

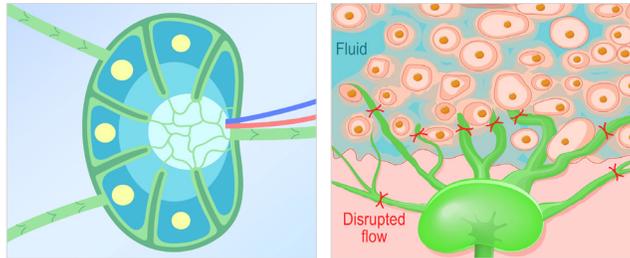


Lymphatic Education  
& Research Network

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# National Indicator Report on Cancer-Related Lymphedema (LE)

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# EXECUTIVE SUMMARY

Since the inception of the **Lymphatic Education and Research Network (LE&RN)** in 1998 (renamed from Lymphatic Research Foundation), substantial progress has been made in raising awareness about lymphedema (LE). *However, there is still a lack of comprehensive public health data informing the impact of lymphedema on patients, families, and society.* Additional research is needed to gain a deeper understanding of the disease's effects on both physical and mental health, as well as its impact on healthcare costs in the U.S. This document helps to collect and coalesce the ongoing efforts to classify and treat lymphatic diseases (LD) appropriately. 

## INTRODUCTION

### Background

Lymphedema (LE) is a chronic disease with no cure and a limited number of effective treatments. Lymphedema, even when treated, leads to various debilitating symptoms, signs, and complications. The lymphatic system, essential for maintaining health, is one of the only body systems that still lacks biomarkers to identify its diseases, and there are no relevant clinical interventions to measure lymphatic function. Additionally, once lymphatic dysfunction is identified, there exist very few appropriate therapy options.

In 2021, the Lymphatic Education & Research Network (LE&RN) received a federal grant, *Expanding the National Approach to Chronic Disease Education and Awareness*, from the Centers for Disease Control and Prevention (CDC) with the sole purpose of expanding and advancing the CDC's work on education, outreach, and public awareness for those living with lymphedema. **Why?** Because the body of evidence about lymphedema is sparse and inadequate.

To accomplish these goals, several strategies were undertaken, including 1) the development of a 23-question survey to address data gaps, with the ultimate collection and analysis of this data; 2) the distribution of the insights acquired from the data; 3) educational activities that can support both healthcare professionals and public awareness; and 4) hosting forums with researchers to discuss current and future needs in lymphatic research.

LE&RN's *National Indicator Report on Cancer-Related Lymphedema (LE)* provides information on the current status of lymphedema comprehension and awareness,

including characterization of the clinical experiences of those in the United States living with lymphedema, stratified by lymphedema subtype (primary or secondary lymphedema), identification of patterns of symptom onset, diagnosis, education, and treatment in cancer-related and non-cancer-related lymphedema patients and, further, identifying the impact of lymphedema on patients' quality of life and functional status.

### What Is Lymphedema?

Abbreviation: (LE)

Pronunciation: lim·fuh·dee·muh

International Variation: lymphoedema



Left leg lymphedema

Lymphedema is a form of swelling; it develops within the body when the lymphatic system is not functioning normally. It may occur regionally, for example, in the leg, arm, head and neck, abdomen, groin, or pelvis, or can be present diffusely across many anatomic regions. *Lymphedema is a chronic disease with no cure and few treatment interventions, rendering it permanent and progressive.* The swelling of lymphedema almost always leads to a host of other debilitating symptoms and complications, including pain, recurrent and sometimes life-threatening skin infections that require emergent care and hospitalization, impaired movement, profound psychosocial and functional derangements, and a lifetime of suffering. Lymphedema is further subcategorized on whether it is based upon inherited characteristics or results from an acquired injury or traumatic disruption of the integrity of a previously functional lymphatic system.

## Primary Lymphedema (Inherited or Congenital)

Primary lymphedema is the rarer form of the disease and, historically, has been subdivided into three categories:

1. Congenital lymphedema, present at birth or recognized early (within two years of birth),
2. Lymphedema praecox, presenting at puberty or up to the third decade of life,
3. Lymphedema tarda, presenting after the age of 35 years.

## Secondary Lymphedema (Caused by Injury or Trauma)

Secondary lymphedema is more common than primary lymphedema, representing an estimated 99% of presentations. Globally, the most common cause of secondary lymphedema is filariasis, the consequence of a parasitic nematode infection. However, in developed countries, the most common causes of secondary lymphedema are related to cancer therapeutics (and occasionally the neoplasm itself), adverse reactions to other therapeutics, chronic venous disease (phlebolymphe<sup>1</sup>), and the adverse effects of obesity<sup>1</sup>.

## What Is the Lymphatic System and Why Is it Important?

The lymphatic system is one of eleven body systems responsible for maintaining health. It has several roles, including maintaining fluid balance in the body, reacting to and dealing with foreign pathogens (bacteria, viruses, parasites, and fungi), gastrointestinal lipid absorption, and subserving immune surveillance and antigen processing. Further, it is increasingly apparent that normal lymphatic function is involved in maintaining the healthy function of almost every organ system in the human body.

## The Problem

When the lymphatic system is altered, either by a primary, inherited disease or a secondary insult, such as trauma, infection, injury, venous insufficiency, radiation, or surgery, the damage to lymphatic vessels results in outward physical signs and symptoms that can cause the swelling known as primary or secondary lymphedema, respectively.

An estimated 10 million Americans are living with lymphedema, and 1 in 3,000 children live with primary lymphedema. Lymphedema spares nobody: people of all ages, sex, race, ethnicity, and socioeconomic status are affected. More research is needed to better understand how social determinants of health and population characteristics impact lymphedema prevalence, incidence, and care. In a small cohort

study conducted recently by researchers at Memorial Sloan Kettering Cancer Center, the investigators observed that Black and Hispanic women were roughly 1.5 to 2 times more likely to acquire lymphedema after removal of the lymph nodes following breast cancer surgery. Studies like these, though limited in number, help the research and medical community define and better understand the issues specific patient populations may face and allow for better preparation for those at risk for lymphedema.

## Why Are There Only Partial Treatments and No Cures for Lymphedema?

There is a historical lack of appreciation and support for the lymphatic system and its interactions with pathophysiologic processes. This deficiency begins at the level of doctoral medical education. A study conducted in 2004 demonstrated that the majority of U.S. medical students are exposed to approximately 30 minutes to 1 hour of lymphatic instruction during their entire four years of training. As a result, recognition of the lymphatic system in health and disease lags far behind our understanding of other human body systems. As an unfortunate consequence, healthcare providers lack the training and awareness to identify a person who may be living with and suffering from lymphedema. Once a diagnosis is correctly made, it often has progressed to the point that treatment is not as effective as if it had been diagnosed in a timely and efficient manner.

As a result, epidemiologic evidence to quantify the subjective burden of this relative disease neglect is virtually nonexistent.

***Yet it is clear: A delay in diagnosis will lead to disease progression, morbidity, and mortality.***

Therefore, educating our healthcare providers and the public is essential to mitigate the gap in access to healthcare and early diagnosis for people living with lymphedema.

Further, early risk reduction of lymphedema has the capacity to prevent ongoing suffering and the psychological toll that runs parallel with the physical burden of the disease itself:

- Feeling alone, isolated, not heard, and neglected
- Helplessness for both those living with lymphedema and the providers who are not equipped with the knowledge to diagnose or treat lymphedema
- Despair in learning that there are few effective treatments and no cures, even if a correct diagnosis is established
- Physically enduring extreme fatigue and heaviness of the extremities
- Enduring chronic pain, skin infections, cellulitis, and ulcers resulting in repeated hospitalizations

- Life-threatening complications from lymphedema, including shortness of breath, cardiac dysfunction, and sepsis from complications such as cellulitis and other infections
- Suffering with a disfigurement that translates into disability, a decrease in quality of life, morbidity and potential mortality, loss of person-years of work, attendant complications, repeated hospitalizations, and rising healthcare costs

## What's New?

- Important developments are taking place in basic biological science, and early investigators are more engaged.
- New diagnostics in the form of molecular, genetic, and humoral factors and imaging techniques are becoming available.
- Therapeutics focusing on lymphatic function are now being created.
- Both in the lymphatic community and all areas of healthcare, the importance of educational reform is mounting as patient and research advocacy groups, like LE&RN, lobby for more research dollars.

## Summary

- **Objective:** LE&RN's Lymphedema Report Card aims to provide insights into the status of lymphedema diagnosis, treatment, and awareness in the U.S.
- **Scope:** This report covers the clinical experiences of lymphedema patients, patterns of symptom onset, diagnosis, education, treatment, and the impact of lymphedema on quality of life.



# STUDY METHODOLOGY

## The Gathered FACTS

As an awardee of the CDC's grant funding mechanism to expand and advance the National Center for Chronic Disease Prevention and Health Promotion's work, Lymphatic Education & Research Network (LE&RN) conducted a three-part study including:

1. A detailed analysis of the LE&RN Global Registry for Lymphatic Diseases (<https://lymphaticnetwork.org/ldregistry>) focused on lymphedema (LE), enrollees (N=529)
2. An anonymous, social media-based analysis of patients living with lymphedema within the U.S. This was a subcohort analysis focused on healthcare interactions (N=2153)

3. An agreement analysis with a cohort of enrollees who attended symposia hosted by LE&RN and self-identified as living with lymphedema

## The Objectives

1. Characterize the clinical experiences of lymphedema patients in the U.S. by lymphedema subtype (cancer or non-cancer-related, respectively)
2. Identify patterns of symptom onset, diagnosis, education, and treatment in cancer-related and non-cancer-related lymphedema patients
3. Identify the self-described impact of lymphedema on patients' quality of life and functional status
4. Disseminate this study's patient-driven data analysis to healthcare providers within the U.S., with a goal to invigorate and expand the impetus for lymphedema diagnosis and treatment

## Data Sources

- In 2016, LE&RN launched *The International Lymphatic Disease and Lymphedema Patient Registry & Biorepository*, recently renamed the *LE&RN Global Registry for Lymphatic Diseases™*, a 500-item online survey geared for self-identified and formally diagnosed patients living with lymphatic diseases (LD) inclusive of primary and secondary lymphedema
- The registry collects longitudinal data annually and is available as an investigative tool for the lymphatic research community
- Data variables include patient demographics, specific diagnoses, past and current medical and surgical history, family and social history, as well as allergies, medications, treatments, and socioeconomic and quality of life measures
- The data from the registry has been the basis for the design of this study and its statistical analysis

## Sampling

- The report focused on registry enrollees who self-identify as individuals living with lymphedema

## Analysis

- The data from the registry formed the basis for the study's design and statistical analysis

## Survey Tool Development

### INTERACTIONS COHORT

- A 23-item online survey tool was developed specifically for enrollees in the registry who self-identified as patients living with lymphedema
- It was further distributed and made publicly available through the Stanford University School of Medicine and LE&RN

- Participant data was completely anonymous, and no protected health information (PHI) or personal information was collected as part of this report.

## ABSTRACT

**Importance:** Lymphedema is an incurable, progressive lymphatic disease that potentiates physical and psychosocial distress. Despite its global impact, patients reportedly encounter lymphatic ignorance throughout the healthcare system.

**Objective:** This study summarizes the clinical characteristics and interactions of lymphedema patients within the healthcare system. A secondary nested cohort study was conducted to assess the generalizability of initial cohort findings.

**Design:** Cross-sectional and nested-cohort designs were implemented.

**Setting:** The LE&RN Global Registry for Lymphatic Diseases was used to obtain demographic and clinical characteristics from lymphedema patients affiliated with LE&RN. An online questionnaire was then anonymously distributed to lymphedema patients through LE&RN’s social media, and questionnaire results were presented to patients via a digital seminar.

**Participants:** Three cohorts were involved in the study, all of which included self-identified and practitioner-diagnosed lymphedema patients: The Global Registry Analysis Cohort included patients who contributed data to the LE&RN Global Registry for Lymphatic Diseases, the Interactions Cohort included patients affiliated with LE&RN who participated in an online questionnaire about interactions with the medical system, and the Seminar Cohort included patients who participated in an online data presentation.

**Measurements:** Demographic and clinical characteristics were extracted from the LE&RN Global Registry for Lymphatic Diseases. A 23-item questionnaire on clinical characteristics, healthcare experiences, and patient satisfaction with lymphatic healthcare was digitally distributed to LE&RN-affiliated lymphedema patients. Seven of the 23 questionnaire items were incorporated into a data presentation. Attendees with lymphedema were asked to answer these questions before and after attending a presentation on the original questionnaire results and whether these data were reflective of their experiences.

## Results

### Subjective Experiences of the Lymphedema Patient Population:

- Responses were obtained from n= 2,548 U.S. participants across the LE&RN Global Registry for Lymphatic Diseases and the Interactions Cohort combined

- Participants’ mean age was 55.6±5 years, and most (86.9%) were female
- Most respondents (51.6%) had a history of cancer
- Participants experienced substantial delays in diagnosis and treatment
- Primary and secondary lymphedema patients reported similar levels of perceived physician disinterest in their lymphedema; however, primary lymphedema patients reported more dissatisfaction with diagnosis and treatment (2.78 vs. 3.12; P<0.01)

## KEY INDICATORS

*This section is an in-depth review of the state of lymphedema (LE) knowledge and care as captured by the five key indicators below:*

1. Epidemiology
2. Access to Care
3. Health Disparities
4. Transition in Care
5. Perceptions Amongst Stakeholders

### INDICATOR 1: EPIDEMIOLOGY

#### INCIDENCE RATES & CURRENT STATE OF KNOWLEDGE

Despite the significant physical, mental, and financial toll (health burden) that lymphedema imposes on individuals, families, and caregivers, we do not have accurate estimates of the prevalence or annual incidence of lymphedema in the U.S. In fact, unlike most other chronic health conditions that affect Americans, there are no formal epidemiologic studies to validate lymphedema statistics.

The prevalence of lymphedema is estimated to be between 3 to 10 million affected individuals in the U.S. These figures are extrapolated from more formally derived estimates through the National Health Services in the United Kingdom<sup>2-11</sup>, and further by enumerating the expected prevalence within individual risk categories (chiefly related to cancer diagnoses) and factored by the population density of these individual causal cancers<sup>12-14</sup>.

Recently, obesity and chronic venous disease have eclipsed cancer as the leading causes of secondary lymphedema. Yet, the impact of these diseases on the prevalence of lymphedema is still largely unknown; thus, the prevalence of lymphedema is most certainly under-enumerated. This observation is aggravated by the lack of consistent disease ascertainment and the undercoding of relevant lymphedema diagnostic codes in the electronic health medical record.

As a result, accurately evaluating the incidence and prevalence of lymphedema is complicated.

Some of the sources of the complexity include:

1. **There is an under-reporting of lymphedema—** Unfortunately, lymphedema is a disease that is not well recognized either by the community at large or the healthcare providers, and, therefore, often underdiagnosed or misdiagnosed and, even when diagnosed, not reliably enumerated, and encoded.
2. **Lymphedema etiology is heterogeneous—** The heterogeneous nature of the etiology may not always capture the diagnosis consistently in electronic health medical records.
3. **There is a lack of standardization—** There are variations in how healthcare providers diagnose and document lymphedema. This is further complicated by inaccurate or incomplete ICD-10 coding of lymphedema, leading to an underreporting of what is encountered in clinical practice, contributing to variations in the prevalence reporting.
4. **There are regional differences in incidence/prevalence—** Lymphedema's prevalence varies significantly by region and population. For example, the prevalence of lymphedema can be influenced by genetics, access to healthcare, and how prevalent certain cancers (like breast, head and neck, and other relevant cancers) might be in different subsets of the population and/or geographic locations.
5. **There is a dearth of population studies—** We lack well-designed and rigorously performed relevant epidemiologic studies<sup>12</sup>.

As such, most of the data obtained for this report is inferential and collected through recent peer-reviewed publications and methods by the Lymphatic Education & Research Network (LE&RN), as described above.

## WHAT WE KNOW FROM THE LITERATURE

Primary lymphedema is defined as a rare disease because it affects 1 in 100,000 people, while secondary lymphedema is the most common cause of lymphedema, affecting 1 in 1,000 Americans<sup>1,12</sup>.

Most published data evaluating the incidence and prevalence of secondary lymphedema comes from the field of oncology:

- An alarming 1 in 5 women who have been diagnosed, treated, and survived breast cancer will face chronic lymphedema for the rest of their lives<sup>15</sup>.
- For those diagnosed and treated with head and neck cancer, over 90% will suffer from some form of lymphedema, with 50% of those complicated by fibrosis<sup>16</sup>.

—An estimated 20 to 60% of women undergoing surgical treatment for gynecologic cancer will experience lower limb chronic lymphedema<sup>17</sup>.

## WHAT IS CURRENTLY LACKING IN THE LITERATURE

- **Standardized reporting.** Unfortunately, providers do not routinely encode lymphedema properly as a diagnosis within the electronic health record. These omissions likely stem from a lack of clinical recognition, failure to acknowledge the medical importance of the diagnosis, and the under-recognition of the importance of disease as an enumerated component of the medical record.
- **Comprehensive surveillance.** There are a number of surveillance systems available across disease areas, such as diabetes, HIV, and cancer, which help to identify patterns and track regional/national trends in those disease areas; this is entirely lacking for lymphatic disease (LD).
- **Proper diagnosis and coding of electronic health records.** Underdiagnosis, underreporting, and improper coding in electronic health records are more likely when lymphedema is mild or secondary to other disease processes like obesity, chronic venous disease, or cancer treatment (results in underestimating the true prevalence).
- **Lack of robust longitudinal data.** There are no national or statewide data sets available. Although the LE&RN Global Registry for Lymphatic Diseases is intended to circumvent this absence with time, a more robust set of longitudinal data is needed to assess the state of the disease better.
- **Lack of population-based studies.** Very few population-based research studies exist to characterize how different factors impact people living with lymphedema.
- **Racial and socioeconomic disparities.** The LE&RN Global Registry for Lymphatic Diseases, in its infancy, does not have the penetration to document the extent of racial and socioeconomic disparities present within its lymphedema population. The anonymous, social media-based study reported here, by its nature, does not have the capacity to investigate these variables. In the future, these knowledge gaps will require intensive, funded investigation.
- **Comprehensive data on pediatric primary lymphedema.**

**Table 1. Demographics from LE&RN Global Registry<sup>37</sup>**

Demographic Characteristic	Non-Cancer Related Lymphedema Patients (N=323)		Cancer-Related Lymphedema Patients (N=206)	
	Number	%	Number	%
<b>Sex</b>				
Male	50	16.2	15	7.5
Female	257	83.2	185	92.5
Decline to State	2	0.6	0	0
<b>Age</b>				
(Mean± SD)	54.2 ±	17.35	65.6 ±	12.6
<b>Race</b>				
White	263	86.23	179	90.4
Black or African American	17	5.6	2	1.0
More Than One Race	13	4.3	7	3.5
Asian	9	3.0	2	1.0
American Indian/Alaska Native	1	0.3	0	0
Decline to State	2	0.7	8	4.0
<b>Ethnicity</b>				
Not Hispanic or Latino	287	92.9	184	92.0
Hispanic or Latino	15	4.9	6	3.0
Decline to State/Unknown	7	2.3	10	5.0
<b>Country</b>				
United States	263	85.1	188	95.4
Canada	14	4.5	4	2.0
Australia	4	1.3	2	1.0
England	8	2.6	0	0
Ireland	3	1.0	1	0.5
France	2	0.65	0	0
Other	15	4.9	2	1.0
<b>Education</b>				
Less Than 12 Years of Education	9	2.9	3	1.5
High School Diploma	52	16.8	31	15.5
Associate’s Degree	41	13.3	27	13.5
Bachelor’s Degree	87	28.2	62	31.0
Post-graduate Degree	93	30.1	71	35.5
Other	27	8.7	6	3.0

Demographic Characteristic	Non-Cancer Related Lymphedema Patients (N=323)		Cancer-Related Lymphedema Patients (N=206)	
	Number	%	Number	%
<b>Income</b>				
<\$10,000–\$30,000	56	17.3	27	13.1
\$30,001–\$50,000	46	14.2	22	10.7
\$50,001–\$80,000	53	16.4	47	22.8
\$80,000–\$120,000	54	16.7	32	15.5
\$120,001–\$150,000	17	5.3	10	4.9
>\$150,000	39	12.1	45	21.8
Prefer Not to Disclose	58	18.0	23	11.2
<b>Occupation</b>				
Employment Insurance	254			
Full-Time Employment	178+18			
Part-Time Employment	39 +17			
Long-term Disability	9			
Homemaker	16			
Retired	86			
Student	11			
<b>Smoking Status</b>				
<b>Ever Use</b>				
Yes	85	26.8	55	27.0
No	232	73.2	149	73.0
<b>Packs Per Day</b>				
1	50	66.7	38	76.0
2	12	16.0	3	6.0
3	0	0	4	8.0
4	0	0	0	0
5	1	1.3	0	0
10	1	1.3	0	0
Other	11	14.6	5	10.0

## WORK AND FINANCE

### Overall

#### Income: Individual Living with Lymphedema

<\$10,000–\$30,000	84	15.8		
\$30,001–\$50,000	68	12.8		
\$50,001–\$80,000	100	18.8		
\$80,000–\$120,0001	86	16.1		

Demographic Characteristic	Non-Cancer Related Lymphedema Patients (N=323)		Cancer-Related Lymphedema Patients (N=206)	
	Number	%	Number	%
\$120,001–\$150,000	28	5.3		
>\$150,000	84	15.8		
Prefer Not to Disclose	83	15.6		

### LYMPHEDEMA-RELATED EXPENSES

Annual Lymphedema Expenses				
<\$500	89	28.8	51	25.6
\$501–\$1,000	55	17.8	41	20.6
\$1,001–\$2,000	63	20.4	42	21.2
\$2,001–\$5,000	58	18.8	45	22.6
\$5,001–\$10,000	17	5.5	9	4.5
\$10,001–>\$20,000	8	2.6	3	1.5
Prefer Not to Disclose	19	6.1	8	4.0

### INSURANCE AND DRUG PLANS

Has Health Insurance				
Yes	288	93.2	193	97.0
No	18	5.8	5	2.5
Unsure	3	1.0	1	0.5
Health Insurance Subgroups				
Private Commercial	78	24.5	65	28.2
Prepaid Health Plan	122	38.2	85	40.0
Medicare	88	27.6	73	31.7
Medicaid	29	9.1	4	1.7
Veteran Affairs	2	0.6	3	1.3
Disability Benefits				
Yes	50	16.2	34	17.1
No	254	82.2	164	82.4
Unknown	5	1.6	1	0.5
All Lymphatic Rx Covered by Drug Plan				
Yes	63	26.0	49	28.0
No	129	53.3	95	54.3
Unknown	50	20.7	31	17.7

**Study 2. Results from the Interactions Cohort (a subset of the Global Registry population who enrolled in the 23-item online survey tool)<sup>37</sup>**

- Overall, n=2154 participants initiated the questionnaire, and n=1805 participants completed it (84.0%).
- Most participants reported a history of cancer (52.75%).
- Congruent distribution between cohorts.

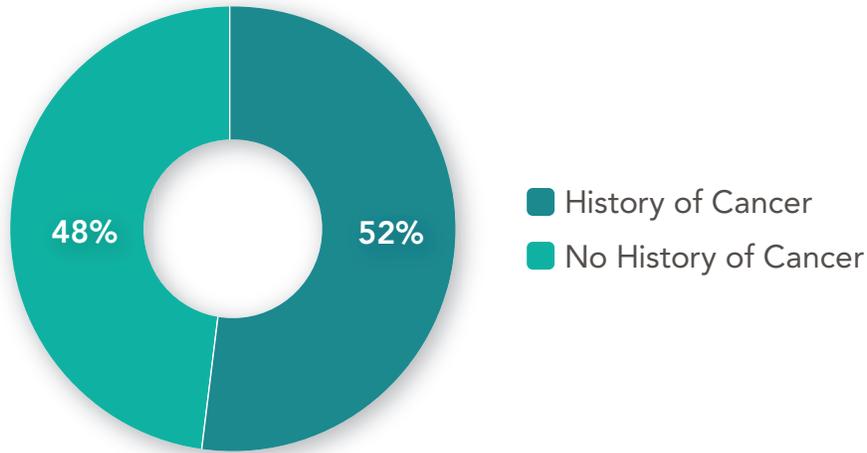


Figure 1. Percentage of patients in the Interaction Cohort with or without a history of cancer diagnosis.

**Cancer-Related Lymphedema Statistics Comparing the Registry Cohort to the Interactions Cohort**

The majority of patients with cancer-related lymphedema reported both lymphadenectomy and radiation components to the initial cancer treatment

(Figure 2). In a follow-up question, most patients reported not having had a discussion with their healthcare provider nor receiving educational materials on lymphedema prior to cancer treatment, highlighting the disconnect between cancer management and post-surgical lymphatic health.

**Most Patients Had Received Radiation and Lymphadenectomy**

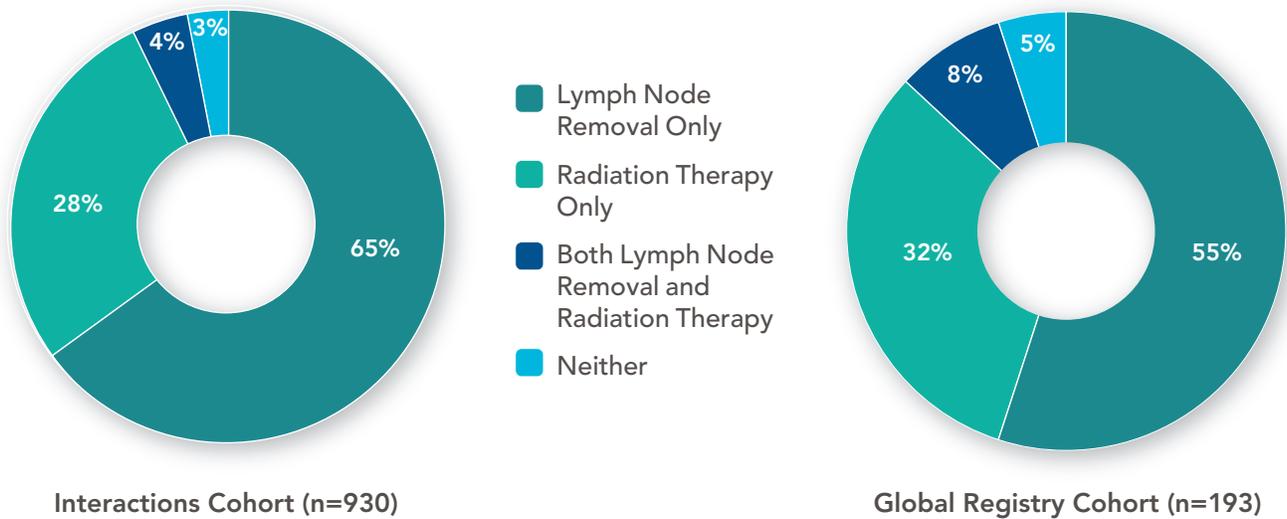


Figure 2. Interactions cohort and Global Registry cohort distribution of patients with radiation, lymph node removal, both, or neither.

## INDICATOR 2. ACCESS TO CARE

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There are several key factors that contribute to access to care for patients living with lymphedema, including:

**A. Experts in the Field of Lymphatic Medicine are Lacking**—Patients' experiences suggest that they struggle to find healthcare providers appropriately trained to recognize, diagnose, and treat lymphedema. In addition, for those diagnosed appropriately, the diagnosis is generally established late in the course of the disease once irreversible structural damage has occurred. This is especially true in locations lacking direct access to academic institutions and/or rural geographic locations (see *Indicator 2B*).

**B. Geography: Where the Patient Lives**—Unfortunately, patients living in rural and underserved locations do not have the same access to specialty care and treatments as those who live near a city with an academic institution.

**C. Lymphedema Care Requires a Multidisciplinary Team**—Treating lymphedema requires numerous clinical providers, including the patient's primary care provider, surgeons, interventional radiologists, oncologists, physical therapists, occupational therapists, nutritionists, and lymphedema specialists. There is an enormous challenge and burden for patients, caregivers, and healthcare providers to coordinate care for patients living with lymphedema. Many patients can be lost to follow-up.

**D. Delayed Appointment Scheduling for Critical Therapy**—Patients experience long wait times for therapy because there is a shortage of trained lymphedema therapists. Unfortunately, a delay in treatment contributes to the worsening of the symptoms and disease progression.

**E. Limited Insurance Coverage and Financial Barriers**—Lymphedema is a chronic disease and requires ongoing monitoring and treatment. Some insurance plans do not routinely and/or adequately cover the needed diagnostics and treatments offered to manage lymphedema (e.g., compression garments, imaging, and some surgical procedures<sup>18</sup>). A recent study conducted in 2023 suggests that less than 12% of individuals with insurance have access to pneumatic compression and surgical treatments for lymphedema<sup>19</sup>.

**F. Stigma of Living with Lymphedema**—Many patients avoid seeking care because of the stigma associated with lymphedema. Furthermore, a delay in diagnosis inevitably leads to irreversible disease progression<sup>20-23</sup>.

**G. Lymphatic Research Lags Far Behind Other Diseases**—The anatomic and functional complexity of the human lymphatic system is difficult to address with current clinical and investigational tools. As such,

the emphasis on lymphatic anatomy and function has lagged far behind other organ systems within the conventional medical school curricula<sup>24</sup>, health sciences research, and clinical practice<sup>25</sup>. Those who suffer the consequences of this neglect are the patients with lymphedema and other lymphatic diseases: having received less funding and attention, they experience the harsh reality that lymphedema lacks innovative treatment options and has limited access to cutting-edge therapies.

## INDICATOR 3. HEALTH DISPARITIES

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Evidence suggests that disparities in access, quality, and education likely lead to differences in outcomes of care for patients living with lymphedema. These disparities can arise due to numerous factors, including socioeconomic status, race, and geography<sup>26-28</sup>. Key issues that impact lymphedema care include:

**A. Socioeconomic Disparities**—Recent publications demonstrate that patients with lower socioeconomic status have more difficulty accessing specialized care for lymphedema. This is due to financial barriers, lack of insurance coverage, and non-covered costs associated with management and treatment.

**B. Geographic Disparities**—Because there is a lack of awareness and limited resources, those living in rural and underserved areas are less likely to be accurately diagnosed with lymphedema and may, therefore, experience further delays in diagnosis and treatment.

**C. Racial and Ethnic Disparities**—Research confirms that there are specific racial and ethnic groups that may be less likely to be diagnosed with lymphedema and even may experience a delay in diagnosis, which can result in major morbidity and mortality (i.e. delayed cancer diagnosis)<sup>27, 29</sup>.

**D. Lack of Education**—Lack of education poses a problem for patients with lymphedema and caretakers and providers who deliver care to those with lymphedema.

**E. Limited Resources for Research and Device Innovation**—Numerous gaps in research exist, including insight into the pathophysiology of lymphedema and the infrastructure for new treatment development. (See *Gaps in the Field of Lymphatic Research*, sponsored by the Lymphatic Education & Research Network in Appendix 4).

## INDICATOR 4. TRANSITION IN CARE

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Primary lymphedema, most commonly presenting in children and adolescents, is rare and chronic. 1/100,000 people in the U.S. have primary lymphedema comprising over 40 diseases, including Prader-Willi syndrome, Turner syndrome, lymphatic tumors and malformations, spina bifida, and genomic

mutations such as Milroy's disease<sup>30,31</sup>. While there are pediatric specialists (primarily pediatric hematology/oncology doctors specializing in vascular anomalies), young adults transferring from pediatric to adult care may be lost to follow-up.

The Lymphatic Education & Research Network (LE&RN) has been instrumental in establishing a paradigm shift in the medical care of individuals living with lymphedema, having established LE&RN Centers of Excellence (COE) with specialty designations, specifically, the Comprehensive Pediatric Center of Excellence.

In 2018, LE&RN Centers of Excellence comprehensive standards were established under the guidance of their Global Oversight Committee. To accomplish this, LE&RN engaged a committee of expert clinicians in the U.S. to create the initial draft of standards. A Global Oversight Committee refined these standards and expanded their global applicability. This Global Oversight Committee reviews all letters of intent and applications submitted by institutions seeking a LE&RN Centers of Excellence designation. Designation awards are determined solely by the Global Oversight Committee. To date, a total of 62 LE&RN Centers of Excellence have been established worldwide, with 39 centers located in the U.S.

*LE&RN Centers of Excellence provide a geographically diverse network of multidisciplinary clinical care and service centers for individuals and families affected by lymphatic diseases. In addition to clinical and social services, the Centers provide professional and lay education in the geographic areas they serve, conduct clinical research, and work with LE&RN locally and internationally in its efforts to continually improve the lives of those affected by lymphatic diseases and their families.*



Map of 62 LE&RN Centers of Excellence

Find a LE&RN Center of Excellence: <https://lymphaticnetwork.org/centers-of-excellence>

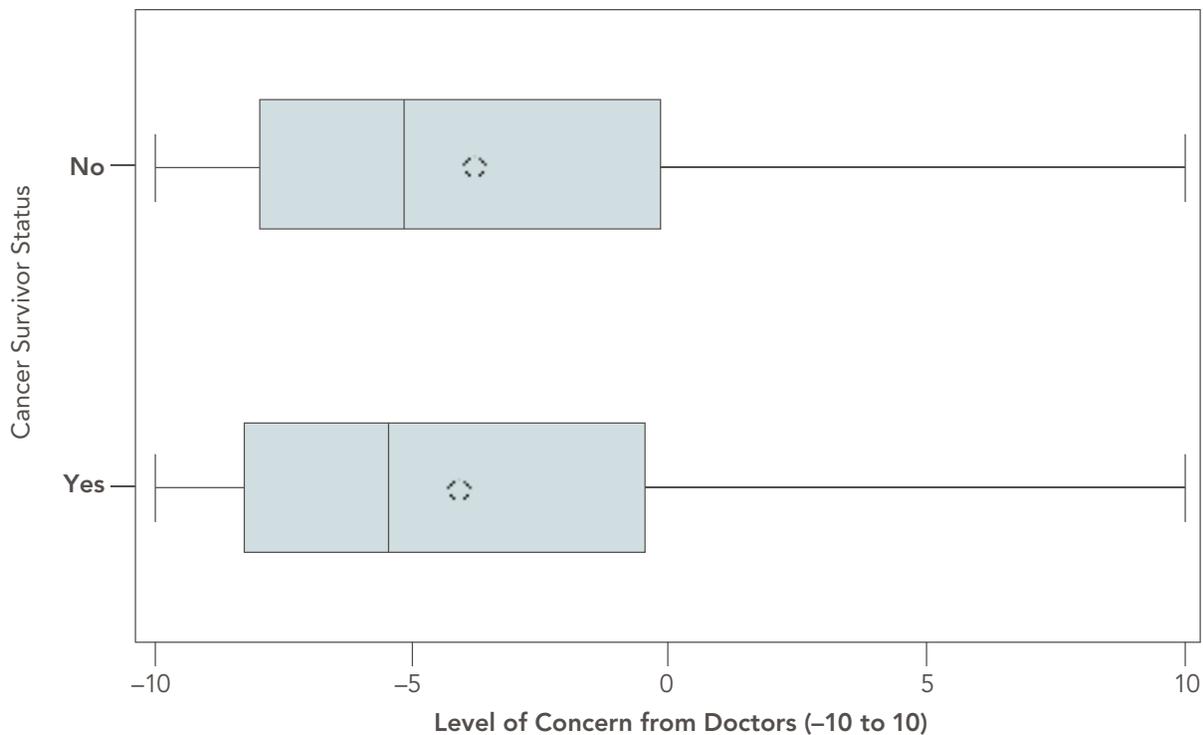
## INDICATOR 5. PERCEPTIONS AMONG STAKEHOLDERS

### The Status of Lymphedema Awareness and Understanding Among Healthcare Providers

Perceptions among healthcare providers vary depending on their training, experience, exposure, and the specific context in which they encounter the disease. While those specializing in oncology may have an acceptable understanding of lymphedema and its causes, most healthcare professionals have limited and varied knowledge levels; this is especially true for primary care providers who have limited training in lymphedema. These perceptions can be, and are, detrimental to the overall outcomes for people living with lymphedema. Patients may remain undiagnosed and experience delays in care, suffering unnecessary and preventable complications. Patients who are diagnosed may face recalcitrant providers because they perceive lymphedema to be hopeless in the face of treatment options that are limited to symptomatic control and without twenty-first century pharmacological interventions. Compounding this vicious circle of limited access to care is the institutional pushback still encountered within the field of lymphatic medicine, including resource constraints, reimbursement issues, and lack of specialized services offered to complex cases of lymphedema.

### The Status of Lymphedema Awareness and Understanding Among Those Living with Lymphedema

It is clear from the studies conducted and presented here that lymphedema substantially impacts patients' well-being and health outcomes. And yet, to date, lymphedema patients face nearly insurmountable barriers to lymphatic healthcare. People living with lymphedema feel alone, isolated, and marginalized. For example, question 21 of the 23 questions in the LE&RN survey tool asked: "In your experience, how concerned have your doctors been about your lymphedema?" Patients with both cancer-related lymphedema and non-cancer-related lymphedema reported that the perceived interest level of their physician regarding lymphedema management was only 3 out of 10 (see Figure 3 on following page). In other words, the patients perceived their doctors were relatively unconcerned with their lymphedema.



**Figure 3.** The mean level of physician interest in lymphedema was rated by non-cancer-related lymphedema patients (-3.81) and cancer-related lymphedema patients (-4.03),  $P > 0.05$ .<sup>37</sup>

## DISCUSSION

*In comparison to the recent past, the recognition that lymphedema (LE) is underestimated, misunderstood, and overlooked represents a form of progress.*

As evidenced in this report, patient advocacy groups like the Lymphatic Education and Research Network (LE&RN), with the support of governmental agencies like the Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), Advanced Research Projects Agency for Health (ARPA-H), and the Department of Defense (DOD), have been actively working to raise awareness for lymphedema to provide educational resources, and to advocate for improved education for both healthcare providers and the community, with the overarching goal to achieve accurate accounting of lymphedema prevalence and outcomes, to reinforce the essential need for support and resources to improve access to care and to ensure equitable healthcare coverage for all people living with lymphedema.

Currently, unlike other chronic diseases such as diabetes and asthma, for which accurate prevalence and incidence data are available, at present we can, at best, rely upon inferences about the prevalence and incidence of lymphedema.

An accurate accounting of all Americans suffering from lymphedema should not be an insurmountable obstacle. A future coordinated effort to accurately collect data is essential to improve outcomes. It is the responsibility of the U.S. medical and surgical associations, third-party payers, and our entire private and government healthcare systems to meet this goal and improve the outcomes with increased education, prevention, and more successfully delivered interventions.

Indeed, the field of lymphatic medicine is poised for major growth as government and private sector funding agencies finally recognize its importance. For example, in the last few years, the CDC has supported the National Cancer-Related Lymphedema Awareness Campaign, reaching millions of Americans through public service announcements. The NIH established a National Commission on Lymphatic Diseases, the Department of Defense's Congressionally Directed Medical Research Program has, in 2023, recognized lymphatic diseases and lymphedema as eligible for research funding for the first time, the United States Congress recently passed the Lymphedema Treatment Act, and, since 2021, over 60 facilities met standards to become LE&RN Centers of Excellence<sup>26</sup>.

Importantly, the data accumulated in this project represents the initiation of an educational imperative for the education of our healthcare providers.

Examples include a formal manuscript summarizing the original research that will target a high-impact, peer-reviewed medical journal. In addition, the material has been presented at a series of national or international meetings, with more to come.

- [The Lymphatic Forum, Banff, Canada](#)—estimated 200 attendees
- [The Society for Vascular Medicine, Washington, DC](#)—estimated 100 attendees
- [The International Society of Lymphology World Congress, Genoa, Italy](#)—estimated 400 attendees
- [The International Union of Phlebology/American Vein & Lymphatic Society World Congress, Miami Beach, Florida](#)—estimated 500 attendees
- [Imperial College, London, UK](#)—estimated 100 attendees
- [The British Lymphology Society, Chester, UK](#)—estimated 200 attendees

In addition, it is anticipated that this work will be presented later this year at the Veith Sympthe annual meeting of the [Soci t  Fran aise de Phl bologie, Paris, France](#).

## IMPLICATIONS

This report has provided a clear outline of numerous problems to address in lymphedema: the current healthcare disparities, access to care, and issues with transition to care that exist for those living with lymphedema. This will require a multifaceted approach:

1. Improving public awareness and educating all stakeholders about lymphedema
2. Focusing on curricular reform to include training and resources for healthcare providers, beginning at the undergraduate level through medical and graduate school, to emphasize the importance of the lymphatic system in health and disease
3. Lobbying for insurance coverage and financial assistance programs that would make lymphedema care accessible to all
4. Determining avenues to reduce the cultural and language barriers that currently exist in healthcare communication
5. Focusing on the transition of care from pediatric to adult care
6. Considering approaches to encourage and expose early trainees and investigators to the study of lymphatic medicine
7. Changing the current funding mechanisms so that lymphedema and lymphatic research is on par with the resources provided to other chronic diseases

## BEST PRACTICES

### Standards of Care

Unfortunately, there are no universally accepted “standards of care” or guidelines for diagnosing and treating lymphedema. This is despite a reasonable body of evidence supporting the efficacy of early and preemptive diagnosis, risk reduction, and surgical and non-surgical treatment interventions to minimize disease burden, symptomatology, and progression<sup>32, 33</sup>.

However, for the present, healthcare providers turn to empiric standard principles of medicine to diagnose and treat patients presenting with lymphedema. To be effective, diagnosis and treatment requires a comprehensive team of experts along with an individualized approach tailored to the patient’s specific needs and circumstances, including the following important principles:

1. **Accurate Early Diagnosis Is Essential:** Healthcare providers assess the patient’s medical history, perform a physical examination (including measuring and recording the disease burden in the affected body regions) and may employ diagnostic tools such as bioimpedance spectroscopy, perometry, lymphoscintigraphy, or MRI to confirm the presence of lymphedema and to determine its severity.
2. **Patient Education:** Education is a critical aspect of lymphedema management. Patients should receive information about lymphedema, risk reduction strategies, and self-care techniques to manage and prevent exacerbations.
3. **Compression Therapy:** Compression therapy is a cornerstone of lymphedema management. It entails using compression garments, bandages, or devices to apply controlled pressure to the affected limb(s) to enhance lymphatic contractility and minimize edema. The compression level and type of garment may vary based on the individual’s needs and should be monitored and approved by a specialist trained to fit compression garments.
4. **Manual Lymphatic Drainage (MLD):** MLD is a specialized massage technique performed by trained, certified lymphedema therapists to manually stimulate the lymphatic system and encourage the movement of excess fluid toward functional lymphatic drainage routes.
5. **Exercise and Movement:** Gentle, low-impact exercises and physical activity can help improve lymphatic flow and overall mobility. Physical therapists trained to treat lymphedema are an excellent addition to the comprehensive treatment team.

6. **Skin Care and Prevention:** Skin care is essential to avoid complications like cellulitis that can arise from lymphedema. Maintaining proper skin hygiene and preventing infections is critical and includes avoiding cuts, burns, and insect bites, keeping the skin moisturized, and avoiding dry and cracked skin.
7. **Weight Management:** Maintaining a healthy weight can help reduce the burden on the lymphatic system. Diet and nutrition guidance may be provided, and seeking out an experienced and trained nutritionist may be of benefit.
8. **Complete Decongestive Therapy (CDT):** CDT is a comprehensive approach to lymphedema management that typically includes a combination of manual lymphatic drainage, compression therapy, exercise, and skincare. It is often delivered in multiple sessions over several weeks.
9. **Surgical Options:** such as surgical debulking through liposuction (suction-assisted protein lipectomy or SAPL), lymphaticovenous anastomosis (LVA), or vascularized lymph node transfer (VLNT) may be considered in cases where lymphedema is recalcitrant to conservative management.
10. **Psychosocial Support:** Lymphedema can be isolating, a burden with significant emotional and psychosocial impact. Supportive care, counseling, and addressing body image concerns are essential for holistic management.
11. **Monitoring and Follow-up:** Regular monitoring and follow-up appointments with healthcare providers help assess progress, adjust treatment plans as needed, and prevent complications.

Two international organizations, The International Society of Lymphology and the International Lymphoedema Framework, have supported these approaches. It is important to note here that there is no comparable approach that is directed specifically to those living with lymphedema in the U.S., an important public health goal that is not difficult to achieve with the proper attention and resources.

## BEST PRACTICES AMONGST SPECIALISTS

- The approaches summarized above are consistently practiced by lymphatic and vascular care specialists. This provider cohort generally includes vascular medicine and surgical specialists but also embraces a smaller cadre of practitioners in dermatology, oncology, cardiology, and physical medicine, among others.
- The approach to the at-risk population includes aggressive objective surveillance with both non-invasive and imaging techniques; when subclinical disease is detected, aggressive preemptive measures are undertaken that can forestall or minimize clinical disease expression.

- Overt disease is managed conservatively through a suite of interventions that are collectively classed as Complete Decongestive Therapy (CDT).
- Surgical referral for debulking procedures or microvascular lymphatic reconstruction is predicated upon the judgment of appropriately trained clinicians.
- These interventions are adequately supported by the data derived from more than 40 years of clinical observation and investigation<sup>34</sup>.

## CHALLENGES AND LIMITATIONS

Several key challenges relate to the current status of lymphedema (LE) treatment, research, and education.

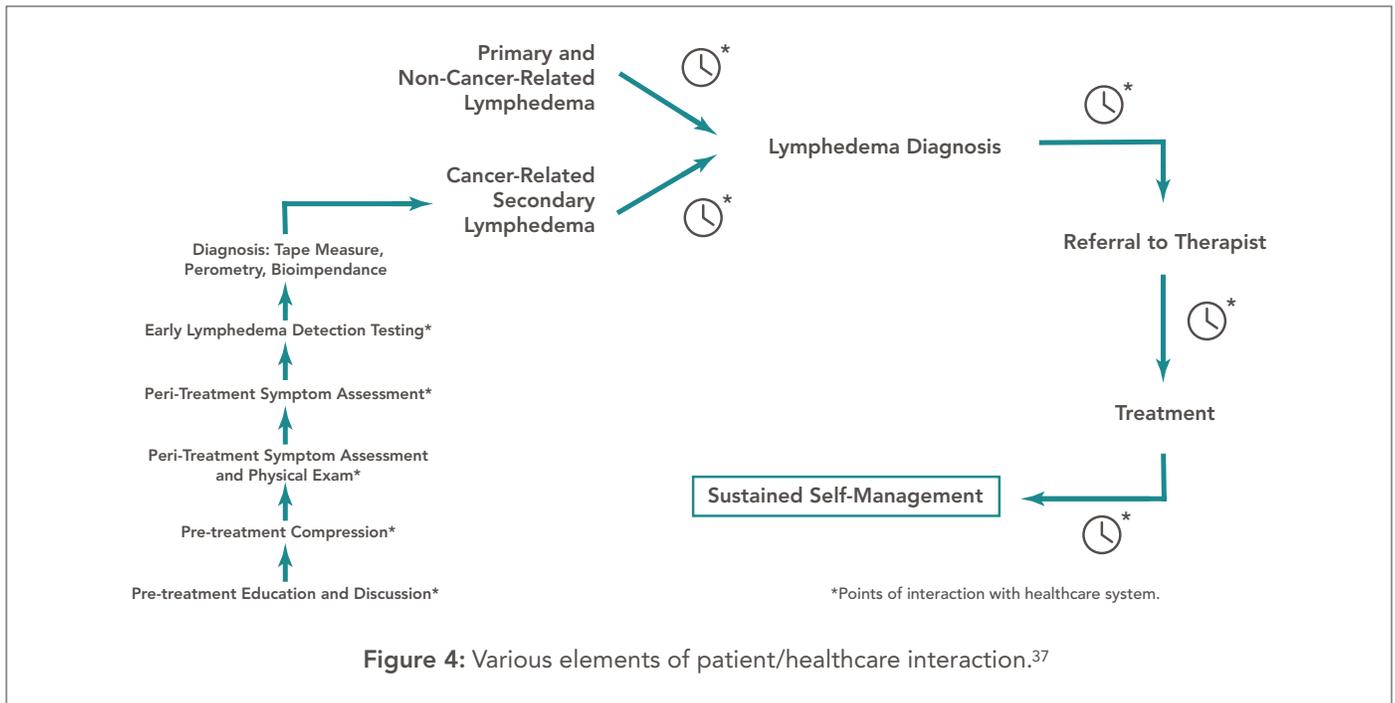
### Challenges:

1. **Lack of awareness and understanding among healthcare providers.** A study conducted in 2004 by Dr. Stanley G. Rockson, Allan and Tina Neill Professor of Lymphatic Research and Medicine at Stanford University School of Medicine, revealed that *only 30 minutes or less of the medical school curriculum across the U.S. was routinely devoted to the lymphatic system in the first two years of medical school training*<sup>24</sup>.
2. **Historical neglect of the lymphatic system in medical education.** Unfortunately, there has not been a change in lymphatic system education in the medical school curriculum over the last two decades since the initial study was conducted.
3. **Institutional pushback from journals and associations.** Although involved in almost every single system in the body, lymphatics receive very little focus or emphasis across the research community. To better understand the population-based impact of lymphatic disease (LD) and lymphedema, this must become a clear focus for organizations with the resources to help lead this endeavor.

### Suggestions for Addressing Challenges:

To address the above challenges, the following steps have been proposed:

1. Implement lymphedema education programs in medical schools.
2. Advocate for more research funding.
3. Collaborate with patient advocacy groups to raise awareness.
4. Include patient advocates in the decision-making processes for clinical, institutional, and research efforts.



## RECOMMENDATIONS FOR THE FUTURE

- **Education:** Increase efforts to educate healthcare providers and the public about lymphedema (LE).
- **Research:** Allocate more funds for lymphedema research to understand the disease better and develop effective treatments.
- **Policy:** Advocate for including lymphedema codes in electronic health records and promote the importance of early diagnosis.

### What's Next?

The inference from the aggregate data and observations must entail an acknowledgment of the marginalization of this patient population and its root causes in insufficient medical education. We propose the following schema (Figure 4, above) to address the various elements of patient/healthcare interaction.

It is also apparent that rectification of medical education will be imperative. While all physician groups are appropriate for this intervention, it is particularly relevant to consider the fields of family practice, internal medicine, general surgery, breast and gynecologic surgery, bariatrics, oncology, dermatology, and cardiovascular medicine. A suite of educational programs can be created, both for virtual education and tailored workshops to be presented at the large national conferences hosted by the organizations that subserve the continuing medical and educational needs of these respective medical specialties.

## CASE STUDIES: PATIENT VOICES

People who are living with lymphedema (LE) and lymphatic disease (LD) often feel isolated due to limited awareness and stigma. Additionally, many researchers who study the lymphatic system may have limited opportunities to connect with people with lymphatic diseases. To amplify these voices, we have shared these narratives highlighting the challenges faced by people living with lymphatic diseases.

**BONNIE:** *"I was diagnosed with lymphedema in September 2015, and I am still trying to wrap my head around my 'Life with Lymphedema.' Thus far, my future looks bleak. I too have run into a diagnosis, but very few answers. Doctors don't seem to know how to help. Treatments are few and expensive. Insurance, including Medicaid, doesn't want to pay for treatment(s) and therapy, so you get worse until you get bad enough to be hospitalized because that will happen without care."*

**DARA:** *"Most of my teenage years were spent hiding and feeling ashamed of the parts of my body that became increasingly deformed. It didn't reach its 'heyday' until my senior year of high school. I remember lying in bed one day that spring...weeks away from graduation, and thinking that I couldn't go on any longer. It was the deepest level of depression I have ever felt. I was at such a mental low that I could not bring myself to move. What was going to come of me if I was completely overtaken by this fluid? I felt like I was literally drowning in my own body."*

... I continue to attempt to manage this disease every single day of my life. Although I have been reminded time and time again that it could 'always be worse,' there are days when it feels like there is nothing worse. I still, 15 years later, have days where I am pushed to the edge. Days when I come home from work and can't use my hands, or even get my clothes off because I have ballooned up so much over the day. I let myself cry on these days because no matter how much you try to look on the bright side, it is hard to live this way."

**AMANDA:** "Since 2002, I have battled an incurable illness known as lymphedema. At the time of diagnosis, little information was known about treating this condition. The resources to maintain the condition were expensive and did not provide a viable solution. Not only was I permanently disfigured, I was traumatized to learn that there was nothing I could do about it. Along my journey, I became a mother in 2005 and again in 2007. Becoming a mother has been my greatest accomplishment. That being said, trying to take care of others is challenging enough, not to mention the added demands of having a chronic illness. Staying active, eating healthy and making healthy lifestyle choices is something I strive for on a regular basis. As a busy mother who works full time, it is not always easy to stay committed to my regime. Through my own personal tribulations, I have managed to significantly reduce my edema to the point it is almost a thing of my past. Currently, I am a motivational speaker, lymphedema warrior, a certified personal trainer, and an all-natural bodybuilder. I coach, train, and speak worldwide to help empower others and take back their health."

**KARA:** "I have been diagnosed with lymphedema and lipedema. Lipedema is a chronic medical condition characterized by a symmetric buildup of adipose tissue (fat) in the legs and arms. The adipose tissue is different from regular fat. It is immune to diet and exercise. Lipedema is usually confused with regular obesity and lymphedema. I am glad I received a diagnosis in 2016. I have had swollen legs and thighs all my life and always felt like it was my fault, especially when puberty hit. My lipedema progressed even more then. I am glad that I have the knowledge of my two conditions. I have taken my health into my own hands and haven't allowed my two conditions to stop me from enjoying life. My lipedema in my arms and thighs has progressed a bit more, but I am thankful to God that I am still mobile. Just remember to have faith, educate yourself on your condition(s), and focus on living a healthy and happy life."

These stories and more can be found at:  
<https://lymphaticnetwork.org/living-with-lymphedema/your-stories/>

## FUTURE DIRECTIONS

- **Research Directions:** Focus on new diagnostics, molecular, genetic (cell-free DNA), humoral factors, and imaging techniques<sup>35,36</sup>.
- **Funding:** Advocate for more research dollars designated for lymphedema (LE).
- **Education:** Emphasize the importance of educational reform in the lymphatic community and healthcare.

## ACKNOWLEDGMENTS

With heartfelt gratitude, the Lymphatic Education & Research Network (LE&RN) recognizes the **Centers for Disease Control and Prevention** for its generous commitment and support in educating and advocating for those living with lymphedema (LE) and other lymphatic diseases (LD). The federal grant award as part of the "Expanding the National Approach to Chronic Disease Education and Awareness" initiative represents a significant opportunity to further the Lymphatic Education & Research Network's mission of advancing research and education about lymphatic diseases, including lymphedema and promoting a better understanding and improving the management of these diseases.

Furthermore, we thank all our community members who volunteered their time to enroll and participate in the LE&RN Global Registry for Lymphatic Diseases and/or the 23-item online survey. We thank the scientists and clinicians who work tirelessly to find improved lymphatic therapies and cures.

**Your contributions are what makes our data stronger, our understanding of the lymphatic system clearer, and what drives new therapies and technology. Knowledge is power.** 

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Research Primary Investigator: Stanley Rockson, M.D.  
Research Team: Kimberley Steele, M.D., Ph.D.; Fabrice Bernard, Ph.D; Catharine Bowman, M.S.  
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American Venous Forum (AVF)

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## APPENDICES

### Appendix 1: List of LE&RN Centers of Excellence as of December 2023



**LE&RN Centers of Excellence (COE)** provide a geographically diverse network of multidisciplinary clinical care and service centers for individuals and families

affected by lymphatic diseases (LD). In addition to clinical and social services, the Centers provide professional and lay education in the geographic areas they serve, are involved in clinical research, and work with LE&RN locally and internationally to continually improve the lives of individuals with lymphatic diseases and their families. The following descriptions relate to the types of Centers of Excellence designated by the Lymphatic Education & Research Network.



**Comprehensive Centers of Excellence** are institutions that can provide the listed services on-site, all within the same institution, and can coordinate the provision of the services. This includes meeting the minimum requirements of at least three Certified Lymphedema Therapists (CLTs) on-site, and demonstrating proficiency in the following areas: diagnosis, imaging, conservative management, assessment tools, interventional therapies, surgery (with a minimum of three surgeons performing lymphatic surgeries), genetics, consultation, research, accountability, collegiality, administration, and community involvement.

- The Boston Lymphatic Center (A Joint Program between Beth Israel Deaconess Medical Center & Boston Children's Hospital, teaching affiliates of Harvard Medical School), Boston, MA, USA
- Cedars-Sinai Health System, Los Angeles, CA, USA
- Center for Lymphatic and Venous Disorders, Stanford University School of Medicine, Palo Alto, CA, USA
- Center of Prevention, Diagnosis and Treatment of Lymphedema—Lymphatic Diseases for Adults and Children Metropolitan Hospital, Athens, Greece
- Centre Hospitalier Universitaire Vaudois—Dept. of Vascular Medicine, Lausanne University Hospital, Switzerland
- The Jill and Mark Fishman Center for Lymphatic Disorders at Children's Hospital of Philadelphia, Philadelphia, PA, USA
- Hospital Center University De Montpellier, Montpellier, France
- Cleveland Clinic, Cleveland, OH, USA
- Columbia University Irving Medical Center/New York Presbyterian, New York, NY, USA
- Derby Lymphoedema Service—Royal Derby Hospital, Derby, United Kingdom
- Johns Hopkins Hospital, Baltimore, MD, USA
- Keck Medical Center of USC, Los Angeles, CA, USA
- Nij Smellinghe Hospital Center of Expertise for Lymphovascular Medicine, Drachten, Netherlands
- The Ohio State University Comprehensive Cancer Center, Columbus, OH, USA
- Oregon Health & Science University Healthcare, Portland, OR, USA
- Penn Center for Lymphatic Diseases and Lymphedema, Philadelphia, PA, USA
- St George's, University of London, London, United Kingdom
- The University of Chicago Medicine, Chicago, IL, USA
- University of Michigan, Ann Arbor, MI, USA
- Uppsala University Hospital, Uppsala, Sweden



### **Comprehensive Cancer Centers of Excellence**

can provide the listed services on-site, all within the same institution, and can coordinate the provision of the services for patients who have developed lymphedema as a result of cancer treatment. This includes meeting the minimum requirements of at least three CLTs on-site and demonstrating proficiency in the following areas: diagnosis, imaging, conservative management, assessment tools, interventional therapies, surgery (with a minimum of three surgeons performing lymphatic surgeries), genetics, consultation, research, accountability, collegiality, administration, and community involvement.

- Brigham and Women’s Hospital, Boston, MA, USA
- City of Hope, Duarte, CA, USA
- Nebraska Medicine Buffett Cancer Center, Omaha, NE, USA
- University of Kansas Medical Center, Kansas City, KS, USA
- The University of Texas MD Anderson Cancer Center, Houston, TX, USA



### **Comprehensive Pediatric Centers of Excellence**

are institutions that can provide the listed services on-site, all within the same institution, for children and young adults and coordinate the provision of the services. This includes meeting the minimum requirements of at least three CLTs on-site and demonstrating proficiency in the following areas: diagnosis, imaging, conservative management, assessment tools, interventional therapies, surgery (with a minimum of three surgeons performing lymphatic surgeries), genetics, consultation, research, accountability, collegiality, administration, and community involvement, as well as referrals for patients no longer treated due to age restrictions.

- Children’s Healthcare of Atlanta, Atlanta, GA, USA
- Cincinnati Children’s Hospital Medical Center Hemangioma and Vascular Malformation Center, Cincinnati, OH, USA
- Nemours Children’s Hospital Delaware, Wilmington, DE, USA
- Texas Children’s Hospital Vascular Anomalies Center, Houston, TX, USA



### **Comprehensive Networks of Excellence**

are institutions with affiliate institutions (within close geographical proximity) that can provide the listed services. For example, University “A” School of Medicine, University “A” Teaching Hospital, University “A” Cancer Center, and University “A” Rehabilitation Facility can provide the listed services and can coordinate provision of the services. This includes meeting the minimum requirements of at least three CLTs within the network and demonstrating proficiency in the following areas: diagnosis, imaging, conservative management, assessment tools, interventional therapies, surgery (with a minimum of three surgeons performing lymphatic surgeries within the network), genetics, consultation, research, accountability, collegiality, administration, and community involvement.

- The ALERT Program at Macquarie University, New South Wales, Australia
- Aristotle University, Plastic Surgery Department, Thessaloniki, Greece

- Centro Linfedema c/o C.C. La Madonnina, Milan, Italy
- Greater Baltimore Medical Center, Baltimore, MD, USA
- Lymphedema Program, McGill University Health Centre, Montreal, Quebec, Canada
- Massachusetts General Hospital, Boston, MA, USA
- Mayo Clinic Arizona, Phoenix, AZ, USA
- Memorial Sloan Kettering Cancer Center, New York, NY, USA
- University of Colorado Health, CO, USA
- University Hospital Zürich and University Children’s Hospital Zurich, Zürich, Switzerland
- University of Washington, Division of Plastic Surgery, Seattle, WA, USA
- Washington University, Saint Louis, MO, USA



### **Referral Network of Excellence**

designation indicates that the institution and/or nearby collaborating institutions can provide the listed services, and that these institutions can coordinate provision of the services. For example, University “A” School of Medicine, University “B” Teaching Hospital, “C” Cancer Center, and Private Practice “D” Rehabilitation Facility can provide the listed services, and can coordinate provision of the services. This includes meeting the minimum requirements of at least three CLTs within the referral network, and demonstrating proficiency in the following areas: diagnosis, imaging, conservative management, assessment tools, interventional therapies, surgery (with a minimum of three surgeons performing lymphatic surgeries within the referral network), genetics, consultation, research, accountability, collegiality, administration, and community involvement.

- Lymphedema Center Santa Monica, Santa Monica, CA, USA
- University of Miami Health Services, Miami, FL, USA
- Vail Health/Shaw Cancer Center, Edwards, CO, USA



### **Lymphatic Disease Surgery Centers of Excellence**

designate those institutions (i.e. a cancer care center or large teaching hospital/network) that can provide the listed surgical services. This includes meeting the minimum requirements of at least three CLTs on-site or within the network and demonstrating proficiency in the following areas: diagnosis, imaging, conservative management, surgery (with a minimum of three surgeons performing lymphatic surgeries within the network), research, accountability, collegiality, administration, and community involvement.

- The Center for Lymphatic Restoration at Swedish Medical Center, Englewood, CO, USA
- The Center for Lymphedema Surgery at The Institute for Advanced Reconstruction, Shrewsbury, NJ, USA
- European Center of Lymphatic Surgery, Brussels, Belgium
- Fondazione Policlinico Universitario “Agostino Gemelli” IRCCS, Rome, Italy
- The Genoa Center for Lymphatic Diseases, Genoa, Italy
- Integrative Lymphedema Institute, Dallas, TX, USA

- Kameda Medical Center, Chiba Prefecture, Japan
- Kaohsiung Chang Gung Memorial Hospital, Kaohsiung, Taiwan
- Maastricht University Medical Center, Maastricht, Netherlands
- Pontifical Catholic University of Chile, Santiago, Chile
- Santa Creu i Sant Pau—Clinica Planas, Barcelona, Spain



**LD Surgery Network of Excellence** designation indicates that an institution (i.e., surgeons in private practice with full clinical and administrative staff) can provide the listed surgical services on-site and within their referral network. This includes meeting the minimum requirements of at least three CLTs on-site and demonstrating proficiency in the following areas: diagnosis, imaging, conservative management, surgery (with a minimum of three surgeons performing lymphatic surgeries within the referral network, i.e., one on-site surgeon and two surgeons with whom they collaborate/refer), research, accountability, collegiality, administration, and community involvement.

- Baptist MD Anderson Cancer Center, Jacksonville, FL, USA



**Lymphatic Disease Conservative Care Center of Excellence** designation indicates that an institution can provide the listed conservative care services on-site or within its own network. This includes meeting the minimum requirements of at least three CLTs on-site or within the network and demonstrating proficiency in the following areas: diagnosis, conservative management, assessment tools, research, accountability, collegiality, administration, and community involvement.

- Hartford HealthCare Rehabilitation Network, Newington, CT, USA
- Moffitt Cancer Center, Tampa, FL, USA
- Mt. Wilga Private Hospital, Hornsby, New South Wales, Australia
- Penrose Hospital Out-Patient Rehabilitation, Colorado Springs, CO, USA
- Sanwari Bai Surgical Center, New Delhi, India
- Therapy Achievements, Huntsville, AL, USA

## Appendix 2: LE&RN Resource Center



The **LE&RN Resource Center** is a complimentary global support service to assist the lymphatic community in navigating the complexities of lymphatic diseases, including lymphedema, lipedema, and lymphatic anomalies. We serve people living with lymphatic diseases and their families, caretakers, and healthcare providers. The LE&RN Resource Center can help find specialized care through the LE&RN Centers of Excellence network, locate certified lymphedema therapists, and provide educational resources. Download the LE&RN Resource Guide for a list of services and programs provided by the Lymphatic Education & Research Network. We encourage you to connect with the LE&RN Resource Center and to refer your patients and colleagues. Contact the LE&RN Resource Line at 1-855-378-8163 or [LRC@lymphaticnetwork.org](mailto:LRC@lymphaticnetwork.org)

## Appendix 3: LE&RN Research Resources

1. **Lymphatic Research Database:** Here, you will find a list of the world's leading lymphatic researchers, their labs, a brief description of their research, and a link to their *PubMed* research database. This page's search engine allows the viewer to search by name, institution, or research topic. Researchers can use this page to find potential research collaborations and partners.
2. **Clinical Trials & Studies:** A compendium of ongoing lymphatic-related clinical trials underway that patients can enroll in if they meet the necessary criteria.
3. **Publications:** Resource sharing a compiled list of peer-reviewed research in lymphatics.
4. **Conferences & Travel Awards:** LE&RN actively participates in the research community and participates in various national and international lymphatic-related conferences. To support rising stars in the lymphatic community, we support trainees and young investigators with travel grants and poster awards.
5. **Lymphedema and Lymphatic Disease Video Symposia:** A compendium of lymphedema and lymphatic disease symposia with a wide diversity of speakers and topics.

## Appendix 4: Gaps in the Field of Lymphatic Research



One of the significant challenges the lymphatic community faces is the lack of research that can help understand lymphatic physiology and diseases and create effective therapies to combat them. The Lymphatic Education & Research Network collected input from leading

lymphatic researchers and scientists to address this issue regarding the gaps in clinical and translational research in lymphedema and other lymphatic diseases. This input has been compiled into the following document:

Click [here](#) to download a copy.

## Appendix 5: Standardized Approach for the Diagnosis and Management of Lymphedema (LE) and Lymphatic Diseases (LD)



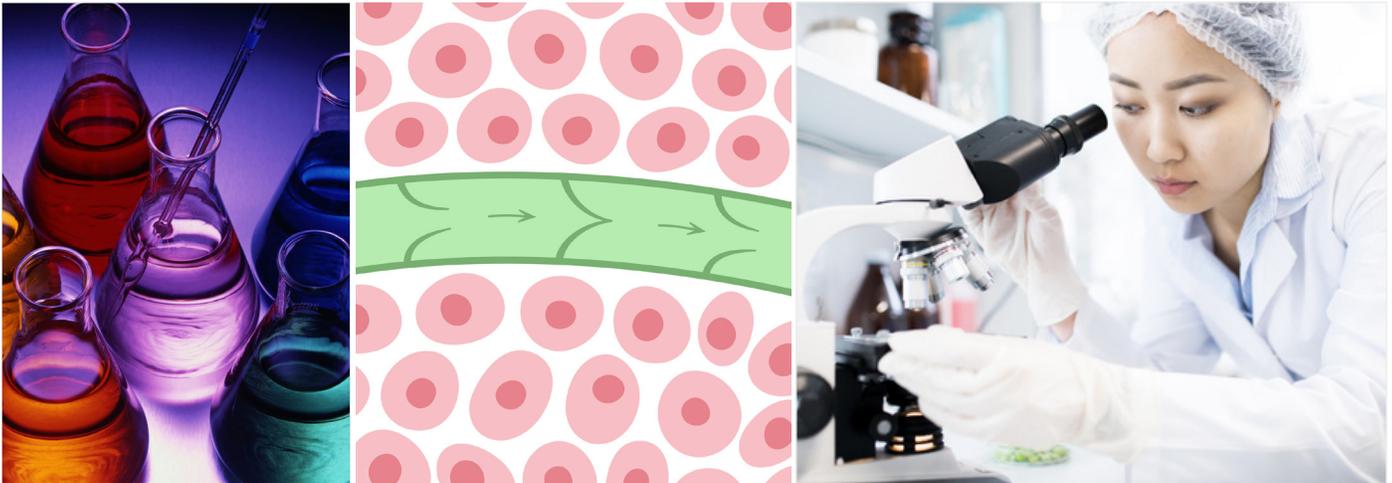
This comprehensive document provides healthcare professionals with a unified framework for assessing, diagnosing, and treating lymphatic diseases. Emphasizing early detection, effective intervention, and improved quality of life, it addresses the global rise in the prevalence of lymphatic diseases and the significant physical, emotional, and economic burdens they impose. The collaboration and contributions of clinical specialists position this document as a vital resource to empower healthcare professionals with guidelines for preventive measures to deliver consistent and effective care.

Click [here](#) to download a copy.

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LE&RN's mission is to fight lymphatic diseases through education, research, and advocacy. We seek to accelerate the prevention, treatments and cures for lymphedema, lipedema, lymphatic anomalies, and the continuum of lymphatic diseases.

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Lymphatic Education  
& Research Network

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