



Lymphatic Education & Research Network



2024 ANNUAL REPORT

www.LymphaticNetwork.org



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FIGHTING LYMPHATIC DISEASES THROUGH EDUCATION, RESEARCH AND ADVOCACY

Founded in 1998, **LE&RN** is at the forefront of raising awareness of lymphatic diseases (LD), such as lymphedema (LE), lipedema, and lymphatic malformation.

LE&RN prioritizes offering free education to the lymphatic community through the **LE&RN Online Symposium Series**, which provides more than 116 hours of expert videos and counting.

The mission of the **LE&RN Global Registry for Lymphatic Diseases** is to establish the world's most comprehensive patient-centered registry to inspire ground-breaking research, expedite the development of treatment options, and establish a path leading to the cure for lymphatic diseases. The **LE&RN Resource Center** is a complementary global support service to assist the lymphatic community in navigating the complexities of lymphatic diseases. The quarterly journal

Lymphatic Research and Biology delivers the latest developments and advancements in lymphatic biology and pathology from the world's leading biomedical investigators.

LE&RN fosters collaboration and knowledge exchange through various programs, including the **LE&RN/Lymph Notes U.S. Lymphedema Therapist Scholarships, Early Investigator Travel and Poster Awards**, and the internationally attended **Lymphatic Forum** conference, which brings together over 200 researchers.

Through our global **Chapters, Centers of Excellence in the Diagnosis & Treatment of Lymphatic Diseases, LymphWalk** fundraisers, and legislative advocacy efforts, LE&RN is building an extensive network of people seeking new treatment options and cures.

Lymphedema impacts an estimated 10 million Americans and more than 250 million worldwide. **Lipedema** impacts up to 17 million American women, and 1 in 6,000 children are born with a **lymphatic malformation**. Yet lymphatic diseases remain invisible to most and are often misdiagnosed or left untreated while funding for research remains limited.

Lymphatic—uncovering the links between lymphatic function, lymphatic diseases, and wellness

Education—serving as an essential educational resource for doctors, patients, and the public at large

& Research—searching for treatments and cures through our specialized research activities

Network—building an extensive network of participants and partners to advance advocacy



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LE&RN 2024 ACTIVITIES

LEADING THE FIGHT AGAINST LYMPHATIC DISEASES

LE&RN is a not-for-profit corporation, founded in 1998, under the laws of the State of New York. 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 (LE), lipedema, lymphatic anomalies, and the continuum of lymphatic diseases (LD).

Some activities of the organization during 2024 include the following:

- **LE&RN Global Registry for Lymphatic Diseases** was upgraded to establish the world's most comprehensive patient-centered registry to inspire ground-breaking research, expedite the development of treatment options, and establish a path leading to the cure for LD.
- **LE&RN Resource Center** was launched as a complementary global support service to assist the lymphatic community in navigating the complexities of LD.
- LE&RN continued its educational and awareness outreach programs targeting academia, government, industry, and the medical and patient communities.
- **LE&RN Online Symposium Series** continues to provide monthly free sessions, which bring the world's foremost lymphatic experts to people living with LD, their families, and professionals.
- LE&RN grew and engaged a diverse audience and continued expanding its website and social media to provide comprehensive updates of news in the field.
- LE&RN produced six issues of *Lymphatic Research and Biology*, an international, peer-reviewed biomedical journal providing a forum for the exchange of cutting-edge scientific developments in lymphatic science and medicine.
- LE&RN advocated for Congressional and National Institutes of Health support for lymphatic research.
- LE&RN continued the **LE&RN/Lymph Notes Lymphedema Therapist Scholarship Program** to provide tuition support to therapists seeking certification in lymphedema therapy.
- LE&RN continued offering a web-based **"Ask the Experts"** feature that allows people living with LD, their families, and professionals to directly ask questions to the most prominent authorities in the field.
- LE&RN celebrated the **10th anniversary of Kathy Bates as Global Spokesperson**.
- LE&RN's **Virtual Expo** continued to provide people living with LD and professionals 24/7 access to available treatments and services.
- LE&RN celebrated its ninth **World Lymphedema Day** with events across the globe.
- **LE&RN International and State Chapters** continued to grow.
- LE&RN outreach expanded to national audiences on multiple media outlets.
- LE&RN expanded to **70 Centers of Excellence in the Diagnosis and Treatment of Lymphatic Diseases across 20 countries**.
- National lymphedema awareness campaign drove **500+ daily visits** to the *LE&RN & Live* website, connecting thousands to free resources.

LE&RN TIMELINE

2024	<ul style="list-style-type: none"> • LE&RN expands to 70 Centers of Excellence, a global multidisciplinary network across 20 countries to advance expert care • LE&RN launches three groundbreaking reports addressing healthcare disparities and improving standards of care: <i>National Indicator Report on Cancer-Related Lymphedema</i>, <i>Standardized Approach for the Diagnosis and Management of Lymphedema and Lymphatic Diseases</i>, and <i>Gaps in the Field of Lymphatic Research</i> • LE&RN celebrates the 10th anniversary of Kathy Bates as Global Spokesperson • Dame Joanna Lumley joins LE&RN's Honorary Board • "A Transformative Year for Lymphatic Disease Research and Treatment" is published in <i>Healthcare Business Today</i>
2023	<ul style="list-style-type: none"> • LE&RN celebrates its 25th Anniversary • The National Institutes of Health Open Session features the establishment of the National Commission on Lymphatic Diseases, a result of LE&RN's advocacy efforts • The LE&RN Resource Center™ was launched as a complementary global support service to assist the lymphatic community in navigating the complexities of lymphatic diseases, including lymphedema, lipedema, and lymphatic anomalies • LE&RN grows to 62 Centers of Excellence and 34 Chapters worldwide • The LE&RN Global Registry for Lymphatic Diseases™ was revitalized to address the urgent need for lymphatic data • LE&RN successfully advocates for Congress to add lymphedema and lymphatic diseases to the Department of Defense's Congressionally Directed Medical Research Program, opening its \$370M medical research budget to lymphatics
2022	<p>LE&RN's advocacy results in Congress calling for creation of a National Commission on Lymphatic Diseases • The National Institutes of Health (NIH) establishes a Working Group to pursue the National Commission • LE&RN succeeds at getting Congress to add LE and LD to the Dept. of Defense's Congressionally Directed Medical Research Programs (CDMRP), opening its \$370M medical research budget to lymphatics • NIH creates categories for LE and LD for the first time in its history • LE&RN welcomes its 50th Center of Excellence into the program</p>
2021	<p>LE&RN announces thirty-five Centers of Excellence in Diagnosis & Treatment of LDs, and held second Global Virtual Summit • LE&RN succeeds in effort to have FY2022 Senate Appropriations Bill continues to call for establishing of National Commission on Lymphatic Diseases • LE&RN is awarded a three-year CDC Lymphedema Awareness Grant for a national campaign</p>
2020	<p>LE&RN announces twenty-five Centers of Excellence in Diagnosis & Treatment of LDs and held global virtual summit of this inaugural program</p> <ul style="list-style-type: none"> • LE&RN succeeds in effort to have FY2021 Senate Appropriations Bill call for establishing of National Commission on Lymphatic Diseases • LE&RN succeeds in effort for FY2021 Senate Appropriations Bill to include CDC Awareness Grant Program for Chronic Diseases like Lymphatic Diseases
2019	<p>LE&RN Spokesperson Kathy Bates testifies before the House Appropriations Subcommittee on Labor, Health and Human Services • LE&RN creates lymphatic researcher database for NIH • LE&RN joins NIAMS (National Institute of Arthritis and Musculoskeletal and Skin Diseases) Coalition</p>
2018	<p>LE&RN creates Physician CME Seminar in Lymphatic Disease Diagnosis and Treatment • LE&RN inaugurates first Legislative Lobby Days in Washington, DC to advocate for research funding • LE&RN authors New York State first-in-nation bill mandating all hospitals give lymphedema information packets to at-risk patients</p>
2017	<p>LE&RN Spokesperson Kathy Bates honored by Research America with "Impact on Public Opinion Award" • LE&RN co-organizes the inaugural biennial researcher event Lymphatic Forum: Exploring the Lymphatic Continuum in Chicago • LE&RN partners with Harvard University Medical Schools for the first Lymphedema Symposium in Boston</p>
2016	<p>March 6th officially established as World Lymphedema Day by U.S. Senate, New York legislature, and countries around the world • International Chapters inaugurated • LE&RN spearheads \$70M US Senate Appropriations request sponsored by Senator Charles Schumer (NY) • Spokesperson Kathy Bates takes LE&RN's mission center stage on a multitude of network television shows and print cover stories</p>
2002–15	<p>LE&RN/Fat Disorder Research Society Lipedema Postdoctoral Fellowship Awards established • LE&RN/NAVBO partnership to establish biennial conference in lymphatics • State Chapters inaugurated • "Ask the Experts" web feature established to connect patients to leading authorities • The LE&RN/LymphNotes Lymphedema Therapist Scholarship Program is founded • Academy Award-winning actress Kathy Bates becomes LE&RN's spokesperson • New York State Legislature awards funding for National Patient Registry & Tissue Bank • In 2013 LRF becomes LE&RN with an expanded mission and opens New York City office • Live-streamed Medical & Research Symposium Series established • LE&RN National Lymphatic Disease and Lymphedema Tissue Bank established • Breakthrough study, blood test for diagnosis of lymphedema published—Stanford University School of Medicine Endowed Chair • First annual Walk to Fight Lymphedema & Lymphatic Diseases • LE&RN National Lymphatic Disease and Lymphedema Patient Registry created • Congressional and National Institutes of Health (NIH) support for lymphatic research and lymphatic diseases secured • Lymphatic Research and Biology, an international peer-reviewed journal, has its first printing • The Biennial Gordon Research Conference Series, Molecular Mechanisms in Lymphatic Function and Disease established • Postdoctoral Fellowship Awards program inaugurated • First-ever Endowed Chair of Lymphatic Research and Medicine at Stanford University School of Medicine established</p>
1998	<p>LE&RN is founded under the name Lymphatic Research Foundation to promote research, treatments and cures</p>



BOARD OF DIRECTORS

Lymphatic Education & Research Network

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- Melissa Aldrich, Secretary
- Debbie Miles, Treasurer
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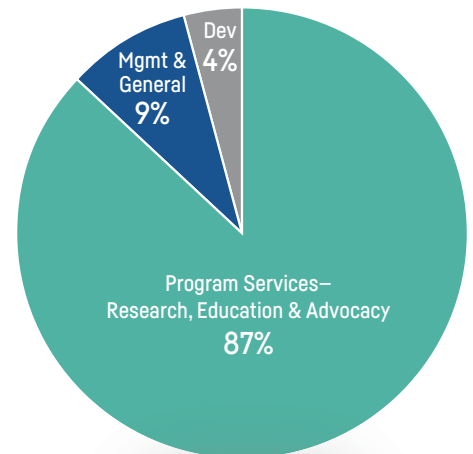
- William Repicci

Accountants

- Cerini & Associates, LLP

2024 AUDITED FINANCIALS

Program Services—Research, Education & Advocacy	\$1,444,913	87%
Management and General	\$ 144,913	9%
Development	\$ 62,333	4%
Total Expenses	\$1,651,386	100%
Annual Revenue	\$1,779,320	
Total Net Assets \$3,598,707		





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