

Perspective

The Onset of Pediatric Human Immunodeficiency Infection- Connecting the Dots: Reminiscences of a Newark Pediatrician

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The screaming started immediately: *"It cannot be true! Children cannot get this filthy disease! How dare you claim such a thing?"* My response was simple, straightforward and sincere: Why would I make this up? Indeed, there was no upside to determining that infants and children, little kids, were AIDS' newest casualties, an even more chilling realization since we did not yet know all the ways it could be transmitted. After establishing the parent-child link through several of my original encounters with women with AIDS having very ill and dying infants and children, it took a bit more detective work and time to sift through other cases I suspected would tell the same story. Nevertheless, there it was, in black-and-white clarity: charts from seven additional children I had followed since 1979 also had symptoms and blood work results definitively linked to a parent's AIDS diagnosis and unfortunately shared a similar fate if not more severe case. Until then AIDS was thought to be acquired by sharing needles or having sex with someone already with AIDS. Now it was becoming clear to me that its littlest victims, infants and children, were infected simply by sharing space in their mother's womb, if she had been HIV infected.

I was relieved when Dr. Richard Rapkin, my supervising attending, agreed I should contact the Centers for Disease Control in Atlanta with my findings. The path from there seemed like the yellow brick road to Oz; all my concerns addressed, and the value and truth of my suspicions confirmed! The government would review the facts, wholeheartedly fund research and this killer disease would quickly be vanquished and children spared. How naïve I was! "The data are a little weak," James Curran, a CDC physician opined in late 1981, several months after the day I had drawn such a harrowing conclusion from drawing Darren's blood. Curran, a gracious, congenial man, was so harried himself that he asked to meet me at Newark Airport as he changed flights one afternoon. I stood practically on top of him as he perused the charts I had brought, anxious to be believed. "Your conclusions are based on a lot of autopsy results," he sighed. "I believe you, I really do, but I think we need more evidence."

The next obvious step was to approach the National Institutes of Health in Bethesda, Maryland, where I had worked with scientists

during my ID Immunology fellowship at Emory University. I hoped my fellowship training at Emory University with Dr Andy Nahmias would translate into more credibility for my findings. Andy, however, though not questioning the reality of AIDS, did not approve that I embraced the disease – and its victims. "You should let other people do the clinical work," he advised, his bushy white-streaked hair haphazardly framing a sharp-featured, probing face. "You hold these kids on your lap, you're being careless. You're sending the wrong message." However, what message should a health worker promote? That one tier of society was somehow better than another based on disease acquisition. The whole idea smacked of a false elitism I detested, of the many refusing to take ownership of the welfare of the few, nor be 'our brother's keeper' when there was both an obligation and obvious need.

Colleagues who had supported me on other issues and observations I had made in the past, seemed to abandon me entirely when it came to this controversial subject. I found this incredibly hurtful, not to mention confusing. "Don't go there," said Dr. Robert Goode, a senior immunologist at Sloan-Kettering with whom I had worked closely on my primary immune deficiency patients. Goode, a big, graying man with a venerable track record, not only thought kids couldn't get AIDS, he didn't believe the disease existed at all. "I think you have good instincts, Jim," he said in his deep voice, "but you're not right this time." At the 1982, annual Allergy and Immunology conference in Miami a group of participants questioned my data, some even hypercritical. "All of these cases could be something else," said one; another; "They're inconsequential. He has no real data." The Academy president finally saved me and chastened them for their poor reception but agreed that I need to gather more evidence. While additional convincing data from these initial cases was need and be fully evaluated, nevertheless all around me in Newark were the ongoing cries and increasing numbers of infants and children with progressive failure to thrive, wasting and rapid and painful deaths. This unexpected and tragic new illness reaffirmed my growing concerns and commitment to careful observation, evaluation and supportive care for these infants and children, whose distress enhanced my own, while fulling my determination to gather clinical data and knowledge carefully, day by day while also providing whatever care seemed appropriate.

One of these cases was really two: Aisha and Taisha, identical twin sisters who lived with their foster mother, in nearby Plainfield, NJ. They were born on the same day to the same mother sharing the same placenta, and their DNA matched in every way. I mixed the two-year-olds up all the time at first, but not because they looked alike. In fact, I never would have guessed they were identical twins, because Taisha was much bigger and sturdier, the picture of health and

developmentally on target. Aisha was tiny, scrawny and constantly ill, looking more like Taisha's younger sibling than her identical twin. It was so clear to me – as it was becoming, even before performing blood tests – that Aisha had AIDS. I wanted to believe it could be something different, maybe a primary immune deficiency, but I knew I was deluding myself; identical twins would both have an inherited immunodeficiency syndrome. The hourglass was already running low from the time I accumulated these initial cases; there was little time to or reason deny or backpedal. Aisha, like my other pediatric immunodeficiency cases, with strange rashes, recurrent salmonella infections, nagging pneumonias, enlarged livers and spleens and chronic diarrhea had an acquired, heretofore unknown disease! As I looked at her on the examining table, a pathetic sight with thin, wiry hair, sloughing dry skin and a bloated, distended belly, and felt only dread at what was to come. Nevertheless, there was also hope there, and a critical lesson for those of us paying attention. If the identical twins both shared the same placenta and DNA but only one got AIDS, then an infectious agent – bacterial or viral, we didn't know at that time, had to be responsible. A genetic defect could not be the cause. It became, in essence, the perfect unwitting experiment to prove such a point critical observation! Aisha was a tough little girl - impressing me with her feistiness and never-say-die way of bouncing back from one infection after another. Her foster mother was inspiring; a big, gregarious, God-fearing woman I immediately liked and respected. She had my home phone number – all my patients' families did – and even her calls were cause for special interest in my household. "Dad, its Praise the Lord for you", a phrase she always said on our answering a call from her that my sons would sing, handing me the receiver. She and I talked a lot and actually became friends, an all too unusual consequence in a doctor-parent relationship. Nevertheless, it was easy with Doris. We were always on the same page, and she understood how angry and frightened I was by this disease. She understood how I did not have all the answers. We ended up forging a pact that would benefit us both: If she complied with all my directions – something I could not necessarily count on with other guardians – then I would make sure Aisha got every possible treatment as soon as it became available, while in the meantime I would use all the available tools I had to treat the frequent identified infections she developed while encouraging her best possible nutritional and palliative care for her frequent painful infections. The problem, of course, was not specific therapies available. I only had gamma globulin, at a cost of \$8,000 per year per patient, to try to stay one-step ahead of the disintegration of their immune systems. Its high cost meant yet another fight for me, another battle to argue with cost conscious colleagues to take heat about But did not relent care- in my experience, the treatment with gamma globulin fulfilled two crucial goals: staving off death from recurrent infections in an immunocompromised host, while granting us important blocks of time for distressed, overwhelmed and fragmented families to understand the dynamics of this overwhelming epidemic. In the three or four hours it took for one gamma globulin infusion, gave me and our staff to use this time to address issues as varied as housing, finances, drug administration techniques to assure compliance and encouraging and fighting for school attendance for our patients. Our goal included in trying to make each child's life as normal as possible during the course of their illness. All members of our team became advocates, social workers as well as health providers for our patients and families. At times this included "shooting from

the hip", taking aim at this elusive, enigmatic illness in a way that at times can only be described as unorthodox. Without known definitive treatments for this new illness that robbed children of their usual defense's against infectious diseases, prescribing drugs and therapies without knowing exactly what would help or what might harm, became a challenging issue. In medical practice, therapy is not supposed to be approached that way!!

Doctors are supposed to know what works before they prescribe a treatment, but then again, babies should not die from a new disease without an attempt at care. "What are you doing?" the hospital pharmacist ranted at me more than once as I arrived to pick up gamma globulin. "This stuff is expensive. It's not approved yet to be used for this new infection." At least he did not argue about my diagnosis of *this new disease*, while many others were quick to say it had to be something else that I just did not correctly diagnose. I also realized that gamma globulin, as useful as it is, would never be enough. We did all the obvious things, watching patients' diets and maximizing nutrition, anticipating infections and starting antibiotics for both treatment and prevention. The only way to move forward, I knew, would be to publish my initial findings in order for the medical establishment and public to understand and accept the threat we were seeing in Newark's children, was sure to spread and needed funding to confront and control.

Gathering together my eight firm cases into article form was both a labor of love and frustration, both gratifying and disheartening. Clearly, there were far more than eight – a single day in our clinic would bring between twelve to twenty potential cases for evaluation – but I felt forced to present only those with the best, most reliable evidence for what latter would be called PHIV. Still, writing evidence down in black and white became a supporting act, generating optimism in that space inside my heart where steady despair had, for many months, claimed sole province. "Until recently," I started in longhand, (remember this was a time when computers were scarce, many of us still used ink pens and with my patient thick medical files lining my desk), "AIDS seemed to be limited to adults, predominantly in those with aberrant lifestyles or exposure to blood products. It seems, however, that the epidemiology of AIDS may now have taken an ominous new turn, with otherwise 'normal' infants and children as additional victims. "The cause of the syndrome remains unknown," I added, shaking my head remorsefully as I wrote this. "Data are accumulating, however, that suggest a transmissible agent is responsible for the immune dysfunction and that certain malignant neoplasms and opportunistic infections then develop thereafter." It was deceptively easy to write, this document encapsulating the pain of broken and poverty-stricken families, so much misery and need and loss, so much which could never be described on paper. The acceptance seemed deceptively easy, too, when the revered *New England Journal of Medicine* contacted me in early 1982 telling me the article would be published later that year.

However, could it really happen? Would my findings become fact, a springboard for the kind of attention needed to generate money and medicines for my Pediatric patients? Could society embrace the idea that AIDS did not discriminate the way some of its people did and then learn to embrace all of its victims, young and old? The answers to all of those questions would be yes – eventually, but not without struggle or even spite, and not without showing me the only easy part

of launching my groundbreaking article would be the ease with which I was blindsided.

“Jim? It’s for you,” my wife Barbara handed me the phone just after I walked through the door late one night, its loud ringing reverberating through our still-empty living room. Though we had lived in our suburban four-bedroom Colonial for several years by that time, some of the rooms still went unfurnished. “Yes? This is he. No comment. I really cannot confirm or deny that. Yes, I understand.” I handed the receiver back to Barbara in disbelief and felt the blood drain from my face. “That was *The Wall Street Journal*,” I told her grimly, pulling off my jacket. “They’re running a story in tomorrow’s paper that says I’m treating kids with pediatric AIDS.” It was the truth, of course, but they did not get it from me. I knew about the rule preventing physicians from publicizing their work in the mainstream press before it ran in *The New England Journal of Medicine*, so I knew this would eliminate my article’s acceptance. Reporters pummeled me with questions a few days later at a hastily called press conference on the hospital campus. Our PR department felt it best if I talked to the press myself since it could not possibly keep up with the phone calls they were receiving. As I stood at the podium, hot lights beaming at me from television cameras, microphones jabbing at my face, I felt almost nauseous with discomfort.

My place, as I had defined it, was with the children and families or in the laboratory. This podium, which I gripped with both hands, was a means of keeping myself steady, I felt strange, cold, and foreign. These people in front of me, who I knew were just trying to do their jobs, were not my friends.

Yet I knew somehow that my ability to answer their questions correctly and well could make the difference between further disregarding or access and treatment for my pediatric patients. This presentation, done right, could benefit the children I was caring for at that time. “It’s not a disease of just gay men,” I explained, wiping sweat off my brow. “It’s just as much a disease of the poor, of women, of heterosexuals, of IV drug abusers as well as now children born to HIV infected mothers.”

“Are you saying that anyone can catch AIDS?” A hush followed that question, a collective breath-holding inspired by the very idea that anyone could be at risk. Any one of them. “As far as we know, it is not that contagious.” I said softly. “But you said children are coming down with it. How are they getting it if it’s not contagious?” “We think through the placenta and blood of the mother or during the birth process.” An up roar erupted in the press pool, with reporters shouting “What?” and “Really?” and looking at each other with quizzical expressions. Then a lower, more insistent voice rose above the crowded room. “Isn’t it normal to publish in the medical journals first? And in that case, why are there no articles by you or anyone else in the scientific press?” *Good question*, I thought. *Wish I could tell you the answer*. “Of course, we intend to publish our research,” I said simply. “How do you protect yourself?” This question caught me a little off guard. I was not there to talk about myself, after all. “I wash my hands,” I held them up, “I’m careful when I handle bodily fluids and needles. I take precautions.” The melee would have gone on all day if I had not stepped off the podium to end it.

Tense and exhausted, I exhaled loudly when I sat down that night

and relayed the incredible scene to my wife, who had seen part of it on TV. She was unimpressed by the media, more skeptical of what they could offer. The next morning, I walked onto the pediatric floor, where several staff and faculty members gathered over coffee with the front section of *The Wall Street Journal* opened, “It says here ‘they fear AIDS is spread by hand contact,’ ‘What?’” I recoiled. “Where did they get that? Can’t they get anything right?” That was not the only misperception bandied about. “Someone at United Hospital thinks you’re grandstanding and another person calls up and asks why you’re trying to capitalize on the AIDS epidemic – to build up your reputation and laboratory facilities?” *Oh, God I thought*. They could not get much farther from the truth than that, but I knew I could choose to either get upset or move forward with what needed to be done.

After *NEJM* pulled my article – still a stunning blow despite its predictability – I called the *Journal of the American Medical Association* to gauge their interest, explaining what had happened. The editor was surprisingly encouraging. “Why don’t you update and rewrite it,” he offered, “and then sends it on to us?” That plan seemed workable – for about four days, until the briefcase containing my first draft and copies of all my documentation was stolen from my car when I stopped at a Shell station one morning on my way through Newark. After paying the cashier inside, I noticed with horror the newly empty back seat as I opened my driver’s-side door to get back in. I was sick about it – paralyzed, really – for three months, the length of time I held out hope of somehow finding the notes intact. The police thought whoever took the bag was probably looking for drugs and, finding none, would throw it away in any one of the dumpsters surrounding the gas station. Subsequently, week after week, I pulled over at every receptacle between St. Michael’s and United Children’s Hospital, on the route from the Shell station on West Market to Clinton Street to Martin Luther King Boulevard, opening the tops and scanning the slimy contents for my precious sheaf of papers.

I posted signs offering a reward. I stopped people on the street and offered them money. I offered endless prayers on high that someone would call me saying they had found it, but I was starting to think that God had placed a big gray cloud over me, that I must have done something very wrong to deserve all this. It was one of the lowest points in my life. ‘*Please, God, help me to stay humble and to persevere*’ that was my morning prayer, had been so for a long time, and seemed to tell me at least in part what I should do next. Persevere. There was nothing else to do. Using hospital records and x-ray reports, I painstakingly re-established my source documentation and re-wrote the article, which *JAMA* finally published in early May 1983 in an issue devoted to AIDS that also included a later-submitted paper by Rubenstein and an editorial by Tony Fauci, then chief of infectious diseases at the NIH.

“It seems to us the data are sufficiently convincing to conclude that at least some of the described infants and children have met the necessary criteria to be designated as having AIDS,” my article concluded. “These observations obviously have important implications. First, they support the hypothesis that an infectious agent is responsible for AIDS. Second, they imply that sexual contact or drug abuse is not required for transmission. Third, they indicate that the disease may be transmitted to an otherwise ‘normal’ host.”

I read my own words on the day they were published with mixed emotions, mostly relief, not caring if their timing coincided with observations made by other doctors around the country. While Newark, because of its demographics, was the epicenter of children's AIDS in the United States, clearly the epidemic by then had stricken other large cities equally hard in their vulnerable populations. Dr. Rubinstein in New York had a group of women and children similar to ours. Dr. Arthur Armann on the West Coast recognized that blood transfusions were causing it in some children there, which we had begun to see as well, especially in hemophiliacs; and Dr. Gwen Scott, who would become one of my dearest friends and colleagues, served a large Haitian community in Miami, soon noted that children there were becoming HIV infected. "*The more people who speak up about these kids, the more I can speak up for them*" became my goal. I liked the strength in numbers these nationwide observations presented. I especially appreciated what they could mean for potential research funding. However, there was no time for personal validation from any of it, since the other side of dispersing public information is dispelling public misperception. More and more of my energy, it seemed, was consumed in correcting erroneous reports and rumors about AIDS and how it spread. I was not always sure the media were in the right camp on that point. The very nature of their work – with bright lights, aggressive correspondents, big and splashy headlines – seemed to require at least an element of sensationalism to keep their readership interested. It seemed easy to exploit innocent children who had contracted one of the world's most feared diseases. It also, unfortunately, seemed easy to misrepresent the dangers to the public in the process.

The yellow hospital gowns, rubber gloves and surgical masks were my first clues that a news crew walking down the corridor had the wrong idea about AIDS. They came one summer day, as others of the media had, to peer deeper into the lives of my patients and their families. However, how could they hope to present the truth if they themselves were misinformed? "What's going on here?" I approached the group, which included a reporter, producer and a cinematographer, and introduced myself. "You know, guys, we're not dealing with radioactive fallout here." "Well, can you give us a guarantee that none of us will come down with AIDS?" the reporter asked, his brown hair perfectly coiffed, his fake smile failing to mask an air of superiority. I wanted to yank every one of those white teeth out his head with pliers, but since I could not, I had to forgive myself later the edginess with which I responded.

"No," I seethed, "I don't know what you do in your private lives. Can you fill me in?" I stood there, my hands on my hips, and waited; "We'll stick with the gowns, if it's all the same," the person mumbled.

Even hospital employees were not immune from acting on fallacies and unfounded fears. One noontime I spotted an orderly leaving a lunch tray on the floor outside a little girl's room. They may as well starve her. How can she get it from there? "Hold on," I stopped the orderly before he could push the meal cart to the next door and he looked at me, startled. "Aren't kids supposed to get food inside their rooms?" "Yeah, Doc, but I can't take no risks. I heard the kids got this thing they can pass on," he said plainly. "I have a wife and kids I got to protect." I picked up the lunch tray and ushered the tall, lanky man into Gisela's room behind me. "Does she look like a lethal weapon to you?" I asked him. "You know, I have a wife too, and I

have kids. If I thought there was any danger, do you think I'd risk their lives?" The orderly looked at his shoes mutely. "And Gisela here is just two years old." I picked her up, her disposable diaper squishing into my forearm, to show him how simple it really was. "She's just a little girl. They are all just little kids, you know. What they need is to be held and hugged and fed." My patience was only veneer-deep on days like that and keeping calm amidst the chaos and aggravation was getting harder and harder. By the time my *JAMA* article came out, we had treated more than 50 young patients with AIDS, six times more than the paper highlighted. The floodgates had opened sending us not only more bonafide cases but also many false positives, kids who didn't have the syndrome but were referred by near-hysterical parents worried they had somehow 'caught it'.

The hysteria also spread to the suburbs, to school boards forced to decide whether to allow PAIDS patients in their schools, making our testimony important to treating these kids and their families with understanding, compassion and common sense, not unfounded fears of casual transmission of HIV. That became another drain on my time, though one I fully undertook as a necessary responsibility.

Our pediatric AIDS staff had increased to one part-time nurse, the indefatigable Mary Boland, as well as one social worker and two medical school fellows I supervised – not nearly enough help needed and we decided together to respond to every PTA and board request for our time, having formulated a series of principles we could promote within the schools. Most of these schools and teachers absorbed our message without problem, and I am happy to say that New Jersey, although conservative in other ways, did a reasonable job accommodating PHIV infected children. We did not have a Ryan White case in New Jersey, as did Illinois, when it initially banned him from attending public school attendance. A few times, however, we did come perilously close.

"I won't have my granddaughters going to school with AIDS kids," a school board advisor in the western part of the state told me, directly. The fact that he was a retired surgeon only compounded the fear and ignorance on health issues present in many communities at that time. Although he did not seem like the flexible sort, I still I drove one night in the fall of 1983 to confront him and his dozen supporters regarding their baseless but deeply held opinions-it was an intimidating scene. Not only did they not want this second-grade girl to attend classes, they also wanted to keep her foster brother out even though he showed no evidence of infection. Every time I tried to talk, to explain the facts, one individual in the front row would mumble, "You are a lying son of a bitch." It was highly distracting and more than a little disturbing conference but typical for the time. It was also very time-consuming so that it felt I was almost never home. I give my wife Barbara a lot of credit – I was largely an itinerant father and she held our family together.

While it may appear as odd, I believe that 'Little League Baseball' helped me endure the overwelling distress I was experiencing from PHIV. LLB salvaged some of my more important and virtuous parenting skills with all my three sons that was sorely impacted by HIV work related obligations. I had volunteered to be their team manager, almost in protest, rather than of any baseball skills. I could not stand how 'jerky' some of the other fathers were, yelling and screaming things at their kids like, "Couldn't you catch that fly ball?" or only

playing some for one inning in the outfield. The hours away from the hospital were an escape for me in many ways. Though I usually coached losing teams, my players were treated like Big Leaguers, with Gatorade at every game, personalized team balls given every player and 'professional' field lines and batter's boxes that I made sure was in place for every game! Maybe guilt drove my extravagance, I do not know. Nevertheless, after AIDS came, and especially as it ratcheted up, I actually had a legitimate excuse every night not to be home on time. I could have let it envelop my whole life, and often did. However, baseball was the thing that got me there. Not that my time with my family was stress-free. They worried about me incessantly and often nagged me – rightfully – about my food choices, my weight or even my unfocused driving skills, and the uncanny, unfortunate ways the former intersected with the latter.

Barbara says I should write a book just about my car accidents! I am a very bad driver, and my preoccupation with my patients has made matters worse. However, where better to sort through your feelings than in the quiet of your car? In addition, where better to eat in order to cram everything into a busy day? Maybe I should not have tried, however, to do all that at the same time. I used food as comfort, no question about it. In the span of gulping down a Taylor-ham-and-Swiss cheese sandwich, my favorite breakfast, my cares seemed more distant, more manageable, and sipping a cup of coffee with it, warmed me inside and out. However, adding the use of my manual stick shift to the meal equaled fender-benders on two consecutive mornings at the very same stop sign in the very same town. "You've got to be kidding me," gawked the very same cop on the second day I had rear-ended someone, as he surveyed the egg bits and coffee splashes coating the dashboard and inside of my windshield. "Are you serious?"

Probably too serious, truth be told. My joking nature was being buried under the magnitude of what I arrived to face each day. More desperately ill kids, more absentee fathers, more drug-addicted mothers, more broken lives about to be completely snuffed out. I could not help save them all, but I also could not help becoming attached. In a perverse way, it felt like I was arranging heartbreak for others and myself though I knew I had no choice in the matter whatsoever.

Whenever I craved inspiration, I had a built-in set of heroes to look toward; the grandmothers, aunts, older sisters and foster parents who stepped in and dealt with whatever came their way. Some of them had seen their own son or daughter die of AIDS and still had the compassion and drive to take care of their children's children, knowing how high the stakes really were for their family. People such as Quinetta's grandmother, Montez, and Georgie's grandparents, Mr. and Mrs. Garcia, whose courage made me braver and whose strength in tragic moments soothed me when I should have been comforting them. The Garcia's were forced to confront the same ignorant reporter I did when the news crew barged into Georgie's room that day, hearing that the little boy's decimated elders had been torn at first in deciding if they could manage to care for him with a fatal disease. Like so many of my patients, he was just an infant but with full-blown PAIDS, his mother having succumbed the previous year, his grandparents learning retroactively what had actually killed their daughter. "We have him on IV gamma globulin once a month now and he's doing just fine," I looked squarely into the camera, lips pressed

into a smile, determined that my words would not be misconstrued this time. "There's no danger of him passing along anything by casual contact." "Yeah, but aren't you worried about this mysterious killer?" The reporter turned away from me indifferently, like an annoying gnat, and veered toward Mrs. Garcia, who was cradling her whining grandson in both arms. "Yeah, we're scared," she admitted, jiggling Georgie and setting a pacifier in his mouth. "We didn't bargain for any of this. However, when we found out, he had been living with us for a few months. What are we supposed to do? Love comes first, then the disease. There is no way we could let Georgie go on living in a hospital. Anyway, he's a tough little kid, and he deserves the best." *The truth is not so boring now, is it?* I grinned and nodded to my assent, thrilled she had been able to illustrate something to the media that, as a physician, I never could: courage trumps adversity every time.

Quinetta and Montez also lived out this same attitude day by day. The engaging little girl was considered old for a pediatric AIDS patient – she was about six when I met her – and she and her grandmother immediately won the sympathies of doctors and nurses with their gentle, earthy ways. Montez, a hulking, six-foot-tall African American woman, had just buried her daughter and taken over Quinetta's care with little thought about how it would affect her own life. I promised myself the first thing I would do if I ever won the lottery was buy Montez some teeth. Though she was missing the front two, she became to me a very beautiful woman. People like her and Doris, Aisha's foster mother, taught me to feel almost secure in my fear, almost at ease in my lack of knowledge. I never had to be better than Montez was just because I was the doctor. Unlike some physicians, who walk into a room and do not really want to hear questions about their treatment strategy, Montez taught me that these are safe conversations and build a sense of mutual trust. Montez continued to hold this 'safety net' over me as Quinetta deteriorated and I futilely reached for answers to her most troubling problems. Her stomach hurt so badly we would find her in her bed rocking on all fours, which seemed to relieve her when nothing else could. However, her pain seemed intractable, and the best diagnosis I could come up with was an atypical infection of the intestinal tract, which we tackled with huge antibiotic pills.

Nothing else could. However, her pain seemed intractable, and the best diagnosis I could come up with was an atypical infection of the intestinal tract, which we tackled with huge antibiotic pills.

"Look," Montez said, sidling up to me in my obvious sadness, "you're doing the best you can." Perhaps I was, but it was not enough. It was never enough. Even kids like Joseph, kids I thought might make it, somehow crashed. Quinetta and Joseph were two of the patients I visited some nights after rounds, a tradition I had started very early in my career. I did not go to check pulses or drug doses, just to be there. The tiny ones would look up at me with those eyes, and the older kids might sit on my lap and talk with me awhile. Sometimes they were asleep, and I would just hold a hand, a leg, or a foot.

Nevertheless, I imagined, although it went against my training, that maybe in those quiet moments I could transmit some type of energy, some healing force, to those kids. I wanted to will them to get well. I guess it was prayer in many ways, though I did not actually say prayers. It brought me peace, and in my soul, I hoped it would bring them so much more.

Joseph, like many of the kids, always clutched a stuffed animal to his side. One evening he had an unusual request: "Can you keep Henry safe for me?" as he handed me his fluffy purple-and-white bunny that just about fit into the pocket of my lab coat. "It's your rabbit," I said, "so you can keep it safe." "But I think I'm going to die soon," Joseph replied. I sucked in my breath than said the 'Doctor thing' "You're going to do fine," I softly replied, and I meant it; *there is no reason for him to die. His pneumonia is under control and his esophagitis was not that bad.* "Please?" he pleaded. "Please keep my rabbit for me?" I relented, pocketing the furry thing in front of Joseph, patting his head and silently intending to put it back in his bed after he was asleep-but after rounds I forgot to replace it. When I arrived at my pitch-dark house at 11:30, it was still there, safe in my pocket. Joseph, however, was not safe. The phone call came at four a.m. telling me he was dead. I have since carried that rabbit in my white coat pocket to the day I retired-a reminder always of how wise and generous our children are!

I was still shuddering inside from that episode when Quinetta started her death spiral a short time later. As we continued managing her intestinal infection, a biopsy revealed the true cause of her agonizing pain, leiomyosarcoma, a very rare soft tissue cancer, which had riddled her gut. Death came quickly after that, but not from the cancer. Quinetta was so weak and tired she choked to death one afternoon on one of her medications. She was eight years old and I had the task of another family to comfort, ask for an autopsy and try to explain the unexplainable death of a child. "It's OK. It's OK," Montez wrapped her big arms all around me and whispered in my ear as I sobbed. I should have been comforting her, but I had nothing left to give. I had no more to offer. I went to Quinetta's funeral as I had gone to all the others, starting with Joey, the little boy who died of neuroblastoma when I was still a resident. Her service, like most, was at Perry's Funeral Home on Mercer Street in Newark, a large parlor in an old central ward of the city about four blocks from the hospital. The fact that I have known Mr. Perry, the funeral director on a first-name basis was an indication of my failures as a physician. He even let me park in one of the reserved funeral-car spots, when I came to pay my respects. "Hello, Charles," I'd say, shaking his hand at the door of his squat, square building on the way in. "Hi, Jim," he would nod back. The first time I went to one of the funerals of a child I cared for who died, I didn't know what to expect, didn't know if I would be welcome, but felt I just had to pay my respects. I needed time and space to grieve, needed closure just as much as the families and usually my presence tolerated and even appreciated. At Quinetta's funeral, however, that was arguable. "The doctors killed Quinetta! The doctors killed Quinetta!" shouted one of her aunts, who ironically had never shown up at the hospital while her niece was sick. "The doctors killed Quinetta!" I was the only non- African American and white person in the building, with my prematurely white hair that

stuck out like snow on asphalt, and everyone looked at me. Montez took me aside afterward and graciously told me not to mind her relative's ridiculous remarks. I understood, but I minded. I minded that I set out to be a doctor who healed children and ended up at their funerals. I minded being virtually powerless to save them or even to make their last days more bearable. I minded the system that thought of every reason not to help instead of devoting all its resources to salvaging these kids and our collective future. I minded terribly. "The bottom line is, AIDS is with us," I told an auditorium full of medical students as I clicked a slide- show projector during a lecture in late 1983. "We have a major problem. We must educate ourselves and our community about this disease and provide compassionate care to the children and adults who have it. We're fighting in our school districts about whether or not we should talk about sex rather than recognizing that the wolf is at the door." I next popped in a slide of a 13th-century cathedral in Venice, where Dr Tony Minnefor, I and our wives had recently traveled to present one of the initial papers on PHIV. The Minnifor family was becoming for Barbara and our children an extended family. Tony had been my mentor from medical school, influencing my career and taught me the skills I need to be a good pediatric infectious disease specialist. At six foot three, Tony and I were a much-unmatched pair which probably caused a few to smile at a short stubby excitable doctor gesticulating with a tall soft spoke giant of a man standing by him. Tony was one of the only pedestrians who share my early belief that children we were seeing together had a new and frightening infectious disease PHIV, AIDS. As I returned to my talk, I smiled at the memory, though a strange pain caught my attention, jabbing me under my breastbone and radiating through my arms. "This church was built in thanksgiving that the plague that had been running rampant was stopped. It's interesting that this was their response," I paused for a second to catch my breath. "The amount of money spent on this church far outstrips the amount of money we have spent trying to stop this disease." *Done.* I turned the projector off and, pulling my notes together, stepped off the stage and into the hallway. Then I clutched my chest and fell to the floor. I was thirty-eight years old, and I was having a heart attack. I will now leave this early part of my medical career, which I had written during my recovery from heart surgery and refer the reader to the rest of this story of the career of a Newark Pediatrician that was published in the AAP Spring Bulletin online in April 16, 2021 the time of my retirement.

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