



Lymphatic Education & Research Network



ANNUAL REPORT 2015



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 disease and lymphedema. Founded in 1998 as the Lymphatic Research Foundation, 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 popular **Medical 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 **Patient Registry and Tissue Bank** provides researchers with access to information

about those afflicted with these diseases and can provide tissue samples from lymphatic disease patients to further research discoveries in the field. 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 the annual **Walk to Fight Lymphedema & Lymphatic Diseases** and through advocacy efforts such as fighting for passage of the **Lymphedema Treatment Act**, LE&RN is building an extensive network of people looking for answers, demanding better treatment options, and, ultimately, finding a cure so that no one will have to suffer with lymphedema and other lymphatic disorders.

Continued ►

"After years of relative neglect, the field of lymphatic research is finally getting the attention it deserves.

Clearly, the biggest impact to this field has been the establishment of LE&RN. Now more than ever, there is great opportunity for scientific advancement. Importantly, lymphatic research will enhance the lives of millions, prevent future disease, and preserve the good health we all wish to enjoy. **Research defines our future.**"

—Stanley G. Rockson, MD, Center for Lymphatic and Venous Disorders, Stanford University School of Medicine



Lymphedema and other lymphatic diseases impact the lives of an estimated 10 million Americans and hundreds of millions worldwide. Yet, these diseases are often difficult to diagnose and to treat, and funding for research is limited.

LE&RN is determined to change that, seeking to stimulate research and education, and to provide a voice for those who have suffered in silence for far too long.

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

“Doctors didn’t know what was wrong with our baby girl’s arm which, we discovered later, is afflicted with lymphatic malformation. The lymphatic system is almost completely ignored among the medical community, making our family’s journey much more difficult.

It is critical that we continue to increase awareness so that both children and adults can get diagnosed, and get help, faster.”

—Elizabeth, mom to Naomi



“Our son Nathan is only three years old, but he participated in his first LE&RN walk this year. We want him to know that even though he suffers with a lymphatic malformation he can help others by calling attention to these often-neglected diseases, and that there are people out there looking for the answers that might help him.”

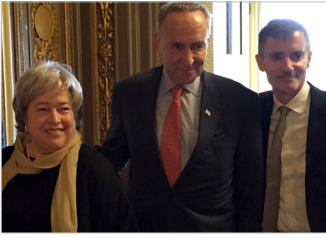
—Sara, mom to Nathan

“My lymphedema diagnosis took many difficult and frustrating years. I hope that through the research and advocacy being done through LE&RN, more primary-care doctors will be able to recognize these disorders which affect so many.

While I still have many challenges, getting the right treatment was critical and now I’m a mom to a beautiful baby girl.”

—Janet, lymphedema patient





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LE&RN 2015 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 disease and lymphedema 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 2015 include the following:

- LE&RN continued its [rebranding effort](#) and expanded programs to meet the goals of the expanded mission of fighting lymphatic disease and lymphedema through education, research, and advocacy.
- LE&RN continued the [International Lymphatic Disease and Lymphedema Registry](#), a national patient registry to stimulate research and support clinical trials and drug development.
- LE&RN continued the [International Lymphatic Disease and Lymphedema Tissue Bank](#), providing biological materials to serve as a source for the clinical and laboratory study of lymphatic diseases.
- LE&RN continued its [grant fellowship award program](#) attracting scientists and clinicians from distinguished research centers around the world and expanding the pool of investigators in the field of lymphatic research.
- LE&RN continued a [grants program](#) that allows young investigators to attend a conference focused on lymphatic research.
- 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 [expanded its website and social media](#) to provide daily updates and a weekly newsletter featuring major events 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 established the [LE&RN/LymphNotes Lymphedema Scholarship Program](#) to provide tuition support to therapists seeking certification in lymphedema therapy.
- LE&RN established 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 the [Face of Lymphedema Challenge](#) where patients and their loved ones submit videos to promote awareness.
- LE&RN established its Honorary Board, headed by [Kathy Bates](#) and including notable celebrities who support LE&RN's mission.
- [LE&RN Expo](#) is a response to the pleas of patients and therapists who find that the array of lymphedema products and services are overwhelming when making choices about treatment, therapy options and training programs. The goal of the Expo is to eliminate this information gap and better connect patients and therapists to the products and services best suited for their treatment regimen. LE&RN's [Virtual Expo](#) is free for the consumer and allows them to explore services on LE&RN Expo website from the comfort of one's home, 24 hours a day, 7 days a week.

LE&RN TIMELINE

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

- Philip Braginsky (Chair)
- Ken Cerini (Treasurer)
- Debbie Miles (Secretary)
- Dr. Joseph Dayan
- Dr. Riku Rautsola
- Dr. Sheila Ridner
- Dr. Doron Ilan
- David Sans

Executive Director

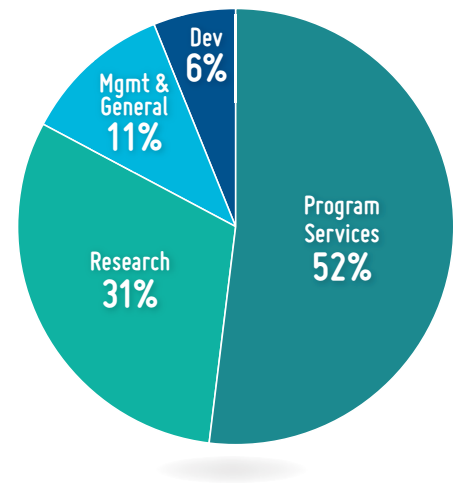
- William Repicci

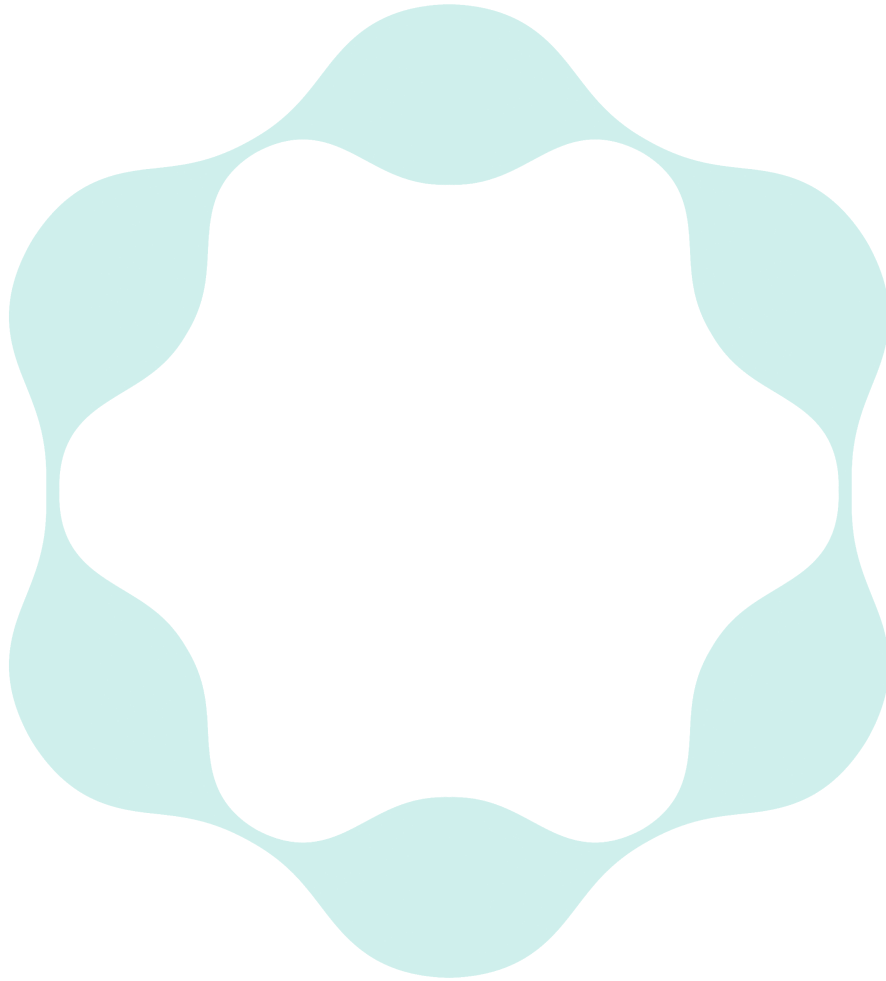
Accountants

- Cerini & Associates, LLP

2015 FINANCIALS

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|---------------------------------------|-----------|------|
| Research | \$261,507 | 31% |
| Program Services—Education & Advocacy | \$432,572 | 52% |
| Management and General | \$92,133 | 11% |
| Development | \$58,002 | 6% |
| Total Expenses | \$844,214 | 100% |
| Annual Revenue | \$866,880 | |
| Total Net Assets \$704,721 | | |





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