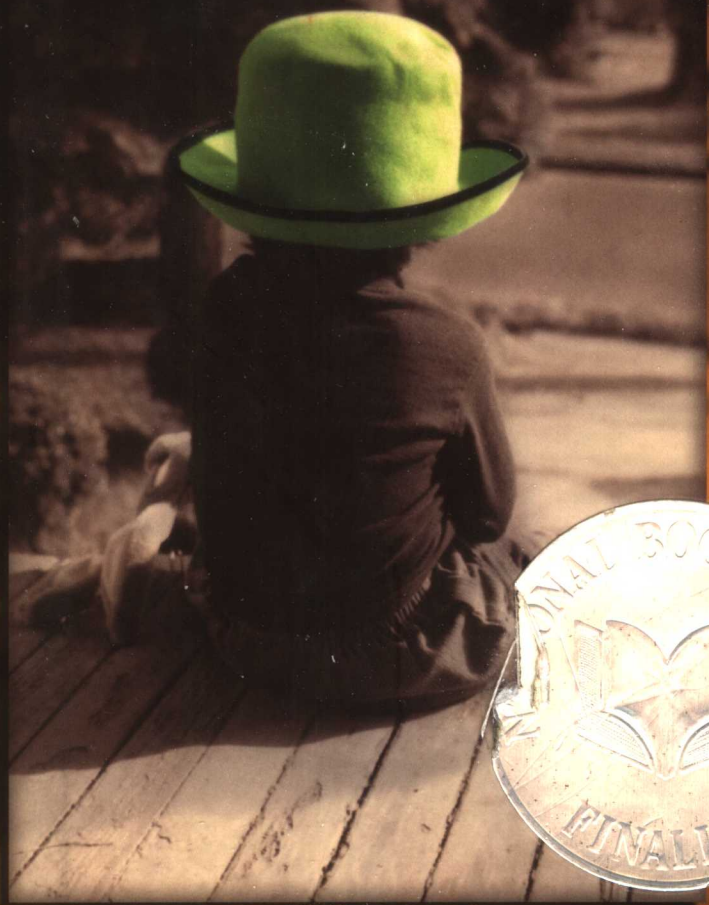


A SLANT OF SUN



One Child's Courage

"Wow. What great heart and bravery in this beautiful book. I loved it."

—Anne Lamott, author of *Operating Instructions*

B e t h K e p h a r t

a *slant* of sun

a slant of sun

ONE CHILD'S COURAGE

beth kephart

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Some names and identifying details of individuals mentioned in this book have been changed.

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For Jeremy,
who leans over my shoulder even now,
and shows me the way

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preface

*I*n the fall of 1991, Jeremy, our two-and-a-half-year-old son, was diagnosed with *pervasive developmental disorder not otherwise specified*, a confounding condition that manifested itself in Jeremy with atypical speech, impaired social interactions, a range of perseverative and compulsive behaviors, and, at times, the sorts of exceptional talents not exhibited by the ordinary child.

In truth, Jeremy's diagnosis carried the weight of the inevitable. For those keyed into the cues, Jeremy had always shown signs of being different. Music, paintings, the moon impressed him; rattles, bottles, the typical baby gear did not. He felt safe with his parents and his grandparents, but he allowed few others into his world. He was not a child who went readily from knee to knee, and by the time other children his age were waving hello, he was hiding beneath his hat or inside my skirts or far away, inside his room.

Jeremy's stance on life became even more exaggerated during his second year. If a person could survive on juice or milk alone, he would have; most solid foods were so displeasing to him that he refused to learn the basic science of a spoon. His strong personal code of likes and dislikes devolved into what, looking back,

could only be fairly classified as obsessions—a violently strong passion first for trains and cars, then for hats, then knights, then planes, then trucks, the obsession with cars persisting throughout and above all the others. Though Jeremy danced with the grace of a dove and demonstrated an acute sense of balance, he was never adept at balls or tricycles, at the act of jumping or skipping, at the simplest execution of arts and crafts. And while Jeremy acquired language at a youngish age, he did not use his words as others do, did not string them together to inquire or declare. Instead Jeremy's words were deployed as epithets, affixed to those things deemed worthy of his notice.

Reflecting back, it is all too easy to identify the early warning signs, to organize them on this page. At the time, however, my vision failed me. I focused far more strenuously on my own weaknesses as a parent than on the cranks and creaks in Jeremy's development. I was a stay-at-home mother who earned my income in solitude at night by writing articles for corporations and magazines, and I was a person with a quiet life—a member of no play groups, aunt to no nieces or nephews, with a personal calendar absurdly stark and bare. I had, in other words, little to compare my son against, and so I assumed that his struggles were caused by the environment I created, my lack of expertise in the rules of mothering, and my inability to locate the proper key to his world. For a long, long time, I drew no conclusions about my son.

It took an insult from a neighborhood baby-sitter to get the message through. It took my husband, my mother, a conversation with old college friends in a motel miles from home to shatter my delusions and force me into action, into meeting with a doctor and submitting to the exams. And though it should have been helpful to have a name for the thing that was so deeply troubling Jeremy, a diagnosis is far from a cure. The fix for children like Jeremy is, I have discovered, a baffling admixture of trial and error. There is, you are told, no time to lose—neural pathways are settling in, lifelong habits are forming, behavioral tics are taking over—and so you push and push for the right con-

coction of language therapy, occupational therapy, play therapy, social therapy without ever having a firm sense of ultimate boundaries or goals. What, in the end, are you fighting for: Normal? Is normal possible? Can it be defined? Is it best achieved by holing up in the offices of therapists, in special classrooms, in isolated exercises, in simulating living, while everyday "normal" happens casually on the other side of the wall? And is normal superior to what the child inherently is, to what he aspires to, fights to become, every second of his day?

My husband is an artist and I am a writer, and Jeremy is the child we created. In him we saw so many aspects of ourselves—compulsivity, aloofness, strong-mindedness, anxieties—and yet the challenge we faced was to free him of our genetic code, our habits. We made up our own rules as we went along—consulting with the therapists who "felt" right, implementing our own idea of appropriateness at home, divining highly personalized theories about progress. It was a lonely business. It pushed us to our extremes. It required more of me than I actually had to give, and at the end of it all, it was Jeremy himself who provided the light and the wisdom that moved us forward.

This is a book about a little boy and his mother. It is about a child who against all odds is learning to live in this world, to even, incredibly, make it better. It is about shame, prejudice, fear, solitude, and their natural counterparts. About reaching out and holding on.

Today Jeremy, our only child, is a successful second grader at a country Quaker school. He is reading difficult books with dramatic emphasis, designing mazes for his father, whizzing around in adult computer programs, asking grown-up questions on class field trips, writing fiction in a daring hand on an oversized notepad, Rollerblading with a vengeance, shooting fourteen baskets into the hoop during gym. He goes to the parties of his Quaker classmates, and he tells me the stories of their lives: James is a musician, Eliza has a new baby sister, Meghan knows how to spell all the words in the world, Will will be an inventor when he grows up. Lately Jeremy has even been learning how to

do recess, discovering games like hide-and-seek, let's-play-house, and store. And though social cues sometimes elude him, though speech can at times catch in his throat, though there are habits that still need overcoming, Jeremy, in my book, has won the battle against his genes. In the process, he has made me who I am today—gentler, more patient, more honest, more faithful, so deeply respectful of the courage of young hearts.

a *slant of* sun


dancing

*T*hey bring him to me just after dawn. I turn, and he is there. They show me how to bend my arms so that I can take him down toward my heart, and there is nothing else to say. The nurse leaves. I fall profoundly, madly into love, peel the aftermath of birth from my son's black-haired crown, try to slow down the shifting of his well-lashed eyes. *Hey, little guy. Over here. It's me. I'm your mom.* He is as light as that part of the dream that, come morning, slips away and slips away again. I bundle him tightly in the blankets provided and stare without comprehension at the nurses, who have now returned with instructions on the care and feeding of newborns. I don't believe that I will ever learn what they are trying to teach me, and I ask them quiet, obedient questions until my husband comes to rescue me and I can lobby for a quick release from the hospital.

Soon I'm being conveyed home in a rusting white Ford Mustang whose only defense against the persistent July heat involves my fiddling with the windows, cracking them just wide enough apart so as to whip up strong blasts of air. It is the hottest day of a long, dry summer, and Jeremy, one day into life, is blanketed and behatted in the car. His head keeps rolling around above his shoulders, though my hus-

band is driving old-man slow, and I feel criminal exposing him to the heat and potholes like this, make him a promise I will never keep: "Hey, after this, no more cars. We'll walk the world."

We sleep in the same room. We lie, most of those first nights, in the same bed, my husband and I curled like parentheses around our son, barricades against the dark. There is nothing to do but to feed him when he cries and study him when he sleeps, take turns tracing the architecture of his bones. He is, for sure, a half-Latin child, so much black hair on his head that I have to snip away the sideburns, a delicate operation that seems to take me hours. It's a misconception, I'm certain, but time itself has come unscrewed. Everything is a still-life drawing; we are complete, we are immune. We sleep whenever Jeremy sleeps, and in the intervals we make formal introductions: this is yellow, this is the moon. My husband constructs a black-and-white mobile and we dazzle Jeremy's vision with bull's-eyes and swirls. When he cries, we walk up and down the hallway reciting T. S. Eliot; he concedes to the hushing persuasion of poetic anesthesia. It is all a held breath until my parents, our friends, our in-laws, distant aunts, and neighborhood children eagerly arrive and toast this child of ours to the highest of heavens. I retreat when I can to the back of the house and feed Jeremy until he seems satisfied.



AFTER THE FIRST three weeks of Jeremy's living are concluded, after it is just me and my baby in the house and there's no one watching eleven hours every day, I begin to teach my son the only thing I know that counts: how to stand in the pulse of a song and feel it tremble. I choose my music carefully. I pillow Jeremy up on the antique rocking