Beyond The Valley Of The Dolls

While climbing meds mountain, these four HIVers fell into the antiretroviral abyss. Here's how they made their comeback. Sparkle!

September 1, 2000 By Rebecca Minnich

Billy Stevenson
Age: 52
Tested positive: 1991
Regimen: d4T, 3TC, Viracept
XTRA FX: Diarrhea

His welcome to the club in 1991 is something Billy Stevenson says he'll never forget: "I was in a hospital bed with pneumonia. Magic Johnson had just announced on TV that he was HIV positive and I started crying. Two minutes later, they came in and told me I was, too."

Stevenson started on combo therapy five years later, and for an excruciating 11 months he could never be more than a few feet away from a toilet. "I had diarrhea so bad I had to wear adult diapers," he recalls. Determined to stay on his meds, he struggled to suck up the drugs' gut-wrenching effects. "There were times I wouldn't make it to the bathroom on time—it was ugly," he says. "I had to have help getting cleaned up." His sheer will to live—and his belief that if he ate regularly and gained weight, he would eventually be able to stop racing the marathon runs—kept him going: "You just reach a point where you make up your mind if you're going to live or die. I decided to go on living."

Stevenson's system gradually got used to the cocktail, although he still does time on the porcelain throne. "The diarrhea never totally went away, but now it's mainly a reaction to stress. The best way to keep it under control is to adhere: eat my meals and take my doses at the regular times, and never skip." Weekly Shiatsu massage is an antidote to stress, as are two herbs, black cohosh and chamomile, known for their antidiarrheal powers. But the two things Stevenson swears by are the company of friends and doing what he loves best—singing in nightclubs.

Richard Daniels
Age: 48
Tested positive: 1993
Regimen: d4T, 3TC, Bactrim, acyclovir
XTRA FX: Protease paunch, lipodystrophy

I'm a dancer, physically active and well toned. I never had much fat on my limbs, so when I lost it, it was shocking," Richard Daniels says of the lipo that crept into his life last year. "I could see all the blue veins right through my skin. It looked hideous." About 18 months after he started a combo of Crixivan, Rescriptor, d4T and 3TC, subcutaneous layers of fat melted from his legs, arms and face, and accumulated in his abdomen. He felt bloated. He broke out in a rash. Just when he thought he'd hit bottom, his hair began to fall out.

"I was in a dance performance where I was in a bright yellow costume," he recalls. "When I saw the video, I was horrified. I looked like a dancing pear." Daniels' metamorphosis was a double whammy: "When you make your living with your body on the stage, this side effect is a major problem. It's not just a matter of vanity."

By June 1999, Daniels was tired of splitting his costumes. Fingering Crixivan as the lipo link, he stopped taking it as well as Rescriptor. His doc added Sustiva to the 3TC and d4T. "That lasted about two weeks," Daniels says. "It made me psychotic." Out went the Sustiva, leaving him on a two-nuke combo. "It's against all conventional wisdom to take d4T and 3TC alone, but, I figured it can't be worse than what I've already gone through."

A year later, Daniels' CD4s are in the 200s, his viral load is around 5,000, and he's feeling just peachy, thank you (no more pear!). His legs and arms are no longer sticks, but his belly still hangs over the belt a bit too much for his liking. The facial wasting is the only lipo-related problem that hasn't improved. (Many experts believe d4T to be a likely cause of facial wasting.)

Three months ago, he started amino-acid supplements (ribose, carnitine and creatine), which he hopes will restore his cheekiness. But either way, Daniels will keep dancing as fast as he can.

Lillian Anglada
Age: 41
Tested positive: 1989
Regimen: Norvir, Crixivan, Viramune
(since March)
XTRA FX: Myopathy, neuropathy

"First YOUR DRUG combo causes side effects, and they give you pills for them. Then they give you another pill for each of those side effects, and before you know it, you're taking 10, 15 things," says Lillian Anglada, whose first cocktail—ddC and Crixivan—led to neuropathy and myopathy, two common PWA complaints. These nerve and muscle conditions don't kill, but the numbness and pain they cause make putting your best foot forward a daily ordeal.

"You can stick a pin in my leg below the knee, and I won't even feel it," says the Manhattan mom, grandmom and veteran ASO volunteer, adding that in a further turn of the screw, her bones seemed to gain all the sensitivity that her flesh had lost. "Now when anything touches my knee, ankle or elbow, it's really painful." Soon this once-independent woman was sentenced to a wheelchair-cum-attendant 24/7. "I couldn't walk around my apartment. Even going to the

bathroom, I needed help. I missed my work. I got depressed."

To relieve the pain, doc "put me on Neurontin, but all that did is make me throw up." Desperate for an alternative, she heard rave reviews about acupuncture, and decided to go and get pinned.

After three months of twice-a-week sessions—including electrostimulation, heat treatments and muscle massage—Anglada not only can walk with a cane but can "do my own shopping, make my meals, do laundry"—all the humdrum she'll never again take for granted. Better, she's back on her feet without having to take another pill. "Nobody but you is keeping track of what all those drugs are doing," she says. "So I had to learn to take charge: Find out what works for you, and stick with it."

Peter Staley
Age: 39
Tested positive: 1985
Regimen: Abacavir, Sustiva, ddI, hydroxyurea
XTRA FX: Euphoria, anxiety, insomnia

A cocktail mixed with Crixivan spelled lipodystrophy for Peter Staley, so last May he switched to Sustiva. But first, the founder of AIDSmeds.com and recipient of amfAR's first-ever Award of Courage for his longtime AIDS activism grilled friends and strangers about their experience of the non-nuke's notorious "nervous system" symptoms, ranging from hyper-realistic dreams to agitation, hallucinations and (worst case only) psychosis. "I prepared myself with information, but it wasn't as bad as I expected," he says through his stiff upper lip.

Staley's main complaints were all in his head, literally. "It was like being drunk or high," he recalls of his Sustiva mornings. "I felt light-headed and euphoric. Actually, I kind of liked it." Not being able to drive to work during the two weeks this lasted put a crimp in this guy-on-the-go's style. But when afternoon rolled around, he discovered another downside: what Breakfast at Tiffany's Holly Golightly called the mean reds. "My palms would start sweating, my skin felt tingly and irritated, my breath was shallow. I was just extremely nervous. I said to myself, 'So this is an anxiety attack.' I'd never had one before." And once tucked in bed, when he downed his one-a-day dose, Staley got his third workout of the drug's TLC: insomnia. (He now takes the bedtime pill with Ativan, a sedative, to help him sleep.)

For Staley, knowing Sustiva's side effects up-front made all the difference in dealing with them. "I could have gotten paranoid when I felt the anxiety symptoms coming on, and made it that much worse," he says. "But I knew what to expect, and I just tried to distance myself from it"—observing his symptoms as if they were happening to somebody else.

One year later, Staley and Sustiva are in a long-term relationship—unless or until resistance do them part. "I love this drug," says this satisfied customer. "The single dose in the evening is so convenient. No more watching the clock or timing meals—it's liberating." Even if it sounds like a sales pitch, Staley means it.

MEDICINE CHEST

Protease Inhibitors (PIs)

Name: Agenerase (amprenavir) Glaxo Wellcome
Side Effects: Diarrhea, nausea, oral tingling and numbness, rash, vomiting

Name: Crixivan (indinavir) Merck & Co.
Side Effects: Anxiety, back pain, diarrhea, headache, insomnia, kidney stones, nausea, rash, stomach upset, vomiting

Name: Fortovase (saquinavir)Roche Laboratories
Side Effects: Diarrhea, elevated liver enzymes, headache, insomnia, nausea, stomach upset

Name: Norvir (ritonavir)Abbott Laboratories
Side Effects: Appetite loss, diarrhea, elevated liver enzymes, nausea, oral tingling and numbness, stomach upset, vomiting

Name: Viracept (nelfinavir)Agouron Pharmaceuticals
Side Effects: Diarrhea, elevated liver enzymes, gas, nausea, rash, stomach upset

Don't Forget: Long-term side effects: changes in blood sugar levels (and potentially development of diabetes), elevations in blood fat levels, and changes in the way the body stores fat (including development of fat deposits in the abdomen and on the back of the shoulders, breasts and limbs, as well as loss of fat in the arms, buttocks, legs and face).

Nucleoside Reverse Transcriptase

Name: Combivir (AZT+3TC) Glaxo Wellcome
Side Effects: See Epivir and Retrovir

Name: Epivir (3TC)Glaxo Wellcome
Side Effects: Hair loss, nausea

Name: Hivid (ddC)Roche Laboratories
Side Effects: Mouth ulcers, nausea, peripheral neuropathy

Name: Retrovir (AZT) Glaxo Wellcome
Side Effects: Appetite loss, fatigue, headache, nausea, stomach upset; more rarely: anemia, muscle loss, pain

Name: Videx (ddI) Bristol-Myers Squibb
Side Effects: Diarrhea, nausea, peripheral neuropathy; more rarely: pancreatitis

Name: Ziagen (abacavir) Glaxo Wellcome
Side Effects: Serious allergic reaction, appetite loss, diarrhea, insomnia, nausea, vomiting

Name: Zerit (d4T)Bristol-Myers Squibb
Side Effects: Facial wasting, nausea, peripheral neuropathy; more rarely: pancreatitis

Don't Forget: Long-term side effects: bone marrow suppression and damage to the mitochondria (cell's energy source). These effects may cause low red and white blood cell counts, muscle pain and loss (particularly in the arms, buttocks and legs), fatigue and peripheral neuropathy; more rarely: lactic acidosis (which can cause liver and kidney failure and death) and pancreatitis.

Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs)

Name: Rescriptor (delavirdine) Agouron Pharmaceuticals
Side Effects: Elevated liver enzymes, fatigue, headache, rash, stomach upset

Name: Sustiva (efavirenz) Dupont Pharmaceuticals
Side Effects: Anxiety, confusion, depression, dizziness, drowsiness, elevated liver enzymes, fever, inability to concentrate, insomnia, nausea, nightmares, paranoia, rash, stomach upset

Name: Viramune (nevirapine) Roxane Laboratories
Side Effects: Elevated liver enzymes, headache, rash, stomach upset; more rarely: liver inflammation

Don't Forget: Resistance develops very easily in the NNRTI class, making adherence to a non-nuke combo a must.

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