

Your Body on HIV Drugs

The medications that have so dramatically improved the course of HIV disease over the past decade can also have a negative impact on people's quality of life. Anyone facing the decision of whether to start antiretroviral therapy has to weigh the potential benefits and risks. On a large scale, the benefits of treatment far outweigh the risks – fewer opportunistic infections and lower death rates. But for each individual, the picture is not so black and white. And the message must be clear to those who are HIV-negative: while treatment works, being on these drugs can be a challenge. This issue of *ACRIA Update* presents this reality in clear relief, focusing primarily on the body-shape changes that many people experience.

The individuals with HIV who share their personal stories in this issue paint vivid pictures of

the challenges of watching the strange and surprising changes in their bodies. Our other contributors discuss the psychological impact of body-shape changes, possible treatments, and data from a study of the side effects people experience and the ways they live with them.

Some people may consider body-shape changes a small price to pay for an extended life, but anyone who has lived with the condition themselves or seen a loved one experience it knows that it is much more than simply a cosmetic irritation. Hopefully, for people who don't appreciate the challenge of living with side effects, this issue of *ACRIA Update* will increase awareness of what life on HIV treatment can be like, and will validate the experiences of people affected by the drugs' side effects.

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Inching Forward: An Update on Lipodystrophy and Possible Treatments

by *Tim Horn*

More than just a tongue-twister, the term "lipodystrophy" can be broken down to reveal exactly what it means. "Lipo" refers to fat and "dystrophy" refers to abnormal growth or change. Put it together in plain English and what you're left with is exactly what's being seen in many people living with HIV – abnormal fat changes.

While researchers and healthcare providers still haven't yet officially defined lipodystrophy, it generally involves two problems that can affect physical appearance – a buildup of fat in some parts of the body and/or a loss of fat in other parts of the body. Some people see an increase in the amount of fat around their gut, on the back of their neck and shoulders (sometimes referred to as a "Buffalo Hump"), and/or in their breasts. The medical term for this is *lipohypertrophy* (excessive fat growth). It's important to note that a buildup of fat around the gut and waist isn't always lipodystrophy. Lipodystrophy usually makes the abdomen look bloated or distended

and often feel hard. This is because the fat increase associated with lipodystrophy (visceral fat) builds up deep within the body, around internal organs, causing the abdomen to swell. If the fat around your gut or waist feels doughy, fleshy, or soft – a good test is to see if you can "pinch an inch" around your waist – it's probably not lipodystrophy but, instead, typical weight gain that often comes with getting older.

Some people lose fat just below the skin (subcutaneous fat) in their legs, arms, buttocks, or face. The medical term for this is *lipoatrophy* (decrease in fat tissue). One of the most prominent features of facial lipoatrophy is sunken cheeks – cheeks that have lost their fullness and appear hollow. Mild facial lipoatrophy may be barely noticeable to the person experiencing it and unnoticeable to others. If the lipoatrophy worsens, the outlines of the facial muscles can be seen and felt through the skin. Facial lipoatrophy can also result in fat loss around the nose and mouth. This can cause deep folds in the skin to form, particularly when

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TH9507 for Lipodystrophy

People who have excess abdominal fat and who are taking anti-HIV drugs will take either TH9507 (an experimental growth hormone releasing factor) or a placebo (dummy pill) for 26 weeks. Participants must be 18-65 years old, with a CD4 count over 100 and a viral load below 1,000.

UK-427,857 for Drug-Resistant HIV

People who have taken anti-HIV drugs from three of the four classes of drugs will take either UK-427 (an experimental HIV CCR5 attachment inhibitor) with an optimized regimen of anti-HIV drugs, or take a placebo (dummy pill) with the optimized regimen, for 11 months. Participants must be 16 or older and have a viral load of at least 5,000.

For the above trials, contact Dr. Douglas Mendez at 212-924-3934 ext. 126 or Dr. Yuriy Akulov at ext. 124.

Research on Older Adults with HIV: ROAH PROGRAM

People in this large study of older adults with HIV will fill out a survey about physical and behavioral health, social networks, quality of life and spirituality. Participants must be 50 or older and be able to read and complete a questionnaire. Study participants will be reimbursed \$25 for one visit.

For the ROAH Program, contact Andrew Shippy at 212-924-3934 ext. 104.

Editor's Notes

- All material in *ACRIA Update* is presented for educational and informational purposes only, and is not intended as medical advice. All decisions regarding one's personal treatment and therapy choices should be made in consultation with a physician.
- *ACRIAUpdate* refers to most drugs by both their commercial and scientific names upon their first reference in an article. Thereafter in the article, they will be identified with the name by which we feel they are most commonly known, either commercial or scientific.

Inching Forward: Lipodystrophy and Possible Treatments *(continued from first page)*

smiling or chewing. The fat that fills out the temples, on the sides of the forehead, and the eye sockets can also be affected by lipoatrophy. When fat in these parts of the face becomes diminished, the result can be a skeletal appearance.

What Causes It?

We don't really know what causes lipodystrophy. All we know is that many HIV-positive people are experiencing one – or both – of the problems discussed above, along with other complications, such as elevated blood lipid levels (cholesterol and triglycerides). We also know that most patients who have lipodystrophy started noticing symptoms once they were on combination-drug therapy.

There are actually three theories being tossed around by researchers, two of which are directly related to the side effects of anti-HIV drugs:

- **Protease inhibitors (PIs):** Some researchers believe that protease inhibitors can impair the ability of certain enzymes responsible for mopping up excess fat and keeping fat cells functional. This might explain why fat accumulates around the gut, breasts, or neck. It's still not clear which PIs are most likely to cause lipodystrophy.

- **Nucleoside reverse transcriptase inhibitors (NRTIs):** Some NRTIs can impair mitochondria, the “power generators” of human cells. A growing number of researchers believe that this might explain many of the side effects seen in people taking NRTIs, including peripheral neuropathy, pancreatitis, decreased white blood cell counts (leukopenia), and possibly lipodystrophy. Test tube studies indicate that the “d” NRTIs – Zerit (d4T), Videx (ddI), and Hivid (ddC) – are the most likely to damage mitochondria, particularly if they are used for long periods of time. There have also been a number of clinical studies linking Zerit to lipoatrophy. While other NRTIs have also been linked to lipoatrophy, the risk appears to be highest in people taking Zerit.

- **HIV itself:** It might be that HIV, and not only the drugs used to treat it, is to blame. Long before the use of anti-HIV drug combinations, people living with HIV were more likely to have higher levels of lipids in their blood and to experience body-shape changes than HIV-negative people. And because many HIV-positive people are living longer while on combination therapy, the HIV-related fat problems continue to get worse. Some researchers have suggested that lipodystrophy might also be related to an imbalance in the immune system that remains after combination therapy is started; even though combination therapy prevents HIV from attacking immune system cells, it may not halt the negative effects of HIV on other cells in the body.

“While a switch from a PI to an NNRTI can help control lipid levels, it isn't clear if it can reverse body-shape changes...”

Can Lipodystrophy Be Prevented?

As discussed above, it's still not clear how or why lipodystrophy occurs in HIV-positive people. However, a great deal of research has documented an association between certain anti-HIV medications and lipoatrophy. This, in turn, has altered the ways in which many doctors choose to treat their HIV-infected patients. For example, based on its connection to lipoatrophy, Zerit is now prescribed much less frequently than it used to be and is being switched for other NRTIs in patients who are currently taking it. This, in turn, may help to reduce the risk of lipoatrophy.

The same principle may hold true in terms of selecting a protease inhibitor. For

example, the PI Reyataz (atazanavir) appears to be the least likely of all the PIs to increase lipid levels, with early evidence also suggesting that it may be less likely than the other PIs to cause abnormal body-fat changes.

How Can It Be Treated?

Because we really don't know what lipodystrophy is or exactly what causes it, we don't know how best to treat it. Developing effective treatments for lipodystrophy depends on a more complete understanding of the nature and causes of the condition.

There are a number of treatment approaches being looked at by researchers, none of which have yet been proven to be effective. But early results from clinical trials and word-of-mouth reports by patients and doctors paint a promising picture. Here's a look at what's being tried and developed:

Switching therapies: Because anti-HIV drugs are believed to be the most likely cause of lipodystrophy, the usual first step is to switch the possible offending drug for one that might not cause the same problems.

PIs – with the possible exception of Reyataz – have been said to be a likely cause of lipodystrophy. In turn, several research teams have experimented with drug switches to help control the problem. For example, some patients receiving a PI in combination with two NRTIs might be able to switch the PI for an NNRTI – usually Sustiva (efavirenz) or Viramune (nevirapine). While a number of studies have confirmed that a switch from a PI to an NNRTI can help control elevated lipid levels in the bloodstream, it still isn't clear if such a switch can reverse the body-shape changes associated with lipodystrophy; data from clinical trials have been conflicting.

For people who have developed lipoatrophy while taking a drug regimen that contains a suspect medication – Zerit or Retrovir (AZT), for example – an option might be to switch to a drug that is less likely to cause lipoatrophy – Viread

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(tenofovir) or Ziagen (abacavir), for example. In a handful of clinical trials, this approach has been shown to prevent further lipoatrophy and sometimes reverse the problem in patients who develop lipoatrophy while taking Zerit or Retrovir. This approach appears to work best if the medications are switched before lipoatrophy becomes severe.

Medications: We don't yet have any medications that have been proven to be safe and effective in reversing the body-shape changes associated with lipodystrophy. However, researchers are exploring possible options in clinical trials.

Thiazolidinediones – sometimes referred to as “glitazones” – represent one class of drugs being studied. These medications, which include Avandia (rosiglitazone) and Actos (pioglitazone), are approved for the treatment of diabetes. They have been shown to stimulate a gene (PPAR-gamma) that plays a vital role in regulating triglycerides, managing blood sugar levels, and promoting the healthy function of fat cells. They have been studied in a handful of clinical trials involving patients with lipodystrophy. Results, however, have been mixed. Some studies found that these therapies helped to reverse lipodystrophy – most notably the fat loss associated with lipoatrophy – while others failed to note any improvements. There are also lingering concerns about using this class of drugs in non-diabetic patients.

Some researchers think that anabolic drugs, such as Serostim (recombinant human growth hormone), might help control some of the body-shape changes seen in some people with lipodystrophy. In studies of Serostim for the treatment of AIDS-related wasting syndrome, it was demonstrated that the drug helped reduce fat buildup and promoted muscle growth. In HIV-positive people with lipodystrophy, a few studies have shown that Serostim might help reduce fat buildup around the waist, breasts, and back of the neck. The drug might also help increase muscle in the legs and arms, ultimately covering up the loss of fat.

Serostim does come with side effects, including increased glucose levels (which can be a big concern for people who are already experiencing this problem) and muscle aches, so researchers are currently experimenting with low-dose Serostim to see if it is still effective and causes fewer side effects. The dose currently being tested in clinical trials is 4mg every day for 12 weeks, followed by a lower dose every day or every other day (for wasting syndrome, the dose is 6mg every day continuously). The manufacturer is negotiating with the Food and Drug Administration (FDA) to determine if Serostim should be approved for the management of HIV-related body-shape changes.

Diet and exercise: A handful of research reports have found that some patients who increased their exercise or started low-fat diets saw a reduction in their lipid levels and body-shape changes. Considering that everyone can benefit from more exercise and a healthy diet, all HIV-positive people – whether they have lipodystrophy or not – are encouraged to speak with a nutritionist or dietician about the steps they can take to improve their nutritional status and activity levels.

Plastic surgery and facial fillers: Surgery to correct changes in body fat caused by lipodystrophy has become very popular in recent years. There are two types of plastic surgery being talked about and used: 1) liposuction, a surgical procedure in which fat is sucked out of a specific area of the body, and 2) facial fillers, a general term for procedures in which fat or fat substitutes are injected into the face to help “fill out” sunken cheeks and other troubled spots (the temples and around the eyes or mouth, for example).

Although there have been no clinical trials of liposuction for the treatment of lipodystrophy, numerous HIV-positive people report that it can help reduce fat buildup in the breasts and at the back of the neck. Generally, liposuction can't be used to remove fat buildup in the abdomen, as there is a risk of internal organs being

punctured or damaged during the procedure. It is also important to note that liposuction to reduce fat in the breasts or at the back of the neck may not be permanent – some people see the fat buildup return, usually just several months after the procedure. Liposuction can also be painful and usually isn't covered by health insurance plans, although some people have had some success getting reimbursed for this expensive procedure.

There has been a lot of interest in restorative therapies – such as facial filler injections and implants – for facial lipoatrophy. One facial filler, Sculptra (poly-L-lactic acid), was approved by the FDA in August 2004, and several others are being studied all over the world for people with facial lipoatrophy. There are important similarities and differences between the various facial fillers being studied, which are reviewed below.

What Are Facial Fillers?

Generally speaking, facial fillers are injectable – or surgically inserted – products that can be used to fill hollows in the face, such as those caused by lipoatrophy. Fillers are temporary, semi-permanent, or permanent. Temporary fillers are broken down and removed from the body over time, a process that can take from weeks to months. Semi-permanent fillers are not readily broken down and removed by the body, thus establishing permanence. However, they can be easily removed from the face in the event of side effects or dissatisfaction with the results. Permanent fillers are much more difficult to remove from the face if problems or unhappiness with the results arise.

Which is best? Most experts seem to agree that temporary or semi-permanent fillers are best. There are a number of reasons for this. First, if research eventually determines the root cause of lipoatrophy and discovers ways to permanently and safely reverse its effects, permanent fillers may prevent the use of such a treatment. Second, some people who have facial fillers injected or implanted are unhappy with the results; the use of tem-

porary or semi-permanent fillers ensures that the results need not be permanent. Third, as the face ages, skin can become thinner and sag. This might cause the outlines of the filler to become visible or more easily felt under the skin, or cause the skin to appear disfigured.

Finally, it's important to recognize that the product selected is only one factor in the success of treatment. It is very important that anyone undergoing restorative therapy for facial lipoatrophy be treated by an expert, meaning a plastic surgeon or dermatologist with experience using the product selected to treat facial lipoatrophy in HIV-positive people.

Temporary Fillers

Autologous fat transplant (AFT): This procedure involves taking fat from one part of the body (such as the butt, hips, inner thighs, or abdomen), cleaning and filtering it, and injecting it into another part of the body, such as the face.

AFT can yield good results and can be very natural in appearance if performed by an experienced specialist. Harvested fat can be frozen and stored if touch-ups are needed in the future. AFT has been shown to last anywhere from six months to two years in some studies involving HIV-positive patients. It might also be possible to increase the length of the benefits through a method that involves injecting fat into the muscles of the face.

Unfortunately, fat can be difficult to harvest from other parts of the body, especially in HIV-positive people with advanced lipoatrophy who are lacking in subcutaneous fat (fat under the skin). Post-surgical recovery can be uncomfortable and take several days. Injected fat can sometimes become abnormally enlarged; this is seen more often in patients who have fat taken from existing "buffalo humps" to fill hollows in the face.

Collagen (Bovine: Zyderm and Zyblast; Human: CosmoDerm and CosmoPlast): Collagen has been used for more than 25 years for cosmetic purposes in the United States, most notably as a filler for facial wrinkles. Because it has

long been approved by the FDA for this purpose, it was one of the first products evaluated and used in HIV-positive people with facial lipoatrophy. Bovine collagen is derived from calf skins; human collagen is grown in test tubes using human tissues. If bovine collagen is used, an allergy test is required before it is injected into the face.

Both bovine collagen and human collagen are widely available, and many plastic surgeons and dermatologists have experience using it (although not necessarily in HIV-positive individuals with lipoatrophy). Post-injection recovery is mild. There may be some short-term swelling and/or bruising at the injection sites.

“Anyone undergoing therapy for facial lipoatrophy should be treated by an expert, meaning a plastic surgeon or dermatologist with experience using the product selected...”

Disadvantages include possible allergic reaction or severe scarring. Repeated maintenance injections can increase the annual cost of therapy. Large volumes of collagen may be needed to restore facial features in HIV-positive people with severe lipoatrophy, so this option is probably best for people with mild-to-moderate facial lipoatrophy.

Calcium hydroxylapatite (Radiance, Radiesse): These products contain synthetic calcium hydroxylapatite, a natural substance found in bones and teeth. It is primarily used in the reconstruction of bony structures. When it's injected into the dermis layer of skin – the deep inner layer of skin that contains cells that pro-

duce fibrous connective tissues including collagen (fibroblasts), hair follicles, oil and scent glands, blood vessels, and nerves – natural collagen forms around the calcium hydroxylapatite, providing long-term, natural-looking fullness.

Calcium hydroxylapatite is approved by the FDA for various uses in the United States, including orthopedic and reconstructive surgery and in dentistry, and has a good safety record. Even though it is considered to be a temporary filler, it appears to have a longer-lasting effect than most other temporary fillers.

These products can be very expensive. They can also cause nodules – hard lumps – at the injection site (they can be felt but not usually seen) in some patients.

Human cadaveric dermis (Cymetra, Dermalogen) and fascia (Fascian): These products are derived from cadavers at the time of death. The dermis or muscle fascia (the gray/white covering over the muscles) is harvested and brought to a lab for sterilization, testing, and processing. Allergy testing isn't necessary.

These products are FDA approved – but not for HIV-associated lipoatrophy – and are readily available. Experts report impressive filling of hollows in the face, at least initially.

Injections of human cadaveric dermis are very temporary, with injections lasting approximately one to three months. This approach can also be very expensive, given the need for frequent touch-ups.

Hyaluronic Acid (Restylane, Perlane, Hylaform): Hyaluronic acid is naturally found in human connective tissues. These three brands are synthetic versions of hyaluronic acid and have been designed to prevent rapid breakdown by the body.

Injections of hyaluronic acid have been shown to last six to 12 months in HIV-positive individuals with lipoatrophy. It is cheaper than many other products, given that fewer touch-ups are needed. The product can easily be removed in the event of side effects or dissatisfaction with the results.

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Personal Perspective: **My Body and My Mind** *by James Laub*

Little did I know when I tested positive in 1987 that such a cruel fate awaited me. I probably would have made a deal with the devil if I could live into the new millennium with my wife and children some eighteen years after my diagnosis and still be relatively healthy. Over the last nine years, when I look in the mirror, I think I did just that.

Lipodystrophy is a cruel reminder of living with HIV and the medications that I've taken for most of the past seventeen years. I only expected to be on medication for a short time, since most of the people I ran with were dying of AIDS, drug overdoses, suicide, or toxicity from AZT.

Oh yeah, I had a real good shot at a decent life. I started taking AZT in 1988, Videx in the early '90s, and then a combination of two nucleosides (if memory serves me). Life was going along pretty damn good despite my diagnosis. I was married to a wonderful, supportive woman, had two healthy, beautiful children, had a good job, and was in relatively good health. All that changed in 1996 when I started a new cocktail that included Invirase from a new class of drugs called protease inhibitors (PIs), that would make AIDS a chronic illness. But at what price?

Six to eight months after starting this new cocktail, I felt the first of what would be many changes in my body. My nipples started to hurt – and not in a pleasant way. I had breast enlargement, buffalo hump, and wasting in my face, arms, legs, and butt. My neck felt as though it belonged on a man much heavier than me. I weighed about 187, but I looked like I weighed at least 220. The glands on both sides of my face were always swollen. It was like having a balloon full of gelatin wrapped around my neck. If I leaned to the right, my neck took the lead and hung away from my body. And if I leaned to the left, the same thing happened on that side. When I walked fast or jogged slowly, the fat around my neck would swing in the opposite direction from the rest of my body. When my movement took my body up, my neck and chin lagged behind, and when my body came down, my neck and chin would still be on the rise and then come crashing into the bottom and sides of my face. I was not a happy camper. I felt like a cross between Humpty Dumpty and Mel Brooks' Young Frankenstein! Yikes! I didn't understand that all of these things were related. Lipo

was a new phenomenon, so the whole package was pretty startling to me. What would I do?

The first thing I did, in 1997, was to switch from Invirase to the non-nuke Viramune. I developed a rash and had to switch that regimen. It was 1998 now and Sustiva had come out, but again I had a bad reaction. I felt like a zombie from lack of sleep, and when I *did* sleep, I felt like I was possessed by the devil with crazy, crazy dreams. I stuck it out, even though the side effects never went away. But my body started yet another metamorphosis, for better and for worse. To my surprise, my chin and neck shrank back to normal (pre-Invirase) size and my buffalo hump shrank (but didn't disappear). Unfortunately, the lipodystrophy in my face and limbs only got worse. This may have been because I lost about thirty pounds without trying to, although no cause was diagnosed. I certainly wasn't on any diet. Quite the contrary. This was a time when people with the virus were encouraged to eat as much as possible and anything we could. Weight loss and weight gain seemed to have a direct effect on my body changes. The less I weighed, the better I felt my upper body looked, and the more I weighed, the more severe the body changes seemed. So I was much happier on the nukes and non-nukes – even with the bad side effects – than I was on the protease inhibitors, which made me gain weight.

In 2001, I went to a new doctor and tried a structured treatment interruption for about eight months. I felt a lot better, but my numbers weren't work-

ing in my favor, so I started yet another regimen. This one included the protease inhibitor Kaletra. My chin and neck started to balloon again.

I dealt with the body changes the best I could. It was difficult at times, especially when someone would ask a question like whether I had been in an automobile accident. Or whether I was taking steroids. I developed a standard response to these inquiring minds. I would tell people that I was lifting weights with my head. That usually quieted them down – although I had one guy ask me if I could show him how it was done. People don't mean to be hurtful, but these comments can really mess with your mind.

Anyone who thinks that these body changes aren't physically painful has probably never had lipo or doesn't have a severe

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case. Just imagine carrying a ten-pound weight around your neck 24/7, 365. It puts an unbelievable amount of strain on your back and neck to the point that discomfort becomes pain. My back now has a permanent arch from hauling around this extra weight all these years.

About two years ago, I started acupuncture to help deal with some of these problems. I was pleasantly surprised with the results. A sense of well-being engulfed my whole body. We worked on the lipo without much success, but my acupuncturist *was* instrumental in getting rid of my buffalo hump. I was getting my treatment one day when she pointed out a little discolored mole on my shoulder. She encouraged me to have a dermatologist look at it. The dermatologist biopsied the mole, then told me it was a malignant melanoma that I would need to have removed by a plastic surgeon. He gave me some documents to give to the surgeon. He also wrote a letter asking the surgeon to remove my buffalo hump, remove the fat under my chin, and fill in my cheeks. Wow! Was this guy aggressive or what?

The surgeon told me I couldn't do it all in one shot, so he asked which one was the most troubling. I didn't have to think twice. Get this hump off my back, pretty please. I had the melanoma and buffalo hump removed together. I asked about payment for the hump, and the plastic surgeon told me that my insurance company (private insurance) covered it since I'm resistant to the nukes (all except Viread) and have a very bad reaction to the non-nukes. Therefore I have to stay on a PI regimen – I'm now on Reyataz, Norvir, and Viread – even though the lipodystrophy inhibits my mobility, causing insomnia and neck and back pain, which only gets worse with continued PI therapy. So something good came out of what I thought would be a nasty experience.

I'm now in the process of getting my chin done and am waiting for approval from my insurance company. It may be a struggle because I have a new carrier. The message here is that sometimes the most unlikely sources in life can become our allies. Between my acupuncturist, my doctor, the dermatologist, and the plastic surgeon, everything and everyone came together for a wonderful outcome. I sleep much better these days and have less pain in my back and neck. I hope to have the neck surgery this summer.

So don't isolate yourself and don't give up. Get out there. See different healers and doctors. You can't know when an opportunity will present itself. Be well and stay healthy.

James Laub lives on Staten Island, New York, is an outreach worker for Project Hospitality, and advocates strongly for access to complementary therapies for all HIV-positive people.

The Eye of the Beholder: Psychological Perspectives on Lipodystrophy

by Kristina Jones, MD with Chuck Finlon, LCSW

Since triple-drug combinations began to be used to treat HIV in 1996, lipodystrophy – including body-shape changes – has emerged as a new and increasing challenge in the HIV epidemic. Body-shape changes can have a substantial impact on quality of life, and the significance of changes to the face is a profound one in our culture. Together, they can cause anxiety about appearance and raise new concerns about stigma and confidentiality. They can also lead to medication adherence problems and may undermine adaptive denial and confidence in health.

Case Studies

"I have an AIDS face," my young male patient explains to me during his first psychiatric consultation. I look at his face; it's perfect, at least by heterosexual female standards, even in proportion and frame, neither thin nor thick, not gaunt, not even angular. He insists that his eyes are hollow, his cheeks sagging, and his face a horrific announcement of his newly diagnosed HIV. I see a man who would not look out of place on the cover of a men's fashion magazine.

I go through the standard questions a psychiatrist must ask. *Is he depressed?* Only about his face. *Is he anxious?* Only when he feels the men of Manhattan are staring at him. *Is he eating disordered?* *Is there overall disconnection between his self-perception of his body, or body image, and his actual physical weight?* There isn't. He goes to the gym a great deal and is meticulous about his diet. He wants a boyfriend. I explain that I think he's having an emotional reaction to his HIV diagnosis, that no one can see that his face is thin, that to my eye, at least, it isn't wasted or changed. He leaves my office puzzled, with sleeping pills to take as needed. He doesn't return to the clinic for further psychiatric consultation, but comes back for HIV medical care and social work follow-up.

Several years later, I interview a patient in the clinic who has severe lipodystrophy. He refers to his "watermelon belly," and his face looks drawn, cheeks hollow, eyes made prominent by the loss of fat around his temples and forehead. The changes impose an artificial aging; he looks old and wise, like a philosopher. His humor catches me off guard. I ask him how he's doing with his face and body changes and he laughs. "Are you kidding me? Like I care that much? All my friends are dead, and I almost died, and now here I am, alive and well. Who the hell cares what I look like? I've been through everything, lost my lover, nearly dead myself, and here I am. I have a partner and a dog, and I only wish I could work, but I'd lose my benefits." I'm incredulous and share his laughter. He's here because he doesn't want to switch his lipodystrophy-causing medication. He doesn't want a new regimen that might give him diarrhea, and his internist has

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The Eye of the Beholder *(continued from previous page)*

sent him to me because he refuses to change the medication that has saved his life, though not spared his face and body.

We discuss the issue. I learn that he is despondent at times but not depressed and offer anxiety medication for his bouts with the intense self-consciousness he feels when going out into large groups of people. I tell him that he's making his doctors nervous; doctors feel guilty and stressed about causing people disfiguring side effects if they can avoid it. He leaves and continues the debate with his doctor until he learns that he will have to take pills to lower his cholesterol. Then he agrees to switch regimens, mostly out of concern of getting a heart attack due to his high cholesterol and the thought of having to take yet more pills to counter the side effects of his HIV regimen.

I remember my friend who died in 1994, not long after World AIDS Day. He lay in the ICU, dying of PCP, all of us gathered round, sobbing, playing him his favorite music, a nurse washing his hair, friends bringing flowers and chocolates he would never eat because he was intubated. We managed to stick chocolate pudding in his nasogastric tube, but he said he could smell it more than taste it, which was funny at the time. He noticed that he had one gray hair – at the age of 29. This was something new for him. “I am the only gay man in the city who wants to grow old. I want to have a whole head of gray elegant hair, like my father has!” he exclaimed. He died in his mother's arms, one gray hair, one beautiful face, ethereal and passionate, and, in our minds, young forever. His death was like the one that Thom Gunn described in his poem, *Lament*, included in his 1992 book, *The Man with Night Sweats*:

*...Nothing remained
But death by drowning on an inland sea
Of your own fluids...*

I share this anecdote about the wish to grow old to give perspective; HIV no longer means imminent death, but living with HIV is hard, and many people suffer with disfigurement caused by HIV treatment. Is this a psychiatric problem per se?

Some people become despondent or clinically depressed because of changes in their appearance, and standard psychiatric and social treatments for anxiety and depression can be quite helpful. Lipodystrophy, however, is as much about the eye of the beholder as it is about the face of the sufferer. Like no other aspect of the epidemic except Kaposi's sarcoma and wasting syndrome, the outward manifestations of lipodystrophy depend upon an onlooker to judge its severity and to perpetuate stigma and shame. It may be more helpful to examine our overvaluation of physical appearance rather than to delve further into the miseries of people faced with the challenge of coping with an altered appearance.

Quality-of-Life Studies of Lipodystrophy

Psychosocial literature on lipodystrophy is sparse, although certain themes are relatively consistent even within this inadequate body of data – changes in body image, self-esteem, social and sexual relations, disclosure issues, locus of control (the sense that a person feels in control of events rather than controlled by them), demoralization and depression, doctor-patient relations, adherence, and economic impact.

A study of 150 patients at a clinic in Spain published in the *Journal of AIDS* in 2002 found that lipodystrophy alone did not influence their overall quality of life. On the other hand, the study concluded that homosexual patients were more vulnerable to the psychological impact of lipodystrophy on quality of life than hetero-

sexual patients. Having lipodystrophy and being unemployed also affected quality-of-life measures. Furthermore, taking psychiatric medications, mainly benzodiazepines or antidepressants, or methadone for opiate addiction was associated with a greater impact of lipodystrophy on quality of life. The study authors were uncertain whether study participants were anxious and depressed as a result of having lipodystrophy or if having a psychiatric illness or being on methadone was the primary cause of a decreased quality of life.

Some studies have shown that lipodystrophy has an impact on sexuality as a dimension of quality of life. In one such study conducted in the Netherlands and reported in the journal *AIDS* in 2001, men

with lipodystrophy reported a severe decrease in sexual activity, enjoyed sex less than they had before, and were less confident in relationships. Since reduced sexual activity was also reported by men without lipodystrophy, though to a lesser extent, the study authors couldn't determine whether the sexual dysfunction was caused by feeling less attractive because of lipodystrophy or due to a decrease in sexual libido caused by protease inhibitors.

A small survey of 33 HIV-positive individuals (14 heterosexual women and 19 gay men) with self-assessed body changes related to HIV medications was conducted in 2000. Several respondents said that their partners no longer found them attractive. Many of the women reported that their husbands had become less interested in them sexually after they developed lipodystrophy. A woman whose husband was HIV-negative said, “He now refuses to have sex with me – only as my body changed has the HIV become an issue in our love lives. Now, he is afraid of catching HIV. Perhaps he was in denial before.” A gay man said, “My lover left me because, as he has no lipodystrophy and no [detectable] viral load, my face was a constant reminder of the HIV he allowed himself to ignore.” The lipodystrophy had apparently broken through the denial about HIV that these peoples' partners had maintained.

*“Feeling demoralized
about facial changes
could lead to
poor medication
adherence,
possibly leading to
drug resistance and
even illness
and death.”*

A German assessment of 313 patient questionnaires published in *AIDS Patient Care and STDs* in 2002 concluded that lipodystrophy didn't seem to affect patients' general attitude toward the quality of their health condition and well-being; however, patients with lipodystrophy were twice as likely to feel recognizable as HIV-positive due to their physical appearance. Lipodystrophy – particularly fat loss in the face – was associated with increased perceptions of stigma and social disadvantages by the respondents.

The Impact on Adherence and Disclosure

It's probably impossible to measure the social impact of lipodystrophy by questioning the person who has the syndrome. The characteristic changes of the face can mean immediate disclosure of HIV status for some patients, complete loss of confidentiality of both HIV status and sexual orientation, and loss of income for people who aren't able to work or whose livelihood is based on appearance and image. It's unclear whether younger people, usually more concerned with appearance and attractiveness, might be more affected by lipodystrophy than older ones, who can focus more on external achievements and accomplishments. Overall, mild facial lipodystrophy appears to be less an issue in the straight than in the gay community.

Functionally, lipodystrophy may change how people deal with HIV. Feeling demoralized about facial changes could lead to poor medication adherence, possibly leading to drug resistance and even illness and death. The importance of this actual or feared lipodystrophy must not be overlooked; the doctor-patient relationship may be undermined if patients feel that their medical providers don't empathize or understand the impact that lipodystrophy can have, further threatening adherence to regular medical monitoring.

A Crisis of Confidence

For people living with HIV, the meaning of illness has many contributing factors. In his 2001 social work thesis, *Lipodystrophy and Body Image in Gay Men with HIV/AIDS: Some Key Psychosocial Issues*, Jesus Martinez, CSW, notes that lipodystrophy emerged at a time when many HIV-positive men were experiencing a Lazarus-like syndrome, new hope regarding their health, and a turning away from death. He says that lipodystrophy could eradicate the hopefulness of the Lazarus syndrome, writing that “a new crisis arises that may precipitate grief-mourning processes rooted in the loss of the ‘appearance of health.’”

Martinez notes that the experience of HIV can feel like an assault to one's identity – HIV can feel like a death of the former sense of self. People with lipodystrophy may lose the “image” of their former selves and the way they interacted with the world. Now they are confronted with an altered image, a challenge to their self-assumptions about their influence and instrumentality. He writes that nonprogressors (people who have been living with HIV for a long time without any symptoms) have to live with the constant threat that their health status may change and the corresponding anxiety that brings; in this context, lipodystrophy raises the possibility that sustained health may not hold.

Body Image in a Gay Context

In her 2002 essay, *Gay and Lesbian Body Images*, included in *Body Image: A Handbook of Theory, Research, and Clinical Practice*, Esther D. Rothblum notes that it has been hypothesized that people sexually involved with men (heterosexual women and gay men) are more focused on appearance than are people sexually involved with women (heterosexual men and lesbians). The result is an interaction of gender and sexual orientation on body image concerns.

Rothblum refers to a study conducted at Yale that was published in *Psychosomatic Medicine* in 1989. According to *Men and their Bodies: A Comparison of Homosexual and Heterosexual Men*, a study of 71 gay and 71 straight men (all HIV-negative), physical appearance was more important to the gay men's sense of self, whereas being physically active was of greater value to the heterosexual men. Gay men stated that they exercised to improve physical attractiveness, whereas heterosexual men exercised to improve fitness, health, and for enjoyment. There were no differences between the gay and straight men on body size satisfaction, eating disorders, or self-esteem. For both groups, the value placed on the body and the distance between ideal and self-acceptance can give rise to distress in many people living with HIV.

Body Image, Body Investment

Cognitive therapy aims to understand how our thoughts and beliefs about situations influence our feelings about those situations. Body image *evaluation* refers to satisfaction or dissatisfaction with one's body, while body image *investment* refers to the mental, behavioral, and emotional importance of the body for a sense of self-worth. In his essay, *Cognitive-Behavioral Perspectives on Body Image*, the psychologist Thomas F. Cash, PhD, writes that a positive self-concept may help the development of a positive feeling about one's body (whatever its shape) and serve as a buffer against events that threaten body image. Conversely, poor self-esteem may heighten one's harsh criticism or hatred of the body.

He notes that cultural messages about the body and interpersonal experiences with others such as parents or siblings influence body perception. The need for social approval may increase a person's investment in socially valued appearance standards. Styles of relationships may also affect body investment. People who are insecurely attached in relationships – that is, individuals seeking love and acceptance yet feeling unworthy – may develop faulty or unhelpful body image attitudes.

The Face as a Metaphor for the Self

Cancer literature on bodily changes or disfigurement following surgery generally acknowledges that facial disfigurement is probably the most challenging and that adolescents tend to adjust less well than adults. Investment in appearance usually changes over time, and people tend to re-evaluate the body part affected by cancer. This can be a healthy strategy when coping with disfigurement.

This is probably because the face, more than the breast or heart or leg, is closely associated with the self. In her brilliant essay, *AIDS and its Metaphors*, the late Susan Sontag wrote that polio

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The Eye of the Beholder *(continued from previous page)*

could be horrifying because it withered the body but spared the face and was, therefore, not considered repulsive or frightening like leprosy or syphilis. She writes:

...the...reaction to polio owes much to the privileged status of the face, so determining of our evaluation of physical beauty and of physical ruin. All...of modern philosophy and modern science has not reduced by one iota this culture's conviction of the separation of face and body, which influences every aspect of manners, fashion, sexual appreciation, aesthetic sensibility – virtually all our notions of appropriateness.

Sontag writes of the religious paintings of Saint Sebastian, Saint Agatha, and Saint Lawrence,

... with the face demonstrating its effortless superiority to the atrocious things that are being inflicted down there. Below, the ruin of the body. Above, a person, incarnated in the face, who looks away, usually up, not registering pain or fear; already elsewhere ... Our very notion of the person, of dignity, depends on the separation of face from body, on the possibility that the face may be exempt, or exempt itself, from what is happening to the body. And however lethal, illnesses like heart attacks and influenza that do not damage or deform the face never arouse the deepest dread.

In her book *Autobiography of a Face*, Lucy Grealy describes what it was like to grow up with a facial disfigurement – in her case, the result of repeated surgeries for a cancer of the jaw, leaving her with half of her jaw removed on one side. Grealy writes that her entire character was formed around her facial disfigurement and people's reaction to it.

The cruelty of children is immense, almost startling in its precision...their open, uncensored stares were more painful than the deliberate taunts of my peers at school, where insecurities drove everything and everyone like some looming, evil presence in a haunted machine...there was only the fact of me, my face, my ugliness.

This singularity of meaning – I was my face, I was ugliness – though sometimes unbearable, also offered a possible point of escape. It became the launching pad from which to lift off, the one immediately recognizable place to point to when asked what was wrong with my life. Everything led to it, everything receded from it – my face as personal vanishing point. The pain these children brought with their stares engulfed every other pain in my life.

One of the many reasons lipodystrophy presents such tremendous challenges is that it attacks the modern and romantic notion of the face as the true representative of the self. Unlike mastectomy, which can result in a sense of being “less of a woman,” the loss

of face, as it were, alters the very notion of the self, or the self as presented to the world.

As has been suggested, older patients may cope better with lipodystrophy than younger ones because of the natural waning of physical attractiveness as we age and the accumulation of life wisdom, education, and inner strength, as well as outer assets or achievements. Lipodystrophy can impose a physical alteration usually associated with old age.

Coping with Lipodystrophy

Anorexic men and women are constantly urged to value themselves in ways other than their quest for perfect thinness, that there is more to them than appearance alone, that their qualities and achievements and relationships are what they should focus on to regain their health. Can we learn anything from this approach?

What can be done for people who are psychologically adversely affected by lipodystrophy? Clearly it makes sense to offer antidepressants to people who become depressed and anti-anxiety medication to those who are anxious about their appearance. In my clinical experience, psychotherapy can be extremely helpful to people for whom lipodystrophy becomes a catalyst to examine issues of self-acceptance, acceptance of homosexuality, anger at homophobic parents or society, and for whom reliance on appearance alone seemed to offer the only avenue to relationships. Additionally, for some, the physical effects of HIV treatment cause a reexamination and a need for therapy or support around the reality of an HIV diagnosis, with all of the fear and possible stigma it may raise.

It's important to continue to educate medical providers and policymakers about lipodystrophy and its sometimes dramatic effect on quality of life. And then a real examination is necessary – confronting the intense superficiality and scrutiny of all of us who are guilty of taking things at face value, pausing to question why we think the face *is* the person, and looking beyond the face and into the person inside.

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[Patient information is composite and changed slightly for purposes of confidentiality.]

Jesus Martinez's thesis, *Lipodystrophy and Body Image in Gay Men with HIV/AIDS: Some Key Psychosocial Issues*, can be found on ACRIA's website: www.acria.org.

Personal Perspective: Doing Everything Right by Name Withheld

It was 1991 and I looked healthy. I had given up all the drugs in my life – alcohol, heroin, cocaine, crack, nicotine. But I was starting to lose weight, too much weight, and I got diarrhea. So I got tested for HIV – my wife kept telling me to. They told me I was near death – my T-cells were 10. So I started AZT and got my weight back, but I stayed in the closet about my status. I wouldn't talk about the virus. I wouldn't go to any HIV programs – no groups, no pictures, no marches, nothing. I kept it from family, friends, everybody.

But I was still off drugs and doing well. I went back to church, wearing many hats and knowing everyone. I was a single parent now, raising four kids, because my wife had passed from the virus that year. And then all of a sudden I started to lose weight again. I had a very good appetite and was eating, but I kept on losing weight. It was wasting syndrome. People in church were coming up to me, saying, "Look at you – you're fading away." I didn't know I was fading away until they said that, and then I noticed that my clothes were drooping off of me. I went from 170 pounds to 123. People thought I was going to die. I didn't see it, but they did. I was still living secretly with the virus – I hadn't told my kids – but people were whispering behind my back, saying, "He has AIDS" or "He's smoking crack." My self-esteem was so low that I didn't want to see anyone. I didn't want to go outside. I wouldn't answer the door.

I started a new regimen and was able to gain my weight back, but not what I had lost in my face. That's when my self-esteem really went down. I started talking to people with my head down and my hands covering my face, especially when I was around people who didn't have the virus. I'd look around and think, "I wonder if they know?" And then, in a matter of months, I got a big belly – I looked as though I was eight months pregnant. I blamed it on beer, telling people that it was a beer belly, even though it was too big to be a beer belly (and I wasn't drinking). And since I wasn't a big guy, the belly really showed. I wore oversize shirts – they helped a little, but not much. It really bothered me when people noticed it. If somebody said, "Wow, look at your stomach – you're getting old," it made me feel really bad.

I grew breasts, so I didn't like taking my shirt off in front of women. I didn't wear athletic shirts in the summer because they looked like maternity shirts. If I had sex, it had to be in pitch dark, which made me feel bad about myself. So I didn't have any partners, female or male. I've found that male part-

ners don't seem to care about my body changes the way I think women do. But I won't shower with other guys. I'll either wait or make sure that I have a robe to put on. I won't wrap myself in a towel. Even around my kids, I always have lots of clothes on. I'll never take my shirt off around other people, no matter how hot it is.

Then I got neuropathy, and my thighs got skinny. The beach and pools were out. I wouldn't go anymore. So in 1999 I started a new combination and my belly started to go down. I actually cared more about how I looked than about how much virus was in my system. I didn't care if my viral load was high and my T-cells were low – I didn't want to start anything new if it might affect my outward appearance.

"I didn't care if my viral load was high and my T-cells were low – I didn't want to start anything new if it might affect my outward appearance."

I enrolled in a study of Sculptra to try to get back my face. I've only had one injection so far, but it made a big difference – it made me feel so good about myself again. I wasn't afraid for people to see me. My belly went away once I changed my drugs to Kaletra, Epzicom and Viread a few months ago. I can see my muscles again. Right now, I feel great bodywise, healthwise, but my face makes me stop and think. When I'm around healthy people, hanging out with the guys or in church or at a club, I cover my face with my hand. I don't want people to judge me.

I have a habit. I look at people's fingernails, I look at their faces – on the bus, on the subway, in a store, anywhere – and I think, yeah, he's got the virus, or no, he doesn't have the virus. I'm African-American, and we don't talk about the virus as much as we should. We just look at each other and judge each other. I'm a Catholic, a strong Catholic, and when we do the sign of peace in church, I'm so afraid of people knowing my status. I don't want them to shy away from me or feel sorry for me. I just want them to keep treating me like they've been treating me.

I've been living with this virus for a long time now and I'm exhausted, exhausted from living with the virus. Sometimes I'm in my house, and I'm exhausted. I do everything right – I don't smoke, don't drink, have a Higher Power, no drugs, sleep right, get my 8 to 9 hours a night. I pray, I meditate, I have community at church. I have an ear for everybody, but now I want somebody to have an ear for me. And I want my face back.

Name Withheld is one of many people living secretly with HIV.

Are People Getting the Help They Need for Side Effects?

by Bruce D. Rapkin, PhD

Over the past nine years, many people living with HIV and AIDS have been treated with highly active antiretroviral therapy (HAART) – three or four drug combinations. Just as the effectiveness of HAART varies from person to person, so too does the profile of side effects and problems related to the medications. In this article, I will focus on the experiences reported by over 300 individuals currently receiving HAART. We interviewed these people for the “Choices in Care Study,” a project that we are conducting with the New York State Department of Health AIDS Institute to look at patients’ perceptions of care in the Medicaid program, including both those in Special Needs Plans (SNPs) and fee-for-service clients. SNPs are Medicaid health plans for people with HIV/AIDS in New York. They offer primary care by providers who are HIV specialists, case management, and other supportive services.

As part of this study, we asked people about the medications they are taking, their pattern of adherence over the past weeks and months, and their reasons for missing medications, including side effects. We also included questions to look at the impact of medication problems on individuals’ emotional well-being, level of activity, and overall health. In a follow-up interview, we also asked a subset of people who mentioned difficulties with their medications whether or not they have sought assistance from their providers and, if so, whether this assistance has helped to resolve their problems. It will be useful to consider some of our main findings to get a sense of the problems people on HAART encounter and how they have tried to get help.

Overview of Sample

We conducted the interviews discussed here between April 2003 and December 2004, including 289 Medicaid fee-for-service clients and 92 Special Needs Plan clients. This sample was quite diverse, including 48% women, 59% African American, and 36% Latino. The average age of the participants was 46 years, with about 25% age 40 or younger and 25% age 51 or older. In terms of education, 35% of the sample had less than a high school education, 40% had a high school diploma or the equivalent, and 25% had at least some college. About 94% reported monthly incomes of \$1000 or less, with about 13% of participants working for pay. Just over 10% of the sample was unstably housed. At this stage in our study, we can use our data to examine trends in the sample as a whole. As our sample grows over the next few years, we will be able to examine choices in care related to gender, ethnicity, age and other important characteristics.

On average, people received their HIV diagnosis 9.7 years ago, with 21% of the participants diagnosed in the past five years and 14% diagnosed more than fifteen years ago. Many study participants reported a history of multiple risk factors for HIV exposure, including 31% injection drug users, 19% men who had unprotected sex with other men, and 80% unprotected hetero-

sexual sex. In terms of health status, 75% of participants reported knowing their current HIV viral load, and of these, 46% said that it was undetectable. Among 78% who were able to answer, 16% stated that their CD4 count was under 200. People in our sample started receiving treatment for HIV an average of 7.3 years ago. In terms of current medications, 41% said that they started their present regimen within the past year, while 25% said that they have had the same prescriptions for three or more years.

Who Is Taking Antiretrovirals?

The majority of study respondents (299 out of 381, or 78%) reported that they were currently taking antiretroviral treatment. The remaining participants stated that they had never taken antiretroviral medications (9%), were not currently taking medications (8%), or were on a prescribed (3%) or self-initiated (2%) drug holiday. Patients not receiving medication for any reason were more likely to have used crack cocaine or heroin in the past three months or to be unstably housed. Of those participants currently prescribed antiretroviral medications, the number of all types of pills (antiretrovirals, other prescription, and non-prescription) taken each day varied, with 36% taking 5 to 9 pills, 31% taking 10 to 14 pills, and 24% taking 15 or more pills per day. Most participants (66%) took pills twice per day, although 10% had to take pills four or more times per day.

Table 1
Reasons for Missing Medications

Reported by 299 Respondents (out of 381)
Currently Prescribed Antiretroviral Therapy

Simply forgot	32%
Fell asleep/slept through dose time	24%
Didn't feel like taking pills	19%
Felt sick or ill	19%
Wanted to avoid side effects	18%
Felt depressed/overwhelmed	17%
Felt like drug was toxic/harmful	14%
Taking pills doesn't fit in my daily schedule	13%
Did not want others to notice me taking medications	12%
Too hard to take so many pills according to a schedule	12%
Ran out of pills	11%
Felt good	11%
I knew what was best for me	9%
Was drunk or high	6%
Didn't fit with meals/didn't have water	6%
Didn't understand regimen	3%

Note: Items reworded slightly for clarity

Medication Adherence

In terms of medication adherence, one out of five participants said that they had missed at least one dose in the past three days. In all, 40% of the sample reported missing medications in the past four weeks, while 15% said that they had not missed a dose in the past one to three months, and 14% stated that they had not missed a dose in over four months. Table 1 shows the reasons participants reported for missing doses. Side effects were cited by 18%, and concerns about medication toxicity were cited by 14% of this sub-sample. The most common reasons cited were forgetting (32%) and sleeping through doses (24%). However, if we consider only those patients who had missed doses in the past week, 39% cited side effects or toxicity concerns.

Symptoms Associated With Medications

We did not ask people directly whether or not they attributed different symptoms they were experiencing to their medications. However, we were able to look at differences in the symptoms cited by people who mentioned medication side effects and concerns about toxicities, compared with people who were not experiencing those problems. We found that people experiencing side effects were 50% more likely to mention numbness or tingling sensations in their limbs, 65% more likely to report nausea, 79% more likely to report fatigue and weakness, and 110% more likely to report fever or chills. Side effects and toxicity concerns were also associated with self-reported problems with memory or concentration (67% more likely) and depressed mood (83% more likely). These differences are still present even when we take into account CD4 count, viral load, overall number of lifetime AIDS-related diagnoses and comorbidities, and current opportunistic infections. Side effects also diminished quality of life in many areas, including significant problems in maintaining social relationships and in carrying out desired activities and roles. For example, 33% of people reporting side effects felt that their health interfered with activities like visiting friends or relatives all or most of the time, compared to 13% of those who did not mention medication-related concerns.

Seeking Help For Side Effects

Given these far-reaching consequences, we decided to examine what people were doing to address side effects and concerns about treatment toxicity. As part of our regular follow-up interview, we discussed help-seeking decisions and experiences with 61 individuals who mentioned that side effects from medications had interfered with their activities or made them feel worse during the past three months. For comparison purposes, we also talked about experiences in care with 41 individuals who did not report any side effects but had one or more other difficulties related to medications, including having a hard time adhering (37%), unanswered questions about medications or lab results (37%), forgetfulness (24%), and difficulty following through on medical advice (17%).

Table 2
Factors Influencing Help-Seeking among People Experiencing Side Effects or Other Difficulties with Antiretroviral Treatment

Difficulty with medication due to:	Side Effects	Other Reasons
Wanting to get things back on track on my own	59%	51%
Need information	44%	39%
Should just learn to live with it	36%	37%
Unwanted changes in care	33%	27%
Embarrassment	20%	22%
Was afraid nothing would help	20%	22%
Worried that getting help would make things worse	18%	15%
Feeling judged – stigma	15%	22%
Felt that the problem was not important enough	15%	20%

Note: Items reworded slightly for clarity

We first asked people whether or not they were seeking help for their concerns. We found that about half of the people in both groups were already receiving professional help. Although the numbers were small, people in the side effect group were twice as likely to be looking for professional help (15% versus 7%) or to be considering help in the future (23% versus 12%). In contrast, only 13% of people experiencing side effects said that they would *not* consider professional assistance, compared with 29% of people with other medication issues.

When we asked people about factors that they considered in deciding whether to seek help, we found similar concerns in the two groups (see Table 2). Although they expressed similar considerations, these factors seemed to carry different weight for people in the two groups. For people affected by side effects, the strongest factor influencing whether they had not or would not look for professional assistance was the fear that nothing would help. Alternatively, people with other treatment issues were mainly deterred by a lack of information.

Experiences In Care

We next considered factors that might have kept those people who were interested in getting help from actually seeking it (39 with side effects and 24 with other treatment issues). For this analysis, we included only those people who had actually started care or who were currently looking, to focus on what interfered with care. Barriers were encountered by relatively few people in both groups, but included difficulty getting appointments, transportation, accessibility, and hours. Significantly, no one reported any difficulties associated with costs of care (as would be expected in this Medicaid population), and no one was refused assistance by a provider.

We next turned our attention to those people who were receiving assistance for their medication-related concerns (30 with side

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Are People Getting the Help They Need for Side Effects? *(continued from previous page)*

effects and 21 with other treatment issues), to examine their experiences in care. Satisfaction with assistance for the specific problem at hand was quite high among both groups, with 83% of those experiencing side effects and 81% of those with other treatment issues indicating that they were “very satisfied,” the highest rating on a four-point scale. In fact, no one in either group indicated that they were “very dissatisfied,” the lowest rating on our four-point scale.

Despite these overall high satisfaction ratings, 33% of people with side effects and 19% of those with other treatment issues did experience one or more problems in getting their need addressed (see Table 3). Compared to the other group, people with side effects were particularly concerned about the lack of time to discuss problems. Although these concerns were relatively infrequent, when they arose they did impact satisfaction. On average, people seeking help for side effects expressed concerns about their care twice as often as people who sought help for other reasons.

Unresolved Problems With Medications

Overall, people experiencing side effects tended to have more difficulty resolving these problems than people who mentioned other treatment issues. Problems were fully or mostly resolved for 28% of people experiencing side effects, compared to 49% of people with other treatment issues. Resolution of problems concerning side effects were most related to help-seeking and to having necessary information. When we asked people what they did to address problems they encountered in care, several expressed a tenor of frustration:

- *It's always about taking the pills.*
- *I feel I had to fight for what I wanted.*
- *Never a clear plan – a feeling of uncertainty.*

A number of people felt that they had to go it alone:

- *I feel rushed. My provider does not take this problem seriously.*
- *I'm doing nothing...dealing with the situation.*

Some people were trying to cope with medication problems independently:

- *I have spaced out medication so my body is not overwhelmed all at once by medication.*
- *I try to remind myself to take meds.*

Others were able to pursue help from their primary care providers (PCPs):

- *They reduced my dosage of medications and they are running more tests.*
- *PCP has helped establish a method/routine to help me get back on track with my meds.*
- *PCP has been advising me and suggested I go into recovery.*
- *I've been given medications to help with back problems.*

Still others sought help from outside sources:

- *I've talked to my gynecologist about it.*
- *Talked to my significant other.*
- *I've talked to the social worker about it.*
- *I'm going to wait and see if the drug study at [local hospital] will help me, otherwise I will make a decision to get off meds.*

Hoops, Hurdles and Help-Seeking

Our results suggest that many people taking antiretroviral therapy are still having difficulty with adherence. Those experiencing the greatest problems following their regimens are most likely to report side effects related to the medications. Reports of side effects were associated with higher levels of many different symptoms. It was clear that patients seeking help for side effects were interested in professional assistance. About fifty percent of patients were already receiving help. Of those not yet receiving help, over 70% were seeking or considering professional assistance. Most people were highly satisfied with the care that they were receiving. However, that did not mean that everything was settled. About 72% of people that we interviewed in depth about side effect problems said that their medication-

related difficulties were not fully resolved. Many people delayed looking for assistance, in part because they handle things on their own and in part due to the fear that nothing would help. Over one third of patients felt at some point that they just had to learn to live with their side effects.

One surprising finding that helps to illuminate this point involves lipodystrophy. We expected to hear more about this concern when we asked about medication side effects. In fact it was rarely mentioned. When we dug a bit deeper into our data set, we found that about 8% of our full sample did mention concerns related to deposition of body fat in response to later interview questions about wellness and prevention. People specifically mentioned the desire to lose weight, control diabetes, or improve diet and exercise. We checked to see whether these weight-related concerns were more common among people who also experienced medication side effects. Instead, we found that only 2% of people with side effects also

“Many people delayed looking for assistance, in part because they handle things on their own and in part due to the fear that nothing would help.”

Table 3
Concerns that Arose in Getting Help with Antiretroviral Treatment from Providers

Difficulty with medication due to:	Side Effects	Other Reasons
Taking care of this problem interfered with my other responsibilities	17%	10%
I disagreed with what the provider told me to do	17%	5%
Family or significant others disagreed with the provider	13%	5%
There was not enough time to discuss the problem fully	13%	0%
The provider did not understand my concerns	10%	10%
The provider did not really get to the real problem	10%	10%
The provider expected me to do too much on my own	10%	5%
My problem was not taken seriously	10%	5%
Instructions were unclear or hard to understand	7%	5%
I did not have confidence in the care I received	7%	0%
I had questions that were not answered	3%	0%
The help offered was not practical	3%	5%
I felt like I was being judged or blamed	3%	0%
I experienced disrespect or discrimination	0%	0%
Average Number of Concerns:	1.23	.57

Note: Items reworded slightly for clarity

expressed concerns related to excess weight, compared to 12% of the people who mentioned other medication problems and 10% of the remaining sample with no medication concerns. In other words, people seemed to focus on weight loss when they were otherwise feeling better. They did not equate weight loss with getting help with a medication problem. Alternatively, weight-related concerns seemed to be less important to people coping with discomfort, fatigue, and other side effects. This finding was specific to weight loss and did not hold true for

other preventive health behaviors, like smoking cessation or cancer screening.

When people in our sample of Medicaid clients *did* seek help for side effects, they encountered few barriers to getting care. However, about one third of patients reported some concern that arose involving the care they were receiving, including advice that interfered with other roles, disagreements about care, providers' lack of time to address problems, and their problems not being taken seriously.

Taken together, study findings point to a need for further education of both consumers and providers. Many side effects do not show up on a lab test. The only way to detect them is from a patient's self report. It seems that some providers need to take time to draw out these concerns and pay more attention to the serious effect that they can have on a patient's well-being. Perhaps more important, consumers must feel comfortable in expressing their concerns. It is indeed troubling to hear some patients saying that they just need to learn to live with side effects or symptoms *before* they seek help. Other patients were focused on coping with current symptoms at the expense of more comprehensive assistance. For some respondents, seeking help for side effects raised the specter of unwanted treatment changes: patients felt that they had to tough out their discomforts in order to stick with a medication that was working. The only remedy for these concerns is open and informed problem solving, with patients and providers working at mutually acceptable strategies to promote longevity and maximize quality of life.

Bruce D. Rapkin, PhD directs the Community Research and Health Disparities Program at Memorial Sloan-Kettering Cancer Center in New York City. His work focuses on developing and strengthening community-clinical research partnerships to promote access to care and quality of life for diverse populations.

[The information presented in this article was collected as part of an evaluation of patient choices and outcomes supported by the New York State Department of Health AIDS Institute.]



is forming a RESEARCH COMMUNITY ADVISORY BOARD (CAB) to bring the perspective of people with HIV and AIDS into the development and execution of our research projects. To ensure that community values and cultural differences are represented, we want this new CAB to mirror the epidemic as it is today – primarily people of color, increasingly female, and growing older.

As a CAB member, you will meet regularly with research staff, review program materials, and help us identify research needs.

For more information about this new CAB, please call David Ward at (212) 924-3934, ext. 125.

Personal Perspective: Eggs on Legs

by Pamela Yelsky

“Oh, my God! When are you due?! Why didn’t Beau tell me you’re pregnant?!” This was the reaction of my former hairdresser (who still cuts my son’s hair) after not having seen me for six months. She was so excited, making it that much more painful for me to tell her that I was *not*, in fact, pregnant.

She looked stunned. What other reasonable explanation could there be for my sway-backed, belly-button-bulging tummy? I realized I had two choices: I could make up some far-fetched story to explain my “ready-to-deliver” look, or I could disclose my HIV status to her and possibly have an opportunity for a little HIV 101.

I chose the latter. I explained that what she was seeing was lipodystrophy, a side effect of taking the HIV medications. In many people who take HIV meds, fat cells are lost in the arms, legs, and buttocks, and fat is gained in the midsection, upper torso, and back of the neck, creating a Neanderthal appearance. People who have been on meds for a long period of time and had persistently low T-cell counts are also candidates for lipodystrophy. That’s me – thirteen years of taking every possible combination of drugs, with T-cells under 200 most of the time (under 100 about 25-30 percent of that time), and I get the added bonus of looking like the Hunchback of Notre Dame!

I’ve always used the phrase “eggs on legs” to describe my appearance – rounded upper back and abdomen, complete with a buffalo hump and the traditional stick arms and legs. And there are times when my abdomen is so hard and bloated that even my “fat” clothes don’t fit!

Not only is this extremely uncomfortable *physically*, it also knocks me off my spiritual and emotional axis. If my head gets involved, it’s a full-on pity party. Generally speaking, I’m an upbeat, positive person, so when the bluesy days come, I give myself permission to have a bad mental health day and quickly turn it around.

I’d be lying, though, if I said that I don’t have angry, resentful days. When I catch a glimpse of myself in a full-length mirror and don’t see “Pam,” I get angry. I get angry for myself and for my husband. He married an attractive, vibrant woman who had legs for days and a really nice butt; now he sleeps with Humpty Dumpty. To his credit, he never complains or makes me feel “less than” because of the physical changes in my appearance. He does, however, worry about how these changes might affect my health and will make comments like, “Do you really need that?” if I’m indulging in something fattening.

It just doesn’t seem fair that, in addition to dealing with the day-to-day challenges of living with this disease, we have to get ugly, too. Outward appearance is so important to self-perception – when my body morphs like some hideous mon-

ster in a science fiction movie, my self-esteem can’t help but be affected. In turn, how I see myself affects the way other people see me – during the year that my regimen included Fuzeon, Norvir and Videx (to name a few of the more offensive medications I was taking), I was convinced that everywhere I went, people knew that I was “sick.”

I was bloated beyond recognition, including having chipmunk cheeks, which I have since learned is a condition called benign parotid hypertrophy (BPH). I was truly miserable, with painful injection site reactions from the Fuzeon in addition to all of my other symptoms and side effects. Quality-of-life issues had me in crisis, and after one year of virtually white-knuckling it every single day, I made the difficult decision in July of last year to stop the injections.

I stayed on the oral regimen for about eight months even though every indication was that it was failing...viral load going up...T-cells going down. Since this was my third “salvage therapy,” I needed to continue taking the same medications until something else came along. In October 2004, when my doctor asked me if I would consider becoming involved in a Phase II clinical trial of a new CCR5 entry inhibitor, I could barely contain my excitement.

Entry inhibitors are an entirely new class of drugs, so most people don’t have resistance to them yet. They work by preventing HIV from entering healthy T-cells. Other approved anti-HIV drugs are active against HIV only *after* it has infected a T-cell. For someone like me who has resistance to the medications in all the other classes, entry inhibitors are very promising.

It took nearly six months for the study to start after I was initially asked to participate; then it was another couple of weeks of waiting after it officially started to see if the HIV in my body entered my cells at the CCR5 level – if it didn’t, I would be out.

When I received the news that I qualified and would begin taking the new drug (or a placebo) a week later, I was both elated and exhausted. All of the anticipation leading up to the study starting and then finding out that I might not qualify had taken its toll. Now I had to wrap my brain around the fact that there was a 25 percent chance that I could receive a placebo. Only time and my labs would tell.

Based on the side effects I had the first week (diarrhea, headache, extreme fatigue) and my bloodwork results after just two weeks, I believe I am not getting a placebo. At the end of two weeks, my doctor took me off of Videx, Reyataz, and Norvir and added Kaletra. I also continued to take Viread and Emtriva, only now it’s in a single pill, Truvada, as once-daily dosage.

Because I had a severe allergic reaction to Kaletra about two and a half years ago, I had to be desensitized in order to incor-

porate it into this powerful new regimen. This involved my being premedicated with Benadryl prior to each dose and starting off with only one gel cap twice a day until I worked up to the maximum of three. At the maximum dosage, it was “Mr. Toad’s Wild Ride” for several weeks. I experienced mottled skin, a prickly “crawling-out-of-my-skin” feeling, a rash on my face and neck, headache, and an unfocused, “wild” feeling. As my liver began to process the medication, these symptoms subsided; however I am intolerant to heat and extremely photosensitive.

After being desensitized to Kaletra, I’m finding the rest of my regimen to be “friendlier” than some of the others I’ve been on, although I haven’t noticed any real improvement or changes in the lipodystrophy. While I’m disappointed that no dramatic changes have occurred, the rational side of me knows that it’s only been eight weeks and my body needs time to adjust to all of the changes.

Good old-fashioned, sweat-producing exercise seems to help a little with the tummy and hump issues, but I feel that in order for it to really be effective, I would need to exercise at least an hour a day, seven days a week. I strive to fit it in at least three times per week, but any more than that is quite challenging, as is eating healthier. My favorite foods only exacerbate the bloating; dairy items and pasta are both “no no’s”

Anything at all with fat in it ends up under my upper arms, across my back, or around my breasts – quite a sight. No Victoria’s Secret bathing suits for me! Again, the things that I’ve had to give up tend to make me a little resentful. I miss ice cream, cheesecake, carrot cake (who wants it without the traditional cream cheese frosting?), and a good old-fashioned cheeseburger. I’ve acquired a taste for some soy products and actually really enjoy tofu cream cheese, but sometimes there’s just no substitute for the real thing.

My ear is always to the ground, hoping the pharmaceutical companies will address the issue of the side effects of their potentially lifesaving medications. They affect all of us living with HIV/AIDS – men ... women ... children ... black ... white ... rich ... poor. Don’t we all deserve a decent quality of life while taking these powerful, often toxic drugs? We need to do more than just “survive” – we need to LIVE.

I dream of the day when there is a drug powerful enough to fight this virulent virus called HIV without destroying the physical body and mental and emotional psyche of its host. Until that dream becomes a reality, I will remain hopeful and ever vigilant in my own personal battle with HIV. I plan to win.

Pamela Yelsky resides in Redondo Beach, California with her husband and stepson. She is actively involved as Board President of Women At Risk (W.A.R.), a non-profit organization that offers services and support to women living with HIV/AIDS. For more information about W.A.R., please go to www.womenatrisk.org.

Inching Forward *(continued from page 5)*

Post-injection recovery can be slightly uncomfortable. Large amounts of hyaluronic acid are needed for patients with moderate-to-severe facial lipoatrophy.

Poly-L-lactic acid (Sculptra, New-Fill): Poly-L-lactic acid is a synthetic product that has a long history of use in reconstructive surgery. Even though it is synthetic, it is eventually broken down and removed by the body, meaning that its effects are temporary. It is the only facial filler to be approved by the FDA for the reconstructive management of HIV-associated facial lipoatrophy. It usually requires between two and six treatment sessions, four to six weeks apart.

The safety and effectiveness of this product for HIV-associated lipoatrophy has been evaluated by the FDA. Even though it is considered to be a temporary filler, it appears to have a longer-lasting effect than most other temporary fillers. Repeat injections, within a year or two after an initial treatment, are likely necessary.

The cost of poly-L-lactic acid can be high, although the manufacturer of Sculptra (Dermik Laboratories) has implemented a sliding-scale fee for the product based on an individual’s income. Multiple sessions can be cumbersome and increase the cost of treatment. Like calcium hydroxylapatite, poly-L-lactic acid can also cause nodules – hard lumps – at the injection site in some patients.

Semi-Permanent and Permanent Fillers

Silicone Oil (Silikon 1000, VitreSil 1000): Silicone comes in both solid and liquid formulations. Solid silicone is rarely used for facial lipoatrophy. Silicone oil is more commonly used, but its safety and effectiveness for cosmetic purposes are still controversial. At present, silicone oil is approved to treat retinal detachment; it is still being investigated for facial augmentation.

Silicone oil is safe and highly effective when injected in very small amounts (microdroplets). It’s also very long lasting, limiting the cost and the need for follow-up procedures.

The most notable disadvantage of silicone oil is that it can’t be removed. It can be toxic and damaging to the face if too much is injected. In some cases, silicone can migrate – usually down toward the jaw line – causing new cheeks to become jowls.

Polymethylmethacrylate (PMMA; Artecoll, Artefill): PMMA is best known for its use in manufacturing hard contact lenses and Plexiglas. The facial filler products contain small particles of PMMA that are surrounded by bovine collagen. Approximately three months after it is injected, the bovine collagen is broken down and removed from the body, but is replaced by natural collagen. The PMMA molecules and the surrounding collagen persist indefinitely. The FDA has indicated that it is safe and effective for the correction of facial wrinkles, lines, and furrows, but has not yet officially approved the product.

(continued on next page)

Inching Forward: Lipodystrophy and Possible Treatments *(continued from previous page)*

PMMA can be removed in the event of side effects or dissatisfaction with the end result. It is also relatively inexpensive. PMMA can cause side effects if large amounts are used. It can sometimes be felt, but rarely seen, under the skin in some people.

Expanded Polytetrafluoroethylene (ePTFE) Implants (Gore-Tex, Gore S.A.M., SoftForm):

These solid implants require minor surgery, via a small incision, under local anesthesia. They have been used for many years to help restore deep facial defects and may be useful for HIV-associated lipoatrophy in terms of filling large, sunken areas. Some experts believe that ePTFE should be used in combination with other fillers, particularly those that spark collagen production in the dermis.

The implants are said to be one of the better options for people with severe lipoatrophy. They can be removed in the event of side effects or dissatisfaction with the end result.

Because minor surgery is involved to insert the implants, there is the possibility of post-operative complications, including infection and swelling. It can cause scarring around the implant and can be visible and felt if not inserted correctly.

Polyalkylimide (Bio-Alcamid):

Polyalkylimide is a synthetic product that can be injected using a high volume, making it a possible option for HIV-positive individuals with severe lipoatrophy. There is very little experience testing or using Bio-Alcamid in the United States. However, it has been used in Europe for cosmetic and reconstructive purposes, with good results, and is the product of choice at a clinic in Tijuana that has yielded a lot of encouraging before-and-after photographs. An American division of the Italian company that makes Bio-Alcamid is planning clinical trials in the United States.

This is a long-lasting filler that can easily be removed in the event of over-filling, side effects, or dissatisfaction with the end results. Thus far, side effects have been minimal.

It is not available in the United States and, as of yet, there is very little sound, scientific data supporting its safety or effectiveness. It can be expensive, especially when international travel to and from clinics offering polyalkylimide injections is necessary.

“Implants are . . . one of the better options for people with severe lipoatrophy. They can be removed in the event of side effects or dissatisfaction with the end result.”

Covering the Cost of Facial Fillers

Unfortunately for many people with HIV, these products – and the expertise needed to inject them safely and effectively – are a costly out-of-pocket expense well beyond their reach. Depending on the product, the cost can range anywhere between \$800 and \$15,000, not including provider fees. Few private health insurance companies cover the cost of these procedures, even for Sculptra, which has been approved by the FDA to treat facial lipoatrophy. And neither Medicaid nor ADAP covers the costs.

Some people with lipoatrophy have had luck getting their insurance companies to pay for facial fillers. Working with their doctors, some have been able to convince their insurance companies that they require the facial filler to restore their features lost to anti-HIV treatment, not simply for cosmetic purposes. This is similar to the successful argument made by many

women with breast cancer who require a mastectomy and request that breast reconstruction be a covered expense.

Hopefully the medical establishment, particularly the HIV medical establishment, will universally accept these facial fillers as necessary restorative therapies for HIV-positive people with lipoatrophy. Fortunately, this is already happening and it may eventually result in routine coverage of these products and procedures by private and public insurers.

Where Do We Go From Here?

Researchers, obviously, have their work cut out for them. While they have come up with a handful of possible theories regarding what might be causing lipodystrophy – and, more importantly, how it might be treated – there are still no definitive answers.

The uncertainties of lipodystrophy research is frustrating, especially for people who are experiencing one or more of its symptoms. The truth is that there are no easy answers to come by. The good news is that this problem has become a major focus of research efforts – there are a lot of scientists working on finding the answers we need.

If you are experiencing any symptoms of lipodystrophy, such as changes in your body shape, be sure to discuss them with your healthcare provider. And don't be afraid to discuss new information that you find in *ACRIA Update* or any other reputable treatment information resources. The AIDS epidemic has taught many of us to be resourceful with treatment strategies that are already available to us. Dealing with lipodystrophy will require the same optimistic approach, at least until effective therapies become available.

Tim Horn is Executive Editor of The PRN Notebook, published by the Physicians' Research Network, and Senior Editor of AIDSmeds.com. This article is an adaptation of two articles focusing on lipodystrophy and lipoatrophy available at www.AIDSmeds.com.

New Protease Inhibitor Approved

On June 22, 2005, the FDA granted accelerated approval to tipranavir, a new protease inhibitor that has been tested in clinical trials at ACRIA. The new drug, developed by Boehringer Ingelheim Pharmaceuticals, will be marketed as Aptivus. It must be administered with ritonavir as part of combination antiretroviral therapy for patients who have shown signs of clinical failure and resistance to other antiretrovirals. ACRIA played an important role in the development of tipranavir through its participation in the RESIST study, which began in 2003.

ACRIA Research Findings Published

The findings of ACRIA's groundbreaking studies, completed during 2003, on one of the fastest growing HIV populations in the country – individuals who have reached their 50th birthdays – have been accepted for publication in peer-reviewed journals. "Perceptions of support among older adults with HIV" appears in the May issue of *Research on Aging*, while "The aging HIV/AIDS population: Fragile social networks" is in the June *Aging & Mental Health*. Both articles are by ACRIA Research Associate R. Andrew Shippy and Associate Director for Research Stephen Karpiak, Ph.D.

Funding Reprieve, For Now

ACRIA's two major New York City treatment education programs – which provide healthcare and treatment education workshops to HIV-positive people and their nonmedical caregivers across the city as well as individual counseling – will remain fully in operation at least until the end of February of next year.

As reported earlier, when priorities were set for the spending of Ryan White Title I funds at the end of 2004, treatment education was dropped from the list. The two ACRIA programs affected were granted contract extensions until the end of August 2005, but after that faced a complete loss of

Title I funds. ACRIA immediately launched an emergency fundraising campaign designed to save these crucial services, appealing to elected officials, foundations and corporations, and individual donors, but with only limited success. For the first time in its thirteen-year history, ACRIA was facing the possibility of having to cut back on the level of its services.

In late June, however, the New York City Department of Health & Mental Hygiene announced that it would delay the implementation of its new funding scheme until March, and would grant six-month extensions to programs currently receiving Title I funds.

This is definitely good news for the agencies and individuals who depend on ACRIA for vital healthcare and treatment information, but it is by no means the solution to the problem. ACRIA's staff and Board are taking advantage of this few months of extra breathing room to step up our efforts to find new sources of revenue and save these important services.

ACRIA to Co-Host Conference

As part of our ongoing commitment to HIV-positive people over 50, ACRIA is joining the Association of Nurses in AIDS Care (ANAC) to host a "preconference" on HIV and Older Adults. This one-day seminar will take place in Orlando, Florida, on November 16, the day before the opening of ANAC's annual conference.

Dr. Stephen Karpiak, ACRIA's Associate Director for Research, will co-chair the event and will present epidemiological data on this growing segment of the HIV-positive population. Research Associate Andrew Shippy will present on ACRIA's ongoing *Research on Older Adults with HIV* (ROAH) study.

North Carolina Training

ACRIA Treatment Educators Donna Kaminski and Lisa Frederick traveled to Charlotte, North Carolina, in June to pres-

ent four days of intensive training and technical assistance to nonmedical service providers serving HIV-positive individuals throughout that state. The trip marks the sixth effort by our National HIV Technical Assistance Program, and the first one to be held in the south.

Nearly twenty individuals attended, representing agencies from both urban and rural areas of the state. The results were overwhelmingly positive, not only in participants' evaluation of the training but in the results of post-training testing of HIV knowledge, which showed an improvement of over 75% over a similar test administered before the training began.

New Members Join ACRIA's Board

ACRIA is proud to welcome three new members to its Board of Directors:

Francisco Costa is a native of Brazil and longtime force in fashion design. He was a principal member of Tom Ford's design team that successfully overhauled Gucci in the nineties, where he earned prominent recognition for his designs for women. In 2002 he was named to replace American fashion icon Calvin Klein as the head designer for the firm that continues to bear Mr. Klein's name.

Deborah Hughes left a successful decade-long career as a model with the Wilhelmina Agency to head advertising and public relations for Carolina Herrera, Inc. She has subsequently worked at the forefront of public relations in the fashion industry, and is currently the head of her own agency with a client roster that includes prominent fashion houses, restaurants, and entertainment ventures.

Isabel Rattazzi is a prominent New York and international socialite and philanthropist. She has been an active supporter of several charities in New York, Italy, and her native Cuba. She is currently compiling a two-volume chronicle of projects by famed architect Peter Marino.

generous contributions

The following persons, corporations and organizations made major donations between March 26, 2005 and June 30, 2005 to support ACRIA's research and education efforts:

Banana Republic
Boehringer Ingelheim
Pharmaceuticals
Broadway Cares/
Equity Fights AIDS Inc.
Robert M. Browne
Calvin Klein, Inc.
Patricia and Gustavo Cisneros
The Diller von Furstenberg
Family Foundation

Estate of Doris B Nash
The David Geffen Foundation
Adam F. Lippes
Paula Cooper Gallery
Paul Rykoff Coleman Foundation
Roche Laboratories
Schering Sales Corporation
Robert Wilson

Thoughtful donations were made in memory of the following individuals:

Johnny Atkinson
Barry Binkowitz, MD
Patrick Englese
Steve Erlanger
Barbara Frey

Joseph Gonsalves
Bennie W. Krueger Jr
Clark D. Moore
Brenda Williams

Contributions in support of ACRIA's vital research initiatives were made in honor of the following individuals:

Arlene and Jerry Binkowitz
Gerard Stricker
J Daniel Stricker
Rodney Reid

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