## **HUMANITIES**

## When the ER Doc Became the Patient's Dad

Brad Buckingham, MD<sup>1\*</sup>

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Website: <u>https://ir.library.louisville.edu/jwellness/</u> Affiliations: <sup>1</sup>University of Kentucky. Department of Emergency Medicine

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I am a dad and an Emergency Physician; that ordering is intentional.

My wife and I excitedly welcomed our third child, our first girl. Her name is Elizabeth and she holds a very special place in my heart. It's a place that, for a period of time, may have been characterized by joy or crushing loss.

After a couple months, Elizabeth was doing well, making eye contact and smiling. I realized early on that making her smile would be one of my life's greatest tasks and treasures. At three-and-a-half months of age she developed a cough with feeding. In early fall, I blamed viral URI season, even though she had no runny nose or fever. A couple of days later she couldn't nurse or take a bottle well. Other than a weak cry, she appeared well.

Somewhat apprehensively, we took the family to the Louisville Zoo - looking back now at photos, we realize how expressionless her face was. That weekend she continued to have trouble and we agreed, perhaps reluctantly, to take her to the pediatrician. As an ER doctor, I knew my daughter looked "not sick," non-toxic and well-hydrated. I expected the "viral URI" diagnosis and to soon return to normal.

"We are headed to the ER," my wife texted. Still thinking like an ER doctor, panic was a last resort. My wife, who also stays calm under pressure, called me from triage. "Dr. Duncan said to bring her straight to the ER and specifically mentioned asking them to test for botulism." Our pediatrician was concerned about her low tone, weak cry, and the fact that Elizabeth didn't flinch or cry with the catheterized urinalysis in the office.

What, and how, does an ER doctor think when his or her loved one heads to the hospital? I wish I could perfectly describe my mindset, but in the whirlwind of it, the only word is surreal. At this moment I began to genuinely worry about my daughter, finally admitting to what I had seen beneath my fear-based denial.

From this moment until discharge to home, time simultaneously flew and crawled. My parents came into town, staying with our boys, so I could go to the hospital. We met my colleague and friend in the pediatric ED. Elizabeth had normal vitals, intact reflexes, but decreased muscle tone. Despite the reassuring appearance, they ordered labs, an IV, and consulted the inpatient pediatric resident.

With boarding in the ED overnight, and only one spot for an adult to sleep, I went home for the night. I researched infant botulism and the differential diagnosis, struggling to figure out how she could have gotten it. We didn't give her honey. We don't can our own foods. It didn't make sense. The next morning, I took supplies from home for what we presumed would be a long stay in the hospital. I went immediately to Elizabeth's side. I had either avoided the truth or just didn't fully notice until then, that there was something unmistakably wrong with my daughter.

Her tone and strength were very diminished. She couldn't hold her head up unsupported. Her cry was weak. She strained out a smile for me, but it was puny. I am all dad now, and I am hurting for my girl.

There was a flurry of activity early on this Tuesday. We saw infectious disease specialists, who presumed something neurologic. Neurology predicted botulism or some devastating life-long neurologic condition, and frighteningly the intact DTRs pointed away from infant botulism. With botulism as a strong possibility, the pediatricians ordered BabyBIG (botulism immune globulin) from Sacramento, CA. In the meantime, Elizabeth had a lumbar puncture, a brain MRI, and more labs (all were ultimately normal). With poor intake and falling from her growth curve, she received an NG feeding tube. The stool botulism test would take several days to result.

Time crawled. The whirlwind of Tuesday had ended. As we waited for the antidote (our only medical hope at this point) we watched our expressionless daughter become weaker. As a descending neurologic weakness, botulism first caused the cough and inability to tolerate feeding. But now she was unable to raise her legs off the bed, and we watched her breathing strength with continuous pulse-oximetry. Not knowing the diagnosis or prognosis, this was the darkest night we had ever had as parents. We cried. We prayed. We reasoned. We tried to sleep. I would gladly take my daughter's place with whatever disease is hurting her.

The next morning arrived. Greeted by our angst and sleepless countenances, the pediatricians arrived and announced, "The BabyBIG has landed." This extremely precise medication would require a reliable IV. Her previous IV had blown when flushed in preparation for the infusion. Multiple attempts, more blown veins, and a screaming child raised the pressure to administer this drug with a very short shelf-life and a long travel history. At the team's request, for the first time, my wife and I both left Elizabeth's room, fully entrusting her to the care of the experts.

I have no clue how long we waited in the hall, but the two friends who brought us lunch aided the wait. When they left, Elizabeth had an external jugular IV, and the infusion was running. If botulism is causing this, we should see improvement in 12-24 hours. We watched. And watched. And agonized. I don't know if I ate anything. I just stared and waited.





<sup>\*</sup>Correspondence To: Brad Buckingham Email: bpbuck2@uky.edu

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Eleven hours after the infusion Elizabeth's legs raised up from the bed. Hovering, my wife and I stared for some time until she started to wiggle her legs in the way that babies do when they wake from sleep. That night, worry was replaced with hopeful anticipation. I stared at my daughter for more hours than I can recall, detecting every minute movement, celebrating each squirm.

The next morning, with smiles on our faces, we reported to the rounding team the new muscle movements we had witnessed. We still felt some diagnostic uncertainty until a smiling Dr. Wehder walked in with a certain joy in her step. The botulism test was positive, and our daughter should have a full recovery. Our neurologist officially removed the other more devastating neurologic conditions from consideration and signed off.

The next day, an epidemiologist from the health department spoke with us, delivering information about infant botulism and contact information for other parents nearby in case we wanted to network with them. Despite the classic example of honey intake, most cases yield no direct cause.

The rest of our stay in the hospital was filled with thankfulness and anticipation of discharge. We joyfully watched Elizabeth improve on what seemed like an hourly basis. She eventually held up her head and took a bottle well enough to discontinue the NG tube. At the request of her thankful parents, Elizabeth was discharged from the hospital 8 days after admission; just in time for my next ER shift. It can be a humbling thing, as a medical professional, to give up your ideas and opinions and trust others to provide care for your loved one. I found this release of control to be healthy - to be fully present, to be fully 'dad,' to be fully there for your loved one.

As an ER doctor, this experience helped me understand the importance of trusting the histories provided by those who know the patient best. Concern from patients' parents, loved ones, and pediatrician should raise the suspicion for serious illness even in well-appearing patients. As a doctor-dad, I will trust our pediatricians and primary care providers to illuminate my blind spots and help me make wise decisions.

As of this writing, my almost two-year-old Elizabeth is doing well. She needed some physical therapy, eventually walking independently at 21 months of age. She is otherwise healthy and happy—thanks to my colleagues and a special medicine from Sacramento. Jacob H., RN, and Drs. Duncan, Zummer, Hall, and Wehder were present at critical times. It has taken me a year and a half to write this. Thinking about my daughter, her condition, and those who cared for her still makes me tear up.

Fellow EPs, we are there for patients just like my daughter. We are there for our colleagues' loved ones. We are there for our own loved ones. And when time calls us to be 'all parent,' our colleagues are there for us. May we always be present for our patients and for one another.

