Diagnosed at birth with a congenital heart defect (CHD), Nicole Sanchez can’t recall that her childhood was any different from that of her brothers — other than annual visits to the cardiologist. Throughout her childhood, she lived like other kids, starting with tap and ballet at age two. Even so, she recognizes that “CHD encompasses your whole life, it is integral to everything you do. There is never a time you do not have it.” Those cardiologist visits, which continue today, have played an important part in her life, and it’s the need for that kind of active participation in health care that she wants to share with others who have CHD.

Nicole was diagnosed with tricuspid atresia immediately after her birth. She had no tricuspid valve and a hypoplastic right ventricle, which means only half of her heart was functioning. As a result, she had surgery within a few days and again at 6 months of age. Then, at age 5, she had a Fontan procedure, which diverts the blood around the nonfunctional part of her heart. In July 2017, she had her 2nd open heart surgery in which surgeons did a Glenn procedure, MAZE procedure, Fontan revision, and a pacemaker placement.

As someone with CHD, Nicole has faced big decisions, such as having kids, and feels that active care participation has made these decisions easier. A parent of two boys ages five and eight, Nicole says her pregnancies and childbirth experiences were handled with caution under the supervision of a high-risk obstetrician. During her second pregnancy, she started taking blood thinners. Although she and her husband might have liked to have more children, they decided to stop with two. She’s remained on blood thinners, which has affected what she can eat and drink.

In addition to serving on the Patient Engagement Council, Nicole has been involved since 2012 in an organization called Mended Little Hearts, which supports CHD families. She is the coordinator of the Bay Area group, is the regional director representing the West Coast, and is active at the national level.

Until a few years ago, Nicole didn’t know there were CHD support groups. In fact, she had never met anyone with a heart defect. Although she’s never felt isolated or alone, she says she’s enjoyed getting to know others in the CHD community. Nicole feels that her parents were essential to her successes and served as great models for health advocacy.

Nicole feels she has a somewhat unusual role as a mother with CHD. “When people find out I have had two children, they have a lot of questions,” she says. She is open and willing to share her story, and possesses good communication skills. As an advocate, she encourages others to tell their stories, and in the medical setting, to speak up if they are having problems and be honest with their health care providers.

Nicole Sanchez
Patient Engagement Council
Congenital Heart Disease Cohort