Sounding The Alarm

LeShandria is a twenty-seven-year-old petite African American woman with a small 5'2 frame. She moves about with an unsteady gait, as if she favors the use of one leg over the other. She described the cause of her limp which occurred at the time of her birth. Her delivery nurse had aggressively grabbed her by the leg and held her upside down unwittingly in a place where there was a damaged bone. This would be the beginning of a series of recurring experiences of unfair treatment at the hands of medical professionals.

LeShandria's parents first learned of her sickle cell disease (SCD) when she was two years old. She had swallowed a dime that was given to her. By 4 a.m. the next morning, LeShandria was running a fever of 103.7 degrees and soon became unresponsive. Her eyes were shut. There was no presence of movement. Two-year old LeShandria slipped into a coma on the way to the ER. Then LeShandria coded. After two minutes, doctors were able to revive her.

Blood tests determined that the dime LeShandria swallowed had infected her bloodstream and triggered a pain crisis, normally experienced by patients with SCD. These crises feel like "your bones are being crushed". LeShandria was born with the disease. Both of her parents were discovered to each carry a dominant sickle cell trait (SCT). Life altered drastically for her as having SCD would prepare her for a life of frequent hospital stays, a strict list of activities and weather conditions to avoid, a sequence of frequent pain crises, and sadly, experiences of prejudice and stigma associated with SCD.

At the age of seventeen, LeShandria visited an urgent care center to be treated for what she thought would be a typical sinus infection. Unbeknownst to her, she was having a pain crisis due to SCD. The doctor prescribed an antibiotic that was foreign to LeShandria's body, a choice that LeShandria expressly questioned. She repeatedly requested her usual medication that proved

effective. The doctor dismissed her concerns. “I know that you have sickle cell, I’m a doctor” he refuted, confident that his word as the professional carried the greater weight.

By day two of the medication, LeShandria experienced chills and fatigue. On day four, she was experiencing a pain crisis and a fever. She was rushed to the hospital. LeShandria mentioned her concern that her flare up was the result of the new antibiotic. “No, that can’t be possible, this is a known antibiotic,” doctors argued. Though LeShandria was released from the hospital, she was rushed back. By this time, she was experiencing seizure-like shivers and temporary memory loss. She didn’t recognize her mother, nor did she know her age. Doctors attempted to give her blood transfusions to no avail.

LeShandria’s mother, who was present at the time, remembered the moment doctors had chosen to forsake any further treatments. They warned that there was a low percent chance LeShandria would make it out of the hospital. Her mother initially requested an allergy test, but her request was ignored. After a drop in LeShandria’s heart rate, abnormal blood counts, and an induced coma, doctors finally acquiesced. “Let’s just give them what they’re asking for,” one doctor said. The test concluded that LeShandria was experiencing an allergic reaction to sulfur contained in the prescribed antibiotic combined with her SCD. This is just one of the many stories where doctors administered incorrect treatments for LeShandria, ignoring the proper actions they knew that they should take.

Other times, LeShandria remembers being overlooked in emergency rooms. In one particular instance, she entered the ER crying out during one of her pain crises. She was placed into the waiting room during which time, a young White kid had entered in and was admitted and treated for an ear infection. He was prioritized above LeShandria despite her agonizing pain.

During another pain crisis, LeShandria's mother attempted to have her admitted to the nearest hospital, but medical staff turned them away because they couldn't handle her SCD and suggested the two find the closest facility equipped to handle the matter. LeShandria recalled her mother begging to let an ambulance transport her to the nearest facility (thirty minutes away) if they could "at least get me out of pain", they refused. A White female entered in crying about chest pains. She was admitted and treated with pain medicine while LeShandria was instructed to remain in the freezing waiting room. For most patients with SCD, extremely hot or cold temperatures are triggers for pain crises. Frustrated and in pain, LeShandria went home and treated herself.

LeShandria's experience with medical gaslighting is a commonly shared experience amongst many of her friends who also live with SCD. "I've literally been on the phone with friends in the hospital in excruciating pain". She would overhear doctors refusing to give pain medicines and denying them certain treatments. The common theme is the outright dismissal of their symptoms as 'just being hysterical". To avoid dealing with racist attitudes and being accused of inventing their pain, many Black patients with SCD make the risky decision of avoiding going to the hospital altogether.

As a preteen, doctors always made a habit of explaining the risks of having children to LeShandria. They implore patients with SCD not to conceive and recommend birth control. Pregnancy would be too difficult. The one pro was that natural vaginal birth would not be extreme compared to sickle cell pain, which is ten times worse than labor pain.

At age twenty-five, LeShandria conceived her first child. She maintained a relatively low level of pain crises until the week she went into labor. "What were you thinking?!" That was a remark from the doctor that treated her. She jokingly asked the question with an underlying note

of seriousness in her tone. “I hope you’re done after this because you know the risk of having babies,” the doctor urged.

After almost a year, LeShandria conceived again. Unlike her first pregnancy, she suffered from both the pressure from the baby in her womb and a pain crisis from her SCD. She was rushed to the ER. LeShandria had become well-acquainted with her body and knew the kinds of treatments that were compatible with her SCD. Doctors disregarded her, explaining that they do not offer those types of treatment. LeShandria could sense that it wasn’t that doctors weren’t equipped to administer the treatment, they did not want to. “I would literally beg and plead with them,” she spoke as the frustration from the memory began to arise. Self-advocacy became a necessary survival tactic for her when dealing with negligent medical professionals.

Life for LeShandria now feels calmer. After the birth of her two children, she happily reports that she experiences less pain crises. She has now discovered a privately-owned Christian hospital where she receives more equitable treatment. The staff actively listens to her unique needs and provides a “safe space” where she feels accepted and valued.

LeShandria expresses that her story underlines the poor-quality medical care experienced by Black women (and other patients of color) living with SCD. They are often presumed uneducated and unable to make decisions about their own health and their pain is often not taken seriously. To evade dealing with racist attitudes, delayed emergency treatment, and being accused of faking pain, many Black patients make the risky decision of avoiding hospitals.

Her story also highlights an important topic in healthcare that continues unaddressed: the lack of education for medical staff treating patients with SCD. Society is vastly uneducated about this disease which is just as dangerous as cancer. Cancer and sickle cell patients often see the same type of specialist because SCD is also a blood disorder. Billions of dollars fund cancer

research. Educational marketing materials are widely available. In contrast, there is a grave lack of support and awareness for the often marginalized SCD community. Many people are uneducated about the inherited disease.

Furthermore, 1 in every 365 African Americans are born with the disease, and 1 in every 13 African Americans carry a sickle cell trait[1]. Consequently, SCD disproportionately affects African Americans as opposed to other ethnicities, providing momentum for a generation of advocates who seek to not only raise awareness of the dangers of the disease, but to expose the racial disparities and unfair treatment of African Americans with SCD.

LeShandria is one of the brave advocates making the decision to speak out. She appeared on a 2020 episode of Dr. Oz alongside many Black women who have dealt with health injustices and medical gaslighting by "trusted" professionals. She seeks to educate her friends and family on how to support loved ones with SCD and how to help them in a pain crisis. It is her hope to see more Black voices amplified to "sound the alarm" on behaviors of medical gaslighting and their dangerous consequences on the lives of patients with SCD. The health of an individual is a sacred ground where there must be a zero-tolerance stance toward racism and discriminatory practices.

[1] National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention. *Sickle Cell Disease (SCD).* 2022.