



LLN January 2010 Newsletter
Our Upcoming Meeting:
Date: Thursday, January 28, 2010 7:00 PM
**Location: Tuscan Sun Wellness and
Massage Center 431 W. Ponce de Leon
Avenue, Suite 7, Decatur, GA 30030**
(404) 370-0880

Topic: Discussion on Nutrition and Exercise for Lymphedema Patients
Speaker: Sandi Stephens, LMT, CLT/MLDT

Tuscan Sun Massage and Wellness Center is located in downtown Decatur, GA near the intersection of West Ponce de Leon and Northern Ave. For map/directions: <http://www.yelp.com/map/tuscan-sun-massage-and-wellness-center-decatur> . Tasty fresh fruit and vegetable refreshments will be provided!

MARCH MEETING: Thursday March 18, 7 PM, Northside Hospital, Atrium of A Woman's Place, Atlanta

Attendees will be treated to two discussion topics: (1) 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. (2) Peter Glasser of Glasser Lymphedema Services, LLC (www.uhealth.net) will discuss a natural approach to treating lymphedema with supplements and herbs, along with MLD.

*March 24, 2010 Lymphedema Education Day
at the Georgia State Legislature*



Volunteers are needed to man our tables, provide food and coffee, and engage legislators and aides in conversation about the need for insurance coverage of lymphedema treatment. Call 770-442-1317 if you can help in this extremely worthwhile cause. We have redone 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 progress notes at <http://www.lymphnotes.com/story.php/id/475/>)



Gary Gunter 2009 Lighthouse Lymphedema Volunteer of the Year

Gary, a member of our LLN Board of Directors, manages our website to keep us all informed, and coordinates presentations at our Lymphedema Education and Awareness Days. He has been a faithful volunteer for our yard sales, and is much appreciated by everyone (especially the newsletter editor). Thanks, Gary!

A message to LLN members from Karen Crippen, about her daughter Bekki:

"Thanks to all of you dear friends for staying with Bekki during this last year and a half of her cancer journey. Many of you supported her when she was raising money for the Breast Cancer Network of Strength last May. Ten days ago she and her escort, her standard poodle, Sanson, modeled in their fashion show and she was named their "Champion of Strength." It was a great day for her. Here is the link: <http://www.my-endurance.net/video/cancer-survivors-fashion-show>. Thanks again; your prayers and support have made this a journey of many blessings."

2010 Lighthouse Lymphedema Network Calendar Dates to Remember:

- Saturday, January 16, 2010: LLN Board of Directors meeting at the Country Club of Roswell.
 - Thursday, January 28, 2010: Our meeting features a discussion of nutrition and exercise for the lymphedema patient by therapist Sandi J. Stephens.
 - Thursday, March 18, 2010: Two topics: HIVAMAT 200® presentation, and discussion by therapist Peter Glasser on a natural approach to treating lymphedema with supplements and herbs along with MLD/CDP.
 - Wednesday, March 24, 2010: Legislative Education & Awareness Day at the Capitol.
 - Saturday, April 10, 2010: LLN Board of Directors Meeting at the Country Club of Roswell
 - Saturday, April 25, 2010: LLN Annual Garage Sale at the home of Elaine & Gary Gunter in Decatur
 - Saturday, June 5, 2010: 7th Annual Gloria Watts-Cox 8K Lymphedema Awareness Walk
 - Saturday, October 16: LLN annual Lymphedema Education & Awareness Day conference, DeKalb Medical Center, Decatur GA
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AMERICAN LYMPHEDEMA FRAMEWORK PROJECT - NEWS ITEMS:

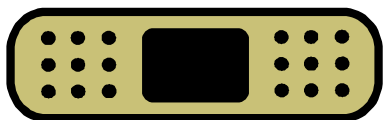
1. Medicare Evidence Development & Coverage Advisory Committee (MEDCAC) Meeting Announcement

The Centers for Medicare & Medicaid Services (CMS) held a meeting on November 18, 2009 in Baltimore, MD to discuss coverage for secondary lymphedema. Details of the meeting purpose and issues are posted at: <http://www.cms.hhs.gov/mcd/viewmccac.asp?from2=viewmccac.asp&where=index&mid=51&>

2. AHRQ call for Public Review of Diagnosis and Treatment of Secondary Lymphedema

Medicare's Agency for Healthcare Research and Quality (AHRQ) has developed a technological assessment review on diagnosis and treatment of secondary lymphedema. The excellent review document is posted at: <http://www.ahrq.gov/clinic/ta/tareview.htm> (*Editor's note: The first 24 pages of this lymphedema technology treatment assessment document constitute a terrific in-depth review of current knowledge in lymphedema diagnosis and treatment – it's truly worth downloading the PDF and saving it as a reference, or printing out those pages as a handy guide.*)

This summary was presented on their website by Jerry Mattys and Maggie Thompson of [Tactile Systems Technology](#), who attended the MedCAC meeting: *"The day started with a review of the questions to answer, and then moved quickly to the technology assessment completed on behalf of AHRQ. The summary of the 125 page document which reviewed the high level evidence in English language articles was that **"although a great deal of research into the diagnosis and treatment of secondary lymphedema has already been undertaken, there is no evidence to suggest the optimal diagnostic test or treatment."***



LLN B.A.G. FUND UPDATE

Since May of 2007:

Total Lymphedema Patients Aided: 68

Arm: 33 for a total of \$15,882.84

Leg: 35 for a total of \$11,288.33

TOTAL BANDAGE AND GARMENT ASSISTANCE PROVIDED: \$27,171.17

Thank you to the following businesses and individuals who donated to the LLN in 2009

Gifts in Honor:

Good work of the LLN
Bernice Cohen
Marge Duncan
Jackie Echols
Elaine and Gary Gunter
Janie Hole
Gwen Forbes-Kirby
Jean Miller
Piedmont Hospital Lymphedema
Therapists and Patients
Stacy Saraydar
Carson Sollenberger
Beverly Thompson
Wilda Warren
Joan White

Gifts in Memory:

Marshall Bone Sr.
Al Fowler
Larry Hart
Libbie Sanders

Donations:

A Woman's Place/Northside Hospital
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Mary Jean Blair
Royce and Becky Bosselman
Bonnie Brazel
Helen Brazel
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Helen Cozzone
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Shelley Smith DiCecco
Barbara Dickson
Marge Duncan
EGP & Associates, Inc.
Kathryn Fowler
Ellen Frank
Emilie Friese
Frontier Adjusters of Atlanta
Charles and Nancy Grande
Gloria Watts-Cox Foundation
Bill Goering Mem. Fencing Tour.

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Robert Goering
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Patricia Grey
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Dr. Harry and Rene John
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Rich Mahaffey
Mathis Hair Works
John Martin, D.D.S.
Carolyn and Dr. Delta McCall
John and Carolyn McCrea
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Charles Pat O'Connor
Beth Ann Owen
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Linton Smith
Lisa Sollenberger
DeCourcy Squire
Sandi Stephens/The Therapeutic Edge
Linda Stovall
William Taylor
Kathryn Thomason
Beverly Thompson
Kim Todd
George Trotti
Juanita Uhlin
Unitarian Universalist Ch. of Atlanta
Judith Vaggi
Roe Vaughn
Wilda Warren
Bill and June White
Doug and Joan White
Philip and Jolene White
Ronald and Rene White

Appreciation and thanks to our 12th State of Georgia Lymphedema Education and Awareness Program exhibitors or individuals for your financial support:

A Woman's Place/Northside Hospital
Bandages Plus
Farrow Medical Innovations
Gloria Watts-Cox Foundation
Gwinnett Medical Center/Sports
Medicine and Rehabilitation
BSN-JOBST
JUZO
JOVIPAK
MEDI USA
Peninsula Medical (The Reid Sleeve
People)
SIGVARIS
Solaris, Inc. (Tribute/Swell Spots)
Tactile Systems
Memory of Larry Hart
Cherry Collier (Designed Program
Brochure)

Special sincere thanks to our 2009
LLN Board of Directors for your
dedication.

Dolores Bradley, PhD
Samantha Cannon, MSOT, CLT
Deb Cozzone
Elaine Gunter
Gary Gunter
Linda Harman
Stephanie Kirkpatrick, MPT, CLT-
LANA
Clint Labarthe
Debbie Labarthe
Kim Mainer, OTR/L, CLT-LANA
Vera Newman
Charles Pat O'Connor
Elizabeth O'Sullivan, JD
Katie Russo
Cole Sanders
Stacy Saraydar, PTA, CDT, CSLT
Janie Smith, PT, CLT
Shelley Smith DiCecco, PT, CSLT
Lisa Sollenberger
DeCourcy Squire, PT, CLT-LANA
Sandi Stephens, MT, CDT
Neely Sullivan, MPT, CLT
Beverly Thompson
Shirley Tucker
Joan White
Janet Wolfson, PT, CLT-LANA

[Genetics of Lymphedema](#) by Kara Levine, M.S. (Coordinator, Lymphedema Family Study, University of Pittsburgh Department of Human Genetics)

Protein-rich lymph fluid continually and naturally seeps out of the bloodstream and collects in the body's tissues at the rate of 1-2 liters per day. The lymphatic system collects this lymph fluid, filters it through the lymph nodes to remove dead cells, bacteria, and toxins, and then returns it to the bloodstream. Muscles pump the lymph fluid through the lymphatic vessels while one-way valves prevent it from back-flowing. Lymphedema is the swelling that occurs when this fluid does not drain properly or adequately from the tissues.

Lymphedema is typically classified as either primary or secondary. Primary lymphedema is caused by a lymphatic system that did not develop properly, and although symptoms are often present at birth, it is also not unusual for symptoms to first appear in puberty or even late adulthood. Primary lymphedema is usually inherited as an autosomal dominant disease with incomplete penetrance and variable expression. "Autosomal dominant" means that both males and females have a 50% (1 in 2) chance of inheriting the lymphedema-causing gene (mutation) from a parent with primary lymphedema. However, there is "variable expression," meaning that it could affect one family member's left foot, another member's right foot and leg, and yet another family member might have swelling in both feet and/or legs. There is also "incomplete penetrance" in primary lymphedema, meaning that some family members might inherit the mutation and have no signs of swelling at all. This incomplete penetrance might appear as a "skipped generation" in some families.

Secondary lymphedema, the most common cause of lymphedema, results from a lymphatic system that has been damaged or blocked by some environmental cause such as surgery, radiation, injury, or infection. Although the initiating circumstances surrounding the onset of primary and secondary lymphedema are different, knowledge of the genetic mechanisms that cause primary lymphedema will lead to a better understanding of the function of the lymphatics, new ideas for treatment of both primary and secondary lymphedema, and possibly even the identification of genetic risk factors that increase an individual's susceptibility for secondary lymphedema. Therapeutic implications of increased knowledge about the genetics of the lymphatic system include the potential for drugs that modify the activity of cell receptors and growth factors involved in maintaining a healthy lymphatic system.

Because of the complexity of the lymphatic system, it is widely accepted that there are many genes involved in its development. Changes (mutations) in any one of these genes could theoretically cause primary lymphedema. "Genetic heterogeneity" is the term used to describe this phenomenon in which different genes can cause the same or a similar condition. Although different genes may cause lymphedema in different families, only one of these genes is typically responsible for the lymphedema in any particular family.

The Lymphedema Family Study has used a combination of linkage analysis and candidate gene screening to identify several causative genes for lymphedema. "Linkage analysis," or "linkage studies," is a method in which the genetic material (DNA) is compared between family members with and without lymphedema. Differences between these two groups within a family can help pinpoint the chromosomal location of the gene causing lymphedema in that particular family. The larger the family, the more information that family provides about the location of a gene. Because there are many genes that can cause lymphedema, different families can help point researchers toward different genes.

By using this method of linkage analysis, the Lymphedema Family Study was able to determine the location of the first lymphedema gene on chromosome 5 in some families with congenital lymphedema (**Milroy's Disease**). Once the chromosomal location was identified, a gene in this vicinity known to be involved in lymphatic development, vascular endothelial growth factor receptor 3 or *VEGFR-3* (previously referred to as *FLT4*), was sequenced in family members with lymphedema. Through this positional candidate gene screening, variation within this gene was found in several participating families. Further studies were performed, and it was determined that these variations were, in fact, disease-causing (causative) mutations.

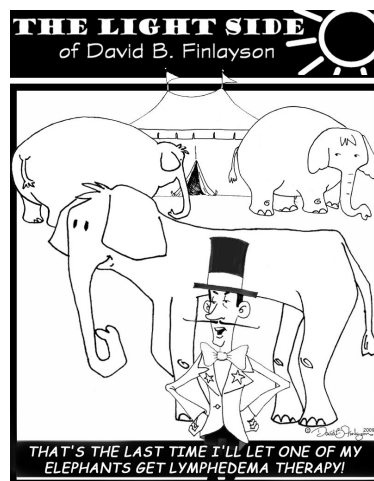
VEGFR-3 belongs to a family of growth factors and growth factor receptors which are known to be involved in the formation of lymphatic vessels during fetal development. We have observed causative mutations in the *VEGFR-3* gene in several participating families. These mutations prevent this receptor from responding to the messages it receives from certain growth factors that signal development of lymphatic vessels; this results in an underdevelopment (hypoplasia) of these vessels. We have identified changes or mutations in the *VEGFR-3* gene in approximately 5% of the families participating in the Lymphedema Family Study.

FOXC2 was the second lymphedema gene found, and was first identified in 2000 by Fang et al. **FOXC2** is responsible for causing the lymphedema-distichiasis syndrome (**LD**). Individuals with LD have lymphedema of pubertal or adult onset as well as distichiasis, which is the presence of extra eyelashes. These eyelashes may simply appear long and thick, or they may become ingrown and irritate the eye, in which case they are often removed. Less frequently, individuals with LD may be born with a heart defect, cleft palate (opening in the roof of the mouth), or ptosis (droopy eyelids). We have identified changes or mutations in the **FOXC2** gene in approximately 7% of the families participating in the Lymphedema Family Study.

In 2008 through candidate gene screening, the Lymphedema Family Study identified 2 additional lymphedema genes, called hepatocyte growth factor (**HGF**) and its receptor **MET**, both of which are located on chromosome 7. The **HGF/MET** biologic pathway is also thought to play a role in the growth and development of lymphatic vessels. Collectively these two genes account for approximately 4% of the families participating in the Lymphedema Family Study **and in one patient with secondary lymphedema**. Our article entitled "[HGF and MET mutations in primary and secondary lymphedema](#)," was published in 2008 in the scientific journal, *Lymphatic Research and Biology*.

Not all hereditary lymphedema is caused by **VEGFR3**, **FOXC2**, or **HGF/MET**, indicating that there is at least one other gene (probably many more) responsible for hereditary lymphedema. The Lymphedema Family Study continues to search for the locations of these additional lymphedema genes. The identification of these other lymphedema genes will be dependent on finding more families with primary lymphedema. Therefore, advances in understanding the underlying causes of lymphedema are critically dependent on the voluntary participation of individuals and families in this research. We are continuing to recruit families in which at least one individual is affected with primary lymphedema. If you have questions or if you and your family are interested in participating, please contact Kara Levine at (412) 624-4659 or toll free at (800) 263-2152 or send an e-mail to genetics@pitt.edu. More information about the inheritance of primary lymphedema, and updates on our research, are also available at www.hgen.pitt.edu/projects/lymph.

EXCITING NEWS!! The newly-revised LLN lymphedema educational brochure entitled "Do You Have a Swelling That Will Not Go Away?" is now available. To view the brochure and review the content, please go to the LLN website - www.lymphedemalighthouse.org and click on "LLN brochure." (It can be printed double-sided and folded in three-part to read properly as a brochure.) Our sincere appreciation is due to the committee for their time spent to create the new look and content information for the brochure: Samantha Cannon, Shelley Smith DiCecco, Jackie Echols, Stacy Saraydar, DeCourcy Squire, and Joan White; and to Janet Nash, who designed the artwork for the brochure. If multiple copies of this brochure would be helpful to a therapist's practice, please contact Joan White @ 770-442-1317.



(Cartoon contributed by David Finlayson, OT, of Occupational Therapy Gadsden (AL), LLC)

LLN INTERNATIONAL SUPPORT PROJECT: LYMPHEDEMA CLINIC IN PERU

From: Caroline Aguirre and Maria Inés Barnechea

Caroline forwarded a note from one of her patients, a school teacher who is now pregnant and has edema plus varicose veins appearing in her legs and knees. She is now wearing compression stockings donated by LLN:

“Hola Caroline!

*The days and weeks go by, and I still didn't write you and thank you. The stockings you gave me are marvelous! It is [a whole new] feeling in my legs while I am teaching, since I started using them. It can't be compared with the ones you can buy here in Peru, which are very expensive, but too soft. My varicose veins look very much better too, so I can hope they could maybe disappear after the pregnancy. **You and your sponsors have been my salvation.** Thank you both a lot!*

Kristina”

Any contributions of unused lymphedema treatment MLD materials and garments are much appreciated!

JOIN LLN ON FACEBOOK! www.facebook.com



Once you are a member, you can go to the bottom-left of your Facebook page where you will find **icons** for photos, videos, and **GROUPS**. Select **GROUPS** - Once there, you can search for Lighthouse Lymphedema Network, and our page will be displayed. You can then join the group. (*Thanks to Clint Labarthe for helping to set this up for us!*)

FUNDRAISING NOTE:

We raised \$604 at the 2009 Piedmont Hospital Holiday Bazaar for the B.A.G. Fund!

12TH STATE OF GEORGIA LYMPHEDEMA EDUCATION & AWARENESS PROGRAM October 24, 2009

LLN is very proud to continue to provide so much valuable information and support for our members and conference attendees!

Our sincere thanks to our outstanding speakers:

- Nicole Stout, PT, MPT, CLT-LANA, discussed her studies on early intervention for breast cancer including the anatomy, reconstruction, breast cancer surgeries, truncal and other upper extremity lymphedema.
- Charles McGarvey, PT, DPT, MS, FAPTA, discussed “Lymphedema Secondary to Pelvic Cancer Treatment: A Review of Literature and Clinical Practice.”
- Helen Gelly, MD, discussed wound care and the lymphedema patient.
- DeCourcy Squire, PT, CLT-LANA, discussed research updates from the International Society of Lymphology of Lymphedema Diagnosis and Treatment conference in Australia this fall.
- Gwen Forbes-Kirby, moderator for teen networking; Stephanie Kirkpatrick, moderator for Parent Networking; Elaine Gunter, overall program moderator

And our sincere thanks to the following businesses or individuals for their financial support of our conference:

A Woman's Place at Northside Hospital, Bandages Plus, CircAid Medical Products, Inc., Farrow Medical Innovations, Gloria Watts-Cox Foundation, Gwinnett Medical/Sports Rehab Services, BSN-JOBST, JOVIPAK, JUZO, USA, MEDI, USA, Peninsula Medical (The Reid Sleeve People), SIGVARIS, INC. Solaris, Inc. (Tribute/Swell Spots), Tactile Systems

Mark your calendar for next year's 13th Annual Lymphedema Education & Awareness Day conference: DeKalb Medical Center, Decatur GA: Saturday, October 16, 2010. [And now, enjoy these pictures from LE&A Day 2009!](#)







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:

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

