Sisters Rise (and Shine)

April 7, 2007 By Regan Hofmann

Okay. It's been waaaaay too long since I've blogged. Not only is my blog embarassingly nearly at the end of the list (he or she who blogs most recently goes to the top) but my last blog referenced Christmas. Now, it is nearly Easter. Though it's hard to believe that because it's supposed to SNOW in New Jersey today. (I'm sitting here in my warm house worrying about all the bright white, just-born baby lambs on the farm down the street. What are they going to do when the snow starts falling? If I call her, my mom will say, "They're animals, they'll be ok." But there's a reason lambs are born in spring: It's supposed to be 60 degrees! I suppose it would be ironic to put tiny sweaters on the lambs...)

Anyway, I'm sorry I've been AWOL...but, I'm back.

They tell me I should write short blogs. Daily. Gonna give it a try...so please read often and comment back. I love hearing from you!

The occasion for this entry is a couple of things, most of them related to "us girls." I am so excited to tell you that POZ/AIDSmeds is launching a special new part of our website totally devoted to women. It's called "Women's Place" and it is an awesome way for women living with HIV, women who love and support women living with HIV and all women who'd like to know more about HIV to get great info (and inspiration) about how to face (or avoid) this virus. To go with "Women's Place" there is a new AIDSmeds Forum (click on "Forums" on the upper right hand page of POZ.com) dedicated JUST TO WOMEN (sorry, boys). It's moderated by Ann from the Isle of Mann, a POZ/AIDSmeds blogger who is such an awesome chick. If you haven't already, pop into the Forum and introduce yourself to Ann and others who are chatting.

I'm so thrilled about these additions to POZ because when I was diagnosed 10 years ago, there was almost nothing available for women (certainly no international website with a whole section dedicated to our concerns or a 24/7 online chat room for women to share trials and tribulations of living with AIDS - or other things ((I plan to go online later today and inquire whether any woman can help me understand how I managed to kill a lavender plant in less than 2 days - no green thumb here!))). Then, there was only a little (albeit lifesaving) newsletter, written and distributed by my friend Dawn Averitt Bridge and a group called W.I.S.E. - and the help and support of Mary Fisher, the daughter of an American senator and AIDS activist who spoke at the Republican National Convention in '96 about how she was living with AIDS. I called her out of the blue because she was the only woman I'd ever heard of who had HIV. Amazingly, she invited me to come visit her. Part of the reason I am an activist today is because of Mary. She made such an impression on me. She was struggling to deal with side effects of her meds, but it didn't stop her from going to speak at an AIDS fundraiser. She had asked me to come along, because I said I wanted to help, and, after bringing down the house with her amazing, inspiring tale, and shaking the hands of so many donors to the AIDS charity she was supporting that night, she faltered only slightly on her way to her car. It made a huge impression on me that someone who was struggling for her own life would physically stress herself out to help her fellow PLWHAs.

Today, no woman living with HIV should feel alone. No person, for that matter.

Yet, for all the resources out there, there are far too many people who don't know about them. Case in point - I spoke a couple of weeks ago to a gathering of several sororities at the University of Pennsylvania. (Funny, I didn't think I was aging until I saw the reflection of my face in the bathroom mirror alongside those of some of the youngest - and prettiest - coeds I've seen since I was eating cheesefries for breakfast at college myself. When did I get so OLD?) These young women asked some of the best questions I've ever fielded about the particulars of HIV transmission - and the larger issues surrounding things like international drug pricing and why we don't yet have microbicides, or a cure.

Amazingly, they knew a lot about AIDS in general. BUT they were still under the impression that it couldn't happen to them. Until I opened my mouth. And I think - though I look like them shot through a time machine that goes far into the future - they saw that HIV could happen to them too. Several of them were involved in AIDS work (one young woman worked at a perinatal AIDS clinic in Philly) but again, that was as close as they believed AIDS would come to their lives. Hopefully, they'll get tested and be careful and thus keep HIV at bay - forever. It's always so exciting for me to talk to a group when there's the chance of preventing HIV infection. I think HIV positive people are, in many ways, the very best prevention tool. Because until a person sees someone who could be them who has HIV, they have a hard time embracing the idea that the risk is real - and this is what's required for people to change their behavior.

Next stop on the speaking tour was Raleigh, North Carolina, where I spoke to a group of men and women at an HIV Forum hosted by Duke University. There, the message was different (most of us were already HIV positive - so I laid off the prevention talk) and the audience was largely from rural parts of the state with little access to care and services. Many people had traveled hours to attend the forum; some had walked miles to get on a bus that brought them to Raleigh. I'm always worried that a woman's story won't translate to a man's needs, but I have found that many of the issues that affect women living with HIV affect men too - issues of finding care and support, bolstering self-esteem, combatting depression, striving to overcome stigma and trying to regain our dignity. Several people came up after the talk - each one of them had an astounding story of survival and though they came to thank me for coming down and sharing my story, I wanted to tell them how much it had helped me to be welcomed by them and to be able to commiserate with others living with the disease - face-to-face. It's one thing to write about HIV from an office on Fifth Avenue in NYC. It's another to have one of POZ's HIV positive readers give me a big hug. And to be able to give one back.

It was really satisfying to let them know that the sharing didn't have to stop there and that they could become part of an online support community even when we couldn't continue to talk in person. I always worry that people don't have access to computers, but am surprised and heartened by how many do - many people access the Internet at their local libraries and ASOs. For those who haven't explored these options, especially those who live in more remote areas with few openly positive people, explore the options for computer access in your area; online forums can be a great support system.

Finally, (I said I'd make this blog short!) I spoke at the New Jersey Women and AIDS Network, a group based in Newark that's been supporting women with HIV in NJ for 13 years. If only I'd known about them when I'd been diagnosed! They are a fabulous group and I love the name of one of their programs so much (Sister Rise) that I borrowed it for the name of this blog. The room was filled with so much love and determination and energy and resolve. I really feel that there’s little that such a group of dynamic, empowered women can’t do. (I bet if I told them about the lambs, they’d be down here in a flash, knitting little sweaters for them.) Standing at the podium in front of nearly a hundred really impressive women, it occured to me that a little sisterly love goes a long way towards making life for those living with HIV a lot better.

My own sister was here visiting me last week with her 2-year-old son. Watching her watch over him was so incredible. For years, she took care of me and my HIV. Because I had her support (along with that of other loved ones and friends), I’ve stayed well enough, for now, to try to help others.

I think the formula for helping women rise above HIV is simple. We can borrow from the old Breck shampoo commerical from the ’70s (the young women at UPenn will have no idea what I’m talking about). It goes like this: A woman with luxuriously shiny hair (she just washed it with Breck) flips her cascading mane around while claiming that she “told two friends, who told two friends, who told two friends and so on and so on” until the whole world of women with access to a grocery store knew about the wonderous nature of Breck shampoo.

I say let’s use the model for HIV. Take some good news (in this case, info about how to thrive inspite of HIV, or how to prevent it - send them to the “Women’s Place” or the all women’s Forum on POZ.com) and tell two friends. Ask them to tell two friends. And so on and so on. Eventually the word will get around. And we can all meet up online. And trade secrets about life with HIV. Or lavender. Or lambs. Or luxurious hair. Together, we sisters can rise - and shine.