

Views

Last September, my husband Dan and I took our 4-week-old daughter for a hike near our home in New York's Hudson River Valley. Violet slept in her baby carrier as we munched on apples and enjoyed views of just-turning fall leaves. Toward the end of the day, Dan turned to me and said, "I feel like we're getting the hang of this newborn thing!" We laughed. Violet was a great baby—calm, bright-eyed—but we were still clueless new parents. "I don't think it's going to be quite that easy," I told him.

It wasn't.

Less than 24 hours later, I sat in the front seat of an ambulance as it raced, sirens blaring, to a nearby children's hospital. Violet's tiny body was strapped to an adult-sized gurney and I could hear her kittenlike cry while two paramedics worked desperately to keep oxygen in her body.

Humans are supposed to have blood oxygen levels of nearly 100 percent. That morning, when we arrived at the pediatrician's office for Violet's "well baby" visit, her levels had dropped to 75 percent. By the end of the day, even after Violet had been put on a ventilator, that was down to 18 percent. Forget what you've heard about blue babies; our girl was gray.

As we soon learned, Violet had been born with a form of critical congenital heart defect (CCHD) that prevents her heart from pumping enough oxygen-rich blood out to the rest of her body. During the months she spent growing inside me, Violet's heart never divided into all four cham-



Saving the Smallest Hearts

Virginia Sole-Smith thought her baby was perfectly healthy—until a routine doctor's visit revealed a heart defect so severe it could have been fatal within hours. The screening test every parent needs to know about.

bers; it also did not form one of the essential valves. The medical term for her anatomy is "single ventricle physiology," but the simplest way to explain it is to say that Violet has only half a heart.

A pediatric cardiologist was able to perform a balloon catheterization to stabilize Violet. Afterward, as she lay unconscious, hooked up to a million wires and tubes, I stared at her and wondered: How could we have missed

that something was so wrong?

I'll probably never stop asking that question, even though Violet's heartbeat had been strong and steady at every prenatal checkup and all through my labor. Some congenital heart defects are detected with prenatal ultrasounds, but Violet's didn't show up on any of mine. We have no family history of CCHD, and its cause is often mysterious.

Nevertheless, we should have

known more. Hospital nurseries can measure babies' oxygen levels 24 hours after birth. That test, called a pulse oximetry screening, is noninvasive, takes fewer than 10 minutes, and costs less than \$15 per baby, but has only been part of the federally recommended newborn screening panel since 2011. Whether that federal recommendation gets followed varies by state and even by hospital. (At least 10 states have yet to require the test as of July 2014 and even those that have don't always enforce it.) New York, the state we live in, was in the process of mandating the "pulse ox" screening—but still, Violet never got the test.

If we hadn't had that pediatrician checkup; if Violet's oxygen levels had plunged too low while she slept the night before; if we didn't live within an hour's drive of a top children's hospital—our world would have broken apart that September day. Getting the pulse ox screening wouldn't have changed the course of Violet's treatment, but we wouldn't have had to nearly lose her before we knew that something was wrong.

Yet our family is one of the lucky ones. During our stay in the pediatric intensive care unit, Violet underwent the first of three expected open-heart surgeries, which will reconstruct her circulation over the course of the next few years. She is now a strong 1-year-old who smiles, babbles, and rolls. And by the time she is 5, Violet should be as healthy as any kid on the playground. She will always have just half a heart. But I carry her other half in mine. **E**