Pass The Scalpel—And The Bucks

Countless HIVers suffer from lipo's puppet cheeks and buffalo humps, but health plans won't shell out to fix 'em. Tim Murphy helps you snag your fair share.

July 1, 2003 By Tim Murphy

Nick (not his real name) is a Chicago actor with HIV-related lipodystrophy, the disorder that can add fat in some places (shoulders, neck, belly, breasts) and subtract it from others (arms, legs, face). A few years ago, Nick had such large fat deposits on his neck and shoulders that the only role he was suited for was the hunchback of Notre Dame. So he had the fat removed with liposuction. But what Nick had thought was his "incredible health coverage" wouldn't pay—even though David Teplica, MD, who's performed lipo correction on many HIVers, declared the work a medical necessity. (Pre-surgery, Nick could barely move his neck, which had swollen to 19 inches around.) He'd spent nearly $14,000, including $4,800 to Teplica and $8,000 to the anesthesiologist and hospital. It was his life savings, but Nick says he had no choice: "If you look sick, people won't hire you for a role." His plan denied three appeals—and now the fat's returning.

Most HIVers' health plans refuse to pay for lipo surgery, especially facial restoration (see "Take This Mug and Stuff It," May 2003). Why the heartlessness? In their member guidebooks, most plans stress that they don't cover cosmetic surgery that isn't "medically necessary." And in all but a few of the cases POZ surveyed, that's precisely how plans have dismissed treatments for HIV-related lipodystrophy, despite repeated appeals from patients and their doctors.

The law offers some recourse, but not enough. California is the only state that requires health plans to cover disease-related reconstructive surgery aimed at improving function or restoring "normal" appearance. But, according to LA's Derek Jones, MD, who plumps HIVers' shrunken faces with liquid-silicone injections, most Cali plans "still ignore this law, citing that there is no FDA-approved treatment…or that this is really a psychological issue." (A few facial treatments, such as collagen and Fascian injections, are approved, but their cosmetic benefits are short-lived. Silicone injections, though permanent, won't be approved—a prerequisite for health-plan reimbursement—until the FDA sees the results of clinical trials that Jones and others are conducting.)

Meanwhile, the federal Reconstructive Surgery Act, similar to California's law, has been languishing in Congress for two years. Abbey Meyers, of the National Organization for Rare Disorders, which lobbies for such legislation, says the act, however broadly worded, was crafted to benefit children with birth defects—and that the bill has stalled because insurers and law-makers

are afraid that the hordes seeking coverage for cosmetic surgery will hitch a ride.

Still, you may have more leverage than you think—if you've got the stamina to play by the rules exactly as they're written. "A lot of times you can get what you want, but you have to bear down for the long haul," says Michael O'Connor, of LA's HIV/AIDS Legal Services, which, he says, has won coverage for some Angeleno HIVers seeking these procedures. "It kills me when people give up out of frustration." This, he notes, is just what HMOs bank on as they diss you again and again. Follow these steps—precisely—and you may have a fighting chance:

Holler "Help!"
Ask your local ASO to find a benefits specialist like O'Connor who can walk you through the process and play advocate. Have your doctor call the Reimbursement Hotline of the American Academy of HIV Medicine (AAHIVM; 1.877.734.6468 or www.aahivm. org)—they'll research your case, help you finesse your plan's internal appeals process (see "Appeal No. 1," next page), and, if necessary, direct you toward appeals options in your state.

Talk the talk from Day One
Remember: You're seeking disease-related reconstructive surgery akin to the kind that insurers must cover, under the federal Women's Health and Cancer Rights Act (WHCRA), after breast cancer–related mastectomies. For heaven's sake, the procedure you need is neither elective nor discretionary (favorite HMO pass-the-no-bucks buzzwords) but medically necessary—due to immobility, discomfort and profound psychological stress.

Know thy health plan inside out—and never stray from it
If you're ever going to have a snowball's chance in Hades of getting this work covered, O'Connor stresses, you've got to tough out the approval process before going under the knife (or needle). Check your plan's guidebook: Even if it lets you use providers outside the network, it likely still wants to approve what you're going to have done, and by whom, before it promises to reimburse you. (If you fly to Tijuana for a mystery-gel injection, then send your plan a $10,000 bill, don't be surprised when they laugh in your newly plumped face.) Most plans declare that they exclude cosmetic surgery other than the specific procedures covered under WHCRA. But don't give up—and do meticulously document every step you take. You'll need the support of a shrewd HIV-specializing primary-care doc (a wiz with HMO billing codes), who will refer you to a specialist who can perform the procedure, be it liposuction or facial implants. A few HIV MDs are even learning to do such work themselves.

Appeal No. 1: within your plan
If your insurer refuses to pay, follow your plan's appeals process to a fare-thee-well (thus begins the "long haul" O'Connor referred to). You and your doctor will want to gather the best evidence of the medical necessity of your desired treatment. New York City benefits attorney Mark Schurzer suggests including everything from photos of your condition to published studies on the bodily manifestations of lipodystrophy to written testimonies from coworkers, friends and family on how lipo has affected you. (Buffalo hump can impede sleep, posture and range of motion; the "dead man walking" look of extreme facial fat loss can cause debilitating, even suicidal depression.)

Schurzer suggests that your doctor or psychiatrist draft a cost comparison of treatment vs. indefinite years on pain meds or antidepressants. Remember the key words: medical necessity (for details on appealing, click on Resources at www.patientadvocate.org).

Appeal No. 2: beyond
your health plan
You've followed your plan's appeal rules diligently—only to get the final heave-ho. Next move: Call your state department of insurance (go to the map at www.statehealthfacts.kff.org and click on your state). Most states have external review boards for folks who've exhausted plan appeals. (Schurzer says the New York board overturns roughly half the cases.) You and your doctor need to prove that your plan is breaching its contract by withholding coverage for medically necessary treatment.

If the external board says no?
"You have the right to sue," says Schurzer—and O'Connor seconds the motion. You'll need an affordable or pro bono lawyer who knows this stuff: Contact your local ASO or the Patient Advocate Foundation (1.800.532.5274 or www.patientadvocate.org) for a referral. Schurzer says that in most cases a judge will rule based on the original appeal to the health plan, which is why you and your doctor should submit the best possible evidence and photos at the very beginning of the internal appeal. O'Connor says when a patient gets this far, the insurer often doesn't even send attorneys to court—and the patient wins by default. "You have to be willing to pursue it to the end," O'Connor says. "That's why it's important to put all your ducks in a row before you begin."

Meanwhile, take heart from San Diego HIVer Steve. His HMO denied his request for liposuction on his buffalo hump, even though the plan was shelling out for drugs to relieve the pain and headaches. Steve appealed—"a tedious task," he says—arguing that he couldn't turn his head while driving. "I was a danger to myself and others," he reasoned—and did the plan really want to go on paying for his pain meds? His HMO finally approved the surgery, and Steve emerged "with only two small scars to show for it." Lesson? Getting your health plan to pay up may be possible after all—if you're ready to face a few humps and bumps along the way.

FIGHT THE POWER

Find this all just a tad infuriating? Tired of having to explain to insurers why lumps of flesh sticking out in peculiar areas of your anatomy make you feel peculiar? Maybe it's time to get busy. Get your doc—and your HIVer friends' docs—to lobby powerful groups, like the AAHIVM, AIDS Action, and National Organizations Responding to AIDS, to petition health insurers and law-makers to rewrite policies to cover lipo-licking procedures. "We listen to our providers," says AAHIVM founder and president Scott Hitt of the 1,500-plus frontline HIV doctors who've joined AAHIVM, which lobbies insurers and government to recognize HIV care as a medical specialty, like oncology. "But so far I've heard more about this issue from friends than providers." With ADAP and Medicaid squeezing publicly insured HIVers, and all kinds of HIV drugs costing so much, coverage for lipo correction isn't many groups' top priority. A little acting up might just change that.

© 2026 Smart + Strong All Rights Reserved.
http://beta.docker.poz.com/article/Pass-The-Scalpel-8212-And-The-Bucks-2904-5556