



INSIGHTS

Strawberry mark: our daughter's journey with an infantile hemangioma

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Pediatric Research (2020) 88:818–819; <https://doi.org/10.1038/s41390-020-1089-x>



We noticed the red mark on our daughter's head right after she was born, but with everything else we were worried about as new parents, we didn't give it much attention. It was faint and no bigger than a dime, so we figured it was just a birthmark. However, as the weeks unfolded, the mark started to get bigger and turn a darker shade of red. Now alarmed, we went to see Penny's pediatrician, and that's when we first heard the term "infantile hemangioma".

Many of our anxieties as new parents were fueled by how little we actually knew about this new adventure. Throughout the pregnancy, we read a great deal of research to prepare us and to assuage our fears of the unknown, so when our doctor told us what the mark on Penny's head was, the first thing we did was try to learn as much as we could about infantile hemangiomas. Unfortunately, as we soon discovered, there wasn't a great deal

known. Still, two pieces of information we read allowed us to rest easy for a while: hemangiomas are benign, and they usually fade by the time children are two. However, the relief these assurances provided was short-lived, as Penny's hemangioma kept growing across the surface of her head and expanding outward, its size increasing nearly ten times from October to January. Worse yet, when Penny was 4 months old, it also began to ulcerate. One evening, while hugging her goodnight, we removed our cheeks from the side of her head to find them covered in blood, the sight of which sent us in to a panic. Nothing we did had caused the hemangioma to bleed, and worries over infection and scarring and our daughter in pain kept us up most of the night.

It was then we sought out and began seeing a specialist, Beth Drolet, MD, Chair of Dermatology, University of Wisconsin School of Medicine and Public Health; Nominating Committee Chair, Pediatric Dermatology Research Alliance (PeDRA); and Past President, Society for Pediatric Dermatology (SPD). Dr. Drolet spent a great deal of time teaching us about infantile hemangiomas and their treatment, providing insights and answers to our questions in a concise and accessible manner, and this information immediately set us at ease. We then started Penny on a regimen of Propranolol three times a day. We were nervous about what a beta blocker would do to a 6-month-old, but before going home and starting the treatment, we tested Penny's reaction to it at the clinic, monitoring her pulse and blood pressure for several hours after taking a dose of Propranolol.

We saw a near-immediate result from the treatment. Within days, Penny's hemangioma was softer and turning a lighter shade of red. More encouraging yet, it noticeably decreased in size within just a couple of weeks. The immediacy of Propranolol's impact was far better than we could have hoped for. We returned to the clinic to see Dr. Drolet a few weeks later and increased Penny's dosage, again testing it and monitoring for 2 h prior to returning home. We then repeated this process once more a month later. By the time Penny was one, her hemangioma was almost flat against her head, and the color was a much lighter shade of red. It was then Dr. Drolet decided to reduce her dosage of Propranolol and phase it out.

With how quickly Penny's hemangioma faded, we worried greatly when problems with it arose after her first birthday, thinking the immediate results were, as the old saying goes, too good to be true. The first cause for concern came when the hemangioma puffed back up after we had stopped giving Penny the Propranolol; however, giving it to her for another month and a half after her first birthday and phasing it out then proved successful. The second came earlier this year in April. By then, Penny's hair had grown out

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Received: 21 July 2020 Accepted: 21 July 2020

Published online: 25 July 2020

significantly and covered the hemangioma entirely. One morning, Penny was running across our living room, and she tripped over her feet, fell, and hit her head right on her hemangioma. We checked, and it seemed fine; when we gave her a warm bath that evening, though, we watched in horror as her hemangioma not only puffed up but hardened. As one of us dialed the emergency line at the doctor, the other was researching what this meant; as it was before, though, when we sought information, there was nothing about this new development. Thankfully, Dr. Drolet's office got back to us immediately that night and explained what had happened and that it was not a cause for concern. They then followed up with us the next day—by this point, the hemangioma had deflated and was exactly how it had been before the fall—just to make sure Penny was fine.

Throughout our journey with Penny's infantile hemangioma, perhaps the greatest aid to our family—aside from the Propranolol, of course—was information. The unknowns of parenting combined with the litany of possible problems that might arise creates a situation in which a red mark can cause debilitating anxiety. We had never heard the term "infantile hemangioma" before we were told our daughter had one, and when we sought out more information on our own, we discovered a scarcity of answers. Understanding

more about infantile hemangiomas, not only what it is but also what causes it, will not only help doctors but also parents conditioned to look for any possible problem with their newborns, who will fill in the blanks with nightmarish scenarios at the appearance of that mysterious strawberry mark. To our doctors—who patiently provided us information, answered all of our questions, and got back to us right away, even on a Saturday night when we were in panic—we are eternally grateful.

In preparing to write this essay, we looked back through photos of Penny from her birth to now, watching the hemangioma grow in size, ulcerate, and then decrease. We can point to the exact time we began the treatment without having to look at the date—that's how quickly and effectively it worked. Other parents who have children with hemangiomas would also be comforted to know this, especially if that hemangioma is obstructing their child's vision or making movement difficult, additional obstacles Penny did not have to deal with simply because of where hers was positioned. Knowledge, as another old saying goes, is power, and parents understanding the causes, implications, and treatment of infantile hemangiomas can allow us to be better advocates for our children and sleep a little more soundly...that is, when we are actually afforded sleep those first few months.