LYMPHEDEMA ADVOCACY GROUP

Building Community • Giving Voice • Advancing Care

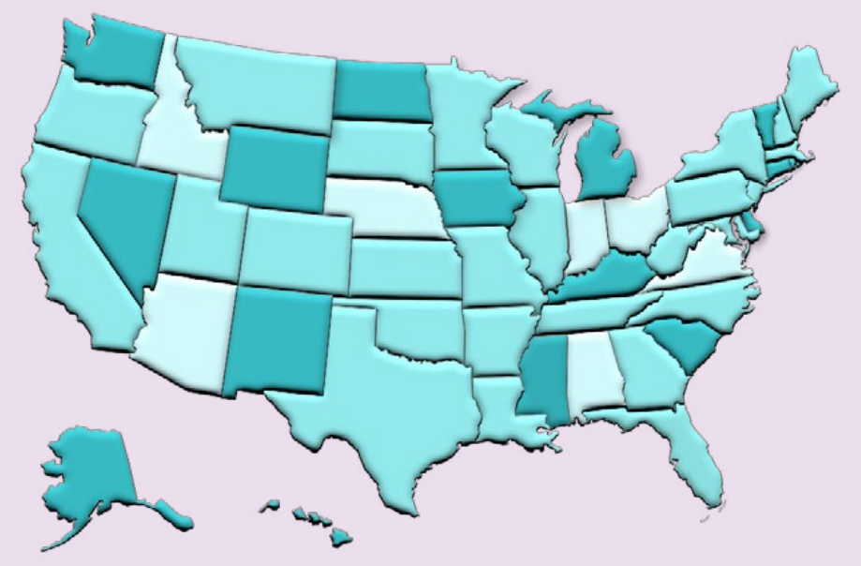
The **Lymphedema Advocacy Group** (LAG) is an all-volunteer patient-centered organization in the United States focused on improving access to care. Executive Director Heather Ferguson founded LAG in 2010, after the birth of her twins, one of whom has primary lymphedema.

This timeline depicts the group's 13-year journey of building a nationwide grassroots effort and learning to navigate the American legislative system. Key elements include networking, coalition building, training and activating advocates to communicate with legislators, and promoting research findings that demonstrate a reduction in lymphedema-related healthcare spending through better patient outcomes.

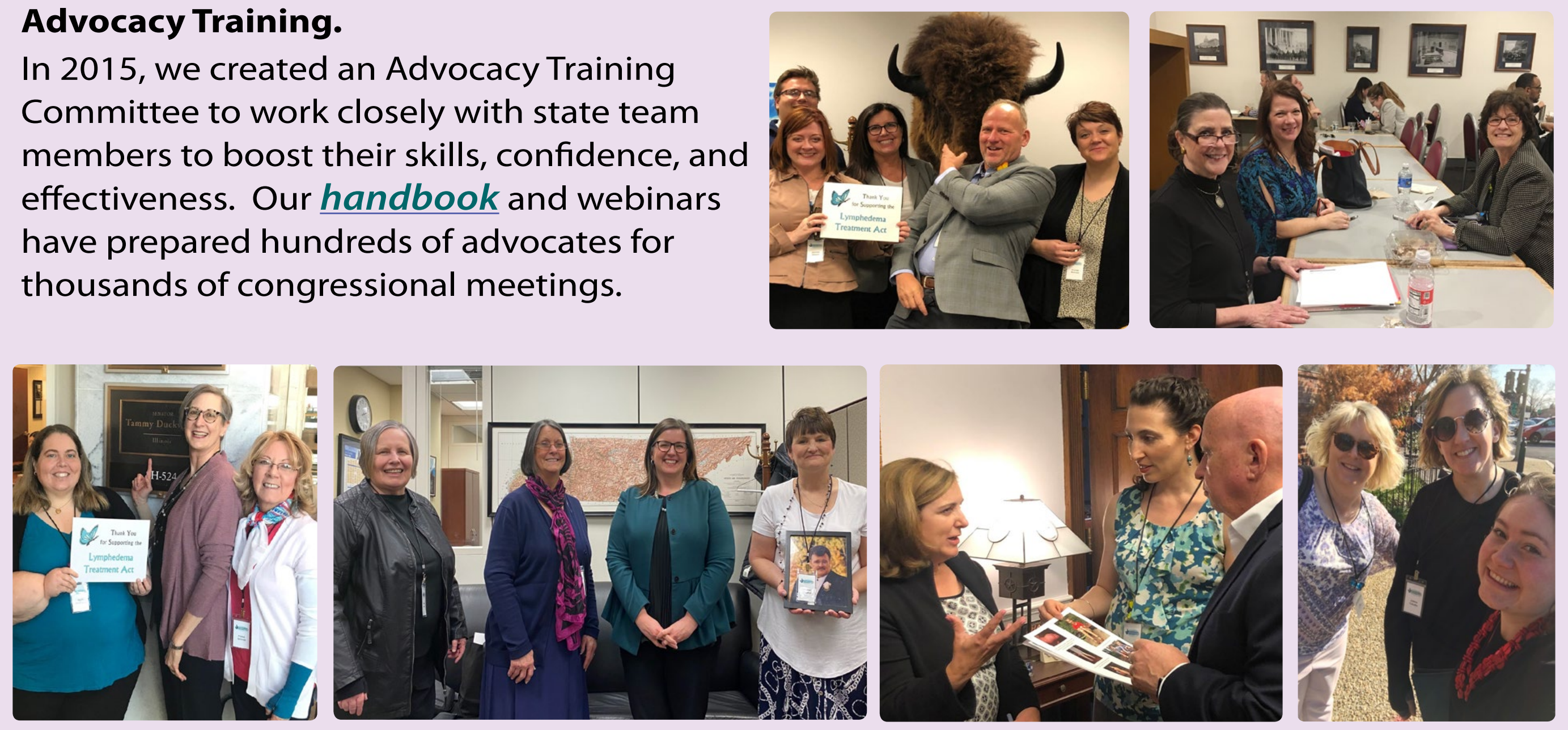
LAG's successful strategies have resulted in wide-spread improvements to insurance coverage for compression garments and supplies for millions of Americans. We are happy to share our timeline as a blueprint for community-building, giving voice, and advancing care. Learn more about us at *LymphedemaAdvocacyGroup.org*.

Building Community

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.



Stakeholders Endorsements/ Coalition Building.
What started with one person has grown to a ***nationwide movement*** with over 13,000 general members, 1,500 state team members, 14,000 followers on social media, and over 40 endorsements from national organizations.

Listening Sessions.
After the LTA was signed into law, key partners spoke with CMS to discuss all aspects of implementation.

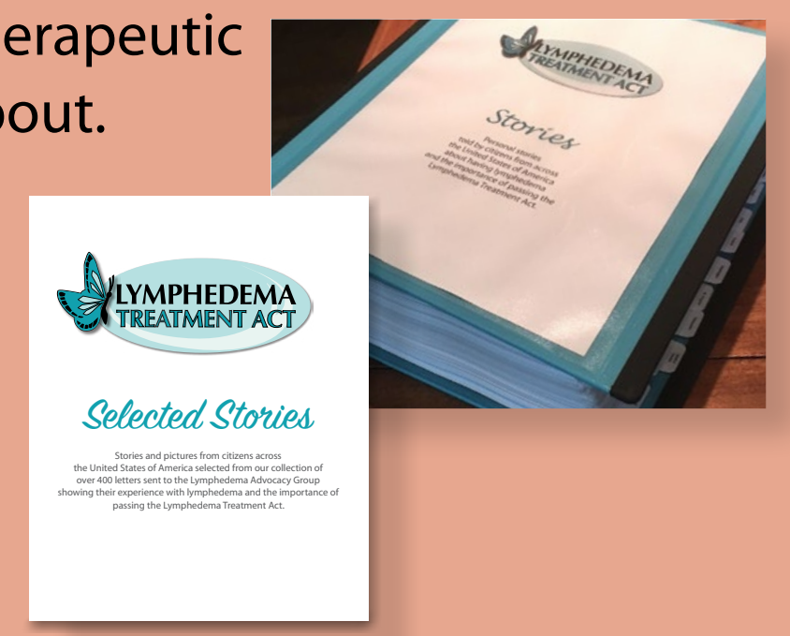
First Major Stakeholders Joined in Support.

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.

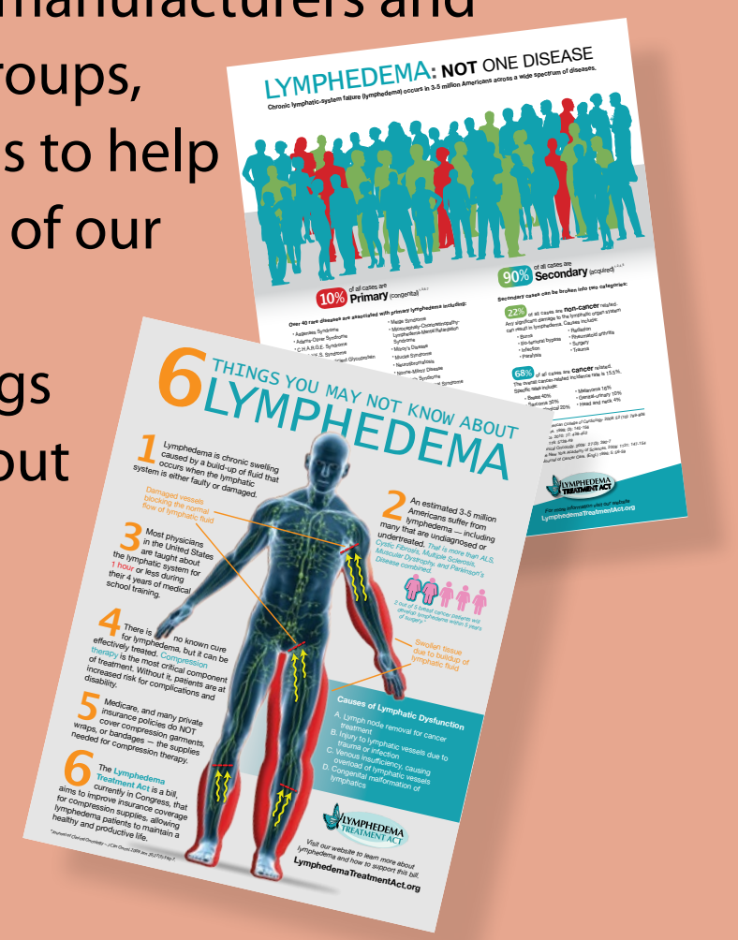
Giving Voice

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. From that point forward, until passage of the bill, our ***Lymphedema Lobby Days*** became an annual event comprised of about 100 people from around the country who met with hundreds of congressional offices over one or two days. Participants described the experience as "life-changing" and one of the "most inspiring and empowering" things they have 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.



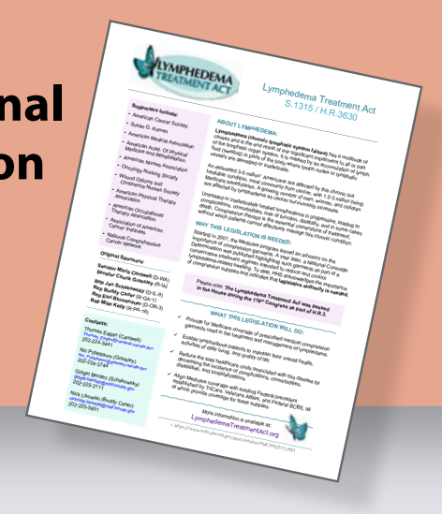
Educational Materials.
We have created numerous ***educational resources***, some geared toward the general public, and others designed for lawmakers and staff. As of 2024, we have provided over 400,000 information cards free of charge to doctors and therapists' offices, manufacturers and distributors, support groups, and anyone who wishes to help spread awareness. Two of our most popular full-page documents are "6 Things You May Not Know About Lymphedema" and "Lymphedema: Not One Disease."



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 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 provided advocates with phone numbers and call scripts, and tools for advocating on social media and for sending letters to newspapers and media outlets.

Virtual Lymphedema Lobby Days.
During the COVID-19 pandemic, meetings with congressional offices were moved online, which facilitated even greater participation. For any future advocacy, we plan to offer both in-person and ***virtual meeting options*** as well as call scripts.

117th Congressional LTA Information Packet.



Patient and Professional Feedback to CMS.
CMS was able to ***hear from key supporters*** before implemenation was finalized.

Congress	Years	Garnered support
111th Congress	2009 2010	58 House Cosponsors
112th Congress	2011 2012	92 House Cosponsors
113th Congress	2013 2014	107 House Cosponsors
114th Congress	2015 2016	261 House Cosponsors 29 Senate Cosponsors
115th Congress	2017 2018	385 House Cosponsors 66 Senate Cosponsors
116th Congress	2019 2020	386 House Cosponsors 71 Senate Cosponsors
117th Congress	2021 2022	385 House Cosponsors 74 Senate Cosponsors
118th Congress	2023 2024	New Coverage goes into Effect January 2024

LYMPHEDEMA TREATMENT ACT

Advancing Care

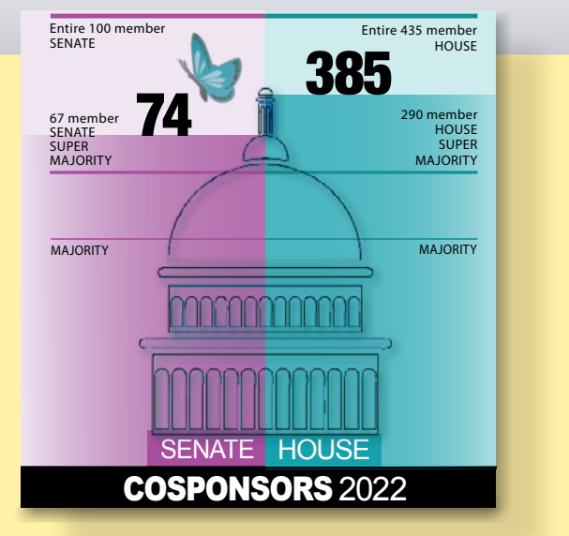
First Time the LTA is Introduced.
Original lead sponsor Congressman Larry Kissell (NC-8) ***introduced*** the Lymphedema Treatment Act to the House of Representatives in 2010.

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

Congressman Dave Reichert serves as Lead Sponsor.
From 2014 through 2018, Representative Reichert (WA-8) ***championed*** the Lymphedema Treatment Act.

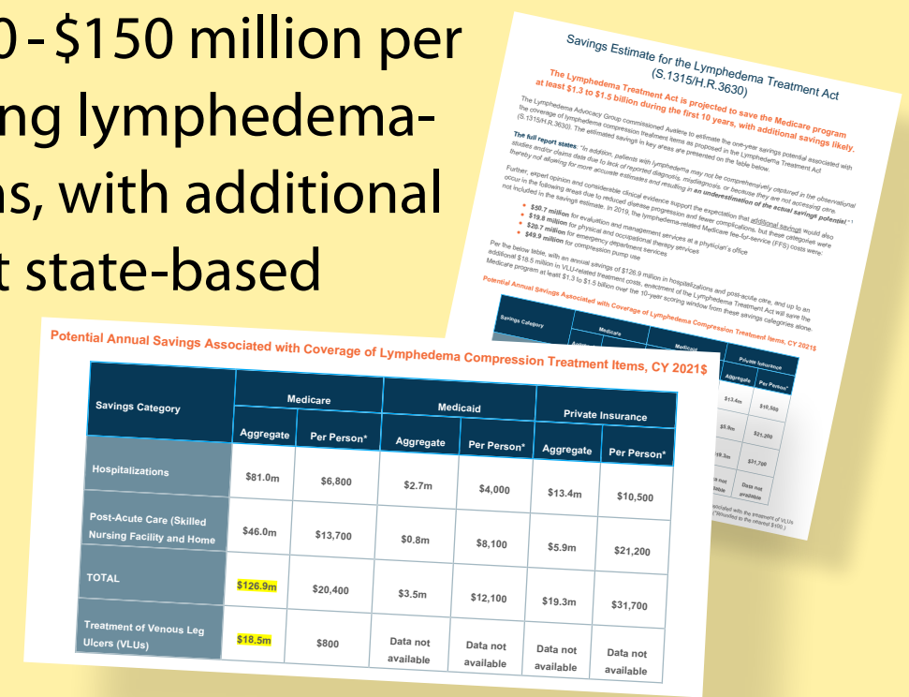
Senate Companion Bill is Introduced for the First Time.
Senate lead sponsor Maria Cantwell (WA) ***introduced*** the Lymphedema Treatment Act to the Senate in 2015.

High Level of Support.
From 2015 to 2022, the Lymphedema Treatment Act had more congressional cosponsors than any other healthcare bill.



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

Savings Analysis.
In 2021 the Lymphedema Advocacy Group ***compiled findings from various studies***. LAG then commissioned Avalere Health to estimate the potential savings in healthcare expenses through 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.



Savings Estimate for the Lymphedema Treatment Act (S.1315/H.R.3630)

Potential Annual Savings Associated with Coverage of Lymphedema Compression Treatment Items, CY 2021$

Savings Category	Medicare		Medicaid		Private Insurance	
	Aggregate	Per Person*	Aggregate	Per Person*	Aggregate	Per Person*
Hospitalizations	$81.0m	$6,800	$2.7m	$4,000	$13.4m	$10,500
Post-Acute Care (Skilled Nursing Facility and Home	$46.0m	$13,700	$0.8m	$8,100	$5.9m	$21,200
TOTAL	$126.9m	$20,400	$3.5m	$12,100	$19.3m	$31,700
Treatment of Venous Leg Ulcers (VLUs)	$18.5m	$800	Data not available	Data not available	Data not available	Data not available

Passed out of Committee.
In July 2022, the Lymphedema Treatment Act unanimously ***passed out of the Energy and Commerce Committee***.

CBO Score issued.

LTA Passes in the House.
In November 2022, the Lymphedema Treatment Act, championed by sponsors Jan Schakowsky (IL-9) and Buddy Carter (GA-1) ***passed in the House of Representatives*** with overwhelming bipartisan support.

Final Rule **released.**

LTA **enacted.**

Full Passage of the LTA, Bill Becomes Law.
In December 2022, the Lymphedema Treatment Act ***passed the Senate and House***.