



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 **August 17-21, 2020**.

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 116th Congress, 2nd Session

LE&RN has a broad legislative agenda for which we advocate throughout the year. This includes support for the LTA and funding a CDC Awareness Program. However, this call to action is specific to two key agendas affecting our community that need your support.

Legislative and Policy Priorities

Medical Research

- **Please create 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, lipdema 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 2021.** 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.

ISSUE BRIEF – ASK #1
Support the creation 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) 2020, Congress funded NIH at \$41.6 billion, an increase of approximately \$2 billion over FY 2019. Congress is again working through the appropriations process for FY 2021, and it is important to let legislators know we support consistent and predictable funding increases for NIH in the next appropriations cycle.

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:

[Sen. Richard Shelby](#) (R-AL), Chair
[Sen. Mitch McConnell](#) (R-KY)
[Sen. Lamar Alexander](#) (R-TN)
[Sen. Susan Collins](#) (R-ME)
[Sen. Lisa Murkowski](#) (R-AK)
[Sen. Roy Blunt](#) (R-MO)
[Sen. Jerry Moran](#) (R-KS)
[Sen. John Hoeven](#) (R-ND)
[Sen. John Boozman](#) (R-AR)
[Sen. Lindsey Graham](#) (R-SC)

[Sen. Richard Durbin](#) (D-IL), Vice Chair
[Sen. Patrick Leahy](#) (D-VT)
[Sen. Dianne Feinstein](#) (D-CA)
[Sen. Patty Murray](#) (D-WA)
[Sen. Jack Reed](#) (D-RI)
[Sen. Jon Tester](#) (D-MT)
[Sen. Tom Udall](#) (D-NM)
[Sen. Brian Schatz](#) (D-HI)
[Sen. Tammy Baldwin](#) (D-WI)

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 create a National Commission on Lymphatic diseases.** 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, lipdema 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 2021.** 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 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