

8-year-old beats the odds against heart and brain birth defects

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Maggie Maine, who is now 8 years old. Photo: Maine family

The day after Maggie Maine was born, doctors told her parents there

was a 70 percent chance she'd never walk, talk or be able to feed or bathe herself.

An MRI had found severe defects in both her heart and her brain.

Relying on their faith, Jeff and Renae Maine decided to focus on the 30 percent chance that the doctor was wrong, that Maggie would grow up to be "normal."

"We're focusing on the positive instead of the negative," said Jeff.

Maggie's prognosis wasn't a surprise. Ultrasounds done before she was born had already found defects in her brain and heart. The MRI only confirmed those findings.

Doctors told the Maines, who live in Bluffton, South Carolina, that about 75 percent of Maggie's cerebellum was missing due to a rare condition called Dandy-Walker variant. Located in the lower, back portion of the brain, the cerebellum plays a vital role in balance and in coordinating muscular activity necessary, for example, to ride a bike.

She also had a heart condition called tetralogy of Fallot, a combination of four heart malformations. These include a hole between the lower chambers of the heart that allows oxygen-poor blood to flow out of the heart to the rest of the body.

Tetralogy of Fallot symptoms include a bluish skin tone, chronic fatigue, especially during physical activity, and a dangerous thickening of the heart walls.

The best news Jeff and Renae heard following the MRI was that Maggie's [heart defects](#) were repairable. She had her first open-heart surgery at just 3 months of age and, a week later, had a pacemaker

implanted into her abdomen.

From that scary, gloomy start, look at her now, at age 8.

While there's no treatment for Maggie's brain defect, her cognitive development has so far been completely normal.

"She's in second grade but she's reading at a fifth-grade level," Renae said. "She loves to write, play the piano and she even takes dance lessons. She's just a normal, energetic little girl."

About the only signs of her condition, her parents said, is that she sometimes has difficulty with balance and that she runs slower than other children her age.

One of Maggie's many neurologists called her development "unexplainable." The Maines prefer "miracle."

Yet, while they've tried to remain optimistic, Jeff concedes there have been "dark days."

"We're human, too, so sometimes the optimism fades," he said.

As for Maggie, her parents say she understands her physical limitations, but at an 8-year-old level.

"She calls her pacemaker her 'battery,'" Jeff said. "We were at the airport recently and she asked if the security scanner would hurt her battery."

Maggie has had four additional [heart](#) surgeries since her early months. There are more to come, yet the prognosis is encouraging.

"Maggie's doing great, although she has challenges ahead of her," said her pediatric cardiologist, Dr. Patrick Broderick with the Savannah Children's Heart Center. "She's had some leakage through the pulmonary valve, for example, so she'll eventually need a new one. We'll try to wait until she's 12, maybe 14 years old before we do that, though."

Broderick said he tried to encourage Maggie's parents by telling them the Olympic snowboarder Shaun White was born with tetralogy of Fallot.

"So now I tell them that she owes me three gold medals," Broderick said.

But Maggie has already decided she wants to be a cardiologist when she grows up. So perhaps someday she'll be doing these procedures herself on another little girl.

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