

Severe Jaundice—a Red Flag for Parents, Doctors and Nurses

By Tracy K. Lischer, Esq.

Back in 1998 when May and her mother brought Melody to our office, my administrative assistant and I had never heard of kernicterus. We had never seen the word *bilirubin*. We didn't know that kernicterus comes from too much bilirubin in a baby's blood or that the yellow staining of the skin we call jaundice is caused by bilirubin. We didn't know that every time we get a bruise from bumping the end of the bed at night, it's the bilirubin in our broken blood vessels turning the lump yellow. Even though both my administrative assistant and I have children, neither of us knew that severe jaundice is a red flag for doctors and nurses. When that red flag is ignored, liability arises.

Most babies have some jaundice. Our son was jaundiced after birth, but my husband and I had no idea that when he was given a tiny black eye mask and put under a light, it was damage to his developing brain that his pediatrician was preventing. When May and her mom came in with Melody, my only experience with jaundice was personal, not professional. Our son's jaundice didn't peak until he was four days old, but in the 1970s no Health Insurance Company or doctor pushed for a 48 hour—or earlier—discharge. In those days, all good doctors knew that jaundice didn't peak until the third or fourth day of life, or later. In those days, doctors and nurses who had practiced before the advent of phototherapy had heard the high-pitched screams of jaundiced infants and seen them arch their backs when the bilirubin crossed over into their brains. They had seen infants who were born normal lose their hearing and their muscle tone because there was no simple way to reverse their rising bilirubin. Once phototherapy was invented and bilirubin could be lowered easily, by simply placing the baby under lights, these doctors and nurses rushed to use it. They knew to keep the

bilirubin level well under 20 mg/dl (milligrams per deciliter), even lower for premature or sick babies.

Our baby boy's bilirubin reached a high of 13.4 mg/dl, I discovered when I read his birth record. The number means something to me only now that I know parents of children with kernicterus, have read the medical literature, and meet regularly with the experts. Because our son was born with respiratory difficulties, he was placed in intensive care under a light and given antibiotics. If he hadn't gotten phototherapy, I learned from Melody's case, his bilirubin could have risen another five points in the next 24 hours, dangerously close to the magic 20 mg/dl, a number that can cause brain damage in even a full-term infant. But he *was* put under a light for 2 days until his bilirubin dropped to 10.1 mg/dl on the first day and 7.8 mg/dl on the second. He was kept in the hospital until it was safe to send him home.

My current paralegal and I have worked with many parents of children with cerebral palsy and deafness from untreated severe jaundice. In every case, had the doctors and nurses followed the simple guidelines that were followed in the 1970s, the baby would have no disability at all.

At that first meeting, May told my administrative assistant and me that Melody was born five weeks premature and was breastfed. I didn't yet know that a baby has to be in the womb for 37 weeks before it acquires a suck reflex. Before discharge, May said, "I told a nurse on Friday that Melody was yellow and I was told that it was normal." Melody was sent home at 48 hours and given an appointment within 2 days for a weight check.

At that visit Melody had lost over 10% of her birth weight and was jaundiced from head to toe. The parents were not told that the jaundice posed any danger. May was instructed to "push feeds" and bring Melody back the following day. A different doctor

was on call that day and when he saw Melody he sent her to the hospital for a bilirubin check. Only after the blood test showed a bilirubin well over 20 mg/dl were these new parents told that jaundice can be dangerous. Melody was put under lights but not given a blood exchange, which could have lowered the bilirubin level more quickly than phototherapy.

Even after Melody was discharged from the hospital the second time, the parents weren't told that jaundice causes permanent brain damage. They weren't told to watch for developmental delays, deafness or cerebral palsy, the hallmarks of kernicterus. They remained with the same pediatric group. May later testified that the doctors in the group "would not say 'kernicterus.'" Since a timely bilirubin check and simple lights prevent the disorder, their aversion to diagnosing it is not surprising.

Melody is now a smart 13 year old who is fed by a G-tube and who, after years of therapy, can walk. She is delightful with curly hair and sparkling eyes. But she is silent. Kernicterus has taken her voice. Weak vocal chords and weak throat muscles preclude her from eating enough to thrive and from speaking. Bilirubin doesn't pass through the blood-brain barrier into every part of a newborn's brain, but it can pass into the parts that govern four functions: motor (causing athetotic, or floppy, cerebral palsy), hearing (causing auditory neuropathy or sensorineural hearing loss), tooth development (causing dental enamel defects) and vision (causing visual disturbances including loss of upgaze).

May met other parents of children with kernicterus at the first PICK (Parents of Infants and Children with Kernicterus) family conference in Richmond Virginia in 2002. There she got to know Yvette, whose son, John was also premature by at least 5 weeks. On the day John was sent home from the hospital Yvette and her husband noticed that his eyes were yellow. Yvette asked the nurse on duty about the yellow tint

in the whites of her baby's eyes. She was told that the yellow tint was "OK." When I deposed the nurses, a different nurse told me, "The eyes are one of the last parts that get jaundiced." And yet, all the nurses agreed, "It has never been our practice to tell the parents what the complications are of jaundice. . . . You don't want to scare a new mother."

No one told John's parents that he was jaundiced at discharge or that severe jaundice is life-threatening, like a high fever or choking. No one told Melody's or John's parents that too much bilirubin causes a baby to be too sleepy to feed and that as the bilirubin crosses into the brain the baby shrieks and arches in pain. The parents had to find out for themselves. They ended up being very, very scared after all. By the time John's bilirubin was measured, it was 33 mg/dl, over twice the number at which phototherapy should have been started. A blood exchange was performed, but it was too late. The bilirubin should have been measured before he was discharged from the hospital after birth.

Zachary's bilirubin was measured on time, and repeatedly, but inexplicably his doctors failed to act on the results. Zachary was born term and healthy, but with a heart murmur. He was discharged at 2 days and told to come back on day 5 to correct the narrow heart valve causing his murmur. His heart doctors took care of this problem, and his surgeons took care of a tear in his bowel, but while he was recovering the neonatologists who are supposed to watch for jaundice dropped the ball. For three days on their watch Zachary's bilirubin hovered around 25 mg/dl with no blood exchange and only minimal phototherapy. By Zach's 6 month check-up it was clear to everyone that he couldn't hear. He now has cochlear implants and works hard on his speech, physical and occupational therapies.

My paralegal and I have reviewed, accepted (and occasionally declined) kernicterus cases in North Carolina, New Jersey, Minnesota, Virginia, Ohio, Kansas and Louisiana. What we have learned about how to prevent kernicterus is no more than any parent learns from the internet as soon as they get a diagnosis. Measure the bilirubin, start the lights on time, do an exchange if necessary. If these simple things aren't done the child will need an attorney: one who understands hyperbilirubinemia, albumin (to which molecules of bilirubin bind so they can be excreted), hyperintensity of the globus pallidus (the hallmark MRI finding of kernicterus), choreoathetosis (different from spasticity caused by hypoxia) and auditory neuropathy; one who is familiar with the 1994 and 2004 American Academy of Pediatrics Practice Parameters for treating jaundice in the healthy term newborn and how to extrapolate from them for treating premature or sick infants, JCAHO's (Joint Commission for the Accreditation of Healthcare Organizations) 2001 Sentinel Event Alert on hyperbilirubinemia, and other literature on jaundice; one who knows the experts and can get the case reviewed; and one who can defeat the usual defenses that arise in any injured baby case, defenses based on the placental pathology or an alleged undetected prenatal infection, an inherited disorder or an unrecognized trauma in utero, intermittent compression of the umbilical cord or some other alternative cause of cerebral palsy (other than bilirubin toxicity).

We're seeing more cases every day. A disorder that was controlled by exchange transfusion in the 1950s, eradicated in the 1960s and 70s after the advent of phototherapy, and began recurring under managed care now threatens newborns in every hospital and every state. Some excellent doctors are doing all they can to prevent it and diagnose it when it hasn't been prevented. But everyone needs to do more. As lawyers we need to refer or associate with attorneys experienced in kernicterus cases or become experienced ourselves. We need to insist upon remedial

measures as part of any confidential settlement. As community members we need to educate the general population that jaundice can become severe in *any* baby and when it does, it has to be treated as a medical emergency by a physician who understands that treatment must be based upon gestational age, hours of life, the total serum bilirubin level and the general health of the child. We need to push in our own communities for universal pre-discharge bilirubin testing. As parents, grandparents and family members we need to monitor the care of our babies and our friends' babies and be proactive with any nurse or doctor who dismisses jaundice as normal in a newborn. My goal as a lawyer who does kernicterus cases is to put myself out of business. Everyone can help.