



## LLN March 2010 Newsletter

### Our Upcoming Meeting:

**Date: Thursday, March 18, 2010 7:00 PM**

**Location: Northside Hospital, Conf. Room  
near A Woman's Place, 1000 Johnson  
Ferry Rd NE, Atlanta GA 30342**

Go here for a detailed map:

[http://www.northside.com/locations/atlanta\\_map.aspx](http://www.northside.com/locations/atlanta_map.aspx)

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**Our Speaker: Yvonne Griffith of Physiomed** will discuss the Hivamat 200®, a gentle vibration pumping-action device designed to help reduce pain, and allow shorter treatment time while maintaining excellent outcomes. It helps to loosen fibrosis and should be used in conjunction with Manual Lymphatic Drainage. [Note to Therapists: a copy of the notes from this presentation can be obtained by e-mailing the LLN newsletter editor, [elaine.gunter@comcast.net](mailto:elaine.gunter@comcast.net) ]

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### *March 24, 2010 LLN's Second Annual Lymphedema Education Day at the Georgia State Legislature*



Volunteers are needed to provide food and coffee (contact Joan White at 770-442-1317 if you can help in this extremely worthwhile cause). Our folks will engage legislators and aides in conversation about the need for insurance coverage of lymphedema treatment. We have rewritten our LLN lymphedema brochure to hand out on this day, and are working on an updated bill to propose by our sponsors. (Also, Heather Ferguson of NC is working on a bill for her state as well as a national bill – see her notes at <http://www.lymphnotes.com/story.php/id/475/>) and more on p. 7 of this newsletter from Bob Weiss.

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### **2010 Lighthouse Lymphedema Network Calendar Dates to Remember:**

- **Thursday, March 18, 2010:** HIVAMAT 200® presentation at Northside Hospital A Woman's Place
  - **Wednesday, March 24, 2010:** Legislative Education & Awareness Day at the Georgia State Capitol, Atlanta
  - **Saturday, April 17, 2010:** LLN Board of Directors Meeting at the Country Club of Roswell
  - **Saturday, April 24, 2010:** LLN Annual Garage Sale at the home of Elaine & Gary Gunter in Decatur
  - **Saturday, April 24, 2010:** Atlanta Health & Wellness Expo at Lenox Square Mall, Atlanta
  - **Saturday, June 5, 2010:** 7th Annual Gloria Watts-Cox 8K Lymphedema Awareness Walk (see flyer inside)
  - **Saturday, October 16:** LLN annual Lymphedema Education & Awareness Day conference, DeKalb Medical Center, Decatur GA
  - **November 2009** - Piedmont Hospital Holiday Craft Bazaar (date to be announced)
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**IMPORTANT NOTE:** As of January 2010, LLN's website has changed to: <http://www.lighthouselymphedema.org>

We sincerely apologize for the loss of our previous URL (and thus how that effects previous publication citations), but we hope that this site name is even easier to remember, and urge you to make this change in your bookmark lists.



## 5th Annual LLN Spring Garage Sale!

**DATE: Saturday, April 24, 2009 (8:00 AM to 4:00 PM)**

**LOCATION: 1625 Sprucewood Court, Decatur GA 30033**

**Coordinators: Elaine & Gary Gunter (770-938-1891)**

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.lighthouselymphedema.org>) is holding its annual garage sale on April 24<sup>th</sup>.

**Large items such as furniture can be dropped off at the Gunters' house any time before the sale, or you can call Gary for assistance with pickup (770-938-1891). Donations of smaller items can be brought beforehand or on the day of the sale.**

**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 for pick-up by these charities.) Revenue generated from the sale will be used to fund initial printing costs of the LLN patient stories book, so your contributions (and purchases!) will be greatly appreciated.



**Location:** Just a couple of blocks inside I-285 and Lawrenceville Highway. Coming south on L'Ville Hwy, go past Montreal Rd, and take the next right into Spruce Valley Road, left onto Sprucewood Rd, and left into Sprucewood Court to # 1625, the Cape Cod style house with **the orange cat mailbox!**

Coming north on L'Ville Hwy from N. DeKalb Mall, go past Frazier Rd and turn left on Spruce Valley Rd.

*The Gloria Watts-Cox  
Foundation, Inc.*

**“EIGHTH ANNUAL  
8K WALK”**

Supporting those suffering  
with Lymphedema



[www.gwcfoundation.com](http://www.gwcfoundation.com)

E-mail: [gwcfoundation@bellsouth.net](mailto: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?**

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

*(or send us your donation!)*

**WHEN:** Saturday, June 5, 2009

**WHERE:** Cliftondale Park  
4645 Butner Rd.  
College Park, GA 30349

**TIME:** 8:00 a.m. sharp

*Pre-registration is  
Highly Recommended*

*To pre-register, go to the website for your  
registration form; indicate shirt size & mail  
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. (5<sup>th</sup> light).
- ◆ Turn Left onto Butner Rd. , go approximately 3 miles to the 4-Way Stop Sign, continue straight for 1/4<sup>th</sup> mile to 4645 Butner Rd. (Fulton County Parks and Recreation).

# AMERICAN LYMPHEDEMA FRAMEWORK PROJECT – UPDATE:

## ALFP Updates:

1. We presented a paper on the ALFP stakeholders meeting at the International Society of Lymphology in Sydney, September 21-25, 2009.
  2. A manuscript on the process and outcomes of the ALFP stakeholders open space meeting has been published in the fall 2009 issue of the Journal of Lymphoedema ([www.lymphormation.org](http://www.lymphormation.org)).
  3. Under the guidance of the research and executive committees, the ALFP conducted a lymphedema therapist survey to ascertain the current practices of lymphedema therapists in the US in November 2009.
  4. On November 18, 2009, a MEDCAC meeting was held to discuss the management of secondary lymphedema in the United States. Jane Armer, PhD, RN, FAAN, and Director of the ALFP, was invited as one of the two guest speakers for the meeting to talk about the current state of research in lymphedema and to discuss the next steps for research. Janice Cormier, MD, MPH, and executive committee member of the ALFP, was invited to be a guest panel member at the meeting. Several steering committee members and stakeholders of the ALFP were also in attendance. Meeting results can be found at [Centers for Medicare & Medicaid Services website](http://CentersforMedicareandMedicaidServices.gov).
  5. Current projects underway include the analysis of data collected from the lymphedema therapist survey and a literature review for the update of the UK Best Practice Document (BPD) for application in the US. Review of the BPD by the ALFP Best Practices Committee took place during fall 2009 and is continuing in winter 2010. Review and selection of the literature by two independent reviewers will take place in 2010, and distribution of the updated document is projected for 2011.
  6. The International Lymphoedema Framework (ILF) will hold the 2<sup>nd</sup> ILF Conference in Brighton Centre, UK, on March 23-25, 2010. For more information please visit [www.lympho.org](http://www.lympho.org).
  7. A 2009 annual progress report of the ALFP will soon be available at [www.alfp.org](http://www.alfp.org).
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## NOTED FROM THE JANUARY 28<sup>th</sup> LLN MEETING AT TUSCAN SUN WELLNESS AND MASSAGE CENTER

431 W. Ponce de Leon Avenue, Suite 7, Decatur, GA 30030

Joan White welcomed patients, therapists, and guests to Tuscan Sun Wellness and Massage Center and thanked Sandi Stephens, LMT, CLT/MLDT for hosting the program. Fruit, vegetables, yogurt and sandwiches were enjoyed before and during the program.

Sandi Stephens discussed nutrition and diet for lymphedema:

- Choose a healthy diet as you would for weight management and remember to watch your salt intake.
- Eat meals around vegetables and fruits.
- Limit carbohydrates and processed foods.
- For cooking, use mono-unsaturated oils such olive oil or canola oil
- For snacks, stick to ½ cup of almonds and other, as they are full of protein and not carbs, but remember to watch the salt and choose unsalted nuts.
- If you have a sweet tooth, use stevia instead of sugar, as it is a natural sweetener and rates 0.0 on the glycemic index.

Wonder foods: Pineapple, grapefruit (white area under skin), all highly colored food like blueberries (have high level of antioxidants), raspberries, plums, etc., plus broccoli, mushrooms, Brazil nuts (high in selenium), red beets.

Ann, with The Nature of Wellness Healing Center, then spoke about acupuncture, humoral phases – disease of disposition, cellular phases – constitutional diseases, and the Healing Template. Lymphedema patient Stephanie Miller told her story of developing lymphedema in her arm after breast cancer surgery. She was always a very active person who could bench press 75 to over 100 pounds. She has removed all soy from her diet. She never adds salt to food and almost never eats out. She does not need a walking stick for balance, but uses one for her right arm to use as a constant rest area. She works out on a treadmill and feels this has helped to reduce her lymphedema in her arm. Her advice, “Do not be concerned about what others think, do what is best for you.”

After a little social time, we moved across the hall to Trinity where Heather King-Smith had us down on mats doing Pilates and then Cheryl Crawford instructed in Yoga. What a fun evening! Our sincere thanks to Sandi, Ann, Heather, and Cheryl for hosting LLN.



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

## ***Weight Lifting and LE: Clearing up misconceptions***

Dear friends of the NLN,

I am pleased to share with you some clarifications related to the study by Dr Kathryn Schmitz and colleagues, [Weight Lifting in Women with Breast-Cancer-Related Lymphedema](#), which was published in the New England Journal of Medicine on August 13, 2009. When the article first appeared there was a huge reaction from the media, and many inaccurate statements were made about the research which were confusing and misleading. The NLN and many of our affiliated clinics received phone calls from patients and professionals expressing frustration about the inaccuracy, reporting and requesting clarification of the study results and what it means for individuals living with or at risk for lymphedema.

First and foremost we thank Dr Schmitz for addressing this issue and clarifying this important information. There is minimal literature available about post breast-cancer-related exercise and its effect on lymphedema.

The NLN Medical Advisory Committee contacted Dr Schmitz and she graciously agreed to write a response to the inaccuracies written in the media to clear up misconceptions about what the PAL trial did and did not show, and the continued need to follow risk reduction guidelines. (See Position Papers on [Risk Reduction](#) and [Exercise](#)).

We are pleased to attach Dr Schmitz' response ([http://www.lymphnet.org/pdfDocs/Weight\\_LE\\_Misconception.pdf](http://www.lymphnet.org/pdfDocs/Weight_LE_Misconception.pdf)) ([Weight Lifting and Lymphedema: Clearing Up Misconceptions](#)), and sincerely hope that this will help to clarify the results of the study and what they mean to individuals living with or at risk for lymphedema. I am also including the [protocols for the PAL intervention](#), and I recommend that LE therapist apply them in their practices.

We would like to hear from you, if you have questions or additional comments regarding the study please visit this site.

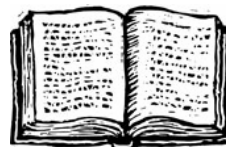
Respectfully submitted,

Saskia R.J. Thiadens R.N.  
Executive Director of NLN

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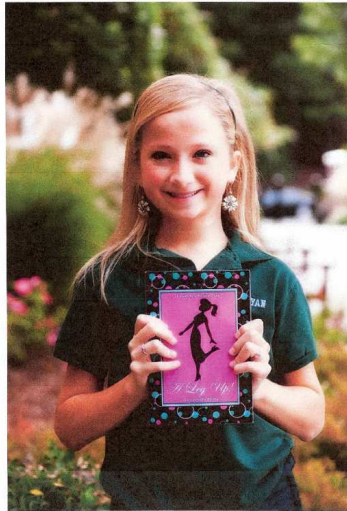
## So, you have lymphedema...

### Share your story with LLN.



The Lighthouse Lymphedema Network is looking for ***your*** stories (patients, therapists, caregivers). We are gathering them for a book we'd like to publish, and we're anxious to go to print as soon as possible. Please contact Vera Newman at [newmanvs@bellsouth.net](mailto:newmanvs@bellsouth.net), or 770-394-3421, for further details if you are interested and would like to share your experiences.

## A Teenager Living with Primary Lymphedema:



When you see Courtney Day, you see a beautiful teenaged girl who appears to have it all. Skinny jeans, stylish boots...but underneath it all sits a compression sock covering her little secret. "How long have you been hiding? Two years...or in the world of me: two years way too long!"

Courtney was diagnosed with primary lymphedema. Through her journey she has garnered the courage to write a book in hopes of helping others truthfully deal with pain and suffering. As she says in her book, "This is where a lot of my faith comes in. I know that there is a reason behind everything that happens to us. I know that God has a divine plan for all of us and that I wouldn't have Lymphedema if I wasn't supposed to do something with it that could help other people. I know that I wouldn't feel so sad and embarrassed by it if I wasn't supposed to turn around and help somebody with whatever they are sad and embarrassed about."

This was not a quick and easy journey. After a year of being passed from doctor to doctor, and experiencing deep pain, many tears, and embarrassment, Courtney finally found an answer, and help from her lymphedema therapist, Emily Smith. Courtney's mom said, "It is not the diagnosis that's the hard part. It's the living with lymphedema day to day- that is hard." Through the "discovery" process, Courtney traveled down her own personal road of hell, and it wasn't easy! "Here's how it sounds in my head every freaking second of the day... 'Lymphedema, lymphedema, lymphedema!' It's enough already! I am so sick of hearing LYMPHEDEMA! It seems like everything's always about my lymphedema. Sometimes I feel like screaming: 'I am a 14 year old girl; I don't feel like doing all this stuff for my lymphedema!'"

Courtney Day may have faced her own hell, but it has given her immeasurable strength which reads on every page of her book. "Lymphedema means having to deal with a lot of things other kids never even dream of experiencing. I know that sometimes we get so frustrated and we just want to give up. I know that we feel like we are 'different' and can't do some of the things that other people do. But, don't let it stop your life. Don't let it slow you down. The better you are at managing your lymphedema, the better you will be at not having to explain to anybody that you have it or what it is."

Courtney has a testimonial on her website from comedian Jeff Foxworthy: "Courtney, thanks so much for sending me your book. I sat down and read the whole thing that night. While I was saddened about what you have to deal with, especially as a teenaged girl (I have two. I know!) I was so encouraged at the way you have come to view it and the way you have decided to live life to the fullest despite it. That's what Jesus said he came for, so that we might have life to the full. I agree with you that everybody is dealing with something. Some are just more obvious than others. You have a powerful story. Use that gift wisely and turn the world inside out!

God Bless, Your friend, --Jeff Foxworthy"

To order your copy of Courtney's book, **A Leg up on Lymphedema**, go to [www.aleguponlymphedema.com](http://www.aleguponlymphedema.com).

(Courtney's therapist and book coauthor is Emily Smith, MT, CLT - she can be reached at 404-918-2513.)



## MORE ON THE NATIONAL LYMPHEDEMA TREATMENT BILL:

Dear Lymphedema Stakeholder,

The time for YOUR action is here!

Our lymphedema diagnosis and treatment bill has been given a bill number and was introduced by Congressman Larry Kissell of North Carolina in the House of Representatives as H.R. 4662, the "[Lymphedema Diagnosis and Treatment Cost Saving Act of 2010](#)".

The bill has the goal of reducing total healthcare costs through avoidance of periodic infections, pain and disabilities resulting from this medical condition. The goals of the bill are:

- to provide diagnosis and treatment of individuals with and at risk for lymphedema according to current medical treatment standards, including manual lymph drainage, compression bandages, garments and devices and exercise;
- to enhance quality of lymphedema patient care by providing therapist qualification requirements;
- to provide for lymphedema patient education in the procedures for self-treatment so as to transfer the treatment from the clinical to the home setting;
- to encourage patient self-treatment plan adherence by providing necessary medical supplies for use at home;
- to expand patient access to qualified lymphedema therapy by extending coverage to qualified, trained lymphedema therapists who may practice under a qualified physician, physical therapist or occupational therapist.

We have a short window for seeking Congressional Co-Sponsors for this bill. I urge every reader of this notice to write or call your Congressman and urge him/her to co-sponsor H.R. 4662 with Congressman Kissell, and to write or call your Senator to request that they co-sponsor an identical Senate bill.

Stress the fact that this bill is projected to save hundreds of millions of dollars every year in the avoidance of costs of treating preventable lymphedema-related cellulitis. This is a quality of care issue affecting insured patients and is complementary to healthcare access issues.

There will only be a few short windows of opportunity for all those of you who have had difficulty in obtaining proper treatment for your lymphedema to take positive steps to correct the situation. We may never have a better opportunity!

Bob

Robert Weiss, M.S.  
Lymphedema Patient Advocate  
National Lymphedema Network

Need a certified lymphedema therapist?  
See the LLN website for newly updated listings of therapists in the Atlanta, Georgia, and Southeastern U.S. areas.  
<http://www.lighthouseymphedema.org>



***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).

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***Remember (especially our professional members such as therapists and doctors): Please 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 for LLN!***

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

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Return service requested to:

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

