

## Lucky

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Benjamin is in his room, playing “Sweet Jane” on his guitar and watching cable news. In the fall, he will be going to college. As we approach this milestone, I’m looking back more, remembering the days when I felt so much in the dark as his mother, when I didn’t know how we would get through his childhood, or what would become of him.

### March, 1993

Benjamin is four, newly diagnosed with asthma. He sits next to the nebulizer, plastic mask over his face, vapor rising from its holes and circling his blonde head. He is watching “Captain Planet,” one of the many superheroes with whom he’s now obsessed. Since the birth of Benjamin’s brother, I am grateful for these nebulizer moments: Benjamin in one place, sitting, quiet, and focused, while I nurse Sam. Benjamin has been angry about sharing my attention with the baby: demanding, unable to wait, quick to dissolve into kicking and screaming tantrums. More and more, I am at a loss as to how to respond to his challenging behavior.

On our last shopping trip before Sam was born, Benjamin picked out Superman pajamas: electric blue with the big red “S” on the chest, a detachable cape, red “boots”

that fit over his legs, above his red sneakers. He insists on wearing this outfit to preschool, where he dashes around, arms extended, chasing bad guys. This is his armor, his protection against the scary vulnerability that comes with asthma and a new baby in the family.

### March, 1996

Benjamin is seven, a first grader. His teacher complains that he doesn't sit still when the children come together on the carpet for group instruction. He leans back on his arms and pushes up on his legs, doing reverse pushups while the teacher is talking. She makes him sit in a chair, behind the other students, hoping it will contain him. He wiggles in the chair, rocks it from side to side, falls out of the chair- all the while taking in every word the teacher says. Before going home, the children write on their "share sheets" something about the school day. Benjamin writes a few words, then fills the rest of the space with exclamation points, unable to stop himself until he reaches the end of the page.

He is big for his age, tall and solid, with no sense of where his body is in space. He steps on toes, collides with objects, invariably bumps into the person walking beside him. At the grocery store, he begs to push the cart, but ends up crashing into the carts of other shoppers, unable to judge the distances or plan his movements accordingly. Red-faced, I take over pushing the cart; he sobs, "But I didn't *mean* to run into them..."

Benjamin hates to wear shoes; he complains that his sox have “lumps” and he will wear only the sox that don’t have seams across the toes. He prefers sweatpants to jeans, and sleeps naked.

Benjamin always needs to know what will happen next. He melts down when plans change, and fears getting lost. The smell of bananas makes him gag.

Benjamin loves basketball, wants to be called “Ben-jammin’,” collects basketball cards and the jerseys of his heroes. At bedtime, he could listen for hours to the chapter books we read to him: the sports stories of Matt Christopher, *Narnia*, *The Wizard of Oz* series. He reads to himself only when required to and with great frustration, complaining that the books that he can read are “boring.” Written homework infuriates him; when we tell him he needs to concentrate, he howls, “I can’t!”

We blame ourselves. Bob’s mother tells us we are not firm enough; if we would just give him “logical consequences,” these problems would go away. Bob’s father says we negotiate too much. Marjorie, the therapist to whom we’ve taken Benjamin for help, attributes everything to anxiety. She shows us a drawing he did in her office, white paper covered with thick layers of hard black and purple crayon marks, typical of Benjamin’s poor fine motor skills and his tendency to perseverate. She says that on the basis of this drawing, we must be prepared for the possibility that our son has been abused. We are horrified, but certain he’s never been in the care of anyone who would mistreat him. She goes on to say that because he doesn’t engage in pretend play at her office, preferring to build things and do art projects, we must not be playing with him enough at home. He is

our first child, and we have done nothing but play with him—but because we have no basis for comparison, and because Marjorie is the expert, we blame ourselves.

April, 1996

It is early morning. Bob and I sit side by side on the neuropsychologist's couch, looking out her windows into the newly budding trees. We've come to hear the test results. Dr. Storti is tall; she wears a stylish suit on her spare frame, new shoes, and a smile that betrays nothing. But her brown eyes are soft; there is some compassion here.

She says that Benjamin is very bright, but has ADHD and a nonverbal learning disability. She says there's a 60- point discrepancy between his very superior verbal ability and his so-so visual-spatial skills. My mouth drops open: in every clinic where I've worked as a child psychologist, a discrepancy of this magnitude immediately qualifies a child for a CT scan of the brain. Dr. Storti says it's amazing that Benjamin is not depressed, given how frustrating it must be to have his intelligence and not be able to produce work that reflects his ability. At this point, I reach overload and fail to process most of what she says next. Bob hugs me and goes off to work; I leave with a 30- page report and a lump in my throat.

Unable to face being alone at home, I go to a nearby restaurant for breakfast, to read the report and pass the time until I can pick up Sam from preschool. I sit in the last booth, the stack of vanilla colored papers in front of me, and off to the side, a half-eaten plate of waffles drowning in syrup. All around me, breakfast is in full swing: coffee cups colliding with saucers, cooks calling out, forks falling, patrons sharing news over toast. I

sit alone, sipping tea. I read through the report, every word, including the ten pages of detailed recommendations. Waves of emotion surge over me: worry about Benjamin's future; anger at the therapist we'd counted on to help us, because she was so blinded by her theoretical allegiances that she failed to see the enormous neurodevelopmental and genetic underpinnings of Benjamin's difficulties; and sadness for Benjamin, not because he'll never be an architect, but because he's had to struggle so long before the adults in his life finally understood how hard it is for him to do some ordinary things. I worry about whether he'll learn to read, when he'll develop some self-control, how his self-esteem will be affected, whether he'll ever learn to wait, what kinds of trouble he'll get into as a teenager, whether he'll ever learn how to keep working at something when it's difficult.

In a strange way, reading this report, I also feel vindicated. Now there is a reason why parenting Benjamin has been so challenging all along, and it has nothing to do with lack of consequences or negotiating too much or anxiety or abuse. We are not the worst parents in the world. We can stop blaming ourselves and start getting our child some more appropriate help.

That April day was a call to action, and I spent the next eleven years going to bat for Benjamin. I educated teachers about his learning differences and his ADHD, helping them to understand that what he produced often did not reflect what he'd learned. I attended IEP meetings, dealt with rigid and insensitive teachers, begged for him to be given a chance at enriched classes when he didn't fit the criteria. I lived with unremitting

worry and tried to ignore the gossip in our small school community about his immature behavior, reminding myself that the parents who so readily judged us would not have lasted one day with a difficult child like Benjamin. I lived through the visits with principals, the school suspensions, the two-sentence book reports, the middle school years of computer hacking and arguments over undone homework. Through it all, I tried to teach Benjamin how to advocate for himself in an educational system where he didn't fit the mold.

Was there a turning point, a place where we paused and felt we were out of the woods? No. But there were small moments, seen only in hindsight, that shimmered with hope: the first time he did as we asked without arguing, the day he read a book just for pleasure, the year he began to work at earning better grades. Sometimes these moments were all that sustained us when the next challenge arose, and there was always a next challenge.

April, 2007

Benjamin has come so far. He is a high school senior with a love of learning, and passions that range from math and economics to physics, politics, and philosophy; from jazz to Mongolian throat singing. With enough AP and college credits to start college as a junior in the fall, he is eager to continue learning and optimistic about his future. He plans to go to graduate school and hopes to be a professor.

Last month, Benjamin reluctantly attended an award ceremony for "Minnesota AP Rising Scholars," where we listened to speeches encouraging the honorees to feel

“special” and proud of the “hard work” that had earned them this award. On the way home, Benjamin scoffed, “This award isn’t about hard work. It’s about luck. All of us Rising Scholars were lucky to be born smart, and that doesn’t make us better than anyone, just lucky.” Am I imagining this, or has living with the challenges that resulted from a roll of the genetic dice, also given Benjamin some hard won humility and wisdom?

Today I am the one who feels lucky. I am lucky to be the mother of this modest, interesting young man with the irreverent sense of humor, the one who has taught me so much about parenting, and courage, and yes, hard work. Do I still worry about him? Of course. He’s going to live away from home for the first time in his life; he’s shy and disorganized and still doesn’t have his driver’s license; he eats too many White Castles and misses the school bus at least once a week. I worry about him making friends at college, getting to morning classes on time, battling homesickness. But compared to the worries I used to have, these are small potatoes.