In the Blood

A son gives as good as he gets

July 1, 1998 By Dennis DeLeon

In one of our Sunday phone calls about my health and viral load, my mother casually mentioned that the blood count measuring cancer-related antibodies in her blood had jumped from 35 (after surgery and six torturous chemo treatments for ovarian cancer) to 190. The test, the CA-125, is like a viral load test: A low number can give you hope; a high number can take it all away. The doctor told her he would retest in two months but did not recommend further treatment.

Everything about my experience with AIDS told me this was wrong. Why not jump on the resurging cancer right away? I've been feverishly switching medications for the past two years whenever my viral load climbs back up. "Push it back down" is my mantra. Due to my sense of PWA empowerment, I monitor my immune system, track new meds in the newsletters and make sure I see an informed medical provider. With cancer, however, things seemed to be different.

While my mother was hospitalized, I visited various cancer organizations in her area and was unimpressed. They were big but had little sense of activism. Instead, they put out pretty pamphlets, sponsored acres of support groups and helped with transportation to and from chemo. They had about as much fire in the belly as a glowing television set.

And to make matters worse, these providers—and patients—had a worshipful respect for cancer doctors. When my mother was in the hospital, the docs and their entourage would breeze in to see her like gods descending from the medical Olympus. If I dared question them, she became upset with me for challenging the great white fathers.

I sat in her hospital room for days, feeling guilty for all the past attention she had focused on me because of the HIV racing through my bloodstream. On those Sunday nights, she'd tell me of the latest treatments that filtered to her local news and provide hope that something would restore my health. I never imagined that a virulent agent could be spreading through her uterus and abdomen. I wished I could go back and urge her to get checked more frequently when intervention was possible. Why didn't I learn as much about her health issues as she learned about mine? Me, always the son, craving care and attention; she, always the mother, listening and giving.

Recently, I asked her permission to call her doctor. I did not actually reach him but his young associate. In cases like this, he said, they don't restart chemo until the symptoms show tumor

growth. “Your mother has a good quality of life now,” the doctor noted matter-of-factly. “We don’t want to bring her back to debilitating treatment.”

After I hung up, I realized that I hadn’t pushed the way I would have if it had been about AIDS. I said nothing about new treatments. I didn’t ask what the blood test meant for her chances of survival. I heard the doctor saying I would lose my mother and please just let her good days go on as long as possible. I chickened out.

But after processing all of that, I remembered who my mother is. She taught me to always look for the hopeful path. That may sound hokey but none of you know Mrs. Josephina Muñoz Batista deLeon. She has never been the Latina housewife stereotype—wearing a perpetual apron and toasting tortillas. When I was growing up, she went to school at night to complete her BA and earned two master’s degrees in education. She taught thousands of elementary-school children in whichever language worked for them. At the age of 72, she is the president of her local teachers’ union and a true fighter for her members.

And because my tenacity in fighting HIV is learned from her, I want to help her to see the hope that comes from speaking your mind, challenging medical authorities and knowing that your life should not be tossed aside just because researchers have not made ovarian cancer a priority. I want to remind her how to kick ass. Maybe the odds are slim with ovarian cancer. But together we can make sure that we are pushing every medical and organizational sacred cow to do more than their best. We deserve nothing less.

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