

MADISON DUGAS' STORY



Madison Dugas is a three-year-old with Down syndrome. She lives in Elizabethtown, and her mom Beth describes her as sassy but sweet. She isn't speaking yet, but she doesn't have any problem sharing what's on her mind with those around her.

Like about 50% of people with Down syndrome, Madison was born with a heart defect. Her mom was about 20 weeks along when the ultrasound indicated she had a profound heart defect, and that there would need to be surgery immediately after she was born. The defect in Madison's heart is called hypoplastic left heart syndrome, meaning the left side of her heart was underdeveloped at birth.

To fix the defect, there were three surgeries, the first being done when she was a week old. The second was done when she was 2 months old. Sadly she went into heart failure shortly afterwards, and it was clear she needed a transplant. Madison was lucky – she was listed for a transplant in early April, and her transplant took place in early June of that year. She was 7 months old when she got her new heart.



Now she is three, and thriving in many ways, although you can imagine the health complications that accompany a transplant. The medicine she takes to keep from rejecting her heart are damaging her kidneys. And she has chronic lung disease and takes oxygen every night. She also has a very compromised immune system, and has been to the hospital so many times for respiratory infections that her mom joked about sharing custody with the hospital. But she is alive, and her support network is up to the challenge of caring for Madison and her complicated health care needs.

As Beth, Madison's mom tells it, the thought that Madison might not be eligible for a heart transplant never crossed her mind, until her health care provider had a conversation with her. He told her the right thing – that simply having an extra chromosome doesn't disqualify her from getting a new heart.