Songs In The Key Of Life

Forget the made-for-TV Survivor -- AIDS makes frying rats for dinner seem like fine dining. Three long-term survivors tell Bob Lederer how they made a miracle

June 1, 2001 By Bob Lederer

In this era of protease-prolonged lives, it's easy to forget that in the early days, most PWAs had to take extreme measures simply to eke out a few extra months. But there have always been a few who managed, by hook, crook or luck, to outpace the reaper. Today thousands of blessed souls still have time to smell the roses 15, 20, even 22 years after infection (POZ founder Sean Strub is one).

What's their secret? Most research into long-term survival is unnecessarily narrow, focusing on genetic quirks or viral strains -- of no immediate practical use for HIVers. Meanwhile, scientists have largely ignored the evidence under their noses: Living, breathing and highly informed PWAs. That's who gay AIDS activist and long-term survivor Michael Callen went to for his landmark 1990 book, Surviving AIDS (HarperCollins), a mix of autobiography (he famously credited his own longevity to "luck, Classic Coke and the love of a good man"), analysis of the research (both establishment and alternative) and conversations with 25 remarkable survivors. While no finger-wagger, Callen did note that most avoided AZT, the only antiretroviral then available, choosing instead prophylactic and immune-supporting meds. In addition, he wrote, "meeting other survivors made it very clear to me that attitude matters. The human mind is a great, largely untapped pharmacy."

In the spirit of Callen, who died in 1993, and the other leading crusader for long-term-survivor research, ACT UP's Aldyn McKean, who died in 1994, POZ spoke with three more remarkable people who have been through AIDS hell and are still around to raise their own. Each is a testament to "attitude matters." Each can also say with Callen: "Even if I were to die tomorrow, I could still take pride in the fact that I have become a long-term survivor of AIDS. With a lot of hard work and luck, I have beaten amazing odds."

Anthony Salandra, 55
Fort Lee, New Jersey
23 years with HIV

Survival Secrets

“After I learned of my HIV status, I completely changed my sexual behavior, so I think I was never reinfected. I always listen to my inner voice about starting, stopping or switching treatments. My work keeps me motivated, and I’m lucky to be very loved by my family and friends. God, luck and an extreme love of life are all reasons why I exist.”

Salandra has traveled the familiar road of many long-termers -- lengthy periods of good health punctuated by frightening flareups, resolving into the even-keel health he enjoys today. Through it all, this former hairdresser’s commitment to serving the AIDS community has remained constant. In recent years he bounced back from disability to full-time work as an AIDS treatment advocate.

1978: Salandra starts two very different relationships that endure today.

One was with Eddie, his cherished lover, who’s HIV negative. “Having another human being so close has been an incredible source of support.” The other was with HIV. “I went on a sex spree in Haiti and came back with dreadful diarrhea.” Stool testing found no parasites, so he gave it little thought. Later, he heard accounts from his Haitian sex partners of chronic illness and wasting.

1985: Many in his local gay scene, including a dear friend, are mowed down by AIDS.

"I worried that I might be infected. I was leading a rather closeted life, but now it was time to put energy into my community.

" He became a GMHC buddy, providing visualization and massage. He later arranged for imports of Mexican isoprinosine, an experimental immune modulator, and delivered AL-721 -- an egg preparation popular in the AIDS underground -- to his ill buddies.

1986: Accompanying a PWA buddy to the doc, Salandra is tested and learns that he’s positive.

“I remember the terror, being so afraid of kissing my nephew that I pushed him away.” But a GMHC psychologist helped him cope. As a diabetic, “I was used to finding answers when there were none,” and he started to look for answers to AIDS. “I heard that antioxidants helped with cancer and figured they’ve got to be healthy,” so he started on high-dose vitamins and nutrients. Within six months, his CD4 count shot up from 480 to 610, where it stayed for years. Salandra also “developed a wonderful relationship with my doctor, which I treasure to this day.” Salandra rejected his doc’s advice to start then-experimental AZT, deciding to wait until his CD4s fell below 300.

1988: Salandra quits hairdressing to work at Hyacinth Foundation, a New Jersey AIDS organization.

“The only place I felt good was around other people with HIV.” Frustrated by disability red tape, he designed an expedited form and spent hours helping PWAs use it, landing him an agency service award.

1992: Salandra is hospitalized after a severe bout of vertigo, later attributed to a simple ear infection."

I thought I had a brain tumor, and it frightened me to death. I had seen all kinds of horrors with PWAs.“ His CD4s crashing, Salandra reluctantly started AZT. ”Even though I lowered the dose, I still thought it was gonna kill me."

1994: Salandra wages a herculean battle with extrapulmonary (outside-the-lung) TB.

First a lump the size of a golfball sprouted on his back, then “I couldn’t talk or breathe.” He was hospitalized for three months and lost 50 pounds. The worst moment came when a doc said, “Do you know how sick you are? You’ll never work again.” That night, “I was a wreck. I lost my will to live.” But the next day, with the help of a supportive nurse, he began to focus on healing. Eight months later, he was back at work.

1995: Salandra develops 15 Kaposi’s sarcoma lesions, and his CD4s drop to six.

In urgent need of new meds, Salandra won a Merck lotto for access to its experimental protease inhibitor indinavir (Crixivan) and began taking the drug, along with AZT and 3TC. It was a turning point: His CD4s began to climb, his viral load dropped to undetectability and the KS resolved. “Nothing would stop me from doing it right. In four years on that grueling combo, I missed only six doses.”

1997-99: The meds cause new health problems: lipodystrophy (with a 100-pound weight gain), high cholesterol and anxiety.

Most troubling, his diabetes, exacerbated by Crixivan, led to a severe foot ulcer that left him immobilized for two months.

2000: In June, he switches from Crixivan to nevirapine (Viramune).

Gradually, his weight dropped to normal (aided by a strict diet), the ulcer healed, his cholesterol took a dive -- even his blood sugar normalized.

2001: After two decades of AIDS, "I can’t go into the Village anymore without feeling very, very sad, wondering whether people are still alive.

But I also witnessed the coming together of the gay, lesbian and trans community. Gay people are no longer only looked at as bearers of AIDS, but as the people who did something about it.“ For the first time in years, ”I actually feel alive. I’m even planning my old age. I won’t be happy unless I have another 20 years -- at least!"

Marsha Burnett, 46

Montpelier, Vermont
14 years with HIV

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.”

Ruben Rodriguez, 50
Brooklyn, New York
19 years with HIV

Survival Secrets

“Most important has been my positive attitude. When I was first diagnosed, I refused to dwell on dying and decided to take care of myself. I stopped drugging, drinking and smoking, exercised, and was always into the vitamin thing. The fact that I got involved in AIDS while in prison has also been important. I wasn’t bothered by the fear of what someone would do to me -- working around HIV, you had to have balls. My big points are that no one should live with this alone. Accept it, and don’t allow it to eat at you.”

Rodriguez spent much of the last two decades in prison and infected with HIV -- and lived to tell about it. In the face of discrimination and brutality against other HIV positive inmates, Rodriguez established AIDS education and support programs in each prison he was sent to, even before he knew his own status. He has continued that work on the outside since his release in 1996.

1981: Rodriguez is sentenced to 15 years to life for what he calls the “flimsy charge” of attempted burglary, his third conviction.

Over the next two years at New York’s Sing Sing prison, he injected heroin, sharing needles and works. Later, he found out that some of his needle-sharing buddies had died of AIDS.

1983: In the first of many prison transfers, Rodriguez is moved upstate to Auburn.

“Talk started to circulate about AIDS. I was seeing people get sick -- they were going away and not coming back. I decided to stop using needles, and to snort heroin instead.”

1985-86: Across New York State, inmates with AIDS are attacked -- one is burned out of his cell; others are taunted or stabbed.

“Medical care was substandard. The attitude of administrators was ’Throw ’em where they won’t be seen.’” Rodriguez became close with a fellow inmate who was HIV positive and, with other inmates falling ill, he began to suspect his own infection. He decided to learn what he could about AIDS, and encouraged inmates to go to the prison hospital to help PWAs write letters, or just to sit and play cards. “The sickness, dying and discrimination struck a nerve among prisoners, who wanted to do something about it.” In 1989, the administration “shipped me out -- as they did with anyone taking leadership.”

1989-91: In rapid succession, the troublemaker is transferred to Attica, Eastern and Walkill, but he works with inmates at each prison to establish a PACE (Prisoners for AIDS Counseling and Education) program.

With a potential furlough on the horizon, Rodriguez decided to quit drugs. “It didn’t go with the good work I was doing. I couldn’t go back out to the same old life.”

1993: Rodriguez finally goes for an HIV test, and comes up positive.

“I guess, up till then, I really didn’t want to know. I was taking care of myself, wasn’t having risky

sex or shooting drugs, hadn't come down with any symptoms, so I didn't see the need. But I did promise myself that once I was eligible for furloughs, I'd get tested, because I knew I'd get in relationships with women and have sex." His CD4s at 520, he declined the prison doctor's suggestion to take AZT. "Everything I read led me to believe it wasn't necessary yet, especially with all its toxicity."

1996: Out on parole, Rodriguez works as a benefits case manager, later becoming a counselor at an alternatives-to-incarceration program.

The next year, with his CD4 count below 400 and "all the stress catching up with me," Rodriguez started on HAART, eventually switching to his current combo, Crixivan, AZT and 3TC.

1998: Rodriguez becomes hotline supervisor at the Osborne Association's AIDS in Prison Project, which offers advocacy and discharge planning for prisoners with HIV.

"This is my life's work. I see now that everything I did in prison was in preparation for what I'm doing now."

2001: Now Rodriguez's CD4 count is at 720 and his viral load is 30,000.

While he had a few side effects early on, he's now facing fatigue, intense foot pain (he's on meds) and "my sex drive is not as strong." Overall, he is upbeat. "I do have ailments, but I expect that--it's part of the disease, part of being on meds. But if I can do what I need to do, then I'm good." As for the prison epidemic, "People are nearly as afraid of AIDS as when they started. Prisoners coming together to help each other forged a sense of community. A lot more are seeking treatment because of the awareness we helped create.

The AIDS in Prison Project accepts collect calls from prisoners: 718.378.7022

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