

TARA MILLS

GOLDEN JACK

BORN CAESAREAN ON A SUNNY TUESDAY AFTERNOON in September, we meet Jack arms first, reaching to the heavens, willing himself from grey to blue to pink. His eyes are pale and clear, and he has a thin shock of white hair. He is cherubic, and I think it's going to be easy; I'm going to be good at motherhood.

At six months, we start missing milestones. We know there's something different about our baby, but neither of us has the courage to give voice to our growing concern. Our worries are met with his own. He sizes us up with a furrowed brow.

At six months, a well-meaning father at baby music nicknames him The Siren because he screams unrelentingly when upset. Before class begins each week, he crawls around the circumference of the room and won't join the circle until he's removed all the vent covers. His teacher is permissive and lovingly calls him The HVAC Man. One day we arrive to find she has innocently rearranged the furniture. He withdraws and is inconsolable. He shakes his head and throws himself against the wall. Things are unfamiliar to him. I hurry out of class with my flailing, red-faced boy and don't cry until I sit down in the front seat of the car, out of sight. This is the beginning of our retreat.

I have always wanted a baby but find myself longing for time and space to pursue my own interests again. The calendar fills with appointments and therapies. I try leaving him for little stretches, but he cries so hard when I go that there's a call to come home before I've left our street. I am the only one he wants. Mendelssohn's *Hebrides* overture plays in the car. Classical music keeps him calm while I drive. "Mom, I love this music," he says at two years old. "It tells me my secrets." He closes his eyes and waves his arms in time with the intense, stormy melody. He cries silently when the music softens.

"Mom, I learned at school today that you don't feel the earth turning around." Jack's brain doesn't register rotary vestibular input, which is a

complicated way of saying he can spin and will never get dizzy. At three years old, I try to keep up with what he says in spite of my own dizziness as I watch him.

There are x-rays, ultrasounds, and therapies: occupational, speech, craniosacral. There are pediatricians, developmental psychologists, and early childhood interventionists. It feels punitive; no one can give us a diagnosis, and I keep trying to will away his differences. His dad buries himself in work, but there is no escape. I am consumed with appointments and waitlists, with grief and love all tangled up in one precious little life.

He wants chocolate cake for his fourth birthday. “Mom, can we write that down?” he asks. I’m making a grocery list at the table as he sits beside me cutting a stack of flyers into tiny pieces. I give him a pencil and a piece of my paper.

“C,” I say. “Can you write a C?”

“Do that one for me, Mom,” he says.

“H is next,” I say. “How about an H?”

“Sure, mom. That’s the one with two sticks and a line connecting.”

We go on like this, spelling CHOCOLATE CAKE, putting it all down on paper. He is content with this; we can connect over letters—the C and the H, all the way down to the K and the E. This is how he knows I love him. Love is always an action.

It’s hard to love Jack with touch. He flinches if touched by surprise, and you have to come at him straight on. He doesn’t let his dad touch him at all. “Don’t touch me,” he says and recoils. It’s only when he’s sleeping that his dad can lay beside him and touch his cheek or hand. Together, we lie in bed with him asleep between us and listen to his heart beating softly against the cave of his chest.

He hits and bites the doctors. He spits at nurses. He throws furniture. His doctors joke that I’ve earned my own medical degree over time, learning to do things he won’t allow them to do. I position him on the x-ray table, attach electrodes, and administer medications. I can touch but still fumble to reach him.

“Mom, tell me about the tadpole becoming a frog.” I tell him all I know and make up the bits I don’t remember—egg then tadpole, tail then legs, gills for underwater and lungs for land.

“And then he gets his ribbit?” he asks. He is little at first, and then he gets big. He is one thing and then transforms into another thing. This is

metamorphosis—first there was the idea of you, and then there was you. In evolutionary speak, Jack wants legs but still has a tail. He wants lungs but still needs his gills.

“Mom, we should catch the moon and put it in the branches of our tree. You reach up and get the big moon, and I’ll get all the little moons.” He really believes we could. He thinks I have the power to bend the world to him. Truth is, I’ve been stuck trying to figure out a way to bend him and make it a little easier, but he does not bend.

“Mom, you are beautiful, so you are *bonita*. You are beautiful—*bonita*.” He latches onto words that feel good in his mouth. He’s learned the word *bonita* at school and likes the way it feels on his lips and tongue, enunciating each syllable. I like the way it feels when he says things like this. He takes pleasure in the physicality of words in his mouth, and I take pleasure in their meaning.

“Mom, do you like me?” he asks.

“Yes, I like you a lot,” I say.

“But do you like me when I ruin things?” He breaks all his toys. He puts holes in walls and destroys the furniture. He gets angry with me and shits in my boot.

“Yes, I even like you when you ruin things. I like you all the time. Even when I’m angry, I still like you.” And I do.

“I like you all the time too, mom. Even when you’re angry.”

We learn to go places built for everyone. Public spaces cannot exclude us. Cincinnati’s old buildings hold us in the beautiful in spite of all that is failing. We touch the lion’s marble foot. We talk about the mummy in his sarcophagus. We stand in front of Cassatt’s *Mother and Child* and hold hands.

He knows to keep his voice low in these places. He knows we have to be careful. He is quiet and looks, and I look too, remembering a life before him, when I studied art history and worked alone in a printshop with zinc plates and acid.

They try to measure everything: big machines take pictures of his brain, electrodes are fixed to his head, blood is drawn. Their words are clinical, polysyllabic, and foreign. Everything microscopic is blown up and examined, but they still don’t know anything. We buy a classroom set of wooden blocks and hope constructing his own world will be a way out of his growing frustration with the one he’s stuck in. We unpack them together and build



Mary Cassatt, *Mother and Child* (c. 1899)

houses, ramps, and roads that cover the living room floor. Things fall apart, and we start again.

I ache to take back all the time I wasted blaming myself and carefully cataloguing the mistakes I made. I have always worried over him in a way my husband does not; he doesn't need to find a reason like I do.

"Mama, do they know about Jack?" his little sister asks before we brave the world and risk a playdate or a trip to the library. At three, she knows he's unpredictable—he lashes out and is easily frustrated and quick to rage. We often leave abruptly. My heart aches for her; a typical childhood is not what she'll get. It can be a struggle to keep her safe, raise them both, and try to be a family. I love them immensely, but I have to love Jack more.

What stories do we tell him to make meaning of his life? "I'm a You-man," he says, "but not all." He identifies with The Thing, a rock-hided superhero in *The Fantastic Four*. His sister leans into me and says, "Mama, he's just human," and she's right. He knows he's partly like us but is also certain he's made of something else.

"When I grow up, I'll wear a belt and have a beard on my face." This is what he knows. Daddies wear belts and have beards. Daddies go to work, and mommies stay home. His rules for us are rigid, and he expects things to stay the same.

We make plans to move back to Canada, where access to the growing list of services we need are covered under a national health plan. Public school hasn't worked out, and we've started using credit cards to pay for therapies we can't afford. We drive north from Ohio to Ontario. We make our way to the east coast and the Isaac Walton Killam Health Centre, Halifax's children's hospital.

The outbursts are more frequent. We can't always identify a trigger, and his behaviours seem malicious. Doctors ask us to log his behaviour using an ABC chart: antecedent, behaviour, consequence. We try to stay two steps ahead of him, to mitigate and offer distractions. We are trained to put him in a therapeutic hold when he rages to reduce the risk of injury.

We give up our privacy for Jack. In-home visits and family histories are documented and repeated. Specialists come into our house to set him up with multiple therapies and aides. Child Services make unannounced home visits. When Jack was young, we hoped for a fix. We tried diets and special schools, read all the special needs books, and wrung our hands over every detail of his care. There is no fix. He is just Jack. Today our hopes are much

simpler: that one day he will make a friend.

It's hard to know if he understands how his behaviour impacts our family and even harder to know if he can help it. Does he feel loved? The little boy we wanted to teach to ride a bike is not what we've been given. I am in mourning for years until I can name the loss.

When he is ten, specialists recommend genetic testing to try once again to label him and give a diagnosis. Everyone is eager to name our family's affliction. They want to name what they cannot understand or at least find its source. At this point, a label doesn't make any difference to us. He disappeared for an afternoon and learned to ride a bike. He's stopped smearing shit on the walls. These are tangible improvements.

They urge us to do the tests, and we agree. The first is a broad stroke look at his DNA, ruling out the common genetic conditions of which he shows symptoms. Finding nothing, they move on to a more detailed and costly micro-array. Here they discover a small anomaly: a duplicate set of genes on chromosome 22 that appears related to autism and a minor heart defect. Researchers admit they don't know much; they need more kids with the same extra bits as Jack. We agree to put his name and results in a database and revisit the clinic in eight to ten years. He will be twenty in ten years. We will be beyond his childhood.

When he is violent, I wonder if we will reach a breaking point. I fear all the love and advocacy will be for naught, and he will end up in the care of the province. I worry about losing him if things fall apart. It breaks you wide open to leave a small child in a pediatric psych unit. It breaks your heart to see that sometimes he'd rather be there than with us.

We give him some of the independence he craves and allow him to walk downtown to the library alone. He walks to the comic book store for dollar comics and the gas station for slushies. I look at his camera while he sleeps and see his adventures documented in photographs of brightly painted graffiti and craggy harbour rocks. There are no faces. He still observes people with a furrowed brow.

We didn't think he'd learn to read or write, but he does. He writes me notes and leaves them on my bed: "I'm sorry I bit you," "I want to go to public school," and "Will you let me have a girlfriend?"

I can't say I wouldn't fix him if we could. But if we took away that little duplication on chromosome 22, what other parts of him would we lose? Would he still be Jack? I love him, and he is a burden.

Today, they rush out the door. My daughter skips down the hill to elementary school with the other kids on our street. Jack, always running late and having to be reminded multiple times to brush his teeth and put on socks, stops at the front door before heading out to his special education school and asks, "Did you cut up my apple?"

He has asked the same question every morning since he started school. "I sliced your apple," I say. "Now get going before I slice you up too."

"Mom," he says, "that's impossible." He pauses only briefly. "Do you know why that's impossible? Do you know why? Do you know?" He is eager to spit out the answer but has learned the script of conversation.

"You're late," I say and move him out the door and into the world. He starts to run but looks back with a broad smile and those clear blue eyes, excited to deliver a clever response.

"It's impossible because I'm made of gold." He throws his head back and laughs, certain that what makes him different is the gold he knows he's got inside. I watch him go and think maybe that's all he needs to know. Maybe, after all these years of tests and searching, that's all we need to know too.