LLN November 2020 Newsletter

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SPECIAL 2020 POST (VIRTUAL) CONFERENCE EDITION!

From our all-day LLN-Sponsored Fall Zoom® Medical Conference Saturday, October 24th 2020

Our 2020 Lymphedema Education & Awareness conference was both a great experiment in the COVID Era and a great success for all participants. We were determined to have our educational conference, and using the Zoom app proved to be an excellent solution. No travel was required for anyone, only the co-hosts and presenters had to dress up a little, just a good Internet connection needed, and a very reasonable registration fee with 5 CEUs available to be earned for attendance. Best of all, we had AWESOME speakers: Wei Chen, MD, and his assistant, Erika Hopkins, PA, of the Cleveland Clinic, and two patients united by having been treated surgically by Dr. Chen and his team.

We have created this special edition of our newsletter to provide highlights of the conference for everyone, especially those who could not attend to see what they missed. Our presentation room was full for our Saturday conference, which covered a wide variety of relevant topics for lymphedema patients, their families & caregivers, and medical professionals. Our excellent vendors demonstrated their latest innovative products for lymphedema & lipedema management in videos which were shown at our lunch and afternoon breaks.

Our Zoom participants appreciated the program with very positive comments about the speakers and the presentations. "It was brilliant, **thank you very much**!! I hope that the post-COVID era will still incorporate the Zoom version." "Patient stories were nothing less than inspirational." "Thank you for having the course despite Covid! It was so good and Dr. Chen was exceptional." "Congratulations on the amazing conference! We have been having some excellent discussions in our clinic generated by the lectures." "Must say....a lot better webinar than most I have attended and it kept my interest!!! In another words....I loved it"

Elaine Gunter, moderator
LLN Newsletter editor

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Wei F. Chen, MD - "Current Concepts of Lymphedema Surgery"

Dr Wei F. Chen gave two presentations on October 24, 2020 at the LLN Conference, explaining the current concepts of lymphedema (LE) surgery and risks of asymptomatic LE. He is a plastic surgeon who is known for his microsurgery and super microsurgery, having trained under Dr Isao Koshima at the University of Tokyo, and previously worked at the University of Iowa Medical School. He now works at the Cleveland Clinic in a unit dedicated to lymphedema surgical research, and is known for his technique of the lymphaticovenular anastomoses (LVA), the "flying squirrel" technique to remove excess skin after liposuction for LE, and the "octopus" multi-connection technique in LVA .

He reviewed progress in diagnosing and treating LE to date, explaining that LE is NOT a clinical diagnosis – i.e., it can be other things (e.g., radiation-induced edema), or it could be LE and not properly diagnosed, and thus untreated, or at best simply mis-treated. Venous insufficiency can cause LE. In the past, a therapist would use a measuring tape & look for presence of the Kaposi-Stimmer sign. Water displacement techniques and perometry were followed by lymphoscintigraphy (radionuclide imaging of the lymphatic system, previously considered the standard test to confirm LE), and MRI & CAT scans (effective but too costly for regular use to monitor lymphatics). Bioelectric impedance spectroscopy and duplex ultrasound are other techniques that are simple & non-invasive for detecting LE beyond stage 0.

However, none of those techniques have the advantages of using indocyanine green lymphography (ICG), a fluorescent dye injection and flow monitoring technique which Dr. Chen considers to be paramount to diagnose in stage 0 and also in tracking lymphatic function for years after surgical procedures. A 0.1-cc injection of ICG (mixed with sterile saline, not sterile water, which can be more painful when injection) is given in 3 locations on one of these sites (back of hand, wrist, top of foot, side of ankle, arm, or leg). At baseline and then again at 4-6 hours to allow uptake time for the dye (since lymph fluid moves slowly in affected individuals), using the Mitaka imaging software and fluorescence detection equipment, one can see individual lymph vessels, pump function, flow velocity, presence of obstruction, and disturbances in lymph vessels. Normal vessels have a linear pattern of dye movement from injection site to collectors. In early obstruction, the body tries to compensate with a "splash" pattern by sending lymph to other collectors; damage eventually ensues as a diffuse pattern. He reports that ICG can give diagnosis of obvious stage III and IV of a limb with primary LE, and then track other limbs of the same patient to diagnose stage 0 if and when present. Thus, his procedure of preventive LVA during stage 0 could be performed to prevent stages II, III, and IV of swelling and tissue changes.

Dr Chen reiterates the use of the ICG to find the stage of LE; then, after diagnosis he explains the techniques used when patients are individualized for treatment with surgery. Later stages of LE may need liposuction first, then lymph/venous anastomoses. These techniques can improve the severity of LE, decrease complications, and improve quality of life for all stages of LE. Super-microsurgery (SMS) in stage 0 can actually effect a cure for that location.

Once LE is diagnosed, complete decongestive therapy (CDT) and SMS are both first-time treatments which can be used. CDT is non-invasive so the patients are not harmed, they are maintained in temporarily better condition, but it doesn't reverse the pathology. Surgery can cause complications, patients can develop infections, have heart attacks or strokes possibly, but it can also create a cure.

If surgery is used, there is no one-size fits all plan for every patient, from the old de-bulking Charles procedure to SMS. Sometimes, liposuction has to be done first, then surgery in more advanced cases. Now, a surgeon can do the LVA procedure to prevent LE in stage 0. Dr. Chen says he has not done any lymph node transplant surgery in the past 5 years, because SMS is so much more effective.

He is an advocate for all plastic surgeons to consider being trained in SMS – then, more patients can get the help they may need. He reported his first case of "cured" LE following SMS in 2012. He cautions that there are lots of insurance coverage problems with SMS because it's new and insurance companies need more education on it (a familiar problem…), so therapists will have to help their patients do a selling job to get coverage. ICG itself is usually covered because it is FDA-approved. Patients will have to look for surgeons trained in SMS at locations in addition to the Cleveland Clinic (they are working to bring it up at the CC's satellite clinic in FL in order to start the process with insurance companies to have the procedure done and covered.

Wei F. Chen, MD - "Lymphedema Risks, Asymptomatic Lymphedema, and Other Recent Discoveries"

Dr. Chen prefaced his second talk by saying that these were his unpublished observations, but he feels that this information is critically important for patients to know, and the issues are very relevant. He discussed some cases he has seen but not published yet – e.g., how ICG can really elucidate long-standing LE cases to show that they are actually LVA-eligible. He emphasized that risk is life-long for development of LE after trauma – in one patient, LE developed in a leg 33 yr after cervical cancer treated with surgery and radiation. Also lymphatic function normally declines with age, just like breathing and cardiac function, and males have greater lymphatic functionality than females.

One misconception that he has encountered is that "LE usually takes 2 yr to manifest itself." What about Stage 0, in which swelling is not detectable by the older techniques? He had case in which he performed LVA on the patient's right leg, but the left leg looked normal. The staff accidentally performed ICG on the left leg instead of the right for the patient, and they found LE, Stage 0, totally asymptomatic. Dr. Chen performed LVA on the left leg, and it is totally OK now. So, his group started routinely doing bilateral leg surveillance by ICG to compare "normal" and affected legs. In 27 patients, all with previously established ICG baselines on their "bad" leg and an initial injury/surgery to the groin, they found a 61% incidence of decrease in lymphatic pump function, linear but not reaching the groin, and a 39% incidence of (pathologic) dermal backflow and the splash/stardust/diffuse dye patterns. This study was done from 12 months to 10 yr out from the patients' initial groin injuries.

Because LE can happen at any age, it is critical that all 4 limbs are screened with ICG and bioelectric impedance. The patient will need lifelong surveillance, and proactive treatment. Asked about truncal LE, and how to treat LE when not in an extremity, Dr. Chen prefers LVA/SMS because it doesn't deform the patient (unlike the old Charles debulking technique!). He has done LVA everywhere except the buttocks (lymphatics there haven't been investigated, but LE in that area improves with LVA to the legs)

Other misconceptions: he also noted that lymphatics grow right back after surgery (our bodies compensate!). Blood pressure cuffs don't cause or exacerbate LE – or an IV line – so using firm pressure should not be a worry in treatment. As long as the SMS incision isn't ripped, doing CDT on the site afterwards is OK. He tells therapists just to keep a good record of everything they do on a patient.

Erika Hopkins, PA-C – "Interpreting ICG (Indocyanine Green Fluorescence Dye) After Injection into a Patient's Lymphatic System"

Erika Hopkins, PA-C, works at the Cleveland Clinic (CC) as Dr. Chen's Physician Assistant, and among many other responsibilities, performs ICG (indocyanine green fluorescence dye) lymphography imaging and interpretations. Her presentation, entitled "Interpreting ICG after injection into a patient's lymphatic system," offered insight into the protocol and diagnostic benefits of ICG lymphography. The CC protocol is a result of 8 years of refining techniques.

FDA-approved in November 2018 for lymphatic mapping, ICG lymphography is now the gold standard for diagnosing lymphedema and is an excellent choice for all patients except those with allergies to shellfish or iodine (the ICG tracer contains iodine). It is non-radioactive and binds to lymph proteins; fluorescent dye is injected just below the surface of the skin at three defined points on the affected limb. Typically, injections are also made into the corresponding limb for comparison. ICG fluoresces at the optimal wavelength (750-800 nm) to be distinguished from hemoglobin and water in the body. (The previous standard technique, lymphoscintigraphy, is done with a technicium-99 radionuclide tracer mixed with other compounds as a colloid, is non-binding, and is usually injected between web spaces of fingers or toes. The image shows the whole body and pooling of the dye can be seen, but multiple factors can affect the dye uptake time.)

Two sets of ICG scans are performed. Following the injections (there is little pain, the injection site is pre-numbed with lidocaine), a series of initial scans are performed at two-minute intervals to view the injection sites and to monitor lymphatic pumping function, which is aided by manual manipulation of the injection area. The initial scans seek to follow

the dye to the axillary (arm) or inguinal (leg) collector sites. The second scan is performed 6 hours later and this second scan is used to determine dermal backflow patterns of "linear" (healthy), "splash", "stardust" and/or "diffuse", listed here in order of the increased progression of backflow, to help with surgical site planning.

The Mitaka fluorescence scanning equipment in use at Cleveland Clinic provides four video images of the limb which can be viewed simultaneously for maximum imaging differentiation of lymphatics and blood vessels:

1. without the dye highlighted
2. with the dye highlighted
3. with the dye highlighted and superimposed over a "picture" of the limb
4. with the dye highlighted within a scanned image of the limb

Imaging procedures vary for patients with secondary lymphedema and those with primary lymphedema. In secondary lymphedema, usually acquired due to an injury to the lymphatic system, the lymph vessels follow the normal anatomical flow in the effected limbs. In primary lymphedema, where a developmental (or congenital/hereditary) disorder existed, there is a deviation from the normal or expected anatomical flow. The lymphatic vessels are more tortuous with no linear connections. For primary LE patients, it is prudent to scan all four limbs for anomalies. The video images are used to assist the surgical team in planning the appropriate surgery. Erika also showed examples of ICGs on patients with various secondary and primary LE conditions.

Following surgery, ICG lymphography is a key part in the on-going care of the patient. Scans are performed post-op at 3 months, 6 months, 1 year and annually thereafter. There is no post-op therapy needed for ICG, although the dye may linger harmlessly in vessels for several weeks until it is fully metabolized.

Rebecca Hammad, MHS, OTR/L, CLT – Patient Story: "My Lymphedema Surgery Story"

Rebecca works as a therapy manager in the post-acute trauma program at the Shepherd Center (a private brain and spinal injury treatment hospital in Atlanta, GA). She developed LE when she was younger while doing a study-abroad program in Costa Rica, and getting numerous mosquito bites which "activated" undiagnosed congenital LE. She developed cellulitis and inflammation, and had to be hospitalized. After treatment, edema remained in one leg. After endlessly searching for information, she finally learned about CDT. In 1999, she was wearing day and night compression garments, having manual lymph drainage (MLD), and maintaining a very healthy lifestyle. Inspired by certified lymphedema therapists who treated her, she became a CLT in 2013.

Her leg LE worsened after her 2nd pregnancy. Several years ago, she gave a presentation at an LLN conference and met Dr. Chen. In 2018, she had her initial assessment with ICG lymphography. Her case seemed mild, but she would get pitting edema very quickly after removal of her compression garment (a flat knit garment during the day and a chip-foam garment at night).

The ICG scans of her legs had no linear patterns, but instead were very diffuse with the dye spread out. She also now had mild swelling in her hands and arms. On her left arm, the dye only went to the forearm and was very diffuse after that. Her right arm was much better and the dye did make it up to her axilla, but still spread out in her hand.

Rebecca said that it was very hard emotionally for her to see that her body had such impaired lymphatics, and it was alarming to see how damaged her lymphatic system was, now diagnosed as congenital LE of all four extremities. She was considered to have severe lymphatic hypoplasia and therefore not a candidate for node transplant. She did decide to move forward with LVA/SMS on her right leg, where Dr. Chen performed 7 incisions with 5 LVA connections. In October 2019, she had her left leg done – although there were no available/transplantable lymphatics, Dr. Chen was able to make 5 incisions with 10 LVA connections. Later she had the LVA/SMS procedure done on her left arm with 4 incisions and 8 LVA connections.

Rebecca had felt that any improvement would be a huge win for her, and she is very pleased with the results, especially with the reduction achieved in her arm. She feels far less heaviness and fatigue in her limbs, and did have a little nerve tingling post-surgery, which has now resolved. She still wears her leg compression garments, but they are now much easier to manage.

Grace Stephen, E-RYT500, IAYT, DC – "Healing Through Movement, Breath, and Nutrition"

Grace Stephen is a Yoga Therapist and Qigong Instructor. Qigong is a practice from China, devoted to improving the Qi (pronounced Chee) or 'life force.' Similar to yoga and tai chi, it can benefit caregivers as well as patients. Grace says she has a mixed media practice – she sees patients at all stages of life and diseases. She notes that in addition to patients, it's important for therapists and caregivers to take care of themselves too. Her takeaways from this talk were the importance of movement, breathing, and improved nutrition.

After injury or trauma, sometimes "the mind wants to give up, but the body finds a way" and a gentle exercise practice like qigong can help the body heal. It can be slow and intentional or vigorous and strong, depending on the practitioner's status. Exercises can be done in bed, in a chair, on the floor, or standing. They improve flexibility, rhythm, strength, and balance.

Breathing lessons are essential to yoga and related practices. "Belly-breathing" can be encouraged by placing a belt around a client's lower belly, abdomen, and chest while they breathe-in and expand the belt. Controlling the breath and timing of the intake and out-flow of breaths will elicit a "relaxation response." This is a helpful skill to have in stressful situations, including painful ones. As the ribcage expands, the practitioner might visualize a balloon or beam of light growing inside them. This deeper breathing technique affects blood flow, heart rate, and the positioning of the organs inside the thoracic cavity.

Grace demonstrated several movements that can be done in sitting or standing positions. These included the 'Breath of Joy' with accompanying arm stretches, 'Coiling Silk,' 'Hitting Tofu,' 'King Shakes,' and 'Constant Bear.' Then Grace showed us 'Legs up the Wall,' a favorite pose for many. She also recommended a dry brushing technique on the skin to improve lymph flow.

Anti-inflammatory nutrition is another area of focus for healing the body. Each person should progress at their own speed making nutritional choices and enlist support from family and friends when making changes. Alcohol can be dehydrating, and over-consumption of salts, oils, sugars, and meats can cause inflammation. But whole foods ("clean", not processed, no additives) and spices such as turmeric with curcumin have healing properties. Check the sugar content of fruits when looking for healthier choices, and use lemon or stevia for additional flavoring. Grace ended by recommending several websites and apps: Define My Day.com, Dr. Michael Gregor's Daily Dozen, Forks Over Knives, and Banyan Botanicals. If you are in the Atlanta area and are interested in more information or attending classes, Grace's website is www.gracefulyoga.org .

Arleen Wood – Patient Story: "My Symphony"

Arleen is a concert pianist, musicologist, and piano teacher and also a patient of Dr. Chen's. She had a 42-year tale of LE in her lower limbs. She thanked her "maestros" internist (Dr. Shep Dunlevie) and her PT (Dr. Shelley DiCecco) for caring for her, and Dr. Wei Chen for changing her life.

In her musical theme, her "sonata" was her supportive family. She developed cancer ("her allegretto") as a young woman and was given a 10% change to live 10 more years. She developed LE and used a pump, which was very painful. But, she loved tennis and competed, and continued running, skiing, hiking, and horseback riding. She had many supportive friends ("accompanists") and traveled a lot (although always afraid of getting sick on a trip). She constantly worked, teaching and performing 7 days/wk. The joys of her life were her husband and her dogs.

Her "largo" was her legs. From 1990-2010, she had many hospitalizations for cellulitis and sepsis in her legs. She did a regimen of therapy at the Mayo Clinic in 1998. By Fall 2017, her left leg had greatly expanded in size and she weighed 174 lb on her petite frame. She found Shelley DiCecco for CDT, and had suction-assisted protein lipectomy (SAPL) surgery on both legs (her "minuet") in 2018, which produced an 18% reduction in her right leg and 31% in her left leg. In Feb. 2020, she found Dr. Chen; her ICG showed severe LE with diffuse patterns and her SAPL surgery on her left calf achieved a 53% reduction in her left leg. In July 2020, she had SAPL performed on her left thigh, and achieved a total 54% reduction in that leg. She now weighs 139 lb.

Arleen was at Cleveland Clinic in the middle of the COVID outbreak, and has the greatest praise for Dr. Chen and his staff. She continues her CDT 2x/week, but is now playing a whole new life symphony indeed!

Our sincere thanks to the following businesses for their financial support of this conference:

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***Thank you, Lighthouse Lymphedema Network*:**

Support LLN on Georgia Gives Day, Tuesday December 1st!

Every day, the Lighthouse Lymphedema Network works to educate and create awareness about lymphedema and related disorders. Please support the LLN for GAgives on #GivingTuesday on Dec. 1st.
By giving any amount, even $5 or $10, you can be part of our mission. While the official date of Georgia Gives Day is December, the website is open to donations year round and you can donate to the LLN any time and at your convenience! Simply go to **www.GAgivesday.org** and search for "Lighthouse Lymphedema Network". Use the DONATE NOW button to make your donation in support of one of our fundraisers and the LLN. Because we have no paid staff, ALL funds raised by the LLN directly serve the lymphedema community through efforts such as our annual conference & newsletters!

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