



Lymphatic Education  
& Research Network



Lymphatic Education & Research Network

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# CASE STATEMENT



LE&RN fifth annual California Run/Walk to Fight LE & LD, Santa Monica, CA, June 2019.



**"We need awareness** so that medical practitioners and therapists are prepared to treat all who come to them with LE and LD. **We need awareness** to inspire communities around the world to embrace this as a common cause. **We need awareness** to encourage our greatest minds to engage in research and our institutions to then make a priority of funding this research. And then we need to make finding a cure a global priority. **Miracles await if we dedicate ourselves to finding them."**

–William Repicci, President and CEO, LE&RN

Cover photo: Kathy Bates is honored as LE&RN's National Spokesperson at the 24 Hour Plays Broadway Gala, New York City, November 2019.

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## THE MISSION

Our mission is to fight lymphatic diseases (LD) such as lymphedema (LE), lipedema and lymphatic malformation (LM) through education, research, and advocacy. We seek to accelerate prevention, treatments, and cures while bringing patients and medical professionals together to address unmet needs.

Lymphedema (LE) affects an estimated 10 million Americans and 250 million worldwide. In addition, up to 17 million women in the United States are estimated to have lipedema, while 1 in 6,000 births result in a child being born with a lymphatic anomaly. More Americans have these diseases than AIDS, Parkinson's disease, Muscular Dystrophy, Multiple Sclerosis, and ALS—combined. Yet, lymphatic diseases remain invisible to most and are often misdiagnosed or left untreated while funding for research remains limited.

Since the **Lymphatic Education & Research Network (LE&RN)** was founded in 1998, this

internationally recognized nonprofit organization and its worldwide members have been determined to change this and find cures through education, research and advocacy.

LE&RN is at the forefront of raising awareness of lymphatic diseases. In 2016, the U.S. Senate established March 6 as World Lymphedema Day® in response to a bill written by LE&RN. Through educational programs and with the help of notable celebrities, LE&RN has brought visibility to these diseases and is committed to advancing advocacy and inspiring patients to feel hopeful and empowered to fight for themselves. 





“I had a double mastectomy and, as a result, I have lymphedema in both arms. If we want to win this fight, we need to stand together and educate the world.”

–Kathy Bates  
Academy Award-winning Actor and  
LE&RN Spokesperson





*LE&RN advocates and New York State Senator Andrew Gounardes (center) at 2019 World Lymphedema Day® resolution designation by the New York State Senate, Albany, NY.*

# LYMPHATIC EDUCATION & RESEARCH NETWORK

## OVERVIEW

The lymphatic system is a circulatory system which is critical to immune function and good health.

When it is compromised and lymph flow is restricted, the physical impact to patients can be devastating, life altering, and can lead to shortened lifespan. LE is one such lymphatic disease. LE is a chronic, debilitating, and incurable swelling that can be a result of cancer treatment, inherited or genetic causes, damage to the lymphatic system from surgery or an accident, or from parasites as in lymphatic filariasis.

**Of the estimated 10 million Americans with LE, the majority are cancer survivors.** This includes up to 30% of breast cancer survivors, 75% to 90% of those with head and neck cancer and from 10%-15% of those who have had other cancers such as prostate, ovarian, and melanoma. Thousands of children are born each year with lymphatic diseases. Veterans are at increased risk of LE due to physical trauma in the line of duty and environmental impact from burn pit exposure. An estimated 70 million people globally of those with

lymphatic filariasis (LF) develop LE. Currently, there are no cures and few treatments for these diseases

Following a history of neglect when it came to LD and LE, a group of advocates emerged in the 1990s determined to change the course of history. In 1998, the Lymphatic Education & Research Network (LE&RN) would be founded as one parent's response to medical professionals and researchers who were unable to provide answers for her daughter suffering from LD and LE. With lymphatic science and research all but non-existent, LE&RN began providing annual grants to research fellows at the world's leading universities, putting LD on the radar in the medical community, in academia, in government, and with pharmaceutical companies.

Advocacy with the National Institutes of Health (NIH) would lead to lymphatics becoming a focus of research there, as well as the founding of the Trans-NIH Coordinating Committee for Lymphatic Research and Medicine. LE&RN was instrumental in establishing the first, and still only, endowed university Chair in Lymphatic Research and

Medicine; Dr. Stanley Rockson holds the Chair at Stanford University and is a driving force as Founding Chair of LE&RN's Scientific and Medical Advisory Council.

LE&RN is committed to making LDs a global health priority and is leading this effort internationally through a host of programs:

**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.

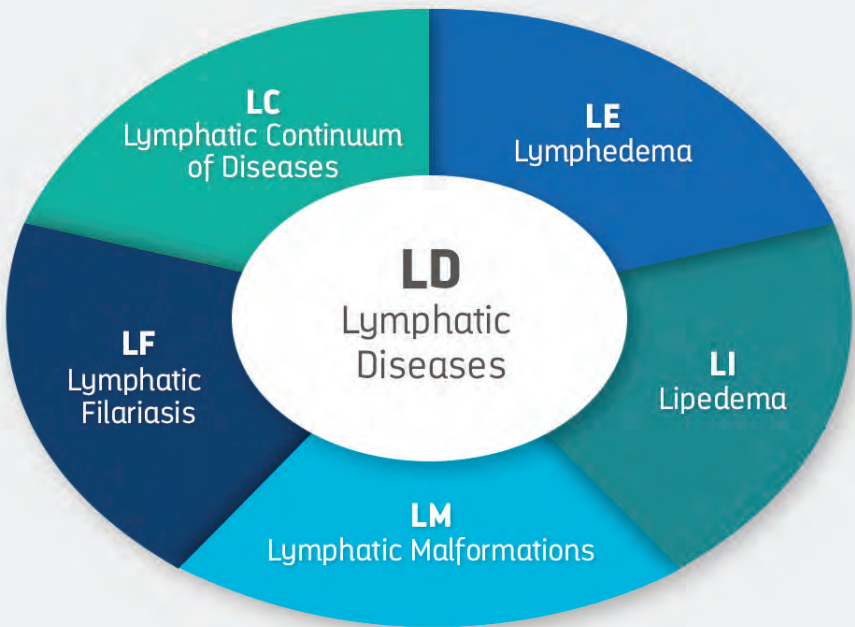
**& Research**—searching for treatments and cures through specialized research activities.

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

LE&RN addresses three obstacles facing LE awareness:

1. Recognition of LE as a disease, rather than by the euphemism of calling it a condition.
2. Making it easier for lymphedema to enter the national conversation by using the acronym LE.
3. Moving the conversation beyond a search for treatments to the expectation that cures be demanded.

Today, it is recognized that beyond lymphatic diseases such as LE, lipedema and filariasis, lymphatic research is impacting research on cancer metastasis, heart disease, Alzheimer's, AIDS, Rheumatoid Arthritis, Multiple Sclerosis, Diabetes, obesity and a host of other diseases. LE&RN legislative action is at the forefront of educating politicians on the need to fund lymphatic research and address the insurance needs of those with these diseases. As a circulatory system that is part of the body's immune response, the possibilities to impact public health globally through lymphatic research are infinite. 🌐



For more information on these lymphatic diseases, visit: [WorldLymphedemaDay.org](http://WorldLymphedemaDay.org).

# PROGRAMS

## EDUCATION

LE&RN offers educational programs targeting academia, the medical and patient communities, and the public at large.

### WHY EDUCATION?

Although the World Health Organization (WHO) estimates as many as 250 million people worldwide suffer with LE, and tens of millions more suffer from the lymphatic disease lipedema, these diseases remain virtually unknown to most. Those who seek treatments too often find that there are no local certified lymphedema therapists. With medical students receiving as little as 30 minutes of lymphatic system training during their education, physicians remain ill-equipped to diagnose and treat patients.

To change this situation, LE&RN has implemented programs that inform and engage patients, therapists, researchers, and the medical community. LE&RN broadcasts a monthly [Livestream Symposium Series](#), which brings the world's foremost authorities in LD and LE to patients, their families,

and medical professionals. These symposia are permanently available for viewing on LE&RN's website, which also offers a world-class library of information and resources accessible to anyone.

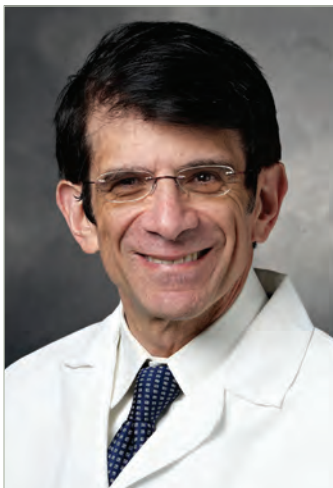
LE&RN sponsors [International Scholarship Awards](#) for young research investigators in lymphatics.

### LE&RN created the first online Continuing Medical Education (CME) course for Physicians.

The course features lectures by leaders in the field and addresses our mission to educate healthcare professionals about LD.

LE&RN established the first-ever standards for [Centers of Excellence in the Diagnosis & Treatment of Lymphatic Diseases](#) to guarantee that patients are able to find the best alternatives for comprehensive institutional care. There are currently 45 Centers globally that have been approved or are undergoing evaluation by LE&RN's global oversight committee made up of sixteen worldwide leaders in the field.

LE&RN sponsors the [LE&RN/LymphNotes U.S. Lymphedema Therapist Scholarship](#) to provide tuition support to therapists seeking certification in LE therapy. This program has led to over



"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





*Travel Award Scholarship winners from around the world at **Lymphatic Forum 2019**, sponsored by NAVBO and LE&RN; Austin, Texas, May 30–June 1.*

100 new CLTs entering the field with a focus on underserved areas.

LE&RN publishes [monthly educational newsletters](#) and multimedia presentations, and uses social media to provide comprehensive updates of news in the field.

LE&RN offers a web-based [Ask the Experts](#) feature, which allows patients, their families, and professionals to directly ask question to prominent authorities in the field.

LE&RN's [Virtual Expo](#) is a web-based resource that brings together lymphatic-related manufacturers, distributors, schools, pharmaceutical companies, and accessory businesses in one place to offer solutions and perspectives for patients and therapists alike. It allows patients and professionals 24/7 access to available treatments and services.

LE&RN is at the forefront of making lymphatic research a priority with the [National Institutes of Health](#) and with both local and national politicians.

LE&RN succeeded in having the FY2021 Congressional Appropriations Bill call for [NIH to Establish a National Commission on Lymphatic Diseases](#).

LE&RN further succeeded in its Congressional request that the [CDC be funded to award chronic disease awareness competitive grants](#) where “lymphatic diseases” was the only specific condition mentioned.

LE&RN has established an [International Biennial Conference \(the Lymphatic Forum\)](#) focused on lymphatic research.



“Thank you for your dedicated efforts, as well as those of Kathy Bates on behalf of LE&RN, to promote our common objective for advancing research on the lymphatic system and related diseases. **We look forward to continuing future work with LE&RN as a strong research partner.**”

–Francis S. Collins, M.D., Ph.D.

Director of the National Institutes of Health

#### Educational Impact:

- Over 100 LE therapist scholarships
- Over 150 young investigator conference scholarships
- More than 500 patient questions answered in *Ask the Experts*
- Over 150 Livestream Symposiums
- More than 400 newsletters
- Up to 20 company profiles in LE&RN's Virtual Expo

#### WHERE WE ARE GOING/ WHO WILL BENEFIT

LE&RN acknowledges the ongoing and urgent need to educate medical professionals, and as such is creating learning modules that the organization is bringing to hospitals across the country. Only when hospitals, doctors, nurses, and therapists are knowledgeable will they be able to diagnose and provide patients with LD with the right treatment.

#### FINAL POINT

Educating and increasing awareness of LD and LE among doctors, patients, and the public at

large will lead to the commitment of resources and research necessary for discovering effective treatments and ultimately, cures. 🌱

## PROGRAMS

#### RESEARCH

LE&RN seeks to accelerate prevention, treatments, and cures through research.

#### WHY RESEARCH?

The cures and treatments of tomorrow are tied to the research we do today. However, lymphatic diseases such as lymphedema and lipedema are under-researched, which leads to few treatments. As a result, medical schools do not properly educate future doctors about lymphatic diseases, which leads to many patients with these diseases going undiagnosed and suffering from a lifetime without proper treatments or hope for a cure. This is propagated by medical researchers who continue to focus their efforts elsewhere as long as there is limited research funding prioritized on lymphatic diseases.

One of LE&RN's first research initiatives and successes was the establishment of the biennial **Gordon Research Conference Series** devoted to Molecular Mechanisms in Lymphatic Function and Disease. In 2016, LE&RN's Spokesperson, Academy Award-winning actress Kathy Bates, was a featured speaker on the first patient panel in the history of the GRC.

LE&RN has awarded dozens of postdoctoral research fellowships to the world's leading universities for over a decade, putting lymphatic diseases on the radar in the medical community, in academia, in government, and with pharmaceutical companies.

Dr. Stanley Rockson was instrumental in establishing the **International Lymphatic Disease and Lymphedema Patient Registry & Biorepository** at Stanford University as a resource

to stimulate research and support clinical trials and drug development. He also launched LE&RN's journal, **Lymphatic Research and Biology**, the only peer-reviewed journal in the field, providing the forum for the exchange of cutting-edge scientific developments in lymphatic science and medicine.

In 2019, LE&RN established a lymphatic researcher database that is accessible and searchable by all 27 NIH Institutes and Centers.

LE&RN secured ongoing Congressional and National Institutes of Health (NIH) support for lymphatic research.

Research Impact:

- 22 research fellowships
- 55 young investigator research poster awards
- Over 100 researcher travel scholarships to conferences



*Dr. Anthony Fauci, NIAID Director (National Institutes of Health), Kathy Bates and LE&RN CEO William Repicci at the 2017 Research!America Awards where Dr. Fauci and Ms. Bates were both honored, Washington, DC.*






LE&RN Spokesperson Kathy Bates gives the keynote address at the twentieth annual American Society of Breast Surgeons Meeting; Dallas, Texas, May 2019.

- Over 700 research articles published in LE&RN's peer-reviewed journal
- 2000 biorepository samples
- 1000 Patient Registry members

## WHERE WE ARE GOING/ WHO WILL BENEFIT

As interest in lymphatic research is expanding, government funding is being curtailed due to budget cuts. LE&RN has the ambition to expand its fellowship program to ensure that it is cultivating a new generation of researchers that will revolutionize medicine in the future. These breakthroughs will ultimately lead to the prevention, treatments, and cures that patients worldwide need and deserve.

## FINAL POINT

**Lymphatic diseases such as LE and LI are life sentences.** Only research can provide hope that quality of life can be restored. The possibilities to impact public health globally through lymphatic research are vast. 

# PROGRAMS

## ADVOCACY AND NETWORKING

*Through several outreach programs and through legislative advocacy efforts, LE&RN is building an extensive network of participants and partners to advance advocacy.*

## WHY ADVOCACY AND NETWORKING?

Successes in bringing LD to the forefront of global attention are tied to two events: unrelenting advocacy on the part of the patients and their networks; and the availability of treatments that give the medical community a reason to invest themselves in the disease.

To this end, **LE&RN has established U.S. State Chapters and International Chapters.**

Each Chapter is the gateway to the lymphatic community and serves as a platform where patients can connect with one another through support groups, with therapists, and at treatment centers.



LE&RN has engaged celebrities to help lead and bring visibility to this fight. **Academy Award-winning actor Kathy Bates became LE&RN's National Spokesperson in 2015.** Ms. Bates has LE in both arms as a result of a double mastectomy. LE affects up to 30% of breast cancer survivors. Since she joined LE&RN, Ms. Bates has lectured at conferences including at the National Institutes of Health, American College of Phlebology, and American Cancer Society. She has also told the story of LD in countless print publications.

LE&RN's outreach expands to national audiences and it has aired stories on "CBS Sunday Morning," "Dr Oz," "USA Today," "NIH Medline Plus," "People Magazine," WebMD," "The Doctors," "The Wendy Williams Show," and a host of other media outlets.

As a result, LE&RN has established **The Face of Lymphedema Campaign** that has brought thousands of new advocates to this cause. It has also resulted in LE&RN establishing an **Honorary Board** that now includes Dame Judi Dench, actors Patricia Clarkson and Steve Guttenberg, Bravo Network's Andy Cohen, and Olympic Gold Figure Skating Champion Sarah Hughes.

Events such as LE&RN's annual **Walk to Fight Lymphatic Diseases**, which occur across the U.S. and globally, connect patients and their families

with supporters, and raise awareness with the public at large.

With the support of the U.S. Senate, LE&RN established an annual **World Lymphedema Day®** on March 6 to be a time when events, lectures, and legislative proclamations put these diseases center stage.

Network and Advocacy Impact:

- National and Global Walks
- Hundreds of patient stories told
- 25,000 Facebook fans
- 34 corporate sponsors
- Over 20 State and International chapters

## **WHERE WE ARE GOING/ WHO WILL BENEFIT**

LE&RN has petitioned the World Health Organization to make LE the focus of World Health Day.

**LE&RN achieved a major milestone** with success in having the FY2021 Senate Appropriations Bill call for the establishing of a **National Commission on Lymphatic Diseases**. The bill encourages the Director of NIH "To establish a National Commission on Lymphatic Diseases to explore and make recommendations on the ongoing expansion and coordination of lymphatic disease




"My mom has lymphedema and so, like all affected families, **I feel that I have lymphedema.** And that's why I support LE&RN in creating the awareness that will lead to a cure."

—Steve Guttenberg, Actor

research NIH-wide.” This victory is the culmination of intense years of lobbying by LE&RN and many committed activists, particularly the tireless work of LE&RN National Spokesperson Kathy Bates.

## FINAL POINT

To succeed at making LD a global priority will require a sustained commitment by those in the political arena, the medical profession, as well as the community ranging from patients and their families to advocates and philanthropic supporters. Together they can increase awareness, inform and influence policies and practices, and fund research to discover new treatments and cures. 

## RECENT TIMELINE

In 2013, LE&RN embarked on a monumental plan. Capitalizing on the success of the first fifteen years, the organization rebranded itself to reflect an expanded mission. Its new name made it clear that education and advocacy became equal partners with its research agenda. From a field led by a few lone voices, a movement started that would change the world.

## 2021 & BEYOND

Moving forward, the focus is on building worldwide networks that foster cure-focused research, physician education, and Centers of Excellence so that no case of lymphatic disease goes untreated.

## EDUCATION

For patient care to evolve, physicians need to become educated about these diseases and their treatments. LE&RN will need dedicated staff to continue to promote its [Physician CME in Lymphatic-Vascular Disease Diagnosis & Treatment](#), with collaboration with AVLS (American Society & Lymphatic Society), ASBrS (American Society of Breast Surgeons), American Venous Forum, and numerous other aligned physician groups.

LE&RN's [Centers of Excellence in the Diagnosis and Treatment of Lymphatic Diseases](#) is a transformational program, which is establishing care centers around the world to meet the need of those living with lymphatic diseases. This program was established through a generous grant by the Stavros Niarchos Foundation in 2020.



**“For years I have suffered alone, in silence, with this disease. I feel embarrassed and deeply ashamed of what lymphedema has done to my body. I am beginning to accept, with the help of those closest to me, that I have nothing to be ashamed of. I feel so moved that a community of people with lymphedema has surfaced and is demanding to be heard-putting voices and faces to a disease people know so little about. I know that part of me will always maintain the hope for answers. Awareness is a very critical step in that journey forward.”**

–Dara M., Patient, Buffalo, NY

With more than 45 institutions now designated as Centers or applying for Center Status, additional support staff is needed to coordinate this program and the patient chapters associated with each Center.

## RESEARCH

**Cures come from research. Research requires funding.** LE&RN is committed to awarding fellowships to post-doctoral researchers from the world's leading lymphatic laboratories. In addition, to bring the best and brightest young researchers into the field, LE&RN seeks to expand its scholarship program.

Researchers need tools to find cures. A new Director position is needed to oversee the International Patient Registry & Biorepository Coordinator. This is necessary to grow its number of bio samples, get patients registered, and link to labs internationally.

## ADVOCACY & NETWORKING

LE&RN has established **World Lymphedema Day®**, which is now a global phenomenon. A Project Director with a dedicated budget is needed to promote and coordinate this event worldwide.

Connecting the world means expanding LE&RN's **Chapters** globally. It also means establishing State and Regional Chapters in the U.S. Capitalizing on this momentum requires a dedicated budget and staff-associate.

LE&RN's **Lobby Days** now bring hundreds of advocates from around the world to Washington, DC where they meet with their legislators and where LE&RN's agenda is presented to the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), Veterans

Administration (VA), and others. It is critical that we have funding to maintain and grow this activity and the expense of a DC Government Relations Firm.

## 2022–2024

### EDUCATION

- Hire Co-Director of Centers of Excellence Program
- Expand and promote LE&RN's CME in Lymphatic-Vascular Disease Diagnosis & Treatment
- Produce 20 Scientific Livestream Symposiums
- Publish 24 newsletters and dozens of breaking news e-blasts

### RESEARCH

- Award 10 two-year post-doctoral research fellowships
- Acquire up to 200 new biorepository samples and expand the Patient Registry by 400 patients
- Expand research staff to 2 full-time positions
- Award 20 scholarships and eight poster awards for young investigators attending key lymphatic conferences



*Dr. James Madara, CEO of the American Medical Association (AMA), and LE&RN Spokesperson Kathy Bates at 2016 LE&RN/AMA Roundtable, Chicago, IL.*

## ADVOCACY & NETWORKING

- Award up to 60 institutions a LE&RN Centers of Excellence in LD designation and establish patient oversight chapters at each institution.
- Expand Washington, DC Lobby Days and Rally to include thousands of advocates who meet with our legislators
- Roll out PSA Ad Campaign with Kathy Bates to expand awareness
- Establish a 24-hour patient HELPLINE with dedicated staff
- Expand International Chapters with full-time staff support
- Hire a Director of Development and Outreach Associate



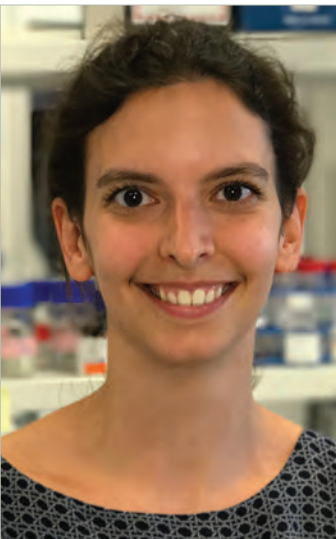
*LE&RN Youth Ambassador Emma Detlefsen introduced at 2017 Research!America Awards, Washington, DC.*



# THE OPPORTUNITY

Listed here are LE&RN’s fundraising priorities for the next two years, which will enable LE&RN to realize its strategic growth plan in the U.S. and internationally.

<b>Two-Year Statement of Need</b>	<b>\$2,177,000</b>
<b>Ongoing Program Support</b>	<b>\$ 350,000</b>
<b>Education</b>	<b>\$ 422,000</b>
Update CME Physician Certification Program	50,000
22 Livestream Symposiums	22,000
Patient Help Line	150,000
Center of Excellence Staff	200,000
<b>Research</b>	<b>\$ 905,000</b>
6 Post Doctoral Research Fellowships	700,000
Biorepository Tissue Sample Acquisition	40,000
International Patient Registry & Biorepository Coordinator	125,000
40 Young Investigator Scholarships	40,000
<b>Advocacy &amp; Networking</b>	<b>\$ 500,000</b>
State and International Chapter Expansion	150,000
World Lymphedema Day® Program Director	150,000
PSA Ad Campaign With Kathy Bates	200,000



**"Events like the Lymphatic Forum are essential.**  
They provide the opportunity to hear and learn about a wide variety of different aspects of the lymphatic field. This enables us researchers to share ideas, to have fruitful discussions and to learn to look at our own project from different perspectives. **During this meeting you can feel that you are part of a well-connected and supporting community,** unified in trying to elucidate one by one, the missing pieces of knowledge of the lymphatic world."  
–Samia Bachmann, Institute of Pharmaceutical Sciences, Zurich

# WHO IS INVOLVED

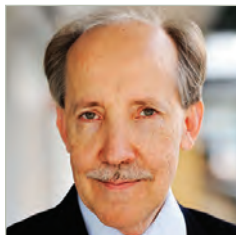
For a full listing of LE&RNs Leadership Team, please visit: [lymphaticnetwork.org/about/leadership-team/](http://lymphaticnetwork.org/about/leadership-team/)



Stanley G. Rockson,  
M.D., FACP, FACC  
Stanford University  
Founding Chair of Scientific &  
Medical Advisory Council



William Repicci  
President & CEO



Kari Alitalo, M.D., Ph.D.  
Finnish Academy  
of Sciences  
Scientific & Medical  
Advisory Council



Kathy Bates  
National Spokesperson and  
Chair of the Honorary Board



Peter S. Mortimer, M.D.  
St. George's Hospital,  
London  
Scientific & Medical  
Advisory Council



Dame Judi Dench  
Honorary Board



Mihaela Skobe, Ph. D.  
Mount Sinai Hospital  
Scientific & Medical  
Advisory Council



Steve Guttenberg  
Honorary Board



Joseph Dayan, M.D.  
Memorial Sloan  
Kettering  
Board of Directors



Wendy Williams  
Honorary Board



Rick Petty  
Board of Directors



Nancy Gray, Ph.D.  
Gordon Research  
Conferences  
Leadership Council

# WHO IS INVOLVED





Images from LE&RN's Global Virtual LymphWalk, April 17, 2021.



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