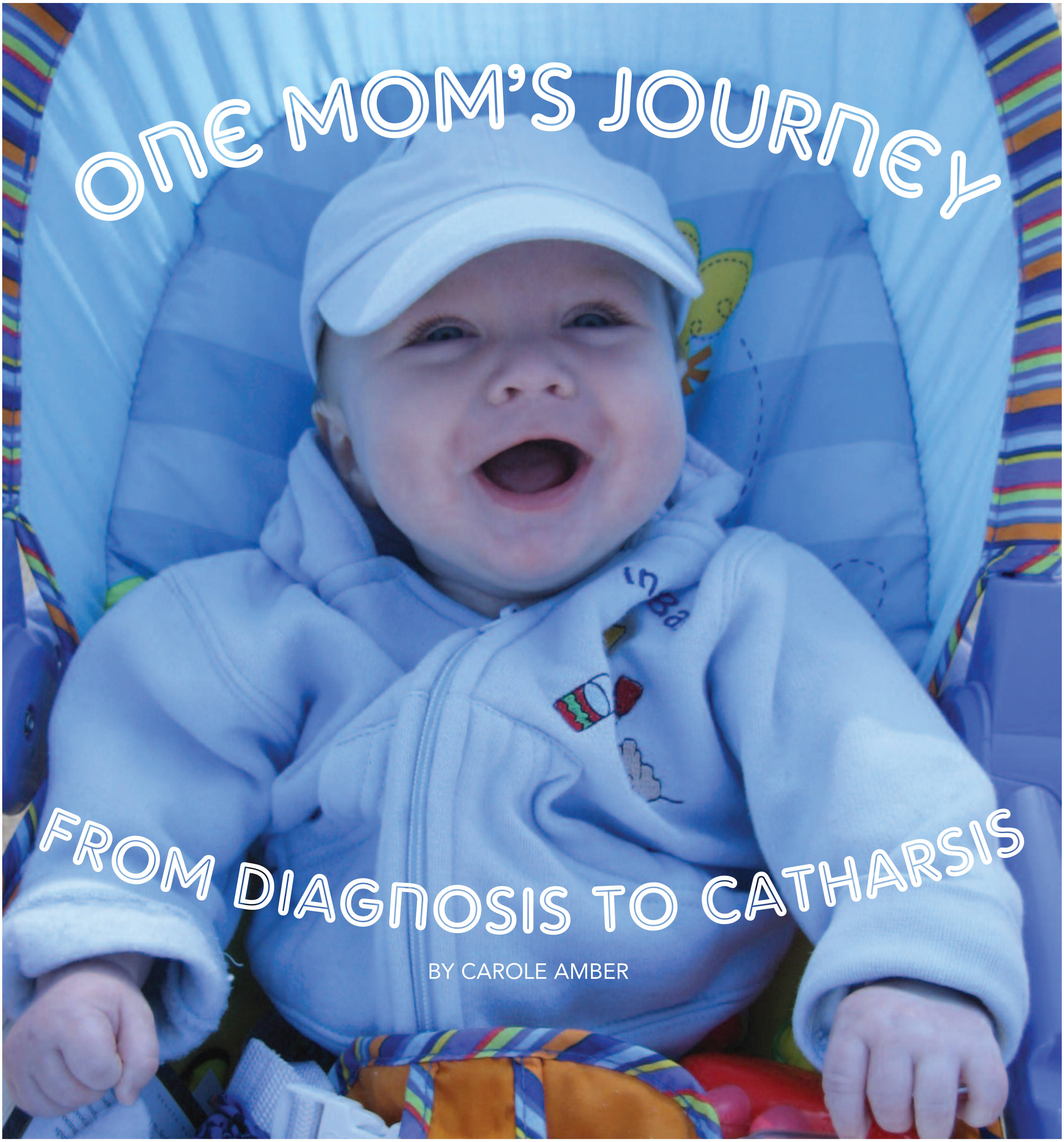
ONE MOM'S JOURNEY

FROM DIAGNOSIS TO CATHARSIS

BY CAROLE AMBER



PHOTOS PROVIDED BY CAROLE AMBER

“Your son TJ may not see his second birthday.” Six years ago, I heard these words as I cradled by baby boy, TJ, in my arms. This moment changed my life forever.

I remember reclining in the passenger seat of our car on the way home from the doctor on that fateful day. It was raining, cold, and disturbingly dark. My mouth hung open, I stared into the distance, and I was in agonizing pain.

Suddenly, I began to see horses and ladybugs floating in my head. I knew that the horses were my family and I. They were standing in a circle, exactly as my family was standing in the doctor's office. Then I saw this adorable little ladybug standing in the middle of the circle. I knew that the ladybug was TJ.

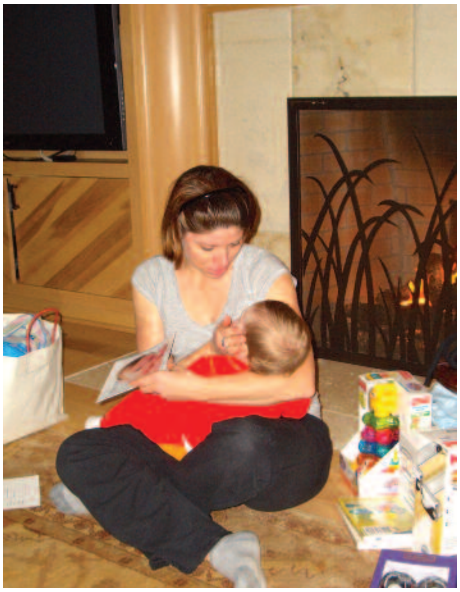
The horses in my head began to sob uncontrollably. They had just learned that their sweet ladybug was going to live a short life. The ladybug was confused. “Why are you crying?” he said. “But I don't know how to be a horse. I only know how to be a ladybug.” It was these words and the peace that they brought that allowed me to find relief in that harrowing moment.

In the days following that car ride, I put pen to paper and wrote the *The Gift of the Ladybug* for TJ. It flew out of my fingers in under two hours. I'm convinced that it was sent from above. I had the story bound, and gave it to TJ for Christmas. I was able to read it to him over and over.

TJ peacefully passed away in April 2009 at 14 months old, due to complications from Leigh syndrome.

Three years after I lost my boy, I decided to share his story in hopes that it would help other families. I published *The Gift of the Ladybug* on TJ's birthday, January 28, 2012.

The Gift of the Ladybug is the tale of love, joy, and acceptance through the eyes of two horses that learn that their son is actually a handsome little ladybug. This book mirrors the way TJ made us feel. His eyes and demeanor would say, "Mom and Dad, I'm okay. It must be this way."



CHERISHED TIME When times got hard, we embodied the story. We would remind ourselves that TJ was our ladybug and that he could never be a horse.

Not only did *The Gift of the Ladybug* provide comfort to my family and me when we needed it most, but it helped us reframe how we looked at our circumstances. When times got hard, we embodied the story. We would remind ourselves that TJ was our ladybug and that he could never be a horse. And if TJ could face his fate with joy, laughter, love, and peace, we could find a way to do the same. Our wise little ladybug gave us a glimpse of what it is like to fly.

The process of bringing *The Gift of the Ladybug* to life was a true joy. Although emotional in every way, each page was an opportunity to honor TJ. From choosing the whimsy font, to placing each word, to working with my illustrator to incorporate photographs of our family, street, and house, *The Gift of the Ladybug* speaks of our life. Every time I lay eyes on it, I'm filled with pride and joy for TJ.

We launched *The Gift of the Ladybug* on TJ's birthday, and gave 70 percent of proceeds to the United Mitochondrial Disease Foundation. By concentrating the sales on one day, we were lucky enough to reach "#1 Mover & Shaker" on Amazon.com.

The ultimate gift of this book is that it is a symbol of peace for all of us. Filled with TJ's life lessons—it is about living fully, with joy, fun, play, and acceptance—and loving ourselves exactly as we are.

THE A•R•T OF ACCEPTANCE

TJ's message of acceptance is the most powerful elixir. I learned that no matter what I face, acceptance is the road to peace. The more I resist the truth of what comes my way, the more it hurts. The more I allow my life to unfold as it does, the more I'm able to live in the present and unlock the joy that already exists around me.

Even though I had the greatest teacher in the world, living in acceptance is a daily practice that I achieve only some of the time. For those times when I struggle to accept my life as it is, I've come up with a trusty acronym that sums up what TJ taught me. I call it the ART of acceptance.

"A" stands for allow. I remind myself to allow my feelings (especially the ugly ones). I know that the faster I allow my feelings to be exactly as they are, the sooner they will lighten their grip.

"R" stands for release. I know that the more that I release my feelings, the less they will control me. A few of my favorites are to scream into a pillow, punch a punching bag, run fast, write it all down in a journal, and/or talk it out with a friend. Once I let my feelings out, I generally feel much better.

"T" stands for trust. Trust that I will be okay. TJ would say that everything is already okay. This can be tricky for me, but I know that it is the key to acceptance. When I'm really struggling, I remind myself that everything is exactly as it is supposed to be. And that even if I cannot understand how, whatever I am facing is serving me in some way.

As I embark on the next phase of my life, I find myself drawn to celebrating all children with special needs as the heroes that they are. If TJ was able to teach me so much, other children facing medical differences surely have lessons to teach.

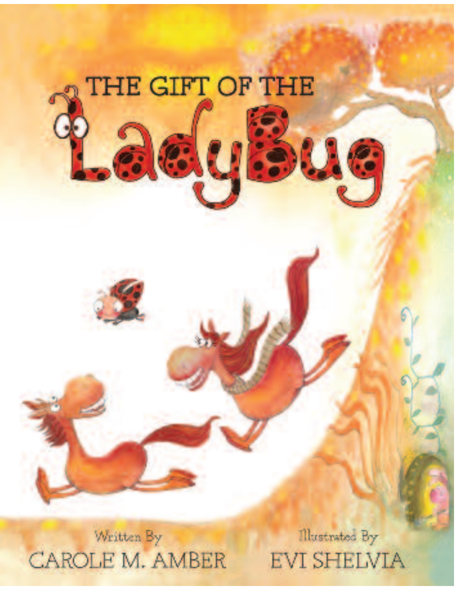
So, this year on TJ's birthday, I hosted Ladybug Celebration Week, a celebration of kids with medical differences around the world (I think of them as ladybugs).

We treated 11-year-old brain cancer survivor Ivory Dakota Isaac to her first trip to New York City!

Ivory taught me how to be brave. After being teased by classmates, Ivory put together a video of healthy kids, as well as children with cancer, to show that they are not that different from each other.

We visited the Elija School for autism.

These kids inspired me to be true to myself. Each child moved to the beat of his own drum, with no apologies. It was awesome.



SYMBOL OF PEACE *The Gift of the Ladybug* is the tale of love, joy, and acceptance through the eyes of two horses that learn that their son is a handsome little ladybug.

We donated books to children with mitochondrial diseases at the University of Texas Mitochondrial Center for Excellence.

These kids taught me how to have fun. They had a blast with face painting, crafts, ladybug wings, and playing.

We surprised eight-year-old mitochondrial disease survivor, Katie Hebert, with an American Girl Doll Party in Houston.

Katie taught me how to love life. Every day is the "BEST DAY EVER" for Katie. I've never seen anything like her unwavering positive attitude and excitement for life.

As I watch these kids thrive as they face difficult medical challenges, I am in awe. How do they find such bravery, fortitude, joy, laughter, and wisdom?

Looking back on my journey from diagnosis to catharsis, it is the lessons that I learned from TJ and other children with medical differences that healed my soul.

ABOUT THE AUTHOR:

Author Carole Amber is most proud of being TJ's mom. After using the death of her 14-month-old son as an inspiration to write the bestselling book The Gift of the Ladybug, she is on a mission to celebrate ladybugs around the world (children with medical differences). Carole is a sought-after speaker and has been featured on CBS, NBC, Fios1, News12, CNN iReport, and on radio shows across the country. She is also an entrepreneur, food editor, and host of food blog ChopSizzlePop.com. She and her husband live in New York City. For more information, visit GiftoftheLadybug.org.