



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 respectfully submit the following comments in support of H 927 and S 618, An Act Relative to HIV-Associated Lipodystrophy Treatment. My name is Joe Carleo and I am the Executive Director of the AIDS Support Group of Cape Cod (ASGCC.) One of the earliest AIDS organizations established in the United States, ASGCC has been providing care and services to people living with HIV/AIDS on Cape Cod for over 30 years. Our mission is to foster health, independence and dignity for people living with HIV/AIDS and Viral Hepatitis by providing care and supportive services. We also work to help reduce the spread of HIV and other sexually transmitted infections through prevention, education and testing services. Our services span all of Cape Cod and the Islands and whenever possible, ASGCC works to address the global epidemic. Today we directly serve approximately 430 individuals and families with HIV/AIDS from every town on Cape Cod as well as on Martha's Vineyard and our prevention work reaches nearly 100,000 residents and visitors to the region each year.

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Prevention & Screening 366 Commercial St, Unit 10 02657
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Over the past 30 years great strides have been made in the treatment of HIV-disease resulting in people with HIV/AIDS living longer and healthier lives. With each advance in treatment we have witnessed HIV- disease move further away from being a fatal disease and toward a more manageable chronic illness for many HIV-infected individuals. However many of the emerging medications and treatment regimens have also come with very serious and sometimes devastating side-effects that have greatly impacted the quality of life for people who experience them.

The most significant step in the overall search for viable HIV-treatment came in the late 1990's when the development of triple combination therapy transformed HIV-disease into a more manageable condition creating new hope for many people living with HIV/AIDS. However these life-saving treatments have also caused lipodystrophy for thousands of people living with HIV/AIDS. Lipodystrophy is a devastating condition for those affected and has a very negative impact on overall quality of life.

While HIV/AIDS has had a significant impact on Cape Cod, Provincetown holds a unique place in the history of the epidemic. With an average HIV incidence rate of approximately 385 cases per 100,000, Provincetown has long had the highest incidence rate per capita in the state of Massachusetts. And despite its reputation of being a very accepting place there remains very significant stigma attached to HIV and especially when the effects of HIV or HIV-treatment are visible like lipodystrophy. This stigma is even further magnified in smaller and rural type communities like Provincetown, and towns all across Cape Cod. Over the years we have seen many clients who have become reclusive and avoid contact and treatment as a result of the disfigurement caused by lipodystrophy. In some cases people have opted to avoid or halt their HIV-treatment in an attempt to control side effects despite the fact that treatment will keep them alive. Lipodystrophy is not only a physically visible condition. It is also has very serious psychological consequences include debilitating pain, depression and anxiety. All of this further compounds the effectiveness of HIV-treatment.

While in recent years the incidence of lipodystrophy has decreased as better treatment options are developed, there are still thousands of people with HIV-related lipodystrophy whose lives would greatly improve with access to treatment for this condition. Yet despite the availability of effective treatment for lipodystrophy most insurance companies continue to refuse to cover the cost of treatment making it inaccessible. This runs counter to the overall goal of keeping people as healthy as possible. For more than 30 years we have worked to find viable and effective HIV-treatment options and to allow people with HIV/AIDS to live healthier, longer and productive lives. It is critical that treatment for lipodystrophy be included as a part of the response to HIV. In addition, the cost of lipodystrophy treatment is far lower than the lifelong costs associated with leaving the condition untreated.

The early days of the AIDS epidemic were very frightening and uncertain. As new treatment for HIV emerged people were anxious to participate in drug regimens in an attempt to save their lives. Over the years we have learned that many early treatment regimens were not perfect. However people who have experienced the impact of serious side effects like lipodystrophy were simply following the drug regimens prescribed by their physicians. The fact that insurance companies continue to deny coverage for lipodystrophy is in essence penalizing the patient for taking steps to stay alive. Insurance companies must work with the medical community and patients to ensure access to medically necessary health care and treatments. I urge you to support H 927 and S 618 which will allow people with HIV-related lipodystrophy access to the medical treatment they deserve. Thank you for the opportunity to submit these comments.

Joe Carleo
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