

Our family was first introduced to the Clinic for Special Children in 2018 when our daughter was born with a significant heart defect at Penn State Children's Hospital. The NICU doctor recommended that we call the Clinic and ask them to do genetic testing for her. Dr. Vincent Carson, Clinical Operations Director and Pediatric Neurologist at the Clinic, came to the hospital to get her blood sample. The genetic testing didn't show anything abnormal at the time. Analisa had open heart surgery at 11 days old, and sadly, she never recovered from surgery. The doctors were very perplexed by this.

Fast forward to August 2019 and our son, Jevon was born. He did not breathe on his own at birth. The doctors couldn't find a reason for this, so he was transported to Penn State Children's Hospital. We again did genetic testing at the Clinic, but this time one of the NICU doctors suggested that the Clinic to specifically test for CODAS syndrome as he was showing some symptoms of this genetic disorder. CODAS syndrome is a rare genetic disorder in which children experience cerebral (brain), ocular (vision), dental, auricular (hearing), and skeletal differences.



*Jevon & Josiah King*

The Clinic quickly processed the genetic test and Jevon was diagnosed with CODAS syndrome at 10 days old. Thanks to the diagnosis and the compassionate care we were provided, we got to bring him home at 6 weeks old! After realizing how CODAS syndrome can affect the heart and kidneys, we finally had answers as to why Analisa, Jevon's sister, did not recover from heart surgery.

In 2021, we welcomed our second son, Josiah, to our family. Shortly after birth, it was confirmed that he has CODAS syndrome as well through quick and accessible genetic testing at the Clinic.

Both Jevon and Josiah see Dr. Laura Poskitt, Pediatrician at the Clinic, every three to six months for primary and coordinated care. Each visit, Dr. Poskitt checks their weight and adjusts their feeds accordingly, as they are both fed through a G-tube, which puts nutrients directly into their stomach. She also coordinates their care with the specialists that they need to see, and answers our many questions. I appreciate how she always takes time for us, and never rushes through their appointments.

Thanks to the care provided by the Clinic, today Jevon and Josiah are happy and cheerful brothers. Jevon loves books and music and communicates by signing. Just last year, he "sang" a song at his church's Christmas service. Josiah loves to play peek-a-boo and is now crawling! Their progress wouldn't have been possible without the coordinated care provided by the Clinic and the genetic answers we were able to receive.

We greatly appreciate how the clinic makes genetic testing affordable and accessible and provides fabulous care for our children.

*The King Family*

