

The Lighthouse

Lymphedema Network Newsletter



September 2021

Shining a Light on Lymphedema

www.lighthouselymphedema.org

Join Us for our Virtually Awesome 23rd Annual State of Georgia Lymphedema Education and Awareness Program

Free for Lymphedema Patients and their Families & Caregivers

\$50 for Medical Professionals, with Continuing Education credits

ZOOM Presentation

Saturday, October 23, 2021

10 AM – 4 PM

Because of the continuing COVID-19 pandemic, this program will be presented via ZOOM. Be sure you have the ZOOM app (it's free, www.zoom.com) on your computer, cell phone, or pad device prior to the conference time.

When registering for this LLN presentation, be sure to give us your valid email address. We will email you the log-in link for the meeting prior to the conference. Easy!

See all our speakers from the comfort of your own home, plus our vendors will have videos demonstrating their excellent products. You can also participate in a Q&A session at the end of the day.

There will be 5 hours of Continuing Education credits offered for participating professionals. (CEUs have been applied for.)

2021 STATE OF GEORGIA VIRTUAL LYMPHEDEMA MEDICAL CONFERENCE

Saturday, October 23, 2021 – 10 AM - 4 PM

FEATURED TOPICS and SPEAKERS

There is No Edema in Lipedema - **STEVEN DEAN, DO**, Director of the Vascular Medicine Program and Noninvasive Peripheral Vascular Laboratory at **The Ohio State University Wexner Medical Center** where he also serves as a professor of clinical medicine. Dr. Dean has been named one of “America’s Best Doctors” several times.

Lipedema Patient Story and Therapist Treatment - **SAMANTHA CANNON MARTIN, MSOT, CLT**, Northside Hospital Forsyth, Cumming, GA Patient: **FRANCINE SCHWARTZ**

Wound Care - **JANET WOLFSON, PT, CLWT, CWS, CLT-LANA**, Instructor in wound care with the **International Lymphedema and Wound Training Institute**. Wound Care Coordinator at Encompass Health of Ocala, FL.

How to Find a Qualified Lymphedema Therapist - **JUDITH NUDELMAN, M.D.**, Providence Community Health Centers, Rhode Island; Clinical Associate Professor, Department of Family Medicine, Alpert Medical School, Brown University; Founder and Co-Director **Step-up Speak-out** advocacy and education for patients with secondary lymphedema; Medical Advisor Dr. Vodder School, International; Medical Advisor National School of Lymphatic Therapy.

The ALERT Program – Diagnosis and Treatment of Lymphedema in Australia - **LOUISE KOELMEYER, BAppSc (OT), PhD, MS**, Director of Australia Lymphoedema Education, Research and Treatment (ALERT); Program and Senior Lecturer at Macquarie University, Sydney, Australia.

Case Study - **KIM KENNEDY, MOT, OTR/L, CLT-LANA**, Penrose St. Francis, Colorado Springs, CO. Ms. Kennedy’s focus is on evaluation and treatment with a focus on hand therapy, UE orthopedics, neuro, vision, lymphedema, and oncology.

Chair Yoga - **GRACE STEPHEN, E-RYT500, IAYT**, professional Yoga therapist, Olgong & Tai Chi instructor, Doctor of Chiropractic, ClubCorp Fitness Team, Acworth, GA, Launch Awareness Yoga Centre, Kennesaw, GA, private practice, Kennesaw, GA

Legislative Update on the Lymphedema Treatment Act - **REBECCA SHARP, LSAP, LAG**, Chair of the Lymphedema Awareness Network of East Tennessee Support Group; Board member of the Lymphedema Advocacy Group for the Lymphedema Treatment Act; Knoxville, TN

CONFERENCE REGISTRATION IS NOW OPEN

Two easy ways to sign up:

- (1) **Register by secure credit card online**, by clicking this event on the calendar on our webpage at www.lighthouseymphedema.org;
- (2) **Use the registration form below and mail it to:** Lighthouse Lymphedema Network, c/o Billie Barron, 140 Swanee Lane, Woodstock, GA 30188.

Include a check for \$50 made out to LLN if you are a medical professional, to cover CEU processing.

Fundraising Is Fun

Southern Loss Association Golf Outing Fundraiser for the LLN

The Southern Loss Association was founded in 1957. It is one of the largest insurance organizations in the country devoted to the education of property claims adjusters.

The Southern Loss Association has designated the Lighthouse Lymphedema Network as one of four charities they support annually. At their recent golf tournament, Joan White, Director of the LLN, was presented with a check from SLA president Carson Lester in the amount of \$4,730.00.

"We are deeply honored to be designated as one of the charities SLA annually supports. The money will be used to help our less fortunate patients with the purchase of garments and other devices. The donation will also support our annual fall medical conference," said Joan. Thanks to all the Aces at the Southern Loss Association!



Susan Freeman, Outing Chair, and Carson Lester, SLA President, with Joan White, LLN Director

Above L-R: Beverly Thompson, Charlotte Murphy, Peggy Meyer, Billie Barron, Joan White, Carson Lester - SLA President, Doug White, and Ellen Frank with the donation for the Lighthouse Lymphedema Network



PRODUCER OF THE GEORGIA 2 DAY WALK FOR BREAST CANCER

The Lighthouse Lymphedema Network will sponsor a cheering station for the Georgia 2-Day Walk for Breast Cancer, October 2-3. We appreciate *It's The Journey* donating a portion of their proceeds to serve breast cancer survivors with lymphedema.

Come cheer with us!

Sign-up at: sharon.s.shepard@gmail.com.

Gloria Watts-Cox Foundation's 19th Annual 5K Lymphedema Walk/Run



This year, the event was a Virtual Walk, and participants had the option of walking, running, cycling, or even riding a scooter or Hoverboard.

Debbie Labarthe and her granddaughters, Kiersten Sollenberger and Brooklynn Carney, rode bikes and a scooter to raise lymphedema awareness and generate funds to help support the Gloria Watts-Cox Foundation (GWCF).

The GWCF was founded by Lee Cox in November 2002 in loving memory of his wife, Gloria, who lost her battle with lymphedema earlier that year at the age of 50.

For more information about this non-profit organization and their annual 5K Lymphedema Walk, please visit their website at www.gwcfoundation.org



Hosting a Fundraiser on Facebook?

Say it's your birthday or World Lymphedema Day - and instead of presents, you'd love to have friends make donations to your favorite charity. Facebook has made this option easy by partnering with Network for Good to process the donations. Network for Good sends a receipt to the donor for tax purposes, but cannot reveal their information to any third parties, like the named charity or you. How can you thank your donors?

During the 14-day period that the Fundraising Campaign is active, the Facebook user (the person hosting the fundraising campaign) IS able to view/activate a 'Donors' button which will display the specific donors and their respective donation amounts. Then, the Facebook user should be able to contact each donor directly (via Facebook's private message app or another means) to say thank you and obtain his/her mailing address if you want a written thank you from the organization.



LLN BANDAGES & GARMENTS FUND 2021 UPDATE

As we approach the fall season, we hope all our readers are safe. We had an online meeting with **It's The Journey** in August. Our Grant writer, Shelley Di Cecco, and I attended to learn about the new rules for next year's grant. We encourage our readers to participate in any event with ITJ, such as our cheering station Oct 2, to show our appreciation for the gifts they bestow upon us each year. We are now accepting applications for compression garment requests using our 2021-22 Grant.

Rebecca Hammad continues to process all garment applications for non-breast cancer patients, and the new **Gwen Forbes-Kirby Foundation Grant** has already served five patients.

Please send any questions or applications for assistance to Janie Smith at darnofell@aol.com.

Lymphedema News



Good News for the Lymphedema Treatment Act

Donations to LymphedemaTreatmentAct.org were used to hire Avalere, a healthcare analytics firm that is well-known and respected on Capitol Hill. They estimated the potential savings if the Lymphedema Treatment Act is passed by Congress.

It's a logical conclusion that the cost of covering compression garments should be lower than the costs of lymphedema complications and hospitalizations, but the data had not been fully analyzed before.

Avalere found that enactment of the Lymphedema Treatment Act will save the Medicare program \$1.3 to \$1.5 billion during the first 10 years, with additional savings likely. Medicaid programs and private insurers will also benefit if this act becomes law.

Not only would the Lymphedema Treatment Act benefit millions of patients, but proactive treatment of lymphedema would save billions of dollars for insurers – a win-win solution for all! Tell your legislators and thank you for your financial and moral support of this legislative effort!



[\[info@LymphedemaTreatmentAct.org\]](mailto:info@LymphedemaTreatmentAct.org)

Lymphatics and the Covid-19 Vaccine

The Lighthouse Lymphedema Network and other organizations recommend that patients receive vaccinations in limbs not at risk for lymphedema. The “Shots in Arms” emphasis with the Covid-19 vaccine created concern for patients with lymphedema risk in both arms. Fortunately, the CDC lists the thigh as an option for such patients to receive vaccinations. For a deeper explanation, we recommend the following article:

<https://www.nytimes.com/2021/04/29/well/live/covid-vaccine-thigh-lymphedema-breast-cancer.html>

*Calling your attention to –
An Excellent Article from the LE&RN Network:*



Lymphatic Education
& Research Network

Advances in Lymphedema

[Stanley G. Rockson](#)

Originally published 10 Jun 2021 <https://doi.org/10.1161/CIRCRESAHA.121.318307>

Circulation Research. 2021;128:2003–2016

Abstract

Lymphedema is a common, complex, and inexplicably underappreciated human disease. Despite a history of relative neglect by health care providers and by governmental health care agencies, the last decade has seen an explosive growth of insights into, and approaches to, the problem of human lymphedema. The current review highlights the significant advances that have occurred in the investigative and clinical approaches to lymphedema, particularly over the last decade. This review summarizes the progress that has been attained in the realms of genetics, lymphatic imaging, and lymphatic surgery. Newer molecular insights are explored, along with their relationship to future molecular therapeutics. Growing insights into the relationships among lymphedema, obesity, and other comorbidities are important to consider in current and future responses to patients with lymphedema.

News from Georgia: Rare Disease Law Includes Primary Lymphedema Screening

The Governor of Georgia has signed into law legislation that will help save the lives of more than 700 babies born in Georgia each year. The law, HB 567, requires the state to screen newborn babies for any disorder on the federal recommended uniform screening panel (RUSP), gives a timeline for the screening to begin, and ensures that resources will be available to fund all conditions added to the RUSP in the future. Each year, new screening tests are developed to diagnose diseases early, so they can be treated proactively. RUSP alignment legislation will require Georgia to keep up with science. Hereditary lymphedema screening will be included under this law. For more information, see the website: [EveryLife Foundation for Rare Diseases](#)



Board member Molly Nettles-Sleigh is on the planning committee for this Denver event!

IN MEMORIAM



Gwendolyn Forbes-Kirby 1953-2021

After serving in the Peace Corps, Gwen worked as a physical therapist for 35 years and specialized in lymphedema treatment for decades. Her contributions and friendships on the Board of the Lighthouse Lymphedema Network are fondly remembered. She fought bravely and hopefully against cancer for more than a year, before passing away in April.

The Gwen Forbes-Kirby Foundation Fund was established before Gwen's death to help patients pay for garments for treatment of lymphedema.

In the first four months, we have already assisted five patients.

Donations may be made to the fund through the LLN website or by mailing a check to the LLN, [10240 Crescent Ridge Drive, Roswell, GA 30076](mailto:10240CrescentRidgeDriveRoswellGA30076).

April 'Nadine' King



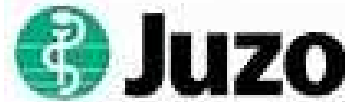
The Lighthouse Lymphedema Network was saddened to lose our new friend to the Covid-19 virus. Nadine was essential to the technical set-up and delivery of our Zoom platform and virtual conference in 2020, and her organization, Black Administration Magic, set up our new website.

Nadine was the IT wizard for the Dean's office at Spellman College where our board member, Dolores Bradley-Brennan, is Vice Provost for Faculty. Nadine also founded the National Association of Black Administrative Professionals and was a terrific example to many people.

The **International Lymphoedema Framework Conference** will be held in Copenhagen, Denmark, November 18-20, 2021. <https://www.lympho.org/>

LLN board member **Shelley DiCecco, PhD, PT, CLT-LANA, CI-CS**, will give three oral presentations as well as a research poster.

Many thanks to our vendors and their products, who support the LLN's mission!



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Follow us on  *Twitter:* @LLymphedema

LLN: Serving the lymphedema community for 27 years www.lighthouseymphedema.org

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 770-330-0036 for information, or e-mail joanwhite59@gmail.com. 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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