# The Lighthouse

## Lymphedema Network Newsletter

### September 2022

Shining a Light on Lymphedema



www.lighthouselymphedema.org

24th Annual State of Georgia Lymphedema Education & Awareness Conference

## Focusing on Childhood/ Primary Lymphedema and Breast Cancer Survivors

Saturday, October 22, 2022, 8:30 AM - 4:00 PM

The Roam Perimeter, Suite 240, 1151 Hammond Drive, Atlanta, GA 30306



#### Imaging and Interventions for Lymphatic Flow Disorders in Children

**Erin Pinto, MSN, RN, CCRN, FNP-BC,** Nurse Practitioner in the Jill and Mark Fishman Center for Lymphatic Disorders at Children's Hospital of Philadelphia.

#### Treatment for Children with Lymphedema

**Betty Westbrook, PTA, CLT,** Founder/Director of Camp WatchMe, Medical Advisor for Brylan's Feat Foundation, Co-Founder of the Pediatric Lymphedema Alliance, Host of Lymphedema Podcast.

### Looking through the Skin with Near-infrared Fluorescence to Assess Lymphatic Health



**Melissa B. Aldrich, MBA, PhD,** Associate Professor, Center for Molecular Imaging, University of Texas at Houston. Dr. Aldrich is conducting research using Near Infrared Fluorescence to see the internal development of lymphedema in breast cancer survivors. Results have shown that "dermal backflow" can be detected using NIRF lymphatic imaging 8-23 months before arm swelling develops in BC related lymphedema. Dr. Aldrich is interested in "translating" lymphatic imaging technology to clinical use.



#### Importance of all aspects of CDT and a Mentally Healthy Me

Brigit Anderson, OTR, CLT, HonorHealth, Scottsdale, AZ.



#### Gadgets and Gizmos for Lymphedema Treatment

**Shelley DiCecco, PT, PhD, CLT-LANA, CI-CS,** Owner/Instructor LymphEd, LLC; Casley-Smith International Lymphedema Instructor & VP; Associate Professor at the Georgia campus for Philadelphia College of Osteopathic Medicine in PT Department; Pelvic Floor and Certified Lymphedema Therapist.

Location: Roam Perimeter Center, 1151 Hammond Dr. NE, Atlanta. To Attend: Please sign up using the <u>enclosed registration page</u> or on our <u>website</u>: <u>https://lighthouselymphedema.org/home/</u> CE credit is available for professionals.

### Helping the Lighthouse Lymphedema Network Help Others



### Georgia 2-Day Walk for Breast Cancer October 1-2, 2022

Since 2002, the Georgia 2-Day Walk for Breast Cancer has raised over \$17.5 million to fund 465 grants that provide breast cancer education, screening, early detection, support services, and continuing care for

PRODUCER OF THE GEBRGIA 2-DAY WALK FOR BREAST CANCER screening, early detection, support services, and continuing care for Georgians. The Lighthouse Lymphedema Network uses It's the Journey grant funding to purchase compression bandages and garments for patients not covered by insurance. These items are essential for treating the lymphedema that affects up to 50% of breast cancer survivors. The 2-Day Atlanta Walk includes a 20 mile section on Saturday and a 10 mile walk on Sunday. <u>Click here to sign up or make a contribution!</u>



### **Gloria Watts-Cox Foundation**

The (GWCF) held their 20<sup>th</sup> Annual (virtual) Walk/Run for Lymphedema on Saturday, June 4. Debbie Labarthe and her granddaughter, Kiersten Sollenberger represented the LLN with their dog, Maggie.

Participants could "Run, Walk, or Roll!" Skateboards, bikes, treadmills, and stationary bikes provided many fun options to exercise and support lymphedema patients and their caregivers, raise awareness, and promote lymphedema education and research.



To learn more and register for the Saturday, June 3, 2023 walk, go to www.gwcfoundation.org.

### The Lymphedema Treatment Act

On July 13, 2022, the Energy and Commerce (E&C) Committee voted unanimously to pass the Lymphedema Treatment Act (H.R.3630/S.1315) out of Committee and to the Union Calendar, where it is number 336. The bill has 356 House cosponsors and 73 Senate cosponsors, making it one of the most widely supported health care bills in the 117<sup>th</sup> Congress. This bipartisan bill will ensure that Medicare covers medically necessary compression supplies for lymphedema patients.

With elections approaching, representatives want to connect with voters. Go to <u>www.lymphedematreatmentact.org</u> for more information, including suggestions and tips about how you can help us advocate for the Lymphedema Treatment



Act. Every email and phone call helps. You may also find a Town Hall event at: www.townhallproject.com

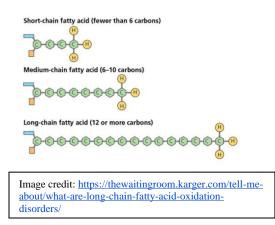
Heather Ferguson, Founder/Director of the Lymphedema Advocacy Group, states: "Speaking with Congress members who are already cosponsors is just as important as meeting with members who are not yet supporting the bill. We need cosponsoring members to help us ensure that the bill gets a vote in the full House and Senate by the end of the year, and to vote for it when that time comes. If the bill is not signed into law during this Congress, then we have to start all over in the next Congress."

## Gut Lymphatics and Long-Chain Fatty Acids

#### By Jean LaMantia

Your Lymphatic System is an essential component of your small intestines.

Your small intestine is a convoluted tube about 16 feet long. It contains millions of finger-like projections, called **villi**, which increase its surface area and absorptive capacity. Each villus contains one lymphatic capillary, called a **lacteal**. Lacteals collect fluid and lipids from the interior of the intestines allowing them to be absorbed by the body. The lacteals merge at the base of the villi in the smooth muscle layer into collecting lymphatics – see figure. Smooth muscles perform a cyclical contraction-relaxation "pumping" activity that helps move lymph fluid.



Dietary fats and oils from foods like avocado, salad dressing, nuts, butter etc. are broken down into **fatty acids**. Chemically speaking, fatty acids are chains of carbons. They can be short (6 carbons or less), medium length (up to 12 carbons), or long (more than 12 carbons). After your food leaves your stomach and enters the small intestines, the short and medium chain fatty acids are absorbed directly from the small intestines into the blood stream.

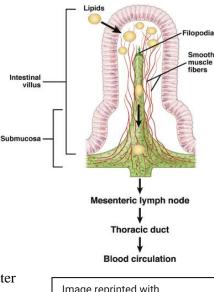


Image reprinted with permission. For more information, please see: Cifarelli V, Eichmann A. The Intestinal Lymphatic System: Functions and Metabolic Implications. Cell Mol Gastroenterol Hepatol. 2019; 7(3):503-513. https://doi.org/10.1016/j.jcm gh.2018.12.002

Long chain fatty acids are combined into lipid transporter spheres, called

**chylomicrons**. Chylomicrons are collected in a milky-white liquid called **chyle** (pronounced "Kyle"). Chyle is transported through the villi into the lacteals, which send it through the central lymphatic system to the thoracic duct of the blood stream, near the collarbone. Once the chylomicrons enter the blood stream, the fats are transported throughout the body.

You can avoid overwhelming your lymphatics with long-chain fatty acids by reducing your intake of certain oils and fats. Drinking more water and avoiding late-night snacks (if this is appropriate for your body) can give your lymphatic system time to process the chyle, so you wake up with better-controlled lymphedema. Understanding how your lymphatics work may help you to stick to your healthy eating goals.

If you like learning about the lymphatic system and its interaction with your diet, then you should join Lymphedema <u>Nutrition School</u>, taught by registered dietitian Jean LaMantia. The next session begins September 13<sup>th</sup>. The first lesson is already recorded and ready for you to start. Lessons 2-12 will be taught live every Tuesday from 1:00-2:30 pm ET. If you



can't attend all sessions, they are recorded. For more information and/or to sign up, please visit Lymphedema Nutrition School https://jeanlamantia.com/lymphedema-nutrition-school/

Jean LaMantia, RD is a registered dietitian, cancer survivor and author of three books including The Complete Lymphedema Management and Nutrition Guide. She's also the creator of **Lymphedema Nutrition School**. You can find out more about Jean, her books and programs and read her blog at <u>https://jeanlamantia.com/</u>

*The Atlanta Journal Constitution* featured LLN president, Joan White in a recent article: 80-Year-Old Advocates for Lymphedema Patients. As board member Shelley DiCecco told the reporter, Joan has "made true monumental contributions to the world of lymphedema, especially here in Georgia."



### **Camp Watchme**

Camp Watchme is a new summer camp for children 5-17 years of age living with lymphedema in the US and Canada. Held at the YMCA in Estes Park, Colorado, this year's camp provided an environment for children to experience camp life while still learning and addressing their lymphedema.

Each child was accompanied by at least 1 family member and was assigned to one certified lymphedema therapist (CLT). The CLT performed therapy with the child twice a day and stayed with the child through numerous activities and learning events. Activities included hiking, rock climbing, yoga, horseback riding, swimming, arts/crafts, a talent show, and everyone's favorite camp food - S'Mores!



Educational sessions from lymphedema experts and adults who were diagnosed with lymphedema as children were woven throughout the camp for both family members and the children.

Children's confidence levels blossomed as they made friends with other children with lymphedema. Many overcame fears to try new activities. Family members found relief from anxiety as they developed new support networks and educational understanding of lymphedema.

LLN board member Shelley DiCecco served as a CLT for the 2022 camp session and writes, "I have been a lymphedema therapist for more than 21 years and this was the most humbling and joyful experience I have ever been a part of in my career!"



For more information, please visit: Brylan's Feat Foundation (brylansfeat.org)





Mail in Registration F	orm			
The 24th Annual - State of Georgia				
Lighthouse Lymphedema Network			<b>REGISTRATION NOW OPEN</b>	
Education and Awareness Conference			Cost is \$90 for Professionals, with CE Credit \$50 for Patients, Caregivers	
Name: First	Last		Register Online: lighthouselymphedema.org	
Address:			By mail, make check payable to: Lighthouse Lymphedema Network	
City St	ateZip Code		Mail to: Lighthouse Lymphedema Network c/o Billie Barron 140 Swanee Ln., Woodstock, GA 30188	
Is this the address you would like the LLN to use for non-electronic communication? Yes/ No			<b>Program Location: ROAM,</b> 1151 Hammond Drive, Suite 240, Atlanta, GA 30346. Upper level, above Old Navy, near Perimeter Mall.	
Another address to receive USPS Mail if needed:			Presentations begin at 8:30.	
Address:			Hotel: Crown Plaza, Atlanta Perimeter at Ravinia, 4355 Ashford Dunwoody Road. The	
City	_StateZip Code		conference room rate is \$129.00 per night. Self- parking is \$12.00 per night. Rooms are limited.	
Best phone number to reach you:				
Please circle one:	Home Busines	s Cell		
E-mail address:				
Professional credentials:				
Professional address:				
City	_StateZip Co	le		

#### CEUs have been applied for.

In order to receive your CE credits, you must attend all day and submit the evaluation at the end of the program. Are you seeking CE credits? YES / NO (please circle one)

Are you a patient? YES / NO (please circle one) If a patient, where is your lymphedema located (arm, leg, trunk, other)? \_\_\_\_\_\_

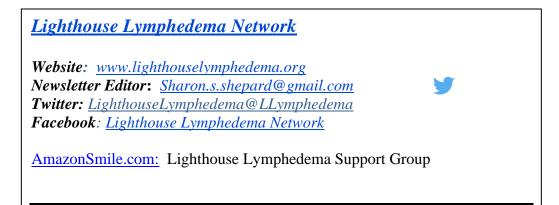
Mail to:

Lighthouse Lymphedema Network, c/o Billie Barron, 140 Swanee Lane, Woodstock, GA 30188. Include check for \$90 made out to LLN if you are a medical professional, \$50.00 for patient/caregiver.

To register by credit card please go directly to our website https://lighthouselymphedema.org.

Many thanks to our Sponsors who support the LLN's mission!





#### 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:

Phone: \_\_\_\_\_\_\_\_(Home) (Work)

E-mail: \_\_\_\_



Enclosed is my tax-deductible donation of \$\_\_\_\_\_ to be used for the General Fund \_\_\_\_\_

(Cell)

B.A.G. Fund \_\_\_\_\_\_ or Gwen Forbes Kirby Foundation 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*. For information, e-mail joanwhite59@gmail.com. You can also make a donation on-line by credit card at: <a href="http://lighthouselymphedema.org/get-involved/donate.htm">http://lighthouselymphedema.org/get-involved/donate.htm</a>. Change of Adduces and Meiled Neuveletter Reserves.

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