

Orianna Berry's Story



Orianna is an adorable, loving little three year old girl who just adores her family and friends. She was born on October 4, 2011 and everything seemed perfect in the world to us. At her first pediatrician visit her doctor discovered that she had a heart mummer. We were referred to a pediatric cardiologist, who determined that she had a heart defect known as Vascular Septal Disorder (VSD). VSD is a heart defect where the child is born with a hole in part of their heart.

As any parent could imagine this was terrifying to us, but the doctor informed us that 80-90% of the time the hole closes on its own. We were informed the time being it would be in her best interests to keep her isolated from other children, because if she caught any serious upper respiratory sickness or infections she could die. At this point she had to start receiving monthly vaccinations for (RSV) Respiratory Syncytial Virus, which were not covered under our insurance, and also incredibly expensive.

As her first year went on Orianna has to go to the doctors 4-5 times a month just to keep an eye on her condition. She needed 2 to 3 echo cardiograms a month to watch the progress of the VSD. The problem was that the hole was not closing. Also during about 6 months in to her first year the doctor discovered another problem called Double Chamber Right Ventricle (DCRV), which is essentially a blockage on the other side of her heart.

Orianna's Cardiologist at this point told us the hole was not closing and that we should have open heart surgery as soon as possible. We scheduled the surgery for 2 weeks after her first birthday, at Columbia Presbyterian Medical Center in NYC.

During the procedure the surgeon discovered that she also had a partial blockage of one of the arteries running to her heart. Thankfully the doctors were able to repair everything and health wise our little girl is doing well now, but a few other problems have arisen. Because of the surgery and the required recovery time Orianna has become developmentally delayed, functioning on the level of a 1 ½ year old child, when she is almost 3 ½. She is a very smart child but cannot speak yet and has extreme anxiety in most social settings. We have also been overwhelmed by the financial aspect of everything that has happened. Most of her doctors and surgeons were out of our network, which we did not discover until we started to get bills.

Orianna is now in preschool and is making progress, but she still requires more help, something that we did not know how to provide for her. One of us had to stop working when all of this started. Daycare was not an option and we had no family around to help us out. This essentially cut our income in half. We still are suffering the after effects of all the out of pocket payments that we made and this is preventing us from getting Orianna the true help she needs to thrive going forward. Now that the Shannon Daley Memorial Fund has found us, we are starting to see a light at the end of a very long tunnel. Any help at all will make a huge difference for our little girl's continued development. Thank you so much for helping our family.

