Dare We Hope?

August 25, 2009 By Regan Hofmann

I just got back to New York from the Centers for Disease Control and Prevention’s annual National HIV Prevention conference in Atlanta. I spoke Sunday night at the opening session, with Craig Washington (of AID Atlanta), Cecilia Chung (of the San Francisco Human Rights Commission), David Munar (of AIDS Foundation of Chicago) and Del Rosa Harris (a SisterLove, Inc. honoree)--four amazing people living with HIV who gave incredible speeches and insights into life with the virus.

I never quite get over the flurry of butterflies that swirl in my stomach when mounting the stage to talk to thousands of people, but the crowd Sunday night was just incredible. I sensed so much support, excitement and determination in that room. What an amazing sensation to feel like you’re having an intimate conversation with a group of people big enough to fill a football field! I really want to thank all of you who gave me a standing ovation. I felt that we were standing in unity over the truths that we all know and live and fight for. It was also so meaningful to me that people came up to me afterwards and said they’d been working in the HIV community for years and were still moved. It gave me great hope that we can re-energize all our wonderful warriors even this far into our arduous battle against AIDS. And, for me personally, getting that kind of response is like getting thousands of B-12 shots all at once! (without the thousands of needle pricks...)

The distinct feeling of renewed commitment and fresh possibility in the air is the result of new leadership in The White House and at the CDC. I think it can be best summed up by something Marjorie Hill (the executive director of the Gay Men’s Health Crisis) said to me. After breakfast on Monday morning, as we sat together listening to Jeff Crowley (the director of the Office of National AIDS Policy at The White House) talk about President Obama’s commitment to developing and implementing a National AIDS Strategy and what Jeff and his team planned to do to solicit response from the community of people living with and affected by HIV (12 town hall meetings around America...the first one started in Atlanta 3 minutes ago - Oriol G of POZ is there, armed with his Flip!), Marjorie asked, “Dare we hope?” I so hope we can!

Magic Johnson also spoke (and was his usual gregarious self); Kevin Fenton (Director of the National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention at the CDC--a great man with one of the world’s longest titles!) and Jonathan Mermin (Director of the Division of HIV/AIDS Prevention at the National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention at the CDC--and equally great guy with an even longer title) gave wonderful talks and Atlanta Mayor Shirley Franklin and Dr. Tom Frieden (director of the CDC) weighed in via video ...read Oriol’s blog for more details and pics...it sums up the whole evening!

We’re all looking forward to hearing what happens at tonight’s town hall...

In the meantime, some of you have asked if I would post the speech I gave...so here it is!

"When I say I work for POZ--a magazine and website for people living with and affected by HIV--and that I do that because I'm a journalist living with the virus--people are stunned. Usually, I have to explain that it's P-O-Z not P-A-W-S, and that I write about AIDS--not kittens.

Twenty-eight years into the AIDS pandemic it shouldn't shock anyone that I have HIV. The fact that it does is why can't stop the spread of this disease. Too many people still think HIV is only a gay disease, or a black disease, or a disease of injection drug users, a disease of sex workers, or something that happens only to promiscuous people instead of seeing HIV as they should--as a disease. Period. When HIV is connected only to certain high-risk behaviors or segments of the population it sends the wrong message. It's true that HIV disproportionately affects certain communities and we must address that truth in our prevention work and focus on MSM, African Americans and Latino people. But the thinking that HIV has a limited sphere of influence is killing people. We must convince people that anyone having unprotected sex is at real risk for HIV and that everyone needs to have safer sex and know their HIV status. And to do these things we have to reduce HIV-related stigma.

People stigmatize those with HIV so that they don't have to believe it can really happen to them. By seeing people with HIV as "other" it excuses people from thinking they need to take precautions. If HIV only happens to gay or black or promiscuous people and you're not any of those things, then you don't have to worry about it, right? That's what I thought.

One of my best friends told me she had a new lover. I asked if she was using protection. She said no. "Didn't my story impact you?" I asked. She said, "Well, I think you must have done something unusual to get HIV." "Like what?" I said. "Like you are a prostitute," she said. "If I needed to sell my body to survive, I would have come to you," I told her. I asked her to think about whether she really thought I was a sex worker and if not, why she imagined that. She said, "If you are different than me, than I don't have to change my behavior."

Breast cancer provides proof that when you remove the stigma surrounding a disease you fight it better and more people survive. When Betty Ford first announced she had breast cancer, the networks had a quandary: they couldn't say "breast" and they couldn't say "cancer." Thirty-plus years later, straight men run through the streets in hot pink t-shirts to raise money for breast cancer. Entenmann's has breast cancer coffee cake. Tic Tacs and M&Ms turn pink and white and the airlines offer pink margaritas in October to raise awareness. When I bought my Ford Mustang, they asked if I wanted the special breast cancer model. I asked if they had one for AIDS and the salesman stared at his shoes. Fighting breast cancer is cool. We need to make fighting AIDS just as cool.

A seminal shift occurred in breast cancer when we convinced women it was okay to touch themselves, when we taught doctors and boyfriends, brothers and husbands to remind their women to perform self-exams and when we convinced women that as frightening as facing a lump could be "early detection equaled survival."

With respect to the Susan G. Komen Foundation and others, I'd like to borrow those notions for HIV and tell people that it's ok to get tested for HIV--it doesn't mean you did something wrong--and that by facing the fear of a potential positive result, you are empowering yourself and possibly saving your own life.

We must make it comfortable for people to get tested. We need to teach doctors to simply say "Yes, of course," when people ask for an HIV test and not pose embarrassing questions. When I ask my GP to test my cholesterol levels, he doesn't ask if I've been frequenting Dunkin Donuts--he just takes my blood.

Doctors shouldn’t ask about your sex life when you ask for an HIV test. I don’t want my doctor to ask me if I have anal sex anymore than he wants to hear my answer.

To fight stigma, we must stop criminalizing people with HIV (with the exception of the few homicidal maniacs who intend to harm). Why would anyone get tested for HIV if knowing your status means you could be sentenced to 25 years in jail for non-disclosure of HIV--even if you told the truth, had an undetectable viral load, used a condom and transmission didn’t occur?

America (and other countries) must get rid of the HIV travel ban and remove HIV from the list of communicable diseases that can prevent someone from visiting. Why would I want to be identified as HIV-positive if I can’t visit friends and family in other nations or if I can not leave the U.S. for fear of being banned re-entry? Few things deepen the stigma around HIV more than our nation telling the world that “those kind of people aren’t welcome here.” I think we’re close to opening our borders.

We must address the needs of the HIV community in healthcare reform and stop making it a requirement for people with HIV to be deathly ill before they are allowed access to care. Why would I want to know I have HIV if I can’t afford to do anything to save my life until it’s almost over?

Normalizing HIV is key to fighting stigma. We should teach everyone (including kids) that you brush your teeth, eat lots of fruits and vegetables, wear your seatbelt, and use a condom. That you should regularly check your blood pressure, get screened for breast and colon cancer, and get tested for HIV. Inclusion of HIV in everyday life--from coffee cakes to sports cars to doctors’ visits--fights stigma.

People living with HIV have to be part of the effort to unravel stigma by not self-stigmatizing--and by disclosing. I know it’s not easy. I spent 10 years in shameful silence, fear and isolation with HIV. It took me a decade to realize I hadn’t done anything wrong--or at least nothing that most people on the planet haven’t also done. I had unprotected sex. For this I should suffer and die, silent and alone? I made the same choice as others, HIV just happened to be present when I made it. The fact that I’m HIV-positive doesn’t make me a bad person, just an unlucky one. In all the times I’ve disclosed, 99 percent of people are really supportive and they often get tested or take their kids to get tested. When people see someone who looks like them living with HIV they believe the risk is real.

I know we can remove the stigma around HIV. We can teach the world that people with HIV deserve the same human rights, dignity and compassion we afford people with other diseases. Especially if the government, the media and political, financial, scientific, spiritual and cultural leaders tell the world that it’s acceptable to embrace people with HIV and show that HIV-positive people are no different than others by offering them the same legal rights and access to healthcare and treatment, health and life insurance, jobs, marriage, adoption and travel, as HIV-negative people.

Reducing stigma will happen when HIV-positive and HIV-negative people fight side-by-side, as we are doing here today. I have faith that President Obama, his AIDS-focused staff in the White House and those of you at the CDC have the brilliance, the desire and the courage to stop this pandemic from spreading--even if that means talking about science and sex and needles and condoms in evangelical churches and schools. Please stay committed to the development of a national AIDS strategy and engage us in a meaningful way in the discussion. The community of people living with HIV will help you teach our fellow Americans that HIV can happen to anyone, and that it should be avoided at all costs. HIV is called a manageable disease. The truth is, it feels like you’ve swallowed a hand grenade with the pin pulled out.

HIV-positive people are not scary things to be vilified, shunned, or locked up. We are part of the solution. Because no one is better positioned to explain to the general public why you should do everything you can to avoid HIV than those of us who battle against it every single day--for our lives."

http://beta.docker.poz.com/blog/dare-we-hope