1. BIRTH

Ms. B was at more than 39 weeks’ gestation and began feeling strong contractions at 10 pm. At 12:30 am, a spontaneous membrane rupture occurred. With joy and great anticipation, Ms. B arrived at the emergency department (ED) of the local medical center, where she was examined and transferred to the labor and delivery suite. She was shaved, given an enema, and placed in a supine position for the installation of a fetal monitor belt and initiation of an IV pitocin drip; none of these actions are considered evidence-based practices. A rotating cast of medical students and residents checked her for dilation and effacement every 15 minutes until the next morning. No one noticed fetal state deterioration on the monitor, but Ms. B sensed something was wrong.

At 6 am the following day, Ms. B was 3 cm dilated on a high-dose pitocin drip. Thirty minutes later, a medical resident found green-stained amniotic fluid, and Ms. B was rushed to the operating room for an emergency cesarean section. By 7:15 am, Jana was born weighing 3.65 kg and measuring 46.7 cm. The baby was hypoxic, and according to the medical records, diagnosed with anoxia, respiratory distress syndrome, transient tachypnea of the newborn, and meconium aspiration syndrome. Awake behind the drapes and unable to see her newborn, Ms. B could detect no sense of urgency among the hospital staff.

Jana was taken to the regular nursery. At the nursery window, Ms. B’s mother noticed that Jana was turning blue and began to frantically bang on the window to alert the nurses. Jana was immediately transferred to the neonatal intensive care unit (NICU). A nurse who saw Jana’s worried grandmother nervously watching everything, closed the window blinds.

For more than 24 hours, there was no communication from the medical team with Jana’s family. Ms. B was ultimately told that almost all babies delivered by cesarean go to the NICU. The silence on Jana’s condition was most disturbing and has continued for the past nine years.

2. GROWING UP

Ms. B left the hospital four days after Jana’s birth with an irregular deep surgical incision that later healed into an uneven diagonal scar. On discharge, Ms. B continued to take frozen breast milk to the NICU and soon learned that her daughter had manifested neurologic brain damage and was unable to breastfeed. After 10 days, Jana was released,
and she remained on pumped breast milk for eight more weeks before switching to formula. Meanwhile, Ms. B’s emotional state deteriorated.

At home, Jana gasped for air and had difficulty with breathing. At age 3 weeks, she was diagnosed with gastroesophageal reflux disease and given a prescription for a proton–pump inhibitor. The baby continued to cry shrilly and exhibited facial grimaces indicative of pain. Her cry was so heart-wrenching that it often brought Ms. B and other family members to tears.

Repeated visits to the ED ended with an explanation that “all babies cry for colic pains” and a prescription for gas relief. After seeing seven pediatricians during her first eight weeks of life, Jana finally was taken to another hospital. An electroencephalogram showed hydrocephaly and an enlarged head circumference, and Ms. B was told that meningeal fluid would self-absorb. Jana’s excruciating cries continued for two years and took a heavy toll on Ms. B and her entire family.

Ms. B suffered from postpartum depression compounded with the additional stress of financial problems, which forced her to work while caring for Jana. She lost a significant amount of weight, was unable to sleep, and was treated with three different antidepressants. At one point, Ms. B contemplated suicide, but her husband intervened.

Jana began teething at age 4 months. At age 6 months, she had three days of high fever (41°C). Jana was hospitalized for 10 days with a diagnosis of fever of unknown origin and treated with aspirin and antibiotics. Three days after discharge, she returned to the hospital for high fever and was tested for TB, meningitis, and other infectious diseases; the results were negative.

Jana was taken to a third hospital and underwent chromosome studies to rule out genetic abnormalities. Tests showed no indication of genetic errors. Two spinal taps at age 7 months showed no pathogen for persistent fever episodes. A hearing test and a vision screening were normal. At age 8 months, Jana was tested for and diagnosed with celiac disease and placed on gluten-free diet. Four months later, she had a tonsillectomy and Nissen fundoplication surgery for reflux disease, projectile vomiting, and insufficient growth.

Jana’s growth began to improve when she was introduced to solid food at age 2 years. She started walking at age 28 months, spoke a few single words at age 36 months, and toilet trained at age 42 months with nighttime bedwetting until age 7 years. At age 8 years, Jana began taking daily growth hormone (somatropin [Genotropin]). Her current height is 107 cm and weight 22 kg.

Ms. B and her husband have a healthy son aged 5 years. The family’s finances have been drained to pay for Jana’s medical care, as she requires speech therapy and schooling. Jana is a lovable child, but Ms. B feels bitter. She recently told me she wishes they could sue the doctor and hospital to help pay for Jana’s expenses. She added, “I know money will not reverse the past, but it can secure Jana’s future. At the very least, I want someone to apologize to me for substandard medical care.”

3. LESSON LEARNED

Living in Beirut for 10 months as a Fulbright scholar allowed me to verify Jana’s case. My interest increased after a cursory review of the hospital records showed contradictory information (e.g., Apgar score of 8/10 for a diagnosis of anoxia and respiratory distress). Although the patient’s bill of rights is posted at each unit, such a concept is not well understood, and Ms. B was not permitted to obtain a copy of the hospital birth records. Similar to other countries in this region, women’s voices are silenced by a medical profession dominated by men. A clinician surplus coupled with a nursing shortage in Beirut has made it difficult for nurses to exercise their skills. Such tasks and duties as cervical assessment of a woman in labor are assigned to inexperienced medical students and residents without immediate supervision. Labor and delivery nurses are not allowed to check for cervical dilatation and effacement, read fetal monitors, or intervene for fetal distress.

A medical facility must adhere to the meaning and purpose of a patient’s right to access medical records, express opposing views, and refuse such procedures as shave and enema prior to birth. Describing her emotional scars, Ms. B told me, “Healing could have begun by a simple apology nine years ago, if only the obstetrician could humble himself and admit to wrongdoing. Instead, we have subconsciously blamed ourselves for so long.”

Dr. Fooladi is a professor at the Florida State University College of Nursing in Tallahassee and a senior consultant at the American University of Beirut in Lebanon.