Marsha Burnett

46; Montpelier, Vermont; 14 years with HIV

June 1, 2001

Survival Secrets

“I listen to my body and eat healthy: lots of greens and fruit. But activism is my lifeblood. If you don’t keep everything exciting day to day, you won’t do well. When God feels like I’ve done all he wants me to do, then I’ll go. But I need to quit smoking, my final vice.”

Without doubt, Burnett’s life has been hard. A two-decade user of heroin, crack and more, this mother of four and grandmother of one has endured drug relapses, breakdowns, infections, rape, separation from her kids and her husband’s AIDS death. Yet Burnett has not only survived and been sober for 10 years -- she’s running faster than ever. Starting out as a local welfare rights advocate, today she takes on the world through her work with the Alliance for Global Justice.

1987: *While still recovering from a brutal rape three years earlier, Burnett gets bad news:* “The guy who raped me was acquitted, the rape crisis center I worked at was defunded -- everything just fell apart.” After years of off-and-on drug addiction, Burnett coped by injecting heroin and cocaine -- which she continued for two years.

1988: *Burnett gets treated for PCP (Pneumocystis carinii pneumonia).* As was typical for the time, the doc didn’t test her for HIV. “I didn’t know anything about HIV. I was living in a deep drug culture, where you hear what you want to hear. I fell through the cracks.”

1989: *In April, her husband is hospitalized with endocarditis; Burnett learns she is pregnant and gets clean.* In July, she was hospitalized for premature labor; after a nurse treating Burnett got a needle stick, Burnett agreed to an HIV test. The day after giving birth to twins, she found out she had HIV.

1990: *Denied access to a drug treatment program, Burnett relapses to cocaine.* She went on high-dose AZT for two months, but quit after it provoked frequent nausea and diarrhea.

1991: *The twins test negative.* But, citing Burnett’s relapse, the state removed them from her custody. Burnett had a breakdown and spent a month in a psychiatric unit. “My fingers went numb from neuropathy, and I was deathly afraid I was gonna be wheelchair-bound, like so many PWAs I’d seen. I was over the edge.” She was diagnosed manic-depressive and sent for a year to a residential AIDS treatment program run by and for African Americans. “That was the turning point.

Working with a psychologist, I learned I'd been self-medicating for years." She returned to recovery and worked with ACT UP to campaign for condoms in local schools. She also began Bactrim (to prevent a PCP relapse), after aerosolized pentamadine provoked an asthma attack.

1992: *Burnett's husband relapses, goes back to the streets, and she leaves him.* As many of her friends cycled in and out of rehab, her husband died of AIDS. "Poor communities are so overwhelmed with living day to day; AIDS has been just another thing to knock us down." The following year, Burnett traveled to Nicaragua -- with three cases of condoms. "Listening to their stories, my perspective on poverty changed. I learned I had to link social issues here with the international movement for justice."

1997: *After learning that relatives are neglecting her children, Burnett takes them home, is arrested for kidnapping, then learns the kids have been sexually abused.* An activist campaign kept her out of jail and with custody of her kids.

1999: *With Burnett's labs looking bad (3 CD4s; 750,000 viral load), she reluctantly starts HAART -- Crixivan, Viramune and ddI -- until her bilirubin (a liver enzyme) shoots up a year later:* "It almost took me out." Her doc substituted Sustiva for Crixivan and d4T plus 3TC for ddI, but within months, she quit that combo, too: "I was gagging on the pills and feeling queasy, plus my schedule made it tough to stick to the program." Soon she was diagnosed with hepatitis C.

2001: *In January, with her viral load above 750,000, Burnett resumes HAART, but quits again after nausea and rapid weight loss.* (She continues to take MAC, PCP and herpes prophylaxis.) She feels better immediately, although she has severe joint pain, for which she takes prescribed opiates. But she made a solemn vow: "I'm never going on antivirals again. With hep C, I need my liver. Nobody can convince me that aggressively treating AIDS in a person with liver disease is good science." She's also stopped measuring her viral load and CD4s: "That information will only bring me down." Her family is appalled, but she's unshakeable. "I want to wake up, thank God I'm here and move on. I'm educating people to fight this damn system. AIDS ain't hindering me -- it's *why* I fight."

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