

HELP FOR GOOD

Tannesha



Stark County
Board of
Developmental
Disabilities



Tannesha

Meet 34-year-old Tannesha Venet, daughter of John and Joni Venet. Her story is shared by her mother, Joni.

“Amazing, Faithful, courageous, dedicated, and loving are a few words, I would use to describe our daughter, Tannesha Venet.

Abandoned in Children’s Hospital Pediatric Intensive Care Unit (PICU) at age 2 $\frac{1}{2}$, she was placed on dialysis, undergoing several invasive medical procedures without parental support. The hospital was her home, nurses and doctors were her family.

Working at Children’s Hospital, I was asked to get a child for a speech evaluation. That day changed our lives forever. Walking in her room my heart was touched spiritually, knowing exactly what God wanted us to do. “We are going to adopt this child.” The adoption was finalized when Tannesha was 5 years old.

Learning dialysis was easy, dealing with the emotional trauma was difficult--so many hospitalizations, life threatening infections. We were so thankful for the prayers from our friends, family and church. I promised I would never leave Tannesha in the hospital and I haven’t.

Seeing how difficult dialysis treatments were, I decided to give Tannesha a kidney. Unbelievably, I was a match, and surgery was in 1996. However, two days post-transplant, she was critically ill. The Diagnosis...[Atypical Hemolytic Uremic Syndrome](#).

We lived in Columbus for six weeks so she could go for daily treatments. Tannesha was 8 years old.



Two weeks later Tannesha was back on dialysis four hours three times a week. Hemo-Dialysis is extremely damaging to your body. We prayed for another kidney to become available. Tannesha received her second transplant in Minnesota 1998. We were hopeful this transplant would be successful. Despite Plasma Pheresis treatments every day for a year, her severe-ultra rare disease reoccurred. Due to her unstable medical condition, we lived in Minnesota for six weeks. By the year 2000, she was back on dialysis. No more transplants, no medication for this ultra-rare disease.

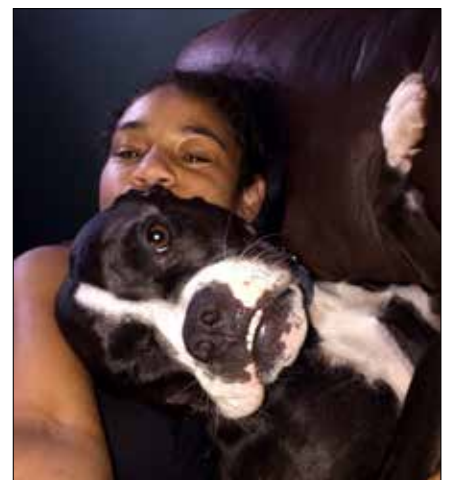


Tannesha had been on dialysis for 26 years. After learning to do home hemo dialysis, we brought her home for dialysis treatments. Tannesha learned how to self-cannulate, accessing her graft independently. She has endured many life threatening infections, and God has sustained her life to tell her story. Don't lose hope. We didn't.



We eventually found a medication, Solaris, for her disease. After much research we went to Baltimore for her third transplant. With God all things are possible. But there was not much time for Tannesha to survive on dialysis. In December 2016, Tannesha received her third kidney at Johns Hopkins Hospital. After 6 weeks, we went home. One day at a time, receiving Solaris infusion treatment twice a month the kidney survived. This is the first time in Tannesha's life she did not require a machine to sustain her life.

Three years after the transplant Tannesha was diagnosed with cancer. She was amazing and incredibly brave. Tannesha and I traveled back to Baltimore for her cancer surgery. Tannesha fought to survive, enduring everything to beat this cancer, and



she did. She weighed 76 pounds when we came home from the hospital.

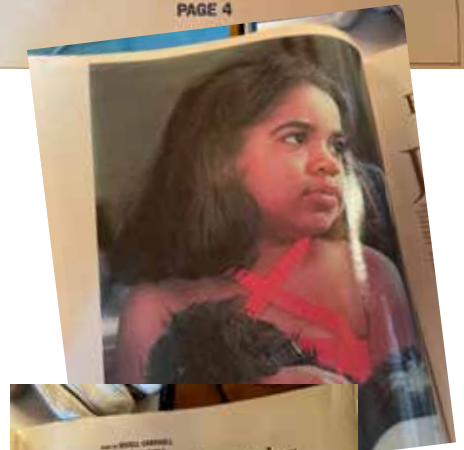
Recently Tannesha has been reunited with her siblings. She eagerly awaits new life adventures. Tannesha has also been volunteering at the Sippo Lake Wildlife Center. She has been taking care of baby animals. This is also something that Tannesha used to do but stopped doing after the cancer surgery. Taking care of animals is one of her passions and she loves doing this volunteer work.

Susan Barillari, Stark DD Service and Support Administrator, shared that Tannesha recently received a Level 1 Medicaid Waiver in order to obtain support in the home for Tannesha. "Both parents were working and had to leave Tannesha home alone. They were concerned because Tannesha has very complex medical issues due to having end stage renal disease (a lifelong condition)," said Susan.

Once the waiver was approved Joni applied and became an independent provider so that she could retire from her job and stay home as Tannesha's HPC provider. Joni would be able to do all of the things that an HPC provider can do, but also provide natural support as her mom.

"In December 2022, Tannesha's family was given an award by the Honorable Judge Dixie Park, Stark County Probate Court, because of their remarkable adoption story as being adoptive parents of Tannesha," said Susan. "Tannesha has an amazing story as survivor of very complex medical conditions with the support of her adoptive parents."

"Tannesha constantly fights to survive," said Joni. "It is an honor to be her mom."



Over the years, the Venet's story has been told and updated in the Akron Beacon Journal by reporter Jewell Cardwell.