Beth Israel Deaconess Medical Center

HARVARD MEDICAL SCHOOL TEACHING HOSPITAL

October 20, 2015

Senator James B. Eldridge, Co-Chair
Representative Aaron Michlewitz, Co-Chair
Joint Committee on Financial Services

Senator James T. Welch, Co-Chair
Representative Jeffrey Sanchez, Co-Chair
Joint Committee on Health Care Financing

Re: Testimony in support of H 927 and S 618
An Act Relative to HIV-Associated Lipodystrophy Treatment

Dear Senator Eldridge and Representative Michlewitz and
Senator Welch and Representative Sanchez,

I am an Infectious Diseases physician at Beth Israel Deaconess Medical Center, and I have provided care for people living with HIV since the early 1990's. Until the late 1990's, I was focused on finding combinations of antiretroviral medications that would help keep people alive. However, as our combination therapies became more potent and I watched people get off their death-beds and start living again, I also started noticing changes in peoples' bodies. Eventually this was termed lipodystrophy. Ironically, the very medications that we were using to help keep people alive were also culprits in distorting their bodies. I knew that if I could walk into a party or stroll down the street and tell which people likely had HIV, that others could too.

Lipodystrophy is not "weight gain". It is an abnormal redistribution of fat that can lead to some combination of severe loss of fat in arms, legs, buttocks, and face, as well as fat gain in the neck, back, chest and stomach. The fat redistribution can be uneven. I have one male patient who has excessive fat in his chest/breast area leading to a large left breast and smaller right one. It is noticeable, and is clearly abnormal appearing unless he wears the baggiest of clothes. He also has such excessive fat redistribution in his neck area that it pushes out his hair in the back and his face sits in a large ring of fat. He suffers from severe social isolation and depression because people stare at him when he goes outside. We (his medical care team) are very concerned about his psychosocial status and have tried to get lipo-reduction surgery approved for his neck and breast to help make his physical appearance less obviously abnormal. However, these procedures have been denied.

Another male patient had had a corneal infection that required surgery. His facial wasting (loss of fat in his mid-face) was so severe it pulled the skin down under his eye, leading to eye difficulty because it did not fully close. We requested that his insurance cover dermal fillers to build up his cheek tissue under his eyes. They determined that this was

cosmetic, and he ended up tapping into retirement funds to pay for this needed procedure.

A female patient lost weight in her legs and buttocks and gained excessively in her abdomen. Her coworkers knew diets don't lead to that type of weight redistribution, so they kept asking her questions, which led to anxiety since this person has not shared her HIV diagnosis with anyone. She has been able to get into a clinical trial studying interventions for lipodystrophy, but not all patients qualify for these.

Having lived through the horror of the early 1990's when too many young people died of HIV/AIDS, I remember that feeling of sadness and helplessness. The advances we have made in HIV care over the last 20 years continue to astound me. Many people can now take one or two pills once a day and we talk about growing old together. Lipodystrophy is one area where I remain horrified and helpless at how it impacts the lives of patients I care about, and that the interventions I believe would be beneficial are denied.

Thank you for accepting this testimony on behalf of people living with HIV and the effects of lipodystrophy.

Sincerely,

Camilla S. Graham, MD, MPH