



*Our website is:*

[www.lighthouselymphedema.org](http://www.lighthouselymphedema.org)

## **LLN September 2012 Newsletter**

### **Coming up in 2012:**

- Our patient stories book and our second cookbook now available for sale, **SPECIAL DEAL: both books for \$25** at our website!

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**REGISTER NOW!**

## **15<sup>TH</sup> STATE OF GEORGIA LYMPHEDEMA EDUCATION AND AWARENESS PROGRAM**

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

**Emory University Hospital Midtown  
550 Peachtree Street, Atlanta, GA 30308**

**Saturday, October 27, 2012**

**7:30 AM-5:00 PM**

**Hosted by  
LIGHTHOUSE LYMPHEDEMA NETWORK  
And EMORY WINSHIP CANCER INSTITUTE**



**EMORY**

**WINSHIP  
CANCER  
INSTITUTE**

A Cancer Center Designated by  
the National Cancer Institute

**To register, go to our website ([www.lighthouselymphedema.org](http://www.lighthouselymphedema.org) )**

**Or, use the enclosed complete program brochure and application.**

**CEUs** are offered to professionals who attend this program.

## OUR FEATURED SPEAKERS:

**Jane M. Armer, PhD, RN, FAAN** - Professor, Sinclair School of Nursing at Missouri University. Dr. Armer is also Director of Nursing Research, Ellis Fischel Cancer Center. She has published more than 60 research articles in the refereed literature, 30 of which are focused on lymphedema, and the majority of which report original research. She holds certification as a lymphedema therapist trained through the Lerner Institute Academy of Lymphatic Studies, a leading educator in lymphedema management in the United States. In 1998, she organized a multidisciplinary group of dedicated oncology clinicians and researchers to form a lymphedema research team at Ellis Fischel Cancer Center, an integral partner in the Academic Health Sciences Center at the University of Missouri. Dr. Armer serves on the Medical Advisory Committee of the National Lymphedema Network, where she has chaired the research committee, and on the board of the Lymphology Association of North America, the professional certifying board for lymphedema therapists. She is director of the American Lymphedema Framework Project, a national partnership with the International Lymphedema Framework (ILF), and manages its project in South Africa.

**David W. Chang, MD, FACS** - Professor, Department of Surgery, Director of the Microsurgery Laboratory, University of Texas M.D. Anderson Cancer Center. He holds joint appointments as clinical associate professor, Dept. of Surgery at Baylor College of Medicine, and adjunct associate professor at the Dept. of Biomedical Engineering at Rice University. Dr. Chang specializes in complex microsurgical reconstructive surgery in cancer patients involving all areas of the body, his primary research focuses in breast reconstruction and restoration of extremity defects such as lymphedema.

**Joseph L. Feldman, MD, CLT-LANA** - Dr. Joseph Feldman is 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 the President of LANA. Dr. Feldman is a physiatrist certified by the American Board of Physical Medicine and Rehabilitation. He is Medical Director of the NorthShore University Health System Lymphedema Treatment Center and Clinical Assistant Professor of Physical Medicine & Rehabilitation, University of Chicago Pritzker School of Medicine. Dr. Feldman is a member of the National Lymphedema Network Medical Advisory Committee and served as Program Director of the 9th NLN International Conference in 2010. Dr. Feldman has treated lymphedema patients since the 1960's. He attended a Leduc Method Lymphedema Management course in 1996 and attended the first Foldi Clinic Complete Decongestive Therapy Physician Course in Hinterzarten, Germany, in 1999. Dr. Feldman participates in lymphedema research projects and has extensively lectured to professional and patient support groups. He was selected as a Chicago Super Doctor for 2012.

**Richard Mistretta, DPM** - Dr. Richard Mistretta, of Affiliated Ankle & Foot, PC, Duluth, GA, will discuss the pathology of the feet and the importance of taking proper care of your feet and its effect on your entire body. Many lymphedema patients have trouble with their feet from severe swelling, having to wear tight garments daily, or from the wrapping with bandages at night. Also, footwear is always a concern - one foot larger than the other, shoes too tight for the lymphedema-affected foot, or too large for the non-affected foot. Dr. Mistretta will cover lymphedema management through the eyes of a podiatrist.

## Many Thanks to Our Sponsors for This Meeting!

A Woman's Place at Northside Hospital  
Ambra LeRoy Medical Products  
Bauerfeind USA, Inc.  
Body of Health  
BSNmedical, JOBST  
CircAid Medical Products, Inc.  
Gloria Watts-Cox Foundation  
JUZO  
LOCOST MEDICAL SUPPLY  
MEDI, USA  
Peninsula Medical Products  
Piedmont Hospital Lymphedema & Compression Services  
Pretty Please Healthcare  
SIGVARIS, INC.  
Solaris, Inc.  
(Exhibiting only: Susan G. Komen for the Cure)



## LLN BANDAGES & GARMENTS FUND UPDATE

Since January 1, 2012, the LLN Bandages and Garments Fund has assisted 32 patients, supplying over \$13,000 worth of garments and compression devices to patients. There are an additional 13 approved patients currently in treatment or being fitted, and we continue to receive applications on a regular basis.

In addition the Bandages and Garments Fund committee has been busy this summer reviewing and revising the application procedures, focusing on simplifying the process and on continuous improvement. One of the largest issues the committee faces with the applications is legibility. Please print clearly when completing the application. Therapists and fitters will be sent the updated Bandages and Garments Application form and the new Therapist Recommendation form via email during August. If you feel that you need to be included on this email distribution and are not currently receiving correspondence regarding the Bandages and Garments Fund, please contact Deb Cozzone at [debcozzone@hotmail.com](mailto:debcozzone@hotmail.com).

Please remember that the products provided through the Bandages and Garments Fund are only available because of your donations and the LLN fundraising efforts. Without the renewal of the Susan G. Komen grant for breast cancer patients, the Fund will be depleted more quickly during 2012 and 2013. If you have any questions or comments regarding the Fund, please contact Deb Cozzone at the address listed previously.

### 2012 Lighthouse Lymphedema Network Calendar Dates to Remember:

- **August 28, 2012 meeting at DeKalb Medical Center (10:30 AM – 12:30 PM Bobbie Bailey Tower Auditorium**, located at the lobby level of the Bobbie Bailey Women's and Outpatient Surgery Center) – **AN OPEN FORUM MEETING:** patients talking to patients, and asking questions to attending lymphedema therapists.
- The next LLN Board of Directors Meeting will be held Saturday, October 13<sup>th</sup> at the Roswell GA Country Club, starting at 9:45 AM. (An LLN Conference Planning Committee meeting will be held at 9:00 AM.)



### Outcome of LLN Fundraising Efforts to Date

1. **Spring Garage Sale held Saturday, April 28, 2012 in Dacula, GA** - The yard sale income was **\$259.50** - a fantastic amount considering that we sold most items for \$0.25 to \$1.00. Thanks to our host, Audrey Woodruff.
2. **Bellmere Gardens Luncheon, Tour, and Plant Sale** – held April 14, 10777 Bell Road, Johns Creek, GA We raised **\$1,284.00** - Our thanks to Vicky Day and her family for hosting this special day, to all of our LLN volunteers, and our special thanks to the Beta Club for serving lunch and helping at the plant sale. We are now planning for a repeat Bellmere Gardens day in 2013!
3. **DeKalb Medical Hillandale Health and Artist Fair** was held Wednesday, May 9, 2012. Shelley DiCecco provided us with the absolutely best location. Beverly Thompson and Joan White sold 6 LLN cookbooks, lots of baked items, a few swags, hand/skin cream, a little of this and that. We made **\$281.00**.
4. **Larry Hart Memorial Golf & Tennis Outing sponsored by the Southern Loss Association** May 2 at Chateau Elan. Beverly Thompson and Joan White happily represented the LLN at this event. 274 golfers participated. The sale of mulligans (a chance to do-over a bad golf stroke during a game by making a charitable donation) and ball tosses made **\$2,417.00** for the LLN BAG Fund.

## Other Lymphedema-Related News:

The **5th annual Thomas Hovatter Lymphedema Awareness Day** was held on June 16th in Johnson City, Tennessee. Thomas Hovatter passed away in 2007 at the age of 43 from complications of lymphedema. His wife, Jennifer, continues her efforts to achieve her dream of raising awareness of lymphedema, promoting the success of research studies to find a cure, becoming a certified lymphedema therapist, and eventually opening a lymphedema treatment clinic in the Johnson City area. As in previous years, Patti Graybeal of Graybeal Orthopedics assisted Jennifer in hosting this event. Speakers included Tiffany Howe of Hampton, VA, who shared some of the difficult challenges and decisions she has faced because of primary lymphedema in her legs and feet and her 12-hour debulking surgery in 2006, and Paula J. B. Stewart, MD, MS, CLT-LANA, a lymphologist who is Medical Director of HealthSouth Lakeshore Rehabilitation Hospital, who presented “The Differential Diagnosis of Lymphedema.” The LLN were represented by Debbie and Clint Labarthe.

Shown in the group picture here are (L-R) Jennifer Hovatter, Tiffany Howe, Patti Graybeal, Dale Ford (TN General Assembly Rep. for District 6), Debbie Labarthe, Clint Labarthe. At right is a picture of Dr. Paula Stewart.



**The National Walk for Lymphedema and Lymphatic Diseases  
Saturday, September 15, 2012  
Eisenhower Park, East Meadow, New York**

**NOTE: As a service to lymphedema patients, LLN provides contact information about certified lymphedema therapists on our website ([www.lighthouseymphedema.org](http://www.lighthouseymphedema.org)). We work diligently to update this information frequently, but we do depend on our therapists to let us know right away if any change is required (such as drop/adds for therapist names at any clinic).**



**SUSAN G. KOMEN RACE/WALK FOR THE CURE** was held Saturday, May 12 at Atlantic Station. Board member Samantha Cannon worked very hard to find bright turquoise LLN team t-shirts which looked terrific with the LLN logo and "Team Lighthouse Lymphedema". (Some LLN team members below left at our booth include Deb Cozzone, Beverly Thompson, Jean Miller, Samantha Cannon, Doug White, Joan White, & Debbie Labarthe. Komen walkers pictured at right include: L-R, Doug White, Stuart Newman, Beverly Thompson, Debbie Labarthe, Jean Miller, and Dolores Bradley.)



**10<sup>th</sup> ANNUAL GLORIA WATTS-COX FOUNDATION 8-K WALK FOR LYMPHEDEMA** was held Saturday June 2, as a loop starting at Clifftondale Park in College Park, GA. Representing the LLN at this event were Diane Bennett, LLN team captain DeCourcy Squire, PT, CLT-LANA of Piedmont Hospital, Debbie Labarthe and her grandson Carson Sollenberger. Behind Carson is GWC Foundation Director, Lee Cox.







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**EMORY WINSHIP CANCER CENTER CELEBRATION OF LIVING 2012**, Saturday, June 23. This event is held for cancer survivors and features sessions on nutrition, yoga, family relationships and much more. Joan White and Jean Miller represented LLN. An important message conveyed was that patients, family, caregivers, and treatment professionals really need to talk to one another frequently.



**TENTH NLN CONFERENCE**  
For Healthcare Professionals  
September 5-9, 2012  
Omni Dallas Hotel  
Dallas, Texas  
Registration Opens August 15, 2011 | Abstracts January 1st 2012



National  
Lymphedema  
Network

*LLN Board member Katie Russo has been accepted into NLN's Lymph Science Advocacy Training Program at this year's conference in Dallas. Congratulations, Katie! This is a unique program for lymphedema patients and advocates. NLN has accepted 9 new participants this year, who were selected from submitted applications, and who represent a diversity of backgrounds and interest; presently NLN has 20 LSAP graduates. The goal of the LSAP Program is to engage and motivate patients and caregivers to action by providing a comprehensive understanding of basic science of the lymphatic system, as well as clinical and diagnostic research of patients living with lymphedema and related disorders. LLN Director Joan White and several LLN member therapists will also be attending the conference.*

## Pictures from our delightful Bellmere Gardens luncheon, tour, & plant sale –April 2012

**Left: Samantha Cannon and Gwen Forbes Kirby, LLN therapists who handled on-site ticket sales;**  
**Right: Betty Williams, our luncheon speaker who demonstrated creative flower arranging to attendees.**





*Cole Sanders*

On Tuesday, May 22, 2012, the Lighthouse Lymphedema Network lost one of our own. Cole Sanders was a long-standing LLN Board Member who dedicated himself to the care of his wife, Libbie, and to our organization. His will be a void left unfilled. He will forever be missed by all of us who knew and worked with him over his many years of dedicated service. His life was forever changed when he lost his beloved Libbie just a few short years ago. Our gratitude and our sorrow are extended to the Sanders family during this difficult time. Please know that you, Cole, and Libbie will forever be in our thoughts and prayers. The family has asked that in lieu of flowers, donations can be made to the LLN. We humbly accept this generous support. If you care to donate, please go to the LLN website ([www.lighthouseymphedema.org](http://www.lighthouseymphedema.org)) and you will see a note to click on for donations. Donations may also be mailed to the **LLN, 11240 Crescent Ridge Drive, Roswell, GA 30076.**

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*Update from LLN's International Assistance Project in Peru, with Caroline Aguirre:*

Hello, everyone at LLN! A small note to let you know that I donated some of your bandages and compression garments to Juana R., who had radiation in the pelvic area and has now lymphedema in one leg. She is a nursing assistant who did not find help in the hospital where she works, because of the lack of information on lymphedema here in Peru. I enclose a letter she sent me, for all of you. Starting with the help I had, following DeCourcy Squire's great training, plus all the donated material I have here to distribute as I seem appropriate, is a great responsibility and I try to do it the best I can honoring the trust you have put in my hands. I have been feeling much better myself this year, and I can work more than before, which is a relief! I was wondering if my energy was ever going to come back... I send you all, all my very best, and hope all is well with you.

Love from Lima, Peru –  
Caroline Aguirre

PS: Translation of the letter from Juana R.:

*"Dear Miss Caroline Aguirre,*

*With these few lines I wish to tell you that I am a woman with a strong faith, I do not believe things to happen randomly, but God puts on our paths the persons that will help us one way or another, and I believe that you have been this instrument that the Lord put on my way to meet through your website.*

*I would like to thank you for your patience and good disposition to explain to me all the knowledge I need, teaching me the required exercises, how to do the bandaging of my compromised limb and all the cares I must have; as you say I must be aware of the importance of this condition but carry on just being constant to maintain life quality. I would also like to thank you for the bandages and compression stockings that you donate to me, you have no idea how useful they will be for my rehabilitation because there here in Peru there is nowhere to find them and not everyone has relatives abroad who could help up with this matter.*

*For all of this I am deeply thankful to you and to the persons that make this noble task possible and I feel relieved by knowing there is someone that can help me. I say goodbye with a big hug and may God bless you and the persons that strive to help others. – Juana"*

**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](mailto:elaine.gunter@comcast.net).

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*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](mailto:elaine.gunter@comcast.net)*

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

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