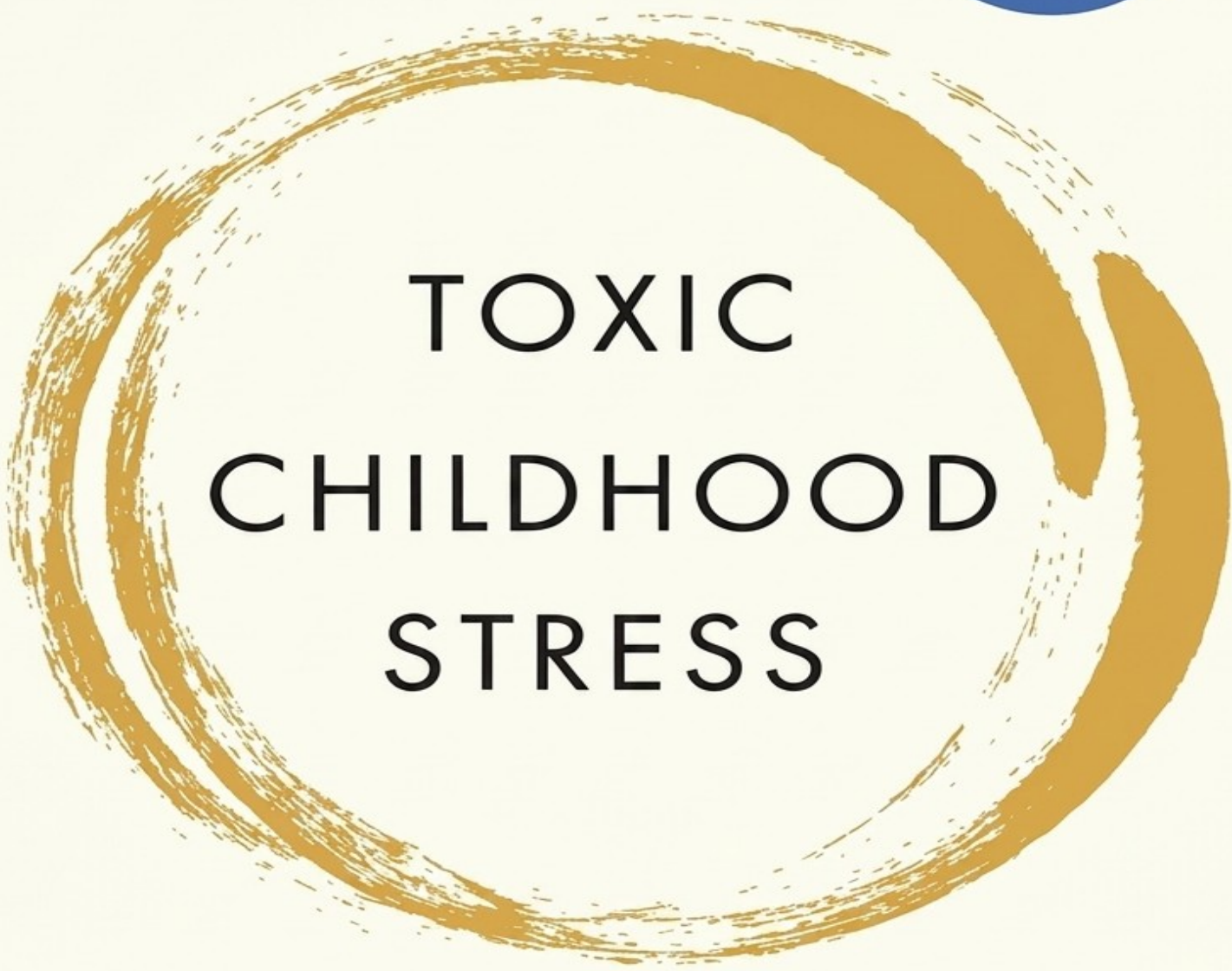


ACE
TEST
INCLUDED



TOXIC CHILDHOOD STRESS

The Legacy of Early Trauma
and How to Heal

DR NADINE BURKE HARRIS

Foreword by Kerry Hudson

TOXIC CHILDHOOD STRESS

The Legacy of Early Trauma and How to Heal

DR NADINE BURKE HARRIS



*To my patients and to the community
of Bayview Hunters Point.*

*Thank you for teaching me more
than any university possibly could.*

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Foreword

ALMOST FIVE YEARS AGO while on a trip to Vietnam I had what some might call a dark night of the soul. It had started as simply feeling a little nauseous but developed into a night of panic, weeping, clinging to my partner in a small, windowless hotel room. In the morning, largely recovered and slightly bewildered, I found myself wondering why, when I was in this beautiful place, in a loving relationship, with a good career and secure life, would fears from my childhood still torment me so brutally and unexpectedly? After all, it was the happiest time of my life, I should have been thriving. It was following that day, with these questions on my mind, that I discovered the ACEs (Adverse Childhood Experiences) questionnaire on an American website. The ACEs questionnaire asks ten questions related to traumatic incidents you may have been exposed to. For each question you answer affirmatively you receive a point which adds up to your ACE score. When I discovered my score was an eight out of ten suddenly everything, suddenly *I*, made so much more sense.

The more I read the more things clicked into place. Finally, after thirty years I understood the *what* and *why* of many of my chronic mental health difficulties and reoccurring physical ailments. Discovering the ACES questionnaire provided great comfort at the time but it wasn't until I read *Toxic Childhood Stress* that I was able to finally able to fully comprehend the *how*. I have been writing about childhood trauma for years now, trying to untangle my own comprehension of it, but this is the book enabled me to understand so much more than I ever believed I might.

If you're reading this, I will assume that you have a particular interest in the effect of childhood trauma, toxic stress and, indeed, in ACEs. Dr Nadine Burke Harris's work in this field has been no less than revolutionary. She is a pioneer in the truest sense of the word, in recognising the importance of childhood trauma when diagnosing and treating medical problems and defining this unexplored link, correctly, as a 'a public health crisis in plain sight.' Not only did she identify the true value of the initial ACEs study

conducted by Vincent Felitti and Robert Anda, but she found a way to apply it effectively to an extremely deprived San Franciscan community which was desperately in need of the resources to tackle its many problems at their root cause. Like many pioneers, she was not without those who wished to push back the tide of progress, but even in the face of this Dr Burke Harris continued to work with partners and advocates so that the concept of medical screening for ACEs and toxic stress might reach other practitioners not only nationally but internationally.

In this book Dr Burke Harris is asked during a lunch, 'I guess the big question is, what can you do if you know you have an ACE score? I mean, is knowing really going to make a difference?' and the answer comes a few pages later when a young woman who has experienced toxic childhood stress first learns of ACEs and expresses what they mean to her, '... I understand now why I am this way. I understand why my siblings are this way. I understand why my mother raised us the way she did. I understand that I can break this cycle for my children and I understand that I'm not a victim, I'm a survivor.'

This book profoundly affected me in much the same way. I was someone who was already aware of their ACE score, something to measure my difficulties by, but it was like looking at a watch but not being able to understand the mechanisms within it, what makes it tick, what makes it slow, what might make it stop altogether.

Statistically, ACEs affect so many in our society that it should be of importance to each and every one of us. However, if you have a closer connection, if you live with someone who has experienced trauma, if you have a child who has experienced toxic stress or a friend or a family member or a partner, I know you'll be looking for answers. This book holds the answers you've been searching for.

If, like me, you have personal, lived experience of childhood trauma, you will know that often it is not the symptoms of toxic stress that are so difficult, but not being able to understand that they are in fact symptoms. The fear and bewilderment at your own behaviours and the frustration that they continue to occur, despite your very best efforts to put your life in order, are often the hardest to bear for both those experiencing the aftershocks of trauma and for their loved ones. The experience of trauma, particularly in childhood, is so often related to things happening to us beyond our control that it is extremely powerful, through the insights this book has to offer, to feel a sense of control of that situation by understanding not just what is happening or why now but also *how* it is happening.

Dr Burke Harris is an extraordinary researcher and writer. But she is also a human, a mother and doctor who has worked on the frontline in one of America's most deprived communities for many years. It is these things that make this an astonishing book. It is written not just with the precision of a scientist's mind, but also with the human heart and feeling of someone who understands the damage that leaving this area unexplored can do, and the passion of someone who wants to change things for good.

I hope that you too will read this and find hope within the pages. I hope that you will find answers. It deserves to be widely read. My greatest wish is that readers will be able to apply it to their understanding of their own lives and that its insights will be applied overall to the various systems of care and public service within the UK. Never has this book been timelier. Whether a medical professional, teacher social worker, MP, parent, partner or friend, what this book gives is the what, why and how of toxic childhood stress and its consequences so that we might dismantle those negative outcomes and robustly tackle these ailments as a society.

I have eternal gratitude for this book. Dr Burke Harris's story is a gift for people like me, who will live with their ACEs for the rest of their life but who can now apply knowledge and compassion to those symptoms. It is so rare that you can say a book is life-changing, but this one truly is. I hope that it will be a life-changing gift to those of you reading it too.

Kerry Hudson

2020

Author of *Lowborn: Growing Up,*
Getting Away and Returning to
Britain's Poorest Towns

Author's Note

All of the stories in this book are true. Names and identifying details of some individuals have been changed in some circumstances to protect confidentiality. Some vignettes are retold from previous published works.

Introduction

AT FIVE O'CLOCK ON an ordinary Saturday morning, a forty-three-year-old man — we'll call him Evan — wakes up. His wife, Sarah, is breathing softly beside him, curled in her usual position, arm slung over her forehead. Without thinking much about it, Evan tries to roll over and slide out of bed to get to the bathroom, but something's off.

He can't roll over and it feels like his right arm has gone numb.

Ugh, must have slept on it too long, he thinks, bracing himself for those mean, hot tingles you get when the circulation starts again.

He tries to wiggle his fingers to get the blood flowing, but no dice. The aching pressure in his bladder isn't going to wait, though, so he tries again to get up. Nothing happens.

What the . . .

His right leg is still exactly where he left it, despite the fact that he tried to move it the same way he has been moving it all his life — without thinking.

He tries again. Nope.

Looks like this morning, it doesn't want to cooperate. It's weird, this whole body-not-doing-what-you-want-it-to thing, but the urge to pee feels like a much bigger problem right now.

"Hey, baby, can you help me? I gotta pee. Just push me out of bed so I don't do it right here," he says to Sarah, half joking about the last part.

"What's wrong, Evan?" says Sarah, lifting her head and squinting at him. "Evan?"

Her voice rises as she says his name the second time.

He notices she's looking at him with deep concern in her eyes. Her face wears the expression she gets when the boys have fevers or wake up sick in the middle of the night. Which is ridiculous because all he needs is a little push. It's five in the morning, after all. No need for a full-blown conversation.

"Honey, I just gotta go pee," he says.

"What's wrong? Evan? What's wrong?"

In an instant, Sarah is up. She's got the lights on and is peering into Evan's face as though she is reading a shocking headline in the Sunday paper.

"It's all right, baby. I just need to pee. My leg is asleep. Can you help me real quick?" he says.

He figures that maybe if he can put some pressure on his left side, he can shift position and jump-start his circulation. He just needs to get out of the bed.

It is in that moment that he realizes it isn't just the right arm and leg that are numb — it's his face too.

In fact, it's his whole right side.

What is happening to me?

Then Evan feels something warm and wet on his left leg.

He looks down to see his boxers are soaked. Urine is seeping into the bed sheets.

"Oh my God!" Sarah screams. In that instant, seeing her husband wet the bed, Sarah realizes the gravity of the situation and leaps into action. She jumps out of bed and Evan can hear her running to their teenage son's bedroom. There are a few muffled words that he can't make out through the wall and then she's back. She sits on the bed next to him, holding him and caressing his face.

"You're okay," Sarah says. "It's gonna be okay." Her voice is soft and soothing.

"Babe, what's going on?" Evan asks, looking at his wife. As he gazes up at her, it dawns on him that she can't understand anything he's saying. He's moving his lips and words are coming out of his mouth, but she doesn't seem to be getting any of it.

Just then, a ridiculous cartoon commercial with a dancing heart bouncing along to a silly song starts playing in his mind.

F stands for face drooping. *Bounce. Bounce.*

A stands for arm weakness. *Bounce. Bounce.*

S stands for speech difficulty.

T stands for time to call 911. Learn to identify signs of a stroke. Act FAST!

Holy crap!

• • •

Despite the early hour, Evan's son Marcus comes briskly to the doorway and hands his mom the phone. As father and son lock eyes, Evan sees a look of

alarm and worry that makes his heart clench in his chest. He tries to tell his son it will be okay, but it's clear from the boy's expression that his attempt at reassurance is only making things worse. Marcus's face contorts with fear, and tears start streaming down his cheeks.

On the phone with the 911 operator, Sarah is clear and forceful.

"I need an ambulance right now, *right now!* My husband is having a stroke. Yes, I'm sure! He can't move his entire right side. Half of his face won't move. No, he can't speak. It's totally garbled. His speech doesn't make any sense. Just hurry up. Please send an ambulance *right away!*"

• • •

The first responders, a team of paramedics, make it there inside of five minutes. They bang on the door and ring the bell. Sarah runs downstairs and lets them in. Their younger son is still in his bedroom asleep, and she's worried that the noise will wake him, but fortunately, he doesn't stir.

Evan stares up at the crown molding and tries to calm down. He feels himself starting to drift off, getting further away from the current moment. *This isn't good.*

The next thing he knows, he is on a stretcher being carried down the stairs. As the paramedics negotiate the landing, they pause to shift positions. In that slice of a second, Evan glances up and catches one of the medics watching him with an expression that makes him go cold. It's a look of recognition and pity. It says, *Poor guy. I've seen this before and it ain't good.*

As they are passing through the doorway, Evan wonders whether he will ever come back to this house. Back to Sarah and his boys. From the way that medic looked at him, Evan thinks the answer might not be yes.

When they get to the emergency room, Sarah is peppered with questions about Evan's medical history. She tells them every detail of Evan's life she thinks might be relevant. He's a computer programmer. He goes mountain biking every weekend. He loves playing basketball with his boys. He's a great dad. He's happy. At his last checkup the doctor said everything looked great. At one point, she overhears one of the doctors relating Evan's case to a colleague over the phone: "Forty-three-year-old male, nonsmoker, no risk factors."

But unbeknownst to Sarah, Evan, and even Evan's doctors, he did have a risk factor. A mighty big one. In fact, Evan was more than twice as likely to

have a stroke as a person without this risk factor. What no one in the ER that day knew was that, for decades, an invisible biological process had been at work, one involving Evan's cardiovascular, immune, and endocrine systems. One that might very well have led to the events of this moment. The risk factor and its potential impact never came up in all of the regular checkups Evan had had over the years.

What put Evan at increased risk for waking up with half of his body paralyzed (and for numerous other diseases as well) is not rare. It's something two-thirds of the nation's population is exposed to, something so common it's hiding in plain sight.

So what is it? Lead? Asbestos? Some toxic packing material?

It's childhood adversity.

Most people wouldn't suspect that what happens to them in childhood has anything to do with stroke or heart disease or cancer. But many of us do recognize that when someone experiences childhood trauma, there may be an emotional and psychological impact. For the unlucky (or some say the "weak"), we know what the worst of the fallout looks like: substance abuse, cyclical violence, incarceration, and mental-health problems. But for everyone else, childhood trauma is the bad memory that no one talks about until at least the fifth or sixth date. It's just drama, baggage.

Childhood adversity is a story we think we know.

Children have faced trauma and stress in the form of abuse, neglect, violence, and fear since God was a boy. Parents have been getting trashed, getting arrested, and getting divorced for almost as long. The people who are smart and strong enough are able to rise above the past and triumph through the force of their own will and resilience.

Or are they?

We've all heard the Horatio Alger-like stories about people who have experienced early hardships and have either overcome or, better yet, been made stronger by them. These tales are embedded in Americans' cultural DNA. At best, they paint an incomplete picture of what childhood adversity means for the hundreds of millions of people in the United States (and the billions around the world) who have experienced early life stress. More often, they take on moral overtones, provoking feelings of shame and hopelessness in those who struggle with the lifelong impacts of childhood adversity. But there is a huge part of the story missing.

Twenty years of medical research has shown that childhood adversity literally gets under our skin, changing people in ways that can endure in their bodies for decades. It can tip a child's developmental trajectory and

affect physiology. It can trigger chronic inflammation and hormonal changes that can last a lifetime. It can alter the way DNA is read and how cells replicate, and it can dramatically increase the risk for heart disease, stroke, cancer, diabetes — even Alzheimer's.

This new science gives a startling twist to the Horatio Alger tale we think we know so well; as the studies reveal, years later, after having “transcended” adversity in amazing ways, even bootstrap heroes find themselves pulled up short by their biology. Despite rough childhoods, plenty of folks got good grades and went to college and had families. They did what they were supposed to do. They overcame adversity and went on to build successful lives — and then they got sick. They had strokes. Or got lung cancer, or developed heart disease, or sank into depression. Since they hadn't engaged in high-risk behavior like drinking, overeating, or smoking, they had no idea where their health problems had come from. They certainly didn't connect them to the past, because they'd left the past behind. Right?

The truth is that despite all their hard work, people like Evan who have had adverse childhood experiences are still at greater risk for developing chronic illnesses, like cardiovascular disease, and cancer.

But why? How does exposure to stress in childhood crop up as a health problem in middle age or even retirement? Are there effective treatments? What can we do to protect our health and our children's health?

In 2005, when I finished my pediatrics residency at Stanford, I didn't even know to ask these questions. Like everyone else, I had only part of the story. But then, whether by chance or by fate, I caught glimpses of a story yet to be told. It started in exactly the place you might expect to find high levels of adversity: a low-income community of color with few resources, tucked inside a wealthy city with all the resources in the world. In the Bayview Hunters Point neighborhood of San Francisco, I started a community pediatric clinic. Every day I witnessed my tiny patients dealing with overwhelming trauma and stress; as a human being, I was brought to my knees by it. As a scientist and a doctor, I got up off those knees and began asking questions.

My journey gave me, and I hope this book will give you, a radically different perspective on the story of childhood adversity — the whole story, not just the one we think we know. Through these pages, you will better understand how childhood adversity may be playing out in your life or in the life of someone you love, and, more important, you will learn the tools for healing that begins with one person or one community but has the power to transform the health of nations.

I

Discovery

Something's Just Not Right

AS I WALKED INTO an exam room at the Bayview Child Health Center to meet my next patient, I couldn't help but smile. My team and I had worked hard to make the clinic as inviting and family-friendly as possible. The room was painted in pastel colors and had a matching checkered floor. Cartoons of baby animals paraded across the wall above the sink and marched toward the door. If you didn't know better, you'd think you were in a pediatric office in the affluent Pacific Heights neighborhood of San Francisco instead of in struggling Bayview, which was exactly the point. We wanted our clinic to be a place where people felt valued.

When I came through the door, Diego's eyes were glued to the baby giraffes. *What a super-cutie*, I thought as he moved his attention to me, flashed me a smile, and checked me out through a mop of shaggy black hair. He was perched on the chair next to his mother, who held his three-year-old sister in her lap. When I asked him to climb onto the exam table, he obediently hopped up and started swinging his legs back and forth. As I opened his chart, I saw his birth date and looked up at him again — Diego was a cutie *and* a shorty.

Quickly I flipped through the chart, looking for some objective data to back up my initial impression. I plotted Diego's height on the growth curve, then I double-checked to be sure I hadn't made a mistake. My newest patient was at the 50th percentile for height for a four-year-old.

Which would have been fine, except that Diego was seven years old.

That's weird, I thought, because otherwise, Diego looked like a totally normal kid. I scooted my chair over to the table and pulled out my stethoscope. As I got closer I could see thickened, dry patches of eczema at the creases of his elbows, and when I listened to his lungs, I heard a distinct wheezing. Diego's school nurse had referred him for evaluation for attention

deficit hyperactivity disorder (ADHD), a chronic condition characterized by hyperactivity, inattention, and impulsivity. Whether or not Diego was one of the millions of children affected by ADHD remained to be seen, but already I could see his primary diagnoses would be more along the lines of persistent asthma, eczema, and growth failure.

Diego's mom, Rosa, watched nervously as I examined her son. Her eyes were fixed on Diego and filled with concern; little Selena's gaze was darting around the room as she checked out all the shiny gadgets.

"Do you prefer English *o Español*?" I asked Rosa. Relief crossed her face and she leaned forward.

After we talked — in Spanish — through the medical history that she had filled out in the waiting room, I asked the same question I always do before jumping into the results of the physical exam: Is there anything specific going on that I should know about?

Concern gathered her forehead like a stitch.

"He's not doing well in school, and the nurse said medicine could help. Is that true? What medicine does he need?"

"When did you notice he'd started having trouble in school?" I asked.

There was a slight pause as her face morphed from tense to tearful.

"*¡Ay, Doctora!*" she said and began the story in a torrent of Spanish.

I put my hand on her arm, and before she could get much further, I poked my head out the door and asked my medical assistant to take Selena and Diego to the waiting room.

The story I heard from Rosa was not a happy one. She spent the next ten minutes telling me about an incident of sexual abuse that had happened to Diego when he was four years old. Rosa and her husband had taken in a tenant to help offset the sky-high San Francisco rent. It was a family friend, someone her husband knew from his work in construction. Rosa noticed that Diego became more clingy and withdrawn after the man arrived, but she had no idea why until she came home one day to find the man in the shower with Diego. While they had immediately kicked the man out and filed a police report, the damage was done. Diego started having trouble in preschool, and as he moved up, he lagged further and further behind academically. Making matters worse, Rosa's husband blamed himself and seemed angry all the time. While he had always drunk more than she liked, after the incident it got a lot worse. She recognized the tension and drinking weren't good for the family but didn't know what she could do about it. From what she told me about her state of mind, I strongly suspected she was suffering from depression.

I assured her that we could help Diego with the asthma and eczema and that I'd look into the ADHD and growth failure. She sighed and seemed at least a little relieved.

We sat in silence for a moment, my mind zooming around. I believed, ever since we'd opened the clinic in 2007, that something medical was happening with my patients that I couldn't quite understand. It started with the glut of ADHD cases that were referred to me. As with Diego's, most of my patients' ADHD symptoms didn't just come out of the blue. They seemed to occur at the highest rates in patients who were struggling with some type of life disruption or trauma, like the twins who were failing classes and getting into fights at school after witnessing an attempted murder in their home or the three brothers whose grades fell precipitously after their parents' divorce turned violently acrimonious, to the point where the family was ordered by the court to do their custody swaps at the Bayview police station. Many patients were already on ADHD medication; some were even on antipsychotics. For a number of patients, the medication seemed to be helping, but for many it clearly wasn't. Most of the time I couldn't make the ADHD diagnosis. The diagnostic criteria for ADHD told me I had to rule out other explanations for ADHD symptoms (such as pervasive developmental disorders, schizophrenia, or other psychotic disorders) before I could diagnose ADHD. But what if there was a more nuanced answer? What if the cause of these symptoms — the poor impulse control, inability to focus, difficulty sitting still — was not a mental disorder, exactly, but a biological process that worked on the brain to disrupt normal functioning? Weren't mental disorders simply biological disorders? Trying to treat these children felt like jamming unmatched puzzle pieces together; the symptoms, causes, and treatments were close, but not close enough to give that satisfying click.

I mentally scrolled back, cataloging all the patients like Diego and the twins that I'd seen over the past year. My mind went immediately to Kayla, a ten-year-old whose asthma was particularly difficult to control. After the last flare-up, I sat down with mom and patient to meticulously review Kayla's medication regimen. When I asked if Kayla's mom could think of any asthma triggers that we hadn't already identified (we had reviewed everything from pet hair to cockroaches to cleaning products), she responded, "Well, her asthma does seem to get worse whenever her dad punches a hole in the wall. Do you think that could be related?"

Kayla and Diego were just two patients, but they had plenty of company. Day after day I saw infants who were listless and had strange rashes. I saw kindergartners whose hair was falling out. Epidemic levels of learning and

behavioral problems. Kids just entering middle school had depression. And in unique cases, like Diego's, *kids weren't even growing*. As I recalled their faces, I ran an accompanying mental checklist of disorders, diseases, syndromes, and conditions, the kinds of early setbacks that could send disastrous ripples throughout the lives to come.

If you looked through a certain percentage of my charts, you would see not only a plethora of medical problems but story after story of heart-wrenching trauma. In addition to the blood pressure reading and the body mass index in the chart, if you flipped all the way to the Social History section, you would find parental incarcerations, multiple foster-care placements, suspected physical abuse, documented abuse, and family legacies of mental illness and substance abuse. A week before Diego, I'd seen a six-year-old girl with type 1 diabetes whose dad was high for the third visit in a row. When I asked him about it, he assured me I shouldn't worry because the weed helped to quiet the voices in his head. In the first year of my practice, seeing roughly a thousand patients, I diagnosed not one but *two* kids with autoimmune hepatitis, a rare disorder that typically affects fewer than three children in one hundred thousand. Both cases coincided with significant histories of adversity.

I asked myself again and again: *What's the connection?*

If it had been just a handful of kids with both overwhelming adversity and poor health outcomes, maybe I could have seen it as a coincidence. But Diego's situation was representative of hundreds of kids I had seen over the past year. The phrase *statistical significance* kept echoing through my head. Every day I drove home with a hollow feeling. I was doing my best to care for these kids, but it wasn't nearly enough. There was an underlying sickness in Bayview that I couldn't put my finger on, and with every Diego that I saw, the gnawing in my stomach got worse.

...

For a long time the possibility of an actual biological link between childhood adversity and damaged health came to me as a question that lingered for only a moment before it was gone. *I wonder . . . What if . . . It seems like . . .* These questions kept popping up, but part of the problem in putting the pieces together was that they would emerge from situations occurring months or sometimes years apart. Because they didn't fit logically or neatly into my worldview at those discrete moments in time, it was difficult to see

the story behind the story. Later it would feel obvious that all of these questions were simply clues pointing to a deeper truth, but like a soap-opera wife whose husband was stepping out with the nanny, I would understand it only in hindsight. It wasn't hotel receipts and whiffs of perfume that clued me in, but there were plenty of tiny signals that eventually led me to the same thought: *How could I not have seen this? It was right in front of me the whole damn time.*

I lived in that state of not-quite-getting-it for years because I was doing my job the way I had been trained to do it. I knew that my gut feeling about this biological connection between adversity and health was just a hunch. As a scientist, I couldn't accept these kinds of associations without some serious evidence. Yes, my patients were experiencing extremely poor health outcomes, but wasn't that endemic to the community they lived in? Both my medical training and my public-health education told me that this was so.

That there is a connection between poor health and poor communities is well documented. We know that it's not just how you live that affects your health, it's also *where* you live. Public-health experts and researchers refer to communities as "hot spots" if poor health outcomes on the whole are found to be extreme in comparison to the statistical norm. The dominant view is that health disparities in populations like Bayview occur because these folks have poor access to health care, poor quality of care, and poor options when it comes to things like healthy, affordable food and safe housing. When I was at Harvard getting my master's degree in public health, I learned that if I wanted to improve people's health, the best thing I could do was find a way to provide accessible and better health care for these communities.

Straight out of my medical residency, I was recruited by the California Pacific Medical Center (CPMC) in the Laurel Heights area of San Francisco to do my dream job: create programs specifically targeted to address health disparities in the city. The hospital's CEO, Dr. Martin Brotman, personally sat me down to reinforce his commitment to that. My second week on the job, my boss came into my office and handed me a 147-page document, the *2004 Community Health Assessment* for San Francisco. Then he promptly went on vacation, giving me very little direction and leaving me to my own ambitious devices (in hindsight, this was either genius or crazy on his part). I did what any good public-health nerd would do — I looked at the numbers and tried to assess the situation. I had heard that Bayview Hunters Point in San Francisco, where much of San Francisco's African American population lived, was a vulnerable community, but when I looked at the 2004