NLN Media Coverage
My Journey Living with Lymphedema

By Julia De Simone

I called it my special leg.

Although it was larger in circumference than my right leg, I never felt sorry for myself growing up. “You can do anything that any child your age can do,” my mom repeatedly reminded me.

At 9 months, she made certain I was walking. And when my kindergarten teacher scowled me for not learning to jump rope fast enough or said I was too clumsy on the balance beam, my parents visited the principal.

It could've been worse

Perhaps I never felt sorry for myself because the day my parents took me to the hospital for a diagnosis, my mom’s eyes fell to another child missing the top part of her skull and another with an arm larger than the other – far more noticeable than my special leg.

As we continued to find a diagnosis and treatment, there were a lot of closed doors. One doctor in particular suggested a radical operation where I’d be left with noticeable scars on each side of my “special leg.” No thank you.

Years flew by and few people noticed my special leg. And if I ever felt sorry for myself, my mom would again remind me of those children she never knew, but never forgot.

A proper diagnosis: lymphedema

Fast forward more than 20 years. Married and pregnant with our only child, my husband and I suddenly realized my leg was noticeably larger and literally weighing me down.
After numerous doctor visits, I finally had a proper diagnosis – primary lymphedema, a congenital malformation of the lymph system in which swelling may be evident at birth or develop later in life. Secondary lymphedema is swelling that occurs due to damage or overwhelming of the lymph system. Common causes are cancer treatment, deep vein thrombosis, obesity, trauma, venous insufficiency and cellulitis. According to the LymphedemaTreatmentAct.org, an estimated 3 to 5 million Americans suffer from lymphedema including many that are undiagnosed or untreated -- more than ALS, Cystic Fibrosis, Multiple Sclerosis, muscular dystrophy and Parkinson’s disease combined.

After finally receiving my long-awaited diagnosis, I started treatment including compression therapy. As I sat with a bandage wrapped on my left foot to my knee, I kidded with my therapists that I was a mummy and this was my next Halloween costume. When I returned to my car, however, I bawled, not understanding why I had to be the person with this. And for the first time, I truly felt sorry for myself.

But then I heard my mom’s words and remembered those other children.

I realized I was never alone – my mom secretly carried that burden for me, blaming herself for my lymphedema all these years.

**What is this?**

Lynn Keeler, occupational therapist and Lymphology Association of North America certified lymphedema therapist at Banner Boswell Medical Center in Sun City, probably has seen that unwarranted blame on parent’s face. The Glendale woman has worked in the field for more than 20 years and has been treating patients with lymphedema for 12 years. Her youngest patient has been an 8-month-old with primary lymphedema of all limbs.

“When I first saw people with lymphedema, I was curious. What was it? What had it happened to them? And, of course, wasn’t there something we could do about it?” she said. “It seemed to me that people wouldn’t be living with these large limbs if they didn’t have to, but I found it hard to believe there was no treatment for it. At the time, lymphedema therapy was not widely known or available. When I learned about it, I decided that I wanted to treat this problem.”

**Kathy Bates and other cancer survivors raising awareness**

Keeler said she’s seen an impressive growth in the awareness of lymphedema in the medical community and the general public in the last decade – largely due to its association with another common disease.

“Cancer patients are receiving more education about the potential for lymphedema and about therapy that is available,” she said.
One of them is Golden Globe and Oscar-winning actress Kathy Bates, best known for such films as “Fried Green Tomatoes” and “Misery.” Bates, who suffers from lymphedema due to cancer, recently became a spokeswoman for the Lymphatic Education & Research Network.

"We encourage them to come out of the closet, so to speak, to share their stories, and hopefully find some comfort in realizing that they are not alone," Bates recently said.

Although Keeler said she’s seen initial heartbreak among her patients, especially those who can’t wear shoes because of their lymphedema, she remains inspired by her patients.

“When asked about the most heartbreaking case I’ve seen, I find it hard to answer. It’s tempting to describe the most extreme cases of swelling, but then I think about the children and their parents. Seeing a teenage girl shy away from sports or struggle to find clothes that will fit over her swollen leg is heart wrenching," she said.

"But more frequently patients inspire me with their attitudes and adaptability. There is certainly hope for lymphedema patients. In my experience, the overwhelming majority of lymphedema cases improve with therapy. Additionally, there is ongoing and exciting research into the lymph system, reducing the risk of lymphedema and lymphedema treatments.”

The 12th International National Lymphedema Network (NLN) Conference will be held Aug. 31 to Sept. 4 in Dallas. The program is aimed at medical professionals with the focus on basic and clinical research in the field of lymphedema and related disorders.

More information on Lymphedema, including treatment services, can be found at lymphnet.org and on Facebook.

*Julia De Simone is a Peoria, wife and mother of one human and six furry animals (almost all rescues) that is passionate about the West Valley and the people, places and organizations that make it a great place to call home. Reach her at juliaadesimoneaz@gmail.com.*
National Lymphedema Network International Conference in Dallas Starts August 31, 2016

By Patricia Egan

The National Lymphedema Network (NLN) invites you to attend its 2016 International Conference: Shaping the Future Through Commitment, Evidence, and New Frontiers, which will take place in Dallas, TX, from August 31 through September 4, 2016. Our opening keynote speaker will be Dr. Stanley G. Rockson, Chief of Consultative Cardiology, Allan and Tina Neill Professor of Lymphatic Research and Medicine, Professor of Medicine, Director, Center for Lymphatic and Venous Disorders, Stanford University School of Medicine, Falk Cardiovascular Research Center. Amy Santiago, Mrs. Central Florida and lymphedema ambassador, will be the Saturday luncheon keynote speaker.

“Together, both Dr. Rockson and Ms. Santiago will highlight the combined basic science, clinical research, and translational objectives of the 2016 NLN International Conference program,” said Dr. Eva Sevick-Muraca, Program Co-Director and NLN Board Member. “Dr. Rockson’s presentation highlights the meeting’s objectives to update the rare disease community with the most recent advances in the diagnostics and treatment of lymphedema as well as the scientific underpinnings of the ‘why’ and ‘how’ lymphatics dysfunction in the first place. Ms. Santiago’s presentation exemplifies the need to use this information to promote patient and clinician awareness that can help to shape policies to impact health care delivery to all patients with chronic conditions that involve the lymphatics.”

The 2016 NLN International Conference will bring together leading researchers, educators, and clinicians from around the world to share their current, cutting-edge innovations, developments, and techniques.
in the field of lymphology. Attendees may receive AMA PRA Category 1 Credit(s). Registration is open online at www.lymphnet.org. For additional information, please call the NLN office at 1.800.541.3259 or 1.510.809.1660.
Sarah Bramblette, MSHL, Joins National Lymphedema Network Board of Directors

National Lymphedema Network (NLN) Board Chair, Michael Cannon, announced today that lymphedema patient advocate and author, Sarah Bramblette, MSHL, has joined the NLN Board of Directors.

Sarah Bramblette brings her experience with lymphedema care and advocacy to the organization’s leadership team. A graduate of the 2014 NLN Lymph Science Advocacy Program (LSAP), she serves on the executive committee of the Lymphedema Advocacy Group, which is working to pass the Lymphedema Treatment Act. Sarah has published articles about lipedema and lymphedema for several news outlets including HealthCentral, WEGOHealth, ObeistyHelp.com, Your Weight Matters Magazine, and most recently for LymphNotes. Her story has also been featured on the syndicated television show The Doctors, and she recently gave a TEDx Talk, “Weight Bias in Healthcare,” focusing on how weight bias delayed her lymphedema and lipedema diagnosis. Bramblette is also the 2014 Obesity Action Coalition Member of the Year.

"Sarah brings important knowledge and experience as a highly effective advocate from the lipedema, lymphedema, and obesity communities to the NLN board. We look forward to working with her as the NLN progresses as a voice for patients, therapists, and the lymphatics field," said NLN Board Chair, Michael Cannon.

The NLN will host its 2016 NLN International Conference in Dallas, TX, this August 31 – September 4, including the 2016 Lymph Science Advocacy Program (LSAP). LSAP applications are available on the NLN website and are due May 15. The conference will bring together hundreds of medical professionals, industry members, patients, and advocates to share breaking knowledge and techniques, promoting a better future for lymphedema patients and professionals.

The NLN was founded in 1988 to create awareness of lymphedema through education and to promote and support the availability of quality medical treatment for all individuals at risk for or affected by lymphedema. For more information about the NLN, lymphedema, its nationwide therapist and support group network, coming events, and more, visit www.lymphnet.org.
Congressman Leonard Lance Honored by the National Lymphedema Network

Lymphedema results from damaged lymph nodes that can cause painful swelling; Lance is advocating for legislation to help pay for treatments

Congressman Leonard Lance (R-District 7) welcomed Lisa Bibbo and her son Michael to his Westfield District Office where the Bibbos presented Lance with a special honor for his championing of the Lymphedema Treatment Act. Lance is an original cosponsor of the bipartisan legislation that seeks to close the Medicare coverage gap for equipment and therapies needed by the nearly six million Americans afflicted with Lymphedema.

“The Lymphedema Treatment Act will improve patient management, prevent life threatening complications and reduce healthcare costs. Those born with this terrible disease and cancer patients who develop it need access to compression equipment to treat the condition effectively. I thank Lisa and Michael Bibbo for their advocacy and leading this effort in bridging the gap between proper diagnosis and access to treatment,” said Lance, who sits on the Health Subcommittee in Congress and chairs the Congressional Rare Disease Caucus.

Lymphedema results from damaged lymph nodes that can cause painful swelling. Compression therapy is an essential component of treatment but many of these compression supplies are not covered by Medicare. Ensuring Medicare covers the supplies needed for treatment would be a major victory for those fighting the disease.

Lisa Bibbo added, “Michael and I are honored to be chosen by the National Lymphedema Network to present this award to Congressman Lance. We truly appreciate his dedication and support and we are so pleased that Rep. Lance’s efforts have been recognized by the national network. Michael and I will continue to do our best pushing this legislation in Washington and advocate passage of the pending bill.”

The Bibbos also traveled to Washington last month to advocate for the Lymphedema Treatment Act.
Help Pass the Lymphedema Treatment Act

The National Lymphedema Network is asking for help to pass the Lymphedema Treatment Act, S. 2373/H.R. 1608. This legislation seeks to improve coverage for lymphedema treatment by amending Medicare to cover compression supplies. Also supporting are the American Cancer Society, American Academy of Physical Medicine and Rehabilitation, Oncology Nursing Society, American Physical Therapy Association, and American Occupational Therapy Association.
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The Bibbos are heading to Washington later this month.
National Lymphedema Network Announces 12th International Conference Speakers Dr. Stanley Rockson and Amy Santiago

The National Lymphedema Network (NLN) is pleased to announce Stanley G. Rockson, MD, prominent lymphology researcher, Stanford University Medical Center, and Amy Santiago, Mrs. Central Florida International and global lymphedema ambassador as the keynote speakers at its 12th International Conference on August 31-September 4, in Dallas, Texas.

Dr. Stanley G. Rockson, Allan and Tina Neill Professor of Lymphatic Research and Medicine and Director, Chief of Consultative Cardiology, Falk Cardiovascular Research Center, Stanford University Medical Center, is an internationally renowned scholar, researcher, and clinician in the fields of vascular and lymphatic systems. He is the author, co-author, and editor of 6 books, 33 book chapters, and 166 scholarly articles. As Editor-in-Chief of Lymphatic Research and Biology, he has overseen 14 volumes of leading peer-reviewed research from a broad range of investigative disciplines, including genetics, biochemistry and biophysics, cellular and molecular biology, physiology and pharmacology, anatomy, developmental biology, and pathology. Dr. Rockson will deliver his opening Keynote speech at the conference on Thursday, September 1.

Amy Santiago is a primary lymphedema patient and NLN Lymphedema Ambassador and Lymph Science Advocacy Program graduate. She has shared her story to inspire many others nationally and internationally as they find ways to live with lymphedema. Amy’s speech, Voice of Significance will accompany the conference’s keynote luncheon on Saturday, September 3.

“Together, both Dr. Rockson and Ms. Santiago will highlight the combined basic science, clinical research, and translational objectives of the 2016 NLN program” said Dr. Eva Sevick-Muraca, Program Co-Director and NLN Board Member. “Dr. Rockson’s presentation highlights the meeting’s objectives to update our community with the most recent advances in the diagnostics and treatment of lymphedema as well as the scientific underpinnings of the “why” and “how” lymphatics dysfunction in the first place. Ms. Santiago’s presentation exemplifies the need to use this information to promote patient and clinician awareness that can help shape policies to impact health care delivery to all patients with chronic conditions that involve the lymphatics.”

The 2016 NLN International Conference will bring together leading researchers, educators, and clinicians from around the world to share their current, cutting-edge innovations, developments, and techniques in the field of lymphology. Attendees of the 2016 NLN International Conference will receive AMA PRA
Category 1 Credit(s)™. April 4 is the deadline for submission of abstracts on topics concerning the lymphatic system and related disorders. Advantageous early bird registration rates are good through April 4. Please see www.lymphnet.org for abstract submission guidelines and early bird registration.

The National Lymphedema Network was founded in 1988 with the mission of creating awareness of lymphedema through education and promoting and supporting the availability of quality medical treatment for all individuals at risk for or affected by lymphedema. For more information about lymphedema, contact the NL at 1.800.541.3259 or visit our website at www.lymphnet.org. The NLN’s 12th International Conference: Shaping the Future Through Commitment, Evidence, and New Frontiers, will take place in Dallas, Texas, August 31 – September 12, 2016. See www.lymphnet.org for program and registration information.
What to Watch for After a Mastectomy or Bilateral Mastectomy

By Jean Campbell

If you have recently had a mastectomy or bilateral mastectomy, you need to be aware of certain situations that can occur after having a breast or breasts removed. Being aware can help you cope with how your body feels and knowing when you need to seek advice or be seen by your surgeon.

There will be numbness in the surgical area; it may last for quite some time.

Watch for any signs of infection, such as odor, swelling, oozing or pain. You need to be seen, as soon as possible, by your breast surgeon, if any of these symptoms occur. If you have had immediate reconstruction following your mastectomy or bilateral mastectomy, you need to also make your plastic surgeon aware of your symptoms.

Phantom Breast Pain: Many women speak of what is frequently called phantom breast pain, which is a feeling of pain experienced in what was the area from which the breast was removed. Phantom breast pain happens following a mastectomy just as phantom pain occurs after a limb amputation.

Cut down a bit of your belly every day by using this 1 weird old tip.

- Lymphedema
- Breast Cancer Awareness
- Cancer Treatment Options
- Treatment for Lymphedema
• **Lipedema**
  The explanation medical science gives for this phenomenon is that the brain is continuing to send signals to the nerves in the breast area that were cut during surgery, even when the breast is not there anymore.

  Following my bilateral mastectomy, I experienced phantom pain where my right breast used to be. Seven years later, I occasionally still get a feeling of being pinched from the inside in that same area.

  **Phantom breast pain is often described as:** Pain and discomfort, a pinching sensation, throbbing, a feeling of pins and needles, a tingling or burning sensation.

  If you have any of these symptoms, don’t self-diagnose yourself as having phantom breast pain; call your surgeon and make him or her aware of what you are experiencing. Be ready to answer whether these symptoms are transient, and if they are interfering with your ability to sleep, self care, or are making routine activities difficult to do.

  **Lymphedema:** We have all noticed women wearing what looks like a tight sleeve on her arm. It is called a compression sleeve. Women wearing these sleeves have a condition called lymphedema, which is swelling of the soft tissues caused by a build-up of lymph fluid. This type of swelling can occur in the hand, arm, chest, or back on the side of your body where lymph nodes were removed by breast cancer surgery or damaged by radiation therapy.

  What you need to know about lymphedema:

  • Lymphedema can occur soon after surgery. Be sure to inform your surgeon if you have any signs of swelling in your hand, arm or the trunk of your body.
  
  • Sometimes, lymphedema can last for years.
  
  • Lymphedema can show up months or years after cancer treatment is over.
  
  • Lymphedema might develop after an insect bite, minor injury, or burn on the arm where lymph nodes were removed or damaged.
  
  • Lymphedema can cause pain and other problems. Many women find it helpful to continue to see a physical therapist or physician who specializes in rehabilitation and that has extensive training in lymphedema management.

  Since Lymphedema can happen days, months, or years following breast cancer treatment, it is so important to take steps to prevent lymphedema such as:

  • Avoiding anything that irritates the skin, and caring for hangnails and torn cuticles immediately.
  
  • Don’t wear tight-fitting clothing or jewelry.
• Do not use steam rooms, whirlpools, saunas, or take very hot baths.

• No sunbathing

• Don’t take injections, have your blood drawn or have blood pressure taken on your affected arm. If you have had a bilateral mastectomy, speak with your surgeon about what parts of the body can safely be used for these procedures. For example, my surgeon recommended that I have all bloods drawn from my right hand in the future, as fewer lymph nodes were removed on my right side.

• Know that playing tennis, golf and racquetball, as well as bowling are considered risky.

• Avoid wear heavy shoulder bags.

• The National Lymphedema Network recommends avoiding lifting heavy packages or objects such as grocery bags weighing more than 8 pounds. Heavy lifting of furniture or any other dead weight is not a good idea.

If you have reconstruction, you need to make your plastic surgeon aware of any pain or swelling you are experiencing.

**Exercise:** Wanting to get back the routine you had before surgery is only natural. However, you need to consult your surgeon and your plastic surgeon, if you had reconstruction, as to when you can begin exercising again. They will need to sign off on what exercises are appropriate while you are healing. You can ask for a referral to a Certified Cancer Exercise Specialist.
Tina Deal is facing her Goliaths through the generosity of others and her faith

By Jackie Hardy

The statement that one phone call can change your life certainly rang true for Irving resident, Tina Deal. It was in 2013, Deal picked up the phone to hear the words—“You have cancer.” Shortly before learning of her breast cancer diagnosis, Deal also lost her job prompting the onset of life-changing events, which would ultimately turn her life upside down.

Deal went from a life of complete independence and serving those within the vulnerable communities to now needing some of the very services she once helped to coordinate and/or volunteer her time and energy to.

“I had to accept help from other people. Well, I wasn’t used to that because I was used to being the one to help,” she states.

With Deal facing unemployment and a major health crisis, she had to quickly figure out what to do as she no longer had healthcare insurance or any stream of income coming in to cover her medical and living expenses.

Deal understood the complexities inherent to breast cancer as she loss both her mother and grandmother to the disease in 1993 and 2000.

“My maternal grandmother had breast cancer and she survived for about 15 years. She was in remission all that time and then it came back and metastasis. My Mom had breast cancer as well and she was also around a 15 year survivor,” explains Deal.

According to a 2012 Center for Disease Control report, a little more than 120,000 African American women were diagnosed with breast cancer; and from 2008 to 2012, breast cancer incidence rates increased 0.4 percent per year in African American women based on a report from the American Cancer Society.
According to the American Cancer Society, early detection is critical in the fight against breast cancer and Deal stayed on top of getting her mammograms prior to losing her job.

“I always went every year diligently for my mammograms,” she advises.

Faced with the reality of having breast cancer and no health insurance, Deal went on the Susan G. Komen website and researched to find medical facilities in her area that the non-profit organization, through the partnering with local cancer treatment facilities, provides patients like her financial assistance.

“I found Baylor Irving, now it is called Baylor Scott and White; and they had the funding to do that. I got the financing from the board {Baylor Irving} and Susan G. Komen.”

The Susan G. Komen foundation covered her medical expenses, but according to Deal they could not continue to provide financial assistance due to lack of funding.

“The funding ran out at Baylor and that was the year Susan G. Komen got hit pretty hard with people not contributing as much as they had at one time, so a lot of programs ran out. They {programs} were not automatically extended, so I had to find some other way,” claims Deal.

Although she was approved for some financial assistance through the Parkland program, according to Deal the waiting period to see a doctor can be long.

“When I was accepted into their program, it took me seven months to get an appointment to see someone, so with the pains that I have: severe pain in my back and thighs all the way to my knees {health issues stemming from nerve damage as a result of her diabetes} and the physical therapy I received offered me no relief,” she exclaims.

To help manage her pain, Deal decided to go back to her former doctor that she saw when she had insurance, but she is unable to receive comprehensive care (i.e. x-rays) because she cannot afford the cost to get necessary testing done to treat and manage her pain.

Deal’s faith is what she says has kept her through all of the difficult financial and medical challenges she has and is currently facing.

“These challenges has taught me to rely on God because there is not a whole lot I can do, but He can do it. I have learned to stand on God’s word through all of this,” she exclaims.

According to Deal, she endured three surgeries in a total of 21 days to aggressively treat her breast cancer. She advises the treatments were physically taxing and contributed to other health issues; respectfully her issues with suffering from lymphedema and osteoporosis.

“Ten days I was taken off of the radiation treatment because it was burning me. When I finished the 45 rounds of radiation I get lymphedema. Lymphedema is something that occurs when you have had breast cancer.”
Based on the National Lymphedema Network website, secondary lymphedema can occur as a result of damage to the lymphatic system and specific cancer-related surgeries such as breast cancer surgery can put patients at risk with getting this condition along with radiation treatment.

Living with this condition as well as with osteoporosis, has physically limited her and has impacted her overall quality of life.

“I can’t give blood from my right arm, I can’t have my blood pressure checked from that arm and I can’t carry more than 10 pounds and I am a right-handed person, so that means my left side has to do most of the work.”

Deal is hoping to get disability assistance and a hearing has been set for the first of February to determine if she will be approved.

In the meantime, there has been a gofundme page set up for her where people can donate to assist her with her medical and living expenses. Her hope is to raise $25,000, as she currently has raised at little over $5,000.

According to Deal, she owes a balance of $15,000 for her rent and she is grateful that the landlord is allowing her to stay as long as she pays the monthly rent.

The two greatest needs for her is to find affordable housing and get the necessary medical testing she needs to treat her osteoporosis as well as funds to have a colonoscopy as colon cancer runs in her family too.

Deal shared how grateful she has been for the generosity shown by people and when asked what these challenging times have taught her as it relates to people; Deal’s response was direct.

“I have learned friends come into your life for a season, for a reason, or for a lifetime and through this experience I have learned those friends who are genuine and who are my real friends.”

Deal wants to continue to serve and be a blessing to others and even feels what she is going through will do just that—bless others.

“Things happen in life and if you find yourself in a catastrophic situation, you got to get on your knees and he (God) will get you through it. God will use your situation to help others and I am being used to be a blessing to someone else,” she concludes.

To donate to Deal’s gofundme page, please visit: https://www.gofundme.com/qx49p9j8
NLN Update on the Lymphedema Treatment Act

2016 may well be the year that Congress votes to approve the Lymphedema Treatment Act, which provides a Medicare benefit category for essential compression garments and supplies needed by lymphedema patients as part of their treatment and self-care management. Lymphedema affects hundreds of thousands of patients across the country—this lymphatic swelling condition can occur on its own, but for many it is a side effect of cancer treatment that adds an immense physical and financial burden to people who are already faced with a long list of medical expenses.

The National Lymphedema Network is proud to be a part of advocacy efforts to carry this important piece of legislation to passage. Recognizing lymphedema patients is key in creating change in the insurance and medical communities to better deliver coverage to patients with this under-diagnosed condition. The Lymphedema Treatment Act will establish a benefit category in the Medicare statute to provide coverage for the compression supplies essential to the treatment of lymphedema. We encourage all members of the lymphedema community to get involved by writing to their senators and representatives to help in the nationwide efforts to raise support and sponsorship of this bill. Many opportunities to get involved are available at www.lymphedematreatmentact.org.

Over the course of 22 years, the NLN has honored more than 250 exceptional individuals who make a difference, from throughout the United States, Canada, and abroad. In addition, March 6th has been recognized as Lymphedema Awareness Day by state legislatures including California, Florida, Missouri, New York, and Virginia.

Our 2016 Lymphedema Awareness Day Awards included recognition of some of the original congressional sponsors of the bill:

Congressional Sponsors and Original Cosponsors of the Lymphedema Treatment Act:
- Representative David G. Reichert (R-WA-8), Sponsor of H.R. 1608
- Representative Earl D. Blumenauer (D-OR-3), Original Cosponsor of H.R. 1608
- Representative Leonard Lance (R-NJ-7), Original Cosponsor of H.R. 1608
- Representative Janice D. Schakowsky (D-IL-9), Original Cosponsor of H.R. 1608
- Senator Maria Cantwell (D-WA), Sponsor of S.2373
- Senator Chuck Grassley (R-IA), Original Cosponsor of S.2373
- Senator Mark Steven Kirk (R-IL), Original Cosponsor of S.2373
- Senator Charles E. Schumer (D-NY), Original Cosponsor of S.2373
Now, as we move into 2016, we see the real possibility of the passage of these bills in both the House and Senate, possibly within the year. While this legislation provides lymphedema patients across the country with hope for better accessibility to care, we must still work hard and work together to bring about this change. You can write to your senator or representative to be sure that they are in support of these important bills, and we can all help give voice to this long-neglected patient community!

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14 March 2016
First Coast News

Click to tell Congress: Pass the Lymphedema Treatment Act!

It’s just cruel. You beat breast cancer and then lymphedema can hit. It can make your arm or leg swell to enormous sizes for the rest of your life.

Compression garments help. But they are expensive.

The Lymphedema Treatment Act would force Medicare to pay for compression. It would save taxpayers money because untreated lymphedema sets off infections and runs up hospital costs.

In Florida 21,000 breast cancer patients on Medicare have lymphedema, according to LTA organizers.

You can help those folks. And it’s easy. Just click here.

The site will automatically send emails to your congressional representatives in Washington.

The bill could pass this year if Congress hears enough support!

Share this post—please.
BERKELEY, Calif. /California Newswire/ — The National Lymphedema Network (NLN) is celebrating Lymphedema Awareness Month this March. The NLN kicked off the month by recognizing lymphedema patients, medical professionals, and advocates on March 6 for its 22nd annual Lymphedema Awareness Day.

On March 6, 1988, the NLN was founded with the mission of creating awareness of lymphedema through education and promoting and supporting the availability of quality medical treatment for all individuals at risk for or affected by lymphedema. In 1994, the NLN established its annual Lymphedema Awareness Day, which has now been adopted as an official holiday by more than a dozen US states.

“Throughout our global lymphedema community, March is the month of awareness, education, and recognition of all those who inspire us,” said Pat Egan, NLN Interim Executive Director and CEO.

It is an exciting year for the lymphedema community, as the Lymphedema Treatment Act is currently being sponsored in the US House of Representatives as HR1608 and the US Senate as S2373. If passed, the bill will establish a benefit category in the Medicare statute to provide coverage for the compression supplies essential to the treatment of lymphedema. The NLN encourages everyone to take this month to get involved by writing to their Senators and Representatives to support the passage of these important pieces of legislation.

The NLN continues to provide information resources, support, and community for lymphedema patients and medical professionals. For more information about lymphedema, the NLN 12th annual conference in Dallas (Aug 31-Sep 4), the Marilyn Westbrook Garment Fund, the Lymph Science Advocacy Program, the NLN Support Group Network, and many other services for patients, caregivers, therapists and clinicians, contact the National Lymphedema Network at 1.800.541.3259 or visit our website at www.lymphnet.org.
The National Lymphedema Network (NLN) held its Lymphedema Awareness Day Awards March 6.

Each year since 1994, the NLN recognizes patients, caregivers, therapists, support group leaders, advocates, and medical professionals who have inspired and served the lymphedema community.

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• Senator Mark Steven Kirk (R-IL), Original Cosponsor of S.2373

• Senator Charles E. Schumer (D-NY), Original Cosponsor of S.2373

• Gloria Thenda Beckwith, patient, Jonesboro, GA

• Karen Beshai, patient, Mesa, CO

• Traci Spohn, Mon General Lymphedema Support Group, Morgantown, WV

• Huyen Lu Vitale, PT, CLT-LANA, Clermont, FL

For information about the Lymphedema Treatment Act, visit www.LymphedemaTreatmentAct.org
March is Lymphedema Awareness Month, and the National Lymphedema Network (NLN) celebrated its annual Lymphedema Awareness Day this March 6!

The National Lymphedema Network (NLN) is pleased to announce its 2016 Lymphedema Awareness Day Awardees as part of Lymphedema Awareness Month. On March 6th each year since 1994, the NLN has recognized those patients, caregivers, therapists, support group leaders, advocates, and medical professionals who have inspired and served the lymphedema community in exemplary ways.

On March 6, 1988, the NLN was founded with the mission of creating awareness of lymphedema through education and promoting and supporting the availability of quality medical treatment for all individuals at risk for or affected by lymphedema. In 1994, the NLN established its annual Lymphedema Awareness Day Award. Over the course of 22 years, the NLN has honored more than 250 exceptional individuals who make a difference, from throughout the United States, Canada, and abroad. In addition, March 6th has been recognized as Lymphedema Awareness Day by state legislatures including California, Florida, Missouri, New York, and Virginia.

The 2016 Lymphedema Awareness Day Awards are given to:

Congressional Sponsors and Original Cosponsors of the Lymphedema Treatment Act:
~Representative David G. Reichert (R-WA-8), Sponsor of H.R. 1608
~Representative Earl D. Blumenauer (D-OR-3), Original Cosponsor of H.R. 1608
~Representative Leonard Lance (R-NJ-7), Original Cosponsor of H.R. 1608
~Representative Janice D. Schakowsky (D-IL-9), Original Cosponsor of H.R. 1608
~Senator Maria Cantwell (D-WA), Sponsor of S.2373
~Senator Chuck Grassley (R-IA), Original Cosponsor of S.2373
~Senator Mark Steven Kirk (R-IL), Original Cosponsor of S.2373
~Senator Charles E. Schumer (D-NY), Original Cosponsor of S.2373
~Gloria Thenda Beckwith, inspirational patient, Jonesboro, GA
~Karen Beshai, inspirational patient, Mesa, CO
~Traci Spohn, Mon General Lymphedema Support Group, Morgantown, WV
March is Lymphedema Awareness Month, and March 6th is Lymphedema Awareness Day. For more information about lymphedema, contact the National Lymphedema Network at 1.800.541.3259 or visit our website.
Lymphedema Awareness Day: Is Lymph node removal with cancer surgery really necessary?

By Ann Fonfa

On March 6th the lymphedema community will celebrate the 22nd annual Lymphedema Awareness Day, otherwise known as Lymphedema D-Day. But despite all these years of awareness, lymphedema is still not curable and remains "an unfortunate side effect" of conventional treatment for cancer. It's time for the medical community to acknowledge that lymphedema is often avoidable and linked to lymph node removal.

It's common practice for oncologists to recommend lymph node removal after cancer diagnosis. Removal of lymph nodes occurs with many cancers - breast cancer, prostate cancer, cervical cancer, colon cancer, melanoma, ovarian cancer, and others too.

The conventional medical view is that lymph nodes contain cancer cells and therefore must be removed. At the same time, cancer is a systemic disease, so removing parts of the body doesn't provide a real solution. In other words, the swollen lymph nodes aren't the problem and neither is the tumor, which is often also surgically removed. The tumor and/or the swollen lymph nodes are a result of the problem.

Surgery doesn't address the underlying cause of why someone got cancer in the first place, and neither does chemotherapy or radiation! This is an important concept to grasp.

Moreover, when lymph nodes capture cancer cells, might they just be doing their job? And if so, is this...
really metastasis, which is what is commonly believed?

Lymph Node Removal in Breast Cancer Patients

Monica Morrow, MD, a well-known clinical researcher and conventional medical doctor, has been studying tissue from breast cancer survivors who have small numbers of cancer cells called micro-metastases in their lymph nodes. Currently, even small findings of cancer cells such as these are considered deadly by the allopathic community.

But Dr. Morrow's findings show that these small numbers of cancer cells do not affect survival rates. Other medical professionals are just beginning to question the common practice of lymph node removal. Surgical removal of lymph nodes, as a way of reducing metastasis, may actually be causing more harm than good because of the potential lifelong complications of lymphedema.

A European study in 1981 evaluated 716 women with breast cancer and found no difference in survival when extra lymph nodes were removed.

Yes, that's right, this study was done in 1981. And yet, how many times in recent years have you heard someone with cancer having surgery to have their lymph nodes removed? I have heard it dozens of times. However, one must ask of this accepted practice, "Has the correct outcome been looked at to justify surgical removal of lymph nodes?"

The key issue that is not being discussed is... what is the most important outcome when the lymphatic system is harmed, either by surgery or radiation?

Studies into Lymph Node Removal Needed

Beginning in the late 1800s massive surgeries were performed for breast cancer. This universal surgery, called the Halstead Radical (after its originator), removed the entire breast, muscle, axillary area (underarm) and more, in an effort to cure breast cancer.

Almost 70 years later European surgeons began offering lumpectomy, a less aggressive partial breast removal surgery, and found that survival rates were similar. In addition, a large clinical trial from the United States proved the same thing with a report on a 10-year follow up in 1985. This study actually compared mastectomy to lumpectomy with and without radiation and over time has continued to show similar survivals for each segment of the trial.

The one area that unfortunately has NOT been re-examined is axillary lymph node dissection. For this reason, lymph node removal during surgery continues to be part of the procedure even though in some, fewer nodes are being removed.

**What has not been concluded from any clinical trials is whether or not removal of lymph nodes**
directly impacts survival. Especially enough to warrant the potential complications that could arise any time in an individual's life afterwards.

Prior studies have not been able to show a survival benefit from lymph node removal. In fact, a 2003 paper stated:

"No published randomized controlled trial exists that demonstrates improved overall survival for patients with cancer of any type undergoing surgery of the regional lymphatics. We believe the presence of tumour in the regional lymphatics indicates the presence of systemic disease, and therapeutic interventions should be directed accordingly."

So are those people with lymph node involvement already dealing with more advanced disease that current medical technology doesn't know how to detect?

Imagine, then, if complementary or alternative therapies were incorporated in an effort to improve survival, instead of going solely to radiation and/or surgery.

After invasive treatments such as surgery and/or radiation, there is often damage, including pain, that lasts for the rest of an individual's life. A damaged lymphatic system means that a person is much more susceptible to illness and injury as the lymphatic system ordinarily helps the body to heal faster and better. Very few, if any, studies in any type of cancers have examined the long-time results of node removal/lymph system damage with these harms in mind.

In a review published in May 2015, Cochrane researchers found that overall survival for participants with melanoma who underwent sentinel lymph node biopsy (SLNB) had no improvement in overall survival. However, recurrence of the melanoma at a distant site occurred more frequently in those participants in the SLNB group.

Lymphedema is Not Just an "Unfortunate Side Effect" of Lymph Node Removal

Imagine a skin burn where ordinarily the lymph cells rush to the area. In a sluggish lymphatic system – one that has sustained damage – there is no "rush" involved. The clogged or swollen area does not easily allow the appropriate immune cells to reach the affected area, and healing can take much longer.

People with leg or lower body lymphedema may find walking difficult or painful. Some people may not be able to pick up their children or grandchildren due to weakness and swelling in their arms. Over time, sensations in the areas may be reduced. Anyone who has had lymph nodes removed is at much higher risk of serious infections like cellulitis, which can lead to sepsis.

And lymphedema can occur at any time. There is no time limitation on the development of lymphedema (the swelling and visible sign of damage to the lymphatic system). And current treatments are only variations on temporary reduction in swelling.
If you have cancer, surgical removal of lymph nodes is a critical subject to discuss with your doctor. Many doctors do things because it's common practice or standard of care, without examining further. But you are a unique individual and every cancer is different - you have to weigh your own risks and benefits.

Make sure you involve an alternative practitioner who specializes in cancer to find out what other options are available to you. Sometimes, it's a good idea to take a step back and not rush into a decision. As an informed patient, it's important that do your own research and be proactive in all your health care choices.
6 March 2016

American Lymphedema Framework Project


Happy Lymphedema Awareness Day!

A message from the Lymphedema Advocacy Group

Today marks the 22nd annual Lymphedema Awareness Day, a tradition started by Saskia Thiadens, founder of the National Lymphedema Network (NLN). Each year, on this day, the NLN honors inspirational patients, exceptional caregivers, and individuals who have made remarkable contributions to bettering the lives of those who suffer from lymphedema.

This year, the NLN has selected our congressional leadership team - the sponsors of our House and Senate bills - in recognition of their outstanding work to improve insurance coverage for compression supplies through passage of the Lymphedema Treatment Act!

Tomorrow, on behalf of the National Lymphedema Network, I will have the pleasure of presenting these awards in person to some of the offices listed below. I have included their phone numbers below my signature, in case you would like to call them to say, "Thank you for sponsoring the Lymphedema Treatment Act, and please do everything in your power to ensure that this bill is passed this year!"

These members of Congress are fighting for us, and we should let them know how much we appreciate it. Several weeks ago our lead House sponsor, Rep Dave Reichert, made a passionate plea, calling on Health and Human Services Secretary Sylvia Burwell to help us in our quest for coverage of compression supplies. You can view this must-see video clip here.

This statement was made in the context of a budget hearing discussing the President’s cancer "moonshot" initiative, and hence why Rep Reichert refers specifically to cancer related lymphedema, but he is working to improve care for all lymphedema patients, and the LTA will ensure coverage of compression supplies for lymphedema from all causes.

Make sure to continue to write and call your own members of Congress, as many times as it takes, if your Representative and both Senators are not yet cosponsors. The links to all our advocacy forms that make it easy to take action are listed under the How You Can Help menu along the left hand side of our
Together, we CAN and we WILL pass the Lymphedema Treatment Act!

Heather Ferguson
Founder & Executive Director
Lymphedema Advocacy Group
LymphedemaTreatmentAct.org

Here are the numbers to call our Congressional leadership team and say, "Thank you for sponsoring the Lymphedema Treatment Act, and please do everything in your power to ensure that this bill is passed this year!"

SENATE:
Senator Maria Cantwell (WA) - 202-224-3441
Senator Chuck Grassley (IA) - 202-224-3744
Senator Mark Kirk (IL) - 202-224-2854
Senator Chuck Schumer (NY) - 202-224-6542

HOUSE:
Representative Dave Reichert (WA) - 202-225-7761
Representative Earl Blumenauer (OR) - 202-225-4811
Representative Leonard Lance (NJ) - 202-225-5361
Representative Jan Schakowsky (IL) - 202-225-2111
Lymphedema a Blessing in Disguise for Nancy Yee

By Shawn Loging

Lymphedema is a condition where fluid builds up in arms, legs or other parts of the body.

And this Sunday, March 6 marks National Lymphedema Awareness Day.

Locally, a Madelia woman with Lymphedema is helping others with the condition all around the globe.

EZ Medical Wraps Owner Nancy Vee says, "I refer to my Lymphedema as my friend because it's with me all the time and without me having this disease, I wouldn't have met all the wonderful people throughout the world that I've met."

A blessing in disguise that has given Nancy Vee a mission in life to bring awareness to the condition of Lymphedema.

It often includes symptoms of swelling as fluid collects in the arms or legs, caused by damage to the lymphatic system.

Mayo Clinic Health System-Mankato Physical Therapist Rhonda Omtvedt says, "Lymphedema itself is not life threatening, but left untreated that skin continues to go through a lot of fibrotic changes and you're at a high risk of infection."

According to the National Lymphedema Network, an estimated 100 million people worldwide are affected by the condition, but many go un-diagnosed.

And for those who are diagnosed, the treatment is often a daily self-administered regimen of manual lymphatic drainage and compression.

Vee says, "Compression to gradually squeeze and move that fluid up into a lymphatic system that will get rid of it."
When Vee was diagnosed in 2013, she quickly realized that she could create something that worked better than what was available on the market with her sister at their upholstery shop in Madelia.

The first time she left therapy, she says the wrap around her leg was falling off.

Vee says, "We're using masking tape, really, I mean come–on man, there's other things out there and that's why we came up with what we did."

Creating her own business, EZ Medical Wraps, where she sews custom made compression foam and sleeves for Lymphedema patients all across the world.

But last month brought a new challenge: her business was one of seven affected by the Madelia fire... and now she's anticipating reopening very soon.

Vee says "I'm excited; I can't wait to get back to work. Yesterday, it was one month yesterday that Madelia strong got really strong."

Vee says their shop is set up and she's waiting on a piece of equipment to make the wraps.

Vee says, "We had a couple of ladies come in this week and made a sleeve, their first sleeve. We're training a few people to help us so we can get caught up quicker and stay caught up because I get messages every day, can we order."

EZ Medical Wraps has been receiving pre-orders for their products

Vee says she's working to bring awareness to Lymphedema to help the public and general practitioner doctors better understand the condition.

There are also legislative efforts to have the compression, short stretch wraps and other equipment those with Lymphedema use to treat the condition covered by insurance because now there are a few that cover some of what can be expensive supplies but not many.

Vee also provides wraps for children with Lymphedema for free and offers discounts to veterans.
March is Lymphedema Awareness Month. That is a very important time of year for me and my lymphedema friends. The condition is rarely heard of because of a lack of education.

Doctors were only given one hour of studies on the lymphatic system in medical school.

**What is Lymphedema?**

Lymphedema, also known as lymphatic obstruction, is a condition of localized fluid retention and tissue swelling caused by a compromised lymphatic system, which normally returns interstitial fluid to the thoracic duct and then the bloodstream.

The condition can be inherited or can be caused by a birth defect, though it is frequently caused by cancer treatments, and by parasitic infections.

Though incurable and progressive, a number of treatments can ameliorate symptoms. Tissues with lymphedema are at high risk of infection.

Symptoms may include a feeling of heaviness or fullness, edema, and (occasionally) aching pain in the affected area. In advanced lymphedema, there may be the presence of skin changes such as discoloration, verrucous (wart-like) hyperplasia, hyperkeratosis, and papillomatosis; and eventually deformity (elephantiasis).

Lymphedema should not be confused with edema arising from venous insufficiency, which is *not* lymphedema. However, untreated venous insufficiency can progress into a combined venous/lymphatic disorder which is treated the same way as lymphedema.

My name is Debbie Parsons. I am 44 years old and I have primary lymphedema that I inherited from my great grandmother. I started showing signs of the defect in 2000. I was treated for water retention for years.

Without knowing I was a stage 1 at that time. In 2011 my new doctor noticed the size of my legs and expressed deep concern.

He was sure it was not water retention. After doing his research, he came back with the diagnosis of lymphedema and informed me that there is no known cure.

By this time I was a stage 3 with very large legs and beginning deformities. If I had been properly diagnosed at the onset of symptoms it could have been reduced to a stage 0. It becomes irreversible at stage 2.
In order to continue to function and remain mobile I have to see a therapist 2-3 times a week for manual lymphatic drainage. I use a compression pump four times a day at an hour each session.

I wrap my legs in compression wraps in between pumping. This is a daily routine and a full time job to maintain.

Having lymphedema for most of LE patients is also dealing with depression, isolation, insecurities etc; It is a painful debilitating disease that few are aware of.

Supplies to keep the LE from getting to the point of being not being able to function can be very costly. Insurance companies are not on board with coverage for LE and products that is required to manage it. Some LE patients are currently wheelchair bound due to the fact insurance companies will not cover medical equipment needed to maintain or even reversed if diagnosed and treated early.

We “lymphies” are working together to get a bill passed to get insurance companies on board to cover proper treatment for lymphedema.

You can learn more about this by visiting www.lymphedematreatmentact.org. It only takes a few minutes to support the bill. It took me a little over a year to get approved for my compression pump.

I currently have a gofundme page set up trying to raise money to purchase Compression products that is needed to treat my legs.

No LE patient should be humiliated to the point of “begging” for financial help to buy medical supplies just to survive this disability because insurance will not cover.

Please help support the Lymphedema Treatment Act.

Willie Parson can be emailed at willieparsons@rocketmail.com.
Men and women battling cancer are shedding their patient statuses with each successful surgery and effective radiation treatment, however, as one battle ends, another begins. The latest hurdle for them is a change in Medicare B coverage for use of pneumatic compression devices (PCDs) to treat secondary lymphedema that will take effect December 1.

Secondary lymphedema is caused by damage or blockage to the lymph system as a result of infection, injury, cancer, removal of lymph nodes, radiation to the affected area, or scar tissue from radiation therapy or surgery, according to the National Institute of Health (NIH). Although a chronic condition, secondary lymphedema can be managed in a number of ways and lymphedema therapists, researchers and patients want the public to know that many of these therapies actually work together to improve patients' limb function.

"A lot of people think that therapists will use the pump to replace the manual therapy, but the manual therapy and the pump work in two totally different ways," said Cynthia Shechter, owner and director of ShechterCare in New York. "We have compression devices in the office and typically we start the session using a basic pneumatic pump and the reason we do that is it's sort of a nice preparatory way to get the limb ready for manual therapy.

Medicare currently reimburses PCDs for those diagnosed with secondary lymphedema as they've done for the last 20 years. During that time they've enabled older patients to manage their condition at home.
This is especially important to the nearly 1 million lymphedema patients eligible for Medicare. Mobility could already be a cause of concern for this 65 and over population who may have to rely on a family member to bring them to therapy appointments.

"My biggest fear as I get older is will I become less flexible?" said Andrea Weinreb, 59 who was diagnosed with secondary lymphedema in 1998. "It's really hard to do stuff when you have lymphedema, it's really hard to put on your compression stockings; it's hard to do anything."

Weinreb, a survivor of cervical cancer, began using a Bio Compression System Sequential Circulator after undergoing lymph nodes transfer surgery in 2008. She wouldn't have been able to afford the device on her own so she says she's lucky she had 100% coverage for the device under her insurance plan. She's wary though of Medicare's new local coverage decision (LCD) which requires a patient to have a severe stage of lymphedema or have had conservative treatments fail in order for a pneumatic compression device to be deemed "reasonable and necessary."

"If I learn that Medicare is worse than what I'm used to then I'm going to have a problem when I turn 65 because I'm going to need what I need."

Lymphedema societies like the Lymphatic Education & Research Network and the National Lymphedema Network are urging the Centers for Medicare & Medicaid Services (CMS) to withdrawal the LCD policy for both medical and technical reasons because of patients like Weinreb.

"They're effectively removing access to treatments for patients that have few treatment options," said Maggie Thompson, vice president of payer relations and government affairs for Tactile Medical. Not only that, she explained the contractors who decide LCDs have also committed a procedural violation of Medicare's National Coverage Determination (NCD).

These determinations work similarly to the way state and federal laws work. Just as state laws cannot restrict a citizen's rights afforded them under federal law, a local coverage decision cannot contradict what is covered under a national coverage decision.

Medicare is following suit of other private insurance companies that have made similar requirements for patients to be reimbursed for PCDs. The fear is more companies could follow suit if Medicare's LCD goes through.

Plus, they made the LCD announcement on Oct. 15 without providing the minimum 45-day public comment period.
"It's very confusing to many of us as to how they arrived at these conclusions around this algorithm for not paying for pneumatic compression pumps until the patient is more severe," said Nicole Stout, DPT, CLT-LANA who is a member.

One theory behind their decision is cost. In 2014 Medicare paid approximately $24 million for pneumatic compression devices out of a $597 million budget according to their Part B National Summary. That same year Stanford University researchers studied patients with cancer-associated lymphedema using PCDs and found that the average annual cost of care for a patient with the condition decreased from $62,190 to $50,000 a year when the patient used the device to treat their swelling (https://med.stanford.edu/news/all-news/2014/12/lymphedema-home-treatment-improves-outcomes-reduces-costs--rese.html).

"There is no evidence to say to us that says we shouldn't use the device until the patient gets to be more severe," said Stout. "It's very constraining to the patients and maybe even putting some at harm who could utilize the device to help them keep their condition in a less-severe stage."

If the LCD goes into effect, Medicare patients do have the right to appeal the coverage decision but Thompson said this is a long multi-step process. The U.S. Dept. of Health and Human Services estimates an average processing time of 547 days.

"I have patients all the time who get denied for a device," said Shechter. Often Shechter is able to get the denial reversed by writing an appeal letter attached with articles and evidence on behalf of her patients.

The bottom line though is precious time to treat lymphedema and keep it in check. Now through Nov. 30, Tactile Medical is asking the public to contact their legislators and urge Medicare to withdraw the policy (http://pcdpolicy.org/).
The National Lymphedema Network (NLN) announced Oct. 27 that registration is now open for the 12th NLN International Conference, to be held Aug. 31-Sept. 4, 2016 at the Omni Hotel in Dallas.

The event hosts lymphedema medical professionals, industry representatives, and advocates to share best practices and new research.

"Our theme for the 2016 Conference in Dallas is 'Shaping the Future through Commitment, Evidence and New Frontiers,'" said NLN Board Chair Patricia Egan. "NLN conferences continue to present groundbreaking research from throughout the world in a forum designed to foster new discussion and exchange between the leading organizations and professionals that are guiding the lymphedema patient and medical community into the future."

The 12th NLN International Conference program consists of instructional and plenary sessions, an exhibit hall featuring industry representatives and presentations, poster sessions, networking events, the Lymph Science Advocacy Program (LSAP) for patients, and four pre-conference instructional seminars. Early-bird discount registration is available at www.lymphnet.org/events/2016-nln-conference.
Serving Size on Label Not Always a Healthy Choice

By Karen Collins

Q: Does the serving size listed on a food label signify the amount that is healthy for me to eat?

A: No, not always. The serving size on the label provides a reference amount for interpreting the other information on the label's Nutrition Facts panel. It's the first item you should look at to see what that food is contributing to your overall eating.

Measure the amount you usually eat and compare to what is on the label. For example, if the serving size for ice cream lists a half-cup, but you eat one cup, if the label says 140 calories, you are getting double that: 280 calories. On the other hand, if you have one slice of whole-wheat bread and the label lists a serving as two slices, or a half-cup of frozen broccoli instead of the one cup that is a standard label serving, then you are getting half as many of the listed calories, as well as fiber and vitamins.

You can also use the serving size to compare nutritional differences between similar foods. For example, if you're looking for a cereal high in fiber, when you can compare the cereal's labels to see which one has more, make sure you are comparing similar amounts.

How much you should eat for a healthy portion depends upon your nutrient needs based on your age, gender, physical activity, overall calorie needs and more. Even for two people with similar overall needs, a portion size that works well for one person may differ from the best portion for someone else if they differ in the other food choices and amounts they select.

Q: Is it true that breast cancer survivors risk developing or worsening lymphedema if they do strength-training exercises with their arms?

A: Exercise, especially of the arms, used to be considered too risky for breast cancer survivors due to fears of lymphedema, which is an accumulation of lymph in the soft tissue with swelling. This condition is not usually life-threatening, but it can seriously impact quality of life, with decreased flexibility, difficulty fitting in clothes, feelings of heaviness and increased risk of recurrent skin infections. Yet lack
of exercise can begin a cycle of physical decline with serious consequences; emerging research now suggests that the best course is safe exercise rather than no exercise.

Lymphedema, which can occur within days or years after cancer or its treatment, blocks flow in the lymph system that transports lymphocytes (white blood cells) and other infection-fighting cells throughout the body, resulting in swelling where the fluid accumulates. For breast cancer survivors, this tends to involve the arms and/or hands. As many as one in three women whose breast cancer surgery includes full removal of lymph nodes in the underarm area (axillary node dissection) experience lymphedema, and radiation therapy to the area may lead to its development, too.

Once lymphedema develops, it doesn't go away, but some steps may make it easier to live with or possibly prevent it, according to the National Lymphedema Network. Avoid extreme exercise of the arm that could potentially be affected because it can promote inflammation or injury. Current studies in breast cancer survivors suggest that starting with low intensity upper-body exercise and progressing slowly does not increase onset of lymphedema and is better than no upper arm exercises as long as any symptoms that develop are monitored closely and treated.

The National Comprehensive Cancer Network guidelines recommend that patients with or at risk for lymphedema be evaluated by a certified lymphedema therapist to ensure it is safe to exercise. Cancer survivors who have lymphedema should wear a garment known as a lymphedema sleeve during all exercise that uses the affected limb, according to the National Cancer Institute. Those without lymphedema do not need to wear this while doing exercise. If you are a survivor and it's unclear whether you have lymphedema and what exercises to do, talk with your physician and health care team.

Resources to help you find a certified lymphedema include the Lymphology Association of North America and the National Lymphedema Network.

- The American Institute for Cancer Research (AICR) is the cancer charity that fosters research on the relationship of nutrition, physical activity and weight management to cancer risk, interprets the scientific literature and educates the public about the results.
National Lymphedema Network Announces 12th International Conference

12th NLN International Conference to bring together medical and advocate community to further progress made serving lymphedema, a chronic swelling condition that can be a common side effect of breast cancer, but often goes misdiagnosed and untreated.

Registration is now open for the 12th National Lymphedema Network (NLN) International Conference, to be held on August 31 - September 4, 2016 at the Omni Hotel in Dallas, TX. The event is a rare opportunity for lymphedema medical professionals, industry and advocates from all over the world to share best practices and new research in support of this prevalent, yet under-served patient population.

Lymphedema is a chronic swelling caused by damage or removal of lymph vessels, often during surgery or cancer treatment, (secondary lymphedema) but can also be hereditary (primary lymphedema). Patients often find it difficult to obtain diagnosis and referral to proper treatment by a Certified Lymphedema Therapist (CLT).

“Our theme for the 2016 Conference in Dallas is ‘Shaping the Future through Commitment, Evidence and New Frontiers,’” said NLN Board Chair Patricia Egan, “NLN conferences continue to present ground-breaking research from throughout the world in a forum designed to foster new discussion and exchange between the leading organizations and professionals that are guiding the lymphedema patient and medical community into the future.”

The 12th NLN International Conference will bring together Certified Lymphedema Therapists, doctors, surgeons, patient advocates and other lymphedema professionals for a robust program consisting of instructional and plenary sessions, an exhibit hall featuring leading industry representatives and presentations, poster sessions, networking events, the Lymph Science Advocacy Program (LSAP) for patients, and four pre-conference instructional seminars. Early Bird-discount registration for Conference, Exhibitor, and LSAP registration as well as Preliminary Program are available online at www.lymphnet.org/events/2016-nln-conference.
The National Lymphedema Network (NLN) is an internationally recognized non-profit organization founded in 1988 by Saskia R.J. Thiadens, RN, to provide education and guidance to lymphedema patients, healthcare professionals and the general public by disseminating information on the risk reduction and management of primary and secondary lymphedema. [www.lymphnet.org](http://www.lymphnet.org)
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The National Lymphedema Network (lymphnet.org) is an internationally recognized non-profit organization founded in 1988 by Saskia R.J. Thiadens, RN, to provide education and guidance to lymphedema patients, healthcare professionals and the general public by disseminating information on the risk reduction and management of primary and secondary lymphedema.
If you are a woman recovering from breast cancer, what are some of the issues you could face? If you have lymphedema, what can you do to help ease the swelling and what things should you avoid?

Ann Frost, physical therapist at The Queen’s Women’s Health Center, says after breast cancer treatment is over, some common issues women can face include:

- Fatigue
- Lymphedema/swelling
- Bad posture
- Weakness
- Pain and stiffness in the shoulders, chest and upper back
- Sexual dysfunction

Lymphedema is a swelling of the chest wall and/or arm, and symptoms include a tight, full, heavy feeling. It can occur at any point after treatment, even up to decades later. Get treatment as soon as you feel symptoms from a PT or an OT with specialized training.

In case of infection – red streaks, sudden rapid swelling, fever, pain – go to an MD or the ER right away. Risk reduction includes exercise, and maintaining optimal weight. Also, avoid needle sticks and sunburn, and don’t take blood pressure from affected arm.

Frost says it is beneficial to exercise if you have lymphedema, and can be safe to travel, though you may need to wear compression garments. You should also check National Lymphedema Network guidelines before you go.
To connect with physical therapist Ann Frost, contact The Queen’s Women’s Health Center’s Physical Therapy Department at (808) 691-7729
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The Kansas City infoZine


Strength Training Exercising for Breast Cancer Survivors

By Karen Collins, MS, RDN, CDN, FAND

Washington, DC - infoZine - Scripps Howard Foundation Wire - Q: Is it true that breast cancer survivors risk developing or worsening lymphedema if they do strength-training exercises with their arms?

A: Exercise, especially of the arms, used to be considered too risky for breast cancer survivors due to fears of lymphedema, which is an accumulation of lymph in the soft tissue with swelling. This condition is not usually life-threatening, but it can seriously impact quality of life, with decreased flexibility, difficulty fitting in clothes, feelings of heaviness and increased risk of recurrent skin infections. Yet lack of exercise can begin a cycle of physical decline with serious consequences; emerging research now suggests that the best course is safe exercise rather than no exercise.

Stretch Bands Photo courtesy of AICR.org
Lymphedema, which can occur within days or years after cancer or its treatment, blocks flow in the lymph system that transports lymphocytes (white blood cells) and other infection-fighting cells throughout the body, resulting in swelling where the fluid accumulates. For breast cancer survivors, this tends to involve the arms and/or hands. As many as one in three women whose breast cancer surgery includes full removal of lymph nodes in the underarm area (axillary node dissection) experience lymphedema, and radiation therapy to the area may lead to its development, too.

Once lymphedema develops, it doesn’t go away, but some steps may make it easier to live with or possibly prevent it, according to the National Lymphedema Network. Avoid extreme exercise of the arm that could potentially be affected because it can promote inflammation or injury. Current studies in breast cancer survivors suggest that starting with low intensity upper-body exercise and progressing slowly does not increase onset of lymphedema and is better than no upper arm exercises as long as any symptoms that develop are monitored closely and treated.

The National Comprehensive Cancer Network (NCCN) guidelines recommend that patients with or at risk for lymphedema be evaluated by a certified lymphedema therapist to ensure it is safe to exercise. Cancer survivors who have lymphedema should wear a garment know as a lymphedema sleeve during all exercise that uses the affected limb, according to the National Cancer Institute. Those without lymphedema do not need to wear this while doing exercise. If you are a survivor and it’s unclear whether you have lymphedema and what exercises to do, talk with your physician and health care team.

**Related Links**
Resources to help you find a certified lymphedema include the Lymphology Association of North America link and the National Lymphedema Network link.
Surgeons take on a vexing consequence of breast cancer treatment

By Stacey Burling

Deb Gleason has had surgery for breast cancer twice. She had breast-sparing surgery on her left side in 2000 and a double mastectomy in 2012 when cancer returned on the right.

Cancer-wise, she's had a clean bill of health since, but the second procedure left her with a miserable, incurable side effect that plagues millions of cancer survivors: lymphedema.

The condition, caused by disruption of the body's lymphatic system, causes arms or legs to swell with fluid and fat. Until the last five years or so, the only treatments available to most patients included a combination of specialized massage, exercises, and compression garments.

Gleason got it in her right arm. She was lucky to avoid pain, but she couldn't fit into her clothes and had to wrap her arm each day in ACE bandages, starting with each individual finger and continuing to the armpit.

"It was very, very annoying," said Gleason, 64, of Telford. "I can tell you I hated that wrapping. I hated it."
That explains why Gleason was eager to try a newer way of treating lymphedema: surgery. Sameer Patel, a plastic surgeon at Fox Chase Cancer Center, transferred healthy lymph nodes from her groin to her armpit, replacing nodes that were removed during her mastectomy.

Just a trace of swelling remains. "I've had remarkable results," she said.

Gleason is among the pioneers trying new surgical techniques, though results range from big improvements to no change. In addition to lymph node transfers, surgeons are doing "bypasses," which redirect built-up fluid into blood vessels.

Two hospitals in this area perform the procedures: Fox Chase and the Hospital of the University of Pennsylvania (HUP). HUP plastic surgeon Suhail Kanchwala, who started doing them about three years ago, estimates fewer than 20 facilities in the country have each done 20 or more bypasses or transfers.

Some surgeons are also doing a liposuction-like procedure to remove the solids that build up in patients with lymphedema.

Saskia Thiadens, executive director of the National Lymphedema Network, said patients and doctors need clinical trials and long-term results to evaluate the new treatments. And, she said, "anybody who has surgery needs to be monitored very closely, not only by the surgeon, but by a lymphedema therapist as well."

We have lymph nodes all around our bodies. They are brownish and look like peanuts, Patel said. Those in our necks can swell when we get an infection. The nodes are part of an alternative plumbing system that collects and processes fluid that leaks from blood vessels and fat from our intestines. Eventually, it dumps the liquid - called lymph - into a vein near the heart.

The nodes themselves are a key part of our immune system. They identify and analyze invading bacteria and viruses so other parts of the system know what - and how - to attack, Kanchwala said. They are among the first places where some cancers spread. That’s why surgeons often remove them.

The trend toward sentinel node biopsies in breast cancer surgery that began in the late 1990s has greatly reduced the number of nodes removed from many women. It targets the first nodes into which a tumor drains. But some patients still lose a lot of them, and some can get lymphedema when only one node is taken.

Patel said 4 percent to 17 percent of women get lymphedema after sentinel node biopsies, compared to 24 percent to 49 percent of those who lose all the underarm nodes.

Lymphedema is also a common side effect for people treated for gynecological, prostate, and head and neck cancers as well as melanoma.
Doctors said cancer survivors are living longer and getting more radiation, another risk factor for lymphedema. Lymphedema often begins soon after surgery, but it can also emerge years later.

The swelling and the constant, time-consuming attention lymphedema requires are painful reminders of cancer. When nonsurgical techniques don't work, patients' limbs can grow very large and hard.

"People say you're lucky to be alive and what are you complaining about?" said Constance Chen, a New York surgeon who is studying lymph node transfers.

"There are people that can't work. They can't wear normal clothes. It's incredibly debilitating and depressing for people."

The surgical treatments are the province of plastic surgeons, who are skilled at moving tissue from one part of the body to another. Few doctors do them, practitioners said, because the microsurgical techniques required are technically difficult and use specialized equipment.

The bypass is a slightly older procedure in which a lymph vessel near a disrupted part of the lymphatic system is surgically attached to a blood vessel, giving trapped lymph a place to flow. It can have a quick, dramatic effect, surgeons said, but Kanchwala worries the connection can clog eventually.

In the transfer, a clump of lymphatic tissue is harvested from the groin or neck. The site is chosen carefully to avoid new lymphedema. Surgeons then transfer this to a limb that needs drainage. The surgeon attaches blood vessels in the transferred tissue to nearby vessels to provide a blood supply. When things go right, lymph vessels in the transferred tissue grow and find a way to hook up to the system. It may be months before patients see results.

Surgeons say they get similar results from bypasses and transfers. They sometimes do both in the same patient.

Data are sparse, but doctors who perform the surgery said a majority of patients say they feel better. Surgeons said they sometimes cannot see or measure these differences, but patients tell them an arm feels lighter or softer. It is impossible to predict who will do well, although obese patients and those with more severe lymphedema are not good candidates.

Patel estimates that 50 percent to 60 percent of patients get a measurable response. Kanchwala says one-third get a measurable change in limb size. A third get no change. The rest report improvement that may not be visible.

Matthew Hanasono, a plastic surgeon at the University of Texas MD Anderson Cancer, one of the first institutions to test the procedures, said 10 percent to 20 percent of patients return to normal and 70 percent to 80 percent report at least some improvement.
"The results are continuing to improve as we get more experience," he said.

Jay Granzow, a UCLA plastic surgeon, said that for patients with the most severe lymphedema, reducing fluid isn't enough because much of the swelling is caused by fat that builds up in the affected tissue. He said he had gotten good results from suctioning out excess fat and fibrous tissue - it looks like curdled milk - in a process called suction-assisted protein lipectomy. Patients must continue to wear compression garments forever. In some cases, he does a bypass or transfer later, but he says patients likely still need compression.

Surgeons agreed the treatments significantly reduce the odds of infection, a huge issue for people with lymphedema. Patients can end up in the hospital after bug bites or tiny punctures to the affected limb.

A paper cut sent Noreen Saggese, a breast cancer survivor from Sewell, to the emergency room with cellulitis, a bacterial skin infection. Another infection from a manicure put her in the hospital for four days. "The infection went lickety-split all the way up my arm into my left breast and across my chest," she said.

Her doctor sent her to Kanchwala for a transfer because he was afraid an infection would kill her. She had the procedure in July. Her range of motion has already improved and the affected arm is a little smaller. "I don't have any heaviness or tight feeling any more," she said.

Chen, who is leading a clinical trial of the bypass, is torn between patients' obvious need for help and her frustration with the unpredictable results.

"I am really struggling with whether or not to continue doing it," said Chen, director of microsurgery at the New York Eye & Ear Infirmary of Mount Sinai. "When people ask me about it, I am very honest about it. I tell them it is not a magic bullet. You need a lot of therapy afterward."

Other doctors are more enthusiastic but warn patients they may not benefit.

"This surgery is never going to replace lymphedema therapy, and I'm very careful to tell patients it's not a cure," Kanchwala said.

Nonetheless, Tonya Miller, a Fox Chase patient from Tacony, is a fan. She had painful lymphedema - she called it her "big arm of waste" - and was prone to infections before her lymph node transfer two years ago. She said she noticed improvement quickly. Her left arm, which had been 24 percent bigger than the right, is now only 2 percent bigger.

"It's totally amazing," she said.
SEBRING — For several years, Lake Placid resident Diane Martin was experiencing extreme swelling in her left arm. After suffering with a progressive increase of the swelling, she was referred by her vascular surgeon to Lynda Yates, a certified lymphedema therapist at Highlands Regional Rehabilitation.

“In order to reduce swelling and move the lymphatic fluid through my body, Lynda massaged my arm and applied compression,” Martin said, who explained that Yates was able to reduce the swelling markedly.

Although the swelling was brought under control, lymphedema is, unfortunately, a condition that returns again. “You have it for the rest of your life,” Martin said.

“Lymphedema is caused by a breakdown in the lymphatic system,” Rowena Badenhorst, director of rehabilitation at Highlands Regional Medical Center, said.

The lymphatic system is part of the circulatory system and a vital part of the immune system. It comprises of a network of vessels that carry a clear fluid called lymph and normally returns tissue fluid to the thoracic duct — the largest lymphatic vessel in the lymphatic system — and then the bloodstream. It works to drain and process excess fluids and other substances like bacteria, viruses, protein and waste products. When the lymphatic system is compromised, localized fluid retention and tissue swelling can occur.

“When this system fails to function at an optimal level, chronic swelling occurs,” Badenhorst said.

For many, lymphedema is caused by the removal of lymph nodes as part of cancer treatment. For others, radiation therapy causes damage to the lymph nodes and affects their ability to function correctly. Still others suffer from lymphedema due to chronic venous insufficiency, or “weak veins.”
According to Badenhorst, swelling is initially caused by failure of the veins to efficiently return blood to the heart. As the extremities swell, the lymphatic system works harder to process the excess fluid. It will eventually become overworked and less effective, resulting in chronic swelling.

Generally speaking, lymphedema develops gradually and may be present for several years before specialized treatment is sought, as is the case with Martin. However, the condition can also come on suddenly.

“A sudden onset can occur, especially when injury or surgery is involved,” Badenhorst said.

In some cases, the underlying cause cannot be identified, and may in fact originate from an inadequately formed lymphatic system.

The swelling brought on by lymphedema can occur in one or more arms or legs and sometimes in all four limbs. However, it can also occur in other parts of the body, such as the breasts, chest, and the underarms.

At first the swelling may be slight and go away with simple measures like elevation or rest. However, as time passes, the swelling can become worse and subsequently lead to other issues, including: changes in the skin and underlying tissue; leakage of fluid from the skin; blistering; redness; susceptibility to infection; and severe swelling of the [affected] limb.

“Wounds may develop that are very difficult to heal,” Badenhorst said.

Factors that may increase the risk of lymphedema include older age, excess weight or obesity, and rheumatoid or psoriatic arthritis.

According to the Lymphatic Education & Research Network, “Up to 10 million Americans, and hundreds of millions worldwide, suffer from lymphedema and lymphatic diseases.” Also, according to LE&RN, more people combined suffer from these diseases over multiple sclerosis, muscular dystrophy, ALS, Parkinson’s disease, and AIDS. Although it affects mainly women, the condition also affects men.

Although the condition is not curable, it can be well managed through a course of treatment called Complete Decongestive Therapy or CDT.
“CDT was developed in Germany and brought to this country by Joachin Zuther in the 1970s. CDT is now recognized by the National Lymphedema Network and the Lymphology Association of North America as the gold standard for the treatment of lymphedema,” Badenhorst said.

CDT is the therapy used at Highlands Regional Rehabilitation.

“CDT is comprised of four components: skin care, manual lymph drainage (MLD), compression therapy, and exercise,” Badenhorst said.

Badenhorst explained that a trained and certified lymphedema therapist applies special techniques within these four areas to bring the swelling under control and to improve the condition of the skin, which in many cases, is severely compromised. Throughout treatment, the patient is thoroughly educated in self-management of the condition.

“With proper treatment and training, most patients can enjoy an active and productive lifestyle, returning to activities that have previously been abandoned,” Badenhorst said.
Vet, Hospital Clash Over Treatment Quality

"I don't know what is worse – this disease or the VA," North Greenbush's Peter Heck says

By Claire Hughes

Peter Heck is not just big, he looks inflated.

At over 300 pounds, the 55-year-old is swollen with fluid — it looks like you could puncture his legs and drain him — due to lymphedema he has suffered for 18 years and the elephantitis it has caused.

Heck spends most of each morning taking care of himself. He gets up early to exercise on his cross-country machine and to meditate. Five days a week, he then unrolls the elastic bandages that are wrapped snugly around his legs, and showers. Then he heads four miles down Route 4 from his North Greenbush home to Seton Health Physical Rehabilitation in Rensselaer. There, a therapist performs a technique known as manual lymphatic drainage (MLD) and wraps his legs back up.

To pay for this care, he uses money from a fundraiser he and his wife, Lori Rysedorph-Heck, held in the fall. He says he's grateful to be able to get consistent therapy. At last. Heck resorted to fundraising out of desperation, after years of fighting for better care at the Stratton VA Medical Center, he said. Heck is entitled to care there because he was a military policeman 30 years ago in South Korea, where he was exposed to the microscopic, threadlike worm that caused his lymphedema. The VA considers him 100 percent disabled connected to his military service. In addition to his health care, he also receives disability payments.
"I don't know what is worse – this disease or the VA," Heck said.

According to the Hecks, the VA has for years dismissed their requests to follow treatment protocols recommended for Peter’s condition, formally lymphatic filariasis. Doctors there readily dispense drugs and medical equipment, but won't provide Heck with the hands-on therapy he needs, they say. Perhaps worse, the Hecks say VA doctors and administrators blame Peter for his problems, casting his complaints as a mental deficiency or bad attitude: he's depressed, non-compliant, too fat.

Heck knows there is no cure for his lymphedema. What he wants is adequate management of the condition, which could make him smaller, more comfortable and more mobile. That's what he's hoping his current therapy will do — for as long as he can afford it.

The Albany VA, through spokesman Peter Potter, said it has provided Heck with the care his condition requires, but that Heck must also do more for himself. Heck is fixated on getting care elsewhere — at Seton or a German clinic renowned for treating lymphedema — and spends his energy fighting the VA rather than complying with medical recommendations, Potter said. "Our interest is not only to treat him, but make sure he is able to do this stuff at home," Potter said. "He's not an invalid. He's able to do this stuff."

Heck and the VA dispute numerous details about the veteran's care, but the main conflict comes down to this: Heck believes he should receive at least six months of care, five days a week, from therapists trained in MLD, then continue to receive professional hands-on therapy to stabilize his lymphedema. This is the recommendation of the National Lymphedema Network — a nonprofit that the U.S. Centers for Disease Control and Prevention refers to for information on care of patients — and a specialist in Boston whom Heck consulted. Although a VA therapist is trained in MLD, Heck said she has inferior skills and does not want to provide the service, but have Heck do it himself at home with a $7,000 compressor the VA purchased for him. Heck says the compressor is meant to complement, not replace, professional hands-on therapy.

The VA's position is that they have offered Heck adequate care — most recently at 50 therapy sessions a year, almost one a week. And they have paid for his FlexiTouch lymphedema pump, a pneumatic compression device, and encouraged Heck to exercise.
Heck became a VA patient in 2007. It was a decade earlier when he had the first symptoms of lymphedema.

One day in 1997, his ankle hurt after his shift at the Hannaford Supermarket in Wynantskill, where he worked in addition to helping Lori with her graphic-design business. His ankle was so swollen that it hung over the top of his shoe.

Heck couldn't remember doing anything to cause the inflammation. He was in great shape then, at 220 pounds. He was a body builder and martial-arts enthusiast; he golfed, skied and roller-bladed.

The swelling did not go down. Not ever.

"From that point on, it never went away," Heck said.

And so began years of watching the lymphedema spread, moving from Heck's ankles and then his hands and finally all four limbs. With his increasing disability came thwarted efforts to figure out what was wrong. Doctors drew his blood and scanned his innards. Cardiologists and rheumatologists tested him for heart disease, Lyme disease and cancer. Finally, through their own Internet research, the Hecks learned about lymphatic filariasis, and decided Peter might have that. They sought out several experts, who agreed.

The disease is spread in tropical and subtropical countries by mosquitoes carrying a microscopic worm from an infected person, according to CDC. The parasite damages the lymph system, resulting in fluid accumulation for a small percentage of patients. The deteriorated lymph system facilitates infections that can cause elephantitis, a hardening and thickening of the skin. All that can be done to treat lymphedema is to decrease swelling and discomfort. The National Lymphedema Network recommends treatment known as complete decongestive therapy, which includes MLD to stimulate drainage of the lymph vessels, followed by compression bandaging. Professional therapy is recommended five days a week until fluid reduction plateaus, and then less frequently to maintain a smaller size, with the patient supplementing the therapy with a compressor and exercise.

Until late last year, when he began paying for his own treatment, Heck never received therapy often enough to reach the plateau, he said. This was true both before and after he arrived at
the VA. His previous, private health insurer approved just 40 visits a year for treatment at St. Peter's Physical Rehabilitation.

Heck's condition was worsening when he signed up for care at the VA in 2007. He needed more frequent treatment, and his health insurance costs, paid by Lori's small business, had become exorbitant. His need for care was taking her time away from work, too.

At first, the VA paid for Heck to get care at St. Peter's. As Heck described it, St. Peter's therapists applied a light-touch massage in a soft-circular motion, applying no more weight than a coin. The technique is intended to stimulate drainage without breaking any lymph vessels. Then therapists wrapped Heck's arms and legs in elastic bandages; up to 15 are used for his legs alone.

The treatments were effective, Heck said. After every six-week session, he would lose up to 100 centimeters total in 13 spots measured along his arms and legs. He would fit into smaller clothes.

The VA would approve MLD for Heck at three days a week for six weeks, according to the Hecks. At the end of each six-week stint, Heck's VA primary care physician would recommend more treatments. Then, according to Heck, he'd wait — anywhere from a couple of weeks to eight months — for approval. As the time lapsed, Heck's condition would worsen. By the time he got back to therapy, he was starting at square one: swollen, hurting, in larger clothes.

The VA disputes Heck's account of his wait times.

It's a sensitive subject after the national VA health system came under scrutiny last year, following reports that patients had died while awaiting delayed appointments at the Phoenix facility.

"Anyone saying it takes six weeks to six months is incorrect," Potter said. "We would be in trouble, if we were supposed to provide a medical service, for not providing that because it sits on an approval desk.

"That's malpractice," he said.

Heck says he received treatment, albeit infrequently, from St. Peter's Physical Rehab until two years ago, when the Stratton VA insisted he get MLD from the in-house therapist that Heck
found wanting. The VA's Potter says that Heck was temporarily finished with treatment at St. Peter's in 2009 — that St. Peter's "discharged him" and he was deemed "independent and self-managing" in terms of his lymphedema. At that time, the VA's therapist provided training on the Flexitouch device and maintenance therapy, according to Potter.

Heck scoffed at this account. St. Peter's was not authorized to determine how frequently Heck was treated, he said. Therapists there merely provided services as approved and paid for. St. Peter's would not comment on treatment of a specific patient from six years ago. A spokesman said generally that a patient's release would not necessarily indicate his treatment should end.

"We might provide episodic care to relieve symptoms for a period of time and complete that episode," said St. Peter's spokesman Elmer Streeter. "That does not mean, however, that the person would not need to be prescribed additional care in the future."

Short staffing at the Stratton VA led the medical center to refer Heck back to St. Peter's between March 2012 and March 2013, when he was approved for 50 treatments, or about one a week, Potter said.

Then two years ago, the VA told Heck he could no longer receive treatment at St. Peter's, because the VA's in-house physical therapist had time to see him. It's standard procedure to require veterans be treated at the VA when the facility has staff who can do the job, Potter said.

Heck missed some treatments because a van that was supposed to pick him up never arrived. Potter acknowledged the problem and said the VA corrected the issue.

Yet Potter also said Heck repeatedly failed to comply with treatment recommendations.

Following knee surgery that Heck received in Syracuse, for instance, the veteran repeatedly canceled appointments at the Stratton VA for recommended post-surgical physical therapy. Heck said that the surgeon in Syracuse told him he could exercise on his own at home, and didn't need to go to the Stratton VA for the PT.
In March of last year, the Hecks sat down with Stratton VA managers to plead their case for more consistent MLD treatment. Unhappy with the VA therapist, Heck wanted to go back to St. Peter's. VA managers told the Hecks they could not agree to that.

"I think Mr. Heck wants to do everything he can to get better," Potter said. "But in his quest to do so, I think he's ignoring that we have qualified people right here."

Heck made his displeasure clear. In response, VA health providers offered him anti-depressants, he said. Heck declined to take them. Potter said Heck balked at having a social worker on his case management team, a standard VA procedure.

A year ago, Heck consulted with Dr. Arin Greene, an expert in lymphedema at Boston Children's Hospital. Given Heck's condition, Greene recommended he receive MLD five days a week for six months, then at three days a week for maintenance thereafter.

"This should be unlimited therapy," Greene wrote in his report. "Stopping the therapy will only cause progression and worsening of his disease. Therefore, the therapy should be continued throughout the rest of his life."

Greene evaluated Heck to have "appropriate affect" — that is, he was not suffering from depression. Because the lymphedema was caused by filariasis, Greene recommended that Heck be seen by an infectious disease expert at Beth Deaconess Medical Center in Boston.

The report remains in his file at the VA, Heck said. No action has been taken on it.

The VA also has not responded to an October inquiry about Heck's care from the Veterans of Foreign Wars Albany service officer, according to Heck. (The VFW officer was not permitted to speak to the press about Heck's case.)

Last summer, the Hecks opened an online GoFundMe account to raise money for Peter's care, and in the fall, they held a fundraiser at Franklin Terrace in Troy, with the goal of raising enough to get Peter to the Foldi Klinik, a specialized lymphology clinic in Germany that Greene recommended. They raised several thousand dollars — not enough for a trip to Germany, but enough to pay Seton for therapy on their own.
Donations continue to trickle in, and the Hecks hope the money will allow Peter to get treated through September.
International Trade and Jax Businesses; Lymphedema; 'Haikus Well-Hung' Art Show

As international trade agreement negotiations between the White House and Congress proceed, we examine how these talks could affect First Coast businesses. We speak with Andrew East, CFO/EVP of Green Cove Springs-based company Alternate Energy Technologies LLC, about the impact of international trade on their company.

We also speak with local activist Candace Bridgewater about raising awareness for lymphedema, a condition caused by the removal of or damage to lymph nodes during cancer treatments. (Lymphedema topic at 31:00-38:30; National Lymphedema Network at 32:15)

And George Cornwell and Keith Marks of the "Haikus Well-Hung" art show join us with a preview of the exhibit happening at CoRK Studios this week.
Diagnosis and Treatment of Lymphedema in Patients with Breast Cancer

Abstract

Lymphedema is a distressing consequence of breast cancer treatment affecting the patient in all domains of quality of life. Early identification and diagnosis are key to preventing long-term consequences. The goal of lymphedema management is to slow the progression and provide symptomatic relief to maintain quality of life. Preoperative education, intensive postoperative follow-up, and long-term survivorship care are important to minimize risk factors for developing lymphedema and to provide a mechanism for early detection, treatment, and patient self-care. An interdisciplinary approach, including nutritionists, physical therapists, psychologists, and advanced practice registered nurses (APRNs), is essential to provide a patient-centered approach to the management of lymphedema. APRNs are critical in providing comprehensive assessments, ongoing follow-up care, and patient education in self-care strategies.

Introduction

Lymphedema is a progressive, chronic, debilitating condition that is considered to be one of the most distressing consequences of cancer treatment for patients with breast cancer (International Consensus, 2006; National Lymphedema Network [NLN], 2011; Ryan, Cleland, & Fu, 2012; Stout et al., 2012; Stout Gergich et al., 2008; Taylor, Jayasinghe, Koelmeyer, Ung, & Boyages, 2006). Chronic, untreated lymphedema has negative effects on quality of life, including range-of-motion impairments, decreased strength, functional limitations, and body-image distortions (Stout Gergich et al., 2008; Stout et al., 2012; Taylor et al., 2006). The incidence of cancer-related lymphedema ranges from 1%–48% (Stout Gergich et al., 2008). Secondary lymphedema ranges from 5%–50% (NLN, 2011; Stout Gergich et al., 2008; Tretbar, Morgan, Lee, Simonian, & Blondeau, 2007) and occurs as a result of swelling following an injury or infection (Tretbar et al., 2007). The overall incidence of breast cancer–related lymphedema ranges from 15%–54%, with a range of 33%–47% after axillary lymph node dissection (ALND) with radiation and 4%–17% after sentinel lymph node biopsy (SLNB) with radiation (Fu, Ridner, & Armer, 2009; Stout Gergich et al., 2008). ALND involves the removal of axillary lymph nodes, and SLNB involves the removal of the first lymph node or nodes where cancer cells are most likely to spread. The variability in incidence ranges is a result of a lack of consistent assessment and diagnostic criteria, causing an unclear definition and prevalence of clinically significant lymphedema (McLaughlin et al., 2008; Ryan et al., 2012; Torres Lacomba et al., 2010). A need exists for standard criteria for the diagnosis, evaluation, and treatment of lymphedema in patients with breast cancer.
The identification of patient risk factors is critical to minimizing the chance of early lymphedema progressing to advanced-stage lymphedema (Stout et al., 2012) (see Figure 1). Secondary prevention, early diagnosis, referral, prompt initiation of treatment to control the disease process, and a surveillance model of care, compared to the current impairment-based rehabilitation model, enables early identification of impairments and prompt intervention (Stout et al., 2012).
National Lymphedema Network Kicks off 2nd Annual “Stomp Out Lymphedema” Virtual Walk

PRLog - April 7, 2015 - SAN FRANCISCO -- The National Lymphedema Network will host its second annual “Stomp Out Lymphedema” virtual walk now through the end of May 2015, with patients and advocates throughout the country signing up and creating teams to raise awareness about lymphedema and fundraise for the NLN’s ongoing Lymphedema Awareness Campaign.

As a virtual walk, “Stomp Out Lymphedema” enables lymphedema patients, practitioners, and their community of support to participate in the 5k walk in their own locales over the course of April or May by making their own fundraising page on the NLN Web site. This grassroots effort allows anyone, especially patients with limited mobility, to take part in the walk.

“Lymphedema has been ignored, misdiagnosed, and left untreated for far too long—the NLN’s Lymphedema Awareness Campaign is designed to change that,” said campaign coordinator and lymphedema patient Robin Miller, “Stomp Out Lymphedema will help us launch the first two parts of the campaign: A series of educational videos, some of which can be viewed now on our Youtube station, and free education kits for cancer patients that we are slated to distribute later this year.”

Registration and other “Stomp Out Lymphedema” event-materials are available at donate.lymphnet.org/stompoutLE15. The NLN team will be hosting their local walk in San Francisco’s Golden Gate Park on Saturday, May 2 at 11:00am (PST). -- contact (415) 908-3681 for details on joining the NLN’s local team. Twitter users can follow the NLN at @lymphnet and use the event hashtag #StompOutLE to enter to win one of the NLN’s weekly giveaways occurring throughout April and May.

The National Lymphedema Network (NLN) is an internationally recognized non-profit organization founded in 1988 by Saskia R.J. Thiadens, RN to provide education and guidance to lymphedema patients, healthcare professionals and the general public by disseminating information on the risk reduction and management of primary and secondary lymphedema. www.lymphnet.org
It took Cynthia “Ms. Cjay” Judge 11 years after her first mastectomy to notice the swelling in her right hand. The two-time breast cancer survivor didn’t know what caused it. Her surgeon put her on a course of antibiotics, and though the swelling became progressively worse, doctor visits often ended with more prescriptions for pills.

Then, on Oct. 23, 2009, Judge woke up unable to get out of bed. Her heart was pounding rapidly, and she felt pain in her hand and arm. She said her arm grew almost six inches in size. A month later, she met Dr. Richard Hodnett, who diagnosed her with lymphedema.

“From the photos taken of me in the early ’80s, I can see that I had lymphedema but was not aware of it,” Judge said. “With lymphedema, it’s either under-diagnosed, misdiagnosed or not diagnosed at all. Medical schools spend maybe a day in class on the lymphatic system, but right now, there are 10 billion people in the U.S. living with lymphedema.”

Lymphedema is a chronic but treatable disease that results in an accumulation of lymph fluid that causes swelling in parts of the body where lymph nodes or lymphatic vessels are damaged or inadequate.

It is usually followed by damage from cancer treatment, but there are also people who are born with lymphedema.

In order to raise awareness of the disease, Judge and breast cancer survivor Christine “Coach Christine” Wunderlin started “The Lymphedema Mavens” radio podcast in 2011, which airs internationally on TheCityFM.com.

The show’s producer, Millian Quinteros, estimates that the podcast has 2,000 to 3,000 regular listeners from around the world, including Germany, Africa and South Korea.
“The only thing that I remember is signing a release form that if I got lymphedema, I wouldn’t sue the surgeon,” Wunderlin said. “I didn’t make anything of it, but when my arm swelled up (to the point) where I couldn’t put my sleeve on, I realized something was wrong. My arm grew 2 inches.”

Wunderlin, who was diagnosed with lymphedema in July 2011, discovered there was something wrong with her arm shortly after flying to Louisiana.

Since cabin pressure that is experienced during air travel is less than the atmospheric pressure on the ground, the decreased pressure within the plane’s cabin may give rise to increased swelling in a lymphedematous limb as tissue pressures are physiologically altered, according to the National Lymphedema Network’s website, lymphnet.org.

“I was more upset about the lymphedema than I was about the breast cancer,” Wunderlin said. “What they don’t tell you is that if you take more than four lymph nodes out, then the probability of getting lymphedema is, like, 80 percent.”

Symptoms of lymphedema include swelling, being susceptible to infections, rashes and other skin texture changes, according to cancer.org.

Those who suffer from lymphedema must wear compression guards to maintain the swelling and use moisturizer.

Many patients, including Judge and Wunderlin, must undergo a manual lymphatic drainage, a massage that moves the fluid from the affected area to healthier parts of the lymphatic system, where the fluid then can be expelled from the body.

Sally Spurgeon, a licensed massage therapist and owner of Therapie, has been treating Wunderlin for almost a year.

She offers two types of techniques: cupping therapy and the manual lymphatic drainage massage technique to move the fluid from the affected area to healthier parts of the lymphatic system. That way, the fluid can be expelled from the body.

“About 60 percent of our clients come in for post-mastectomy massage,” Spurgeon said. “Some women develop lymphema, and some don’t. Everybody is different. Those who do experience it deal with fluid buildup, which can be painful and disabling.”

Recently, lymphedema has received attention from well-known names such as “American Horror Story” actress Kathy Bates and Wesley Warren Jr., the Las Vegas man whose scrotum grew to 132 pounds.

Warren was featured on the podcast shortly before he died in 2014.
Las Vegas proclaimed October to be Lymphedema Awareness Month thanks to the efforts of Judge and Wunderlin. Recently, North Las Vegas deemed March as Lymphedema Awareness Month.

Because Medicare does not cover compression garments and other lymphedema treatment compression supplies, Wunderlin and Judge are pushing for the Lymphedema Treatment Act. The federal bill would enable coverage for compression, support patients’ adherence to their maintenance phase of treatment by covering their doctor-prescribed supplies and reduce the total health care cost associated with lymphedema by decreasing the incident of complications, and the presence of other disorders and disabilities resulting from the disease, according to lymphedematreatmentact.org.

There is no cure, and if ignored, lymphedema can cause deformities as well as skin or other infections.

“There’s a stigma about having lymphedema,” Judge said. “It’s not really talked about. That’s why we’re trying to bring attention to it.”

To reach North View reporter Sandy Lopez, email slopez@viewnews.com or call 702-383-4686. Find her on Twitter: @JournalismSandy.
Those in Cancer Recovery, Especially, Should Know about Lymphedema

By Lisa McPartland

Have you heard that Friday is Lymphedema Awareness Day in New York and about 20 other states?

Wait. You've never even heard of lymphedema? Join the not-so-exclusive club.

I remember when I first noticed the swelling in my left ankle. I thought it was the result of rolling off a sandal in the summer of 2008.

After the swelling continued to crawl up the leg over the course of three years, and countless doctor appointments offered no answers – except I was "getting old" – I learned that the leg was afflicted with a chronic condition called lymphedema.

It was bittersweet news to hear. After being diagnosed with cervical cancer in 2004, I underwent a hysterectomy at the age of 29. This included the removal of lymph nodes to ensure the cancer hadn't spread. On Dec. 21, 2004, I learned that I was clear of cancer.

That surgery, however, left me with a lifetime fight against secondary lymphedema, a swelling that occurs when the lymphatic system, a large portion of the immune system, is damaged and lymph fluid cannot properly drain from the body. (Mine is secondary because it was the result of surgery – those with primary lymphedema are born with it.) Instead of staying contained within the lymphatic system, the fluid flows into the surrounding tissues.

In October 2011, I began treatment at the Lymphedema Center at Roswell Park Cancer, where the therapists educated me on the causes and treatment methods.

Most patients undergo manual lymphatic drainage, which is a massage that moves the fluid from the affected area to healthier parts of the lymphatic system, where the fluid then can be expelled from the body. Compression wraps and compression stockings then are used to limit how much fluid remains in the affected area.
There is no cure, and if ignored, lymphedema can cause deformities as well as skin and other infections.

Since my diagnosis, I've done much reading about lymphedema, and I've found several groups that are working on research in the hopes of finding a cure. I am secretary of the newly formed New York State Chapter of the Lymphatic Education and Research Network. Upon visiting lymphaticnetwork.org, you can see my face among the many who have joined the Face of Lymphedema Challenge, a video project during which patients can exclaim, "I have lymphedema!" to raise awareness. Patients' friends and family may make donations to further the cause.

Also, LE&RN and the National Lymphedema Network (www.lymphnet.org) are marking March 6 as Lymphedema Awareness Day (the NLN refers to it as Lymphedema D-Day), and about 20 states, including New York, have passed resolutions in the hopes of educating more people and raising research dollars.

Both LE&RN and NLN also offer educational materials and are great tools to start your own research. I wanted to cry when I discovered from LE&RN that up to 10 million people suffer from lymphedema in the United States – more than multiple sclerosis, muscular dystrophy, ALS, Parkinson's disease and AIDS combined. I was baffled.

How can so many people suffer from a disease about which doctors know so little?

How is there so little awareness when so many people are facing or recovering from the cancer treatments that could cause it?

I find myself angry at times. The discomfort, pain, swelling, and constantly having to cover the affected area cause quality-of-life issues that are invisible to most. I've learned to mask my bulky leg under flowing dress pants and ankle-length skirts. It's especially difficult during the hot, humid summer months. In addition to the warmth of the compression garments, the heat and humidity cause more swelling, sometimes limiting what I can do with the few warm days we see in Buffalo.

The anger is short-lived because I realize how lucky I am to still be here. I’m frustrated because I was not warned of this side effect before my surgery. I don't believe the knowledge would have persuaded me to skip surgery, but some warning would have helped me to better prepare afterward to prevent lymphedema. The Mayo Clinic has a list of tips for reducing the risk – protect the affected area from injury, rest it, keep it clean and avoid heat and tight clothing – but I didn't even know I had something to prevent.
This is why I tell my story every chance I get. We need to demand that doctors make this part of their continuing education and that we are taught methods to prevent lymphedema if we are going to be prescribed a treatment that might cause it.

The word "lymphedema" should be highlighted during every cancer treatment conversation.

If you are facing radiation or are having surgery for cancer or other reasons, or if you already have unexplained swelling, inquire about lymphedema. I speak out not only on Lymphedema Day, but almost every day, in the hopes of making one more person aware that this condition can happen to anybody and that help is available.

Lisa A. McPartland is a contributing writer to The Buffalo News, a cancer survivor since 2004 and a lymphedema sufferer since 2008.
Bringing Attention to the Suffering of Swelling

By Kimberly Rubenstein

Susan Wright’s fight with endometrial cancer ended nine years ago, but she faces a lifelong battle that’s a result of doctors removing 27 pelvic lymph nodes to ensure she was cured of the disease.

The battle isn’t against a tumor, but against disfiguring swelling she’s prone to as a result of her lymph nodes being removed. A cut or scrape could lead to infection that causes her legs to balloon to multiple times their normal size. Overexertion or staying too sedentary could upset the flow of lymph fluid, which no longer moves normally in her body on the side where the nodes were removed, causing the swelling.

The condition is called lymphedema, and it’s one that Wright, 60, of Gig Harbor, has had to learn to live with. It involves regular trips to therapists who manually move the lymph fluid; vigilance in avoiding cuts on her legs or feet (she doesn’t go barefoot); and wearing thigh-high compression hose most hours of the day — the worst part for Wright.

“In my early 50s, I didn’t see myself wearing something like that,” she said. “In the summer, it’s like wearing long underwear.”

Cancer survivors and others who suffer from the condition — including some who are born with it — say little attention is given to the disease, despite its prevalence. Advocates fighting on behalf of lymphedema sufferers say that of the nearly 240,000 men and women who get breast cancer this year, 40 percent will end up with lymphedema at some point after treatment.
HOW IT OCCURS

Removal of lymph nodes during surgery for cancer allows doctors to see if a cancer has spread. But the lymph nodes don’t grow back, depriving the overall lymph system of points and routes to filter harmful substances that eventually need to be returned to the bloodstream.

The result is fluid buildup in the tissues, which causes the pain and swelling of the limbs. Without proper treatment, the limbs will not go back to their normal size — and sometimes the damage is irreversible.

For years, lymphedema seemed to fly low on the radar of medical practitioners, said Bonnie Pike, a Tempe, Arizona, breast cancer survivor who now advocates on behalf of lymphedema sufferers. She ended up diagnosing herself after she could not find a doctor or surgeon who could identify the disease.

“Doctors don’t have a lot of experience with it, and nobody ‘owns’ it,” Pike said. “Oncologists don’t own it, surgeons don’t own it.”

She points to surveys of medical schools that show relatively little time is spent educating future doctors on the lymphatic system.

Melissa Mercogliano, doctor of physical therapy and owner of the Center for Orthopedic and Lymphatic Physical Therapy in Port Orchard, discovered the reality when she started her career. She was treating many women who were cancer survivors and had the condition. She began specializing in the treatment of lymphedema in the late 1990s. Part of the treatment involves a special massage that moves lymph fluid to nodes that are still functional, called Manual Lymphatic Drainage.

The onset of lymphedema means several visits each week to a physical therapist, occupational therapist or massage therapist trained in the drainage technique. Following that, the affected limb is wrapped in compression bandages to reduce swelling — and must be wrapped and re-wrapped for several days or weeks. Once the swelling has reduced and the size of the limb has
stabilized, the patient is fitted for skintight compression garments that they will wear every day for the rest of their life.

“It requires lifelong management,” said Mercogliano, who treats a wide array of patients affected by lymphedema, including those who have experienced orthopedic trauma or surgery or repeated infections. “It’s kind of like being diabetic,” she said, adding that self-massage and using the compression garments are a daily ritual for sufferers.

FOUND RELIEF

The condition still eludes many physicians today. Ron U’ren, 69 of Port Ludlow, is a patient at Mercogliano’s clinic. For years he suffered from the swelling with no relief, getting frequent infections and having to medically retire from his job at Boeing. He wore compression stockings, but physicians never referred him to a therapist for treatment.

He was recently referred to the practice after switching to a new podiatrist. He has seen his legs reduce in girth by almost roughly a third. He can now touch his toes and walk to get exercise during the day.

“I have started to lose weight ... to get more physical,” he said.

The awareness seems to be spreading among surgeons and oncologists working with breast cancer patients. That’s been the experience for Kathryn Simpson, a South Kitsap resident who was diagnosed with breast cancer in August 2013. After she went through chemotherapy and was preparing for surgery, her surgeon brought it up and recommended the preventive steps of physical therapy. She was treated by Mercogliano and wears a compression sleeve to ward off lymphedema when she is active. She is on guard against any sign of swelling; she’s acutely aware that a cut or bee sting could throw her system off balance and cause lymphedema.

“It’s definitely a different paradigm than the carefree self I used to be,” she said.
Even for those aware of the condition, there are barriers for treatment. Pike said that finding a practitioner to treat it can be difficult, and that it’s important to look for a therapist that has specialized training in Manual Lymphatic Drainage.

“If anyone with a PT (physical therapy) or OT (occupational therapy) license is allowed to treat it, but they don’t have to know anything about it,” she said.

Massage therapists can also be trained in the technique. Mary Briner, who practices at Well Being Health Center in Poulsbo, has been certified in a specific type of Manual Lymphatic Training. She said it’s a rare certification for massage therapists because of the time and expense of the training.

The lack of insurance coverage can also be a barrier. While companies might cover treatment by an occupational or physical therapist, compression bandages and garments (which can cost thousands of dollars) are often not. Sufferers have formed the Lymphedema Advocacy Group to lobby lawmakers in Washington, D.C., to pass a bill that requires Medicare coverage of all aspects of lymphedema treatment — therefore setting a precedent for Medicaid and private providers.

**HOPE FOR SUFFERERS**

Pike feels there is hope for lymphedema sufferers. She points to a $2 million grant the National Institutes of Health awarded last year to Georgia Tech to better understand the underlying causes of lymphedema. She’s hopeful that more research into how the lymphatic system works will help improve treatments, even if a cure is not in sight.

Mercogliano said there are local doctors who are educated on the condition and refer patients to her before the onset of lymphedema. “We catch them and teach them to watch for it before it gets too significant,” she said. Her hope is that awareness on the part of doctors and patients would continue to increase so that fewer would suffer before getting treatment.
For those who she does care for who have long had the condition, hope comes in progress against the swelling. During a recent appointment, Mercogliano remarked at how much smaller U’ren’s legs were, decreasing in circumference from 62 centimeters to 40 centimeters.

“Your lymph system is going to work so much better,” she said.

“Now my legs aren’t slowing me down,” U’ren replied.

**RESOURCES**

- National Lymphedema Network: http://www.lymphnet.org/
- Lymphedema resources for breast cancer survivors: www.stepup-speakout.org
- Resources on the disease and fight for insurance coverage: http://lymphedematreatmentact.org
- Society for Oncology Massage: http://www.s4om.org/
Woman Wants to Help Other Suffering from Lymphedema

Becky Sharp lives with a condition that makes her life miserable and her insurance won’t cover the medical supply that would help.

Sharp was diagnosed in 2010 with melanoma centered just below her left knee, and treated by an oncologist in Houston. As part of her treatment, the lymph nodes in Sharp’s groin area were removed.

Sharp now has lymphedema affecting primarily her legs, and as a complication of the lymphedema, cellulitis.

According to American Cancer Society, lymphedema is a build-up of lymph fluid in the fatty tissues just under the skin. It most often occurs in the arms or legs, but also can occur in the face, neck, abdomen or genitals.

Although some people are born without lymph nodes or their lymph nodes do not work properly, most lymphedema is caused by change or damage to the lymph system — often a result of cancer, cancer treatments, tumors or diseases. Breast, prostate, pelvic area, lymphoma and melanoma are the cancers most likely to bring on lymphedema, the ACS website reads.

Although Sharp has had issues with lymphedema since soon after her treatment for melanoma, the problems became much worse in the last two months, since she went to Texas to visit her mother, who was hospitalized in serious condition.

“I was so swollen from sitting at the hospital, I didn’t know I almost had a stroke,” Sharp said.

That is, until she herself had to be treated by physicians at the same hospital.

Sharp is retired and Medicare does not cover the compression garment, called a sleeve, that helps push the fluid out of her legs.
“My hope for survival is centered on this sleeve, and this sleeve costs $400 every few months,” Sharp said. “I need another sleeve, but I can’t afford it."

Sharp said the lymphedema has taken away her ability to leave her house except on rare occasions, and even then she tires quickly. Nevertheless, she gets exercise to help keep it in check as much as possible inside her home.

She has an upcoming appointment with a physician in Oklahoma City and will find out then whether her left leg can be saved.

Some days Sharp sinks into self-pity, but she promised her aunt she would not give up.

“My goal is to educate the public,” Sharp said.

The most important things she wants people to be aware is that they should wear sunscreen when they are outside to protect themselves against skin cancer and to take care of themselves in other ways as well.

According to the ACS website, signs of lymphedema can include swelling; a feeling of fullness or heaviness in part of the body; changes in skin texture, firmness or color; aching, tingling or other discomfort; loss of movement or flexibility in nearby joints; trouble fitting into clothes in one area, such as a sleeve or pant leg.

Early on, skin usually stays soft, but over time, the swollen area may become hot and red and the skin hard and stiff.

“If you have had lymph nodes removed or radiation treatment, look closely at your body in front of a mirror,” the ACS website reads. “Compare both sides of your body and look for changes in size, shape, or skin color. Get to know your body and what’s normal for you. This way you can spot changes and get treatment right away. Let your doctor, nurse or lymphedema therapist know if you notice any of the signs listed above.”

Cellulitis, an infection under the skin, is a serious threat to people with lymphedema, the ACS website reads.

People who suffer from lymphedema can be helped by maintaining a healthy weight; exercise; compression garments; avoidance of injuries, burns and infections; and wearing proper garments.

Additional information can be found at National Lymphedema Network, lymphnet.org; Lymphology Association of North America, lclt-lana.org; and American Physical Therapy Association, apta.org.
Sharp wants to start a local lymphedema support group. Anyone interested in contacting Sharp to learn more can call (580) 540-4214.
21 September 2014

The Orlando Sentinel


Social Media Lead Patients to Orlando Health for New Treatment

By Scott Powers

People might not expect to find life-changing medical treatment 2,400 miles from home via Facebook, but Amy Caterina did.

The San Diego woman, who suffers from a chronic, painful swelling of the arms or legs called lymphedema, saw posts on Facebook about a fairly new treatment being done by surgeons at Orlando Health.

She came to Orlando and consulted with Dr. Jeffrey Feiner at UF Health Cancer Center at Orlando Health, then returned and had the surgery Aug. 14.

"Facebook is the curse and the blessing for many people. And with people with lymphedema, it is absolutely a blessing," Caterina said.

It was no accident that she found her treatment on Facebook.

Orlando Health's first vascularized lymph-node transfer, performed in March 2013, was live-posted to social media. The hospital sent dozens of updates and pictures through Facebook, Twitter and Instagram during the surgery, and has promoted the procedure heavily on social media, including on YouTube and the company's health blogs.

"We knew this was something groundbreaking," said Katie Dagenais, an Orlando Health public-affairs manager who was part of that social-media-broadcast team. Since then the Orlando
Health doctors have conducted 120 consults with patients interested in the surgery, and 20 of them — about 17 percent — said they learned about it through social media.

The surgeons have now done the procedure 55 times, and seven of the patients, including Caterina, came from out of state.

As many as 6.8 million Americans have lymphedema, which prevents lymph fluid from draining from body tissues. The fluid builds up, causing chronic, painful, disfiguring and even immobilizing swelling. Many patients must wear special compression garments, have daily compression massages and have the fluid drained regularly.

The condition is a side effect developed by many cancer patients, particularly breast-cancer survivors, who have had lymph nodes removed or damaged in the cancer treatment.

"Once you develop lymphedema, you have to do that the rest of your life. You have to maintain it," said Dr. Richard Klein at Orlando Health. "If you don't do it, the lymphedema will continue to swell and you will end up with a large arm that is very firm, third-degree lymphedema, which is the worst case possible."

After dealing with many such survivors while overseeing the hospital's Plastic and Reconstructive Surgery Center, Klein got interested in a treatment emerging in Europe. In late 2011 he traveled to Paris to check out the vascularized lymph-node transfer surgery being done there.

Healthy lymph nodes are harvested from one part of the body and transplanted to areas affected by lymphedema. Klein brought the procedure back to Orlando, and with Feiner and Dr. Kenneth Lee began performing it here.

In a presentation that Klein made at a National Lymphedema Network conference in Washington, D.C., in early September, he reported that Orlando Health patients who had the treatment for arm lymphedema averaged a 25.8 percent decrease in arm volume after three months and a 60 percent decrease after nine months. Leg results were a little less dramatic: he reported an 18.1 percent decrease after three months, and 19.5 percent after nine months.
Surgeons doing the procedure still are few and far between, and Orlando Health remains the only hospital in Florida offering the operation, Klein said.

Caterina's lymphedema developed after her successful treatment in 2007 and '08 for vaginal cancer, which included the removal of several lymph nodes. She has chronic swelling in both legs, though her right leg is particularly bad.

Married with two teenage children and a career as an investment adviser, Caterina felt condemned to the disease until she read Facebook posts from Orlando Health, forwarded to her through an Internet group called Lymphedema Support and Awareness.

So far, Caterina, 50, said she thinks she sees a little decrease in swelling in her right leg, where she had the surgery, but it's still early, and she's keeping her expectations low.

"I am personally very happy where I am right now. If this helps me not get any bigger, I would call this a success. If we can at least stop it, I'm happy. If we can reduce the swelling, I'll be even happier."
Frye Regional Medical Center Becomes Affiliate Treatment Center with National Lymphedema Network

Frye Regional Medical Center has become an Affiliate Treatment Center with the National Lymphedema Network. Occupational therapists, Nennisha Mitchell OTR/L, CLT, Stephanie Hollar OTR/L, MLT, and Deanna Foster OTR/L, CLT are certified lymphedema therapists that care for patients throughout the Unifour area.

Lymphedema occurs when the lymph system is damaged or blocked which causes uncomfortable and sometimes debilitating swelling. Lymphedema is a chronic and progressive disease that continues to worsen over time when not treated.

Now that Frye is part of a National Lymphedema Network, those suffering from lymphedema can search the network to locate a qualified lymphedema program and be assured that therapists uphold the rigorous standards necessary to help them heal.

Frye Regional Medical Center is an acute care facility that has been serving the medical and health care needs of Catawba County and central western North Carolina since 1911.

The hospital’s main campus includes a comprehensive heart center, accredited cancer center and bariatric surgery program, orthopedics, a designated spine unit, inpatient and outpatient rehabilitation, neurosciences, a women’s center with level II nursery and pediatrics.

FryCare Physicians, LLC provide hospitalists and critical care coverage. Frye has several extended campuses to serve families throughout the area, including FryeCare Outpatient Imaging Center, Cardiopulmonary Rehabilitation, FryeCare Heart Diagnostics, Infusion Care, Vein and Wound Center, Piedmont Therapy, offering sports and industrial rehabilitation; South Campus for psychiatric services; the Frye Wellness and Education Center houses an accredited Center for Diabetes Self-Management Care, perinatal education and community wellness classes; Tate Surgery Center; Unifour Pain Treatment Center; and FryeCare Urgent Care in Conover. For employers, Frye provides industrial health services through Hart Industrial Clinic.
Frye Regional Medical Center is accredited by the Joint Commission, the nation’s oldest and largest hospital accreditation agency. To learn more about the hospital, visit www.fryemedctr.com, for a physician referral call 828-315-3391 or 1-800-339-8758.
Lymphedema is a feared complication of cancer treatment and one that negatively impacts survivorship. The incidence of breast cancer–related lymphedema ranges from 6% to 70%, but lymphedema may be a common and under-reported morbidity. No standard guidelines for its diagnosis and assessment exist. Although the true etiology of lymphedema remains unknown, radiation, chemotherapy, type of breast surgery, and extent of axillary surgery are commonly cited risk factors. However, the relationship between the number of nodes removed and the risk of lymphedema is not clearly correlated. Clinical trials are focusing on ways to reduce the need for axillary dissection even in the setting of a positive sentinel node, to help minimize axillary morbidity. Risk-reduction practices, including avoidance of skin puncture and blood pressures in the ipsilateral upper extremity, and precautionary behaviors such as wearing compression garments during air travel continue to be advocated by the medical and survivor communities, despite a lack of rigorous evidence supporting their benefit. Emerging data support exercise in at-risk and affected women with lymphedema when started gradually and increased cautiously.

Introduction

The most recent survivorship data from the Surveillance, Epidemiology, and End Results (SEER) database demonstrate a significant increase in the number of US cancer survivors over the last 30 years, from roughly 3 million in 1973 to nearly 12 million in 2008.[1] As a result, issues of survivorship have stimulated new focus for clinical trials, not only to determine the most effective therapeutic regimen (surgery, drug, or radiation) but also to identify the one with the least influence on future quality of life. Lymphedema has long been a feared complication of surgical cancer treatment, and notably one that negatively impacts survivorship. Fear of lymphedema stems from patient concerns regarding the chronic, progressive nature of the condition and the clinician’s relative inability to predict or prevent its development. Furthermore, decades of physician and allied health teachings based on opinion and theory have perpetuated the myths shrouding lymphedema risk, prevention, and treatment.

A vast body of literature documents the occurrence of breast cancer–related lymphedema, with more than 1400 articles indexed in PubMed-MEDLINE databases alone. Importantly, lymphedema also exists after surgery for non–breast-cancer-related malignancies, but data documenting this occurrence are rare in comparison. Recently, Cormier et al found only 47
studies between 1972 and 2008 with more than 10 patients that prospectively evaluated lymphedema as a primary or secondary outcome after treatment for melanoma, bladder, sarcoma, penile, prostate, vulvar, cervical, endometrial, or head and neck cancers.[2] The authors’ analysis of these studies demonstrated the overall incidence of lymphedema to be 16.3% after melanoma, 10.1% after genitourinary cancers, and 19.6% after gynecologic malignancies, and notes that lymphedema rates are higher when the lower rather than upper extremity is affected. Given the abundance of breast cancer data, this review will focus on breast cancer–related lymphedema. However, the principles and controversies discussed are relevant regardless of the type of malignancy to which the lymphedema is attributed.

Incidence and Diagnosis

The incidence of breast cancer–related lymphedema has been difficult to quantify due to delayed onset of symptoms and the lack of standardized diagnostic criteria. A recent meta-analysis reports the incidence of breast cancer–related lymphedema to range from 0 to 3% after lumpectomy alone to as high as 65% to 70% after modified radical mastectomy (removal of breast and axillary lymph nodes) with regional nodal radiation.[3] Overall, 80% to 90% of women who will develop lymphedema do so within 3 years of treatment,[4,5] but the risk persists years later as the remaining 10% to 20% will develop lymphedema at a rate of 1% per year.[5] Petrek et al followed 263 patients and found that nearly 50% developed lymphedema by 20 years.[5] These data suggest that lymphedema is probably more common than generally reported, and clearly the length of follow-up in a given study influences the reported incidence. A uniform definition of lymphedema does not exist. Although volume displacement methods are considered the gold standard for diagnosis, these methods are cumbersome and unable to identify subclinical lymphedema. Thus, displacement methods are rarely used in clinical settings. Circumferential arm measurements performed with a nonelastic tape measure are commonly used to determine upper extremity size differences. It is essential to obtain baseline preoperative measurements of the ipsilateral and contralateral extremities, as differences of up to 2 cm may naturally exist between the dominant and nondominant arms at baseline.[6] Published literature demonstrates significant heterogeneity, as studies lack agreement on the location and minimal number of measurements performed. Furthermore, they use multiple definitions of what constitutes lymphedema, including measurement changes greater than 2 cm, volume increase of more than 200 mL, or percentage increases in volume (> 10% or > 20%) compared with baseline when controlled for changes in the contralateral arm.[7,8] Aside from objective measurements, some studies define lymphedema by patient subjective symptoms or patient perceptions of swelling.

Controversy remains as to whether a measurement change or a patient’s perception of swelling should be considered diagnostic. While a measurement change is objective, measurements may be affected by inter-rater and even intra-rater variability affecting reproducibility. Perhaps more importantly, a defined measurement change may be asymptomatic in an obese patient, while a thin woman may be bothered by more subtle measurement changes not meeting measured criteria for lymphedema. Alternatively, a patient’s perception of swelling may more accurately diagnose symptomatic lymphedema, but this perception may be influenced by sensory changes from the surgery and additional adjuvant therapies. Further, women with
surgery in their dominant arm may perceive functional issues to a greater degree than if it were
the nondominant arm that was affected.[9] In fact, one study found only 41% of women with
perceived swelling had circumferential arm measurement changes greater than 2 cm, the
objective threshold used in the study to define lymphedema.[9] Several contemporary studies
have evaluated the differences between measured and perceived lymphedema and have
validated patient perceptions against physical therapist–directed measurements.[4,10] These
studies conclude that each evaluation method is valid but not interchangeable, and they do not
endorse one method over another.

The clinical introduction of a single-frequency bioelectrical impedance device manufactured by
Impedimed (Mansfield, Australia) can minimize both inter-rater and intra-rater variability seen
with other measurement techniques. The device produces easily interpretable values
measuring the changes in extracellular fluid when compared with the unaffected contralateral
upper extremity. A score increase of 10 or more or one that registers outside the normal range
should prompt intervention with a compression garment or a referral for physical therapy.
Some investigators report that measurement of bioimpedance has improved sensitivity in
detecting subclinical lymphedema up to 4 months prior to standard measurement changes.[11]
For these reasons, the current National Lymphedema Network (NLN) breast cancer–related
lymphedema guidelines recommend that all breast cancer patients receive pre- and post-
treatment measurements (of any type) on both arms and encourage the use of bioimpedance
spectroscopy or infrared perometry as alternatives to tape measures, to limit measurement
variations.[12]

Is It All About the Nodes?

Over the years, many retrospective studies have reported risk factors for lymphedema. Axillary
dnode dissection (ALND), mastectomy, obesity, radiation, infection, and ipsilateral upper
extremity injury consistently rank as the most influential causes of damage or disruption to the
lymphatic system and thus lymphedema. However, the magnitude of association between
breast cancer treatment factors and lymphedema is inconsistent across studies.[8] Tsai et al
reviewed 98 studies conducted in the United States and Canada through January 2008 for
lymphedema risk factors.[8] The authors report a significantly increased risk for lymphedema in
women undergoing mastectomy compared with lumpectomy (risk ratio [RR], 1.42; 95%
confidence interval [CI], 1.15–1.76), ALND compared with no dissection (RR, 3.47; CI, 2.34–
5.15), ALND compared with sentinel lymph node biopsy (SLNB) (RR, 3.07; CI, 2.20–4.29),
radiation therapy vs no radiation therapy (RR, 1.92; CI, 1.61–2.28), and positive vs negative
axillary lymph nodes (RR, 1.54; CI, 1.32–1.80). While this meta-analysis demonstrates a
comprehensive, contemporary review of lymphedema risk factors, the heterogeneity of the
data must be considered, as 11 different definitions for lymphedema were used and follow-up
ranged between 1 month and 30 years.

Though the most intuitively obvious risk factor for lymphedema is the number of nodes
removed, the relationship between the number of lymph nodes removed and the risk of
lymphedema remains unresolved. Several retrospective studies have shown that the number of
nodes removed and the risk of lymphedema do not correlate.[13,14] Others find an increasing
risk of lymphedema as more nodes are removed.[15-17] Despite various lengths of follow-up,
from 6 to 60 months, the prospective trials vetting SLNB as the standard of care for axillary staging demonstrate significantly reduced rates of lymphedema after SLNB (0 to 7%) compared with ALND (12% to 16%).[18-21] These studies certainly support the concept that the risk of lymphedema is proportional to the extent of axillary surgery. Importantly, though, they also confirm that even with SLNB a small but clear risk of lymphedema remains. A recent study by Goldberg et al suggests that it is not the number of lymph nodes removed but instead the degree of dissection and disruption of the lymphatic system that results in lymphedema.[22]

The authors reviewed 600 women having SLNB with a median follow-up of 5 years and found an overall incidence of lymphedema of 5%. When stratifying the data according to the number of nodes removed, they found no significant association between the mean, median, or range of number of nodes excised and lymphedema ($P = .93$). Furthermore, the authors completed a subset analysis of the women having more than 10 lymph nodes removed at SLNB. None of these women developed lymphedema. Interestingly, when these SLNB patients having > 10 nodes removed were compared with a separate group of women having 10 to 17 nodes removed at ALND, 11% of the ALND patients had measured lymphedema ($P = .04$). The fact that women having more than 10 nodes removed during SLNB did not develop lymphedema but women with the same number of nodes removed after ALND did reaffirms that the relationship between the nodes removed and lymphedema is complex. Perhaps it is the relative magnitude of lymphatic destruction and individual patient ability to form collateral lymphatic channels, rather than the number of nodes removed, that influences lymphedema risk. For example, a patient with many nodes removed at SLNB and no finding of lymphedema may have more lymphatic collaterals and therefore will have suffered relatively less lymphatic disruption despite a larger than “normal” number of SLNs removed. On the other hand, women having ALND and a relatively small number of total nodes excised may have suffered an overall greater degree of lymphatic disruption and therefore develop lymphedema. Unfortunately, the number of nodes within each patient’s nodal basin and the patient’s ability to protect or form new lymphatic collaterals during or after treatments is unknown. Therefore, simply the number of nodes removed may be insufficient to determine lymphedema risk.

If, however, the degree of lymphatic disruption or damage is the key driver of lymphedema risk, then it is plausible that radiation can also act primarily or synergistically to influence lymphedema risk. Axillary radiation alone is not without complications, as these patients can have a 2- to 4.5-fold increase in the risk of lymphedema. A recent meta-analysis by Shah and Vicini finds lymphedema in 9% to 65% of patients after lumpectomy alone (no nodal surgery) and regional nodal radiation and in 58% to 65% of women after mastectomy alone and regional nodal radiation.[3] Additionally, the synergistic effect of surgery and radiation is well documented to result in a 3.5- to 10-fold higher risk of lymphedema when compared with surgery alone.[3,23,24]

Finally, accumulating data suggest that chemotherapy may also affect lymphatic destruction. Norman et al found anthracycline-based chemotherapy regimens increase the risk of lymphedema.[25] Their prospective review of 631 breast cancer survivors followed for 5 years found an elevated hazard ratio (HR) of 1.46 (95% CI, 1.04–2.04) for lymphedema among breast cancer patients receiving anthracycline-based chemotherapy vs no chemotherapy. This risk persisted after stratifying for stage at diagnosis or number of positive nodes. Furthermore, the
authors concluded that treatment combinations involving ALND or chemotherapy resulted in approximately four- to five-fold increases in the HRs for lymphedema (HR, 4.16 [95% CI, 1.32–12.45] for SLNB/chemotherapy/no radiation) compared with no treatment. While further validation of this finding is needed, the concept that chemotherapy independently influences lymphedema risk demonstrates that this risk can be affected not only by locally directed therapies but also by systemic ones.[25]

**Changes in Surgical Management**

Changes in the surgical management of the axilla have been instrumental in reducing axillary morbidity, especially lymphedema. SLNB is now the standard of care for axillary staging, as its accuracy, low false-negative rate, and low rate of axillary recurrence have been documented in more than 70 studies. Current research to further minimize morbidity from axillary surgery focuses on reducing the need for completion axillary dissection in the setting of a positive axillary node. The American College of Surgeons (ACOSOG) Z0011 trial published in early 2011 documents the first prospective randomized data showing that at a median of 6 years follow-up, SLNB alone does not result in inferior survival in women with T1 or T2 tumors and one or two positive sentinel nodes who received breast conservation surgery, chemotherapy and/or hormonal therapy, and whole breast radiation therapy.[26] In the study, more than 70% of the women with a positive SLNB had no additional positive nodes, suggesting that in select cases SLNB can be both diagnostic and therapeutic. While this trial is viewed as practice-changing, it is important to note that the trial called for standard whole breast radiation but did not standardize the radiation tangents other than to say that third field–directed axillary radiation was forbidden. As a result it is possible that radiation tangents were adjusted higher in node-positive women who were randomized to the SLNB-only arm. If standard radiation tangents cover approximately 30% to 50% of the level I and 25% of the level II axillary nodes,[27] then adjusting the tangents “higher” has the intention of covering more nodes than standard. These data are important from the perspective of morbidity, as an adjustment in the tangents may result in increased rates of axillary morbidity above what is seen with standard whole breast tangents and SLNB alone. The radiation ports are currently being evaluated retrospectively. An additional prospective trial, ACOSOG Z1071, is evaluating the validity, accuracy, and false-negative rate of SLNB after neoadjuvant chemotherapy in women who present with node-positive disease at diagnosis. The investigators hypothesize that SLNB after neoadjuvant chemotherapy will appropriately and reliably stage the axilla and therefore allow elimination of ALND in women converted by neoadjuvant chemotherapy from node-positive to node-negative status. The trial accrued quickly and results are pending. Remaining questions to be answered include that of which women may be able to forgo axillary surgery (SLNB or ALND) altogether.