March 5, 2014

Joint Committee on Financial Services
Massachusetts Legislature

Testimony of Fenway Health in support of H986, an Act relative to HIV-associated lipodystrophy treatment

Fenway Health strongly supports H986, an Act relative to HIV-associated lipodystrophy treatment, which would mandate that private insurers and MassHealth cover treatment for lipodystrophy. This is a very important medical health condition affecting many people living with HIV. Lipodystrophy is a medical condition correlated with HIV and treatment with antiretroviral medications. The current arrangement whereby insurance companies can refuse to cover treatment of this medical condition is bad for medical care of people living with HIV/AIDS.

Fenway Health serves 22,000 patients. We are the largest provider of HIV services in New England. We are a Ryan White Care Act Part C provider of HIV medical care, as well as serving as a center for HIV clinical research since the earliest days of the AIDS epidemic. About 10% of our 22,000 patients are living with HIV. Since the early days if the HIV/AIDS epidemic Fenway Health has been at the forefront of HIV prevention and care as well as research, training, and advocacy.

Lipodystrophy has particular negative consequences for people living with HIV, including Fenway patients. This condition, a disturbance in the way the body produces, uses, and stores fat, can cause fat loss and fat build-up. Often a person’s face is sunken and distorted due to this condition. People already stigmatized by living with HIV and who are concerned about unauthorized disclosure of their status can become the unwanted object of attention, ridicule, and harassment by people who notice their lipodystrophy. Some individuals become shut-ins, and many become depressed and stop taking their medications as a result. This further exacerbates the problematic U.S. HIV treatment cascade, whereby only 25% of people living with HIV in the U.S. are virally suppressed.

Lipodystrophy can also cause intense physical pain and lead to further medical complications. The extensive collection of fat can cause a rapid progression of a degenerative disease of the spine and neck. This can result in intense pain and further disfigurement.

While breast reconstruction is covered for survivors of cancer, treatment for lipodystrophy is not consistently covered by insurance in Massachusetts. Lack of insurance coverage for lipodystrophy prevents patients from accessing needed care.
We strongly urge you to rectify this important HIV/AIDS medical concern by supporting H986, which would treat lipodystrophy the way we treat other medical conditions. Health care providers should be able to prescribe treatment for lipodystrophy to their patients so that they can get the treatment they need and live their lives free of pain, stigma, and the agonizing effects of lipodystrophy.

Sincerely,

Stephen L. Boswell, M.D.
Chief Executive Officer
Fenway Health