

### Vascular Anomalies Center

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May 7, 2019

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

To Whom It May Concern:

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.

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.

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.

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

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