Gabriel's Story

Gabriel was born on March 12, 2014 a perfectly healthy newborn, or so we thought. When Gabriel was just 24 hours old the nurse was doing routine tests and the pulse oximetry numbers were extremely low so he was taken to the nursery for monitoring and additional tests, his nurse and the pediatrician doctor heard what they thought was a heart murmur so he was whisked away to UVA by the emergency transport team. We were told he almost didn't make it as he coded on the way to the hospital. After arriving at UVA where more tests were performed, it was determined he had a congenital heart defect called, Hypo-plastic Left Heart Syndrome. Hypo-plastic Left Heart Syndrome, or HLHS is a heart defect where the left side of the heart is so underdeveloped it practically does not exist, nor function. We were informed Gabriel would need open heart surgery, and not just one but 3. This was a complete shock to us, just a few hours before we thought we had a healthy newborn and then are being told our baby needs heart surgery. Parents today often find out during pregnancy if their child has HLHS – yet we were not aware of Gabriel's diagnosis, which made it that much harder to comprehend.

He had his 1st surgery "The Norwood" on Tuesday March 18, 2014, which was the hardest and longest day of our lives. Gabriel's recovery was amazing and he was able to come home on Friday March 28, 2014, just a week and a half after having major open heart surgery! Gabriel received his 2nd surgery "The Glenn" on August 1st, 2014, and was discharged on August 9, 2014. After his 2nd open heart surgery, Gabriel just never made any advancements, he stayed little in size (not gaining any weight) he wasn't making an progress in physical therapy and on January 20, 2015 he was admitted to the hospital to have a ng tube put in to help him with his weight issues. What was suppose to be a 2 day stay turned into over 2 weeks, he was finally discharged home but was only home for 1 week before we rushed him to the ER at UVA where they admitted him on 2/9/15 and on Thursday February 12, 2015 he went to the heart cath lab where they proved without a doubt that Gabriel needed a new heart (he coded, they had to use shockers on him). They started the process that day to have him officially listed for heart transplant.

On Thursday February 18, 2015 he was officially listed on the National Heart Transplant waiting list. On February 20, 2015 he took a turn for the worse and had to be intubated and closely monitored in the PICU. On Tuesday March 3, 2015 Gabriel had surgery to have a tracheotomy, gtube and new picc line put in, he did extremely well during surgery and later that day his cardiologist informed us that they had accepted a heart for Gabriel. He received his new hero heart transplant on Wednesday March 4, 2015!!

Gabriel has had many many additional surgeries, and hospitalizations, so many we stopped counting. After one of his heart cath procedures he developed Staph Infection which caused him to have many strokes and resulted in permanent brain damage. In 2016 Gabriel got Norovirus and Campylobacter Virus. It took three trips to the hospital to determined he had those two viruses and finally he was able to receive the treatment he needed to help his body to get rid of those viruses. He lost half of his body weight because of the viruses and needed a NG feeding tube to help him get the nutrients his body desperately needed. He was so weak and regressed a lot because of the viruses he was no longer able to stand up when he had just started to try and walk, he could barely even sit up. But by the Grace of God and the wonderful GI team, Gabriel kicked those viruses butts and began to recover. He needed extra PT & OT therapies to help his body get strong again and to relearn how to do things. After a couple of months he had gained all of his weight back and then some, he was also walking and even starting to say a few words! In 2017 he had his follow up with his neurosurgeon from Children's National in DC. Besides his permanent brain damage everything else looked great and no surgery would be needed and he was discharged from having to be seen again! Super praise!!

In 2024 he began seeing Endocrinology. GI and a nutritionist due to his short stature and growth for his age. In 2025 he also added a developmental pediatric specialist to his team of doctors that he sees.

One thing we learned is even though a heart transplant saved his life, his little life is still so very fragile due to his compromised immune system. Gabriel has heart transplant clinic appointments every 3 months providing everything is well. Each and every clinic appointment with his transplant team includes bloodwork, height/weight check, an EKG, an echocardiogram, and checking his oxygen saturation. Once a year he also has a heart Cath which includes a biopsy of his heart. A tiny sample of heart tissue is obtained during cath to help determine if he may be going into rejection, which can be a transplant recipient's most detrimental outcome. We are hopeful that further medical research and diagnostics can eliminate the need for such a frequent, invasive procedure, but currently he has a heart cath & biopsy annually. Another aspect of post-transplant life is anti-rejection medication. Gabriel will also be on this for life. Every 12 hours he takes medication that lowers his immune system's response to attacking a heart it doesn't recognize. This is vital. It is possible for rejection to be treated, but it is also possible that rejection could cause damage to the heart and require a 2nd transplant. As with all medications, there are side-effects. More commonly, it means he is more susceptible to getting sick, and his recovery could take longer because his immune system is suppressed.

He's reached so many milestones we never thought he'd ever reach and are truly so thankful! He has 4 older sisters whom he simply adores! He loves playing video games, playing with his cats, loves DC/Marvel superhero toys/movies/everything, SpiderMan is his favorite!