Treatment for Lipodystrophy: It’s Now the Law!

What you need to know about insurance coverage for treatment of HIV-associated lipodystrophy

On August 10, Governor Charlie Baker signed into law An Act Relative to HIV-Associated Lipodystrophy Syndrome Treatment, and the law will go into effect November 9. This first-of-its-kind legislation, sponsored by Senator Mark Montigny and Representative Sarah Peake, requires public and private insurers to cover treatment of a debilitating side effect of early HIV medications. This law means that some of the longest-term survivors of the HIV epidemic will finally have access to critical health care they need and deserve.

The information below explains the law, and what to do if you are seeking treatment. If you have further questions, contact GLAD’s legal information line at 617-426-1350, www.GLADAnswers.org, or AIDs Action Committee’s legal hotline at 617-450-1317.

What is lipodystrophy?
Lipodystrophy is a disfiguring side effect of some early HIV treatments, characterized by painful, abnormal changes in body shape, such as fat growths on the back of the neck that press on the spine, and facial wasting that is seen as a public disclosure of HIV status. Lipodystrophy causes profound and unnecessary suffering: spinal malformation and posture problems, headaches, restricted mobility, depression and anxiety, suicidality, and stigma.

What does this law do?
Although there are effective treatments for lipodystrophy, including liposuction and facial fillers, insurers have routinely denied claims for these services on the improper grounds that they are cosmetic. This law rectifies that problem. It requires that private insurers, MassHealth (the Massachusetts Medicaid program), and the Group Insurance Commission (for state employees) cover medical treatments for HIV-associated lipodystrophy. In other words, you will now be able to get the medical care that you need.

What treatments for lipodystrophy are covered?
The law does not place any limit on what treatments or therapies are covered. To quote the legal lingo, the law requires “coverage for medical or drug treatments to correct or repair disturbances of body composition caused by HIV associated lipodystrophy syndrome including, but not limited to, reconstructive surgery, such as suction assisted lipoectomy, other restorative procedures and dermal injections or fillers for reversal of facial lipoatrophy syndrome.”

What do my health care provider and I need to do to obtain approval for coverage?
The provider who is undertaking the treatment may need to submit a request for prior authorization with your insurer. However, the law ensures coverage with a statement from a treating provider that “the treatment is necessary for correcting, repairing or ameliorating the effects of HIV associated lipodystrophy syndrome.” Please be sure that your doctor knows to include this important language in the request.
What if I have applied for treatment in the past and been rejected?
That does not matter. Your doctor can submit a new request for prior authorization and you will not be denied because you were rejected for the same procedure in the past.

When does this law go into effect?
This law is effective November 9, 2016.

How was this law passed?
GLAD convened the Treat Lipodystrophy Coalition (TLC) in 2013, after representing several people with lipodystrophy who were experiencing profound suffering but could only get medical treatment if they lawyered up and threatened to sue their insurer. Together with then State Representative Carl Sciortino, the original bill sponsor, we realized that a more systemic solution was needed and the idea for this legislation was born. The TLC brought together people living with HIV, advocacy and service organizations, and dedicated physicians and medical professionals. Thanks to the leadership of legislative sponsors Representative Sarah Peake and Senator Mark Montigny, the commitment and work of TLC partner organizations, the efforts of our community’s long-time State House advocate Arline Isaacson, and most importantly the courage and persistence of people living with HIV who have shared their stories, the TLC successfully passed this first-of-its-kind legislation that will make a powerful difference in people’s lives. Learn more at www.glad.org/tlc

Treat Lipodystrophy Coalition Members

Co-chairs: George Hastie and Andrew Fullem

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