

Beginning - We had just left Anna with her surgery team. It was a cold drizzly Seattle December day. Wonderful and technically superior staff at Seattle Children's Hospital would now guide her long awaited kidney transplant. To give Anna a chance at a "normal" life - our eldest son Andrew was two miles away at the University of Washington Medical Center, about have one of his strong healthy kidneys removed. Having two out of our four children undergoing surgery was daunting, but we trusted in God that this was the right time and place for it to happen. We also knew that Andrew was safe in the care of his new wife Carly. As of the date of the surgery, they had only been married six months, but Andrew had known this was day was going to happen since the day Anna was diagnosed in 2009.

Holding hands and walking to a waiting room to begin our excruciating wait to the other end of the surgeries, Anna's phone that we had taken possession of starting buzzing. Looking at it, "Who would be calling her at this time?" - we saw that it was a merely a timer. Anna had set this timer back in August of 2014 to an approximate date and time of the expected transplant. The timer hit zero exactly at the moment it was about to happen! This was an amazing and emotional reminder that this surgery was the culmination of years of turmoil, trials, and sickness - yet also joy, generosity, and kindness poured over our family by others.

Anna was born on January 14, 2000. Seemingly a normal birth, 8 pounds 2 ounces, and a total surprise after three boys! We were so excited! Quickly after birth though, there were complications. Anna was not nursing well - not sucking very hard at all, and very limp with very low muscle tone. She need nutrition badly. In the hospital, we even tried cup feeding - with one of those little cups that come on top of liquid medicine bottles - with no success. Very little worked. She struggled. As time in hospitals these days are limited, we were sent home with a struggling little girl, and many instructions in care. The staff at the

hospital thought that her struggle with eating was due to the vigorous suctioning at birth, the result of swallowing meconium just before she was born. They thought she would improve quickly. Two weeks passed - slowly. We tried everything we could to get her to eat. Consultations with nursing specialists did not help. Bottles were not in our plan, yet we even tried that to no avail. Bi-weekly trips to Anna's pediatrician confirmed our suspicions of a dramatic, much feared weight loss.

Making matters even worse, Anna's mom came down with a cold and sore throat, and as viruses go - Anna got it. An unstoppable force, the cold grew to RSV (Respiratory Syncytial Virus - a pneumonia type sickness). We watched with growing fear as Anna's lips slowly turned blue and her chest began sucking inward as she struggled mightily for each breath. A cough developed that sounded like an adult smoker's cough. Back to the doctor we went. I will never forget our pediatrician holding Anna in his hands. Anna had dropped in weight to just over five pounds. She was limp and floppy, almost lifeless, as he checked her over. Fearing for her life, the pediatrician immediately admitted her in the hospital.

Anna quit breathing that first night in the hospital. Thankful that the doctor had admitted her earlier in the day, we thought about what could have been had he not. Fears of losing our first and only daughter became real. Medical staff hooked her up to the life support. She was getting worse, and now it was not just the RSV virus and malnutrition. We were told she had some kind of life-threatening kidney disease. The most "to the point" doctor we had ever had told us she had been born with it. Prognosis was not good. Anna would need kidney dialysis and a transplant, but only if she lived that long. Right now - she was too little for a transplant. The youngest patient the doctor had seen undergo a successful transplant was three, and he had died within a year of the transplant. We did not know if we would walk out of the hospital with our little girl. It was time to put our

daughter in God's hands and let her healing begin. Prayers from all of our friends and family, and spread globally, were lifted up for Anna.

Miraculously and much to the medical staff surprise, after three weeks in the pediatric intensive care, Anna's kidneys began to work. Over time, she was able to breathe on her own. The kidney doctor simply could not explain it. We will never forget the final visit to the kidney doctor about three months after she came out of the hospital. Her kidney function was within the normal range! The doctor was completely dumbfounded, almost mad that she was wrong. She had never seen anything like this happen! While we were praising God for Anna's healing, she sat in confusion and a weird dismay that she was wrong on her diagnosis!

The next two years were rough, to say the least. We worked daily with Anna to gain muscle, overcome her cough, and improve her eating, and therefore weight. We experienced an intense but thankful journey that got Anna to a healthy smart pre-teen. We were thankful to God for the healing and we were thankful that we had our seemingly healthy and recovering "little one." But this story doesn't end there.

Middle - The regular, periodic, and routine doctor checkups always looked for indications of changes in Anna's health. Up to fourth grade, she was tracking low on the growth curve, but on the curve. We were always relieved after each appointment. Until the fourth grade visit. That is when things changed. Suddenly it seemed, Anna was diagnosed with a life threatening disease (End Stage Renal Disease (ESRD)). She was in Stage 4! Her kidneys were simply no longer growing, and were no longer doing the job her body needed them to be doing. Prognosis - transplant. The doctors were insistent that through maintenance and careful observation though, we could get Anna straight to transplant and avoid any messy dialysis. The message delivered by the medical staff was earth shattering

yet we knew God had worked in Anna's life at birth, and we knew that He was still there. We had faith that it would be OK. Still – very hard news.

Carrying that faithful message forward to our family, we let our three boys know of Anna's ESRD diagnosis. Andrew was just turning eighteen years old - the minimum age to donate a vital organ. Andrew immediately and without hesitation said "I will be the one!" He was insistent that he would give Anna that chance to be well. That chance to live beyond a "terminal" diagnosis – which if left untreated, ESRD is. The process of kidney donation is complicated, and thorough. There would be screening and donor matching, all of which would come later. For now – it was time to treat the disease with maintenance, medications, and care that would get Anna as far as she could get with her existing kidneys. That is where we embarked next.

How do you tell a fourth grade girl that pizza, and specifically cheese, is bad for you and must be avoided? Milk? She drank so much milk. The kidney diet is similar to a diabetic diet. No phosphates (cheese, milk) or Potassium (banana). The list of medications was long, but would delay transplant for a few years. Phosphate binders allowed Anna to eat a little what was considered banned foods, but my milk drinker rapidly became a non-milk drinker. It was a new way of life, but it did not change who Anna was. She continued to have a significant impact on people, whether it be at school, church, or any other social setting. Anna was an amazing kid through this challenge.

Throughout the years of pre-transplant, we as a family were blessed by so many organizations, but two dramatically made the journey better. At an appointment at Seattle Children's Hospital, we were told of the expected cost of the transplant. It would be in the hundreds of thousands of dollars – not all of which would be paid by insurance. Seattle Children's united us with Children's Organ Transplant Association (COTA). The mission of

COTA is to assist transplant (all organs) families in defraying the high medical cost that they will most certainly incur. This organization served us beyond our wildest hope in that it collected donations from individuals into a tax-free fund to help us offset our expected expenses. It served us so well over the years. The second organization that impacted us was Dutch Brother's Coffee, own locally by Kevin Parker. His organization selected Anna as a recipient of \$2 drink day where \$1 of every cup sold goes to Anna via COTA. Through a daylong drive, \$12,000 was raised and donated to COTA on behalf of Anna, which also helped us defray the cost of her upcoming transplant. We saw the generosity of people, and the genuine care for people in need through this experience. For that, we are eternally grateful.

The hope was we could get Anna directly to transplant, but as time wore on for her, she continued to feel worse and worse. Her weight was dropping, she was weak, and continually felt sick. Admitted to the hospital, we had to make a decision. To continue along the path without dialysis, or a path with. Anna chose dialysis with the support of her faithful doctor, and that unexpected journey began. Three days a week, pulled out of school, to have her blood filtered through a machine. The good things were the friends she made, specifically two girls where were also going through dialysis. The worst though was when she would go into dialysis feeling healthy, and two hours later be admitted to the hospital for an infection that had spread to her body, through the dialysis. She was under constant attack by her body and viruses. She needed a break – and she needed a transplant. Thankfully – the date had been established for August 2014. In August, we excitedly headed for Seattle. Transplant – here we come!

We arrived in Seattle not having a place to live. The remarkableness of people demonstrated themselves again as within twelve hours – we were set up in a mother-in-law quarter type apartment in a Bellevue house own by friends of a friend. It was an amazing

gift. A last minute visit to the doctor for labs and we would be on our way to transplant. All we had to do first was buy food and necessities for three months of living. Rebecca and I headed to Target while Anna took a shower and got ready for her next day – a big day. Andrew was on his way over from Spokane. Then the news came. As a result of her past blood infections, it was determined by her doctors and other staff at Seattle Children’s that her body’s immunity system was too “amped up”. It would attack any transplanted organ, and would not lead to success. Out of an abundance of caution, and with extreme disappointment by all – the transplant was cancelled. Now - how would we tell Anna? What would her reaction be? We were scared. She had made it this far only to be turned around to face more dialysis. We told her. Her reaction? “Does that mean I get to go the Band Camp??”. Wow – what a spirit and what a girl! Faced with this challenge and disappointment – she just wanted to go to Band Camp! We came home to Spokane with the promise of housing in December (the next scheduled transplant window), and a happy girl that she would be once again connected with her friends. The timer was set – transplant in December.

We cleared Anna’s timer that was flashing at us. We knew it was going to be a long day with both of our kids in surgery. We waited. Like anticipating a new birth, we were anticipating Anna’s new life with a healthy kidney. The surgery took most of the day – first the surgeons prepared Anna’s body for the new kidney, then they waited for the new kidney to arrive from the U of W. Concern at the U of W was that all the kidney would not be able to be restored / reconnected to all the arteries due to how small the arteries were in parts of the new kidney. Happily and quoting Anna’s Pediatric Surgeon – “We were able to reconnect all of the arteries even though there was thought that we wouldn’t be able to. The U of W forgets we are a children’s hospital.... We have very small tools, and they all have happy faces on them!” It was quite a moment when we saw Anna for the first time in

intensive care. She was in so much pain, and I could not help. It was scary, but normal. Over the next few days, she began to recover from the surgery, and then was moved to recovery wings. Two weeks there, and then sent to our temporary living quarters where she would recover for another three months. The surgery was a success!

Today, Anna is post-transplant by almost four years. Anna's body has had some rejection to the transplanted kidney but we are working very closely with Seattle Children's hospital to stay on top of that. With about 30% of the transplanted kidney now dead - the reality is there will need to be another transplant, and this time it will be done in the adult hospital. There are challenges ahead for all of us, especially Anna, but we are grateful for our story that got us to where we are today.

End – Or Really The Beginning Again – A Note to Anna - This past Sunday, June 10, 2018 – we watched as you eagerly, confidently, and healthily walked across the stage to obtain your well-earned diploma. A new stage of life for you and a new stage of life for us is ahead. You see, there was a time in our life when we took pictures of you because we wanted that one picture that would have to last us a lifetime. We experienced the terrible pain of imagining we may not have you but for just a few more days! We contemplated not having your physical presence in our lives, only a mere memory, and a wonder on what would have happened if “only if”. We prepared ourselves for losing you, we braced for the worst, while praying for the best.

We are so proud of you and what you have become. You have a gift to love people, and we know that is a gift from God. You are beyond talented in photography, and drama, and music, and the world awaits what you will do with it. Had I had to think about what would have been, I could only imagine that you turned out half as good as you did! You have completed our family of mostly men, exposed us to the world of you, and taken the

world by storm. You have so many friends that we cannot count, and we know what you add to people's lives. You are a blessing beyond all blessings.

My hope and desire for you is you use your talents that God has given you for His purpose – embrace the challenges you face and grow even more from them. Capture your life and moments in your photography and drama, and educate those who do not know you on the blessings of life you have divinely been given. Be an example to those who are at the beginning of their medical journeys and use YOUR story to motivate and challenge others. The world would be a very different place without you in it – you have already left an unforgettable impact. I know, because we feel it in our hearts every time we look at you, and we see your life through your pictures. Go forward – live your story.