments Fund.

Greatest successes for 2016:

- In March we received a grant from It’s The Journey, Inc. for the fourth year in a row. Grant funding purchased garment solutions for 21 breast cancer survivors in 2016, and additional funding is available for the first quarter of 2017.
- In April we received a grant from Komen Greater Atlanta. Grant funding purchased garment solutions for 12 breast cancer survivors from the 13-county metro Atlanta area, and additional funding is available for first quarter of 2017.
- We expanded our service by assisting patients in 12 previously unserved counties in Georgia.
- We provided 82 lymphedema patients with a garment solution specific to their needs. This is a 13% increase over 2015.
- Over $32,000 from a variety of sources funded the support for these 82 patients.

Greatest need for 2017:

- The large increase in applicants and the loss of one of our major funding sources will significantly impact the number of patients served in 2017 unless the LLN can secure new sources of funding. Do you have experience in this area? Grants, fundraisers, matching donations and other avenues to raise funds for the LLN and the Bandages and Garments Fund? Please contact Deb Cozzone or Joan White to share ideas and get involved.

All of the good work of the Bandages and Garments Fund would not be possible without the generosity of the garment manufacturers and garment providers who have worked side by side with the LLN. In addition, we heartily thank and appreciate the certified lymphedema therapists and other organizations and individuals who have supported the Fund. The LLN and Bandages and Garments Committee are grateful to all of you—without your help, we could never serve as many people as we do. Thank you!

Another gift to LLN: The North American Vodder Association of Lymphatic Therapy (NAVALT) began in 1992, and for 25 years they were a premier nonprofit organization dedicated to the advancement of the (Dr. Robert) Vodder Method for lymphedema therapy through quality, education, and research. After 25 years, NAVALT has decided to dissolve. They have selected the Lighthouse Lymphedema Network as one of four nonprofits to receive a donation of $1,155.15 and to honor Joan White and the LLN who have worked tirelessly over these many years to focus on lymphedema awareness.
Joan White with Hope Knosher, who led us in yoga exercises twice.
2017 Lighthouse Lymphedema Network Calendar Dates to Remember:

Saturday, January 28 - LLN Board of Directors meeting
Saturday, March 4 – Nurses and Medical Professionals Intensive Program, 8:00 AM – 1:00 PM, Piedmont Hospital Rich Auditorium, Atlanta, GA
Saturday, March 4 – Open Forum meeting for patients & caregivers, 1:30-3:00 PM, Piedmont Hospital Rich Auditorium, Atlanta, GA. Speakers from the Medical Professional Conference will be present to answer your questions.
Thursday, April 20 – LLN Open Forum Meeting, Shepherd Spinal Center, 2020 Peachtree Rd NW, Atlanta, GA, 6:00-8:00 PM. Rebecca Hammad, OTR/L, CLT will present “Managing edema after neurological injury with techniques used to treat lymphedema.”
Saturday, May 13, 2017 Komen Atlanta Race for the Cure.
Friday, September 29 – Sigvaris Tour and class for therapists, Wyndham Hotel, Atlanta (more details coming!)
Saturday, October 7 – LLN Board of Directors meeting
Tuesday-Wednesday, October 11-12 - LLN joint conference for patients & caregivers with NLN, Coronado Beach Resort, Disney World, Orlando, FL
Thursday-Saturday, October 12-14 (NLN Conference for medical professionals is Oct 12-15) same location

The LTA is incredibly proud to be finishing 2016 with 29 Senate and 260 House cosponsors! LTA will be hosting its next Lymphedema Lobby Days in Washington, DC March 26th-28th, 2017 LLN was a bronze level supporter in 2016.

Each Congress we have made it further than the last, and we will persist until all lymphedema patients have coverage for their compression supplies! While we didn't make it across the finish line this year, we are ready to hit the ground running as soon as the new Congress begins in January. Our bill sponsors, Rep. Dave Reichert and Sen. Maria Cantwell, will be reintroducing the LTA early in 2017, and we will continue to build on the tremendous accomplishments of this Congress.

Heather Ferguson
Founder & Executive Director, Lymphedema Advocacy Group, LymphedemaTreatmentAct.org

An informative article about the LTA from CURE Magazine: http://www.curetoday.com/community/bonnie-annis/2016/07/the-lymphedema-treatment-act

The Lymphedema Treatment Act

A bill introduced in 2014 to help patients with lymphedema is still on the floor in Congress awaiting approval. The Lymphedema Treatment Act is a federal bill currently under review. Introduced in 2014 by four United States representatives, this bill would help provide coverage for the medically necessary compression garments for patients suffering with lymphedema. Before discussing the Lymphedema Treatment Act further, it’s important for you to understand the medical condition. Lymphedema an incurable medical condition and can be caused by injury, trauma or congenital defects in the lymphatic system. The lymphatic system covers the entire body. It is a very intricate structure of nodules that filter lymphatic fluid. As muscles in the body contract, they apply pressure to the lymphatic vessels and this
in turn, causes lymphatic fluid to move through the body. The lymph nodes contain a series of one-way valves allowing the lymphatic fluid to flow in only one direction. When the normal flow of the fluid is blocked, a condition called lymphedema occurs. The lymphatic fluid collects in surrounding tissues and causes painful swelling.

Lymphedema can be a common side effect from breast cancer surgery. In many breast cancer surgeries, doctors remove the sentinel lymph node in order to assess whether cancer has spread. If cancer is found in the sentinel lymph node, more nodes may need to be removed to contain the cancer. As these nodes are removed, the natural flow of the lymphatic fluid is disrupted and fluid can begin to collect in the upper arms or other areas. Since each patient is different, there is no way to know, at the time of surgery, which ones will be affected and suffer from lymphedema. Lymphedema doesn’t always appear immediately after surgery. It can occur any time afterward and can be exacerbated by injury, insect bites, needle sticks or even having blood pressure taken on the arm where lymph nodes were removed.

The management of lymphedema includes manual lymphatic drainage, which can be performed by a licensed lymphedema therapist, through compression pumps or with compression garments. “Compression garments,” according to the breast cancer website, “are designed to do just what their name suggests: apply pressure to the arm, hand or trunk to keep lymph moving in the right direction. All of the garments are made of flexible fabric. Sleeves are tighter at the bottom than they are at the top. This helps create the graded (or ‘gradient’) pressure that keeps the lymph moving out of the arm.” Compression garments are made from various materials including spandex, wool and latex. There are many websites that offer compression garments. One of the sites, Lymphedivas, offers stylish garments in a variety of colors and designs.

Compression garments for lymphedema are expensive and are often considered “medically unnecessary” by some insurance companies that will not cover treatment. Representatives Dave Reichert (R-WA), Earl Blumenauer (D-OR), Leonard Lance (R-NJ) and Jan Schakowsky (D-IL) introduced the Lymphedema Treatment Act, H.R. 1608. This bill is to aid senior adults in obtaining compression garments. These representatives were concerned that those suffering with lymphedema and are under the Medicare plan would be unable to have access to compression garments because they were not covered by current Medicare guidelines. Reichert says, on his website, “We should be enabling seniors who suffer from lymphedema to have the best possible access to necessary treatments for their condition. Making sure that Medicare covers compression garments is a common-sense way to give individuals real hope to fight back against this chronic condition and obtain their best possible quality of life.”

Although this bill is specifically targeting the Medicare system, it would set a precedent for all insurance companies, hopefully making medically necessary compression garments available to those who need them.

The Lymphedema Treatment Act is currently active in the 114th Congress, which runs from the beginning of 2015 to the end of 2016. You can read more about the bill here and find out how you can contact your representatives to urge them for their support.

This bill is important to me because I suffer from lymphedema. When I had surgery for breast cancer, I was never told I was at risk of developing lymphedema. I had four lymph nodes removed in my right arm and two removed in my left. Months after surgery, I began to notice an uncomfortable swelling and tightness in my upper arms. I did not know what it was, and went to see my doctor who me I had lymphedema. She recommended that I see a certified lymphatic therapist to receive manual lymphatic drainage.

I did the drainage for several months and did receive some relief, but the fluid kept coming back and collecting around my upper arms, so my doctor prescribed compression sleeves and gauntlets. When I went to purchase them, I was shocked to find the sleeves were almost $200 each and the gauntlets were just under $70 each. I was thankful I had good insurance and was able to get two pairs per year, but I’ve found that the sleeves and gauntlets wear out quickly from daily use. I need at least seven pairs so I can rotate every day of the week, but I can’t afford them and my insurance won’t cover any more for two years. The compression sleeves and gauntlets help contain the swelling and allow me some flexibility of movement. They do not cure lymphedema.

Those of us who suffer daily with lymphedema rely heavily on our garments. Hopefully this bill will pass and we’ll see new changes in insurance company policies in the very near future.

- Bonnie Annis is a breast cancer survivor, and was diagnosed in 2014 with Stage 2b invasive ductal carcinoma with metastasis to the lymph glands. She is an avid photographer, freelance writer/blogger, wife, mother and grandmother.
2016 Donations

In Honor:
Casey Butler
Deb Cozzone
Monica Goering
Rebecca Hammad
Laura Hoffman
Jean Miller
Mary Miller
Stacy Saraydar
Carson Sollenberger
All our cancer survivors
@Therapeutic Solutions
Beverly Thompson
Joan White

In Memory:
Thyjuan Antonine
Woody Bates
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Ray Fink
Larry Hart
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Richard Newton
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Dan Tinkler
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Tim Bick
Candace Bridgewater
Janet Butler
Michael and Lori Cannon
Claire Cherry
John Cherry Jr.
Krista Cherry
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Our sincere thanks to those businesses that financially support our conferences and Bandages and Garment Fund:
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The LLN Board of Directors makes the LLN a huge success:
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Joan White, Director

Thanks to those organizations who have awarded the LLN grants to help support our arm patients through our Bandages and Garment Fund:
It’s The Journey
Susan G. Komen Greater Atlanta Affiliate
Thank you, Lighthouse Lymphedema Network:

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

Donor’s Name: ____________________________________________________________

Address: __________________________________________________________________

Phone: (Home) ______________________ (Work) ______________________ (Cell) __________

E-mail: ____________________________________________________________________

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

The Lighthouse Lymphedema Network is a 501(C) (3) non-profit organization. Please make all checks payable to the Lighthouse Lymphedema Network and mail to the LLN, 10240 Crescent Ridge Drive, Roswell, GA 30076. Call 770-442-1317 for information. You can also make a donation on-line by credit card: The donation page is: http://lighthouselymphedema.org/get-involved/donate.htm.

Change of Address Request: We try to keep our mailing list updated constantly; if you have any changes that should be made to your mailing or e-mail addresses, please send this information to the LLN address above, or by e-mail to elaine.gunter@comcast.net.

Remember: Don’t forget to give us your e-mail address if you want to be reminded about meetings, to receive the LLN newsletter as a PDF file (in color!), and to help us save mailing costs! elaine.gunter@comcast.net.

LLN’s website is http://www.lighthouselymphedema.org

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