



LLN March 2012 Newsletter

See inside for ordering information for our LLN books:

- *The Puzzle: An Inside Glimpse of Lymphedema*
 - *LLN Favorite Recipes Cookbook*
-

www.lighthouselymphedema.org

BELLMERE GARDENS LUNCHEON, TOUR AND PLANT SALE FUNDRAISER BENEFITING THE LLN

Saturday, April 14, 2012, 12:00-3:00 PM
Cost: \$30.00 (covers catered luncheon and tour)

Garden Location: 10777 Bell Road, Johns Creek, GA 30097

Here's how to order tickets:

Send a check to: Vicky Day, 10785 Bell Rd., Johns Creek, GA 30097

Please include your name, email address, and number of tickets desired so that we can confirm receipt of your check and your attendance.

Directions: Bellmere Gardens is located at 10777 Bell Rd., Johns Creek, GA 30097-1803. Johns Creek is slightly northeast of Atlanta. If you live in any other part of the Atlanta area, take I-285 N. Merge onto GA-141 N (Peachtree Industrial); at the split, veer left towards Cumming onto GA 141 which is now Medlock Bridge Road. Turn right onto Bell Rd. Bellmere will be on the left. Look for the balloons. Once on the driveway, you will see the Garden House sign.



The event includes lunch served by Beta Club members, master gardener container garden demonstration, a walking tour on your own of the gardens, and a plant sale. The Beta Club members will help with loading the plants in the cars. Invite your co-workers, friends, family, & neighbors. You may reserve an entire table of 8.

LLN Director Joan White was a Featured Guest on the Radio Show “Lymphedema Mavens” January 19, 2012 (<http://www.thecityfm.com/program.php?folder=mavens>)

Listen to Joan’s **Lymphedema Mavens** Radio Podcast <http://thecityfm.com/mavens/ldm011912.mp3>

The Lymphedema Mavens



Coach Christine Wunderlin and Ms. C-Jay Judge (Nevada Patient Advocate for the Lymphedema Treatment Act) take you on a journey of understanding, healing, recovery and restoration as they speak with experts in the field, survivors of cancer, and those afflicted with Lymphedema; a common cancer side effect. Hear personal stories, medical information, and strategies to live a fuller more enjoyable life. Learn about advocacy in progress to change the laws regarding treatments, and how you can help. The Mavens are on it!!

Do you know about **NORD, the National Organization for Rare Diseases?** They have a whole website page devoted to lymphedema and national resources for information:
<http://www.rarediseases.org/rare-disease-information/rare-diseases/byID/239/viewAbstract>

The Gloria Watts-Cox Foundation, Inc.
“TENTH ANNUAL 8K WALK”
Supporting Those Suffering with Lymphedema

WHEN: Saturday, June 2, 2012 **WHERE:** Cliftdale Park, 4645 Butner Rd.
TIME: 8:00 a.m. sharp College Park, GA 30349

Pre-registration is Highly Recommended:
E-mail gwcfoundation@bellsouth.net

Indicate your shirt size, & mail check or money order made payable to:
Gloria Watts-Cox Foundation, Inc., 2734 Waleska Way, East Point, GA 30344

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)



LLN BANDAGES & GARMENTS FUND UPDATE

The first quarter of 2012 has been productive for the LLN Bandages and Garments Fund. To date, the Fund has assisted 16 patients. 10 of these 16 have been provided garments through the 2011-2012 Susan G. Komen for the Cure Greater Atlanta Affiliate grant, and the other 6 have been provided supplies through the general fund. So far in 2012 we have already supplied over \$7,200 worth of garments and compression devices to our patients. There are an additional 13 approved patients currently in treatment or being fitted, so all of these numbers increase every week.

A special thanks to the Susan G. Komen for the Cure Greater Atlanta Affiliate and all of our compression specialists and or garment manufacturers: through your efforts and support, the LLN has been able to assist 31 breast cancer survivors who have developed lymphedema. This is over 50% more patients than we originally estimated in our proposal, and we owe much of that to you. **(Unfortunately, we did not receive a grant renewal for 2012, so please support all of the LLN fundraisers so we can continue to support lymphedema patients!)**

Finally, the Bandages and Garments Fund committee will begin a review of current procedures focusing on continuous improvement as we move into the second quarter. Any changes will be communicated to the therapists and fitters through email. If you are not on the appropriate distribution list or you aren't sure, or if you have any questions or comments regarding the Fund, please contact Deb Cozzone at debcozzone@hotmail.com.

Bill Goering Memorial Fencing Tournament

The annual Bill Goering Memorial Fencing Tournament took place in Denver, CO, on January 28-29. The head coach and owner of the Denver Fencing Club, Nathan Anderson, once again donated all proceeds to the Lighthouse Lymphedema Network's Bandages and Garments Fund. This was the 5th consecutive year that the LLN benefited from this tournament, and we all heartily thank Nathan and the tournament sponsor, Monica Goering, for their support. Over \$4,500 was raised for the Bandages and Garments Fund. Thank you to all the organizers, officials, participants and support staff of the Bill Goering Memorial!



Nick Gianoutsos, winner of saber



Nathan Anderson presenting the proceeds check to Deb Cozzone

Update on the National Lymphedema Treatment Bill: HR 2499 has **62** cosponsors. Visit the website www.LymphedemaTreatmentAct.org for a list of those Congresspersons who have signed on as sponsors. Hardly any Representative from the Southern U.S. is listed as a co-sponsor, so we need to get busy and contact them to express our desires for their support of this bill!

2012 Lighthouse Lymphedema Network Calendar Dates to Remember:

- Saturday, April 14, 2012 – **Bellmere Gardens Luncheon, Tour and Plant Sale** Fundraiser for LLN, \$30/ticket, 12:00-3:00 PM, 10777 Bell Road, Johns Creek, GA
- Saturday, April 28th, **Yard Sale** to benefit LLN at the home of Audrey Woodruff (2695 Amberly Hills Trail, Dacula, GA 30019)
- Wednesday, May 2, 2012 –**Southern Loss Association sponsors second annual Larry Hart Memorial Golf Outing** at Chateau Élan Resort, 100 Rue Charlemagne, Braselton, GA 30517. Joan White and Beverly Thompson will represent LLN, but others are invited to join them for the fun. The proceeds from the sale of mulligans and the ball toss will be donated to the LLN.
- Wednesday, May 9, 2012 – **DeKalb Medical Center/Hilandale Craft and Health Fair.**
- Saturday, May 12, 2012 - **Komen Atlanta Race for the Cure, at Atlantic Station, Atlanta.** The LLN is organizing a Team to Walk. If you would like to be a part of our team, please call Samantha at 770-310-8100 (samanthac68@yahoo.com). **Delores Bradley** is our co-captain (dbradley0110@gmail.com). We will be wearing LLN team t-shirts with the LLN logo and "Team Lighthouse Lymphedema Network." Remember that Komen Atlanta has provided us with grant money to support our Bandages and Garments Fund.
- Saturday, June 2, 2012 – 8th Annual **Gloria Watts-Cox Foundation Walk for Lymphedema**, 8:00 AM sharp, Clifftondale Park 4645 Butner Rd, College Park, GA 30349
- Saturday, June 23, 2012 - **Celebration of Living**, a health and wellness fair sponsored by Emory's Winship Cancer Center



Atlanta
Legal Aid
Society

The LLN meets the Atlanta Legal Aid Society, Inc.

The Lighthouse Lymphedema Network has benefited in multiple ways from the Susan G. Komen for the Cure grant. One benefit has been to meet and share information with other organizations with a passion to serve the lymphedema community. One such entity is the Atlanta Legal Aid Society, Inc., and their Breast Cancer Legal Project. The Breast Cancer Legal Project advocates for lymphedema treatment for eligible patients.

“The Cancer Legal Initiative and the Breast Cancer Legal Project at the Atlanta Legal Aid Society, Inc. provide free civil legal services to low-income cancer patients and survivors in the five metro Atlanta counties of Fulton, Clayton, Cobb, Gwinnett and DeKalb. Our mission is to provide comprehensive and compassionate legal services that have a direct impact on health and quality of life to low-income individuals who are living with or are affected by all types of cancer. We collaborate with other agencies, organizations, and health professionals to incorporate legal services into the holistic care of those we serve.”

Fighting cancer is a daunting challenge: medical, social, emotional, and - at times - legal. We help our clients navigate employment-related issues and insurance coverage denials. We also assist our clients in appealing denials of Social Security disability benefits and unemployment insurance benefits. We prepare estate planning documents, and help clients with family law matters, such as divorce, child support and custody. Additionally, we defend clients against wrongful evictions, and we provide advice to homeowners in financial crisis. We also assist clients with issues that may arise with public benefit programs, like food stamps and Medicaid.

Cancer takes a toll on any family's finances, and low-income individuals dealing with the realities of a serious illness need an advocate who can help them cut through red tape, get the care they need, and help them provide for themselves and their families. If you or someone you know would like to contact the Cancer Legal Initiative or Breast Cancer Legal Project, please call our intake line number at (404) 614-3969 to be screened for eligibility for our services.”

Mark your calendars for the 15th Lymphedema Education & Awareness Day on October 27th, 2012, at Emory University Hospital Midtown in Atlanta. (Out-of-town attendees can stay at the Meliá Hotel - 590 West Peachtree Street NW, Atlanta, GA 30308 - across the street from the hospital.)

We are already lining up excellent speakers:

1. **Jane M. Armer, PhD, RN, FAAN**, Professor, Sinclair School of Nursing at the University of Missouri Medical School, Director, Nursing Research, Ellis Fischel Cancer Center and Director of the American Lymphedema Framework Project will talk about her research, her work in South Africa in which the LLN contributes garments, bandages and other devices, plus she will bring us up-to-date on the American Lymphedema Framework Project.
2. **Richard Mistretta, DPM**, of Affiliated Ankle & Foot, PC, Duluth, GA. Dr. Mistretta will discuss proper foot care, footwear, and the relationship these factors have on extending lymphedema management success after the patient with swelling has been released from treatment.
3. **Joseph L. Feldman, MD, CLT-LANA**, Co-director of the American Lymphedema Framework Project. Dr. Feldman is one of the founding board members of the Lymphology Association of Lymphology (LANA), and is President of LANA. Dr. Feldman is a physiatrist certified by the American Board of Physical Medicine and Rehabilitation. He will discuss his work with lymphedema patients, specifically children. We hope that he will also be able to sit in with our parent and teen networking sessions to answer questions.

THANKS TO OUR SUPPORTING VENDORS WHO ARE EXHIBITING AT THE 15th Lymphedema Education & Awareness Day



**JUZO
MEDI USA
BSN MEDICAL
SOLARIS, INC
BAUERFEIND USA
BODY OF HEALTH
CIRCAID MEDICAL PRODUCTS
PRETTY PLEASE HEALTHCARE
SUSAN G. KOMEN FOR THE CURE
PENINSULA MEDICAL PRODUCTS
GLORIA WATTS-COX FOUNDATION
A WOMAN'S PLACE AT NORTHSIDE HOSPITAL**



Annual LLN Spring Garage Sale!

DATE: Saturday, April 28, 2012 (8:00 AM to 4:00 PM)

LOCATION: 2695 Amberly Hills Trail, Dacula, GA 30019 (off New Hope Road)

Coordinators: Beverly Thompson 770-476-2671

Directions: (A) Take I-85 North to GA-316 E via exit 105 toward Lawrenceville/Athens. Exit on the Sugarloaf Pkwy exit, and turn right. Go straight toward New Hope Road. Turn slight right onto New Hope Rd SE. Turn right onto Amberly Hills Trail SE. 2695 Amberly Hills Trail is on the right.
OR: (B) Using Lawrenceville Hwy (US Rt 78), go north toward Snellville/Athens. Turn left onto Grayson Pkwy SW/GA-84. Stay straight to go onto Grayson-New Hope Rd SE. Turn right onto New Hope Rd SE. Turn right onto Amberly Hills Trail SE.

The **Lighthouse Lymphedema Network**, a group established to help patients, caregivers, and medical professionals by increasing awareness of lymphedema (a condition that causes swelling, usually in the arms or legs but sometimes in other places in the body – to learn more, please go to our website: <http://www.lighthouselymphedema.org>) is holding its annual garage sale on April 28th.

Call 770-938-1891 if you need assistance with pickup of large items such as furniture before the sale. Donations of smaller items can be brought beforehand or on the day of the sale.

We ask our donors to please have all items properly labeled with a price before drop-off. Doing this in advance will save a lot of effort and time for those volunteers who are setting everything up (and you know best what your item might be worth).

LLN volunteers are urgently needed to help set up, collect money, and clean up at the end of the day. (All unsold donated items will go to the local Goodwill or the Kidney Foundation, so everything left over must be boxed for pick-up by these charities.) Revenue generated from the sale will be used to fund the Bandages and Garments Fund, which helps support lymphedema patients, so your contributions (and purchases!) will be greatly appreciated.



CONGRATULATIONS TO LLN BOARD MEMBER SHELLEY SMITH DICECCO on successfully completing her PhD program. She presented her findings on lymphedema therapy research to her committee of advisors on March 7th, and to her college and community on March 29th.

LLN'S SECOND ANNUAL SPECIAL SPEAKER SERIES
REVIEW OF PRESENTATION BY JANICE CORMIER, MD, MPH, FACS



On the evening of Feb. 29, Janice Cormier was our guest speaker for the 2nd Annual Lighthouse Lymphedema Special Speaker's Series, held at Piedmont Hospital in Atlanta. She also presented Grand Rounds for the medical staff at Piedmont Hospital and her presentation was televised to outlying hospitals in Piedmont's Network. Dr. Cormier is an oncological surgeon specializing in melanoma at MD Anderson Cancer Center, in Houston, TX. She discussed her study of lymphedema development in melanoma patients, with respect to the frequency of lymphedema development and surgical options for treatment.

As treatments for cancer become more successful, those living with the side effects of the treatments will be growing in numbers. Secondary lymphedema can, unfortunately, be one of the treatment side effects. Because its onset can be delayed, most often occurring 2-5 years in melanoma surgery patients, it can easily be overlooked. (The rate of lymphedema occurrence following treatment in breast cancer patients is 20-40%, and it may occur decades after the original surgery.) This does not follow the traditional 1 year timeframe that most post op issues are monitored. Dr. Cormier also acknowledged that there is possibly a lifelong risk of lymphedema development.

The primary treatment for melanoma is surgery, so the lymph node dissections are very thorough. Even with deeper dissections, upper extremity melanoma patients appear to have a lower incidence of lymphedema development, possibly because they do not have the trauma of extensive chest surgery as happens with a radical mastectomy. Leg surgery patients have a high incidence of lymphedema occurrence, and usually with more severe consequences.

Dr. Cormier stressed the importance of early intervention and encouraged physicians to continue to monitor for the onset of lymphedema, and treat it as soon as it becomes symptomatic and not wait until swelling is visible. She prescribes compression garments for all leg patients as part of her protocol to be used with extensive standing/use and flying. Treating lymphedema early is cost effective.

Studies on the surgical treatment of lymphedema appear to be heavily biased with consequences to the non-lymphedematous body part not addressed or under-reported. Two types of surgery are demonstrating success: 1. Liposuction performed by Dr. Hakan Brorson (Lund University, Sweden) on persons with lymphedema has had promising results for a particular population. The patients receive CDT prior to the surgery. A large part of the success is from the government providing a new compression garment every 4 months along with the patient being compliant with wearing the garment 24 hours/day. 2. A colleague of Dr. Cormier has recently published a study with promising results from attaching lymphatic vessels to veins in the area. This procedure is still experimental and is not yet covered by insurance.



The Lymphatic Filariasis Shoebox Project:

From Jennifer Hovatter in Tennessee:

"I am collecting shoeboxes to put soaps and other necessities in to be sent to Africa and India for Lymphatic filariasis patients. My goal is to work with the Centers for Disease Control and Prevention and remote area medical staff, to get these shoeboxes to these Lymphatic filariasis patients in my husband Thomas' memory. He passed away from Lymphedema 4 years ago and I am devoting the rest of my life to advocating for Lymphedema patients. If anyone can help donate soaps and / or shoeboxes, please do so. In a year or two, I will be going to Africa or India for my Public Health field study and will be working with these wonderful people who suffer from this horrible disease. They can't always get the treatment that they need because of the area that they live in, there is no access to compression garments or bandages for them, and their living conditions are not the best. Lymphatic Filariasis is a type of Lymphedema caused by a parasite that is a microscopic thread-like worm, and is spread from person to person by mosquitoes. It is known as a neglected tropical disease. I am challenging you to tell everyone that you know to help with this, PLEASE! These people are in desperate need of help - this is NOT a disease to play around with. This project will be a continuous, going on all year, every year."

**SEND YOUR CONTRIBUTIONS TO: Jennifer Hovatter, 1005 Somerset Drive
Johnson City, Tennessee 37604, ph: 423-282-8922, jennyjh@earthlink.net**

Lymphatic filariasis, considered globally as a neglected tropical disease, is a parasitic disease caused by microscopic, thread-like worms. The adult worms only live in the human lymph system. The lymph system maintains the body's fluid balance and fights infections. Lymphatic filariasis is spread from person to person by mosquitoes. People with the disease can suffer from lymphedema and elephantiasis, and in men, swelling of the scrotum called hydrocele. Lymphatic filariasis is a leading cause of permanent disability worldwide. Communities frequently shun and reject women and men disfigured by the disease. Affected people frequently are unable to work because of their disability, and this harms their families and their communities. To learn more about lymphatic filariasis, see the CDC Lymphatic Filariasis Home Page:
<http://www.cdc.gov/parasites/lymphaticfilariasis/disease.html>



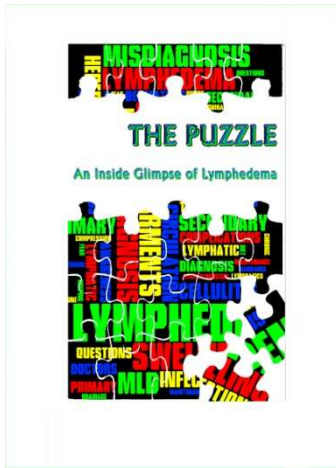
SOUTHERN LOSS ASSOCIATION SPONSORS SECOND ANNUAL LARRY HART MEMORIAL GOLF OUTING

Wednesday, May 2, 2012

Chateau Elan Resort, 100 Rue Charlemagne, Braselton, GA 30517

The proceeds from the sale of mulligans and the ball toss will be donated to the LLN.

LLN PROUDLY ANNOUNCES THE PUBLICATION OF TWO NEW BOOKS!



This book was compiled so that people who have been touched by lymphedema can share their stories, trials and tribulations, sadness and disappointments, strength and hopes. It is intended to encourage, educate, and inspire patients and loved ones, who can feel isolated and uninformed. We hope to increase awareness and general knowledge of a condition that is often overlooked and misdiagnosed, yet which can have monumental physical and emotional impact on the lives which it affects. Not every story has a happy ending, yet there is hope. By sharing these stories with one another, we can learn from the struggles and successes that others have experiences, and can help each other to live well with lymphedema.

As the center of family life is our kitchens, we hope you will enjoy cooking, baking, and simply creating memories from our recipes. This book is a collection of recipes from members, family, and friends of the Lighthouse Lymphedema Network. This cookbook makes a great gift for all occasions, or just for you!

*The Lighthouse
Lymphedema Network*



Both of these books will be available by credit card order through our website, <http://www.lighthouselymphedema.org>, or by contacting Beverly Thompson at 770-476-2671. Or, you can order our books by mail with this form & check payable to: Lighthouse Lymphedema Network Books, 10240 Crescent Ridge Drive, Roswell, GA 30076

| | | | |
|--|--|------------------------------|----------|
| Name: First | | Last | |
| Mailing Address: | | | |
| City | | State | ZIP Code |
| Preferred Telephone Number | | | |
| Email Address | | | |
| Number of Copies you would like to order: | | | |
| The Puzzle _____ | | LLN Cookbook _____ | |
| \$19.95 per copy | | \$12.00 per copy | |
| (+ \$5/copy shipping) | | (+ \$5/copy shipping) | |
| \$ | | | |
| Total Amount Enclosed (Check Payable to Lighthouse Lymphedema Network) | | | |

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 save mailing costs! elaine.gunter@comcast.net

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

Return service requested to:

**LLN Newsletter Editor
1625 Sprucewood Court
Decatur GA 30033 USA**

