

For Brian's Sake

by

Kathleen Mosko

&

Brian Mosko

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## SYNOPSIS

For Brian's Sake is a true and timeless story of a mother and son healing, learning, and loving against all odds. Kathleen takes you on her journey through divorce, domestic violence and sexual, emotional, and financial abuse from abusive husbands and family. She relays the carnage they all have on her, influencing her life choices. This book shows how her parents taught her lessons that led her to life-long addictions and bad relationships. And, shows how tightly those ideas wove their way into the fabric of who she identifies herself to be.

Kathleen gives birth to a child she longed for, only to discover he is brain damaged, with multiple birth defects with the life-threatening medical condition, CVID, common variable immune deficiency, which few are willing to help her deal with. One obstacle after another makes her constantly redefine her world and how she copes. People she thinks will be there to help, walk away in her greatest hours of need. Her trust in others is so compromised, she travels inward to survive and help her son. Having only her gut instincts to trust, she finds the knowledge she needs along the way.

Adding to the things she knows and becoming independent, Kathleen attends college, and graduates while caring for her son. For most of the time, he attends classes with her and is there while she does her studying and research on campus.

Along her journey, Kathleen meets situations which defy all logic and place her and her very sick child in a nether-world underground. She contacts the Ohio State Attorney General, convincing him to unseat an incompetent judge. Because of prejudices about his condition, Kathleen uses innovative ways to be useful for her son's healing, well-being and education. She arrives at a point where she is forced to make critical decisions because of her health which places them in financial straights yet to be overcome. Kathleen chronicles the language her son developed. The words, definitions and the tale he spins to pass the time without friends, is written as an intertwined children's story, in hopes of making sense of their situation.

She demonstrates what it's like to care for a sick son in a world that judges single mothers with a special-needs child. Kathleen worries about her son's mental abilities and, as his milestone benchmarks protract, becomes increasingly apprehensive that he may never attain some of them. She enlisted as many tangible and intangible free resources as she possibly can.

Her choices made, Kathleen must live within the parameters of what her son is able to do and a life situation full of restraints. Some of those choices help her son to flourish as an independent person and develop skills, abilities and knowledge that place him in contention on a world stage with others vying for recognition in New York City in the modeling and talent industry. Pleased with his progress, Kathleen now feels her son has a way of looking to the future with health-care even though she may lack resources to provide it for him as he ages.

When the neighborhood turns bad, Kathleen is forced to relocate her family again to a safer place. Financial disaster strikes when her new husband loses his job shortly after buying their dream home. As Kathleen sees her only small window of opportunity closing rapidly, the decision is made to uproot the family and move to an area of the country where jobs will be plentiful no matter what the state of the economy. As part of the relocation, Kathleen must find new doctors to manage her son's condition. To her amazement, medical test results show no trace of the condition her son was treated for in Ohio. Ethical and moral questions arise, once again destroying a few more of the last threads of trust Kathleen has in people.

Moving means her son finishes high school in a new environment, a plus in his short life. For the first time, Kathleen is satisfied her son feels like he fits into a world of peers. Graduating with honors from the only Catholic high school in Southern Nevada, her son receives an early admittance letter to UNLV for the following fall, reaching the ultimate goal she set out to achieve. Along the way, Kathleen also discovers who she is, redefining herself yet again.

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## **BIO**

Kathleen graduated from Kent State University in 1996, some 25 years after high school. It was the real turning point in her thought process about writing. After taking advance writing classes there, she wrote for several years, keeping those writings with the intention of one day putting them into book form. She earned a Bachelors of General Studies Degree with a concentration in Conflict Resolution minoring in Psychology, which poised her for what she would face in raising a special needs child. She also is six credit hours away from a dual degree in graphic design.

Her education includes a broad sweep of classes for circumstances arising during mediations including real estate. She received her Ohio Supreme Court Mediation training in Oct./Nov. of 1994. Additionally, she studied conflict resolution from multiple perspectives for parent-teen, victim-offender, K-12 mediations, neighborhood disputes and trained to train facilitators for Round Table Discussions in Racism. She completed all mandates for Practitioner's Status with the Academy of Family Mediators as of August, 2000.

During the course of Kathleen's pursuit for her degrees, she also taught her son kindergarten and first grade in a conference room provided by the university. She blended her studies with his, never forgetting his condition and educational needs.

A conscience decision was made by Kathleen on Brian's behalf to afford him the best parochial education possible which led him to attend her alma mater of which Christopher Columbus, Director of Harry Potter fame is an alum as well.

Work experiences of Kathleen's include mediating full divorces, parent/teen mediations, custody disputes, parental rights and responsibilities, shared parenting/companionship and property disputes.

She was the first Center Coordinator/mediator at The Solace Center, a supervised visitation site for parents and children where Kathleen also taught parenting classes. Kathleen taught mediation skills at the General Motors Lordstown Assembly Plant through the Continuing Education Program at Kent State University.

She developed a community-based start-up mediation program receiving court referrals and later developed a mediation program for parents and teens creating a Policy and Procedure Manual for that purpose. During her work in Portage County, Kathleen did on-site mediations for the Ravenna Police Department and training for the officers. She also provided training to law enforcement officers from the Portage County Sheriffs' Department, Streetsboro Police Department and Windham Police Department. She mediated cases from the Portage County Department of Human Services and at a drug and alcohol intervention program. She taught high risk children in an alternative school about conflict resolution and how to de-escalate their anger.

Kathleen founded Trumbull Mahoning Mediation and Conflict Resolution Group, Inc. winning a New Business Challenge award of \$20,000 as seed money for a “New Concept” business benefiting the Trumbull and Mahoning counties. This start-up company was developed exclusively by Kathleen in an effort to help others avoid the perils she experienced.

She was part of the lobbying effort in Washington DC for 12.8 million dollars in funds to be released to the IDF, Immune Deficiency Foundation searching a cure to her son's rare “orphan” medical condition.

When her son Brian lost his \$12K a month treatment funding, her phone crusade calling Ohio State representatives and anyone else that would listen, ended in reinstatement of funding. Her efforts also helped others in Ohio going without this life-saving medication.

When Brian received a Wish from the Make A Wish Foundation, the family adopted that special charity, engaging in many fundraising events. His Wish became the driving force behind Kathleen

teaching her son to plan a gala event from the ground up by developing a fundraising birthday extravaganza, hosting 250 people. Together they raised \$1,350. for the foundation.

She invited celebrity John Travolta who, though unable to attend, sent a letter with his best wishes and autographed picture. His compelling portrayal of David Vetter in the movie, *The Boy In The Plastic Bubble*, which told the story of the boy with the same medical condition as her son was Kathleen's inspiration for the invitation. Kathleen also landed an appearance from Drew Tyler Bell of *The Bold and Beautiful* who graciously signed autographs at the party.

After speaking with aides for the John Kerry Campaign, Kathleen was able to secure a meeting with his “front people.” A discussion took place to showcase Brian as their spokesperson for Stem-Cell research. However, due to time constraints the showcase became impossible.

Kathleen's above unique life experiences, from being a cancer survivor and becoming handicapped herself, gives her the qualifying expertise to write “For Brian's Sake.” She writes not only from her heart, but with firsthand knowledge of the vast maze parents of special needs children must navigate. Kathleen also learned and wants to pass on how to put yourself on your to do list. She displays how, with special nurturing of a child, one can blossom the person within.

## PROLOGUE

Tall grass swished as I ran just inside the field, along the rocky driveway. I was hoping the darkness made it more difficult to see us, my footing was unstable.

“Shh, Brian, don't cry,” I whispered holding him close to my body.

I stumbled, dropping the bag of our belongings. Having prepared myself to break the fall, I fortunately kept my footing and stayed upright. Already across the street by the time I recovered from the stumble, I left the bag, time was of the essence. With my head down, holding Brian close to me, I heard the motor turn over in Frank's truck.

The sound startled me into looking back toward the house. Again, I lost my footing, falling into the grass. This time, I didn't get up.

*Maybe the grass is high enough to shield us from view,* I thought.

The damp, musty smell of the earth filled my nostrils. I ignored how the dew, already heavy on the stalks, soaked through our clothes.

“Shh,” I whispered again. I was certain that Brian could feel my fear by how tightly I held him.

“Please, don't cry right now; Mommy loves you buddy. Everything's gonna be okay,” I said in a barely audible tone.

The beam of headlights cut through the darkness at the end of our driveway. Hearing the crunch of gravel under the tires grow closer paralyzed me like a deer caught in headlights.

*We'll be alright if we just stay quiet and low.*

Brian and I became one, nestled together in the safety of the elevated stalks.

*HE'S HUNTING US DOWN!* Panic flushed over me.

No one ever defied Frank and got away with it. He'd make somebody pay for this. Experiencing his anger before, I knew what he might be capable of. What will happen if he finds us? Does he have

his gun with him; does he really want to kill us? Is he in that crazed frame of mind, ready to do the unthinkable?

He didn't see us. The sound of the truck's motor got softer as it's headlights dimmed.

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Earlier, on a quick pass through the kitchen, my trembling hands grabbed medicine and supplies necessary for Brian. Although his clothes were tiny, and only shoving a few things in for myself, everything still didn't fit into the big, black garbage bag. Brian looked at me with his trusting, deep brown eyes as I put on his jacket. I managed to slip my sweatshirt on as I scanned the house. There were so many important things I wasn't able to take.

Maybe the black of the bag will help camouflage us in the darkness, I thought as I went through a fast mental checklist of everything a special-needs child must have.

*Tomorrow is our anniversary. How did things go so wrong? What did I do to deserve this? Maybe, if I'd done something different, something better, I wouldn't be spending my anniversary this way. Or **maybe**, he wanted to spend the Fourth of July with someone else.*

I was determined to make this second marriage work. I married for life and understood taking the bad with the good. There just wasn't much good for a long time. I was lonely when Frank went to the racetrack. I was lonely even when I was with him. Loving him so much, I wanted to be a good wife and show him I was worthy of his affection, but it never came. I could never please him. There were moments of passion, but I came to realize that was to satisfy his needs, not mine.

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Just minutes before, Frank had finished yet another of his more severe tirades. He threw three, eight-inch clay flowerpots past my head into the wall just above Brian's playpen. The plants were everywhere; the dirt was everywhere; the broken shards of the pots were everywhere. Two five-inch

gaping, jagged holes exposed insulation in the wall. Minutes prior, Brian was in that very spot, playing. Once Frank's rage ran its course, he screamed at me to clean up the mess before he got out of the shower.

At that moment something in me snapped. I realized Brian might very easily become a casualty of Frank's abuse, leaving him dead; or worse, a vegetable. The events of this night forced me to change my reality. I knew the decisions I made now would affect us forever. Our lives depended on me making the right ones.

Quietly, I opened the window to Brian's bedroom, which faced the street, making sure the latches to the screens didn't screech. After tying it hastily, I heaved the full thirty gallon garbage bag over the window sill onto the ground below.

I waited in Brian's room until I heard the water hit the basement shower stall. There wouldn't be much time until Frank came upstairs and saw I didn't clean up his mess. With an adrenalin rush, I snatched Brian from his crib, and escaped through the side door just at the top of the basement steps. The front door, which was closer to Brian's room, didn't open because Frank had nailed it shut. I slipped out silently so Frank wouldn't hear me and come running after us. I didn't have much time.

Our dog, Rocky, didn't bark since he was used to me going out at night with Brian, responding to tow calls. Up until Brian's birth, Rocky was my surrogate child, my loving companion, my comforter who went almost everywhere with me. Rocky was Brian's dog, now. At 111 pounds of Doberman-Shepherd mix, Rocky was still a moosh with us. For Rocky, however, there was no difference tonight, not knowing we were escaping.

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I loved the home we built. Our three acres sat on the highest plot of dirt in the middle of eighty-eight acres. After three years of apartment living, with neighbors so close you could say "bless you"

when they sneezed, this was a very welcome change. I didn't realize how private a person I was until I started to enjoy the peace and quiet of our new home. It was close enough to town, but far enough away to get the true feeling of rural life. Instead of noisy neighbors, you could hear the horses neigh in the field next to our property.

There was so much space I felt like a pioneer. In a half-mile radius, there were only three neighbors. Because the woods ran between the neighbors on either side of our house by several hundred yards, I never got to meet them. Larry and Helen's house was directly across from ours. Their house was much farther back from the road. The rest of the property was trees with overgrown fields. You could smell the clean in the air, and when someone finally mowed, the aroma was of wheat, not grass.

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Our house sat 150 feet off the road. On this frightful night, it looked like five football fields. Pumped full of adrenalin, my heart pounded so hard it hurt my chest, and my body quaked with fear. There were no street lamps and none of our security lights was on. The cloak of darkness would be our friend tonight; a camouflage for our dangerous journey. I swiftly retrieved the garbage bag I'd thrown out the window, clutching Brian with one arm, the bag of possessions in the other, and ran for the driveway.

*I need a phone. I need to call the cops. I need to find someone to rescue us from all this torture and pressure.* I have no idea where I got the kind of strength it took to do what I did. I certainly didn't know where I was going to get the strength to do what I had to do next.

The eighth mile distance to Larry and Helen's, directly across the street, was my Olympic run. Between our houses was a roadway, two gravel driveways, a rocky field with tall grass, and a freshly

dug pond. I wasn't sure if I could run all the way carrying both Brian and the bag. I was normally the type of person who, when faced with fear, froze. Tonight, we had no choice. I ran.

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Larry and his wife, Helen, didn't approve of the way Frank treated Brian and me, but they wanted to stay out of our problems. They knew, if something happened to me, they'd still be his neighbors, and feared that helping me would bring retaliation from Frank.

On a few occasions, Larry was witness to Frank's rage. Larry was in the garage the day I interrupted Frank and he threw a couple of crescent wrenches at me. At twenty feet away, I still wasn't able to dodge them. One hit me square on the right elbow as I fled back through the door. The pain was excruciating. I was amazed the intern at the hospital bought my story about falling. He didn't even ask me if I was hurt anywhere else. I thought people in his position were supposed to suspect abuse and report it.

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As soon as I heard the whine of the motor fade and knew Frank was out of sight, I somehow raised myself upright, with Brian still locked in my arms, and ran my final Olympic sprint. I reached the safety of my neighbor's porch and saw the faint flicker of light from the TV coming through the sheers hung on the big picture window in their living room.

Helen answered my loud knock and instinctively turned on the porch light. She saw me holding Brian, out of breath and opened the door.

“Frank's after us! Please, turn the porch light off,” I pleaded. The light went out.

“What happened?” she wanted to know.

I calmed down enough to explain about the flowerpots, but my body was still shaking.

“Can I please use your phone to call the cops?”

Helen handed me the phone as she told her son to go to the field and recover all our earthly possessions, which were stuffed into an aptly named “garbage bag.” It struck me that our lives had been reduced to this. I had no idea if we would ever see our home again.

## CHAPTER ONE

### THE FOUR AND A HALF MONTH PREGNANCY

I can remember the minute I got pregnant. It was 4:10 a. m., August 15 (my father's birthday), 1988, sleeping on the backseat of our crew cab at a truck stop on a North Carolina highway. Frank and I were on our way to pick up a couple of cars to resell back in Ohio. We did that run a lot so he could have extra money at the racetrack. It was always about his racing habit.

He was particularly horny that night and crawled into the backseat to have his way with me. I was sound asleep when he woke me up tearing at my clothes. It was my responsibility to practice birth control. I tried to tell him I wasn't ready. As usual, it really didn't matter. If he wanted something, he took it.

When he was done, he got off me and said, "You have ten minutes to clean up, or I'll leave you here." He'd left me before, at home, so I didn't doubt him. I hurried into the stinky latrine, took care of what I could, and rushed out to jump into the moving truck already pulling away. I looked at him and he was laughing. Roadside rest areas are a very unsavory place for a woman alone.

There were times I tried to talk to Mom about what was happening – the spousal rapes.

"It's your duty, Kathie; he's your husband."

In her mind, it wasn't rape, because I was married. I should be willing to give it to him whenever he wanted it. For a while, I thought it was something about **me** that wasn't right.

*Is it normal for him to be so rough to the point I bleed and hurt for hours after being with him?*

In my mind, I thought that's what it was like to be with a "real man." At least, that's what he told me. Later, I found out it wasn't me, and it wasn't normal. I trusted Mom to tell me the truth about these things. The truth was, she didn't know any better herself. I didn't know how to make him stop hurting me. Since raping me was so commonplace, I didn't think of this particular spousal rape as anything

unusual at the time, until the doctor, trying to calculate my due date, asked, “When was the last time you had unprotected sex?” The roadside rest-stop came back to me instantly.

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My two older sisters, Theresa and Mary Ann, both had hysterectomies by the time they were my age, one with cancer, the other with precancerous cells. At 35, I figured I was headed for a childless life, fighting the inevitable family history of cancer. That weighed heavily on my mind. I was experiencing some female problems again, so I made the dreaded appointment to see my gynecologist.

I was shocked when they called with my lab results from the doctor's office.

“Kathleen, this is Dr. Casale's office calling with your lab results...we need you to schedule your first prenatal visit.”

“Are you sure you have the right file in front of you?”

The nurse laughed and assured me she did. Speechless, I started to cry.

“Are you still there?” the voice asked.

“Yes, what do I do next?” I asked in a choking voice. I made the appointment for the following week and hung up. I was stunned, not at all like I imagined it would be. It wasn't like in the movies where two people fall into each other's arms crying with joy, pledging to be the best parents on the planet. I'd been dreaming of this moment since I was a little girl. I embraced it by myself.

My dreams were coming true, I was secretly the happiest new mommy in the world. I just sat there crying a happy cry.

Thank God, Frank wasn't there when I got this call. I needed some time to digest the information and deal with my own raw emotions before I presented him with the news. It didn't matter to me; I was finally going to be a mommy, and I loved this baby with my whole heart and soul from that moment on. How it was conceived was never an issue with me.

Frank was livid when he heard the news. He swore, “You won't have this damn baby.” “You **will** have an abortion!” he demanded.

*What did he expect after raping me without protection?*

I told him, “I'd rather be divorced than have an abortion. I've been divorced, and I know I can live with that!”

Oddly enough, he stopped screaming, and I thought he'd come to grips with the pregnancy. I was so wrong. Frank secretly started planning for our removal; I just didn't know it yet.

It was late October when I found out I was already three months along. It was a bittersweet time for me and my family. Mom's birthday was November 12, and just a week or so before, Dad was diagnosed with lung cancer at the Cleveland Clinic. He was in shock. With treatment though, he thought he could beat it. Two days later the Clinic called again to apologize. They had read the wrong results and called the wrong patient. He was out of his mind with joy. Once again, two days later the Clinic called saying they made another mistake and Dad really did have lung cancer.

“I'm ready to crawl out of my skin I'm so angry,” he screamed as he slammed the phone down. He was sad, then happy, then sad again, all in a matter of four days. After all those emotions, he got angry as hell, and had no one to blame.

I decided to wait till Mom's birthday when everyone would be at the house to share the news. The wait was agonizing. Twelve days is a long time to keep a secret like that!

I gave mom a blank picture frame with a note stuck to the glass.

“For a picture of your newest addition.” She read it but didn't get it. She showed it to my dad. He got it. “She's pregnant, Helen.” Dad was giddy, reaching to hug me. My parents were ecstatic.

Crying, Mom looked at me in utter delight. “Kathie, you...you're pregnant?” she stammered.

“Congratulations, Kathie, how far along are you?” my middle sister asked. Mary Ann was happy for me and gave me a hug.

I could tell Theresa was struggling with the news, because she was very standoffish. Her husband, Bill, hugged me, “Congratulations Kath,” he said, which added insult to injury. I figured it was going to be a problem for her. Since Theresa couldn't have children of her own, she and Bill had adopted a little girl.

Mary Ann has two biological daughters. Even my brother, Steve has a biological daughter, and he wasn't married. My brother half-heartedly congratulated Frank and shook his hand. It pretty much went the way I expected.

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Because I was an “older, first-time mom,” my doctor wanted an amniocentesis done to know what, if any, birth defects we needed to prepare ourselves for, and, in that event, discuss terminating the pregnancy if necessary. I was okay with the test but turned apprehensive once I did more research on what an amniocentesis is. A secondary byproduct of the amnio was knowing the sex of the baby.

There's a “margin” of pregnancies lost with the invasion into a woman's uterus full of amniotic fluid and a baby. The doctor had to be very precise where he punctured my abdomen and pushed a gigantic needle into my uterus to extract the fluid. As uncomfortable as it was, I did everything they told me to the letter. Where the baby was lying was of utmost importance. If the doctor went too deep or into the wrong place, the needle could hit the baby and I would deliver a stillborn.

I went through that once with my mother. When I was only ten, my little sister, Ellen, was stillborn. It tore our family up. Back then there wasn't such a test as an amniocentesis. We had all

wanted Ellen so badly. The doctor said Mom had a thirty pound tumor on her uterus while she was pregnant and that's why Ellen died. It devastated me. To this day I silently celebrate my little sister's birthday, August 21.

In the '60s, they didn't recognize stillborns and were shown no dignity. Mom was still in the hospital so Dad and we kids had to bury Ellen ourselves. Not even our priest would come. It was our understanding of the Catholic church teachings then that a baby wasn't a life until it drew a breath of air, but Mom had carried her the full nine months. The hospital gave Ellen's body to the funeral home where they put her in a white infant casket. I only have the memory of a ten-year-old as to where we were standing at the cemetery. Mom always wanted a headstone for Ellen, but never got even a marker.

I didn't want to go through that ever again.

With the results of the amnio back, I decided it would be a good thing to tell Dad about the test, boy or girl. It might give him a renewed sense of hope. I had the name Brian Joseph ready for this day.

"It's a boy" the balloon read. We stopped by their house to give "Grandpa" (and "Grandma") the news. This baby would be their only grandson. Dad started making all kinds of plans, including buying him a fishing pole to teach him his passion.

Dad was still thinking he could beat the cancer. He was willing to try any kind of treatment to put it into remission. We all suspected it wouldn't happen, though it gave Dad incentive to keep trying. Additional testing and a second diagnosis of pancreatic cancer as well was the clincher. His time was short. It was absolutely heart-wrenching.

I made the most of every visit and visited often, almost every day. I stopped on my way home from work and found myself shopping on their side of town so I could drop in. I finally got up the courage to ask Dad to take a couple of pictures with his hands on my belly. He obliged me. I wasn't sure he'd live till May 14, Mother's Day that year and my due date. It was important to me for him to

hold his only grandson and have a picture of him holding Brian, even if it meant he was only holding my belly. At least, I could show Brian the picture when he was older and tell him Grandpa Joe held him. Without expressing the sentiment, Dad knew why I wanted that picture.

A head cold and ear infection sent me to the doctor shortly after finding out I was pregnant. “Your fever is too high for the baby, I’ll have to give you something to bring it down,” he said. But, Dr. Casale cautioned, “This medicine plus the antibiotics have a high incident of deafness for your baby as a side effect.”

At that point I didn't have much choice, either run the risk of Brian dying from the fever and infection or being deaf. I chose deaf. Without realizing it, I started making life and death decisions for Brian long before he was born. With that, I was on bed rest for two weeks, which miffed Frank since I wouldn't be working, bringing in my share.

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My siblings accused me of getting everything I wanted, because I was the baby of the family. Years later, Theresa even threw it up to me about getting to go to a private Catholic high school. What they failed to realize was, simply because I *was* the youngest, I ended up with the tail-end of everything. I was stuck with hand-me-down clothes. I was told by my third grade teacher that, Theresa had looked far sweeter in one particular dress she'd also worn. I got the last of Mom's patience. I was in her space, literally, 24/7 outside of school, and the last of Dad's energy. All Dad wanted to do after a day's work was to eat, sit, read the paper, and watch TV till bedtime. Now, I get the tail end of Dad's life. I'd have gladly changed birth order with any one of my siblings.

It was all so heartbreaking. Dad and I finally got a little closer while Frank and I were building the new house I designed. Excited for us, Dad thrust himself into the project as an “advisor.” On the sidelines mostly, Dad was there really just to stick his nose in and stay out of Mom's way at

home. He was actually pretty helpful, **and** he helped me rake out the dirt to spread seed for the lawn. Our lawn covered almost a full acre, so I really did need the help.

Frank didn't let his own father help since he felt he was such a screwup. I think Frank liked Dad because he treated him like a son; the way Frank thought a son **should** be treated. Dad respected Frank man to man, something his own father never recognized he'd become.

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My father was a quiet person.

“His silence is deafening,” Mom would say. Sometimes, the biggest response she got was a head nod in recognition. All too often though, she spent her days in silence, sentenced to an overwhelming quiet she never did get used to.

I was a junior in high school when Dad found out he was going deaf. He bought hearing aids and wore them, but sometimes turned them off. When he didn't want to hear what we were talking about, he'd belly-laugh and animatedly turn them off while saying, “I can't hear you!”

His time was fast approaching, and I knew I'd fiercely miss him and his presence. I didn't want to say goodbye for Brian's sake. Dad was suffering a great deal, and yet, I was selfish and wanted him to stay. I wanted to enjoy Brian *with him*. It was going to be hard to let go.

In my quiet moments throughout the years since, I've talked to Dad telling him about Brian and letting him know I tried to teach Brian the things he'd taught me: how to hold a hammer and nail; how to catch worms after a summer rain at dusk; how to marvel at the beauty of the heavens at night; and how to make a go-cart from scratch. It was gut-wrenching to know those things would never be taught to Brian by Dad. I have since tried to keep Dad's spirit alive for Brian.

On Dad's birthdays, Brian and I will sit and watch the video of Dad's retirement party I threw for him at our new house. While watching, I tell Brian a little bit about his grandfather and some family history. We have lemonade and offer a toast, "To Grandpa Joe."

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I agreed to sing at the 25<sup>th</sup> anniversary show of Fiddlesticks, a talent show production from my alma mater, John F. Kennedy High School. Although I was seven months pregnant, the sound coming out of my mouth was better than it ever had before. That is, until I got laryngitis a couple of weeks before the show. I didn't want my act cut, hoping Dad would be well enough to hear me sing one last time on stage. By the day of the performance though, Dad was too sick to attend. He never heard me sing again.

Our joke was, I got my voice from Dad; he didn't sing often, but he sang well. Mom, on the other hand, sang all the time, but not so well. Some time before I got pregnant, after months of saving up money out of the grocery till, I made a recording at a professional studio. I ended up using that to lip sync at the performance. It was also the one I copied and had the nurses put in Brian's incubator to play in his very own Cassette player.

The whole draw of the event was twofold. One, I would get to sing on stage and secondly, Chris Columbus was the MC. He is an alum of JFK, the writer of *The Gremlins*, and director of "Harry Potter" fame. We were all pumped up when the news came that he agreed to do the show. Backstage, he asked me if I knew what I was having. "Yes. We're not telling everyone yet, but it's a boy."

"I won't tell anyone," he promised. Yet, as he introduced me, he announced that I told him I was having a boy. I guess it was okay, not that I could do anything about it then, anyway. Though, if I ever see him again, I have a bone to pick with him about that!

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I busied myself waiting for Brian, collecting books and tapes, getting furniture arranged, and putting together a cardboard chest of drawers for diapers. The afternoon the day I went to the hospital, I finished wallpapering the nursery. I used pastel rainbow paper for the bottom half and clouds on a blue background for the top with a bunny border covering the connecting edges. Never would I guess how bad things were going to get, and maybe it was a blessing to be so naïve about what was to come.

I was only pregnant one more week. The rest of the pregnancy was going alright until Monday the 27<sup>th</sup> of March. I was drying off from my shower when I felt my water break. *How could this be happening? Brian isn't nearly done. I still have almost two more months to go. I'm only 32 weeks!* I said a little prayer that everything would be normal and got dressed. My feelings dare not show in front of Frank. I was nervous and excited and very apprehensive. He didn't want me to be pregnant, and I couldn't let on I suspected there might be complications.

At 10:00 p. m. I went into the family room where Frank was watching Monday night TV to tell him it was time to go to the hospital. Unresponsive, almost cavalier about the request to take me, Frank was silent the entire way into town. I kept thinking, *Brian is on his way!* I was so excited.

In my mind, I was pregnant a total of about four and a half months.

## CHAPTER TWO

### BRIAN'S BIRTHDAY

By 1 p. m. Tuesday, some fifteen hours later, the doctor was starting Pertussin, a medicine used to bring on labor. I was told to walk the halls to try bringing it on. I saw women who came in after me become new mommies and take their bundles of joy home with them. I was worried. I didn't have any strong labor pains and had only dilated 2 centimeters. Ten centimeters was the magic number, I was sure the Pertussin would do the trick.

Dr. Casale was worried about infection setting into my uterus with an open birth canal having had the mucus plug released when my water broke. He said if the Pertussin didn't work I would have a C-section in the morning. The Pertussin brought on labor alright. The contractions were 1 ½ to 2 minutes apart for the better part of nine hours. The nurses quickly prepped me just in case Brian started to crown.

When they say you lose all your modesty when you have a baby, no truer words are spoken. About every half hour or so someone came in the birthing suite to root around inside me, sticking their gloved hand into my private parts till they weren't private to anyone including me. I never did dilate any further. I was exhausted and somewhat hungry, having not eaten in two days. The doctor quit the meds and let me get a little sleep. Tomorrow would be Brian's birthday!

It was very early Wednesday morning, but I didn't mind. Things were moving in fast motion by 6:30 a. m. Frank showed up around 7:00, and the spinal was administered shortly after.

I could hardly breath from the numbing meds in the spinal, and I heard the doctor speaking softly to the nurses in the delivery room. I just delivered Brian C-section after 33 hours of labor. The doctor announced the time of birth, "A boy, at 7:34 a. m., March 29<sup>th</sup>." He peeked around the surgical curtain and asked, "What's his name?"

“Brian Joseph,” I answered.

He looked back at the baby in the nurse's hands, “Welcome, Brian Joseph.”

Like on TV, I waited for them to place Brian on my chest, to see him, kiss him, and tell him mommy loves him very much. The minutes passed.

I heard a faint cry. I started to cry.

There was a flurry of activity by the area where they took Brian. *Where's my baby? I want to see my baby!* The murmmers got louder, and I heard someone say something was wrong with his Apgar Score. *I can't understand, why won't they give me my baby?*

Dad coughed. He was standing at the doorway of the room.

“Dad, is that you?”

“Yes.” I could hear the restraint in his voice.

*He must be choked up because he just witnessed his only grandson being born.*

What he was witnessing was everyone working on Brian's lungs, getting them to inflate.

“Where's Mom?” I asked Dad.

“Theresa's going to bring her in a few minutes,” he answered. “Mom 's running late.”

He was scheduled to have a chemo treatment at the same hospital that afternoon. Weakened from the treatments, Dad still mustered enough energy to not miss Brian being born.

When they were monitoring me and my belly, nothing indicated that Brian was ever in fetal distress. But something was wrong. I could tell by the way Dad was answering me; his voice was different. I was confused by what was happening in the room and stressed by the way Frank was acting. I just wanted to hold my Brian.

The sterile smell of the room, the chill of the air, the harsh glare of the lights all made me feel disconnected, like I was in a nether world. Frank was at the head of the table on which I was placed. Looking at Frank I said, "I'm so proud to give you a son." He turned his head away. He was there because it was expected of him--just going through the motions. "Kiss me?" I asked. Reluctantly came a quick peck. It may have been two decades ago, but those are the moments you never forget.

"Can I see him now?"

The nurse said, "We're still cleaning him up."

Someone told me later they were waiting for the Mobile NICU Ambulance to transfer him to a hospital thirty miles away with a NICU (Neonatal Intensive Care Unit) for preemies.

A spinal block was used so there wouldn't be much stress on Brian from the gas and chemicals to put me out. I was pretty much aware of everything going on in the room, though I couldn't see. I sensed they were stalling and didn't know why.

"Does he have all his fingers and toes?"

One of the nurses said, "Yes." But it was the **way** she said 'yes' that bothered me.

"He has a full head of hair, and his body is covered with it, too," another one said.

*I just want to see him; LET ME SEE HIM!* I thought.

"Is he okay?" I asked. A nurse answered, "We're just trying to make it easier for him to breath with a little oxygen."

They were very vague explaining Brian's condition.

"We'll bring him in to see you once you get in your room," she said.

It never occurred to me something was drastically wrong with Brian. My hope was to have a problem-free delivery and be home with Brian 24 hours later. At 35, I was healthy and ready. I'd lived

enough and sewn enough wild-oats to settle down and raise my son. But, nothing in my past could have prepared me for the journey I was about to take.

I could feel the tug on my belly as the doctor sutured me up from the inside, then, I heard the sound of a staple gun closing the outer skin. One of the nurses pushed hard on my stomach to help me deliver the afterbirth. The doctor disappeared as soon as he was done. *Maybe that's why I can't see Brian, because he wasn't done sewing me up yet*, I rationalized.

Patiently, I waited to hold Brian. I was moved to a room away from the other new mommies.

A nurse and doctor were soon standing at my bedside with an incubator to the right of me. All I wanted was to hold my precious little boy. It was so painfully cruel. The tiny body inside was hooked up to all kinds of tubes and wires. They said it was Brian. That was my first look at my son. Two round openings in the side of the incubator let me see his tiny face, but they had something taped to his mouth for him to breathe.

The doctor was a short, attractive man of Indian decent, "I'm Dr. Dayal." In fairly good English he said, "We're going to take your son by a Mobile Emergency Room Ambulance to St. Elizabeth's Hospital in Youngstown. There is a level-one team preparing to take care of his difficulties."

*Difficulties? What kind? How long would he be in the hospital? Was he going to be okay? Was he going to die?* I never asked those fateful questions though they weighed heavily on my heart. As he explained things to me the nurse attending Brian handed me a Polaroid picture. "You can look at this picture while pumping to bring on your breast milk," she said. The picture was of Brian all hooked up in the incubator lying on his stomach. He looked like a little frog with his legs splayed out to the sides laying on his belly.

"Can I hold him?"

"No, it'll be too difficult to unhook him, and it wouldn't be safe for him," Dr. Dayal said.

*I wonder why they didn't let me hold him before they put all those things on him?*

Years of people telling me what was good for me trained me to be dutifully patient and not rush to hold this fragile, tiny body called my son. My Brian. My upbringing of holding doctors in high esteem gave me the ability to believe and agree with everything they told me. I was a good little girl, listening to anyone in authority. I was so used to this passive behavior, it never occurred to me to ask those important questions, or demand to hold him.

“You can see your son at St. E's after you're released,” Dr. Dayal said, and they left with Brian.

Frank was long gone. He had other more **important** things to do.

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The nurses didn't tell me I would fill up with milk by evening and my breasts would be engorged, ready to explode. If they didn't hurt so much, it was kinda nice being a D cup! Before I got pregnant, I was like the auto club, AAA.

I tried to pump, but nothing came out. I was so stressed. The nurse told me to relax and it would just start to flow.

She didn't tell me **how** I was supposed to look at this Polaroid of Brian and relax. A picture of this tiny baby all hooked up to tubes and machines was supposed to bring out the best in me so I could express milk. WHAT WERE THEY THINKING?! I didn't even know what he felt like or what he smelled like! There was nothing in my memory bank to use as a motivator.

Some battle-ax nurse walked in telling me I should put hot compresses on my breasts and handed me a stack of towels. Looking over her shoulder as she walked out, she says, “Wet them in the bathroom sink and hold them to your breasts.”

*I just had major surgery, woman! How am I supposed to get out of this bed and make hot compresses for myself. She **must** be out of her mind!*

It was all a part of my recovery, the sooner I got up and moved so all my systems kicked back in, the sooner I could go see Brian. I was so alone and scared. Here I was in St. Joseph's hospital in Warren, and my baby was in St. Elizabeth's in Youngstown. There were four cities between me and my baby.

“Can I have the number for St. E's to check on Brian?” I asked a nurse when she came to take my vitals.

“That's a good sign, you wanting to check on him,” she told me.

“Sometimes, when a baby and mother are separated,” she continued, “there's a detachment and the mother and baby have a hard time bonding.” I don't get that, how could any mother ever be detached from her baby?

Frank stopped by for a few minutes, wearing nice clothes and saying he was going out to eat and celebrate. I later discovered he was going on a date.

*What's going to happen to me and my Brian? This is supposed to be the happiest day of my life besides getting married. How come my joy is tainted with so much pain?*

“Will you take my milk to St. E's for Brian?” I asked Frank.

“Find someone else to take it, I'm busy. You know I think him sucking on your tits is disgusting.” He didn't want any part of it, even if it was his baby's nourishment. He told everyone else he couldn't do it because he had to stay by the phone in case he got a tow call.

We had other guys running tows all the time when Frank was at the races, so why couldn't he use them now? Further discussion was of no use. Though it was difficult, I pumped enough milk for two days at a time, and instead, either my brother or sister took it to St. Elizabeth's.

Mom and Steve were Brian's first visitors in the hospital. Steve took Dad's Polaroid to take some good pictures of Brian for me and Dad while I was in St. Joseph's hospital.

“He's beautiful,” mom shared. I read the worry on her face as she spoke. Steve took Mom to see him again. When she spoke to me about Brian, there was something in her voice that told me things were bad.

“Will you take me to see Brian before we go home?” I asked Frank.

“Yeah, if you don't take too long,” he answered. I made a beeline to St. Elizabeth's. as soon as I was released. That was the first time Frank saw Brian, too. In five long days, he hadn't gone to see his son. The nurses were charting all that information, closely watching how we reacted to Brian.

In order to be in the NICU unit, visitors had to first sterilize their hands and put on gowns in a sanitizing room before going in. It was a few more days before I got to hold Brian for the first time, but the nurses did let me stroke him inside the incubator.

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I glanced at some of the other babies in the incubators and it broke my heart. It was overwhelming to see them. One, across the room, a girl, was only one and a half pounds. One baby dressed in blue next to Brian was crying incessantly. He **looked** healthy; his weight was far more than Brian's. I judged him to be close to full-term. There were nurses attending to him, but he was inconsolable. One walked with him and talked to him, rocking him and whispering in his ear. She shhh'd him, yet nothing calmed him down.

When I came back the next day it was quiet. I spied an empty incubator. I looked at the nurse that attended the baby the day before.

“Was he well enough to go home?” I queried.

She replied, “To his Maker,” as she shook her head, no.

Tears welled up in my eyes, and I couldn't see until they spilled down my cheeks. This was long before the HIPPA laws.

“His mother decided she would 'hotbox' some cocaine to bring on labor. She was tired of being pregnant. He was born hooked on cocaine.” (Hotboxing is when someone takes in continuous hits from cocaine in a pipe.) I was heartsick.

How could any mother do a thing like that? I waited so long, fought so hard, and was willing to do anything for Brian! I just couldn't wrap my mind around this. I had my Brian to think about now, and I said a prayer for him.

“We lost him during the night, he wasn't strong enough to withdraw from the cocaine cold turkey. We can't give babies anything to help the withdrawal.”

I turned to my precious little baby. “Thank God, for giving me the strength, wisdom, and courage to do the right thing for him.” I looked back up to see her eyes filled with tears as well.

## CHAPTER THREE

### IN THE ABSENCE OF BRIAN

Our dog, Rocky, was wiggling so out of control with his stump of a tail it was comical. He was so excited to see me. I was his caretaker and he knew it. I can't imagine what Frank did or didn't do with him while I was gone. Rocky was downright joyful to see me. He tried to jump on me, but I knew enough to keep my distance. He would've ripped me open for sure.

When I arrived home the house seemed so big and empty. Brian wasn't with me yet. I was exhausted from my first day out of the hospital and wanted to lay down. Frank had other plans for me.

We were living mostly in the basement of the new house. Though the house was an L shaped ranch, I had thirteen steps to go down to the basement. Steps I was instructed not to go up or down until my next doctor's visit. Frank's response: "You haven't been a good enough wife to me to have the rest of the house finished." Finding the land, using my income to get the loan, designing the house and drawing the blueprints, as well as working alongside the Amish crew to build it, laying shingles, and raking the lawn wasn't being "a good enough wife."

"There's a load of dishes that need washing." He didn't allow me to use the dishwasher upstairs. "And the laundry needs doing before you do anything, including laying down," he commanded.

I turned away and started to cry. When he heard my sobs he yelled, "Just shut your f\_\_king mouth and get that stuff done." I tried to tell him I could feel the tug at my stitches, that my incision really hurt.

*I just had major surgery and all he's worried about are dishes and laundry? What a jerk?*

"I don't care, I better not catch you in bed until the work is done!"

I cried the whole time I did chores. I was never taught to fight back for myself. I resolved myself right then to the mantra, "Whatever it takes, for Brian's sake," no matter what indignation I had

to endure. Brian didn't ask to be born. When I was done, I sat in my grandmother's rocker in Brian's room and cried. *How was I ever going to get through all of this?* Little did I know this was just the beginning.

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The doctors were still assessing Brian's condition, taking blood samples, testing for O2 levels from pricks on his heels. (To this day, he still bears those scars, there were so many.) One of Brian's Neonatologists, Dr. Rossi, conferred with me that Brian may need a blood infusion.

“Why?”

“We had to take so much blood to test for his oxygen level. His lungs were underdeveloped when he was born and have limited lung functioning. We want to make sure his brain is getting enough oxygen, too.”

She added, “His blood volume is very low, and he could be in serious danger.”

“When do you need to do this?”

“It may be tonight, or not for two or three more days.”

“Can I give him my blood?”

“No, it has to be typed and then washed. We may not have enough time; besides, you're breastfeeding.”

I shared this with Mom in front of my brother at the hospital. Steve immediately asked if he could be Brian's donor. It was the height of the AIDS scare, and I was out of my mind thinking Brian could get it through tainted blood. (It was around the same time the tennis player, Arthur Ashe, was diagnosed with AIDS from a blood transfusion during open-heart surgery.)

The doctor didn't want Steve to get tested, “It'll take three days to get the supply to me. I don't know if Brian has that much time before I need it.”

Steve was willing to take that chance, go all the way to the lab in Cleveland, wait to have the tests done, then draw enough blood to be washed. He was type O negative; so Brian could use his blood. For that one shining moment in Steve's life, it was the most heroic thing I'd ever heard my brother do. (For years when I was younger, Steve was physically abusive to me, and for the better part of twenty years after I turned fourteen, he didn't speak to me except to be verbally abusive.)

"Dr. Rossi, please, he's my nephew! Let me get the test. Where do I go? Who should I talk to? What procedure and protocol should I ask for?" Steve pushed.

"You can't just walk in there; you need a script to do what you're suggesting," she said. "Please, sir, we have blood here to give Brian should he need it."

"But you don't know if it's not tainted," he continued. "I'm O negative; he can use my blood!" Steve insisted.

"I'm sorry, sir, I understand your concerns, but if you go up there, do all that, and Brian needs an infusion before it's ready, it'll be wasted. His mother might not let us give him the blood we have and that could jeopardize his life," she explained.

"Please, just let me do this, if he needs it before then that's okay, at least he'll have this option," Steve told her. She wouldn't tell him what he wanted to know. She didn't give him a script. I felt so helpless for Brian. I was notified that Brian was administered the infusion. My brother and I were devastated.

It wasn't till Brian was four that I was able to have him tested for HIV. Lurking eerily in the back of my mind, I just had to know if we would be facing AIDS complications somewhere down the road. For now, there were too many more immediate concerns. I learned to take things as they came, not to own too many things I didn't have any control over.

With continuous testing of Brian's O2, he was finally well enough to be on his own and off the oxygen. Seven months is a crucial stage intrauterine for the development of a baby's lungs. Brian's weren't inflated at birth which gave him the low Apgar Score. They administered a medical procedure to unstick his lungs and inflate them. The doctor gave him almost pure oxygen in his incubator for nine of the sixteen days he was in the hospital.

Each day I begged the doctors to let me bring Brian home so Dad could hold his beloved grandson. Dad was getting weaker and weaker; I knew it wouldn't be long. I tried to barter with the doctors, promising them I'd bring Brian back to the hospital every day. Once I saw Brian, I was an emotional mess without him.

The nurse took Brian out of the incubator still hooked up to all the wires and offered him to me. I felt so overwhelmed with joy, like my heart was going to burst. It was pounding hard and my hands were trembling. *Finally, I get to hold my precious little one, kiss him and smell him.* He was so tiny and beautiful, more so than I remembered from the day before. I cried. Sometimes, parents don't bond when children are taken at birth for health reasons and it gets complicated. There was nothing complicated about my role with Brian. I was his Mommy and always would be. That was that, no matter what else happened.

Then, the call came I'd waited for. The hospital called to let me know Brian was almost ready to come home.

“Pack an overnight bag to stay at the hospital for us to observe you interacting with Brian,” the nurse said.

He was going home with a monitor that went off if his heart went below a certain setting, or if he stopped breathing. I was instructed to know what to do and attended a special Infant CPR lesson

held just for me. The Nurse Clinician following Brian's case explained to me Brian was going to be developmentally delayed.

“What does that mean?”

“It means that he'll need to play catch-up. First, he'll need to finish what wasn't done intrauterine, and then, he'll need to do all the things a normal baby would be doing. His milestones will be delayed, and it all depends on how fast he grasps learning things to know how long it will take for him to get on track and be age appropriate.”

“How long are you thinking?”

“There's no way of knowing how long it'll take. Some babies recover nicely in a short period of time and others may never recover completely. It also depends on what other complications develop that are related to his early birth and other factors,” she added.

*Oh my God, I can't ever let Frank know this. I am so on my own with Brian!*

Tears rolled down my face. The nurse gave me a compassionate look. I think she knew that was a lot to take in, and she needed to wait for my reaction. I just nodded.

“Here's my card, if you have any concerns or need any help. I can guide you to whatever resources you may need. I'll be checking in with you and Brian at the clinic from time to time, so if you need anything, you can get hold of me there as well. Do you have any questions?”

“No, not for now.” *Yeah, I have a million questions, where do I start?* I was shaken to my core. What would that mean for Brian? Would he be considered mentally retarded? I didn't understand all the ramifications completely. Nothing in my life experience ever prepared me for this.

Brian was 4.62 pounds when they let him come home. (I had bought heavier pieces of roast beef than that to cook!) I thought I was ready to take my little boy home, but not really. They didn't give me

an instruction book to go along with him. However, they did give me a list of things I needed to do immediately for him.

“Take very good care of him,” the last nurse told me.

“I promise,” I answered.

We waited for Frank to pull the car around to pick us up.

*If this is the first sixteen days, what more is in store for us? Where am I going to find the strength to cope?*

## CHAPTER FOUR

### BRIAN COMES HOME

There were two stops I felt compelled to make before we brought Brian home to his new life. The first was to the National Shrine of Our Lady of Lebanon, the nearest Catholic Shrine dedicated to Mary the Mother of Jesus. Danny Thomas, the actor, helped build it. The same person who built St. Jude's Hospital. It was on our way home, sorta, and I wanted a priest to bless Brian and pray for him. I found comfort knowing the connection in case I might need to take Brian to that hospital. The Shrine was a place I felt safe, my Mom and Dad often took me there to mass as a young girl.

I also wanted to thank God for entrusting me with this precious life and dedicate Brian's little soul to Him just in case something happened to him before he was Baptized. I offered up Brian's life to do good things. Being so unprepared for this, I prayed for the strength and wisdom I needed to be the best mom I could be.

They say God doesn't give you anything He doesn't give you the strength to handle, so I had to trust that was so. *"God, help Brian and me,"* I prayed.

The second stop was my parent's place. As we walked over the threshold with Brian in my arms Dad said, "I knew you could do it! I knew you would be the one to have me a grandson!" Brian was sixteen days old when Grandpa Joe got to meet him. Dad was in tears, he was so full of joy. I only saw him cry twice before. Of course, Mom was teary and couldn't speak. We had a great big sob-fest.

Steve got a bed pillow and I placed Brian on it in the middle of the kitchen table. He fit in the center very nicely, his heart monitor alongside of him. Being an electrical technician, Dad was curious about the machine protecting his grandson and asked me lots of questions about it, most of which I couldn't answer.

Dad stared at Brian on the pillow, stroking his tiny little hands, smiling from ear to ear. Brian's hands weren't any bigger than Dad's thumb. *I wonder what's really going on in his mind? Is he thinking about all the things he's going to miss out on?* He was as proud of Brian as if he were his own son. He was still strong enough to hold Brian, so I picked him up to let Dad cradle him. (When I'm reminiscing, this is one of the scenes I play out in my mind.)

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Among the list of things they assigned me to do for Brian was to establish a relationship with a pediatrician. Dr. Basaran, the doctor I chose before I delivered, wasn't at St. Joseph's hospital. Someone said he was out of town and Dr. Shabani, so, the female on-call doctor, took over. She was the one who had made the decision to send Brian to St. Elizabeth's. I didn't know anything about her so I went to Dr. Basaran, anyway. He copped a real attitude and I became very uncomfortable with him.

Taking a look at Brian in the exam room, he said, "Well, Brian, what made you stay at the hospital so long?" I figured that must be my cue to tell him what all is wrong with Brian!

"He was on O2 for nine of the sixteen days he was in, along with...." I proceeded to fill him in with medical terms he would understand. When I got done he looked at Brian and said, "So I see your mother is a Neonatologists!" I was stunned. *Why, because I used big words? Of course I used medical terms, you're a damn doctor! Why wouldn't I use them; I learned what they meant, and I hoped you would know what they meant, too! Duh!*

"No, doctor, I was just repeating what the doctors at the hospital taught me about my son, and I thought that's how I should explain it to you." As far as I was concerned, that would be our last encounter. I made the commitment to Brian right then and there I would find him the best professional help I could, and would go wherever I needed to get him healthy. I realized Dr. Basaran and I couldn't work together. Two more visits is all it took for me to find another doctor. That was the first doctor I

fired (not to his face), but certainly not the last. I later got a bill from him for the delivery room charge. HE WASN'T EVEN THERE! I was fuming when I took the bill to his office.

“Can you explain to me why you sent this bill to me and my insurance company?” I asked the receptionist.

“That's the fee for the doctor when he was in delivery,” she stated.

“Well, you weren't there and neither was he. I was, and it was some other on-call doctor that took care of Brian,” I firmly countered.

“This is the portion of that fee your insurance won't cover,” she continued.

“Since he wasn't there, I shouldn't be getting a bill from him. I should be getting a bill from the doctor that treated Brian,” I claimed.

“No, this is what you owe Dr. Basaran,” she reiterated.

“Okay, I'll call the insurance company and let them know Dr. Basaran wasn't even there, that Dr. Shabani was. I'll tell them they shouldn't pay this bill and my next call will be to report your office for insurance fraud if you don't take it off my bill. I'm not paying any portion of this six hundred dollars and neither is my insurance company,” I said in anger.

I figured it would be a long relationship between us and the insurance carrier, and I didn't want to have them investigating me. I needed them. It was up to me to make sure things were always in order. I never got another bill from them... not even for the visits.

When I left the hospital my discharge nurse offered a support system if I felt I needed to tap into it. I was smart enough to know I was out of my league. I could make proper decisions if I was informed with the right information. I talked to someone at the hospital who gave me the name of a pediatrician, Dr. Stephanie Dewar. I needed a doctor for his checkups and shots. Even though it would be thirty miles away from home, Brian had to be in better hands with someone from Youngstown than

with any doctor I could find in Warren for his specific set of conditions. Dr. Dewar practiced at the Pediatric Clinic at St. Elizabeth's. This clinic dealt mostly with ordinary infant medical care. I didn't realize till much later it was a clinic for poor patients. In my mind, I was still upper middle class, but our "adjusted income" status said otherwise.

And so, the trek began. In his first year of life, I took Brian to St. Elizabeth's three times a week, and Rehab every two weeks, never missing a single appointment--all 9,000+ miles. The "powers" were watching me and how I handled Brian, so I was very careful they had no reason to take him away from me. That was always my biggest fear.

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Six days after Brian came home from the hospital I had to take him back. His monitor kept going off, and it wasn't due to the leads being loose on the pads. They kept him overnight to run a test on the machine and on Brian to see whether it was the monitor or Brian. The tests came back normal, so we collectively decided to give it another go. Brian was only in for a couple of days, but it was very worrisome.

The monitor went off 37 times in 7 months. I had to chart each event on a paper given to me by the At Risk Clinic staff. He wasn't much bigger than my hand from fingertip to wrist, and I was clumsy at first to administer CPR. I didn't want to further hurt him, yet, I had to get him breathing and his heart going. His brain lacked the autonomic response of breathing and pumping the heart. That's a frightening fact for a parent to know. It took time for his brain to do this automatically.

Each time the monitor screamed with the ear-piercing sound, it was just as scary as the first. Frank never went for training, nor did any of my family members.

The first time it went off, I awoke from a fitful sleep, trying to remember all the steps I learned to save his life. I thought, *OH my God, he's gonna die! Do something Kathie!* Immediately, I was

shaking trying to find out why it went off. The lights blinked a different color if he wasn't breathing or if his heart took too long between beats. It didn't matter, I started CPR and brought him around.

Picking Brian up gingerly from his bassinet beside my bed, I just sat there for a very long time holding his warm, helpless body locked in my arms, gently rocking the two of us.

I whispered, "Mommy loves you." I didn't want to let go; I couldn't let go. My arms were locked, holding him snugly to me. It was probably two o'clock in the morning when the alarm went off and woke Frank out of a dead sleep. I wasn't ready to put Brian down, but Frank yelled, "Put the damn kid down and go to sleep!"

"No," I wanted to blurt out, *WHAT A JERK!* I thought.

"My arms are locked; I can't!"

"Well, find a way to unlock them so you can go to sleep, your rocking is bothering me!"

By then I was exhausted but couldn't relax. I took Brian and the monitor to the nursery to rock him until I was comfortable enough to put him back in his bassinet. My incision still hurt when I was lifting the monitor which weighed seven pounds and Brian, who now weighed a whopping 4.12 pounds. That pretty much set the stage for the next thirty-six times, and in seven months of him being on the monitor, it never got any easier. As much as I hated that machine, it was Brian's lifeline for the time being. He and I would literally, have to outgrow it.

In the end, I did what I was told. I always did what I was told. Dutiful wife, dutiful daughter. I was fast approaching the time when I wouldn't be listening to people any longer. I was developing a gut instinct so strong that I used it as my compass, not other people's orders and advice. If I didn't stand up for Brian, who else was going to?

Even as good as a doctor's intentions are, I found that no one would care as much about Brian as I would. They all had their own set of worries, and besides, what they did was a job. They went home to their own children and families.

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Almost all of the pictures Brian has of Frank were staged. Just like the one of Frank carrying him across the threshold of our home. I gave Brian to him, and reluctantly, he took him so I could snap a shot of them together on Brian's first day home. Frank didn't do the same for me.

Brian had lost some weight and looked like a little Biafran baby. I bought a special outfit to bring him home in...it was HUGE! Even his premie clothes were too big. His whole tiny little foot was the size of the first two joints of my pinky finger. I put three pairs of socks on him to put his premie booties on to go to the doctor. I took pictures of him lying next to his Cabbage Patch Premie doll, Joey. (He still has Joey on his rocker in his bedroom, today.) Brian was fifteen inches long, Joey was twelve. I bought a few outfits for Brian from the Cabbage Patch line, and they became Joey's when Brian finally started to grow. It was funny to see Brian as tiny as his doll.

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My breasts were so happy to see Brian. They were always full, hurting most of the time. Nursing Brian was a nightmare at first. I had extremely rich milk and lots of it, but it was difficult to get Brian to suckle. Just because you can pump milk, doesn't mean that an infant will take your breast when offered. I could not get him to nurse.

I called the hospital, I called the LaLeche League, then I talked to a mom with eight children...all breastfed! She gave me the winning advise. Bless that woman for having eight babies worth of experience! I was to put one of those fake nipples over mine and let him suck for a few

minutes, then trick him by taking it away and giving him me. It took some doing, but, within a couple of days, we were on our way to sixteen months of bonding. Brian was literally glued to me between the monitor and breastfeeding. One problem down, and God knows how many others to go!

By the following week Dad took a turn for the worse and we knew the end was close. It was already going on the fourth week of April. Theresa and I hurriedly planned a private Baptism for Brian so Dad could be there. His Baptism would be May 6; time was running out. Dad was now only able to get out for chemo and the doctor.

## CHAPTER FIVE

### DAD HANGS ON

“Will you and Raymie consider being Godparents to Brian?” I asked Kathi.

“When will it be, Kathie?” she inquired.

“May 6<sup>th</sup>. Dad's getting weaker and we want to have him there,” I answered.

“Ill have to talk it over with Raymie and call you back; is that okay?” she asked.

Raymie and Kathi loved my parents. Raymie loved my dad especially because Dad took him out on his boat to fish. Ray loved to fish as much as Dad, and he trusted Frank enough to lift him onto the boat. So, Frank, Raymie and Dad went on a fishing trip Raymie never would forget.

I wanted Frank's cousins to be Brian's godparents. It was important to me that I ask Catholics who I felt would stay a part of Brian's life. Kathi and Raymie are wonderfully caring people and practicing Catholics, one of the criteria for being godparents in the Catholic faith. I felt comfortable with them that if anything ever happened to me and Frank, Brian would be a part of loving, Catholic relatives. I don't think my siblings understood that. None of them remained Catholic after they became adults. I think they felt slighted I didn't ask any of them.

Kathi called to accept; they would be driving all the way from St. Louis. Actually, they lived on the Illinois side of the river, across from St. Louis. The twelve hour trip was no easy task to drive, because Raymie is paralyzed from the mid-chest down. At best it's an uncomfortable drive, yet they were willing to do it for Brian. Brian never saw Raymie as handicapped. He grew up knowing what Raymie's limitations were and accepted them without question. He's Uncle Raymie, and that's all there is to it.

Saturday, May 6<sup>th</sup> came quickly. Between all the doctors and specialists I took Brian to, and all the driving, his Baptism was a welcome break. I was almost surprised Frank came. Then again, his

cousins **were** Brian's godparents. How could he not be there? They stayed with us for their entire visit, and Kathi got to feed Brian a small amount of baby food, which she was happy to do. Frank's father didn't show up for the event, nor did Frank's two sisters. His mother didn't take off work to come to the actual Baptismal ceremony, yet managed to come for the food at the party.

*What's the point? Oh yeah, she didn't have to cook for herself and it was free food.*

I had to get special permission to have Brian's Baptism private. Under the circumstances, I found only one priest that would let it be done at his parish. He couldn't perform the Baptism due to prior obligations so he allowed the Deacon to do it. It used to be that a baby wasn't brought out in public until their Baptism, six weeks after birth. Times have changed. It's now up to six months-old and it's a group Baptism. I didn't have that kind of time. Between Dad's cancer and Brian being so medically fragile, I didn't want to take any chances.

The party was at Theresa and Bill's house after the ceremony. My brother-in-law was awesome about everything. Since Theresa didn't work he was the one who actually paid for it. I will be forever grateful for everything they ever did for us. Her house was finished the nicest with custom drapes and fine china. She had plenty of room for the twenty-five or so guests with a big backyard and patio for the spillover. Theresa really knocked herself out with a buffet luncheon, candelabras, fresh-cut blue flowered centerpiece, and blue napkins--the works! Everything looked so beautiful.

Longingly, I thought I should have been able to have the party at my house but, even since our house was built eight years prior, I was still living in the basement and rooms weren't finished. I always felt like my family thought I was second class. Just because I didn't have the kind of wealth to live on the East side of town, I still thought I had class and was intelligent.

I got as many pictures of Dad holding Brian as I could. In them, you could see how drawn and utterly frail Dad was. The picture of all of us as a group at the church was the last one Dad was ever in. It was also his last outing; it drained him of every ounce of energy he had left.

I can't explain the peace of mind Brian's Baptism gave me, knowing that if something happened to him now, he was good to go straight to Heaven. I had taken care of his soul as well as nurture his body. I was at peace. So much pressure was on me to know about everything he needed simply by the position I held as mommy. And, I took my job seriously.

During my pregnancy, I ate right, stayed away from chemical fumes and cigarette smoke. You name it, I was on top of it. I drank only orange-pineapple juice, milk or bottled water, not trusting the well water. I watched what I ate only gaining thirty-two pounds. For the longest time I beat myself up blaming myself for Brian's problems. When I had a chance to step back, I realized all the things I did were right, and what happened was completely out of my hands. I live the premise that all things happen for a reason. I just didn't know what the reasons were at the time.

A week after Brian's Baptism was Mother's Day. My original due date. Frank had nothing planned nor did anything special for me. After I got back from church with Brian, I asked Frank to take a picture of him and I by the Dogwood tree in the backyard. He obliged. I always made sure Brian was dressed in day clothes and not just in jammies. He had on a special little outfit for the picture.

Since, as a family, nothing had been planned, I took Brian to see Mom and Dad. They were ecstatic to see him...they always were. I had to nurse Brian while I was there, and Dad got the idea that what better picture to take on Mother's Day than me nursing my new baby. He took a couple, one for them and one for me. I thought that was awesome in light of how Frank felt about breastfeeding.

By the time Mother's Day came, the doctors at the At Risk Clinic at St. Elizabeth's had discovered more of Brian's problems. The Clinic was pleasant enough, with caring nurses, but it was

still a cold, sterile place with overhead lights that never dimmed, like an interrogation room. There were several charts on the walls from different pharmaceutical companies telling new mothers what to look for, as well as plastic models that doctors could use to demonstrate an infant abnormality. Brian's biggest problem at the moment was that he wasn't able to eliminate waste. So, for three months, I had to help train his sphincter muscles to do "stinkies." I was instructed to use a rectal thermometer every diaper change to stimulate his muscles into action. At times very messy, it wasn't the most pleasant task. They didn't give me instructions on "how" it should be done, so there was plenty of trial and error. But, I really didn't mind, because I knew it was helping Brian.

It was important to me to establish and maintain a routine. I needed some kind of order in my life, and the routine became my saving grace.

When Brian was tiny it was easy to carry him and the monitor around in a laundry basket. Even Joey hitched a ride. I lined the basket with a bed pillow, one of the harder foam ones so he wouldn't sink in. I did housework and dishes, and when Frank was gone, I sang. (Frank hated my singing, making fun of me when I did, and wouldn't allow it in his presence. I never understood that since I was a trained vocalist and didn't sing off-key.)

Brian was always at my side. As he grew, I rigged his stroller so both the monitor and Joey fit in with him. It was so much easier than carrying around the basket. I could push him from room to room without him waking up. A baby seat was always on the counter for when I was cooking, but nowhere near the stove. His highchair was stuffed with a small blanket folded so he wouldn't slip out.

With Brian in the stroller, it was finally better for me so my incision could heal. With all the lifting, I hadn't been healing properly and my insides felt like they were constantly ripping open. It hurt, a lot! But I kept my mouth shut. Frank was gone a great deal so I had to do everything myself.

As Mom said, "You made your bed, now you have to lay in it."

I always thought that was pretty cruel, but it was the truth. I couldn't stick my family with any of this--it was my own doing and I needed to take care of it.

I had to keep doing what I needed to. I would have gladly accepted the help if someone would have offered but no one came to help. Mom was busy during Dad's final days, and it wasn't until after he died that she was able to come keep me company, playing with Brian while I took a hot bath in my sunken tub. I had to go so many times a week to the hospital with Brian, besides cooking and cleaning at home, it left little me-time, if any.

I busied myself between housework, taking Brian to all his appointments, and going to see Dad. His decline was rapid. His final days were coming quicker than I wanted. By the following week, he was pretty much on the couch most of the time. He still got dressed, but didn't feel like doing anything. Frank and I decided Capt'n (Frank's nickname for Dad) needed cable TV to pass away the time. We paid for the initial installation and first three months of service. Dad was a happy camper.

Mom said he watched a lot of the Discovery, National Geographic, and science channels. His favorite channel was the one about outdoors and fishing. When the pain became too intense, cable was a distraction for him, and it helped pass away the long lonely hours Mom spent just watching him die.

My middle sister, Mary Ann, dealt with Dad's dying in a way I didn't understand. I know she was busy with her two girls and their school activities, but Dad wasn't going to be here much longer. Anything that could be put aside, I felt, should. Theresa and Bill were making regular visits with their daughter, Bekki; and Steve, although he was living at the house, was getting regular visitation with his daughter, Kantele. (He never did marry her mother.) Even Steve's old girlfriend, Cathy, who was also Mom and Dad's neighbor, visited with her son and daughter. Mary Ann kept calling Mom to check on Dad's condition and told her she had this or that to do. Mom told me about it and said she was hurt for Dad that Mary Ann didn't come around with the girls.

After Mom told me about it, I took it upon myself to call Mary Ann.

“Do you know how bad Dad is?” I asked her.

“Well, yeah.” There was hesitation in her voice.

“Mom said she hasn't seen much of you and the girls,” I added.

“Kathie, I work twelve hours a day, and the girls have activities too,” she defended.

“Well, I think, you should come more often, and with the girls. Cancel stuff if you have to 'cause he's not gonna be here much longer, Mary Ann.” It may have been none of my business, but, I felt I had to say what Mom couldn't.

“Look, I have things I have to take care of, and the girls are in a lot of activities. I'll stop by as soon as I can.”

“All I'm saying is, you can't wait too much longer 'cause he's not gonna be here forever.”

“I'll see what I can do,” she said as we hung up.

It was a few more days before Mom said she showed up.

I think dad was hanging on for Father's Day, which fell on June 18 that year. Mary Ann sent him an early Father's Day card and came to see him the weekend before the holiday. You could tell she was rattled by how he looked and didn't stay long. Because of the card, I think Dad figured he made it past Father's Day, so he gave up the fight. By then, he was doped with morphine so time was distorted for him, and hospice had been there for about a week.

“Kathie, the Hospice nurse said that Dad's really bad and the family should be called,” Theresa said. It was June 13<sup>th</sup>.

“Frank, I'm at home now, but my sister just called. The Hospice nurse said that the family needs to be by Dad's side.” Frank just said, “OK.”

I was headed to see Dad but decided to stop by our body shop and towing company on my way. Frank was in the middle of sanding a car panel when I walked in, but as I did, the phone rang. It was a tow.

“Please get over to the house as fast as you can,” I pleaded.

“I'm going on this tow, I'll get there when I can,” he told me. “I don't want to be standing around just waiting for him to die.” I left. I needed him now more than ever as a friend and my husband and something else was more important.

It was three o'clock when I got to my parent's. Each hour Dad's vitals weakened. He was laying on the couch and mom sat next to him. I brought Brian in and took Dad's hand to touch his head and stroke his face.

The phone rang, it was Cathy, Mom's neighbor. (There were a lot of Kathie's. Kathie, with an ie, Cathy with a C/y, Kathi with just an i. It was confusing at times but we are all around the same age and that's what happens when a name gets popular.)

“Kathie, why don't you bring Brian over here for us to watch until he needs to be nursed, or you need to leave?” she volunteered. Cathy was such a thoughtful, nice, down to earth person.

“I think I might take you up on that if it isn't too much for you,” I stated, half in question form giving her an out if she wanted it.

“No, really, it won't be too much. The kids are here so if Brian should need you, I'll just send one of them over to get you real quick.” Her gesture was such a welcome relief.

I gathered all the things I had brought for Brian and walked over to her place. She met me at her porch steps.

“Thank you so much for taking him,” I said.

“Not a problem, you know I'm a sucker for babies,” she added, “and he's a little cutie.”

We went inside so I could quickly explain the heart monitor to her and how to arouse him with CPR. It struck me that she was willing to do this for Brian and I, but my own family wouldn't.

“Call over at home if you need me for anything, or just send one of the kids. He should be okay though,” I said.

Rushing back, I got on the phone to call Frank. He still wasn't there.

“I'm still tied up with that tow; I'll get there when I can,” he said in an agitated voice.

“I know you really don't want to sit around and watch him take his last breath, neither do I. But, the nurse said he's probably waiting till all the family members are here. Please get here as soon as you can,” I pleaded once again.

Bill was out of town for his job, but Mary Ann made it without her girls. Theresa was there, but not her daughter, Bekki. Steve's daughter wasn't there either.

We were in the living room as Dad fluctuated between smoking a pretend cigarette and casting and imaginary fishing line. *What a statement on who he was!* He'd smoked Lucky Strike cigarettes since he was nine years old--*he didn't look so lucky to me*--and his passion was fishing. He was happiest when he could combine the two. There he'd sit at the back of his 28 foot cutty-cabin boat, with three or four poles cast over the transom at any given outing. Each one of the poles had four leads, so he, theoretically, could catch a dozen or more fish at a time. With a cigarette in his mouth, he was damn near in heaven. Or, that's what he thought then.

As we stood vigil, I recalled something dad would do at night when he put me to bed.

“I don't know if dad did this with you,” I asked my siblings, “but when he would put me to bed, I said my prayers with him. He always told me to say an extra Hail Mary for a happy death.” I looked in each of their eyes, but they didn't respond to me. I kept going.

“I didn't understand it then. I didn't know what a happy death was, but I guess I do now as an adult. It really does make sense.” Mom looked up at me with her sad, tiny, dark brown eyes. “Hail Mary, full of grace....” I said the entire prayer, Mom saying it with me. The others just stood there still while we prayed.

I called Frank at the shop one last time, and they said he had already left, that he was on his way. It was 5:45 p. m. Frank got to the house at six. He was the last to arrive. He walked in, knelt down by the couch, and said, “I'm gonna miss you Capt'n.”

I leaned over to dad and whispered in his ear, “Go to the light, Dad, go catch some fish. It'll be okay, we'll take care of Mom.”

With Mom's one hand holding Dad's and her other on Dad's chest, she felt his last heartbeat. Dad died at 6:10 p. m. He was only sixty nine years old. My ally against Frank was gone. I was numb. A flash of all the things he taught me came rushing back. *How am I going to ever teach all those things to Brian?* I was mad he left and didn't get to enjoy the one who needed him the most, Brian, or was it me?

I can hardly remember anything from the moment Dad died until the wake at the funeral home. I was overcome with such sadness I couldn't even think. I vaguely remember Ken and Terry Seibold coming down from Mantua, Ohio. He was a racing buddy of Frank's. Terry cooked dinner so I was able to take a hot bath and relax. She kept an eye on Brian. I was okay with that for two reasons: I was there, and she had four kids of her own.

I remember getting out of the tub, putting on my robe, coming out to thank her, and hearing a dripping noise from somewhere. I had dried my hair and the sink wasn't leaking. It was me. I was so relaxed I had milk “letdown.” We all laughed except Frank. He didn't think it was funny at all. I wiped it up and went back to get dressed.

## CHAPTER SIX

### THE FUNERAL

I know I took care of Brian, however, whatever happened in those following days is fuzzy. Frank was a pallbearer, but I don't remember him being alongside me for any of it, if he was at all.

Steve asked, "Do you need some help going up to the casket?" I nodded, yes. I'm sure that shocked just about everyone there. It sure did me. In all the years of abuse from Steve, that was the last thing anyone expected my brother to do, especially me. I was so emotionally drained, after Brian's birth, his Baptism, and now Dad, it was like I was having an out-of-body experience, just going through the motions on autopilot. Brian was in my arms as I walked up to the casket with Steve. I didn't feel like standing in a receiving line. My incision still hurt, Brian was heavy and I had to carry the monitor. I didn't think to ask Steve to carry the monitor. I didn't want to bring the stroller into the funeral home, their viewing rooms being small. I sat in the back of the room where dad was laid out. The receiving line was at the other end of the room by the casket.

Dad looked like he always did when he fell asleep in his Lazyboy chair, fingers intertwined across his stomach. Dad laid there in the one suit he owned, medium blue, that he wore whenever there was something important to attend. This qualified. He requested to be buried in it when he and Mom made their final arrangements. What a favor they did for us in that respect.

*Bye dad, I love you. May your soul and all the souls of the faithfully departed through the mercy of God rest in peace, Amen.*

Tears flowed down my cheeks dropping onto Brian. I didn't have another hand to wipe them. As I looked at Dad I kept thinking, *why did you have to smoke those damn cigarettes? I need you and you're not going to be here for me! How am I going to raise Brian without you? Our lives would be so*

*much different if you were still here. Please, help me with Brian if you can from where you are now.* I stood there for a long time, touching his hand.

When I was ready, Steve walked me back to the bench. The tears fell on Brian wetting his outfit in one spot as I rocked him, no...us...back and forth. The priest was saying a rosary which was another of Dad's favorite things to do. Later, Mom gave me his prayerbook and rosaries for Brian. I just sat and wept. It was pretty much all a blur.

We buried Dad two days before the holiday. Father's Day came and went. I could hardly breath, the loss was so great. You never really are prepared for how great the loss of a parent is. I didn't have any time to grieve. I'll grieve later, I kept telling myself. I hit the ground running the next week, going to the At Risk Clinic twice and to an assessment of Brian's physical body. Brian was just ten weeks old when Dad died. Thank God for the extra time we had with him. If I'd have gone full-term, we would've only had a month, and most of it Dad was not even able to function. It was a bittersweet trade-off.

“You know, Kathie, your Dad apologized to me one night when he couldn't sleep for putting me and you kids through this. He admitted to me he should've quit smoking years ago. He said he just couldn't kick the nicotine habit, it was too strong for him to overcome,” Mom said.

I got into a groove doing housework, taking care of Brian, and making sure I didn't piss off Frank to give him a reason to be nasty to me or Brian. It really didn't take even that. He was just plain mad Brian existed. The thought of Frank making a less than perfect baby was more than he could handle. Brian had two strikes against him. Not only was he born, he was born less than perfect. Frank's attitude never improved, no matter what I did to make him see Brian in a different light. Frank expected me to answer phones at the shop and take Brian out, even in the middle of the night, if he

needed one of the other tow trucks. He held me to my tasks at the shop like before Brian was born, on top of everything else I had to do for Brian. We didn't speak about Dad openly again. He was simply gone from our lives. No grieving, just gone.

## CHAPTER SEVEN

### FINDING BRIAN'S WEAKNESSES

“There's a Children's Rehabilitation Center in Trumbull County you can take Brian to,” Dr. Abram said. It was a **strong** suggestion that I take Brian. The doctor at the At Risk Clinic, Dr. Joseph Abram, was a Pediatric Developmental Specialist who pretty much called all the shots on how and what happened to the babies that came to the At Risk Clinic at St. Elizabeth's. I found him off-putting to say the least, but he was in a position of authority AND he was a doctor. From my upbringing, he may as well walk on water. I made the appointment to get Brian assessed and talk to the “financial” people. It was a “for profit” center.

On my way out, I took one of the brochures about the facility and actually read it. Low and behold, one of the board members just happened to be Dr. Abram. *Oh, what a surprise!* The schedule was for me to take Brian for one hour every two weeks, for half an hour of physical therapy and half an hour of occupational therapy. On the following two week visit, he got half an hour of speech therapy and half an hour of developmental therapy. I was shown the particular therapy for that two week period and was supposed to do it at home with Brian.

*Wait a minute, here I am wracking my brain to do time management for all the appointments, and this place wants **me** to do the therapy? I'm already doing six hours of therapy a day with Brian. There's got to be a better way to do this. I'm not saying I'm above doing it, but I'm only one person, they don't know I'm alone in this, and I've got a lot on my plate already!*

“Is there any other program for physical therapy?” I asked one of the nurses at the clinic one particularly tiring day.

She gave me a name and number to call. I enrolled Brian in a program at the hospital with Christine Price, a pediatric physical therapist. She was wonderful with Brian; he loved seeing her. He

did everything she wanted him to. Christine gave me so many helpful hints the rehab therapist never even thought of. Dr. Dewar was pleased I was happy with her. I told her how good she was with Brian. Dr. Dewar liked Christine and thought she'd be a great match for us.

Time dragged on, but I kept Brian in both programs for a while until I was sure he was in the right one. Each visit to the doctor or to the clinic found something more wrong with Brian. The nurses were very supportive and Dr. Dewar, his pediatrician, was just incredible. Her guidance was priceless. Not only was she his doctor, she was my coach, talking to me, mother to mother. She had three children of her own, and her son was almost the same age as Brian. We were raising our sons together, rather, at the same time. Her world was light years away from mine, yet we connected on some level...motherhood.

All Brian's milestones had to be taught rather than them coming naturally. He had to be taught to swallow properly. It took me till he was fourteen months old to stop him from drooling. When he was able to eat table food, I put a single Cheerio on a spoonful of milk so he would have to hold it down with his tongue, and give it to him. Because he had to hold down on the Cheerio to swallow the milk first, then eat the Cheerio, he did. As he did that I stroked his throat in the direction I wanted the milk to go. I was stimulating his throat muscles to be used more, and therefore, they were being strengthened.

Not only did his sphincter muscle not work, but it was discovered Brian had an inguinal hernia. Dr. Dewar said we'd just wait to see if it didn't descend on it's own. She was very hesitant to do any kind of invasive surgery on Brian unless it was absolutely necessary. She felt he was still too weak to make it through a surgery. Eventually it corrected itself.

A pediatric surgeon was responsible for taking care of Brian's "potty" problem. After three months of treating him on my own, he was enlisted to resolve the problem and he did.

Brian did everything late. He rolled over at eleven months, crawled at thirteen months, and didn't walk until he was eighteen months. His balance was bad and he fell a lot. I carried him so he wouldn't get bruised, because I didn't want the doctors to think I was abusing Brian. I carried him a lot until he was four...until he was too heavy for me to carry for any length of time. His right eyelid drooped; that's evident even today when he gets tired. The medical term is "Ptosis" of the eye.

Christine showed me how to exercise his legs to strengthen them. That's when I noticed two things no one else had. His right side was not responding the same way his left was. Dr. Dewar said it was right-sided weakness, but it was damn near paralyzed. I think she wanted to downplay it because of all the other complications.

I worked extra hard with therapy on that right side. Also, when I laid him down in the playpen to sleep, I noticed his arm was twisted and contorted, and he'd put it in a backward position. I'd correct it and he'd put it back that way again. He was three and a half months, yet I never noticed it until then. I guess I was just a little occupied. I asked Christine about it on the next visit.

"What am I to make of him sleeping with his arm twisted and contorted? When he sleeps it's really noticeable."

"I'm not sure, let me do some checking, and I'll get back with you on that," she answered.

"I think it might be Erb's Palsy," she shared on our next visit.

"You'll have to ask the doctor about it. I could loose my license telling you this. You should definitely ask him about it," she almost whispered.

"Dr. Abram, could Brian have Erb's Palsy?" I asked at our next At Risk Clinic appointment. He didn't give me an answer. I was fast losing my patience with him, he was so evasive. I just wanted answers. I could take the truth. *The more I know about Brian's conditions the more I can help him.* I told him that, but he just said that things were "coming along" with Brian.

*How stupid does this man think I am? I need to find Brian another doctor, and soon, before this one kills him with his ego!*

Since St. Elizabeth's is a teaching hospital, there was a medical library in the building. I found it and spoke with the Librarian. I explained I needed answers to make a more informed decision about Brian's care. With a very caring smile, in a quiet tone, she leaned into my space and almost whispered, "I'm not really supposed to let the general public in to do research. If you come back between four and five, right before I leave, I'll let you look up the information on your son's conditions."

"Erb's Palsy is a paralysis of the arm caused by injury to the upper group of the arm's main nerves (specifically, spinal roots C5-C7), almost always occurring during birth. Depending on the nature of the damage, the paralysis can either resolve on its own over a period of months, necessitate physical therapy, or require surgery," the medical book said. The old fashioned term for it was "waiter's-tip hand." It often looks like someone is sneaking money to a person by putting their hand backwards at their side. The elbow often protrudes slightly when you do that, almost as if the back of the wrist is being put on the hip. My Aunt Irene was born like that. It left her handicapped for life. I determined right then he would get as much physical therapy as he needed to correct this problem. At least it was one we could work on.

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The At Risk Clinic was monitoring a phenomenon with Brian's head. The nurses would tell me about his head growing two centimeters a week when they were doing his vitals. I had no clue as to what that meant. I needed an explanation. Dr. Abram started talking about bringing in a Pediatric Neurosurgeon, Dr. Stephen Kalavsky, to review Brian's case and do a neurological profile for him. *They can't operate on Brian without my consent; all they're gonna do is talk. It'll be okay, Kath. The*

*more I know, the more I can help.* Dr. Abram brought up the idea of a full assessment, because he suspected Brian had hydrocephalus. I agreed to the assessment.

My research about hydrocephalus uncovered what happens when the skull bone closes. It is called stitches. I wanted to know what Dr. Abram thought of how fast the stitches would close over, how much time he thought Brian's would take.

“What about the stitches Dr. Abram?” I asked. He was writing on Brian's chart with his back to me. He smugly said, without looking up or turning around, “That's when you have a cut and get stitches to sew up the wound.”

“You know those aren't the stitches I'm talking about doctor, I'm talking about the ones in Brian's head closing in his brain,” I controlled my response.

He paused for a moment, threw his pen across the papers, slammed his hands on the top of the desk, pivoted just enough to look at me, and said, “And just *where* did you get that kind of information?”

“Well doctor, I've been asking you how Brian is doing, and I feel you've been avoiding my questions. So, I did my own research about hydrocephalus,” I answered as calmly as I could.

With that, he walked out of the room. A nurse came in and said, “You're done. You can go make next week's appointment at the desk.”

During this time, Brian was taken off the heart monitor. I think we were both ready to be done with it. The first few weeks were scary for me, but like with everything else, I managed to keep my fears in check and get on with life. There were so many things to “get on” with.

It was then I decided Dr. Abrams was done as Brian's doctor, but I needed to figure out how to get rid of him. So I talked to Dr. Dewar in the hallway when I saw her walking toward me.

She said, "It's up to you if you want to bring Brian to the At Risk Clinic. *That information changes everything! I thought I **had** to take Brian to the clinic. They didn't tell me I had a choice! So I do get to call the shots, not that arrogant egotistical jackass!*

I'll help you all the way if you choose to stop coming to the At Risk Clinic. I can follow Brian close enough to make sure he's okay," she shared.

"I'll think about it, he wants to do an assessment and bring in Dr. Kalavsky," I told her.

"I know he called to ask my opinion, I feel it's a good move." She asked, "How do you feel about it?"

"I think it's a good idea to have the assessment. I don't have an updated, complete picture of where Brian really is right now health-wise. This might give me some answers," I said.

The next visit I met with Dr. Stephen Kalavsky, a cross between Albert Einstein and the professor from ***Back to the Future***, to discuss about the numbers they were monitoring. There must have been quite a water cooler discussion about Brian.

Test, more tests. We were summonsed to a results conference. By "we" I mean Brian and me. For the sixteen days Brian was in the hospital, Frank only saw him the first day I was able to go, one other day and the day he picked us both up once Brian was allowed to come home. He wasn't at this, or any other appointments either.

Through the window of the conference room clouds hung low in the late October sky. I saw the rain start, it was cold and damp and Brian was fussy. I wanted to keep him together since everyone would be watching how I handled him. I was always afraid if I did the wrong thing, someone would take him away from me. That nagging feeling never went away.

The conference room was small but there was enough room for eight adults and one baby. I sat nearest the window at the end of the table, furthest from the door. Just above my head was the x-ray viewer, the one that lights up to show the ominous news to patients.

In they came, one at a time. Dr. Abram, Director of the At Risk Clinic, started introducing them; his assistant, the child-life coordinator, Dr. Kalavsky, the in-house minister, Dr. Dewar, and a social worker. I was already there and of course, Brian in my arms. The social worker was the only one at the time who offered her support. "If the information you hear is too overwhelming, you can let me know." I waited as they shuffled papers and adjusted their seats.

*I wonder what the news could be? Could it be any worse than the preceding months when they handed Brian to me attached to a machine that warned me of his imminent death, when I couldn't get Brian to nurse from me, or when dad died, or when the doctors told me Brian wasn't able to defaecate on his own, or when I discovered he had Erb's Palsy and was paralyzed, or is it because of Brian's head growing two centimeters a week, or maybe it's some other unknown malady they found? Whatever it is, I'm about to find out.*

The conference started by someone asking me, "Do you have anyone to be with you or is anyone else coming?"

"No, there won't be anyone else, you can proceed."

*No matter what the new is, just give it to me already!*

Dr. Kalavsky, the Pediatric Neurosurgeon began explaining the x-ray he had put in front of me on the light box. He pointed to an area of Brian's head on an x-ray film the CAT scan made, slightly inside the skull line where it was light gray.

"This," he started, "is hydrocephalus, or excess fluid on the brain. There is no way for the body to drain off all the extra amount of fluid formed so it starts to collect. It's now seeping into the lining of

his skull and into an area of the brain that has some space left for it to travel. That's why your son's head had been growing approximately two centimeters a week.” “When a baby is born,” he continued, “their skull is in four sections. It's designed that way so the head can travel through the birth canal. As a baby's head grows, the bones close forming one solid bone structure, the skull. Once the skull completely closes, there won't be any more room for the fluid to go, creating pressure on Brian's brain. In Brian's brain the location of the most fluid is in the frontal lobe.”

He looked at me and paused, “Treating it is next to impossible with a successful outcome due to it's location and how I'd have to access it with a shunt. A shunt is a drainage tube that's placed within the affected area and would have to be replaced periodically as your son grows, to lengthen the drainage tube.” He further adds, “it is best to usually wait until the patient becomes “acute” before I operate in order for me to reach the frontal lobe. That's the location of a person's reasoning center. (Our long-term memory, planning and drive are also there. Full cognitive maturity of the frontal lobe doesn't occur until around age 25.) “There's a high probability of massive brain damage and Brian is fast approaching that threshold.”

*NO WONDER THEY'RE ALL HERE!* I'm stunned, and relieved. *I have one more answer! Now it's up to me to decide what to do about it. I need more information. I don't trust these people to give me the straight answers I need now. I'm gonna do my own research. Just because they got to the medical books first doesn't mean I can't hold my own with them. I'm not stupid!*

“There is a great likelihood your son may be in a non-responsive state...or..he could be trainable to maybe do janitorial work.” Once the operation occurs,” he continues, “you shouldn't expect too much from him. After the shunt is in place, you can take him home and love him and bring him back in three years for an extensive evaluation like the one he's just gone through.