LEARNING FROM LIVING WITH HIV

June 19, 2008 By Regan Hofmann

Good morning (and I mean morning...the sun is just coming up). This will be a brief blog as I am in the hospital with a nasty (is there any other kind?) staph infection in my knee. I've been here since monday, being poked and prodded and given a whammy of an antibiotic via IV...struggling to choke down the food (how can anyone make bad raspberry ice?) and trying to not let my brain rot by watching the travesty that is American TV...(I am totally hooked on "She's Got the Look" - the 35+ version of "America's Next Top Model" - speaking of which, read this week's interview with AIDS activist and ANTM contestant Nnenna on poz.com).

Ending up flat on your back like this without warning, wondering whether you really can recover certainly makes you reflective. My first morning, a volunteer came into my room and asked whether I wanted the services of a chaplain. I looked at the nurse and said, : "I AM going to make it out of here, right?" And she nodded emphatically. The volunteer explained it was standard operating procedure. I explained that I was leaning about Buddism at the time, though I was raised Catholic. At that, she brightened considerably and asked whether I wouldn't like a rosary. "Pink or black?" she inquired. "Oh pink, please," I said thinking, if nothing else...it could double as prayer beads. They were already blessed, she reassured me.

Regardless of any spiritual leaning, it is certainly times like these that make you seek wisdom from beyond yourself. Which reminded me of an amazing speech given by Dennis deLeon, head of the Latino Commission on AIDS at their annual Cielo Latino benefit in May that I wanted to share with you. Dennis' life's work has been lauded over and over, and I have seen him accept awards before. But this particular speech struck me because it is so indicative of his desire to give back - always - even when it is his turn to receive.

I found his "list" of his life's lessons so helpful. I hope you will too. And thanks to you Dennis, for providing unwaivering inspiration to all of us fighting AIDS - both in the world at large, and inside our own bodies.

When I emerge from the hospital ward, I promise to post the pictures of the UN...as well as a video of President Clinton from UNGASS.

Wish me a quick escape from hospital hell!

Dennis' speech:

ELEVEN THINGS I HAVE LEARNED FROM LIVING WITH HIV FOR OVER 20 YEARS

by Dennis deLeon

1. BE THE BEST INFORMED PERSON YOU KNOW ABOUT MEDICAL TREATMENTS. EVERY YEAR, DOUBLE YOUR KNOWLEDGE ABOUT THE DISEASE, HOW IT GROWS AND HOW IT CAN BE DEFEATED.

2. BE AGGRESSIVELY INVOLVED WITH CLINICAL TRIALS BECAUSE THEY OFFER THE REGULAR HEALTH MONITORING AND ACCESS TO NEW MEDICATIONS. DEVELOP THE ABILITY TO TELL WHEN YOU ARE GETTING A PLACEBO AND, IF YOU WANT, OPT OUT OF THE TRIAL.

3. LIVE LIKE YOU ARE GOING TO DIE TOMORROW. TRY THINGS YOU NEVER DREAMED OF AND STOP ?RESUME BUILDING.? DO THINGS YOU ENJOY AND THAT PAY YOU SOMETHING FOR DOING IT. SO IF YOU DIE YOU WERE AT LEAST DOING WHAT YOUR WANTED.

4. SEE THE BEAUTY OF THINGS AND PEOPLE AROUND YOU AND IF THEY DO NOT APPEAR BEAUTIFUL, WORK HARDER TO SEE THE BEAUTY IN THEM. WHY? BECAUSE BEAUTY CAN SUSTAIN YOU.

5. NEVER BECOME A ?VICTIM? OR THE DESIGNATED PERSON WITH AIDS IN THE ROOM. YOU ARE MORE THAN THAT AND SHOULD NOT BE DEFINED BY A DISEASE. YOU ARE NOT A VIRUS SO DON?T ACT LIKE ONE.

6. MAKE YOUR FAMILY PROUD. MY WAY WAS TO GIVE THEM NEWS OF THINGS I ACCOMPLISHED, NEWS WITH MY NAME IN IT SO THEY CAN CIRCULATE THE WORD TO ALL THE EXTENDED FAMILY AND FRIENDS. GOD KNOWS I HAVE PUT THEM THROUGH GRIEF SO MUCH GROWING UP. THEY DESERVE AT LEAST A FEW BRAGGING POINTS. ALL THEY REALLY CARE ABOUT IS THAT YOU WERE VALUABLE AND VISIBLE TO OTHERS AND THAT IT REFLECTS WELL ON THEM.

7. DEVELOP AN ACTIVE SENSE OF OUTRAGE AND ENCOURAGE OTHERS TO DO SO. THIS IS SO CRITICAL. PEOPLE WILL THINK YOU ARE ASLEEP UNLESS YOU SHOUT BOO TO THE POWERS THAT BE AROUND YOU ONCE IN A WHILE. IF YOU ARE NOT OUTRAGED BY INJUSTICE THEY WILL BURY WITH INDIFFERENCE, BUREAUCRACY AND PITY BEFORE YOU ARE DEAD.

8. SPREAD LOVE WHERE EVER YOU GO. NO ONE LIKES YOU IF YOU ARE ANGRY OR REGRETFUL ALL THE TIME. KISS, HUG, REWARD, SURPRISE, AND DO ALL THESE AND MORE LOVING THINGS TO COMPLETE STRANGERS AND ACQUAINTANCES IN YOUR LIFE. FOR EXAMPLE, LOVE IS TO GET ON AN ELEVATOR AT THE FIRST FLOOR AND CONNECT WITH EVERYONE BEFORE YOU GET OFF AT YOUR FLOOR.

9. SEE THE CONNECTIONS. NEVER THINK YOU ARE THE ONLY ONE. YOU?RE NEW FAMILIES ARE PERSONS WHO BECAME INFECTED THROUGH DRUG USE, INDIGENT GAY MAN OR TRANSGENDERED PERSONS AND WOMEN WHO TRUSTED THEIR SEX PARTNERS. THE SHAME, PRIDE, PAIN, SCORN AND FIGHT FOR RESPECT OF ALL THESE GROUPS MUST BECOME YOURS BECAUSE YOU ARE PART OF THEIR WORLD.

10. DON?T FORGET SEX. IT FEELS GOOD AND CAN BE DONE SAFELY. DON?T STOP DOING IT EVEN WHEN YOU ARE LIVING WITH HIV/AIDS. IT?S AS MUCH A PART OF LIFE AS SPRING IS A SEASON.

11. IN ALL OF OUR STRUGGLES FOR FAIRNESS AND EQUALITY REMEMBER THIS: THERE ARE NO PERMANENT FRIENDS OR PERMANENT ENEMIES ONLY PEOPLE SHARING COMMON INTERESTS.

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