Tearrianna Cooke-Starkey

Osteogenesis Imperfecta

Six year old Tearrianna Cooke-Starkey was diagnosed with Osteogenesis Imperfecta (OI), also known as brittle bone disease, shortly after birth. Tearrianna was born with a broken arm and multiple other fractures at various stages of healing. She had short, bowed limbs along with a large, disproportionate head. OI was presumed, and later confirmed by genetic testing. OI is a rare bone disease where collagen, a structural protein, is defective, causing bone fragility.

Only in kindergarten, Tearrianna has already had over 40 broken bones and almost 20 surgeries. She has scoliosis and lordosis of her spine, severe curvatures that compromise her breathing. Tearrianna experiences pain and discomfort on a daily basis. She is cautious and guarded with her activities, though she longs to play with the other children at school. "She does not want to break bones so she chooses to not engage in certain activities," her grandmother and adoptive mother Marnie explains. "Her self-preservation often takes priority over playing with other kids."

Tearrianna is susceptible to pneumonia as a result of restrictive lung disease. She also lives with a colostomy bag due to poor bowel motility and chronic constipation, and requires a feeding tube for nutrition. She experiences frequent dental issues including worn and broken teeth, caused by dentinogenesis imperfecta, a companion disorder to OI.

Tearrianna's family has developed a close relationship with Laura Tosi, MD, a pediatric orthopaedic surgeon at Children's National Medical Center, who has performed multiple surgeries to help Tearrianna gain stability and mobility. After several rods in her legs, Tearrianna can now stand on her own and walk with a walker, but typically scoots on the floor to get around home. The older and stronger she gets, the fewer fractures she will endure.

Life for the Starkey family is challenging. Marnie and her husband Ted serve as full time caretakers. "With Tearrianna's special handling needs and various medical issues, we have not been able to find someone we are comfortable leaving her alone with," Marnie explains.

"One of our biggest issues is always explaining why Tearrianna cannot do what other kids her age do," Marnie says. "She asks about getting bigger and taller, if she will always have special bones, and if she will live with us forever." Tearrianna laments being dependent on others for all activities of daily living. She needs assistance with nearly everything; at only 33" tall, she cannot reach anything or navigate steps or stairs.

Tearrianna enjoys SpongeBob, playing with Barbies and watching YouTube videos, like other kids her age. She loves music and arts and crafts. Her family's number one wish is for her to be able to live a healthy and fulfilling life. They know that advancements in research have already improved the lives for children and young adults with OI, but further research is needed.

"Rods and bisphosphonates have been the norm for many years now," Marnie explains. "Kids with scoliosis are difficult to treat or brace with their unique and challenging anatomy." The Starkeys would like to see advancements in pediatric orthopaedic implants that are less prone to migration, and drug treatments that are as effective as the current IV medications to reduce time in the hospital. "So much more is possible when researchers have the budget to continue their work."