

LLN September 2011 Newsletter

Coming up in 2011:

- Expansion of the LLN website to include more information on lymphatic diseases.
 - Our patient stories book and our second cookbook now available!
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www.lighthouselymphedema.org

REGISTER NOW!

14TH STATE OF GEORGIA LYMPHEDEMA EDUCATION AND AWARENESS PROGRAM

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

HILTON GARDEN INN – ATLANTA PERIMETER CENTER

1501 Lake Hearn Drive, Atlanta, GA 30319

Saturday, October 15, 2011

7:30 AM-5:00 PM

Hosted by

LIGHTHOUSE LYMPHEDEMA NETWORK

Our Featured Speakers:

David Finegold, MD (Pediatric Endocrinology, Pediatrics and Clinical Biochemical Genetics, Univ. of Pittsburgh) *“Lymphedema Genetics: Of Mice and Men”* and *“Lymphatic Genetics in the Future: A Ride on the Starship Enterprise”*

Young-sup Yoon, MD, PhD (Cardiologist and Stem Cell Biologist at Emory University): *“Novel Cell-based Therapy for Experimental Lymphedema”*

LeAnne Fox, MD (CDC Division of Parasitic Diseases and Malaria) *“Lymphedema Management in Lymphatic Filariasis: A Global Perspective”*

Program Location: Hilton Garden Inn – Atlanta Perimeter Center, 1501 Lake Hearn Drive, Atlanta, GA 30319.

Conference will be held in the lower level of the hotel. The hotel is located at the intersection of 285 and Ashford Dunwoody Road, just inside the perimeter. Going east on 285, exit Ashford Dunwoody Road turning right. Immediately turn right on Lake Hearn Drive to reach the hotel. For reservations, please call 404-459-0500 before October 3rd; mention the Lighthouse Lymphedema Network to receive the conference rate of **\$74/night**.

See our enclosed registration brochure for the conference!



LLN BANDAGES & GARMENTS FUND UPDATE

On April 18th, we received a check in the amount of **\$1,000.00** from Deb Cozzone's father. This money is for the BAG Fund, and honors Deb, our Fund Coordinator. Thanks for all the hard work that you've done, Deb!

The LLN Bandages and Garments fund has had an active 2011. From January 1st to August 15th, we assisted **26** patients. This is more than we assisted during all twelve months of 2010. As usual, summer has proven to be our busiest time. During the three month period from May 1st to July 31st, we provided garments for 15 patients—more than all twelve months of 2009! **We have assisted 18 arm patients and 8 leg patients so far this year, for a total of \$10,297.46.** There are currently 17 additional approved patients in the process of finishing treatment and receiving garments.

The Susan G. Komen for the Cure Greater Atlanta grant monies that were received in April have been put to good use. Two-thirds of our arm patients qualify for the grant based on medical history and geographical location. Our site visit and first quarter report to Komen showed that we are assisting more patients than anticipated for less money than estimated in the original grant application. This is great news, and we are making a real difference in the lives of more and more breast cancer survivors, thanks to Susan G Komen for the Cure Greater Atlanta.

The Bandages and Garments Fund continues to appreciate all of our garment vendors, our fitters, and our garment providers. You all have been fantastic in helping us stretch our dollars and reach as many patients as possible. We have not had to turn a single patient away due to lack of funding. Together we are all making a difference in the lives of numerous lymphedema patients.

Finally, a small policy change has been put in place for the fund. Each approved Bandages and Garments fund recipient will pay a small amount of the total cost of his/her garments. This provides the opportunity for the patient to invest in his/her care and allows us to assist a wider base of individuals. The Bandages and Garments fund application form has been modified to include this requirement. If you need a new application form (revised date: 08/11), please contact Deb Cozzone at debcozzone@hotmail.com. Please discard all previous revisions of the form.

Other Fund-raising Efforts:

On relatively short advance notice, our ace LLN fund-raising team also raised **\$340** at the DeKalb-Hillendale craft show for the BAG Fund, selling such items as handmade lotion and soaps, denim dresses, baked goods, necklaces, knitted dishcloths, handmade soaps, and other items. (Our thanks to therapist Shelley DiCecco for arranging our participation at this event, and to Joan White, Deb Cozzone, Beverly Thompson, Shelley, and anyone else who donated baked goods and other items!)

2011 Lighthouse Lymphedema Network Calendar Dates to Remember:

- September 17 - Randi Passoff Memorial Walk for Breast Cancer
- September 24-25 - It's the Journey 2-Day Walk for Breast Cancer, Atlanta
- October 1 - LLN Board of Directors Meeting
- **October 15 – 14th State of Georgia Lymphedema Education and Awareness Conference, Hilton Garden Inn, Lake Heron Drive, Atlanta, GA**

Also: for Healthcare Professionals only:

- 23rd International Congress of Lymphology, September 19-23, 2011, Malmo, Sweden
- Tenth NLN Conference, September 5-9, 2012, Omni Dallas Hotel, Dallas, TX. For more information go to www.lymphnet.org

LLN supports American Lymphedema Framework Project in South Africa

From their website: (<http://www.alfp.org/index.php?pid=news>): "The Lighthouse Lymphedema Network (LLN) based in Atlanta, GA, has contributed two large suitcases and two large boxes full of new and gently used bandages and compression garments for treatment of persons with lymphedema (for the lymphedema treatment training project in South Africa led by Dr. Jane Armer of the University of Missouri Medical School)." LLN is very happy to be able to share their bandages and garments for this worthy international project!

LLN supports efforts to pass the National Lymphedema Bill:

In addition to contacting our elected representatives, the LLN Board also approved supporting the cost of a second printing of 10,000 informational cards about lymphedema to be distributed by Heather Ferguson's volunteer staff in North Carolina. If this national bill is passed, it will be a huge step in recognizing lymphedema and other lymphatic diseases, not to mention the tremendous financial help to all of us who have lymphedema. (See: <http://lymphedematreatmentact.org/about-the-bill/> for more details.)

The Lymphedema Diagnosis and Treatment Cost Saving Act of 2011, HR 2499 has been reintroduced!

It is now very important that you send letters to your members of Congress through the www.LymphedemaTreatmentAct.org website.

Please use the submission forms and personalize the pre-written letter by adding a few sentences. Complete instructions are at the website and the entire process will only take you a couple of minutes.

I am also very excited to announce that the American Cancer Society, American Physical Therapy Association (APTA) and American Occupational Therapy Association (AOTA) have just endorsed the 2011 bill! Together we can get this bill passed if each of us does our part by getting the support of our own members of Congress.

Heather Ferguson, www.LymphedemaTreatmentAct.org, info@LymphedemaTreatmentAct.org

NATIONAL LYMPHEDEMA TREATMENT ACT UPDATE

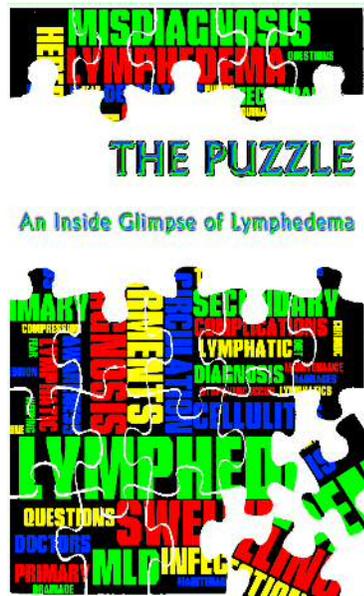
On May 25th a stakeholder's meeting took place at the DC office of Congressman Larry Kissell, our bill sponsor, to review a recently completed draft of our bill. Since the start of the new Congress in January, his office has been working with the professional bill writers of Legislative Counsel to revise last year's bill based on stakeholder input. The organizations represented were: the American Cancer Society, American Physical Therapy Association, American Occupational Therapy Association, Oncology Nursing Society, National Breast Cancer Coalition, Lymphatic Research Foundation, National Lymphedema Network, Lymphology Association of North America, American Lymphedema Framework Project, North American Lymphedema Education Association and patient advocates from the Lymphedema Advocacy Group.

The draft will now be sent back to the bill writers for a final round of revision. There was excellent consensus amongst the stakeholders and Congressman Kissell plans to reintroduce the bill no later than July 1st. Although this process has been more time consuming than expected, the result will be a much stronger bill!

"Lymphedema Awareness Day" in Tennessee

(NASHVILLE, TN), June 10, 2009 -- The Tennessee General Assembly voted unanimously to declare June 18 as "Lymphedema Awareness Day" in Tennessee. The Resolution, HJR259, was sponsored by Representative Dale Ford (R-Jonesborough), Vice-Chair of Healthcare Facilities and member of the Healthcare Task Force. Also, Matthew Hill (R-Johnson City) and House Health Committee Chairman Joe Armstrong (D-Knoxville) co-sponsored the bill and it is supported by General Welfare, Health and Human Services Chairman Rusty Crowe (R-Johnson City). This legislation was brought forth to bring awareness to this disease as well as to honor the memory of Thomas Hovatter of Johnson City who died on June 18, 2007 of the disease.

LLN PROUDLY ANNOUNCES THE PUBLICATION OF TWO NEW BOOKS!

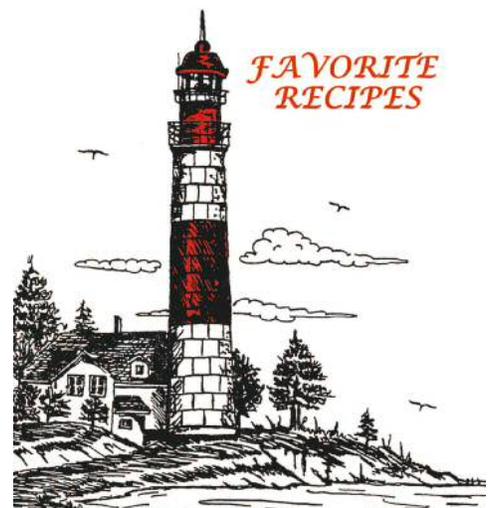


This book was compiled so that people who have been touched by lymphedema can share their stories, trials and tribulations, sadness and disappointments, strength and hopes. It is intended to encourage, educate, and inspire patients and loved ones, who can feel isolated and uninformed. We hope to increase 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.

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:

- *Friendship*
- *Hostess*
- *Shower*
- *Christmas*
- *Birthday*
- *Office Gifts*
- *Or, just for you!*

*The Lighthouse
Lymphedema Network*



Both of these books will be available for initial discounted sale at our 14th State of Georgia Lymphedema Education and Awareness conference October 15th, 2011, and afterwards 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 Payment:

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)

Please mail your completed order form and payment to: Lighthouse Lymphedema Network Books, 10240 Crescent Ridge Drive, Roswell, GA 30076

Joan White reports on the International Society for Lymphology (Toronto, Canada, June 2011):

What an absolutely fabulous and well organized conference! Delegates came from far and wide, representing many different countries and disciplines. In addition to the professional conference, ISL also hosted a one-day patient conference under the direction of the Lymphedema Association of Ontario. Other national framework partners besides the American Lymphedema Framework Project (ALFP) included the Canadian Lymphedema Framework, the Japanese Lymphedema Framework, and the International Lymphedema Framework chaired by Christine Moffatt, CBE. Other countries presenting included France, Australia, Denmark and Greece. It was an honor to be simply in the same room with these professionals. Our own LLN member DeCourcy Squire, PT, CLT-LANA, presented two workshops: "Self-Management of Lymphedema" and "Managing Head & Neck Lymphedema." Many vendors exhibited during the conference, and were extremely helpful in explaining their products. The 2012 ISL conference will be held in France in late June.

From the National Lymphedema Network's Lymph e-channel – "World Championship, Lymphedema Patient Extraordinaire"

On Saturday, July 29, top athletes from around the world converged upon a picturesque Southern California locale, all vying for the title of "Fittest Person on Earth." The annual 2011 World CrossFit Championships were held in Carson, CA and among these world-class athletes was our very own, **Deborah Cordner**. From previous e-Channel circulars, we have become familiar with Deborah's journey and her personal story. She is no stranger to overcoming obstacles, including taking control of her lymphedema. This year the Games were particularly challenging with the inclusion of an unexpected first event - swimming 210 meters in the open ocean. Faced with this curveball, Deborah, while unprepared for this challenge, still gave it her all. Even though Deborah didn't quite make it to the top, her achievements are still commendable. It is amazing to know that a lymphedema patient can compete with the best athletes in world. Deborah has shown us that we do not need to give up on our dreams and passions. True to character, Deborah is not giving up, and we hope to see her succeed at next year's CrossFit World Games.

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 save mailing costs! elaine.gunter@comcast.net.

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

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