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## **Koby Joseph Kiffe (Age 3)**

**Son Of Troy Kiffe,  
Cenac Towing  
Company**

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It took 10 years and many of tears before our Angel came to us. Getting pregnant was hard, but not knowing if your child will live is even harder.

Koby entered this world 10 weeks premature. Low amniotic fluid was all the doctors could say was the reason for his early arrival. If it were not for a very close watch on my pregnancy, Koby would have died in my womb. But thanks to technology, Koby made it only a couple of days before Mothers' Day. However, with the joy of his birth also came sadness with the findings in his health.

At first, visually, he was found to have an imperforated anus and a rash all over his body due to friction from a dry birth. Everything else seemed to be fine until his lab work came back. His creatinen levels were beginning to rise, signifying his kidneys were beginning to fail. His first surgery was performed at only four days old, weighing in at only 3 lbs., 1 oz. They found that he had a blockage in his urethra, so they put him a vesticostomy on his right side so he could release his urine in hopes that his levels would come back down. They also installed a colostomy on the other side of his tiny belly so that he could have bowel movements as well.

After nine days of watching his levels rise, we were given an option to either seek help from another hospital or let nature take its course. There was no option to Troy or myself. Koby was going to have every opportunity to survive, as long as we could help it. Then, along came Dr. Frank Boineau, Nephrologist at Tulane University. He told us that Koby would have to be placed on Peritoneal Dialysis and had less than a 20% chance of survival. The only words that we heard were "there was a chance of survival." Koby was to be the smallest and youngest to ever be placed on dialysis, as far as Dr. Boineau knew. This was the beginning of a very long, hard and trying time for us all, and it still has not let up to this day.

The transfer to Tulane was unnerving. With the lack of hope given at the other hospital, it was hard to have any hope here as well. But we were not willing to give up just yet. The first consultation we had at the hospital was Dr. Steiner, a pediatric surgeon genius. Finding a place to put a catheter for his dialysis was going to be difficult with him already having two ostomys currently attached to his very tiny belly. However, with lots of hope, praying and skill, it was accomplished.

Dialysis began immediately with hardly any problems or leaks. Finally, his creatnine began to drop and we could all breathe a sigh of relief for a little while.

But still, we had a long way to do. We stayed in the hospital with Koby for 3 ½ months. During this time, a few surgeries were performed on Koby to repair herniated ostomys.

Once it was realized that Koby was going to be able to come home with us one day, we started preparing to bring our son home. We trained for three weeks on how to be sterile in every way possible to prevent our son from getting peritonitis, which is an infection in the peritoneum. We were taught one on one how to perform dialysis on Koby so we could take him home and do the treatments every night. We had to turn his room into a sterile environment, install a scrubbing sink and much more before we could bring him home. We had to learn how to give shots to our son, one every day for the first two to three years of his life for growth hormones and red blood cell replacement medications. To this day, we cry every time we inject Koby. We had to learn how to watch for signs of infection by watching for dehydration, swelling and so on. Honorary doctors degrees are what we should have been given.

In the midst of all of this, the bills began pouring in. Koby wasn't even home yet, and we were already bombarded with thousands of dollars in hospital bills. All we could do was pile them up. We had neither the money nor the time to deal with this at that point. We attempted to seek financial assistance, but to no avail. Once we had the skills taught to us so we could bring our son home, we were able to leave the hospital, but not without fear. Our son looked like a science experiment. He had tubes, buttons and holes all over his little body. Not by any means a normal baby.

We were now home, but not for long periods of time. Hospital visits were more frequent than home stays. We had clinic one to two times per month. Koby had several hospital visits for cloudy dialysis fluid, bloody dialysis, being impacted because of dehydration from dialysis, low oxygen levels when he would catch a simple cold and several dehydration episodes because of severe reflux. Some of these visits would last up to two weeks at a time. Surgery stays were often too. Koby had a total of 11 surgeries in his first two years of life. Some of his surgeries were dialysis catheter placement, colostomy bag placement, right testicle removal, gastric feeding tube placement, etc. He has had too many to name them all. He still needs at least four more surgeries in the next year or so: removal of mucus fistula from his bladder; kidney transplant; reconstruction of his anus and reversal of his colostomy.

Although his transplant will take place within the next year, he will need anti-rejection medication for the rest of his life so his body will not reject his kidney. Kidney transplant is not a cure, it is only a treatment that cans last 10-15 years without any complications. Koby will have to undergo several more transplants through his life.

None of these issues that plague Koby have ever slowed him down. He can charm anyone with just a look and the blowing of a kiss. He is very active and loving at all times. He is delayed in all areas of physical development, but not a sign of delay with the love in his heart. He undergoes daily injections, dialysis, colostomy bag changes and more without ever losing his smile. It takes lots of love to get this little guy through day to day, but both of his parents are here to make sure he gets the daily dose of love and encouragement he needs, and we can't forget, lots and lots of kisses