LLN September 2013 Newsletter

Check our exciting new website – more services and information for lymphedema patients, caregivers, and professionals. Order our books, too!

HAPPY 20TH ANNIVERSARY TO THE LLN!

www.lighthouselymphedema.org

REGISTER NOW!

16TH STATE OF GEORGIA LYMPHEDEMA EDUCATION AND AWARENESS PROGRAM
“EMERGING TECHNOLOGIES IN LYMPHATIC RESEARCH”

Co-sponsored by Georgia Institute of Technology and the Lighthouse Lymphedema Network

Saturday, October 12, 2013 – 7:30 AM-4:30 PM
Marcus Nanotechnology Research Center, Georgia Institute of Technology,
354 Ferst Drive, Atlanta, GA 30308

Conference fee (covers food): $50 for patients, caregivers, and family members
$65 for medical professionals

Hotel: Georgia Tech Hotel & Conference Center, 700 Spring Street, Atlanta GA 30308
Conference rate $112/night

An educational and awareness conference for patients, caregivers and professionals!

To register, go to our website (www.lighthouselymphedema.org) or, use the enclosed complete program brochure and application.

**CEUs are offered to medical professionals who attend this program.
#### Many Thanks to Our Sponsors for This Meeting!

A Woman’s Place at Northside Hospital  
Bauerfeind USA, Inc.  
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(Exhibiting only: Lymphatic Research Foundation, It’s the Journey, Susan G. Komen for the Cure/Greater Atlanta Affiliate)

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#### An Exciting New Lymphedema Therapy Article from Solaris’ July e-NEWS:

A recent study, led by Memorial Sloan-Kettering Hospital evaluates the safety and effectiveness of using acupuncture as a means of treating upper extremity lymphedema.

The study included 33 participants, each receiving acupuncture treatments twice a week over a four week period. For each session, acupuncturists inserted 14 needles at sites on the affected and unaffected arms, legs, and torso. Researchers found that 11 of the 33 participants experienced a significant reduction in swelling and 18 experienced a small reduction. Participants reported lasting improvements in swelling several weeks later with no serious side effects. Promising results from this initial study encouraged the clinical trial currently being led by Dr. Barrie Cassileth and breast cancer specialists from MSK. The hope is that the clinical trial will provide more insight and stronger conclusions about safety implications and potential benefits of using acupuncture in lymphedema treatment.

Another exciting new article, co-authored by therapist John Jordi of the Siskin Hospital for Rehabilitative Therapy in Chattanooga, TN: “Clinical Feasibility of Noninvasive Visualization of Lymphatic Flow with Principles of Spin Labeling MR Imaging: Implications for Lymphedema Assessment.” Just published in the Journal of Radiology, the article describes work John did with Vanderbilt University to visualize lymph flow in the body. Go here for the article:

[http://radiology.rsna.org/content/early/2013/07/12/radiol.13120145.abstract](http://radiology.rsna.org/content/early/2013/07/12/radiol.13120145.abstract)
LLN BANDAGES & GARMENTS FUND UPDATE

2013 STATUS UPDATE: To date in 2013, the LLN Bandages and Garments Fund has assisted 37 patients, and we have an additional 11 patients in process. Our grants from Susan G. Komen for the Cure, Greater Atlanta Affiliate, and from It’s The Journey have allowed us to assist 18 breast cancer patients so far this year, and additional applications are coming in weekly. Thank you to all of the garment manufacturers, providers and therapists who have helped us help others. We are on track for another record year of assistance throughout Georgia.

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

2013 Lighthouse Lymphedema Network Calendar Dates to Remember:

- October 5th – LLN Board Meeting 9:30-12:00, Roswell Country Club
- October 12 - 16th State of Georgia Lymphedema Education & Awareness Program "Emerging Technologies in Lymphatic Research," at the Marcus Nanotechnology Research Center, Georgia Institute of Technology, 354 Ferst Street, Atlanta, GA
- December weekends prior to Christmas – Board members volunteer again to wrap packages at Barnes & Noble bookstores in Atlanta as a fundraiser for the BAG Fund. In 2012, we raised $470 this way.
- February 2014 – Physician Intensive Presentation being planned (DeKalb Medical Center will sponsor CMEs.)

LLN’s Second Open Forum Meeting August 20th at Gwinnett Medical Center in Duluth, GA - The LLN’s Samantha Cannon, PT, and Gwinnett Medical Center hosted our second Open Forum at Gwinnett Medical Center Tuesday, August 20th. This informal meeting and discussion brought together patients with lymphedema, therapists and garment fitters. Thanks to Jobst and LoCost Medical who supported the event and showed their products!

Dear Supporter,

While we wait for the reintroduction of the Lymphedema Treatment Act there are a variety of things you can do to support its eventual passage, all outlined under the "How You Can Help" menu on our website. If you have not yet made a submission to our "My Lymphedema Story" campaign, please consider doing so. We hope to have all 50 states represented, but right now do not have any stories from the following states/territories: AL, AK, HI, ID, KS, LA, MN, MO, MT, NE, NM, ND, RI, SD, UT, VT, WV, WY, DC & all other territories. You can read the stories submitted to date on our blog. Also, your state’s advocacy team could really use your help. For more information please visit the "State Teams" page of our website and/or review the attached State Team Handbook. So far we have 201 state team members in 38 states, a great start but still a long way from having members from every Congressional district in the country! Remember that this is an all grassroots effort and our continued progress depends on the involvement of people just like you.

Last but not least, this marks the one-year anniversary of the addition of the "Action Center" to our website. This vital tool enables you to quickly and easily write your members of Congress, contact the media, and more. The Action Center, while being a costly on-going expense, has been a huge boon to our advocacy efforts! We are so very grateful for the support we receive from the following sponsors, who make the Action Center and our website possible: mediUSA, Solaris, JoVIpak, Juzo, Jobst, Lymphedivaas, FarrowMed, and Sigvaris. We wouldn't be where we are today without the support of the many individuals, organizations and industry partners who have gotten behind this patient-driven movement… thank you all!

With gratitude,
Heather Ferguson
Founder and Executive Director
Lymphedema Advocacy Group
www.LymphedemaTreatmentAct.org, info@LymphedemaTreatmentAct.org
From Team LLN Leader Samantha Cannon: “What better way to raise awareness for the Lighthouse Lymphedema network than getting up on a beautiful Saturday morning and wearing bright blue shirts with the lighthouse logo to show our support. That is exactly what 20 of us had the opportunity to do May 11, 2013 when we supported the Komen Race for the Cure at Atlantic Station in Atlanta, GA. It was very exciting with Vera Newman winning the prize for most family members and running the race. She brought about 6 people. Dolores and her husband brought the youngest supporter with their daughter, Sydney. Deb Cozzone got most everyone involved with spinning the wheel to win items from the Lighthouse and coupons to purchase the cookbook. Several of us took turns talking to individuals and giving out pamphlets to educate the masses on who we are and to answer any questions that arose from hearing the words “lymphedema”. The weather held out this year and it was a beautiful day. Next year, let’s see if we can’t double our support and get more walkers and wheel spinning going on. Try it…I bet you will like it!”
DEKALB MEDICAL/HILLANDALE SPRING ARTIST MART and HEALTH FAIR FUNDRAISER
This event was held on Thursday, May 2, 2013, from 7:00am to 5:00pm. Rene Ferguson and Christy Dial represented the LLN. They sold LLN’s book *The Puzzle*, our cookbooks, dishcloths, hand lotion, baked items, hand-knitted scarves to raise money for our BAG Fund.

New Lymphedema Support Group Formed in Tennessee! The Lymphedema Awareness Network of East Tennessee (LANET) support group has been formed in Knoxville, Tennessee. They meet monthly at Bearden Library Branch. For more information, contact Becky Sharp at 865-607-3476. A newsletter for LANET is also being developed.

Second Annual Bellmere Gardens Luncheon and Tour Fundraiser for LLN

(LLN Director Joan White, event Chair Vicky Day & program organizer Vera Newman)

This event was held April 27 at the home of Jim and Deen Day Sanders in Johns Creek, GA. **We raised $3,085.00!!** Our thanks to Board member Vicky Day and her family for hosting this special day, to all of our LLN volunteers, and to the Beta Club for serving lunch.

From the newsletter of

*Haiti is close to eliminating lymphatic filariasis (the world’s leading cause of lymphedema)*

Despite the horror of the Haitian earthquake, it did concentrate Haiti’s at-risk population in the tent camps, where efforts to combat filariasis could be organized. Haiti’s public health experts are one step closer to completely ridding its population of a disease that has long plagued the country. For the first time, millions of Haitians are now protected from the infectious, parasitic disease called lymphatic filariasis (LF). With some of the highest rates of LF in the world, Haiti remains one of four countries in the Americas where LF is still endemic. The disease is spread by mosquitoes infected with filarial worm parasites and can lead to severe, irreversible disfigurement (elephantiasis) and chronic pain. The World Health Organization has called for the elimination of LF by 2020. Haiti, in conjunction with several public health partners, began administering a community treatment program in 2005, but was stymied due to funding limitations and the crippling 2010 earthquake. Adequate community protection from LF has been achieved despite the complexities of administering medication in camps and tent communities. Coverage was highest among internally displaced persons in camps. CDC’s program is funding three rounds of treatment for residents of Port-au-Prince using earthquake relief funds. Haiti has leveraged these funds and other support from partners, treating more than eight million people. The treatment regimen, at 50 cents per treatment, with the added benefit of de-worming for other parasites, is considered a public health best buy. For more information on lymphatic filariasis, go to: [www.cdc.gov/parasites/lymphaticfilariasis](http://www.cdc.gov/parasites/lymphaticfilariasis).
For any of you currently undergoing chemotherapy, here is an interesting article about a safe way to exercise while undergoing treatment, under the direction of a physical therapist - from Atlanta area therapist Angelo Rizzo, PT, of Therapeutic Solutions (a cancer survivor himself):


Winship Cancer Institute "Celebration of Living" – June 22nd, 2013 at Peachtree Presbyterian Church, Atlanta, GA - Beverly Thompson, member of the LLN Board of Directors, and her sister Jean Miller, represented LLN at this event. This was a day of fun, celebrating, and learning in tribute and support of cancer survivorship. There were informative exhibits and workshop sessions, as well as entertainment and good food.

The Lymphedema Association of Ontario (Canada) is another excellent resource we have recently learned about. They have an excellent website and newsletter (but you have to spend $25 to join their organization to get it): http://www.lymphontario.ca/recruiting-lymphedema-patients-for-foot-study.html

HAPPY 20TH ANNIVERSARY TO THE LLN!

In 1993, the Lighthouse Lymphedema Network held its first meeting in the home of its founder, Joan White. Those present included patients, family members, one occupational therapist, and one massage therapist. The occupational therapist and massage therapist would go on to get their certifications in treatment of lymphedema patients.

From the beginning, the group was focused on education and creating awareness. We were definitely "pioneers." In 1993, the Internet was still in its infancy compared to today's standards. Therefore, getting information to the public about lymphedema was met by challenges. Word of mouth and constant determination has made the LLN one of the most respected and ongoing lymphedema support groups in the country.

As an organization dedicated to helping others, we charge no membership fees, and rely on volunteers and fund-raising efforts. We currently have 1075 names in our LLN database, 117 certified therapists listed on our website, and we have helped at least 158 Bandages and Garments Fund recipients (which is 15% of our total membership).

Don’t miss the great and inspiring personal stories at the LRF blog at http://lymphaticresearch.wordpress.com/!

Research Notes
Studies are being conducted at The Herbert Irving Comprehensive Cancer Center at New York-Presbyterian Hospital/Columbia University Medical Center (two-year pilot study of a microsurgery technique coupled with imaging technology that seeks to prevent lymphedema) and at Vanderbilt University where researchers are exploring a possible link between the lymphatic system and hypertension. Go to www.lymphaticresearch.org for more information.
On Saturday, June 8th, the Gloria Watts-Cox Foundation held their 11th Annual Lymphedema Walk to support/honor those who suffer from lymphedema. The 5-mile loop started at Cliftondale Park in College Park, GA. Representing the LLN at this event were Debbie Labarthe and her grandson, Carson Sollenberger, who has congenital lymphedema. Also pictured is GWC Foundation Director, Lee Cox. Carson was recognized for finishing the Walk in 62 minutes and achieving 1st place in the “Boys” category.

Update from LLN’s International Assistance Project in Peru, with Caroline Aguirre:
Hello, I am trying to see what I can do to make the lymphedema world move over here in Peru. I have concluded that the best way to spread knowledge is to offer basic lymphedema therapy training workshops. For starters, I am sure that no one will read the requested textbook before the lymphedema therapy training course (+ it is in English) so I thought that giving basic courses could replace that hurdle. After much resistance I have given in to the Facebook wave… and I have created this page to spread the word about the workshops I want to do: www.facebook.com/cuervoblanco.info. I do hope you approve of this modus operandi, and if you feel like it, you can click on the "Like" button for my page to help me launch this technological adventure!

Many good vibes for you,
Caroline Aguirre

A new website from Bob Weiss, our favorite lymphedema activist!

In response to your many requests over the years, we are launching our LymphActivist website. The web site is dedicated to lymphedema patients and the therapists who treat them, and will cover a number of the topics I have been interested in over my 17 years of lymphedema advocacy. Get the latest Medicare and insurance information as I see it, news on current lymphedema research, cost-efficacy of lymphedema treatment, patient's rights to coverage and informed consent, and Medicare and insurance appeals.

Our web site is still under construction, and we add material daily. Please return to the website frequently for updates. You can access LymphActivist's Site at http://www.lymphactivist.org

- Robert Weiss, M.S. and Pearl Hiat Weiss, B.A., B.R.E.
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.

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.

LLN’s website is http://www.lighthouselymphedema.org

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