When Joel and I got married, the theme verse at our wedding was Psalm 115:1 – “Not to us, O LORD, not to us but to your name give glory, for the sake of your steadfast love and your faithfulness.” Little did we know just how evident that verse would become in our family. We welcomed our first child, a son, in September, but not in the way that first-time parents dream about. At our 20-week ultrasound, my husband and I were told that our baby had a diaphragmatic hernia. His diaphragm didn’t form correctly for whatever reason, so his stomach was up in his chest cavity, which shifted his heart to the right and affected his lung development – primarily the left lung because that’s the side the hernia was on, but also the right lung because the heart was pushing on it. We were told that it could be associated with other syndromes that would be considered “lethal,” but there were no indications of that at the time. For example, he had all his digits on every limb and no extra fingers or toes, and he was a good size. This condition affects about 1 in 5000 babies. Survival is 50/50. We had lots of extra doctors’ appointments from that point on – mostly ultrasounds with the perinatologist (high-risk pregnancy doctor) to check our baby’s growth and my fluid, but also a couple with the pediatric cardiologist to check our baby’s heart because the extra pressure from the abdominal contents can affect the structure and function of the heart. We were also able to meet with the surgeon and neonatologist (the doctors who work in the Neonatal Intensive Care Unit – NICU) before our son was born. To make matters more interesting, I was diagnosed with borderline gestational diabetes (which affects about 7% of pregnant women) at 32 weeks and because of our baby’s complications they treated me as if I had it. I also tested positive for Group B Strep (which affects about 40% of pregnant women). From the day we found out about our baby’s defect, Joel and I have prayed that God would be glorified through our baby, whether through life or through death. That’s still what we pray for Abe now, and will continue to pray throughout his life.

Abraham was born on September 23 after an uneventful labor and delivery. The severity of his hernia couldn’t be determined from the ultrasounds, so we weren’t sure what to expect after the delivery. We had prepared ourselves to not be able to hold him. The midwife put him on my belly and Joel cut the cord, but then the NICU team took over. They intubated him (put a breathing tube down his throat) immediately and did a whole lot of other stuff I don’t even know about. The x-rays showed that there was a lot of stuff up in his chest, indicating that it was a pretty severe hernia. He was put on a high-frequency oscillating ventilator to help him oxygenate his blood with only one lung really working, and that one not even optimally. He was also started on sedatives and narcotics. He had a tube doing down to his stomach to keep it suctioned out to give the left lung as much of a chance as possible to grow. He had a line going into his belly button for quick, easy, and painless blood draws, which were frequent. He had a PICC line in his arm for IV nutrition and administration of any supplemental medicines. He had oxygen probes on his hand and foot, a blood pressure cuff around his leg, and 3 leads on his chest to monitor heart rate and breathing rate. He got puffy from lack of movement and all the drugs. He had his own room to minimize noises because babies who are sick like that are ultra-sensitive to stimulation, including touch. We were instructed to only use firm, steady pressure to touch him because any stroking would be irritating to him.

The second day of Abe’s life, the neonatologist almost sent him to Minneapolis because he had about maxed out the support that Avera could give him. He got to stay, but it took 2-1/2 weeks before he was stable enough to have surgery to put all his organs back in place. He was switched to a conventional ventilator when he was 12 days old, and that was the first time I got to hold him. It took 3 or 4 nurses to help transfer him with all his tubes and wires. Abe’s surgery went well, and the surgeon said that he was pleased. He told us that “everything” was up in Abe’s chest – meaning his stomach, intestines, spleen, and the left lobe of his liver. Only about one-third of Abe’s diaphragm was present, so the surgeon had to put in a synthetic patch for the other two-thirds. Only about 10-15% of babies with diaphragmatic hernia require a patch. Abe did well after surgery, too. He never needed any extra support. He got a hole in his right lung the day after surgery, but it was most likely unrelated to the surgery. They stuck in another chest tube (he already had one from the surgery) to let the extra air out, and he recovered quickly. I think at that point he had 11 tubes and wires connected to him. Slowly the tubes and wires got to come out as Abe improved and remained stable. He was extubated when he was 3-1/2 weeks old, and that was the first time we heard him cry. He had his first oral feeding (breastmilk through a bottle) when he was almost 4 weeks old. Some of the major hurdles to overcome were to wean off the ventilator, wean off the pain meds (remember they were narcotics), get his digestive system working (since it was basically non-functional for his first month of life), and to take enough breast milk orally to gain weight without needing IV nutrition. The last week or so was the most frustrating because progress seemed so slow, but after 6 weeks of living in the NICU, we got to go home!

Throughout our pregnancy, Abe’s stay in the NICU, and with our continuing follow-up appointments with specialists, God has been teaching me. I experienced his “peace that passes understanding” as I trusted in Him. I learned to thank God for the blessings in the midst of the challenges, and I learned humility and gratitude on a whole new level.

When we first learned about our baby’s diagnosis of congenital diaphragmatic hernia, I went through a range of emotions, as you would expect. Disbelief, fear, anger, worry, doubt, inadequacy, asking “Why us?” and thinking “This isn’t what we signed up for.” Some of my thoughts those first few days scared me. I felt that it would’ve been easier to have a miscarriage than to deal with all these complications and a 50% survival rate for our baby carried to term. I understood why people want to get abortions when they find out their baby isn’t “normal” because it’s such a blow to your expectations. That was never an option for us, and it scared me to even have that thought pass through my head. I was jealous of all the other women I knew who were pregnant with a normal pregnancy. I would never wish something like this on anyone else, but every time I saw someone who was pregnant, it was a constant reminder to me that something was wrong with our baby. I struggled with Psalm 139:14 that says we are “fearfully and wonderfully made.” How could that be true with our baby when there was something wrong – something that required surgery to fix in order for him to live? Why would God do this to our family after we’d already been through medical crises with both my mom and my dad? It took me a while to process it all and to come to terms with our new reality and change my expectations. Overall, though, I experienced God’s peace in an incredible way. The pregnancy itself wasn’t scary to me because I knew our baby was safe in utero. That was a blessing from the Lord! There was plenty to worry about, and I did to some extent, but Joel reminded me of God’s sovereignty and I had to consciously decide to trust in Him, no matter what the results would be. The labor/delivery is one thing I was apprehensive about. My coping strategy was to not think about it much.

When my labor was just starting – before I woke Joel up – I was starting to freak out a little bit. This baby was coming and there was nothing I could do to stop it. This is when the hard part starts. I also was scared of the pain associated with the whole process and how I would handle it. As I was lying in bed, my mind racing with all the what-ifs, I prayed. I knew it wasn’t going to help me or our baby to be worried and worked up, so I prayed for God’s peace. I asked him to help me calm down, and for him to protect our baby. And that was that. I woke Joel up, we got our things together, and off we went to the hospital. I wasn’t worried or stressed or fretful during the labor, delivery, and even for the first several days after Abe was born – some of his most critical days. God gave me his peace during that time. I take no credit, because I’m a good worrier. Experiencing his peace helped me to trust Him more, too. It was a good cycle….He gave me peace, I trusted Him more and left more in His hands. Now if only I could do that with every situation I deal with! I certainly had a few more freak-out times, like the day before Abe’s surgery, watching him go through the operating room doors, and when he was nursing but not gaining weight. My faith was weak, but God’s faithfulness endured. Strengthening one’s faith typically doesn’t come easily. I trusted in the LORD because the situation was completely out of my control. There was nothing I could do for my son to help him. He was in the LORD’s hands, and God used the doctors, nurses, surgeons, and other members of the NICU team to heal him. In a way I was forced to trust in Him, and as a result my faith has been strengthened. I’ve got a ways to go yet, though. I was still fearful for Abe’s life just last week when there was a shooting in Madison. Joel reminded me to “Trust in the LORD” with Abe’s life even now. You’d think I’d have that figured out by now, but I don’t. It’s going to be a lifelong process I think.

When I started writing Abe’s story, I was including all the blessings along the way. But it got way too long! There were so many good things that happened – and bad things that didn’t happen – that I actually started keeping a list while we were in the hospital so I could look back at it when I was discouraged by Abe’s slow progress or just having a tough day. Really, there are SO MANY blessings that we experienced. Even some things that weren’t initially what we thought we wanted ended up being the source of God’s provision and demonstrated his faithfulness and sovereignty. For example, I thought it was just plain mean of God to bombard us with all these issues with our first child. Like adjusting to being parents isn’t hard enough! But since Abe *is* our first child, both of us were able to stay right in the NICU with him the whole time. We didn’t have to worry about taking care of an older child or taking turns being with Abe. When we first found out about Abe’s defect, I complained that now we had the whole second half of the pregnancy to worry about our baby and whether or not he would survive. But knowing so early allowed us to change our expectations (like not being able to hold him right away, preparing to see our baby with tubes and wires all over the place), and more importantly it allowed us to pray on behalf of our unborn child and to ask others to pray, too. We’re so thankful for the communication tools like e-mail, Facebook, and the website Joel keeps updated for us. What an effective means of recruiting prayer warriors! Our prayers weren’t always answered in the way we expected, but they were always answered. Some people commented that it must’ve been hard for us to see our baby hooked up to so many tubes and wires. But we were so grateful for them because they were keeping Abe alive! The same thing with holding Abe…..people would say how hard it must have been to not be able to hold our son until he was 2 weeks old, but we were grateful that we got to hold him before surgery….we weren’t sure if we’d get to or not.

God also exceeded our expectations on several occasions. We prayed that Abe would recover from surgery quickly, and that he would pick up on nursing quickly since he missed the critical learning period in those first few days. Abe had just one minor setback after surgery (the collapsed lung), and his level of support didn’t need to be increased at all! And, right after he was extubated and we heard him cry for the first time, he started sucking on his pacifier without hesitation. Incredible! He also got the hang of nursing right off the bat. It took a little while for him to take enough from nursing for the NICU team to be happy, but he didn’t have oral aversion or difficulty with his suck-swallow-breathe coordination. He really wowed the NICU nurses with his speedy recovery and how well he did overall. Most babies with this condition have some pretty serious setbacks starting 24-hours after surgery. Not Abe. He kept improving. Here are several other blessings we experienced:

* I felt great throughout the pregnancy – no morning sickness or nausea (just more gas than usual)
* No one ever mentioned terminating the pregnancy, ever
* The hernia was left-sided, which is a better prognosis than right-sided. Only a part of the liver was in the chest – It’s a worse prognosis if the whole liver moves up because the liver is such a huge organ
* I was able to manage my borderline gestational diabetes with diet without needing any medicine. And ice cream with peanut butter ended up being a good evening snack for me.
* Avera had a pediatric surgeon and the NICU support necessary for Abe’s condition so we didn’t have to go to Minneapolis or Omaha right off the bat. It was wonderful to be so close to home and our friends and family.
* We heard of several other people (like our nephew, my dad’s cousin’s daughter, my co-worker’s great-nephew) who had diaphragmatic hernia and were doing great now
* All our appointments after the initial diagnosis had good results – our baby was a good size, the head circumference/lung ratio was good (which can be indicative of survival), and the Biophysical Profile scores (an ultrasound test) were always the best they could be. Plus, our weekly appointments ended up being on Fridays – we didn’t even plan it that way!
* Abe was born on a day when we’d had appointments scheduled so we already had work off
* We had a natural labor/delivery like we wanted - no drugs, no induction, no C-section), and honestly, it wasn’t even very painful! I’d included that as a prayer request in the updates we sent out, and some people laughed at me, but my prayer was answered!
* Abe’s APGAR scores of 8 and 9 were excellent, even for healthy babies
* We got to stay at the hospital with Abe – just down the hall (but we had to share a twin bed). We could see him anytime day or night, even in our pajamas if we wanted. We also got meal vouchers for free meals at the cafeteria. And as a results, we’re now addicted to their monster cookies!
* Abe’s arterial line (the one that they used to draw blood) lasted almost 2 weeks – that’s longer than usual, and it reduced the number of heel pokes he had to have
* His PICC line (the one used to give him nutrition and medicine) lasted a long time, too. Once that came out, he had to have his IV replaced several times, and it took multiple attempts each time it had to be replaced.
* Abe didn’t have to have any blood transfusions
* He didn’t have to be transferred to Minneapolis
* Abe’s heart didn’t have any structural or functional defects
* Surgery went well, and Abe didn’t need any increase of support after surgery. He also didn’t need to have an intentional abdominal hernia if everything didn’t fit when it was put back in place.
* I had excellent milk volume from pumping. We still need to figure out what to do with dozens of shoeboxes of frozen breastmilk….it’s a good problem to have.
* Surgery was effective in allowing the left lung to grow and his heart to shift back to the left
* My great aunt and uncle who live in Sioux Falls did our laundry for us and had us over for several meals
* Abe showed hardly any signs of withdrawal from the narcotics. Usually that’s a frustration and something that keeps these babies in the hospital longer
* After surgery, Abe liked to be held. We had over 2 weeks of snuggling to catch up on!
* Joel was able to stay with me the whole time – he had plenty of sick time banked from his many years at work. I can’t tell you how amazing that was.
* Both of our employers & co-workers were completely understanding of our situation and did all that they could to help us.
* Our insurance has covered all of the expenses associated with Abe’s hospitalization except for what we knew we would have to pay. Let me tell you, that’s a big chunk of change!

In addition to the blessings and focusing on the good things, I learned some humility, too. We learned to ask for help, and to accept help and gifts. This wasn’t necessarily hard to do, but it was an adjustment. Joel and I both like to serve, so it’s hard for us to be served. But we needed to ask people to bring us things from Madison, to take care of our mail and newspaper until we got it figured out, and to make sure that our cat didn’t destroy the house while we were away. We were so thankful for everyone who was so willing to step up and help in any way they could. I also learned humility because there was nothing I could do for Abe that would fix him. Sure, I could love on him, change his diaper, take his temperature, read to him, and help calm him down after the nurses flipped him (which was quite the ordeal those first few weeks – just rotating him from front to back took 4 nurses and made him really mad!). But none of that was going to help him get better. I had to rely on the doctors, nurses, and other medical professionals to take care of Abe. I had to trust that they knew what they were doing and would do what’s best for him. Tough stuff for a planner who likes to be in control. And ultimately I had to trust God, who gave Abe life and was holding it in the palm of his hands.

Along with that, we experienced what it means to be part of the family of God in a new way. We were bombarded with cards, care packages, Facebook messages, and e-mails from family, friends, our church family at West Center, and even from several people we don’t even know. That was one of the most humbling things…to know that churches across the country were praying for Abe, and they had never even met us. There was someone in their church who knew us or they had just heard about Abe’s situation through someone connected with the church. It’s really incredible to think about. Abe was also prayed for internationally. We know of people in Japan, Singapore, Hungary, Indonesia, and Sierra Leone who were praying for him. It’s not that those prayers were any more special than the local ones, but it just opened my eyes to how big the family of God is. It was a picture to me of how the body of Christ is supposed to work. We’re supposed to take care of each other and lift each other up, encourage one another, bear each others’ burdens and rejoice with each other. It’s amazing to do that with so many brothers and sisters in Christ.

Abe is 4-1/2 months old now, and he’s doing great! He graduated from seeing the cardiologist, and the gastroenterologist and surgeon are pleased with his progress. He’s on the small side, but he continues to gain weight consistently, which is the important part. Abe’s namesake is the Biblical Abraham, the father of many nations. We chose that name because it’s not one you hear all the time, but it’s a familiar name that we liked. We weren’t really considering the parallel journeys of faith of the Biblical Abraham and our Abraham, but it fits, doesn’t it? Our Abraham is a constant reminder of God’s love and faithfulness. He’s a living example of the power of prayer. He’s also our pride and joy. God has used Abe to teach us a lot in his short life, and I anticipate we have lots more learning to do. We continue to pray that God will be glorified through Abe, and we rejoice in the ways that’s already happened – from knowing that people who don’t normally pray were praying for him, to the testimony his story has been of answers to prayer. Thank you for praying for Abe and for us, and for joining us on this journey. “Not to us, O LORD, not to us but to your name give glory, for the sake of your steadfast love and your faithfulness.”