

Shay's Story

If you saw my daughter, Shay Gammon, playing on the playground, you would be hard-pressed to single her out as a chronically-ill child. You would see her swinging and giggling, and you would never guess that she has endured more in her brief lifetime than most adults.

By the age of three, Shay had survived three open-heart surgeries. She was just four days old the first time she was operated on; her heart was the size of a walnut and her chest was so small they had to leave it open after the procedure until the swelling went down. As a result, I have seen my child's heart. I've watched my daughter struggle to breathe, throw up blood and refuse to eat. But through it all, I have been ever-mindful that our family is among the "lucky" ones. Shay was given a huge head start in her fight because her condition was diagnosed in utero. Had she been diagnosed too late, Shay might have many more obstacles to overcome or she might not be here at all.

Shay was born with a complex congenital heart defect (CHD). We do not know what caused it. CHDs are the most common and the most deadly birth defect, occurring in nearly 1 of every 125 children born. They range from relatively minor defects that may heal themselves or are repairable with minimally invasive procedures, to complex defects that require one or more open-heart surgeries. Some may require an operation as early as the first week of life. Even very complex CHDs can be missed on routine prenatal ultrasounds and the warning signs may not be seen until the newborn is home. Unfortunately, the delayed diagnosis and treatment of some CHDs may cause serious, life-long damage beyond the CHD itself.

In Shay's case, though many things had gone wrong as her heart developed, many things went right in her diagnosis and treatment. Our first stroke of "luck" was having an obstetrician who orders ultrasounds (some do not), and then having an experienced ultrasound technician who was also very cautious. When the tech could not see all four chambers of Shay's heart, she had me come back—twice. It is not unusual for an ultrasound

technician to assume the baby is just positioned wrong when they can't see all the chambers and to not follow up. We were referred for further testing, including a fetal echocardiogram to confirm Shay's diagnosis—Hypoplastic Left Heart Syndrome (HLHS). HLHS is one of the most severe and deadliest of identified CHDs. The child is essentially born with only half of a heart. The valves, aorta and ventricle on the left side of the heart are either very small or absent, preventing proper circulation and oxygenation of blood. When diagnosed in utero, medical intervention is started immediately following delivery. Without any intervention, HLHS is always fatal.

Although receiving Shay's diagnosis in utero cast the remainder of pregnancy into a surreal, emotional experience, it was a blessing. We knew that Shay could be delivered at a hospital experienced in treating children with heart defects, receiving specialized medical attention immediately following birth. Had she been born at our local hospital without us knowing what was happening within her tiny chest, our obstetrician has said she probably would have died. Without early diagnosis, by the time she started showing symptoms of heart failure and was flown to the nearest specialized center for treatment, her brain would have begun to starve from lack of oxygen. If she survived, her potential quality of life would have been greatly diminished.

For some infants with CHDs, particularly those with HLHS, there is a brief window of time in which it is optimum to operate on their hearts. A baby that has been diagnosed late is likely to be in heart failure, making her less stable. Instead of attending immediately to the defect, doctors must spend time stabilizing the infant. Sometimes other organ systems are affected by the poorly functioning heart.



It is not unheard of for a child with a CHD to die following open-heart surgery not from their heart, but from other organs damaged prior to the surgery during heart failure. Early diagnosis is the key in giving CHD children the chance at a relatively normal life.

Although CHDs are a common birth defect, very few people are aware of the symptoms, which may be vague or similar to other benign conditions that can be explained away if you are not aware of heart defects. Despite how common and serious heart defects are, too many medical professionals still do not consider a diagnosis of CHD until it is too late.

Each day that passes in our lives with Shay, we continue to be thankful for how well she has done. We would not choose for her to bear the burden of life with a complex CHD. But, her gift is to show what can happen when everything goes right, even after it has gone wrong. During so many pivotal points, the medical professionals in her life made decisions that resulted in optimum results. She is walking, talking, laughing proof of that. — Anne and Bill Gammon



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