

TO: Members of the Commerce Committee
FROM: Mary McNamara
DATE: 2.24.2021
RE: HF 56 Lymphedema compression treatment coverage

Chair Stephenson, Rep. Elkins, and members of the Commerce Committee,

Thank you for the opportunity to share my story with you. My name is Mary McNamara and I have lived with lymphedema and its challenges for more than 30 years. When I first found out what was wrong with my limbs swelling up, there were no doctors that specialized in Lymphedema. As a result of my lymphatic system not working, I was always going to the doctor with infections that required antibiotics. Countless times, the infections turned septic and required hospitalization. Lymphedema took over my life and took away my ability to be active because my ankles would swell to the point of splitting my skin. It was difficult walking, forget running.

Then I found the right doctor and treatment which gave me control over my health and my life again. It allowed me to be active with my children and run a business for 26 years. There is no cure for lymphedema but there is compression treatment and therapy that works well in maintaining my swelling. Lymphedema gets worse over time. Every year, I need to get a 'tune-up' where I need to go to a physical therapy therapist specially trained in lymphedema to do lymphatic drainage, compression wraps, and to get measured for new compression garments that have become part of my everyday life. They are a necessity for keeping me healthy and out of the hospital. Utilizing all the tools available to me, I have only been hospitalized for a severe infection once in many years. In addition, I have had very few infections with the need for antibiotics which is better as well.

Here is a typical day which takes roughly 2.5-3 hours daily to manage my lymphedema:

4:30-5:00 a.m. Use Flexitouch pump on left leg for 1 hour – requires laying down and not moving.
Apply heavy skin cream to protect my skin from the harsh compression stockings that are worn daily.
Put on compression garments w/gripper gloves to push the fluid back up the leg.

9:00-10:00 p.m. Remove compression stockings and wash them by hand.
Use Flexitouch pump on right leg for one hour.

Bedtime: Put on Tribute compression leg sleeves to go to bed.

I would not be doing this routine every day if it did not work. I require custom made flat knit stockings. They are thick, heavy duty and ugly. They are hot and sweaty. They are neither stylish nor fun to wear. However, I cannot live without my compression stockings. I have tried to cheat and not wear them on a special occasion, and I have paid dearly for it with severe swelling, not being able to find shoes to fit and accommodate the swelling, infections, etc. It is not worth it. I cannot go anywhere without them. When I fly, I carry them with me so there is no chance of my tools getting lost.

Everyone here has heard of ALS, Cystic Fibrosis, Muscular Dystrophy, Multiple Sclerosis, and Parkinson's Disease. However, there are more people with Lymphedema than there are of the diseases I just mentioned **COMBINED**. Please vote for insurance coverage for lymphedema treatment and compression therapy and say yes to HF 56. Thank you for your consideration.