

Heather Ferguson, founder and executive director, Lymphedema Advocacy Group, Charlotte, N.C.

PHIL HALL | 03.17.2014 | SUPERSTAR OF THE WEEK



A couple of weeks ago, this website received a large amount of positive feedback for an article on why businesses should get behind the Lymphedema Treatment Act, a proposed piece of federal legislation that is currently in the U.S. House of Representatives. And while we are grateful for the level of reader support, we need to give credit where it is due: the person behind getting this legislation passed is Heather Ferguson, the driving force behind the Charlotte, N.C.-based Lymphedema Advocacy Group.

Why is she so passionate about this subject? Well, let's find out!

Q: What inspired you to create this organization? And is this the first time you started a nonprofit?

Heather Ferguson: I am a mom on a mission. My seven-year-old son Dylan was born with congenital primary lymphedema. Like most people, I had never heard of lymphedema until it touched my family.

When Dylan was less than a year old, he was prescribed his first gradient compression garment. Imagine my shock and horror when I learned that these items, which are the cornerstone of lymphedema treatment and something that he would need for the rest of his life, were not covered by insurance.

I knew that untreated or undertreated lymphedema was progressive. Without continuous compression my son would face disfiguring and potentially disabling swelling. He would also be at increased risk for serious and chronic infections that could even be life threatening.

How could our insurer deny my child coverage for these medically necessary doctor-prescribed treatment supplies, without which he'd have no chance of leading a normal and otherwise healthy life? And even if they didn't care about the welfare of my son, why would they want to pay for complications that were more costly than the treatment that could have prevented them?

I spent nine months appealing their denials. As a result, they granted coverage for Dylan's compression garments for one year. I was heartbroken. I realized that I, and later Dylan, would be forever fighting for this coverage. So I vowed to do everything in my power to correct the underlining problems from which this lack of coverage stemmed.

In 2009, I worked with my state representative, and miraculously, in only four months time, we introduced and passed a North Carolina lymphedema treatment mandate. The following year I got the first

Lymphedema Treatment Act bill introduced into Congress. However, I quickly realized I wasn't going to be able to get that bill passed alone. So in order to develop the kind of broad grassroots support that would be needed, I founded the Lymphedema Advocacy Group. This is the first nonprofit I have started.

Q: Despite the rising awareness related to breast cancer and other cancer-related conditions, most people are not familiar with lymphedema. Why is there so little public discussion about this condition?

Heather Ferguson: There are multiple reasons lymphedema has suffered from lack of awareness.

One factor is that very little time is spent on the lymphatic system in general in medical school. As one doctor jokingly described to me, discussion of the lymphatic system in med school was akin to "it exists, let's move on!" Therefore, due to lack of knowledge amongst many medical professionals, patients often go undiagnosed or misdiagnosed.

Still, other doctors are able to recognize the condition, but have no understanding of how the disease is treated, or that treatment even exists at all, so they can't refer patients appropriately. I have heard from so many patients whose doctors told them for years to just keep their feet up, limit their salt intake, take diuretics, and so on.

But perhaps worst of all, are the doctors who are dismissive about lymphedema. So many cancer survivors have told me their lymphedema is harder to deal with than their cancer diagnosis and treatment was, and yet, their doctor has shrugged it off as if it is a minor nuisance. They are made to feel as though they ought to be happy to just be alive, and shouldn't complain about this "swelling".

Consequently, so many patients suffer silently. And once the disease advances and the swelling becomes readily visible, many patients become self conscious and retreat even further. All too often, undiagnosed patients are made to feel ashamed, and told they are just fat and need to lose weight. In reality, their growing size has nothing to do with diet or lifestyle.

Lymphedema is a serious medical condition that needs to be brought out of the closet! Hopefully, someday, there will be a cure. But until then, patients need and deserve access to coverage for the treatments that can effectively control their symptoms and manage this disease.

Lymphedema is not a benign swelling; it is not a mere cosmetic condition or inconvenience. Lymphedema is the result of a compromised lymphatic system, and hence a compromised immune system. So much physical pain, heartache, disability, and medical costs could be avoided, if patients received proper and timely diagnosis and coverage for their compression treatment supplies.

We need the cancer organizations to stop shying away from talking about "cancer's dirty little secret," as the Washington Post put it in a 2010 article. It's wonderful that more patients are surviving cancer, but with that is coming an ever-increasing number of lymphedema patients. Cancer patients deserve to be told about their risk of acquiring lymphedema. In some cases, lymphedema could even be prevented, if survivors were given proper education on how to reduce their risk factors.

Q: Part of your mission is to get passage of the Lymphedema Treatment Act. Why is it important for this legislation to become law?

Heather Ferguson: The root of our coverage problems stems from the fact that Medicare does not cover the compression supplies used in the treatment of lymphedema. This denial is based on the technicality

that these items do not meet the definition of any of their benefit categories. Only Congress has the authority to revise the statute defining these categories. Passage of the Lymphedema Treatment Act will add compression garments to the DME (Durable Medical Equipment) category.

Fortunately, once Medicare covers something virtually all Medicaid and private plans follow suite. So this is the best way to bring coverage of compression supplies to all lymphedema patients, regardless of their age, insurance plan, or the cause of their lymphedema. State mandates only apply to private plans sold within that state, so even if we had mandates in all 50 states, all Medicare and most Medicaid beneficiaries would still lack coverage for compression supplies.

Q: How can people become involved in spreading awareness of lymphedema and its treatments?

Heather Ferguson: All of the ways in which people can spread awareness and support passage of the Lymphedema Treatment Act are listed on our website, www.LymphedemaTreatmentAct.org, under the "How You Can Help" menu.

We are an all-volunteer, grass roots organization, so each person's involvement matters greatly. If each person would just help to raise awareness in their own community, and make contact with their own members of Congress, it would make such a difference!

We have a quick and easy-to-use submission form for sending letters to Congress through our website. We also provide information cards, free of charge, to anyone willing to distribute them. These, and others ways to get involved, are all on our website.

It's unbelievable and unacceptable that a disease with more sufferers than multiple sclerosis, AIDS, muscular dystrophy and Parkinson's disease combined has remained in the shadows, and lacking adequate insurance coverage, for this long. For my son, and the millions like him, I aim to change that!

Editor's note: Let's repeat Heather Ferguson's website again: www.LymphedemaTreatmentAct.org. We ask that you take a few minutes to visit this website and lend your support to Ferguson's cause.