Amanda: diagnosed at age 23

At 23 years old, I had the world at my feet. I was newly married and ready to put my new college degree to good use. I was healthy, and then the next minute, I wasn't. At 23, my body failed me.

What a way to begin a story. But it gets better, so hang with me.

Everyone has awoken feeling sick before, and that is how my story began. I woke up feeling dizzy and weak. As the day progressed, my symptoms worsened until my husband, Justin, took me to the ER. I was too weak to fight him. As I crumbled to the ground on the way to the hospital I realized he had been right to take me. I was too dizzy to stand, let alone walk. Justin had to carry me to the car, drive to the entrance, and find a wheelchair to get me into the hospital.

As he wheeled me in, my eyes were closed, but I peeked at the nurse when she shot out of her seat and said, "Honey, you're yellow. How long has she been like this?" From there the questions didn't stop.

I was pumped with new blood, questioned incessantly, and finally, left to rest. The hours felt like days. All I was really conscious of was Justin in the chair near me, with his worried expression that always makes him look grumpy. I recall the awful fluorescent lights, so typical of any hospital. Eventually they

decided to send me to a bigger hospital, better equipped to help me. The decision triggered an unnerving thought: there is something seriously wrong.

In the middle of the night, I was transported by ambulance to Vidant Medical Center, where we spent the next two weeks. My mom came down to be with us, spending Mother's Day worrying over me. There were a lot of needles, tests, questions. A lot of sleepless nights filled with blood pressure checks and pokes. A lot of waiting. And finally, the words came; the words that would change me, my family, and my worldview forever. “We think you have a rare liver disease called PSC, Primary Sclerosing Cholangitis.”

We learned that PSC is a chronic bile duct disease that damages the bile ducts inside and outside the liver. The ducts become inflamed leading to scarring and blockages. This prevents bile from flowing out of the liver, causing liver cirrhosis. Some cases are fast moving, like mine, while others transpire over many years. The cause is unknown, there is no cure, and the only effective treatment is a liver transplant.

The information came too quickly. I was just trying to push through my immediate thought, “I'm going to die,” when the doctor rolled into the next stunner: “You will need a liver transplant.”

I am happy to report that I did not die. My body tried to, but I'm still very much alive. And this where the story gets good.

When you need a liver transplant, you must be evaluated to determine if you *truly* need a liver, and if you are a good candidate for transplant. The evaluation process is extensive. For 3 days, I drove to the hospital and underwent physical, financial, and psychological testing. The questions they ask in the psychological evaluation are golden. Questions like, “Are you anxious about needing a liver transplant?” No, I'm fine. It's no big deal… Who comes up with these questions, anyway?

I passed the tests. I questioned that inwardly, but doctors know best, right? I waited on the transplant waiting list for months. I got sicker, yellower, and itchier from the bile building up in my body. I tried medications to help the itch, to no avail. I snapped at my husband for no reason because the constant itching put me on edge, it took over my mind. I was indescribably tired all the time, even upon waking. I was emotionally spent from trying to live when my body didn't have the energy to. I felt guilty for being sick, for worrying everyone. I answered absurd questions like “Why are you yellow?” Questions that I didn’t realize could ever be asked. I continued working for a few months, but finally had to stop when I pushed myself too hard and ended up in the hospital. I desperately wanted to continue living as I had before, but eventually had to accept that my body could not keep up. I felt like a shell of who I used to be.

I spent a few months waiting for the phone to ring, willing my doctor to call with the bittersweet news that someone had died and their liver was a match for me. I was on constant alert, not caring that my

phone's ringer volume was on full blast even in church services and sleeping with my phone next to my head. I wished against all that is natural for my lab numbers to worsen so that I could move up on the transplant list.

After a few months at a standstill, my hepatologist suggested a living donor. It is remarkable, but because the liver regenerates, living donation is possible for many people. Well, to put it frankly, I hated this idea. But when you're slowly dying, and the numbers aren't reflecting your poor health accurately, and there aren't enough livers to go around, and God works on your heart… One can change their mind. And with time, I relented.

This new plan required me to be listed at a different hospital – one that performed living donor transplants. We chose the Hospital of the University of Pennsylvania in Philadelphia. Once I was officially listed there, potential living donors could come forward for additional information and testing.

I had a living liver donor. Her name is Madalyn and she is my hero.

Maddie is an old friend. I grew up in a small town where everyone knows everyone, to a fault. We were the type of friends with many ties – volleyball, church, shared classes, the same ex-boyfriend… Yes, I'm serious. After graduating, when we were both in town, we'd meet for coffee, a shared love of ours. Months would pass with no communication, but we considered each other good friends. It was during one of those gaps in communication that I received a text from Maddie.

"Hi! I was wondering how I could be tested to be your donor?"

I checked the name again. Maddie. I had read it right. She wanted to give me half her LIVER? Maddie was a single mom, finishing college, about to become a teacher. She was too busy and too young and too *everything* to do something so huge.

Later, Maddie told me that she's heard God's voice twice, in a supernatural, almost audible way. The first was when she was pregnant but unaware; God told her she was pregnant. Sure enough she was. This time, she heard Him tell her, "You need to be tested to be Amanda's donor." Immediately she balked. With a toddler, college, and an impending job search, there was just no way. But God didn't relent, so she took a giant step in faith and reached out to me.

Although she was not the only potential donor, Maddie was what the doctors called my "target candidate." She was young, healthy, and the correct blood type. At one point in the testing, the doctors remarked that Maddie's liver was exceptionally large, as if it was made to be donated. We had smiled at that, saying, "Well, that's because it was."

At long last, we received official word that I would receive 65% of Madalyn's liver on August 11, 2015. She was a perfect match. This gave us two months to prepare. It doesn't sound like a lot of time, but when you are simultaneously excited, exhausted, sick, scared, and ready… it is long enough.

A liver transplant calls for an early morning. It also calls for no sleep the night before. One of my dearest memories is sitting in the lobby of the transplant house the night before, deliriously tired with Madalyn and our moms. We were good and sleepy for surgery the next morning, which lasted five hours for Madalyn and seven for me.

I don't remember much of the first two days post-transplant due to the anesthesia's after-effects and the strong pain medication. I know I slept a lot. Later, I was told I was given to the choice to either walk from my stretcher to the hospital bed, or have someone transfer me. Apparently I elected to walk, which makes me proud. I have pictures from this time that I do not remember being taken, that I had insisted on. Even drugged Amanda wanted to capture every moment.

After one day, we were moved from the ICU to the transplant floor, and on day two, I saw Maddie for the first time. We were exhausted. Her visit lasted all of 5 minutes, before she was waddling back to her room down the hall. At the beginning, everything seemed to take so much effort, even keeping our eyes open.

The hospital days were filled with reading, physical therapy, HGTV, and sleep. Each time the nurses came in with medications, they would quiz me on each pill and its function. The most important were the anti-rejection medications, which suppress the immune system so it does not attack the new, "foreign" liver. For this reason, it is imperative that I take anti-rejection medication for the remainder of my life. At first, all pain medicine was administered through a self-controlled pain pump, but I was soon transitioned to oral medication.

After one week, Maddie was released from the hospital. On day 9, I followed, along with three bile drains. Because neither of us lived locally, we were released to the transplant house, located four blocks from the hospital. We stayed there for 2 months, reporting back often for labs and check-ups. Each appointment held new milestones: weight gained, drains removed, medications adjusted. The rest of our time was spent exploring Philadelphia, mostly on foot. Walking takes a lot of core strength, so the going was slow at first, but we grew stronger each day.

Eventually we all returned to "real life." I returned to North Carolina, excited to see Justin who had returned to work three weeks after my surgery. Balloons and streamers littered the house for my homecoming. It was a party to celebrate a new life.

At the time of this submission, I am 2 years post-transplant. The recovery process has not been without bumps, but I feel I have conquered the worst of it. I have done the hard parts: the waiting, the uncertainty, the surgery, and the first big virus after transplant. While I will always be monitored, and there is a small possibility of my PSC returning, there is also a huge possibility that it will not. So I choose to view my life for what it is - an amazing second chance. I am not the person I used to be; I lost the girl I was in May of 2014 when the letters “PSC” were uttered. But I have gained more than I ever imagined. I have a greater appreciation for life. I am utterly in love with feeling like a human being. I love waking up each morning and remembering that my liver works. I can take long walks with my husband. I can climb mountains. I have dreams that I can actually work towards and see with stars in my eyes, without an inner fear that I won't reach them. I run my own business; I travel often. I have a future. And it is all due to the Lord, my donor, and my surgeons. I am forever indebted.