

**STATEMENT OF**  
**KATHY BATES**  
**NATIONAL SPOKESPERSON**  
**LYMPHATIC EDUCATION & RESEARCH NETWORK**  
**REGARDING**  
**FISCAL YEAR 2020 APPROPRIATIONS FOR THE**  
**NATIONAL INSTITUTES OF HEALTH AND CENTERS FOR DISEASE CONTROL**  
**AND PREVENTION**  
**SUBMITTED TO THE**  
**HOUSE COMMITTEE ON APPROPRIATIONS**  
**SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION,**  
**AND RELATED AGENCIES**

**April 9, 2019**

**Key Recommendations:**

- 1) Provide the National Institutes of Health (NIH) with \$41.6 billion for FY 2020 and advance lymphatic disease research by expanding resources and encouraging better coordination among relevant institutes and centers
- 2) Establish a National Commission on Lymphatic Disease Research at the NIH to identify emerging opportunities, challenges, gaps, structural changes, and recommendations on lymphatic disease research
- 3) Provide the Centers for Disease Control and Prevention (CDC) with \$7.8 billion for FY 2020 and enable programmatic activity on lymphatic disease education and public awareness

Chairwoman DeLauro, Ranking Member Cole, and distinguished members of the Subcommittee, thank you for the opportunity to appear before you as you consider FY 2020 appropriations for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).

My name is Kathy Bates, and I have lymphedema. I was diagnosed with breast cancer almost 7 years ago and had a double mastectomy. My surgeons felt it necessary to remove 19 lymph nodes from my left armpit and 3 from my right. I am profoundly grateful to the doctors who cured me of cancer, but the cost of that cure means I am forced to live with this incurable disease for the rest of my life.

#### ABOUT LE&RN

I sit before you today as the National Spokesperson for the Lymphatic Education & Research Network, also known as LE&RN. Our mission is to fight lymphatic diseases and lymphedema through education, research and advocacy. With chapters throughout the world, LE&RN seeks to accelerate the prevention, treatment and cure of these diseases while bringing patients and medical professionals together to address the unmet needs surrounding lymphatic diseases.

#### ABOUT LYMPHEDEMA AND LYMPHATIC DISEASES

The lymphatic system is a circulatory system that 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. Lymphedema (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. Stanford University estimates that up to 10

million Americans have lymphedema. This represents more Americans than those living with AIDS, Multiple Sclerosis, Parkinson's disease, Muscular Dystrophy and ALS – combined. The World Health Organization puts the global number of people with this disease at 250 million. There is no cure. There is no approved drug therapy. And there are currently only three drug studies worldwide seeking a treatment. Psychosocially bruised by a disease that leaves us deformed, we do our best to hide our lymphedema. We are currently isolated and alone.

Lymphedema is an equal opportunity disease, affecting women, men and children alike. Many are born with congenital or hereditary lymphedema. Others, like our veterans, get the disease as a result of physical trauma, bacterial infection, or as result of exposure to burn pits. Like seven million other Americans, I developed lymphedema after I was treated for cancer. In my case, within a week of having a double mastectomy, I began to feel the symptoms of the disease: chronic swelling in my arms, pain, and loss of mobility. I learned that I could now expect a lifetime of severe bacterial infections called cellulitis, which can prove fatal. I learned that those of us with LE faced a lifetime of time-consuming daily care regimens. These include manual lymph drainage massage, wrapping oneself in compression garments and using a pneumatic pump to control the swelling. Forever. Compression garments aren't even covered by Medicare. We are working to expand access through the Lymphedema Treatment Act, and we are hopeful this bill will pass this year. But it is clear that this community deserves more options.

Lymphedema is an ignored disease. A study concluded that physicians are currently getting an average of only 15-30 minutes of study on the lymphatic system in their entire medical training. This leaves them ill-prepared to diagnose the disease. Misdiagnosis leads to improper treatment. Those who are diagnosed find it difficult to find certified lymphedema therapists. Few medical centers exist that are prepared to address lymphatic diseases. Surgeons are

experimenting with treatment that could alter the course of the disease. However, the necessary basic research is not being done to inform their procedures. And currently, Medicare and Medicaid do not cover some of the basic treatment needs of these patients – such as compression garments, which we must all wear daily.

### FY20 APPROPRIATIONS RECOMMENDATIONS

It is time for a challenge worthy of our great country. We ask that within 20 years, we will make lymphedema a truly treatable disease. To reach this goal will require a commitment to important medical research. LE&RN joins the broader medical research community in thanking Congress for continuing to provide the National Institutes of Health with proportional and sustainable funding increases over the past several fiscal years, and we ask you all to continue to prioritize these activities by providing at least a \$2.5 billion funding increase for FY 2020 to bring NIH's budget up to \$41.6 billion.

We also urge the Subcommittee to work to expand and advance the lymphatic disease portfolio at the NIH. In late 2015, the NIH hosted a Lymphatic Symposium, where experts in the field identified a scientific roadmap that could build the research portfolio up to a level of at least \$70 million annually over subsequent years by funding meritorious grants on critical topics. In an effort to further support and enhance emerging lymphedema and lymphatic disease research activities, we ask the Subcommittee to encourage further collaboration among relevant institutes and centers conducting research in this area. We also call on the Subcommittee to work with your colleagues to establish a National Commission on Lymphatic Disease Research, which can thoroughly examine the portfolio and make recommendations on how best to advance this emerging scientific area under NIH's current structure. Currently, the National Institutes of Health spends approximately \$25 million annually on lymphatic research, and only \$5 million of

this is dedicated to clinical lymphedema research. Experts state with confidence that there is no other disease affecting more Americans that receives so little attention. It must also be noted that study of the lymphatic system is poised to bring miracles for a host of diseases that are part of the lymphatic continuum: obesity, heart disease, diabetes, Rheumatoid arthritis, cancer metastasis, AIDS, Crohn's disease, lipedema, and a host of other diseases. Recent research discovered lymphatics surrounding the brain, which now has us studying its impact on Alzheimer's disease and multiple sclerosis.

LE&RN also joins the public health community in asking Congress to provide the Centers for Disease Control and Prevention (CDC) with \$7.8 billion through FY 2020 and to establish funding to increase awareness, education, and surveillance of lymphatic diseases. The CDC's National Center for Chronic Disease Prevention and Public Health Promotion has programs dedicated to improving surveillance, physician education, and public awareness for several chronic diseases. We encourage the Subcommittee to establish merit-based programmatic activity in this area that will allow CDC to work with stakeholder organizations to expand important initiatives on lymphedema and lymphatic diseases. Formal study of the lymphatic system and of lymphatic diseases is virtually nonexistent in the current curricula of U.S. medical schools, and misinformation routinely leads to misdiagnosis and under-treatment. This delay and misdirection of treatment results in irreparable physical and psychosocial harm to patients suffering from these already debilitating diseases. CDC can help to address this lack of public and provider awareness.

Thank you for the opportunity to testify before you today. LE&RN looks forward to working with you all to advance medical research and public health activities that will improve patient outcomes for the members of our community suffering from these debilitating diseases.