

# *Thriving Blind*

Stories of Real People  
Succeeding Without Sight

**Kristin Smedley**

Thriving Productions  
Ivyland, Pennsylvania

Thriving Blind  
Stories of Real People  
Succeeding Without Sight  
By Kristin Smedley

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To the three people  
Who are responsible for gray hairs on my head  
And laugh lines on my face:  
Michael Jr, Mitchell, and Karissa,  
You show the world what thriving looks like every day  
And you are the reasons I am thriving in my life.  
God sent me the best of the best  
When he sent the three of you to me.

To the two people  
Who are responsible for  
My resilience despite adversity:  
Mom and Dad,  
You've shown the world  
How unconditional love sets us up to thrive.  
Your constant support, cheering, and cleaning up my  
kitchen  
Have enabled me to thrive as a mom.  
God sent me to the best of the best,  
When he sent me to both of you.

*I am blessed.*



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# Foreword

*By Erik Weißenmayer*

My first reaction to Kristin Smedley’s refreshing new book, *Thriving Blind*, was: “Wow! It’s about time a parent lays out the fundamentals to a successful life for their blind children.” Kristin would know. She’s the mother of two blind boys, both born with a rare eye disease, Leber Congenital Amaurosis (LCA)—as Kristin said, “a double dose of darkness,” and as a family member mused bitterly, “like winning the lottery twice.”

However, Kristin’s parental lens began to shift and her mind began opening to all the possibilities awaiting. She eloquently writes, “I was empowered to set extraordinary expectations.” Clearly and frankly, she points out the key factor in the equation: her role as a parent. She beautifully presents how her beliefs and fears, her perspective and mindset, could become either her boys’ biggest barrier or the boys’ most powerful catalyst.

Kristin states that when someone wants something badly enough, they seek out the best resources and role models. That desire led her on a quest to meet blind people around the country who were living their dreams. About five years ago, I invited Kristin and her family to my house in Colorado. Young boys at the time, Michael and Mitchell tumbled around on our wrestling mat and climbed on my home climbing wall. We ate pizza, and the boys pet my guide dog, who was off duty, of course, as well as our three chickens. Kristin and family went away with a little more

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belief that an exciting and fulfilling life as a blind person was possible. Since then, Kristin has made it a point to meet successful blind women and men around the country. Some of them such as Tom Wlodkowski and Lonnie Bedwell are dear friends of mine. She illuminates their stories and dissects their positive traits in the chapters of *Thriving Blind*.

The results of Kristin's exploration are reflected in this book, but also in the lives of her boys who have played on championship baseball teams, taken honors classes, played and sung in bands, dated girls and gone to proms, and attended college. As Kristin writes, "Their lives are about their dreams."

The story of my family and me is strikingly similar. I describe my parents as the broom and the dustpan. My dad would sweep me out into the world only to be shattered. Then my mom would gather up the broken pieces and rebuild them, only to have my dad sweep me out again. It was a repeating anti-intuitive process of failure and fortification.

When initially diagnosed with a rare disease that the doctors said would take my sight completely as an early teen, my desperate mother brought me to an empty church, wrapped her arms around me, and prayed for a miracle that would restore my sight. As a little boy, I prayed alongside her—to see like my brothers, to catch a football, and to charge down the basketball court on a fast break. I prayed for sight so that my parents wouldn't bring me to dark places and sound so desperate and scared.

But just like Kristin, ultimately, my mom's attitude changed, and she became my biggest advocate for living a full life. She was a mother lioness fighting for my every opportunity. When I was about to start school, it was still rare for visually impaired children to be mainstreamed at a public school. Meeting with a group of close-minded administrators, my mom dug in and stated forcefully, "I



have a distant cousin who was born prematurely. The incubator made her blind. You know what they taught her at the school for the blind? They taught her to tune pianos. Now there's nothing wrong with tuning pianos. It's perfectly respectable. The funny part is that my cousin was tone deaf." My mother burst into strained laughter. "You know what she does now?" My mom paused and then delivered each word separately and deliberately: "She does nothing. She can't make a bed or cook a meal. She can't even peel an orange by herself. And what's going to happen to the poor thing when her mama and daddy die? Where's she gonna go? What's she gonna do? Who's gonna peel her oranges then? My baby can move around the house and neighborhood on his own. He can take out the garbage and vacuum the floor. He can look at comic books. Puts his head right against the page, but he can see them. He can swim in the pool, dribble a basketball. He plays football with his brothers. They let him be quarterback and yell out, 'Erik, over here. This way,' and he throws it right to them. He's not going to tune pianos, and he's not going to sit around the house waiting for the dinner bell. He's going to go to a normal school, with normal children, and even if I have to go to school with him, he's going to learn."

I'll never know how my mom had the courage to so forcefully oppose the establishment. She knew very little about blindness. However, she believed in me. I was just a skinny little boy with thick glasses. I was an unwritten book. But somehow she saw strength, opportunity, and promise, while others saw only problems, obstacles, and limits. I thank her for that powerful belief every day.

My dad pushed me in other ways and taught me a lot about what I now call "a No Barriers Mindset." In middle school, with only very limited vision, I loved to perform stunts on my mountain bike. I'd sit at the top of my steep driveway wearing an Evel Knievel t-shirt and black leather

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gloves. After a few deep breaths, I'd launch myself down the drive, around the corner, and over a wooden ramp positioned at the bottom. I'd soar off the ramp and land on another ramp, eight feet past the first. Then I'd circle the cul-de-sac with one hand on the handle bar and the other raised victoriously in the air, waving to the imaginary crowd. But one day while pedaling back up the driveway for another jump, my bike and the ground seemed to swerve side to side, and I just managed to put my foot down before I toppled over. My vision was swimming and growing fuzzy. I told myself that I was only imagining my diminished sight, that it was only the temporary blinding flash of the sun in my eyes, anything but the truth. I tried to make the jump a few more times, but the ramp and the pavement beneath seemed to blend together. I'd either pop off the side of the ramp or miss altogether.

At the top of the driveway, my father was spray painting an old chest. Although I didn't notice him, he couldn't help but notice me. He grimaced each time I missed, wanting so badly to run down and command me to stop before I got hurt, but he held his ground. He knew he couldn't come running each time I confronted a challenge. Finally, he saw me give up in disgust and angrily push my bike into the garage. Saying nothing to my dad as I stormed inside, I slammed the door. My father looked at the dull wooden ramp and at the can of spray paint in his hand. Then he walked into the garage and studied the rack of different colored spray paints until his eyes stopped on bright orange.

The next day over breakfast, my father encouraged me to try the ramp again. I hesitantly pedaled down the driveway as he watched anxiously from the top. When I rounded the corner, I immediately noticed something vastly different. I could clearly see the outline of the ramp; it shone bright orange in the sun. I could smell the aerosol odor of spray paint as I hit the first ramp dead on, flew

across the gap, and touched down on the landing ramp. Soon my confidence was back. I even convinced my two brothers to lie down on their stomachs between the ramps so that I could jump over them. They reluctantly agreed, and I'm happy to report that both of them survived.

With the right support, encouragement, and belief, your child will survive, too. In fact, as Kristin so poignantly describes, "They'll do better than survive. They will thrive."

*Erik Weihenmayer is the author of three books, Touch the Top of the World, The Adversity Advantage, and No Barriers, and is a filmmaker and prominent international speaker. Totally blind, he has climbed Mt. Everest and the Seven Summits, and kayaked the mighty rapids of the Grand Canyon. He is an ice climber, para-glider, skier, mountain biker, and has more than 50 skydives to his credit. He has been honored as National Geographic's Adventurer of the Year and was recently named one of the 25 greatest adventurers of the last 25 years. His greatest achievement is the founding of No Barriers 13 years ago, which now serves almost 10,000 challenged people annually. His message to young and old, challenged or not challenged, is to live a No Barriers Life. Erik resides with his wife Ellen and two children in Golden, Colorado.*

*See [www.touchthetop.com](http://www.touchthetop.com) for more information.*

# A Double Dose of Darkness An Introduction

I stood at the back of the large room setup in a typical conference style: a basic black stage with about a hundred plain folding chairs facing it. The room was split in half by an aisle down the middle of the perfectly lined up chairs. Typically at a conference I excitedly enter the space and bounce around the room to chat with folks and find a great seat. But not this time. Here I hesitated for a long while before making my way, ever so slowly, begrudgingly, down that aisle to look for a place to sit.

Although I didn't want to get too close to the front of the room or even anyone in the room, I needed to find a good seat where I could hear everything the presenters had to say. After all, I had a lot to learn. I didn't *want* to learn from them; I *needed* to learn from them. I walked closer to the front, my feet moving slower, slower. Walking away from the back of the room toward the stage, I was walking away from my dreams and into my nightmare.

Holding back tears as I looked around, I saw a group of empty seats on the right. Next to the seats were two parents apparently trying to please their daughter. I guessed she was about fourteen or fifteen years old. She sat with her feet up on her chair and her legs crossed in a format that the forever elementary school teacher in me calls "crisscross

applesauce.” She was rocking quickly, forward and back, forward and back. As she rocked, her mother handed her a drink.

“What is that? Is that orange juice? I didn’t want orange juice!” she yelled.

Her mom, looking exhausted, apologized and said she would go find something better for her. Next, her father came to her with food.

“These aren’t chocolate chip cookies! I said I want cookies! Chocolate chip!” she demanded. He quickly went back to the snack table to get the right cookies.

My heart pounded. My stomach was in a knot. I couldn’t believe what I was seeing. I’m sure I didn’t hide my look of horror. More upsetting was the fact that the others nearby witnessing this family didn’t seem upset at all. Most had a look of understanding, an “I get it” look. Some even seemed to have a look of *acceptance* about what was happening.

Next, I glanced to the left of the aisle where there was another family sitting near a group of open seats. A mom and her perhaps thirteen-year-old son were in a heated argument. The boy was slumped in the chair, arms crossed, legs stretched out in front of him with his ankles crossed. His back was turned to his mom. She was whispering in what seemed an attempt to not cause a scene, but her voice was escalating. I leaned in to hear her.

“Absolutely not! It is completely inappropriate,” the mother said.

“God, Mom—you don’t let me do anything!” her son huffed.

“You are being completely obnoxious!” she scolded.

“Skateboarding is not obnoxious!” he fired back.

“Skateboarding in a hotel is obnoxious, unsafe, and RUDE,” she replied.

This family was arguing over what was and was not appropriate in terms of skateboarding in a hotel! I was

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intrigued. I wanted—needed—to know more about them.

That conference was a meeting for families with children who are blind due to Leber Congenital Amaurosis (LCA), a very rare eye disease causing blindness. The children in the families I encountered on either side of the aisle were blind. The girl who was upset with her family’s “snack service” was blind. The young slumped-in-the-chair skateboarder was blind. And I was there because I had recently found out that my newborn son was blind, too. My baby, Michael, was diagnosed with LCA at five months old. This conference was my first experience meeting children like him, and moms like me.

Do you remember that scene in the movie “My Cousin Vinny” where Joe Pesci’s character finally presents a great argument in court and wins over the courtroom—and the friend of his nephew stands up and shouts: “Him! I want him!”? Well, after witnessing the skateboarding argument I

*I was consumed by the fact that my baby could not see. He couldn't see my smile. He couldn't see his toys. He was blind. That's all I thought about. My son was blind. Sigh. Cry. Repeat.*

turned to my little family and yelled: “Here! I want to sit here!”

I wanted to sit with the family that looked and acted “normal.” Not that any of us are “normal” per se, but they didn’t “act blind.” They were having a typical family argument. The boy seemed like a typical teen. I wasn’t interested in how he was able to skateboard without sight. I wasn’t concerned about what else he enjoyed. I wanted to know more about the fact that their issue had nothing to do with blindness. Blindness wasn’t mentioned at all. I thought, “How could that be?” At that point in my life, every second of every hour of every day I was consumed

by the fact that my baby could not see. He couldn't see my smile. He couldn't see his toys. He was blind. That's all I thought about. My son was blind. Sigh. Cry. Repeat.

The encounters I had in that center aisle led to my first “aha moment” in my journey of raising blind children. While I didn't know a thing about raising a blind child, I decided that day that I wanted the kind of life in which I would debate skateboarding etiquette with my son, not whether I served him the correct juice or not! I made the choice at that moment to get myself as close as possible to people that I wanted to be like and I wanted my son to be like—moms, dads, and kids that were not just surviving blindness, but *thriving*. I wanted to know what they knew, do what they did.

## **Blindsided**

I knew there was something not quite right about his eyes. Then, in the summer of the year 2000, in a little exam room at Children's Hospital of Philadelphia, I was told my baby was “very blind.” I knew he was having some vision issues. But *blind*? I remember the doctor's stunned face when I asked: “Blind? How blind?” Then my second question: “What will he do?”

The answers were like bricks piling on my heart. No baseball. No driving. No normal life.

The news slammed me to the floor, literally. Since the moment I found out I was pregnant with Michael I pictured him as the starting pitcher, the football quarterback, and the class president. I envisioned a life of me cheering on the sidelines as he achieved his dreams, not him on the sidelines where life would pass him by. In that tiny room I was told the life I had planned for him was gone. While the doctor mentioned the white cane and Braille, I heard dependence and loneliness.

In that exam room in Philly, my family and I were given no hope, no resources, not even a pamphlet about

how to raise a blind child. However, we were given the name of a doctor that we were told was the number one person in the United States for the rare eye disease my baby was suspected of having: LCA. As luck would have it, Dr. Irene Maumenee was on the East Coast at Johns Hopkins in Baltimore. Typically, it can take up to a year to get in to see a specialist of Dr. Maumenee's caliber. But nothing about my journey has been typical. Our local specialist made one phone call to Dr. Maumenee, and she made herself available to see us on short notice. The appointment with Dr. Maumenee turned out to be a pivotal moment in my family's journey with LCA and with my journey as a mom. Not only was Dr. Maumenee knowledgeable about our rare eye disease, she informed us about a small parent group she had been working with that was coordinating resources for LCA families. Dr. Maumenee encouraged me to contact the group and get involved in their online email support group for LCA parents. (In the year 2000 there was no Facebook or any social media platform to easily connect with others with a rare disease.) The listserv, the email support group, would become a wonderful resource to connect with other families.

I emailed the listserv group: "Hi. My name is Kristin. My baby was just diagnosed with LCA. I don't know any blind people and have no idea where to begin. Any advice would be wonderful." The group was very welcoming. Many members posted replies to console me and acknowledged the devastation they knew I was feeling. For two weeks, every time Michael slept I jumped on the email list to read posts. I stayed up all night to read them. Two weeks of posts that discussed "no light perception," schools for the blind, white canes, loneliness, developmental delays, education laws...oh dear God. Just two weeks prior I was searching online mommy groups for fun activity ideas; now I was weeding through the devastating messages about a life I couldn't wrap my head or heart around.



The email list is where I found information regarding the conference I mentioned in the opening of this book. The LCA family conference was full of families on a similar journey. The conference also had a few eye specialists available to talk about this rare disease. However, with so little known about the disease at that time, the majority of information was about coping with blindness and resources for raising blind children, nothing about hope for treatments or a cure or anything at all to make my baby not blind or even not *so* blind.

At the time when I entered the back of that conference room I was crying about this diagnosis every day. Every. Single. Day. I cried when I knew Michael wasn't seeing me smile at him. I cried over the thought of him trying to play with friends. I cried as I thought about typical preschool activities that my son would not be able to do. I couldn't face my friends who had "normal" kids. I couldn't face my future that seemed so dark. Although stepping into that conference room was excruciating, it was the step I needed to take to face my fears of raising a blind child. I was forced to immerse myself in the very topic I wanted no part of, but needed to know everything about. Fortunately, I met two people there who changed the trajectory of my journey in raising blind children: Kay Leahy and her blind son Patrick. You'll read about them and their impact on me later in this book.

Kay and Pat were the first of many people I have been blessed to have come into my journey and change my perception of possibility for my boys.

Boys. Plural. I actually have two sons that have LCA. Mitchell was born three years after my first son and was diagnosed with LCA, just like Michael. I used to call it a double dose of darkness. A family member says: "We hit the lottery twice" in a cynical tone. I believe we did win the lottery. Three times. I have a sighted daughter in addition to my blind sons. My three children have taught me more

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about perception, resilience, and inclusion than all of the books I have ever read. They have taught me more than any YouTube video or TED Talk I have ever watched. Keep reading and you'll see why.

## Reach

When my first son was diagnosed with blindness, the root of my devastation was fear because I had never known a single blind individual. I had no idea what was possible for a blind person. The first blind person I met was my own son. The second was Patrick. The third was a super cool guy, Erik Weißenmayer.

Erik Weißenmayer's first big claim to fame (he's got a few!) is that he was the first blind person to summit Mt. Everest. You read that right: Erik is blind. He has no sight whatsoever. None. Nada. He can't see his hand in front of his face, yet he climbed the highest mountain. So what have you accomplished today?

The book *Touch the Top of the World* tells Erik's story of losing his sight in his teen years, getting angry, and eventually, my favorite part: accepting his blindness and rising strong, so strong. The pages of the first half of my copy of the book were saturated with my tears. It's **that** difficult of a journey. In fact, when I sent a copy of the book to my mom, she called me when she got about a third of the way through and was upset with me for sending her such a heart-wrenching story! I'll tell you what I told her: You have to keep going—the second half of the book, the part where Erik moves into acceptance and thriving, is so worth the agony you go through in the first half.

The second half of the book is full of details about mountain climbing. Frankly, I don't want my children to climb the highest peaks, thank you very much. However, as I read about Erik figuring out how to communicate with his team, and how to work around ice and snowstorms, my eyes opened wider and wider to the possibility of my sons

being able to work around the obstacles that would surely come their way.

Presently, Erik has climbed the highest mountain on all seven continents. He speaks around the globe about living life with “No Barriers,” reaching for your dreams, and using adversity to your advantage. People call Erik “inspirational.” But for me he’s a life changer. Erik is successful. He is a husband and a dad. He is fun-loving, kind, and adventurous. But the best thing about Erik is that he is completely comfortable in his own skin. For me, he’s all the things I hope my sons will become. All the things I thought were lost when I heard: “Your son is blind.”

My family and I had an opportunity to visit with Erik and his family at their home in Colorado a few years ago. My children still talk about the wrestling mats, climbing walls, kayaks, and chickens (yes, chickens!). Interestingly, Erik is not just an inspiration to me, my boys, and people who are living with blindness. Erik is a wonderful example to my sighted daughter that her brothers will live normal lives (although Karissa will likely debate that her brothers are too annoying to be normal; sibling rivalry is alive and well at my house, too).

Ralph Waldo Emerson once said, “Our chief want is someone who will inspire us to be what we know we could be.” I didn’t realize how much I wanted that on the day of the first blindness diagnosis, how much I needed inspiration, and, well, **proof** regarding what a blind person could do, could be. As it turns out, a person without sight can do pretty much anything they want. Okay not *everything*. None of us can do everything. But you get what I mean, and you’ll see proof of it in the coming chapters. Seventeen years ago, I didn’t know about all of this possibility and options and “normalness” surrounding blindness. I had no idea that my sons would absolutely be able to achieve the greatness they are destined for.

Meeting Kay and Patrick opened my eyes to the

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possibilities for blind children. Meeting Erik blew the roof off of possibility. The most extraordinary thing is that Michael was only six years old when he met Erik. Children start out so innocently believing the world is at their fingertips. Michael was no exception. He had big dreams. Huge. That encounter with Erik kept Michael's mind open to dream and reach for all he wanted in life, as opposed to surrendering to the closed minds of people that wanted him to live within their limits and boundaries.

### **How I See It**

So often people ask me how my boys have not only had the courage to step into life with confidence and joy, but also with such optimism. I'd love to take credit that I am just an ahmaaaaaazing mom. But the reality is that interaction with people like Erik, Patrick, and others is a part of a life lesson. A person can succeed without sight in whatever they choose to do. Some want to climb mountains. Others want to be a stay-at-home parent. The possibilities for thriving as a blind person are endless, just like possibilities for those living with sight are endless.

When I perceived blindness as a burden, I set out to simply survive the challenge with no expectation of greatness for my boys. So I was swallowed up in a journey of despair and devastation. Once I met successful blind adults, my perception of life without sight changed. My mind was open to the endless potential that existed for my sons. That change in perception empowered me to **Set Extraordinary Expectations** that my sons would indeed find their greatness and fueled me to get tools like Braille and the white cane into their hands. What's been the outcome of these expectations? My boys have played on sighted baseball teams and won championships. They have been in honors programs in top-notch public schools. They participate in more extracurricular activities than my gas tank can keep up with. Michael is in college with big plans

for his life ahead, and Mitchell is following closely behind. They have had typical and not-so-typical life struggles. They date girls and go to proms and parties with friends. Michael is a singer and keyboardist in a rock band. Mitchell has a slew of followers on YouTube. Many of my dreams for them may not come to be. But their lives are about their dreams, not mine. Watching them achieve what they set out to do is a dream come true for me.

## **Ignite!**

In his book *The Talent Code*, Daniel Coyle writes about his theory of how successful people come into their greatness. He makes the case that incredibly high-achieving folks are not born with some kind of supernatural gift. Instead, there are factors involved in their journey that catapult them to their greatness. *Greatness can be learned* is his theory. Mr. Coyle believes all of us, if we follow his formula, can learn to be great. I so agree, simply because I witness it over and over again.

Mr. Coyle believes that once a person has a spark set off in them, it propels them to achieve. Seeing others do what you are interested in doing helps ignite a spark needed to soar to the highest levels. That ignition fuels us to find resources and experts to work through the obstacles that come our way.

People that are achieving their greatness, succeeding without sight, ignited a spark in me and my boys. These role models changed the trajectory of our once very bleak journey. I am honored to introduce you now to thirteen people who inspired me and my children and continue to ignite our journey as we **Set Extraordinary Expectations** for our lives. My hope is that everyone, blind and sighted, that reads this will be ignited to do the same.

With so much gratitude,  
*Kristin*

Kristin Smedley



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