



Lymphatic Education & Research Network



2019 ANNUAL REPORT



Lymphatic Education & Research Network

www.LymphaticNetwork.org

FIGHTING LYMPHATIC DISEASE AND LYMPHEDEMA THROUGH EDUCATION, RESEARCH AND ADVOCACY.

LE&RN is at the forefront of raising awareness of lymphatic diseases, such as lymphedema (LE) and lipedema (LI). Founded in 1998, LE&RN provides annual grants to **Research Fellows** at the world's leading universities, putting lymphatic diseases on the radar in the medical community, in academia, in government, and with pharmaceutical companies.

Through LE&RN's education programs, such as our **Livestream Symposium Series**, medical practitioners, therapists, patients, and family members can benefit from hearing presentations given by the world's leading lymphatic and lymphedema experts.

LE&RN's **International Patient Registry and Biorepository** provides researchers with access to information and bio-samples from patients with 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.

Through events such as our countrywide **Walk to Fight Lymphedema & Lymphatic Diseases** and through legislative advocacy efforts, LE&RN is building an extensive network of people seeking new treatment options and cures.

Lymphedema and other lymphatic diseases impact the lives of an estimated 10 million Americans and more than 250 million worldwide. Yet, these diseases remain invisible to most and are often misdiagnosed or left untreated while funding for research remains limited. In 2018 LE&RN addressed four main strategies: First, creating a Physician CME Seminar in Lymphatic Diagnosis and Treatment; Second, inaugurating LE&RN's first Lobby Days in Washington, DC to advocate for research funding; Third, the establishment of standards for lymphatic disease *Centers of Excellence*; Fourth, passage of a bill in New York State mandating all hospitals give lymphedema information packets to all at-risk patients.

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 2019 ACTIVITIES

LEADING THE FIGHT AGAINST LYMPHATIC DISEASE AND LYMPHEDEMA

LE&RN is a not-for-profit corporation, founded in 1998, under the laws of the State of New York.

The Organization's mission is to fight lymphatic diseases such as lymphedema and lipedema through education, research and advocacy. LE&RN seeks to accelerate the prevention, treatment, and cure of lymphatic diseases while bringing patients and medical professionals together to address the unmet needs surrounding lymphatic disorders.

Some activities of the organization during 2019 include the following:

- LE&RN continues to expand the [International Patient Registry and Biorepository](#) at Stanford University as a resource to stimulate research and support clinical trials and drug development.
- LE&RN continued its [grant fellowship award program](#).
- LE&RN continued its [educational and awareness outreach programs](#) targeting academia, government, industry, and the medical and patient communities.
- LE&RN continued its [monthly live-stream symposium series](#), which brings the world's foremost authorities in lymphatic disease and lymphedema to patients, their families, and professionals.
- LE&RN continued [expanding its website and social media](#) to provide comprehensive updates of news in the field.
- LE&RN produced four issues of *Lymphatic Research and Biology*, an international, peer-reviewed biomedical journal providing the 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/LymphNotes 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 patients, their families, and professionals to directly ask questions to the most prominent authorities in the field.
- LE&RN spokesperson, Academy Award winner [Kathy Bates](#), continued her advocacy and was honored by Research America.
- LE&RN's [Virtual Expo](#) was updated to allow patients and professionals 24/7 access to available treatments and services.
- [World Lymphedema Day](#) celebrated its 4th year with events across the globe.
- [International](#) and [State Chapters](#) continue to grow.
- LE&RN outreach expanded to national audiences on multiple media outlets.
- LE&RN inaugurated a program to establish global [Centers of Excellence in the Diagnosis and Treatment of Lymphatic Diseases](#).

LE&RN TIMELINE

2019	<ul style="list-style-type: none"> • LE&RN creates lymphatic researcher database for NIH • LE&RN Spokesperson Kathy Bates testifies before the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies • LE&RN's New York #LymphWalk marks 10-year anniversary, breaking attendance and fundraising records • LE&RN Spokesperson Kathy Bates honored at The 24 Hour Plays Broadway Gala for her advocacy work with LE&RN • LE&RN joins NIAMS (National Institute of Arthritis and Musculoskeletal and Skin Diseases) Coalition
2018	<ul style="list-style-type: none"> • 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 establishes standards for lymphatic disease Centers of Excellence • LE&RN authors New York State first-in-nation bill mandating all hospitals give lymphedema information packets to at-risk patients
2017	<ul style="list-style-type: none"> • 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
2016	<ul style="list-style-type: none"> • 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
2015	<ul style="list-style-type: none"> • LE&RN/Fat Disorder Research Society Lipedema Postdoctoral Fellowship Awards established • LE&RN/NAVBO partnership to establish biennial conference in lymphatics • State Chapters inaugurated
2014	<ul style="list-style-type: none"> • "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
2013	<ul style="list-style-type: none"> • LRF becomes LE&RN with an expanded mission and opens New York City office • Live-streamed Medical & Research Symposium Series established
2012	<ul style="list-style-type: none"> • 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
2010	<ul style="list-style-type: none"> • First annual Walk to Fight Lymphedema & Lymphatic Diseases • LE&RN National Lymphatic Disease and Lymphedema Patient Registry created
2008	<ul style="list-style-type: none"> • First-ever Endowed Chair of Lymphatic Research and Medicine at Stanford University School of Medicine established
2006	<ul style="list-style-type: none"> • Postdoctoral Fellowship Awards program inaugurated
2005	<ul style="list-style-type: none"> • Grants and Awards Programs established
2004	<ul style="list-style-type: none"> • The Biennial Gordon Research Conference Series, <i>Molecular Mechanisms in Lymphatic Function and Disease</i> established
2003	<ul style="list-style-type: none"> • Lymphatic Research and Biology, an international peer-reviewed journal, has its first printing
2002	<ul style="list-style-type: none"> • Congressional and National Institutes of Health (NIH) support for lymphatic research and lymphatic diseases secured
1998	<ul style="list-style-type: none"> • LE&RN is founded under the name Lymphatic Research Foundation to promote research, treatments and cures

BOARD OF DIRECTORS

Lymphatic Education & Research Network

- Debbie Miles (Chair)
- Philip Braginsky (Secretary)
- Ken Cerini (Treasurer)
- Dr. Joseph Dayan
- Dave McDowell
- Dr. Sheila Ridner
- Dr. Doron Ilan

President and CEO

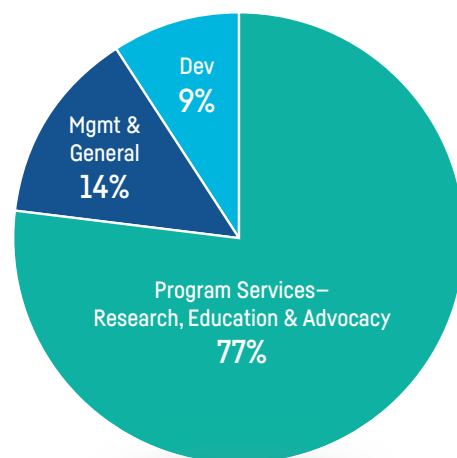
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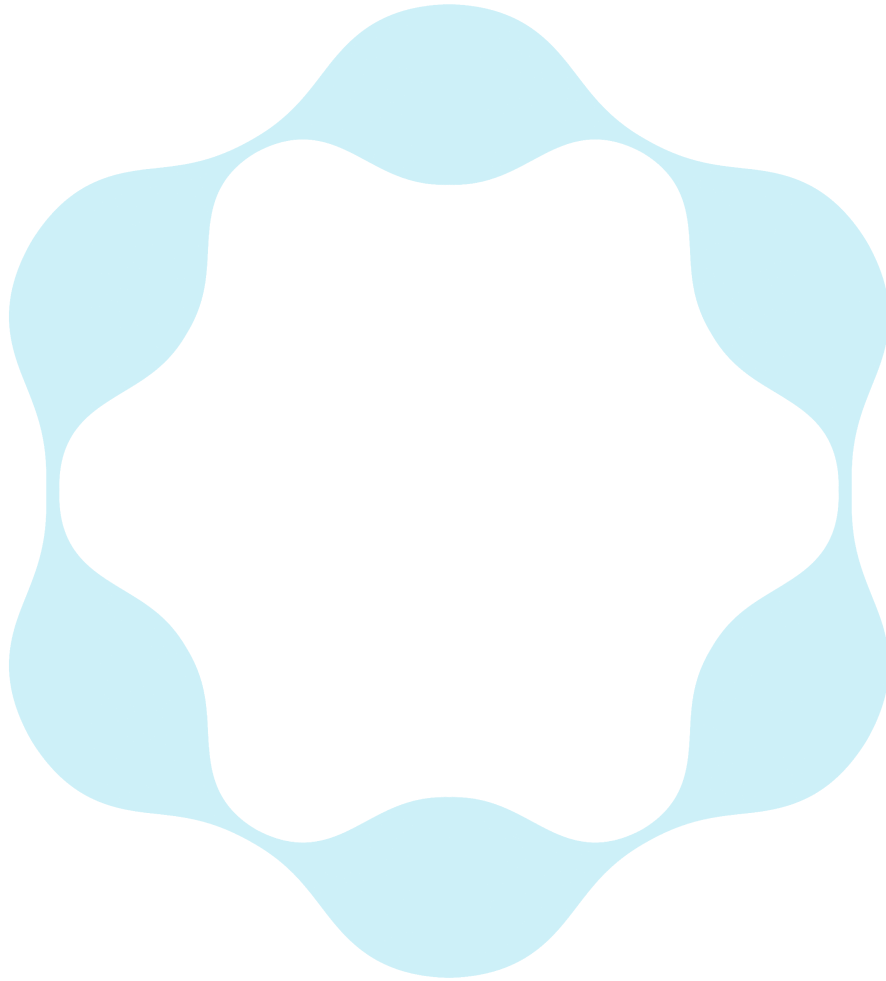
Accountants

- Cerini & Associates, LLP

2019 AUDITED FINANCIALS

Program Services—Research, Education & Advocacy	\$ 701,833	77%
Management and General	\$ 128,497	14%
Development	\$ 87,295	9%
Total Expenses	\$ 918,896	100%
Annual Revenue/Released Research Fund	\$1,052,828	
Total Net Assets \$351,133		





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261 Madison Avenue, 9th Floor, New York, NY 10016
516-625-9675 • LERN@LymphaticNetwork.org

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