

Before the Joint Committee on Financial Services in Support of H. 986
“An Act Relative to HIV-associated Lipodystrophy Treatment”
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Submitted by:
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Good afternoon, members of the Committee on Financial Services. My name is Bennett H. Klein, and I am the AIDS Law Project Director at Gay & Lesbian Advocates & Defenders (GLAD). 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.

Since the beginning of the HIV epidemic, access to health care has been of paramount concern to people with HIV. Many barriers, including those imposed by insurers, have been addressed. At one time it was common for health care providers to refuse to treat people with HIV, a problem which rarely occurs today. Similarly, in the early decades of the epidemic, at a time when hospitalization was common, some insurance plans imposed monetary caps of \$100,000 (or less) for lifetime AIDS-related medical expenses, a limit not placed on even far more expensive health conditions. Those discriminatory caps have also been relegated to history’s dustbin. In fact, Massachusetts has been a national leader in ensuring sound access to medical care for people with HIV and in recognizing that combatting discrimination and stigma are critical to public health efforts to end the epidemic.

It has long been a cause for great celebration that with new drug treatments most people with HIV can live normal lifespans, but an HIV diagnosis is always profoundly life altering. HIV remains the most stigmatized health condition in America today, and insurance discrimination and barriers to health care still exist.

Insurers’ refusal to cover medical treatment for lipodystrophy is one of the most important, but under-recognized, problems faced by people with HIV today. Lipodystrophy is an abnormality of fat distribution caused by HIV and the antiretroviral medications that save people’s lives. It results in a variety of disfiguring and stigmatizing body shape changes. Lipodystrophy can cause physical impairment as well as depression, anxiety and a range of other psychosocial impairments.

Many of the psychosocial impairments caused by lipodystrophy are due to its visible effects and its association with a highly stigmatized disease. As one medical article observed, “the main negative impact of lipodystrophy is attributable to stigmatization,” and that “[s]ome patients with lipoatrophy [facial wasting] feel that they have the word ‘AIDS’ permanently written on their face.” Martinez, E., Garcia-Viejo, M.A., Blanch, J., & Gatell, J.M. “Lipodystrophy syndrome in patients with HIV infection: quality of life issues,” *Drug Safety* (2001), p. 161. Another medical article described the effects of lipodystrophy as “a scarlet letter, revealing an individual’s health problems at first glance to all those with whom he comes into contact.” Talmor, M., Hoffman, L.A., & LaTrenta, G.S. “Facial

atrophy in HIV-related fat redistribution syndrome: Anatomic evaluation and surgical reconstruction,” *Annals of Plastic Surgery* (2002), p. 16.

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. The Henry J. Kaiser Family Foundation “HIV/AIDS at 30: A Public Opinion Perspective,” (2011), p. 2. Similarly, 29% would be uncomfortable having their child in a 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.

Over the course of the epidemic public health experts have consistently agreed that responding to the need for privacy of HIV status – in light of HIV’s stigma – is key to getting people tested for HIV and into treatment. Treatment for the disfiguring and debilitating effects of lipodystrophy is necessary for the physical and psychological health of people with HIV as well as for public health efforts to combat the epidemic.

In spite of the compelling need for treatment, private insurers and MassHealth routinely deny this care to patients with HIV. 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.

It is simply unacceptable that in 2014, people with HIV are denied medically necessary treatment. GLAD urges this Committee to favorably report H 986. It addresses a key failure in our obligation to provide medical care to people with HIV. In addition, it furthers critical public health goals to fight the HIV epidemic and will result in maximum benefit to a deeply suffering population for very little cost.

Thank you for the opportunity to comment.