



Why This Boy's Life Depends on Wearing Stockings

BY ANNA BISARO ON OCTOBER 22, 2014

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Two 8-year-old boys are playing on a playground. One of them, Dylan, is wearing what appear to be stockings under his shorts. When other kids ask him about it, he can barely open his mouth to speak before his twin brother, Devdan, jumps to his defense. There is nothing wrong with his brother, it's just something he has to do.

Dylan will always have to wear those “stockings,” compression garments that keep his legs from swelling up. Since birth, his lymph nodes have not worked properly to drain fluid from his limbs, especially his legs. He has lymphedema, a disease that will be with him for life. Lymphedema comes in two forms: primary and secondary. Primary is the result of a genetic mutation while secondary results from traumatic injury, or often, radiation treatment for cancer. For Dylan, it was genetics; Lymph fluid in his legs gets blocked there and does not drain well, causing them to swell.

“He’s never asked that question, ‘Why me and not [my brother]?’” Heather Ferguson, the boys’ mother, said of Dylan. She has not sheltered him from the facts and not tried to keep anything from him.

Often, however, lymphedema is a side effect caused by cancer treatments and cancer patients will develop lymphedema in their arms, and sometimes, only in one limb. It can be harder for older patients, Heather said, who are not used to dealing with it and may be ashamed of the garments they now have to wear to keep their limbs from deforming.

But Heather did not know anything about lymphedema when Dylan was first diagnosed, and neither did his doctors. She brought her 3-month-old son to the hospital because the swelling in his legs seemed to be getting out of control, and she feared it could be a heart problem. After days of testing, the doctors sent her home with the name of a disease they found on Google, after they typed in his symptoms.

And that was it.

But a Google search showed that lymphedema is progressive, and, if not treated, can cause major deformities as the fluid hardens in the limbs. Heather’s panic escalated. She took him to a specialist in Charlotte, North Carolina, where she learned the proper therapy techniques and treatment options. The family adopted a new normal and it has been that way ever since.

The average cost for treatment of lymphedema is in the area of \$1,000 per year on average. For Dylan, a growing boy, Heather and her husband need to buy compression garments more often than the average four to six times per year because he is growing so fast, so the cost is quite a bit more. He also needs custom garments because of his size.

If Dylan, or other lymphedema patients do not do their massages and exercises regularly and choose not to wear the garments, their limbs will continue to swell. As the fluid sits in their limbs, it hardens tissue and can actually cause deformities.



Dylan and his brother

Lymphedema also has other complications. Affected limbs are more prone to developing infections like cellulitis or lymphangitis which are bacterial infections of the skin and lymph nodes, respectively. Often, injuries to the affected limbs are entry points for these infections. Lymphedema patients can also develop rare skin cancers if they let the disease go untreated.

Sometimes, lymphedema goes undiagnosed, because like for Dylan's doctors, it is a disease they have never seen before. It is estimated that 1.5 for every 100,000 children are affected, but for breast cancer patients the prevalence is much higher, with a 15 to 20 percent chance that the patient will develop secondary lymphedema.

Heather discovered pretty quickly that health insurance companies did actually not cover these necessary medical expenses. At the time Dylan was diagnosed, the only state in the United States that required insurers to cover lymphedema costs was Virginia.

"I, and later Dylan, would be forever fighting the insurance companies," Heather said.

She started the Lymphedema Advocacy Group, which began as a fight for insurance coverage in North Carolina for lymphedema patients, now has grassroots organizations in every state except Vermont. The main goal of the group is to educate. If congressmen, on the state or federal level, understand the struggles of lymphedema, they might better understand why patients need insurance to cover their care.

Heather and other volunteers help create educational packets and raise money for their efforts. A recent golf tournament run by JHE Production Group raised more than \$30,000.

“I’m just a mom. I don’t have political expertise,” Heather said. “But, I had to at least try. I couldn’t live with myself knowing the uphill battle he would have to face.”



Heather, Dylan, his brother Devdan, and their father, Brian.

Some states, like California and Louisiana, have made strides towards requiring insurers to pay for lymphedema costs, and Heather won the battle in North Carolina in 2010. She is now leading the charge in Washington, meeting regularly with congressmen to push the Lymphedema Treatment Act.

Dylan is lucky in a sense, because lymphedema is something he has always known. He puts on compression garments like he puts on underwear – it’s just part of his routine. But the Lymphedema Advocacy Group has given older patients hope, and a sense of empowerment, Heather said, in the face of disease that they maybe want to hide out of embarrassment. It has done the same for her.

“Having the legislation to work for was something very tangible to bring people out of the closet,” Heather said. “This whole journey has been my way of dealing with this in a proactive, positive way.”

Heather homeschools the boys, which helps with the therapy; she can do the 45-minute massage Dylan needs every day while he reads in the mornings.

Juggling home schooling the boys, full-time advocacy and another part-time job on the side is not easy, Heather says, but she manages.

“If we all just took the one issue we cared the most about, and put some time and energy into doing something about it, the world would be an amazing place,” she said.