

The Lighthouse

Lymphedema Network Newsletter



February 2022

Shining a Light on Lymphedema

www.lighthouselymphedema.org

LLN Offers Virtual Training for Lymphedema Therapists and Patients

The Fluid is Ours to Direct – Lymph Drainage and MLD Pathways

With Shelley Smith DiCecco, PhD, PT, CLT-LANA, CI-CS



Saturday, April 2, from 10-12, this webinar will explain the physiology or nature of normal lymphatic drainage and standard pathways of the lymphatics in healthy systems. Dr. Shelley will also show alternative pathways for lymphatic dysfunctions, and additional lymph node groups one may stimulate to assist in lymphedema drainage. Simple tricks therapists, patients, and family members can use to find viable pathways will be discussed and demonstrated.

CCH Educational credits for therapists - only \$25. Patients are free.

Please register for Zoom webinar: www.lighthouselymphedema.org

Lymphedema Treatment Act Gains Co-Sponsors and Momentum



Medical-grade compression garments are essential for lymphedema treatment. Many patients wear compression 23 hours a day, and the expensive garments break down quickly. The Lymphedema Treatment Act seeks Medicare coverage of compression supplies. A recent study showed that this legislation would *save* the Medicare system \$1.3-1.5 billion in the first ten years, due to health improvements for lymphedema patients.

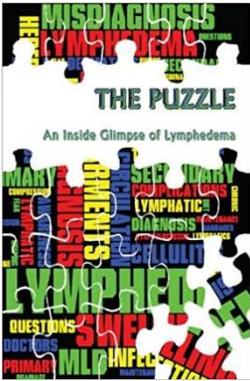
Now, we need Congress to vote on the Lymphedema Treatment Act. A supermajority in both houses (71 of 100 senators and 331 out of 435 house representatives) have already signed-up to co-sponsor the active bills, S.1315 and HR.3630, which should provide a bi-partisan Win-Win-Win for Medicare, fiscal conservatives, and lymphedema patients. If you have a few minutes, our advocates at www.lymphedematreatmentact.org ask everyone to [email your representatives](#). Ask them to make the LTA a priority and bring these bills up for a vote this year. Millions of Americans have lymphedema and need your support.



LLN Board Members have been active lobbyists for the Lymphedema Treatment Act. Debbie Labarthe and her grandson Carson traveled to Washington, DC three times for Lymphedema Lobby Days. They shared Carson's story of growing up with congenital lymphedema. In 2016, Carson visited his GA-11 Representative, Barry Loudermilk, a fellow baseball player and early Co-sponsor of the Lymphedema Treatment Act.



Books By Lymphedema Survivors



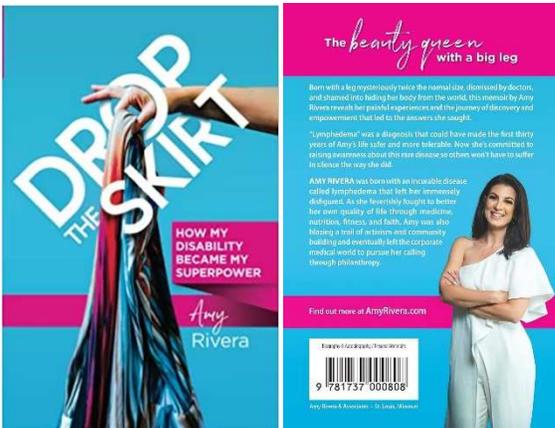
The Puzzle, An Inside Glimpse of Lymphedema was put together by the Lighthouse Lymphedema Network in 2011 and is used in therapy courses to illustrate the experiences of lymphedema patients.

Patients and caregivers share stories of mysterious swelling, frustrating journeys to diagnosis and treatment, endurance, resilience, and hope for future improvements. Education is key to understanding this condition so it can be quickly diagnosed, treated, and eventually solved.

Contrast the stories of Pat O'Connor and Carson Sollenberger, born 50 years apart with Congenital Lymphedema. Carson's family spent more than a year seeking his diagnosis, found a vascular team in 2004, and soon discovered the Lighthouse Lymphedema Network. Carson's lymphedema has been treated successfully, and he is able to enjoy sports without the interruptions Pat experienced in the 1960's.



Trailblazers like Pat O'Connor and Joan White used their experiences to create support networks for patients. These networks have helped thousands of patients find care for lymphedema, and they inspire medical research and development.

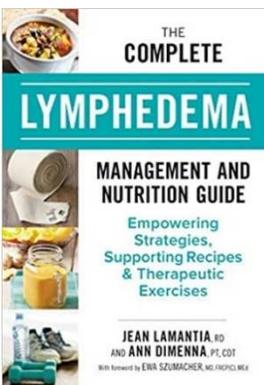


Drop The Skirt: How my Disability Became my Superpower

Amy Rivera was born with lymphedema in her right leg but did not receive diagnosis or treatment for more than 30 years. As a teenager, she won the Miss Junior American Coed Pageant, but became known as “the beauty queen with the big leg.”

While hiding her lymphedema under skirts, Amy became a nurse, wife, and mom. Eventually her lymphedema was diagnosed, and in 2018, she received surgery from Dr. Jay Granzow. She now works as a patient advocate and founded [Ninjas Fighting Lymphedema](#).

Her book [Drop The Skirt: How my Disability Became my Superpower](#) features highlights of her lifelong journey with lymphedema. As Dr. Granzow recently posted on FB: "It's been a long road for Amy, but she continues to raise awareness and pay it forward." Debbie Labarthe says [Drop the Skirt](#) “really captures the strength and perseverance that Amy endured so she could learn to love herself, use her voice to become a self-advocate, enhance her quality of life, and along the way, she discovered her true purpose and passion to help others.”



The Complete Lymphedema Management and Nutrition Guide

Registered dietitian, [Jean LaMantia](#), is inspired to help others by her experiences surviving lymph node cancer. She hosts [Lymphedema Nutrition School](#), a 10-week on-line group program to educate and improve the nutrition for those with lymphedema.

She teamed with lymphedema therapist, Ann DiMenna, to publish [The Complete Lymphedema Management and Nutrition Guide](#). Their book contains more than 50 recipes to support an ideal diet for lymphedema management - they are anti-inflammatory, low sodium, low fat, and emphasize adequate fluid and protein.



Inflammation, the Anti-Inflammatory Diet and Lymphedema

Acute (short term) inflammation is the body's normal response when cellular 'first responders' like white blood cells gather to heal an injury or infection. In **chronic (long term) inflammation**, these cells are unable to leave the area after a crisis period and create an inflammatory environment.

Researchers from Memorial Sloan Kettering Cancer Center and Yale University have described how inflammation becomes a risk factor for developing lymphedema after cancer, and how lymphatic damage can lead to a cycle of chronic inflammation and/or metabolic syndrome.

- ⇒ Lymphatics aren't working properly
- ⇒ Lymphedema develops
- ⇒ Lymphatics fail to absorb or transport fat
- ⇒ Fat deposits are created
- ⇒ Chronic inflammation develops
- ⇒ Lymphatic vessels are formed in an environment of inflammation and don't work properly
- ⇒ Cycle continues

One key to break out of this cycle is to reduce the inflammation with an anti-inflammatory diet.

What is an Anti-Inflammatory diet?

Our food is made up of nutrients. Some of these nutrients contribute to inflammation in the body while others reduce the inflammation. A variety of studies have shown that by changing what we eat we can change the level of chronic inflammation in our bodies – as measured by various blood tests including hs-CRP, CRP and IL-6.

What nutrients and foods are considered Anti-Inflammatory?

Anti-inflammatory nutrients include omega-3 fatty acid, antioxidants, vitamins B6, B12 and folic acid, vitamin K, selenium, zinc and various phytochemicals.

Since we eat foods and not nutrients, here are some foods that are considered **anti-inflammatory**:

- **Omega-3 rich fish** including salmon, sardines, herring, mackerel, and rainbow trout
- **Vegetables** - especially carrots, sweet potato, kale, broccoli, and leafy greens
- **Fruits** - especially citrus, peppers, berries, melon, and pineapple
- **Nuts** - especially Brazil nuts and almonds
- **Oils high in omega-3** - especially olive, canola and high oleic sunflower
- **Herbs and spices** - especially turmeric, garlic, ginger, onion, and chili peppers

Nutrients that **promote** inflammation include saturated and trans fats, omega-6 fatty acids, refined sugars, and high glycemic foods.

These foods could contribute to **inflammation**:

- Meat - especially organ meats, eggs and high fat dairy
- Processed foods - especially sugary fatty junk food
- Oils high in omega-6 or saturated fats – especially coconut, palm, corn, and grapeseed

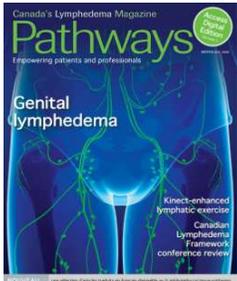
To achieve an anti-inflammatory diet, emphasize filling half your plate with vegetables and fruits, choosing whole grains, less processed food and including fish and plant-based proteins...and don't forget to season your foods with herbs and spices!

Bottom line from Jean:

I believe that if you begin to make changes to your usual eating pattern, you may experience a reduction in chronic inflammation throughout your entire body. And, while untested as yet, this reduction in chronic inflammation may have a beneficial effect on your lymphedema and/or may help to offset other health risks posed by the inflammatory lymphedema environment.

[Jean LaMantia](#) is a registered dietitian, cancer survivor, co-author of the book *The Complete Lymphedema Management and Nutrition Guide*, and creator of the program *Lymphedema Nutrition School* an on-line group program for people with lymphedema that want to improve their nutrition. To find out more about Jean or read her blog, go to www.jeanlamantia.com. Jean is teaming up with the Lighthouse Lymphedema Network to share recipes and articles on nutrition to help reduce the effects of lymphedema. Look for more of her contributions to our newsletter and website.

LLN Board Member News



Shelley Smith DiCecco's article, "Let's talk genital lymphedema - Improving ways to diagnose and treat the taboo area," was featured in the Winter edition of [Pathways](#), Canada's Lymphedema Magazine.

Dr. Smith DiCecco is an Assistant Professor at the Georgia's Campus for the Philadelphia College of Osteopathic Medicine in the Physical Therapy Department. She has been a board member for the LLN since 2002 and founded [LymphEd](#) in 2017. In 2021, Shelley presented at the International Lymphoedema Framework Conference in Copenhagen, Denmark.

On April 2 from 10-12, Shelley is offering a webinar through the Lighthouse Lymphedema Network, titled, *The Fluid is Ours to Direct: Lymph Drainage and MLD Pathways*. Register: www.lighthouselymphedema.org

Molly Sleigh served as faculty chairperson for the American Vein and Lymphatic Society Congress held in Denver, CO on October 7-10, 2021. She helped plan and organize the lymphedema section of this conference, presented, and engaged in a professional debate with Drs. Karen Herbst and Tom Wright on the topic of Compression Use with Lipedema.



Dr. Sleigh served as a co-author for "[The Standard of Care for Lipedema in the United States](#)" which was published in *Phlebology* in December 2021.

Rebecca Hammad, MHS, OTR/L, CLT, received an [Innovation Award](#) from the National Board for Certification in Occupational Therapy. Rebecca is a Therapy Manager for the Spinal Cord Injury Program at Shepherd Center in Atlanta, where she started a lymphedema program to offer complete decongestive therapy (CDT) interventions to individuals experiencing acute and chronic edema after injury or illness. She modified traditional CDT to manage swelling after paralysis, reducing the risk of applying compression to a limb with absent sensation. Rebecca and her team have treated more than 700 patients since 2015.

Spring 2022

- Feb. 12 [It's The Journey](#) Giving Gala at the Georgia Aquarium. LLN receives a grant for \$19,463.00
- Mar. 6 **WORLD LYMPHEDEMA DAY**
- Mar. 15-17 [Power Lymphatics Symposium](#) – for therapists and health professionals - virtual and in Las Vegas
- Apr. 2 **LLN Webinar** - Lymph Drainage and MLD Pathways with Dr. Shelley Smith DiCecco
- Apr. 21 [Southern Loss Association](#) Golf Outing - Fundraiser for the Lighthouse Lymphedema Network
- Apr. 22-24 [Fat Disorders Resource Society](#) Conference – virtual and at Intercontinental Hotel, Cleveland Clinic
- Apr. 30 Lighthouse Lymphedema Network Board Meeting

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It's The Journey

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People.Health.Care.

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Please accept my gift/donation in appreciation for your efforts to support, educate, and create awareness about a serious medical condition called lymphedema.

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You can also make a donation on-line by credit card at: <http://lighthouselymphedema.org/get-involved/donate.htm>.

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elaine.gunter@comcast.net.

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