



The Lymphatic Education & Research Network's (LE&RN) advocacy efforts remain a priority during the COVID-19 (coronavirus) pandemic. To maximize our grassroots efforts across the country during the current situation, a virtual **National Week of Action** is scheduled for **March 22-26th, 2021 as a kick off to our yearlong advocacy efforts.**

We need your active participation to educate Members of Congress about lymphatic diseases (LD), how LD affects you, and what Congress can do to support those living with diseases including lymphedema (LE), lipedema, lymphatic malformation and other lymphatic diseases.

We are urging you, and our entire community, to call and/or email Congressional representatives to discuss our policy priorities.

The LE&RN National Week of Action is designed to make it easy to ask your elected officials to support issues important to the LD and LE community.

Take Action:

- **Email** your Senators and Member of the House of Representatives to share your experience and ask them to help us (information on *the ask* provided below).
- **Call** the offices of your Senators and Member of the House to share your experience and ask them to help us (information on *the ask* provided below).

To find and contact your U.S. Senator:

1. Visit www.senate.gov.
2. Conduct a search using the **Find Your Senators** pull-down menu (select your state and click Go).
3. On the results page are links to Senator websites and links to an online contact form (forms vary by Senator).

To find and contact your U.S. Representative:

1. Visit www.house.gov.
2. Conduct a search using the **Find Your Representative** ZIP Code search box (enter your ZIP Code and click Go).
3. On the results page is a photo of your Representative, links to the Representative's website (shown as a small screen icon), an online contact form (shown as a small envelope icon), and a local map.
4. If your ZIP Code overlaps multiple congressional districts, the results page will include boxes for you to enter your ZIP Code+4 or street address to find your Representative.

Lymphatic Education & Research Network
Legislative Agenda
117th Congress, 1st Session

Legislative and Policy Priorities

Medical Research

- **Please support the implementation of a National Commission on Lymphatic diseases.** Lymphatic disease research is currently underfunded by the NIH. A Commission is needed to determine the need for lymphatic research NIH-wide as a response to the over twenty-seven million Americans living with incurable, progressive and debilitating lymphatic diseases such as lymphedema, lipedema and lymphatic malformation. Congress has directed NIH to create a National Commission on Lymphatic Diseases in FY2021 and we ask for continued support in its implementation.
- **Please include “lymphatic diseases” as a category eligible for study in the Department of Defense (DOD) Peer-Reviewed Medical Research Program (PRMRP) in FY 2022.** Lymphatic diseases disproportionately affect active duty service members and first responders, as these diseases often arise from trauma, bacterial infections, burn pit exposure, and as complications of cancer treatment.

Education and Awareness

- **Please provide \$5,000,000 for a Chronic Disease Education and Awareness Program at the Centers for Disease Control and Prevention (CDC).** Formal study of the lymphatic system and of lymphatic diseases is virtually nonexistent in the current curricula of U.S. medical schools. Routine misdiagnoses lead to prevalent under-treatment of lymphatic diseases and lymphedema. Delay and misdirection of treatment often results in irreparable physical and psychosocial harm to patients. A CDC program focused on surveillance, provider education, and public awareness would increase diagnoses and improve patient outcomes.

Lymphedema Treatment Act

- **Please ensure access to treatment for patients with lymphedema by supporting the Lymphedema Treatment Act (2021 bill awaits being reintroduced).** Treatment options to manage lymphedema are extremely limited. This legislation when reintroduced would expand access to compression garments for Medicare beneficiaries suffering from this disease. We will reach out to all advocates once the LTA is reintroduced to provide the bill number and contact information for key legislative offices in this bipartisan effort.

ISSUE BRIEF – ASK #1

Support the implementation of a National Commission on Lymphatic Diseases and Support Meaningful Funding for Medical Research

Background:

The National Institutes of Health (NIH) forms the cornerstone of this nation's biotechnology industry. 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. In 2020, NIH's annual investment in all lymphatic diseases remains at approximately \$25 million, with only \$5 million of this dedicated to LE clinical research.

In fiscal year (FY) 2021, Congress funded NIH at \$42.9 billion, and directed NIH to create a National Commission on Lymphatic Diseases. Congress is again working through the appropriations process for FY 2022, and it is important to let legislators know we support consistent and predictable funding increases for NIH in the next appropriations cycle as well as the implementation of the National Commission. We support funding the NIH at \$46.1 billion in FY2022.

Talking Points:

- The National Institutes of Health supports research into LD and LE across a number of Institutes. We call on Congress 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.
- Without meaningful financial support, the development of treatment options will be delayed, and we will lose the next generation of young investigators to other fields.

Please note if your member is on the [House Committee on Appropriations](#) or [Senate Appropriations Committee](#) as they have the direct ability to [increase](#) NIH's funding.

ISSUE BRIEF – ASK #2
Support Lymphatic Disease Research through the Department of Defense

Background

Lymphedema and other lymphatic diseases disproportionately affect active duty service members and first responders, as these diseases often arise from trauma and as complications of cancer treatment. In order for “lymphatic diseases” to be listed as a condition eligible for study, it must be included in the Defense Appropriations Bill. For this to occur, there must be strong support for this action in both the House and Senate, particularly among key members of the House and Senate Defense Appropriations Subcommittees.

Talking Points

- “Lymphatic diseases” is not currently listed as a category eligible for study through the Department of Defense’s Peer-Reviewed Medical Research Program (PRMRP).
- Studies have shown that lymphatic diseases have increased incidence amongst active duty service members and first responders, as they often arise from trauma and as complications of cancer treatment.
- The lymphatic disease research community asks that your office contact your colleagues on the Defense Appropriations Subcommittee to communicate your support for this request.

Members of the Senate Department of Defense Subcommittee:

Senate Defense Appropriations Subcommittee Members

Jon Tester (D-Mont.), Chair	Richard Shelby (R-Ala.), Vice Chairman
Richard Durbin (D-Ill.)	Mitch McConnell (R-Ky.)
Patrick Leahy (D-Vt.)	Susan Collins (R-Maine)
Dianne Feinstein (D-Calif.)	Lisa Murkowski (R-Alaska)
Patty Murray (D-Wash.)	Lindsey Graham (R-S.C.)
Jack Reed (D-R.I.)	Roy Blunt (R-Mo.)
Brian Schatz (D-Hawaii)	Jerry Moran (R-Kan.)
Tammy Baldwin (D-Wis.)	John Hoeven (R-N.D.)
Jeanne Shaheen (D-N.H.)	John Boozman (R-Ark.)

ISSUE BRIEF – ASK #3

Support funding CDC Chronic Disease Education and Awareness Program at \$5,000,000

Background

There are significant opportunities for CDC to improve public health and lower healthcare costs through targeted awareness, physician education, and public health campaigns conducted in collaboration with stakeholder organizations and communities. The progression of many chronic diseases, including those with a sizable national impact, can be mitigated or reversed through the dissemination of proper health information. However, over recent years CDC has lacked the resources and flexibility to actively support critical and timely public health efforts in emerging areas of concern. Formal study of the lymphatic system and of lymphatic diseases is virtually nonexistent in the current curricula of U.S. medical schools. Routine misdiagnoses lead to prevalent under-treatment of lymphatic diseases and lymphedema. Delay and misdirection of treatment often results in irreparable physical and psychosocial harm to patients.

Talking Points

- The Chronic Disease Education and Awareness Program is intended to focus on surveillance, provider education, and public awareness which would increase diagnoses and improve patient outcomes.
- This program seeks to provide collaborative opportunities for chronic disease communities that lack dedicated funding from ongoing CDC activities. Such a mechanism allows public health experts at the CDC to review project proposals on an annual basis and direct resources to high impact efforts in a flexible fashion.

Please note if your member is on the [House Committee on Appropriations](#) or [Senate Appropriations Committee](#) as they have the direct ability to [increase](#) the program's funding.

SAMPLE PHONE CALL AND E-MAIL SCRIPT:

Good Morning/Afternoon,

My name is _____, and I live in _____ (city/state – *establishes that you are a constituent in their congressional district*).

I am an advocate with the Lymphatic Education & Research Network, an internationally recognized non-profit organization founded in 1998 to fight lymphatic diseases and lymphedema through education, research and advocacy.

Over twenty-seven million Americans suffer from lymphatic diseases such as lymphedema, lipedema and lymphatic malformation. Currently, there are no cures and few treatments for these diseases, which are progressive, deforming, debilitating and often shorten life-span. Lymphatic research also impacts research on cancer metastasis, heart disease, Alzheimer's, AIDS, Rheumatoid Arthritis, Multiple Sclerosis, Diabetes, obesity and a host of other diseases.

{Share your LD/LE experience. Be concise and let them know how your journey has affected your life. Consider developing 3 or 4 impactful statements or examples to share. You will not have time to share a timeline or story.}

I am calling today to ask for _____ (Name of Senator or Representative)'s help.

- **Please support the implementation of a National Commission on Lymphatic Diseases that was directed by Congress in FY2021.** NIH currently spends only \$25 million annually on lymphatic disease research and only \$5 million of this on clinical research of lymphedema. A Commission would determine the need for lymphatic research NIH-wide as a response to the over twenty-seven million Americans living with incurable, progressive and debilitating lymphatic diseases such as lymphedema, lipedema and lymphatic malformation.
- **Please include “lymphatic diseases” as a category eligible for study in the Department of Defense (DOD) Peer-Reviewed Medical Research Program (PRMRP) in FY 2022.** Lymphatic diseases disproportionately affect active duty service members and first responders, as these diseases often arise from trauma, bacterial infections, burn pit exposure, and as complications of cancer treatment.
- **Please provide \$5,000,000 for a Chronic Disease Education and Awareness Program at the Centers for Disease Control and Prevention (CDC).** Formal study of the lymphatic system and of lymphatic diseases is virtually nonexistent in the current curricula of U.S. medical schools. Routine misdiagnoses lead to prevalent under-treatment of lymphatic diseases and lymphedema. Delay and misdirection of treatment often results in irreparable physical and psychosocial harm to patients. A CDC program focused on surveillance, provider education, and public awareness would increase diagnoses and improve patient outcomes.

Please consider me a resource if you have any questions about lymphatic diseases or the Lymphatic Education & Research Network that I can answer or pass along to the national office staff. Thank you for your time and consideration.

Sincerely,

YOUR NAME
CITY, STATE