**ABOUT LYMPHEDEMA:**

Lymphedema (chronic lymphatic system failure) has a multitude of causes. It is marked by an accumulation of lymph fluid (swelling) in parts of the body where lymph nodes or lymphatic vessels are damaged or inadequate. Millions of Americans are affected by this chronic but treatable condition, most commonly from cancer.

Untreated or inadequately treated lymphedema is progressive, leading to complications, comorbidities, loss of function, disability, and in some cases even death. Compression therapy is the essential cornerstone of lymphedema treatment, without which patients cannot effectively manage their condition. Coverage for compression will enable patients to maintain their overall health, activities of daily living, and quality of life.

**CONGRESSIONAL INTENT - WHY THIS LEGISLATION IS NEEDED:**

Starting in 2001, the Medicare program issued an advisory on the importance of compression garments. A year later, a National Coverage Determination announcement was published highlighting such garments as part of a conservative treatment regimen intended to reduce and control lymphedema-related swelling. Despite the announcement, HHS has yet to officially provide coverage for compression supplies, indicating legislative authority is needed.

Lymphedema is the end result of any significant impairment to all or part of the lymphatic organ system. To exclude the primary treatment for all causes of lymphedema (i.e. compression therapy) is equivalent to excluding treatment for all forms of heart or lung disease.

A growing number of Medicare beneficiaries are affected by lymphedema as cancer survivorship increases.

**WHAT THIS LEGISLATION WILL DO:**

- Provide for Medicare coverage of doctor-prescribed compression supplies under the Durable Medical Equipment (DME) category.

- Reduce the total healthcare costs associated with this disease by decreasing the incidence of complications, co-morbidities and disabilities resulting from this medical condition.


Please visit our website to learn more. [LymphedemaTreatmentAct.org](http://LymphedemaTreatmentAct.org)
LYMPHEDEMA: NOT ONE DISEASE

Chronic lymphatic-system failure (lymphedema) occurs in 3-5 million Americans across a wide spectrum of diseases.

Over 40 rare diseases are associated with primary lymphedema including:

• Aagenaes Syndrome
• Adams-Oliver Syndrome
• C.H.A.R.G.E. Syndrome
• C.L.O.V.E.S. Syndrome
• Carbohydrate Deficient Glycoprotein (types 1a, 1b, 1h)
• cardio-facial-cutaneous Syndrome
• Choanalatresia-lymphedema Syndrome
• Congenital Lymphedema (non-Milroy’s)
• Ectodermal Dysplasia Anhidrotic
• Immunodeficiency Osteopetrosis
• Lymphedema Syndrome
• Fabray’s Disease
• Gorham’s Disease
• Hennekam Syndrome
• Hypotrichosis Lymphedema Telangiectasia
• Klippel-Trenaunay Syndrome
• Klippel-Trenaunay-Weber Syndrome
• Lipedema
• Lymphedema Distichiasis Syndrome
• Lymphedema Myelodysplasia (Emberger Syndrome)
• Lymphedema Praecox
• Lymphedema Tarda
• Lymphedema-Distichiasis
• Macrocephaly-Capillary Malformation
• Maffucci Syndrome
• Meige Syndrome
• Microcephaly-Chorioretinopathy-Lymphedema-Mental Retardation Syndrome
• Milroy’s Disease
• Mucke Syndrome
• Neurofibromatosis
• Nonne-Milroy Disease
• Noonan’s Syndrome
• Oculo-Dento-Digital Syndrome
• Paralysis
• Radiation
• Rheumatoid arthritis
• Spina bifida
• Thrombocytopenia with Absent Radius Syndrome
• Trisomy 13,18,21
• Turner’s Syndrome
• Velocardiofacial Syndrome
• W.I.L.D. Syndrome

Secondary cases can be broken into two categories:

22% of all cases are non-cancer related.
Any significant damage to the lymphatic organ system can result in lymphedema. Causes include:

• Burns
• ilio-femoral bypass
• Infection
• Melanoma 16%
• Genital-urinary 10%
• Head and neck 4%

68% of all cases are cancer related.
The overall cancer-related incidence rate is 15.5%. Specific rates include:

• Breast 40%
• Sarcoma 30%
• Gynecological 20%
• Melanoma 16%
• Genital-urinary 10%
• Head and neck 4%


For more information visit our website
LymphedemaTreatmentAct.org
6 THINGS YOU MAY NOT KNOW ABOUT LYMPHEDEMA

1. Lymphedema is chronic swelling caused by a build-up of fluid that occurs when the lymphatic system is either faulty or damaged.

2. An estimated 3-5 million Americans suffer from lymphedema — including many that are undiagnosed or undertreated. That is more than ALS, Cystic Fibrosis, Multiple Sclerosis, Muscular Dystrophy, and Parkinson’s Disease combined.

3. Most physicians in the United States are taught about the lymphatic system for 1 hour or less during their 4 years of medical school training.

4. There is no known cure for lymphedema, but it can be effectively treated. Compression therapy is the most critical component of treatment. Without it, patients are at increased risk for complications and disability.

5. Medicare, and many private insurance policies do NOT cover compression garments, wraps, or bandages — the supplies needed for compression therapy.

6. The Lymphedema Treatment Act is a bill, currently in Congress, that aims to improve insurance coverage for compression supplies, allowing lymphedema patients to maintain a healthy and productive life.

Visit our website to learn more about lymphedema and how to support this bill. LymphedemaTreatmentAct.org

The **Avalere Health**¹ cost analysis for the **Lymphedema Treatment Act** demonstrated that nationally, 0.57% of all Medicare patients are diagnosed with lymphedema. Based on this and state Medicare data², here are the estimates of affected Medicare beneficiaries in each state.

<table>
<thead>
<tr>
<th>State</th>
<th>Estimate of Medicare Patients with Lymphedema</th>
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<th>Estimate of Medicare Patients with Lymphedema</th>
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2. [http://kff.org/medicare/state-indicator/total-medicare-beneficiaries/?currentTimeframe=0](http://kff.org/medicare/state-indicator/total-medicare-beneficiaries/?currentTimeframe=0)
As stated by the National Cancer Institute, “The goal of lymphedema treatment centers on controlling limb swelling and minimizing complications.”¹

Under current Medicare policy, lymphedema patients have coverage for Manual Lymphatic Drainage (MLD), performed by a qualified Medicare provider such as a physical or occupational therapist, and, when certain conditions are satisfied, a pneumatic compression pump. The function of both of these treatment modalities is to reduce the volume of stagnant lymph fluid in the affected body part or parts.

The function of compression is to maintain the affected body part in its reduced state and prevent it from swelling further. Without the use of compression garments and/or the other compression supplies outlined in the Lymphedema Treatment Act, MLD and lymphedema pumps provide no lasting benefit and do not enable the patient to maintain their condition.

Medicare does recognize and acknowledge the necessary role compression plays in the treatment of lymphedema.

Lymphedema pumps, if prescribed, may be covered by Medicare (per National Coverage Determination 280.6²) after "a four-week trial of conservative therapy” has shown little or no benefit. This “conservative therapy” must include the “use of an appropriate compression bandage system or compression garment”. The Decision Summary of the Decision Memo for Lymphedema Pumps (CAG 00016N³) states providers should, "Encourage patients to use compression garments between pump sessions to prevent reaccumulation of fluid”.

Pumps are generally used for an hour a day. A person cannot perform most any activity of daily living while using the pump. As demonstrated by the images below, the compression sleeve that comes with a pump (seen left) is far different from the compression garments and other compression supplies that must be worn continuously to prevent fluid reaccumulation (shown to the right and center). The Lymphedema Treatment Act will close the unintended gap in coverage that prevents Medicare beneficiaries from accessing these medically necessary, doctor prescribed compression supplies, which are the cornerstone of the standard of care for lymphedema.

¹ http://www.cancer.gov/about-cancer/treatment/side-effects/lymphedema/lymphedema-hp-pdq#section/all
SECTION 1: 
Existing Federal Action or Precedent 
Regarding Compression

1. CMS Decision Memo on Pneumatic Pumps  
Standard management of lymphedema typically includes positioning (elevation), manual lymphatic drainage, exercise, and compression garments or wraps. Patients should use compression garments between pump sessions to prevent reaccumulation of fluid.

2. MEDCAC Meeting on Lymphedema Treatment Protocols (2009)  
When isolating individual modalities of treatment, the highest level of confidence was found in compression.

3. Tricare Coverage of Compression for Members of the Military  
“Medical grade compression (pressure) stockings are a covered benefit as durable medical equipment. TRICARE covers two pressure stockings per limb per calendar year when medically necessary.”

4. Women’s Health and Cancer Rights Act (WHCRA) of 1986  
The required coverage includes: Treatment of physical complications of the mastectomy, including lymphedema.

SECTION 2: 
Evidence for the Effectiveness of Compression

“Following achievement of maximal volume reduction with Complete Decongestive Therapy, patients should be fitted with a compression garment.”

6. Cochrane Database of Systematic Reviews ~ Physical therapies for reducing and controlling lymphoedema of the limbs (2008)  
The use of compression bandaging and garments was more effective than garments alone. Additionally, they noted that when comparing no treatment to the use of compression garments alone, the garments were deemed beneficial.

The evidence supports the use of compression bandages and garments as the most “basic” level of care to be provided in countries with even the most sparse of resources.

Studies with follow-up periods of six months to five years showed that compression garments are effective in reducing and/or maintaining lymphedema of the arm and leg both in primary and secondary lymphedema.

Regarding compression bandaging: Lymphedema requires constant compression, if discontinued edema will recur rapidly.

Compression is “an essential component of combination physical therapies” and that conservative treatment (including compression) “leads to significant reductions in limb volume.”

“It is well known that lymphedema, left untreated, will progressively become worse. The earlier lymphedema is detected and properly treated, the better will be the outcome. Early detection and treatment can lead to near normalization of a swollen limb or an edematous trunk, and a greater chance of minimizing or avoiding significant complications.

“Patients should be advised that lymphedema is a life-
long condition and that compression garments must be
worn on a daily basis. Patients can expect stabilization 
and/or modest improvement of edema with the use of 
the garment in the prescribed fashion.”

13. Clinical Journal of Oncology Nursing ~ Demystifying 
Lymphedema: Development of the Lymphedema 
Putting Evidence Into Practice Card (2008)\textsuperscript{15} 
Non-adherence with low-stretch compression bandaging 
and compression sleeves represent risk factors for 
progressive lymphedema, and continued use of comp-
ression bandaging allows for further volume reduction 
even during maintenance therapy.

14. Canadian Medical Association Journal ~ Clinical 
Practice Guidelines for the Care and Treatment of 
Breast Cancer: Lymphedema (2001)\textsuperscript{16} 
Evidence supported the use of compression 
garments and their use as the “primary therapy” for 
lymphedema.

15. Annals of Oncology ~ Conservative Treatment of 
Postmastectomy Lymphedema: A Controlled, 
Randomized Trial (1991)\textsuperscript{17} 
Both groups improved however there were no signif-
icant differences and the authors concluded “a good 
result could be obtained simply and economically” in 
the group treated with compression alone.

SECTION 3: 
Evidence for Reduced Healthcare Expense

16. Journal of The American Physical Therapy Associa-
tion ~ Breast Cancer Related Lymphedema: 
Comparing Direct Costs of a Prospective Surveillance 
Model and a Traditional Care Model (2012)\textsuperscript{18} 
Determined that the annual direct cost to manage early 
stage lymphedema with compression garments and 
minimal therapy was $636.19 versus $3,124.92 in the 
more advanced stages.

17. Journal of Clinical Oncology ~ Incidence, Treatment 
Costs, and Complications of Lymphedema After Breast 
Cancer Among Women of Working Age: A 2-Year 
Follow-Up Study (2007)\textsuperscript{19} 
“Poorly managed lymphedema may lead to complica-
tions needing medical attention, which increases the 
costs of care.”

18. Rehabilitation Oncology Journal ~ Effects of 
Complete Decongestive Therapy on the Incidence 
Rate of Hospitalization for the Management of 
Recurrent Cellulitis in Adults with Lymphedema\textsuperscript{20} 
The study revealed that treatment, primarily 
consisting of compression including bandaging and 
custom garments, reduced the average annual hospi-
talizations among the study participants from 8.5/year 
down to 0.67/year, a decrease of 12 fold.

19. The American Journal of Infection Control ~ Outcomes 
and management costs in patients 
hospitalized for skin and skin-structure infections 
(2011)\textsuperscript{21} 
Found that the length of stay per episode was 9.5-17.2 
days and cost ranged from $40,046 - $80,939 per hospital stay. Costs are expected to have risen 
modestly since that time.*

*Note that even at the lower end of the cost range 
per hospitalization, a 12 fold reduction in hospitalizations 
per year could be expected to decrease the cost from 
$343,391/year to $26,830/year.
May 6, 2016

The Honorable Maria Cantwell
United States Senate
511 Hart Senate Office Building
Washington, DC 20510

Dear Senator Cantwell:

On behalf of the physician and medical student members of the American Medical Association (AMA), I am writing to express our support for S. 2373, the “Lymphedema Treatment Act.” This bill would help fill a treatment gap for patients with lymphedema by providing for Medicare coverage of certain lymphedema compression treatment items as durable medical equipment (DME) items.

Lymphedema afflicts millions of Americans, with the majority of cases caused by cancer treatments that damage the body’s lymph transport and immune functions. When left untreated or under-treated, lymphedema is progressive and can put patients at greater risk for serious infections or other costly complications. While certain treatments for breast cancer-related lymphedema are required by law to be covered by private insurance plans, Medicare beneficiaries with lymphedema currently lack coverage for compression therapy, an essential component of care they must use to manage their chronic disease. As a result, many patients are not receiving appropriate and evidence-based treatment, which results in a decline in their health status and quality of life. Your bill would fix this treatment gap by specifically covering certain lymphedema compression treatment items under Medicare as DME items as long as they are prescribed by a physician or non-physician health professional to the extent authorized under state law.

The AMA applauds your leadership in sponsoring the Lymphedema Treatment Act and is pleased to support this important bill.

Sincerely,

James L. Madara, MD
August 05, 2015

The Honorable David G. Reichert
United States House of Representatives
1127 Longworth House Office Building
Washington, DC 20515-0601

Dear Representative Reichert:

On behalf of millions of cancer patients, survivors and their families, the American Cancer Society Cancer Action Network (ACS CAN) commends you for your leadership in introducing H.R. 1608, the Lymphedema Treatment Act of 2015.

The Lymphedema Treatment Act of 2015 would require Medicare to cover all necessary medical supplies appropriate for the treatment of lymphedema for beneficiaries. The Medicare program currently does not cover the critically necessary compression supplies used in the daily treatment of lymphedema. Patient access to physician prescribed compression supplies can prevent recurring infections and eventual disability in lymphedema patients. Currently, compression supplies used for the treatment of lymphedema patients are not classified under any existing Medicare benefits category.

Lymphedema affects millions of Americans nationwide, and there is currently no known cure. Patient access to medical supplies that help treat lymphedema is imperative, and important for patient quality of life. Patients who have undergone surgery or radiation therapy for cancer, namely breast cancer, may be at a high risk of developing lymphedema. Also, surgical procedures treating breast cancer often require the removal of lymph nodes which puts breast cancer survivors at an even higher risk. This is why the Lymphedema Treatment Act is so important, and we look forward to working with you on the legislation during the 114th Congress.

Thank you again for your leadership on this important issue. Please contact Keysha Brooks-Coley on my staff at 202-661-5720, or Keysha.brooks-coley@cancer.org if we can be of assistance in any way.

Sincerely,

Christopher W. Hansen
President
May 24, 2016

The Honorable Maria Cantwell
United States Senate
511 Hart Senate Office Building
Washington, D.C. 20510

The Honorable Charles Grassley
United States Senate
135 Hart Senate Office Building
Washington, D.C. 20510

Dear Senator Cantwell and Senator Grassley:

On behalf of the more than 93,000 members of the American Physical Therapy Association (APTA), I write to thank you for introducing the **Lymphedema Treatment Act (S. 2373)**, which will be invaluable in assisting Medicare beneficiaries who are impacted by lymphedema.

APTA commends the legislation and its provision of improved Medicare coverage for compression supplies, including compression garments, bandaging systems, and other devices necessary for the treatment of lymphedema. This legislation provides extensive and detailed descriptions of the categories of lymphedema treatment supplies that would be required to be covered, while authorizing the Secretary to expand coverage for additional supplies so long as those items are determined to be effective in preventing or treating lymphedema. Currently, Medicare beneficiaries lack coverage for the compression therapy necessary for the treatment of lymphedema. Passage of this legislation would ensure access to these indispensable items for individuals suffering from lymphatic impairments and conditions.

Physical therapists provide a crucial role in the treatment of lymphedema. While there is no cure for this condition, early detection, treatment, and management are crucial to alleviating symptoms. Physical therapists aid in manual lymph drainage as well as the fitting and adjustment of compression garments. Additionally, physical therapists provide patients with specialized exercises to be performed while wearing compression garments and are an important source of information regarding how to avoid injury and infection, improve skin care, and utilize diet to decrease fluid retention.

Thank you for your commitment to improving the lives of individuals suffering from lymphedema. Please contact Stephanie Katz, Senior Congressional Affairs Specialist, at stephaniekatz@apta.org or 703-706-3177, if you have any questions or would like additional information.

Sincerely,

Sharon L. Dunn, PT, PhD, OCS
President

SLD: sjk
June 22, 2015

Honorable David Reichert
1127 Longworth House Office Building
Washington, DC 20515

RE: Support of H.R. 1608, the Lymphedema Treatment Act

Dear Congressman Reichert:

On behalf of the Oncology Nursing Society (ONS), I write to thank you for introducing H.R. 1608, the Lymphedema Treatment Act. H.R. 1608 will improve insurance coverage for the doctor-prescribed compression supplies that are the cornerstone of lymphedema treatment.

As you know, lymphedema is a chronic condition affecting millions of Americans that is most often caused by cancer treatments that damage the body’s lymph system or immune functions. Due to the painful swelling that results from lymphedema, compression therapy is an essential component of treatment. Despite being an ongoing necessity, compression supplies are not covered by Medicare. H.R. 1608 would close this coverage gap by requiring Medicare to cover lymphedema compression items.

In addition to providing cancer treatment, oncology nurses maintain principal responsibility for managing treatment side-effects. Maximizing quality of life and minimizing treatment side-effects such as lymphedema are central goals of oncology nurses. H.R. 1608 will afford our nurses the opportunity to be more effective caregivers and ultimately will result in more successful outcomes for cancer patients nationwide.

ONS is a professional organization of over 35,000 registered nurses and other healthcare providers dedicated to excellence in patient care, education, research, and administration in oncology nursing. ONS members are a diverse group of professionals who represent a variety of roles, practice settings, and subspecialty practice areas. Oncology nurses are leaders in the healthcare arena, committed to continuous learning and leading the transformation of cancer care by advocating for high-quality care for people with cancer.

Please know that ONS and its members very much appreciate your leadership on the issue of access to lymphedema treatment. We stand ready to work with you and your staff to reduce and prevent suffering from cancer. We would be happy to discuss ways in which ONS may be of assistance in this endeavor, and would encourage you to contact Alec Stone, MA, MPA, ONS Director of Health Policy, at astone@ons.org. We look forward to engaging in an ongoing dialogue to address issues of importance to our cancer patients and ways in which we can promote public health.

Sincerely,

[Signature]

Margaret Barton-Burke, PhD, RN, FAAN
President, Oncology Nursing Society