



LLN September 2009 Newsletter

IMPORTANT: MEETING CHANGE NOTICE

Our Upcoming Meeting:

Date: Thursday, Sept. 24, 2009 7:00 PM

**Location: Piedmont Hospital Executive Dining Room (next to Rich Auditorium)
1968 Peachtree Rd NW, Bldg 77, Atlanta**

Topic: "What do Lymphedema and Politics have in Common?"

Speaker: Andy Lord, lobbyist with Georgia Capitol Solutions, Inc.

As a timely follow-up to our March legislative effort (see below), Andy will discuss the challenges lymphedema patients and physicians are facing to change legislation for lymphedema coverage by medical insurance. He will also address questions from our audience.

(Park in the North Parking Lot at Piedmont Hospital. Look for the LLN meeting signs. If you cannot climb the steps to the auditorium area, enter through the Rehab Services entrance and follow the signs to the elevators.)

2009 Lymphedema Education Day at the GA State Legislature



On **March 11, 2009**, a one-day educational event was 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. Joan White reports: Our LLN members did not know until they arrived that March 11 was "round-about day", which means the bills passed in the House were going to the Senate, and vice versa. We did, however, make some good contacts. The LLN has been invited to speak at Clayton College this spring. The insurance committee chair and others on the health committee did stop at our tables. We had two minutes to speak at the Woman's Caucus. Many students visiting the Capitol, plus employees and others stopped by to talk, and we felt our purpose of education and awareness was fulfilled. Food was definitely a huge attraction! Our sincere thanks go to Elizabeth O'Sullivan for organizing our day at the Capitol and being our legislative contact. Thanks to those who volunteered: Elizabeth O'Sullivan, Linda Harman, Janie Smith, Laura Hoffman, Beverly Thompson, Deb Cozzone, Libbie Sanders. Our special thanks to Clint Labarthe who worked under a short deadline to create our video with testimonials from Deb Cozzone, Elaine Gunter, Emily Richards, Dolores Bradley, Minna Danison, Dianne McNabb, and Carson and Lisa Sollenberger. DeCourcy Squire produced a video of treatment for lymphedema. We ran both videos during our Legislative Day, and they will be very beneficial in the future when we attend events like the 2-Day Walk, the Celebration of Living and the Komen for the Cure run/walk.

We plan to have 2 Lymphedema Education Days in the 2010 session, at the beginning and end. One benefit of this year's work is that we met Andy Lord, with Georgia Capitol Solutions, who recommended that we work through the Boards of Human Resources and Community Health, attending their monthly public meetings to gain visibility.

***Reminder: Sat. Oct. 24th: 12th State of GA Lymphedema Education & Awareness Program.
St. Joseph Hospital Auditorium, 5665 Peachtree-Dunwoody Rd, Atlanta GA 30342
7:30 AM-5:00 PM (See registration flyer included in this issue.)***

Reminder: Piedmont Hospital Holiday Crafts Bazaar – Thursday, November 12, 2009

Location: Piedmont Hospital Holiday Craft Bazaar, Building 77, parking in the North Lot behind Bldg. 77. Donations of baked goods, knitted or crocheted garments and other craft items are appreciated. Proceeds will support the LLN BAG Fund. Contact Joan White to donate items for sale or to work at the booth: 770-442-1317. Last year we raised \$886!

Our LLN Volunteers at the Lymphedema Education & Awareness Day for the Georgia State Legislature



L: LLN's Joan White, Beverly Thompson, Libbie Sanders, Janie Smith, and Laura Hoffman with examples of compression garments and video loop on lymphedema



R: Joan White, Linda Harman, Janie Smith, Elizabeth O'Sullivan, Deb Cozzone, and Beverly Thompson ready to go with food and lymphedema education/information for the GA legislators and aides to digest!

March LLN Meeting - A Big Success!

Our sincere thanks to **Emil and Jason Alexander of Peninsula Medical Supplies for their discussion of "A discussion of the new RianCorp laser therapy treatment and Reid Sleeve products"** therapy for lymphedema at our March 26th meeting at Northside Hospital in Atlanta. 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 Northside's Lymphedema Clinic and its certified lymphedema therapists – Janie Smith, and Jane Thiery - for hosting the meeting.



ANNUAL LLN SPRING GARAGE SALE

Saturday, April 25, 2009 – Crabapple Academy, Alpharetta, GA

Our advertiser is Carson Sollenberger, who was born with primary lymphedema. He took his sign to-the-road to encourage sales. Thanks, Carson for all your help. **The garage sale reports a profit of \$443.60.** Our sincere thanks to Lisa and Adam Sollenberger, Clint and Debbie Labarthe, and Terry Sollenberger for organizing the sale. Special thanks to Carson Sollenberger, Janet Wolfson, Beverly Thompson, Linda Harman, Joan White and Don Beck (and his truck!) for your help. Our appreciation to those who donated items for the sale. Thank you to Crabapple Academy for allowing us to use their parking lot for our sale.

UPDATED LLN CALENDAR OF EVENTS FOR 2009/2010:

- September 19, 2009 – Saturday - LLN Board of Directors Meeting at the Country Club of Roswell – 10:00am
- **September 24, 2009 – Thursday, 7:00 PM – LLN Meeting** at Piedmont Hospital Executive Dining Room. Andy Lord, lobbyist with Georgia Capitol Solutions, Inc.: “What do Lymphedema and Politics have in Common?”
- October 3-4, 2009 - Saturday & Sunday - 2-Day Walk sponsored by *It's The Journey*
- **October 24, 2009 – Saturday - 12th State of Georgia Lymphedema Education & Awareness Program, 7:30 AM – 5:00 PM, St. Joseph's Hospital Auditorium**
- November 12, 2009 - Piedmont Hospital Holiday Craft Bazaar
- December 5, 2009 – Board of Directors meeting at the Country Club of Roswell – 11:30am
- **January 2010 - LLN Meeting at Tuscan Wellness, 431 West Ponce De Leon Avenue, Decatur, GA – Discussion on Nutrition and Exercise by Sandi Stephens, LMT, CLT/MLDT**



LLN B.A.G. FUND UPDATE

Since May 1, 2007, as of 7/13/09:

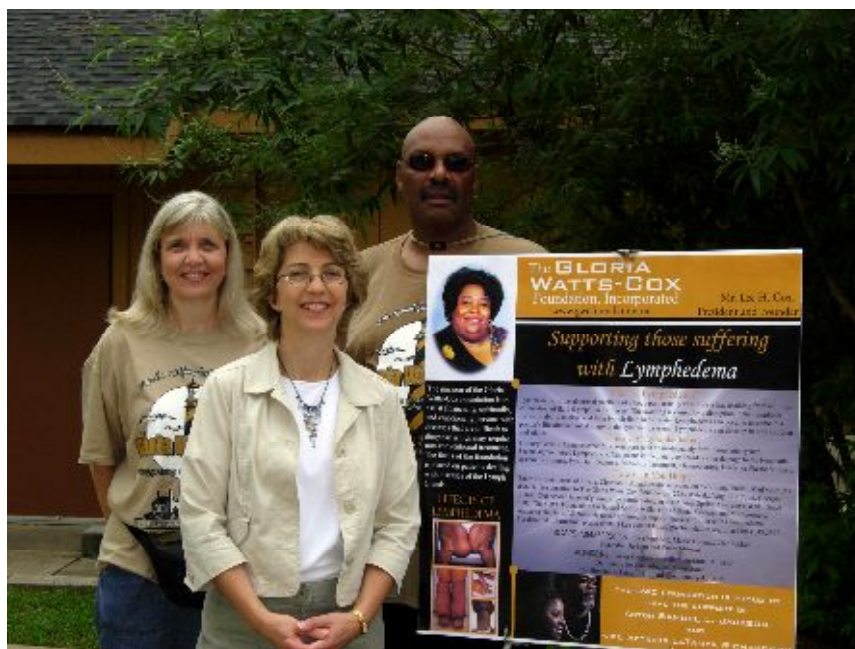
Completed: We have helped 60 patients, for a total of \$24,568 (32 arm patients and 8 leg patients)

In Process: There are currently 8 outstanding approved applications.

Recently, a lymphedema treatment clinic closed in CA. All of their remaining products were donated to the LLN to be used for our needy patients. Our thanks for their generosity!

7th Annual Gloria Watts-Cox 8K Lymphedema Awareness Walk, Saturday, June 6, 2009

Deb Cozzone and Debbie Labarthe, representing the LLN, participated in the Walk, a 5-mile loop which began/ended at Clifftondale Park in College Park, GA. They are shown below with Lee Cox, Gloria's husband. The Gloria Watts-Cox Foundation was founded 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.



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 at the Denver Fencing Center on April 18th in Denver, CO. This tournament is sponsored by Monica Goering in memory of her late husband, Bill, 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. Deb Cozzone, a niece of the Goerings, was able to attend the tournament again this year to accept the donation. Deb reports that the event made over \$1,700.00 and matching funds made the total donation to LLN over **\$3,400.00**. Once again, we are very appreciative to Mrs. Goering for thinking of the LLN as the charity of choice.

SOUTHERN LOSS ASSOCIATION ANNUAL GOLF AND TENNIS TOURNAMENT

April 23, 2009, Chateau Elan Golf and Tennis Club, Winder, GA

The Lighthouse Lymphedema Network was the designated charity in the selling of ‘mulligans’ and “strings” in memory of Richard “Larry” Hart at the annual golf and tennis tournament sponsored by the Southern Loss Association. Joan White and Beverly Thompson represented the LLN to receive **\$1,684.00** collected from the sale.

Our appreciation and thanks to the Southern Loss Association and the tournament organizing committee for their generosity. We will never forget Larry, his stories, his laughter, the joy he brought to others. He loved to sing and we remember one of his favorite songs as being “Hello, Walls”. God has you in his keeping now, Larry, and we have you in our hearts!

Other news:

Beverly Thompson attended the *2009 Emory Winship Celebration of Living* June 20th at Peachtree Road UMC, Atlanta. It was a wonderful event honoring cancer survivors. The program opened with Emory Winship healthcare professionals sharing stories of their personal experience with cancer. Breakout Sessions included: Caring for the Caregiver; Cooking for Your Health; Mindful Meditation. The Keynote Speaker was Kris Carr: [CrazySexyCancer](#) Author, filmmaker and Cancer Cowgirl. She had a very inspirational story of survival with courage, strength and humor. (See www.kriscarr.com.)

Shelley Smith DiCecco, PT, CSLT is a certified lymphedema physical therapist in the Atlanta region and a doctoral candidate at Texas Woman’s University. **Shelley is inviting you to participate in a study about the quality of life of those with edema or lymphedema.** The purpose of this study is to better understand symptoms of those with these conditions and to investigate how those symptoms affect one’s quality of life. Participation in the study is completely anonymous. To participate, you will need to complete two questionnaires located at the following website:

http://www.surveymonkey.com/s.aspx?sm=atkTthPF6wWSstAKfig6BQ_3d_3d.

The entire process should only take you about 15 minutes. If you have any questions or concerns about participation, please contact Shelley at shelley.dicecco@dekalbmedical.org, or at (404) 501-8114.



OTHER LYMPHEDEMA SUPPORT GROUP NEWS: In addition to a strong unity of spirit in promoting education and awareness for lymphedema and related lymphatic diseases, support groups lend assistance and a shoulder for all lymphedema patients, family members, caregivers, therapists, and the medical community. We need more support groups in this country!

1. AMERICAN LYMPHEDEMA FRAMEWORK PROJECT

On March 16, 2009, over 70 stakeholders in the area of lymphedema met in Glenview, IL for the American Lymphedema Framework Project Stakeholders Conference. Included in this group were lymphedema patients and advocates, certified lymphedema therapists, industry representatives, researchers and professors, medical doctors, nurses. The meeting was conducted using an open-space format. The American Lymphedema Framework Project (ALFP) is a national collaborative initiative developed under the leadership of recognized clinical experts and investigators in the field of lymphedema in partnership with the International Lymphoedema Framework.

ALFP will embrace a leadership role in:

- Increasing lymphedema awareness and treatment
- Defining best practices of lymphedema care
- Influencing healthcare policy
- Improving clinical outcomes
- Establishing quality research programs
- Establishing a minimum data set for clinical care and research

It is important for all lymphedema patients to get the best care possible, so please visit the ALFP website <http://www.alfp.org/> and make your voice heard.

2. HILTON HEAD ISLAND SUPPORT GROUP

For eight years, Dr. Madeline Chatlain, OT, CLT-LANA and owner of Hilton Head Occupational Therapy, Hilton Head Island, SC, has dreamed of starting a lymphedema support group. On March 27, 2009, Joan White, Director of the Lighthouse Lymphedema Network, was invited to present "The Advantages of Having a Support Group". Beverly Thompson, LLN board of directors member, accompanied Joan to Hilton Head. The purpose of this meeting was to inspire the patients and family members present to move forward, and to coordinate the group with assistance from Dr. Chatlain.

Joan described starting the LLN in 1994 with a meeting around her kitchen table. There were 2 other patients, family members, an occupational therapist and a massage therapist present. The small group felt like pioneers going across the country in covered wagons, with no Internet or e-mail service, and little information on lymphedema - which was not a word yet present in insurance language. Nevertheless, the hardy group set goals, and now all these years later, the LLN is one of the most respected support groups in the US with 1000 members worldwide receiving our newsletters.

3. EMORY WINSHIP CANCER INSTITUTE 2009 CELEBRATION OF LIVING, Saturday, June 20, 2009 at Peachtree Road United Methodist Church, Atlanta, GA: Once again, the LLN participated in this exceptional program. Beverly Thompson and Linda Harman represented us this year. They showed the two continuous-loop videos prepared for our education day at the GA State Capitol.

4. TENNESSEE NEWS: Jennifer Hovatter worked diligently to have June 18th designated as Lymphedema Awareness Day in Tennessee; this bill passed the TN legislature in June. Jennifer is a woman on a mission; our applause to her for her dedication and mission of honoring her late husband Thomas's life. **The second annual Thomas Hovatter Lymphedema Awareness Day was celebrated on Saturday, June 20, 2009 in Johnson City, TN.** DeCourcy Squire and Debbie Labarthe were invited to speak. Jennifer is attending East Tennessee State University and will be majoring in Physical Therapy, going on to get post-graduate lymphatic therapy training and certification. Her dreams are to help find a cure for lymphedema and to open up the Thomas Hovatter Lymphedema Clinic in Johnson City.

5. THE LLN BOOK – "Living Well with Lymphedema": We have a new editor, Vera Newman (newmanvs@bellsouth.net), who will help edit our stories and assemble the book for publication. The book review committee has had their initial meeting with Vera to review the contributions to date. She is already looking into having the book cover and interior pages designed by local art students. Many more story contributions are urgently needed by the end of September!

LLN 2009 INTERNATIONAL SUPPORT PROJECT: LYMPHEDEMA CLINIC IN PERU



From: Caroline Aguirre and Maria Inés Barnechea

Sent: Monday, March 02, 2009

“On behalf of all of my patients I would like to thank you from the bottom of my heart for your exceptionally generous donation of garments, bandages and other products. A cousin of mine who lives in Seattle and travels to Peru twice a year was able to fit most of them in one of his suitcases. The rest will follow in his next trip.

I received this suitcase filled with all your wonderful gifts on February 18th. What a surprise to discover all the goods! The first to benefit from your help were:

- An arm patient that finished her intensive course mid-January and was waiting until next May to get an adequate compression garment from Spain. While waiting, we tried local compression products. They did not work and in approximately 15 days she regained almost a month of volume reduction. Thank God she maintained her regained mobility! We were both ecstatic to find a Juzo sleeve and a Medi glove that fit her with just a 0.5” difference for wrist and elbow. I am hoping that this rapid volume increase is mostly fluid and will reduce quickly with this sleeve worn constantly. I should see her on Saturday to see how it went after her 1st week.

- A 94 year-old lady who has mixed lymph and venous edema legs. She is a bright, funny, little person with a pronounced hunchback causing trouble walking. Even if she is very courageous, my heart was broken at the idea of using the bandages I have had produced here. They work well, but are very thick and very heavy. Same thing for the padding, I can use industrial furniture filling that I have cut into strips or cotton-covered foam, but both would have been much too bulky for her. It was a delight to be able to use the medical reusable padding and bandages you sent for her.

I am about to finish inventorying all of the products. I have created a list with codes to identify them and space to insert information about when and to whom each item was given. I find it important to be able to keep track of these transactions. I have already contacted a local seamstress to see what fabric there is on the market here to make garments and how we can design it. The garment issue here is a big worry.

As you know, this year María Inés Barnechea and I plan to open a Lymphedema Institute in Lima, and we hope to have a doctor associated with our clinic. This is only possible because of the thoughtful help from people like you. The LLN members have always been there for me since my training with DeCourcy Squire last year, when you helped me with a significant scholarship.

Thank you so much for helping us to make this dream possible!” - *Caroline Aguirra*

[NOTE: Additional materials, through generous donations of LLN members & vendors, have been sent to Lima this year. Cole Sanders also donated many garments from his late wife, Libbie – see next page.]

In Memory of Libbie Sanders, a Much Loved LLN Board Member and Lymphedema Patient



LIBBIE SANDERS

Wife, Mother, Friend, the true spirit of Christmas

When you say “Libbie”, you also think of Cole Sanders, her husband. They were an incredible team, loving parents and doting grandparents, and adoptive parents to hundreds of their sons’ friends. When we first met Libbie and Cole, Libbie’s legs were already extremely deformed and in serious condition from her lymphedema. It was actually Cole who found - on the Internet - the diagnosis for her condition/disease. Over the years, we watched Libbie battle her health problems with great determination. Libbie and Cole became active members of the Lighthouse Lymphedema Network, serving on the board of directors, hosting monthly meetings, summer luncheons, sponsoring the LLN website, and always being there for us.

Libbie and Cole ran their business out of their home, but when Libbie needed to go outside, she always used her scooter. The very last time we saw Libbie was March 11, 2009, at the Georgia State Capitol, where the Lymphedema Legislative Committee was hosting an education and awareness forum. Cole was in bed with a severe lung infection. He always took Libbie to everything, but this day, he said, “Libbie, I simply am too ill to go out”. Libbie asked: “If I find a way to go, would it be OK?” Cole had no idea what Libbie was planning, but said yes. Libbie arrived at the State Capitol with Bubba, their long-time friend and helper for the family. She came wheeling in on her scooter with Bubba in tow, pulling a suitcase full of cookies and fruit. They had traveled from Decatur to downtown Atlanta via the MARTA rail and bus system. We were all so excited to see her and could not believe how she had gotten to the Capitol. This was our Libbie, always wanting to help, and always there for all of us. March 11th was a Wednesday, and Libbie died on Sunday, March 15th.

Libbie, our angel, your legacy includes your courage, determination, spirit, and love of family and others. We miss you, dear friend; God now has our angel!

Training Class Announcement Reminder:

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

- 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: mkmccclure@yahoo.com

Telephone: (412) 343-2033

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.lymphedemalighthouse.org>

Return service requested to:

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