



Brian T. Maurer, PA-C, practices pediatrics at Enfield Pediatric Associates, Enfield, Connecticut. He is the author of *Patients Are a Virtue* and a member of the JAAPA editorial board. Visit the author at <http://briantmaurer.wordpress.com/>.

A jaundiced view: More than meets the clinician's eye

“He’s getting IV hydration, supplemental oxygen, and morphine for the pain. He seems to be a bit more comfortable now—certainly much better than when he came in,” I say in the most reassuring voice that I can muster.

The woman sitting in the chair slowly nods her head, keeping her eyes turned toward the young black boy lying in the hospital bed. She has strikingly beautiful skin, almost golden brown in color. “You think he needs antibiotics at this point?” she asks me.

“He doesn’t seem to have fever. I’ve ordered a chest x-ray. We’ll see how things look after we review the film.”

“How is his spleen?” Her words begin to take on the authority of an attending physician.

“A bit enlarged, as we would expect with sickle cell disease. We’re keeping an eye on that as well. At this point it looks like a straightforward pain crisis,” I say, as if there were nothing complicated about unadulterated suffering.

When she glances up at me, I notice for the first time that her eyes are yellow. She reads the subtle shock betrayed by my face and smiles a long easy smile. “I was wondering how long it would take you to notice,” she says, somewhat nonchalantly. “What do you think: alcoholic hepatitis, substance abuse, maybe HIV?”

Caught off guard, I stammer indistinctly. All three are possibilities, I suppose, and yet—once again I study her face. Somehow her features seem somewhat familiar to me.

“Well, you can rest easy—it’s none of the above. You see, I’ve got sickle cell disease, too.”

Now I remember her. “Didn’t you used to be a social worker on the sickle cell service at Mount Sinai in the ’80s?” I ask her.

“Bingo!” she says. “Were you one of the students who rotated through the service?”

“Yes, I spent some time at the community health center as a resident in training back then. I thought you looked familiar, but I just couldn’t place your face.”

“You work here in the hospital now?”

“Just per diem. I take an overnight shift every once in a while to help fill the gap when there isn’t a family practice resident available to take call. Otherwise, I work in a pediatric practice north of the city. How about you?”

“Oh, I had to quit working some years back. My health hasn’t been good. With this disease I guess I’m lucky to still be alive at my age.”

I take a few steps closer to where the woman sits.

“Whatever happened to the director of the service?” I ask her. “Her name was Bernice; Bernice something—she had a hyphenated last name.”

I recognize the name as it rolls off the woman’s tongue. “She passed away several years back. You knew she had beta thalassemia, yes? Everybody knew. She got pregnant and almost died, but she had a son. Afterwards, I asked her, ‘Bernice, would you do it over again?’ and she said yes, it was worth all the suffering just to see her little boy’s face.”

“Is this your son?” I ask.

She turns her face to the boy, who now snores with his head thrown back on the pillow. “No, he’s my nephew. He lives with me now that my sister’s gone.”

“I’m sorry to hear that she passed. She had sickle cell disease, too?”

“Just a carrier. She died in an automobile accident—hit by a drunk driver.”

I stand in the momentary silence of an eternity.

“We’ve had a lot of heartache in our family,” she muses.

“Not the least of which is the curse of this no-good disease.”

“It must be devastating—”

“Devastating? You got that right. And that’s only the disease itself. You got all the other extraneous stuff to go along with it.”

A puzzled look involuntarily flashes across my face.

“No, you wouldn’t know,” she smiles. “People see you in the street, take your order in a restaurant, service your car, sell you stamps at the post office. They look at your eyes—those yellow eyes—and they think, ‘Here’s another addict, another alcoholic, another hooker with HIV.’ They never say anything in words, but the look on their faces lets you know what they’re thinking. It’s like you’ve been tried, judged, and convicted before you even got the chance to ask for whatever it was you wanted. It’s a horrible way to live—horrible all ’round.”

I recall a time during my residency when we transferred a boy with sickle cell disease to the PICU. He had developed pneumococcal septicemia. Despite high doses of antibiotics, his damaged immune system failed to fight off the microbial onslaught. Toward the end the police brought his father from prison to the bedside in shackles. A judge had granted the father’s plea to see his son one last time before he died.

Now, with 3 decades of medical practice behind me, I reflect that I still have much to learn about the myriad ways that any given disease can impact the lives of those who suffer from it. **JAAPA**