# Lymphatic Education & Research Network

www.LymphaticNetwork.org

## INTERNATIONAL CAMPAIGN TO FIGHT LYMPHATIC DISEASES & LYMPHEDEMA

Since 1998, LE&RN has been dedicated to fighting lymphedema (LE) and lymphatic disease (LD). The World Health Organization estimates that over 150 million people worldwide have secondary lymphedema, while primary lymphedema affects an additional 1 in 300 live births. Nearly 1.4 billion people in 73 countries are threatened by lymphatic filariasis, commonly known as elephantiasis. Over 120 million people are currently infected, with 40 million disfigured and incapacitated by the disease.

The Centers for Disease Control (CDC) warns that the incidence of secondary lymphedema among cancer survivors is 20–40%. Lymphedema is estimated to affect up to 10 million Americans. This is more than AIDS, Parkinson's disease, Muscular Dystrophy, Multiple Sclerosis and ALS combined. The continuum of diseases impacted by the lymphatic system includes heart disease, AIDS, diabetes, rheumatoid arthritis and cancer metastasis. Yet, lymphatic diseases routinely go undiagnosed and untreated, and research is grossly underfunded. Together, LE&RN and its worldwide members are determined to change this through education, research and advocacy.

#### **EDUCATION**

- International Livestream Symposium Series for patients, researchers and medical professionals
- Scholarships for lymphedema therapists
- International Scholarship Awards for young research investigators in lymphatics
- Monthly educational newsletters and multi-media presentations
- Worldwide access to the field's top authorities through Ask the Experts web feature

#### **RESEARCH**

- International Research Fellowship Awards
- The LE&RN International Lymphatic Disease & Lymphedema Patient Registry & Tissue Bank
- Lymphatic Research & Biology (the world's only peer review lymphatic journal)
- NIH Collaboration & research funding initiatives

#### **ADVOCACY**

- International chapters
- Celebrity spokesperson engagement
- Established World Lymphedema Day<sup>™</sup> on March 6th to promote events worldwide that fight lymphatic diseases
- Political Initiatives focused on research, education, and standard of care



### TO WIN A FIGHT, YOU FIRST NEED TO JOIN IT



Academy Award-winning actress Kathy Bates, LE&RN's spokesperson.

"I'm KATHY BATES. I had a double mastectomy two years ago and as a result I have lymphedema in both arms. If we want to win this fight against lymphedema and lymphatic disease, we need to stand together and educate the world. Join me. I urge you to become a member of LE&RN."

#### We will never cure lymphedema and lymphatic disease if we stay invisible.

We need to stand together and we need to have our friends and family in this fight as well. Lymphatic disease and lymphedema need to become an international priority. The days of suffering in silence are behind us.

Join LE&RN in this fight at LymphaticNetwork.org

And plan or join an event for World Lymphedema Day, March 6.

Visit LymphaticNetwork.org/wld/

#### **Learn More About Lymphatic Diseases**

**Lymphatic Continuum (LC)** refers to the continuum of diseases impacted by the lymphatic system including heart disease, AIDS, diabetes, rheumatoid arthritis, and cancer.

Lymphatic Filariasis (LF) threatens 1.4 billion people in 73 countries. Commonly known as *elephantiasis*, 120 million are currently infected by this mosquito-carrying parasitic disease. Over 40 million of those affected by LF are disfigured and incapacitated by the disease.

LE Lymphatic Continuum of Diseases

LF Lymphatic Filariasis

LM Lymphatic Malformations

Lipedem

Lymphedema (LE) is a chronic, debilitating lymphatic disease that results in disfiguring swelling in one or more parts of the body due to a damaged lymphatic system.

WHO estimates over 170 million people suffer from LE worldwide. The swelling is caused by a combination of lymph stagnation and the structural alterations in the tissues. Lymphedema can be genetic or inherited (Primary) or it can occur as a consequence of a surgical procedure, infections, radiation therapy, or other forms of physical trauma (Secondary).

**Lymphatic Malformations (LM)** are rare, non-malignant masses consisting of fluid-filled channels or spaces caused by the abnormal development of the lymphatic system. LM is usually apparent at birth or by two years of age and most commonly affects the head and neck.

**Lipedema (LI)** is an adipose tissue disorder or a lipid metabolism disorder that affects approximately 11% of women, often in the hips and legs, but also in the upper arms. Lipedema fat is relatively unresponsive to diet and exercise. Lipedema is both an excess buildup of fat cells in a particular area, and the expansion of those fat cells.

