

Girl? Interrupted

Gregory Plemmons, MD

From the Division of Hospital Medicine, Department of Pediatrics, Vanderbilt University, Nashville, Tenn

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Address correspondence to Gregory Plemmons, MD, Division of Hospital Medicine, Department of Pediatrics, Vanderbilt University, 2200 Children's Way, Nashville, TN 37232-9452 (e-mail: gregory.plemmons@vanderbilt.edu).

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THEY WERE WANTING to adopt a child from overseas and had finally received information from their agency about a toddler in China. As a pediatrician, I'd been reviewing medical records of foreign adoptees for almost a decade, sifting through photos and garbled translations, attempting to patch together what was known about each child's health and condition. There were always plenty of holes—always more than the record would show—when you couldn't lay hands on a child. Uncertainty in medicine never felt more rife than when you were reviewing records of a child 8000 miles away.

"He has a low birth weight and his lips appear thin. I'm worried about fetal alcohol syndrome."

"She's microcephalic. That means her head is very small. Do we know anything about the mom's pregnancy history?"

Each time, there were always more questions than answers. On the worst days, I felt like an insurance appraiser; on the best, like a proud obstetrician, especially when families returned with healthy sons and daughters in tow, jet-lagged but seemingly free from disease. Most days, however, I walked a line between caution and hope, knowing the reality of children who were placed for adoption from abroad. There were no children in orphanages who hadn't been harmed in some fashion, if nothing else than the fact that they'd been abandoned or rejected, or simply orphaned. *Orphanos*, from the Greek: bereaved. Some conditions were treatable—cleft palates, tuberculosis—but many were not. Brain development and emotional health could be as stunted as growth. It was relatively easy to repair a small hole in a heart. It was not so easy to undo the rest.

Ling's file was fairly sparse: a few scanned pages of medical history, some blurry JPEGs. In one photo, she wore a pink tank top–style dress. In another, she was wear-

ing a white T-shirt with a soccer ball on the front, lettered, oddly enough, with the word BOY. Chromosomes said 46 XX. The translation of Ling's record suggested that she had the condition of congenital adrenal hyperplasia, or CAH. Although CAH is relatively uncommon, more than 30 states now screen for the condition at birth, although this isn't the case for much of the rest of the world. CAH is a common cause of ambiguous genitalia in girls, and it can be lethal in boys if untreated. It wasn't exactly clear what testing had been done on Ling, but she was obviously being raised (or at least presented) as a girl. What would CAH mean for Ling's health in the long term? I knew that would be the first question her prospective parents would ask me. I did some reading, spoke to some colleagues. Most female CAH subjects needed hormone replacement. Girls with CAH had a higher incidence of sexual dysfunction. But overall, the evidence suggested that they could lead relatively normal lives with treatment. It also appeared that girls with CAH had a slightly higher incidence of same-sex attraction, for reasons that weren't entirely understood.

After reviewing Ling's records, I picked up the phone. Ling's adoptive parents lived 2 hours away. Telemedicine is nothing new for most physicians who practice adoption medicine. We often find ourselves fielding phone calls from parents traveling to Vladivostok (*is it scabies?*), reviewing video snippets by e-mail. Still, I wasn't sure how this conversation would go, although they had already seen the records and the probable diagnosis of CAH. I always tried to start on a positive note. I discussed what I knew about CAH and hormone replacement therapy. I waited until the end to tell them about the higher incidence of same-sex attraction, not sure what to expect, and frankly worried it might play into their decision. They lived on a military base in the heart of the Bible Belt. *Conservative? Don't ask, don't tell, don't pursue?* Both parents listened on speaker phone as I made the disclosure—followed by a pregnant pause in the truest sense of the phrasing.

"Oh," they laughed, obviously sensing my uneasiness. "We're not worried about *that* at all. We read all about it on the Internet." Like many adoptive parents, they had already done some groundwork. "We just want to know

Gregory Plemmons is Associate Professor of Pediatrics at Monroe Carell Jr. Children's Hospital at Vanderbilt University in Nashville, TN. He received his M.D. from the Medical University of South Carolina and M.F.A. from Bennington College. His fiction has appeared in *Best New American Voices*, *Yemassee*, and *TheYalobusha Review* and was the recipient of the Barry Hannah Award for Short Fiction in 2008.

more about the treatments. How often will she need to see the doctor?"

"It depends. Maybe 3 or 4 times a year," I said, relieved. I suggested that they request an ultrasound of Ling's abdomen to be performed in China, if they could get one. Two weeks later, we received the results. It appeared that Ling had a testicle inside one of the folds of her vagina. She didn't have CAH at all. Ling was apparently a true hermaphrodite, a condition much rarer than CAH. Joy turned overnight to something else. Raising a child with CAH would be one thing, I thought, but how could I prepare them for what parenting an intersex child might involve?

Declining a child is emotionally wrenching for families, some of whom have waited for years. In some cases, when families decline a referral, it's not always about the child; they've lost trust in the agency, the system. If the information provided hasn't been accurate or truthful, what other things might have been withheld? In the end, I didn't fault them. I understood and respected their decision. It wasn't up to me to decide the best fit. Two hours from where I practiced, an adoptive mother had recently made international news when she'd put her 7-year-old son on a plane back to Russia. Still, I wondered about this child whom I'd only known on pa-

per. What future awaited her or him? Would Ling remain in China or be adopted abroad? Would Ling continue to be raised as a girl? I had no idea how people of intersex fared in China. My only frame of reference was here in the United States, where I had read historical accounts of patients being assigned a sex at birth, often arbitrarily, and undergoing corrective surgery, sometimes with tragic results. Things now seemed much better, at least in this country. I wasn't so certain about China. I googled *intersex, Chinese*. The first thing that popped up was the Mandarin term for intersex, which appeared to be *yinyang ren*. I thought I understood the *yinyang* of gender; *ren* simply meant "people" or "human." Unlike in English, in spoken Mandarin there is no gender distinction in personal pronouns. The same word could mean *he, she, or it*. At least Ling's native language might be easier, I thought. I wasn't so sure about the rest.

The couple I was assisting eventually found a child with cleft lip, also from China. They accepted the referral and soon afterward arrived back home. The defect had already been surgically repaired overseas. You had to look closely to see the scar—a tiny half-moon above the smile. It wasn't the first thing that you noticed. Three years later, I don't recall now if the smile belonged to a boy or a girl, but I still wonder about Ling. *Yinyang ren*. People, human.