

Hello! Thank-you for the privilege of letting me share with you today what CCS has meant to the Kenworthy family. I'm Donnell, and my son is DJ.

20 years ago, when DJ was born, we thought we had prepared ourselves for the birth of our fifth child, born when my husband and I were pastoring a small church on the north coast in Humboldt County. Minutes after his birth we knew that DJ had severe complications, and a transport team was called from UC San Francisco. My husband and I explained to the discharge nurse that we could not cover these costs. It was a frantic time and decisions for DJ's care were coming fast and furious and we felt like we were in **freefall**. This nurse assured us there were safety nets in place for our son.

Within 24 hours DJ was diagnosed with heart conditions requiring multiple surgeries, including open heart. DJ stayed at UCSF for 2 months. I did not know that you could actually LIVE in the hospital, but I learned you could as night after night I was given a bed to stay close to my son as he fought for his life. CCS provided housing, food vouchers, coordination and payment for his complicated care.

We were overjoyed when DJ came home but in the months following DJ faced more complications and more hospitalizations. He also needed a gastrostomy-tube placed to feed him. A CCS paneled doctor at UCSF did the surgery.

Just prior to his first birthday, his local doctors were stymied as DJ began turning blue 4 and 5 times a day, gasping for oxygen. He needed the specialty care of a CCS paneled pulmonologist in San Francisco. He spent three months in ICU where he was diagnosed with severe malacia, and received a tracheostomy and a vent to help him breathe. As this drama played out in DJ's life, CCS coordinated services for 16 hour-a-day nursing care required for DJ to return home.

At home his bedroom had been outfitted like an ICU for his needs. He was an active little guy, bouncing around his crib, causing his nurses to lament, "I thought he was just going to lie there!" DJ amazed everyone when he healed enough to have his trach and vent removed just before his second birthday.

Our safety net, CCS, continued to support us as we moved from Humboldt to Yolo County. We no longer had a 5 hour drive or a medical flight for the care DJ needed. We could drive him 20 minutes to CCS paneled providers like pulmonology, gastroenterology, cardiology, nutrition, respiratory, and primary care. We were grateful for this support when DJ had his second open-heart surgery at age 5.

Sometimes we did feel that things could have gone better with CCS. I have often wished that we as parents could provide more frequent feedback through a survey process. Sometimes we felt adrift when services or medications were denied.

Transition out of CCS is looming as DJ ages out at age 21. I feel that CCS could do a better job of preparing and supporting families in identifying and securing providers in their communities.

What has been great about having CCS is that, like recently when DJ had pneumonia, when insurance denied the medication ordered by a CCS paneled pulmonologist, I was able to call Ellen, our care coordinator, who knows DJ's needs and made sure he received timely access to what he needs. CCS **has** been and **continues** to be a safety net alleviating fear and anxiety, helping our family heal, literally saving DJ's life, and for that I am grateful.