



LLN January 2016 Newsletter

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LLN: 22 years of serving the lymphedema community

www.lighthouselymphedema.org

Our 2015 Volunteer of the Year, LLN Treasurer Larry Ashmore!

"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 today 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. Larry retired as a VP at SunTrust Bank, and immediately started teaching classes at Georgia State University to share all the knowledge he acquired during his career. We thank Larry Ashmore for his service to the LLN, and recognize him today as our 2015 Volunteer of the Year."



LLN Director Joan White and our awesome treasurer, Larry Ashmore

LLN 2016 1st Patient Forum, Thursday April 7, 6:00-8:30 at Northside Hospital

Therapist **Angelo Rizzo**, MS, PT, CLT of Therapeutic Solutions, Inc., will present "The role of exercise in cancer and lymphedema care plans." The meeting room is located in the Northside Hospital Outpatient Facility, located at 993 building D, Johnson Ferry Road, Suite 250, Atlanta. (Suite 250 is on walk level and parking costs will be covered.) **Rita Scala**, Medical Education Adviser with BSNmedical Inc./Farrow Wrap/JoVIPak will be in attendance to demonstrate some products. Light refreshments will be served.

18TH State of Georgia Lymphedema Education & Awareness Conference a Big Success!

Our Speakers



L-R: LLN Director Joan White, Dr. Babek Mehrara, Dr. Brandon Dixon, lipedema patient Carla Harrison, therapist DeCourcy Squire, Dr. Karen Herbst, therapist Molly Nettles, Dr. Angela Cheng

Our 18th annual conference was indeed a resounding success, with high marks from our attendees on the informative presentations, especially on our highlighted topic of lipedema. We had 138 total attendees, including speakers and vendors.

We were able to raise support for the Bandages and Garment Fund as follows: (1) **\$534** was made on the sale of the baskets, silent auction, book, mugs and other items; (2) the Gloria Watts-Cox Foundation gave us a donation of **\$800**; (3) Solaris increased their annual donation to the BAG Fund to **\$4,000** for products.

Bobbie Allen was our lucky winner of a really big gift basket in our drawing of visit-the-vendors game cards.

Comments from conference participants:

- *Loved the entire day and all of the speakers! Enjoyed seeing everyone and learning about lipedema.*
- *Dr. Mehrara gave a fantastic presentation - clear and concise.*
- *This was the best conference ever!*



We also thank Bob Hartel of Solaris for sponsoring the speakers dinner on Friday night, October 23 at the Brio Tuscan Grille!

Many thanks to everyone who donated to this year's Georgia Gives Day – We raised \$2895 for LLN! Thanks to our terrific team leader, Molly Nettles, and to everyone who contributed!

SHARE THIS INFORMATION WITH YOUR PHYSICIAN!

LLN CONTINUES ITS EDUCATIONAL EFFORTS FOR MEDICAL PROFESSIONALS: 2016 PHYSICIAN-INTENSIVE PROGRAM



In partnership with Georgia Regents University, LLN will hold another Physician Intensive Educational Program about lymphedema

*Thursday, February 25th from 5:30 – 9:00 P
at the Snelling Center at Edgar's Grille
3165 Washington Rd, Augusta, GA 30907.*

This free program is ONLY for physicians and Physician Assistants.

Registration is required: email bhunterbb@kennesaw.edu

This will be a CME-Accredited (3.00 AMA PRA Category 1 credits) dinner lecture; physicians & PAs will be presented with research to help increase their knowledge of lymphedema, especially for properly diagnosing and treating this condition.

Our speakers will be lymphologist Stanley Rockson, MD of the Stanford University School of Medicine and Brandon Dixon, PhD of GA Tech, who researches the biomechanics of lymphedema. Therapist Molly Nettles, OTR/L, CLT, Clinical Coordinator of Lymphedema Services at Georgia Regents University Cancer Center will coordinate this program.

2016 Lighthouse Lymphedema Network Calendar Dates to Remember:

- January 30, 2016 – LLN Board Meeting , Roswell Country Club
- February 25, 2016 – LLN Second Physician Intensive at Snelling Center, Augusta, GA
- April 7, 2016 – Open Forum meeting for Patients, 6:00-8:30 PM at Northside Hospital; therapist Angelo Rizzo of Therapeutic Solutions will speak on the benefits of exercise for lymphedema patients. Light refreshments will be served.
- October 22, 2016 – 19th State of Georgia Education & Awareness Conference, Doubletree Hotel-Buckhead

We thank all of our wonderful vendors & exhibitors who participated in our fall conference, and provide support to us year-round:

*Biacare
Gloria Watts Cox Foundation
Impedimed
Peninsula BioMedical
Lymphedema Treatment Act*

*Body of Health
Juzo USA
Lohmann & Rauscher
Sigvaris, Inc.*

*BSN Medical/Farrow Wrap/JoVIPak
Lipedema Products
Medi USA/CircAid Medical Products
Solaris, Inc.
Fat Disorders Research Society*

The following pictures are of our vendors' tables, and from the conference.





Gwen Forbes-Kirby leads the "arm" discussion group.

Dr. Herbst leads the lipedema discussion group.



Shelly DiCecco leads the "leg" discussion group;

Moderator Elaine Gunter leads the panel discussion with Drs. Herbst & Dixon.



From the Conference: A Synopsis of Dr. Karen Herbst's Lipedema Presentation

By Molly Nettles, OTR/L, CLT-LANA, STAR/C

Lipedema is a congenital fatty enlargement of the legs almost exclusively seen in women. It may affect 11% of the female population according to an epidemiologic study by Foldi E and Foldi M. Typically, women with lipedema present with disproportionate bodies with larger legs and hips than arms and waist. Symptoms include: worsening of swelling and achiness by the end of the day; pitting edema; "painful fat"; heaviness; sensitivity to pressure (light or deep); hematoma; easy and frequent bruising; fragility of blood capillaries; joint laxity with flat feet and knee mal-alignment ("knock knees").

Tissue Changes in Lipedema: The literature describes four stages of lipedema. Stage I is marked by cellulite, finely dimpled but mostly smooth skin surface, increase in fatty tissue in the area of the buttocks and hips (saddle bag). The skin appears flat, but the subcutaneous adipose tissue layer is thickened. Stage 2 Lipedema is marked by coarsely dimpled skin surface with larger indentations (mattress skin); presence of "nodules" (nut-to-apple-like) within the subcutaneous fatty tissue; the skin surface becomes "harder" and uneven due to the presence of these nodules; folds of fat or pockets appear at the inner knee areas as the lipedema extends; nodules are palpable in the adipose tissue. Stage 3 lipedema is marked by palpable nodules which vary in size from a walnut to a fist; fatty lobes develop; hematoma may be present. Stage 4 is marked by lipo-lymphedema. Lymph flow is impaired due to the pressure of the fatty tissue which surrounds it. Lymph formation and movement of lymphatic fluid becomes disturbed resulting in lymphatic insufficiency. Lobes become larger due to increased formation of fatty tissue. At this stage, the feet can be affected and the Stemmer sign is positive. (This describes a thickened skin fold at the base of the 2nd toe or 2nd finger; considered positive for LE when this tissue cannot be lifted, but can only be grasped as a lump of tissue.)

Location of Symmetrical Fat Deposits in Lipedema: Type I: Buttocks, leaving the rest of legs unaffected; Type II: Between the buttocks to knees, with folds of fat around the inner side of the knee; Type III: Between the buttocks and malleoli (sides of the ankle); Type IV: Arms; Type V: Between the knees and malleoli, feet remain unaffected, and cuffs of fat can be present bilaterally at wrists, medial and distal knees, and ankles.

Treatment of Lipedema: Treatment for lipedema is multifaceted. Eating a healthy diet, consuming food that is not processed is beneficial. Exercise/movement that is low impact is best. Water exercise, whole body vibration, and use of a rebounder are helpful in promoting lymphatic circulation. Manual lymphatic drainage, when performed by a trained clinician, can be instructed as a component of a home program. Compression bandaging is indicated for those with Stage IV lipo-lymphedema. However, caution should be exercised to avoid overtreatment if no response is obtained. Wearing low level compression on the arms and/or legs, 8-25 mm Hg or 20-30 mm Hg, is helpful in aiding lymphatic circulation. For those with obvious swelling/edema in the tissues, lymphagogues (agents that increase the formation and flow of lymph) such as amphetamines, ketoprofen and rutosides (derived from quercetin) are recommended. Anti-inflammatories that may be helpful to anyone suffering with Lipedema include selenium, quercetin (antihistamines), arginine, ketoprofen. Mucous-reducing drugs for those with "spongy" tissue include guaifenesin, and n-acetyl cysteine. In summary, there are now many excellent resources online and in print for those suffering with lipedema. Never hesitate to speak with your physician or therapist regarding questions or needed direction.

Fat Disorders Research Society 2016 Conference: Living with Lipedema and Dealing with Dercum's Disease, April 8-10, St. Louis, MO. Topics include surgical and non-surgical treatment options in managing both lipedema and Dercum's disease. Begins April 8 at 5:00pm and ends April 10 at 3:00pm. Price is approximately \$150-\$200. Contact information: <http://fatdisorders.org/society/events/fdrs-conference-2016> or info@fatdisorders.org.

A Thank-you note to LLN from a Bandages & Garments Fund Recipient:

"Thank you so very much for paying for my custom-made compression stockings. I have been in Piedmont Hospital's Lymphedema Therapy Clinic, and have received great care. I could not have been able to afford the stockings without LLN's help. Thanks to you, I now have the proper custom size stockings. Thank you so much, I am a very grateful patient!"

Lymphedema Treatment: A Paradigm Shift – a summary by Gwen Forbes-Kirby, PT, CLT-LANA

In 2015, from the NIH Lymphatic Symposium to the LLN Conference in October, this was the resounding theme. The treatment of lymphedema can no longer be practiced in a void, and we must work at understanding the lymphatic system in its entirety if we are to achieve the best outcomes. As research moves at an unparalleled rate, we are seeing the lymphatic system in a different way, and are now looking at it as an integral system that can have an active and significant effect on all the systems in our bodies. Where we once claimed the eye and brain free of lymphatics, research is now showing some eye diseases are directly affected by the lymphatics' activity, e.g., drainage of cerebral spinal fluid from the CNS into meningeal lymphatics. Studies have shown a reduction of this drainage in mice with Alzheimer's disease.

Where we once thought the flow into the lymphatic vessels was passive we have seen instances where cells "crawl" into the vessels during an inflammatory state. Lymph flow plays a critical role in immune cell trafficking with the node being the center of the complex. One study presented at the NIH conference demonstrated the possibility of communication between the lymph node and primary cancer tumor was what allowed metastasis of cancer cells into the node to occur.

Nodal filtration may be dependent on molecular weight. Lymphatic vessels have been shown to mediate the removal of immune cells from the tissue. The lymphatics have a role in the formation of a salt barrier which, when immune cells pass through, their ability to kill can be increased. The role the lymphatics play in immune mediated diseases has been studied revealing their contribution to pulmonary fibrosis, inflammatory bowel disease and the common result of poor wound healing in diabetics. When T cells are reduced in organ transplants there is less chance of rejection while increasing lymphangiogenesis in heart transplants is most likely beneficial.

There are studies under way on the lymphatic system's role in almost every part of the body in disease and health.

Dr. Babak Mehrara discussed the cellular mechanisms of lymphedema at the 2015 LLN conference. He advocated that lymphedema was not just the result of lymphatic injury but the development of fibrosis in addition to the injury that results in lymphedema. Lymphedema progresses as scar tissue develops around the vessels and they become more fibrotic. His theory is that lymphedema is a cumulative failure. He cited a study by Thomas Wynn showing that fibrosis is chronic inflammation. While the inflammatory response is required for healing, it must be modulated. In the absence of T cells, there is no swelling, and therefore no lymphedema. T cells can prevent the lymphatics from growing.

So the question arises: Now that we know how specific components such as immune cells, genes and specific proteins work, can we design targeted treatments? Lymphedema starts as fluid and becomes fat. We know from the research that fat and inflammation are directly related. He cited a clinical trial where researchers are looking at hormones to decrease fibrosis. He also mentioned a topical medication that has demonstrated a positive response on the lymphedema but has bad side effects.

It is this author's opinion that our treatments will be as varied as the system itself. While what we are now calling lymphedema seems to mainly be a disruption of the skin lymphatics, could we call a fatty liver a failure of the liver lymphatics treating the skin with a topical medication and the liver with genetic material? As our knowledge of the lymphatic system grows it will be more important than ever for those working in the fields of research, medical management and treatment of lymphedema to work at keeping up with the most recent knowledge to provide the best possible outcomes for those whose lives are affected by this condition on a daily basis.



LLN BANDAGES & GARMENTS FUND UPDATE

2015 provided the LLN's Bandages and Garments Fund the chance to reach more lymphedema patients throughout Georgia than ever before! 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. Some of our successes for 2015:

- In February we received a grant from It's The Journey, Inc. for the third year in a row. This grant funding allowed us to purchase garment solutions for 31 breast cancer survivors in 2015.
- We expanded our service by assisting patients in 7 previously unserved Georgian counties.
- We provided 71 lymphedema patients with a garment solution specific to their needs.
 - Over \$31,000 from a variety of sources funded the support for these 71 patients: LLN Fundraisers, Fundraisers benefitting the LLN, Private Donations, Grant funding from It's the Journey (2014-2015 and 2015-2016 grant period); In-Kind Donations from manufacturing partners; Scholarship from manufacturing partners

All of this good work would not be possible without the generous partnerships with garment manufacturers and garment providers named below. Also, we heartily thank 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 help as many people as we do!

All About You, A Woman's Place, Barney's Pharmacy, BiaCare, BSN medical, CH Martin – Fayetteville, CH Martin – Stockbridge, Custom Compression Consultants, Juzo USA, Life Boutique, Mary Lou's Garden, Medi USA, Never The Same Boutique, Piedmont Compression Services, Pretty Please, Sigvaris, Inc, Solaris, Inc, SunMed Medical Solutions.



Greetings from the Lymphedema Advocacy Group of Georgia! Many may wonder what the Lymphedema Advocacy Group is, what they do and how to join. The Lymphedema Advocacy Group (LAG) is a national organization with advocacy groups in all 50 states. Grassroots people from various disciplines, such as lymphedema patients, their families, doctors and nurses have come together to petition Congressman and Senators to cosponsor the Lymphedema Treatment Act (LTA) HR 1608. Lobbying for passage of this bill has been in effect since 2010. When passed, Lymphedema patients will receive much needed services and compression garments which will enable them to maintain this chronic condition and live healthier lives.

Passage of HR 1608 requires co-sponsorship from State Congressman. It is from the efforts of the constituents and advocacy group members that co-sponsorship of the bill occurs. In an effort to educate, increase awareness and request support, constituents and members of LAG contact their state Congressman by sending emails and scheduling appointments to speak with them or their HLA's.

As a result of constituents and LAG members' concerted efforts, the House LTA bill now has 171 cosponsors, and a bill S 2373 was just introduced in the Senate by Maria Cantwell (D-WA), with Chuck Schumer (D-NY), Chuck Grassley (R-IA), and Mark Kirk (R-IA). Four of Georgia's 14 Congressmen (Reps. Hank Johnson, John Lewis, David Scott, and Sanford Bishop) have become co-sponsors; can we get the other 10? Go to this website to see if your Representative is a co-sponsor: <https://www.congress.gov/bill/114th-congress/house-bill/1608/cosponsors>.

Becoming an advocate is free; you determine the amount of time you wish to dedicate. Resources and information about the LTA and how to become an advocate can be found on our website at: [Lymphedema Treatment Act.org](http://LymphedemaTreatmentAct.org). You may sign up for a free webinar at: <https://attendee.gotowebinar.com/recording/8354609787963401218>

Sherilyn Bell, Georgia Team Leader
Lymphedema Advocacy Group & Advocacy Training Team

In Honor:

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 Trinity and Jonathan Maiden
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Grant which benefits our arm
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 It's The Journey

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**Special thanks to the
 following businesses that
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 Bandages and Garment Fund
 throughout the year:**

A Woman's Place at Northside
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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.

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Phone: (Home) _____ (Work) _____ (Cell) _____

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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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