



Stakeholder Support Letters to Senate Champions

S.1315 / H.R.3630
117th Congress

HEATHER FERGUSON

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704-965-0620

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May 7, 2021

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

The Honorable Chuck Grassley
135 Hart Senate Office Building
Washington, DC 20510

RE: The Lymphedema Treatment Act

Dear Senators Cantwell and Grassley:

The undersigned organizations write to express our support for the Lymphedema Treatment Act, S.1315, and to thank you for your leadership in introducing this important legislation. Amending the Medicare statute to enable coverage for prescribed medical compression garments will help millions of Americans with lymphedema access the care they need to manage this chronic disease.

Medical compression garments are the essential cornerstone of treatment for lymphedema. Numerous studies and an abundance of real-world data have demonstrated that the use of prescribed medical compression garments significantly improves health and quality of life for patients through reduced incidence of infections, hospitalizations, and other costly yet preventable complications.

Lymphedema affects an estimated 3-5 million men, women, and children, with 1.5-3 million being Medicare beneficiaries. The most common cause is cancer treatments that remove or damage lymph nodes – affecting 40% of breast cancer survivors and 15% of cancer survivors overall – and as survivorship increases, so too do the number of cases of lymphedema.

The COVID-19 pandemic has further limited access to care for lymphedema patients, and many have experienced a worsening of their condition. Closing this unintended Medicare coverage gap and ensuring that this at-risk population has access to the medical supplies necessary to safely and effectively manage this chronic disease has never been more crucial.

Thank you again for your support and leadership on this important issue. We look forward to working with you to ensure that this bipartisan and broadly supported bill is enacted into law during the 117th Congress.

Sincerely,

American Academy of Physical Medicine and Rehabilitation

American Association of Nurse Practitioners

American Cancer Society / Cancer Action Network

American Lymphedema Framework Project

American Medical Association

American Nurses Association

American Occupational Therapy Association

American Physical Therapy Association

Association of American Cancer Institutes

Breast Cancer Action

Cancer Legal Care

Dana-Farber Cancer Institute

Disability Rights Legal Center

Greet the Day

Lighthouse Lymphedema Network

Lipedema Foundation

Living Beyond Breast Cancer

Lobular Breast Cancer Alliance

Lymphedema Advocacy Group

Lymphatic Education and Research Network

Lymphology Association of North America

Minnesota State Retiree Council, AFL-CIO

National Comprehensive Cancer Network

National Lymphedema Network

Ohio State University Comprehensive Cancer Center –

James Cancer Hospital and Solove Research Institute

Oncology Nursing Society

Ovarian Cancer Research Alliance

Phelan McDermid Syndrome Foundation

Seattle Cancer Care Alliance

Sidney Kimmel Comprehensive Cancer Center

Society of Gynecologic Oncology

Society for Vascular Nursing

Susan G. Komen

Moffitt Cancer Center

Penn Medicine, Department of Physical Medicine and Rehabilitation

UNC Lineberger Comprehensive Cancer Center

University of Vermont Cancer Center

Wound, Ostomy, and Continence Nurses Society

October 9, 2019

The Honorable Mitch McConnell
Majority Leader
United States Senate
Room S-230, The Capitol
Washington, DC 20510

The Honorable Chuck Schumer
Minority Leader
United States Senate
Room S-221, The Capitol
Washington, DC 20510

The Honorable Nancy Pelosi
Speaker
U.S. House of Representatives
H-232 U.S. Capitol
Washington, DC 20515

The Honorable Kevin McCarthy
Minority Leader
U.S. House of Representatives
H-204 U.S. Capitol
Washington, DC 20515

Dear Majority Leader McConnell, Speaker Pelosi, and Minority Leaders Schumer and McCarthy:

On behalf of the 1.5 million Medicare beneficiaries living with chronic lymphatic system failure (lymphedema), the undersigned organizations urge you to pass the Lymphedema Treatment Act, H.R.1948 / S.518, in this calendar year. The Lymphedema Treatment Act improves the coverage for the treatment of lymphedema from any cause by amending Medicare statute to allow for coverage of compression supplies.

Lymphedema, like other chronic conditions, has no cure, but its effects can be mitigated through proper management. As stated by the National Cancer Institute, “The goal of lymphedema treatment centers on controlling limb swelling and minimizing complications.”¹

The most vital components of treatment are medical compression garments and supplies prescribed to reduce complications and disease progression by controlling swelling. For example, in 2004, the Commonwealth of Virginia mandated private insurance and Medicaid coverage for lymphedema compression supplies. This coverage has proven to improve patient outcomes and quality of life, reduce utilization, and reduce costs. Specifically, a ten-year longitudinal study of Virginia’s lymphedema treatment mandate found over a 40% reduction in physician and therapy visits, and a greater than 50% reduction in hospitalizations.²

As policymakers strive to help beneficiaries live healthier and more productive lives, we encourage you to pass this legislation that has been cosponsored by 333 House members and 65 Senators, making it the most supported healthcare bill currently before Congress. The measure will address the growing number of cancer-related cases, as well as those beneficiaries who acquire lymphedema from other causes or who are born with a compromised lymphatic system.

¹ National Cancer Institute. (2015). Lymphedema (PDQ®)—Health Professional Version. <http://www.cancer.gov/about-cancer/treatment/side-effects/lymphedema/lymphedema-hp-pdq#section/all>.

² Weiss, R. (2016). Cost of a lymphedema treatment mandate-10 years of experience in the Commonwealth of Virginia. Health Economics Review 6: 42. <https://doi.org/10.1186/s13561-016-0117-3>.

The Lymphedema Treatment Act is a bipartisan, common-sense solution that closes an unintended gap in Medicare coverage. The Centers for Medicare and Medicaid Services (CMS) acknowledged the necessity of compression therapy in the treatment and management of lymphedema in its National Coverage Determination for Pneumatic Compression Pumps.³

The federal government recognized its importance when it included coverage for compression garments for the treatment of breast cancer-related lymphedema in the Women's Health and Cancer Rights Act of 1998.⁴ Furthermore, lymphedema compression supplies are already covered by Veterans Affairs, TriCare, and Medicaid plans in 44 states plus the District of Columbia.⁵

It's time to ensure that Medicare beneficiaries with lymphedema have coverage for these vital, prescription medical supplies that are the cornerstone in the standard of care for the chronic condition. It is imperative that Congress pass the Lymphedema Treatment Act this year.

Sincerely,



Heather Ferguson
Founder & Executive Director
Lymphedema Advocacy Group
Heather@LymphedemaTreatmentAct.org
704-965-0620

Together with the following organizations and hospitals:

American Academy of Physical Medicine and Rehabilitation
American Association of Nurse Practitioners
American Cancer Society Cancer Action Network
American Lymphedema Framework Project
American Medical Association
American Nurses Association
American Occupational Therapy Association
American Physical Therapy Association
Boston Children's Hospital, Vascular Anomalies Center
Breast Cancer Action

³ The Center for Medicare and Medicaid Services (CMS). (2019). National Coverage Analysis (NCA) for Lymphedema Pumps (CAG-00016N). <https://www.cms.gov/medicare-coverage-database/details/nca-details.aspx?NCAId=50&ver=6&NcaName=Lymphedema+Pumps&DocID=CAG-00016N&bc=gAAAAABAAAA&>.

⁴ The Center for Medicare and Medicaid Services (CMS). (2019). Women's Health and Cancer Rights Act (WHCRA). https://www.cms.gov/ccio/programs-and-initiatives/other-insurance-protections/whcra_factsheet.html.

⁵ Lymphedema Advocacy Group. (2019). Federal and State Plans that Provide Coverage for Medical Compression Supplies. <https://lymphedematreatmentact.org/wp-content/uploads/2019/01/Federal-and-Medicaid-Compression-Coverage-List.pdf>.

Cancer Legal Care
Dana-Farber Cancer Institute
Disability Rights Legal Center
Essentially Women, a division of VGM Group, Inc.
EveryLife Foundation for Rare Diseases
James Cancer Hospital & Solove Research Institute at The Ohio State University
Lighthouse Lymphedema Network
Living Beyond Breast Cancer
Lymphatic Education & Research Network
Lymphology Association of North America
Moffitt Cancer Center
National Comprehensive Cancer Network
National Lymphedema Network
Oncology Nursing Society
Ovarian Cancer Research Alliance
Penn Medicine Cancer Rehabilitation
Phelan McDermid Syndrome Foundation
Seattle Cancer Care Alliance
Society for Vascular Nursing
Society of Gynecologic Oncology
Susan G. Komen
UNC Lineberger Comprehensive Cancer Center
University of Vermont Cancer Center
Wound, Ostomy, and Continence Nurses Society

CC:

Sen. Chuck Grassley, Chair, Committee on Finance
Sen. Ron Wyden, Ranking Member, Committee on Finance
Rep. Frank Pallone, Chair, Committee on Energy and Commerce
Rep. Greg Walden, Ranking Member, Committee on Energy and Commerce
Rep. Richard Neal, Chair, Committee on Ways and Means
Rep. Kevin Brady, Ranking Member, Committee on Ways and Means
Sen. Maria Cantwell, Committee on Finance
Sen. Todd Young, Committee on Finance
Rep. Jan Schakowsky Committee on Energy and Commerce
Rep. Buddy Carter, Committee on Energy and Commerce
Rep. Earl Blumenauer, Committee on Ways and Means
Rep. Mike Kelly, Committee on Ways and Means

Todd M. Fruchterman, MD, PhD
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May 16, 2019

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

The Honorable Todd Young
185 Dirksen Senate Office Building
Washington, DC 20510

Dear Senators Cantwell and Young:

The legislation addressing the Lymphedema Treatment Act, S.518, is of interest to 3M. Three to five million Americans suffer lymphatic dysfunction and chronic lymphedema. Lymphedema is chronic swelling, most typically seen in the upper and lower extremities. When left untreated, lymphedema places increased financial burden on the United States health care system. Patients experience decreased quality of life due to skin integrity challenges, weeping and draining legs, increased risk of cellulitis or infections requiring frequent hospitalizations, decreased activity, inability to work, depression, social isolation, and financial challenges. Although this disease is not curable, it is treatable. Evidence-based, best practice care identifies compression therapy as the most critical component of lymphedema treatment.

Although compression therapy is identified as the most important component to effectively treat lymphedema, the supplies required to deliver compression – bandages, multi-level wraps, and garments are not covered by Medicare and many private insurance companies. The Lymphedema Treatment Act supports the coverage of these supplies.

3M supports this legislation to give patients access to the evidence-based products that include compression therapy supplies and garments required to treat and control the devastating effects of this disease. 3M believes passage of this legislation will improve patient's adherence to their treatment plan, decrease patient complications and hospitalizations, and improve overall quality of life for these patients.

Thank you for your consideration of this matter.

Sincerely,

A handwritten signature in blue ink, appearing to read 'Todd M. Fruchterman', with a long horizontal flourish extending to the right.

Todd M. Fruchterman, MD, PhD

August 18, 2021

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

The Honorable Todd Young
United States Senate
400 Russell Senate Office Building
Washington, DC 20510

Dear Senators Cantwell and Young,

On behalf of the Alliance of Wound Care Stakeholders (“Alliance”) and our co-chairs Dr. Caroline E. Fife and Dr. Matthew G. Garoufalis, we would like to express our strong support for S.1315, the Lymphedema Treatment Act. This important legislation would provide comprehensive Medicare coverage for the treatment of patients with lymphedema or for the prevention of venous stasis ulcers resulting from venous insufficiency. Our members treat patients with these diseases so this issue is very important to us.

The Alliance is a nonprofit multidisciplinary trade association of physician specialty societies, clinical and patient associations whose mission is to promote evidence-based quality care and access to products and services for people with chronic wounds (diabetic foot ulcers, venous stasis ulcers, pressure ulcers and arterial ulcers) and lymphedema through effective advocacy and educational outreach in the regulatory, legislative, and public arenas. This letter was written with their advice and guidance since as stated above many of them treat patients with lymphedema and venous disease. A list of our members can be found on our website: <http://www.woundcarestakeholders.org/about/members>.

Lymphedema is a chronic disease of the lymphatic system that results in disfiguring swelling in one or more parts of the body. This chronic swelling condition results in a disease process that is non-repairable. It can be hereditary (primary lymphedema) or it can occur after a surgical procedure, infection, radiation or other physical trauma. Lymphedema can become a problem after surgery or radiation treatment for nearly any type of cancer. In breast cancer, for example, it can appear in the arm on the same side as the cancer after the lymph nodes are removed during cancer surgery.

Lymphedema can also be caused by venous disease/venous insufficiency. Venous leg ulcers (VLUs) affect about 1-3% of the American population and are the most common of all lower extremity ulcerations. Venous leg ulcers have been estimated to affect 500,000 to 600,000 people in the United States costing 1.5 to 3 billion dollars annually (Ma, Henry, O’Donnell Jr. Thomas Francis Jr, Rosen, Noah Andres, Iafrati, Mark David, “The real cost of treating venous ulcers in a contemporary vascular practice.” Journal of Vascular Surgery, Vol 2. No. 4. 2014 355-361)

The primary risk factors for venous ulcer development are older age, diabetes, obesity, previous leg injuries, deep venous thrombosis, and phlebitis. Venous ulcers are usually recurrent, and an open ulcer can persist for weeks to many years. Venous ulcers account for 80 percent of lower extremity ulcerations. Lymphedema can develop secondarily following ulcer or wound formation, but it can also be a contributing or precipitating factor to chronic ulcerative disease.

The associated lymphedema can be controlled through the use of compression therapy. While the Centers for Medicare and Medicaid Services’ (CMS) and its contractors do cover some products and devices to

treat lymphedema, there is not comprehensive coverage for the treatment of lymphedema or for the prevention of venous stasis ulcers which is so necessary.

Lack of access to the clinically recognized treatments necessary to best care for these conditions leads to higher costs and poorer health outcomes, including recurrent infections, progressive degradation in condition, and, too often, disability. The Alliance strongly recommends that Congress grant CMS the statutory authority to cover compression garments under the Medicare benefit. This change would be in alignment with resolution 126 that the American Medical Association's passed in 2017 requesting that CMS cover and reimburse for gradient compression stockings as prescribed by a physician under the durable medical equipment portion of coverage, including for cases of preventative use and for patients without a present venous stasis ulcer. Again, such change would have a substantial impact via improved outcomes and quality of life, reduced costs for beneficiaries and the health care system, and decreased federal spending.

Thank you for your efforts on behalf of patients with wounds and lymphedema and the providers who treat them. The Alliance strongly supports the Lymphedema Treatment Act and hopes that with the bipartisan support that this legislation enjoys that it will move swiftly through both chambers.

Sincerely,



Caroline E. Fife, MD, CWS, FUHM
CWS



Matthew G. Garoufalis, DPM, FASPS, FACFAOM,

Alliance of Wound Care Stakeholders Co-chairs



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Executive Director

May 14, 2019

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

The Honorable Todd Young
400 Russell Senate Office Building
Washington, DC 20510

Dear Senator Cantwell and Senator Young:

The American Academy of Physical Medicine and Rehabilitation (AAPM&R) is pleased to offer support for S. 518, the Lymphedema Treatment Act. The Academy applauds the effort of this legislation to ensure access to vital compression garments for lymphedema patients seeking to improve and maintain daily function.

The American Academy of Physical Medicine and Rehabilitation is the national medical specialty organization representing more than 9,000 physicians who are specialists in physical medicine and rehabilitation (PM&R). PM&R physicians, also known as physiatrists, treat a wide variety of medical conditions affecting the brain, spinal cord, nerves, bones, joints, ligaments, muscles, and tendons. Physiatrists utilize cutting-edge as well as time-tested treatments to maximize function and quality of life. With appropriate rehabilitation, many patients can regain significant function, and live independent, fulfilling lives.

If you have any questions or require more information, please contact Reva Singh, Director of Advocacy & Government Affairs, at rsingh@aapmr.org or 847.737.6030.

Sincerely,



Nneka Ifejika, M.D., M.P.H., F.A.H.A.
Chair, Health Policy & Legislation Committee





**American Cancer Society
Cancer Action Network**
555 11th Street, NW
Suite 300
Washington, DC 20004
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www.acscan.org

May 8, 2019

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

The Honorable Todd Young
United States Senate
400 Russell Senate Office Building
Washington, DC 20510

Dear Senators Cantwell and Young:

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 S. 518, the Lymphedema Treatment Act.

The Lymphedema Treatment Act 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 116th Congress.

Thank you again for your leadership on this important issue. Please contact Stephanie Krenrich on my staff at stephanie.krenrich@cancer.org if we can be of assistance in any way.

Sincerely,

Lisa A. Lacasse
President



AMERICAN COLLEGE OF SURGEONS

Inspiring Quality:
Highest Standards, Better Outcomes

100+years

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May 27, 2021

The Honorable Maria Cantwell
U.S. Senate
511 Hart Senate Office Building
Washington, DC 20510

The Honorable Chuck Grassley
U.S. Senate
135 Hart Senate Office Building
Washington, DC 20510

Dear Senators Cantwell and Grassley:

On behalf of the more than 82,000 members of the American College of Surgeons (ACS), we would like to express our support for the Lymphedema Treatment Act, S.1315. This bipartisan legislation is an important step in ensuring access to treatment for Medicare patients who are suffering from lymphedema.

Lymphedema (chronic lymphatic system failure) has a multitude of causes, one of which is surgery as a component of cancer treatment. Untreated or under-treated lymphedema becomes progressive, leading to increased morbidity, thus placing a costly burden on patients and the health care system. These risks and higher costs can be effectively mitigated with proper, consistent treatment.

Complete Decongestive Therapy (CDT) is the standard of care for lymphedema and is a multimodal treatment that is only effective when used in its entirety. Current lack of Medicare coverage for an essential component of CDT, the compression supplies used in daily treatment, presents a roadblock for patients to access the full spectrum of care. As a result, many patients suffer from recurrent infections, progressive degradation in their condition and eventual disability because they cannot access the compression supplies required to treat their condition.

This legislation aims to improve insurance coverage for the medically necessary, doctor prescribed compression supplies that are the cornerstone of lymphedema treatment. Although this bill will only change Medicare law, ACS believes it will set a standard for Medicaid and private insurance to follow.

Again, thank you for your leadership in introducing the Lymphedema Treatment Act. We look forward to working with you as this important legislation moves through Congress.

Sincerely,

David B. Hoyt, MD, FACS
Executive Director

American Lymphedema Framework Project

Jane M. Armer, PhD, RN, FAAN
Professor, Sinclair School of Nursing
Director, American Lymphedema Framework Project
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May 22, 2019

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

On behalf of the American Lymphedema Framework Project, we are writing to inform you that our organization offers its endorsement of S.518, The Lymphedema Treatment Act.

We recognize the importance of this initial step in standardizing and providing diagnosis, treatment and education to patients with, or at risk for, lymphedema.

We support patient adherence to the treatment plan through the provision of necessary medical supplies for use in the home.

We envision a standardized level of care for patients with lymphedema, and look forward to future collaborative efforts.

Sincerely yours,



Jane M. Armer, PhD, RN, FAAN
Director, American Lymphedema
Framework Project
MU Sinclair School of Nursing



Joseph L. Feldman, MD, CLT-LANA
Co-Director, American Lymphedema
Framework Project
University of Chicago
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CC: Heather Ferguson



JAMES L. MADARA, MD
EXECUTIVE VICE PRESIDENT, CEO

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July 10, 2019

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

The Honorable Todd Young
United States Senate
400 Russell Senate Office Building
Washington, DC 20510

Dear Senators Cantwell and Young:

On behalf of the physician and medical student members of the American Medical Association (AMA), I am writing to express our support for S. 518, 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

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Alexandria, VA 22314-1488
703/684-2782
www.apta.org

June 7, 2019

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

Dear Senator Cantwell:

On behalf of the more than 100,000 members of the American Physical Therapy Association (APTA), I am writing you to extend our support for the Lymphedema Treatment Act, S.518, which will provide increased assistance to Medicare beneficiaries who are impacted by lymphedema.

The mission of APTA is to build a community to advance the physical therapy profession to improve the health of society. Physical therapists play a unique role in society in prevention, wellness, fitness, health promotion, and management of disease and disability by serving as a dynamic bridge between health and health services delivery for individuals across the age span.

APTA has long supported this legislation's purpose to provide Medicare coverage and payment for lymphedema treatment items and supplies (eg, compression garments, bandaging systems, and other devices that are necessary). This legislation offers detailed descriptions of the types of items that would be covered, while allowing the Secretary discretion to allow more if deemed effective. Currently, many of these items and services are either not covered or only covered on a limited basis. Passage of this legislation takes important steps to reduce the total health care costs associated with lymphedema and ensures access to these supplies for individuals with lymphatic impairments and conditions.

Physical therapists play a crucial role in the treatment of lymphedema. While there is no cure for this condition, early detection, treatment, and management can help alleviate symptoms. Physical therapists assist in manual lymph drainage and fitting for compression garment wear after the process is complete. They also aid in helping patients with the proper exercises to improve cardiovascular health, which in some cases may help decrease swelling. Furthermore, they provide critical information on how to avoid injury and infection, improve skin care, and use diet to decrease fluid retention.

We applaud you for your commitment to improving the lives of those with lymphedema. Please contact Baruch Humble, senior congressional affairs specialist, at baruchhumble@apta.org or 703/706-8509, if you have any questions or would like additional information.

Sincerely,



Sharon L. Dunn, PT, PhD
Board-Certified Orthopaedic Clinical Specialist
President

Vascular Anomalies Center

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May 7, 2019

Anesthesiology

Mary Landrigan-Ossar, M.D., Ph.D.

Cardiology

Mary P. Mullen, M.D., Ph.D.

In support of S497/HR930 the Lymphedema Treatment Act of 2019

Dermatology

Marilyn G. Liang, M.D.

To Whom It May Concern:

Endocrinology

Stephen Huang, M.D.

We are writing this letter to support the above bills for patients and families that struggle day to day with the challenges of Lymphedema. Through the Vascular Anomalies Center at Boston Children's Hospital, our multidisciplinary team of specialists has had the privilege of working with patients of all ages that are diagnosed with lymphedema from all over the world.

Gastroenterology

Victor L. Fox, M.D.

General Surgery

Beinda Hsi Dickie, M.D.
Steven J. Fishman, M.D.
Heung Bae Kim, M.D.

Hematology/Oncology

Cameron C. Trenor III, M.D.
Denise Adams, M.D.

There is no cure for lymphedema. It is something patients struggle with their entire lives. Not only can this disorder be cosmetically displeasing and socially isolating, but it can be of significant medical consequence. If conservative measures are not available to patients early on in the diagnosis and consistently through life, worsening of the disease and its consequences will inevitably lead to higher medical costs.

Radiology

Ahmad Alomari, M.D.
Gulraiz Chaudry, M.D.
Rush Chewing, M.D.
Darren Orbach, M.D., Ph.D.
Horacio M. Padua, Jr., M.D.
Harriet I. Paltiel, M.D.
Raja Shaikh, M.D.

Neurology

Mustafa Sahin, M.D., Ph.D.
Siddharth Srivastava, M.D.

Neurosurgery

Edward Smith, M.D.
R. Michael Scott, M.D.

Orthopedic Surgery

Samantha Spencer, M.D.

Otorhinolaryngology

Reza Rahbar, D.M.D., M.D.

Pathology

Harry P.W. Kozakewich, M.D.
Alyaa Al-Ibraheemi, M.D.

Lymphedema is caused by the malformation or dysfunction of lymphatic vessels. As a result, protein-rich fluid can pool in the subcutaneous tissues and put pressure on the overlying skin. This can lead to significant swelling in the affected area, most often the extremities and/or genitalia. The swelling leads to heaviness in limbs and decreased mobility overtime if not properly managed. Overtime due to the buildup of fluid and consequential swelling, lymphatic fluid can leak out of openings in the skin. This can lead to pain, skin breakdown, foul-smelling drainage, and recurrent cellulitic infections requiring antibiotics, wound care and prolonged hospitalizations.

Plastic Surgery

Arin Greene, M.D.
John B. Mulliken, M.D.
Salim Afshar, D.M.D., M.D.
Joseph Upton, M.D.
Amir Taghinia, M.D.

Although there is not cure for lymphedema, there are some very effective conservative measures that patients can use to help minimize and control their symptoms. Medical grade compression stockings are the mainstay of what we recommend for our patients. These stockings help to push fluid out of the tissues and back into the circulatory system, therefore decreasing swelling, skin breakdown, and risk for other complications. It is imperative for patients to have access to proper fitting, well-made, elastic stockings in an effort to maintain skin integrity and slow down the progression of the disease. Manual lymphatic drainage and

Pulmonology

Debra Boyer, M.D.

Nurse Practitioner

Heidi Abendroth, FNP
Bridget DeYoung, MS, CPNP
Vicki Hamel, RN
Meghan O'Hare, RN, CPNP
Erin Spera, MS, CPNP

Social Work

Jacqueline Wehrl, LICSW

Administrative Supervisor

Amal Scott

pneumatic compression devices are other effective conservative therapies utilized by patients with lymphedema to control symptoms. Despite the fact that these devices can decrease the need for more specialized medical care and frequency of hospitalizations, many insurance carriers deny patients access to them. If patients are denied access to proper conservative therapies, their risk for problems increased greatly. The increased costs to insurance carriers once a patient gets to the advanced stages of lymphedema far outweigh the costs of stockings and pneumatic devices.

Access to conservative therapies is not only important for the individual patients' overall health maintenance, but also quite the cost-effective for insurance companies in the long run. We offer support for the above bills to afford patients with lymphedema access to the medical care they deserve.

Please do not hesitate to contact us with further questions.

Sincerely,



Denise Adams, Department of Hematology/Oncology and Co-Director of the Vascular Anomalies Center



Erin Spera, CPNP
Vascular Anomalies Nurse Practitioner

**BREAST
CANCER
ACTION**

May 7, 2019

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

Dear Senator Cantwell,

I am writing to offer Breast Cancer Action's formal endorsement of S.518, The Lymphedema Treatment Act.

Breast Cancer Action is a national, feminist, grassroots education and activist organization whose mission is to achieve health justice for all women at risk of and living with breast cancer. We are committed to ensuring that women living with a breast cancer diagnosis have access to needed treatments, including treatment for lymphedema.

For women diagnosed with breast cancer, the financial toll can quickly become yet another devastating side-effect of the disease. Health care coverage of breast cancer treatments should certainly extend to the ongoing health effects related to those treatments, including lymphedema.

All women should have access to needed treatment. Breast Cancer Action and allied organizations have been working to pass The Lymphedema Treatment Act for nearly 10 years, and as we wait for it to pass, women continue to go without medically necessary devices and equipment or make difficult choices between this equipment and other needs. Socio-economic status shouldn't mean that women with the debilitating effects of lymphedema get blocked from access to needed equipment and treatment.

On behalf of Breast Cancer Action's tens of thousands of members, thank you for introducing this important piece of legislation, and we look forward to its swift passage.

Sincerely,



Karuna Jaggar
Executive Director



CANCER LEGAL CARE

LAWYERS ON YOUR CANCER CARE TEAM

May 8, 2019

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

Dear Representative Cantwell:

As attorneys and advocates for individuals battling cancer, Cancer Legal Care thanks you for your leadership in introducing the Lymphedema Treatment Act (S.518).

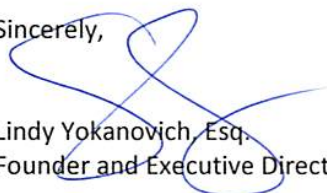
Lymphedema is a painful and potentially disfiguring side effect of cancer treatments caused by fluid buildup swelling affected body parts. More than three million Americans have lymphedema including forty percent of breast cancer patients. Left un- or undertreated, lymphedema causes additional medical complications, decreased quality of life, and increased morbidity.

While there is no cure, there is an effective, multipronged treatment for this chronic disease. However, Medicare patients are particularly vulnerable as Medicare does not cover a critical prong of the treatment: the compression supplies. Without the compression supplies, patients cannot receive the full treatment and, as such, are highly susceptible to re-swelling. Despite not covering the compression supplies, Medicare will cover the costly hospital visits required by individuals with uncontrolled lymphedema.

The Lymphedema Treatment Act would correct this defect in Medicare coverage by extending Part B Durable Medical Equipment coverage to compression supplies as prescribed by doctors for lymphedema patients. LTA would allow the more than 5,000 Medicare-eligible Minnesotans with lymphedema access the gold-standard of treatment.

Cancer patients must overcome too many obstacles. To leave them without coverage to manage this chronic side effect of their cancer treatment harms not only the patient but the overall Medicare budget. Appropriate and timely treatment remains the best weapon against both lymphedema and ballooning health care costs.

Sincerely,



Lindy Yokanovich, Esq.
Founder and Executive Director





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

– and –

The Honorable Chuck Grassley
175 Hart Senate Office Building
Washington, DC 20510

Dear Maria Cantwell and Chuck Grassley,

On behalf of Cancer Support Community Greater Philadelphia (CSCGP), I'm writing to inform you that we would like to offer our formal endorsement of the Lymphedema Treatment Act (S.1315/H.R.3630). Through my work at CSCGP, I facilitate an ongoing Lymphedema Networking Group, where I have met many cancer survivors affected by Lymphedema. These men and women have fought through so much in their cancer experiences. It is truly a shame that many of them also need to battle with their insurance providers to receive the care they need to manage their Lymphedema. Through our members sharing their experiences, we understand how compression garments can be greatly beneficial for Lymphedema management. We feel it is unacceptable for Medicare to not provide coverage for this service. Of course, it is also unfortunate that private insurance companies have also denied and/or limited coverage for compression garments. We fully support the Lymphedema Treatment Act and hope to see coverage improve for Lymphedema care.

It is CSCGP's mission to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. We provide a comprehensive professional program of social and emotional support and education designed to enhance the mind, body, and spirit of people whose lives have been affected by cancer. We have found that Lymphedema is a part of the cancer journey for many of our members and will continue supporting them, as we hope you will too!

Sincerely,
Courtney Connison, MSW, LSW



DANA-FARBER
CANCER INSTITUTE



BRIGHAM AND
WOMEN'S HOSPITAL



Craig A. Bunnell, MD, MPH, MBA
Chief Medical Officer
Dana-Farber Cancer Institute
Harvard Medical School

Dana-Farber Cancer Institute
450 Brookline Avenue
Boston, Massachusetts 02215-5450
617.632.5024 tel
617.582.7328 fax
www.dana-farber.org

May 21, 2019

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

The Honorable Todd Young
185 Dirksen Senate Office Building
Washington, DC 20510

Dear Senators Cantwell and Young:

On behalf of Dana-Farber Cancer Institute, I want to thank you for introducing the Lymphedema Treatment Act, S.518, which requires Medicare coverage of compression supplies used to treat lymphedema under the durable medical equipment benefit.

Dana-Farber is one of only ten NCI-designated, freestanding comprehensive cancer centers in the country and plays a leading role in making life-changing breakthroughs in cancer research and patient care. We appreciate your leadership on this important issue and believe passage of this legislation would bring significant benefits to the patients and families we serve at Dana-Farber.

As you know, lymphedema is the accumulation of lymph fluid (swelling) where lymph nodes or lymphatic vessels have been removed or damaged, most often as a result of cancer treatment, such as surgery or radiation therapy. Lymphedema can be progressive, leading to complications, comorbidities, loss of function, and disability, which can result in long term physical and psychosocial survivorship issues. Effective management of lymphedema through use of compression garments are critical to supporting cancer patients and enhancing their overall health and quality of life. As a result, S.518 would provide meaningful benefits to cancer patients and survivors in increasing the accessibility and affordability of medically necessary treatment supplies.

The Honorable Maria Cantwell
The Honorable Todd Young
May 21, 2019
Page 2

Thank you again for your leadership on this important issue. Please let us know if there's anything we can do to help advance these efforts.

Sincerely,

A handwritten signature in black ink, appearing to read 'CAB', with a large, stylized flourish extending from the end of the signature.

Craig A. Bunnell, MD, MPH, MBA
Chief Medical Officer
DANA-FARBER CANCER INSTITUTE

CAB/lmfc

April 25, 2019

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

This is my formal endorsement of the Lymphedema Treatment Act (S.518/H.R.1948).

I've specialized in this field for over 20 years, am the author of a book chapter on the subject and served on the American Society of Breast Surgeons Expert Panel on lymphedema that published its findings in the *Annals of Surgical Oncology*¹. I currently serve on the Board of the Lymphology Association of North America that administers the examination certifying medical professionals in the treatment of lymphedema (CLT-LANA). The gold standard of lymphedema treatment is the application of MEDICAL COMPRESSION GARMENTS. This fact is well researched. Compression garments are medical devices. They may look like familiar support stockings and sleeves, but they are different. Compression garments for lymphedema have specialized characteristics that are necessary for the treatment and control of this complex condition. I continue to practice full time in this field. Nearly every day, I see patients with the consequences of poorly treated lymphedema because their insurance companies and Medicare are denying them the correct medical treatment.

It is unacceptable that the only proven effective treatment for lymphedema, medical compression garments, is not covered by many insurance carriers including Medicare. The Lymphedema Treatment Act would rectify this error.

Lymphedema is a chronic, progressive disease of the lymphatic system that leads to enlargement of affected body parts as well as serious infections. The lymphatic vessels are the conduits of cellular debris that has to be destroyed within the lymph nodes to protect us from bacteria, viruses, tumor cells and other foreign matter that would kill us if we did not have a lymph system. So, lymphedema is not just a liquid swelling problem, it is an immune system defect. As lymphatic debris progresses and builds up under the skin, the affected person's skin becomes stretched, hardened and damaged making the skin an ineffective barrier to foreign matter and a breeding ground for more bacteria to get into the body. As the body part becomes larger, it becomes heavier, leading to damage to tendons and joints. The condition becomes ever more expensive to the person and insurance companies because of the infections, hospitalizations, and damage to other tissues. The condition becomes disfiguring, socially isolating and can become disabling such that the person may not be able to work.

Medical compression devices, in the form of specialized compression garments and bandages, treat these defects and reduce the secondary complications of the disease. Thank you.

Sincerely,



Nancy A Hutchison, MD

References:

1. McLaughlin, S.A., DeSnyder, S.M., Klimberg, S. et al. *Ann Surg Oncol* (2017) 24: 2827. <https://doi.org/10.1245/s10434-017-5964-6>
2. Stubblefield, M. (2019) *Cancer rehabilitation: Principles and practice* (2nd ed.) (pp. 1075-1099) New York: Springer Publishing Company.
3. Hutchison, N. *Diagnosis and Treatment of Edema and Lymphedema in the Cancer Patient. Rehabilitation Nursing* (2018) 43(4):229-24



ALEXANDER T. NGUYEN, MD, FACS, CLT
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www.lymphinstitute.com ♦ info@rmlatx.com

May 6, 2019

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

The Honorable Jan Schakowsky
2367 Rayburn HOB
Washington, DC 20515

The Honorable Earl Blumenauer
1111 Longworth HOB
Washington, DC 20515

The Honorable Todd Young
400 Russell Senate Office Building
Washington, DC 20510

The Honorable Buddy Carter
2432 Rayburn HOB
Washington, DC 20515

The Honorable Mike Kelly
1707 Longworth HOB
Washington, DC 20515

Re: The Lymphedema Treatment Act, S.518 and H.R.1948

Dear Senators and Representatives Cantwell, Young, Schakowsky, Carter, Blumenauer, and Kelly:

On behalf of myself and the Integrative Lymphedema Institute, I offer our formal endorsement of the Lymphedema Treatment Act, H.R.1948, and its Senate companion bill S.518.

In my capacity as an Oncologic Reconstructive and Lymphedema Surgeon, in addition to being a Certified Lymphedema Therapist, I have dedicated my career to comprehensive lymphedema care. I understand the effects of lymphedema, a serious medical disorder that affects millions of people throughout the United States. Lymphedema is a chronic, progressive, incurable but manageable condition in which swelling occurs in one or more extremities of the body. There are millions of women suffering from secondary lymphedema, following treatment of breast cancer alone. Some of the most common cancers causing lymphedema include breast cancer, gynecological cancers, melanoma, lymphoma, and sarcoma. In addition, many suffer from primary lymphedema, which occurs in babies and children and can also occur later in life.

For virtually all lymphedema patients, medical compression is the cornerstone of treatment to limit symptoms and to slow the progression of debilitating consequences. The timely and appropriate treatment of this condition would reduce costs of complications, infections, hospitalizations, and government disability expenditures. Most importantly, appropriate care with compression can improve quality of life.

Currently Medicare does not cover the medically necessary compression supplies used daily in lymphedema treatment, citing they do not fit under any benefit category. This bill would rectify this gap in coverage to provide the medically necessary compression supplies for proper treatment of this disease without a cure. Prevention of disease progression with compression is essential to patient care.

Thank you for your leading role in the sponsorship of the Lymphedema Treatment Act.

Sincerely,

Alexander T. Nguyen, MD, FACS, CLT



STEPHANIE FAJURI
Program Director, Cancer Legal Resource Center
DIRECT: 213.736.1031 x7432
FAX: 213.736.1428
EMAIL: Stephanie.Fajuri@drlcenter.org

April 10, 2019

The Honorable Maria Cantwell
511 Hart Senate Office Building
Washington, DC 20510
– and –
The Honorable Todd Young
400 Russell Senate Office Building
Washington, DC 20510

Re: Lymphedema Treatment Act (HR1948/S518)

Dear Senators Cantwell and Young,

I am writing on behalf of the Cancer Legal Resource Center to offer our organization's formal endorsement of the Lymphedema Treatment Act (HR1948/S518). This bill would expand the definition of Durable Medical Equipment under Medicare Part B to include lymphedema garments and bandages, thus allowing lymphedema patients to get the medical treatment they need.

Disability Rights Legal Center (DRLC) was founded in 1975 and is the nation's oldest cross-disability civil rights organization. We advocate for the rights of people with disabilities in order to eliminate discrimination and other legal barriers that keep people with disabilities in poverty. Our mission is to champion the rights of people with disabilities through education, advocacy, and litigation. The Cancer Legal Resource Center (CLRC), a program of the DRLC, supports this bill. The CLRC specifically provides legal assistance to cancer patients and caregivers, and recognizes that these individuals face many unique challenges. Every year CLRC's dedicated attorneys, staff members, and volunteers help thousands of patients and their families confront these challenges by providing individualized information about federal and state laws as well as locally available resources in a wide range of areas, including health insurance appeals, government benefits, disability benefits, financial assistance, advance planning options, and many others through our toll-free national telephone assistance line.

Many of our callers both nationally and locally in California have concerns about lymphedema and insurance coverage. Lymphedema is a chronic, progressive, and incurable condition that affects cancer patients when surgery, removal of lymph nodes to determine whether cancer has spread, radiation, or scar tissue build-up following radiation or surgery causes damage to the lymphatic system. Lymphedema often occurs in breast cancer patients, and may also affect individuals with uterine, prostate, vulvar, ovarian, head and neck cancers, lymphoma, or melanoma.

Untreated lymphedema results in the swelling of an arm, leg, or other body part because lymph fluid cannot drain properly. This swelling causes pain, difficulty engaging in the activities of daily



DISABILITY RIGHTS ADVOCACY CENTER

April 15, 2019

Page 2 of 2

life (including work), repeat hospitalizations, and can even cause total disability. While there is no cure, lymphedema can be treated and managed effectively.

Compression garments and bandages form an integral component of a successful lymphedema treatment regimen and are particularly important for the daily self-care necessary to control swelling and prevent development, or worsening, of associated health problems. Patients with lymphedema require the use of compression garments and/or bandages throughout the remainder of their lives.

Currently, Medicare does not cover compression garments or bandages. Medicare *does* cover costly visits to the hospital for systemic infections and other complications due to lymphedema that has not been properly controlled. Therefore, the cost of compression garments and bandages to control lymphedema is far less than the cost of repeat hospitalizations for untreated lymphedema that has progressed. Expanding the definition of Durable Medical Equipment under Medicare Part B to include lymphedema garments and bandages would help alleviate, not add to, the Medicare budget and eliminate unnecessary pain and suffering for millions of Medicare beneficiaries.

This important legislation would ensure that lymphedema patients who rely on Medicare can get the help they need to manage their conditions, alleviate pain, and continue as contributing members of society. The CLRC strongly supports the Lymphedema Treatment Act.

Sincerely,



Stephanie Fajuri, Esq.
Director, Cancer Legal Resource Center
Disability Rights Legal Center
350 S. Grand Ave., Suite 2010
Los Angeles, CA 90071
Stephanie.fajuri@drlcenter.org

CC: Heather Ferguson, Executive Director, Lymphedema Advocacy Group



June 27, 2019

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Development & Medical
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*The EveryLife Foundation for
Rare Diseases is a 501(c)3 organization
Tax ID # 26-4614274*

**1012 14th Street, NW
Washington, DC 20005
(202) 697-RARE (7273)
www.everylifefoundation.org**

Honorable Maria Cantwell
U.S. Senate
511 Hart Senate Office Building
Washington, DC 20510

Honorable Todd Young
U.S. Senate
400 Russell Senate Office Building
Washington, DC 20510

Dear Senators Cantwell and Young:

On behalf of the EveryLife Foundation for Rare Diseases, thank you for your leadership in introducing S. 518, the Lymphedema Treatment Act. The EveryLife Foundation is a nonprofit dedicated to advancing the development of treatment and diagnostic opportunities for rare disease patients through science-based public policy.

We strongly support the Lymphedema Treatment Act which would provide a Medicare benefit category for coverage of the physician-prescribed compression supplies used in the treatment and management of lymphedema.

Lymphedema is chronic swelling (edema) caused by a build-up of fluid (lymph) that occurs when the lymphatic system is either faulty or damaged and is associated with over 40 rare diseases. There is no cure for lymphedema, but it can be effectively treated.

Compression is to lymphedema as insulin is to diabetes. Compression treats the disease and prevents complication, enabling patients to remain healthy and productive while reducing overall healthcare expense.

Currently, Medicare does not cover these critically necessary compression supplies as they are not classified under any existing Medicare benefits category.

Without compression garments, the disease progresses, often resulting in hospitalization for life-threatening cellulitis infections. Compression stockings are the most effective and least expensive treatment to control the disease and can save overall health care dollars.

Thank you for supporting the Lymphedema Treatment act which would help prevent the needless suffering of millions of Americans who have lymphedema, improve the quality of their lives and reduce overall healthcare costs.

Sincerely,

Julia Jenkins
Executive Director

May 20, 2019

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

The Honorable Todd Young
United States Senate
400 Russell Senate Office Building
Washington, DC 20510

Dear Senators Cantwell and Young:

On behalf of millions of cancer patients, survivors and their families, Greet The Day commends you for your leadership in introducing S. 518, the Lymphedema Treatment Act.

The Lymphedema Treatment Act 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.

The Lymphedema Treatment Act is so important, and we thank you again for your leadership on this important issue.

Sincerely,



Johnette du Rand
Program Director

501(c)(3) Nonprofit Organization
Tax ID number 20-2497449

PO Box 8294, Newport Beach CA 92658
949-544-1-GTD (1483) ● GreetTheDay.org



LIGHTHOUSE LYMPHEDEMA NETWORK
10240 Crescent Ridge Drive, Roswell, GA 30076
770-442-1317
www.lighthouselymphedema.org

May 20, 2019

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

The Honorable Todd Young
400 Russell Senate Office Building
Washington, DC 20510

Dear Senator Cantwell and Senator Young,

On behalf of the lymphedema patients across the United States, the Lighthouse Lymphedema Network thanks you for your leadership in introducing **S.518, the Lymphedema Treatment Act**.

The Lighthouse Lymphedema Network was founded in Roswell, GA, in 1994. It is a non-profit 501(C)(3) organization of individuals who are lymphedema patients, family members, therapists, caregivers, or who have a genuine interest in lymphedema. Our goal is to educate, promote awareness, and provide support for lymphedema patients, the medical community, family and caregivers, insurance companies, the general public, and other lymphedema support groups.

Lymphedema is a medical condition affecting an estimated 1.5 to 3 million Medicare beneficiaries who are not currently receiving treatment from Medicare according to the current medical standard of care. What is worse is that Medicare is spending billions of dollars every year treating largely preventable lymphedema-related cellulitis infections.

Lymphedema is incurable, progressive, and, if left untreated, the swollen area(s) can become fibrotic and prone to serious, debilitating infections. Over time, untreated lymphedema results in disfigurement, disability, and even death.

The Lighthouse Lymphedema Network applauds your effort to close this coverage gap so that lymphedema patients can access the compression treatment supplies needed to manage this chronic condition. Please contact us with questions.

Sincerely,

Joan White, Director
Lighthouse Lymphedema Network

Designated a comprehensive cancer center by the National Cancer Institute

☎ 919-966-3036 · 📠 919-962-8472

April 11, 2019

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

The Honorable Todd Young
400 Russell Senate Office Building
Washington, DC 20510

Dear Senators Cantwell and Young:

On behalf of The UNC Lineberger Comprehensive Cancer Center (UNC LCCC), thank you for reintroducing the Lymphedema Treatment Act, S.518, which provides Medicare coverage of compression items as durable medical equipment. UNC LCCC supports this important piece of legislation.

As you are aware, lymphedema is swelling of tissues resulting from blockage of the lymphatic system. It is most commonly caused by removal or damage to lymph nodes as part of cancer treatment from surgery, to radiation or the cancer itself. Lymphedema can occur months to years after cancer treatment has been completed, contributing to long term physical and psychosocial survivorship issues. Complications include infections or even a soft tissue cancer, both of which may be mitigated with treatment, making S.518/H.R.1948 important to cancer survivors to improve access to care and affordability of treatment.

The UNC LCCC is one of the nation's premier cancer centers for the prevention, detection and treatment of cancer. The UNC LCCC is a top-ranked center in the United States designated by the National Cancer Institute as a Comprehensive Cancer Center. In particular, we have a large and vibrant program in breast oncology, and many patients in this program would benefit from better lymphedema care. We thank you for your leadership on this important issue.

Sincerely,



H. Shelton Earp, III, MD
Director, UNC Lineberger Comprehensive Cancer Center
Director, UNC Cancer Care
Lineberger Professor of Cancer Research
Professor of Medicine & Pharmacology



May 21, 2019

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

The Honorable Todd Young
400 Russell Senate Office Building
Washington, DC 20510

RE: The Lymphedema Treatment Act, S.518

Dear Representatives Cantwell and Young:

I write to thank you for championing the Lymphedema Treatment Act. As President and CEO of the Lymphatic Education & Research Network (LE&RN), I am all too aware of the millions of Americans who suffer from lymphedema. The disease itself is traumatizing. This is then only exacerbated by their struggle to receive treatment, which is often not covered by insurance. The Lymphedema Treatment Act addresses this inequity by ensuring Medicare covers compression garments—a cornerstone of lymphedema treatment.

The Lymphatic Education & Research Network most strongly supports S.518, and we thank you for your advocacy on behalf of all those suffering from lymphedema.

Sincerely,

William Repicci
President & CEO



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

Dear Senator Cantwell,

On behalf of the Lymphology Association of North America (LANA), I am writing to inform you of LANA's support of S.518, The Lymphedema Treatment Act. When enacted, S.518 will improve the quality of care for Medicare beneficiaries who have lymphedema and related vascular disorders by mandating coverage for the full spectrum of medically necessary lymphedema treatment including compression garments and bandages. The LANA Board believes this legislation will reduce health infections and disabling limb swelling.

LANA is a lymphedema therapist certification board founded in 1999 with support from the American Cancer Society. LANA's mission is to promote standards for management of individuals with lymphedema.

The LANA Board thanks you for sponsoring S.518 and for the time you and staff have devoted to this important legislation.

Sincerely,

Joseph L. Feldman, M.D.

Joseph L. Feldman, M.D., CLT-LANA
President

cc: Heather Ferguson

William G. Nelson, M.D., Ph.D.
Marion I. Knott Director and Professor of Oncology
Director, Sidney Kimmel Comprehensive Cancer Center

The Harry and Jeanette Weinberg Building
401 North Broadway / Suite 1100
Baltimore, Maryland 21287
410-955-8822 T
410-955-6787 F
bnelson@jhmi.edu



April 22, 2019

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

The Honorable Janice D. Schakowsky
2367 Rayburn House Office Building
Washington, DC 20515

Dear Members of Congress:

As the largest Comprehensive Cancer Center in the State of Maryland, we at the Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins University thank and applaud your sponsorship of the Lymphedema Treatment Act (S518/HR1948). Lymphedema is a condition that affects up to 60% of women with a history of breast cancer, and this piece of legislation is poised to improve coverage for compression supplies for lymphedema treatment.

NIH-funded research conducted by faculty at our institution underscores the importance of reducing barriers to lymphedema treatment, especially for breast cancer survivors. Patients with lymphedema face great short-term and long-term financial and emotional costs. Previous research estimates lymphedema costs to be \$15,000 annually in the first two years.[1]

A 2018 study by our own Dr. Lorraine T. Dean in the *Journal of Supportive Care in Cancer* suggested high costs have long-term impacts. Her study estimated that women with breast-cancer related lymphedema face up to over double (112%) of annual out-of-pocket healthcare costs as women without breast-cancer related lymphedema, even 10 years after cancer treatment (\$2,306 versus \$1,090).[2] Patient interviews affirmed that these excess expenditures have implications for jobs and consumer credit that affect them for generations.

The Lymphedema Treatment Act requests an amendment of Title XVIII of the Social Security Act (Medicare) to cover certain lymphedema compression treatment items as durable medical equipment, thus alleviating the patient out-of-pocket costs for an item that is critical to lymphedema self-management. This legislation can lower costs for patients, with negligible short-term and long-term financial impact to insurers. A 2016 report found that expanding insurance coverage to include lymphedema treatment in one state had a less than 0.1% impact on insurance claims, and less than 0.2% impact on insurance premiums after 10 years, while lowering costs for lymphedema treatment and lymphedema-related hospitalizations.[3]

Thank you for your leadership on this important issue that can improve lives for those with a history of cancer.

Sincerely,

A handwritten signature in black ink, appearing to read 'W. Nelson', with a stylized flourish at the end.

William G. Nelson, M.D., Ph.D.

CC: Rep. Anthony G. Brown, Rep. David Trone, Rep. A. Dutch Ruppertsberger, Rep. Andy Harris, Rep. Steny Hoyer, Rep. Jamie Raskin, Rep. John B. Sarbanes, Rep. Elijah Cummings, Sen. Benjamin L. Cardin, Sen. Chris Van Hollen

1. Shih, Y.-C.T., et al., *Incidence, Treatment Costs, and Complications of Lymphedema After Breast Cancer Among Women of Working Age: A 2-Year Follow-Up Study* *Journal of Clinical Oncology*, 2009. **27**(12): p. 2007-2014.
2. Dean, L.T., et al., "It Still Affects Our Economic Situation" *Long-Term Economic Burden of Breast Cancer and Lymphedema*. *Journal of Supportive Care in Cancer*, 2018: p. [in press].
3. Weiss, R., *Cost of a lymphedema treatment mandate-10 years of experience in the Commonwealth of Virginia*. *Health economics review*, 2016. **6**(1): p. 42.

May 13, 2019

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

The Honorable Janice Schakowsky
2367 Rayburn House Office Building
Washington, DC 20515

The Honorable Todd Young
185 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Buddy Carter
2432 Rayburn House Office Building
Washington, DC 20515

Dear Members of Congress:

On behalf of Moffitt Cancer Center in Tampa, Florida, thank you for your leadership in introducing the Lymphedema Treatment Act (S518/HR1948). As one of the nation's leading cancer treatment centers, we applaud your efforts to improve coverage for the compression supplies that are vital to lymphedema treatment.

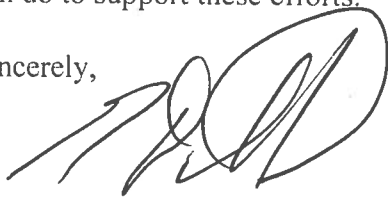
Lymphedema is most commonly caused by the removal of or damage to lymph nodes through surgery, radiation, or cancer itself. Lymphedema can occur immediately following treatment, or not until months or years later, contributing to long-term physical and psychosocial issues.

Approximately 15% of all survivors are affected by lymphedema. While there is no cure, it can be effectively treated. When untreated or under-treated, lymphedema is progressive, leading to complications, comorbidities, loss of function, and disability.

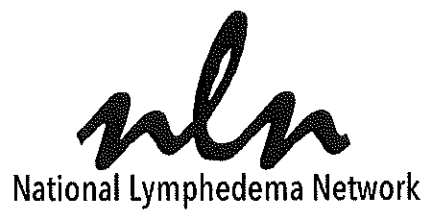
Effective management of lymphedema through the use of compression garments and supplies is critical to supporting patients and enabling them to maintain their health and quality of life. This legislation would provide meaningful benefits to cancer patients and survivors by increasing the accessibility and affordability of these doctor-prescribed medical supplies.

Thank you again for your leadership on the important issue. Please let us know if there is anything we can do to support these efforts.

Sincerely,



G. Douglas Letson, MD
Executive Vice President
Physician in Chief
Moffitt Medical Group President
Moffitt Cancer Center



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

The Honorable Todd Young
400 Russell Senate Office Building
Washington, DC 20510

August 22, 2019

Dear Senators Cantwell & Young,

On behalf of the National Lymphedema Network (NLN), I am writing to inform you that our organization endorses S.518, the Lymphedema Treatment Act.

Since 1988, the NLN has provided information, support, and guidance to patients, caregivers, advocates, and clinicians throughout the United States. We maintain a toll-free hotline for patients, as well as a network of certified lymphedema therapists whose credentials we review annually. The NLN also hosts annual international conferences and publishes newsletters read by both healthcare professionals and patients alike. Our most sought-after service continues to be the Garment Program.

Created by lymphedema patient Marilyn Westbrook and her husband shortly before her death in 2007, the fund helps patients in financial need get the garments they desperately need. Through this program and in collaboration with generous support from our industry partners, the NLN is able to provide many patients with proper compression garments. Yet thousands of patients remain without proper garments.

On behalf of our patients, we thank you immensely for your support of the Lymphedema Treatment Act and look forward to the day when all patients with lymphedema have access to proper treatment and can be provided with medically necessary compression garments.

Sincerely,

A handwritten signature in black ink that reads 'Jeannette N. Zucker'. The signature is written in a cursive style with a large initial 'J'.

Jeannette N. Zucker (Aug 30, 2019)

Jeannette Zucker
Executive Director
National Lymphedema Network

A handwritten signature in black ink that reads 'Michael Cannon'. The signature is written in a cursive style with a large initial 'M'.

Michael Cannon
Board Chair
National Lymphedema Network

Cc: Heather Ferguson
Founder and Executive Director
Lymphedema Advocacy Group



Oncology Nursing Society

125 Enterprise Drive • Pittsburgh, PA 15275-1214
Toll Free: 866-257-4ONS • Phone: 412-859-6100 • Fax: 412-859-6165
help.ons.org • www.ons.org

March 1, 2019

The Honorable Maria Cantwell
United States Senate
Washington, D.C. 20510

RE: Support for S. 518, the *Lymphedema Treatment Act*

Dear Senator Cantwell:

On behalf of the Oncology Nursing Society (ONS), I write to thank you for sponsoring S. 518, the *Lymphedema Treatment Act*. This bill will improve insurance coverage for compression supplies that are the cornerstone of lymphedema treatment.

As you well 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. Your legislation would close this coverage gap by requiring Medicare to cover lymphedema compression items under the Part B durable medical equipment (DME) benefit.

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. This bill 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 39,000 registered nurses and other health care 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 professional roles, practice settings, and subspecialty practice areas. Oncology nurses are leaders in the health care 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. If ONS may be of assistance in this endeavor, please contact Donna (Dede) Sweeney, ONS Director of Government Affairs, at dsweeney@ons.org.

Sincerely,

A handwritten signature in blue ink that reads "Laura Fennimore".

Laura Fennimore, RN, DNP. NEA-BC
President, Oncology Nursing Society

Jasmine Zheng M.D.
Assistant Professor

July 14, 2019

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

Dear Senator Cantwell:

On behalf of University of Pennsylvania Department of Physical Medicine and Rehabilitation, I'm writing to inform you that we would like to offer our formal endorsement of the Lymphedema Treatment Act (S.518/H.R.1948).

I am a practicing cancer physiatrist at Penn Medicine and frequently evaluate, diagnose, and manage lymphedema. Many of my patients have lymphedema as a result of cancer treatment, while others have lymphedema as a result of congenital lymphedema, Milroy's disease, Klippel-Trenaunay Syndrome, lipedema, organ transplantation, chronic venous insufficiency, or trauma. Despite the cause of lymphedema, the international standard of care for treatment includes lymphedema therapy and long term use of compression garments that at a minimum needs to be replaced every 6 months.

Lymphedema is a life-long condition that requires ongoing medical management along with continuous compression. The current international standard of care for lymphedema requires use of appropriate compression on a 24-hour basis. Failure to provide adequate compression can lead to significant medical, psychological and functional morbidity. Specifically, patients are left vulnerable to worsening lymphedema, potentially life-threatening cellulitis infections, chronic pain and non-healing wounds. Unfortunately, Medicare currently does not cover these medically necessary compression garments, despite the evidence for the increase in morbidity and mortality associated with untreated lymphedema and the international standard of care to treat with 24-hour compression garments. Furthermore, many patients are unable to financially afford the costs of compression garments that can be several hundred dollars a year.

I ask that you support the Lymphedema Treatment Act (S.518/H.R.1948) to ensure that your constituents receive the medically prescribed care that they need. Please contact me if any additional information is required.

Sincerely,



Jasmine Zheng, MD
Assistant Professor, Dept. of Physical Medicine and Rehabilitation
Penn Medicine
1800 Lombard Street, First Floor
Philadelphia, PA 19146
215-893-2600 (p)
215-893-2632 (f)

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

The Honorable Todd Young
400 Russell Senate Office Building
Washington, DC 20510

May 6, 2019

Dear Senator Cantwell and Senator Young,

On behalf of the Seattle Cancer Care Alliance (SCCA), I'd like to thank you for your ongoing efforts to pass the Lymphedema Treatment Act (S.518).

SCCA—along with its partner organizations the Fred Hutchinson Cancer Research Center, Seattle Children's Hospital, and University of Washington Medicine—is an NCI-Designated Comprehensive Cancer Center that provides patients with access to cutting-edge cancer treatment and the latest innovations in cancer care. Our consortium of organizations drives some of the best clinical outcomes in the region and in the country and is making pioneering changes in how cancer is treated—extending lives and even finding cures.

Lymphedema—a condition that results in swelling—often occurs as a result of cancer treatment, which may cause damage to lymph nodes and lymph vessels. Lymphedema can be painful and debilitating for patients. Compression garments offer a simple yet critical treatment for lymphedema, but currently they are not covered by Medicare. This legislation would play a critical role in expanding access to these garments, improving the lives of the patients we treat and those all over the country.

SCCA joins the Lymphedema Advocacy Group and other cancer hospitals in supporting the Lymphedema Treatment Act. We appreciate your leadership on this issue and offer our support for your efforts.

Sincerely,



Aaron Crane
Interim Executive Vice President & Chief Financial Officer
Seattle Cancer Care Alliance



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NATIONAL OFFICE

SOCIETY FOR VASCULAR NURSING
9400 W. Higgins Rd., Ste 315
Rosemont, IL 60018
info@svnnet.org
www.svnnet.org

October 1, 2019

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

The Honorable Todd Young
185 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Jan Schakowsky
2367 Rayburn House Office Building
Washington, DC 20515

The Honorable Buddy Carter
2432 Rayburn House Office Building
Washington, DC 20515

Dear Members of Congress:

On behalf of the Society for Vascular Nursing (SVN), I write to thank you for sponsoring S. 518, the Lymphedema Treatment Act. This bill will improve insurance coverage for compression supplies that are the cornerstone of lymphedema treatment.

Lymphedema is most commonly caused by the removal of or damage to lymph nodes as a part of cancer treatment. It results from a blockage in the lymphatic system, which is part of your immune system. The blockage prevents lymph fluid from draining well, and the fluid buildup leads to swelling. Patients with Lymphedema are often treated by vascular medicine providers, including vascular nurse practitioners. A key treatment is compression therapy to reduce the affected limb to near normal size and prevent complications related to edema. Despite being an ongoing necessity, compression supplies are not covered by Medicare. Your legislation would close this coverage gap by requiring Medicare to cover lymphedema compression items under the Part B durable medical equipment (DME) benefit.

This bill will afford our nurses the opportunity to be more effective caregivers and ultimately will result in more successful outcomes for vascular patients nationwide.

Founded in 1982, the SVN is a not-for-profit international association dedicated to promoting excellence in the compassionate and comprehensive management of persons with vascular disease. The Society's mission is to provide a professional community for nurses focused on advancing the care of persons living with vascular disease through excellence in evidence-based practice and education.

The SVN appreciates your leadership on this issue of access to lymphedema treatment. If SVN may be of assistance in this endeavor, please contact Joanna Bronson, Inter-Society Relations Director, at jbronson@vascularsociety.org.

Sincerely,

Patty Flanagan, MSN, RN-BC
President, Society for Vascular Nursing

Stephen D. Nimer, M.D.

Director, Sylvester Comprehensive Cancer Center
Professor of Medicine, Biochemistry & Molecular Biology

June 20, 2019

The Honorable Maria Cantwell

511 Hart Senate Office Building
Washington, DC 20510

The Honorable Jan Schakowsky

2367 Rayburn House Office Building
Washington, DC 20515

The Honorable Todd Young

185 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Buddy Carter

2432 Rayburn House Office Building
Washington, DC 20515

Dear Members of Congress:

On behalf of the Sylvester Comprehensive Cancer Center, we thank you for introducing the Lymphedema Treatment Act (S.518/H.R.1948), which seeks to improve access of medical supplies vital to lymphedema treatment and management. We applaud your efforts in advocating for this important issue as Lymphedema affects an estimated 3-5 million men, women, and children in the United States.

Lymphedema is a chronic and potentially progressive condition which is characterized by swelling and discomfort, often seen in patients undergoing cancer treatment given the removal of or damage to lymph nodes. At Sylvester, our mission is to alleviate the burden of cancer through compassionate, patient-centric care, and we believe policies like this will help support patients and enable them to maintain a healthier quality of life.

While there is no cure, Lymphedema can be effectively managed and treated by increasing the accessibility and affordability of these prescribed medical supplies of bandages and compression garments. This legislation lessens the opportunity for lack of treatment which can otherwise result in worsening symptoms and an increase in complications, comorbidities, loss of function, and disability.

Thank you again for your leadership on this meaningful legislation. We support your continued efforts in advocating for the successful passage of the Lymphedema Treatment Act.

Sincerely,



Stephen D. Nimer, M.D.



Historic Past,
LIMITLESS FUTURE

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March 4, 2019

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

The Honorable Todd Young
United States Senate
400 Russell Senate Office Building
Washington, DC 20510

Dear Sens. Cantwell and Young,

On behalf of the Wound, Ostomy and Continence Nurses Society, I thank you for your introduction of S. 518 -- The Lymphedema Treatment Act. As primary health care providers for the majority of patients with venous leg ulcers, we believe S. 518 is a vital piece of legislation that Congress should quickly pass. Founded in 1968, the Wound, Ostomy and Continence Nurses Society (WOCN) is a professional, international nursing society of more than 5,000 healthcare professionals who are experts in the care of patients with wound, ostomy and/or incontinence needs.

As you are aware, Lymphedema is a condition resulting in swelling in the arms and legs caused by a disruption in the lymphatic system. As your legislation speaks to, lymphedema can be controlled by the use of compression therapy; however, there are other conditions, such as venous leg ulcers (VLU), which can also be treated with the use of compression therapy. In fact, compression therapy is considered the gold standard for treatment of lymphedema and for the prevention of VLUs. The medical literature supports appropriate compression as a means to reduce the incidence of costly recurrence of both of these afflictions.

Venous Leg Ulcers (VLUs) affect about 1-3% of the American population and are the most common of all lower extremity ulcerations. The primary risk factors for venous ulcer development are older age, obesity, previous leg injuries, deep venous thrombosis, and phlebitis. Venous ulcers are usually recurrent, and an open ulcer can persist for weeks to many years. Venous ulcers, or stasis ulcers, account for 80 percent of lower extremity ulcerations.

United States Senate

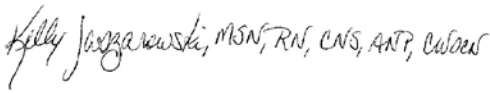
March 4, 2019

Page 2

Unfortunately, the Centers for Medicare and Medicaid Services (CMS) will not cover compression therapy, either for the treatment of Lymphedema or for the prevention of VLUs, despite the large scope of the problem. Congress should consider the direct and indirect costs associated with the current suboptimal treatment of the 1.4-3 million Medicare beneficiaries estimated to suffer from lymphedema, and the approximately 500,000 additional patients suffering from VLUs. Lack of access to the gold standard needed to treat these conditions results in many beneficiaries suffering from recurrent infections, progressive degradation in their condition and, too often, disability. If S. 518 is passed, and CMS is granted the statutory authority to cover compression therapy, the federal government can reduce costs associated with these diseases by decreasing the incidence of complications and disabilities.

WOCN strongly endorses S. 518 and thank you for bringing this issue the attention it deserves. If we can be of assistance to you in any way, please contact Chris Rorick of the Society's staff at chris.rorick@bcplaw.com. Thank you again for taking up this important cause.

Sincerely,

Handwritten signature of Kelly Jaszarowski in black ink, with the text "Kelly Jaszarowski, MSN, RN, CNS, ANP, CWCN" written below it.

Kelly Jaszarowski, MSN, RN, CNS, ANP, CWCN
WOCN Society President