Lighthouse
Lymphedema
Network

www.lighthouselymphedema.org

LLN April 2020 Newsletter

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LLN: Serving the lymphedema community for 27 years

22nd State of Georgia Lymphedema Education and Awareness Program

Sponsored by the LLN

October 23-24, 2020

Location: ROAM Perimeter
1151 Hammond Drive, NE, Suite 240
Atlanta, GA 30345

SAVE THE DATE! Make plans today to attend this exciting conference. Visit the LLN website (www.lighthouselymphedema.org) frequently to find out more details, and to register starting May 1st.

The purpose of this conference is to educate and create awareness about lymphatic disease.

Friday 10/23/2020, 8:00 AM-4:30 PM mini-course speakers will be Dr. Wei Chen, an attending plastic & reconstructive surgeon, and clinical professor of plastic surgery at the Cleveland Clinic, who will present "What are the latest techniques in lymphedema reconstruction?", and Mindy Bowen, RN, BSN, CAPA, RN – BC, will present "Nurses making the difference for patients with lymphedema." Dr. Chen & Ms. Bowen will explain the Mitaka Indocyanine Green [ICG] fluorescence visualization process, which shows the degree of functioning or non-functioning of a patient's lymphatic system (after injection of the ICG dye). **This mini-course will be open to medical professionals only,** especially oncology nurses and other nurses, physicians, surgeons, and lymphedema treatment therapists. We will provide a light lunch, plus snacks and beverages.

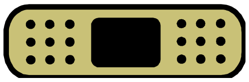
Saturday 10/24/2020, all-day conference, open to lymphedema patients, families, caregivers. We will have a number of excellent speakers (**see next page**), and our program will also feature patients sharing their stories of lymphedema diagnosis, treatment and everyday living - plus we will have our excellent supporting lymphedema management product vendors, exhibitors and a door prize giveaway. We will provide a continental breakfast and a light lunch, along with snacks and beverages throughout the day. **Cost is $50 to cover food**.

Speakers for the Saturday, October 24th All-Day Medical Conference:

- Kimberly Lairet, MD, FACS, will discuss her experiences as a breast cancer surgeon
- Rebecca Hammad, MHS, BS, ED, OTR/L, CLT will discuss her success with working with patients at Shepherd Spinal Center in Atlanta.
- Patient Harley Smith will present his story.
- Grace Stephen, RYT500, IAYT Professional Yoga Therapist, Qigong & Tai Chi instructor, and Doctor of Chiropractic, will discuss nutrition and exercise.
- Mindy Bowen, RN, BSN, CAPA, RN –BC, will speak on the success of the work she and Dr. Chen did at the U. of Iowa (before he recently moved to the Cleveland Clinic)
- Tim O'Malley, representative with Mitaka, will be present both days to answer any questions about the ICG fluorescence visualization process instrument.
- Question & Answer session with all speakers in the afternoon

A heartfelt message to all of you from the LLN:

We know it's been an even greater challenge for everyone during this time of the COVID-19 pandemic, requiring staying at home, practicing social distancing, and paying even more attention to disinfection - just trying to conduct daily life (like getting groceries) on top of all the good practices you would already be doing for your lymphedema care. We are truly all in this together, we are thinking of you, and we WILL get through it!



LLN BANDAGES & GARMENTS FUND 2020 UPDATE

During this time of uncertainty, we at the LLN hope and pray you and your families are staying healthy. The LLN BAG FUND has received its first check from It's The Journey, and we have accepted seventeen applications already. We are proud to announce we have added three new counties this past grant period and we look forward to serving all counties eventually in the state of Georgia.

We want to thank all of our therapists, providers, and compression materials companies for reaching out to the LLN and giving us the privilege to be part of your patients' care. The need for compression treatment is so great and the never-ending work you provide for each patient is admirable.

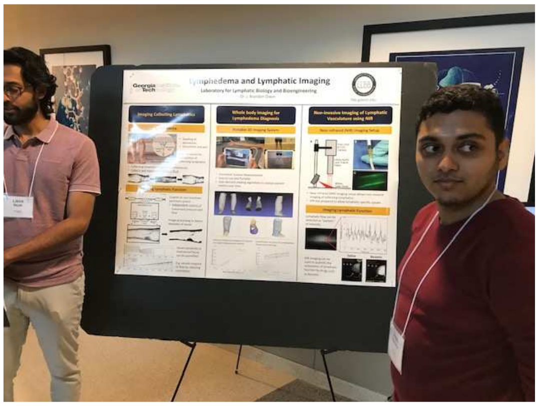
Please contact me with any questions or concerns you may have at darnofell@aol.com.

Lymphatic Research at Georgia Tech: A Behind-the-scenes Tour
Held Saturday, February 8, 10 AM – 12 PM

We sincerely thank Brandon Dixon, PhD, Associate Professor and Woodruff Faculty Fellow, George W. Woodruff School of Mechanical Engineering, Parker H. Petit Institute for Bioengineering and Bioscience, Georgia Institute of Technology and his graduate students for hosting an extremely informative and very well run program on the research being done on the biomechanics of lymphatic disease in six GA Tech laboratories, a tremendous growth since we first visited. *(His students pictured below are: Alexandra Atalis, Febrice Bernard, Matthew Cribb, Yarelis Gonzalez-Vargas, Yanina Kuzminich, Lauren Liebman, Ria Michalaki Anish Mukherjee, Likhit Nayak, Zhanna Neplyushchikh, Lauren Sestito, Kim To, & Ki Taw Wolf.)*

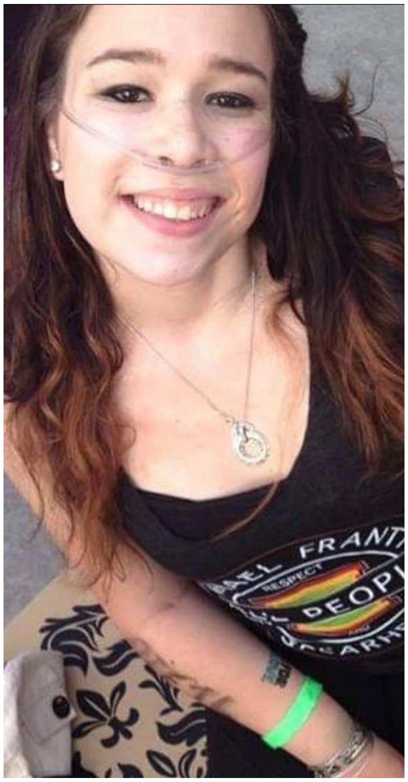

Dr. Brandon Dixon & his grad students who gave us the tour


We also appreciate all our LLN attendees who came out on a snowy day in Georgia!



Lymphatic Education
& Research Network

Melanie Rose Chaite
November 26, 1993 — February 12, 2020



On February 12, 2020, many members of our community lost a dear friend and we all lost a hero. Melanie Chaite was born with lymphatic disease and lymphedema, and she struggled with these enormous health challenges throughout her life. She was only 26 years old when she died Wednesday, surrounded by family and friends.

Melanie inspired the founding of this organization and the accomplishments that have followed these last 22 years. She became the very heart of a movement that is changing the world for millions.

"The essay that I wrote for my college application spoke of a game of tug-of-war I played before senior year of high school at band camp," Melanie said in her Keynote Address at the 2012 New York Walk to Fight Lymphedema & Lymphatic Diseases. "I use this game as an analogy to what my own struggles have been, a kind of tugging against this disease for my quality of life, while also realizing I have to rely on my other teammates and supporters to pull with me."

"I am faced with serious medical challenges. That is why I am standing here to represent the millions of others suffering from lymphedema from around the world. I also represent the smaller population of patients who suffer from rare, chronic, and progressive lymphatic disease and malformations in other parts of the body. Personally, knowing that I am part of this incredible, history-changing movement that has been able to make such progress is really a profound experience."

The Board and Staff of LE&RN are deeply saddened by Melanie's passing and we extend our condolences to her mother Wendy (LE&RN's Founder), her father Benn, brother Daniel, and to her extended family and friends. We will continue to be inspired by the brave example of Melanie's life, which reminds us daily of the reason we must achieve our mission.

(Melanie was a champion for lymphatic disease and inspired the founding of the Lymphatic Education & Research Network, LE&RN, by her mom, Wendy. *Melanie spoke at one of our LLN fall conferences through a video.)*

SIGVARIS

“Faces of Lymphedema" video:

LLN was approached by Danielle Edgecombe, Product Manager for Sigvaris, to help create a video for March 6, Lymphedema Day. LLN Board members and therapists participated and helped to arrange for a nice variety of 10 patients for the video. The inspiring video can be viewed on the LLN website, https://lighthouselymphedema.org/home2/ - check it out!

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2020 Lighthouse Lymphedema Network Calendar Dates to Remember:

- October 3-4, 2020 - Georgia 2-Day Walk for Breast Cancer produced by It's The Journey
- October 15, 2020 - Southern Loss Association Memorial Golf and Tennis Outing, Chateau Elan. LLN is the charity of choice for this event.
- October 23, 2020 - Course on surgical procedures sponsored by the LLN, ROAM Perimeter, 1151 Hammond Drive, Suite 240, Atlanta, GA. Medical Professionals Only
- October 24, 2020 - 22nd annual all day lymphedema conference, ROAM Perimeter, 1151 Hammond Drive, Suite 240, Atlanta, GA

From Breast Cancer 2019: ‘Prehab’ can help reduce odds of developing painful lymphedema

By Cindy O. Herman For The Daily Item, Oct 29, 2019

LEWISBURG — At the American Society of Breast Cancer Surgeons last year, actress Kathy Bates shared her story of surviving breast cancer surgery in 2012 only to develop lymphedema, a condition that causes swelling in the arms after breast surgery. “When I get on a plane, I have to wear my compression sleeves,” she said. “I can’t lift heavy things, I can’t go into hot water because putting heat on it makes it swell, but cold isn’t good because it constricts everything.”

“Lymphedema penetrates every part of life. It’s a miserable, miserable condition,” said John F. Turner, MD, FACS, Medical Director of the Thyra M. Humphreys Center for Breast Health at Evangelical Community Hospital. “To me, after local recurrence or metastatic disease, it is the third worst problem that occurs after breast cancer treatment.” It’s also been one of the most neglected areas of breast cancer care.

“The doctor told Kathy Bates, ‘Just be glad you’re alive,’” Turner said, anger showing in his expression. That’s not how Turner responds to his patients.

Lymphedema can occur any time a lymph node is damaged, whether through surgical removal or even a biopsy. The 600 to 650 lymph nodes in the body remove impurities like bacteria and viruses in our systems. Cancer cells also get caught up in the lymph nodes and can spread throughout the body, so until about 13 years ago, the medical community urged removing lymph nodes of breast cancer patients.

However, about 30 percent of those patients developed lymphedema. More recent studies have looked at sentinel nodes, a group that tends to become cancerous before the other nodes. If the sentinel nodes are negative, you can presume the rest are negative, as well. Further, by treating the cancer systemically, with chemotherapy or hormone therapy, the cancer can be killed throughout the body, including the lymph nodes.

Avoiding damage to lymph nodes almost diminishes the risk of lymphedema, but today, patients have powerful tools to fight even a slim chance of lymphedema. **"One of the biggest things we have done in the area of lymphedema prevention is prehab,"** Turner said. **The opposite of rehab, which occurs after an injury or surgery, prehab watches for a problem and treats it as early as possible.**

"In the 1980s, lymphedema patients sometimes developed massive arms," said Clint Stetler, physical therapist and certified lymphedema therapist (CLT) at Physical Therapy of Evangelical. "We don't see that at all anymore."

An important part of prehab is finding fluid build-up in the arm before swelling occurs. For that, nothing beats an L-Dex machine, which looks a bit like a treadmill. A patient stands barefoot on the L-Dex and grasps two handles while a very low current of electricity passes through the tissues in the body. The amount of fluid in the left and right side is compared to see if swelling is beginning.

"It really doesn't get any simpler," Turner said. "There's no pain involved. No needle stick. You just stand there." "That test can actually detect lymphedema before it can be visually observed or measured with a tape measure," Stetler said. "With the L-Dex we're catching lymphoma sooner so that it is almost reversible with treatment."

Treatment includes specific massage to manually drain the lymphatic pathways; compression sleeve; compression wrap/bandage; sequential compression pump; exercise and skin care to prevent infection. "The vast, vast majority of patients have returned to normal, and they don't have to wear the sleeve anymore," Turner said.

Skin care is key to preventing lymphedema because any cut or damage to the skin can cause infection and affect lymph nodes. "Avoid bad sunburn. Be cautions of bug bites and cuts on the skin. Anything that jacks up the lymphatic system," Stetler said.

Wearing gloves when doing things like gardening is recommended. "You can't eliminate the risk of hurting your hand, but you're going to markedly lower the risk," Turner said. And though it's hard to quantitate the number of lymphedemas avoided because of the L-Dex and education, he added, "I do know the incidence of lymphedema is palpably lower in my practice than it used to be."

Stetler agreed, saying if patients are consistent with L-Dex scans and wrapping their arm if early swelling is detected, it shouldn't progress to lymphedema. "And if it does," he said, "we will treat it and control it."

Property Claims Forum · Southern Loss Association · Since 1957

Southern Loss Association, Inc.

The Premier Property Claims Organization for the Southeastern USA

The SLA's spring golf and tennis outing has been cancelled, but the LLN has been designated as the charity of choice for their fall outing, scheduled for October 15 at the Chateau Elan resort north of Atlanta. Thanks to the generosity of the SLA, our long-time supporter, LLN will receive the income from the sale of mulligans and the ball toss game. Founded in 1957, the Southern Loss Association is one of the largest claim organizations in the country devoted to the education of property adjusters. The purpose of the SLA is to serve as a forum for the discussion, study and consideration of loss adjustment problems, coverage questions, policy forms, laws and statutes common to all insurance companies.

Another enlightening article; thanks to board member & therapist Janie Smith for forwarding it!

From Discovery Magazine, written by Josh Barney, 3-21-2016, posted at (https://www.news.virginia.edu/illimitable/discovery/they-have-rewrite-textbooks)

“They’ll have to rewrite the textbooks”

It’s a stunning discovery that overturns decades of textbook teaching: **researchers at the UVA School of Medicine have determined that the brain is directly connected to the immune system by vessels previously thought not to exist.** “I really did not believe there were structures in the body that we were not aware of. I thought the body was mapped,” said Jonathan Kipnis, a professor in the Department of Neuroscience and director of the Center for Brain Immunology and Glia (cells in the central nervous system, or CNS). How these vessels could have escaped detection when the lymphatic system has been so thoroughly mapped throughout the body is surprising on its own.

But the true significance of the discovery lies in its ramifications for the study and treatment of neurological diseases ranging from autism to Alzheimer’s disease to multiple sclerosis. Kipnis said researchers no longer need to ask questions such as “How do we study the immune response of the brain?” or “Why do MS patients have immune attacks?” “Now we can approach this mechanistically – because the brain is like every other tissue connected to the peripheral immune system through lymphatic vessels in the meninges (the membranes covering the brain).”

Kevin Lee, who chairs the Department of Neuroscience, recalls his reaction the first time researchers in Kipnis’ lab shared their basic result with him. “I just said one sentence: ‘*They’ll have to rewrite the textbooks*.’ There has never been a lymphatic system for the CNS, and it was very clear from that first singular observation – and they’ve done many studies since then to bolster the finding – that it will fundamentally change the way people look at the CNS’s relationship with the immune system.”

The discovery was made possible by the work of Antoine Louveau, a postdoctoral fellow in Kipnis’ lab. The vessels were detected after Louveau developed a method to mount a mouse’s meninges on a single slide to that they could be examined as a whole. After noticing vessel-like patterns in the distribution of immune cells on his slides, he tested for lymphatic vessels, and there they were. The impossible existed!

“Live imaging of these vessels was crucial to demonstrate their function, and it would not be possible without collaboration of Tajie Harris,” Kipnis noted. Harris is an assistant professor of neuroscience and a member of the Center for Brain Immunology and Glia. Kipnis also saluted the ‘phenomenal” surgical skills of Igor Smirnov, a research associate in the Kipnis lab, whose work was critical to the imaging success of the study.

The unexpected presence of the lymphatic vessels raises a tremendous number of questions that now need answers, both about the working of the brain and the diseases that plague it. For example, take Alzheimer’s disease. “In Alzheimer’s, there are accumulations of big protein chunks in the brain,” Kipnis said. “We think they may be accumulating in the brain because they’re not being efficiently removed by these vessels.” He noted that the vessels look different with age, so the role they play in aging is another avenue to explore. And there’s an enormous array of other neurological diseases that must be reconsidered in light of the presence of something that science insisted did not exist…”

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 3007*6. 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 help us save mailing costs! **elaine.gunter@comcast.net**.

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

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