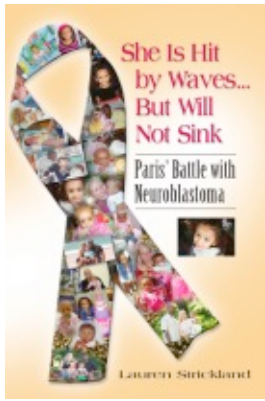


She Is Hit by Waves... But Will Not Sink

Paris' Battle with
Neuroblastoma



Lauren Strickland



Paris Strickland was diagnosed with neuroblastoma, a rare and deadly form of childhood cancer, at only 9 days old. No parent should ever have to hear the words "your child has cancer." Paris' mother, author Lauren Strickland, documented her thoughts, feelings, and experiences so that the approximately 650 people whose children are diagnosed with neuroblastoma every year can see they are not alone in this journey and that, at many times, others are feeling the exact same way.

SHE IS HIT BY WAVES... BUT WILL NOT SINK: Paris' Battle with Neuroblastoma

by Lauren Strickland

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Paris' Battle with Neuroblastoma

**She Is Hit by Waves ...
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Lauren Strickland

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ISBN 978-1-62646-973-0

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Published by BookLocker.com, Inc., Bradenton, Florida.

Printed in the United States of America on acid-free paper.

BookLocker.com, Inc.
2014

| First Edition

Dedication

To my daughter Paris, who has been an example of extreme strength and has shaped our lives for the better, to our family and friends, and to the children fighting this disease today and those who will be unfairly chosen to fight tomorrow.

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Acknowledgements

This story would not have been possible if it were not for the following very important people that have helped us along this journey. Without them I would have never been able to survive.

My daughter, Paris, who is the bravest, strongest person I know.

My husband, Ralph, for being a phenomenal father to our daughter. He is always loving and caring and never once saw her as anything but beautiful. As a husband, he has always been supportive and by my side through the roughest of times.

My entire family, especially my mother, Mary, step-father Tom and sister, Jennifer. Regardless of how much inconvenience it may have caused, no matter how much the cost, no matter how many sleepless nights, no matter how horrible the news, we all were ready to battle with everything we had and never gave up.

Individuals who have helped to make this book possible: Debra B. McCraw, freelance writer and editor; Veronica Hernandez with MAC makeup; Christy Weiss with Sunny Photography; Todd Engel with Engel Creative; and Booklocker Publishing.

Our friends and co-workers within District 200 and Joseph Academy who have supported us during this difficult journey.

Our extended families fighting neuroblastoma whom we have met along the way and the strangers who have entered our lives, showing us that we can handle any challenge that comes our way with endless support.

The educational staff of District 204: Ms. Allen, Mrs. Anderson, Mrs. Calkins, Mrs. Donovan, Ms. Hafer, Ms. Kalvaitis, Mrs. Rejniak, and

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Ms. Schultz for being compassionate educators and ensuring that Paris receives the best educational experience possible.

Our friends at Northwestern Hospital in Chicago for their ongoing support for our family.

The local businesses, professional athletes, and teams that have donated to our fundraising efforts.

Our faith in God. We can't do anything but put it in his hands.

The Ronald McDonald House of New York City and volunteers for providing a home away from home.

Barbara Zobian, president of the New York Chapter of the Candlelighters Organization, and Rich Block, for ongoing support, providing an abundance of resources, and always going above and beyond for children and their families.

Midwest Miracle Mile Flights of Milwaukee, Steve Simon and Southwest Airlines, the staff of Corporate Angel Network, and Miracle Flights for providing medical transportation, making our out of state trips financially easier.

The Band of Parents organization and The Truth 365

And last but not least, our entire team, including volunteers, nurses, personal secretaries, social workers, physical therapists, nurse case managers, at-home nurse care providers, doctors, and surgeons at both Children's Memorial Hospital in Chicago and Memorial Sloan-Kettering in New York. In particular, I want to recognize Dr. Alden, Dr. Greyhack, Dr. Yasmin Gosiengfiao, Dr. Kramer, Dr. Kushner, Dr. LaQuaglia, Dr. Modak, Dr. Morrison, Dr. Reynolds, Dr. Waldon, Jacquie Toia, and Lisa Vanbokel who have worked so closely with our family throughout our journey thus far.

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Preface

My name is Lauren Strickland, and I am about to share my personal experience with neuroblastoma. My daughter, Paris, was diagnosed with the rare childhood cancer at just 9 days old. Yes, you read that correctly. I said 9 days old. I wanted to document my thoughts, feelings, and experiences so that the approximately 650 people whose children are diagnosed with neuroblastoma every year can see they are not alone in this journey and that at many times, others are feeling the exact same way. Should you find yourself on this journey, you may feel like at times you are going insane, as the road is rough. But if you look hard enough and maintain a hopeful spirit – and trust me, sometimes you have to dig really deep – good will come.

Before I begin this reflection process, I want to acknowledge all of the caretakers, whether you are the mothers, fathers, step-parents, aunts, uncles, guardians, or siblings who care for children with cancer. What we do is remarkable. There is no other job in the world like it, and it is by far the hardest, being physically, mentally, and emotionally exhausting. At times you feel like you just can't do it anymore, not for another second. But then you look at your child, and you gain an inner strength that makes you get up and continue on to the next day to face a new challenge. So for the times that you feel powerless, helpless, motionless, confused, depressed, sleep deprived, enraged, and like you can't continue, remember that you can.

After hearing our story, people are often first in shock and then in awe of how I have handled the situation as a mother. They proceed to tell me how strong I am, how they admire my strength and can't even begin to imagine what my life looks like. I truly appreciate those kind words. I often hear, "How do you handle it?"

My response is simple, "I do not have a choice – what else am I supposed to do?" I've realized that you don't know how much strength you have until being strong is the only choice you have.

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I can't do anything but be strong. I can't sit around feeling sorry for myself and Paris, crying all of the time. I honestly don't have time to break down half as much as I would like too. Crying doesn't get the job done, and I have to fight to the end for Paris with all the strength that I wasn't even aware that I had. Sometimes I have to force myself to appear strong when I really don't feel any strength, but somehow I am able to manage and get through the day. Sometimes I begin to think I don't have it in me to break down; that I've built this permanent wall with limited emotions since I've been going strong for so long. I've almost forced myself to become emotionally immune to a certain degree.

When I do get a minute to myself, which is very rare, or when Paris' scans are stable and I have a moment to reflect on what life has dealt me, I allow myself to break down because I finally have time to process my emotions. If I were not in this situation and if I were looking in on someone else's life, I couldn't begin to understand or comprehend what they have to deal with on a daily basis.

In my eyes, Paris is the brave and courageous one. She is my best friend and my inspiration. She is really the driving force that keeps me going through all of the components of this unexpected outcome. Her determination, her overall demeanor, and her strong-willed character fit her perfectly. Of course there are times that I have thought to myself, this is too much to handle and that I can't fight for a single second longer – it's that emotionally and physically draining. But my quitting ultimately means giving up on Paris, which quickly puts things back into perspective. It's a fight for life. Even when she is suffering most, her little smile, loving stares, and unpredictable comments always amaze me. She is such a strong individual who has had to endure so much since the beginning of her life on Earth.

I am told that Paris is a hero, an inspiration, a role model. That she has so much strength, that she's a fighter. I admire that other people feel very passionately about Paris. She is just a little girl with no choice in this unfortunate matter, and since she has fought her whole

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life, she doesn't know any other way to be. She considers her trials and tribulations as simply part of her life.

My husband and I have to make difficult treatment decisions that result in countless unbearable and painful experiences, which could very well be classified as torture to the average person, in attempts to keep her alive. That's a hard pill for me to personally swallow, to consciously allow individuals to do horrendous things that one would never dream of, to my child, just to keep her alive. That took an emotional toll on me as a parent; it becomes mentally and physically exhausting and guilt driven, not to mention extremely stressful, but it's my reality and her way of life.

The lifestyle that we have encountered, I wish upon no one. The dynamic that I am living in is almost impossible to explain, but I'm going to try. Writing this book was personally therapeutic, and it allowed me to express my thoughts and feelings so that others may take what they see as valuable while they battle through the most unimaginable times. The book is also for Paris so that one day she can have a journal of the obstacles and constant battle that she fought every day to live.

As I analyze my story, I realize that I cross paths with people at certain times who have a lot of meaning to my life or that things that have happened in the past tend to resurface at my greatest times of need. I have met certain people at strange, unpredictable times that have happened to make the most thought-provoking comments right when I needed them. I found it helpful to listen to other families who shared their stories of neuroblastoma. The best advice that I can give is to remember that the only common bond is the word, "neuroblastoma." After that, every child is different. I hope that people take what they need, what's relevant or personal to them, after hearing my story and feel supported throughout this lifelong journey.

Everyone's experience with neuroblastoma is different, and there is no one way or right way. Everyone learns as they go, and they make

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decisions that sit well with them personally. What I chose to do others may be opposed to and vice versa. My goal is to provide you with as many resources, stories, and contact information as I can in an attempt to alleviate stress upon entering this “family.” I remember when Paris was first diagnosed, I felt alone. I didn’t even know what to ask or how to pronounce the medical terminology, but with time it came almost naturally and I began to feel as if it were second nature. I am hoping that this book gives you some guidance in a world that is very complicated, unknown, and scary, where fears are high and all we have is hope that binds us together.

Chapter 2: From Normal to Abnormal

I vividly remember telling my principal that I was pregnant and would only be taking the allowed three months of maternity leave. I also told him that I had plans to finish my administrative certificate and that I was a woman who wanted to have a baby but also wanted to work. He quickly responded, “Once you see that baby, you won’t come back. Should I look for someone else? I have a feeling that you won’t be coming back.”

I responded, “I’ll be back. Just wait and see.”

I had every intention to returning to work after my leave had ended. I worked very hard to get where I was and had plans on taking my career further. My leave chose me; I didn’t choose to stop working for the year to take care of Paris. I missed my co-workers and the routine of a normal day. I had become a stay-at-home mother, which also had its benefits because I was able to spend every minute with Paris, watching her grow. I was solely responsible, impacting her growth and development every step of the way.

At 9 days old my whole agenda had changed. Not one thing that I had planned for had remained the same, and I had to plan all over again for something bigger.

On November 26, 2007, six days after Paris was born, we noticed that her abdomen was extremely distended to the right. Ralph and I took her to our local hospital where her pediatrician was established and immediately questioned the distended area. She examined Paris’ abdomen and found it to be within normal limits. The medical notes specifically state that the distention was considered normal and was related to Paris being “full,” as we had reported that she just ate. The pediatrician attributed it to gas. When she dismissed our concern as being nothing out of the ordinary, we didn’t question it and went

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home. She assured me that I was a new young parent and that it was nothing to be concerned about and reiterated that Paris was healthy.

After three days, her abdomen was still distended and did not look as if it decreased in size. We were concerned, as it certainly did not resemble an infant being full or having gas. It literally looked as if my six-day-old baby was nine months pregnant. No one can fathom the description of her abdomen until they actually see the picture. Once they do, they are in complete shock.

On November 29, my mother and her friend came over to my house to help watch Paris, allowing me to get some much-needed rest. Both my mother and her friend are in the medical profession, and when they arrived, I told them about Paris' abdomen and our visit with the pediatrician. I asked my mother to confirm what I saw, and upon first glance she, too, was very concerned and instructed me to call our pediatrician back right away and request to be seen that day. The first available opening was at 4 p.m.

My mother and her friend instructed me to take a nap before our appointment, as I was sleep deprived, and assured me that they would take care of Paris. As a new mom, I personally battled with having someone else watch Paris, but I knew I needed some rest and still didn't feel 100 percent. As I went upstairs to lie down, I just couldn't fall asleep. I felt this push to force myself to stay awake and check on Paris to make sure she was alright. I didn't end up napping that day but instead talked with our visitors about my concerns with Paris. I suppose my "mother's instinct" knew that something was wrong.

I remember calling my husband to inform him that Paris' abdomen had not decreased in size and we were going to the pediatrician again to assess the situation. He was concerned and wanted to leave work early to meet me at the appointment, but I assured him not to worry and said, "There's no emergency. We think everything is fine, but we were going anyway."

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I asked him to meet me there after work. My mother and stepfather accompanied me to the appointment at 4:00 p.m. As we waited in the waiting room, a part of me began to worry. I began to think the worst, as her abdomen hadn't resolved itself in three days. I began to question what if something was wrong but quickly adjusted my way of thinking, verbally reassuring myself by saying, "What could really be wrong, the pediatrician said she's healthy." I think at that point I was teeter-tottering with the realization that something very well could be wrong, I just didn't know what it was so I was trying to convince myself that it was really nothing.

I was called into the office where the pediatrician again examined Paris. She noticed and examined the same distended area that I brought to her attention three days prior. Her facial expression now seemed more concerned, as I think she herself thought that it would have resolved itself. I remember sitting in the office and my mother questioning if the area could be a mass of some sort and insisted that we were not leaving until further imaging was done to rule out the possibility of a mass.

This time, the pediatrician noted in her report that there was "an asymmetric bulge in the right upper quadrant, positive palpable soft mass, does not feel hard like liver." She also examined her back indicating that "right thoracic area positive for lump with vascular pattern under skin, firm non-mobile, not tender." She noticed and noted that Paris had some twitching of the right lower extremity. Comparing these observations to those from our last appointment, the diagnosis of Paris' back and abdomen changed from normal to abnormal. The pediatrician documented in the additional note section that there is a sudden growth of a right-upper-quadrant abdominal mass and a right-back lump. She wanted to rule out tumor versus cyst, hydronephrosis versus ovarian pathology, but given the combination of symptoms, she needed to rule out neuroblastoma versus Wilms tumor versus leukemia, which she doubted. After the examination and now alarming concern, the pediatrician advised us that we take Paris

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to the emergency room for lab work, an ultrasound, and further imagining.

My mom, stepfather and now Ralph arrived in the waiting room of the emergency room and waited and waited. At this point, I was in a complete daze. I remember holding Paris and rocking her, cuddling her, and crying hysterically. An ultrasound tech took Paris. The imagining took an extremely long time, so my mother and I demanded to see where Paris was and sit with her during the imagining. Another tech brought us into the room. My mother saw a mass on the image. She questioned the tech, and he said he hadn't seen anything like that before. Then he left the room and said he needed to consult with another tech and never returned.

As we were waiting in the ultrasound room, I remember asking my mom, "What does that mean, Mom, what does that mean?"

My mom responded, "I think she has cancer, and I think it's very bad." Now my hysteria has just become worse. We returned to the waiting room with complete confusion and shock. They kept Paris to perform a CT scan. Again, we were in the waiting room for an extremely long time. After reflecting on the incident, I think that it took so long because they didn't sedate Paris and had to take multiple images. We sat in the waiting room from 4:30 until 10:30 p.m., my emotions ranged from panic to hysteria. I remember making one phone call in particular to my friend that I worked with. All I remember is calling her crying, saying, "Yolanda, I'm at the hospital with Paris." I asked her to please pray for my baby.

In all honestly I was in complete shock and can't vividly remember the events of that night clearly. Cancer, Cancer, Cancer ... what did she have? What were these words that sounded so foreign to me? I knew what they were but couldn't piece the puzzle together. I feel like I was in a trance, not remembering anything clearly. I remember tidbits, and it is so difficult even now to put the pieces together to retell a coherent story of that evening. I remember rocking back and

forth. I remember feeling blank. At some points, it seemed like everything was moving around me quickly and I couldn't move. At other times, it felt like everything was moving in slow motion. I remember chanting at one point, repeating "What's wrong with my baby?" over and over. I don't remember anyone speaking. I can only place myself sitting in the waiting room in the chair second to the left.

I received another phone call from the doctor to confirm that Paris had a mass, and the world stopped. Somehow, we moved from the waiting room and someone brought us into a holding room, I assume because the imaging area was closing for the night. The doctor and our pediatrician arrived at some point, and I vividly remember them telling us that it greatly appears to be neuroblastoma, but there's a chance that it could be a Wilms tumor.

As I was gathering our things and walking out, I remember someone making a comment in passing that I better pray that it is a Wilms tumor and not neuroblastoma.

The doctor discussed the results of the ultrasound and CT scan. The ultrasound of the abdomen showed a soft tissue mass adjacent to the spine. That report was followed by a CT scan of the chest, abdomen, and pelvis, which showed a mass that measured 7.4 by 2.9 by 4.1 centimeters. It spanned from the T7 to T12 vertebral bodies with intraspinal extension, placing Paris at risk for spinal cord compression. The mass extended to the nerve root foramen of T8, T9, and T10. The extension of the tumor surrounded the inferior vena cava and straddled the right hemidiaphragm. It destroyed her seventh and eighth ribs. An emergent MRI confirmed spine compression and the primary thoracic neuroblastoma.

I believe that those traumatic words permanently caused me to shut down, and my coping strategy was to blank out everything after I heard them. I looked around, and all of a sudden I saw my mom, stepfather and Ralph – the look of fear and disbelief that appeared instantaneously on their faces are permanently engraved in my mind.

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Their faces indicated that something horrific was about to happen. I immediately got the impression that she was going to die. Images flashed through my mind. I just met Paris nine days ago, and now someone was telling me that there was a chance she was critically ill with cancer that had the potential to kill her. We were instructed to go straight to Children's Memorial Hospital in Chicago, as Rush was not specialized in working with children.

From this point on, my recollection of events are in disarray or non-existent. The entire situation and information that I had just been given literally put me into a state of shock. Somehow I got in the car. Everything was moving in slow motion around me. I remember hearing people talking, but it all sounded like muttering. I can't recall any part of the conversation for the entire 45-minute drive from Aurora to Children's Memorial Hospital, located in downtown Chicago. The only thing I remember is sitting next to Paris, all bundled up in her snowsuit, wide awake with her big brown eyes staring at me the entire way. Everything else felt black around me as if everyone else did not exist. I remember resting my head on her as we drove. Everything in my mind was empty, blank and dark. I felt helpless, and the next thing I remember is pulling into the emergency room area at the hospital. I felt like I wasn't in control of my mind. I was just going through motions, and somehow they were correct, but I can't recall them to this day.

When we arrived at Children's Memorial Hospital, the emergency team was waiting for us. My sister had arrived and was waiting for us as well. At this point, it was well past 11 p.m. From that point forward, everything happened so quickly. The oncology team decided to do an MRI on Paris to determine how severe the tumor was. By the time we got settled in a room and I glanced at the time, it was past 1 a.m. On November 29, we began our inpatient stay at Children's Memorial Hospital, where we would remain until December 12.

Chapter 5: Our Journey Begins

December 1, 2007

The team discussed our religious beliefs with us and advised that if we wanted to have Paris baptized that we perform it immediately, as they believed her little body may not be able to tolerate the intense toxic chemotherapy that she would soon endure. Just imagine getting this news. We agreed for Paris to be baptized at the hospital, which is considered the sacrament. Although you can participate in the baptismal ceremony again later in a church, the child would only be truly baptized once, and that is in the hospital. We decided to do this, without a white gown, extended family or friends, and without celebration of her life. We were baptizing her in a plea to God to allow her to remain on Earth and watch over her through this horrific situation. The chaplain came into our hospital room and baptized Paris with Ralph and I feeling and looking like pure shit, crying at the thought that we were baptizing her because we thought we might lose her. Her godfather is a stranger, a bystander from the hospital who we don't even know. I am very thankful that my sister was there to sign the certificate as Paris' godmother.

Every inpatient roommate Paris had in Chicago and New York, as well as the people with whom we have crossed paths along this journey, have taught us something along the way. Our first roommates, Ellen and her daughter Kelly, at Children's was no exception. Ellen had been down this road many times before with Kelly, who had been diagnosed with medulloblastoma at only 4 years old. I honestly couldn't have been paired with a more appropriate roommate that night. Ellen was calm, probably after years of practice, realistic, tough, and positive all at the same time. Looking back, she taught me a lot of life lessons and gave me valuable advice during those first couple of inpatient days. She also gave me a crash course on the days to come, preparing me for my future.

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We began our treatment plan at 10 days old. Early on the morning of December 2, 2007, Paris underwent a biopsy of the thoracic area, specifically T9 and T10. Biopsies require a sample of the tumor to be taken. The doctor removes the sample and examines it under a microscope to find any cells that may be cancerous. It is said that neuroblastoma cells tend to be blue in color.

Later that day, the doctors placed a broviac/central line for Paris to receive chemotherapy and medications. This catheter is passed through the vein to end up in the chest (thoracic) portion of the large vein returning blood to the heart (vena cava) or in the atrium of the heart. Between December 2, 2007, and January 30, 2008, Paris endured four cycles of Carboplatin, Etoposide (VP16), Cytosan, and Doxorubicin through a central line rather than undergoing surgery to remove the tumor. Initially, surgery was too risky of an option because the tumor was compressing her spinal cord. The chemotherapy regiment was on an outpatient basis. We would arrive at the hospital early in the morning, and Paris would receive ondansetron, a medication to prevent nausea and vomiting, before starting her scheduled chemotherapy. We were then able to take her home in the evening rather than spending the night in the hospital. Paris also received an oral antibiotic of co-trimoxazole/trimethoprim-sulfa for three consecutive days each week for the duration of treatment to prevent pneumonia.

Chemotherapy treatments commonly used to treat neuroblastoma include cyclophosphamide or ifosfamide, cisplatin or carboplatin, vincristine, doxorubicin, etoposide, teniposide, and topotecan. Chemotherapy uses chemicals to kill cancer cells, but in the process, it may also damage normal, healthy cells, putting her at an increased risk for developing secondary cancers later in life. It is not guaranteed that the tumor will respond to the chemotherapy that is being used. The treatment plan must constantly be changed, as tumors develop a resistance to specific types of chemotherapy over time.

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Chemotherapy often causes mouth sores, pains within the mouth, or excess spit. These conditions can be eased by swishing magic mouthwash (made with Maalox/Mylanta, Benadryl, and Lidocaine), which should be made by the pharmacy, or Orajel mixed with mouthwash. Mouth sores can be treated with an herbal extract called Golden Seal.

Paris contracted thrush and mucositis, which is a contagious disease; caused by fungus (*candida albicans*) and typically occur in individuals who have a weakened or suppressed immune system due to chemotherapy. The small white eruptions on the mouth, throat, and/or tongue can be treated with Nystatin or fluconazole. To ensure the condition doesn't return patients need to swish four times a day for the full 14 days.

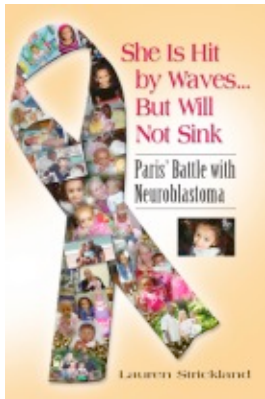
Those dreaded words, "I'm sorry, your daughter has cancer." Never in a million years would I think that I would be that parent. Sometimes things can change drastically within seconds. The world is actually a dangerous place where bad things can happen, things that you never dreamed of. From a father's perspective after having a daughter for the first time, the thought typically is, "This is my daughter, and I'm going to dedicate my life to protecting her and saving her from anything harmful." When Ralph learned of Paris' diagnosis, he lost that ability to protect her from anything because he simply didn't have control over this.

One of the memorable things that one of my "cancer mom" friends said to me early on, as she happened to be a veteran in this, is, "It will get easier, you will learn things along the way, and sooner or later you will be telling them what to do." That advice, even though it didn't seem like it at the time, came to be true. I have become my daughter's advocate. I have become knowledgeable about medical decisions in ways that I never thought I would be, and over time, it has gotten easier, as it has become part of my life. One of the main things that I

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want to stress is that Paris is first and foremost an individual. She has cancer, but cancer doesn't control her, nor should it control any other child. Cancer doesn't primarily control our family lives either. It's an unfortunate part of our lives, but it doesn't lessen our level of hope or dictate how we live, how we spend our finances, and the goals we strive for. We as people adapt to change – we may not like situations that arise, but we have no other choice but to deal with what we encounter.

When we were given an option, we had to choose from two evils: do we want to try and fight this or plan for her funeral? To us, quality of life was a very important factor when considering treatment options. I personally had to put myself in Paris' place and say to myself, if I had cancer and my mother had to decide what was best for me, would I be grateful that I was alive but with limitations? I said that we will fight to the very end, but I wouldn't be selfish either, considering the quality of life every step of the way. I want her to have a quality of life and not be resentful that she can't have a "normal life." I have had to prioritize certain things that I'd be willing to sacrifice, such as her hearing, vision, cognitive functioning, energy level, height, mobility issues, endocrine issues, ability to reproduce, or the necessity of certain organ function. I find myself asking Ralph what are we going to do, and his response is always, "What we have to do." Life is going to do what it's going to do. I learned that you can't plan.



Paris Strickland was diagnosed with neuroblastoma, a rare and deadly form of childhood cancer, at only 9 days old. No parent should ever have to hear the words "your child has cancer." Paris' mother, author Lauren Strickland, documented her thoughts, feelings, and experiences so that the approximately 650 people whose children are diagnosed with neuroblastoma every year can see they are not alone in this journey and that, at many times, others are feeling the exact same way.

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by Lauren Strickland

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