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Voices in the Band: A Doctor, Her Patients, and How the Outlook on AIDS Care Changed from Doomed to Hopeful

Abstract

[Excerpt] I wanted to write a book about my patients and my colleagues and how we made it through the roller-coaster last decade of the twentieth century, how we moved from helplessly watching our patients die to being able to offer them a treatment course and a fairly normal life expectancy. In that time we saw some patients literally return from death's door. This kind of dramatic success has not been seen in any other field of medicine, except perhaps following the introduction of penicillin many years ago. I wanted to try to answer the question "What was it like?" What was it like to care for patients with AIDS, a disease that didn't even exist when I was in college? How did we deal with dying patients for whom we had a diagnosis but no treatment? How did we care for patients that many in society rejected, patients that many even within the field of medicine rejected? What happened in those years, when the prognosis for a patient with HIV went from nearly hopeless to very hopeful?

Keywords

AIDS, healthcare, HIV, treatment

Comments

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Voices in the Band

**A Doctor, Her Patients, and How the
Outlook on AIDS Care Changed from
Doomed to Hopeful**

Susan C. Ball

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Introduction

I am an AIDS doctor. I originally did my residency training in internal medicine, and in 1992 I started working for Dr. Jon Jacobs at the Center for Special Studies, the AIDS care center in New York City. At that time the idea of an HIV specialist was in its infancy. While we knew what caused AIDS, how it spread, and how to avoid getting it, we didn't know how to treat it or how to prevent our patients seemingly inevitable progression toward death. The stigma that surrounded AIDS patients from the very beginning of the epidemic in the early 1980s continued to be harsh and isolating: mention AIDS and people imagined promiscuous homosexuals and heroin addicts, all of them skinny and covered with purple spots. They remembered those early photos of diaper-clad, emaciated men with scraggly beards looking fearfully into the face of the priest or nun leaning over their hospital bed. People looked askance at me: What was it like to work in that kind of environment with those kinds of people?

My patients are "those kinds of people." They are an array and a combination of brave, depraved, strong, entitled, admirable, self-centered, amazing, strange, funny, darwin- gifted, exasperating, wonderful, and sad. And more. At my clinic most of the patients are indigent and few have had an education beyond high school, if that. Many are gay men and many of the patients use or have used drugs. They all have HIV, and in the early days far too many of them died. Every day they brought us the stories of their lives. We listened

to them and we took care of them as best we could. My patients have the kinds of voices that are rarely heard, coming as they do from a hip-wiggling drag queen or a drug-using Hispanic man who lives in a shelter, or from a welfare-dependent single mother of four who lives in her subsidized two-bedroom sixth-floor walk-up out in a remote part of the city that I will likely never see. My colleagues and I heard the stories; and in caring for our patients we created more stories, with all the small victories, the horrible deaths, the humor, and the sadness. We worked hard to be good doctors and our patients helped us become better ones as we took our tumultuous journey together.

I wanted to write a book about my patients and my colleagues and how we made it through the roller-coaster last decade of the twentieth century, how we moved from helplessly watching our patients die to being able to offer them a treatment course and a fairly normal life expectancy. In that time we saw some patients literally return from death's door. This kind of dramatic success has not been seen in any other field of medicine, except perhaps following the introduction of penicillin many years ago. I wanted to try to answer the question "What was it like?" What was it like to care for patients with AIDS, a disease that didn't even exist when I was in college? How did we deal with dying patients for whom we had a diagnosis but no treatment? How did we care for patients that many in society rejected, patients that many even within the field of medicine rejected? What happened in those years, when the prognosis for a patient with HIV went from nearly hopeless to very hopeful?

The advances of medicine in the last twenty years or so have introduced ever more sophisticated technology, persistent clamoring for cost control, streamlined algorithms for patient care, and a lopsided two-tiered system divided between the rich and the poor. My experiences caring for patients with HIV brought me up against some of the best and worst aspects of medicine as I tried to care for patients who often were born into bad circumstances or made bad choices or were burdened with mental illness, domestic violence, or lack of family or education.

This is a book about HIV and AIDS and an important period in the history of the epidemic, but there is more to it, as I found in its writing. The care and treatment of patients with AIDS has changed, but the disease itself has not, nor have those who suffer from it, though they have shifted further out on the margins of our society. I want to tell people about these patients and how I cared for some of them during that time at our large academic medical

center in New York City. Those years and experiences changed me as well, as I made the transition from trying to help patients as they died to trying to help them live long, healthy lives.

My colleagues and I struggled to care for the poorest of the poor and the sickest of the sick, and this book follows the stories of several of those patients. But as the smothering blanket of mortal illness gradually lifted from our patients, we could see a deeper story emerging. We could recognize the tremendous value of our multidisciplinary approach and how each and every patient helped us along the way. We learned as doctors, as a team, and as people; each of us vulnerable, each of us trying to do the best we could.

In the end, it is the patients who are at the heart of this story.

I am an AIDS doctor. For more than twenty years I have taken care of many patients and I am happy to say that Stewart and Olive are doing well.

I took care of Etta. And I wish that she had taken her medication.

Chapter One

1992 Beginning

After all of these years, I still remember that egg, a half-eaten hard-boiled egg held delicately in his dark, slender fingers. The egg had a bite taken out of it and he was looking at the egg with a perplexed expression, as if he wasn't quite sure what he held. The whites of his large eyes shone brightly. His eyelashes were long and dusty looking. I stood next to his bed and leaned in a bit to look at him with my face on his level. He smiled at me, showing partially eroded gums and a lot of egg in and around his teeth. I wanted him to put the egg down. I didn't want to see him take another bite of it. Please, I found myself thinking, please don't take another bite.

The several vases in Mac's hospital room held flowers that were long dead. Milk and juice cartons cluttered every surface. Crumbs and items from his breakfast tray, including what appeared to be most of the shell and peelings from the egg, covered the pale blue blanket on his bed. A navy baseball cap with a stiff brim sat sideways on his head. One of Mac's friends had decorated the hat with plastic eyes and pink glitter.

I smiled back at him and said, "Hello, Mac, how are you today?"

Mac blinked slowly and I tried to avoid looking at those teeth. His long lashes rested on his cheeks. "Hello, doc."

"Can I sit down?"

He nodded yes and I sat at the end of his bed. I could see where his very skinny legs raised the blankets and I made sure not to sit on them. "How is your breakfast going there?"

“Oh, it’s all right, I guess.”

I watched as he slowly put his egg down on the tray. I was thinking, leave-it-there-leave-it-there-leave-it-there. He delicately picked up an empty packet of sugar and turned it over.

“How is your appetite?”

“All right, I guess.”

We were silent for a minute or so. Mac tried to pour the empty packet of sugar into what I was certain was a cold cup of coffee. Several open packets of sugar had already been emptied onto the tray.

“Are you getting out of bed?”

He smiled again and watched the sugar packet in his fingers. “Not today. Not yet.”

Silence. Mac moved slowly. It was like watching a movie frame by frame. I heard a nurse calling to someone out in the hallway. Mac turned the sugar packet again in his fingers. I sat up straighter to ease my back but I didn’t look away from Mac’s face. I wanted him to see that I was focused only on him.

“Mac, if the nurses come and help you, will you get out of bed and sit in a chair today?”

“I might.”

“Do you want to?”

He turned the sugar packet a couple of times without looking up.

“I might.”

I felt a flicker of worry. The day, my work, the rounds, the notes and meetings and phone calls, it all waited out there for me, tapping its foot. I didn’t want to feel impatient and I didn’t want Mac to feel that I was impatient. But we needed to move forward. I needed Mac to answer my questions and I needed to have him hear the words; even when I knew that he could no longer organize his thoughts the way he once had, the way a healthy man at his age should.

“Mac, I spoke to your sister Laverne and also to Briana. You remember Briana, your social worker? She spoke to Laverne as well. We were talking about whether you can go home or not.”

Mac continued to work silently at the empty sugar packet in his slender fingers.

“Mac, Laverne cannot care for you at her house. You know that, right?”

“I don’t want to go to her house.”

“Well, Mac, we can’t let you go back to your house. We can’t let you go back there to live.”

Mac didn’t say anything. I waited.

Finally, after putting down the empty sugar packet he said, “I would like to go

back there, to my own house.”

I didn’t answer him right away. “I know,” I said, nodding. “I know that’s what you want. I know that’s where you’d like to be. But, Mac, for now you’re just not strong enough to go there. We can’t let you go there on your own. And Laverne can’t look after you enough.” I put my hand on the blanket and felt his skinny leg.

“You have been talking about me,” he said.

“Yes, I know, we have been.” I nodded again as I spoke.

He was looking at his tray and his hand absently strayed up to brush away a piece of egg that clung to his lip. He didn’t look up.

I felt suddenly tired. It seemed clear that I was talking for me and that Mac was lost. He didn’t understand. He was being polite and saying words that would fit into the mold of our conversation. I looked at him and felt this little tug somewhere, maybe in my shoulder, maybe in my hand, to reach out to this man who no longer commanded himself, who couldn’t say anything more complicated or articulate than that he wanted to go home. Still, I had to keep going. “We talked together, Briana and I, and we talked to Laverne. And now I am talking to you to see how you are.”

He swiped again at the bit of egg on his lip. “I want to go home.”

“I know.”

He picked up a spoon and held it carefully.

“We just—we just can’t let you go back to your house, Mac. You wouldn’t be safe there on your own. You can’t get out of bed. You need a lot of care.”

“Yeah.” Mac put his spoon into the Styrofoam coffee cup and started stirring. He did seem to be listening. He blinked a few times. His eyelashes were so long.

I kept going, wanting to be done. “Mac, our thought is—and what we are going to try to do is—to get you to a place where you can get some good nursing care. I hope that if you rest a bit and get a little of your strength back, then maybe, well, let’s just see if you can get a little stronger.”

He looked up at me and blinked. He gave me a slow smile that lit up his face entirely, like someone cranking up the dimmer switch in a previously shadow-filled room. Despite the lingering presence of some egg, I could see there the sweet sexiness and charm that he surely once flaunted. I looked at that smile and sensed myself holding my breath. I smiled back at him.

Mac was thirty-three years old. Less than three months ago he had been working as a fashion assistant somewhere near Thirty-fourth Street and in the evenings whooping it up downtown with a pile of friends. I had just told this thirty-three-year-old man that he needed to go to a nursing home. He smiled at me and as I smiled back I thought, oh damn, this really stinks.

“Mac,” I said, “we’re going to talk some more about this. Have a little more breakfast, OK? I’ll see you later.” I saw that he’d looked back down at his tray and his fingers strayed toward the egg as I left his room. I shook my head and looked at the polished gray linoleum floor. What was happening? How had this happened?

But there it was: 1992 at one of the most prestigious medical centers in the city of New York, even in the whole country. The AIDS epidemic was roaring through the big cities in the Northeast, clustering in Miami and Atlanta, and ravaging the gay populations of San Francisco and Los Angeles. I was seeing Mac on rounds on one of the first days at my job as an attending physician on the HIV service at one of the New York-very-big-deal hospitals, an Ivy League-incredibly-smart medical center. I had joined the staff of the Center for Special Studies, the young HIV/AIDS clinic, and I’d assumed the care of 130 patients, ten of whom were in the hospital. There were three full-time and three part-time physicians caring for five hundred HIV-infected patients at our clinic. No one wanted to come to a clinic with HIV or AIDS in its name. No one wanted to be associated with such an awful diagnosis; the Center was thus named to protect our patients. People who had tested positive for the virus came to our clinic that had started as a one-room outpatient site three years prior. The Center itself had opened in 1991 after a beautiful renovation of the entire top floor of the hospital. We shared the space with the group doing clinical research on some of the various HIV medications that were in development.

Our inpatient floor operated twelve floors below the clinic. Before seeing Mac in his hospital room, I had seen five others so far that day. I’d seen Nilson of the perpetual scowl and John of the wondrously immaculate manicure. Both of them had *Pneumocystis pneumonia*. I’d seen Yolanda with raging herpes simplex and Hank who, while nearly falling asleep, was asking me for more morphine. Admitted for multiple complaints, Olive was undergoing tests but didn’t seem to have anything wrong at all.

All ten of my patients in the hospital had AIDS, and half of them were dying. In 1992 no one knew how to treat patients with AIDS. We’d made some progress recognizing and treating some of the opportunistic infections that we saw—infections that take advantage of a weakened immune system—but often the patients came into our offices and emergency rooms

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with problems we'd never encountered and had no idea how to treat: weird rashes or inexplicable shortness of breath; sudden inability to walk or rapid worsening of eyesight. Maybe some of this would become routine; we didn't know. The epidemic was moving into its second decade and still our emergency rooms and hospitals held too many dying patients for whom we had no diagnosis other than AIDS.

Mac's soft, doe-like gaze stayed with me as I sat down at the nursing station. The guy could barely feed himself. His thoughts and words seemed like those of a man in his nineties, not his thirties. He couldn't get out of bed but he wanted to be in his own apartment. His thoughts were slow and disorganized, but essentially he wanted what it is so natural to want. Especially in times of stress or fear or anxiety, we all want a little corner of some place to have as our own, a quiet haven or sanctuary. No different from anyone else, Mac wanted his familiar walls around him, his familiar window and curtains and cat lying on the Oriental rug. But he couldn't get up on his own. He couldn't get himself a glass of water or take a shower. He couldn't eat and he couldn't appreciate how totally helpless he was. So I talked to him about nursing homes. I talked to him about getting stronger. It felt dishonest to me. I smiled and looked into his face and did not tell him that it was completely unlikely to think that he would ever go home. I did not tell him that we had nothing further to offer him here at our big, important hospital.

His mental deterioration made him docile and quiet. He didn't rage or scream. Perhaps this made the acceptance easier in some ways, for his family and for him. But the horror of his progressive decline was hard to take in. His illness had forced changes in his life that none of us would have imagined. He wore diapers. When the nurses helped him up to sit next to the bed he needed to have a sheet wrapped around him and tied to the back of the chair so that he would not fall out of it. He could no longer brush his teeth. He didn't have pain. He could eat a little, when he was up to it, but a meal seemed to take hours and he left much more on the tray or the bed than he actually ingested. He had AIDS, that's all we knew; no other specific infection or cancer or stroke or anything that we could pin our puffed-up medical opinions on. A scan of his head showed only a vast shrinking of the undulating matter of his brain, with big, dark blackness where there should have been functioning white matter. And for this we knew of no treatment. So we watched and the nurses watched and those who loved him watched helplessly as his condition worsened and the man they knew faded away.

At the nurses' station my colleague Stan sat writing his progress notes. One of the people on his inpatient list was a twenty-six-year-old gay man named Edward, whose parents had come this morning from Florida because he was dying. His partner had died a year ago and now he was on the same path. I'd seen the parents earlier in the hall and they both looked fragile and dazed. Such a nice guy; quiet, friendly, unassuming, and in the last four months Edward had lost more and more weight and never received a diagnosis beyond advanced immune suppression. The nurses really liked him and could not have been more kind to the parents. Stan struggled with Edward's approaching death as well. There were scans and blood cultures and specialist consultations, but Edward had AIDS and that was all we really could say.

"How's Edward?" I asked Stan as I sat down next to him and pulled Mac's chart from the rack.

"Dying. Morphine drip." Stan didn't look up from writing in the chart. There were three other charts in a pile next to him.

"How are his parents doing?"

"Mother's a wreck, father doesn't talk." He lifted his head a bit and wiggled his pen in his fingers, still looking at the chart where he'd been writing. "They are so sweet, so ...," he paused, "so *nice*. They asked me if he could get some ice cream with his lunch. The guy hasn't eaten in probably five weeks. I said, sure, of course he can have ice cream." He wasn't looking at me as he spoke. He shook his head. He gave what I'd call a half laugh. The half laugh over something so terrible it's come around to being funny. But it's not funny.

"How long has he been on the morphine drip?"

"Just since last night. But I don't think he's going to need it for very long."

"Has he spoken?"

"Nah," Stan said, now looking at me. "He can't really talk at this point, he barely opens his eyes."

"Oh brother."

"Yeah." He looked back down at his chart and started writing.

I sat next to Stan and looked at the chart in my hands. It had Mac's identification label stuck on the spine. A maroon plastic chart with all the data of a man's illness inside.

Suddenly there was a huge crash out in the hallway and the sound of breaking glass; a man yelling and a woman calling loudly for help. Everyone around me jumped up and looked toward the hallway. It seemed that all the people started yelling at once. The clerk grabbed the phone and, dialing furiously, called, "Where's security? Where is security?"

Stan quickly moved into the hall and shouted, “Dennis, get back in your room!” As I followed Stan to the hall I heard him say, “Broke the fucking window.” He sounded surprised and he walked quickly toward the crash.

One of the nurses rushed toward us from down the hall and breathlessly said to the clerk, “Call security, and call Dr. Berry, stat. That Dennis, that guy, Jesus, he scared me. He threw his chair into the window. There’s all glass in the hall. Damn that guy, he is like some kind of wild man. Judy, do you have any Haldol in your drawer?” She was breathing hard and put her hand on her chest over her blue scrub shirt. Her dark red hair had been pinned up and now fell in locks around her face.

Down the hall, the guy, Dennis, stood talking to Stan, who was at least a foot taller. Dennis’s wrists trailed the long gauze restraints that had previously tied him to his bed. His hair and beard needed a trim. He wore two hospital gowns, one of them on backwards, and his feet were bare.

“My fucking lunch!” He suddenly yelled up into Stan’s face.

“OK, Dennis, OK, your lunch is coming,” Stan said in a cajoling, friendly voice. “Dennis, just get back in your room now. Dennis, come on, buddy, there’s glass all over the floor.” He gently put his hand on the patient’s shoulder and walked him back into his room. Stan looked down the hall and saw me and raised his eyebrows. He gave an impressed nod of his head: the window really was broken.

I saw the cart with the lunch trays parked outside another patient’s room three doors away. Instead of waiting for his lunch to be delivered, Dennis had thrown his chair through the window of the door to his room. It’s always possible that they’d skipped him and not brought him lunch. Maybe he had a test scheduled and they hadn’t brought him breakfast, either. Maybe, maybe. I imagined Dennis in a line at the Social Security office or at the office for Medicaid benefits. I remembered the time years ago when I went to the Social Security office myself because they’d confused my number with someone else’s. I stood in line for over two hours to get to the woman who finally helped me. How would Dennis do in a long, snaking line like that, seeing the people behind the glass, the ones who were supposed to be helping, as they talked and laughed among themselves and seemed to be doing any number of random things: copying papers, talking on the phone, writing on a pad of paper, and basically ignoring the line on the other side of the glass? I’d been grumpy and impatient after two hours and I now shook my head, smiling to myself, thinking about a guy like Dennis waiting in that line. I thought of flying chairs and broken glass. At the Social Security office all the chairs were fastened to the floor and the glass divider between the office workers and those in line was about a foot thick. Now I knew why.

I heard Dr. Berry's name paged stat overhead. A nurse ran by holding a small bottle of something and a syringe. Two heavy security guards came hustling past, hurriedly putting on bright yellow gloves. AIDS patients freaked people out. The hospital security guards always wore yellow rubber gloves when they came to our floor. Annoying, ridiculous rubber gloves. The men looked like they were about to do the dishes. They stepped gingerly over the glass outside Dennis's door and went into his room.

I returned to the nurses' station and picked up Mac's chart. Soon Stan joined me, sitting down heavily in his chair. He was chuckling, shaking his head. "Can you imagine doing *that* for the food here?"

I laughed and asked him, "No one's hurt?"

"Jane's a little freaked. She thought he was going to throw the chair at *her*."

"I thought that glass was, like, bulletproof."

"It has that chicken wire in it but it sure is smashed. He got a little cut on his foot."

"What did they give him?"

"Vitamin H." Stan shook his head again. "Nothing like a little Haldol before lunch." He picked up his pen and continued writing his note.

Dennis had AIDS, too. Dennis and Mac and Edward, all with AIDS. I looked at the patient list I'd written on a half piece of progress note paper. My inpatients all had AIDS; that is, their HIV infection had progressed and their immune systems were compromised. People used the two terms as if they were synonymous: AIDS and HIV. But not every patient infected with HIV had a diagnosis of AIDS. HIV meant infection with the virus but AIDS meant the virus had beaten down the immune system, rendered one vulnerable to infections and cancers that the body can usually fight off.

As I looked at my list of ten patients I felt an ominous creeping sensation come over me. These names represented people in my care now. Were they all going to die? Was everyone on this list a living dead person? I shook my head, literally shook that thought right out. I could not think about my patients that way. I thought again about Mac and his beautiful smile and the egg all mushed in his teeth. I thought about Dennis barefoot in the hall with broken glass on the floor around him. No, these were very much living characters. I pictured their faces one by one. Edward, too, though dying, remained very much alive for those who loved him, including his parents and the nurses.

We had so much to learn about AIDS, a disease that we knew best as frightening and unpredictable. The epidemic started quietly in the United States with clusters of unusual illnesses among gay men. I was a first-year medical student in

1982 when I heard the expression gay-related immune deficiency (GRID). No one knew what caused it, no one could predict which gay man would get it. Within two years GRID had evolved into acquired immune deficiency syndrome (AIDS), and those at risk included gay men, injection drug users, hemophiliacs, and Haitians. Soon a few women and some children joined the lists of those diagnosed with the illness. By 1985 the human immunodeficiency virus (HIV) had been identified as the causative agent. It became clear that AIDS arose from a viral infection that could be transmitted through sex, blood, shared needles, and from a pregnant mother to her unborn child. Pooled blood products had caused nearly every hemophiliac in the country to be infected with HIV prior to screening of the blood supply. Discovery of the virus led to the development of a straightforward blood test to determine whether an individual was infected with the virus through detection of an antibody, a protein made by the immune system. Screening of blood donors became mandatory in 1985, making transfusion-related transmission of HIV highly unlikely.

When I began working at the Center for Special Studies in 1992, my patients were fairly evenly divided among gay men, men who were current or former intravenous drug users, and women. About half of the women had acquired the infection from their sexual partners. The other half had been infected through intravenous drug use. Because many of our patients were indigent and few had jobs, government assistance paid for the medical care of most people being treated at CSS. So far I had met only one patient educated beyond high school.

Stan, our colleague Maggie, and I made up the full-time medical staff responsible for the majority of the five hundred HIV-positive patients enrolled in our clinic. Stan was easygoing and confident with his patients, in contrast to Maggie, who tended to be stressed out and anxious. Both of them had begun working at CSS a year before I got there, having just completed their residency training at the medical center. Maggie took me around on my first day and reviewed the patient list with me. She had nicknames for most of the patients or endearing comments to make about them, saying things like, he's a sweetie, I love her, he's an angel, he's such a peach, and so on. She expressed great worry and concern about several of the patients and she got teary-eyed telling me about them. She brushed the tears away, saying she'd not had a good night's sleep. I was struck by her sincerity but also by the intimate way in which she referred to her patients. I wondered if she could be effective if she was so emotionally involved. Having worked in a general medicine clinic for four years before coming to join Maggie and Stan, I had some experience and a sense of how I interacted with patients. These first days on the job introduced me to what my two colleagues had already

been doing for a year, caring for patients with HIV and AIDS. It felt like I was hopping onto a fast train going off into a dark land, headlight slicing through the unknowable night.

With Dennis settled down, Stan finished his notes and headed back to the clinic. It was nearly two o'clock and time to go to support group. I put Mac's chart back on the rack and walked down the hall to take the elevator to the twenty-fourth floor. When I got to the conference room, people were already sitting in most of the big leather chairs around the table. I recognized many of the people and remembered most of their names. A small, unfamiliar woman with a lot of curly dark hair sat at one end, and she smiled at me as I sat down. Dr. Berry and Stan talked quietly together and I heard Stan say something about the fucking lunch that made Dr. Berry laugh. A few people, including Dr. Jacobs, came in behind me and chose to sit in the chairs that stood along the wall. The entire twenty-fourth floor had originally been the home of the hospital squash courts, and all of the rooms in our clinic have very high ceilings. In 1989 Dr. Jacobs had somehow persuaded the hospital to give up squash and take care of patients with HIV instead, a concept that now sounds amazing. I'm still not sure how he did it.

The woman with the dark curly hair looked at the clock, and then she looked at Dr. Jacobs. The room got quiet and Dr. Jacobs spoke up: "I'm glad everyone is here. This, as you know, is our support group. We haven't met in a while; maybe some of us are recovering from our last support group." There was some laughter and rolling of eyes. "We're happy to have a new support group leader with us today. This is Janice who is highly recommended. Let me just add that we will be meeting here at this time every other week, and again, all the care providers are invited and encouraged to be here." With that everyone looked at Janice, the woman with the curly hair, who said hello and looked around the room.

Janice gave a brief summary of her background and noted that she had led a couple of other support groups, including a group for HIV-positive men that met downtown. She had not facilitated a group of care providers such as ourselves but hoped we would all benefit from the time spent in that room.

It got very, very quiet.

No one spoke. Most people looked at the table in front of them. Occasionally someone would look up and meet the eyes of the person across the table. There were small smiles and then the eyes would go back to the tabletop. Here we are, I thought. All of us are here because we're taking care of patients with HIV. All the people in this room have chosen this work. I thought of Edward downstairs with

his parents sitting there at his bedside. Waiting. I glanced at Stan. He'd told me yesterday that in the past year, thirty of his patients had died. Thirty! I thought of my patient John, who lay in a bed downstairs with his second case of *Pneumocystis* pneumonia and a collapsed lung. He still required oxygen but was recovering, it appeared. He'd seemed happy to meet me as his new doctor and had told me about his life. He loved his job as a stylist in a hair salon. He waved his hands around as he spoke and I watched them, entranced by his expressive gestures and perfectly polished fingernails. If he hadn't been wearing an oxygen mask he would not have looked sick. But he'd been admitted to the intensive care unit and only three days ago had been taken off a respirator and moved to the regular inpatient floor. Was John going to die very soon? He had only four CD4 cells. A healthy HIV-negative person usually has over five hundred of these cells—also called T cells. Without T cells John's immune system could no longer function adequately against certain kinds of infections.

I thought of Mrs. Perlucci, a woman I had taken care of last year before I came to work at CSS. Mrs. Perlucci died of pancreatic cancer after a brief but dramatic illness. In several short weeks I watched as she changed from an elegant elderly woman to an emaciated, yellow, wincing vision of death. It had been hard to be her doctor; so little to offer, so little difference to make. Did Stan watch that happen thirty times last year? Stan with his kind eyes and reassuring smile. Did he hold their hands and hug their parents? What about the social workers here in the room, or the nurses? Those thirty patients had been under their care as well. What do you say about how it feels? I found myself wondering, could I go through that? I'd chosen to be here. I wanted to work with these patients. I remember clearly that first support group and the almost overwhelming grief and loss that I sensed in the hearts of those around the table.

I wondered whether John's parents were alive and whether they knew that their son had AIDS. Edward's parents were with Edward. Would John's parents come to the bedside of this soft-spoken, handsome man and touch one of those beautifully manicured hands of his? I pictured an older woman washing her dinner dishes at a sink by a window. Turning to answer the telephone, she wipes her hands on her apron. I picture her sitting down with an anguished cry when she hears the news. I know this vision is out of a movie. Stan, Dr. Jacobs, the others around the room, they have been witnesses to indescribable sadness. The silence in the conference room seemed both deafening and endless. No one spoke, no one moved. Janice sat quietly with her hands folded on the table in front of her. She looked at us.

I found myself holding back tears. Should I talk about being afraid of all my

patients dying? Should I mention that I felt unnerved by the degree of illness in my patients, all so sick and so young? All the people in the room, my colleagues, were like heroes to me, coming to work every day to care for dying patients that others shunned. I worried that I couldn't be as strong as they all seemed to be. I'd seen them chatting in the halls and joking in meetings. But no one underestimated the seriousness of the work. In that reverberating silence I heard everyone struggling to contain their own sorrow. Did my thoughts have any importance in the midst of all the despair and death that our patients were dealing with? Here we were in support group. I was the new kid; was I supposed to talk?

At the thought of opening my mouth to speak, my eyes filled with tears. I struggled to contain my overflowing emotions. To my great surprise and admitted relief, the young woman next to me suddenly started sobbing loudly. I hadn't seen her before and didn't know her name. She had long brown hair and wore the short white coat that marked her as a student or first-year resident.

"I'm just the psych intern," she choked out. "I haven't been here very long. My father is sick and I have a test in the fall that I need to study for. He's in California. We don't get along very well." She was crying so hard it wasn't easy to understand her. I looked across the table and noticed the eyebrows of my colleagues all high up on their faces. They looked at this woman with concern, surprise, and some puzzlement. Her comments seemed unexpected, under the circumstances. Janice shifted in her seat and inclined her head. She looked ready to hear more, not entirely certain if she should speak.

From across the table Dr. Berry asked, "Are you... ? Have you... ? Is your mother ... ? Is there anyone taking care of your father?" As one of the full-time psychiatrists hired by CSS for our patients, Dr. Berry was responsible for supervising the psych interns who spent time on our service. It amazed me that she could come up with a sensible, focused question when my own mind felt like a jumble of patients' faces and tears.

"No, they're divorced. My sister lives near him and she is seeing him in the hospital. I don't know, I just, I can't, it's so hard ..." And then she continued sobbing.

Someone reached across the table to her with some tissues which she took and wiped her nose and her eyes. "I haven't seen any patients yet," she said, twisting the tissue in her hands. "I am afraid to see patients who are really sick right now." Some heads nodded around the room.

Gerald, who didn't seem to be able to speak without running his hands through his hair, spoke up. "Gee, uh, well, that is, um, well," and then he turned to Dr. Berry with a look that said "Help!" Gerald recently stepped into the job of office

administrator, a large step, as he freely admitted to everyone. He'd previously worked at the clinic as a social worker, but his new role entailed much more responsibility and he wanted to be supportive as well as provide guidance for the staff.

Dr. Berry asked the intern, "Do you think that you need to take a break, perhaps, and maybe not have the pressure of seeing patients for a while?" Gerald nodded along with this question.

The intern said, "Oh, I don't know, I don't know what to do, I am not sleeping and my test is in September."

At this point Janice said, "Do you, I'm sorry, what is your name?"

"Wendy."

"Wendy. Wendy, do you think that the work here might be too difficult for you right now? You have a lot going on in your life. It may be too much to ask."

Wendy wiped her eyes some more and seemed to get herself under control. "I feel guilty about studying when I know my father is sick and then I think that we haven't talked very much in the last ten years but we used to fight all the time and now I know he wishes I were a dermatologist." The laughter at this could have been heard down the hall. Comic relief never seemed so apt a phrase.

Even Wendy managed a smile. "I'm just, I think I need some more sleep and I need to study more even though it is sometimes hard to concentrate." Janice nodded her head as did Dr. Berry.

"Wendy," said Dr. Berry, "why don't we talk after support group and we'll figure out how to make this work for you."

Stan said, "Derm's for wimps," to more laughter around the room.

Wendy blew her nose and the silence returned. This time I didn't feel quite as uncomfortable as everyone sat quietly with their thoughts. And the silence did not last as long.

Briana, a social worker, spoke up and told how she had been on the subway and a panhandler had come through the car announcing that he was hungry. He had AIDS and would someone please give him a dime, nickel, or penny. As he approached she realized it was one of her patients. Most of the people in the room smiled at this. Stan asked if she gave him any money.

"I gave him two dimes and told him to call us for an appointment."

To a chorus of chiding Briana added, "I know. I'm a cheapskate."

"Well, you probably don't get paid that much," added Gerald, looking pointedly at Dr. Jacobs.

Dr. Jacobs had been staring at the floor through much of this, though with a hint of a smile on his face. He now looked up at Gerald and said, "What are you

looking at me for? You're the administrator, you give her a raise." We all laughed again, especially Gerald.

Chapter Two

1992 So Much to Learn

The first time I heard about HIV it was called by another name. None of us appreciated then that we were hearing about an illness whose initial impact would be like the earliest shivers and creaks of an earthquake that would shake the entire world.

In the summer of 1982, after my first year of medical school, I met some friends for lunch at my roommate's house in Philadelphia. One of the people there was a fourth-year medical student at a big hospital in New York City. He told us of an illness occurring in gay men that made them very sick and sometimes killed them. No one knew what it was or what caused it. He mentioned that people used the term GRID, which stood for gay-related immune deficiency. The student said that more and more cases of this strange but terrible illness were showing up in other hospitals in New York, and that cases were now being reported in other cities around the country. We talked, that day, of how or why gay men would be victims of a disease like this. From the student's description it sounded scary and ominous.

Within the next two years I'd seen several cases of this illness on my ward rotations. The patients were all young people in their twenties and thirties and they were desperately sick. Some had terrible pneumonia caused by *Pneumocystis*, an organism that had only rarely been seen before. Some patients were covered with purple spots and carried the diagnosis of a sarcoma that was supposed to affect only old men in Greece. Others were just skin and bones,

unable to eat, or feverish for reasons that we could not figure out. Gay men made up the majority of our patients, with others being intravenous drug users, both male and female, and the sexual partners of those drug users. In recognition of this broader patient population, the name for the illness became acquired immunodeficiency syndrome (AIDS).

At about this time, in 1984, I heard a lecture by an infectious diseases specialist at the University of Vermont. He spoke of an illness affecting large portions of communities in Central Africa, in Uganda and the Democratic Republic of the Congo, known then as Zaire. It was recognized in Africa as “slim disease” because patients had severe, unremitting diarrhea and could not eat. They became profoundly wasted and after months of sickness they died. A high prevalence of tuberculosis in these regions complicated and generally worsened the course of this illness, which predominantly affected young adults and working-age people. Because the ill could not work and required someone to care for them, economic downturns were becoming apparent in these already impoverished regions. The infectious diseases specialist giving the talk noted the link between “slim disease” and the acquired immune deficiency syndrome, formerly GRID, now being seen in the United States. Research indicated that AIDS and “slim disease” were manifestations of the same condition. Increasing numbers of cases were being diagnosed in the United States, such that by the end of 1984, over seven thousand Americans had died of or were suffering from AIDS.

Before 1981, while I was in college, this illness didn't even exist. Yet by the time I finished medical school and began my training in internal medicine, AIDS patients made up the bulk of cases in many inpatient medical hospital units. The stigma around the disease spread even faster than the disease itself, especially in those early years when the cause was unknown and the effect always devastating. The unknown frightened people. In hospitals, housekeeping services didn't want to clean the rooms of those patients. Wary food service employees left meal trays outside the hospital room doors of patients who were too ill to sit up, much less get out of their beds and walk across the room to the door. Once, during residency, I mentioned AIDS to a colleague as we took the elevator upstairs. The man standing next to me jumped away from me. He looked aghast, as if just hearing the word AIDS might be contagious.

The huge stigma surrounding patients with HIV came from fear of the illness and judgment of the lifestyles of the patients. AIDS was associated with homosexuals and drug addicts. In 1985, when the human immunodeficiency virus was identified, it became clear that virus replicated in white blood cells and therefore could be found in blood and body fluids. AIDS could be transmitted only

through blood or through sex. Sharing needles for injection drug use could transmit infection as could exposure through vaginal or anal intercourse. Prostitution became a risk factor for AIDS. Babies were born with the virus from their infected mothers, and hundreds of recipients of blood or blood product transfusions also became sick. Many hemophiliacs became infected before measures were taken to protect the blood supply. Transmission did not occur from hugging or handshakes or toilet seats or breathing the same air. Nonetheless, the stigma of an AIDS diagnosis brought out the worst in people. Doctors and nurses refused to care for HIV-infected patients, employers fired them, families rejected them, and schools expelled them.

And yet many people responded to those in need. The mystery and severity of the illness fascinated some just as it repelled others. Where did it come from? Why now? Why did it progress this way? How could it be stopped? The glaring need for help brought many to the field. Caring for AIDS patients began without guidelines or algorithms, no textbooks or handbooks or cheat sheets. Trying to treat an illness that we didn't understand put us on the very forward edge of medicine. A clear sense of a new frontier existed for those providers drawn to devote themselves to the care and treatment of patients with AIDS.

I grew up in a small college town three hundred miles from New York City. I went to college in New England. A year abroad after high school and several foreign study programs had nurtured in me a love of travel and an interest in other cultures and people. I graduated from medical school in Philadelphia and went back to upstate New York for my residency. My medical education and training corresponded almost exactly with the development of the AIDS epidemic in the 1980s. I remember seeing those first cases as a wide-eyed student, and as a resident I cared for terribly sick AIDS patients in the emergency room, in the intensive care unit, and on the medical wards. It seemed that the patients were all my age. Some were drug addicts, some were hemophiliacs. Many of the male patients were gay.

At first we wore masks, gloves, gowns, hats, and booties, covering ourselves from the unknown threat that lurked somewhere within these horribly sick patients. As we tried to protect ourselves, our costumes dramatically reinforced the patients' sense of fear and isolation. Even after identification of the virus, and knowing the virus couldn't be transmitted casually, admitting offices usually placed hospitalized AIDS patients in rooms by themselves.

The implications of this forced separation always weighed on me. Many of the gay men already struggled with their families over issues of homosexuality. Having a hateful, frightening disease made their situation all the more tragic.

After residency, now thirty years old, I moved to New York City to be with my

girlfriend as she completed her own residency program. I worked in a general medical clinic and took care of a lot of middle-aged and elderly men and women who didn't want to take their blood pressure medicine. I eventually wanted to work with underserved populations in Africa or India, and I studied for a master's in public health at Columbia University on what I thought was my way to spending the first part of my career working abroad. AIDS patients came to the ER in the hospital where I worked; they had pneumonia and tuberculosis, brain abscesses and rapidly progressing blindness. A few came to the general medicine clinic, but this occurred less frequently. More often they presented to the emergency room and waited to be admitted, or they stayed sick at home, away from the doctors. No AIDS clinic existed at the time.

A diagnosis of AIDS was considered a death sentence. As a result, many of the people who knew they were at risk did not want to be tested for the virus. They did not want to know, and definitely did not want anyone else to know, that they had HIV. Sometimes people without any risk save their own vulnerability to popular paranoia came to the emergency room thinking they had the virus. They asked for the test, wondering if, on some doorknob or toilet seat, they might have become infected with this strange and deadly disease. Occasionally one of my clinic patients asked to be tested. I had a charming, nearly deaf elderly man from Ukraine who wanted an AIDS test. This took me by surprise, but finding out what led him to ask for the test proved difficult. "Why do you want this test?" I asked him.

He leaned in and cupped one hand behind his ear. "Eh?" He winced as he spoke.

"WHY DO YOU WANT THIS TEST?" I asked again, quite a lot louder.

"AIDS test. Yes." His left hand stayed cupped behind his ear.

"WHY?"

He just nodded at me.

"DO YOU HAVE ANY RISK FACTORS?"

"Eh?"

"RISK FACTORS? FOR AIDS?"

"Eh?"

"DO YOU EVER SLEEP WITH PROSTITUTES?" By this time I was shouting. I almost started laughing, imagining what the secretaries outside my door were thinking. I did send the test. It came back negative.

One of the nurse practitioners I worked with wanted to build up her own panel of patients, but she refused to take on a patient with HIV. Her aversion to "that kind of patient" surprised me a lot. I realized I didn't need to go anywhere far away to take care of an underserved population. Clearly, caring for AIDS patients would

expose me to new cultures and people. I felt an urge to reach beyond the clutter of masks and gloves to ease the loneliness of my patients. Besides, I wanted to stay with Shari and we talked of starting a family. I sent my resume to Dr. Jacobs when I heard about the program at Cornell. In 1992 he called me and offered me a job at CSS. I said yes.

I got to Stewart's room shortly after nine in my second week at CSS.

"Hello, Stewart, how are you this morning?"

"Oh, Dr. Ball, I'm, well, I, what do you think? How am I doing?"

"You are definitely better, but here, put your oxygen back on, here you go. You need to wear this."

"Yes, I know, yes. I am, but I'm, you know, it's just that my breathing, I, it's just that, how am I?"

"You look a little short of breath. Certainly better than before."

"I am. I'm short of breath. But I'm better, right? I still am short of breath. Can you tell me anything? Did you see my chest X-ray?"

"You haven't had an X-ray since yesterday morning. Remember we talked about the results?"

"Yes, no, I mean, yes. You said it was OK. It's just that, it's just that, it's not PCP right? I don't have that. I just have pneumonia, right?"

"I think it is PCP. I can't tell for sure without the bronchoscopy," a procedure he'd so far refused. "But we are treating you as if you have PCP. And you're getting antibiotics for bacterial, regular pneumonia as well."

"So it might not be PCP?"

"Without the bronchoscopy I can't say for sure. We're treating you for both just to be on the safe side."

"It's not something else? I don't have anything else?"

"Do you want something else?"

"No, I mean, you really think it's PCP. You do?"

"Yes, I do."

"But I'm getting better, right? So it might not be PCP. It could be something else. It could just be pneumonia. I could be getting better from something else."

"We really think this is PCP. All your symptoms make us think that's what you have. Your T cells are very low. You haven't been on anything to protect you against PCP. It is possible that you have a different kind of pneumonia, but PCP is at the top of our list. You are getting better; that's good. But you must wear your oxygen."

“But, Dr. Ball, I’m getting better, right? My X-ray is OK? You said my X-ray is OK?”

“Your X-ray is OK. It’s not great, it’s not worse than before. The X-ray may not improve as quickly as your symptoms do. But yes, I think you are getting better.”

“I’m better, right?”

“Yes, Stewart, yes, you’re better. Your breathing is better and your fevers have gone. You need to still wear your oxygen, OK? Let me take a listen to you.”

Stewart’s skin was clammy and his thinning hair stood straight up on his head. A short man with dark brown eyes and an expression of worry that never left his face, Stewart personified anxiety. He relentlessly asked the same questions, interrupted the answers to ask the questions again. He repeated the answers but didn’t seem to digest the information; or else, more likely, he wanted a different answer and so asked the question again. I listened and repeated myself and listened and repeated myself. I tried not to get annoyed with him. Sometimes I succeeded. He made me think of Valium, but whether the Valium was for him or for me was not clear.

He leaned forward in his bed as I lifted his damp gown from his back. With my stethoscope I listened to the little crackles his lungs made when he took a deep breath, like the sound in your head when you eat toast. His rate of breathing was slower than the other day when he could barely talk, but still faster than it should be for someone just resting in bed.

PCP. *Pneumocystis pneumonia*, the best known of all the dread diseases associated with AIDS. An opportunistic infection, it was the most frequent index illness in those with HIV who were untreated or unaware of their infection. In the 1980s, before it was recognized that there were treatments to prevent the onset of PCP, this pneumonia developed in nearly three quarters of those infected with HIV, and many of those patients died. People still die from PCP, unfortunately. Even today, the occasional patient comes to our emergency department with fever, shortness of breath, and a dry cough. These patients may be unaware of their HIV infection or may not be getting care despite knowing they have the virus. Some patients see the doctor but don’t take the medications to suppress HIV and eventually their immune systems falter.

PCP used to stand for *Pneumocystis carinii pneumonia*. It now just stands for *Pneumocystis pneumonia*. Antonio Carinii and Carlos Chagas identified pneumocysts in rats and guinea pigs in the early twentieth century; hence the name. In the 1950s, several cases of PCP among malnourished children in orphanages in Iran marked one of the first documented outbreaks of this illness. In the early

1990s genetic typing recognized that Dr. Carinii's *Pneumocystis carinii* infected only rats and did not infect people. Since 1999 the pneumocyst that infects humans has been recognized as *Pneumocystis jiroveci* (pronounced yee-roh-veet'-zee, after Otto Jiroveci, a Czech parasitologist), but we continue to refer to it as PCP.

Details of nomenclature aside, in 1992 we diagnosed PCP more than any other opportunistic infection associated with HIV and Stewart almost certainly had it. He'd used heroin to soothe his nerves until 1986, when his blood tested positive for HIV and he finally quit drugs. He'd been a patient at our clinic for four years and his T cell count was a very low 25 per cubic milliliter. Prior to his coming to CSS, Stewart had developed a severe allergic reaction to a common antibiotic routinely used to prevent the development of PCP in patients with low T cell counts. He'd been hospitalized for weeks with a life-threatening rash that caused much of his skin to peel off. Stewart had never been a very calm person, and this awful experience popped his anxiety level off the meter. He became caught between his understandable distrust of medications and his terror of dying. This resulted in a hyperattentiveness to any kind of symptom. I knew his phone number by heart from all the times I called him back to hear about his congestion, his cough, the prickly feeling on his right arm, the dry throat, runny nose, loose stool, hard stool, watery eyes, white tongue, feeling of breathlessness, wax in his ears. If ever I offered a treatment or medication for one of his ailments, he asked me dozens of questions about it, asking the same questions over and over. What was the medication? What did it do? It's for my cough. Will it work? What are the side effects? Does it cause a rash? What did it do to other people who took it? It's for a cough. What kind of medication was it? Would the medication help him? And then, since I was suggesting a treatment, he'd ask what the implications were. Would his symptoms get better? Did they mean he was getting worse? I'm not getting worse. Do you think I have AIDS? I do have AIDS. But I'm not worse. I'm not worse? Do I need a test? Do I need another test? Do I need a CT scan? When he ran out of questions he would start the list over and ask the same questions again. I wondered if Valium came in six-packs.

He could become fixated on what I considered a minor symptom and I couldn't always convince him that he didn't need a certain test or intervention, often one a friend or family member recommended. Sometimes the relentless questions wore me down and I ordered tests that might not really be indicated or treatments that could have been avoided. At the same time his anxiety led him to refuse medications or tests that he really needed. The current hospital admission and his refusal to undergo the bronchoscopy exemplified this behavior. Bronchoscopy involves looking at the lungs from the inside with a tiny light at the end of a very

tiny flexible tube. Lung fluid can be withdrawn and lung tissue biopsied using the fiber-optic tube. The fluid or the biopsy allows us to make a definitive diagnosis of PCP. Without the bronchoscopy we can only treat PCP presumptively, that is, without certainty. The resident on the pulmonary service who attempted to get Stewart's permission for the procedure gave him an exhaustive explanation of what a bronchoscopy involved. He answered Stewart's questions for twenty minutes, and then Stewart said no. The resident looked as if he needed a stiff drink after that episode. But ultimately, without the information that the procedure could provide, we didn't know if Stewart had PCP. We treated him as if he did, and fortunately he improved.

"What do you hear, Dr. Ball, I'm better, don't you think? Do you think I'm better?"

"I think your lungs sound better. Your fever is down, your oxygenation has improved. This is good."

"So I can go to the bar mitzvah?"

"The what?"

"My nephew, the bar mitzvah in Florida."

"When is the bar mitzvah?"

"Saturday."

"This Saturday?"

"Yeah."

"Is Karen going?"

"My wife?"

"Your wife."

"No, she hates my sister. Just me going."