Let’s Kick Some Viral Ass! [VIDEO]

July 18, 2012 By Regan Hofmann

I remember almost everything about the day I saw my only sister for the first time after I was diagnosed with HIV.

It was sixteen years ago in a train station in New Jersey. She’d come home from DC for the weekend. Tracy is two and a half years younger but most people who meet us assume she’s older. Not, as you will see below, because she looks it but rather because her comportment is stately, her thoughts and the expression of them, focused and measured. She always shows grace under pressure and, since the days of our youth when I tried to beat up some little boy in our neighborhood who had a fascination for ripping the shells off snails, has always intervened diplomatically when my Irish blood surged in the face of some injustice I felt needed righting with passionate response.

That day at the station was no exception. I’d already broken the news to my mother. I planned to tell my sister face-to-face. It’s just what you do when you need to let your best friend know that something terrible has happened.

But from the minute she stepped off the train and strode stoically down the long platform, I could tell she already knew. My mother had told her. I pretended to myself I was upset but I was relieved. Sitting beside my mother and watching her absorb the news I have HIV felt like being there when she discovered my dead body. It was like that, in a way. Because then, in 1996, no one was sure you could survive the virus. The shock and awe that moves through people who hear you have HIV for the first time is never fun to watch. But today, thanks to scientific advances and my own journey towards peace and comfort with the news, I can quickly reassure those who I tell that I’m going to be okay, that they’re not going to get it, and that the fundamentals of my life aren’t altered simply because I have to take daily treatment to keep a retrovirus at bay.

If Tracy was (or is) upset that I have HIV, she has never shown me. And the fact that she treats me exactly as she did before I had HIV has helped me enormously. It says, without her verbalizing it, that having HIV does not change who I am, who I am to her or who I am in the world. That is a powerful sentiment when much of society would like you to believe you are other, different, dirty, derelict, a deviant not deserving the support and compassion we offer people with every other type of disease (with maybe the exception of other sexually transmitted infections, addiction and mental health issues).

When we were close enough in the train station to speak, I opened my mouth, but no words emerged. I was like a fish, too near the surface of the water, my mouth gaping open and closed. She rescued me by saying, simply, “We’re going to kick this thing’s ass.”

And that was that. She asked if I was hungry and without waiting for me to answer headed for Burger King.

Since we were little girls, we always shared our ketchup. We’d remove a wrapper from a burger and empty 10 or so of those mini packets on the paper to make a small condiment lake. And we double-dipped our fries. That’s just what you do with someone who’s your best friend.

I had spent countless, sleepless nights imagining the wide swath of her potential responses and my counter responses. But no iteration came close to the idea she’d acknowledge the fact that I have HIV, and act totally normal. Let alone eat out of the same pool of tomato paste.

She was sympathetic and wanted to understand what having this virus in my body meant for my health and my future. But, a lawyer, she had already researched the subject and the few questions she posed were ones to which she already knew the answers. She asked them, I suspect, more to show me that she cared, she understood and to indicate that she was willing to be an active partner in my health and longevity.

In the 16 years I have lived in spite of HIV, she has never changed her tune. She doesn’t avoid the subject; she asks regularly how I feel, if I’m adherent, how my personal life is unfolding in the face of the complexity of being openly HIV-positive--and she jokes about the virus. Our code name for it is “high-five.” (Get it? “Hi” and “V” - the Roman numeral for “five.”)

But it’s a small part of our daily conversations. A normal part. Not a hidden bogeyman, not a pink elephant, not a dark secret, not a topic that makes us squirm.

We went to the Vagina Monologues when we were both in our twenties. Until that night, neither of us had said the word “vagina” out loud, let alone to each other. Despite the fact that the vagina is a central part of womanhood, its existence had not been acknowledged until we sat side by side in a dark Off-Broadway theater screaming in unison with the audience, “vagina, vagina, VAGINA!” at the top of our lungs. And just like that, it became just a word, just a body part, just a normal part of a normal life.

It is the things we don’t discuss, the things we hide, lie about, deny and wrap in silence and shame that have the power to hurt us. When we find the courage to address whatever it is life throws our way, whether it be that we have contracted a sexually-transmitted disease, or any of the other things that happen, we can come to terms with, embrace and overcome things that if left hidden, suppressed or ignored, will eventually hurt us.

Saying a word that conjures something taboo over and over and over again renders the word, and the thing, just a word, and a thing.

I’ve said HIV and AIDS so many times now, I say them with the same inflection I say “butterfly” or “seesaw.” While obviously recognizing the dire pandemic they reference, I think the key to ending AIDS lies in being able to discuss it--calmly, openly, even-handedly, without hysteria or prejudice. If more people had talked calmly, openly, even-handedly, without hysteria and prejudice about vaginas when I was younger, I doubt I’d be living with HIV. Again, it is when we don’t discuss things that we pave the way for them to hurt us.

The normalcy with with my sister treats the news I have HIV takes all the bluster out of the stigma surrounding the disease. On her watch, a mere retrovirus will not be allowed disproportionate power to screw up my mental and physical health. We are, simply, going to kick its ass. No hang-wringing. No squeamishness. No fear. No question.

Her attitude about the virus allowed me to study it with an intellectual curiosity. And to accept and, as weird as this may sound, appreciate it. I respect all nature. HIV is an incredible natural creation. Some people have speculated whether HIV was invented in biological warfare labs. But I doubt humans could create something this beautifully resilient. It is almost a perfect virus. Capable of tricking some of the smartest cells in the body to believe erroneously that it isn’t there. Capable of lying in latency in reservoirs, waiting until it’s safe to re-emerge. A virus that causes illness and fatality, but not until years after initial infection which means the host has ample chance to inadvertently spread it to other hosts. It is a virus capable of creating a global pandemic that currently comprises 34 million people, including 1.2 million Americans. It is a virus that can enter the body of every type of person on any continent. The virus has no natural path for die off. The rate at which it kills is slower than the rate at which it spreads so its presence is assured, unless all who know they are living with it discover that fact and can access life-sustaining treatment.

And therein lies the reason Tracy and I decided to appear in the CDC's new "Let's Stop HIV Together" campaign. Humans may not have been clever enough to create HIV but we have been clever enough to understand how to control and prevent it. There are now 30 medications that not only sustain the health of people with HIV but also simultaneously prevent viral spread as the risk of transmission can be lowered by 96% in all who access treatment and take the medication as prescribed. Treatment doubles as prevention. We have also made great leaps forward in understanding how we may one day soon develop a functional or sterilizing cure and headway is being made on vaccines and other biomedical tools of prevention.

We can now end AIDS--science has proved it's possible. To do it, we need to assure all people that knowing your HIV status is key, we need to make it safe for people to come forward to get tested and linked to care (as no one is going to do either if we criminalize those living with the virus), we need to find innovative solutions to pay for access to treatment so that those who are living with HIV can get the treatment that slows viral spread. And, we need to cure HIV because the world can't pay for a lifetime of pills for tens of millions of people and because no one should have to spend their life taking pills if another solution is available.

Fast-tracking cure research is integral to dissolving HIV-related stigma and for inspiring people to come forward for testing, treatment and hopefully, one day the cure itself. I am much more committed to taking better care of myself if there's a good shot I can live to see the cure.

I never thought I'd survive long after my diagnosis. As I drive down to DC for the XIX International AIDS Conference later this week (AIDS2012.org; it runs July 22-27 but I'm going early to cover pre-conference stuff and the Quilt, more on that soon--for a preview, Quilt2012.org) I will be thinking about that day so many years ago when my sister's concerned, empathetic but ultimately matter-of-fact response set the tone for how I would live in the face of HIV.

Her compassion, acceptance of the facts, courage, lack of judgement and support have been as effective medicine as the countless antiretrovirals I have taken. As we head into the conference and hopefully a new phase of HIV awareness and advocacy around the world, I ask all parents and friends, co-workers and lovers and acquaintances of people with HIV to do a simple, but profoundly helpful, thing: see those of us living with the virus exactly as we were before the virus entered our bodies and our lives.

I am the same woman I was before HIV set up shop in my immune system. Well, that's not entirely true. I am more evolved for having to face the unwanted guest. A life with HIV has taught me greater tolerance, patience, determination and courage. It has reset the bar of my pain threshold and rejiggered my priorities. A life lived with acute awareness of its impermanence is a rich life indeed.

I offer my most profound thanks to my sister Tracy, the woman standing beside me in this campaign; a woman who has stood firmly beside me from day one. I send my love and gratitude to all the other friends and family members, lovers, partners, spouses, co-workers, etc. who also appear in this campaign beside the people living with HIV they love and support. I applaud all who

come forward and plaster their face and story in the public eye in the name of ending AIDS. It isn't always easy I know.

And, finally, I give enormous kudos to the CDC for evolving from stick-figure depictions of people living with HIV to this warm, real, human campaign that shows that HIV can and does happen to every type of person. And that those people are good, normal people who are not different than the rest of society--or from who they were before the virus entered their bodies and lives.

Please share this campaign with your friends and family. Get tested yourself and ask your children and friends and parents and neighbors and grandparents and others to get tested. It's free, it's safe and you can get a result quickly. And if you need help and treatment, it is available. And visit the campaign website and tell the CDC what you think. It's actagainstAIDS.org.

Here's the PSA:

Sixteen years after I met my sister on a train platform I will see her on another train platform--the one in Union Station in Washington, DC. (They have put up a billboard of us there.) I know it will move me to tears to look up and see her beautiful, unflinchingly strong self up there beside me because it was her decision to stand by me in the face of HIV that has enabled my survival. She is a huge part of how I got from terror on one train platform, to triumph over HIV on another a decade and a half later.

She may not realize it this but that day when Tracy vowed to do away with HIV, so did I. And I will die trying. We are so much closer to kicking this thing’s ass than we have ever been. We end AIDS in three necessary steps. Get everyone tested. Get everyone who needs it access to treatment. And cure it as fast as humanly possible.

Please stand with us. When those of us who have the virus are supported by those of you who don’t, our collective power is enough to stop the pandemic. Together, we end AIDS.

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