



Heart to Heart Global Cardiac Care

SITE: SAENZ NATIONAL
CHILDREN'S HOSPITAL
LOCATION: SAN JOSE, COSTA RICA
COLLABORATION LAUNCHED: 2021

Measurably Expanding Access Since 1989

MARCH 8–19, 2022
CARDIAC TRAINING MISSION 2
PATIENT STORY



PATIENT PROFILE

Child	Julian Z.
Age	5 years old
DOB	January 6, 2017
Home	San Jose, Costa Rica
Parents	Karolina and Andres
Diagnosis	Truncal valve insufficiency; s/p truncus arteriosus repair (2017, Costa Rica)
Open heart surgery	Truncal valve replacement with mechanical valve, RV- PA conduit replacement (March 17, 2022)
Discharged from PICU	March 21, 2022

Based on an interview conducted in Spanish by Lucie Everett, Heart to Heart staff.

HOUSEHOLD AND FAMILY

Julian is an only child. He is five years old and lives with his parents, Karolina and Andres, in San Jose, Costa Rica. A cheerful and lively little boy, Julian is energetic and loves to dance. He takes hip hop lessons and, according to his teacher, is one of the more playful children in his class.

Karolina and Andres were aware that their baby might be born with congenital heart disease (CHD), given that Andres himself was born with Tetralogy of Fallot, a complex but common heart defect. In 1984, when Andres was born, there were no treatment options for a child born with severe CHD in Costa Rica. In fact, it was not until two years after his birth, in 1986, that open heart surgery would first be performed on a child in his home country.

In 1993, at the age of nine, Andres's symptoms had become acute: he was unable to walk or eat and was extremely cyanotic. That same year, Andres underwent an open heart operation which was described to him as "experimental." Now, worried about his own son, Andres understands what his parents must have gone through.

CHILD'S DEVELOPMENT AND MEDICAL HISTORY

Julian was diagnosed with CHD prenatally during a routine ultrasound appointment. Andres and Karolina shared with us their heartbreak upon hearing their newborn baby's prognosis – doctors gave Julian no more than six months to live: "That day was so very difficult...an absolutely negative prognosis." In fact, a death certificate was issued for Julian. "We had it at home in case at any moment it were to happen. We wouldn't need an autopsy, we could just give the certificate."

As an infant, Julian underwent a truncus arteriosus repair in Costa Rica. However, his struggle was not over and his condition worsened. But Andres and Karolina never gave up hope. Thankfully, that same year, visiting doctors from the U.S. informed them that surgery to repair Julian's heart was possible.

CURRENT CONDITION

When Heart to Heart met five-year-old Julian, his truncal valve was no longer functioning well. On March 17, 2022, Heart to Heart and Saenz surgical specialists worked closely to replace his insufficient truncal valve with a mechanical one; and by replacing the RV-PA conduit implanted in infancy, they were able to improve the flow of blood to his lungs for oxygenation. Julian's postoperative recovery was smooth and he was discharged from the PICU just four days after his surgery.

There is a higher incidence of CHD in children born to a parent with CHD. The lives of Andres and Julian reflect this reality and their stories serve as a reminder of the need to expand access to life-saving heart care for children and adults worldwide.