Life: Do Good Intentions Kill?

Starting now, PWAs must speak and fight for themselves.

October 1, 1994 By Kiki Mason

There I was, in a meeting with Liposome Technology Incorporated (LTI), feeling betrayed. Not by the drug company, mind you, but by the activists in the room who were supposed to be on my side as a person with AIDS. Negotiations with the makers of liposome-coated chemotherapy drugs had pretty much proceeded on a quiet level, with members of Treatment Action Group and ACT UP/New York's Treatment and Data Committee plowing through the rhetoric of the drug company and our friends at the FDA without arousing any great activist furor. Recently, the one person with KS who had been actively involved in the negotiations had died and I had to thrust myself into the spot reserved at these things for the "person who actually has it." I can tell you I didn't feel wanted.

Perhaps the attendees looked askance at the militancy of my opening remarks, in which I suggested that if LTI didn't have the funds for a truly compassionate program while awaiting FDA approval then the drug license should be sold to someone who did. The activists sat through my strident discourse with a "been there, done that" expression collectively settling in on their faces. While I, too, have been around the rhetoric block a few times, my anger was heartfelt because I have the disease. As I so tartly pointed out, the failure of LTI's drug wouldn't mean a falling stock price for me or loss of face in the activist community. It would mean death.

Which is the nature of the ugly concrete wall -- topped by barbed wire and guarded by machine gun points at various places along the route -- which has gone up since AIDS ran into the national consciousness. While PWOAs (people without AIDS) are more understanding than ever, they cannot die for us. Dying is a highly individual act. It really is true that we're born into the world alone and we leave alone. When I came to grips with my AIDS diagnosis, I had nursed many people through a variety of illnesses and had buried several. Fear of AIDS had driven my actions for years but I never truly understood AIDS until the day I got my test back. Then I got it. You may have a lover or close friend who has it, you may be a caregiver or an activist, you may be doing the right thing, but you can't jump over the wall. You can't be there.

There is a natural suspicion between the two camps. You could infect me, says the negative. I'm going to make you watch, says the positive, because I want you to feel as much pain as I do. The negative has nothing left to give, while the positive is afraid of being left. The division doesn't prevent business as usual from happening. After all, this is America now, where barriers of all

kinds are permitted. After race, class, gender and sexual orientation, what's one more?

As the meeting with LTI dragged on, I thought that I had the answer. We who had the disease were discussed like hunks of meat destined for different hooks. One activist even took it upon himself to lecture me about the dangers of people with a disease attempting to obtain medication before it had been properly approved. Another activist involved in this discussion now ducks my phone calls because I asked him if, aside from studying the disease at the library, he had ever sat down with a group of people who have KS to talk about what they want. On our initial meeting I had asked this man, who is negative, why he was doing all this. "For you guys, of course," came the reply. When I became difficult and none too grateful for his help, he refused to listen anymore. I see the same pattern with negative executive directors making career moves and boards of directors without positive members making decisions that affect us.

At various times over the past few years I have tried, if only for a day, to pretend that "it" doesn't exist, to live my life like a normal 34-year-old with a career and goals and hope for the future. Make-believe never lasts long. We cannot pretend that this barrier between positive and negative does not exist. While LTI and its community-relations firm have been engaging the activists in mutual masturbation, I've gotten more than 25 new lesions and have endured chemotherapy. My anger at people who are supposed to be supporting me is real but I've also realized that I must take matters into my own hands because I have the most vested interest. As PWAs we often expect other people to take care of our battles, but some wars can only be fought by ourselves. We all love -- and need -- to be taken care of. When we give up control of the institutions that are supposed to be serving our needs, however, the process loses touch with reality and no one is served.

To both sides, I say don't give up. To the negatives fighting alongside us, I say don't pretend to understand what it's like, just stand up and act like your lives are on the line. To the positives my message is simple: Forgive them their ignorance, for they cannot understand. Then make sure they do.

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