

Our Sarcoma Story

For some time in 2006, into 2007, I had been after my husband, Adam, to have a lump on his lower back looked at. One thing after another kept happening, though, and the trip to the doctor just never really happened. Several months earlier, Adam had had his gallbladder removed due to “elevated liver levels.” Several months later, his levels were still very high, and he was always exhausted.

He did finally see his doctor, who noted that he thought it was likely a calcified broken rib from when my husband used to play college basketball, and that there was nothing to worry about. This did not sit well with me. It sat even worse when the “broken rib” lump started growing, aching, and turning hot. Adam went back to his doctor who suggested that this was probably a fatty tumor, again nothing, and that he would refer him to a surgeon for easy removal. We saw the surgeon, who suggested that it likely was a fatty tumor, but that for safety’s sake, before operating, he would like to have a CT scan done. I think since my husband was 31 at the time, healthy, a very tall former basketball player, that no one believed anything major could possibly be wrong with him.

Adam had the CT scan done, within two days we received a frantic call from the surgeon’s personal nurse. We needed to come in the next day for a biopsy, this was not a fatty tumor. The next day Adam was at the surgeon’s; we learned that whatever this thing was, that it had tentacles, and was pretty gnarly-looking. Within a day or two, we got a pathology report, saying this was benign. We relaxed, somewhat, despite no one seeming to understand what this thing inside of him was. Within two weeks Adam was being prepped for surgery. At the time, we had four small children. The 7, 6, and 3 year-olds went to my mom’s, our 6 month-old rode along with me in the sling. I paced nervously at the hospital, baby on chest, as he was wheeled in to surgery. They told me to expect it to take 45 minutes.

Three hours passed, and we still paced. Suddenly a nurse burst through the waiting room door, asking me to okay emergency pain medication and a spinal block for my husband, who apparently was unable to consent. A few minutes later the surgeon came in, showed me a horrific Polaroid of my husband’s side, told me they had had to remove 2 ribs, a portion of his lung, that his lung had collapsed, that he had two active drain lines in his body now, that they had removed a tentacled tumor the size of a children’s football from my husband, that they had to repair part of his side with mesh, and that he would be shocked if this wasn’t it. “It,” I said, “cancer?” He said yes. I could tell that he was as shaken as I was by what had just happened. We would have to wait for pathology to see if there were clear margins (there weren’t), and Adam was headed to ICU.

My husband had entered the hospital, expecting to leave that evening, now he was being transferred to ICU, with intense breathing issues, and a huge portion

of his torso missing. My head was spinning. The next week brought many struggles. We faced each of them with children running in and out of the hospital room, and a baby always present there in the sling. I had people ask, "how will you get through this? How can you all do this with a young family?" Our answer has always been the same, "how can we not, our other option is to give up fighting, and Adam dies, and that was never an option."

The pathology showed a massive, invasive Desmoid-type tumor that is so rare that doctors can't really even agree on what to classify it as. Some call it a fibromyotosis and others a fibrosarcoma. Whatever it was, it was surely a cancer in my husband's body. He went on to have another surgery a month later in January, to try and clear the margins, and then we waited.

We learned that only twenty-five people in the US each year would be diagnosed with Desmoid tumors, that they are particularly aggressive, and that they leave many people amputees. We found, and fired, a couple of oncologists who didn't seem to get it. I got sick of doctors acting put out by having to deal with "rare cancers." If one more person told us that if Adam had had something like breast or colon cancer, they would know exactly what to do, I would have screamed.

We finally found a wonderful Sarcoma Specialist in Dr. Howard Rosenthal in Kansas City (where we lived at the time). He not only knew about Desmoid tumors, but he had treated them. He pulled no punches and he sugar-coated nothing. He had read the research, and knew what other places were doing with Desmoid tumor patients. He laid out all the different treatment options, and as a team we decided what to do.

I realized then that one of the reasons I had disliked those prior oncologists is because they seemed wholly unconcerned by how drastically this affected our life. As if maybe the statement, "it may not even come back again," was any comfort to us just because it was unlikely that Adam should have gotten this in the first place. Regardless, my husband had a massive twelve inch scar, and many missing body parts that did very much concern us for the future.

We decided to wait and see what happens, as we learned if it did come back, it was most likely to do so in the first two years. In June, we had a clear CT scan, we rejoiced. Maybe we could beat these odds, and make it past that two year mark. We were scheduled to return for another CT scan in October. By August, Adam was once again exhausted and I swore I felt a lump again. He promised we would call Dr. Rosenthal. We got in the next week.

Dr. Rosenthal felt what I felt, and sent us downstairs for another CT scan. And there it was, yet another tumor, a regrowth the size of a grape. Within two weeks Adam was back in surgery. They opened up his scar and by the time they got it out, the tumor was the size of a baseball. They were growing faster, literally sucking the life from him.

Once again, our team met, Dr. Rosenthal suggested radiation therapy. This was a one shot deal, though, we learned. Adam was 32. Once we killed this tissue, we would never have another chance at radiation again. We had to make a tough decision, did we burn our bridges now, roll the dice, hope this would fix it, and that we wouldn't need treatment again, or did we try waiting again? If they came back post-radiation, Adam would be looking at a year-long stint of very aggressive chemo. The options were bad either way.

We rolled the dice, and by the end of October, Adam was receiving daily radiation therapy. He got blue tattoos to place the machine in the right spot and they irradiated a huge portion of his back every day. He got severely nauseous and tired, but worked through the radiation, as he is our family's only income. I cannot describe for you the strength my husband possesses, I watched him endure burns, puking, exhaustion, and then get up the next day and not only do it again, but go to work and snuggle with the kids at night.

He did seven weeks of radiation, every day of the week except Saturday and Sunday. We made it together. He now has a large portion of his torso that is rough, leathery, extremely tender to the touch, and burned permanently brown, but so far, our luck has held. He finished radiation a year and a half ago. We go to visit Dr. Rosenthal, the sarcoma specialist, every six months, driving back to Kansas City to make sure it happens. We will visit him for the rest of Adam's life, as even though the recurrence chance decreases after two years, it never goes away completely. I always laugh and say that we will probably personally put Dr. Rosenthal's kids through college, but we're very happy to do so, because he gives it to us straight.

As we approach the two year mark in December, I think back a lot to that time of cancer. Some of our kids remember it, others don't recall it at all. Some days I would love cancer to be nothing more than a faint memory to them, and other days, I feel like it is so important that they know how close we came to losing daddy, and how important that fight was. We talk about the cancer freely, and there is no missing Adam's massive scar and radiation burns, but as the memory of that horrible year and a half of fighting cancer fades into the past somewhat, it is almost surreal. I can't believe we did that with four small kids, that it all happened so fast, so furious. A few months after Adam finished radiation, we took the kids to Disney World to celebrate, and give them a break from the craziness. Nothing would make me happier than if we can take them every few years until we're ninety. I plan to have Adam along for every single trip.