

TREATMENT *for* LIPODYSTROPHY

SOUND
&
COMPASSIONATE
*HEALTHCARE
FOR PEOPLE WITH
HIV*





Lipodystrophy causes abnormal, excessive fat accumulation, frequently on the back of the neck in what is referred to as a “buffalo hump” (pictured in the medical stock photo above). People with lipodystrophy suffer physical pain, spinal structural damage and often debilitating depression.

The word “lipodystrophy” is unfamiliar to many people. Lipodystrophy is a debilitating and disfiguring side effect of HIV medications. It is a serious medical condition that requires treatment. And it is one of the most under-recognized challenges of the HIV epidemic.

In the late 1990s new antiviral medications known as “triple combination therapy” transformed HIV from an almost always fatal disease to one that – while still profoundly life altering – people could live with over the course of a normal lifespan. These powerful medications, however, created lipodystrophy, a metabolic disorder characterized by an abnormality of fat cell function that results in a range of disfiguring body shape changes. These include what is colloquially referred to as “buffalo hump” (an abnormal fat growth on the back of the neck), “horse collar” (abnormal fat growth in the front and side of the neck and under the chin), and severe wasting in the face and limbs. Lipodystrophy is not weight gain; it is

an abnormal redistribution of fat in the body.

People suffer with untreated lipodystrophy. Many people experience pain as well as spinal, postural and mobility issues. Lipodystrophy's highly visible and very disfiguring redistribution of fat is seen as a public disclosure of HIV – still the most stigmatized health condition in America. Lipodystrophy is a leading contributor to depression and other psychosocial impairment in people with HIV.

**None of these harms was necessary.
There exist safe, effective and
inexpensive treatments for
lipodystrophy.**

In this book you will read about people who are so disfigured they do not leave their homes; people who have contemplated suicide; a man who is a long-term survivor of the AIDS epidemic who gets called “freak” or “monster” in public; and a woman who lives with permanent structural damage to her back. None of these harms – nor the suffering experienced by many others – was necessary. There exist safe, effective and inexpensive treatments for lipodystrophy, including liposuction and dermal facial injections. While insurers and MassHealth pay to repair disfigurements due to other health conditions, they do not cover these treatments for lipodystrophy.

Massachusetts has been a national leader in ensuring sound and compassionate medical care for people with HIV. These stories are an opportunity to learn about what more needs to be done to provide people with lipodystrophy sound and effective treatment for a severe condition.

For more information visit www.glad.org/tlc

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“[Lipodystrophy] is significantly associated with impaired quality of life in both men and women with HIV. ”

- Confresco, J., Freedland, E. & McComsey, G. “Treatment options for HIV-associated central fat accumulation,” AIDS Patient Care and STDs (2009), p.5.



The severe physical and psychological pain of the excessive fat accumulation on John's upper back and around the front of his neck has forced him into a life of isolation. He has considered stopping his life-saving HIV medications and even contemplated suicide.

I Don't Want Anybody to See Me

John Wallace

John Wallace only leaves his home to buy groceries or pick up his medications. The once outgoing Vietnam-era Marine veteran now passes most of his days alone, watching TV in his South Boston apartment. His partner of 15 years passed away a decade ago.

"I don't want anybody to see me," says the 64-year-old.

What John doesn't want people to see is how badly he has been disfigured by lipodystrophy, a metabolic complication of his HIV medications that creates abnormal fat distribution in his body.

Lipodystrophy has caused an excessive accumulation of fat on John's upper back (commonly known as a "buffalo hump"), which

he tries to conceal by wearing his hair long. It causes headaches and prevents him from turning his head. His neck is engulfed by fat, making his head appear abnormally large. The disproportionate accumulation of fat in his torso makes his body lopsided, which throws off John's balance and restricts his ability to do even basic housecleaning chores.

Feeling hopeless about his condition, it's often a struggle for John to get through the day, despite taking medication for depression. "I've thought about suicide many times," he says. "But it goes against my Catholic faith. And it would devastate my sister. "

Last year, in the hope of alleviating his lipodystrophy John stopped taking his HIV medications. After about a week he became so ill that his sister caught on and persuaded him to resume his medication regimen.

Despite the physical and psychological harm John has suffered since his lipodystrophy developed around 2003, he has had difficulty accessing treatment. The majority of health insurers, including John's, refuse to cover treatment, claiming it is cosmetic and therefore not medically necessary.

MassHealth denied John's request for prior authorization for his lipodystrophy treatment. He considered appealing the decision but did not follow through because the process felt too daunting. John has not reapplied for treatment since then, believing that he'll just be disappointed again.

"I just decided that I wasn't going to get it, I guess," he says. "I just gave up."

Occasionally John forgets about how he looks, until he glimpses himself in a mirror or notices a child staring. "It's horrible," he says of such reminders. A year ago John broke down at the Registry of Motor Vehicles after being photographed for a new driver's license. "I looked at the picture and I started crying right there in the middle of the Registry," he recalls.

"Living with lipodystrophy isn't really living" says John. "I'm just existing. Getting treatment would allow me to live a normal life again. I don't want to suffer anymore." ♦

I'm Not Living a Life That I Should Be Living

Mark S

Mark forces himself to leave his Boston apartment each day, just to visit Dunkin' Donuts. He knows it's unhealthy to live like a recluse, but the 10-minute walk feels like a 10-mile journey because of the way people react to Mark's appearance: a construction worker near the Filene's building calls him a freak; at the Park Street T stop, a woman refers to him as a monster.

Every lingering look and overheard comment lands like a punch. "It's so discouraging," Mark says, "It just makes me want to go home again and not deal."

For 10 years, Mark has suffered from lipodystrophy, which has given him a large fat pad on the back of his neck ("buffalo hump"), significant fat around his neck and underneath his chin, and significant fat accumulation in his torso. His cheeks and temples are sunken from the loss of fat in his face.

Mark's lipodystrophy has also led to chronic depression. Seeing his reflection in a window, he says, is "almost sickening." Mark has contemplated suicide. His support group for HIV-positive men helps him cope better with his condition.

Mark, 57, also suffers physically. He can't look over his shoulder or sleep comfortably. He has two compressed discs in his spine. The concentration of weight in his torso, neck and back causes his hips to ache when he walks. He stopped volunteering at a senior lunch program – one of his few social outlets – because he couldn't manage physical demands like setting up tables.

Like others with lipodystrophy, Mark has had trouble getting treatment. MassHealth refused to cover liposuction surgery to

repair his lipodystrophy.

Mark thinks about how if his lipodystrophy was alleviated he'd visit his brother and nephew in New York and spend Thanksgiving with his extended family; he could volunteer again at the senior center; he'd go to the movies and wouldn't feel ashamed to be in public.

"Such a burden would be lifted from me," Mark says.

"I can't stress enough how devastating lipodystrophy is and how much your life changes because of it," he says. "I know how much I stay in and I know how much of an effort it is just to drag myself outside. I'm not living a life that I should be living." ♦

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George Hastie had the worst case of buffalo hump his surgeon had ever seen, causing him severe, debilitating pain in his back, neck, and shoulder.

Fighting for Treatment

George Hastie

George Hastie had the worst case of buffalo hump his surgeon had ever seen, a hump that had caused permanent physical damage to George's back. Yet, in December of 2006, Tufts Health Plan denied prior approval for surgery on the grounds that the hump caused him "no impairment of a bodily function," forcing him to undertake a complicated and lengthy appeal process to receive the treatment he had long needed.

George was unusually qualified to launch an appeal. He holds a master's in public health and has long worked on the frontlines of the HIV/AIDS epidemic. He had a supportive employer who allowed him to reduce his work week to four days, giving him time to gather the proper documentation to support his appeal.

He set about working with his surgeon, his primary care doctor, his HIV specialist, his physical therapist, and his acupuncturist to appropriately convey the structural damage he was suffering because of the hump, and the medical necessity of removing it.

“Unless you understand what insurers are looking for and what the requirements are, it’s not easy to win an appeal,” George explains.

The buffalo hump, a consequence of George’s lipodystrophy, caused severe chronic pain in his back, neck, and shoulder; he was diagnosed with two herniated discs and missed months of work. Daily activities like washing dishes, sitting at his desk at work, or ly-

[George suffered] severe chronic pain in his back, neck and shoulder; he was diagnosed with two herniated discs and missed months of work. Daily activities like washing dishes, sitting at his desk at work, or lying on his back were painful endeavors. Driving was difficult, if not dangerous

ing on his back were painful endeavors. Driving was difficult, if not dangerous, because the hump restricted George’s ability to turn his head. His posture was stooped.

The buffalo hump made the Boston resident self-conscious about his appearance. He intentionally grew his short hair long in an effort to hide it and wore turtlenecks most of the time. In 2005, when he got married, he concealed the buffalo hump under a scarf.

Six months after Tufts first declined to cover his liposuction treatment, George learned that his appeal was successful. He underwent surgery to remove the hump – over three pounds of it. Despite the permanent damage, George is in a lot less pain, his posture has

improved, and his range of motion is better. He is less self-conscious and has cut his hair.

But since most people do not have the time, financial resources, expertise, and provider support to undertake a successful appeal of an insurer's denial of lipodystrophy treatment, George knows he was lucky. He hopes for the passage of legislation that would require health insurers to cover lipodystrophy treatment for all qualified patients.

"There were so many things that contributed to me being successful that would have been really hard for other people," he says. "I know there are people that don't have that support and are isolated and are going without treatment." ♦

**“[Lipodystrophy]
can cause physical
and psychological
discomfort...resulting in
poor social functioning
and social isolating.”**

**-Power, R., Tate, H.L., McGill, S.M. &
Taylor, C. “A qualitative study of the
psychosocial implications of lipodystrophy
syndrome on HIV positive individuals,”
Sexually Transmitted Infections (2003),
p. 138-139.**

A Walking Advertisement for HIV

Andrew Fullem

Andrew Fullem, Director of the Center for HIV at John Snow Inc., has been living with HIV for 17 years. While Andrew now enjoys life, there was a time when he avoided looking at his reflection whenever possible.

Andrew was part of early randomized clinical HIV drug trials. Those drugs had harmful side effects, one of which was lipodystrophy. In Andrew, that meant severe facial wasting, a sinking of the cheek, eye, and temple areas of the face, and loss of fat tissue under the skin.

“You see pictures of yourself 18 months ago and you have a full face, and now you’ve got sunken cheeks and ridges next to your eyes,” Andrew says. “Every time you look in the mirror you see it. So you learn not to look in mirrors. In the men’s room washing your hands, you just don’t look up.”

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Andrew attempted to get his insurer, Blue Cross, to cover a treatment which involves using injectable fillers to restore the natural contours of his face. Blue Cross rejected his application, saying it was purely cosmetic. Since he works in the field, he knew that a long-drawn out battle was likely to follow. So he decided to pay for his procedure out of pocket: “I just didn’t have the energy to fight the

insurance company.”

Andrew has experienced pointing, commenting, and staring. “In a community where HIV is known about, a person with lipodystrophy is like a walking advertisement for HIV,” he says. “You’re almost a non-person. Before you even have a conversation with somebody, you think that everyone knows.”

Andrew views the insurance denial as discrimination against

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You’re almost a non-person.”**

people with HIV. “There aren’t a lot of other diseases out there that we say, ‘It’s okay to look like you’ve been ravaged and just suck it up and suffer,’” he says. He is also concerned that many people stop taking their HIV medications because they know that insurance companies refuse to cover lipodystrophy treatment.

“If you put someone on a drug whose side effects will lead to physical disfigurement like lipodystrophy, then people are likely to stop taking their medication and will try to manage their HIV in some other way.”

When people are forced to go through the long and laborious process of getting insurance coverage, they can be made to feel like they don’t deserve treatment, that they are asking something special from the system for them, or that they’ve done something wrong.

“We have the means to make it easier for people to truly live, and I mean live with a capital L, with HIV,” says Andrew. “Let’s make that happen.” ♦



The abnormal fat accumulation in Jean's upper arms makes lifting them painful, and causes bruising with the frequent blood pressure monitoring she must do for her health.

A Three-Year Battle for Medical Treatment

Jean Marcoccio

In November of 2012, Jean Marcoccio had surgery to remove the large buffalo hump on the back of her neck, alleviating the chronic headaches and sleeplessness that plagued her for years. She's more physically comfortable and also less self-conscious about her appearance out in public. MassHealth, Jean's health insurer, covered the surgery. That's the good news.

Now, the bad news: it took nearly three years of wrangling by Jean and her doctors to get coverage for the operation. Jean's buffalo hump was caused by HIV-related lipodystrophy, and health insurers routinely deny coverage for treatment on the grounds that it is cosmetic or otherwise not medically necessary. Jean, 65, was no exception to this rule.

She appealed MassHealth's denial of coverage. For two years, Jean's doctors were repeatedly asked to provide further documentation, more photos, and additional explanations. In the end, MassHealth's approval came down to sheer luck. Frustrated, Jean called MassHealth to personally plead her case. "I finally got a really nice woman on the

phone and she helped me win approval.”

In Jean, the lipodystrophy also caused significant and disfiguring fat accumulation in her upper body – including under her arms and in her upper arms – and significant fat loss in her buttocks, thighs and legs. Her body is very unbalanced, which aggravates pre-existing back problems and leg ailments. “Sometimes I just want to come home and sit down and cry because it hurts so bad,” says Jean, a former social worker and case manager.

About seven years ago, MassHealth rejected Jean’s request for coverage for a procedure to remove the significant fat accumulation under her arms. Fortunately, Jean’s daughter worked for a plastic surgeon who generously agreed to perform the surgery for the \$2000 cost of the anesthesia. Jean, who lives on a fixed income, and her daughter, who held three jobs, pooled their resources. “We used our credit cards,” she says.

Jean is now attempting to get approval from MassHealth for a procedure to remove the abnormal fat accumulation in her upper arms. Lifting her arms over her head is painful, and it is difficult for Jean to get her blood pressure taken, which she must do frequently, because the cuff doesn’t fit around her arm. Her arms bruise because her sleeves are so constricting, but going out with short sleeves is unbearable because of the way people react to her appearance.

As with her buffalo hump surgery, Jean’s surgeon has already fielded about four requests from MassHealth for more information. “Instead of outright denial, they keep asking for more information,” she says. “So the doctor has to keep writing more and writing more.”

Jean is grateful for the commitment her health care providers have made to ensuring she receives the lipodystrophy treatment she needs, but she knows it requires tremendous time and patience from them.

“Sometimes you want to say, ‘Oh my god, I can’t do this anymore,’” she adds. “You want to give up and I guess maybe that’s the point – they want you to give up. But I can’t.” ♦

People Look at Me and Say, ‘HIV’

Bob

Bob is a long-term survivor of HIV who was diagnosed in 1990. He has also twice battled cancer and won. But some of Bob’s most challenging moments have come from his struggle with lipodystrophy.

Bob began experiencing lipodystrophy in the 1990s, when “fat just started redistributing itself in my body. It became profoundly noticeable in my neck and in my chest.” He also lost most of the fat in his arms, legs and buttocks. “I was completely disproportionate,” he says. He suffered back pain and an irregular gait as a result.

Around 2004, while Bob was recovering from cancer, a huge volume of fat accumulated around his neck, including bulbous protrusions behind each ear. “Walking down the street I would catch people pointing,” says the 51-year-old, who lives outside Boston. “It affected me in a very bad way. ... Thoughts of wanting to become a shut-in became quite prevalent.”

Bob, who asked that his last name be withheld because he fears stigma, began avoiding public events. “It has to do with the feeling

**“I feel like I walk in a room and
people look at me and say, ‘HIV.’ I
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that I’m being judged,” he says. “I just feel like I walk in a room and people look at me and say, ‘HIV.’ And that honestly has changed my life, in a very negative way. I just don’t feel like I live a full life anymore because of it.”

Bob received a referral from his primary physician for a reputable

plastic surgeon to perform liposuction, but his insurer, Blue Cross Blue Shield, immediately denied the surgeon's request, viewing the treatment as merely cosmetic. Bob appealed. Two of his doctors, his physical therapist, his acupuncturist, and his chiropractor attested to his medical need for the treatment. "My primary doctor said, you can take care of the problem now or ignore it but in three to four years from now he's going to need major back surgery and it's going to cost you a lot more," says Bob.

"My primary doctor said, you can take care of the problem now or ignore it but in three to four years from now he's going to need major back surgery and it's going to cost you a lot more."

Blue Cross again refused to cover any medical treatment related to Bob's lipodystrophy.

Bob finally called Blue Cross Blue Shield himself. "I was very emotional at that point," he says. "I said, how can you deny this when all of these facts are in front of you?" Four days later, he received a letter of approval for the liposuction surgery.

After all that, the surgeon was unfortunately unable to perform the procedure because the fat around Bob's neck was too thick to be liposuctioned – a consequence of the long delay in his treatment. ♦

A Life Curtailed

Joe Clement

“It’s a win-lose situation for me,” says Joe Clement of the HIV medication that keeps him alive. The extreme side effects cause what Joe calls “this ‘morphed image’ when I look at myself in the mirror. I can’t stand it.”

For 16 years, the 57-year-old artist has been living with lipodystrophy, which has caused a “buffalo hump,” or dorsocervical fat pad, to grow on the back of his neck. The significant fat accumulation all around his neck and under his chin makes his head appear abnormally large. There is excess fat on his back and abdomen. He also has “facial wasting” and abnormal, excessive fat loss in his buttocks, arms, and legs (symptoms known as lipoatrophy).

The buffalo hump causes headaches, disc degeneration, difficulty sleeping, and chronic back and neck pain. Joe cannot lie on his back or fully turn his head. Because of the extreme fat loss in his buttocks, sitting in certain chairs – like seats on the T – causes uncomfortable numbness. Running, which Joe once enjoyed, is now too painful.

The condition has so altered Joe’s appearance that old friends sometimes don’t recognize him. Once a man with a healthy self-image, Joe now avoids appearing in family photos and feels defensive about his appearance on the rare occasion he goes out. “When I meet people,” he says, “I want to say, ‘I don’t really look like this. It’s not me.’”

In the past, Joe has stopped taking his HIV medication so that he could lose the abnormally distributed and disfiguring weight and feel better. But he knows that negatively impacts his health in other ways.

Lipodystrophy has also caused Joe to become depressed and withdrawn. In September 2011, Joe attempted suicide. “On a daily basis, I really don’t go too far from the house,” says Joe, who lives in Lowell.

With the support of his medical and mental health providers, Joe sought liposuction surgery. MassHealth refused to cover it on the grounds that it is cosmetic and not medically necessary.

Joe is perplexed and frustrated at the barriers to effective treatment. He believes that health insurers should cover treatment for lipodystrophy in the same way they cover breast reconstruction surgery for women who have mastectomies because of breast cancer. “I used to be a very outgoing, active person. And now I find myself just isolating because of the lipodystrophy.” ♦

Lipodystrophy has caused Joe to become depressed and withdrawn. In September 2011, he attempted suicide. “On a daily basis,” he says, “I really don’t go too far from the house.”

Living in Constant Fear

Amit Dixit

In 1994, at the age of 26, Amit Dixit was diagnosed with advanced AIDS. At the time, his father did not want to tell anyone in their South Asian community. He feared that AIDS would be a mark on his family and would make it more difficult for other family members to get married.

Fortunately, Amit received good treatment for his HIV, and today, at the age of 46, his HIV disease is stable.

However, due to his life-saving antiretroviral medications, Amit developed lipodystrophy. He experienced abnormal fat growths under his chin, known as a “horse collar,” and at both sides and the back of his neck, known as a “buffalo hump.” He also had acute fat loss in his cheeks.

Lipodystrophy had a devastating impact on Amit’s life. He couldn’t sleep because of the “buffalo hump,” and it distorted his normal body shape. It was always visible to others – people stared at him as he walked down the street, resulting in social isolation and depression. “I lived in constant fear that the lipodystrophy would identify me as HIV-positive,” Amit says, “especially in my South Asian community, where HIV is even more stigmatized than in Western society.” He stopped attending Indian community celebrations such as Diwali, the Indian New Year, which his friends and family have attended since his youth.

Amit twice sought surgery to treat his lipodystrophy. And twice, his insurer, Harvard Pilgrim Health Care, denied his doctor’s requests for prior authorization. He despaired. He didn’t appeal on either occasion – the appeals process was daunting, and he had no idea what to do in order to get the denial of treatment changed.

He began seeing a psychologist due to the depression and anxiety he was experiencing, which Harvard Pilgrim did pay for. Understanding that the key to treating his depression and anxiety

was treating his lipodystrophy, his psychologist encouraged him to try again – and this time, to seek out a lawyer to help him.

Dr. James May, a surgeon at Massachusetts General Hospital, submitted a request for prior authorization for treatment, which Harvard Pilgrim denied for a third time. But this time, an attorney at Gay & Lesbian Advocates & Defenders took his case for free. Amit's lawyer spent countless hours on the appeal, interviewing Amit and

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"buffalo hump." [P]eople stared at
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depression.**

working with his HIV doctor, psychologist, and Dr. May on their letters of support. The lawyer wrote a brief citing 15 medical journal articles verifying the harms caused by lipodystrophy and made legal arguments about why treatment for lipodystrophy should be covered by Amit's insurance.

Within a week of submitting this appeal, Harvard Pilgrim called to tell Amit that they would pay for his treatment.

Treatment has changed Amit's life; he feels like a normal person again. But he also knows it's not practical for every person who needs treatment to get the kind of help he got; he was fortunate his case was taken up for free, because like most people, he wouldn't have been able to afford an attorney otherwise. ♦

A Simple, Life-Changing Procedure

Michael Achille

Michael Achille, a resident of South Orleans, Massachusetts, began developing severe lipodystrophy in 2001-2002 as a result of his HIV medication.

Michael's lipodystrophy manifested itself as a buffalo hump, a fat pad on the back of his neck that grew and quickly became debilitating. The abnormal fat accumulation caused his head to pitch forward and caused significant pain, including splitting headaches and terrible backaches. The buffalo hump made sleeping and driving very difficult, as he could not lie on his back nor turn his head easily. While pain medication such as Vicodin helped alleviate some of the symptoms, this was not the long-term solution he was hoping for.

Eventually, Michael's doctor told him there was a simple procedure that would provide him with relief: liposuction to remove the buffalo hump. Unfortunately, MassHealth denied his surgeon's request for prior authorization. His surgeon urged Michael to appeal, and he did, gathering documentation from all his medical providers to prove the medical necessity of treatment.

Michael went to the appeal hearing in Taunton, and he couldn't believe the response: the MassHealth doctor stated that Michael's pain and debilitation didn't matter. The hearing officer even made the Finding of Fact that his "lipodystrophy causes sleep disturbance, debilitating headaches and backaches, as well as psychological distress."

Despite this, the Appeal decision goes on to state, "The MassHealth representative noted that it is not a question of whether the appellant needs this procedure or can benefit from it but rather one of the requested service not being a covered service by Massachusetts." As a result, the hearing officer denied Michael's appeal without even considering whether the surgery was medically necessary. Her hands were tied.

“I was so upset and didn’t know what to do,” Michael says. Fortunately, he was able to find a lawyer to represent him for free. The lawyer filed a Request of Rehearing directly with the Medicaid Director, Dr. Julian Harris, making the case for medical necessity as well as legal arguments in favor of treatment. Michael was relieved when he learned that Dr. Harris determined that Michael should receive liposuction surgery.

“The day my buffalo hump was removed through a simple liposuction procedure was life changing. I got instant relief. It was like I was normal again.”

“The day my buffalo hump was removed through a simple liposuction procedure was life changing,” Michael explains. “I got instant relief. I was delirious with joy. It was like I was normal again.”

Michael is sharing his story because he knows it is not possible for everyone who needs this treatment to make an appeal and find a lawyer to take their case directly to the Medicaid Director for consideration. In fact, many people don’t seek treatment, because they’ve heard it’s not covered and therefore don’t know what to do.

Michael was lucky, but medically necessary treatment shouldn’t be left up to luck. ♦

Facts About HIV-Associated Lipodystrophy Treatment

What are the body changes caused by lipodystrophy?

Lipodystrophy results in both abnormal accumulations of fat and abnormal loss of fat. Abnormal fat accumulation may manifest as a significant fat pad on the neck (colloquially called “buffalo hump”), fat accumulation around the front of the neck and under the chin (colloquially called “horse collar”), and increased abdominal girth. Abnormal fat loss occurs most prominently as wasting in the nasolabial folds of the face as well as in the limbs.

How does lipodystrophy harm people with HIV?

Lipodystrophy has severe physical and psychosocial consequences. Fat accumulations on the neck can cause pain, headaches, restricted movement, inability to sleep, and spinal and postural problems. In addition, substantial medical literature concludes that lipodystrophy results in “impaired quality of life in both men and women with HIV,” including depression, isolation, poor social functioning, and increased stigma associated with HIV. One medical study described facial wasting as “a scarlet letter” disclosing a person’s HIV status while another report observed that patients with facial wasting feel that they have the word “AIDS” permanently written on their face.

How do people with lipodystrophy describe their experience?

“I’ve described myself as a monster. It’s difficult to leave to my house.”
Mark, Boston resident

“I used to be a very social, very outgoing, active person. And now I find myself just isolating because of the lipodystrophy.”
Joe, Lowell resident

Does lipodystrophy harm the broader public health?

Yes. The stigmatizing impact of lipodystrophy has caused patients to discontinue their HIV medications. This in turn can lead to strains of HIV that are resistant to treatment.

Why is this bill necessary?

Effective medical treatments for lipodystrophy include liposuction to remove accumulated fat and injectable facial fillers to correct facial wasting. Insurers routinely deny claims for these services on the grounds that they are cosmetic. People with HIV should receive treatment to correct the harmful side effects of their medications.



The abnormal fat accumulation in Jean's upper arms makes lifting them painful, and causes bruising with the frequent blood pressure monitoring she must do for her health.

Read Jean's story on page 16



The severe physical and psychological pain of the excessive fat accumulation on John's upper back and around the front of his neck has forced him into a life of isolation. He has considered stopping his life-saving HIV medications and even contemplated suicide.

Read John's story on page 6



George Hastie had the worst case of buffalo hump his surgeon had ever seen, causing him severe, debilitating pain in his back, neck and shoulder.

Read George's story on page 10

A Bill to Require Insurance Coverage for Treatment of a Debilitating and Disfiguring Side Effect of HIV Medications

This bill requires private insurers, MassHealth, and the Group Insurance Commission to provide medical treatment for lipodystrophy, a disfiguring side-effect of lifesaving, but highly toxic, HIV medications.

HIV antiviral medications, known as “triple combination therapy” or “the cocktail,” revolutionized AIDS care in the 1990’s, extending the lives of people with HIV. These medications also can result in lipodystrophy, the abnormal distribution of body fat. The condition creates “visible disfiguring and stigmatizing morphological changes” in body shape and appearance, causing profound physical and psychological harm to people with HIV.

While there are inexpensive, effective medical treatments for lipodystrophy, insurers routinely deny claims for treatment on the basis that they are cosmetic and not medically necessary.

For more information, including a list of organizations and medical professionals who support this bill, visit [**www.glad.org/tlc**](http://www.glad.org/tlc)

