



Lymphatic Education & Research Network



2016 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 and lipedema. 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 Lymphatic Disease and Lymphedema 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 an estimated 150 million worldwide. Yet, these diseases remain invisible to most and are often misdiagnosed or left untreated while funding for research remains limited. In 2016 LE&RN addressed three obstacles facing lymphedema awareness: First, recognizing lymphedema as a disease rather than a condition; Second, the commitment to use the acronym LE to simplify recognition of the disease; Third, to acknowledge our goal of finding cures.

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 2016 ACTIVITIES

LEADING THE FIGHT AGAINST LYMPHATIC DISEASE AND LYMPHEDEMA

Lymphatic Education & Research Network (LE&RN) is an internationally recognized nonprofit organization founded in 1998 to fight lymphatic disease and lymphedema through education, research and advocacy. With worldwide chapters LE&RN seeks to accelerate the prevention, treatment and cure of the disease while bringing patients and medical professionals together to address the unmet needs surrounding lymphatic diseases, which include lymphedema and lipedema.

Some activities of the organization during 2016 include the following:

- LE&RN established the [International Lymphatic Disease and Lymphedema 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](#) with six awardees from around the world.
- LE&RN continued its [educational and awareness outreach programs](#) targeting academia, government, industry, and the medical and patient communities.
- LE&RN continued its [bimonthly 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 secured ongoing [Congressional and National Institutes of Health](#) support for lymphatic research.
- LE&RN continued the [LE&RN/LymphNotes U.S. Lymphedema Therapist Scholarship](#) 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](#), was a featured speaker at the Gordon Research Conference on Lymphatics, which held its first patient session in its 80-year history. Ms. Bates also keynoted the American College of Phlebology Conference.
- LE&RN expanded its Honorary Board, headed by [Kathy Bates](#) and including notable celebrities who support LE&RN's mission. [Steve Guttenberg](#) joined.
- LE&RN's [Virtual Expo](#) was expanded to allow patients and professionals 24/7 access to available treatments and services.
- [World Lymphedema Day](#) is established by unanimous vote of the United States Senate. The bill was written by LE&RN.
- [International Chapters](#) are established starting with Europe, Canada and India. Several new State Chapters are established.
- LE&RN outreach expanded to national audiences with pieces on [CBS Sunday Morning](#), [Dr. Oz](#), [USA Today](#), [NIH Medline Plus](#) and a host of other outlets.
- LE&RN members met with the CEO of the [American Medical Association](#) to discuss the need for physician education and certification in lymphatic disease issues.

LE&RN TIMELINE

2016

- **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 Schumer (NY)
- Spokesperson **Kathy Bates takes LE&RN's mission center stage** on a multitude of network television shows and print cover stories

2015

- **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

- **"Ask the Experts"** web feature established to connect patients to leading authorities
- The **LE&RN/LymphNotes Lymphedema Therapist Scholarship Program** is founded
- **NYC Walk to Fight Lymphedema and Lymphatic Diseases** crosses Brooklyn Bridge for the first time
- **The Face of Lymphedema Challenge** and **Membership Campaign** are kicked off
- Academy Award-winning Actress **Kathy Bates becomes LE&RN's Spokesperson**
- **New York State Legislature awards funding** for National Patient Registry & Tissue Bank

2013

- LRF becomes **LE&RN** with an expanded mission and opens New York City office
- **Live-streamed Medical & Research Symposium Series** established

2012

- **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

- First annual **Walk to Fight Lymphedema & Lymphatic Diseases**
- **LE&RN National Lymphatic Disease and Lymphedema Patient Registry** created

2008

- First-ever **Endowed Chair of Lymphatic Research and Medicine** at Stanford University School of Medicine established

2006

- **Postdoctoral fellowship** awards program inaugurated

2005

- **Grants and Awards Programs** established

2004

- The **Biennial Gordon Research Conference Series**, Molecular Mechanisms in Lymphatic Function and Disease established

2003

- **Lymphatic Research and Biology**, an international peer-reviewed journal, has its first printing

2002

- **Congressional and National Institutes of Health (NIH)** support for lymphatic research and lymphatic diseases secured

1998

- **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
- Dr. Riku Rautsola
- Dr. Sheila Ridner
- Dr. Doron Ilan

President and CEO

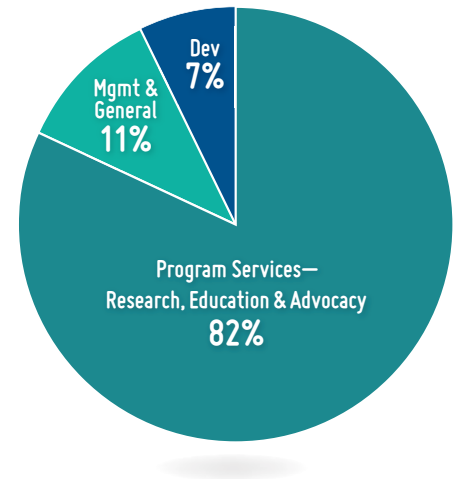
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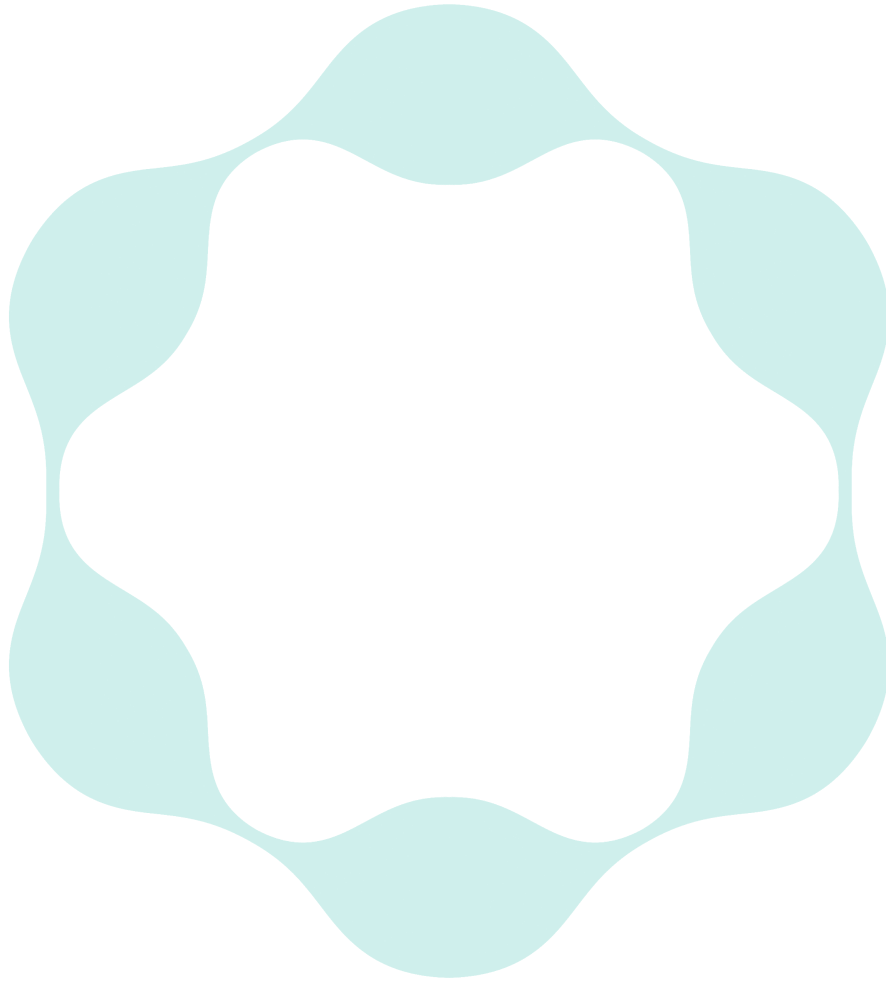
Accountants

- Cerini & Associates, LLP

2016 FINANCIALS

Program Services—Research, Education & Advocacy	\$791,056	82%
Management and General	\$116,768	11%
Development	\$70,378	7%
Total Expenses	\$978,202	100%
Annual Revenue/Research Fund	\$968,348	
Total Net Assets \$412,858		





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