

A Miracle, and Nothing Less

Essay: Life Experiences

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“He may be blind...” These were the words that reverberated through my mind, my brain unable to decipher the rest of what the doctor was saying. Blind. Blind. Blind echoed through my brain.

No, was my anguished response. Not my baby. He’s already been through too much. We stood, the doctor, my husband, and I, beside his incubator, as Doctor Weaver pulled out paper and pencil and began drawing diagrams. ...

Not too long ago, Joel had come off the ventilator which had enabled him to live after over a month of oxygen had been pumped into his lungs. I knew the facts about too much oxygen’s effects on the development of eyesight. I’d read the books, but I’d hoped this particular side effect would be a miss, rather than a hit. So much for hoping.

I forced myself to focus on the doctor’s words. Retinopathy of prematurity. Prematurity. Joel had been born at twenty-five weeks. At four months early, his life, his very existence had been a battle since then, well, actually, four days before his birth. That’s when my appendix ruptured. Four days of infection. Four days until acute gangrene had set in and put my body into labor, leading to an emergency C-section. And there I was again, not focusing on the doctor’s words. I tuned back in.

Oxygen rich blood had caused cells to start growing across my baby’s eyes leading to options that went from bad to worse. Option one: do nothing, and hope the growth stopped. If it did, great. If it did not, total blindness would ensue. Option two: A cryo-surgery would be performed. A freezing probe would kill the encroaching cells, keeping them from growing completely across his eyes, but it would also destroy his peripheral vision. He would never be

able to see anything except from what was right in front of him – not above, not below, nor to the sides.

Further conversation revealed the doctor was not optimistic that the growth would stop, but he could give us a couple of days to hope. Sunday was the last possible day to make the decision, and once it was made, the surgery would happen almost immediately. Hope for a miracle and do nothing, then risk total blindness, or follow the doctor's recommendation and consign our son to tunnel vision, but, I queried, wasn't that better than no vision? My brain whirled with the overriding question. What was the right choice?

It didn't help that our first impression of this doctor was not good. His bedside manner was terrible. No compassion appeared to come from him. In the paraphrased words of Joe Friday, "Just the facts, Ma'am," seemed to define his personality. Could we trust him?

In the ensuing days, we did as he suggested, and asked for a second opinion. It turned out that Doctor Weaver was world – yes world – renowned. He was the one who pioneered this surgery. He was the man who had saved countless premature babies from total blindness. He was a hero in the world of ophthalmology. Nobody second-guessed him.

Sunday arrived too soon. My husband went to the meeting with the doctor while I went to church with our other four children. With four, and now five, children, we'd learned the fine art of divide and conquer. We were determined to keep life as normal as possible for the other four. We asked for prayers during church. During the Sunday school hour, I went to our outdoor chapel and prayed, and cried, and sang hymns, and prayed some more.

When my husband returned home, it seemed my prayers were not answered. The examination had determined the cells were still growing. Surgery was slated for the next day. Though it was certainly not the outcome I'd prayed for, I continued praying.

The next morning, Joel was transferred from Forsyth to Baptist hospital by ambulance. Danny and I met him there. We kissed our three-pound baby boy and sent him off to surgery, knowing we had at least four hours of waiting ahead of us. The minutes dragged by. Warned of everything from complications with the surgery resulting in blindness, to death from the anesthesia, each second's tick felt like a gong in my heart. I couldn't help myself from the cry of Why? that kept circling through my head. How much did that tiny baby have to suffer? Four months early. Over a month on a ventilator fighting for his life. A surgery, called a PDA ligation to close a valve between his heart and lungs, something that normally closes on its own with a full-term baby, but not one with such a low birth weight. A clinical trial of a drug called dexamethasone was offered, and we waited on edge to see if he received the drug or whether he was in the placebo group. Then, first glimmer of hope. His lungs started working, and he finally came off the vent. A sigh of relief. Were we home free? But no, now the vision issue, and who knew what would happen next. We fought to stay optimistic, even though it became harder and harder. Thank God for the caring nurses who often carried us over the roughest patches.

Finally, about five hours later, Dr. Weaver appeared in the waiting room, drenched in sweat. In his usual brusque manner, he told us that the surgery had gone as well as could be expected, and Joel had survived the anesthesia. He warned us that he was back on the ventilator, but not to worry, he'd come off it as soon as he got through the effects of being put to sleep and the surgery. But then, right before he turned to go back into the hospital, he looked at us and told

us, “I injured my back, and wasn’t even sure if I’d be able to get through the surgery, but I did.” Then, with a kind smile he finished, “It’s in God’s hands now.”

Stunned, we thanked Dr. Weaver and watched him leave the room. We turned to each other in shock. This physically large, and larger than life doctor, this man who, we’d thought, was consumed by his ego, this man who, we’d thought, was too controlling and stern, this man, with five simple words, had shattered our misconceptions. “It’s in God’s hands now.” With those words, we realized we’d misjudged him. He might not ooze compassion, his demeanor might come across as egotistical, but the reality was, he was a quiet man, guided by faith. Our confidence in the outcome grew. Prayers wouldn’t only be coming from us, and our prayers would be not only for our son, but also for this outstanding physician.

Time passed. Joel didn’t wake up from the anesthesia when expected. Hours later and he still dozed in a coma state. Fears grew and prayers continued. When he finally woke up, his eyes were so swollen they seemed to take over his entire face, but he was awake. As the nurses cared for him, we drew our first relieved breaths in days. It was over. Hopefully, that would be the last roadblock in our baby’s path to survival and the opportunity to live a full and wonderful life.

He returned to Forsyth and his excellent care by compassionate nurses who helped us as much as they cared for him. Two, in particular, JoAnn and Cindy adopted Joel and our entire family into their care. They reminded us when we got discouraged, “Peaks and valleys. Peaks and valleys.” There would be good days, and there would be bad days. Slowly, oh so slowly, Joel grew, adding ounces, then finally pounds, to his birthweight of two pounds, two and one-half ounces. Time marched on. Finally, a week after his original due date, he passed his car seat test and came home.

The story doesn't end there. Multiple trips to Dr. Weaver resulted in a prescription for glasses, to, as Dr. Weaver said, open his world." Here the hurdles continued. Glasses for tiny babies at that time, were challenging to find. Optometrists didn't carry them as standard fare, and, for some reason, were unwilling to procure them. Enter another hero into Joel's life, Dr. Doug, as he liked to be called. I'd gone to several larger optometrists and been shut down almost as soon as I'd walked through the door. When I walked into C Optical in Salisbury, N.C., I truly had no hope. A much smaller establishment, it was the last on my list. I really didn't know where I'd go from there. But I needn't have worried.

Dr. Doug took one look at my face, and another at my tiny infant and asked how he could help. I burst into tears as I explained what I needed and my previous lack of success. Within minutes, we were looking through a catalogue. Dr. Doug promised to order the glasses immediately. Within days, Joel had glasses, and his world did open up. Watching his face light up when he saw things for the first time is hard to put into words, but absolute joy comes the closest.

Life went on with many visits to various doctors. My husband and I learned more about the medical world than we ever expected to. It was fascinating to see how Dr. Weaver tested infants' eyes. Not old enough to read an eye chart or even verbalize the names of animals, Dr. Weaver used animated stuffed animals to gauge Joel's ability to see. Even with the surgery, Joel had poor vision, negative 2800 in one eye and negative 2850 in the other, with only 17 degrees of peripheral vision; in laymen's terms, he was legally blind.

Then, when he was in third grade, Joel developed cataracts, a diagnosis that sent my heart tumbling down to my feet. Again, why him passed through my mind. He didn't deserve this. But God works in mysterious ways, and something that seemed terrible became something else

entirely. Dr. Weaver and a colleague performed the two cataract surgeries, followed by weeks of eye drops and patches, then finally, we took Joel in for the final post-surgery check. After the initial examination, Dr. Weaver smiled. “We tightened up a few things while we were in there,” he said. My confusion at his ambiguous statement clarified with heart-stopping disbelief. “Joel’s vision is now 20/40,” he told us with the greatest of joy. That stern, somewhat unapproachable doctor’s eyes twinkled with happiness. “I thought you’d like to know, the only reason his eyesight isn’t 20/20 is because his brain has never seen anything with perfect vision, so it doesn’t know how to recognize it. The best we can do is 20/40.” Fascinating. His eyes had the capability of 20/20, but his brain did not. Regardless, we were thrilled for Joel that he could put his glasses aside.

Years went by with peaks and valleys continuing. Having 17 degrees of peripheral vision makes the day-to-day elements of life that we take for granted challenging, and the ability to drive a car an impossibility. Even walking is difficult. Since Joel can’t see what’s above or below his eyes, stumbling on uneven ground or sidewalks occurs frequently. And seeing anything coming at him from above or the side is impossible. However, as the lack of periphery had always been part of Joel’s reality, his normal life, he had no idea what he was missing until one day when he was in his chorus class in high school. The teacher took them into the dance room to practice choreography. Equipped with a full wall of mirrors, the room gave Joel a visual he’d never had. In the mirrors, he could see his classmates beside him, something he’d never seen before.

He came home in shock. “I had no idea what I’d been missing.” He honestly couldn’t even sort out his emotions. I held him as tears ran down his cheeks. “All those people,” he hesitated; “All those people were around me, and I didn’t even know until I saw them in the

mirror.” He was torn between being horrified and amazed. It reminded me of the doctor’s words about his new vision. His eyes could see 20/20, but his brain couldn’t recognize it. In the same way, those people surrounding him had always been there, but his brain had no way of recognizing that fact until he saw them in the mirror, and he had no way to process it.

As I held my son while he cried, I couldn’t stop my own tears. Watching him struggle with something that’s ordinary for most of us was a painful reminder. This was, is, and always be his life. I can’t always fix the struggles he faces. I can’t put a band-aid on many of the hardships and heartaches of his life. Every parent faces that reality, and I had faced it with my other children, but for Joel, with his physical disabilities, there were just so many more challenges.

I thank God every day for allowing both of us to live. I am equally grateful for the life that he’s lived so far. He’s a fighter. He’s a survivor. He charts his paths and goals and doesn’t take no for an answer. He makes things happen. I am so, so unbelievably proud of him. And yet, I wish he didn’t have to fight for the many facets of life that we accept as normal. I wish more situations would be easy for him. I am beyond grateful to the doctors and medical teams who saved our lives and for those who did all in their power to allow Joel to live life on his own terms. But, like most mothers, I will always wish I could do more to smooth the path in front of him. Regardless, I have faith. He will continue to thrive.