



LLN January 2013 Newsletter

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

Thanks to our new 2013 website sponsors:
Rivertown Lymphedema Clinic (permanent), MEDI USA and CircAid (Jan-mar), and Solaris (Oct-Dec)!

www.lighthouselymphedema.org

SPICE UP YOUR SPRING!

LLN'S 2013 BELLMERE GARDENS ESTATE LUNCHEON, TOURS AND PLANT SALE FUNDRAISER

This year's event will include a delicious luncheon, a tour of the Jim & Deen Day Sanders family home in Johns Creek, GA with a wonderful collection of American antiques, as well as the magnificent Bellmere Gardens. Our plant sale will feature spices, herbs, and planters.

Saturday, April 27, 2012, 12:00-3:00 PM, Cost: \$45.00/person

Tickets go on sale February 15, 2013

Our 2012 event was terrific; don't miss this opportunity to support LLN's fundraising activities! Directions will be provided.



LLN was selected to be an approved charity receiving donations through the first **Georgia Gives Day** on December 6th. This was an initiative sponsored by the Georgia Center for Non-Profits. Donations could be given on-line at their secure website to directly benefit approved charities in Georgia. If successful, this mechanism will become a permanent annual process to help many deserving organizations. **LLN received \$210 in donations on this day.**

Although Georgia Gives Day has passed, people can continue to donate through the Georgia Gives website, www.GAgives.org, which will continue to serve as a live, year-round and state-wide resource where the public can search for and support the local charities that touch our lives every day.

Upcoming Meeting: March 21 - LLN Open Forum Meeting at A Women's Place at Northside Hospital, 1000 Johnson Ferry Road NE, Atlanta, GA 30342, 6:30–8:30 PM

Patients, caregivers, family members, and medical professionals, bring your questions, concerns and ideas. Northside Hospital and the Lighthouse Lymphedema Network invite you to an evening of sharing with a little Q&A time. MEDI USA and CircAid Medical Products (now a MEDI Company) will demonstrate their products. Light refreshments will be provided.



LLN BANDAGES & GARMENTS FUND UPDATE

The Bandages and Garments Fund has had a banner year. Due to the Susan G. Komen for the Cure grant and an excellent year of fundraising activities, such as the Bill Goering Memorial and the Larry Hart Golf Outing and others, we have assisted 53 patients with arm or leg lymphedema this year. As of November 2012, \$19,471.25 had been spent on helping qualifying patients to receive compression garments or bandages. Our biggest fundraising efforts go to the BAG Fund to help others, so it is critical for everyone to participate in our fund-raising activities. If you need any information or an application for assistance, please contact our Bandages and Garments Fund Director, Deb Cozzone, through the Contact Us on the LLN website, or at the LLN main phone number, 770-442-1317.

2013 Lighthouse Lymphedema Network Calendar Dates to Remember:

- January 19 - LLN Board of Directors Meeting, Country Club of Roswell, 9:00 AM
- January 26 - Bill Goering Memorial Fencing Tournament, Denver Fencing Center, Denver, CO.
- February 28- LLN will participate in the Health & Wellness Expo at Atlanta Tech. College, 10 AM-2 PM, free event.
- March 21 - Open Forum Meeting, at A Women's Place at Northside Hospital in Atlanta, GA 6:30-8:30 PM, with light refreshments served. CircAid and MEDI-USA will demonstrate their products.
- March 26 – Southern Loss Association-sponsored Larry Hart Memorial Golf and Tennis Outing, Chateau Elan, Braselton, GA. The proceeds from the sale of mulligans and the ball toss will be donated to LLN.
- April 13 - LLN Board of Directors Meeting, Country Club of Roswell, 9:00am
- April 27 - "Spice up Your Spring" - a luncheon, home tour & plant sale at Bellmere Gardens Estate, Johns Creek, GA.
- May 11 - Susan G. Komen Race for the Cure, Atlantic Station, Atlanta GA
- August 2013 - Open Forum Meeting at Gwinnett Med. Ctr., Duluth, GA 6:30-8:30 PM, with light refreshments served
- 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

LLN's first Open Forum Meeting was held August 28, 2012 - The LLN and DeKalb Medical Center/Rehab Results Group hosted our first Open Forum at DeKalb Medical Center on Tuesday, August 28. This informal meeting and discussion brought together patients with lymphedema, therapists and garment fitters. There was a brief presentation about some of the numerous activities of the LLN, including the newsletter, annual conference, Bandages and Garments Fund, outreach to South Africa, LLN books and legislative efforts supporting the Lymphedema Treatment Act. Two groups were then formed--one for arm patients and one for leg patients. Each group included a lymphedema therapist and garment fitter. Open discussion time provided an opportunity to share ideas, experiences and questions and to learn from the experts. This Open Forum was a big success!



Farewell to a Much Beloved Friend of LLN

This year the LLN honors someone who has given so much to make the LLN a success: a person who has worked in the trenches, and who never asked for much, but gave and gave and gave. We thank DeCourcy Squire, PT, CLT-LANA, and Casley Smith School instructor for her service, dedication and her tireless work for the LLN. DeCourcy has recently accepted a position starting a lymphedema program at Hennepin County Medical Center in Minneapolis; our loss is certainly Hennepin's gain. We wish to honor DeCourcy today with our thanks for her years of service to the LLN and for all the therapists she has trained to take proper care of us patients. DeCourcy was a founding member of LLN and remains an Honorary Board member. She is a graduate of the University of Maryland at Baltimore with a BS in Physical Therapy. She is a Certified Instructor in the Casley-Smith Method of Treatment for Lymphedema, and serves on the Best Practices Document Committee of the American Lymphedema Framework Project. We all know that DeCourcy has longed to move back to the north and especially to Minnesota. Words cannot express our appreciation and thanks to DeCourcy for her years of service and dedication to the LLN since its inception.

Thanks to our Board Members who volunteered to help wrap gifts at the Barnes & Noble bookstore Cumberland Mall on several days/shifts in December. Customers could give tips to the charities who participated in this fundraiser, and we made **\$447.50**, so we will definitely do this fundraiser again in 2013 and at several Barnes & Noble locations.

LLN supports efforts to pass the National Lymphedema Treatment Act

Here is updated information from their website, www.LymphedemaTreatmentAct.org :

"As this Congress draws to a close I'd like to share with the National Lymphedema Network members some important information regarding the Lymphedema Treatment Act. This will prevent any confusion as we enter into the new Congress in January of 2013. Representative Dave Reichert of Washington State's 8th Congressional District will sponsor the Lymphedema Treatment Act in the 113th Congress! Representative Reichert currently serves on the Ways and Means Health Subcommittee, to which our bill has been referred. We have seen that he and his staff believe in this issue and are working hard on it. We are truly delighted by his recent commitment to sponsor our bill.

We are very pleased that the overwhelming majority of our cosponsors will be returning to office next year. Although cosponsors do not carry over from one Congress to the next, members typically sign back on to bills they cosponsored previously. From the 111th Congress to the 112th 90% of our reelected cosponsors signed back on, so please keep the pressure on your Congressperson to cosponsor if they haven't already. Please view the current cosponsor list then send a letter to your Congressperson if you don't see his/her name on the list.

Be aware that bills also do not carry over from one Congress to the next. All bills that have not been passed into law must be reintroduced in the next Congress. In the process, they receive a new bill number. We made considerably more progress in the 112th Congress than the 111th, and together we'll go even further during the 113th Congress. To receive the most up to date information on the bill status and the simple ways you can help, please subscribe to the monthly Lymphedema Treatment Act e-Newsletter.

The federal legislative process is long and tedious, and can feel frustratingly slow at times, but those who succeed do so because they have the will to endure the process. With your help, we will persevere as long as it takes and we will succeed! "

Heather Ferguson, Executive Director, Lymphedema Advocacy Group, www.LymphedemaTreatmentAct.org

Also, see Bonnie Lasinski Pike's column at the Literary Mama website:

"This month's article is about lymphedema. The editors were boggled to learn about it, since they had never heard of it before, and were glad to help me get the word out about it. It's called "My Fat Arms," and you can find it here:

<http://www.literarymama.com/columns/archives/2012/10/my-fat-arms.html> "

(There is also a link in this terrific article to another lymphedema information website: <http://stepup-speakout.org/>)

LLN Director Joan White attended a lymphedema educational summit sponsored by The James, the hospital on the campus of The Ohio State University in Columbus, Ohio, August 14, 2012. Jane Armer PhD, Joseph Feldman MD, Janice Cormier MD, Michael Bernas MS, and others were speakers. Joan said it was good to see others sponsoring lymphedema programs where patients are included in the audience.

See our brand-new LLN website! www.lighthouse.lymphedema.org

We welcome new LLN Board member Tom Kincheloe, OTR/L, CLT, who is owner and clinical director of Rivertown Lymphedema Clinic & Rehab in Myrtle Beach, SC. Tom has offered to serve as our new website administrator (and many thanks to Clint Labarthe for all of his years of faithful service as our previous webmaster!). In addition to generously contributing the cost of hosting the LLN site and our domain name, Tom will work with Bret Martin, a consultant and website designer at Delta Airlines, to build a brand-new LLN website with many more features, such as giving directions and contact information for a therapist when you click on her/his name. Thanks, Tom and Bret - and everyone, please go to the website ASAP and check out all of the exciting new features!

Joachim Zuther, Education Director of the Academy of Lymphatic Studies, announces the availability of the new 3rd edition of the textbook **Lymphedema Management**. "The first two editions have been wide distributed, aiding thousands of practitioners and patients worldwide, and this new edition represents an exciting step forward for the field of lymphedema therapy. In addition to all features presented in the previous editions, which have been updated, some topics have been extensively revised. New contributors (many of whom are internationally recognized practicing clinicians) include Jane Armer, who also wrote the foreword, Judith Nudelman, Marga Massey, Michael Bernas, Janice Cormier, Maureen Mc Beth, and many more. New sections include: expanded diagnosis and evaluation, lymphedema taping, expanded treatment of the head and neck, trunk and external genitalia (male and female), treatment and compression strategies for patients with wounds, paralyzed limbs, morbid obesity, and advanced-stage involvement, to include a multitude of treatment adaptations and nuances (foam, step-by-step instructions, garment selection and adaptation), plus lymphatic imaging, quality of life issues, surgical options (reconstruction, liposuction) and lymphatic microsurgery."

10th NLN Conference, Sept. 9-12 in Dallas, TX

Board Member Katie Russo attended the conference to become certified through the Lymph Science Advocacy Program (LSAP), a training program for patients and advocates at the 10th NLN Conference:

Living with lymphedema, I am used to feeling marginalized, or somehow, an “outsider,” either trying to mask my physical and psychological differences, or having to explain them, even to members of the medical community. It is frustrating that pain associated with this disease is nearly impossible to express in terms that anyone not personally experiencing it can comprehend. In order to be understood, Lymphedema must be viewed as a syndrome that encompasses more than just swelling. It affects us physically in countless ways, and hugely impacts our emotional, mental, and spiritual selves. It colors our outlook on the world and our conceptions of ourselves. Thus, I was particularly interested in attending the conference to gain insight into how Lymphedema is publicly discussed and perceived. The tone of the conference was set by the keynote speaker, an elite-level athletic competitor who lives with the challenges of lymphedema. Her story resonated with my own experience, and her attitude and accomplishments were truly inspirational. Throughout the conference, I was impressed with the insights and empathy of presenters. It was encouraging to hear accurate messages about the patient experience. The imposing quality of life issue is often completely minimized and overlooked because lymphedema is considered non-life-threatening. However, the threat is there; a life lived under the shadow of lymphatic dysfunction is compromised every day that the patient feels alone and unheard. “We Are Here,” and we need a voice. I felt that this year’s conference helped facilitate that dialogue. I hope that the voices will continue to unite into a force for positive steps toward a cure and improved treatment methods, as well as the essential understanding of lymphedema as a whole-person disease, not just swelling.



Vera Newman and LLN Director Joan White

CONGRATULATIONS TO OUR VOLUNTEER OF THE YEAR, VERA NEWMAN!

As chairperson of the book committee, she gave us direction and led the committee to create our book *The Puzzle: An Inside Glimpse of Lymphedema*. This was a project that seemed to grow in intensity, but the committee was diligent in its quest to produce a book that the LLN would be proud of and that patients and professionals would be touched by the stories. The book was written to encourage, educate and inspire patients and loved ones, who can often feel isolated and uninformed. Not every story had a happy ending, yet there is hope. By sharing these stories with one another, we can learn from the struggles and successes that others have experienced and can help each other to live well with lymphedema. Vera serves on our Bellmere Gardens Luncheon, Tour and Plant committee, and our website committee. Let us honor Vera Newman for her dedication to the LLN as our 2012 Volunteer of the Year.

Our Sincere Thanks for our Supporting Vendor Donations on the 15th Lymphedema Education & Awareness Day:

A Woman’s Place at Northside Hospital, Ambra LeRoy Medical Products, Bauerfeind USA, Inc., BiaCare (Zeeland, MI), Body of Health, BSN-Medical/Jobst, Circ-Aid Medical Products, Inc., Gloria Watts-Cox Foundation, JUZO, LoCost Medical Supplies, MEDI USA, Peninsula Medical Products, Piedmont Hospital Lymphedema & Compression Services, Pretty Please Healthcare, SIGVARIS INC., Solaris Inc., SynMED Inc. Also exhibiting: Lymphatic Research Foundation and Susan G. Komen for the Cure.

Speakers from our 15th State of GA Lymphedema Education & Awareness Day



L-R, Dr. Jane Armer, Dr. David Chang, Dr. Joseph Feldman, & Dr. Richard Mistretta



LLN Director Joan White & moderator Elaine Gunter



Therapist Samantha Cannon



Vicky Day with daughter Courtney's book



Patient Speaker Deborah Dobbins



Our registration team! Front: Justin & Kyle Cozzone, Delores Bradley; Rear: LLN treasurer Larry Ashmore, and conference registrar Deb Cozzone

Vendors from our 15th State of GA Lymphedema Education & Awareness Day





Program comments from attendees:

"Exceptional program, thank you"; "Loved the Courtney Day video!"; "Dr. Chang's presentation was awesome"; "Samantha Cannon's presentation was fantastic"; The ALFP update was very informative"; and from speaker Dr. Mistretta: "It was truly a pleasure speaking with the patients and other lymphedema clinicians at Emory. Joan and the rest of the Lighthouse Lymphedema Network really put on a top notch meeting. The patients and clinicians all seemed thrilled and impressed with the whole program."



Joan White introduces the Maiden Family



LLN Treasurer Larry Ashmore & therapist Shelly Smith-DiCecco



***Immediate Opening for A Physical Therapist
Myrtle Beach, SC***

Rivertown Lymphedema Clinic and Rehab, LLC (RLCR), a privately-owned outpatient rehab facility in beautiful Myrtle Beach, has an urgent need for a **Physical Therapist** to fill a full-time position. CLT or CLT-LANA credentials preferred, but not necessary. Wound care certification and/or outpatient rehab management skills a plus.

Pay is high percentage commission rate of PT's/PTA's revenue with exceptional annual earnings of up to \$100K or more possible, depending on desired work pace, motivation and schedule flexibility.

RLCR is a fast-growing hands-on, evidence-based rehab clinic established in 2009. We have developed an excellent reputation with many area physicians, and we have an increasingly growing referral base.

Interested candidates should fax resumé with cover letter and references to **(843) 742-5704**, or email with attachments to **erivertownlymph@scoast.net**.

Brief Summaries of our Primary Speakers' Presentations: (See our website for more complete descriptions of all of our speaker presentations)

1. **Jane Armer, PhD, RN, FAAN, Sinclair School of Nursing, University of Missouri. “Findings and Reflections from a Decade of Study in Breast Cancer Survivorship: Implications for Patients and Health Care Professionals.”** Dr. Armer focused on lymphedema (LE) of breast cancer survivors (BCS), who are at lifetime risk for developing LE, whether within a month of their treatment, or decades later, and must deal with its effects on their quality of life. Having means of coping and learning to solve problems have big impacts on their lives. Dr. Armer presented a model of post-breast cancer treatment outcomes, identifying pre-disposing factors such as treatment or genetics that may place patients at greater risk. Social support systems and a patient's own problem-solving capabilities have been identified as critical components.
2. **Dr. Joseph Feldman, MD, CLT-LANA, Pritzker School of Medicine, University of Chicago. “The Challenge of Pediatric and Adolescent Lymphedema.** 90% of primary LE patients have no family history, but represent spontaneous gene mutations, and their #1 challenge is to obtain a correct diagnosis. Secondary LE can occur in response to malignancies, surgery, and trauma, medical treatments such as radiation, infections, and even insect bites. Using a multi-disciplinary team (pediatrician, certified LE therapist, lymphologist, dermatologist, vascular surgeon, plastic surgeon, and certified garment fitter) is critical for LE patients, as is properly done complete decongestive therapy (CDT) and manual lymph drainage (MLD). Diagnostic evaluation, including level of function tests, is now critical for insurance coverage. A child's HT/WT should be measured at every treatment visit. Parents should learn MLD to properly bandage the hands and feet of infants with LE, and bandaging shouldn't interfere with their normal movement. Only flat-knit garments should be used, and must be made to measure every 4-6 months as a child grows. These garment classes are most appropriate for children (6 months – 1.5 yrs, class I; 1.5 – 6 yrs, class I-II; 6 -14 yrs, class I-II; > 14 yrs, I-II or more). Night-time compression is very helpful. The British interactive website, <http://LYMPH4KIDZ.com>, is a great resource for children to use and learn about LE. Fortunately, the Affordable Care Act will provide coverage for children up to age 26 with pre-existing LE, as of 2014.
3. **Dr. David Chang, Director of the Microsurgery Laboratory at the University of Texas M.D. Anderson Cancer Center. “Overview of Surgical Treatment for Lymphedema.”** Dr. Chang described previous surgical treatment procedures for LE, and newer techniques such grafting a lymph node from a leg to an arm, a technique that has had inconsistent results and can possibly cause development of LE in the donor site, and lymphovenous bypass procedure, in which the lymphatic system is closed at certain points and drainage is moved into the venous system. This newer research is being conducted as “super microsurgical technique.” He has performed about 100 bypasses so far, leading to a new classification of 4 stages of LE. This technique doesn't work for everyone, but early intervention in stages I or II of LE is more effective than in stages III or IV. Good candidates for this surgery still have some lymphatic function and any fibrosis is minimal in their affected tissues. This technique can improve the severity of LE, reduce complications, and improve quality of life, but it isn't a cure and doesn't always work. The ideal LE treatment would repair or re-establish lymphatic function and provide a complete cure.
4. **Dr. Richard Mistretta, Affiliated Ankle and Foot, PC, Duluth, GA. “The At-Risk Foot and Lymphedema.”** Discussed: (1) identifying disorders complicating LE; (2) a 4-system anatomical approach to identify LE risk factors; (3) referring a patient to a LE specialist; and (4) educating patients to avoid relapses and complications. A patient's vascular, neurological, dermatological, and musculoskeletal status should be reviewed before confirming a diagnosis of LE. There are a number of common conditions for LE patients, they represent risks. Constant monitoring is very important during CDT for LE. Family members should be involved to help check the patient's feet daily. CDT should be suspended until treatment has been completed if there is a complication such as an infection. Dermatological skin disorders can sometimes delay CDT. Prevention techniques include not going barefoot, and inspecting feet daily. Patients should seek medical attention promptly for potential foot problems. Proper hygiene for foot care is critical. Diabetics must not use corn starch as a drying agent on their feet- they could develop yeast infections! Patient education is critical, and success in foot and ankle treatment for LE patients is a team effort, with the podiatrist, certified lymphedema therapist, and family/caregivers all assisting the patient.

2012 Donations to the LLN

In Honor:

All Certified Lymphedema
Therapists
Deb Cozzone
Courtney Day
Jane Jackson
Norman, Jamie, Trinity and
Jonathan Maiden
Geraldine Perry
Carson Sollenberger
Lisa Sollenberger
DeCourcy Squire
Beverly Thompson
Joan White

In Memory:

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William "Bill" Goering
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Larry Hart
Sandy LePage
John Ross
Libbie and Cole Sanders
Jack Streidl

2012 Donations:

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Custom Compression Consultants
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Day/Peyton Foundation
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Kathryn Thrift
Jacqueline Valme
Elizabeth Warner
Wilda Warren
Doug and Joan White
Phil and Jolene White
Ron and Rene White
Mr. and Mrs. W.G. Witcher, Jr.

Our sincere thanks to the following businesses for your financial support of the 15th State of Georgia Lymphedema Education & Awareness Program:

A Woman's Place at Northside
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Ambra LeRoy Medical Products
Bauerfeind USA, Inc.
BiaCare
Body of Health
BSNmedical/JOBST
CircAid Medical Products, Inc.
Gloria Watts-Cox Foundation
JUZO
MEDI, USA
Peninsula Medical Products
Piedmont Hospital Lymphedema &
Compression Services
Pretty Please Healthcare
SIGVARIS, INC.
Solaris, Inc.
SynMED Inc.
**Also our thanks to the following for
exhibiting at the conference:**
Susan G. Komen for the Cure
Lymphatic Research Foundation

To the LLN Board of Director always our thanks for your dedication and support:

Larry Ashmore, PhD
Dolores Bradley, PhD
Samantha Cannon, MSOT, CLT
Deb Cozzone
Vicky Day
Shelley Smith DiCecco, PhD, PT,CSLT
Elaine Gunter, MT (ASCP)
Gary Gunter
Laura Hoffman
Tom Kincheloe, OTR/L, CLT, WCC
Gwen Forbes-Kirby, PT, CLT-LANA
Stephanie Kirkpatrick, DPT,CLT-
LANA
Clint Labarthe
Debbie Labarthe
Vera Newman
Charles Pat O'Connor
Katie Russo
Stacy Saraydar, PTA, CDT, CSLT
Janie Smith, PT, CLT
DeCourcy Squire, PT, CLT-LANA
Sandi Stephens McGriff, LMT, CDT
MLDT
Beverly Thompson
Shirley Tucker
Joan White

**Finally, thank you to our many
volunteers!!**

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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