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Maria
An unexpected meeting between a doctor and a girl with AIDS bears fruit for HIV prevention efforts.

by Mahlon Johnson

I was elated to be going home, to be leaving the National Institutes of Health with minimal damage. I had started making desperate pilgrimages here after receiving a scalpel wound while conducting an AIDS autopsy many years earlier. I’d come in search of a miracle that might reverse the moment when a slipped knife turned me, a young pathologist, into an HIV patient. So far, the new therapies had worked. I’d returned to my hurried life and almost forgotten about the virus. But every year I don a patient’s gown and return to Bethesda, Maryland, from my home in Tennessee for special blood tests that are the crystal ball to my future.

The NIH researchers had wanted to biopsy a lymph node in one of my legs, if their surgeons could find an enlarged one to cut on. On this trip (my sixth), to my relief, they could not, and the legs that had carried me through thirty years of daily workouts had been granted another reprieve. So after being drained of blood, I was released with no incisions, no stitches, only a Band-Aid to hide the latest invasion of my flesh. I was free to go home and diagnose disease, not live it.

Usually the NIH’s airport shuttle waiting area is packed with patients, many bald or wearing turbaned bandages and dragging black nylon travel bags on wheels. Lost in the vortex of disease, they come hoping that Oz can help them get home, back to Kansas, to something resembling a normal life. For now, the waiting area was empty. I took a seat in the back corner.
While checking the shuttle schedule, I heard a voice say, “I didn’t hit you.”

A young Latina girl and a heavyset Anglo woman in a tan raincoat had just entered the waiting area. They sat down in the row of empty chairs in front of me. The girl, maybe ten or eleven, had brown pigtails sticking out like bent antennae; she clung to a stuffed brown bear with a shiny, worn “V” nose. She looked away, tightened her Walkman’s earphones, and pulled the bear closer, flattening his nose against her chest. The woman, hands cupped in her lap, added, “I just bumped you. I didn’t hurt you. Why do you say such things?”

The girl turned farther away from her. She watched people leave the hospital lobby and seemed desperate to escape the woman, desperate to enter some other world. She pulled up the frayed wool collar of her old navy jacket, then shifted the bear, as if suddenly aware that he couldn’t breathe. She pulled her legs up and curled around her companion, glancing wistfully at the empty space in the corner. Despite these efforts at distance, she seemed strangely tied to the white woman.

“Are you feeling OK?” No response. “Want a Coke?” The woman sounded disheartened. The girl didn’t seem to hear. The woman quietly studied the girl, then cautiously reached over to her. When the girl didn’t flinch, the woman began to stroke her wiry hair. After a few minutes she stopped, dropped her hands back to her lap, and stared at them.

**From Oz To The Airport**

On the shuttle van I settled into the back seat. The girl, followed by the woman, slid on to the seat in front of me. In the afternoon light the youngster’s face looked older than her thin, childlike frame had suggested. The woman leaned forward and questioned the driver about their drop off at Baltimore-Washington International Airport. Seemingly reassured, she sat back and looked around the van, smiling faintly when she saw me. I smiled back. “You come up here often?” I asked. She shook her head. “This is our first trip, but, God willing, we’ll be back.”

“Leukemia?” I asked quietly, hoping it was nothing worse. The mother flinched but didn’t respond. She moved her bag to her right side to give the girl more room. I wondered about her reticence. After all, most childhood leukemias could be treated, if not cured. But the girl’s demeanor was not that of a hopeful child visiting Oz for a cure. It was that of a wearied conscript who had battled too long. “Acute leukemia?” I whispered again, hoping the query would not penetrate the girl’s earphones. The woman shook her head again, her face now contorted with pain. She searched my eyes for signs of trust, then after some hesitation, whispered, “HIV.” I nodded slowly, my fears confirmed. “You came to the right place,” I told her. “I hope so,” she replied. “It’s her last chance.”

The woman explained that she and her husband, a Miami minister, loved children and had adopted five over the years. Four had been healthy boys, but their
last, a newborn girl, had been different. She hadn't gained weight like her brothers had, and by age three she was sickly. Eventually, she got a bad cold that became pneumonia. The doctors said it was *pneumocystis carinii* pneumonia. That's when they discovered the HIV. They sought out the girl's birth mother, but she already had died of the AIDS that she had transmitted to her daughter. The doctors had tested the adoptive mother, the minister, and the boys for HIV—all were fine.

AIDS doctors started the girl on AZT, which for years worked well. But three years ago it failed, and her CD4 (also called t-helper) cells, which organize our defense against infections, started a relentless decline that went unchecked by prayers or newer drugs. They'd tried protease inhibitors. But nausea and diarrhea from the drugs had stripped Maria (not her real name) of twenty pounds. Meanwhile, her CD4 cell count had dropped to 90, well below the waterline for AIDS. As a last resort, Maria and her adoptive mother had come to the NIH's National Institute of Allergy and Infectious Diseases to enroll in a pediatric clinical trial, hoping that new drugs and an immune enhancer might break what was now a free fall. I looked over at Maria, trying to imagine what it would be like to grow up in clinic waiting rooms. I wondered what kind of life she dreamed of having.

Resting her chin on the bear's head, Maria continued to stare from the world of her headphones out the side window. She wrapped both arms tightly around the bear, who was standing stoically on her bluejean-clad legs. We sped along the Maryland interstate in silence, as the mother, deep in thought, gazed out at a marsh lined with cattails making their last stand against the highway. Eventually she turned to me. “The doctors say it'll be several weeks before they can tell if the drugs are working. Even then, they may not work for long.” I tried to reassure her about the effectiveness of the new drugs, quietly praying that they would continue their miracles on me, too. But I knew that they hadn't helped some others, and I tried to imagine watching my own child fail to respond to miracle drugs when other people were rising like Lazarus from AIDS’s massive tomb.

**Tired Of Being Sick**

Are you an AIDS researcher? she asked. “Not on this trip,” I replied. I told her that I had cut myself on an AIDS autopsy. “Oh, no!” she cried, searching my eyes for signs of fear. After a mute moment she shook her head, then looked at me with newfound trust and blurted out, “Things are going to be tough when we get home. It’s been easy in the hospital. Maria listens to the doctors. I think she’s intimidated by their white coats. But at home...she’ll go out with her friends, get diarrhea, and stop taking everything for days.”

Maria started fidgeting with the dial on her Walkman and glanced at us with a
frown. She knew her mother was talking about her. The woman reached over and gently pulled at her headphones. “Maria, this man’s a doctor. He has HIV, too! Talk to him.” Maria glared at her, the betrayer of her secret, avoiding my sheepish smile. She turned back to the window but then glanced back suspiciously at me as if I’d claimed to be a long-lost cousin.

“You hanging in there?” I asked, trying to sound cheerful. She didn’t turn, but shrugged slightly. “A lot of better drugs should be coming out in the next couple of years.” I paused to see if she was listening. “They’re supposed to work better—fewer side effects. Things could get better if you can just hang on.”

Maria turned her head a little and pulled on the bear. The sun reflected off her pigtails and expressionless face. Her eyes held a hint of disbelief, as if still trying to fathom a doctor having HIV. She searched my face for illness. She loosened her hold on the bear but said nothing. Then she whispered, “The pills make me sick!” with an anger and finality that made me wonder if she’d ever take them again. “Me, too,” I responded. “But you’ll get a whole lot sicker if you don’t take them.” She pulled up the collar on her jacket, convinced that no one understood her and her private mourning over the loss of her dream for a normal life. “I’m tired of being sick,” she said, then turned back to the window and adjusted her earphones.

“Maria’s afraid that some kids at her school are starting to ask questions about why she’s sick a lot. She’s so afraid that someone will see her taking all those pills and spread it over the school and tell Tommy, the little boy she eats lunch with every day. She’s sure her friends will leave her.” The woman paused and took a deep, tense breath, wrestling with the notion. “But the principal doesn’t think so. He thinks it would be better for her to tell the school, not hide it. They’re having an AIDS education program.” Maria, still fixed to the window, shook her head violently. “She won’t even consider it. She won’t listen, not even to my husband.” Maria pulled up the bear and closed her eyes. Seeing the signs to the airport, the woman grew silent, nervously sorting through her purse as if bracing for their return to a harsher world.

A Heartbreaker

As we climbed off the van, I waited for Maria, seeking one last chance to make her understand the importance of taking the new medications, hoping that she would respond to them and join the rest of us who had. Maria slowly stepped down from the van and moved up the sidewalk away from us, bear under one arm. She searched the sidewalk as if looking for a trap door to escape from her adopted mother, from HIV, and from me.

“How long will it take for you to get home?” I tried again to sound cheerful. She shrugged, barely looking up. “I bet it’ll be fun to see all your friends. Your mom says you’ve got a nice boyfriend.” She fought back a smile and looked away. Hopeful that she might be listening, I pressed ahead. “I bet you’ll be a real heartbreaker
in a couple years.” Still looking down, she smiled and started pivoting back and forth. “I heard you might help with an AIDS awareness program at school.” She kept rocking. “You can keep your friends from getting sick by talking in school. They won’t listen to teachers, but they would to you.” She stopped pivoting.

A moment later her mother, towing a big suitcase, came to say goodbye. We exchanged addresses like expatriates in a disquieting land. Then I hugged her and extended my hand to Maria. She took it shyly. I watched as they hurried off, disappearing into the terminal crowd.

Maria Stands Up

A month later I found a worn manila envelope bulging from my mailbox. It was postmarked Miami. Tearing it open, I pulled out a soft blue Bible and a note. They were from Maria’s adopted mother.

“Dear Dr. Johnson, I wish you could have been at Maria’s school last Wednesday for the AIDS program. We were so proud. It took some coaching but she stood up in front of the whole school and told them about her HIV and that her mother had probably gotten it from a man and then died from it. She stood up there all alone and almost started crying but she was very brave. She told them she didn’t want anyone to be afraid of her because you only get AIDS from sex and drugs and she didn’t want anyone else to get AIDS and have to take all the pills. The principal was proud too and spoke about how you get AIDS, but Maria was better. After she was done, some of the kids clapped and her friends came up, even her boyfriend. Her best friend even hugged her…I thank God.”

The Centers for Disease Control and Prevention would tell you that AIDS is expanding rapidly in the Hispanic community, particularly among young women. Recent studies evaluating beliefs about HIV transmission in Hispanic adolescents suggest that compared with teenagers as a whole, this group is least likely to be knowledgeable about HIV transmission or to practice safe sex. Research also indicates that peer education is more effective than the traditional adult-as-teacher model in reaching adolescents, because teenagers are more likely to listen to their contemporaries than to adults. Educational programs led by the heroic Marias of the world who determinedly battle HIV with pills every day could represent the miracle we seek in the struggle to limit HIV infections among the next generation.

We may never know the full impact of Maria’s timid speech to her school. But word of her courage, which spread swiftly throughout the Hispanic community, has surely made an impression on a key audience. Undoubtedly, knowledge of her story has saved others. It has inspired at least one rider of the NIH shuttle in his own struggle against HIV.