

March 24, 2022

Dear President Biden,

Twelve years ago, I sat glued to my TV until late at night, watching each member of Congress speak and then vote, and breathed a sigh of relief when the Affordable Care Act passed! Prior to the ACA, my husband and I lived in fear of losing our employer-based health insurance, because we knew we were unable to buy our own policy for one of our sons, who had been born a few years earlier with a congenital defect.

We will be forever grateful to you and President Obama for ensuring that people with preexisting conditions can no longer be discriminated against. However, grave challenges remain for Americans like my son, who have health insurance, yet are still denied coverage for medically necessary care.

In 2008, I had the great privilege of introducing you and Dr. Bill Biden at a rally in Charlotte, NC. I was selected precisely because of the struggles we had faced accessing care for my son. I shared my family's story at the podium and was also honored to be able spend a few minutes alone discussing this with you and Dr. Biden. That day changed my life.

Thanks in part to your encouragement, I went on to lead a national effort to pass a bill called the Lymphedema Treatment Act (H.R.3630/S.1315). This legislation will improve access to vital treatment supplies for millions of Americans who, like my son, have a chronic condition called lymphedema. Amazingly, thanks to the power of grassroots advocacy, this is the most supported healthcare bill for the third consecutive Congress, and currently has 72 Senate and 338 House cosponsors!

Primary (congenital) lymphedema like my son Dylan was born with is rare, but secondary lymphedema is not, and is a common side effect of cancer treatment. An estimated 3 million Medicare beneficiaries and 5 million Americans in total struggle with this chronic condition, the majority of whom are cancer survivors.

I applaud your leadership on the Cancer Moonshot Initiative, however, it's important to note that 15% of survivors overall, and 40% of breast cancer survivors, will develop life-long lymphedema as a result of their cancer treatment. Increasing survivorship is a wonderful thing, but will also mean more people developing lymphedema, and it's critically important that these patients have access to the healthcare they need to live full and productive lives after beating cancer.

The Lymphedema Treatment Act is a simple, commonsense, bipartisan bill that could be passed right now, to immediately improve the health and lives of millions of survivors, plus millions of other Americans, who, like my son, have lymphedema due to other causes. Further, this bill will save an immense amount of money due to avoided complications and hospitalizations.

I know you have an unprecedented number of critical issues before you, but if a member of your administration could please urge Congress to pass this commonsense, bipartisan bill this year it would mean the world to millions of American families who have a loved one who struggles with this chronic and potentially debilitating disease. Please help us.

I am enclosing a one-page facts sheet and a few personal photos below. Thank you for service to our nation. I wish you and your wonderful family all the best.

Sincerely and gratefully,



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



Me and Dr. Jill Biden, 2008



My family at the event, 2008



A more recent picture of my sons,
Devdan (on the left) and Dylan (on the right)

Lymphedema Treatment Act

(H.R.3630/S.1315)

BACKGROUND

The Lymphedema Treatment Act provides a technical correction to the Medicare statute and eliminates an unintended gap in coverage for up to 3 million Medicare beneficiaries suffering from lymphedema. It will also set a precedent for the millions of additional patients on Medicaid and private insurance plans that align their coverage with Medicare.

Tremendous bipartisan support, making it the most cosponsored healthcare bill for three Congresses:

- **115th Congress** – 385 House and 66 Senate | **116th Congress** – 386 House and 71 Senate
- **117th Congress** – as of 3/24/22, 339 House and 72 Senate cosponsors

No opposition and supported by over 40 patient and professional groups, including:

American Cancer Society, American Medical Association, Oncology Nursing Society, Susan G. Komen, American Physical Therapy Association, and American Occupational Therapy Association.

Passed by the House during the 116th Congress as part of H.R.3.

Modified language for the 117th Congress, based on Technical Assistance from CMS and questions from CBO during the 116th Congress, will ease implementation and reduce costs. Per CMS recommendation, the current bill creates a new benefit category for lymphedema compression supplies, rather than adding them under DME. Streamlined language is estimated to reduce the score by one-third, while preserving the intent of the bill and improvements to patient care.

SAVINGS

A recent savings analysis from Avalere Health estimated that enactment of the Lymphedema Treatment Act will save the Medicare program \$1.3 to \$1.5 billion during the first 10 years, with additional savings likely.

TIMELINESS

The Lymphedema Treatment Act aligns with the healthcare priorities of the current administration:

- **Making Medicare coverage more comprehensive.**
- **Improving care for cancer patients and chronic conditions.**
- **Addressing health disparities.** Recent data has shown that women of color are three times more likely than white women to develop breast cancer-related lymphedema, which is the leading cause of lymphedema in the United States, and once acquired, it is more difficult for them to obtain adequate treatment due to the gap in insurance coverage for their prescribed medical compression supplies.
- **Lowering prescription costs.** There is no pharmaceutical treatment for Lymphedema – doctor prescribed medical compression garments are the treatment used daily by lymphedema patients to manage their disease, just as prescription drugs are essential to the management of other chronic diseases. Lymphedema patients currently face significant barriers to obtaining treatment due to the out-of-pocket expense associated with purchasing their prescribed compression garments.

COVID has increased the urgency of passing the Lymphedema Treatment Act for this vulnerable patient population. Lymphedema patients are often cancer survivors and frequently have other comorbidities. Without access to the medical supplies needed to manage this chronic disease patients suffer from a significantly higher rate of complications, many of which require urgent medical care at a time when our healthcare system is already strained by the pandemic, and increases their risk for COVID exposure.