

## LLN WINTER 2009 NEWSLETTER

**Our Upcoming January Meeting Location:**  
**Thursday Night, January 29th, 6:30 PM – 8:30 PM**  
**DeKalb Medical Center Women's Building**  
**2701 North Decatur Road, Decatur GA 30033**

**Topic: Pros and Cons of Compression Pumps for Lymphedema Treatment**  
**Speakers: Samantha Cannon, MSOT, CLT, and DeCourcy Squire, PT, CLT-LANA**



General Information - 404.501.1000

### **Directions:**

*FROM INTERSTATE 285: Take the U.S. Highway 78 West exit (#39A). Turn left at the second traffic light, which is DeKalb Industrial Way, and right onto North Decatur Rd. The DeKalb Medical Ctr campus is 1/4 mile on the left.*

*FROM DOWNTOWN ATLANTA: From 10th St, turn onto Peachtree St traveling for ~1 mile, then turn left onto Ponce de Leon Ave (U.S. Hwy 29/78/278). Travel east on Ponce de Leon Ave for ~ 4.2 miles. Turn left onto Scott Boulevard (U.S. Hwy 23) and continue for ~ 2 miles. Turn right onto North Decatur Rd for ~ half a mile to its intersection with Church St. DeKalb Medical Center is located on the right, just past the intersection of North Decatur Rd and Church St.*

***The Women's Center is the new building on the NE corner of the campus (N. Decatur Rd & Winn Way): there is parking underneath the building. Take the elevator to the 4<sup>th</sup> floor and follow the meeting signs.***

### **MARK YOUR CALENDARS:**

**MARCH LLN MEETING:** Our March "Shedding Light on Lymphedema" meeting will be held at the Auditorium, Northside Hospital, 1000 Johnson Ferry Road, Atlanta, GA 30042-1606. (Park in the decks behind the hospital) on **Thursday, March 26, at 7:00 PM**, and will include a discussion of the new RianCorp laser therapy treatment for lymphedema by BioHorizon.

# Lymphedema Education & Awareness Day at the Georgia State Legislature

## Update on 2009 LLN Legislative Efforts to Date

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 will blanket national legislators with letters from members and friends explaining what lymphedema is and why it should matter to them as public representatives. We also encourage you to contact your state and federal representatives about this issue, and have provided a sample letter for you to use at our website (<http://www.lymphedemalighthouse.org>) as well as links to websites which will provide names and addresses for you by your zip code location (see below). These listings will be updated in January 2009 when new members are officially sworn in to begin their terms.

[http://clerk.house.gov/member\\_info/index.html](http://clerk.house.gov/member_info/index.html)

[http://www.senate.gov/general/contact\\_information/senators\\_cfm.cfm](http://www.senate.gov/general/contact_information/senators_cfm.cfm),

[http://clerk.house.gov/member\\_info/wpmemberlabels\\_110.wpd](http://clerk.house.gov/member_info/wpmemberlabels_110.wpd)

### OTHER LEGISLATIVE EFFORTS:



**From the National Lymphedema Network:** <https://www.lymphnet.org/>

### LE Insurance and Legislation Update

“By the time you read this, the New York State Senate will have either acted upon an important lymphedema bill, or left it to die in committee. This bill, S02348B Fuschilo, was approved unanimously in the New York Assembly as A05892B Maisel, and it has many provisions which fall squarely within the NLN’s mission “to create awareness of lymphedema through education and to promote and support the availability of quality medical treatment for all individuals at risk for or affected by lymphedema.

- Section 1 adds the requirement for the Health Department to investigate causes, treatment facilities, and prevention of lymphedema to its existing requirements of cancer;
- Section 2 adds reporting of all diagnosed cases of cancer-related lymphedema. Currently there are no reliable and authoritative statistics on the prevalence of lymphedema in New York State. This information is urgently needed by legislators to understand how large the affected population is;
- Section 3 provides an important breast cancer patient protection (duty to inform) which is currently the law, but which is generally not practiced with respect to information relating the risk of lymphedema with each treatment option;
- Section 4 provides the same protection as Section 3 for the prostate cancer patient, adding duty to inform of risk of lymphedema for each treatment option;
- Section 5 adds primary and secondary lymphedema, lymphatic disease, lipedema, and vascular disease to the existing list of childhood medical conditions in the definition of “children with disabilities”;
- Section 6 adds lymphedema and lymphatic diseases to the healthcare and wellness education and outreach program of the NY Department of Health. The NLN has already assisted the NY Health Commissioner with a brochure on lymphedema following breast cancer treatment.

The NLN wrote a letter to Senator Skelos, Chairman of the Senate Rules Committee, urging his efforts to report the bill out of his committee, to be voted on by the NY Senate in this legislative session. NLN Medical Advisor Bonnie Lasinski, whose clinic is in New York, wrote a letter to Senator Skelos, informing him of the importance of the bill to lymphedema patients in New York.

On June 19<sup>th</sup>, a sixth Administrative Law Judge made a completely favorable decision on an appeal by a Medicare beneficiary that her compression garment was reasonable and medically necessary in the treatment of lymphedema, and that the garment was covered by Medicare as a prosthetic device benefit according to §1861(s)(8) of the Social Security Act. One month later, another lymphedema patient won her appeal to her Medicare HMO on the same basis. It’s a hard road, but we’re making some headway.”

**(by Bob Weiss, Lymphedema Legislative Advocate – NLN Lymphlink, Oct/Dec 2008)**

## Other News: Lymphatic Research Foundation's New Executive Director



Dear Friend:

On behalf of LRF's Board of Directors and staff, it is my pleasure to share with you some very exciting news. As you may know, over the past year we have undertaken an organizational assessment and recruitment process to put in place LRF's first executive director. Establishing and funding this professional position represents a significant milestone in LRF's growth. Moreover, finding someone with the skill sets and experience needed to bring LRF to the 'next level' is an important step in growing LRF's organizational capacity and securing our future as we begin *a second decade of progress for lymphatic research*.

With the guidance and expertise of The Support Center for Non-Profit Management, Jacqueline Reinhard was selected to serve as LRF's Executive Director from among a panel of impressive applicants. Jackie began working with us in July and is already making a remarkable contribution to day-to-day operations in our East Hills offices. Her professional career spans twenty five years in both the not-for-profit and for-profit sectors. Jackie's most recent position was Executive Director of The ALS Association Greater New York Chapter. Under her expert leadership, the Chapter experienced significant growth and achieved new levels of organizational professionalism. She has also held executive leadership positions at The College Board and NatWest Bank.

As LRF's Founder and President, my new and evolving role will be to work closely with Jackie to provide strategic leadership to increase awareness of the critical importance of lymphatic research. I will also be continuing advocacy efforts at the National Institutes of Health and with our Federal and State legislators and leading LRF's programmatic efforts and outreach programs.

Jackie is eager to get to know LRF's supporters and to hear your impressions and hopes for the future of LRF's work. Please feel free to give her a call, send a note or email ([jreinhard@lymphaticresearch.org](mailto:jreinhard@lymphaticresearch.org)), or – for those in the vicinity – stop in to visit and welcome her. We value your input.

With very best regards. . .

Yours truly,

A handwritten signature in black ink that reads "Wendy Chaite". The signature is written in a cursive, flowing style.

Wendy Chaite  
Founder and President

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### LOCAL CHAPTER NEWS:

From Debbie Miles in Hilton Head, SC: "**The Will Miles Lymphatic Research Foundation** was started on September 21<sup>st</sup>. Wendy Chaite, director of LRF, helped kick it off with a bang. Work is beginning on some great fundraisers to work on research."

**The Circle of Hope Lymphedema Foundation** in West Prospect, CT, has unfortunately ended operations. This large Northeastern U.S. organization, founded by Jeanne Tasis, brought hope and help to many lymphedema patients.

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### LLN FUNDRAISING EFFORTS:

Joan White and Beverly Thompson made \$90 for LLN on the sale of **Macy's Shop for a Cause** certificates on September 20<sup>th</sup> (right after the September Board Meeting). Joan added: "Just as Beverly and I were putting away the booth at Macy's today, Dianne Pinard came up to us (she was representing Vera Wang perfume - our table was set up in the fine jewelry/perfume area). She has had lymphedema for some time and did not realize that the LLN was here to give her support. She was in so happy to talk to us. Beverly and I agreed that it was worth our time to stand for two hours to make \$90, just to meet Dianne!"

LLN made \$745 at the **Piedmont Hospital Holiday Bazaar**, held on November 13<sup>th</sup>! Our thanks again to Joan and Beverly for working the booth all day long, and to all the folks who donated craft items for sale! This income will be applied to the BAG Fund.

Also, our sincere appreciation to **Jill Ponder, with Sigvaris**, who has sent a \$300.00 donation for the BAG Fund on behalf of A Woman's Place at Northside Hospital. Thank you, thank you!!



## **MISSION 2009:**

LET'S GO ELECTRONIC TO THE MAX! PLEASE SEND US YOUR E-MAIL ADDRESS SO THAT WE CAN SEND YOU THE NEWSLETTER AS A PDF FILE, AND SAVE LLN AT LEAST \$1.50 ON EVERY NOT-MAILED COPY!! ALSO, IF YOU'VE CHANGED YOUR PREVIOUSLY PROVIDED ADDRESS, PLEASE SEND US THE CORRECTION ASAP.



## **LLN B.A.G. FUND UPDATE**

Since May 2007, LLN has helped 49 patients to date with bandages and garments, for a total of more than \$20,000 from donations. We now have a number of applications on hold as we work to raise additional funds to continue this excellent program. Please consider a donation to help others!

We received a very generous donation of \$625 from the Gloria Watts-Cox Foundation for the BAG Fund at our 11<sup>th</sup> State of Georgia Lymphedema Education and Awareness Day. On November 14<sup>th</sup>, Deb Cozzone and Joan White met with the staff at A Woman's Place at Northside Hospital, to discuss how best to help our needy lymphedema patients.

### **LLN Patients' Stories Book**

We are still looking for submissions to LLN of your stories of successfully living with lymphedema, to help inspire others to seek treatment and support group interaction. The stories can be as short as just one paragraph. We're not looking only for patient/therapist stories; we also want to focus on other areas of interest, such as: Wounds, Sexuality, Bandaging & Garments, Anatomy, Exercise, Self-Care, Diet & Nutrition, Life Choices, and Treatment. Our book will be dedicated to Pat O'Connor, who has always championed LLN publishing such a book to increase awareness and education through stories told by the patients who are living and coping with lymphedema, as well as the impact that lymphedema has on family members, caregivers, therapists, and the medical community.

**Save the Date!** 2009 12<sup>th</sup> State of Georgia Lymphedema Education & Awareness Program at Piedmont Hospital - Saturday, October 24.

**NEWS FROM THE 11<sup>TH</sup> STATE OF GEORGIA LYMPHEDEMA EDUCATION & AWARENESS PROGRAM - Saturday, October 18, 2008**

More than 100 patients, caregivers, family members, therapists, doctors, and vendors attended this all day session at Piedmont Hospital. Clint Labarthe and Deb Cozzone were recognized as LLN's 2008 Volunteers of the Year. Presentations by Drs. Peter Rossi, Ken Harper, John Mullins, and Paula Stewart were excellent, with a lot of new information for lymphedema patients. Expert panel discussions allowed everyone to ask specific questions and get even more information pertinent to their own health issues. The workshops were enthusiastically attended, even the off-site aquatic exercises. Our vendor area was completely filled with new and exciting products, and we had many participants in our vendor-visit bingo game. LLN offers sincere thanks to the presenters, vendors, attendees, and all of our members who helped to set everything up, and especially to Piedmont Hospital – their meeting space was perfect for us! (We also thank Bandages Plus, who were unable to attend, but generously donated their vendor fee anyway.)

*The next three pages of pictures are from this year's program -*







**Our sincere thanks to the following businesses or individuals for your donations to LLN in 2008.**

**GIFTS IN MEMORY:**

Elise Bick  
Mark Brown  
Helen McCray Coe  
William "Bill" Goering  
Harvey Hoff  
Rosalie Link  
Ruth Lord  
Marianne Lynnworth  
Alice Massey  
Jennifer McInnis  
Myrtle Petersen  
Richard Saraydar  
Katherine Scondras  
Tracey Lurie-Sklar  
William and Lurline Squire  
Sonja Ward

**GIFTS IN HONOR:**

Sarah Danison  
Courtney Day  
Jonathan and Trinity Maiden  
Georgia Patton  
Libbie Sanders  
Stacy Saraydar  
Carson Sollenberger  
Beverly Thompson  
Joan White

**DONATIONS:**

11 Alive/MyATLTV  
Mr. and Mrs. Robert Angeletti  
E. J. Baker  
Woody and Sunnie Bates  
Ted and Ann Beasley  
William and Betty Bell  
Diane Bennett  
Kenneth F. Bick  
Marion Boehme  
O.C. and Mary Bosbyshell  
Royce and Becky Bosselman  
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Marvin and Donna Kaiser  
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Stephanie Kirkpatrick  
Charlotte & Norris Klesman  
Clint and Debbie Labarthe  
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Walter and Vivian Reed  
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Juliet Saraydar  
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Ronald and Rene White  
Louise Wright  
Julius Zorn, Inc. (Juzo)  
**11<sup>TH</sup> STATE OF GA LYMPHEDEMA  
CONFERENCE SPONSORSHIPS:**  
Woody and Sunnie Bates  
Myrtle Petersen Memorial Fund  
A Woman's Place at Northside Hospital  
Bandages Plus  
BSN-JOBST  
CircAid Medical Products  
Gloria Watts-Cox Foundation  
Gwinnett Medical/Sports Medicine &  
Rehab/Lymphedema Program  
JOVIPAK  
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SIGVARIS, Inc.  
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Upcoming LLN Board Meetings for 2009: Sat. January 24

Sat. April 12

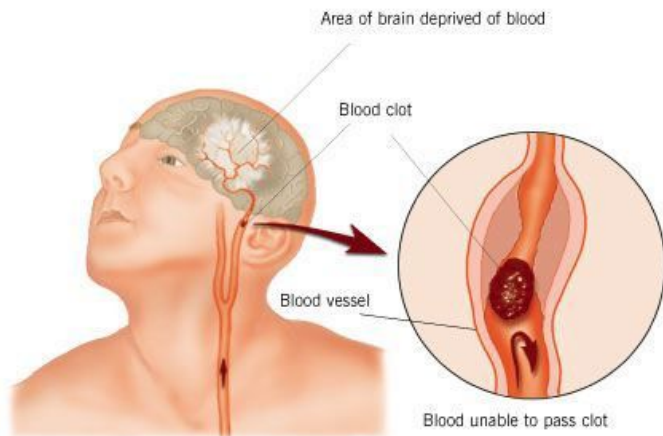
Sat. September 19

All meetings are 10:00 AM-12:00 PM, at the Country Club of Roswell meeting room.

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- **DID YOU KNOW?**

## Blood Clots/Stroke – Now, There’s a Fourth Indicator: the Tongue.



### **STROKE IDENTIFICATION: Remember The 1st Three Letters....S.T.R.**

It only takes a minute to read this... A neurologist said that if he can get to a stroke victim within 3 hours he can totally reverse the effects of a stroke...totally. He said the trick was getting a stroke recognized, diagnosed, and then getting the patient medically cared for within 3 hours, which is tough.

### **RECOGNIZING A STROKE: Remember the "3" steps, S-T-R.**

Sometimes symptoms of a stroke are difficult to identify. Unfortunately, the lack of awareness spells disaster. The stroke victim may suffer severe brain damage when people nearby fail to recognize the symptoms of a stroke. Now, doctors say a bystander can recognize a stroke by asking three simple questions:

**S \*Ask the individual to SMILE.**

**T \*Ask the person to TALK and SPEAK A SIMPLE SENTENCE (Coherently, i.e., "It is sunny out today.")**

**R \*Ask him or her to RAISE BOTH ARMS.**

If he or she has trouble with ANY ONE of these tasks, call 911 immediately and describe the symptoms to the dispatcher.

### **New Sign of a Stroke ----- Stick out Your Tongue**

Another 'sign' of a stroke is this: Ask the person to 'stick out his tongue.' If the tongue is 'crooked', i.e., if it goes to one side or the other instead of going straight out, that may also be an indication of a stroke.

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

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

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Return service requested to:

**LLN Newsletter Editor  
1625 Sprucewood Court  
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