INSIGHTS Family reflections: neonatal sepsis

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Enzo was born on June 27th, 2018. He was perfectly healthy and full-term, and we took him home excited to get situated as a family of 4. When he was 18 days old, we could tell something was wrong with him. He spent most of the prior night laying on me and breathing heavily. He had a slight fever in the morning, but we treated the fever with Tylenol and he slept for most of the morning. At one point, he woke up and just was not very responsive and was a bit mottled. We took his temperature and it was 102.5. We hurried him to the pediatric ER at our local hospital, where they whisked him back before we had even finished checking in. It was heartbreaking to watch him get poked and prodded, but eventually they received antibiotics from the pharmacy and stabilized him enough to take him up to the PICU. Because his body was working so hard, they ended up sedating and intubating him.

The morning of his third day there, they were able to remove the ventilator and wake him up. Blood cultures showed that he had an *Escherichia coli* infection, and further imaging showed that he had hydronephrosis of his left kidney. Shortly after that, I noticed the words "neonatal sepsis" in his MyChart portal. Sepsis is the body's overwhelming and life-threatening response to infection that can lead to tissue damage, organ failure, and death. Sepsis overwhelms the body extremely quickly, and quick treatment is critical to the patient's prognosis. The theory was that what started as a UTI backed up to his kidneys, and then entered his bloodstream. They were able to adjust his antibiotics to ampicillin to combat the infection, and we were in the hospital for 12 days while he received the full course of antibiotics. It was a very difficult stay, both physically and emotionally, but we were incredibly thankful to be taking him home again.

An important side note: we had heard the instructions to not give Tylenol to a baby under 3 months of age, but our presumption was that it was weight-related, so we gave him a very small dose since he was a big baby anyway. Later, we discovered that the true reason why this is directed, and why they instruct parents to call the doctor for a fever above 100.5 in babies <3 months old is exactly what we went through. High fevers in infants are likely an infection that can end up in sepsis, and Tylenol masks the fever, which can delay the seeking of treatment.

We had a follow-up ultrasound and appointment with a pediatric urologist, who determined that he had a megaureter that was contributing to the hydronephrosis. Our options were to put him on preventative antibiotics or utilize a wait-and-see approach with monitoring. In conjunction with his urologist, we chose not to put him on antibiotics, and are currently monitoring him with periodic ultrasounds with strict instructions to take him to the ER if he ever spikes a high temperature. There has been mild improvement, but both the megaureter and hydronephrosis are still present. He may grow out of the megaureter as he gets

bigger, but if he does not grow out of it, we may eventually need to consider surgery to correct it.

Thankfully, and this may have something to do with how young he was when he had sepsis, he does not seem to have experienced any long-term effects. He is thriving, has excellent motor skills, and is overall a very happy, silly, and smart boy.



Sepsis is still fairly low on the public's medical conditions familiarity list. Everyone knows what cancer and heart disease are, but not many people know what sepsis is. We had heard of it in the past, but we were not aware of the prevalence of sepsis in the medical world. Our memories of our hospital stay are a bit fuzzy, but we are not sure that anyone ever mentioned the word sepsis to us. Thankfully, our hospital had a protocol in place for suspected sepsis and were able to attend to him quickly. Last year, Enzo was honored as the honorary chairman of our local Sepsis Alliance chapter's Sepsis Challenge, an annual fundraising event held across the country to raise awareness of sepsis.



While Enzo did not suffer any physical or emotional effects from sepsis, a lot of children do. More research into how sepsis affects



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the body and finding ways to minimize those effects would improve the recovery period for children with sepsis. More sepsis awareness, both in the medical community and general public, will also help improve outcomes. All medical centers should have sepsis protocols that must be followed with anyone presenting with symptoms of sepsis, along with personnel trained in these protocols. The general public should be made more aware of the symptoms of sepsis and what to do if they suspect one of their loved ones may have sepsis. The Sepsis Alliance has an acronym for these symptoms.



The difficult part with children, especially infants, is that fevers are fairly common—teething, seasonal illnesses, etc. What helped us get to the ER guickly was the knowledge of the fact that any fever above 100.5 in an infant under 3 months of age warrants immediate medical care. We may have had him there sooner had we not given him Tylenol, but thankfully we still got him there in time. If Enzo had been 6 months older, we may have just chalked it up to teething and given him Tylenol, masking the fever and potentially resulting in a different outcome. While parents certainly should not overreact and take their child to the hospital for a fever that may be due to teething, there should be a heightened awareness of the other symptoms and risk factors for sepsis, so that parents can get the medical attention their child needs in a timely manner. The general guidelines for handling fevers in babies under 3 months old and instructions to not give Tylenol to those babies should be expanded upon to provide more detail behind those recommendations. Had we known the true reasons behind those recommendations, he may not have ended up in the PICU.