



Building Community • Giving Voice • Advancing Care



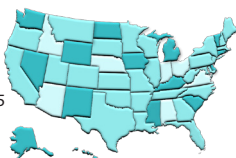
The **Lymphedema Advocacy Group (LAG)** is an all-volunteer advocacy organization in the United States. Executive Director Heather Ferguson founded LAG in 2010, after the birth of her twins, one of whom has primary lymphedema. The group's focus is the federal **Lymphedema Treatment Act (LTA)**. Passage of this bill is a critical step toward the group's mission to improve insurance coverage for lymphedema compression supplies.

This poster depicts the group's 11-year journey of building a nationwide grassroots effort and learning to navigate the American legislative system. Effective strategies include networking and coalition building, training and activating advocates to communicate with legislators, and promoting research findings projected to translate into a reduction in lymphedema-related healthcare spending.

The group has taken a bill about a little-known disease and turned it into the most broadly supported healthcare legislation in the United States Congress. The timeline represents LAG's landmark events and successful strategies. Other groups can use the timeline as a blueprint to guide community-building, giving voice, and advancing care.

#### State Teams.

We created regional **teams** of advocates in 2013, and by 2015 we had teams in all 50 states.



#### Advocacy Training.

In 2015, we created an Advocacy Training Committee to work closely with state team members to boost their skills, confidence, and effectiveness. Our **handbook** and webinars have prepared hundreds of advocates for thousands of congressional meetings.



#### Building Community

#### Stakeholders Endorsements/ Coalition Building.

What started with one person has grown to a **nationwide movement** with approximately 12,000 general members, 1,500 state team members, 14,000 followers on social media, and over 40 endorsements from national organizations.



#### First Major Stakeholders Joined in Support.



#### Lymphedema Advocacy Group's Inception.

The group was founded in 2010 by **Heather Ferguson**, with a board representing all aspects of the lymphedema community – patients, family members, clinicians, and industry members. Heather learned that insurance would not cover her son Dylan's garments. She responded by developing a list of about 40 friends and family members willing to advocate for him, and everything grew from there.



#### Lymphedema Lobby Days.

In 2010, twelve Lymphedema advocates, most of whom were founding members of LAG, made the first trip to Washington, DC, to raise support for the LTA. Since that time, our **Lymphedema Lobby Days** have become an annual event, and usually comprises about 100 people from around the country who collectively meet with hundreds of Congressional offices over one or two days. Many participants describe the experience as "life-changing" and one of the "most inspiring and empowering" things they have ever done.



#### Lymphedema Stories.

We began the **My Lymphedema Story** campaign during our first year of existence and have amassed over 1,000 of these deeply personal and often raw and emotional narratives. They are invaluable for helping others understand lymphedema's impact, and many patients have said their lymphedema journeys are very therapeutic to write about.



#### Educational Materials.

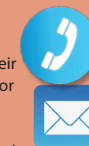
We have created numerous **educational resources**, some geared toward the general public, and others designed for lawmakers and staff. We have provided over 300,000 information cards free of charge to doctors and therapists, support groups, and anyone who wishes to help spread awareness. Two of our most popular full-page items are our "6 Things You May Not Know About Lymphedema" and "Lymphedema: Not One Disease" documents.



Current LTA Information Packet.

#### Advocacy Tools.

Many of our advocates tell us they have never contacted their members of Congress before or actively advocated for any cause, so providing **tools** that enable them to do so easily and effectively is essential. Advocates have sent over 45,000 emails to Congress through our website, many of which went to multiple offices, since each citizen-advocate is represented by three members of Congress. We also provide advocates with phone numbers and call scripts, and tools for advocating on social media and for sending letters to newspapers and media outlets.



#### Giving Voice

#### Virtual Lymphedema Lobby Days.

Due to the COVID-19 pandemic, meetings with congressional offices were moved online, which has facilitated even greater participation. In the future, we hope to offer both in-person and **virtual meeting options** and call scripts.



2009 2010 2011 2012 2013 2014 2015 2016 2017 2018 2019 2020 2021

111th Congress  
58 House Cosponsors

112th Congress  
92 House Cosponsors

113th Congress  
107 House Cosponsors

114th Congress  
261 House Cosponsors  
29 Senate Cosponsors

115th Congress  
385 House Cosponsors  
66 Senate Cosponsors

116th Congress  
386 House Cosponsors  
71 Senate Cosponsors

117th Congress (as of 12/12/2021)  
311 House Cosponsors  
68 Senate Cosponsors

#### First Time the LTA is Introduced.

Original lead sponsor Congressman Larry Kissell (NC-8) **introduced** the Lymphedema Treatment Act to the House of Representatives in 2010.



#### Progressive Support.

The Lymphedema Treatment Act has garnered more support in each successive session of Congress.

#### Congressman Dave Reichert serves as Lead Sponsor.

From 2014 through 2018, Representative Reichert (R-WA) **champions** the Lymphedema Treatment Act.



#### Senate Companion Bill is Introduced for the First Time.

Senate lead sponsor Maria Cantwell (WA) **introduced** the Lymphedema Treatment Act to the Senate in 2015.



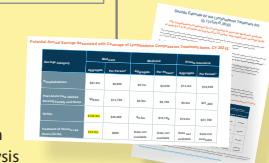
#### LTA Passes in the House.

In 2019, the Lymphedema Treatment Act was **passed** in the House of Representatives by our current lead House sponsor Jan Schakowsky (IL-9).



#### Savings Analysis.

In 2021 the Lymphedema Advocacy **compiled findings from various studies**. It then commissioned Avalere Health to estimate the potential savings in healthcare expenses through the enactment of the Lymphedema Treatment Act. Their analysis concluded that improved access to compression garments would save the federal government over \$130 - \$150 million per year through preventing lymphedema-related hospitalizations, with additional savings likely, and that state-based and private insurance plans would also see significant savings.



#### Advancing Care