

nlm LymphLink

The Next Chapter

A fresh, digital evolution of LymphLink - bringing information, insights, and community connection straight to you as we open a new era of learning, advocacy, and shared experience.

The NLN continues to champion support, education, and advocacy for everyone affected by lymphatic diseases.

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National Lymphedema Network



National Lymphedema Network

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NLN LymphLink

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Mission Statement

The National Lymphedema Network's mission is to empower our community of lymphedema practitioners and patients by providing educational opportunities, networking opportunities, and interventional resources. We aim to inspire clinicians to provide world-class care for people with lymphedema by promoting best practice guidelines and standards of care.

**Deadline for the next issue is
May 28, 2026**

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The goal of this publication is to provide information specific to the needs of lymphedema patients and health care providers.

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Letter from the Co-Executive Directors

Dear NLN Community,

We are thrilled to reintroduce *LymphLink*, a long-beloved publication now returning in a fresh digital format. This moment represents more than the revival of a trusted resource; it marks a renewed commitment to connection, education, and the collective strength of our lymphatic community.

Over the past year, the National Lymphedema Network (NLN) has continued to evolve with purpose. We have expanded programs, strengthened partnerships, and deepened our focus on supporting clinicians, uplifting patient voices, and advancing access to quality lymphatic care. Bringing *LymphLink* back in a modern, accessible format is an important part of that forward movement. It allows us to highlight innovation, share resources and celebrate the work happening across the country - quickly, clearly, and in a way that reaches more people than ever before.

Looking ahead, we are especially energized as we prepare for the 2026 NLN Summit: *Whole Body Healthcare*. This year's theme reflects our commitment to expanding lymphatic awareness across the broader healthcare community and highlighting the lymphatic system as a foundational component of whole-person health. By bringing together clinicians, researchers, industry partners, and individuals living with lymphatic disease, the Summit creates a shared space for learning, collaboration, and innovation. We believe this gathering will play a vital role in advancing understanding, strengthening interdisciplinary practice, and elevating the visibility of lymphatics across every corner of healthcare.

This issue captures the passion, dedication, and momentum driving the NLN community forward. From new educational opportunities to growing Ambassador engagement, from advocacy efforts to community-centered initiatives, we are excited for what lies ahead. Thank you for being part of this journey with us, and for the commitment you bring to the individuals, patients, and communities you serve - whether through lived experience or clinical care.

We look forward to continuing this next chapter together.

With appreciation,



**Jennifer Williams, PT,
DPT, CLT-LANA**
Director of Clinical
Education



**Kristy Newman, PT,
MSPT, DPT, CLT-LANA**
Director of Industry
Relations & Membership

The Inception of NLN Newsletter moving into LymphLink

Saskia R.J. Thiadens, RN
Founder, National Lymphedema Network

The return of a historic voice dedicated to education, advocacy, and access to care

I vividly remember picking up a patient from the recovery room at UCSF following breast reconstruction surgery in 1986. Her arm was enormously swollen and appeared as though she was having an allergic reaction to the intravenous infusion. I immediately called her surgeon to express my concern. He told me not to worry, that there was nothing that could be done - she should "just learn to live with it."

As a nurse, I could not accept that attitude. Shortly thereafter, in 1987, I opened the first Lymphedema Clinic, the Aurora Lymphedema Clinic, in San Francisco. Very quickly I became aware of the enormity of this disease and how little was known about it. The phone did not stop ringing. Patients, young and old, local and from afar, were calling the clinic, and it became clear that this was a much bigger problem than I had anticipated. This realization prompted me to found the National Lymphedema Network (NLN), *with its mission 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.*

At that time, we did not have the luxury of computers or the internet, and the question was how to communicate with patients and healthcare professionals across the country. My immediate thought was a newsletter. My clinic patients were enthusiastic and not only provided financial support but also reached out to friends and family to help spread awareness. Before long, physical therapists from around the country began calling, and shortly thereafter the NLN Newsletter, later known as *LymphLink*, was born.

The first NLN Newsletter, Volume 1, published in January 1989, consisted of four pages, and we printed 500 copies. My patients and family members spent a



Saskia RJ Thiadens, Founder of the NLN

weekend sorting the newsletters by state and creating mailing lists that included the American Cancer Society, Susan G. Komen, the National Institutes of Health, and various cancer centers. Two weeks after the mailing, our phone did not stop ringing. Some clinicians called, but most of the calls came from patients who were thrilled to finally have a nonprofit organization they could reach out to for support, to share their frustrations and concerns, and, most importantly, to learn about treatment options and referrals.

At the same time, we established NLN membership, and numerous massage therapists and physical and occupational therapists joined. Dr. Joseph Feldman became not only our first member but quickly became an active participant in NLN activities. In 1991, I formed

The Inception of NLN Newsletter... Continued

the first NLN support group and was overwhelmed by the number of patients and family members who joined, many of whom had been long deprived of information and support.

In 1993, I was invited to join the committee of the International Society of Lymphology (ISL) in Washington, DC, and brought forty patients from around the country to a scientific congress—an unprecedented step intended both to connect them with experts and to make visible the urgent lack of care in their home communities. The first NLN conference took place in San Francisco in 1994 and drew more than 300 healthcare professionals and patients from around the world. Our NLN Conferences continued to host patient summits, and I founded the Lymph Science Advocacy Program (LSAP) to train patients to become advocates

in their own communities. On March 6, 1994, I founded Lymphedema D-day, a special day set aside each year to honor inspirational patients and professionals. In 2000, the NLN launched a nationwide campaign to promote the submission of statewide resolutions, with Virginia becoming the first state to adopt one, followed by thirty-two others.

A nationwide NLN insurance coverage task force was created, consisting of patient activists and professionals, and a formal request was submitted to Medicare for coverage of Complete Decongestive Therapy. In 1997, we established our website, www.lymphnet.org, and immediately received an overwhelming response from patients and professionals around the world. During this time, the NLN participated in breast cancer legislation by circulating petitions

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The Inception of NLN Newsletter... Continued

nationwide. With the support of Dr. Ernie Bodai, a landmark rider was added to both a California state bill and a federal bill, providing insurance coverage for patients who developed lymphedema following breast cancer surgery.

In 1998, the NLN recognized the need for unity and was instrumental in bringing together instructors, schools, and other key players, including the American Cancer Society, to found the Lymphology Association of North America (LANA), which today has approximately 3,000 CLT-LANA therapists. We also created the Medical Advisory Committee and a Research Committee, resulting in national presentations, National Institutes of Health-funded projects, and numerous evidence-based publications. By 2008, the NLN had developed sufficient influence that the newly formed National Accreditation Program for Breast Centers (NAPBC) required standards for patient education regarding the risk of developing lymphedema.

With a strong editorial committee in place, the quarterly newsletter evolved into *LymphLink*, (2008) expanding to thirty-eight pages with a circulation of 10,000 copies distributed worldwide.

I retired from the NLN in 2016 and in 2018 created a Screening and Early Detection program for Melanoma patients at Sutter Health in San Francisco, with the goal to standardize among all people diagnosed with cancer. In the meantime, I am proud of the new NLN leaders and continuing growth of Lymphology around the world. The return of *LymphLink* in 2026 represents a return to what mattered most from the beginning—clear communication, education, and a willingness to listen to patients as well as professionals.

When *NLN Newsletter/LymphLink* first appeared, it offered information and reassurance at a time when very little existed. Today, despite many advances, patients still face confusion, misinformation, and barriers to care. The continued role of *LymphLink* is to provide reliable knowledge and connection, and to remind us why the NLN was founded: so that no patient is ever again told that nothing can be done.



The first LymphLink Edition, 2008

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National Lymphedema Network

2026 SUMMIT

Whole Body Healthcare



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Early Bird Rate: \$299

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REGISTER NOW >

This summit **explores the lymphatic system as a foundational component** of cardiovascular, pulmonary, gastrointestinal, neurological, orthopedic, and oral-facial health. The event is **designed for all professionals** who care for patients across the lifespan and across clinical settings.

Our mission is to bridge disciplines, **promote whole-system wellness**, and spark new possibilities for collaborative, patient-centered care. Educational sessions will demonstrate how lymphatic science informs everyday clinical decision-making in medical, surgical, and rehabilitation environments.

Featured Topic Tracks Include

- Post-surgical recovery, wound healing, and inflammation
- Head and neck oncology, dysphagia, and airway management
- Integrative & adjunctive therapies for better outcomes
- Oncology rehabilitation
- Visceral and gastrointestinal health
- Orthopedic trauma, sports medicine, and return-to-activity
- Brain-Body connections
- Chronic inflammatory and systemic conditions

Who Should Attend

- Physicians (MD/DO) and Physician Associates
- Nurses and Nurse Practitioners
- Speech-Language Pathologists
- Respiratory Therapists
- Dentists and Oral Myofunctional Therapists
- Athletic Trainers
- Massage Therapists
- Physical and Occupational Therapists

Continuing education approval will be pursued for multiple professions including CME, nursing CE, ASHA CEUs, and rehabilitation professional CEUs.

Lymphedema Awareness Month



March is Lymphedema Awareness Month, a time to elevate visibility, education, and support for the millions of people affected by lymphedema worldwide. Awareness matters because lymphedema is often misunderstood and under recognized, even though it can have a major impact on comfort, mobility, skin health, and quality of life. While there is no cure, early recognition, consistent management, and the right support can make a life changing difference.

Why March 6 Matters

Lymphedema Awareness Day was founded by NLN's visionary founder, Saskia RJ Thiadens, to promote awareness and honor the real challenges people with lymphedema navigate every day. March 6 was chosen because it marks the incorporation of the National Lymphedema Network as the first nonprofit organization dedicated to lymphedema. What began as an NLN observance has grown into a global movement now recognized as World Lymphedema Day. It is a day when people around the world unite in support of those living with lymphedema and recognize the providers advancing care through education, innovation, and advocacy.



Evonnia "Evy" Dominguez, NLN Marketing Associate

Ways You Can Participate

This month is about more than awareness. It is about community. Patients, caregivers, clinicians, and advocates all play a role in making lymphedema more visible and better understood.

Share Your Story

A short post, photo, or reflection can help someone feel less alone and encourage earlier diagnosis and treatment. Share your story with the NLN Community by emailing marketing@lymphnet.org.

Start a Conversation

Talk with friends, family, coworkers, or healthcare providers about lymphedema. Many people still do not know what it is, and your voice helps change that.



First Lymphedema D-Day Award, March 6, 1994

Lymphedema Awareness Month Continued

Stay Informed and Share Resources

Visit lymphnet.org for education and tools you can share. The more we understand the lymphatic system, the stronger our community becomes.

Awareness Month Offers and Ways to Support NLN

Throughout March, new members can receive 10% off NLN memberships. Joining strengthens year-round education, resources, and connection for the lymphedema community. Membership supports reliable information, community programs, and practical tools that help patients and clinicians feel better supported.

👉 [Join NLN this March and save 10% on membership.](#)

Inspiring Stories

"While life sucks most days trying to navigate it, I remind myself that I have the control to shape how I respond to it all. It allows me to take some power back, and still get to love and enjoy life despite the inconveniences."



Gratitude for the Experts Behind the Work

Lymphedema Awareness Month is also a time to recognize the clinicians, researchers, and advocates who strengthen the lymphatic community through steady behind-the-scenes work. NLN Medical Advisory Committees help shape Position Papers and strengthen guidance across areas like treatment and diagnosis, surgery, compression, phlebolympheema, and risk reduction. NLN is also deeply grateful to Clinical Focus Group facilitators, the Start Strong Committee, the Garment Program Committee, and the Patient Support Team for their leadership and commitment to education, access, and connection.

**Together, we make lymphedema visible.
Together, we make a difference.**

"I went from fighting insurance battles and waiting months for garments to make informed decisions about LVA surgery. Education turned fear into something manageable."



10% OFF Memberships!

MARCH 1 - 31

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Your Commitment Creates Momentum.
Awareness Grows When We Grow Together.



Lymphedema Awareness Month



National Lymphedema Network

Lymphedema Life Impact Scale Validation in Spanish

Validación de la escala del efecto del linfedema en la vida en español



Do you have lymphedema?

Institution / Department: The Unit on Vascular Malformations at the Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD) at the National Institutes of Health (NIH) is conducting a research study to validate the Lymphedema Life Impact Scale (LLIS) in Spanish. We are interested in learning the utility of this scale in Spanish and the differences between the Spanish and English versions.

Who can participate: Any individual 18 years old or older with upper and/ or lower lymphedema that prefers to seek medical care in English or Spanish

What's involved:

1. Fill out an eligibility questionnaire in this link <https://ctss.nih.gov/llis/inicio.html> (5min)
2. Send us your username to llis_nichd@mail.nih.gov
3. Join us for a Telehealth to go over the LLIS questionnaire (30min)

How to join the study / Contact details:

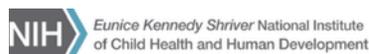
Website: <https://ctss.nih.gov/llis/index.html>

PI: Sarah Sheppard, MD PhD

AI: Daniela Garlisi, MD

Email: llis_nichd@mail.nih.gov

Phone: 301-827-0863 (Dr. Garlisi) Fax: 301-480-2827



¿Tiene linfedema?

Institución/Departamento: La Unidad de Malformaciones Vasculares del Instituto Nacional de la Salud Infantil y el Desarrollo Humano Eunice Kennedy Shriver (NICHD) de los Institutos Nacionales de la Salud está realizando un estudio de investigación para validar la "Escala del efecto del linfedema en la vida (LLIS)" en español. Nos interesa saber qué tan útil es esta escala en español, y cuáles son las diferencias entre las versiones en español y en inglés.

Quién puede participar: Cualquier persona mayor de 18 años con diagnóstico de linfedema de las extremidades superiores o inferiores, que prefiera recibir atención médica en inglés o español.

En qué consiste:

1. Complete el cuestionario de elegibilidad en este enlace: <https://ctss.nih.gov/llis/inicio.html> (5 min)
2. Enviar su nombre de usuario a llis_nichd@mail.nih.gov
3. Únase a nosotros en una consulta de telesalud para revisar el cuestionario LLIS (30 min)

Cómo participar en el estudio / Datos de contacto:

Sitio web: <https://ctss.nih.gov/llis/inicio.html>

Investigadora principal: Dra. Sarah Sheppard, MD, PhD

Instructora principal: Dra. Daniela Garlisi MD Correo

electrónico: llis_nichd@mail.nih.gov

Teléfono: 301-827-0863 (Dra. Garlisi)

Fax: 301-480-2827

STRIDE Introduction

Professional guide to compression garment selection for the trunk and upper limb

Brandy McKeown and Suzie Ehmann

This document presents a second iteration of the STRIDE algorithm for selection of compression therapy in lymphoedema. Building on the original 2019 algorithm, which was focussed on the lower limb, this second iteration expands the remit of STRIDE to cover the upper limbs, breast and trunk.

This Journal of Wound Care special issue brings together a wealth of knowledge on upper-body lymphoedema, compression therapy and the STRIDE algorithm, presented in six articles on the following areas:

1. Anatomy, pathophysiology and assessment of upper-body lymphoedema¹
2. The science of compression textiles and garments for upper-body lymphoedema²
3. Categorising compression devices, garments and accessories for upper-body lymphoedema³
4. Using the STRIDE algorithm for compression selection in upper-body lymphoedema⁴
5. Case studies of the STRIDE algorithm for compression selection in upper-body lymphoedema⁵
6. Delphi study on the STRIDE algorithm for compression selection in upper-body lymphoedema.⁶

This document represents the consensus of clinical experts from multiple countries, unified in their commitment to advancing compression therapy through evidence-based practice and international collaboration. Statements have been supported with references to published evidence where possible, with unreferenced claims being founded on the expert consensus of the authors.

The STRIDE algorithm prioritises individualised patient-centred care, tailored to the multiple needs of specific patients. As such, STRIDE accounts for the complexity seen in clinical practice and aims to avoid simplistic one-size-fits-all methods.

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At the core of this complexity-informed approach, STRIDE moves compression selection beyond a traditional focus on pressure dosage alone. Instead, it incorporates other textile properties, such as stiffness, containment, graduation and fatigue. It also takes account of how compression aligns with anatomical variations in oedema distribution, tissue texture and body shape specific to a patient's clinical presentation. This nuanced approach addresses the intricate anatomy of the upper limb, breast and trunk, where diverse shapes and tissue textures present complex clinical challenges that require specialised solutions.

Wear the Mission During Lymphedema Awareness Month



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STRIDE Introduction Continued

The STRIDE algorithm also emphasises the dynamic nature of compression and the need for treatment to evolve alongside the patient's needs. Lymphoedema is not static, and compression requirements shift based on changes in tissue texture, swelling patterns and other aspects of clinical presentation. This is particularly critical for the upper limbs and trunk, where anatomical diversity demands adaptable solutions.

The STRIDE algorithm is intended to provide clinicians with a precise, structured and evidence-based framework for clinical decision-making. Selecting the most appropriate and effective compression options should optimise clinical outcomes in upper-body lymphoedema, helping control swelling and other symptoms and improve patients' quality of life.

Declaration of interest: Sponsored by Haddenham Healthcare and the US Medical Compression Alliance (USMCA); Brandy McKeown has been a paid consultant or speaker for HMP Global/Wound Source, L&R, LymphaPress, Juzo and Sigvaris; Suzie Ehmann has been a paid consultant or speaker for L&R, Urgo, OVIK, Compression Dynamics and Medline

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To view the entire STRIDE algorithm document, please scan the QR code or click on the image.



A Clinical Viewpoint on When Manual Lymphatic Drainage Isn't: Protecting Patients From Harmful Practices

Micky Frackleton PTA/CLT/LMT/CES/CPT

Manual lymphatic drainage (MLD) has long been a mainstay in the management of lymphedema and has also been recognized within the wellness community for its therapeutic touch. MLD is not a singular technique, but a set of shared principles grounded in scientific knowledge that serve as the foundation for training across multiple established institutions.

Well-known institutions include Vodder, Földi, Leduc, and Casley-Smith. Despite stylistic differences, all share core principles: gentle, superficial techniques applied to intact skin and explicitly excluding wound disruption and forced fluid expression. The NLN's position paper on MLD reinforces these standards. MLD is therefore not a vague marketing term.

However, in some plastic surgery postoperative aftercare settings (most commonly associated with aesthetic procedures), the established term 'lymphatic drainage' is used in ways that significantly deviate from accepted protocols. In these environments, the term is afforded a measure of credibility while being removed from its clinical context, and its meaning is replaced with a variety of non scientific approaches found within body sculpting practices, recovery houses, recovery centers, healing houses, spas, hotels, or individual offices advertising lymphatic services.

Those providing these services have training that is often derived from uncredentialed programs not grounded in developed, reviewed, or standardized safety practices, exposing uninformed patients to unnecessary and unsanitary risks. There is no found literature supporting the routine practice of forcing fluids from incisions or reopening incisions for drainage as part of postoperative care. Legitimate seroma management involves sterile needle aspiration by physicians for symptomatic fluid collections or surgical drainage in cases of infection.

This is not an argument against ethical postoperative support therapies, but against the misuse of established clinical terminology to legitimize unvalidated and unnecessary practices such as forcing fluids out of an incision or the more extreme practice of reopening an incision to manipulate the exudate.

This appropriation of any portion of the term MLD could appear as any of these names: Body sculpting lymphatic massage, Lymphatic sculpting, Contour lymphatic massage, Snatched lymphatic massage, Brazilian lymphatic massage, Body contour drainage, Aesthetic lymphatic massage, Cosmetic lymphatic therapy, or High-definition lymphatic massage.

The practice of forcing fluid out of cannula incisions and aggressive manipulation creates issues that may not resolve without permanent changes or disfigurement. These actions, especially by unlicensed providers using "squeeze massages", are associated with a range of problems:

- **Increased Inflammation and Tissue Damage:** Aggressive pressure can trigger the body's trauma response, increasing inflammation and damaging delicate, healing tissues.
- **Infection Risk:** Manual expression without sterile protocols or medical supervision significantly increases the risk of introducing bacteria into the surgical site, potentially leading to an infected seroma or other serious infections.
- **Fibrosis (Scar Tissue) Formation:** Trauma from harsh massage can exacerbate the formation of hard, lumpy scar tissue, which can compromise the aesthetic outcome of the surgery.
- **Pain:** The process can be extremely painful, leading to patient distress, pain, and even drops in blood pressure and fainting.
- **Delayed Healing:** Damaging the healing tissue and increasing inflammation can slow down the overall recovery process.

A Clinical Viewpoint... Continued

Concerns regarding unqualified postoperative care have drawn the attention of the American Society of Plastic Surgeons (ASPS). In their 2023 article 'Aftershocks: Beware of unlicensed healing houses,' they focus on unregulated aftercare facilities that appear to have legitimate medical staffing. "Unlike surgical centers and hospitals, they aren't regulated and don't require any specific type of accreditation to operate." These facilities are able to circumvent qualified staffing requirements by having a nurse or medical professional serve as the public face, but this doesn't guarantee that a medical professional will actually provide the hands-on patient care. In these settings, postoperative patients often have their first encounter with improper lymphatic treatment, placing their care in the hands of individuals working outside their scope of practice, unaware that such aggressive and unsafe techniques are inappropriate and expose them to significant risk.

States are taking notice and taking action against these unsafe practices. While numerous cases exist of practitioners working outside their scope of practice with post-operative clients, the Florida case reported by the Miami Herald in 2022 is illustrative.

The Miami Herald article states: "A South Miami-Dade woman who calls herself 'The Squeeze Lady' had her license as a massage therapist revoked Wednesday by the state over lymphatic drainage massages she wasn't licensed to do and, the state said, did in an unsanitary manner."

The article itself uses the term 'lymphatic drainage' to describe her actions, though what she performed was actually incisional drainage—forcing fluids from open incisions. She had unknowingly provided evidence against herself through Instagram videos showing these procedures, and this evidence led to her license revocation. The Florida Department of Health stated: "Massage does not include exuding fluids from open wounds. Properly performed lymphatic massages use sequences of gentle strokes to stimulate the flow of fluid through the lymphatic system. Post-surgical drainage massages are outside of the scope of massage therapy in the state of Florida."

The following images are drawn from publicly available social media content and are presented to illustrate commonly promoted postoperative treatments. Each of them is using the term lymphatic in their description of service. These images are not to single out but to show how many businesses are comfortable with and posting them as lymphatic massage.

2



The intent of this article is to bring awareness of the misappropriation of MLD and encourage my colleagues to publicly distinguish their work from postoperative 'body sculpting and lymphatic draining massage,' and to participate in developing position statements on their own sites and supporting lymphatic organizations in addressing postoperative misuse. Protecting our professional standards ultimately protects the patients who trust us with their care.

Conflict of Interest: The author declares no conflict of interest in relation to this article.

1. American Society of Plastic Surgeons. "Aftershocks: Beware of Unlicensed 'Healing Houses.'" 2023. <https://www.plasticsurgery.org/news/articles/aftershocks-beware-of-unlicensed-healing-houses>
2. Miami Herald. "South Florida 'Squeeze Lady' loses massage license over post-op lymphatic drainage." 2022. <https://www.miamiherald.com/news/health-care/article259491029>

Disclosure: A Clinical Viewpoint represents the professional opinions and experiences of the contributing clinician. The perspectives shared are their own and do not necessarily reflect the official position of the National Lymphedema Network. This article is intended for educational purposes only and should not be interpreted as medical advice.

2026 Summit - Whole Body Healthcare Featured Speaker: Dr. Wei Chen

Dr. Chen will explore how emerging insights into lymphatic brain surgery are reshaping our understanding of Parkinson's disease and other neurodegenerative conditions. He will also examine the systemic effects of lymphatic dysfunction, highlighting how disruptions in this often-overlooked system influence whole-body health. Together, her sessions offer a powerful look at the lymphatic system's role in both neurological and multisystem disease.



**Lymphedema
Awareness Month
Webinar with Didi Okoh
March 24 at 3pm EDT.**

Paralympic & World Bronze Medalist, Ambassador for Diversity in Sport and Lymphedema Awareness Advocate Didi Okoh will be the guest speaker in a special webinar to mark Lymphedema Awareness Month, join us and learn about Didi's inspirational story.

Diagnosed with lymphedema after years of uncertainty, Didi turned challenge into purpose. Today, Didi champions diversity in sport and professional spaces, inspiring young people to pursue their dreams without limitation. "Your condition doesn't define your goals—you do."

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Neuro-Lymphatic Therapy and Emerging Research Trends: Bridging Peripheral and Central Lymphatic Function

Carmen Recupero, CLT-LANA, WCC, CMT, LPTA

Over the past decade, the discovery and expansion of research on the central nervous system's lymphatic and glymphatic systems have reshaped our understanding of fluid dynamics, immune signaling, and neuroinflammation. While manual lymphatic drainage (MLD) has long focused on peripheral lymphatic transport, emerging evidence suggests that central nervous system lymphatic pathways may also be clinically relevant to patients with chronic inflammation, traumatic brain injury, neurodegenerative conditions, and persistent post-viral syndromes.

This evolving body of literature raises important clinical questions:

- Can manual therapies influence glymphatic function?
- What role does cervical lymphatic clearance play in central nervous system waste removal?
- How should lymphedema therapists interpret this research responsibly?

Central Nervous System Lymphatics: A Brief Overview

In 2015, functional lymphatic vessels were identified within the meninges, challenging the long-held belief that the brain lacked classical lymphatic drainage. Subsequent research has described a perivascular fluid transport system—commonly referred to as the glymphatic system—that facilitates the clearance of metabolic byproducts such as amyloid-beta, tau proteins, and inflammatory mediators.

This system appears to be most active during sleep and is influenced by arterial pulsatility, respiratory patterns, and body positioning. Importantly, cerebrospinal fluid ultimately drains into deep cervical lymphatic pathways, not just the superficial head and neck; reinforcing the connection between central and peripheral lymphatic structures. For clinicians trained in complete decongestive therapy (CDT), this anatomical continuity is familiar. The difference now lies in growing evidence suggesting that impaired cervical drainage may influence broader inflammatory burden.

Clinical Implications for Lymphedema Therapists

It is essential to state clearly: current research does not claim that manual therapy “treats” neurodegenerative disease. However,

Neuro-Lymphatic Therapy... Continued

emerging data through recent white papers support the concept that lymphatic clearance pathways are integral to neuroimmune balance and that certain modalities such as specific MLD, sound waves at certain frequencies and photo biomodulation as well as posture, and our tried and true movers of peripheral lymphatic fluid: arterial pulsation, respiration, muscle contraction and peristalsis all can facilitate this natural process.

These mechanisms align with long-standing principles within manual lymphatic therapy—namely, that fluid transport is pressure-sensitive, rhythm-dependent, and influenced by autonomic tone.

Several areas of interest include:

- Traumatic brain injury and post-concussion recovery
- PTSD and stress-related neuroinflammation
- Long COVID and persistent inflammatory states
- Neurodegenerative disease risk modulation
- Chronic migraine patterns

Specific manual lymphatic techniques that prioritize deep abdominal preparation, gentle cervical work, diaphragmatic regulation, and thoracic duct facilitation may support systemic inflammatory modulation. However, protocols should remain evidence-informed and conservative.

These now tens of thousands of white paper studies now underscore a broader shift toward viewing lymphatic function as central—not peripheral—to immune and neurological health.

Evidence supports that:

- The cervical lymphatic system is a major outflow pathway for CNS drainage
- Lymphatic vessels play a role in immune signaling
- Inflammation and impaired drainage are interconnected

Until more interventional trials are published, clinical application should focus on:

- Optimizing cervical and thoracic lymphatic pathways—including the deeper olfactory and meningeal pathways
- Supporting sleep hygiene
- Educating patients on respiratory and positioning strategies
- Collaborating with interdisciplinary providers

Future Directions

The next decade will likely bring:

- Imaging studies measuring lymphatic changes pre- and post-manual therapy (some already complete)
- Expanded research in TBI and PTSD as well as Autism, and ADHD populations
- Investigation into long-COVID inflammatory clearance
- Clarification of autonomic influence on lymphatic propulsion
- More defined integration between lymphedema therapy and neurorehabilitation

The intersection of neuroimmunology and lymphatic science represents a significant shift in our field. For certified lymphedema therapists, this moment invites thoughtful engagement—grounded in anatomy, tempered by scientific rigor, and guided by patient safety.

As research advances, the lymphatic profession has an opportunity to contribute responsibly to this evolving understanding of fluid physiology and systemic health.

Disclosure:

The author is an educator in lymphatic therapy and consults within the healthcare sector. No product endorsements are included in this article.



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Adjustable Velcro® Wraps in Decongestive Therapy: Mechanism-Based Differences and the Role of Knitted-Band Systems

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Abstract

Adjustable Velcro® wraps (AVWs) have emerged as an important alternative or adjunct to traditional short-stretch bandaging in the management of chronic oedema, lymphoedema, and lymphovenous disease. While AVWs are often grouped as a single category, their mechanical behavior, textile construction, and application methods vary significantly, influencing clinical performance and patient concordance. This article synthesizes current evidence on pressure, stiffness, elasticity, and microcirculatory effects of compression systems, integrating findings from recent comparative studies and case-based research. Knitted-band systems such as Easywrap® are highlighted as an example of how textile engineering—distinct from laminated strap designs—can influence conformity, breathability, and consistency of delivered compression. These distinctions do not imply superiority but underscore the need for mechanism-based selection criteria that extend beyond nominal dosage. AVWs with simplified application, predictable stiffness, and improved conformity may support self-management, enhance adherence, and maintain therapeutic pressures more consistently across diverse patient presentations.

Keywords: adjustable Velcro wraps, compression therapy, stiffness, lymphoedema, venous leg ulcer, decongestive therapy, Easywrap®.

Introduction

Compression therapy remains the cornerstone of conservative management for lymphoedema, chronic oedema, and venous leg ulceration. Complex Decongestive Therapy (CDT) is widely recognized as the gold-standard approach, with compression identified as “the main resource for lymphedema treatment, both in the volume reduction phase and in the maintenance phase” (Bergmann et al., 2021). Traditional multilayer bandaging is effective but labor-

intensive, requires skilled application, and may limit hygiene, mobility, and patient autonomy.

Adjustable Velcro® wraps (AVWs) have emerged as a practical alternative or adjunct, offering ease of application, removability, and the ability to maintain therapeutic pressures between clinic visits. Evidence demonstrates that AVWs “create a semi-rigid compression system that provides resistance to tissue movement...promoting both lymphatic and venous function” (Stanton, 2024). Their low resting pressure and high working pressure mimic the hemodynamic behavior of short-stretch bandages, supporting venous return and lymphatic flow.

However, AVWs are not interchangeable. Differences in textile construction, strap architecture, stiffness, and application method directly influence clinical performance. This article reviews these distinctions and highlights the role of knitted-band systems such as Easywrap® as an example of how textile engineering can support more consistent dosing and improved patient concordance.

Compression Therapy and Lymphovenous Physiology

Lymphatic and venous insufficiency frequently coexist, and many chronic wounds are more accurately described as lymphovenous in origin. Stanton (2024) emphasizes that clinicians must “recognise the interconnected nature of the venous and lymphatic systems,” noting that oedema in venous disease is often accompanied by lymphatic overload and lymphostatic tissue changes.

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Adjustable Velcro... Continued

Compression therapy addresses both systems by (Box 4, Stanton 2024):

- reducing capillary filtration
- improving venous return
- enhancing calf muscle pump function
- increasing lymphatic reabsorption
- stimulating lymphangion contractions
- breaking down fibrosclerotic tissue

Stiff compression systems—those with a high static stiffness index (SSI)—are particularly effective in lymphovenous disease because they generate high working pressures during ambulation while maintaining tolerable resting pressures.

Mechanical Properties of Adjustable Wraps

Recent comparative studies have clarified how AVWs differ in stretch, interface pressure, and stiffness. Benigni et al. (2023) demonstrated that wraps vary widely in stretch (0–124%), influencing both achievable resting pressures and SSI. Wraps with 50–60% stretch generate high stiffness at moderate resting pressures, while long-stretch systems allow higher resting pressures but produce lower SSI.

Stiffness is clinically meaningful:

“The higher the SSI, the greater the calf ejection fraction” (Benigni et al., 2023).

The JWC supplement comparing seven AVWs—including Easywrap Strong—found that Easywrap® had:

- second lowest variation in lying pressure
- highest mean SSI (13.2 mmHg)
- highest elongation ratio (137%)

These findings suggest more consistent pressure delivery and improved containment, though the authors note that larger independent studies are needed.

Textile Construction: Knitted vs. Laminated Designs

Most AVWs use laminated straps composed of bonded layers of foam, textile, and hook-and-loop material. These designs vary in stiffness, breathability, and conformity. In contrast, Easywrap® uses knitted short-stretch bands, a distinction highlighted in the JWC supplement:

“Wrap 5 (Easywrap®) is made from a knitted fabric, while...all other wraps are made from laminated layers of fabric.”

Knitted construction offers:

- improved conformity to irregular limb shapes
- enhanced breathability
- reduced bulk
- more predictable short-stretch behavior
- natural 50% overlap for even pressure distribution

Impact on Microcirculation and Tissue Oxygenation

Compression therapy also influences microcirculation. A 2019 study of an adjustable padded wrap showed significant increases in skin tissue oxygenation (StO₂), particularly in upright sitting:

“Chair-sitting...increasing StO₂ significantly (32.25%) during wear...24.8% higher than baseline post-intervention” (Chohan et al., 2019).

Supine and long-sitting positions also demonstrated meaningful improvements. These findings reinforce that compression can enhance tissue oxygenation independent of position, supporting tissue health in patients with reduced mobility or venous compromise.

Application Method and Patient Concordance

Ehmann et al. (2018) demonstrated that application method and textile construction have a direct impact on real-world performance of adjustable Velcro wraps. In this case series, laminated wraps with interlacing strap designs required greater dexterity and trunk mobility, making them more challenging for patients with limited hand strength or restricted reach. When these interlacing systems were applied incorrectly, they were more prone to gapping, slippage, exposed skin, and in some instances re-ulceration.

In contrast, wraps constructed with overlapping, knitted straps provided more reliable containment, particularly for large, irregularly shaped, or fibrotic limbs. The overlapping design reduced the likelihood of pressure gaps and skin trauma and was easier for patients and

Adjustable Velcro... Continued



caregivers to apply consistently. As reported by Ehmann et al., knitted overlapping bands were less susceptible to user error and better supported safe self-management across a wider range of functional abilities.

"Although each product performed as marketed in vitro, performance in clinical setting varied greatly dependent on patient presentation and functional skill level."

These findings support the need for selection criteria that extend beyond dosage.

Easywrap[®] as an Example of Mechanism-Based Design

Easywrap's[®] knitted-band construction, simplified overlapping application, and two pressure options (Light and Strong) illustrate how textile engineering can support:

- more consistent pressure delivery
- improved conformity
- reduced bulk
- enhanced breathability
- easier self-management
- fewer application errors

The dosage is selected by ordering Light or Strong, but the knitted architecture helps patients actually achieve the intended dose, addressing the variability documented in earlier AVW designs.

Conclusion

Adjustable Velcro[®] wraps are an important component of modern decongestive therapy, offering a practical alternative or adjunct to traditional bandaging. However, AVWs differ significantly in textile construction,

Adjustable Velcro... Continued

stiffness, application method, and clinical performance. Evidence from comparative studies and case-based research demonstrates that these differences influence conformity, breathability, pressure consistency, and patient concordance.

Knitted-band systems such as Easywrap® illustrate how mechanism-based design can support more predictable dosing and improved usability without implying superiority. As the field advances, selection criteria for AVWs should incorporate textile behavior, stiffness, limb shape, dexterity, and patient goals—not dosage alone. A more nuanced, mechanism-driven approach will support individualized care, enhance adherence, and improve outcomes in lymphoedema and lymphovenous disease.

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From Fear to Advocacy: Veronica's Lymphedema Story

Interview with Veronica Seneriz by Jennifer Williams, NLN Co-Executive Director

Lymphedema is often described in clinical terms, but for many individuals and families, it is a lived experience shaped by fear, resilience, and generational strength. In this conversation, Veronica Seneriz — a patient advocate, founder of Lymphie Strong, and the current Patient Services Director for the Lymphatic Education and Research Network — shares the early chapters of her journey, from a startling billboard on a Texas highway to the profound lessons learned from her father's courage. Her story reveals not only the challenges of navigating a misunderstood condition, but also the power of community, advocacy, and opportunity. What follows is an intimate look at the moments that shaped her path and continue to fuel her commitment to helping others.

A Billboard That Changed Everything

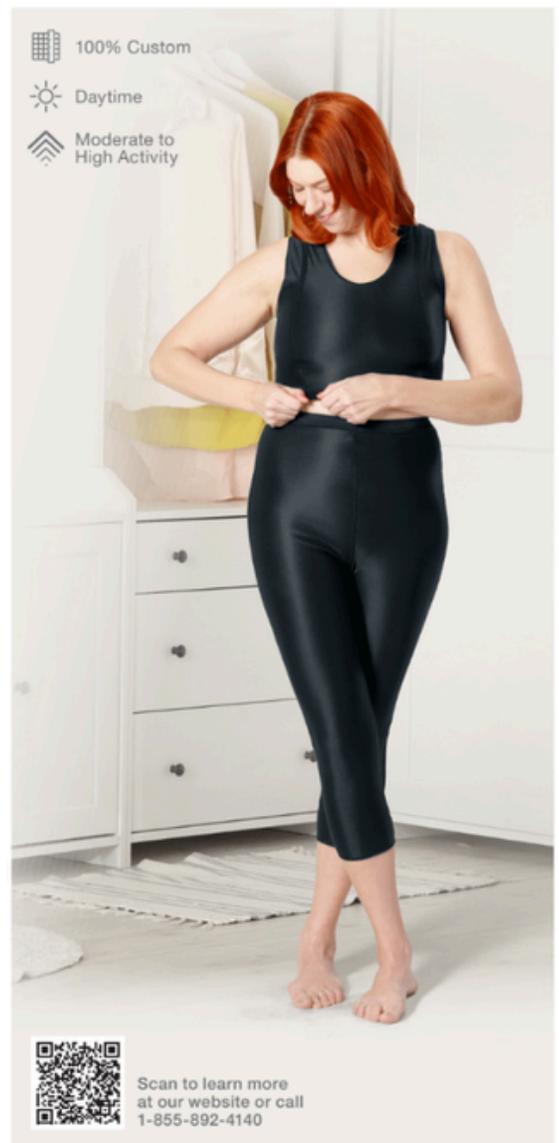
J: Can you share a bit about your lymphedema journey and how it first began for you?

V: Believe it or not, my lymphedema journey started with a billboard. I was driving down the freeway. I had just graduated from college – Texas A&M – and I was on the way to my first day of my first real job in the real world, and **I saw a billboard that had two legs that looked like my father's one leg.** And for those of you that don't know, I'm third generation behind my father and my grandfather. A total of 6 – Lymphedema runs like a river in my family, and a total of 6 family members are impacted, but until that point in time, I had never seen a picture, or read an article, or even read the name lymphedema before and I almost crashed! *(laughs)*

It immediately grabbed my attention – I wasn't focusing on the road, and then I realized that I was still driving. *(laughs)* So after work that day, I came around, and this was in 1988, before the smart phone, before anything – before google, or the digital era that we are in today... where we have information that is instantly accessible, back then it wasn't, so I literally pulled over to the side of the road, and I wrote the number down and I called my parents. I told my dad that I think we have something called lymphedema, and he said, 'What's that?', and I said, 'I have no idea, but I just saw two legs that look like your one leg and we make an appointment and figure it out.' So we went to that appointment, and by then



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I had been swelling [in my right leg] for 4 years, and in the beginning, I didn't want to tell my dad because I had witnessed my father endure – I think we had counted it one time and he endured about 100 bouts of cellulitis. He used to go to the hospital 70 times per year. My mom had a go-bag with his pajamas, toothbrush, just ready to go at the drop of a hat. So many times we were woken up in the middle of the night headed to the ER – the people in the ER knew us when I was a kid, and somebody would take pity on me and come bring me a cup of water or a snack while my parents were dealing with what they were dealing with. I distinctly remember, even as a child, that there was one time that my father's temperature was so high - I think it was like a 105 - that they dumped him in an ice-cold bath.... I was young - this must have been like 1981- and I... at that time **I knew that my dad was different and that he had a possibility to die from whatever it was, and it scared me.** So that fear was embedded when my swelling started, because while I was watching this transpire. So, I didn't want to tell him at first and then my mom she said, you know, 'You've got to tell your dad.' She said 'Don't worry, I'll be here with you. We can tell him together.' So, we sat

down, and I said, 'Dad I have something to tell you.' He was joking around – he liked to joke around – you know, smack talk, always telling jokes trying to make people laugh. He's like 'Oh, yeah? What do you have to say?' And I said, 'Um, **my leg is swelling too, it's been swelling...**' And he turned around, and he punched a hole in the wall. And I had never ever, up until that point, seen him have that type of reaction with anything. And I was stunned, and he said – he turned around with tears in his eyes – and he said (*tearful*) 'I'm so sorry I gave this to you. I don't know what it is, but I'm so sorry that I gave this to you.' And when I saw him upset, I straightened up and I said, 'Don't worry we'll tackle it together!' (*laughs*) So the billboard moment was that becoming of the two generations... this was 1988, I think Guenter [Klose] said that CDT came to New York in 1991, so this wasn't too far after that – [Therapy] took him on right away, they reduced him 45%. He fit in a shoe again, he could fit into jeans – I mean, his life completely changed. I helped him roll bandages- the whole nine yards. He went for 8 weeks and stayed with me in my apartment - I had just moved to Houston.

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From Fear to Advocacy... Continued

Early Dismissal and Missed Opportunities for Care

But with me, I think I was like 105 pounds at the time – I was so young – and they told me, **'Don't worry. You'll never be as bad as your dad.'** So, I didn't get a handout, I didn't get anything about compression, I didn't get anything about MLD, just go along on your way. And my dad, God bless him, he tried to impart the wisdom, 'Wear your compression' – all the dos and don'ts – don't get in the sauna, don't get in the hot water – all that. But that only went so far – that was never the replacement for treatment. So fast forward 12 years, I went to a clinic in Houston that essentially worked on me for about 10 minutes and then put me on a pump for an hour, and they called that CDT.

J: *I don't think Guenter would like to hear that.*

V: *(laughs)* But I didn't know what I didn't know, and I share these bits because they make up who I am as an advocate now. So, I went through that treatment for two months, and at the end, they gave me my pump and sent me on my way.

J: *Did they give you a compression garment?*

V: No, I asked them. I said, 'Aren't I supposed to have some sort of compression garment?' and they said, 'Oh yeah, you can look at this wall and pick one that might fit you. Just pay for it at the front.'

J: *Interesting. When did you get diagnosed, and what was your experience like?*

V: I was diagnosed at the time with my father, but I didn't receive treatment.

A Turning Point in Hawaii

J: *So, you had a formal diagnosis?*

V: Yeah, I had a formal diagnosis, but then 12 years later when I went to another CDT clinic – another therapy clinic in Houston on my own – this was not the same place as where he went to, this was a different therapy clinic. And I didn't know the gold standard at the time included MLD

and the bandaging and wrapping. The first challenge was being dismissed for being "too mild", the second challenge being my ignorance – the lack of education on the gold standard of treatment... I went on what was supposed to be a dream vacation – I flew from Houston to Honolulu – and my first time to Hawaii, you know, the heat, I'm going to have fun in the sun and all these plans... I was there for a week, and within a couple of hours of stepping off that plane – I was unilateral up until that point – within a few hours of stepping off the plane, my left leg blew up, so then I had lymphedema in both legs – I was blind-sided! Because my dad only had it in one leg, I thought it was just going to travel up the way it did on his. It never even crossed my mind that it could jump to another part of the body. I couldn't wrap my head around that, at the time, and I mean I was on the floor crying. There was a time zone difference. I kept calling my dad and he'd never pick up. Finally, I get him on the phone, and I'm like 'My leg! My leg!' He says, 'Oh yeah, your grandfather had it in both legs.' *(pauses)* Now you tell me?! *(laughs)*

J: *Do you think that the reason he didn't say anything was because of old stigmas of not talking about medical issues long ago?*

V: Absolutely, absolutely. My grandfather was a farmer and so my dad was born and raised on a ranch, and so, it was very much you pull yourself up by your own bootstraps' mentality, and there's no crying in baseball, and there's no crying – they did not believe in medicine per say. Any time they had any ailment, it was always some type of home remedy that was whipped up. They just didn't go to town to go to the doctor – going to town from the rural into the city was like a big event. They just didn't even do that. So yeah, I do believe you're right.

Diagnosis, Genetics, and the FOXC2 Discovery

So, anyway, fast forward to using the pump. I used the pump religiously, and I mean religiously, for almost four years. And then one fine day, I didn't know that you were supposed to clear your trunk before using it. I didn't know anything about clearing channels or even diet. What I did do was work out every day. I did step

From Fear to Advocacy... Continued

aerobics every single day. So, one fine day, it stopped reducing - my legs wouldn't go down, and I kept trying and trying, and, by the third attempt to put it on and see no difference in the circumference of my ankles.

Again, I had a meltdown, and I told my dad, I said, 'I don't know what's going on, but this pump's not working.' He says, 'I don't have any clue. You're on your own. I never used a pump before.' So then it was my well woman exam, and my doctor had been my doctor by that point for 15 years - my gynecologist. So when I went up to the table, he said, 'Oh, my goodness. Veronica, what the hell?' And I had never heard him use a cuss word. It was almost like friend to friend. And he said, 'What the hell?' And I burst into tears. I said, 'I've been using this pump, I have primary lymphedema, hereditary... This pump doesn't work, and found out the clinic I went to was shut down for Medicare fraud. **I don't know where to go. I don't know where to go.**' I'm crying. I mean, I'm like... (*simulates hyperventilating*) like I'm at a funeral, you know? So, he says, 'Go meet me in my office. Let's just do the exam.' So, there I was, mascara is all messed up, and sitting on his sofa. And this is another moment in my story that I think is important, because he picked up the phone. He went to both Harvard and Yale, so he liked to talk about his fraternity brothers. He's mentioned that stuff from time to time. So, he picked up the phone, and he says 'I have a patient, she's very dear to me. She's been my patient for 15 years. She has primary lymphedema. And I want... (*shaking her finger*) Don't interrupt me.' He said, 'I'm not asking you to treat her. Don't interrupt me. Listen, I want to know that if she had BCRL, where would you send her?' I had no idea what BCRL meant at that time. And I'm listening, and he writes down these notes. 'Yeah. Okay, bye. See you later. Bye.' (*simulates hanging up a phone*) And he said, 'You need to go to [here].' And so, he writes the order. Turns out... the lymphedema clinic, the outpatient rehabilitation was two miles from my house. That whole time. Two miles. So I ended up going for six weeks, getting the gold standard [treatment], but my CLT - who ended up being my CLT for 10 years before I moved - she said, 'You're not going to reduce what was, no fault of your own, but **you're undoing 20 years of swelling at this point.** This is not going to go away in 6 weeks. You're going to have to work at this.' So that's what I did.

And I reversed - took me a whole year. And I reversed all of my swelling, and my father was my mentor. In the beginning, I would call trying to get the garments on, and I'd say, 'Man, I can't. I'm over here sweating, and it's taking me 30 minutes just to put on one leg, you know? How am I going to go to work like this?' And he laughed. He goes, 'Ah. I'm old. I'm twice as old as you, and I can put it on like that. Keep on practicing. At some point, we'll race. And whoever wins buys dinner.' So, he made it a game. (*laughs*) It was like, instead of woe is me, like, what are you talking about? You know, I'm twice as old as you, and I can do it. Don't tell me you can't do it. So, I finally got good at it. I finally called him, I said, 'Hey, I can get this garment on now. I can get both legs on. He goes, 'Oh, now you want to race an old man. What kind of person are you?' (*laughs*) I was like, 'Oh, I can't believe I fell for that.' He says, 'You're so gullible.'

J: *But it got you through that part where you were struggling and you were able to move forward.*

V: Yeah, but he knew how to incentivize me. He knew which buttons push to get me over the emotional side and just power through. And that was the thing about my dad and his lymphedema - he was never sad about it. He never cried, maybe did on his own, and in private, but I never saw him. **He was always laughing, and he was always outside, and he didn't walk perfect, but he got his cane, and he kept moving.** Kept moving. That's where "Move That Lymph" that came from.

J: *That's such a valuable lesson to learn on its own, even though we know that there's so much research out there to support movement.*

V: Well, I learned by watching him before I read it in the clinical research.

J: *With the pump, when you were using it for four years religiously, did you, at any time, see swelling in your pelvis or in your trunk? Did you have any fibrosis in the in the groin?*

V: No, the only other places that I have felt swelling in addition to my legs, is in the [left] shoulder blade area.

From Fear to Advocacy... Continued

I've had swelling there for a while. I wore the chest compression. I wore nighttime and daytime garments. But my CLT advocated for me to get a pump - she advocated for me to get the chest portion without the head attached, and it took [the company] six months, but [they] developed a custom program for me. I used it for six months, and after that I didn't have any swelling.

J: *Are you still using the device?*

V: It doesn't fit me anymore. There's swelling that I've gotten in my left arm. So again, left shoulder, left arm. My left arm - it's already happened twice, where the first time was in 2022. I got to do CDT. She worked on my arm. She wrapped my leg. She didn't wrap my arm. She just did MLD on it, and it went away.

J: *Have you received any answers as to why the swelling has happened in your upper extremity?*

V: No, that would be a next step for me. You know, as big of an advocate as I am, I haven't explored. You know how sometimes they say you're better helping other people than yourself sometimes? (*laughs*)

Finding Real CDT and Reversing 20 Years of Swelling

J: *I want to go back to your diagnosis for a moment. I'm curious, were you diagnosed by a therapist or officially by a doctor?*

V: No, by therapist.

J: *When did you receive an official diagnosis from a doctor? Was it when you had gone to the gynecologist?*

V: The gynecologist was the first person that wrote the order for CDT - the first MD. But **my official diagnosis didn't come until 2016**. In Houston, there's a lymphologist that actually trained with Guenter [Klose] at Foldi. He is a CLT and an MD, and he was responsible for the hyperbaric oxygen wound healing, but he also did lymphedema and wounds - all under the same umbrella. And I thought that you had to have a wound to go see him, but then I found out that wasn't true. That was a whole other story in and of itself, because when I went to



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go see him, you walk in and it's at the hospital. So they asked me to change into the hospital gown there, and I'm in a chair... And the first thing he did was he pulled out this jeweler's loupe. He says, 'Okay, if you lean forward, I'd like to examine your eyes.' And in my mind, I was like, 'Oh my God, this guy is a quack.' (*laughs*) And he's leaning it, and in my mind, I'm thinking, my swelling is in my legs, you idiot - not my eyes. I'm like, what if they have the wrong chart? All these things are going to my mind. And he does both eyes, and he scoots away, and he starts scribbling all kinds of notes. It's a laptop. And he says, 'Yup, you have Lymphedema-Distichiasis Syndrome.' 'What's that? I thought I just had regular vanilla flavor.' (*laughs*) I made a joke, and he started laughing. He goes, 'Ha, ha, I get it. Lymphedema vanilla.' So just the **Lymphedema-Distichiasis Syndrome** is a FOXC2 genetic mutation, and the genetic marker is the double row of eyelashes. He said, 'I have been a lymphologist,' - I want to say he said 1994, or early '90s - 'and until now, you are only the second patient, and I do this on every single patient that I encounter. You are only the second. But this is the way I was trained... If you had visited me two years prior, we could have got

From Fear to Advocacy... Continued

testing on you and your whole family' - like who was the carrier [of the gene mutation]. Apparently there had been a research project related to hereditary lymphedema, but I missed the boat.

J: *Did he do any testing? Like Lymphoscintigraphy?*

V: To be honest, I don't think that [the hospital] even had that technology. I will tell you that my first ICG was at the NLN [Conference].

J: *Oh, was it during the conference in Cleveland?*

V: Yes, when I met Dr. [Wei] Chen in person for the first time. Me and [another person] both had ICG done for the first time on the stage of the NLN. So that was my first and only "test." I've never been tested, per say.

J: *Did you get to keep the results?*

V: No. He said that they weren't official, like a part of a chart.

J: *Well, that makes sense as part of a learning session. Have you talked to anyone about surgery?*

V: I'm holding out. I don't know if this is popular-unpopular. That's probably the number one question people ask me - fellow patients. They're like, 'Why haven't you had surgery, Vern?' And honestly, in my heart of hearts, I'm waiting for number one, robotic surgery. And I'm waiting for a pill. Because I feel like... I feel like with the surgery to take off whatever fibrosis is there, and how could we connect whatever? And then in my mind, with the medication to follow up, kind of like the heart. Like when you have heart surgery. They fix your heart, but did they put you on high blood pressure medicine and statins. So, I don't know - this is my own theory.

J: *What support from clinicians, family, or community has mattered most to you?*

V: I would have to say that after my father passed away, **the lymphatic community as a whole stepped up.** Because I had family that didn't understand what it was like to have lymphedema, and I family that had lymphedema that didn't want to talk about it, you know? So, I want to say the community as a whole, because, when I started the blog and the Facebook groups, it had patients, CLTs, clinicians, doctors. Everybody was in the group - it wasn't just one aspect. Their support helped me through my grief.

The Lymphedema Paradox

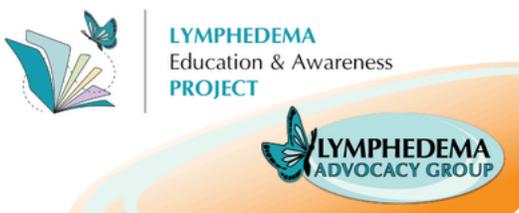
J: *What do you wish more people understood about Lymphedema?*

V: That it's progressive. It's progressive. And to the point of... we should treat lymphedema in the same way that we treat heart disease, diabetes, anything else that is progressive. And I've been using this phrase on my own - I kind of made it up about a month ago. But after listening for patients for five years, if I were to ever go for my master's degree in public health, I would do my thesis on this - There needs to be what's known as a **Lymphedema Paradox.** What that means is there's a window from the onset of swelling to the point to where your swelling is so bad, you can't get in the car to go get treatment. And right now, there are so many people

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From Fear to Advocacy... Continued

whose families call me - spouses, brothers, sisters... And they say, 'Is there anybody that can come see my loved one at home in the bed?' So, lymphedema will eventually, if it's not treated, become a barrier in itself to treatment, and that's a paradox.

J: *That is a very valid point.*

V: Yeah. And that's the same thing with congestive heart failure, and other illnesses - whatever that line in the sand is - **there comes a point to where it affects so many things** that you can't treat one thing without offsetting another. I feel that lymphedema is that way, because if your limbs become so big that you can't drive yourself, then you've got to get somebody else or be transported by ambulance, you're trapped. You're trapped. And that's lethal. There was at least one story where they had the California fires. There was a man who lost his life, because he could not get up out of the house because his legs were so bad. And I'm sure it's happened to other people that there's so many cases that are not documented.

J: *Absolutely. Unfortunately, it also lends to the dire need for more therapists, more people that are specialized to treat this. We have such an emergent situation for CLTs, because there's hundreds of thousands of patients, and there's only thousands of therapists.*

A Father's Tough Love and a Life Changing Wake Up Call

V: The other thing, Jennifer, I didn't share this part, but I'll go ahead and share it now. There was a very profound moment. So I was still kind of resistant to going and getting treatment. I don't know why. Maybe it was like a deer in the headlights - frozen. This was in October of 2014, and my husband, one Sunday morning, said, 'Let's go see your father.' It was like 6 o'clock in the morning when he said this. And I said, 'Okay.' *(laughs)* I looked at him so funny, like this is a random time to go see my dad, but okay, let's go. He says, 'Yeah, maybe we'll go to breakfast, maybe we'll watch the game. Maybe Dallas is going to play tonight.' And so we go, and we surprised him. We knock on the door... He comes to the front door, opens it, and his hair

is sticking up like a parrot. He had just rolled out of bed, and he was wearing shorts. That was the first time I had ever seen my father wear shorts in my adult lifetime. The last time I'd seen it was probably when I was seven or eight years old, and by then I'm 40 years old. And I was shocked. I was shocked because the two legs I saw did not look like they belonged to the same person. His lymphedema leg had severe, severe discoloration - It looked like bark. Very brown and lots of papillomas. I didn't know those words, but now I do... thanks to NLN and other education that I've gotten. I stood there shocked, and my husband was oblivious. He just walked in, says, 'Hey, Pete, how you doing? We're going to make some breakfast, or you want to go somewhere?' He goes in, opens the refrigerator. But my dad and I locked eyes. My dad's like, 'Hold up, man. I need to talk to my daughter privately for a few minutes.' 'Oh, yeah, yeah, yeah, go talk. Let's see what I can whip up.' He was just oblivious! *(laughs)* And all of a sudden, I felt like I was 12 years old again. So he comes outside, and he was a smoker like many in his generation. And he breaks out the cigarettes, and he goes like this (simulates tapping on her palm)... And he lit it up, and he says, 'What I'm about to tell you, I'm only going to say it one time. And once this conversation is over, I will never repeat it. So, you better list it up. You better listen up good.' And I said, 'Okay.' *(laughs)* He says, 'I saw you looking at my leg. I saw your reaction. And I said, 'Yeah. I've never seen you wear shorts before. It was a surprise.' The he said, '**Who the hell do you think you are?**' And I said, 'What?' He said, 'I saw that look, that up and down look. Your look translated to: how did you let your leg get that way?' In other words, he was saying that I was judging him. I said, 'No I wasn't. No, it wasn't.' *(laughs)* I mean, I'm laughing now, but in the moment, it was very serious. He said, 'Yes, you were. I'm going to tell you right now. I've got this in one leg, and I use a cane. If you don't get your [stuff] together, you're going to end up in a wheelchair. And I am not going to feel sorry for you. Don't come crying to me, then. You have what is known as opportunity. You have a college education. You have a good job. You have good transportation, reliable transportation. You have time off. You have FMLA. You have a husband. You have a good support system. You live in Houston, home to MD Anderson of all places. So don't tell me there's not a lymphedema clinic over there. And most of all, you know what you have? You have the

From Fear to Advocacy... Continued

diagnosis. All of that is called opportunity. There are people in this world that maybe only have one or two of those things, and you have all of them. What are you doing with it? What are you doing with it? There's a point in time where you have to realize, **if you don't fight for you, nobody else will fight for your life.**' And the cigarette's going down, and he said, 'It's all up to you, and, by the way, my leg is like this because I didn't have what you have. Your mother and I, we busted our tails to provide this house, to put foot on the table. You and your brother, tell me, tell me one thing you lacked in your childhood. And this is the price. But do you see me crying?'

J: *Was that a turning point for you?*

V: Oh yeah. It was like he took a bucket of water - cold water- and just threw it on me. Because it was true! It was true. All of it was true. He could have said it in a softer way. It was tough love. He put that cigarette out, went inside, and started laughing, and true to his word, he never mentioned it again and never repeated it, never... But it stayed with me. And so, when I talk to other patients, and I see these case studies that are presented, I don't think that people have swelling that becomes enormous - it doesn't happen overnight - but in my mind, I'm thinking, what opportunities did they lack?

J: *That's a great way to think about it.*

V: Did they not have insurance? Did they not have a support system? Because you have to have all of those things, not only in the treatment of the CDT, but also surgically as well. I have talked to so many patients who have come back from surgery, and whatever support system was supposed to be there, backed out, and **they struggled and somehow made it through.** You have to have the opportunity, and I don't know how to translate that better.

J: *I think that's a perfect translation - opportunities. I think that we always call those on the clinician side, barriers - that they are their barriers to treatment. We talk about lack of transportation, lack of support, because I don't have to tell you, you need that support if you think you need to bandage, and a patient doesn't*

have a flexibility to do so, to even help launder some of those bandages, maybe with donning and doffing garments... we tend to call those barriers, but I like the way you voiced it, and how your father voiced it, because having insurance is an opportunity to go then use that insurance. That's an opportunity to be able to change. I think that's a beautiful way to say that. So, we have to think about those things, and maybe that's a nice way for therapists to talk about those things when patients are saying, 'Well, I can't do this. I can't do that.' Let's say, what opportunities do you have?

V: It doesn't even just apply just to lymphedema, I think it applies to any chronic condition, but especially lymphedema, because there's such a lack of awareness and education on the lymphatic system as a whole.

J: *What helps you stay motivated or hopeful on difficult days?*

V: I stay hopeful because I'm not a patient that has undergone a lot of cellulitis bouts or anything like that, but when I see people who have, and have friends who have, the way they have survived... They are like superheroes. I always say it's like a testament to the human spirit of how you can fight for your life. I mean, even it goes septic and recover from that. It's amazing to me. **For the first time in my life,** having been selected for **the ARPA-H Glide project,** and working with Rice University, that **has given me a lot more of hope** than anything. I would have to say in that case me, it has motivated me professionally. On a personal level, my son. My son is autistic, and he has cognitive disability. The things he says just cracks me up sometimes, because he's so deadpan. Sometimes, we, as adults, we overcomplicate things, and we get wrapped up in our own bubble, and we get wrapped up on ourselves, and he just says, 'Oh, Mom, just take a deep breath. Oh, Mom, you'll be okay.' The simplicity and the goodness of his nature just about solved my frustrations away. He's the light of my life, for sure.

J: *If you don't mind me asking, does he have lymphedema?*

V: No, but that's one of my worst nightmares, and why I do what I do. Because it would be very, very hard for him

From Fear to Advocacy... Continued

to understand or comprehend what it would take to bandage for six weeks.

Looking Ahead: Hope, Research, and the Future of Lymphatics

J: *What advice would you give to someone newly diagnosed?*

V: I would say to advocate for oneself. **Always advocate for yourself, and understand that this is a marathon, not a sprint. And to give yourself grace to learn. Be patient with yourself. Be kind to yourself. Give yourself grace.** I have met patients, fellow patients who have come to me so angry. They're so bad. And they have every right to be because the world, the healthcare system up until that point has failed them. Their families have failed them. Their friends have failed them, But I've seen them grow in my Facebook group. And you could see the change in tone after three months, after six months, after year, after year, they're helping other people. 'This is what worked for me. This is how I solved this.' And it's just amazing.

J: *What does lymphedema awareness month mean to you personally?*

V: On the one hand, I say those of us who have it and work in it, it's lymphedema awareness day every day, 365 days a year. But I do understand that, obviously, we need the national [awareness], but we don't just need awareness. I kind of don't like the word awareness. Because to me, it's a little bit too passive. I'd like to try to change it to raising our voices... education... curing... advancing treatments... I'd like to change it to action. It's okay for someone to be aware, but what are we going to do about it? I also think that it's an opportunity or a time where people can reflect and think about how they can contribute to their own local communities. I'm done hearing people say, well, 'They should do this.' 'They should do that.' No, you should be saying, 'How can I help you accomplish these gaps that we have? How can I help you?' And you don't even have to leave your house to do it. You can call, you can email your senator, your congressman... volunteer to make calls, volunteer to be a buddy for somebody ... reach out to other people. Host a Zoom support group. There's all kinds of

things! The days of us pointing fingers and saying they should be doing this, and they should be doing that...now think about what you can do to contribute. My dad always used to say, 'If you're not part of the solution, you're part of the problem.' (laughs)

J: *How do you hope the conversation around lymphatics evolves in the future?*

V: I hope that that lymphatics becomes just as commonplace as the heart, as a circulatory system. I hope that we have a blood test for lymphedema and lymphatic anomalies. I hope that people understand that they have to exercise to move their lymph, and not just for heart, muscle, or to lose fat. I think the science should catch up to other diseases. Technology - you could do a heart transplant or lymph node transplants. And I know you can do that from one place to another, but now you could get a fake heart- a 3D printed heart. So, I really hope that the technology is able to evolve once some of these research projects come into fruition under ARPA-H. And that if and when they do, under ARPA-H for the next 5 years, then even more money is opened and evolves, just maybe we don't even know what we don't know. 10 years ago, we didn't know that the lymphatic system extended to the brain, and that it would just end it here. (gestures to her neck) And, uh, so maybe there, I mean, maybe we don't know what we don't know right now. Dr. Dhruv Singhal really opened my eyes because of all of the [lymphatic] mapping and telling the story of how the lymphatic anatomy was in a textbook from 1874. I think he's really onto something there... bringing the invisible to the visible. I think he worded it perfectly. **Let's bring the invisible to the visible... Maybe we'll be labeling the lymphatic system on a frog in high school.** Who knows? When I was in high school, we did a frog, and a snake, and a pig - the pig has a lymphatic system. Why not?

Veronica's story reminds us that lymphedema is never just a diagnosis — it is a lifelong negotiation between knowledge, access, support, and self-advocacy. Her father's tough love, the community that stepped in when she needed it most, and her own evolution into an advocate illuminate what is possible when opportunity meets determination. As we honor Lymphedema Awareness Month, her voice underscores why education, early intervention, and compassionate care matter so deeply. Her journey continues to inspire a future where no one faces lymphedema alone.

Join NLN for Expanded Member Benefits and Partner Programs

NLN membership connects you to a growing set of tools, education, and support designed for patients, caregivers, and clinicians. Through partnerships with trusted organizations and industry experts, members gain access to resources that support whole-person wellness, stronger care delivery, and a more connected community.

Education and Learning

Members can access NLN's learning platform for live virtual courses, on-demand education, and special programming throughout the year. These offerings support continuing education for professionals and practical, patient-friendly learning for those managing lymphatic conditions.

Wellness and Lifestyle Support

Members can access NLN's learning platform for live virtual courses, on-demand education, and special programming throughout the year. These offerings support continuing education for professionals and practical, patient-friendly learning for those managing lymphatic conditions.

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For clinicians, clinic owners, and small businesses, membership includes access to partner resources that support your online presence and communication. These services can help improve local visibility, strengthen digital outreach, and support long-term growth. Join today to get your discount.

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EoS FITNESS snap 24/7 fitness ANYTIME FITNESS

*\$28 enrollment fee waived for standard and premium gyms 3/1/26 12:01 a.m. - 5/31/26 11:59 p.m. PT.

Active & Fit Direct program is just one of the benefits that the NLN offers to all members. Members - [Log in to sign up today!](#)

Community Connection

NLN membership includes access to member forums and private groups that make it easier to connect with others, share insights, and stay informed on NLN updates and opportunities.

NLN continues to add new partnerships throughout the year, so members are encouraged to check back regularly for expanded benefits and new collaborations.

Join the NLN to Access Member Benefits

March Special - 10% off with code MARCH10

Help Move Lymphatic Research Forward

APTA & NLN Research Collaboration

The National Lymphedema Network is proud to announce that we are partnering with the American Physical Therapy Association to explore burnout in lymphedema therapists.

We are seeking physical, occupational, and massage therapy practitioners who are certified lymphedema therapists to take part in a research study investigating professional burnout and its impact on well-being and clinical practice. Participation involves completing a confidential online survey and questionnaires.

Your insights will contribute to a better understanding of how therapists experience and manage burnout, ultimately supporting improved mental health in the profession and informing future practice improvement opportunities.

If you are interested or would like more information, please contact bethany.beckwith@lymphnet.org.

Thank you for helping advance this important work!

Lipedema: Understanding the Whole Picture

Volunteers are needed for an online survey to fully understand the impact of lipedema on overall quality of life, sexual health and continence, and physical dysfunction. Learn more [here](#).



The graphic features the NLN logo at the top left. The main text reads "Step Into Success 2026". To the right is a circular emblem with the text "EMPOWERING NEW CLTS THROUGH MENTORSHIP" around the perimeter and "START STRONG" in the center. Below the main text is a section titled "Introducing the Start Strong Program" with a descriptive paragraph: "A transformative mentorship initiative designed to support and guide new Certified Lymphedema Therapists as they embark on their professional journey. Gain valuable insights from expert clinicians, participate in community forums and virtual roundtable discussions, and access a comprehensive clinical toolkit and industry resource library. Build a strong foundation for a successful career in lymphedema therapy." At the bottom are three icons: "Community Support" (people icon), "Clinical Toolkit" (briefcase icon), and "Industry Resource Library" (book icon).

Start Strong is just one of the professional development programs that the NLN has to offer

Learn More About Membership

March Special - 10% off with code MARCH10



Upcoming NLN Events

**Community Voices:
Book Discussion with
Dr. Cindy Howard**

Join our free virtual community book chat with Dr. Cindy Howard, author of *Positively Altered*. Connect, learn, and ask your questions live.

Friday
03.13.2026

Starting At
3:00 PM ET

Free to Attend

Meet The Author:
Dr. Cindy Howard

Community Voices: Book Discussion Series with Dr. Cindy Howard
Friday, March 13
3:00 pm ET

**Free
Community
Webinar**

**Turner
Syndrome**

Thursday, March 19, 2026
7:00 pm ET

NLN Community Webinar - Turner Syndrome
Thursday, March 19
7:00 pm ET

**Networking
Meeting**

Join us at our quarterly Local Networking Meeting, a welcoming gathering designed to connect healthcare professionals from all disciplines who are interested in lymphatic education, collaboration, and community building.

This is your chance to:

- ✓ Connect with local healthcare professionals
- ✓ Share insights and real-world experiences
- ✓ Build referral and collaboration networks
- ✓ Contribute to a growing lymphatic care community

March 20, 2026
6:00 - 7:45 PM

The Ann Arbor District Library - Pittsfield Branch
2359 Oak Valley Drive, Ann Arbor, MI

Guest Speaker
Matt Ban, OTR/L, CLT-LANA

lymphnet.org (800) 541-3259

NLN Networking Meeting in Michigan
Friday, March 20
6:00 pm ET

**FREE
WEBINAR**

SPONSOR SERIES

**Effective Clinical Treatment
for Breast Cancer Related
Lymphedema**

Presented by Lesli Bell,
PT, DPT, CLT-LANA

LIVE WEBINAR IN COLLABORATION WITH

March 31, 2026 at 7:00 pm ET

NLN Sponsor Series - Effective Clinical Treatment for Breast Cancer Related Lymphedema
Tuesday, March 31
7:00 pm ET

Upcoming NLN Events



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FREE WEBINAR

SPONSOR SERIES

**From Certification to Clinical Confidence:
Thriving in Your First Year as a Lymphedema Therapist**

Presented by Brian Espinola,
PTA, LMT, CLT-LANA, WCC

LIVE WEBINAR IN COLLABORATION WITH

SIGVARIS GROUP

April 7, 2026 at 12:00 pm ET

NLN Sponsor Series - Thriving in Your First Year as a Lymphedema Therapist
Tuesday, April 7
12:00 pm ET



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Networking Meeting

Join us at our Local Networking Meeting in **New Jersey**, a welcoming gathering designed to connect healthcare professionals from all disciplines who are interested in lymphatic education, collaboration, and community building.

This is your chance to:

- ✓ Connect with local healthcare professionals
- ✓ Share insights and real-world experiences
- ✓ Build referral and collaboration networks
- ✓ Contribute to a growing lymphatic care community

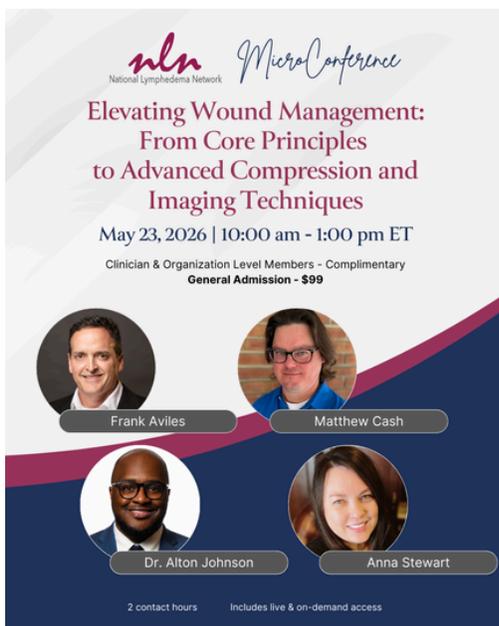
April 18, 2026 at 10:00 am

The Valley Hospital, S1 Conference Center
4 Valley Health Plaza, Paramus, NJ

Guest Speaker
Courtney Lozano, LCSW

lymphnet.org (800) 541-3259

NLN Networking Meeting in New Jersey
Saturday, April 18
10:00 am - 1:00 pm



nl *MicroConference*
National Lymphedema Network

**Elevating Wound Management:
From Core Principles to Advanced Compression and Imaging Techniques**

May 23, 2026 | 10:00 am - 1:00 pm ET

Clinician & Organization Level Members - Complimentary
General Admission - \$99

Frank Aviles Matthew Cash

Dr. Alton Johnson Anna Stewart

2 contact hours Includes live & on-demand access

NLN MicroConference - Elevating Wound Management
Saturday, May 23
10:00 am - 1:00 pm ET



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NLN Clinical Focus Groups

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