

## Parker Hoelper's Story



Parker was born on June 11, 2015, and we enjoyed two seemingly normal, healthy months with him. When Parker was 2 months old, he became jaundiced and the whites of his eyes yellow. After a visit at his pediatrician's office, he had labs completed and within hours was sent to the ER because the results showed very elevated bilirubin and liver panel numbers. Many tests were run and the pediatric ER doctor believed it was a liver disease called biliary atresia but couldn't be positive without a liver biopsy. Biliary atresia is a condition in which inflammation develops within the bile ducts. The inflammation can occur in any of the bile ducts both inside and outside the liver. This leads to bile duct damage, reducing the flow of bile, which causes scarring of the liver.

Within two days Parker arrived at the Children's Hospital of Philadelphia (CHOP) under the care of a phenomenal team of doctors. Parker had the liver biopsy completed within hours of arrival and many other tests performed. His team of doctors believed it was biliary atresia and their best surgeon performed the five-hour Kasai procedure on Parker. The diagnosis of biliary atresia was confirmed during the procedure. During this surgery, the surgeon removes any problem bile ducts outside the liver. The small intestine is then attached to the liver. This provides a path that can allow bile to drain from the liver. Parker did well through the surgery, but it was unsuccessful in helping his liver function correctly.

In December of 2015, Parker was placed on the official waiting list for a lifesaving liver transplant. Biliary atresia made it difficult for Parker to grow and reach normal milestones. Parker had numerous hospital stays, and transports to CHOP for fevers, cholangitis, and GI bleeds that were all complications of biliary atresia. Many medications, vitamins, and shots were needed to manage his liver disease and the itching caused by his high bilirubin. Parker struggled to gain weight and needed a NG feeding tube, and was put on a special formula only diet to help his body take in as many calories as possible.

While Parker waited on the list for a liver, we began searching for a possible living donor for Parker since both of blood types weren't compatible and we were ruled out as possible donors. Without hesitation, Lauren Slater (Parker's moms' best friend since kindergarten) offered to be his donor and completed testing with UPENN where she was found to be a perfect match for Parker.

On July 12, 2016 both Parker and Lauren underwent the biggest, most important surgeries of their lives. After a full day of being in transplant, Lauren was able to donate a portion of her liver successfully to Parker! Both Parker and Lauren showed true strength and perseverance to recover. Lauren made a complete recovery; her liver regenerated itself and looks fantastic! We are thrilled to report that Parker's specialists are all impressed at how healthy his new liver looks and is functioning. For the first time since Parker was born, we are able to watch him grow healthier, rather than sicker.

Life after transplant has its ups and downs, but we are very lucky at the progress Parker is making. His energy level is nonstop, which means he is feeling great! Since transplant, it is important that Parker takes his immunosuppression medications every 12 hours. We go to CHOP weekly for labs to make sure his liver numbers stay normal and that his immunosuppression medication levels stay under control. Parker's immune system is compromised so he easily gets sick, and his body has a difficult time fighting the illnesses. Viruses elevate his liver enzymes and cause his medication levels to become unsafe for his kidneys, and he has needed two liver biopsies to rule out rejection. He is working with the feeding team and speech therapy to catch up on milestones he missed when he was very sick. Add an unrelated double hernia surgery to the mix, and we can say he has certainly kept us on our toes!

Parker's strength and resilience are unbelievable; he amazes us every day. We look forward to and have hope for what the future brings. We are extremely grateful for the support from the Shannon Daley Memorial Fund and the community who are all behind us as we navigate life after transplant. Thank you, we are beyond appreciative!

