

#### LLN October 2020 Newsletter

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LLN: Serving the lymphedema community for 27 years

### WE'RE GOING VIRTUAL-LY!

22<sup>nd</sup> State of Georgia Lymphedema Education and Awareness Program

For lymphedema patients, their families & caregivers
And medical professionals
Will be conducted on-line as a ZOOM presentation

Saturday, October 24, 2020 10:00 AM – 3:30 PM \$50 Registration Fee

Because of the continuing COVID-19 pandemic, this program will be presented via ZOOM.

You will need to download the ZOOM app (it's **free**, <u>www.zoom.com</u>) on your computer, cell phone, or pad device <u>prior to the conference time</u>. Then, when registering for this LLN presentation, give us your valid email address; just prior to the conference, we will email you the log-in link for the meeting. <u>Easy!</u> You'll see all of our speakers, plus our vendors will have videos of their excellent products. There will be 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.) 2020 is the Year of the Nurse – we're inviting as many nurses as possible to participate.

#### **CONFERENCE REGISTRATION IS NOW OPEN** – there are two easy ways to sign up:

- (1) **Register by secure credit card online**, by clicking this event on the calendar on our webpage at <a href="https://www.lighthouselymphedema.org">www.lighthouselymphedema.org</a>;
- (2) Use the registration form on the next page and mail it with your check for \$50 (made out to LLN) to Lighthouse Lymphedema Network, c/o Billie Barron, 140 Swannee Lane, Woodstock, GA 30188.

Name			<u> </u>	
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**Witaka** - Our sincere thanks to Mitaka USA for their sponsorship of Dr. Chen for our conference!

An important message from the Lymphedema Association of North America (LANA) to our CLT members who participate in our virtual meeting:

"We are so pleased to continue to network with your organization on promoting lymphedema knowledge and care. We, at LANA, would be pleased to offer a \$200 off registration code for the LANA exam for all your CLT attendees. This will be valid until 12/31/2020 with the promo code LLN20.

Louisa Boyd, OTR/CLT-LANA

#### 2020 VIRTUAL STATE OF GEORGIA LYMPHEDEMA MEDICAL CONFERENCE

Saturday, October 24, 2020

#### TIME SCHEDULE

10:00 – 10:05 AM	Welcome: co-hosts Dolores Bradley Brennan, PhD, and Elaine Gunter, MS, (ASCP)
10:05 – 10:50 AM	Dr. Wei F. Chen - "The degree of functioning or non-functioning of a patient's
	lymphatic system after injection of the ICG (indocyanine green fluorescence
	visualization) dye"
10:50 – 11:00 AM	Q&A
11:00 – 11:15 AM	Rebecca Hammad, MHS, OTR/L, CLT – "Patient Story"
11:15 – 12:00 PM	Erika Hopkins, PA-C "What a patient should know prior to a surgical procedure"
12:00 – 12:05 PM	Q&A
12:05 – 12:35 PM	Lunch Break
12:35 – 1:20 PM	Dr. Wei F. Chen "What are the latest techniques in Lymphedema Reconstruction?"
12:35 – 1:20 PM 1:20 - 1:30 PM	Dr. Wei F. Chen "What are the latest techniques in Lymphedema Reconstruction?" $Q\&A$
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1:20 - 1:30 PM	Q&A
1:20 - 1:30 PM 1:30 - 1:40 PM	Q&A Arlene Wood: "Patient Story"
1:20 - 1:30 PM 1:30 - 1:40 PM 1:40 - 2:25 PM	Q&A Arlene Wood: "Patient Story" Erika Hopkins, PA-C: "Nurses making a difference for patients with lymphedema"
1:20 - 1:30 PM 1:30 - 1:40 PM 1:40 - 2:25 PM 2:25 - 2:30 PM	Q&A Arlene Wood: "Patient Story" Erika Hopkins, PA-C: "Nurses making a difference for patients with lymphedema" Q&A
1:20 - 1:30 PM 1:30 - 1:40 PM 1:40 - 2:25 PM 2:25 - 2:30 PM 2:30 - 2:45 PM	Q&A Arlene Wood: "Patient Story" Erika Hopkins, PA-C: "Nurses making a difference for patients with lymphedema" Q&A Break

#### **OUR FEATURED SPEAKERS**

**Dr. Wei F. Chen** is and attending plastic and reconstructive surgeon and clinical professor of plastic surgery at Cleveland Clinic, Cleveland, OH. He is internationally recognized as one of the foremost experts in lymphatic micro-and supermicro-surgery. He pioneered several novel, specialty-defining procedures such as the "octopus" (LVA) vascularized lymph vessel transplant, the "flying squirrel" liposuction, and the hybrid lymphatic reconstruction. He has published 53 peer-review articles, completed 28 visiting professorships and has given 121 invited lectures and keynote presentations around the world. Dr. Chen was recognized by the Marquis Who's Who in 2015 as one of the most influential American reconstructive plastic surgeons. He went on to receive the Marquis Lifetime Achievement Award in 2020.

**Erika Hopkins, PA-C**, Graduated from The Ohio State University with a BA in psychology. In 2019 Erika graduated from the University of Pittsburgh, Master of Science in Physician Assistant Studies. Ms. Hopkins works at the Cleveland Clinic, Cleveland, OH. She is responsible for H/P, pre and post-operative care, ICG lymphography imaging and interpretations. Super-microsurgery/surgical techniques, wound care, patient education.

**Grace Stephen, E-RYT500, IAYT,** professional Yoga therapist, Oigong & Tai Chi instructor, Doctor of Chiropractic, ClubCorp Fitness Team, Acworth, GA; Launch Awareness Yoga Centre, Kennesaw, GA; private Practice, Kennesaw, GA

#### **Patient Speakers:**

**Rebecca Hammad, MHS, OTR/L, CLT**, works as a Therapy Manager in the Post-Acute program at the Shepherd Center in Atlanta. In working with her patients, she wanted to be able to provide better therapeutic interventions for managing swelling post neurological injury, so she set out to become a certified lymphedema therapist and start an edema management program at the Shepherd Center. She is a patient of Dr. Chen.

**Arlene Wood** is a pianist and teacher, and a patient of Dr. Chen.

#### An excellent article summary by lymphedema specialist Dr. Stanley Rockson & colleagues:

In: insight.jci.org <a href="https://doi.org/10.1172/jci.insight.123775">https://doi.org/10.1172/jci.insight.123775</a>

## Pilot studies demonstrate the potential benefits of anti-inflammatory therapy in human lymphedema

Stanley G. Rockson, Wen Tian, Xinguo Jiang, Tatiana Kuznetsova, Francois Haddad, Jamie Zampell, Babak Mehrara, Joshua P. Sampson, Leslie Roche, Jinah Kim, and Mark R. Nicolls

BACKGROUND: Lymphedema is a common condition affecting millions around the world that still lacks approved medical therapy. Because ketoprofen, an NSAID, has been therapeutic in experimental lymphedema, we evaluated its efficacy in humans.

METHODS: We first performed an exploratory open-label trial. Patients with either primary or secondary lymphedema received ketoprofen 75 mg by mouth 3 times daily for 4 months. Subjects were evaluated for changes in histopathology, with skin thickness, limb volume, and tissue bioimpedance changes serving as secondary endpoints. Based on our encouraging findings, we next conducted a placebo-controlled trial, with the primary outcome defined as a change in skin thickness, as measured by skin calipers. Secondary endpoints for this second study included histopathology, limb volume, bioimpedance, and systemic inflammatory mediators.

RESULTS: We enrolled 21 lymphedema patients in the open-label trial, from November 2010 to July 2011. Histopathology and skin thickness were significantly improved at 4 months compared with baseline. In the follow-up, double-blind, placebo-controlled trial, we enrolled 34 patients from August 2011 to October 2015, with 16 ketoprofen recipients and 18 placebo-treated subjects. No serious adverse events occurred. The ketoprofen recipients demonstrated reduced skin thickness, as well as improved composite measures of histopathology and decreased plasma granulocyte CSF (G-CSF) expression.

CONCLUSION: These 2 exploratory studies together support the utility of targeted anti-inflammatory therapy with ketoprofen in patients with lymphedema. Our results highlight the promise of such approaches to help restore a failing lymphatic circulation.

TRIAL REGISTRATION: ClinicalTrials.gov NCT02257970

## LLN BANDAGES & GARMENTS FUND 2020 UPDATE

We hope all of our readers are safe as we go into the fall season. We had a virtual meeting with It's The Journey in August, and Deb Cozzone represented the LLN to qualify us for the application for the 2020-2021 grant. ITJ has informed us the grant will not exceed \$20,000 next year. Many grantees have been adversely affected by COVID 19, so the LLN has only spent less than half of our first received check from ITJ. Per their protocol, we will not receive the second half of our grant at this time, but we will continue to accept applications and will be re-evaluated if we need the money. I encourage all therapists to submit their patients' applications so we can use the grant funding that was given to LLN. The ITJ has been supportive of our efforts, and we want to continue to show the organization we need and appreciate the gift they give. Thanks for the support we receive from the companies that donate compression garments to the patients.

Rebecca Hammad works closely with the different companies and provides much needed garments for many patients. We look forward to continued applications and Shelley DiCecco will be preparing our 2020-2021 grant application for consideration. Please contact Janie Smith with any questions or concerns at darnofell@aol.com.

An important announcement from the Lymphedema Education & Research Network:



# LE&RN Scientific & Medical Advisory Council (SMAC) Members deliver research breakthrough

On September 9, <u>Science Translational Medicine</u> reported the discovery of a novel gene responsible for primary lymphedema. This discovery is heralded as essential for the proper diagnosis of patients with primary lymphedema and opens possibilities for the development of improved treatments for lymphedema.

LE&RN SMAC member Dr. Miikka Vikkula (The Human Molecular Genetics laboratory of the de Duve Institute–UCLouvain) made the discovery. He then collaborated with fellow LE&RN SMAC member Professor Kari Alitalo, Director of the Wihuri Research Institute at the University of Helsinki, Finland, to understand how these mutations cause the disease. Working together, the laboratories could show that the mutations result in loss of the normal function of the ANGPT2 protein that is known to play a role in lymphatic and blood vessel maturation.

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







L&R USA, Inc.





#### 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 Return service requested to:

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