



www.lighthouse lymphedema.org

LLN April 2013 Newsletter

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

SIGN UP NOW FOR THIS DELIGHTFUL FUNDRAISER FOR LLN!



Spice Up Your Spring

At the home of Jim and Deen Day Sanders

**Join us at the private Bellmere Estate
10777 Bell Road, Johns Creek
Saturday, April 27, 12:00 – 3:00**

- ❖ Savor a delicious luncheon in the lovely Garden House
- ❖ Enjoy a demonstration of creating 2 herb gardens
 - ❖ Tour the magnificent home filled with one of the finest collections of American antiques
 - ❖ Stroll through the lush gardens and grounds

Tickets: \$45.00 (110 tickets available)

All proceeds benefit the Lighthouse Lymphedema Network

Register on-line at lighthouse lymphedema.org,

Or for more information, contact Vicky Day at vicky@peyday.net

Directions: Bellmere Gardens is located at 10777 Bell Rd., Johns Creek, GA 30097-1803. Johns Creek is slightly northeast of Atlanta. If you live in any other part of the Atlanta area, take I-285 N. Merge onto GA-141 N (Peachtree Industrial); at the split, veer left towards Cumming onto GA 141 which is now Medlock Bridge Road. Turn right onto Bell Rd. Bellmere will be on the left. Look for the balloons. Once on the driveway, you will see the Garden House sign.

Also: Raffle tickets will be sold for 6 herb gardens created by the Master Gardener!



LLN BANDAGES & GARMENTS FUND UPDATE

GRANT NEWS - Thanks to the grant writing efforts of Shelley Smith DiCecco, PT, CSLT, PhD, the LLN Bandages and Garments Fund will benefit from **two** grants in the 2013 – 2014 grant year. For the first time, the LLN has received a grant from It's The Journey. ITJ has awarded the LLN \$12,300 to assist breast cancer survivors who have lymphedema. These funds are not restricted to specific counties in Georgia, and will allow us to assist breast cancer survivors throughout the state. Together, these two grants will offer us the opportunity to double the number of breast cancer survivors we have assisted in past years.



(L-R, Glenn Martin, Chairman of the Board of It's The Journey; Joan White, LLN Director; Deb Cozzone, LLN Bandages and Garment Fund Administrator; Laurel Sybilrud, ITJ Grants Chair; Kimberly Goff, ITJ Executive Director)

In addition, the LLN has been awarded an additional \$19,000 from Susan G. Komen for the Cure – Greater Atlanta Affiliate to assist breast cancer survivors with lymphedema. (We received the first half of these funds on April 1.) These funds are earmarked for individuals in the Komen-designated 13-county area of greater Atlanta.



(L-R, Eryn Marchiolo, Mission Director, Susan G. Komen for the Cure, Greater Atlanta Affiliate, Deb Cozzone, Joan White, and Cati Stone, Executive Director, Komen/Atlanta)

HELPING PATIENTS and THERAPISTS: Recently Deb received this note from a certified lymphedema therapist whose recommended patient was assisted by the Bandages and Garments Fund:

"XXXXXX has her Tribute. It is wonderful! Thank you so much for helping her. She is really sick right now with chemo, so the garment is perfect for her to get some relief from wrapping. I just want to say thank you for all you and the folks at the Lighthouse do. It is so hard at times to do this job with insurance coverage limiting a patient's ability to get garments. It makes it so much easier when we can at least help with the first set, and then help them prepare mentally and financially for how they will obtain the second set. Y'all are certainly blessing many."

And another one we received from a patient recipient of the fund:

"Thank you so much for the help in getting me a lymphedema garment. I could never have afforded one without help...I am so grateful for everything. When I am back on my feet, I hope to give back to the community. Thank you for all of the generous work you are doing."

2013 STATUS UPDATE: To date in 2013, the LLN Bandages and Garments Fund has assisted 13 patients, and has an additional 11 patients in process. Our recent grants will allow us to assist numerous additional breast cancer patients this year, which will mean another record year of serving lymphedema patients in Georgia.

THANKS TO ALL OF OUR SUPPORTERS: Without the generous help of our partners, the success of the Bandages and Garments Fund would be limited. In addition to the grants mentioned above, we regularly receive assistance from these partners in the form of complimentary garments, discounted garments, fitting services, and financial donations. In the past year, the following businesses have supported the Fund in one or more of these ways:

A Woman's Place at Northside Hospital
All About You
Barney's Pharmacy
BSNmedical
CH Martin, Fayetteville
CircAid Medical Products
Compass Healthcare
Compression Ratios
Custom Compression Consultants
Duramed
Gloria Watts-Cox Foundation
It's The Journey
JUZO

MEDI, USA
Mercy Medical Supply
Peninsula Medical Products
Piedmont Hospital Compression Services
Pretty Please Healthcare
Sigvaris, Inc.
Solaris, Inc.
Susan G. Komen for the Cure Greater Atlanta
Affiliate
Therapeutic Solutions
Tuscan Sun Wellness Center
Wynn's Pharmacy Services

IMPORTANT NOTE TO CLTs: Please note that you should be using the Bandages and Garments application with a revision date of 09/12. This was e-mailed to all of the therapists on the Bandages and Garments Fund e-mailing list on February 27. If you have an older version, please contact Deb Cozzone (see below) for the most recent application form. We are collecting a variety of required data for grant writing/reporting, and it is crucial that we get all of the necessary data. In addition, please make sure that you are writing your recommendations using the Therapist Recommendation Form. This form will simplify the application process for you and keep the follow up questions to a minimum. Finally, please verify that the application is complete and clearly legible.

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:

- April 13 – **LLN Board of Directors Meeting, 9:00 AM – 1:00 PM**, Roswell Country Club
- 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
- June 1 – The 11th Annual **Gloria Watts-Cox Foundation Walk for Lymphedema**, 8:00 AM sharp, Cliftdale Park 4645 Butner Rd, College Park, GA 30349
- June 22 - **Celebration of Living**, a health and wellness fair sponsored by Emory's Winship Cancer Center at Peachtree Presbyterian Church in Buckhead, Atlanta, GA
- August 20 - **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
- 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

LLN's Second Open Forum Meeting to be held August 20th, 6:30-8:30 PM at Gwinnett Medical Center in Duluth, GA - The LLN and Gwinnett Medical Center will host our second Open Forum at Gwinnett Medical Center Tuesday, August 20th. This informal meeting and discussion will bring together patients with lymphedema, therapists and garment fitters. Light refreshments will be provided. Therapist and LLN Board Member Samantha Cannon is coordinating this presentation.

2013 Bill Goering Memorial Fencing Tournament

The annual Bill Goering Memorial Fencing Tournament took place in Denver, CO, on January 26 and 27. This year proffered the most competitors in the history of the tournament and two days of excellent epee, foil and saber bouts. All entry fees from the tournament were donated to the Lighthouse Lymphedema Network for the 6th consecutive year, resulting in a donation of **\$5,180** for the Bandages and Garments Fund.

Deb Cozzone attended the tournament to represent the LLN and to present Nathan Anderson, Denver Fencing Center Owner, with a letter of appreciation. Pictured below are Deb, 1st place Saber winner Jeremy Morse, and Nathan Anderson. Jeremy is holding the first place trophy, which previously belonged to Bill Goering and was donated to the DFC by Monica Goering. At the conclusion of the tournament, the year and the winner's name is engraved on a plaque affixed to the trophy, which is kept and displayed at the Denver Fencing Center.





**SOUTHERN LOSS ASSOCIATION SPRING GOLF OUTING
Held at Chateau Elan Resort, Braselton, GA, March 26, 2013**

Southern Loss Association Spring Golf Outing benefited the LLN through the sale of mulligans and the ball toss. Although the weather was extremely cold and there were a few snowflakes, the event raised **\$1,462.00** to help our less fortunate patients through our Bandages and Garment Fund.

Welcome to two new LLN board members!

Billie Hunter-Barron has volunteered to join the board as our website administrator, and will work closely with Bret Martin to continue to develop the website. **Kathy Cannon will be our legislative team leader**; her first goal will be to get all of the legislatures/congresspersons in Georgia on board with sponsorship of the national bill.

LLN would like to thank Northside Hospital Lymphedema Program for hosting the patient meeting on March 21st. Thanks also to therapists Janie Smith, PT and Jane Thiery, PT, who prepared the delicious food. After the presentation, a Q&A session was held, and then MEDI USA and CircAid Medical Products (now a MEDI USA company) representatives Geoff Schull and Suzy Loudermilk did a terrific job of demonstrating their lymphedema management products.



The Gloria Watts-Cox Foundation, Inc.
“ELEVENTH ANNUAL 8K WALK”

Supporting Those Suffering with Lymphedema

WHEN: Saturday, June 1, 2013

WHERE: Clifftondale Park, 4645 Butner Rd, College Park, GA 30349

TIME: 8:00 a.m. sharp

Pre-registration is highly recommended:
To register, call Lee H. Cox at 404-349-3992

DIRECTIONS TO THE WALK

From Atlanta

Take I-20 West to the I-285 South exit at Camp Creek Parkway. Go right to Butner Rd. (5th light). Turn left onto Butner Rd, go approximately 3 miles to the 4-Way stop sign, and continue straight for 1/4 mile to 4645 Butner Rd.

16TH STATE OF GEORGIA LYMPHEDEMA EDUCATION & 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 Street, Atlanta, GA 30332**

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

Speakers:

Brandon Dixon, PhD, Assistant Professor, Georgia Institute of Technology, Atlanta, GA

David C Zawieja, PhD, Director, Division of Lymphatic Biology, Texas A & M Health Science Center
College Station, TX

Stanley Rockson, MD, Professor of Lymphatic Research and Medicine, Chief of Consultative Cardiology,
Director, Stanford Center for Lymphatic and Venous Disorders, Stanford University, Stanford, CA

Therapist:

Stephanie Kirkpatrick, DPT, CLT-LANA Physical Therapist/Certified Lymphedema Therapist, Lymphedema Clinic
The Emory University Hospital Clinic Radiation Oncology Department, Atlanta, GA

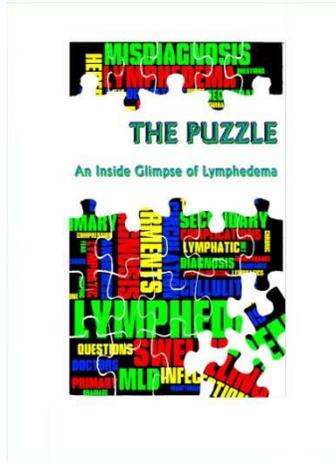
Patient Stories:

Joan White, Founder of LLN
Melanie Chaite, Lymphatic Research Foundation

Workshops:

- (1) Emerging Technologies in Lymphatic Care and Diagnostics**
- (2) Future Directions in Lymphatic Research**

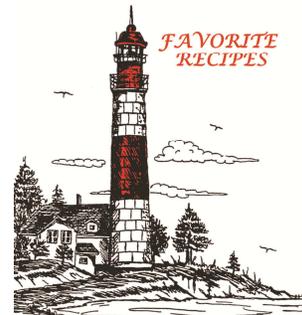
LLN PROUDLY ANNOUNCES THE PUBLICATION OF TWO NEW BOOKS!



This book was compiled so that people who have been touched by lymphedema can share their stories, trials and tribulations, sadness and disappointments, strength and hopes. It is intended to encourage, educate, and inspire patients and loved ones, who can feel isolated and uninformed. We hope to increase awareness and general knowledge of a condition that is often overlooked and misdiagnosed, yet which can have monumental physical and emotional impact on the lives which it affects. Not every story has 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 experiences, and can help each other to live well with lymphedema.

*The Lighthouse
Lymphedema Network*

As the center of family life is our kitchens, we hope you will enjoy cooking, baking, and simply creating memories from our recipes. This book is a collection of recipes from members, family, and friends of the Lighthouse Lymphedema Network. This cookbook makes a great gift for all occasions, or just for you!



Both of these books will be available by credit card order through our website, <http://www.lighthouselymphedema.org>, or by contacting Beverly Thompson at 770-476-2671. Or, you can order our books by mail with this form & check payable to: Lighthouse Lymphedema Network Books, 10240 Crescent Ridge Drive, Roswell, GA 30076

Name: First		Last	
Mailing Address:			
City		State	ZIP Code
Preferred Telephone Number			
Email Address			
Number of Copies you would like to order:			
The Puzzle _____		LLN Cookbook _____	
\$19.95 per copy		\$12.00 per copy	
(+ \$5/copy shipping)		(+ \$5/copy shipping)	
\$ Total Amount Enclosed (Check Payable to Lighthouse Lymphedema Network)			



Dear Supporter,

Our sponsor for the 113th Congress, Congressman Dave Reichert (R) of Washington State, who is a member of the powerful House Ways and Means Committee to which our bill has been referred, is working on preparations for reintroduction of the Lymphedema Treatment Act. His first task in preparing the bill is to see what framework might make the bill more palatable to members of Congress in this highly divisive and cost-conscious environment.

Congressman Reichert's second task is to secure a Democratic "co-lead" for the bill who is a member of the Ways and Means Health Subcommittee. The best-case scenario, especially in these partisan times, is to have legislation introduced by a member of both parties. The Chairs of the Congressional committees were only recently announced and the full membership of each subcommittee is not finalized, so the most appropriate co-lead cannot be chosen quite yet.

Meanwhile, the Lymphedema Advocacy Group board is looking for Democratic and Republican co-leads to simultaneously introduce the bill in the Senate when it is ready. ***Please be mindful that this process of preparing for reintroduction will take time, but will be worth the wait. We are very fortunate to have such an experienced new sponsor who can use his stature in Ways and Means to promote our bill and ensure it is optimally positioned for passage when it is reintroduced!***

Heather Ferguson

Founder and Executive Director, Lymphedema Advocacy Group

info@LymphedemaTreatmentAct.org

www.LymphedemaTreatmentAct.org

Note: LLN has donated \$500 to the Lymphedema Advocacy Group to help cover some of their printing costs for spreading the word about helping in the passage of this critical bill. Please consider donating too – if this bill is passed, we ALL benefit!

Health and Wellness EXPO, Thursday, February 28, 2013 at Atlanta Technical College - Gwen Forbes-Kirby, PT, CLT-LANA spoke to the Atlanta Technical College Physical Therapist Assistant (PTA) students. Gwen explained the function of the lymphatic system and how a malfunction in this system causes lymphedema. The students asked many questions and were thankful for the information. Joan White was the LLN representative at the booth where students, faculty, and others stopped to inquire about lymphedema. Winners of the door prizes of our book and cookbook were Dental Hygiene Instructor Candace Marshall and student Faye Evans.



Therapist Gwen Forbes- Kirby with Students at Atlanta Technical College

From LLN's International Service Project in Peru:

A small note to report that I have used your kind donations for Frida Lock, a school teacher in Chinchá (a town 3 hours by bus south of Lima). She has had primary leg lymphedema for 37 years now, which luckily for her, remained in an "early stage" and un-swells quite well with elevation. On the picture enclosed, she is with her daughter Pamela who attends her mother's sessions and helps her through the exercise routine and with the bandaging. I was told she is quite authoritarian for the exercises, and Frida cannot bypass any of the movements! Frida has asked me to forward you the following letter she sent me by email. I send you my warmest regards from Lima, for you and all the ones who help the LLN,
Caroline Aguirre



Translation: LETTER OF THANKS

Dear Sirs:

Through this letter I express my gratitude for donating me bandages for my lymphedema treatment, a condition I have had since I was 8 years old. I am a Peruvian woman of 45 years old, and I live in the province of Chinchá, in Ica. I located Miss Caroline Aguirre through her website. She has assisted and informed me about the condition I have, and I now attend therapy sessions where she has generously given me the bandages and implements for the treatment I require. My greatest apprehension was to have to run errands, because I dreaded feeling my leg swell and grow weak, and I lived with the urgency of having to hurry back home to sit down and elevate it, which relieved it greatly. Having a compression garment now has taken a huge load off me, and I am free to live my life which makes me so very happy! Very gratefully I bid you farewell and regards,
Frida Liliana Sifuentes Lock



NEW ADDRESS FOR THE LYMPHATIC RESEARCH FOUNDATION:

261 Madison Avenue, 10th floor, New York, NY 10016.

Our phone number, 516-625-9675, is unchanged.

We are delighted to announce the opening of our new location in Manhattan. Our new office, in the heart of midtown, will provide LRF with greater access to New York's dynamic philanthropic and non-profit communities and world-class health care organizations, and allow us to expand our operations and reach.

LLN appreciates your donations, even creative birthday presents! Gwen Forbes-Kirby celebrated her 60th birthday on March 2 with a Hawaiian luau theme. In lieu of gifts, Gwen asked that her guests donate to the LLN. Thank you to her friends and family for donations totaling \$525.00 in honor of Gwen.

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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