



Lymphedema: The Under-diagnosed and Under-insured Disease that Affects Millions of Americans

Take a Stand and Support the Lymphedema Treatment Act on March 6

WASHINGTON, D.C. (March 4, 2015) – For most of her life, Sarah Bramblette’s legs were abnormally large. She had no idea what caused the problem and the recommendation from doctors was always the same – to lose weight.

For years that was all she heard, until eventually she learned she had lymphedema—a chronic disorder that causes swelling, pain and cellulitis, which, if left untreated, can lead to death.

“Growing up with lymphedema, any time I tried to lose weight, it didn’t work. It didn’t matter what I did, I was gaining weight.”

What was actually happening had nothing to do with weight; it was lymph fluid retention. Her lymph drainage system had shut down and was not properly circulating the protein-rich fluid. Over time it caused more and more swelling in her limbs. She experienced severe discomfort, her legs leaked fluids and her life took a drastic turn for the worse. For a while she didn’t know if she’d even survive.

“In my sophomore year of college (1996) it started to get worse. By 1999, my legs were weeping fluid. I didn’t understand what was going on. My pants would be wet, and I thought, what is this stuff coming out of my legs?”

Bramblette’s story isn’t unusual. Millions of American’s suffer from lymphedema and don’t know it. They are also unaware of the treatments available to them.

Lymphedema most frequently affects the limbs, but can occur in any part of the body. Complete decongestive therapy is the standard of care and has multiple components, the most important of which is compression. These doctor-prescribed compression garments and devices are currently not covered by most public and private insurance companies.

The highly specialized and often-custom medical garments provide “gradient pressure” to move fluid from higher-pressure areas to lower-pressure areas, which reduces swelling. The garments must be worn daily. If swelling is left unchecked, patients can experience the buildup of permanent scar tissue as well as serious infections like cellulitis, which often requires emergency hospital visits and IV antibiotics.

Lymphedema is an incurable disease. It can be hereditary, or caused by surgery or injury – anything that damages the lymph nodes or lymphatic drainage system. Cancer treatments that remove or damage lymph nodes are the most common cause.

Due to lack of public awareness and medical provider education, patients suffering from lymphedema often go undiagnosed, and once they are diagnosed, they are still frequently unable to access care because their insurance does not cover their doctor-prescribed compression garments and devices. Compression for lymphedema is what medication is for many other diseases – indispensable.

That is where the Lymphedema Treatment Act comes in. The Lymphedema Advocacy Group – many who suffer from the disease themselves – are working to build support for this federal bill that would enable Medicare coverage for compression garments. Although the legislation relates specifically to a change in Medicare law, it would set a precedent for Medicaid and private insurers to follow.

“It is so important that we make sure lymphedema patients have access to the treatments that can help ease their pain and improve their quality of life,” said U.S. Rep. Dave Reichert, R-WA. “I was proud to sponsor the Lymphedema Treatment Act last Congress and will be reintroducing it this year as soon as possible.”

Heather Ferguson, who founded the Lymphedema Advocacy Group, is spearheading the bill. Her son Dylan, now eight, was born with lymphedema in his legs and feet. When she realized very little was known about her son’s disease and that coverage wasn’t available, she got to work.

“Imagine first struggling to find out what is wrong with your child, then learning he has an incurable disease. Then you’re told your insurance won’t cover the treatment that will keep him from suffering from disfiguring and disabling complications and infections that are so serious they can lead to death,” she said.

By not covering compression supplies, insurance companies are forced to instead cover far more costly emergency hospital visits and medications that easily could have been avoided if patients had the garments and devices they needed.

“The Lymphedema Advocacy Group is working tirelessly to see that this bill is passed. It will significantly improve the quality of life for millions of Americans with lymphedema, while also reducing the total healthcare costs associated with the chronic disease,” Ferguson said.

Now that she has an accurate diagnoses, Bramlette must buy two new pairs of compression garments every six months because the garments’ elasticity wears out, making them ineffective. She’s struggled to afford the garments throughout the years. She decided to help others by becoming an advocate as well as a board member for the Lymphedema Advocacy Group. Recently she was featured on “The Doctors” television show. That segment can be found at <http://www.thedoctorstv.com/videos/lymphedema-treatment-act>.

To raise awareness, the public is encouraged to learn more during the month of March – Lymphedema Awareness Month. March 6 has been designated as Lymphedema Awareness Day. Those with lymphedema, doctors, therapists, family members and anyone else interested in helping are encouraged to get involved by visiting www.LymphedemaTreatmentAct.org.

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Media Contact

Elizabeth Baker, 509-910-1097, elizabethannebaker@gmail.com

About Lymphedema Advocacy Group

The Lymphedema Advocacy Group (LAG) is an all-volunteer nationwide organization of patients, caregivers, healthcare professionals and industry partners. Its mission is to advance lymphedema care in the United States by advocating for improved insurance coverage for the diagnosis and treatment of the disease. For this purpose the organization works to increase awareness of and education about lymphedema amongst lawmakers, insurance providers and other relevant entities. LAG supports attempts to improve coverage at both the state and federal levels and encourages all members of the lymphedema community to become active participants in this process. Visit www.lymphedematreatmentact.org to learn more or contact us at info@LymphedemaTreatmentAct.org.