

LLN April 2011 Newsletter

Coming up in 2011:

- Publication of our long anticipated book.
 - Publication of our second cookbook with an emphasis on healthy eating.
 - Expansion of the LLN website to include more information on lymphatic diseases.
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www.lighthouselymphedema.org

MARK YOUR CALENDARS NOW TO SAVE THE DATE!

14TH STATE OF GEORGIA LYMPHEDEMA EDUCATION AND AWARENESS PROGRAM

An educational and awareness conference for patients, caregivers and professionals!

HILTON GARDEN INN – ATLANTA PERIMETER CENTER

1501 Lake Hearn Drive, Atlanta, GA 30319

Saturday, October 15, 2011

7:30 AM-5:00 PM

Hosted by

LIGHTHOUSE LYMPHEDEMA NETWORK

Some of our Featured Speakers:

David Finegold, MD (Pediatric Endocrinology, Pediatrics and Clinical Biochemical Genetics, Univ. of Pittsburgh) “Lymphedema Genetics: Of Mice and Men” and “Lymphatic Genetics in the Future: A Ride on the Starship Enterprise”

Young-sup Yoon, MD, PhD (Cardiologist and Stem Cell Biologist at Emory University): “Novel Cell-based Therapy for Experimental Lymphedema”

Program Location: **Hilton Garden Inn – Atlanta Perimeter Center, 1501 Lake Hearn Drive, Atlanta, GA 30319.** Conference will be held in the lower level of the hotel. The hotel is located at the intersection of 285 and Ashford Dunwoody Road, just inside the perimeter. Going east on 285, exit Ashford Dunwoody Road turning right. Immediately turn right on Lake Hearn Drive to reach the hotel. For reservations, please call 404-459-0500 before October 3rd; mention the Lighthouse Lymphedema Network to receive the conference rate of **\$74/night.**

Conference registration information will be provided in the next issue of the newsletter – You will now also be able to register on-line at our website!



Fox Theatre Silent Auction and Entertainment

Thursday, February 23, 2012, 7:00-9:00 PM

This event, to be held in the Egyptian ballroom of the Fox Theatre, will benefit the Lighthouse Lymphedema Network and its continuing education and awareness events for lymphedema patients, caregivers, the medical community, insurance companies, and the general public. We are soliciting items or services to be donated for the auction. Our program will include heavy hors d'oeuvres, music, and an emcee. More information to follow!

March 22, 2011 LLN's Third Annual Lymphedema Education Day at the Georgia State Legislature



Deb Cozzone, Beverly Thompson, Vera Newman, Linda Harman, Pauline Meyer, DeCourcy Squire, Laura Hoffman, and Gillian Wolfson participated in this year's presentation. They engaged legislators and aides in conversation about the need for insurance coverage of lymphedema treatment. These volunteers also provided food and handed out our LLN lymphedema brochure, as well as continuously showing a DVD (prepared by Clint Labarthe) with Heather Ferguson's presentation about the lymphedema treatment bill that was passed in NC. Heather also provided cards about the national bill effort to distribute. **Representative Debbie Buckner recognized the Lighthouse Lymphedema Network on the floor of the legislature and mentioned the national bill. Rep. Buckner recommended that all Georgians also contact their Congressional representatives and push for them to "get on board" to sponsor the National Lymphedema Treatment Act.**

LLN Board members who participated in the 3rd annual Lymphedema Education Day are pictured below: Pauline Meyer, Deb Cozzone, Linda Harman, Vera Newman, and Beverly Thompson.



Solaris donates lymphedema garments to South African patients (& LLN helps!)

Compression garments will benefit cancer survivors and others living with the challenge of lymphedema

- Linda Owen Pedroley - Published: Feb. 21, 2011 <http://nursing.missouri.edu/magazine/nursing-in-practice/2011/solaris-donation/index.php>



Left, Vickie Parker, OT, CLT-LANA, lymphedema therapist at Ellis Fischel Cancer Center, research associate with the Armer lymphedema research project, and instructor for the Norton School course in South Africa; and Jane Armer, right, examine a leg compression sleeve donated by Solaris, Inc.

Often misdiagnosed and untreated, lymphedema can be managed with the use of complete decongestive therapy (CDT) including the use of compression garments, which help control tissue swelling associated with the condition. While the cost of compression garments is generally covered at least in part by health insurance in the U.S., patients in other parts of the world may have a more difficult time affording them. But thanks to a generous donation by Solaris, Inc., dozens of breast cancer survivors with secondary lymphedema and persons experiencing lymphedema due to other causes in South Africa and some surrounding countries will benefit from their use.

After talking with Sinclair School of Nursing professor Jane Armer at a lymphedema management training course in Dallas, Texas, in 2010, Solaris CEO Kathy Weatherly, OT, CLT-LANA, offered to donate compression garments that had been returned to her company for sizing reasons. Armer regularly travels to South Africa to facilitate the teaching of a course in lymphedema management and conduct research. To date, 53 nurses and physical, occupational, and massage therapists have been trained in the specialty of lymphedema therapy through collaborative efforts among the University of Missouri, the University of Western Cape, Tshwane University of Technology, and the Norton School of Lymphatic Therapy. Armer offered to transport the garments during one of her upcoming trips to South Africa. Solaris generously donated 112 compression garments for arms and legs affected by lymphedema, worth on average up to \$1,000 each, and arranged to have them transported to South Africa by Armer and her colleagues.

“This is a significant and much-welcomed contribution to cancer survivors and others living with the challenges of lymphedema in South Africa and nearby countries,” Armer said. “This generous gift will improve the lives and well-being of 112 persons in need and help raise awareness that lymphedema is a manageable chronic condition – there is treatment which improves quality of life and function.”

Solaris is a founding sponsor of the American Lymphedema Framework Project, which is directed by Armer and housed at Ellis Fischel Cancer Center since its founding in 2008. Solaris is a leading compression and therapeutic garment manufacturer based in West Allis, Wis.

The LLN membership is adding two suitcases full of gently used bandages, sleeves, other items, plus two boxes full of new product for this worthy project in Africa.



LLN BANDAGES & GARMENTS FUND UPDATE

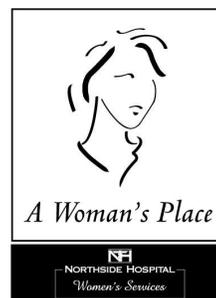
LLN wins **\$20,000** Grant from Susan G. Komen for the Cure to support our Bandages and Garments Fund!



Thanks to the persistence and hard work by Deb Cozzone, Board Member and manager of our Bandages & Garments Fund, LLN has been awarded this grant which will help us to expand our assistance for arm compression garments to breast cancer patients in the 10 metro Atlanta area counties who have developed lymphedema and are unable to afford proper compression garments. Deb and other LLN Board members have worked very hard on grant applications for the past several years, so we are really pleased and much honored to be receiving this grant. LLN received a check for the first half of the grant money on April 1, 2011. We will receive the second \$10,000 in October. (Pictured above: Kelly Dolan, Executive Director, Susan G. Komen for the Cure-Greater Atlanta, LLN Director Joan White, Deb Cozzone, and Eryn Marchiolo, Grants Manager, Susan G. Komen for the Cure Greater Atlanta.)

And there's more good news!!

We also received a check for **\$3,985.00**, an incentive donation to A Woman's Place at Northside Hospital from BSN Medical/JOBST. AWP designated the LLN as the recipient of this check. Our sincere thanks to both Jobst and A Woman's Place (one of our very active garment fitting sites for lymphedema patients) for supporting LLN's outreach activities to help more lymphedema patients.



But wait, there's still more!!

Board member Christina Jeffries, who works for Primerica, entered its PRIDE IN PRIMERICA, PRIDE IN OUR COMMUNITY essay contest. Each employee contestant had to describe the purpose of their favorite charitable organization, and how it had changed their lives and the lives of others, in their local communities as well as in broader outreach. There were 40 entries in all, with the top 3 receiving \$5,000 and 7 more entries were awarded \$500 each. **Christina's entry won \$500 for the 14th State of Georgia Lymphedema Education & Awareness Conference, to be used for a speaker honorarium for Dr. David Finegold of the University of Pittsburgh!**

Here is part of her entry:

***My story:** My lifelong primary lymphedema (LE) was worsened by a post-surgical infection, and my doctors had no idea how to treat me properly. I was finally referred to a certified lymphedema therapist at Gwinnett Medical Sports Rehab Center, who confirmed that I had LE. After getting proper treatment, the swelling in my legs & my skin texture also improved dramatically. My life has truly been changed for the past 6 years. I religiously perform my bandage wrapping and wear compression garments daily. I know there is no cure, but I'm one of the lucky ones with good insurance and I'm able to get my compression garments and I can see a certified lymphedema therapist to help move the fluid in my body so it doesn't build up. If this happens it could cause more damage. The bandages and garments that are needed for this special treatment are very expensive and really expensive to someone who has no insurance, Medicare, or Medicaid that will help them cover these costs.*

The LLN has enabled me to become involved in the organization and raise funds for others in need through the BAG Fund. Our organization has many volunteer activities and it was all started by a group of patients like me and a couple of therapists who wanted to bring awareness of this condition to others. We know that my surgeons and oncologists do not warn their cancer patients that developing lymphedema after treatment is a risk they should be aware of. I am a member of the LLN because I want to be more involved. We have helped more than 150 indigent patients in the last 5 years with garments sets for free and we are working on state and national legislative initiatives to get more care for LE patients from insurance companies. We send out a newsletter to more than 1100 members worldwide, we have an annual State of Georgia Education & Awareness Conference every fall to educate patients, and we maintain an active website to get good information out to patients looking for help and answers to this disease. The LLN's goal is to bring hope to all LE patients.

And there's STILL more!

Teresa Mullet of Hesston, KS, has sent LLN a check for \$2,000 **from the Mennonite Foundation** honoring the terrific website support work of our long-time Board member, Pat O'Connor (<http://www.lymphedemapeople.org>). Teresa is very appreciative of Pat for what he is doing to educate others about lymphedema. (On his website, Pat says: “*To all my lymphedema family throughout the world. Out of respect and admiration for your courage and strength, I dedicate this site to you.*”)

Larry Hart Golf Outing: The Lighthouse Lymphedema Network was the beneficiary of the charitable proceeds at the Southern Loss Association golf and tennis outing held March 29, 2011, at Chateau Elan Resort in Braselton, GA. The golf outing was in memory of Larry Hart, the long time business partner of Doug White who is the husband of Joan White the LLN executive director. Representing the LLN, Joan and Beverly Thompson accepted the cash donation of \$1,674.00 from the sale of mulligans and the ball toss. This generous donation will be added to our Bandages and Garment Fund which helps our many needy leg lymphedema patients.

Another possible source of matching contributions for LLN: Some employers will match your contributions to a 501(c)(3) charity like the LLN through their Matching Gifts Program. Each year we also get a matching fund donation from Microsoft's Matching Gifts Program. The more donations we receive, the more we can help our needy patients, and we can invite more speakers who are experts in lymphology from outside GA, and even outside the USA.

Bill Goering Memorial Fencing Tournament Proceeds Contributed to LLN



The LLN was the recipient of all funds raised at the Bill Goering Memorial fencing tournament held in Denver, CO, on January 22-23, 2011. The tournament is sponsored by Monica Goering in memory of her late husband Bill Goering, a well-known fencer who devoted much of his life to the sport as a competitor, a referee and a mentor to many younger fencers. Nathan Anderson, Owner and Head Coach of the Denver Fencing Club, is the tournament organizer. Deb Cozzone, niece of Monica and Bill Goering, attended the tournament and accepted the donation with gratitude on behalf of the LLN. 120 competitors participated in the Bill Goering Memorial this year, which held brackets in various age groups in all three weapons: epee, foil, and saber.

The tournament raised \$3,500.00 for the LLN, and an anonymous donor matched the donation to make a grand total of **\$5000.00** for the LLN. Our sincere thanks are extended to Monica Goering, Nathan Anderson, and all of the competitors who participated in the Bill Goering Memorial in 2011.



In Memoriam: Randi Passoff, Founder of the 2-Day Walk and It's The Journey

Randi Passoff, 61, of Sandy Springs, died September 22, 2010. Mrs. Passoff founded the Atlanta 2-Day Walk for Breast Cancer. Randi's friends have formed "Randi's Army." On September 17th, Randi's Army is holding the Randi Passoff Memorial Walk for breast cancer. Please add this event to your calendar and join the walk.

Congratulations to LLN Board member Laura Hoffman on her new job as coordinator of the Compression Therapy Services Program at Piedmont Hospital! Piedmont is now servicing its lymphedema patients in-house. Also, Tammy Malone has started her own business, Custom Compression Consultant, as a mobile independent dealer.



THE LLN COOKBOOK –

The LLN Board Members are busily working on another cookbook, filled with delicious and nutritious recipes. This project will be another effort to raise revenues for the BAG Fund. Good nutrition plays a critical role in helping lymphedema patients maintain a strong immune system and keep their weight down. The cookbook will be available for sale May 1st for \$12. Thanks to Linda Stovall, who has chaired the cookbook committee, and to everyone who submitted recipes.



WHEN: Saturday, June 4, 2011

WHERE: Clifftondale Park, 4645 Butner Rd., College Park, GA 30349

Time: 8:00 a.m. sharp

DIRECTIONS TO THE WALK From Atlanta

- Go I-20 West to I-285 South exit at Camp Creek Parkway.
 - Go Right to Butner Rd. (5th light).
- Turn Left onto Butner Rd. , go approximately 3 miles to the 4-Way Stop Sign
 - Continue straight for 1/4th mile to 4645 Butner Rd.

(Fulton County Parks and Recreation).

To Register Call Lee H. Cox at 404-349-3992 or

E-mail to gwcfoundation@bellsouth.net

2011 Lighthouse Lymphedema Network Calendar Dates to Remember:

- April 9 - Board of Directors Meeting 10:00am
- May 7 - Komen Race for the Cure 5K/1 Mile Walk, Atlantic Station, Atlanta
- June 4 - Gloria Watts-Cox Foundation Walk for Lymphedema
- June 9 - Academy of Lymphatic Studies invites patients and family members with lymphedema to a brief meeting and social to help new lymphedema therapists. Your input is valuable to them as they will be the next generation of lymphedema therapists. St. Joseph Hospital, Thursday, June 9, 5:30pm, Educational Rooms 1--3, ground floor of the hospital. Juzo is providing the food for the evening.
- June 16-18 - 3rd International Lymphoedema Framework Conference, Toronto, Canada. Patient day is Saturday, June 18th. For more information and to register <http://www.lympho.org/registration-2011.php>
- September 17 - Randi Passoff Memorial Walk for Breast Cancer
- September 24-25 - It's the Journey 2-Day Walk for Breast Cancer, Atlanta
- October 1 - LLN Board of Directors Meeting
- October 15 – 14th State of Georgia Lymphedema Education and Awareness Conference, Hilton Garden Inn, Lake Heron Drive, Atlanta, GA



Invitation from Instructor John Jordi, PTA, CLT-LANA (Siskin Rehab Hospital, Chattanooga, TN) to Join Students from the Academy of Lymphatic Studies [ACOLS], Thursday, June 9 at 6 PM, in the educational rooms 1--3 on the ground floor of St. Joseph's Hospital in Atlanta, GA. (Saint Joseph's Hospital is located just inside the perimeter next to the Medical Center MARTA Station at 5665 Peachtree Dunwoody Road, N.E. Atlanta, Georgia 30342. See a map at http://www.stjosephsatlanta.org/patient_and_visitors/directions.html)

"The Academy of Lymphatic Studies would like to invite patients and family members with lymphedema to have a brief meet and greet social to help the new lymphedema therapists. Your input is valuable to them as they will be the next generation of lymphedema therapists. What do you as a patient want from your therapist? What do you want them to realize your limitations could be? As a newly certified therapist, what is the most important thing that you want me to know about you?"

The event is co-sponsored by Juzo, and refreshments will be provided. Here's your chance to make a difference as a lymphedema patient for these future certified therapists!

Our thanks also go to Juzo for a \$1324 incentive donation to LLN!



LLN February 23th Lymphedema Educational Presentation at Piedmont Hospital, Atlanta:

Dr. Andrea Cheville (Associate Professor of Physical Medicine and Rehabilitation, College of Medicine, Mayo Clinic) provided an update on research in the field of lymphedema, and discussed the outcomes of her recent research on hyperbaric medicine therapy, exercise, and imaging techniques. (We had a terrific turn-out for this LLN-sponsored event.)

Hyperbaric Oxygen treatment (HBO₂) has been used experimentally for LE. Breast cancer patients sit in room-sized hyperbaric chambers and undergo 2 atmospheres of pressure of oxygen for 2 hours at a time, with a maximum of 21 treatments. Measured by perometry (the use of infrared light to measure the volume of a limb), there was a definite reduction effect in the HBO₂-treated group compared to a control group. However, this was not a proper randomized control trial (RCT), so these results cannot be generalized yet. Contraindications for this treatment are pre-existing asthma and cardiac problems. Eye and cardiac exams are required.

Dr. Cheville discussed the SPECT scan imaging technique used at Mayo Clinic (A single-photon emission computerized tomography (SPECT) scan lets your doctor analyze the function of some of your internal organs. A SPECT scan is a type of nuclear imaging test, which means it uses a radioactive substance and a special camera to create 3-D pictures. While imaging tests such as X-rays can show what the structures inside your body look like, a SPECT scan produces images that show how your organs work. For instance, a SPECT scan can show how blood flows to your heart or what areas of your brain are more active or less active.) This technique allows reduction of x-ray exposure to incident (nearby) lymph nodes. Protection of lymphatics during cancer treatment allows them to heal more quickly. The body tries to re-establish lymph drainage channels, and can consolidate remaining uninjured nodes to be more efficient. The body can also utilize existing but underused drainage pathways to create new active ones.

There are some new experimental treatments for reversing established LE, such as vascularized groin lymph node transplants. So far, this technique has only been used for upper extremity LE cases, such as breast cancer patients. Results from two small trials were not reported by standardized techniques. One trial showed definite reduction after 56 months when reduction in hand size was the primary criterion. Another trial had mixed results after 5.6 yr.

Cold laser (low-level light therapy) has been used with some good results reported. This technique can soften fibrous skin tissue, and increase the number of macrophages (white blood cells important in defense against infections). Dr. Cheville said that the initial study design had some problems, and it was not a full RCT. A number of additional trials have been conducted since then. Side effects with this treatment are benign, but we don't know if the benefits are sustained or transient, so the question remains – should it be used as primary or as adjunct therapy for LE?

Use of pumps is still a hotly contested topic. Dr. Cheville said that more good work is needed to know how well the pumps work, but she said that they should be used in conjunction with Complete Decongestive Therapy (CDT) and wearing compression garments. She recommended that patients rent a pump initially to try it out.

Her Conclusions:

- LE is degrading to quality of life
- CDT is effective but laborious
- Lymph node sparing approaches so far have only been applied to breast cancer patients and benefit is only theoretical
- HBO₂ is promising but needs a proper RCT for validation
- Lymph node transfer surgery needs much more work and validation
- Cold laser needs more study
- Exercise can be beneficial – better-functioning muscles may in turn help make lymph nodes work better.

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.

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: The Lighthouse Lymphedema Network, 10240 Crescent Ridge Drive, Roswell, GA 30076; 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 save mailing costs!

LLN's website is <http://www.lighthouselymphedema.org>

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