

World AIDS Week 2009: World AIDS Day Eve

December 9, 2009 By [Shawn Decker](#)



Monday November 30: World AIDS Day Eve in Jacksonville, FL

Despite the lack of sleep, I woke up feeling alright, though I warned Gwenn that she may have to carry me for the day's work, which is the best thing about being a tandem. If one of us is off, the other steps up... kind of like an in-love Penn & Teller with AIDS.

The alarm went off, and I winced, but was eager to start the day off with a phone interview with a writer from CNN.com who'd contacted us on ShawnandGwenn.com a few days earlier. Surprise media requests are always welcomed, because it's a quick way to raise awareness and humanize HIV. After the interview, the day got better and better when I met one of my favorite positoid cyberpals, Dab Garner.



Through his [Dab the AIDS Bear Project](#), Dab works hard to raise money and awareness for HIV/AIDS while staying on top of the politics of AIDS as well. He lives in Jacksonville, but jet sets around quite often; he'd just gotten back into Jacksonville. I was happy to meet Dab in person, it was low-key and gave me a boost of positive energy going into the talk. Once I met everyone else involved with the event, a luncheon Awards ceremony honoring those who go out of their way to support the HIV/AIDS efforts in the community, immediately set me at ease. In fact, I almost forgot I was sick.

The day was going to be a breeze, I thought. Inside the room there were a lot of friendly faces, as well as an ice sculpture of a ribbon... but the red light was so faint that it appeared to be pink. You know, like the breast cancer awareness ribbon.



By the end of our talk, my spirits were high but my light, too, was a bit faint. After a round of hugs, Gwenn and I were off to the airport. The flight to San Diego for a talk the following day at California State University- San Marcos connected in Charlotte, and we were flying out quite quickly to avoid having to fly cross country twice the next day, including a post-talk red-eye flight. Since World AIDS Week is, by nature, hectic, we try to book our travel in the least exhausting way possible.

Plus, getting in the day before allowed for lots of time to rest, which I desperately needed.

Once we got to the Charlotte airport, we checked into Starbucks. There was enough time for a Decker's Daily fuel-up, but before I could take the first sip I felt a tickle in my nose; I immediately knew it was a nose bleed. I rushed to the bathroom, cleared out my nostril and got out my Stimate. After a nasal blast, the nose kept drizzling... and drizzling... and drizzling... I texted Gwenn with the bad news, and I won't go into detail about how awful it is to be in an airport stall for a half an hour with a symphony of rotating, nervous traveler's and their stomach issues on both side of ya.

I called my buddy, Mark, at American Homecare Federation, in a desperate attempt to get a blood-clotting hook-up in Charlotte, but Gwenn and I discussed our strategy at that point, and it was obvious what we needed to do because, even if I got a blood-product treatment, I'd be on the other side of the country if it didn't work out. That's a long way from my blood docs at home, and if something more serious was happening I wanted to be close to my medical team... World AIDS Week is the busiest time of the year for me as an educator. But first and foremost I am someone who is living with a variety of health issues, and it seemed like every one of them were knocking on airport bathroom stall door.

We called our contact, Cathy, who'd booked our event last February, and gave her the bad news... she was bummed, but was so understanding and graceful about our predicament. After a long phone call with our airline, we rebooked our itinerary for the week, with the hope that 24 hours at home and a blood product treatment would be enough to get me through the rest of the week...

As we drove home from the airport, Gwenn called our friend, Christina, who is a piercer in town who knows her way around needles. (She also helps a family member with their injectable treatments.) Now, I addressed this in My Pet Virus, but I'll give the Cliff Notes version here. I've never self-infused because at age 10, as a mild hemophiliac, I had an experimental surgery on my nose that made bleeds there less common. The next year, I was diagnosed with HIV and, without common bleeding episodes and a limited life expectancy, teaching me how to self-infuse didn't seem like an important project for my family or doctor. I hate explaining that, but feel I must. Lots of people with severe hemophilia can't understand and think I'm a wuss; don't hate the player, hate the game.

Plus, I've always figured I could hit a vein if push comes to shove. With HIV lab tests and all the times I've been stuck in my life, I kind of know the routine. The problem is that lugging around needles and factor isn't part of my routine, because usually, for me, Stimate does the trick.

As Christina infused me her main man, Micah, looked on. Just a few weeks ago, I saw Micah bleeding when he fought in a cage... yes, like one of those UFC cages. Micah was engaged in a Thai boxing match against a giant of a man... it was awesome, especially when he won. But I have to admit, watching someone I care about dodging punches and kicks that would kill me was nerve-racking. So when he looked all worried that I was sick, it was just payback for the emotional rollercoaster he put me on. Always a joker, Micah couldn't help but ask: "What would happen if I

got jacked up on factor before my next fight?”

It was a good question. (Here’s [a Rocky-esque video](#) I made of Micah kicking butt in 2005.)

The nose bleed stopped, and I went to bed, hoping that the next day I wouldn’t have anymore bleeding issues, and we could continue the rest of our educational journeys, four days which would include a flight to Newark, then down to Orlando, then back to Roanoke, Virginia for a talk at Virginia Tech... I wasn’t thinking about any of that when my head hit the pillow, I was just happy to be home in my own bed beside Gwenn.

I slept for eleven hours.



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