



Lymphatic Education & Research Network



2020 ANNUAL REPORT



Lymphatic Education & Research Network

www.LymphaticNetwork.org

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 (LI), and lymphatic malformation (LM).

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 Lymphatic Disease 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. LE&RN's scholarships and awards program encourages the best of your investigators to pursue lymphatic research. The **Lymphedema Therapist Scholarship** program trains new CLT therapists residing in underserved areas.

Through our global **Chapters, Centers of Excellence in the Diagnosis & Treatment of Lymphatic Diseases**, events such as our national **Walks to Fight Lymphatic Diseases**, and through 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. In 2020 LE&RN addressed four main strategies: Promoting a Physician CME Seminar in Lymphatic Diagnosis and Treatment; Second, Lobbying in Washington, DC to advocate for a National Commission on Lymphatic Diseases; Third, establishing *Centers of Excellence*; Fourth, advocating for a CDC Awareness Grants program for chronic diseases.

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 2020 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 (LD), such as lymphedema (LE), lipedema (LI), and lymphatic malformations (LM) through education, research and advocacy. LE&RN seeks to accelerate the prevention, treatment, and cure of LD while bringing patients and medical professionals together to address the unmet needs surrounding lymphatic disorders.

Some activities of the organization during 2020 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 building support for 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 LD and LE 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 six 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/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 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.
- LE&RN's [Virtual Expo](#) continued to provide patients and professionals 24/7 access to available treatments and services.
- [World Lymphedema Day](#) celebrated its 5th year with events across the globe.
- International and State [Chapters](#) continued 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 hosted its first [Centers of Excellence Virtual Summit](#) attracting over 600 internationally.

LE&RN TIMELINE

2020	<ul style="list-style-type: none"> • LE&RN announces twenty-five Centers of Excellence in Diagnosis & Treatment of LDs and held global virtual summit of this inaugural program • 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	<ul style="list-style-type: none"> • 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
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 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	<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>
2015	<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</p>
2014	<p>“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</p>
2013	<p>LRF becomes LE&RN with an expanded mission and opens New York City office • Live-streamed Medical & Research Symposium Series established</p>
2012	<p>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</p>
2010	<p>First annual Walk to Fight Lymphedema & Lymphatic Diseases • LE&RN National Lymphatic Disease and Lymphedema Patient Registry created</p>
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, Molecular Mechanisms in Lymphatic Function and Disease 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

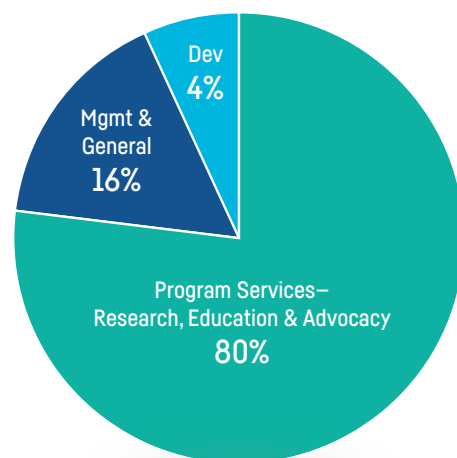
- William Repicci

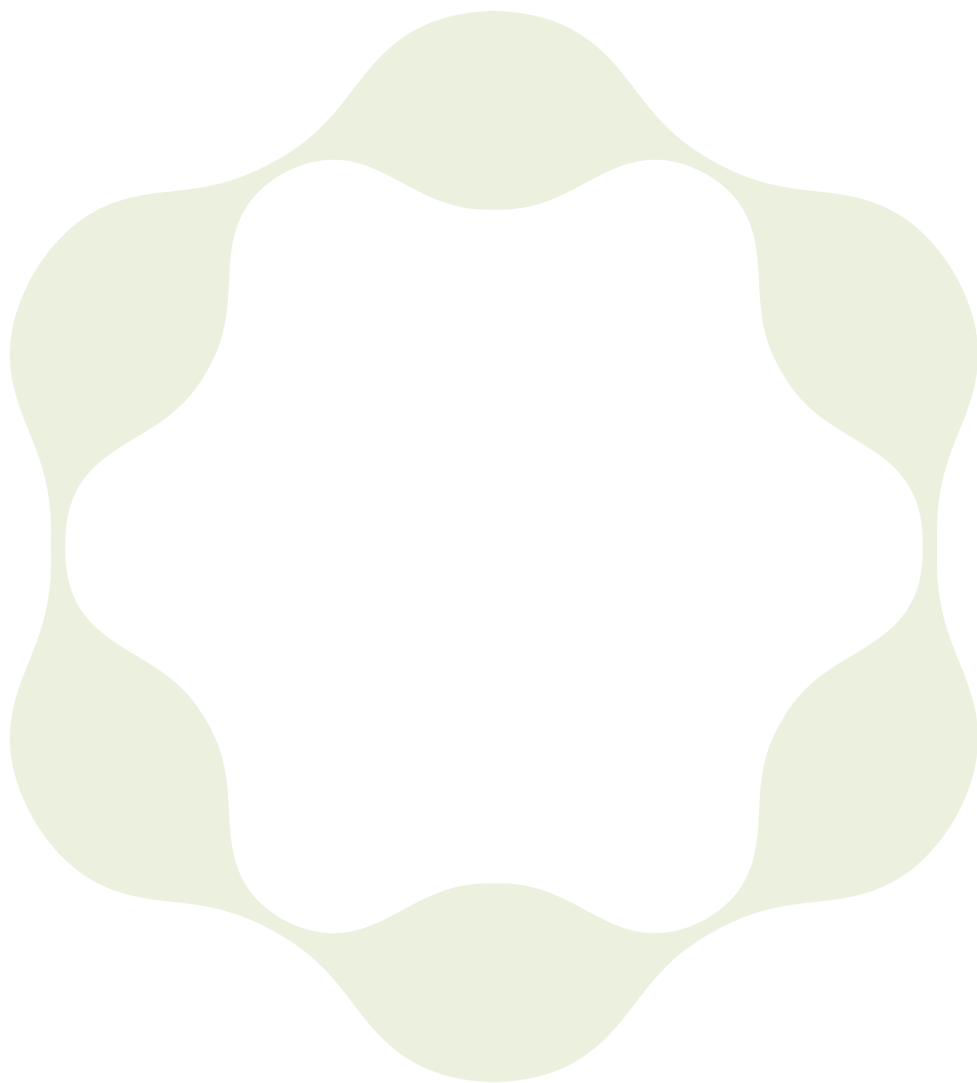
Accountants

- Cerini & Associates, LLP

2020 AUDITED FINANCIALS

Program Services—Research, Education & Advocacy	\$624,884	80%
Management and General	\$126,270	16%
Development	\$ 31,324	4%
Total Expenses	\$782,478	100%
Annual Revenue/Released Research Fund	\$944,978	
Total Net Assets \$513,633		





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154 West 14th Street, 2nd Floor, New York, NY 10011
516-625-9675 • LERN@LymphaticNetwork.org

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