

I just want to focus on the good, like seeing my mother cells, and learnin about my sister." So we drove to Crownsville in our separate cars.

I don't know what I expected the former Hospital for the Negro Insane to look like, but it certainly wasn't what we found. Crownsville Hospital Center was on a sprawling 1,200-acre campus, with bright green hills, perfectly mowed lawns, walking paths, weeping cherry trees, and picnic tables. Its main building was red brick with white columns, its porch decorated with wide chairs and chandeliers. It looked like a nice place to sip mint juleps or sweet tea. One of the old hospital buildings was now a food bank; others housed the Police Criminal Investigation Division, an alternative high school, and a Rotary club.

Inside the main building, we walked past empty offices in a long, empty white hallway, saying, "Hello?" and "Where is everybody?" and "This place is weird." Then, at the end of the hall was a white door covered with years' worth of dirt and handprints. It had the words MEDICAL RECORDS stenciled across it in broken block letters. Beneath that, in smaller letters, it said NO THOROUGHFARE.

Deborah gripped the door handle and took a deep breath. "We ready for this?" she asked. I nodded. She grabbed my arm with one hand, threw the door open with the other, and we stepped inside.

We found ourselves in a thick white metal cage that opened into the Medical Records room—an empty, warehouse-sized room with no staff, no patients, no chairs, no visitors, and no medical records. Its windows were bolted shut and covered with wire and dirt, its gray carpet bunched in ripples from decades of foot traffic. A waist-high cinder-block wall ran the length of the room, separating the waiting area from the area marked AUTHORIZED PERSONNEL ONLY, where several rows of tall metal shelves stood empty.

"I can't believe this," Deborah whispered. "All them records is gone?" She ran her hand along the empty shelves, mumbling, "Nineteen fifty-five was the year where they killed her. . . . I want them records. . . . I know it wasn't good. . . . Why else would they get rid of them?"

1920s 1930s 1940s 1950s 1960s 1970s 1980s 1990s 2000s
2001

33 The Hospital for the Negro Insane

There were several things I'd promised Deborah we'd do together: seeing her mother's cells was first; figuring out what happened to Elsie was second. So the day after we visited Christoph's lab, Deborah and I set out on a weeklong trip that would start at Crownsville, where we hoped to find her sister's medical records, then go through Clover and end in Roanoke, at the house where Henrietta was born.

It was Mother's Day, which had always been a sad day for Deborah, and this one hadn't started well. She'd planned to take her grandson Alfred to see his father in jail before we left town. But her son had called saying he didn't want Deborah or Little Alfred visiting until he could see them without looking through glass. He told her he wanted to learn about his grandmother, Henrietta, and asked Deborah to send him whatever information we found on our trip.

"I been waiting for him to say that his whole life," she told me, crying. "I just didn't want him to have to get locked up in prison to do it." But once again, she said, "I'm not gonna let that stop me."

No one had to tell us something awful had happened at Crownsville—we could feel it in the walls.

"Let's go find someone who can tell us something," I said.

We wandered into another long hallway, and Deborah began screaming. "Excuse me! We need to find the medical record! Does anyone know where it is?"

Eventually a young woman poked her head out of an office and pointed us down the hall to another office, where someone pointed us to yet another. Finally we found ourselves in the office of a tall man with a thick white Santa Claus beard and wild, bushy eyebrows. Deborah charged over to him, saying, "Hi, I'm Deborah, and this is my reporter. You may have heard of us, my mama's in history with the cells, and we need to find some medical record."

The man smiled. "Who was your mother," he asked, "and what are the cells?"

We explained why we were there, and he told us that the current medical records were in another building, and that there wasn't much history left at Crownsville. "I wish we had an archivist," he said. "I'm afraid I'm as close as you'll get."

His name was Paul Lurz, and he was the hospital's director of performance and improvement, but he also happened to be a social worker who'd majored in history, which was his passion. He mentioned for us to come sit in his office.

"There wasn't much funding for treating blacks in the forties and fifties," he said. "I'm afraid Crownsville wasn't a very nice place to be back then." He looked at Deborah. "Your sister was here?"

She nodded.

"Tell me about her."

"My father always say she never went past a child in her head," she said, reaching into her purse for a crumpled copy of Elsie's death certificate, which she began reading slowly out loud. "Elsie Lacks . . . cause of death (a) respiratory failure (b) epilepsy (c) cerebral palsy . . . Spent five years in Crownsville State Hospital." She handed Lurz the

picture of her sister that Zakariyya had hanging on his wall. "I don't believe my sister had all that."

Lurz shook his head. "She doesn't look like she has palsy in this picture. What a lovely child."

"She did have them seizures," Deborah said. "And she couldn't never learn how to use the toilet. But I think she was just deaf. Me and all my brothers got a touch of nerve deafness on account of our mother and father being cousins and having the syphilis. Sometimes I wonder, if somebody taught her sign language, maybe she'd still be alive."

Lurz sat in his chair, legs crossed, looking at the photo of Elsie. "You have to be prepared," he told Deborah, his voice gentle. "Sometimes learning can be just as painful as not knowing."

"I'm ready," Deborah said, nodding.

"We had a serious asbestos problem," he said. "Most of our records from the fifties and earlier were contaminated. Instead of cleaning each page of the records to save them, the administration decided to have them carted away in bags and buried."

He walked to a storage closet near his desk, its walls lined with shelves and file cabinets. In the back corner he'd crammed a small desk, facing the wall. Lurz had been working at Crownsville since 1964, when he was a student intern in his twenties, and he had a habit of collecting potentially historic documents: patient records, copies of old admissions reports that caught his attention—an infant admitted blind in one eye with facial deformities and no family, a child institutionalized without any apparent psychiatric disorder.

Lurz disappeared into the closet and began muttering amid loud clunking and shuffling noises. "There were a few . . . I just had them out a couple weeks ago . . . Ah! Here we go." He walked out of the closet carrying a stack of oversized books with thick leather spines and dark green cloth covers. They were warped with age, coated in dust, and filled with thick, yellowed paper.

"These are autopsy reports," he said, opening the first book as the scent of mildew filled the room. He'd found them while rummaging

in the basement of an abandoned building at the hospital sometime in the eighties, he said. When he'd first opened them, hundreds of bugs scurried from the pages onto his desk.

Between 1910, when the hospital opened, and the late fifties, when the records were found to be contaminated, tens of thousands of patients passed through Crownsville. Their records—if they'd survived—could have filled Lurz's small storage room several times over. Now this stack was all that was left at Crownsville.

Lurz pulled out a volume that included some reports from 1955, the year Elsie died, and Deborah squealed with excitement.

"What did you say her full name was?" Lurz asked, running his finger down a list of names written in careful script next to page numbers. "Elsie Lacks," I said, scanning the names over his shoulder as my heart raced. Then, in a daze, I pointed to the words *Elsie Lacks* on the page and said, "Oh my God! There she is!"

Deborah gasped, her face suddenly ashen. She closed her eyes, grabbed my arm to steady herself, and started whispering, "Thank you Lord . . . Thank you Lord."

"Wow. This really surprises me," Lurz said. "It was very unlikely she'd be in here."

Deborah and I began hopping around and clapping. No matter what the record said, at least it would tell us something about Elsie's life, which we figured was better than knowing nothing at all.

Lurz opened to Elsie's page, then quickly closed his eyes and pressed the book to his chest before we could see anything. "I've never seen a picture in one of these reports," he whispered.

He lowered the book so we all could see, and suddenly time seemed to stop. The three of us stood, our heads nearly touching over the page, as Deborah cried, "Oh my baby! She look just like my daughter! . . . She look just like Davon! . . . She look just like my father! . . . She got that smooth olive Lacks skin."

Lurz and I just stared, speechless.

In the photo, Elsie stands in front of a wall painted with numbers for measuring height. Her hair, which Henrietta once spent hours

combing and braiding, is frizzy, with thick mats that stop just below the five-foot mark behind her. Her once-beautiful eyes bulge from her head, slightly bruised and almost swollen shut. She stares somewhere just below the camera, crying, her face misshapen and barely recognizable, her nostrils inflamed and ringed with mucus; her lips—swollen to nearly twice their normal size—are surrounded by a deep, dark ring of chapped skin; her tongue is thick and protrudes from her mouth. She appears to be screaming. Her head is twisted unnaturally to the left, chin raised and held in place by a large pair of white hands.

"She doesn't want her head like that," Deborah whispered. "Why are they holding her head like that?"

No one spoke. We all just stood there, staring at those big white hands wrapped around Elsie's neck. They were well manicured and feminine, pinky slightly raised—hands you'd see in a commercial for nail polish, not wrapped around the throat of a crying child.

Deborah laid her old picture of Elsie as a young girl next to the new photo.

"Oh, she was beautiful," Lurz whispered.

Deborah ran her finger across Elsie's face in the Crownsville photo. "She looks like she wonderin where I'm at," she said. "She look like she needs her sister."

The photo was attached to the top corner of Elsie's autopsy report, which Lurz and I began reading, saying occasional phrases out loud: "diagnosis of idiocy" . . . "directly connected with syphilis" . . . "self-induced vomiting by thrusting fingers down her throat for six months prior to death." In the end, it said, she was "vomiting coffee-ground material," which was probably clotted blood.

Just as Lurz read the phrase "vomiting coffee-ground material" out loud, a short, round, balding man in a dark business suit stormed into the room telling me to stop taking notes and demanding to know what we were doing there.

"This is the family of a patient," Lurz snapped. "They're here to look at the patient's medical records."

The man paused, looking at Deborah, then at me: a short black

woman in her fifties, and a taller white woman in her twenties. Deborah gripped her cane and stared him in the eye with a look that just begged him to mess with her. She reached into her bag and pulled out three pieces of paper: her birth certificate, Elsie's birth certificate, and the legal document giving her power of attorney over Elsie, something she'd spent months getting, just in case anyone tried to stop her from doing precisely what we were doing.

She handed them to the man, who grabbed the autopsy report book and started reading. Deborah and I glared at him, both so furious at him for trying to stop us that neither of us realized he was one of the only hospital officials who'd ever tried to protect the Lacks family's privacy.

"Can Deborah get a copy of that autopsy report?" I asked Lurz. "Yes, she can," he said, "if she submits a written request." He grabbed a piece of paper from his desk and handed it to Deborah.

"What am I supposed to write?" she asked.

Lurz began reciting: "I, Deborah Lacks . . ."

Within moments she had an official medical record request on a torn piece of paper. She handed it to Lurz and told him, "I need a good blowed-up copy of that picture, too."

Before Lurz left to make photocopies, with the bald man close behind, he handed me a stack of photos and documents to look at while he was gone. The first document in the stack was a *Washington Post* article from 1958, three years after Elsie's death, with the headline:

OVERCROWDED HOSPITAL "LOSES" CURABLE PATIENTS

Lack of Staff at Crownsville Pushes Them to Chronic Stage

The second I read the title, I flipped the article facedown in my lap. For a moment I considered not showing it to Deborah. I thought maybe I should read it first, so I could prepare her for whatever awful thing we were about to learn. But she grabbed it from my hand and read the headline out loud, then looked up, her eyes dazed.

"This is nice," she said, pointing to a large illustration that showed a group of men in various states of despair, holding their heads, lying

on the floor, or huddling in corners. "I'd like to have this for my wall." She handed it back to me and asked me to read it out loud.

"Are you sure?" I asked. "This is probably going to say some pretty upsetting things. Do you want me to read it first and tell you what it says?"

"No," she snapped. "Like he told us, they didn't have the money to take care of black people." She walked behind me to follow along over my shoulder as I read, then she scanned the page and pointed to several words on the page: "Gruesome?" she said. "Fearsome black wards?"

The Crownsville that Elsie died in was far worse than anything Deborah had imagined. Patients arrived from a nearby institution packed in a train car. In 1955, the year Elsie died, the population of Crownsville was at a record high of more than 2,700 patients, nearly eight hundred above maximum capacity. In 1948, the only year figures were available, Crownsville averaged one doctor for every 225 patients, and its death rate was far higher than its discharge rate. Patients were locked in poorly ventilated cell blocks with drains on the floors instead of toilets. Black men, women, and children suffering with everything from dementia and tuberculosis to "nervousness," "lack of self-confidence," and epilepsy were packed into every conceivable space, including windowless basement rooms and barred-in porches. When they had beds, they usually slept two or more on a twin mattress, lying head to foot, forced to crawl across a sea of sleeping bodies to reach their beds. Inmates weren't separated by age or sex, and often included sex offenders. There were riots and homemade weapons. Unruly patients were tied to their beds or secluded in locked rooms.

I later learned that while Elsie was at Crownsville, scientists often conducted research on patients there without consent, including one study titled "Pneumoencephalographic and skull X-ray studies in 100 epileptics." Pneumoencephalography was a technique developed in 1919 for taking images of the brain, which floats in a sea of fluid. That fluid protects the brain from damage, but makes it very difficult to X-ray, since images taken through fluid are cloudy. Pneumoencephalography involved drilling holes into the skulls of research subjects,

draining the fluid surrounding their brains, and pumping air or helium into the skull in place of the fluid to allow crisp X-rays of the brain through the skull. The side effects—crippling headaches, dizziness, seizures, vomiting—lasted until the body naturally refilled the skull with spinal fluid, which usually took two to three months. Because pneumoencephalography could cause permanent brain damage and paralysis, it was abandoned in the 1970s.

There is no evidence that the scientists who did research on patients at Crownsville got consent from either the patients or their parents. Based on the number of patients listed in the pneumoencephalography study and the years it was conducted, Lurz told me later, it most likely involved every epileptic child in the hospital, including Elsie. The same is likely true of at least one other study, called “The Use of Deep Temporal Leads in the Study of Psychomotor Epilepsy,” which involved inserting metal probes into patients’ brains.

Soon after Elsie’s death, a new warden took over at Crownsville and began releasing hundreds of patients who’d been institutionalized unnecessarily. The *Washington Post* article quoted him saying, “The worst thing you can do to a sick person is close the door and forget about him.”

When I read that line out loud, Deborah whispered, “We didn’t forget about her. My mother died . . . nobody told me she was here. I would have got her out.”

As we left Crownsville, Deborah thanked Lurz for the information, saying, “I’ve been waiting for this a long, long time, Doc.” When he asked if she was okay, her eyes welled with tears and she said, “Like I’m always telling my brothers, if you gonna go into history, you can’t do it with a hate attitude. You got to remember, times was different.”

When we got outside, I asked Deborah if she was sure she was all right. She just laughed like I was crazy. “It was such a good idea we decided to stop here,” she said, then hurried to the parking lot,

climbed into her car, and rolled the window down. “Where we goin next?”

Lurz had mentioned that any other remaining old records from Crownsville were stored at the Maryland State Archives in Annapolis, about seven miles away. He didn’t think they’d have any from the fifties, but figured it wouldn’t hurt to look.

“We goin to Annapolis see if they got more of my sister medical records?”

“I don’t know if that’s a good idea,” I said. “Don’t you want a break?”

“No way!” she yelled. “We got lots more reportin to do—we just gettin hot now!” She screeched off in her car, smiling and waving the new picture of her sister out the window at me as I jumped in my car to follow.

About ten minutes later, as we pulled into the parking lot of the State Archives, Deborah bounced in the seat of her car, gospel music blaring so loud I could hear it with my windows up. When we walked inside, she went straight to the reception desk, reached into her bag, pulled out her mother’s medical records, and waved them in the air above her head, saying, “They call my mother HeLa! She’s in all the computers!”

I was relieved when the receptionist said the archives didn’t have Elsie’s medical records. I didn’t know how much more Deborah could take, and I was scared of what we’d find.

The rest of the day was a blur. As we drove to Clover, each time we stopped, Deborah leapt from her car, clutching the new photo of her sister and thrusting it into the face of every person we met: a woman on a street corner, the man pumping our gas, a pastor at a small church, our waitresses. Each time, she said, “Hi, my name’s Deborah and this is my reporter, you probably heard of us, my mama’s in history with the cells, and we just found this picture of my sister!”

Each time, the reaction was the same: sheer horror. But Deborah didn’t notice. She just smiled and laughed, saying, “I’m so happy our reportin is going so good!”

As the day went on, the story behind the picture grew more elaborate. "She's a little puffy from cryin because she misses my mother," she said at one point. Another time she told a woman, "My sister's upset because she's been looking for me but can't find me."

Occasionally she'd pull over to the side of the road and motion for me to pull up beside her so she could tell me various ideas she'd come up with as she drove. At one point she'd decided she needed to get a safe deposit box for her mother's Bible and hair; later she asked if she needed to copyright Henrietta's signature so no one would steal it. At a gas station, while we waited in line for the bathroom, she pulled a hammer from her backpack and said, "I wish the family would give me the home-house so I can make it a historical place. But they won't, so I'm gonna take the doorknob so at least I have something from it."

At one point, Deborah climbed from her car looking near tears. "I been havin a hard time keepin my eyes on that road," she said. "I just keep lookin at the picture of my sister." She'd been driving with both of Elsie's pictures on the passenger seat beside her, staring at them as she drove. "I can't get all these thoughts outta my head. I just keep thinkin about what she must've gone through in those years before she died."

I wanted to take the picture from her so she'd stop torturing herself with it, but she wouldn't have let me if I'd tried. Instead, I just kept saying maybe we should go home, it had been an intense couple days, and perhaps she wasn't ready for so much reporting at once. But each time, Deborah told me I was crazy if I thought she was stopping now. So we kept going.

At several points during the day, Deborah said I should take her mother's medical records into my hotel room when we stopped for the night. "I know you'll have to look at every page, take notes and everything, cause you need all the facts." And finally, when we checked into a hotel somewhere between Annapolis and Clover around nine o'clock at night, she gave them to me.

"I'm going to sleep," she said, walking into the room next to mine. "Knock yourself out."