RIDING (HIGH) ON THE CITY OF NEW ORLEANS (PART I)

December 18, 2006 By Regan Hofmann

I woke up a week ago Sunday in my hotel room in New Orleans to the sound of Jack La Lanne?s voice. The image of the ?70s fitness king bare-chested?and surprisingly well muscled?filled the TV screen. He was standing waist deep in a swimming pool, still pumping iron at the age of 92.

?To die?? he said in between grunts, ?That?s simple. To live?that?s the hard thing.?

As I struggled to raise my head from the pillow (I?d had one Hurricane too many) I agreed entirely with old Jack.

I?d gone to NOLA for NAPWA?s ?Staying Alive? conference. This was my first ?Staying Alive? and I was really excited at the idea of seeing so many powerful AIDS leaders, advocates, activists and people living with HIV assembled in one place. I also had a fair amount of trepidation at the thought of seeing the aftermath of Katrina first hand. I arrived in New Orleans on Wednesday afternoon and the cab took me downtown. The part of New Orleans that is its financial lifeblood?the French Quarter/Bourbon Street area?seemed untouched by the deluge (most of it was spared by the flood waters). The streets were lined with massive palm trees dressed in white lights for the holiday season. Zydeco music blaring from open storefronts competed with jazz, blues and rock blasting from clubs with their windows flung wide despite unseasonably cool weather. Stores hawked beads (for those of us too shy to show some skin), hot sauce and feather boas (I had to have a blue one). A sense of cheerful resilience permeated the city better known for its disproportionately high murder rate than for its ability to breed survivors. While it would be unfair, and maybe inappropriate, to compare the spirit of New Orleans in the aftermath of natural disaster to the spirit of New York after terrorist attack, I couldn?t help but feel that there was similarity in the upbeat defiance of those who had stayed?and those who had returned to the city?after the tragedy. (More to come on our special tour of the 9th Ward, including pictures, in part II of this Blog?)

Everyone made a point of saying ?Welcome to New Orleans? with a tone so emphatic that I believed that it was more than a pat response to unloading yet another sucker from a cab?a falsely friendly greeting given to those come to drink in the debauchery of the town. It seemed the perfect place to assemble nearly 400+ people most of whom had survived bouts with HIV/AIDS.

We kicked off the first day with a plenary session led by NAPWA?s executive director Frank Oldham. Though I am usually nervous before public speaking, I found myself strangely calm as I walked to the podium to address my fellow PLWAs and conference attendees. I told the story of how, as my plane descended to New Orleans, the guy seated next to me asked why I was going to the city. ?I?m the editor of a magazine for people living with HIV/AIDS,? I?d said without pause. ?I?ve lived with the virus for 10 years and we?re having a conference, sponsored by the National Association of People Living with AIDS,

to address how we can improve access to care and treatment for those of us with HIV.? He didn?t even blink. He said he was in sports marketing. It seemed my matter-of-fact disclosure had engendered in him a similar matter-of-fact response. He asked me lots of good questions about the disease and said he?d go get tested. He passed me in the baggage area, waved congenially and offered me good luck. I relayed to the audience at the conference that a LOT had gone into being that blasé about disclosing.

After 10 years of struggling with stigma and shame; ten years of remaining silent, forgoing emotional support, care and compassion because I was afraid of what would happen if I told people I had HIV, I have found that you can divulge your truth and receive understanding and support?even from perfect strangers on planes. I?ve gone through much to make it possible to just spit out my truth without hesitation or fear of repercussions. With full respect for peoples? right not to disclose, I said that I have seen the power we as people living with HIV/AIDS have to change the way the world sees AIDS by showing our faces and telling our stories. I have learned that when I present the fact that I?m HIV positive in a straightforward, unapologetic, unashamed manner, people usually respond in kind. Usually.

I don?t think people with HIV/AIDS should forever have to run around revealing their HIV status or details of their personal health (anymore than anyone with any other medical condition might feel compelled to). If I?ve learned anything in this past year of disclosure, it?s that nearly everyone is concealing something, and many people are struggling with health conditions we don?t know about. BUT there is a difference between exercising your right to privacy regarding a medical condition and needing and wanting to divulge that condition but feeling unable to do so because of fear of being stigmatized, discriminated against, criminalized or rejected. By sharing our stories now, I think we can alter how people see HIV/AIDS and get us more quickly to a day when people living with the virus can keep their status confidential because they prefer to?not because they feel they have no other option. I also believe that living in shame is not good for your health. I know some people who choose not to disclose and it?s not shame keeping them quiet. But, more often than not, I hear of people not telling of their status out of fear and worry.

Too many people with HIV live in isolation and secrecy. We?re not helping ourselves, or others, by keeping mum. In fact, I believe we?re actually perpetrating the stigma by staying silent. I can say this because I did it for 10 years and I?m not proud that I accepted the mantle of shame that society was all too ready to drape over me though all I did was something every sexually active person I?ve ever met has done: have unprotected sex. It took me a decade to say to myself, ?Hey, wait a minute. Why am I suffering like this? Why should I be in this much pain over something that nearly everyone else on the planet does? Why should I be condemned when all I did was a natural act that resulted in the transmission of a retrovirus??

In my speech at the conference, I talked about breast cancer and how when Betty Ford first announced her diagnosis, the networks struggled with how to report her story as they weren?t allowed to say ?breast? nor ?cancer.? And while the diseases, the histories of how they?ve been portrayed in the media and people?s perceptions of them are different, there is a similarity between how we once saw breast cancer (and how many women with the disease once felt) and how we now see AIDS (and how many of those who have HIV/AIDS now feel). I told the audience that I covered a ?Survivors Ball? for breast cancer patients when writing for the last magazine I worked for and how I felt angry and jealous that those with breast cancer could openly congregate to support one another while nearly every week I get a letter, e-mail or phone call from someone who?s never told anyone their HIV status. I said I hoped that one day, we could successfully reposition the way the world sees AIDS, in much the same way that was done for breast cancer.

I told the audience that showing our faces with pride and dignity could help reduce stigma. HIV/AIDS has, for too long, been the monster under the bed feared by those who?ve never seen HIV/AIDS in someone they know (or someone who looks like someone they could know). I said it?s time to lift up the dust ruffle and make the world look that ?monster? in the face. It?s been my experience that you can fear, even hate, an invisible thing like a virus, but when that virus is connected to a friendly face on a real person, suddenly, it?s much harder to fear and hate the embodiment of the disease. Many people I?ve met over the last year who had never met anyone with HIV had a different opinion of the disease after knowing that they?d been living right beside someone with it for 10 years. Knowing someone with the disease helps people see HIV through a more humanitarian lens.

I said that what is missing from the many multi-million dollar campaigns we see all over TV or all over our cities in outdoor ad campaigns, is people living with HIV. All due respect and thanks to Eve, Christy Turlington, Blondie, Ludacris and other celebs, but they aren?t going to make those uninitiated in the ways of HIV/AIDS feel different, let alone comfortable, about HIV. Celebrity-based campaigns may be hugely effective at raising awareness and money, but they lack the one critical element that will ultimately work to change people?s perceptions (and correct their misperceptions) of those of us living with HIV/AIDS: personal accounts of how we are living with the virus. Having us show our faces and tell our stories will make people believe this can happen to them. Only when people believe HIV is a real and present danger do they think to change their behavior. The reason we?re still seeing 40,000 new infections annually of a disease that?s 100% preventable? It?s simple: too many people still think HIV can?t enter their world. They believe it when they see someone familiar to them tell the story of how they got HIV?and how they struggle to live with it. (This is one of the reason?s Marvelyn?s new ad campaign is so amazing. Watch for it, particularly on MTV and BET. It?s fantastic.)

I also said there is no one ?face of AIDS.? Marvelyn blogged about this also (if you haven?t read the Blogs she penned for BET and POZ for World AIDS Day week, please do.) I am so tired of the media, and even the AIDS world, jockeying to position AIDS as a gay disease, a straight disease, a black disease, a white disease, a man?s/woman?s/child?s/granny?s disease. It?s embarrassing that we?re still even using the phrase. Can you imagine saying ?the face of cancer,? ?the face of Alzheimer?s,? the ?face of MS?? The moniker of the ?face of AIDS? should neither be tossed around like a steaming hot potato, nor coveted to secure media coverage and funding. As we all know, the face of AIDS has always been diverse?and it?s only getting more so. The only reason people use the phrase is because, increasingly lately, AIDS has no face. Or, too few public ones.

POZ has limited pages in each issue?and there are only so many opportunities in the mainstream media?to get all the amazing people living with HIV into the spotlight. So, in conjunction with NAPWA, POZ is launching a movement called ?Our Dignity.? It will provide a platform (on the web and in communities around the U.S.) for people living with HIV to come forward, proudly and unapologetically, to share their story. Our hope is that by showing America, and the world, a critical mass of people living with the virus, we will change their opinions of what HIV is?and isn?t?and inform, empower and inspire them so that they change their behavior, stay safe and treat those infected with HIV with the dignity they deserve. To me, reducing stigma is about helping people to understand that HIV is a human rights issue, and that those living with the virus deserve at least the same deference that is afforded to those enduring any other illness. It?s just a retrovirus, nothing more, nothing less. (To emphasize this point, I often reminded people that I have a sexually TRANSMITTED disease, not a SEXUALLY transmitted disease. I point out that sex was just the portal through which the virus entered my body?and that if HIV were airborne and nasally transmitted, for example, there would be no stigma around it. There is nothing wrong with my sexual organs, I tell people. My bloodstream carries a potent virus that has the ability to

make my immune system malfunction. So, get all weirded out if you will at my sickly immune system, but, for the record, there?s nothing wrong with the parts of my body that I use during sex.)

Knowing I was preaching to the converted, I said if we can reduce stigma, people will be more inclined to get care and treatment, get tested and disclose?all of which will contribute to better access to care and can help minimize future infections (through helping people with HIV to have better compliance which can lead to lower viral loads and encourage safer sex and disclosure) and get those who need it into (and keep them in) care earlier thus prolonging the high cost of late stage disease care. Not to mention that those of us living with the disease will probably be healthier, given more compassion, support and care.

I ended my talk asking anyone who was ready to tell their story on videotape to sign up at the POZ/NAPWA booth. I seriously thought we might get 10 people. We were approached by more than 50. More than we could accommodate at the conference (we?re setting up more videotaping sessions to capture the stories we missed in New Orleans). It amazed me to see how many people were ready to come forward with their stories. And it seemed fitting, on that final day of the conference, which coincided with the anniversary of the day that Martin Luther King Jr. received the Nobel Peace Prize, that we would experience the critical mass of people living with HIV who were poised to take back that which society had taken from them, that which maybe they let go of themselves?their basic human dignity.

After I spoke, Bishop Joyce Turner-Keller, a formidable beauty from Baton Rouge took the podium. She brought the house down with her speech, and at the end, had the whole crowd chanting ?Our Dignity! Our Dignity! Our Dignity!? Talk about goose bumps.

There were more inspiring talks given by the likes of the remarkable Julie Davids (of CHAMP?stay tuned for New Orleans Blog part II in which I?ll recount my trip to the aquarium with Julie?), Carrie Broadus, Kevin Fenton, Robert Greenwald, Dr. Marjorie Hill (of GMHC) and many other incredible leaders. My only regret was that the conference wasn?t taped. (We?re going to look into the possibility of web casting ?Staying Alive 2007? so that those who don?t attend can still participate!)

After four days of listening to speakers and participating in breakout sessions, I felt, firsthand, the indefatigable will of all those living with HIV who had gathered to advocate for access to care. The spirit of the PLWAs gathered in New Orleans echoed the spirit of those who answered Martin Luther King?s call for civil rights, the spirit of those continuing to fight FEMA for funds and the right to rebuild their lives and homes in NOLA, the spirit of those who endured 9/11, and the spirit of tough individuals like Jack La Lanne, all of whom refuse to relinquish the fight.

Laissez les bon temps rouler.

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