



Heart to Heart Global Cardiac Care

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



HOUSEHOLD AND FAMILY

Fourteen-year-old Deborah was born with complete atrioventricular septal defect (CAVSD), also known as atrioventricular canal (AV canal), and Down Syndrome. She and her family live in San Carlos, Costa Rica, quite close to the Children's Hospital in San Jose. The type of CHD with which Deborah was born is very common among babies born with Down Syndrome. In fact, 40% of children born with Down Syndrome also have some kind of congenital heart defect (often CAVSD).

Deborah is quite shy when first meeting people, but cheerfully opens up once she feels comfortable. When we met her in March 2023, Deborah's mother told us that her daughter aspires to be a model. It was clear she was a natural! With a cool pink streak in her hair, she posed for the camera as we took photos of her in the pediatric ward at the Children's Hospital. Her mother told us that, since Deborah would be turning 15 in June, their family was in the process of organizing a *quinceañera*—and Deborah would need to decide on her dress soon. She knew she wanted a pink dress, to match the streak in her hair.

PATIENT PROFILE

Child	Deborah C.
Age	14 years old
DOB	June 13, 2008
Home	San Carlos, Costa Rica
Parents	Rosa
Diagnosis	CAVSD, subaortic stenosis, Down Syndrome; s/p CAVSD repair, resection of subaortic membrane
Open heart surgery	Re-do subaortic membrane resection, septal myectomy
Date of procedure	March 17, 2023
Discharged from PICU	March 21, 2023

CHILD'S DEVELOPMENT AND MEDICAL HISTORY

Deborah's CAVSD was repaired early in childhood. When Heart to Heart medical volunteers examined her, our joint team found she had subaortic stenosis, a narrowing below her aortic valve, impairing its function. Deborah needed another open heart surgery to repair this defect. Children born with certain types of CHD (including heart valve defects) may need to undergo a series of surgeries, each of which must be performed within a particular timeframe determined by a variety of factors like the patient's weight, heart size, and severity of symptoms. For this reason, it is of utmost importance for patients to have access to cardiac centers able to provide comprehensive cardiac care, including routine follow-up appointments with cardiologists.

TREATMENT AND FOLLOW-UP CARE

On March 17, Deborah underwent an operation to repair her heart defect. Her open heart surgery was performed by a joint Heart to Heart-HNN team at the National Children's Hospital. Thankfully, Deborah's surgery and recovery were fairly smooth and her prognosis is good: she will be able to dance to her heart's desire at her 15th birthday party!

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