Light from Lucas

bob vander plaats



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Dedication

Light from Lucas is the result of a life-journey—a life-journey of love. Those on the journey have experienced many peaks and valleys, and some beautiful rainbows. Ironically, we have discovered the true source of light in the darkest times of the journey. Thus this book is dedicated to all the traveling companions on the "Lucas journey." Most specifically, this book is dedicated . . .

to my family

Darla—Lucas's mother—You are the reason we have been allowed to experience the life of Lucas. Your love, your care, and your attention to detail have benefited Lucas with an extended life span that has astounded the educated community. I love you.

Hans, Joshua, and Logan—Lucas's brothers—You have grown to be young men. I have been blessed by the maturity, wisdom, and understanding I have witnessed in each of you that shames most adults, particularly me. I believe God has placed you in front of, alongside of, and behind Lucas for his ongoing protection, care, and love. I love you guys.

and to our angels

Ruth—Lucas's friend—Your servant attitude and genuine love for Lucas and our family is the model for Christian community. Thank you for being part of our family. We love you, Ruth.

Children's Care Hospital and School—Lucas's caregivers. You stand in the gap by caring for and loving Lucas in a selfless and most professional manner. You are a blessing to many children and families. Thanks for making Lucas, and us, feel at home.



Acknowledgments

Kristi Dusenbery

Light from Lucas would not be a reality without the encouragement, guidance, and talent of Kristi Dusenbery. All I can really say is, "thank you." From the very beginning, you affirmed my interest in putting Lucas's story into words. Without your constant and persistent encouragement, *Light from Lucas* would still be a dream.

You are much more than an editor of this book. You are a partner and contributor to its completion. Your prompting, insight, creativity, and talent complement the story of Lucas and have greatly enlightened its life applications.

Focus on the Family

God is awesome! Right from the first concept of putting Lucas's story into a book, I mused with Darla that I would love to see it published with the Focus on the Family seal. Little did I know that this was God's plan . . . right from the beginning.

Focus on the Family inspires me with their authenticity. You have lived up to your billing. Dr. Dobson, Tom Minnery, Larry Weeden, Liz Duckworth, Nanci McAlister, and all the others are steely-eyed focused on the needs and the purpose of the family.

I had goose bumps the first time Larry Weeden told me that Focus on the Family had an interest in publishing *Light from Lucas.* The book is better because of the professional and insightful influence of Liz Duckworth. And *Light from Lucas* is in your hands because of the detailed actions of Nanci McAlister.

Darla and I will strive to reflect the Focus on the Family seal daily!

Joni Eareckson Tada

I was told you don't acknowledge the author of the foreword. I'm not very good at following protocol. Tears filled my eyes, and I got a lump in my throat when I read the words Joni wrote for this book. She has been a valued and constant source of inspiration for people with disabilities and their families.

Besides being an inspiration to Darla and me for years, Joni simply captured the intent of *Light from Lucas*: "inspiring all of us to overcome the hurdles, and discovering God's purpose, in our lives." Thanks, Joni!

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Foreword

I've gotten used to being on display. Whether it's the child studying my wheelchair, the senior citizen across the way smiling sympathetically, or the waiter eyeing me carefully as I use my bent spoon to eat pieces of hamburger, I'm aware that people are watching. Some might watch out of pity, some out of admiration. All watch, I sense, with unspoken questions.

It's part of the territory that comes with living in a wheelchair.

It's what Lucas and his family face every day. But like the Vander Plaats family, I choose to think that people's unspoken questions are, for the most part, good-natured. That's because the author of *Light from Lucas* and I, as followers of Jesus, are constrained to think the best of others. We are called to be on display (as any Christian is). We are encouraged by God's Word to smile from the inside out as the strength of God shows up bountifully through our special challenges. When people eye Lucas in his wheelchair—when people see the smiles on the faces of Bob, Darla, and their sons, I believe they are thinking, *What an amazing family. How great their God must be to inspire such faith and confidence.*

I'm convinced this is why they chose to tell their story in this special book. I don't think they mind the fact that their family is "on display." It's why the book is called *Light from Lucas*. This young man inspires people who observe him. His entire life—with all its challenges and struggles—showcases 1 Corinthians 12:24-26, where we learn that "God has combined the members of the body and has given greater honor to the parts that lacked it, so that there should be no division in the body, but that its parts should have equal concern for each other. If one part suffers, every part suffers with it; if one part is honored, every part rejoices with it."

And I can't help but get a lump in my throat when I think that Lucas's dad decided his son's story was important enough to share—share with people like me and you.

No doubt about it. Your thinking will be illumined by the "light" shared in *Light from Lucas*. You will learn about a family whose hearts are settled and whose peace is profound. Don't worry, though—it's not sugarcoated; there are plenty of hard places with which you'll identify. The most important thing is, you just may end up deciding, *If Lucas can make it and, by the grace of God, overcome his limitations, I can too.*

Joni Eareckson Tada

Joni and Friends International Disability Center Summer 2006

Chapter One

Expect the Unexpected

"Bob . . . Bob, wake up! We're going to have our baby." Darla's voice was filled with anticipation and excitement as she informed me it was time. This Sunday morning would be the day we would experience the birth of our third child.

We had run this drill twice before—giving birth to two healthy, "normal" boys. Hans was five going on an intellectual fifteen, while Joshua was in the midst of his terrible twos. We felt fully prepared for this baby. Naturally, the baby would have unique personality traits and physical characteristics, but we knew all about the labor and delivery process and the many demands of having a newborn. Although we didn't know the gender of the baby, all our expectations seemed to be in order.

When I was a high school business teacher and basketball coach, I would tell my students of my ambition to have five sons. I joked about my plans to create the perfect basketball team, composed solely of my own genetics. I had already identified Hans as my point guard. He was gifted at handling the ball and had an uncanny feel for the game. Joshua would be my shooting guard. He loved shooting. He also loved kicking, hitting, and anything else that would produce offensive assault on a worthy opponent. Uncles Stan and Jerry were his favorite targets.

This Sunday, June 13, 1993, I was certain Darla would deliver

another member of the perfect starting lineup. Maybe he would be a talented forward, the ideal complement to the skill sets of Hans and Josh. I was well on my way to coaching a championship team composed exclusively of my offspring. Wow!

Unfortunately, the plans I teased my students about were quickly thwarted when reality proved far different from lighthearted expectations. Darla did indeed give birth to a son, but thoughts of championship basketball games grew faint as our delivery room drama unfolded.

The baby was breeched in the birth canal, preventing a vaginal delivery. I looked on as doctors and nurses administered an epidural and began cutting into Darla. I looked on as our son was brought harshly into the world, and I looked on as the medical personnel rushed around him with an urgency signaling something very wrong.

His head was abnormally large and completely out of proportion to his frail body. His lips and skin were parched blue, his body craving oxygen. He wasn't pinking-up, a problem that heightened the suspicions of everyone in the room. As I looked on in fear, the doctor took my arm and led me away from the commotion. He had ordered an air ambulance to transport our newborn son from our hometown hospital in Sheldon, Iowa, to a better-equipped hospital in Sioux City. The words he spoke still ring in my head today: "Babies with issues don't belong in rural hospitals."

Issues? What did he mean, "Babies with issues"? This was my baby . . . Darla's baby . . . a future member of the Vander Plaats basketball team. Darla and I were the perfect couple: We started out in the church nursery together; we were kindergarten classmates and high school sweethearts; we had two normal sons. Now we had a baby with issues? It didn't make any sense. As thoughts whirled through my mind relentlessly, I determined to remain calm outwardly, appearing strong for Darla and those attending our son.

In the midst of this sudden sea of instability, I reached for stability by phoning our parents. This birth announcement was quite unlike those we made with Hans and Josh. It was void of laughter, excitement, and statistical information. Instead, the conversation consisted of stunned reality and requests for help. "Mom, can you stay with Darla at the Sheldon hospital? Dad, can you go with me to St. Luke's in Sioux City? Can you make the necessary phone calls to family and friends? Dan and Beth, can you look after Hans and Josh? Please tell everyone to pray for the son we've yet to hold."

Circumstances were spinning out of control and I was pretending to be strong. Friends, doctors, family members, nurses, strangers, flight technicians, and people requesting signatures came in and out of my confused consciousness, yet I still recall them with vivid detail.

Kissing Darla good-bye, I headed for the van. My dad was with me as I began the one-hour drive to Sioux City. Words are inadequate to describe the intense loneliness I felt as the helicopter carrying our son passed overhead. I was completely helpless. The drive was consumed with rushing thoughts and questions: I don't even know him. He is my son and I can't do a thing for him. Will he be all right? What went wrong? How is Darla? What about Hans and Josh? What will the future hold? Where is God? What if our baby dies? What if he lives?

When we reached the hospital we were quickly directed to the neonatal intensive care area. The specialists explained the best-case scenario first, saying our son could just be a big baby, with a big head, struggling to breathe. The optimist in me became hopeful. Then they explained other possibilities. He could have a syndrome that would go undiagnosed for several months. He may have birth defects that could result in a multitude of disabilities. His cranium could be filled with fluid and house almost no brain, resulting in death within weeks or even days. My rising hopes were dashed as I signed for the necessary tests.

Once the tests had begun, the rushing stopped. It was time to catch my breath and begin processing the chaos. After a deep sigh and a moment of prayer, I picked up the phone to call Darla. She was surely experiencing the same numb helplessness. A mother is designed to nurse, bond, and care for her newborn. That normal process had been coldly interrupted with the chopping of helicopter propellers. Now Darla sat in a hospital surrounded by people, but all alone. No Bob. No Hans. No Josh. No baby. She was left with bland walls and recovery procedures, enduring physical and emotional pain.

Our phone conversation was mostly business. We discussed the doctor's information in detail. To the best of my ability, I described the tests that were being performed on our son and we talked about the range of possibilities—from mild to severe disabilities, from normal life to death. Words were sober as our phone call drew to a close, and the question Darla finally asked still sends a chill down my spine as I remember it. "What are we going to do if he's not right?" The emotion in her voice characterized our fear. We were set adrift by the unraveling of the day, and terrified about the future. What began as excited anticipation and predictability had turned into a moment-by-moment battle for composure.

I am rarely at a loss for words, but Darla's question hit me like a ton of bricks and I struggled for an answer. *What will we do if he isn't right?* I paused in silence, remembering my role in this reality drama: *I am the man. I am supposed to be tough. I should be able to handle anything that comes my way.* My voice was quiet and broken as I said, "We'll get through it. We'll get through it." Dear Incas.

I love you! I wish I could have expressed my love for you on the day you were born, but the doctors and nurses wouldn't let me near you. And to be honest, I didn't know if I wanted to be close to you at the time.

It still bothers me that your mom and I were not able to appropriately welcome you into the world and into our love and care. Your traumatic birth surprised everyone including Mom and me. We were scared for you and scared for us.

During the nine months that your body was being knit together, you were housed, protected, and nourished by your mom. Just as with Hans and Josh, you and Mom bonded during pregnancy. It is a beautiful process and one of God's greatest gifts to mothers. Mom loved being pregnant and she was good at it.

You need to know that your mom paid attention to every detail during your incubation. She loves to read and read everything she could find to enhance your development in the womb. But regardless of the many pages she read, there weren't any books or warning signs to adequately prepare us for your birth.

God made only one YOU . . . for only one US.

The separation you felt at the time of your birth was a parting from Mom. The separation Mom felt was a parting from you. I didn't feel any immediate separation; I felt confused and disappointed. You were not what I was looking for, and I really didn't know you. You see, dads are spectators in the pregnancy game. Yeah, I enjoyed putting on a good show to convince people that I felt just as pregnant and attached to you as Mom did, but the fact is—I didn't have a clue. I had no idea how God would use you and your unique abilities to impact my self-absorbed life.

It is a privilege to devote this book to you, Lucas. You have taught me many life-lessons and it is my hope that relaying these lessons will impact the lives of many others.

Thanks for accepting me. Thanks for teaching me. Thanks for loving me. And thanks for bringing so much joy to my life.

"I love Lucas ... I love Lucas. Yes, I do! Yes, I do! He's my buddy, buddy ... buddy, buddy, buddy. I love you ... I love you!"

I do love you, Lucas, more today than the day you were born, more tomorrow than today.

Dad

[&]quot;I Love Lucas" is a song I sing to my son. It fits the tune of "Frère Jacques."

Afferword

Lucas and I just finished an early morning cruise. I enjoyed my coffee and he enjoyed his ride in the Suburban. He is doing so well. When I sing to him, he tilts his head back and frames his mouth with his hands as if holding a note to join in the singing. I love it when he does that. He actually likes to listen to his dad sing!

He squints, wrinkles, and coos when I talk to him, joining in the conversation. He is a great young man who continues to bless me, Darla, our family, and others with his presence. Through many moments of medical uncertainty we have wondered if Lucas would live to be a teenager. I'm proud to say that upon publication of this book, Lucas is 13 years old and full of more joy and life than ever before. The simple courage with which he lives continues to be an inspiration and we are so thankful for every day we have with him.

When we named him, we weren't aware that Lucas's name derives from the word "light," but it seems a perfect fit for the boy who has brought light into so many lives.

Through Lucas, God continues to soften my heart and open my eyes to the many emotional and physical needs of families and individuals affected by disabilities. Lucas has awakened a passion in me to honor such people, helping them experience the best possible quality of life and celebrate every moment they have here on earth.

Darla and I are excited to be working with an organization in our community to build a state-of-the-art camp for people with disabilities, a place where campers of all ages and abilities can participate in challenging activities and experience success. Hiking, canoeing, and horseback riding should not be reserved for the "normal." Camp High Hopes will provide extraordinary opportunities for extraordinary boys and girls, men and women.¹¹

I know God is pleased when a young man with Down syndrome laughs wildly while catching his first fish, or a woman confined to a wheelchair is able to climb a tree for the first time in her life! These are His children, just like you and me, and He wants them to enjoy the world He created.

Darla and I would love to have you join us on this life's journey. Look around you. There are people with disabilities in your town and in your neighborhood who need friends. There are moms and dads of disabled children who need an encouraging word or a helping hand.

We never imagined, 13 years ago, what God had in store for our family. Lucas will never be the basketball player I expected, but he has become so much more. He has become my hero and, as long as we're together, Lucas will be teaching and I will be learning.

Thank you for sharing this glimpse into our lives. I pray that the story of Lucas has blessed you, and you will find new inspiration to face your days with a little more faith, a little more hope, and a lot more love.

Notes

- Off the Practice Field . . . Coach Lou Holtz. University of Notre Dame. November 5, 1986. http://und.cstv.com/sports/m-footbl/archive/96season/nd-game08/nd-m-fb-ev-gm08-ccon.html Accessed April 25, 2006.
- The White House: John Kennedy. http://www.white-house.gov/history/presidents/jk35.html April 25, 2006.
- 3. *Chariots of Fire.* Dir. Hugh Hudson. Twentieth Century Fox, 1981.
- 4. J.J. Redick. ESPN. February 12, 2005.
- 5. Rabbi Paysach J. Krohn, *Echoes of the Maggid* (New York: Mesorah Publications, 1999).
- Patrick Fagan and Robert Rector, *The Effects of Divorce on America.* Heritage Foundation. June 5, 2000. http://www.heritage.org/Research/Family/BG1373.cfm April 25, 2006.
- Ronald Wilson Reagan: Remarks by Patti Davis. Ronald Reagan Presidential Foundation. June 5, 2004. http://www.ronaldreaganmemorial.com/remarks_by_Patti_Davis .asp> April 25, 2006.
- Johann von Schiller, World of Quotes http://www.world-ofquotes.com/author/Johann-Von-Schiller/1/index.html April 25, 2006.
- 9. Edgar Guest, *Collected Verse of Edgar Guest* (New York: Buccaneer Books, 1976).