

Measurably Expanding Access Since 1989

SITE: NATIONAL CHILDREN'S HOSPITAL (HNN) LOCATION: SAN JOSE, COSTA RICA COLLABORATION LAUNCHED: 2021 MARCH 8–22, 2023 CARDIAC TRAINING MISSION 4 PATIENT STORY



PATIENT PROFILE

Child	Ezequiel F.
Age	8 years old
DOB	August 20, 2014
Home	San Rafael Arriba, Costa Rica
Parents	Esteban
Diagnosis	BAV, severe AV insufficiency; s/p coarctation repair, balloon aortic valvuloplasty
Open heart surgery	Ross procedure
Date of procedure	March 16, 2023
Discharged from PICU	March 30, 2023

"Sometimes I wish I could be like a normal kid and I could only come to the hospital when I hurt myself or if I need a vaccination."

 EZEQUIEL F., 8 YEARS OLD HEART TO HEART PATIENT

HOUSEHOLD AND FAMILY

Eight-year-old Ezequiel was born with a bicuspid aortic valve (BAV) and coarctation (narrowing) of the aorta. He lives with his mother and two older siblings in Desamparados, Costa Rica, about 40 minutes from the capital city of San Jose.

Ezequiel is an intelligent, expressive boy. During our conversation, he shared his experiences growing up with congenital heart disease (CHD): "I don't really like having CHD. I can't do anything... well, I can do some things. But at school, they don't let me do much. I just sit and paint. I can only run a little bit."

CHILD'S DEVELOPMENT AND MEDICAL HISTORY

Ezequiel underwent his first surgery when he was just one week old. He needed additional surgeries at three months, and then again when he was two years old.

The heart defects that Ezequiel was born with, coarctation of the aorta and BAV, mean that his heart cannot pump sufficient blood to the body. BAV is present at birth in 2% of the population, technically making it the most common birth defect worldwide. It is often the cause of heart valve disease and related symptoms in adulthood, but in cases like Ezequiel's, where BAV occurs with coarctation, timely intervention in childhood may be necessary. Although life-threatening, this type of CHD is treatable and children like Ezequiel can live full lives, able to run and play freely.

TREATMENT AND FOLLOW-UP CARE

In March 2023, Ezequiel was operated on by a joint Heart to Heart-HNN team. His surgery, a Ross procedure, involved replacing the aortic valve with his own pulmonary valve. A homograft valve was then placed in the pulmonary position. The surgery was lengthy and challenging, but thankfully, successful and Ezequiel returned home about two weeks later.

In the future, Ezequiel will need additional re-intervention to replace his pulmonary homograft valve, either through open heart surgery or in the cardiac cath lab. Although there is a wide timeframe over which the homograft valve deteriorates, typically patients require re-intervention by IO to I5 years after their initial repair.

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