

Arrival

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Ambulatory Pediatrics 2008;8:351-3

We were sitting in the waiting room, among the toys and magazines. I felt—not serene, but expectant. Uncertain. Nancy, the nurse, came to take us back to the exam room. “It’ll just be a minute,” she said as she left us. Theresa lifted Laura from her car seat and set her, still sleeping, on the clean paper of the exam table. I got out colored pencils and a notebook for Ellie. We were paging through *People* and *Us* when Dr E came in, knocking softly. He closed the door, crossed the room, and turned toward us.

“We got the lab tests back,” he said. “Nancy called and had them faxed down here.” He paused.

“Laura does have Down syndrome,” he said.

Ellie was coloring quietly. From where I was standing, I could see the first tears forming in Theresa’s eyes.

“I believe,” he said, “that these children come to the families most able to take care of them.”

No one said anything. Ellie kept drawing her rainbow, keeping the colored lines parallel. There was a bump in the first line she’d drawn, and she copied it through all the succeeding lines, the blip softening into a gentle swell. Ellie, meticulous, precise, absorbed: our gifted child. She didn’t seem to register the news. Theresa stared up through tears. I felt nothing, only the grip of fact, and so I began asking questions, setting them out like planks heaved across quicksand. What do we do. Whom do we contact. What do we need to know.

I thought a lot about that moment in the weeks following. The way Dr E turned toward us, the door easing toward an institutional click. His face, pinker than usual, the hush in his voice, his gentleness. All said that news was coming. I thought about it whenever someone said They can lead full lives or They are truly a gift or But didn’t you test, as I came to see that Down syndrome is, for most people, an implicit and disturbing question. The question had been put to me too, something I was dimly aware of, there in the cramped exam room. What had been asked of me, I couldn’t yet tell, but clearly an answer was called for.

Laura was born at 7:02 AM on February 26, 2001, after a labor described by Theresa as “blessedly brief.” I woke up at around 3 AM, to Theresa saying, “George. I think my water just broke.” “OK,” I said, “OK. OK. OK.” I be-

gan stuffing underwear and socks into an overnight bag. We called Kai and he came over to stay with Ellie. We woke up Ellie and told her we were going to the hospital. The first and second contractions were 11 minutes apart; the second and third were 4 minutes apart. Theresa wanted to strip the bed. She wanted to *red up* a little, the Pittsburgh slang for tidying. I said, “For God’s sake, get in the car, we can nest later.” Four hours later, Laura was born into a half-empty maternity ward, without anesthesia or complications. She weighed 7 pounds, 3.5 ounces.

We were allowed a few hours of ignorance. Our nameless daughter was whisked off for the obligatory bath, eye-drops, and heel stick. She was gone for a long time, but I didn’t suspect a thing. It was late morning, and I was annoyed. My daughter had been born. I wanted her back so my family could be together.

Soon after Laura was brought in, Dr E arrived; he greeted Ellie warmly, then began to examine our newborn. As he moved the stethoscope’s disk lightly across her chest, he seemed more intent than usual. When he mentioned Down syndrome, a silence sharpened in the room, but the moment passed. As he hastened to point out, many typical features were absent. There was no heart murmur. The palate was not cleft; it was not even highly arched, though the arch was somewhat pronounced. The “simian crease,” a single line across the palm, was not there. And though most babies with Down syndrome are hypotonic—“floppy”—our daughter’s muscle tone seemed good.

What defied explanation were her eyes. They were vaguely Asian, almond-shaped, the same striking appearance that had led to the condition’s original name: *Mongolian idiocy*. Fortunately, I had the answer for that one. My mother is Japanese.

We consented to the test. Somewhere in Portland, a pathologist would isolate a nucleus from one of Laura’s cells. Then he would stain the chromosomes, count them under a microscope, and disclose the range of possible futures. It was, as Dr E said, *for peace of mind*. He left the room. A little later, a nurse came in, drew blood, and said we would know in a week.

Balloons arrived, flowers, baskets of jelly beans. There were phone calls, e-mails. Through it all, Down syndrome was there and not there, a tremor, a disturbance, a mirage. It was the universe a half-step to the left, one we might enter, might not enter, had already entered. It was there in a phrase like *simian crease*—I thought, isn’t that kind of, well,

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offensive? It was in the long pause as the pediatrician on call cradled our daughter's head in beefy hands, intent, compassionate, saying, "I notice the eyes are slightly almond-shaped"; and it was in my quick, already automatic response, saying, "My mother is Japanese." I held up one generation against another. I held up what I was against what she might be.

Ellie waited patiently for us to quit talking. She was seething with happy uncertainty. She wanted nothing other than the chance to hold her sister, and to stay within 6 inches of Theresa at all times. The three of them snuggled in the bed. "So," we said, "what do you think of your little sister?" She said, "Good," with emphasis, drawing out the vowel, as she only did for the best things: sleepovers, cotton candy, new sibling. We asked her about names. "What about Esmerelda?" said Theresa. "Mom," said Ellie. I said, "What about Sillyhead?" "Dad," she said, "stop it." I said, "What if we call her Ellie Is a Sillyhead? That way we could say 'Ellie is a Sillyhead' every time we wanted to talk to her." "Dad," she said, reproving. Clearly the situation's gravity had escaped me.

It was the end of February in a dry winter. Normally, in western Oregon, the rain begins in October and doesn't really end until July. But it had been sunny, and all winter we walked around guiltily, enjoying the good weather, which we knew we'd pay for, down the road, in wildfires and reduced salmon runs. We didn't care. It was nice out and we weren't suffering from SAD. It felt like that in the hospital, a temporary stay, a grace period, the sunlight shedding calm possibility through plate glass. The next morning, in the cafeteria, I ate dry eggs and French toast, looking idly at the new wing under construction next door, its broad webwork of shadows falling across the completed building, the bundled rebar and coils of wire piled in future rooms. Back upstairs, where my wife and still-nameless daughter were sleeping, there were men in hard hats in the elevators and the halls, asking directions through the pleasant beiges and stenciled decorations of the maternity ward.

We signed the discharge papers. I slipped our copies into the plastic bag, next to the sheet inked with Laura's footprints. I slung the duffle over my shoulder, and the nurse checked our ID bracelets against Laura's before wheeling us out. Strangers beamed at us in the elevator. The nurse inspected our infant car seat. She shooed the smokers away from the hospital entrance. We told her about the lab tests we were waiting on, and she said, "Yes, some of us were wondering about that."

By the time we returned for our two-week checkup, we had discounted the possibility of Down syndrome. Laura was nursing, if not with the avid concentration her older sister had shown, then well enough. She could track a set of jingled keys. When we heard nothing after one week, I called Nancy, Dr E's nurse. Nancy said that they were still waiting on the lab, but that sometimes these things took a little longer.

We could not go back. We could not undo the crucial moment, the precise and unrecorded time of day when the initial error in cell division occurred, adding an extra

chromosome to the beginning of what Laura would be. Now the infant before us bore that chromosome in each and every cell. It was in the shape of her eyes, the texture of her hair, in her brain and joints and heart.

I wanted to rewind the tape to yesterday, to a refrigerator filled with casseroles baked by neighbors and friends, phone calls from family back east, and Ellie eager to hold Laura: she sat cross-legged on the carpet, her arms stiffly ready, cradling an emptiness in the shape of a child. We lowered Laura into her arms, saying, "Careful, support her head," remembering how fragile Ellie had seemed, five and a half years ago. A weak afternoon sunlight splayed its rhombus across them. Laura blinked. Her hands opened and closed slowly, with no force, and I dandled my index finger against the translucent fingertips, remembering, once again, the improbable size of newborn children: they seem scaled to another world. Again I remembered feeling the same way with Ellie, and felt the pleasure of layered time, the easy spiral of repetition and variation, intricate as a Bach invention. I looked at Laura's eyes, thought of my mother, and was reassured. We smiled down at our infant.

Even now, I remember this ignorance with intense nostalgia. We were under a spell: we had wished for normalcy and had been granted two weeks, a time outside time, when we could hope for anything at all. Because our wish was not denied, denial made it true. When the spell was broken, the child before us assumed her true appearance. She was unchanged and transformed. Her eyes were Asian in appearance, not fact: the almond shape derived not from my mother's lineage, but from genetic accident. The palate was definitely arched, though not extremely so. The murmur was faint, but there.

Theresa said she felt as if our baby had been stolen and replaced with a collection of medical problems. Steadying her voice seemed a pure act of will: the sobs that racked her reminded me of the birth. I listened, blank, disoriented. Past and present had been disjoined; pattern, as I knew it, was gone; this girl was not like Ellie; the days after Ellie's birth were not like this. Theresa had wept then, as well, but the predominant mood was joy. A research scientist to the core, she would smile through tears and say, "Hormone levels." I remembered the river of time widening, slowing, the current broadening almost to stillness, our vistas a plain of light. We'd had that again for two weeks, a bright, sure, forward-moving calm, and it had led to the lip of a waterfall.

It was only years later that the question occurred to me: Why should anyone be unhappy at all, at the birth of a child with Down syndrome?

Had the question occurred to me, in the early months of Laura's life, the answer would have been obvious: Laura was very sick. Beyond her heart defect were awful possibilities, from hearing loss to playground taunts. There were percentages for most things, and incalculable worries beyond the percentages. We were living at the heart of The List.

And yet the obvious answer was insufficient, because the core of what I felt, the draining, uncertain terror, had been

there before I knew a single item on the list, before I knew that children with Down syndrome got heart defects, before I even knew what a chromosome was. That, to me, is the odd thing. Clearly, though I knew nothing about Down syndrome, I believed things about it anyway. Some part of me, in my thirty-five years on earth, had learned that Down syndrome was a tragedy.

Nobody, so far as I know, receives the news that a newborn child has Down syndrome, shrugs, and continues to decorate the nursery. We were undone by the news for a long time. That response was instant and visceral, and it seems to me now that my assiduous research was only a part of that response. Every fact was a decoration of anxiety. I had reacted to my daughter's birth like an articulate animal, with a gut sense that she was different, and I had been trying to understand that gut sense, or transcend it, or both. In the world's estimation, we had one daughter who was Normal, and one who was Abnormal. It took Laura's arrival to show me that I had bought into that distinction too. I had worshiped in the Church of Normal without knowing it, and—however awkwardly—had been trying to read myself awake.

One of the first things I noticed—after strangers staring at the oxygen tank, the collapse of the future, and the feeling that middle age had arrived early—was the absence of the apostrophe: in the United States, it is Down syndrome, not Down's syndrome. I had read, somewhere on the Web, that since John Langdon Down neither had nor owned the condition, the possessive is inappropriate. Similarly, the phrase "Down's kids" is frowned on, because children should be thought of as individuals first. Over the years, I've come to agree. Laura is Laura, not a Down's kid.

But I don't make a big deal of it. In practice, I've heard medical professionals and parents say "Down's" and "Down's kid," because it's shorter and more convenient.

I liked the confusion. If I said "Down syndrome," my hearer would likely assume the apostrophe was there, and I would know it wasn't. I felt like a native speaker, versed in tones inaudible to outsiders, able to hear presence and absence at once. Present, the apostrophe was Laura as we had suddenly, shockingly, come to reconceive of her: a Down's kid, her life entwined with a condition inseparable from her humanity. It was the extra chromosome, the squiggle, the black mark that made all the difference. Absent, it was disability and deficit and defect, the hole in the heart, delays in speech, everything we would struggle against. There and not there, like the fifteen suspended days after Laura's birth when we knew and did not know, our worries and hopes flowering like blood cells in culture. A charmed and lost time.

It was a paradox to raise a child by. Down syndrome would have to be present and absent for us; or more precisely, we would need to practice a presence and absence of mind. We would need to study our daughter's condition, absorb everything we could about it, its medical and legal and social and educational aspects, all in order to disregard it. It would have to become, in the best sense, second nature. In this way, we might find a provisional balance, as someone on a shifting deck steadies a view of the horizon: a balance informed by principle, yet more subtle than principle, a daily negotiation of love and difference. In the fullest knowledge of the 47th chromosome, we might return to the old ambiguities of raising a child. I felt as if we had crossed a border in the dark.