The New AIDS Look

Sick of singing the lipodystrophy blues but don't want to stop the drugs? Here are some HIVers who said no to their lumps, humps and hollows -- and yes to plastic surgery. Stacie Stukin goes inside the operating room.

June 1, 2000

Puppet Face. Protease Paunch. Crix Belly. Buffalo Hump. Boobs-on-a-Stick. These monikers have become part of the PWA vernacular, dark humor used in private among those who know firsthand that lipodystrophy wreaks havoc on bodies. Ropy, veined legs, sacks of skin for butts, protruding bellies, carved-out faces, triple-D-cup breasts and lumps of fat on the neck or shoulders are some of the physical manifestations of a syndrome neither fully defined nor curable. While the mainstream may not have caught on to these telltale signs, PWAs recognize one of their own instantly. They pass one another on the street and exchange knowing looks. Her belly bulges as if she's slightly pregnant; his face is wasted down to the bone. His neck is so thick his shirt hangs oddly; her legs are like toothpicks.

These body transmutations are disconcerting, to say the least. Some PWAs are able to roll with the punches, seeing the etched lines on their faces as sexy symbols of survival, wounds worn proudly from the war called AIDS. Others feel saddled with what one PWA has termed "the uglies" -- affecting everything from self-image to dating and job security. Observes Los Angeles dermatologist Robin Schaffran, MD, "I've had patients who want to go off medication because of lipodystrophy. These body changes have become a serious psychosocial issue." For some, exercise is their savior, a way to feel better about the body they no longer recognize. But as a tool for trimming down the waist and beefing up wasting legs and arms, exercise doesn't always produce results. Diet changes are an obvious response, but studies so far have not shown diet to be effective in reducing lipo-produced fat deposits. Human growth hormone helps some reduce humps and bellies, but it also can cause unpleasant side effects, such as joint pain (reducing dosage will often eliminate these problems). When PWAs like Warren Fernandez try them all, taking better care of themselves than they ever have, they still face the ultimate paradox of state-of-the-art combination therapy. "I never felt so good," Fernandez says, "but I never looked so bad."

So Fernandez chose to go under the knife. Although a drastic solution to some PWAs, plastic surgery and cosmetic dermatology now offer a range of procedures that can make gaunt or deeply lined faces appear robust and healthy, or remove unwanted humps and fat. While there is no data on how many PWAs are choosing this option, doctors at one Los Angeles-area plastic surgery and dermatology practice estimate that they treated 225 HIV patients for lipodystrophy last year. With

cosmetic options come other benefits -- a boost in self-esteem and a chance to look in the mirror again without the constant reminder of HIV. That was the case for Lillian Thiemann, 45, of New York City, who chose to have some of her own harvested fat reinjected into her cheeks. “No matter how hard I tried to say to myself, ’I’m happy to be alive, don’t let vanity get in there,’” she explains, “it was difficult not to see myself anymore.”

Fernandez, 38, opted to receive facial injections of a material called Fascian, which filled the hollow sockets that his cheeks had become. Fascian is a material derived from the connective fatty tissue of cadavers, which is then irradiated to rid it of disease, reconstituted into a powder and put into a syringe with saline. It’s injected into the fat layer under the skin surface. Theoretically, once the saline is absorbed by the body, the remaining fascia bonds with the body’s naturally occurring collagen and forms a matrix with the host’s fat, keeping the cheeks looking plump and healthy.

“I had a very sunken look,” Fernandez recalls. “I looked like someone close to starvation. Even though I am in no way ashamed of being HIV positive, it became a marker, a stigma.” In other words, it’s easier to be openly positive and healthy looking -- like images in the drug ads in these pages -- than to be openly positive and visibly ill. Lipodystrophy is fast becoming today’s Kaposi’s sarcoma lesions -- the “face of AIDS” that serves as an uncomfortable reminder that all is not well in this age of protease-based hope.

On a sunny afternoon in March, Fernandez is sitting outdoors in a West Hollywood café. He is fit from his daily trips to the gym, and his tanned skin looks dark and smooth against his royal blue sweater. His face, framed by silver-rimmed glasses, shows no signs of wasting, and the lines that remain are the ones he inherited from his father. The procedure cost $1,200. Fernandez couldn’t really afford it -- he’s currently living on disability benefits and not working full time -- but he says the sacrifice to pay off his physician in monthly increments was worth it. “I like my face now. I think it’s masculine and handsome,” Fernandez says. “But I realize I’m fortunate. There are so many people who couldn’t even afford to pay it off over time.”

He’s right. Federal law mandates that public and private insurance cover reconstruction for women who have lost a breast to cancer therapy. But PWAs who want to cosmetically correct their therapy-induced lipodystrophy are mostly on their own, counting coins to see whether they can pay out of pocket. “Once again, we’re dealing with a class issue with HIV,” says Mary Lucey, AIDS policy analyst for the City of Los Angeles. “People who are wealthy will get their fat sucked out and get implants. Meanwhile, others struggle just to afford their meds.”

It’s no surprise that the insurance industry’s idea of medical necessity differs greatly from what some PWAs deem necessary. Says Jacques Chambers, the manager of the insurance benefit program at AIDS Project Los Angeles (APLA), “Since these procedures relate to psychological issues of self-image, insurance companies treat it like any other plastic surgeries.” In other words, they very rarely cover it. Even some HIV doctors don’t consider lipodystrophy a priority. Says Marki Knox, MD, a Santa Monica-based gynecologist, “Basically the attitude is, the drugs are saving your life, so don’t complain about the cosmetic aspects. But it’s just not that simple. To look funny on

top of being HIV positive is really a slap in the face."

A few PWAs, like Nora Drake (not her real name), 49, of Los Angeles, have fought to get insurance to cover portions of their surgeries. Because she is legally blind in one eye and because her buffalo hump prohibited neck mobility, driving became a hazard. She petitioned her insurance company, Blue Cross of California, arguing that the surgery was medically necessary, and finally they agreed to pay for liposuction to remove the fatty tumor that was growing on her back. In fact, this wasn't Drake's first attempt to lose her hump. Nearly two years ago, she had a surgeon cut into her back and remove more than six pounds of tissue, but as is not unusual, the fat deposit returned. One man interviewed by *POZ* had surgery and, later, liposuction for a buffalo hump so intrusive that he couldn't button a shirt collar or wear a tie. He says his plastic surgeon speculated that the fat would grow back, estimating that his patient might have to return for liposuction every six months to control the hump's growth.

Profound psychological suffering often underlies the decision to have corrective surgery. Drake says she felt like she was turning into a monster. She was too ashamed to let her husband see her naked, and it was affecting their sex life. Many of her friends and family are unaware of her HIV status, and she feared her drastic body changes would soon clue them in. "If someone put their hand on my back affectionately," she says, "I thought, 'Oh, no, they're feeling my hump.' It felt gross and I was starting to worry." Of the many lipo-corrective procedures available, buffalo-hump removal is the one insurance companies are most apt to cover, APLA's Chambers explains, especially when someone can demonstrate that the growth is a serious physical impairment.

But paying thousands of dollars to nip, tuck, suck out or shoot in raises questions not only about how PWAs view their own bodies but about how society now expects those with HIV to look. Inevitably, these value judgments affect the way PWAs, employers and insurers make decisions. Daniel Wolfe, author of *Men Like Us* (Ballantine), a newly published guide to gay men's health, says, "Questions about what is medically necessary often reveal a kind of generalized discomfort with people with AIDS acting and looking healthy. A frail, sick person with AIDS is familiar, but a healthy looking, sexually appealing person with AIDS is discomfiting and ominous," particularly to mainstream America. Relegating such surgery to the merely cosmetic disregards what some people deem imperative. It also ignores the reason PWAs consider surgery in the first place: not general dissatisfaction with looks or aging, but discomfort dealing with the unforeseen side effects of life-extending treatments. For many years, Wolfe says, insurance companies would not pay for reconstruction or prosthetics for a woman who received a mastectomy. "It took women to say no and fight for reimbursement and prioritization of appearance as something vital to health," he says. "Perhaps PWAs will have to do the same."

John Barrow (his online name) of Miami says that after his face "basically collapsed," he did extensive research and decided to get injected with Artecoll, an unproven poly-plastic. Since Artecoll has been used safely in the United States for implants such as hip replacement surgery and is approved for facial injections in Canada and Europe, Barrow chose to find a local doctor who would do the procedure off the books. Barrow says he happily spent $2,000 on "an excruciatingly painful" procedure. A few months later, noticing little improvement into his looks, he paid another

$2,000 when he had Perlaine, an arthritis treatment (also not U.S.-approved for plastic surgery), injected in his cheeks, which he says improved their sunken look a little. “I would take the meds even if they made my skin look like an alligator belt,” Barrow says, but dealing with these visible side effects has been a painful experience for him. “For the first time,” he says, noting that he’s not open about his status, “people in my family were asking, ’What’s wrong with you?’”

The thought of PWAs correcting every imperfection in their looks -- whether it’s related to HIV, the drugs or simply aging -- makes Guy Trebay uncomfortable. A columnist for *The Village Voice*, Trebay has written about gay male body image in the age of AIDS. He thinks any intervention that helps PWAs improve their quality of life is a good thing, but he also recognizes that we don’t live in a body-loving culture. “The images for what’s a healthy body are far too narrow,” he explains. “There’s already enough self-punishment going on and no one needs that, regardless of their health status. We need to get beyond the idea that the only thing we read as healthy is a body that looks like a bendable action figure.”

The media bombard us daily with images of muscular boys and rail-thin women; PWAs, like anyone else, fall into the trap of aspiring to remake their bodies according to these impossible standards. But PWAs have another burden. The virus already takes control away from HIVers in so many ways -- from the strict scheduling the meds impose to drug-induced bouts of diarrhea. To find that no amount of exercise or diet can control the body changes of lipodystrophy can be pretty demoralizing. Lisa Croyden, a patient advocate at UCLA’s Center for Clinical AIDS Research and Education, puts it this way: “Our looks were our last vestige of control over our bodies. Now we’ve even lost that. I don’t think anyone I know is looking for the perfect body. I think they’re just looking for the body they had.”

Mary Lucey understands the impact that body image has on PWAs, yet her frustration has surfaced as she watches friends and colleagues consider cosmetic procedures. “Here we go dancing around the issue again,” she exclaims. “Instead of figuring out why people’s bodies are changing, we just try to alter people and cover up the damage. In the end, removing a hump is not going to fix the underlying problem.” After years of advocacy, several studies to uncover the causes of lipodystrophy are underway, though they may take years to bear fruit. For now, it seems, PWAs are left bearing the responsibility to cope with their quickly morphing bodies and sensitizing the people around them. PWA Bruce Randall, 48, of New York City, wasn’t up to the task. He went to Belgium for Perlaine injections in his cheeks because, he says, “It was like wearing a scarlet letter on my face. I can wear clothes to cover up my body, but I can’t wear a bag over my head.” Randall wasn’t looking for a makeover; he just wanted to recognize himself in the mirror.
