An Opus Like No Other

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A PAIR OF twins in the newborn nursery - *Yay, I'll take them!* I imagined two humans in perfect synergy. The previous pair of twins I had cared for were a delight for me, a newly minted pediatric intern. Very quickly, I realized this pair would be different.

They were perfect, but in a different way. They were yin and yang. Baby Girl had big cheeks, symmetric rolls on her thighs, and soft plump skin. She was vigorous, and I had to apply my newly found tricks to keep her calm. Her brother, Baby Boy, was frail and still. I could make out faint, irregular breathing noises. There was no decipherable movement from his body. As I approached the crib, I saw his bulging eyes and slightly protruding tongue. Instinctively, I palpated his dorsalis pedis pulse and found dark purple nail beds and icy feet. Looking up towards his head underneath his beanie, I could see red, beefy, and gelatinous material emerging out from the margin of his skull that had abnormal, jagged edges. His skull was half a bowl holding his brain tissue.

He was diagnosed with "anencephaly" prenatally. His parents were counseled: "He will die. We just do not know when. It could be minutes or days or weeks." This uncertainty was unimaginable to me. Even with this news, the parents named both their children before coming into the hospital and called them by name immediately after they were born.

Baby Boy was dying when I first met him during his first day of life. I was not accustomed to seeing children die. A third of my rotations intern year focused on healthy children. I had never seen one baby actively dying and another baby clearly thriving together in one crib.

Baby Boy's body created its own symphony. He made irregular, audible respiratory vocalizations, all slightly different from the last. His protruding tongue made the faintest crackles. *Crrr, bop, ugh, hmphf.* One afternoon, I spent an hour with his nurse watching how she cared for him. I remember vividly the several moments where we looked at each other wide-eyed when he would have a prolonged pause in breathing. My own heart seemed to pause. "Is this it?" I thought. *My first dead child.* A millisecond before I was going to call my attending, he would gasp, as though reprimanding me for giving up on him. I greatly admired this nurse's ability to talk to him — "Take a deep breath, c'mon now, you can do it, c'mon. . ." — as if she said this regularly to her other patients. She was gentle and calm.

During the next few days, I had several conversations with the twin's parents, and they would frequently appreciate both of their children's idiosyncrasies, such as Baby Boy's slowed, infrequent blinking and Baby Girl's robust kicks, both children at vastly different levels. Their parents dressed both babies in various lovely outfits with matching accessories like socks and gloves. Though I was sure there was a great deal of unspoken grief and turmoil, I saw them have moments of joy and lightheartedness. Though not explicitly stated, I gathered they preferred to maintain some level of normalcy when speaking of and to Baby Boy. They never denied the concerning changes in his health, such as his limbs appearing duskier or his longer pauses between breaths, but they also did not neglect the little things, like that his long nails needed trimming or that he grasped briskly with his palms showing his intact palmar reflexes. I sensed there was also a sense of intense determination to treat Baby Boy with the same parental love as Baby Girl.

He eventually died at 3 AM on his fourth day of life. His mother was breastfeeding Baby Girl and noticed there were a few less sounds coming from him, an observation guided by the unique intuition of a mother. She looked to him and she knew. The tumultuous, ominous orchestra of his body's organs finished. She cried with her husband and healthy baby girl by her side.

When she recounted this story to me the next morning, I tried hard to hide my grief. I felt sad for those he left behind, though admittedly I felt relieved that the family was spared the logistical challenge of caring for him outside the hospital. I caught a glimpse of a pile of his clothes, and I could conjure up Baby Boy's erratic ensemble. *Crrr, bop, ugh, hmphf.*

After what felt like a prolonged silence, I gestured to examine Baby Girl just to do something, an effort to justify my own presence there. I felt like I had nothing left to

offer them. At some point after I finished my exam, the parents asked me a question about how things would go after leaving the hospital. I had admired their resolve for the last few days while Baby Boy had been alive, but I did not know how they would be after his death. They were clearly sorrowful but resolute. We spoke about their family members back home who had been supporting them and their thoughts on how to talk about Baby Boy to their two older children. We also talked about Baby Girl's weight and her next pediatric appointment. I pondered how they could carry on after such a life shattering event. Their love for Baby Girl and their other children seemed to carry them forward despite their devastating loss. They shared their preference to leave the hospital that same day to start their long car ride back home. They collected their things over the next several hours, including all of Baby Boy's belongings which were assembled into a memory box provided by the nursery social worker. The medical team worked together to help prepare them with what they needed. Finally, when all things were ready, the family waved goodbye to all the nursery staff as they made their way out and left.

Later that day, I left the hospital and found a moment to pause and think back on the day. I closed my eyes for several minutes and called to mind his special traits, his short-lived life, and his family. Tears fell quietly down my cheeks. The next day, my attending, the newborn nursery nurse practitioner, and I met together to reflect on the experience of taking care of their family. Soon after starting, all three of us were teary-eyed. Though I do not remember precisely what was said, I do remember being impressed that this situation moved them deeply and that their ample years of experience as pediatricians did not desensitize them to these moments.

Over the years, I have thought often of Baby Boy. His existence brought joy to his parents despite its fragility. His death showed me the strength of a family who experienced a terrible loss yet continued to care for their other children without pause. This experience was my prelude into the reality of being a pediatrician. In my future encounters with end-of-life care, I would remember that parents and children should be spoken to and treated as normal people, like his parents reminded me, despite my own internal fears and anxieties. I remember that a child who is dying should be cared for like the child they are, which was embodied by this nurse. When I grapple with the thought that I seemingly have nothing to offer a family, I remember that my role as a doctor has not ceased but has shifted and that I can adapt to support them. With each devastation that I may bear witness to as a pediatrician, I hope to be able to remain empathetic to the suffering of families and the shared experiences of my fellow health care workers.

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