

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,

The AIDS Law Project of Gay & Lesbian Advocates & Defenders strongly supports H 927 and S 618, An Act Relative to HIV-Associated Lipodystrophy Treatment. Through strategic litigation, public policy advocacy, and education, GLAD works in New England and nationally to create a just society free of discrimination based on gender identity and expression, HIV status, and sexual orientation. GLAD's AIDS Law Project was founded in 1984 and is one of the nation's oldest legal programs protecting the rights of people with HIV.

Lipodystrophy is a side-effect of the powerful HIV medications introduced in the late 1990s that transformed HIV from a fatal condition into a chronic and manageable one. These medications saved lives – and medical costs – but they also created a metabolic abnormality of fat cells that has left many people with disfiguring and debilitating body shape changes. Lipodystrophy causes severe fat accumulation behind the neck (called, “buffalo hump”), under the chin (called, “horse collar”), and in the torso. It also causes severe fat loss and wasting in the cheeks.

The harm from lipodystrophy is profound. The suffering from lipodystrophy includes: spinal problems, restricted movement, headaches and neck pain, inability to sleep, depression, and suicidality.

The facial wasting from lipodystrophy is experienced by many as a disclosure of their HIV disease, still the most stigmatized health condition in America. The fear of public disclosure of one's HIV status caused by untreated lipodystrophy is still well founded in our society. Fears and misunderstanding about HIV continue at surprising levels. For example, 45% of Americans report being uncomfortable with the idea of having their food prepared by someone who is HIV-positive. *HIV/AIDS at 30: A Public Opinion Perspective*, The Henry J. Kaiser Family Foundation (2011), p. 2. Similarly, 29% would be uncomfortable having their child in a

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classroom with an HIV-positive teacher. Kaiser Family Foundation, at p. 7. And roughly one in four Americans still believe that one can get HIV from sharing a drinking glass or are unsure about whether this is the case. Kaiser Family Foundation, at p. 6.

There are simple and effective treatments for lipodystrophy: liposuction to remove abnormal fat accumulation and facial fillers to repair wasting in the cheeks. Unfortunately, however, while insurers cover restorative procedures for the side effects of other medical treatments, such as breast reconstruction and testicular replacement related to cancer treatment, they improperly characterize treatments for lipodystrophy as cosmetic.

I hope that we can all agree that it should be intolerable in Massachusetts today to deny care to those who have survived AIDS only to become suicidal or shut-ins, or who get called “freak” or “monster” when walking down the street.

It will take so little to end this suffering and restore full functioning to our longest-term survivors of the HIV epidemic. The Center for Health Information and Analysis released its report in May 2014 and indicated that this legislation would result in an average annual increase over five years to a typical member’s monthly premium of between \$.01 (0.00%) and \$.10 (0.02%). **There has not been a less expensive mandated benefits law passed by the legislature in the last ten years.** In fact, it is far cheaper to treat lipodystrophy than to pay for the consequences of ignoring it.

**This legislation has a unique and built-in cost containment component.**

Lipodystrophy is an historic problem. It affects only a small, finite number of people with HIV who took the first wave of antiretroviral medications in the 1990s. Data from the Department of Public Health indicate that between 184 and 459 people with HIV would seek treatment. The population needing treatment will decline, not grow, over time.

This legislation is also critical to public health efforts to end the HIV epidemic. While current HIV medications do not cause lipodystrophy, long-standing perceptions about harmful side effects can still be a disincentive for people to enter treatment. We now know that treatment not only saves lives and medical costs, but also prevents HIV transmission to others. Any disincentive to treatment today is too high.

GLAD has been able to win some insurance appeals for a small number of people with lipodystrophy. What is striking about these few situations is that it took either litigation – or the possibility of litigation – to force these payors, both MassHealth and private insurers, to provide this necessary care. GLAD attorneys spent significant time working with doctors to get detailed letters of support and submitted memoranda citing scores of medical articles discussing the profound harm caused by lipodystrophy. This is simply not a solution for the majority of people with HIV who need medical treatment. It is not practical for all people who need this treatment to get legal representation and file the extensive appeals that have afforded care for a few. Moreover, most people, hearing that claims are always denied, are too discouraged or intimidated to even take the first step. And physicians who provide skilled, compassionate health care to people with HIV should be spending their time with patients, not lawyers.

Passage of H 927 and S 618 will provide the maximum humanitarian and public health benefit for a minimal, time-limited fiscal impact. This legislation will become a national model for addressing one of the most under-recognized challenges of the HIV epidemic.

GLAD strongly urges you to report this legislation out favorably.

Sincerely,

A handwritten signature in blue ink, appearing to read 'B. Klein', is positioned below the word 'Sincerely,'.

Bennett H. Klein  
Senior Attorney and AIDS Law Project Director