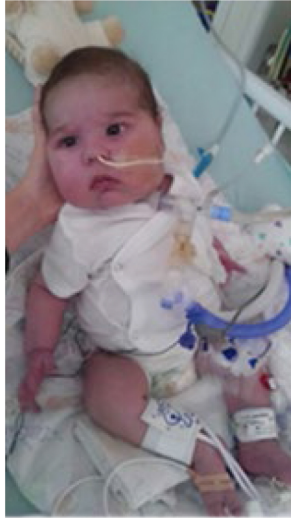


# Andrew Arias' Story



Andrew was born on July 22, 2013. When I was 14 weeks pregnant, an ultrasound showed Andrew's heart was not forming properly, so we were referred from Hunterdon Medical Center to Children's Hospital of Philadelphia (CHOP). Then he was diagnosed with Hypoplastic Left Heart Syndrome (HLHS). This is a birth defect that affects normal blood flow through the heart. As the baby develops during pregnancy, the left side of the heart does not form correctly.

The day Andrew was born started his first battle in life, when he was born his umbilical cord was around his neck 4 times, but he was ok! Within 30 minutes of his birth, they placed a central catheter to keep him alive, then was transferred to the CICU. He needed to stay with oxygen 24 hours a day and be fed through a nasogastric feeding tube. A week later he got his first heart open surgery and a pick line placed on his left leg. We thought he was going to have just a couple of reconstruction heart surgeries, but his heart got worse. Soon we got the heartbreaking news, he needed a new heart and he was placed on the waiting list. We didn't have any idea how long we were going to wait, all this time he had to be in the CICU. When he was two months old, we had been offered a new heart, but that day around 6pm we got a call and they said that the heart was not as good as expected. Days later Andrew got a tracheostomy and after that Andrew felt happier of having something less that bothered his face. At 3 months old, I remember that I was sitting next to my baby's crib and noticed his heart rate went from 100 to 200 beats per minute with the nurse changing his feeding tube for fluids, everything seemed very strange, I thought "something is not right", then minutes later a doctor came to me and told me in a soft voice, I think there is a possibility for a new heart but please don't get too excited until we make sure it is the right one for your son, but we are going to be ready for it. Minutes later I received a call and that person said to me, we got a heart for your son and it is not a good one, it is an excellent heart. At that

moment I knew that the heart came from God through our prayers. We can't describe the feeling of happiness for our son and at the same time the sadness knowing that another child and how that family could be feeling.

Hours later Andrew went for surgery for around 4 hours. It was a success! I never felt so happy to see him with so many cables and tubes in his body after surgery. He started having beautiful rosy cheeks, and pink nails, it was not purplish any more, and in total we stayed 5 months in the hospital. Two days before Christmas Andrew was sent home for the first time, with around 12 different medicines and depending on a respiratory ventilator. That was the most lonely and exciting Christmas ever in our lives. He started getting stronger and by the age of 9 months, he was removed from the respiratory ventilator. Over the next couple of years he got at different times painful mouth ulcers, ear infections and a lot of hospitalization due to his lower immune system and had a couple of eye surgeries.. "No matter what he had been through he continues to be happy and sweet", when everything seems to be going better.

Andrew got some mouth sores as he had happened before and we had to go to (CHOP) hospital and stayed about a week for recovery, the Doctors did couple of biopsies to find out the reason why Andrew was having the mouth sores, but the team at the hospital could not find an answer, they said Andrew was like a puzzle. One of the doctors from oncology felt Andrews belly because she thought the ulcer may be relater with the liver, then she order a ultrasound of his belly, and result shows some dark spots in his belly, and because of that, they did an colonoscopy and the result were shocking to us. Andrew showed signs of Post- Transplant Lymphoproliferative Disorder (PTLD) cancer, but to confirm those result, they did an endoscopy and the result were same, Andrew was diagnosed in 2018 with cancer (PTLD) cancer , and that was caused from one of his heart medicines that he still needs. We drove 1 ½ hours to go to (CHOP) so Andrew could receive his chemotherapy. On February 6<sup>th</sup>, Andrew completed his 9 cycles of chemo and now we are waiting for positives results from Andrew's (PET) scan. During all this time Andrew didn't feel any pain, and that make us feel very blessed because in a lot of cases kids with (PTLD) experience some pain in their belly.

Thank you to the Shannon Daley Memorial Found for give us the opportunity to share our brave boy story and that way show that in life nothing is impossible when we believe in God and put all our faith in his hands.

