



## LLN January 2014 Newsletter

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See the LLN Website ([www.lighthouselymphedema.org](http://www.lighthouselymphedema.org)) for summaries of our Lymphedema Education & Awareness Program speaker presentations

*LLN: 20 years of service to the lymphedema patient community through education and assistance!*

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[www.lighthouselymphedema.org](http://www.lighthouselymphedema.org)

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### Next LLN-sponsored Open Forum for Patients & Therapists:

**Thursday, February 13<sup>th</sup> -6:30-8:30 PM**

**St. Joseph's Hospital, in Classrooms 1,2,&3 on the ground floor,  
5665 Peachtree Dunwoody Road, NE, Atlanta, Georgia 30342.**

[Directions: <http://www.emoryhealthcare.org/saint-josephs-hospital/stjh-directions.html>]

**Our speaker will be certified garment fitter Tammy Malone. She will discuss the pros and cons of different compression garments and other devices for lymphedema patients.**

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### ***LLN adds outreach for lymphedema education to physicians:***



As part of a long hoped-for educational effort, the Lighthouse Lymphedema Network and DeKalb Medical Center are jointly sponsoring a **Physician Intensive Program** on Thursday, February 27, 2014 at Maggiano's Little Italy Restaurant, Buckhead-Atlanta location.

### **2014 Lighthouse Lymphedema Network Calendar Dates to Remember:**

- January 25, 2014 - LLN Board of Directors Meeting at the Country Club of Roswell.
- February 13, 2014 - Open Forum Meeting at St. Joseph's Hospital, Atlanta
- February 27, 2014 – Physician Intensive Presentation (DeKalb Medical Center will sponsor CMEs.)

# 16<sup>TH</sup> STATE OF GEORGIA LYMPHEDEMA EDUCATION AND AWARENESS PROGRAM

## *“EMERGING TECHNOLOGIES IN LYMPHATIC RESEARCH”*



Speakers Dr. Brandon Dixon, Stephanie Kirkpatrick, Dr. Stanley Rockson, Dr. David Zawieja, & LLN Director Joan White



Melanie Chaite speaking via DVD to us



CEU Registration activities

### *Comments about our 16<sup>th</sup> State of Georgia Lymphedema Education & Awareness Program:*

- From our speakers: “The meeting looked to be a great success and it is really pleasing to give a talk to a group that is so appreciative! We don’t always get that from our scientific or medical colleagues!” Also: “Thank you for the kind invitation! It would be a privilege to return again at your future invitation.”
- “Loved hearing Joan’s story”
- Other comments: “Very good” “More scientific, but great”
- “Melanie Chaite’s DVD presentation = Awesome!” “What a smart, brave young lady! Proving again the love of a mother is very powerful.”
- About our speakers: “Fabulous! Outstanding! Exciting info specifically about anti-inflammatory meds.” “The near-infrared imagining was very interesting! It is exciting to know that Atlanta has GA Tech doing research on the mechanics of the lymphatics, and that they received a \$2 million grant from the NIH for this work – how wonderful to have this research being done in Atlanta.”
- “The food delicious”; “Wonderful location”; “Atrium so beautiful!”; “Well done, thanks!”
- “The patient stories add that special personal touch.”



**In Memory of LLN's Volunteer for Life,  
Pat O'Connor**



**Members of the LLN Board recite Pat's  
poem "I Am Free"**

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I am free to embrace the dawn...to bask in the warmth of the morning sun.

I am free to wander through the stars at night...to behold the glory of my God and worship His goodness.

I am free to be intoxicated by the aroma of a rose...glistening with the dew, to rejoice in all the glory of a wondrous creation.

I am free to create beauty, whether through the pen, a camera...a brush...to create beauty in a world where so many create ugliness.

I am free to laugh and to bring laughter into another's sorrowful life.

I am free to go beyond my own pain...to bring comfort to another...to bring healing to an aching heart.

I am free to go beyond my selfishness...to choose a life of selfless giving to others.

I am free to reach out and touch the heart of another, to bring comfort and hope.

I am free to wipe away the tears of another hurting spirit...to lift them up...to help heal their broken heart.

I am free to journey within...to face my fears...to overcome them with victory in my spirit...instead of living in fear and doubt.

I am free to allow bitterness...to be turned into a sweet nectar.

I am free...to be me. Free to say "I don't want to be anyone else, but me".

I am free to look into the mirror and respect the person I see, to like my values... to know who I am deep inside.

I am free...in so many, many ways...seemingly too many to list.

***But...perhaps most important...***

I am free to choose who I am and how I live.

I am free to choose life...instead of allowing myself to be destroyed by the shadows of despair or even death.

I am free to love...to dream...to forgive...to choose kindness and gentleness.

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***I am free...***



Selling the LLN books!



View of the beautiful atrium area – We had ~140 attendees!

### Thank You to Our Sponsors for Their Financial Support of This Meeting!

A Woman’s Place at Northside Hospital; BiaCare; Body of Health; BSNmedical/JOBST Compression Products; Gloria Watts-Cox Foundation; JUZO, USA; LoCost Medical Supply; LSC Distribution; MEDI, USA/CircAid Medical Products, Inc.; Peninsula Medical Products; Piedmont Hospital Lymphedema & Compression Services; Sigvaris, Inc.; Solaris, Inc.

Thanks also to Peninsula Medical for donating a Reid Sleeve product in our raffle, and to Solaris for a \$3,000 donation of garments to LLN for our Bandages & Garments Fund.

### Pictures of our wonderful supporting vendors





## LLN FUNDRAISERS



**LLN received \$2006.00 this year on Georgia Gives Day, 11/13/2013, through your generous donations - Thank you for responding to our e-mail request, and helping us to help others!**

### **DEKALB MEDICAL/HILLANDALE MEDICAL CHRISTMAS SHOWCASE**

This event was held on Friday, Dec. 13th, 2013, from 7:00 am to 5:00 pm. Joan White and Pauline Meyer represented the LLN. They sold LLN's book *The Puzzle*, jewelry, our LLN cookbooks, dishcloths, hand lotion, baked items, and hand-knitted scarves, and raised \$403.20 for our LLN General Fund!



Kathryn Abebe, PT, DPT, CLT of Benchmark Physical Therapy of Austell said they raised ~ \$500 in October for LLN as their charity of the month. Thanks for your support!!

## **BARNES & NOBLE**

**Gift-wrapping Fundraiser:** Beverly Thompson, Jean Miller and Joan White worked 3 shifts and made \$212.50 wrapping gifts at Barnes and Noble during the holidays. We are often asked, "How can I help the LLN"? A simple way is volunteering to wrap gifts at Barnes and Noble during December. There are B&N's offering this fundraising opportunity all over the city, so next year, simply call the one closest to where you live and sign up for a shift of 4 hours. What a wonderful way to give back to the LLN!



## **LLN BANDAGES & GARMENTS FUND UPDATE**

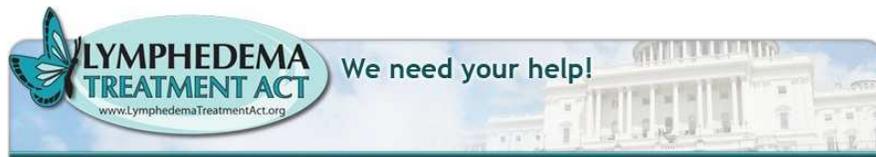
### *2013 Status Update*

In 2013, the LLN Bandages and Garments Fund assisted 61 patients, another record-setting year. 10 additional patients have been approved and are in the process of finishing treatment and getting their garments. Thanks to the grants from It's the Journey and Susan G. Komen for the Cure, Greater Atlanta Affiliate, the LLN has assisted 34 breast cancer patients this year. As always, we sincerely appreciate the support of all of our garment manufacturers, providers and therapists who have helped us help others.

If you have any questions or comments regarding the Bandages and Garments Fund, please contact Deb Cozzone at [debcozzone@hotmail.com](mailto:debcozzone@hotmail.com).

### *Two Bandages and Garments Recipients "Pay It Forward"*

This fall, two Fund recipients "paid it forward" to help us help others. Ms. W. volunteered to be a patient on whom therapists-in-training could practice their newly-learned techniques during DeCourcy Squire's Casley-Smith training class held here in Atlanta. Ms. L. has expressed an interest in volunteering and helping the LLN in any way she can. These two individuals are great examples of how we can all "pay it forward"! Thank you!



Congressman Dave Reichert (R-WA), Chairman of the Subcommittee on Human Resources of the Committee on Ways and Means has had the Lymphedema Treatment Act rewritten, and hopes to reintroduce it in Congress in 2014. Rep. Reichart has approached three other members of the House, Rep Braley (IA), Rep Blumenauer (OR), and Rep Lance (NJ), to ask them to introduce the LTA bill with him as original "co-leads." As always, everyone should contact their Congressional representatives to express their support for passage of this critical bill. For more information, see the LTA website: <http://lymphedematreatmentact.org/>



### ***Lymphedema Review Article:***

Thanks to Paul Volonino for bringing this open access review article to our attention: "Lymphedema and Therapeutic Lymphangiogenesis" by Yukihiro Saito, Hironori Nakagami, Yasufumi Kaneda, and Ryuichi Morishita. *Hindawi Publishing Corporation, BioMed Research International, Volume 2013, Article ID 804675, 6 pages* - <http://dx.doi.org/10.1155/2013/804675>. This review highlights the lymphatic biology, the pathophysiology of lymphedema, and the therapeutic lymphangiogenesis using hepatocyte growth factor.

(As a side note, this online publishing source has been verified to be a consortium put together by a number of journal publishers, including Nature Publishing Group. In October, Bonnie Pike of the NLN commented on an "article published in Science magazine about a bogus research article prepared by a biologist to test the review process involved in accepting articles for publication by on-line science journals, called "open access" journals because the content is available without a subscription. The sting operation found that 60% of open access journals readily agreed to publish the article. These journals charge scientists to publish their studies and many are not peer-reviewed. Since some of our foremost lymphedema researchers are choosing to publish this way, it's something we need to be aware of. (Please note, though, that even subscription journals may well have poor review processes, but these were not tested by this sting operation)." So, check your references carefully!)



### **International Lymphoedema Framework**

St Luke's Crypt – Sydney Street – London SW3 6NH – UK, [www.lympho.org](http://www.lympho.org)

### **Research Update**

In 2013, thanks to a research grant from one of our industry members, the ILF will begin two global research projects in partnership with our National Frameworks countries.

- LIMPRINT Study: the development of a database to collect Prevalence data that will allow ILF and its partners to provide National Health Authorities with the information to improve the management of lymphoedema (Reimbursement, Patients, pathways,...).
- A multinational Observational study involving 264 patients.

### **Information from the American Lymphoedema Framework**

Jane Armer, Nicole Stout and the ALFP team (R. Weiss, J. Feldman, B. Stewart, J. Cormier and Y Shih) have just completed their systematic review of "*Care delivery models and economic analysis in Lymphoedema: Health Policy Impact 2004-2011*" and have published it in the recent issue of the journal *Lymphology* (*Lymphology* 46 (1) pages 27-41).

**New Lymphedema Support Group Formed in Knoxville, Tennessee!** The Lymphedema Awareness Network of East Tennessee (LANET) support group has been formed in Knoxville, and a newsletter is also being developed. They are holding a meeting on Tuesday, January 14, 2014 from 5:30-6:30 PM at the Bearden Branch Library Meeting Room, 100 Golf Club Rd, in Knoxville. Their speaker will be LLN Director Joan White, who will discuss "The Twenty Year History of the LLN." For more information, contact Becky Sharp at 865-607-3476.

**Congratulations to therapist Janet Wolfson**, who was a very active member of the LLN board of directors prior to moving to Tampa, FL area. She is starting a support group in Tampa, and has recently become an instructor with the International Lymphedema & Wound Care Training Institute, the organization for which Dr. John Macdonald is a faculty advisor. We are hoping that Janet will come to our 2014 LE&A Day fall conference to include a course in wound care for our professionals.

## Update notes from our international support projects:

**Hello to everyone, from Caroline Aguirre in Lima, Peru:**



(1) Do you remember **Ariana** who came last year for primary leg lymphoedema? Well, I received an email from her mother; apparently they were able to travel to Europe (I guess to the Földi Clinic) for treatment which is great because she will be able to get real compression garments and not just the bandages I could offer here. I have not seen them yet, but as one says: no news, good news! (2) Your bandages were also given to **Luchi**; she is lucky to have a kind and supportive husband, Carlos for all the exercises and bandaging processes. I think it is the first time I have met such a committed and caring partner. (3) Some other bandages were given to **Eliana**. Unlike Luchi she is fighting her battle alone and has great energy and will continue to do so. I am forwarding a letter that she sends to you:

Dear **LIGHTHOUSE LYMPHEDEMA NETWORK**

*The present letter is to express my thankfulness for the donation of bandages for the treatment of the lymphedema I have, as a sequel of the radiotherapy courses I received due to a breast cancer. This action, full of humanity and recognition of the condition I have reconfirms my conviction that good and kindness exists. May you accept my deepest gratitude for this gift. Thank you again in relation to this matter and please receive my kind personal regards,*

*Eliana Fung Sam*

**Another LLN International Project:** In November, LLN also sent another box containing donated bandages & garments to Dr. Jane Armer's lymphedema project in South Africa. Here is a note from a recipient:

*Dear Dr Jane: I have been receiving treatment from Sister Isla Muhl in Cape Town for 8 weeks and was privileged to use some of the donated equipment which you brought to South Africa. Thank you very much indeed. I truly appreciate your generosity which has helped to make a vast improvement to the condition of my very swollen right leg.*

*Thank you once again, and kind regards,*

*Elizabeth Kluge*

## **2013 Donations to the LLN**

### **Memory:**

Jayne Beske  
Kenneth Bick  
Billie Boswell  
Larry Hart  
Joan Henry  
Charles "Pat" O'Conner  
Libbie and Cole Sanders  
Marion Lee Taulman

### **Honoring:**

All who suffer with lymphedema  
Jean Miller  
Piedmont Hospital Lymphedema  
and Compression Program:  
(Bernice Cohen, Jackie Echols,  
Laura Hoffman, Gwen Forbes-  
Kirby, Stacy Saraydar)  
Carson Sollenberger  
Beverly Thompson  
Doug White  
Joan White

### **Donations:**

Meredith Altshuler  
Larry Ashmore  
Barney's Specialty Medical  
BenchMark Physical  
Therapy/Austell  
Kenneth Bick  
Ruth Binney  
Body of Health & Life/Julie Mills  
Becky Bosselman  
Raloy and Carole Brown  
Martha Bunch Trust  
Kris Burnett  
Samantha Cannon  
Penny Clarke  
Bernice Cohen  
College of William and Mary  
Foundation  
Carol Crochet  
Patricia Deluca-Kerr  
Denver Fencing Center  
Barbara Dickson  
Cavell Dudley  
Jackie Elliott  
Virginia Fenlon  
Craig and Ruth Ferguson  
John Fletcher  
Alison Franklin  
Jan and Sandy Fritz  
Gloria Watts-Cox Foundation  
C.W. and Caroline Goering

John Goering  
Leslie Goering  
Monica Goering  
Robert and Charlotte Goering  
Patricia Grey  
Elaine and Gary Gunter  
Tom and Betty Hansen  
Winnie Mae Hargis  
Mary Sue Holcombe  
Anne Holloway  
BJ and Cheryl Honeycutt  
Patricia OKeefe Hutton  
Todd Kathan  
Alonzo Kirby  
Stephanie Kirkpatrick  
Virginia Krueger  
Julia Krulic  
Clint and Debbie Labarthe  
John Lively  
Susan Loudermilk  
Tammy Malone  
Donald Martin  
John Martin  
Medical Aid Supply House  
Andrea Merli  
Ann Meyer  
Pauline Meyer  
Microsoft Matching Gifts Program  
Jacqueline Miller  
Robert and Jean Miller  
Martin Morley  
Ann Morrow  
Stuart and Vera Newman  
Thomas Noble  
Susan Nussrallah  
June Park  
William and Virginia Phillippi  
Diane Prunte  
Kathleen Puri  
Karen Quinn  
Eric Robinson  
Kenneth Ryan  
Stacy Saraydar  
Eva Schaum  
Michelle Scobie  
Solaris, Inc.  
Craig and Terry Sollenberger  
Southern Loss Association  
DeCourcy Squire  
Brenda and John Strickland  
William Syke  
Therapeutic Solutions/Angelo Rizzo  
Beverly Thompson  
Nathan Thompson  
Juanita Uhlin  
Robert and Pearl Weiss  
Doug and Joan White

Phil and Jolene White  
Ronald and Rene White  
Jean Witcher

### **Honoring the LLN Board of Directors:**

Larry Ashmore  
Billie Barron  
Dolores Bradley  
Kathy Cannon  
Samantha Cannon  
Deb Cozzone  
Vicky Day  
Shelley Smith DiCecco  
Elaine Gunter  
Gary Gunter  
Laura Hoffman  
Gwen Forbes-Kirby  
Stephanie Kirkpatrick  
Clint Labarthe  
Debbie Labarthe  
Vera Newman  
Stacy Saraydar  
Janie Smith  
Beverly Thompson  
Shirley Tucker  
Joan White

### **Special thanks to our business supporters:**

A Woman's Place at Northside  
Hospital  
BSNmedical  
BiaCare  
Body of Health  
Compression Products  
Gloria Watts-Cox Foundation  
JUZO  
LoCost Medical Supply  
LSC Distribution  
MEDI, USA/CircAid Medical  
Products  
Peninsula Medical Products  
Piedmont Hospital Lymphedema &  
Compression Services  
Sigvaris, Inc.  
Solaris, Inc.

**Grants from It's The Journey and Susan G. Komen for the Cure** help provide bandages, garments and other devices for our arm lymphedema patients through our Bandage and Garment Fund.

## **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. You can also make a donation on-line by credit card: The donation page is: <http://lighthouselymphedema.org/get-involved/donate.htm>.

**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 above, or by e-mail to [elaine.gunter@comcast.net](mailto:elaine.gunter@comcast.net).

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**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 help us save mailing costs! [elaine.gunter@comcast.net](mailto:elaine.gunter@comcast.net)**

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

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