



ANNUAL REPORT 2023

Lymphedema Advocacy Group

A 501 (c) (4) nonprofit corporation

Website: www.lymphedematreatmentact.org

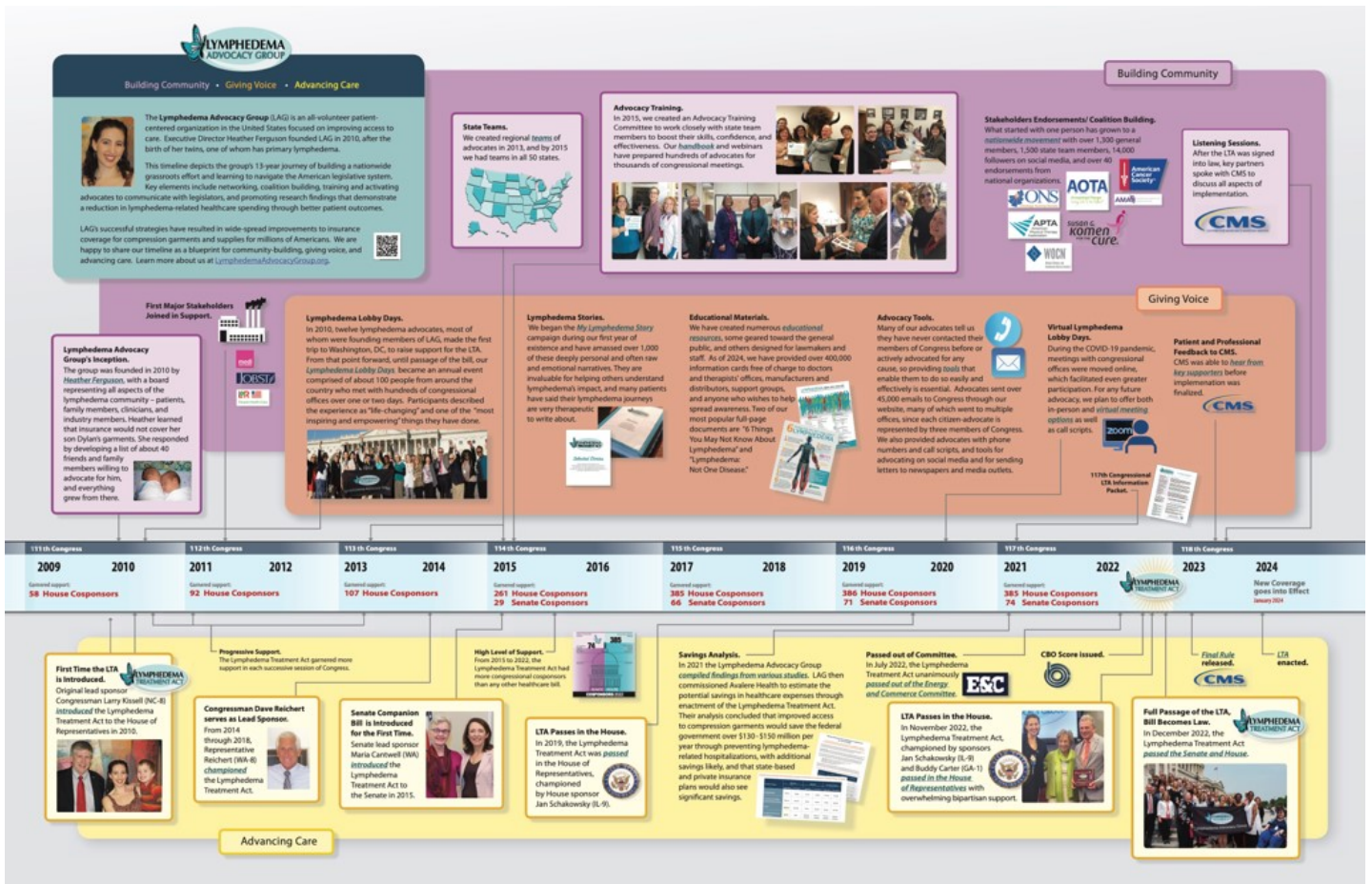


TABLE OF CONTENTS

Timeline	3
LYMPHEDEMA ADVOCACY DEFINED	4
Executive Director’s Comments	4
Mission	5
Objective	5
Highlights to Passage in the 117 th Congress	6
LEGISLATIVE SUMMARY	7
Timeline of Lymphedema Advocacy Group’s Lobbying Efforts	7
HOW THE LYMPHEDEMA TREATMENT ACT BECAME LAW	8
Building Community	8
Giving Voice	8
Advancing Care	8
Legislative Outreach	9
Implementing Legislation to Action in 2023	11
LYMPHEDEMA TREATMENT ACT RECAP	12
Bill Summary	12
Lymphedema Treatment Act Final Rule - Summary	12
Lymphedema Treatment Act Final Rule - Frequency	12
Lymphedema Treatment Act Final Rule - Coverage Requirements	12
Lymphedema Treatment Act Final Rule - Deductibles and Copay	13
BOARD CHAIR LOOKS AHEAD	14
Letter from the Board Chair	14
THE LYMPHEDEMA ADVOCACY GROUP	16
2024 Officers	16
Directors	16
In Memoriam	16

Timeline

The following graphic illustrates the steps taken to pass the Lymphedema Treatment Act over an almost 13 year period.



LYMPHEDEMA ADVOCACY DEFINED

Executive Director's Comments

Dear Lymphedema Patients, Caregivers, Advocates and Partners:

2023 ushered in an exciting period for the Lymphedema Advocacy Group. Nearly 13 years after the bill was first introduced, the Lymphedema Treatment Act was passed by Congress on December 23, 2022. With a mandated effective date of January 1, 2024, throughout the year we were busy partnering with the Centers for Medicare and Medicaid Services (CMS), other government agencies, and fellow stakeholder groups to implement the new coverage.

The Lymphedema Advocacy Group kicked off 2023 by being the first group to meet with CMS to communicate our priorities for the new coverage. We then assisted other stakeholder groups in preparing for their Listening Sessions with CMS, ensuring that each subsequent group addressed remaining education gaps. Additional meetings with government agencies included the Domestic Policy Council and the Office of Management and Budget.

We also engaged our community of advocates, culminating in over 700 public comments on the Proposed Rule, and were very proud that almost all the suggestions in the [Lymphedema Advocacy Group's comments](#) were incorporated into the Final Rule. The comprehensiveness of the new coverage reflects the strength of our advocacy and the importance of the patient voice in policy making.

Our leadership was recognized by the Oncology Nursing Society, who kindly awarded me their President's Award at their national conference on April of 2023. And by Voter Voice, a national advocacy tool platform, who featured the Lymphedema Advocacy Group in their annual report, noting our high level of advocate engagement and effectiveness.

More work lies ahead, but we entered 2024 confident that no goal in improving patient care is unattainable if we continue to work together and tackle each challenge with the same resilience and passion that the Lymphedema Advocacy Group has become known for.



A handwritten signature in black ink that reads "Heather Ferguson". The script is fluid and cursive.

Heather Ferguson
Founder and Executive Director
Lymphedema Advocacy Group

Mission

The Lymphedema Advocacy Group is an all-volunteer organization of patients, caregivers, healthcare professionals and industry partners. Our mission is to advance lymphedema care in the United States by advocating for improved access to care for the diagnosis and treatment of the disease.

“Thanks to the leadership of Representatives Schakowsky and Carter, plus support from hundreds of members on both sides of the aisle, patients like my teenage son, who was born with a rare congenital form of lymphedema, will now be able to access the treatment supplies they need to lead healthier and more productive lives. Other insurance plans typically follow the coverage standards set by Medicare, so we are hopeful that soon every American suffering from this chronic and potentially debilitating disease will have better access to care.”

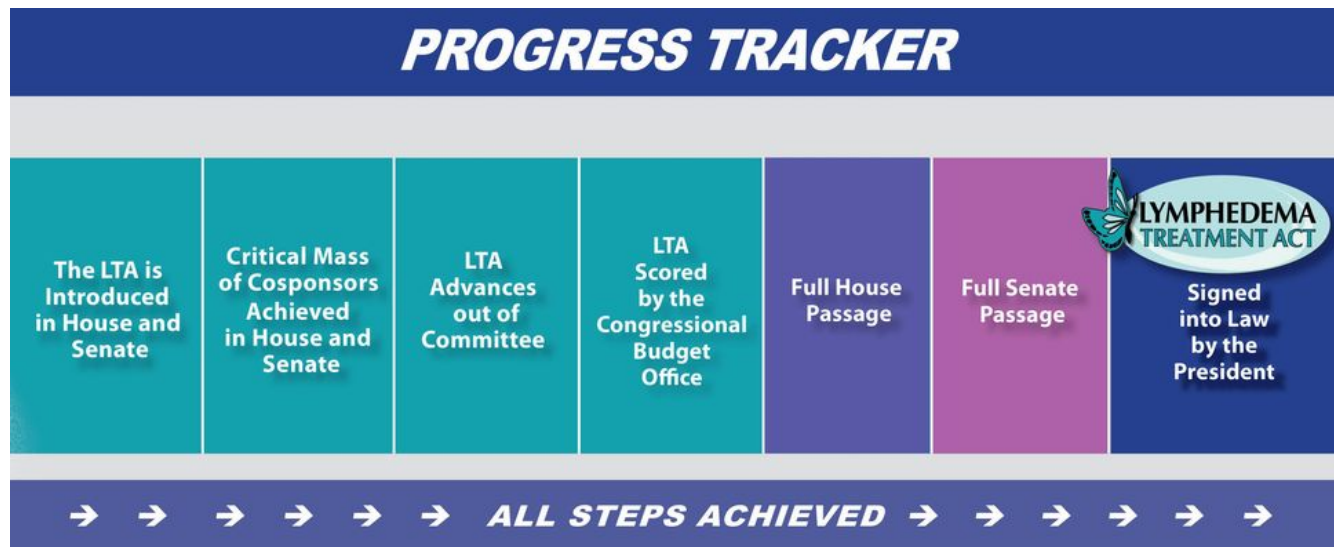
Heather Ferguson, Founder and Executive Director of the Lymphedema Advocacy Group.

Objective

For this purpose, we work to increase awareness of and education about lymphedema amongst law makers, federal and state agencies, insurance providers, clinicians, and other relevant entities. We support attempts to improve coverage through both state and federal legislation, as well as through regulatory action and policy decisions, and encourage all members of the lymphedema community to become active participants in this process. Our initial legislative objective was the Lymphedema Treatment Act, a federal bill passed by Congress in December 2022. The official title of the bill is: amend title XVIII of the Social Security Act to provide coverage of certain lymphedema compression items under the Medicare program. Improvements to coverage for compression garments and supplies began in January of 2024.

Highlights to Passage in the 117th Congress

Every bill must be introduced during each congressional session until passage. So, during each congressional cycle, a lead sponsor must file the bill with their respective chamber. During the 117th Congress, which convened in 2021 and 2022, Lymphedema Treatment Act Lead Sponsor Representative Jan Schakowsky (D-IL-9), a Democrat from the 9th District in Illinois, introduced the Lymphedema Treatment Act (House Resolution or H.R. 3630) on May 28, 2021, with 147 original cosponsors. In the Senate, Lead Sponsor Senator Maria Cantwell (D-WA), a Democrat from Washington state, introduced the LTA (Senate or S. 1315) on April 22, 2021, with 53 original cosponsors. During the 117th Congress, the LTA secured overwhelming bipartisan support with 379 total cosponsors, 311 House and 68 Senate, and was the most supported healthcare bill.



Once a bill is introduced, it must pass out of the relevant committee before a vote on the floor can take place. In the House, the Energy & Commerce Committee controls healthcare legislation. The LTA passed unanimously out of Committee on July 22, 2022. In the Senate, the Finance Committee controls healthcare legislation and voted to move the bill forward. The Congressional Budget Office (CBO) analyzed the bill and supportive materials that the LAG provided in support of the bill and scored the bill. This score provides Congress with a 10-year estimated cost/savings benefit analysis.

The LTA passed in the House with a vote of 402-13 on November 17, 2022, and was passed into law as part of the 2023 Consolidated Appropriations Act on December 29, 2022.

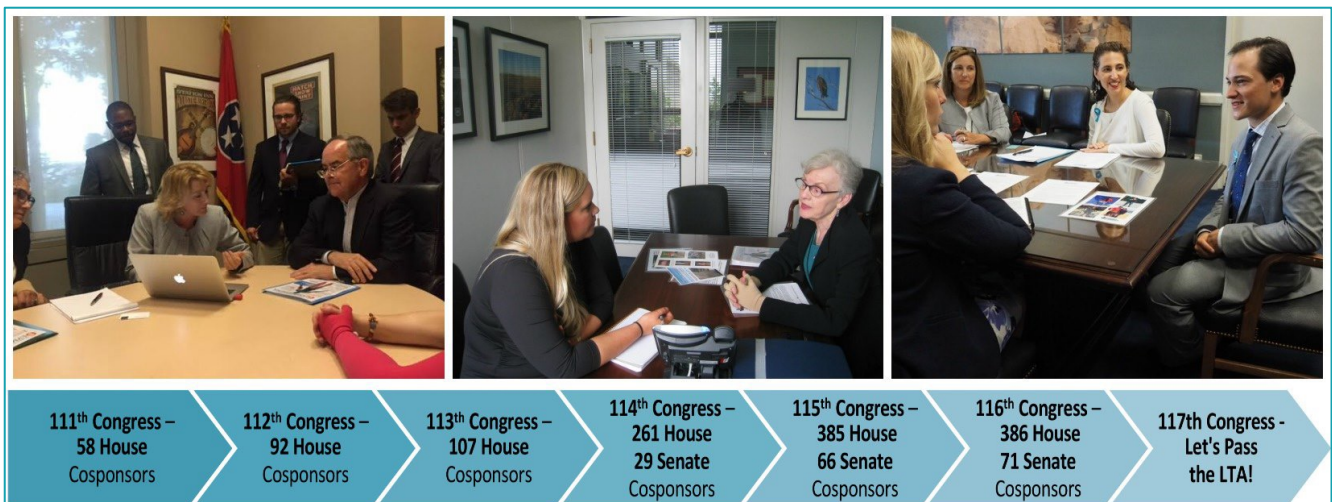
LEGISLATIVE SUMMARY

The Lymphedema Advocacy Group undertook a 12-year, 10-month 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.



Photo 2 December 2022 legislative meeting with LAG board members Becky Sharp and Judy Woodward, Representative Buddy Carter (GA), LAG Executive Director Heather Ferguson and LAG Board Chair Sarah Bramlette.

Timeline of Lymphedema Advocacy Group's Lobbying Efforts



HOW THE LYMPHEDEMA TREATMENT ACT BECAME LAW

Building Community

- Built a Community of Lymphedema Advocates
- Established regional teams in 2013
- Established state teams in 2015
- Provided advocacy training
- Created an Advocacy Training Committee to effectively train advocates
- Developed handbook and webinars to prepare advocates
- Secured stakeholder endorsements and coalition building
- Garnered 12,000 general members and 1,500 state team members
- Achieved 40 endorsements from national organizations
 - *AMA, Susan G. Komen, American Cancer Society, APTA, AOTA, ONS and more*

Giving Voice

- Developed relationships with major stakeholders to support our cause.
- Added key industry partners, including industry leaders Medi, Jobst, L&R
- Organized and conducted in-person Lymphedema Lobby Days on Capitol Hill
- Cataloged over 1,000 lymphedema stories
- Created and provided educational materials and advocacy tools
- Sent over 45,000 emails to Congress
- Held virtual Lymphedema Lobby Days

Advancing Care

- Proving Savings
 - Compiled findings from various studies on lymphedema cost savings
- 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.

Legislative Outreach


Meeting with elected officials and their staff was an important part of the Lymphedema Advocacy Group's lobbying efforts.

In 2023, VoterVoice, a grassroots digital advocacy organization, highlighted the Lymphedema Advocacy Group's successful communication and legislative outreach efforts to pass the Lymphedema Treatment Act in their 2023 Advocacy Benchmark Report.



Lymphedema Treatment Act
Aug 11, 2023 · 🌐

Kudos to our advocates! Your online actions have been recognized and shared as an example to others. LAG is excited to have been a part of VoterVoice's Annual Advocacy Benchmark Report, providing insights to help shape the industry's future. Check out the report here: <http://fiscalnote.com/Benchmarks>
#AdvocacyBenchmarkReport #IndustryInsights




2023 Advocacy Benchmark Report

DOWNLOAD ↓

info.votervoice.net
2023 Advocacy Benchmark Report | VoterVoice

Pro Tip: Empower Your Advocates

We asked VoterVoice clients with the highest levels of engagement in 2022 to share their tactics for success. Here are their best practices to communicate effectively with advocates:

"Effective advocacy is a marathon, not a sprint. Educate your members on why their ongoing engagement is necessary to get results. Keep them informed of what their own elected officials have or haven't done to help you reach your goal, and impress upon them the importance of their constituent voice so they feel empowered."

— Heather Ferguson, Founder & Executive Director, Lymphedema Advocacy Group

Lymphedema advocates took part in thousands of meetings with congressional representatives over the 12-year period that the Lymphedema Treatment Act was active, culminating in the passage of the Lymphedema Treatment Act in the House on November 17, 2022, depicted below.

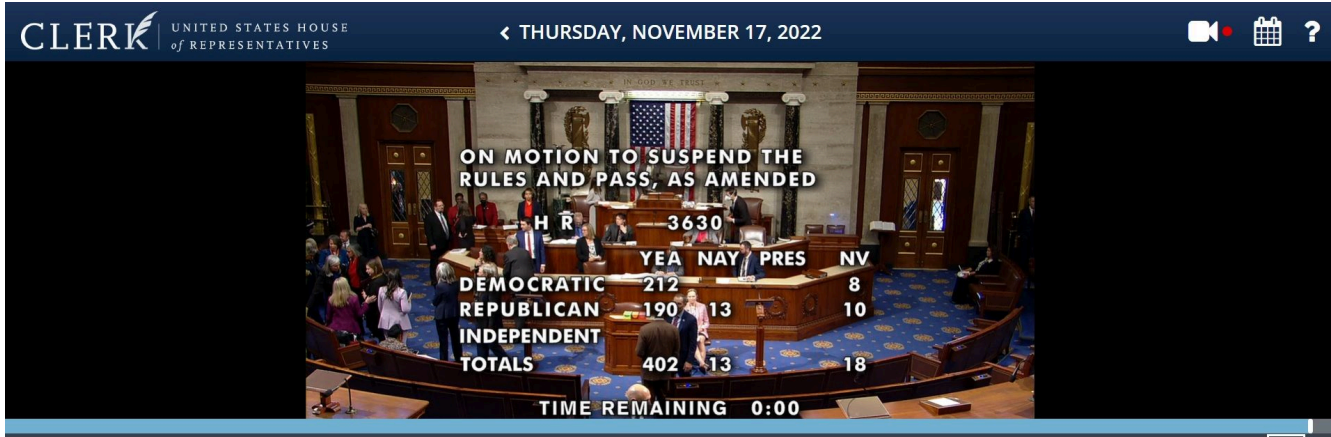


Photo 3 Screenshot of the final summary of the vote in the House of Representatives on Thursday, November 17, 2022.

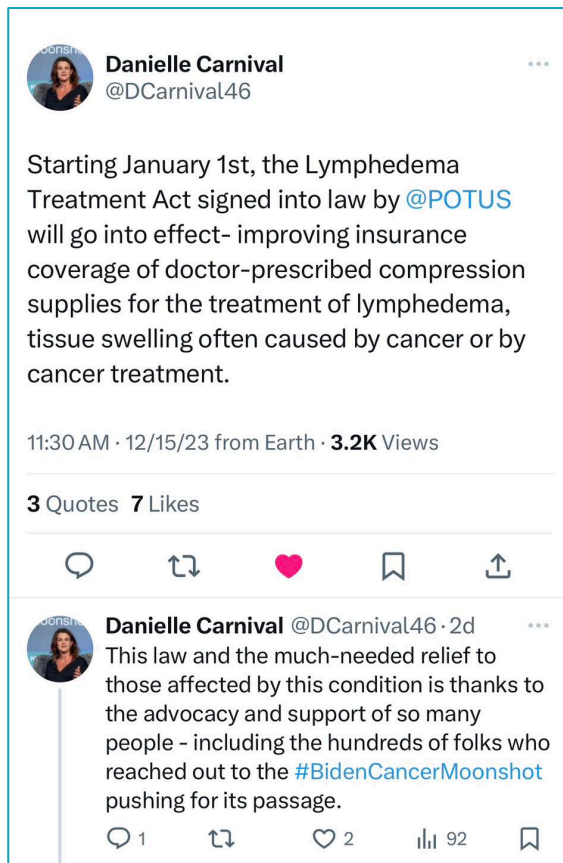


Figure 1 Recognition from Danielle Carnival, Deputy Assistant to President Biden for the Cancer Moonshot.

CANCER MOONSHOT AND LYMPHEDEMA

Since the bill’s passage in December 2022, LAG has been actively engaging elected officials to support its mission to advocate for improved access to care for the diagnosis and treatment of disease. Cancer is the leading cause of lymphedema.

Implementing Legislation to Action in 2023

Once the bill was signed into law in December 2022 with an effective date of January 1, 2024, the Lymphedema Advocacy Group jumped into action to ensure that the implementation of the bill would meet the needs of the lymphedema community. Members of LAG attended policy meetings, presented at major healthcare conferences and engaged the lymphedema community to participate in the Centers for Medicare and Medicaid Services (CMS) events.

Members of LAG attended the following meetings:

- CMS Listening Session - January 2023
- Domestic Policy Council - March 2023
- Office of Management and Budget - April 2023 & October 2023

LAG coordinated CMS listening sessions with other stakeholder groups:

- Lymphedema Advocacy Group advocates
- Lymphology Association of North America
- National Lymphedema Network
- American Vein and Lymphatic Society
- US Medical Compression Alliance
- American Occupational Therapy Association
- American Physical Therapy Association
- Alliance of Woundcare Stakeholders
- Susan G. Komen

Members of LAG presented at the following healthcare conferences.

- Fat Disorders Resource Society Atlanta, GA - April 2023
- Oncology Nursing Society Congress San Antonio, TX - April 2023
 - Executive Director Heather Ferguson received the 2023 ONS President's Award
- American Vein and Lymphatic Society World Congress Miami Beach, FL - Sept. 2023
- National Lymphedema Network Philadelphia, PA - October 2023
- LANA & American Cancer Society Summit St. Louis, MO - October 2023

Engaging our community

- Voter Voice recognition
- May DC Celebration Reception & Awards
- May DC Congressional Thank You Meetings
- Proposed Rule Informational Zooms
- Public Comment Instructional webinars
- Public comment stats and accomplishments
- Rare Voice Awards Finalists

LYMPHEDEMA TREATMENT ACT RECAP

Bill Summary

- Passed into law as part of the 2023 Consolidated Appropriations Act
- Medicare will cover medically prescribed compression garments
- Coverage began January 1, 2024
- Includes standard fit and custom-made compression garments
- Covers all patients with a diagnosis of lymphedema

Lymphedema Treatment Act Final Rule - Summary

- Custom and standard fit daytime and nighttime garments
- Custom and standard fit gradient compression wraps with adjustable straps
- Bandaging supplies for any phase of treatment
- Accessories including but not limited to donning and doffing aids, padding, fillers, linings, and zippers

Lymphedema Treatment Act Final Rule – Frequency

- Daytime garments - 3 sets (one garment for each affected body part) every six months, standard or custom fit, or a combination of both
- Nighttime garments - 2 sets (one garment for each affected body part) every two years, standard or custom fit, or a combination of both
- Bandaging supplies - no set limit in the rule
- Accessories - no set limit, will be determined on a case-by-case basis depending on the needs of the patient

Lymphedema Treatment Act Final Rule – Coverage Requirements

- To be eligible for the above coverage, you must have the following:
 - Lymphedema diagnosis
 - Prescription for the compression supplies
- The coverage will begin January 1, 2024
- There will be no retroactive coverage - You cannot submit claims for any garments or supplies purchased or ordered before January 1, 2024

Lymphedema Treatment Act Final Rule – Deductibles and Copay

- For traditional Medicare - these supplies will be covered under Part B, so the annual Part B deductible and 20% coinsurance apply to all compression supplies
- For Medicare Advantage and all other types of insurance - out-of-pocket costs will vary depending on the specific terms of your plan. It is likely that your compression supplies will be subject to the same copay and deductibles as supplies covered under the DMEPOS (Durable Medical Equipment, Prosthetic and Orthotic Supplies) section of your policy

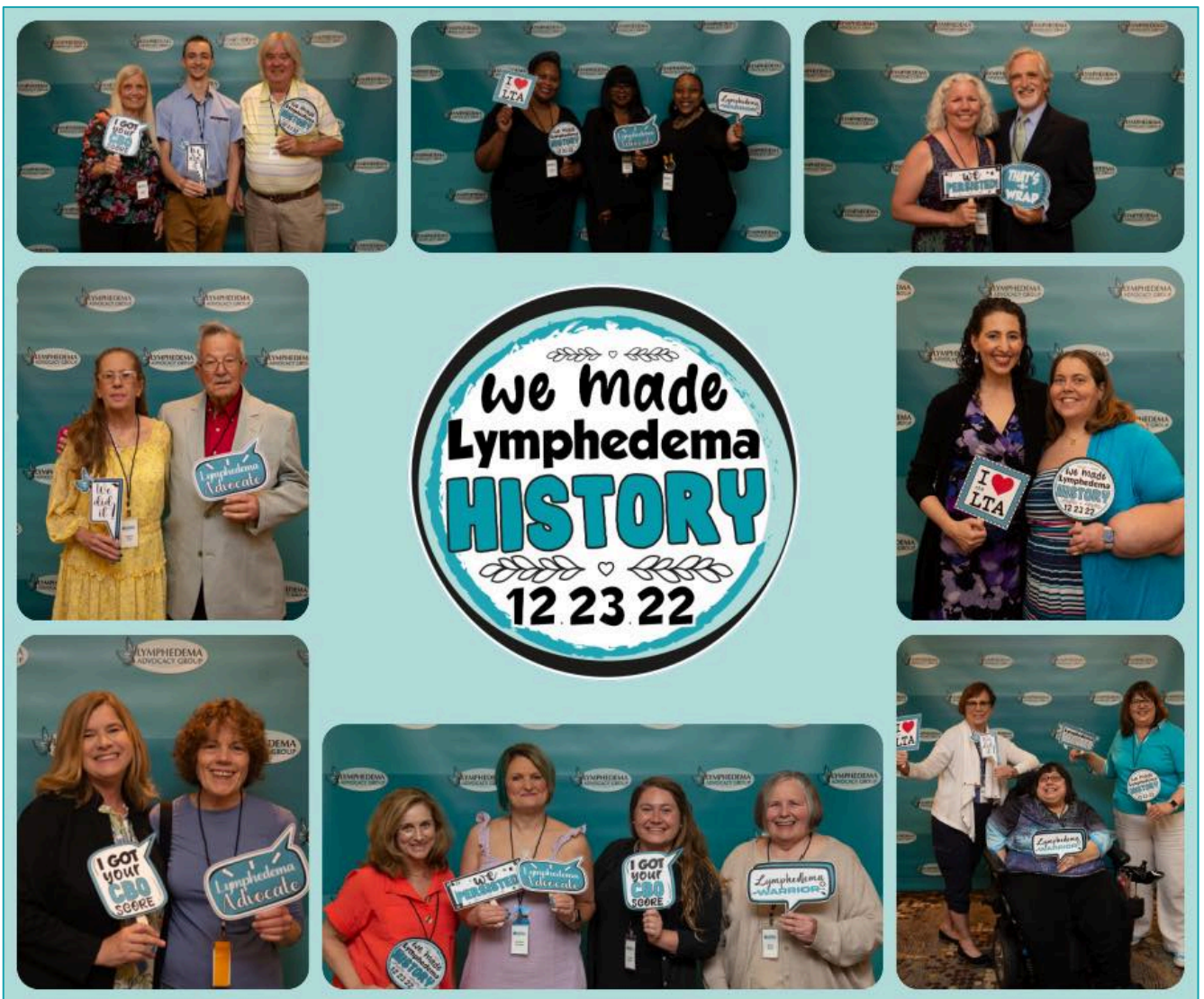


Photo 4 Lymphedema Advocates celebrating the passage of the Lymphedema Treatment Act.

BOARD CHAIR LOOKS AHEAD

Letter from the Board Chair

This year, I'm thankful for the passage of the Lymphedema Treatment Act and that as of January 1, 2024, lymphedema compression garments and supplies are a covered benefit under Medicare Part B!

Thanks to the work of the Lymphedema Advocacy Group, not only does Medicare now cover compression garments and supplies, but the allowable quantities are based on the number of affected body areas, so that patients like me are able to get the quantities they need.

I've been a Medicare beneficiary since 2013, and during that time my health had declined without access to compression to manage my lymphedema. Episodes of cellulitis became more frequent, and mobility more difficult. I look forward to once again having the ability to adequately treat and manage this chronic condition.

The new Medicare coverage will be the most compression coverage I have ever had, even better than what I had with private insurance through an employer. I look forward to being able to once again properly manage my lymphedema, and for the first time, treat the lymphedema in my arms, in addition to my legs.

I am also thankful for the members of Congress who passed the bill, the organizations that helped with the implementation of the coverage, and especially for the advocates who reached out to their members of Congress and who submitted public comments to CMS.

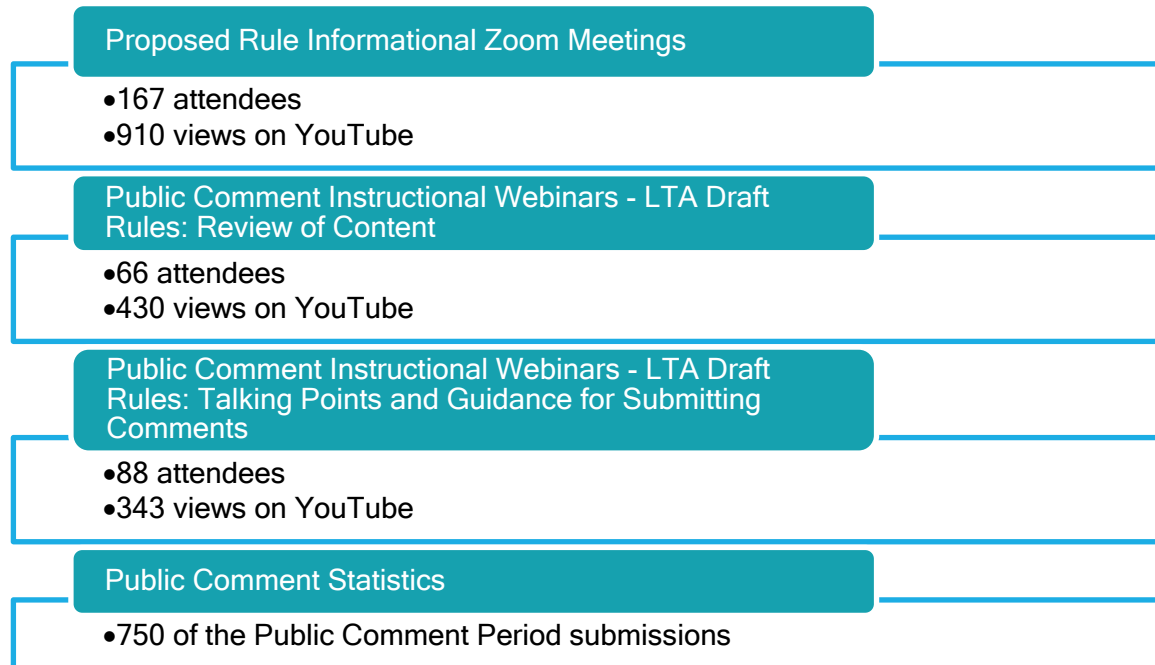
We've accomplished amazing things together, but our work is not done! We've once again shown how powerful the patient voice is in improving access to care and I look forward to continuing our success in future advocacy.



Sarah Bramblette, Board Chair, Lymphedema Advocacy Group

Community Engagement

Our patients, caregivers, stakeholders and industry partners provided necessary feedback to CMS to ensure that patients' needs will be met. The Lymphedema Advocacy Group hosted public forums and webinars to educate our community and increase the quantity and quality of public comments to the proposed rule. As a result, over 750 of the public comment submissions were submitted due to the efforts of the Lymphedema Advocacy Group.



“The Lymphedema Advocacy Group aims to provide patients, caregivers and stakeholders with the information they need to access care and thrive.”

Sarah Bramlette, Board Chair of the Lymphedema Advocacy Group

Education

LAG educated our patient and stakeholder community regarding upcoming CMS deadlines and information sessions.

Communication

LAG sent hundreds of newsletters and reminders regarding the upcoming CMS rules.

Next Steps

LAG continues to develop new methods to educate our lymphedema community.

THE LYMPHEDEMA ADVOCACY GROUP

2024 Officers

Sarah Bramblette, Chair
 Becky Sharp, Vice Chair
 Debbie Labarthe, Secretary
 Jamie Hart, Treasurer
 Michael Cannon, Asst.
 Treasurer

Directors

Amy Caterina
 Cindy Cronick
 Debbie Crow
 Tiffany Detlefsen
 Patti Graybeal
 MJ Hitz

Jennifer Hovatter
 Eric Johnson
 Naydza Muhammad
 Dr. Said Nafai
 Lindsay Ryback
 Franci Schwab
 Judy Woodward

Executive Director

Heather Ferguson



In Memoriam

Recognizing board members who left us too soon:
 Bill McCann, Elaine Eigeman and Lois Tiemann