



LLN March 2009 NEWSLETTER

Our Upcoming March Meeting Location:
Thursday Night, March 26th, 7:00–9:00 PM
Northside Hospital Auditorium
1000 Johnson Ferry Rd, Atlanta GA 30042
(located at the intersection of Peachtree-Dunwoody Road & I-285; parking decks behind the hospital.
The auditorium is in the front of the hospital;
follow meeting notice signs.)

Topic: “A discussion of the new RianCorp laser therapy treatment and Reid Sleeve products”

Speakers: Emil and Jason Alexander of Peninsula Medical Supplies

IMPORTANT REMINDER: MARCH 11, 2009

Lymphedema Education & Awareness Day at the Georgia State Legislature

2009 LLN Legislative Efforts

On **March 11, 2009**, a one-day educational event will be held in the South Wing of the Capitol Building for the 2009 Georgia legislative session to raise awareness and understanding of what lymphedema is, and how important early and continuing treatment is for this chronic condition. Legislators and their aides will be able to talk to patients and therapists, see videos of patients talking about dealing with lymphedema in their daily lives, and receive educational brochures to take with them, as part of our continuing efforts to raise visibility for the critical need for coverage of lymphedema treatment by health insurance companies. Therapists will also be present to demonstrate treatment for lymphedema management. Before/after treatment pictures of lymphedema patients will be shown on a running loop on a laptop computer.



LLN members will be present to answer questions, provide information and refreshments, and give out LLN and Lymphatic Research Foundation brochures as reference materials for legislators and their aides. (Elizabeth O’Sullivan is LLN’s legislative committee leader for this project.)

January LLN Meeting A Big Success!

Our sincere thanks to Samantha Cannon MSOT, CLT and DeCourcy Squire, PT, CLT-LANA, for a terrific presentation on the Pros and Cons of compression pump (more correctly, intermittent sequential gradient pump) therapy for lymphedema at our January 29th meeting at DeKalb Medical Center. This topic proved to be of high interest to patients and therapists, attracting our largest monthly meeting attendance ever. If you are interested in the notes from the meeting, please e-mail the newsletter editor (see back page). We are also very appreciative of DeKalb Medical Center Lymphedema Clinic and its certified lymphedema therapists - Carol Crochet, Shelley Smith, and Angela Staples - for hosting the meeting.



4th Annual LLN Spring Garage Sale!

DATE: Saturday, April 25, 2009 (8:00 AM to 4:00 PM)

LOCATION: Crabapple Academy, 285 Rucker Road, Alpharetta, GA 30004

Coordinators: Lisa & Adam Sollenberger

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.lymphedemalighthouse.org>) is holding its annual garage sale on April 25th. Sale fliers will be distributed to the parents whose children attend the Crabapple Academy child care center, encouraging them to deliver any items they would like to donate (and to come and buy!)

Large items such as furniture can be dropped off at the Crabapple Academy from 7:00-9:00 PM on Friday the 24th. Smaller items can be brought then, or on the following morning.

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 up for pick-up by these charities. **The Sollenbergers' telephone number is 678-493-5079, for additional information.** Revenue generated from the sale will be used to fund initial printing costs of the LLN patient stories book, *Living Well with Lymphedema*, so your contributions (and purchases!) will be greatly appreciated.

Driving directions:

1. Coming north from Atlanta, take GA 400-N/US-19 north toward Cumming/Dahlonega (8.2 mi from I-285)
2. Take exit 7B at Holcomb Bridge Road/GA 140-W (turn left at the ramp, toward Roswell) for 1.9 mi.
3. Holcomb Bridge Rd/ GA-140 W becomes E Crossville Rd/ GA-92 W; follow this for 1.3 mi.
4. Take a slight right onto Crabapple Road for 2.1 mi, and then turn right onto Rucker Road for 0.2 mi.
5. Crabapple Academy is at 285 Rucker Road.

LLN CALENDAR OF UPCOMING EVENTS FOR 2009:

- **March 11, 2009 - Wednesday – LLN Legislative Education & Awareness Day at the Georgia State Capitol, South Wing, downtown Atlanta**
- **March 26, 2009 – Thursday – LLN Meeting at Northside Hospital Auditorium** – Discussion by Peninsula Medical representatives on laser therapy treatment of lymphedema and Reid Sleeve products
- **April 18, 2009 – Saturday - LLN Board of Directors Meeting at the Country Club of Roswell – 11:00am**
- **May 9, 2009 –Saturday, Atlantic Station - Race for the Cure sponsored by Susan G. Komen for the Cure Greater Atlanta Affiliate (LLN will have its exhibit there.)**
- **June 6, 2009 – Saturday, Cliftondale Park, College Park, GA - Gloria Watts-Cox Foundation Walk for Lymphedema**
- **September 19, 2009 – Saturday - LLN Board of Directors Meeting at the Country Club of Roswell – 10:00am**
- **October 3-4, 2009 - Saturday & Sunday - 2-Day Walk sponsored by *It's The Journey***
- **September 24, 2009 – Thursday – LLN Meeting at Tuscan Wellness, 431 West Ponce De Leon Avenue, Decatur, GA – Discussion on Nutrition and Exercise by Sandi Stephens**
- **October 24, 2009 – Saturday - 12th State of Georgia Lymphedema Education & Awareness Program, 7:30 AM – 5:00 PM, St. Joseph's Hospital Auditorium (see page 5 for full description of program)**
- **November 2009 - Piedmont Hospital Holiday Craft Bazaar (date to be announced)**
- **December 5, 2009 – Board of Directors meeting at the Country Club of Roswell – 11:30am**
- **January 2010 - Discussion on acupuncture as an ancillary lymphedema treatment; location to be announced**



LLN B.A.G. FUND UPDATE

BAG Fund update – Deb Cozzone, coordinator

75 applicants have been helped as of Jan 2009 / campaign to implement HUHO

Currently four (4) vendors (Juzo, Jobst, Medi, and Sigvaris) have agreed to provide an *off-the-shelf* (arm or leg) garment for lymphedema patients.

Other source for assistance: The Patient Advocacy Foundation (PAF) [www.patientadvocate.org] has contacted LLN, and stated that they will help patients receive assistance for bandages, garments, and other devices needed by lymphedema patients. PAF has a Lymphedema CareLine team at 1-866-949-1978 .

Don't forget to give us your e-mail address if you want to be notified about meetings and to receive the LLN newsletter as a PDF file (in color!).

Symposium on Advanced Wound Care & Wound Healing Society Meeting – April 26-29, Gaylord Texan Hotel and Convention Center, Dallas, Texas

The SAWC/WHC conference is the largest wound care meeting in the U.S. It attracts physicians, nurses, podiatrists, dieticians, therapists, pharmacists, and researchers interested in gaining knowledge about wound care products and new treatment protocols. Basic to advanced practice in all fields related to wound management and prevention will be discussed. (Go to <http://www.sawc.net> for conference information).

Be sure and send your stories for our book, "Living Well with Lymphedema" to our new editor, Kathy Kaercher (kak@mindspring.com).

*The Gloria Watts-Cox
Foundation, Inc.*

**“SEVENTH ANNUAL
8K WALK”**

Supporting those suffering
with Lymphedema



www.gwcfoundation.com

E-mail: gwcfoundation@bellsouth.net

The Gloria Watts-Cox Foundation, Inc., (GWCF) is a non-profit organization, founded after a very special woman, Gloria Watts-Cox, died on February 1, 2002, after struggling many years with a condition referred to as Lymphedema. The GWCF was founded in order to provide financial assistance to others who are struggling with this condition.

The 8K walk was created to raise funds for the medical treatment of persons suffering from Lymphedema and to promote research for proper treatment of Lymphedema patients.

HOW CAN YOU HELP?

**Come and Join Us for the
8K WALK!**

(or send us your donation!)

WHEN: Saturday, June 6, 2009

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

TIME: 8:00 a.m. sharp

*Pre-registration is
Highly Recommended*

*To pre-register, please mail your registration
form and check or money order made payable
to:*

The 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).



Saturday, October 24, 2009
12th State of Georgia Lymphedema
Education & Awareness Program

LOCATION: ST. JOSEPH'S HOSPITAL AUDITORIUM
5665 Peachtree-Dunwoody Rd NE, Atlanta, GA 30342
(For driving directions to St. Joseph's, go to <http://www.stjosephsatlanta.org/>)

TIME: 7:30 AM – 5:00 PM

Mark your calendar now for LLN's annual patient education conference. It just keeps getting better every year, judging by the feedback LLN receives from attendees! This conference brings together lymphedema patients, family/caregivers, therapists, doctors, and vendors of lymphedema-related products. Our goal is to encourage interaction of all of these groups, and to provide maximum latest-information exchange for everyone.

This year's program will feature the following excellent speakers and their discussion topics:

1. Nicole Stout, PT, CLT-LANA – upper extremity lymphedema
2. Charles McGarvey, PT, MS, DPT, FAPTA – lower extremity lymphedema
3. David Beless, MD – wound care for lymphedema patients
4. DeCourcy Squire, PT, CLT-LANA – research update from the International Society of Lymphology for lymphedema diagnosis and treatment

Special sessions will include Q&A sessions with our speakers, Teen Networking, Parent Networking, and much more.

We will have a large number of vendors present, and attendees will have ample time to visit their exhibits and discuss their products extensively.

\$ NOTE: There will be an “early bird” registration discount incentive for those individuals planning **\$** to register for our LE & A program in October. **The \$50 registration fee will apply until October 15, 2009.** After that date, the registration fee will increase to \$60, so remember to send in your registration early! Additional details and registration forms will be available at the LLN website (<http://www.lymphedemalighthouse.org>).

CORRECTION: For our out-of-town attendees, our nearby hotel is the **Courtyard Glenridge Perimeter** located at **5601 Peachtree Dunwoody Road, Atlanta 30342.** Their number is **404-843-2300,** or the national & reservations toll-free number is **800-321-2211.** We have obtained a special rate of **\$69/night.**

OTHER LYMPHEDEMA SUPPORT GROUP NEWS:

- Joan White, LLN Director, is going to Hilton Head, SC, on March 27th, to meet with Madeline Chatlein at the Hilton Head Occupational Therapy Clinic, and Debbie Miles and other members of the Will Miles Lymphatic Research Foundation and support group, started in September 2008.

- Joan White will also be participating in the newly-launched American Lymphedema Framework Project (ALFP) at a meeting in the Chicago area on March 16. Jane Armer, PhD, RN and Joseph Feldman, MD are co directors of the ALFP. Joan would like to take to this meeting ideas/input from LLN members that you feel are important priorities for lymphedema in this country, so send them to the editor’s e-mail address below ASAP, please!

- John Jordi (Siskin Hospital for Physical Rehab in Chattanooga, TN;) is holding a certification training class for lymphedema therapists on March 12, and is interested in getting input from lymphedema patients on what you would want these therapists to think about during treatment and evaluations for their future patients, and what they should ask you about having lymphedema and about treatment you have had. Contact John at jjordi@siskinrehab.org.

PERSONALS: Nancy (oldteechor@comcast.net) would like to exchange e-mails with other lymphedema patients who have swelling in their legs all the way up into their thighs. She is especially interested in finding patients who have been able to keep their measurements from creeping up from increased swelling. She is also interested in finding others with chronic pain, and discussing what they have found to be helpful in achieving a relatively painless day.

Training Class Announcement:

Do you have arm swelling after breast cancer? Are you a professional who treats arm lymphedema?

Announcing: Breast Cancer Recovery Program[®] (BCRP)

One-day Exercise/Relaxation Course for survivors and medical professional certification

BCRP is the first exercise/relaxation program to demonstrate significant improvement in arm swelling, arm flexibility (range of motion), mood, and quality of life and excellent compliance in a controlled research study.

WHERE: **Courtyard Atlanta Glenridge Hotel
5601 Peachtree Street, Atlanta, GA 30342**

WHEN: **October 25, 2009**

- INCLUDES:
- Certification for Medical Professionals
 - Home Exercise/Relaxation Program for Survivors
 - FLOW[®] DVD
 - Written Lymphedema Related Educational Material
 - Practice in Exercise and Relaxation Techniques

CONTACT: Marjorie McClure, OTR/L, CLT-LANA
Email: mkmclure@yahoo.com Telephone: (412) 343-2033

Reminder for LLN’s Thursday, September 24th Meeting:

Tucson Wellness Center, 431 West Ponce de Leon, Avenue, Decatur, GA
Presentation: “Nutrition and Exercise” by Sandi Stephens, LMT, CLT/MLDT

LLN 2009 INTERNATIONAL SUPPORT PROJECT: LYPHHEDEMA CLINIC IN PERU

Caroline Aguirre, a recent graduate of DeCourcy Squire's Casley-Smith certified lymphedema therapist training class, is a massage therapist who hopes to start a lymphedema treatment clinic in Lima, Peru. She faces many challenges because of the poor financial climate, lack of information, and the extreme needs of patients in her country. The LLN Board of Directors has voted to adopt this clinic as our first ongoing outreach support project. Recently, LLN was given a very generous donation of new products from the Healthtronix Lymphedema Clinic of Richardson, TX. Farrow Medical Innovations also donated a Farrow Wrap thigh-wrap garment. These items, plus a large box of new bandages, tapes, and padding materials, and a number of used (but still effective) bandages, garments and other devices in good shape and clean will be shipped to Peru. If you would like to support this project financially, or with your usable materials, please contact us at 770-442-1317 for additional information.

Caroline says:

"We would like to give our heartfelt thanks to everyone who collaborated in collecting and donating the lymphedema bandages and products that have been sent to Peru through the Lighthouse Lymphedema Society, to be used in a future Lymphedema Institute in Lima. Two of us are responsible for this project:

- María Inés Barnechea, who works in the "Mesa de Concertación para la Lucha contra la Pobreza" (Collaborators in the Fight against Poverty) <http://www.mesadeconcertacion.org.pe> and a member of the "Las Amigas de Betania" breast cancer patients and survivors support group.

- Caroline Aguirre, who works as a massage therapist in Lima (<http://www.cuervoblanco.info>) and volunteer assistant of the "Las Amigas de Betania" support group since its creation in 2004.

Since I finished my training, I have been busy trying to obtain items for the treatment of lymphedema to use in my practice. Some substitutes were produced to replace the low-stretch bandages and reusable padding, but gauze for bandaging finger and toes, and funds to purchase garments are still not available. Two other factors added to the already complicated situation: In Lima, most lymphedema patients cannot afford intensive treatment, and my work alone is inadequate in a city of 8 million people. Therefore, we teamed up this year to create a social help NGO (non-governmental organization) to spread awareness and help underprivileged patients. María Inés is responsible for the designing of the administrative structure and I for the practical lymph know-how.

Following our plans, by the end of April 2009 our project should be well-defined and certified in order to begin the fund raising process. We will be glad to update you on our progress as we go along, and once again we thank you very much for your support in the creation of this initiative."



Caroline Aguirre is at left, and Maria Inés Barnechea is on the right

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.

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

Return service requested to:

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

