

INTRODUCTION

A Life That Matters

GABRIELA MORALES WAS beautiful—or at least I could imagine how beautiful she could become. Born to a poor Mexican family, Gabriela’s early life had been terribly compromised by a congenital malformation of her face that led many to turn away from her, cruelly taunt her, even presume she was possessed by evil spirits.

Gabriela, now sixteen, was raised in a shantytown in Tijuana and had been introduced to the staff of the World Craniofacial Foundation, an organization I established in 1989, by an American mission worker. Noting her abnormally wide-set eyes and dramatically malformed nose—which had been made even more unsightly by a well-meaning but untrained physician soon after she was born—the missionary imagined that, with our help, the very shy girl with big dreams could, in fact, fulfill them one day.

At home in Dallas, when I read reports and saw photographs of Gabi, I was quickly sure that one day she could have a normal face—a birthright I believe all the world’s children possess. The foundation successfully raised funds to send her and her parents to Mexico City, where surgeons at an extraordinary reconstructive plastic surgery and teaching center—established three decades ago by my dear friend and colleague Dr. Fernando Ortiz Monasterio—could successfully transform Gabi’s face and set her young life on a very hopeful new course. And when I met dark-eyed and engaging Gabriela in person on a bright April morning in Mexico’s capital city, I was certain that she, like thousands of other patients I’ve met during my five-decade career, had a bright future indeed.

The Hospital General Dr. Manuel Gea González, located in Mexico City’s frenetic Tlalpan district, is surrounded by a high metal-barred fence, its entrances guarded by policemen carrying automatic weapons. On any day, literally thousands of impoverished Mexicans wait patiently for services, often for many hours, yet early every Tuesday morning, the hospital’s plastic and reconstructive surgery unit becomes what its eighty-six year old founder calls “the most exciting clinic in the world, the only place I want to be”—a clinic where young patients like Gabi come from throughout the country to be evaluated by a team comprising some the finest craniofacial surgeons in the world.

In my travels around the globe, performing surgeries and helping establish surgical centers in countries where top-quality medicine is seldom practiced, it is clinics like this one that demonstrate to me that even the very poor *can* receive excellent medical care at costs that don’t bankrupt healthcare systems. And with every

passing day, I believe more strongly that Gabriela and everyone like her *can* be offered the basic human right of a normal face.

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Consider what life entails for children like Gabi before they are treated; imagine the constant rejection and soul-killing ridicule and the virtual impossibility of succeeding in school, making friends, or one day falling in love. For many centuries, people with facial deformities were locked away, and oftentimes, infants with terrible deformities were simply not allowed to live. And still all too often today, people with shocking facial abnormalities are shunned, hidden, shamed, and tormented.

I've believed passionately since I was a young surgeon in Dallas in the early 1960s that all the world's children deserve to lead normal lives, yet for one child in every five hundred, a normal life is impossible without craniofacial surgery. Forty years ago, medicine offered little hope to patients with severe deformities of the skull, jaw, and face, but in pioneering utterly new surgical protocols that once were unimaginable, it's been my goal—and my life's great joy—to help profoundly change the outlook for these patients and their families. What once was impossible is now a practical reality because of the advancements of modern medical technology and the extraordinarily well-honed skills of a host of professionals.

A craniofacial surgeon never operates alone. He or she serves as both surgeon and impresario, performing incredibly intricate surgical techniques as well as coordinating the work of a highly skilled, interdisciplinary team in which each member is absolutely essential to a positive patient outcome. Pediatric neurosurgeons, pediatric anesthesiologists, neuroradiologists, pediatric intensivists, neuro-ophthalmologists,

pediatric ophthalmologists, otolaryngologists, orthodontists, speech pathologists, geneticists, anthropologists, pedodontists, pediatric nurses, psychologists, and social workers play vitally important supporting roles, and developing and coordinating a cadre of exceptional professionals can sometimes pose many complexities.

My patient Michael Hatfield, for example, was born with eyes on the sides of his head and without a nose. As a young boy, Michael was shocking to look at, and his mother reported that “people assume he’s retarded, incapable of interaction or emotion, just one of nature’s rejects.” Without a series of complex surgeries, Michael’s life would be effectively over as it began.

By the time he was eighteen, I had operated on Michael four times, creating new eye orbits in the front of his skull, moving his eyes naturally close together, creating a nose whose structural base was a piece of his rib, and sculpting natural-looking cheeks, forehead, and ears. The surgeries were anything but simple, yet Michael was always accepting, determined, and confident. He eventually became quite outgoing and vivacious, playing football and tennis, and developing his natural leadership skills—and he and I became very close. Surgery on another patient prevented me from attending his high school graduation in Corpus Christi, Texas, but I was as proud as his parents were when he enrolled in Emory University in Atlanta, then returned to Texas to attend law school at the University of Houston. Today, Michael is married and the father of a six-month old son, and he’s creating a career focused on innovative ways for companies to maximize their employees’ inherent potential. It’s work Michael was made for, and it’s hard for me to describe how full

my heart is when I consider how rich his life has become—and how terribly at risk he was for having no life at all.

Ashley Ashcroft was born with a huge hole in the center of her face. Her upper lip, palate, and the floor of her nose were missing, and her abilities to eat, breathe, smell, and talk were seriously compromised. Ashley *had* to have surgery in order to survive. But more than merely survive, I wanted her to *live* in ways that fulfilled her enormous potential. After seven surgeries over many years, Ashley emerged as a strong, fiercely intelligent, self-directed, and beautiful young woman. No longer limited in any way, Ashley attended college, then trained as a certified physician's assistant, and today she works in the ophthalmology department at MD Anderson Cancer Center in Houston. Ashley grew comfortable with and interested in the world of medicine during her many years as a patient, and, like me, she discovered how wonderfully rewarding a life of caregiving can be. She, like Michael and hundreds more patients, have constantly reminded me over the years that young lives like theirs must *never* be sacrificed to their deformities, and that every one of us—young and old—deserves a face with which we can bravely meet the world.

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Long ago, medicine intrigued me as a career because it would allow me to pursue science, help others, and explore the challenges of what couldn't yet be accomplished—but might be. Early in my training, I discovered that I was drawn to surgery; I considered many options and specialties, but ultimately only reconstructive plastic surgery truly captured my imagination at a time when even many major, large-city hospitals lacked plastic-surgery departments.

More than 16,000 surgeries and nearly fifty years later, I've been blessed not only to have helped transform thousands of patients' lives, but to have transformed my own as well. This work has given deep meaning to the totality of my life and has allowed me to discover my core sense of purpose—not just cutting, sawing, and sewing, but freeing the *spirits* of my patients, allowing them to look comfortably in the mirror and understand that they are not freaks but, in fact, are vitally important members of the human family

Along the way, I've observed a striking phenomenon: many young people with terribly disfiguring diseases possess special gifts—insights, sensitivities, and a kind of profound humanity that you commonly only see in people far older—gifts that aren't readily visible until you get to know them. People like Michael, Ashley, and Gabriela who lack normal skulls, jaws, noses, or eyes nonetheless express a kind of courage to face what life brings that is infrequent in other patients I treat. Their buoyant personalities and resolute perseverance inspire and renew me and virtually everyone they encounter.

I've also come to know another kind of patient—victims of unspeakable violence whose faces have been destroyed by evildoers—and my heart breaks for them. I've met a number of women in Uganda, for example, whose noses and ears were cut off by enemy tribesmen as a kind of wicked blood sport. And the morning I met Gabriela in Mexico City, I also met Magdalena Ayala, a twenty-two-year-old Guatemalan woman whose husband had horrifically sliced off her nose, lips, and chin with a machete in a fit of rage. Like the Ugandan women, Magdalena seemed robbed of her soul. She was vacant eyed, empty, far-removed from the world, and I tried to

understand that perhaps that is the only response possible when your face is taken from you.

The sole light in Magdalena's life was that, with the help of the Guatemalan government, she had come to a hospital where her face and her soul could slowly be returned to her in a series of highly complex surgeries. But for years to come, she and those Ugandan women who had suffered similar attacks would re-experience that terrible violence every day of their lives—simply by looking in the mirror.

Whether they are victims of violence, accidents, or were born with disfiguring congenital disorders, I've been struck by how often my patients become dedicated to helping others with similar challenges—volunteering in clinics, doggedly raising funds for research, assisting individual patients and their families, speaking publicly to raise awareness of the worldwide need for help, even pursuing medical careers in craniofacial surgery or related specialties.

Like those of us who work in this field, craniofacial patients—and those who once were—remain particularly sensitive throughout their lives to the truth that each person deserves not just to exist, but to thrive. In valuing individual lives and striving to make them better, we value all of humanity.

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Sixteen-year old Gabriela, who soon would undergo the first of several surgeries, and whose face would one day become one she was proud of, reminded me of the time long ago when I was her age. Growing up in Kansas, I suffered from asthma from the time I was very young, struggling to breathe, often requiring oxygen, and I vividly remember hearing my parents discuss with doctors the possibility that I

might die. By the time I reached my early teens, I remained isolated from schoolmates, housebound, lonely, and awkward, just as Gabriela was, and I couldn't imagine becoming an adult, let alone one who might live a valuable life.

But I eventually grew healthy enough that in a few years I began to work as an intern in my father's dentistry practice and I dared imagine the possibility that I could become a physician. I began to drive myself toward that end, becoming absolutely single-minded, even obsessed with my personal pursuit of excellence. In college, I demanded the very best of myself and was often the last person to leave labs and study groups, reading late into every night, ensuring that my grades were always very high and ultimately graduating from medical school in the top tenth of my class. As a young surgeon, I intensified an already unflinching dedication to hard work and extremely high standards, and I owe my career accomplishments not to superior intellect, talent, or luck, but to two other attributes that shape the totality of who I am.

The first is a deep desire never to fail. That drive has made me a fine surgeon, I know, and has helped me play a seminal role I'm proud of in the development of craniofacial surgery. In operating rooms, thousands of times, it's been a critical ally as I've painstakingly lifted young faces away from terribly misshapen skulls, then reshaped those skulls with complex tools, simple scalpels and saws, as well as with my fingertips and hands. Each time I've created a new skull, nose, ear, or chin for an unfortunate child, and for thousands of adults as well, I've been blessed by my compulsion to do my work extremely well.

The second attribute that has served me well is a strong and emotional kind of compassion—rooted in my childhood, I'm sure—for youngsters whose deformities

destroy their opportunities to *live*. I ache for them; my life is richest when I'm able to help them, and my great cause is encouraging people everywhere to open their hearts and recognize that possessing a face you aren't forced to hide is a fundamental human right—as important to a fully lived life as freedom from fear or want.

As I reach my mid-seventies, that pursuit of excellence, that compassion—and a *passion* for this work that still springs me out of bed each morning—continue to grow. I'm very optimistic about the progress we're making in the developed world in bringing treatment to everyone who needs it. But in developing countries, much remain to be accomplished, and I devote the majority of my time to sounding a clarion call not just for understanding, but for *action*. The need is too great and the lives of children who possess tragic faces are too precious for me to simply sit by and wish them well. No one needs to become a craniofacial surgeon to offer assistance; there are hundreds of ways we all can bring awareness, funding, and vital work to this great cause. Your compassion and commitment, I can vouch, will be met with the priceless knowledge that you have helped give young people faces, and thereby have given them the great gift of themselves.

When people possess normal faces—when they can see, hear, speak, and chew normally, and when they're not forced to hide their faces from the world—their spirits can soar, and nothing in life seems more important to me than that possibility, a hope that lifts each of us toward the best lives we can make.

Our faces are *us* in a very fundamental way. Four of our five senses are located in our faces and heads; it's with them that we encounter and understand the world around us. Just as importantly, with our faces we give those with whom we interact a

vital glimpse of who we truly are. Our faces communicate—far more accurately and eloquently than does speaking, in many ways—what our minds believe and our hearts hold true. Imagine expressing love, for example, without a face behind which you're comfortable. Imagine the despair of ever receiving it.

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On the pages that follow, you'll meet a number of the young people with heartbreaking craniofacial abnormalities whose challenges and boundless courage have stirred me to become such a tireless advocate on their behalf. As the book unfolds, I recount not just my own journey but also the stories of children from around the world whose lives might otherwise have been lost, people who remain bright in memory and very dear in my heart.

I think of Lynn Beaver, the remarkable young woman with Crouzon's syndrome who, in 1974, was the first patient whose face and skull I re-sculpted and whose life was renewed in wonderful ways. I remember, too, Georgette Couvall, who was born in 1975, the obstetrician who attended her birth telling her father, "It's a girl, but I've never seen anything like her." Yet over the course of thirteen surgeries and many years, I was able to transform Georgette into a beautiful young woman and she became a dear friend, someone who today works tirelessly in support of other craniofacial patients and on behalf of the World Craniofacial Foundation.

I can never forget ten-year old Petero Byakatonda, a Ugandan boy who also suffered from Crouzon's. With the help of the foundation to which I continue to devote my energies, Petero was able to travel to Dallas for surgery, and I remember

him singing in his native Lugana as he was wheeled into surgery, “God, we have come in front of you. Please bless us and keep us.”

My heart still aches for Romanian twin sisters Anastasia and Tatiana Dogaru, conjoined at the head, who shared far too many vital brain structures as well as compromised hearts and kidneys, we discovered, for our surgical team to attempt to successfully separate them. And I still marvel at the astonishing journey of Egyptian twins Mohamed and Ahmed Ibrahim, whom we did successfully separate in an extraordinarily complex procedure that we planned for more than a year and that endured for thirty-six hours. A year later, in a second, utterly groundbreaking operation performed on the now separated boys, we constructed new skulls for each of them—something unimaginable only a few years before—and today they are schoolboys thriving at home in Egypt.

The Ugandan women, robbed of ears, noses, and their very selves, will always haunt me, of course, as will Magdalena, the victim of her husband’s unspeakable violence, and I’ll always delight in my memory of Gabriela’s bright and optimistic smile that day I met her in Mexico City, remembering that, like her, I was once young and hopeful and determined to live a good life.

Gabi and thousands of children like her have been the focus of my work; they have given me countless rewards, and they continue to be my cause. The book you hold in your hands is a call to action—a call for us to do everything we can to help young people like Gabi fulfill the great promise of their lives. It’s also a call, a reminder, to each of us to be inspired by how they have overcome terrible disfigurement and to transfer that awareness to our own lives, working to transform

our own shortcomings, set-backs, and personal challenges into lives we continually renew for the better. Life *is* transformation, and, in our own ways, each of us can—like so many of my patients—overcome any obstacle, no matter how great.