

Facing Forward

By Deborah Breslow



Chart in hand, Kenny's

doctor was ready for his next patient. "Doctor," Jay asked tentatively, "what happens now? Can Kenny play baseball without a cage? Can he play goalie in soccer? Is there a chance he might play football?"

"Let me be more clear, Mr. Breslow. Kenny has no restrictions. He should go out there and be a normal kid." He turned and knocked on a closed exam room door.

"Words to live by," I pondered. But for this family, it meant changing a 10-year mindset. Without coming up for air, medical research, diagnostic testing, and surgical intervention had consumed our lives. Encounters with fear, uncertainty, public curiosity, and questioning had become routine. Did "living normally" fit into the realm of our existence?

"Doctor," I called, "here's a pen and pad." I began to dictate: "The situation is no longer life threatening. The progression of disease has ceased. The worst is over."

His face softened. "You don't need it in writing, Mrs. Breslow. You need to believe it. It's time you greet the world facing forward." Digesting his words, I could hardly react.

As we approached the parking garage, Kenny was quiet. Did he comprehend the good news? "That was easy," I noted. "Not that easy," he reflected. "It hurt when he was pinching my nose."

"He just wanted to be sure the bone had set," I assured him.

"Maybe, but he didn't have to press so hard."

We drove home from New York, each in our own thoughts. The ride was uneventful: lighter traffic, lighter hearts. The doctor said he was okay and to come back in six months. Surgery was not scheduled; scans were not needed. We spoke atop soft couches in his private office. No gloves, medical instruments, examining table, or bright lights. None required.

"Greet the world facing forward," he'd suggested. Admittedly, this concept was extrinsic to us. The pain of the familiar had become easier than the fear of the unknown. Would it be difficult for us to see the world, and the world to see us, with a new pair of glasses?

On a more personal level, how much

was this about Kenny's need to move ahead as it was about mine?

There are strings attached to giving birth to a child with a rare medical condition. At first you blame yourself. The guilt consumes you. You want to retreat, but you can't. Your better sense prevails. "I must find out what's wrong with my son and how best to treat him. I will find the right doctor, the best hospital ..."

Twinges of remorse are replaced by self-pity: "Why me?" you ask yourself. "Poor me," you wallow. Then miraculously, your inner voice takes over. These feelings may be normal for many, but they are nonsense for you.

Having reached a higher awareness, you take action. While he undergoes consultation, you become the researcher, the facilitator, the advocate. You may begin to refer to your child as sick. Though this is unfair (as most labels are), it lets others know your life is different—you have been tested in a way that they have not. When people say, "I don't know how you do it" or claim you as a saint, you remind them that if they were dealt the same hand of cards that they would act accordingly. You rise to the challenges that come your way.

When the child is a baby, his experience is yours. You rationalize that because he is so young, he won't remember pain, blood, sutures, or scars. Soon you become more thick-skinned. When speaking about a part of your child's body, you are detached. You refer to dilated blood vessels, arterial maps, capillary bridges, and high flow lesions with clinical skill and objectivity. Medical discussions take place as though you are speaking about an

inanimate object, not your child.

Unable to put one foot in front of the other, you reach out for help. His illness has a ripple effect. Family, friends, caregivers, and clergy come to your aid. People who love you want to help you.

Though members of your community—your child's clinicians and educators, friends, and neighbors may see you as having it together—you live in the cocoon of your mind. Stoically hiding your true feelings, you never exhibit distress. You rise to the occasion. There are times you consider how life may have been otherwise. You may wish to shut the door on reality. But you can't—for the sake of your child, your marriage, your family.

Being in crisis, living in crisis becomes the norm. Plans are made to be broken. You thrive on adrenalin. Fun and relaxation are for other people, people who don't have to endure what you endure regularly. In some ways, you become the sick child. If you own it, then he doesn't have to. All time, energy, and effort associated with taking care of him becomes who you are. You forget where you end and he begins.

With the passing of 10 years, Kenny has learned to roll with life's ups and downs. Continuous medical intervention has resulted in countless life interruptions. Bearing a facial difference has evoked unkind behavior from others—teasing, staring, hurtful remarks.

Yet, his level of acceptance and resilience is unsurpassed. His experience has offered him a greater understanding of life. He always lands on both feet. He is



Deborah
Breslow and
her son, Kenny.

sensitive, funny, and surrounded by friends. Psychosocial intervention during the early years of diagnosis and medical treatment helped to foster healthier reactions to his personal trials and the insensitivity of others. His physical self is ever-changing. Daily life can be tumultuous, but his sense of self is untainted. His inner strength does not falter.

I consider the concept of letting my guard down. After all, if he can, why can't I? Wrapped in a blanket of fear and worry for 10 years, I am challenged to retreat from that person—to be someone else. But who? If Kenny is no longer sick and the situation is no longer acute, my existing mindset can no longer be. I am reminded of the term cautious optimism. Perhaps that is a middle ground.

From early on, his doctors had warned us that there was no predictability to the progression of his disease. "We don't know what's happening in the deeper blood vessels, the ones that can't be seen," they explained. We've been urged not to look under the rug, focusing only on what his surgeons had the knowledge and clinical expertise to control. But worry and uncertainty always got the best of me.

Reaching out to a friend who has dedicated her adult life to the advocacy of children with rare craniofacial conditions, she shares the experience of her adult son. After 17 years of intervention, he is now married, living a normal life. Reflecting on her involvement throughout his life, she admits that it overtook her.

Expressing her current role in his life, she believes she has moved on. "That was another country, and I'm outta' there!" Though she continues to be concerned, the responsibility for coping with his birth defect and subsequent residuals are his.

He has eloquently shown her that it is his life to live. The challenges he bears, the demons he continues to encounter and conquer are his—not hers.

Following our conversation, I am struck by the notion that though younger in years, Kenny too has faced life with grace.

For him, good news from the doctor may not require "new glasses." He's seen his life for what it is. He has learned to accommodate. I may have contributed some to this framework, but it is Kenny who has prevailed. Taking the adversity in stride, he's turned it into something great.

What's in a face? What does it tell the world? Does it reveal who we are? Is it fair for another human being to judge one's character by looking at a face that may be different, disfigured, unsightly, bruised, swollen, bandaged, or pained? The answer is simple. Our face is merely a part of our body.

What we choose to do with that face, with our persona, is what contributes to who we are. Normal or not, like it or not, it's what we have. Being comfortable in our skin invites people in—gives them the opportunity to know us.

I know this is so because of our experience. We have a deep understanding of and respect for inner beauty. It is not seen with the eyes.

Kenny is my power of example. He lives the truth. Preparing for a new day, I can make a choice. Step by step, I will not look back. I choose to greet the day facing forward.

Kenny was born with a rare vascular anomaly called arteriovenous malformation (AVM). The condition affects his nose, cheek and lip. Kenny receives ongoing care from Alejandro Berenstein, MD, Director, Center for Endovascular Surgery, Roosevelt Medical Center and Barry Zide, MD, DMD, Professor of Surgery (Plastic) NYU Medical Center. They are both located in New York City, NY. Visit Ms. Breslow's website at <http://members.aol.com/djbreslow/funnyface/index.html>.

Deborah Breslow is a freelance writer and the mother of three boys: Robbie (11), Kenny (10) and Danny (7). She lives in Wyckoff, NJ with her husband, Jay.

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