PORTAL is one of 29 networks in the National Patient-Centered Outcomes Research Network (PCORnet), which seeks to improve the nation’s capacity to conduct comparative effectiveness research by creating a large, representative network of care delivery systems and their data assets. The PORTAL network consists of Kaiser Permanente, HealthPartners, and Denver Health, and their 11 affiliated research centers.

Loretta Nierat
Patient Engagement Council
Congenital Heart Disease Cohort

Loretta’s son Sean was born with congenital heart disease (CHD). Today, after having graduated from college in May 2017, he is a Product Marketing Manager for cyber security in Silicon Valley. As a parent advocate, Loretta feels it is important for parents to seek care if they think something is wrong with their child, to educate themselves on the condition and treatment, and to empower their children to advocate for themselves in age-appropriate ways. Because Sean’s condition is genetic, the Nierats had elected not to have more children. There are no extended family members nearby, so the Nierats learned to manage on their own. While this has not always been easy, the Nierats describe themselves as “strong individuals” and Loretta also credits some of Sean’s success to his positive outlook on life and likable personality.

Sean was born to Loretta and her husband in 1995 in Santa Clara, California. When he was 7 days old, his breathing became labored. Loretta was not sure how serious it was, but she followed her instinct and took him to the doctor. Within 15 minutes of their arrival, he was in the emergency department. He had no pulse in his toes, which meant no circulation in his legs.

Doctors said they were not sure Sean would survive the night. However, they quickly diagnosed that the problem was his heart, and he was taken by ambulance 45 miles away to UCSF Medical Center, which specializes in treating infant heart emergencies. Doctors there said Sean needed open heart surgery, which occurred the following morning. His surgery was successful, but Loretta learned later that another baby who had a similar surgery immediately before Sean by the same surgeon did not survive.

The Nierats were told that Sean would need another surgery, probably as a teenager, and that he should not play strenuous sports that would bring up his heart rate. He was able though to participate in gymnastics as a child and later in sailing, kayaking, horseback riding, golfing and more. When he was almost 18, the pediatric cardiologist he’d had since birth retired, and he was transferred to an adult congenital heart disease (CHD) specialist.

Since he had been doing so well for so long, Loretta thought Sean’s condition would require only a minor procedure during adulthood. In 2014, however, midway through Sean’s freshman year at Southern Methodist University in Dallas, the cardiologist told him he needed open heart surgery. This news was especially troubling given that Loretta had just been diagnosed with breast cancer and was undergoing treatment. Sean had his second successful surgery that summer.

Because of her experience as a CHD family member who over the years has balanced caregiving responsibilities with work and her own health problems, Loretta brings the perspective of a caregiver to PORTAL’s Patient Engagement Council. As a parent advocate, she suggests that parents tell children about their condition at an early age, explaining in simple terms when they are young and then providing more details and vocabulary as they grow older. In addition to involving them, it is important that they can speak for themselves (for example, at camp) when parents aren’t present. Another recommendation is to ask the doctor what physical activities are allowed; and for doctors to share that information even when they are not asked.

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