



LLN 2008 SPRING NEWSLETTER

OUR UPCOMING MARCH MEETING:

**Saturday, March 29, 10:00 AM – Noon, Northside Hospital Lymphedema Mgt Program
Women's Center Atrium, Northside Hospital, 1000 Johnson Ferry Road, Atlanta, GA 30042-1606**

Topic: "Breast Cancer Genetic Testing"

**Speaker: Selvi Palaniappan, MS, CGC
Northside Hospital's certified genetic counselor**

Ms. Palaniappan will speak on breast cancer genetic testing--- what it is, how it's done, and who should have it done. In this informative presentation, she will discuss (in easy to understand language) who is at risk for breast cancer, how hereditary families are identified, what genetic counseling involves, and much more. At the conclusion of her presentation, Selvi welcomes any questions the audience may have. Therapist Janie Smith, PT, CLT, will host LLN for this meeting at Northside Hospital Lymphedema Management Program. Ingrid Adams from CircAid Medical Products will also speak about their non-elastic compression therapy products.

Directions:

- Going South or North on 400, exit at the Glenridge Connector, turn right at the traffic light at Peachtree Dunwoody Road, then turn left. Go to the next traffic light past the entrance to Northside Hospital and St. Joseph Hospital, turn left and follow to the entrance of A Woman's Place. The Atrium area is immediately outside A Woman's Place. Parking is in the deck across from this location.
- From I-285 West, exit at Peachtree Dunwoody Road onto 400 going south, exit at Glenridge and follow directions as above.
- From I-285 East, exit at Glenridge Road, turn left on Johnson Ferry Road, left on Peachtree Dunwoody Road, and left at the traffic light to A Woman's Place.



CONGRATULATIONS!! 11 Alive Community Service Award winner, Joan White, will be honored at the formal program on Thursday, April 3, 2008, at the Hyatt Regency, downtown Atlanta. The program will be televised on Channel 11 and Channel 36 on Friday, April 4 and Saturday, April 5.

April LLN Saturday Program: Saturday, April 26th, 10:00 AM-Noon: DeKalb Medical Center, 2701 North Decatur Road Decatur, GA 30033. DeCourcy Squire and a panel of other therapists will answer your questions.

(Directions: From Interstate I-285: take the U.S. Hwy 78 West exit (#39A). Turn left at the second traffic light, DeKalb Industrial Way, turn right onto North Decatur Rd. The DeKalb Medical Center campus is one-quarter mile on the left. Park in the parking deck located across from the emergency room. Enter the hospital through the main entrance located across from the Woman's Center. Take Elevator A to the ground floor. Once on the ground floor, make a left then follow the signs to the Auditorium/Theater. From downtown Atlanta: From 10th Street, turn onto Peachtree St traveling south for approximately 1 mile, then turn left onto Ponce de Leon Ave/U.S. Hwy 29/78/278. Travel east on Ponce de Leon Ave for approximately 4.2 miles, then turn left onto Scott Blvd/U.S. Highway 23 for approximately 2 miles. Turn right onto North Decatur Rd & travel approx. ½ mi to the intersection of North Decatur Rd and Church St. DeKalb Medical Center is located just past the intersection of North Decatur Road and Church Street. Park as stated above.)

***OUR SINCERE THANKS TO CIRCAID MEDICAL PRODUCTS,
WHOSE GENEROUS DONATION IS SPONSORING THIS ISSUE OF
THE LLN NEWSLETTER. PLEASE SEE THEIR AD ON PAGE 2!***



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Nathan Anderson, Goering Fencing Tournament organizer, presents a check for LLN to Deb Cozzone.

Bill Goering Memorial Fencing Tournament Proceeds Contributed to LLN

On January 27, 2008, the LLN was the recipient of all funds raised at the Bill Goering Memorial fencing tournament held in Denver, CO. This tournament is sponsored by Monica Goering in memory of her late husband, Bill Goering, 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 this year to accept the donation, and to express the LLN's appreciation to Nathan Anderson, the tournament organizer, and Owner and Head Coach of the Denver Fencing Club.

Over 70 competitors participated in the tournament this year, which had competitions in various age groups for all three weapons: epee, foil and saber. The tournament raised \$1,605 for the LLN, and an anonymous donor matched the donation to make a grand total of \$3,210 for the LLN.

Our sincere thanks are extended to Monica Goering, Nathan Anderson, and all of the competitors who participated in the Bill Goering Memorial in 2008.



LLN B.A.G FUND UPDATE

Since May 1, 2007, LLN has dispersed Bandage and Garment Funds for the following applications:

Completed:

- We have helped 25 patients, for a total of \$11,243. (Averaging: \$450 / patient.)
- 13 patients have been paid for from our General BAG Fund (totaling: \$3917, averaging \$301/ patient)
- 12 patients have been covered by the Komen Grant (totaling: \$7326, averaging \$610 / patient, for breast cancer/arm lymphedema cases only, in specific Metro Atlanta area counties)

In Process:

There are currently 13 outstanding applications: 2 Komen, 9 General, and 2 TBD (incomplete applications)

From the Solaris "Lymphomaniacs"© E-Newsletter, February 2008:

Klose Training & Consulting, Allina Hospital & Clinics, and the Sister Kenny Rehabilitation Institute are pleased to announce the **Inaugural Klose Lymphedema Conference, to be held May 16-17, 2008, at Allina Commons in Minneapolis, MN.** Professor Ethel Foldi, MD, world-renowned lymphologist and Physician-in-Chief of the Foldi Clinic in Hinterzarten, Germany, will deliver the keynote address and participate in problem-solving sessions. For more information contact Lisa@klosetraining.com.

****Reminder to LLN Board of Directors:** Our Spring Meeting is April 12th, 10:00 AM at the Country Club of Roswell meeting room



Symposium on Advanced Wound Care & Wound Healing Society Meeting

April 24-27, 2008

San Diego Convention Center, San Diego, CA

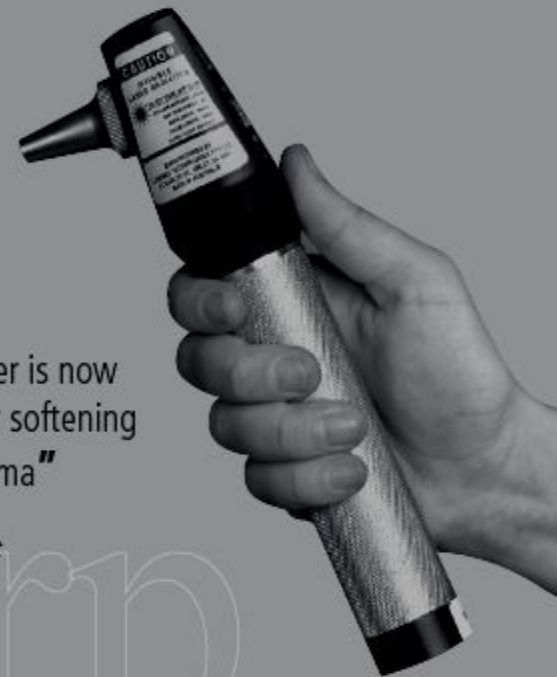
The SAWC/WHS conference is the largest wound care meeting in the U.S. It attracts physicians, nurses, podiatrists, dietitians, therapists, pharmacists, and researchers interested in gaining knowledge about wound care products and new treatment protocols. Basic to advanced practice in all fields related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



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THOMAS HOVATTER LYMPHEDEMA AWARENESS DAY

JUNE 18TH, 2008, JOHNSON CITY, TENNESSEE

Thomas died last year from complications of lymphedema and his loving wife, Jennifer, is sponsoring this one-day meeting in his honor. Please contact Jennifer at 423-282-8922 for details.



3rd Annual LLN Spring Yard Sale!

DATE: Saturday, May 3, 2008 (8:00 AM to 4:00 PM)

LOCATION: 115 Leyden St, Decatur, 30030

The 2008 LLN Yard Sale will be held at the home of DeCourcy Squire. Your contributions of items to sell will be gratefully appreciated. All proceeds from the sale go to LLN for the General Fund.

Please contact Elaine and Gary Gunter, 770-938-1891 (He has a truck to pick up large items) about dropping off items for sale, or to volunteer to help with the sale – It's time to clean out your attic or garage, and remember that everything is a treasure to somebody else at the right price. If you have something unusual and have a good idea of its possible asking price, let us know. We will provide labels for pricing everything, and we can also use some additional tables for that Saturday, if they could be loaned to us.

Directions from I-285:

Turn **RIGHT** onto LAWRENCEVILLE HWY/ US-29 S/ GA-8 S.
Turn **LEFT** onto DEKALB INDUSTRIAL WAY.
Stay **STRAIGHT** to go onto N ARCADIA AVE.
N ARCADIA AVE becomes SAMS XING.
Turn **RIGHT** onto E COLLEGE AVE/ US-278/ GA-10.
Turn **LEFT** onto MEAD RD.
Turn **RIGHT** onto LEYDEN ST.
End at 115 Leyden St Decatur, GA 30030-3519

Directions from I-75/85, exiting at North Avenue in downtown Atlanta:

Start out going **NORTH** on W PEACHTREE ST NW toward PONCE DE LEON AVE NE.
Turn **RIGHT** onto 3RD ST NE.
Turn **RIGHT** onto PEACHTREE ST NE.
Turn **LEFT** onto PONCE DE LEON AVE NE.
Turn **SLIGHT RIGHT** onto E LAKE RD NE/ US-278/ GA-10. Continue to follow US-278/ GA-10.
Stay **STRAIGHT** to go onto E LAKE DR.
Turn **LEFT** onto 3RD AVE.
Turn **LEFT** onto LEYDEN ST.
End at 115 Leyden St Decatur, GA 30030-3519



THE LYMPHATIC RESEARCH FOUNDATION:

Research is LRF's Gift to the Lymphedema Patient Community

For those who were not able to attend our recent conference, LLN is delighted to update our readers on the work of the Lymphatic Research Foundation (LRF) which was featured in one of the conference presentations. LRF was founded in 1998 by Wendy Chaite, Esq., a mother of a child who was born with systemic lymphatic disorders and lymphedema, and who like so many faced with similar diagnoses, are shocked and dismayed to discover how little is known about the lymphatic system, its diseases, and the primitive (and in some cases, non-existent) treatment options. With determination to provide hope and a better future for millions of patients worldwide, LRF was created to advance scientific research of the lymphatic system and to find improved treatments and cures for lymphedema, lymphatic diseases, and related disorders.

The lymphatic system is vital to the health of every individual and plays an important role in many bodily functions (e.g., circulation, fluid drainage immunity, fat absorption, etc.) and a myriad of diseases (e.g., cancer, obesity, infectious and autoimmune diseases, etc.). And for those of us who know all too well – it is at the core of many lymphatic disorders and diseases, including lymphedema.

Recognizing that scientific discoveries serve as the foundation for advancements in medical care, LRF has been a driving force in bringing 21st century tools, technologies, and knowledge to the neglected field of lymphatic research and medicine. Today, thanks to the catalytic efforts of LRF, lymphatic research is considered a hot and explosive field¹ and there are exciting and promising research projects underway focusing on understanding the underlying mechanisms of lymphatic dysfunction, and finding improved treatments for lymphedema and other lymphatic disorders. A simple search of the National Library of Medicine database shows that in just one research topic area (lymphangiogenesis), there has been a 15800% increase in articles published in the last six years!

LRF has been instrumental in creating the forum and opportunities for lymphatic research to flourish, including establishing a biennial premiere conference series devoted to lymphatic function and disease (Gordon Research Conference); an international peer-reviewed quarterly scientific journal published by a leading biomedical publisher (Lymphatic Research and

Biology); and an international grants program, initially focusing on expanding and strengthening the pool of outstanding young investigators in the field of lymphatic research. In addition to promoting basic and translational research, LRF's presence in our nation's capitol has greatly impacted governmental support for lymphatic research and diseases (Congressional and the National Institutes of Health). LRF's leadership is working closely with government leaders to develop and support national programs and initiatives which are having a transformative impact.

Most recently, LRF has helped to establish the first-ever Endowed University Chair in Lymphatic Medicine and Research at Stanford University; and a National Lymphatic Disease Patient Registry and Tissue Bank is scheduled for Phase One (Patient Registry) start-up by year end, 2008. As LRF continues to establish national programs to support and advance lymphatic research, it is always the needs of the lymphatic disease community and the goal of improved treatments and ultimately a cure for lymphedema and lymphatic disease that remains the true heart of the organization's mission and vision.

For further information and to view LRF's informative and inspiring video (100% donated), please visit the Foundation's website at www.lymphaticresearch.org.

Reminder for LLN's September Meeting:

Saturday, September 27th, 10:00 AM-Noon:

Southern Regional Health System Rehabilitation Services, 11 Upper Riverdale Road, Riverdale, GA 30274. (770-991-8070) Melanie Hammond, OTR/L, CSLT, will host this meeting. (Directions will be provided in the Fall Newsletter.)

¹ [Nature](http://www.nature.com), Vol. 436, July 28, 2005

Update on 2008 LLN Legislative Efforts to Date



Members of the LLN Legislative Committee (Elizabeth O'Sullivan, Linda Harmon, Janie Smith, Elaine and Gary Gunter, DeCourcy Squire, Ann Dickinson, and Joan White) have met twice with GA Representative Debbie Buckner (D-district 109) to try once again to plan the most effective ways to introduce legislation to improve diagnosis and care for lymphedema patients in GA.

Rep. Buckner summarized what actions had occurred with the previously proposed Lymphedema Treatment Bill: Two years ago, a steering committee was put in place by Rep. Len Walker (R, #71) for bills to be considered by his overall committee, and they heard testimony from our group. At that time Joan White had hoped for a mandate to the medical insurance companies in GA, but the climate in the GA legislature was (and still is) poor for such actions to be taken. A resolution did pass for medical schools to provide additional training for their students in diagnosis and treatment of lymphedema (although we do not know if that was actually implemented anywhere in the curricula of the medical schools in the state).

The previous treatment bill proposed that the GA Department of Community Health undertake a 5-year pilot study examining treatment offered to employees (including teachers) covered by the state medical insurance program and state Medicaid recipients. At the end of the last session, Rep. Buckner received a summary report with some numbers provided but the data were very difficult to interpret usefully.

Elizabeth O'Sullivan and Rep. Buckner discussed the previously proposed legislation, and agreed that mandates were not likely to be successfully passed. Rep. Buckner said that the pilot study is also not likely to get funded in a time of fiscal shortfalls, but she will continue to try to move forward, and she will enlist Republican co-sponsors who would have the power to get the bill pushed through.

Rep. Buckner strongly urged that LLN hold a Lymphedema Awareness Day at the capitol before the end of the 2008 session, and have members present to hand out information leaflets, give testimonials, demonstrate compression garments and document their yearly

costs. She said it takes a massive effort to inform legislators, many of whom may have no personal knowledge of lymphedema as a condition. LLN could also be recognized as group from the floor of the House.

Elizabeth O'Sullivan said that we should introduce a lymphedema awareness resolution as an "educational effort" (the medical school curriculum effort was an "urging resolution"). Rep. Buckner said that she needed to do a follow-up letter to the heads of the medical schools in the state to see which ones, if any, actually implemented curriculum changes as requested. DeCourcy Squire added that we also need to contact the Physical Therapy and Occupational Therapy schools in GA to raise awareness of the need for more of those students to receive further training as certified lymphedema therapists. Rep. Buckner said that she will do a letter as a survey to all these schools and hospitals to see if there have been any curriculum changes, improvements, etc., and ask specifically if the hospitals have an outpatient lymphedema treatment program, and if so, what treatment protocol is used. (LLN will provide a brief statement about what the recommended treatment protocol should be.) She will send two copies of the survey letter to each hospital/school, one to the CEO and one to the Rehab Department, using such resources as the GA Hospital Association Mailing List.

The committee developed plans for the Lymphedema Awareness Day, including having a table with handouts, posters, and our LLN display board. We would need a prepared statement for a press conference, and should contact some local media health writers. Efforts to secure a meeting space in the most appropriate areas to interact with legislators this session were unsuccessful, however, so we are making reservations for next year now.

As a first step, Joan White and other committee and board members will give an educational presentation on lymphedema to the Bipartisan Women's Legislative Caucus luncheon on Wednesday, March 19 (using some of the prepared posters already developed, as well as the recently re-edited and reprinted LLN brochure as a handout, and an excellent summary article on lymphedema by Dr. Peter Mortimer). Ann Dickinson, who works in the Secretary of State's Office, will try to bring Secretary Karen Handler to the luncheon. (Her office handles licensure, which may be a future option for certified therapists.)

***The Gloria Watts-Cox
Foundation, Inc.***

**"SIXTH 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 7, 2008

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).**

FROM THE NATIONAL LYMPHEDEMA NETWORK:

(1611 Telegraph Avenue, Suite 1111, Oakland, CA 94612, © 2008)

GROUNDBREAKING MEDICARE APPEALS COUNCIL DECISION COMPRESSION GARMENTS USED IN LYMPHEDEMA TREATMENT MEET MEDICARE DEFINITION OF PROSTHETIC DEVICES

This is an important announcement from Robert Weiss, the NLN's Legislative expert

On February 20, 2008 a Medicare Administration Appeals Judge affirmed an earlier Administrative Law Judge's determination that compression garments used as part of the medical treatment of lymphedema meet the definition of "prosthetic devices" in the Social Security Act, and are coverable by Medicare.

This most recent case follows two earlier cases where the Appeals Council reversed two different ALJs who supported providers who denied reimbursement based on the unsubstantiated claim that compression garments "were not covered by Medicare". Three other ALJs decided in favor of three different Medicare Beneficiaries, finding that the compression bandages, sleeves, stockings, devices and directional flow garments were medically necessary and coverable in the treatment of lymphedema as "prosthetic devices".

Unfortunately these cases are not precedent-setting, and there is no desire by the Centers for Medicare and Medicaid Services (CMS) to change their medically unsound policies. CMS has also recently denied a formal request to change their HCPCS Coding manual to recognize the function of these items in the treatment of lymphedema, and to code them as prosthetic devices.

What actions can be taken to move CMS into action?

Every denial of compression bandages or compression garments must be appealed by the patient. The procedures for appeal are found in the denial letter. The appeal process will involve a re-determination appeal and a reconsideration appeal to Medicare Administrative Contractors, who will side with the denial, and then to an Administrative Law Judge where a fair hearing can be obtained.

Every lymphedema supply manufacturer must make a formal request to CMS for a recoding of their products with an "L-Code" as prosthetic devices when used in the treatment of lymphedema.

And every affected citizen, whether suffering for or at risk for lymphedema must write his or her Congress Member requesting that CMS revise their policies to cover the treatment of lymphedema according to current standards. Since CMS has refused repeatedly to even consider a change, urge your legislator to consider sponsoring the proposed "Lymphedema Diagnosis and Treatment Cost-Saving Act" which has been presented to legislators over the last 5 years.

I am prepared to help in all these matters, and have materials which will be helpful. Please contact Robert Weiss at: LymphActivist@aol.com



2008 NLN Conference

From the website of the National Lymphedema Network:

See <https://www.lymphnet.org/2008conf/about.htm> for complete program and registration information)

The Scientific Conference Committee looks forward to welcoming you to the 8th Biennial National Lymphedema Network (NLN) International Conference jointly sponsored by the Northwestern University's Feinberg School of Medicine. *Lymphedema: Riding the Wave of Discovery* will take place August 27-31, 2008, at the Sheraton Hotel and Marina in San Diego, California.

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.

(If appropriate) My gift is made in memory of: _____, or

My gift is made to honor: _____

Donor's Name: _____

Address: _____

(city) _____ (state) _____ (zip) _____

Phone: (Home) _____ (Work) _____ (Cell) _____

e-mail: _____

Enclosed is my tax deductible donation in the amount 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, and currently have 900+ names to receive each newsletter issue! If you have any changes that should be made to your address, or know of other changes that should be made, e.g., names to be added, deleted, or corrected – or address and e-mail information changes, 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. We strive for accuracy on our list, and also to keep costs down. We especially need constantly updated information on therapists and clinics. Thanks for your help!

Interested in Volunteering to Help With LLN Activities?

I would like to: help with the 2008 Lymphedema Education & Awareness Program _____; become a member of the Board of Directors _____; serve on the legislative committee _____; help with fund raising _____; bring refreshments for a meeting _____; call me & I will help where needed _____:

My suggestions for future meeting topics: _____



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