A Queen for Connie

Blunt talk from Los Angeles AIDS diva

May 12, 1995 By Connie Norman

Connie Norman is California's self-described AIDS diva, a former drag queen, ex-hooker, ex-IV drug user, ex-high-risk youth who is today a happily and out-of-the-closet post-operative transsexual married to the most wonderful man on the planet. My only regret is beign HIV positive because I really wanted to outlive my five precious, adorable, Himalayan kitties." Norman is cohost of Gay and Lesbian Newsmagaine*, shown on cable access in Long Beach, California, and her column "Tribal Writes" appears bi-monthly in Update magazine. She is director of public policy for the All Saints AIDS Service Center.*

Honey, if anyone wants one reason to volunteer at an AIDS agency, I've got it. Being an AIDS activist and then working for and AIDS service organization (ASO) has involved me in a constant dialog about health care. If anyone has taken control of her health, it's me. I certainly believe that information is power. But it boils down to how much you want to live. I want to be here on this planet every minute that I can and I'm willing to do whatever I can do—comfortably—to stay here.

I found out that I am HIV positive in 1987, so my relationship with meds goes back a long way. The first drug I took was AL-721—yes, the rotten egg thing. It was dreadful, like having to eat vomit every morning. I stayed on it for a couple of months. Then, as information started coming out that "there ain't nothing there" –well, I was very happy to quit AL-721.

Honey, I've done it all. Hypericin and the DL23 or 223 and the whole vitamin thing. I did dextran sulfate for a while. And all the antiretrovirals. I can't take AZT—it makes me very ill and I just can't tolerate the side effects. My husband and I both have AIDS and we've tried all the treatment du jour as they came up, especially anything alternative or holistic.

Currently, I'm taking 3TC and ddC in combination the side effects form that combination aren't so bad. I also take TMP/SMX (Bactrim) as a general prophylactic—I haven't had PCP yet but I'm waiting. I'm also taking Difulcan, Mycobutin and, oh yes, I started Tagamet today. It's an ulcer medicine but seems to have some benefits for people with AIDS by increasing appetite and stopping itching, which I've also been going through—a bout of chronic itching. No visible rash, just itching.

The last time we counted I had 52 CD4 cells, and the percentage was 5 percent. That's a lovely

percentage, isn't it? Well, it could be lower.

I've also been known to self-prescribe medicines. Right now I've got shigellosis. I went to the doctor after I had been just dead with this, so to speak, for a week. Of course I already knew what I had; I'd never had this particular disease before but I diagnosed myself from reading about the different things it could have been and talking to people. The treatment is ciprofloxacin (Cipro), which I happened to have around the house because I'd used it to treat severe swelling during a previous lymph node infection. I started taking it as soon as I was sure I had shigellosis. So I'd already managed to knock the bug back a bit before I got to the doctor.

My doctors have gotten over any irritation they may have had about me diagnosing myself. If I'm sick I'm not going to get in the car and go to the office just so they can tell me what I already know. Not that I would let a prolonged bout of illness go on and on without professional diagnosis, but when you're living with AIDS you have to make things as convenient as possible for yourself. If you go to the doctor for every little sniffle, honey, they're going to be running your ass around for two days doing tests just to cover their own asses. So you learn to self-triage.

I have a very good relationship with my doctors. But that's something that developed over time. I put my doctors on notice that I think of them less as my doctors and ore as my research assistants. My physician, Dr. Thomas Baker, was kind of pissed off about that at first.

I got him when I went to my HMO, Kaiser, right after I first got diagnosed. This little man came into my room with gloves on and a scared look on his face and I said "oh, no, uh uh." So I called Kaiser and said, "Look, I want a fag. I want him to look like a fag, sound like a fag and smell like a fag." So they gave me this big queen, Dr. Baker, just what I asked for.

I don't get this fuss about HMOs. I think if you're aggressive and assertive enough you can get excellent healthcare. Take nothing for granted. Stay informed and aware—read the brochures they give you and then take it a step farther and do your own research. If you do all that you can get excellent care. But if you allow yourself to be herded in with the rest of the cattle you'll find yourself waiting for weeks to get an appointment. And the HMO doctors take a very conservative view in the provision of healthcare. They don't go out on a limb. So you have to be very aggressive, assertive and know what's going on.

So all in all, I'm taking 13 pills a day. And I smoke marijuana. But the core of my medical treatment plan, more important than any of the drugs, is what I call "Get A Life."

Sue me, but I believe that all of the medicines and all of the prophylactics are eventually going to come up against this virus and lose. You can either sit and wait for that to happen or you can go ahead and live your life. That's really the most effective early intervention we have. There's literally millions of toxins out there—how many are you going to prophylax against? Eventually something's going to getcha. So don't waste time waiting for Mr. Goodcure.

I live a day at a time. I can't project into the future because the future is frightening. And I can't go

by where I’ve been with my health because I’m never going to be there again. My CD4 cells aren’t going to climb back to 500. You just have to be here now with your disease and deal with it that day for whatever the disease is that day. So my best health plan is doing what I want to do and having a rich, full and active life. That’s the single most important thing a person with AIDS can do for themselves-just get out there and live.
