The Hills Are Alive

July 21, 2007 By Regan Hofmann



Okay...time to finish up chronicling the Taipei trip. After visiting the Garden of Mercy and Harmony House on Saturday morning, we headed to the Lung YingTai Cultural Foundation for the Taipei Salon hosted by Dr. Lung Ying Tai.

Dr. Lung hosts the Taipei Salon to discuss issues of cultural import. Also speaking with me on the panel was Nicole Yang, of Harmony House. Though I received much press in Taipei, it is people like Nicole, who stays up seven nights a week with the AIDS orphans and people living with HIV, and Hank, who is one of the first HIV positive people to come forward in Taiwan, whose stories must be told. I am grateful to Dr. Lung for providing a platform for all of our tales.

The subject of the Salon was “Global Issues and Me: Getting Involved in Taiwan” and Nick Papp from AIT gave a presentation about how fighting HIV/AIDS was one of the ways people in Taiwan could become better global citizens. Then, he showed a really tough-to-watch film about people around the world - in Uganda, Russia and Thailand - living with and some dying from HIV/AIDS. It’s always so hard to watch films like these because I feel so sad for others who don’t have access to medication or the support of their family. I feel guilt too, and fear, as there but for the grace of God go I. Still, it’s important to show the reality of what it’s like to live with HIV around the world. It seems so strange to me that when we have the treatment that people are still dying of AIDS in 2007. By the millions.

People in Taiwan and Vietnam found it really hard to believe that people are dying of HIV in America. They were shocked to hear that not all Americans have health insurance and that many can not, or struggle hard to, afford to pay for their AIDS meds. In Taiwan and Vietnam, healthcare and medicines are 100% covered by the government. I tried to explain that you can get covered if you are disabled, but they could not understand a system that only helps you when you are direly ill - so sick you can’t work. I said we had Ryan White and ADAP to help cover some of what private insurance, Medicaid and Medicare did not cover; still, they were amazed that one of the richest countries in the world would let its citizens die of AIDS when treatment was readily available.

I explained that our federal government has been incredibly generous in their pledge of PEPFAR dollars internationally. Still, they could not imagine how America would help the world and not help its own citizens. Many of the questions were hard to answer; I want to be a good ambassador of sorts for the U.S. but I also need to tell the truth. I was asked repeatedly about the pricing of AIDS meds globally. I struggled to explain how if the drug companies reduce prices around the world they will not have the money to continue to search for new and improved treatment, but my response was met by quizzical looks and the comment: but we have what we need to save lives now.

It?s nearly as hard not to have the answers to questions like these as it is to watch the effect of lack of access to treatment and information around the world. And it?s especially hard to watch these stories right before you have to go speak. Somehow, I managed to pull myself together and wipe the tears from my eyes (and reposition my smudged eyeliner) before they turned the lights up and I had to go on stage. After all, I was the light relief. The symbol of hope. I had to smile and tell them it was going to be okay.

This is one of the hardest parts of speaking in such an upbeat manner about HIV. I do believe that we can have normal long lives and experience the acceptance of our friends, families, societies and governments. But I also know that so many people struggle to overcome fear to access medical care and ask for the support of people around them. I don?t want people to think it?s easy ? I?ve been nearly broke struggling to pay for health insurance and meds and if it weren?t for my family I may very well have had to live in a place like Harmony Home myself. And, it took me ten years to come forward. That?s a decade of deliberating. And still, there are times when I?m afraid. But, there is such strength to be garnered from facing that fear and finding others living with HIV and having us band together and tell each other that we will find a way to survive and to help each

other do so. After my talk, a young man and his female friend ? a doe-eyed, fawn-like creature who exuded the strength of a mother lion ? came forward. He told me he?d been an IV-drug user and that he had HIV. He was scared to go on treatment but from what he told me of his health and labs, it sounded like it might be time for him to consider it. He said it helped him to see me so healthy after 10 years and to hear that the side effects off the drugs could be tolerated. He said he would visit his doctor and asked if he could meet other HIV positive people his age in America. I told him about Mentors and the forums on POZ.com and AIDSmeds.com ? and I shared with him OurDignity.com so he could eventually see lots of people living with HIV. Many more people than I imagined speak English and have access to the web in Asia ? particularly the young people. We gave each other a hug and he said he?d let me know what his doctor said. When I struggle emotionally with this work, I think that even if one person like this young man feels or gets better because of this program, it is worth it all. The next time I feel wobbly before I speak, I will remember him - and I'll get up no matter what I feel like, and fight to change people's perceptions and misinformation - powered by the thought of people like him who need the world to change its collective mind. Each new person I meet reinforces my arsenal; each time it gets easier to get up there and talk.

After the salon, and a brief interview with the evening news (I have the clip and will post it soon), we walked out into the heat that hits you like a brick wall in the face. I exhaled deeply for what seemed like the first time in a week and Sean and I decided to spend the next day catching our breath before getting on the plane to Vietnam.

Sunday morning, we went to the National Palace Museum and saw some extraordinary pieces of Chinese art?then headed up a Mullholland-esque road in the mountains to an Alpine-like meadow in a park in the foothills outside of Taipei. All we needed was a little edelweiss to believe we were in Austria, on the set of ?The Sound of Music.? However, the only music to be heard was the high-pitched whine of the cicadas as they puffed up their bellies and blew the air out of some part of their body (note to self: research how the cicada sings) and our own huffing and puffing (mine, more than Sean?s) as we walked up and down zillions of stone stairs en route to a waterfall.

The wind picked up and a stinging, prickly rain fell, masking the sweat that covers your body the minute you step outside in summer in Asia. I have felt so many deep emotions on this trip and often cannot let them out in the moment. I wanted to cry when holding the AIDS orphans, who are so hungry for love; when hearing Hank?s tale of how he has forsaken physical pleasure, getting his release from meditation instead; and hearing how fearful people are of taking medicine that can save their live because they have heard how it burns the stomach and they don?t have enough food to buffer their insides. But at those times, I must smile and tell people it?s going to get better ? saying we?re going to fight discrimination and stigma so that HIV positive babies can find love and new homes, that people living with HIV can have rewarding sex lives and that we?ll find a way to get medicines and food to all who need it ? someday.

Instead, I let my tears fall in the mountains, mixing with the rain and sweat sliding down my face, masked by the song of the cicadas and the water falling off the lip of the ridge. Up in the hills, only Sean and nature heard my cry.

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