

MY

PICTURE

FAMILY

PERFECT



WHAT HAPPENS  
WHEN ONE TWIN  
HAS AUTISM

MARGUERITE ELISOFFON



*"My Picture Perfect Family* is the story of a family's dedication to helping their daughter succeed against all odds. The explosive 10-year-old who made no eye contact, talked to imaginary friends and turned out the lights in my office, blossomed into a beautiful 18-year-old who was able to go to college. Every time I saw Samantha, I felt I was taking a nail out of her coffin."

Dr. Harry Wachs, Founder of The Vision & Conceptual Development Center and co-author of *Thinking Goes to School*

*"My Picture Perfect Family* tells the spirited and honest story of how Marguerite Elisofon and her family successfully found their way through life with a child on the autism spectrum. It's an optimistic and inspiring illustration that if you refuse to give up or give in, you can, indeed, achieve your dreams."

Margaret Poggi, Director of LearningSpring School

"This is a timely and important work about a topic that is going to be more and more a subject of interest in the intellectual marketplace. The (autism) spectrum is far wider and more complex than previously appreciated and *My Picture Perfect Family* adds to our understanding of how we must go about bringing out the best in, and releasing the potential of, this varied complex and interesting group of individuals. Parents will read, learn, and be both inspired and assisted."

Don Kerson, MD, author of *Getting Unstuck: Unraveling the Knot of Attention, Depression, and Trauma*

"This relevant depiction of navigating the world with a child growing up with autism encourages, educates and inspires. Marguerite Elisofon's tells her story of how, through persistence, courage, creativity and humor, she and her husband recognized and strengthened the gifts of their unique twin children. *My Picture Perfect Family* is an important read for parents and professionals connected to the world of autism."

Allison Kleinman, Founding Director of the Jack & Shirley Silver Center for Special Needs

“Therapies, education, and innovative programs will never be enough of a substitute for the support of a loving family. Marguerite Elisofon’s real-life account of her family’s journey is an example of what we should all strive for while celebrating the most ‘minuscule’ milestones and maintaining a sense of humor. As someone who continues to work through the challenges of Asperger’s syndrome, it was refreshing to root for Samantha and anticipate the victories that await her in adulthood. *My Picture Perfect Family* reminds us there is no such thing as a perfect family. Just those who are doing the best they can to navigate the labyrinth of Autism Awesomeness!”

Jesse Saperstein, autism advocate and author of *Getting A Life With Asperger’s*

“The Elisofons aren’t your average family. Together they face and steadfastly surmount a myriad of challenges related to the autism spectrum that no parenting book can prepare anyone for. In *My Picture Perfect Family*, Marguerite Elisofon shares her family’s struggles and achievements with personal stories so close to the bone I felt I was the family cat curled up in a corner sometimes wanting to nuzzle, sometimes wanting to hide, but always wanting to come back for more.”

Liane Holliday Willey, author of *Pretending to be Normal: Living with Asperger’s Syndrome* and *Safety Skills for Asperger Women: How to Save a Perfectly Good Female Life*

“*My Picture Perfect Family* presents the powerful and engaging story of raising a child with autism, as well as a bittersweet memoir about family life. This first book from Marguerite Elisofon is a hard-earned victory, exploring heretofore inadequately touched territory that boldly delves into challenging content with a uniquely heartwarming touch that is both poignant and probative. A read not to be missed.”

Jacob Miller, award-winning poet and author of *The Last Word*

“*My Picture Perfect Family* is a beautiful story of parental love and resilience. Marguerite Elisofon’s memoir of raising her two remarkable children is heartbreaking, honest, and filled with humor. It is the story of how Samantha Elisofon, the lead actress in my upcoming feature length film, became the outstanding young woman she is today. Samantha’s spontaneous joy and authenticity stand out on film as much as they shine on the pages of this inspiring memoir.”

Rachel Israel, Director of *Keep The Change*

“Parents know it’s not the level of a child’s autism that matters, but how it impacts on the child’s life! Undoubtedly, the entire family, especially siblings are affected too. Imagine being a parent of twins... one with and one without autism?

This heartwarming story gives the reader a thought-provoking and insightful understanding of how a mother warrior fought to ensure that her disabled child had the same access to education and other opportunities as any other without a disability.

Having been there myself, albeit in a different way, I embrace this book. Marguerite shows us that autism is a condition to nurture, and that those affected can contribute to society, rather than be dependent on it.”

Nuala Gardner, author of *A Friend Like Henry* and *All Because of Henry*

“*My Picture Perfect Family* takes an honest look at family life while raising a daughter on the autistic spectrum. In our social circles it is imperative that we appear perfect in every way, and that includes our children. But what happens when a high-achieving couple, seemingly with everything, must confront the fact that their daughter is ‘not perfect’? They love her, they fight for her, and she transforms the family into something stronger and more resilient than they might have been had they had that ‘perfect’ daughter. Humorous, bittersweet and instructive, Elisofon’s memoir brought me right into the heart of a mother who always believed in her daughter and never stopped trying to bring out the best in her. It reminds us that our job is not to live a ‘perfect’ life according to contemporary standards, but that we fully embrace and love what we have. For what we have is, without qualification, the true perfection.”

Lynne D. Feldman, MA, JD, author of *Integral Healing*

“In this brave and moving memoir, Marguerite Elisofon relives the battles and setbacks she withstood to give her daughter with autism a fighting chance. Her skills as a writer and her passionate advocacy for her child make *My Picture Perfect Family* more than just one family’s story: it’s a universal tale that will resonate with anyone who’s ever faced an unfeeling bureaucracy on behalf of a loved one. You root for her as she fights for her daughter to get the education and support she deserves, and cheer when that child, now a beautiful young woman, defies the odds to graduate from college and set out in the world. It’s a compelling and fascinating book that should inspire all of us to do more.”

Barbara Peterson, author of *Blue Streak: Inside JetBlue, the Upstart That Rocked An Industry*



“With unabashed candor, *My Picture Perfect Family* opens the door to the events, feelings, and family dynamics of raising an autistic daughter. It is at once new and unfamiliar, yet filled with the same feelings of apprehension, disappointment, hope, pride and above all, the love that all parents feel for their children. Her tale is both touching and powerful. We end up learning what the cognitive and emotional variations of spectrum disorders are in a way that no clinical approach ever could. Of course the book is a must-read for those interested in the subject; but the appeal is for all parents, whose children’s trials and tribulations are their own, intensified here by the prism that creates\* the autistic spectrum.”

Alan Wikler Psy.D, Clinical Psychologist

“Autism is not a new word today. But many readers may not be aware about the struggles and triumphs a family faces when a loved one has the challenge of autism. In *My Picture Perfect Family*, Marguerite Elisofon opens a door into the life of her family. We meet her daughter Samantha, and follow her as she evolves through therapies and social hurdles, schools and friends, family and her twin brother, into a young woman who graduates from her school at eighteen. May her story be an inspiration to other families who struggle with their loved ones every day through the message this book gives: 'No matter what, keep the smile'.”

Soma Mukhopadhyay, Founder of Helping Autism through Learning and Outreach (HALO)

# My Picture **Perfect** Family

WHAT HAPPENS WHEN ONE  
TWIN HAS AUTISM

By Marguerite Elisofon



Marguerite Elisofon is a New York City writer and the author of *My Picture Perfect Family*, a memoir about how her family navigated life with a child on the autistic spectrum before the internet and support groups existed. She also blogs about parenting young adults and disability related issues in *The Never Empty Nest*, which was featured on Fox 5 News. Her essays have been published in literary magazines such as: *Existere: Journal of Arts and Literature*, *Write for Light*, *Hobo Pancakes*, *Wild Violet* and *Kaleidoscope*. A Vassar graduate, Marguerite was born and raised in New York City, where she still lives with her husband, Howard, in their never empty nest.



# Dedication

To my family..... I could never have written this story without you.

Howard – My rock and the love of my life.

Matthew – Your sensitivity, intelligence, and amazing sense of humor carried us through the best and worst of times. I'm so proud of you for sharing these gifts with the world through your movie script, *Being Charlie*.

Samantha—My inspiration. Your determination and *joie de vivre* is the true definition of never giving up. I'm so proud of you for exceeding so many people's expectations and for showing the world your talents in the film, *Keep the Change*.

# **I Am Not My Diagnosis**

**Apraxia  
(sensory disorder)**

**Static  
Encephalopathy**

**Exotropia**

**Non Verbal  
Learning  
Disability**

**(PDD-NOS) Pervasive  
Developmental  
Disorder--Not  
Otherwise Specified**

**Atypical  
Autism**

**(ASD) Autistic  
Spectrum  
Disorder**



“The child may have a disorder or set of problems, but he is not the disorder. He is a human being with real feelings, real desires and real wishes.”

“All children have within them the potential to be great kids. It’s our job to create a world where this potential can flourish.”

Dr. Stanley Greenspan



# My Picture **Perfect** Family

## WHAT HAPPENS WHEN ONE TWIN HAS AUTISM

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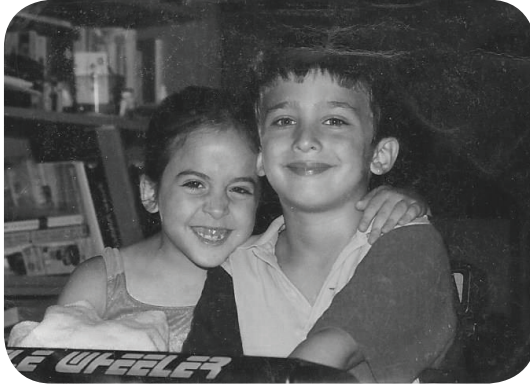
Epilogue

Afterward

Acknowledgments

# Chapter 1

## Twins



We always smile in our family photos, and in spite of my daughter's challenges, she often wears the warmest, most winning smile of all. Whether Samantha is dressed in her polka-dotted hoodie, beaming from a Central Park swing, or perched beside her twin brother, Matthew, in his Power Ranger jeep—one proprietary arm resting on his shoulder, as though they're on a date—her smile is relentlessly radiant. Her teeth are white and dazzling enough for a Crest commercial, and her whole face shines with joy. In our living room photo gallery, she squeals in wild delight on a roller coaster, but hugs me too tightly in our yearly holiday card, as if she's worried I might float out of the frame.

Her twin brother, Matthew, also puts on a smile for our family photos, but his eyes, the color of faded denim, often tell a different story. Sometimes he forces a brief grin to get back to reading or throwing his football. Other times he can't escape the camera before it captures a depth of emotion beyond his years.

### Fantasy vs. Reality

In my 20s, I'd dreamed about having boy/girl twins. What could be better than a complete family with only one pregnancy? I'd fantasized the perfect, instant foursome. In my 30s, that fantasy made more sense to me than ever, but my 42-year-old husband, Howard, cautioned: "Watch out what you wish for."

Ever the wary attorney, Howard was what my parents called a "*Hamish* guy," (responsible family man). He was 5'7" to my 5'9", dynamic and driven without being Napoleonic. An accomplished securities litigator, my husband was proud

of his Brooklyn roots, and clients liked him for being down to earth. I appreciated Howard's ironic sense of humor, his steadfast intelligence, and the way he made me feel safe.

"I think we should get ourselves checked out," he continued, ever the chronic worrier. "We're older parents, and I don't want to try for a year or two only to discover we have a problem." Howard reasoned with his usual vision of a worst case scenario.

My husband's pessimism often prevented problems before they occurred. This time my gynecologist (and fertility specialist) discovered I needed medical intervention. Praying that I would be one of the lucky ones who got pregnant right away, I embarked on a cycle of Pergonal and intra-uterine insemination. Six weeks later, I sat in the gynecologist's waiting room, hoping there'd be no more needles, and no need to cope with the months (or years!) of disappointment faced by so many couples. It was hard to look into the stoic faces of the not-so-young couples sitting in the waiting room with me. I shuffled through *Parents* magazine, reading the same few sentences for almost an hour while waiting for the doctor's verdict.

When I was finally allowed into the examining room, my gynecologist announced: "Congratulations, you are definitely pregnant! Your hormones are sky high, and your sonogram reveals you have a 60% chance of twins."

My heart pounded so hard I imagined the doctor could hear it in the background, like the soundtrack of a movie. "When will we know for sure?"

"Today, we can see two spots on the sonogram, but we can't be certain yet. In two weeks, you'll come back. If the embryos continue to grow between now and then, we'll hear two heartbeats. Then you're up to a 90% chance."

I jumped out of the chair and hugged the doctor before calling Howard with the good news. "You better sit down," I warned playfully. "I'm pregnant and guess what?"

"We're having twins?"

"The sonogram has two spots."

Leaving the doctor's office, I felt overcome with excitement. I didn't care that it was unseasonably cool and starting to drizzle. I bought a pink and blue baby album on the way home and pasted the sonogram with twin dots on the first page. The perfect beginning of what I imagined would be a book of perfect photos. What if we had a boy and a girl, making my wish come true? Would I dress them in his and hers matching outfits? Send them to the same schools? Would they be best friends? Splash each other in the ocean







and build sand castles together at the beach? Would they be athletic like Howard or artistic like me? One of each, I dreamed on, or maybe they'd be different altogether?

On December 26, 1990, after only 33 weeks, I gave birth to fraternal twins: Matthew Spencer and Samantha Eve. Matt kicked open his amniotic sac and worked his way out into the world eleven hours later, weighing four and a half pounds. The nurses said he was the “lucky one” because the labor process had given his lungs the opportunity to mature. Unfortunately Samantha’s amniotic sac had to be surgically cut open, forcing her out of the womb before she was ready. Five minutes after her brother, she was pulled into the world, weighing four and three-quarter pounds. Exhausted on the hospital bed, I didn’t even get a chance to see my infant daughter before the doctors whisked her away. Later Howard told me she was beautiful, oval faced with perfect little features.

Both twins spent the next sixteen days in the NICU at Lenox Hill Hospital. Matt stayed to gain weight and wait for his sister. My infant son looked shriveled like a little old man with milky blue eyes, but otherwise he was fine. Samantha, on the other hand, struggled to breathe. She lay in a special open incubator so doctors could treat her immediately. During her time in the NICU, my daughter suffered an air pocket on her lung, heart fluctuations, and jaundice. Plastic prongs blew oxygen into her tiny nose to help her breathe; a mask covered her eyes to protect them from the bilirubin lights used to treat her jaundice. Despite the open incubator, Howard and I were only able to stroke her cheeks because her hands and feet were connected to IVs and purple with bruises. Wires were also taped to her chest, monitoring her heart.

For almost a week, I couldn’t hold her. Samantha was frighteningly small and fragile—barely the size of my forearm—with ribs slowly rising and falling beneath her translucent skin as she struggled to breathe. I found myself holding my breath between each of hers, worrying each time I touched her face. What if I distracted her from breathing? *Please breathe, sweetheart*, I begged her silently. *Just inhale and exhale. I promise to help you with everything else.* I stroked my daughter’s cheek with feather-light fingertips. But what if I didn’t touch her enough? She went down to three pounds before gaining enough weight to come home. Would Samantha suffer from “refrigerator treatment?” I shuddered at the term used to describe mothers who don’t touch or interact with their babies—an early, rejected theory on autism.



In Samantha's first few months, she cried longer and more loudly than her brother did. Sometimes she seemed inconsolable—no matter how much Howard and I rocked and soothed her, she continued to wail furiously. It was hard to believe that our tiny, delicate daughter with low muscle tone and difficulty breathing had the energy and lung strength to cry in shrill, piercing screams for protracted periods. There were days it seemed like no matter how much attention and affection we showered on Samantha, she was thirsting for more.

On other occasions, tenderly touching her would provoke a crying fit. One day Samantha slowly tried turning her head as she lay in her crib on her stomach. About three quarters of the way to the other side, she stopped with her face pressed into the mattress. I knew this was a normal developmental step for any infant, but for Samantha it was a herculean effort because of her low muscle tone. With her face flushed and damp, she seemed trapped and exhausted. Worried she might suffocate, I nudged my daughter's face that one last inch. Immediately Samantha started to howl, struggling to turn her face back to the opposite side. My daughter didn't want my help. What she wanted—and would continue to want for many years—was to accomplish the task independently. From birth, it seemed my daughter's mantra was: "Don't help me. I want to do it myself." Her stubborn determination would turn out to be a curse as well a blessing.

All premature babies need time to catch up, the doctors told us, but it seemed Samantha kept falling further behind as her brother sprinted ahead verbally and cognitively. The contrast between our twins helped Howard and me to recognize Samantha's developmental delays very early. At eleven months, Matt used over a 100 words; Samantha had only ten. When her brother chattered, asked questions and pointed, she was silent, rocking and staring into space. She didn't reach for things and didn't answer to her name the way her twin did. Further, when she wasn't colicky and screaming, Samantha had chronic ear and throat infections which some doctors told us contributed to her language delays.



Our pediatrician said not to worry; there was still plenty of time. Luckily,

Howard and I stopped listening to that advice.

On Thanksgiving, we visited Howard's older brother Bob and his wife, Jane, in Connecticut. When we walked through the door, Matthew toddled toward his aunt and uncle, exchanged hugs, and then scampered off to play with his cousins.

Then Uncle Bob, a pediatrician, knelt down to reach out to Samantha. "Can I have a hug and a smooch, Samantha?"

Aunt Jane, a psychologist, said, "Me too."

Samantha stared right through them, but allowed herself to be hugged by her uncle, going limp as a rag doll. She completely ignored Aunt Jane and then wandered off into the living room.

"There's something wrong with Samantha, isn't there?" Howard asked his brother.

"I think you ought to take her to a neurologist and have her tested." Bob sounded concerned. "She may have pervasive developmental delays," he continued as we followed Samantha into the living room.

"What exactly does that mean?" I scooped up my beautiful little girl and cradled her in my arms. She felt so warm, snuggled up against me. It was always chilly at my in-laws' house because they kept the thermostat down.

"It means she's not looking at or relating to people the way most babies do at her age," Jane answered my question. "You should try to find out why."

I started to shiver as Samantha rocked against me and the drool spilled over her chin.

"I think you should see a neurologist and Dr. Stanley Greenspan. He's supposed to be the best in the country for children with developmental delays," Jane recommended.

Howard and I looked at each other, and I saw my terror reflected in his eyes.

The following week I brought Samantha to a pediatric neurologist at Mt. Sinai. She cried for the entire bus trip up Madison Avenue. Once Samantha started crying—no matter why—she was almost inconsolable. Her screaming was so loud and shrill that I was afraid people on the bus would think I was torturing her.

"Why don't you try a pacifier?" the (well-meaning, know-it-all) mother of a toddler across the aisle suggested.

"Pacifiers don't work on my daughter." I forced myself to speak politely. "She spits them out and throws them away."

The woman shrugged and shook her head while other passengers sighed, glared or just prayed for our exit. Maybe they thought they could have done better?



When we finally arrived at the doctor's office, Samantha went silent. I'd been hoping the pediatric neurologist would reassure me, but he turned out to be a taciturn man with a gravelly voice. "She's normal in every respect for a 12 month old except for human relatedness," he pronounced after examining her. "I had a hard time making eye contact with her, but was able to do so with a great deal of effort. I think it's malleable." His tone was matter of fact.

Malleable? What did that mean?

"That's good news," my mom said later on the phone. "She's not mentally retarded. You must be so relieved."

"Relieved! If she won't make eye contact, she could have autism." My voice shook. "I need a second opinion."

### **Plastic Keys And The Matador**

Our second opinion came from Dr. Stanley Greenspan, a world-renowned child psychiatrist who specialized in developmentally delayed children. It took two months to get our first appointment, and that's when the race to save Samantha's life began. Dr. Greenspan impressed me before we even met. During an initial phone call, I asked him what I could do to engage Samantha before our first appointment.

"Find anything that interests her, and then get down on the floor and play," he suggested.

I sighed. "But what if nothing interests her?"

"Think hard," he encouraged. "Any object will do. Even if it's just something she likes to put in her mouth."

I remembered how Samantha had sucked some brightly colored plastic keys Matt had long ago abandoned. "She's picked up some toy keys a few times, but drops them right away."

"You get down on the floor with her, almost nose to nose," he instructed. "Wave the keys in front of her face and tease her with them." He sounded like a cheerleader. "Put them in your mouth and then see if she takes them and puts them in her mouth. If she does, make a game out of the keys going back and forth between you."

"I'll try." I wanted to sound optimistic and grateful, even though his suggestion didn't seem very promising.

Nevertheless, I dutifully crouched down on the parquet floor, waved the plastic colored keys, and clicked them together two inches from her face. "Look what I have, Sammy."

I put the red key in my mouth and let the other keys dangle so close to her

mouth that I could feel her breath. I sucked on the red key as though it was the most scrumptious cherry lollipop I'd ever tasted. As Samantha looked slowly toward me, I said "YUMMY, YUMMY!"

The tiniest flicker of interest crossed her face.

I pulled the key out of my mouth and licked my lips. "Want some?" No response.

I put the red key back into my mouth and jiggled the rest of them so close to hers they almost touched her lips.

Slowly, one small hand reached for the keys and took them out of my mouth. I was delighted to see her shove two keys into her mouth.

I savored the moment before following Greenspan's instructions to gently reclaim the keys. "No, mine!" I joked.

Samantha took them back, smiling at me. She seemed to understand it was a game. We exchanged the keys a few times before she lost interest, and I began to believe Dr. Greenspan might be the genius everyone said he was. Maybe those silly plastic keys would unlock the first of many doors to the faraway land my daughter inhabited. I couldn't wait to see Dr. Greenspan and report on how I'd engaged her. Greenspan finally saw Samantha for the first time at fourteen months. I was hoping he could give Howard and me a road map, with new and better games that would help our daughter catch up to the other toddlers racing toward pre-school.

"This is a marathon, Marguerite, not a sprint," Dr. Greenspan warned at the end of our first two and a half hour session.

Easy for him to say, I thought. He had three normal children, and at least one of them would probably follow him to Harvard. Dr. Stanley Greenspan sat in a brown leather easy chair with chipped wooden armrests. For a world famous doctor with a four month wait list, his home office in an exclusive area of Bethesda was downright shabby. Toys were scattered everywhere: stuffed animals, dolls, cars, airplanes and Legos. Some of the toys were broken and spilling out of plastic containers. Others had migrated to the floor of the waiting room, where anxious parents sat on threadbare couches, and toddlers ate Cheerios on the stained sand-colored carpeting.

Even in rumpled corduroys and white tennis shoes, Dr. Greenspan was an impressive man who radiated confidence. He was 6'1", a former wide receiver for Harvard, still lean and lanky in his early 50s. Bald and unassuming, he could engage Samantha in conversations and higher levels of play than Howard and I. Greenspan kept Samantha interested longer and redirected her attention when it wandered. Then Howard and I sat on the floor with our daughter while Greenspan supervised our "play" and made suggestions. At the end of each session, we listened

to the doctor tape record his observations of Samantha, her progress from our last visit, the goals for our next visit, and how we might achieve them.

Dr. Greenspan diagnosed Samantha with sensory disorder and static encephalopathy, a chronic, unspecified brain disorder. In the 1990s, insurance companies favored vague discouraging medical terms. No one said the A-word, but when Samantha was eighteen months old, her pediatrician finally offered the diagnosis “high-functioning autistic spectrum disorder.” This diagnosis included confusing terms like PDD (Pervasive Developmental Disorder), atypical autism and later, PDD-NOS (Not Otherwise Specified).

We were already so devastated and overwhelmed by our daughter’s rigid, embarrassing, and unpredictable behavior that the A-word couldn’t make us feel much worse. At that time, Samantha routinely screamed “NO ICE! I SAID NO ICE,” when a waiter poured water into her glass. She had broken a babysitter’s eyeglasses for no apparent reason, and she’d once screamed for eight consecutive hours on vacation, causing our family to abort and head home. The rest of us never really understood her behavior, and the myriad labels she received neither shed much light on our situation nor offered any clear treatment program.

With Samantha, even crossing the street was fraught with danger. She wouldn’t allow me to hold her hand, only her *wrist*. Every time we stepped off the curb, there was a chance she’d go limp, sit down in the middle of the street, or pull away from me. If I tried to pick her up, she’d shriek, stiffen her body, arching her back, and hit me. Picking Samantha up off the street was like trying to lift a 30 pound sculpture with flailing arms and legs before the light changed.

On the advice of Dr. Greenspan and our pediatrician, we started speech and occupational therapy. But it was already clear these therapies wouldn’t cure our daughter. Her speech and language improved slowly, but she still didn’t interact much with the world around her. She didn’t point at an ambulance racing down the street with screeching sirens. Unlike most kids her age, she didn’t ask why the sky was blue or what clouds were made of. It was always Matthew who made the observations.

“Look at our plates, Mommy,” he’d say, pushing their red melamine plates together. “They make an eight!” Or when a Barney tape ended, he’d point at the credits scrolling up the screen. “It’s like an elevator,” he declared.

But Samantha just stared at the screen and drooled.

Nevertheless, Dr. Greenspan remained cautiously optimistic. Speaking into the tape recorder at the end of her session, he reported: “Today Samantha presents as a warm and related child who is very loving and affectionate toward her parents. She was able to play for a longer period with Mom on the floor. This time she

was able to ‘close more circles.’” (Closing circles was Greenspan’s term for the back and forth, reciprocal play and responses of child and parent.) “Mom needs to give Samantha more time to respond,” he continued talking into his recorder. “Let the child decide whether the doll should eat the cookie or drink the milk first. Then if Samantha doesn’t respond or walks away, try to engage her with humor.”

Howard was impressed with Dr. Greenspan, and that was saying a lot. The doctor was able to convince my husband that our daughter was making progress, even when Howard saw none. For the first few years of Samantha’s life, Howard missed work four times a year to travel to Bethesda and help me cross examine the doctor. We even stayed overnight so Samantha wouldn’t be too tired or cranky to perform at her best.

At home our daughter returned to her own isolated world. She often sat on her bed, her hazel eyes unfocused, staring at nothing and no one. The twins rarely interacted, unless Matthew initiated some simple physical play. In the bath tub, he liked to splash his sister vigorously. “C’mon Samantha,” he begged, longing for a playmate. “Splash back!”

Sometimes she slapped weakly at the water, but other times she didn’t even lift her hands to defend herself. Instead her face squinched up, and she started to cry.

“C’mon let’s splash Matt together,” I urged her, wiping my own eyes. “Just do what I’m doing.” I wanted to take her hands and help her push the water toward her brother, but I knew my help would make her scream.

One day, when they had just gotten out of the bath, Matt started twirling his penis. “Look, Sammy, I have a weenie and you don’t. N’yah, n’yah, n’yah, n’yah, n’yah.”

“I want a weenie.” She reached for it.

“It’s mine.” Covering it protectively, he ran out of the bathroom toward Howard, who was in the living room paying bills. “Go to the weenie store and get your own!”

“Mommy, I want a weenie.” She rushed after her brother. “Get me a weenie!”

“Only boys have weenies,” I laughed, following her. “Girls have vaginas. They’re just as good. You’ll see.”

“What’s going on?” Howard looked up from the bills.

Samantha looked down at herself doubtfully. “I want a weenie. A weenie AND a vagina.”

“Sorry sweetie.” I took a moment to wink at Howard. “Nobody gets both, and you don’t get to choose.”

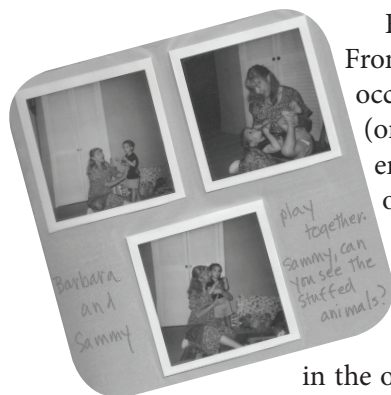
“I WANT a weenie!” She lunged at Matthew.

Laughing, Matthew pretended to be a bullfighter, waving a pink towel at Samantha as though it was a toreador's cape. "Here it is," he teased. "If you want it, come and get it." He turned and ran, dripping bathwater onto the living room rug.

To my delight, Samantha became an enthusiastic bull, chasing her matador brother around our coffee table. Howard and I laughed till tears ran down our faces and we couldn't breathe. Matthew's penis engaged his sister a lot longer than his plastic keys. Howard and I knew the "weenie game" would have to end soon, but we allowed it for a week or two. Even Sigmund Freud would have been amused. I was sad, but not surprised when Samantha's new therapist told me the game had to stop. Barbara Fields was a Dr. Greenspan liaison, and her job was to help us engage Samantha in anything that interested her. The "weenie game" was engaging, but inappropriate. Of course, Barbara Fields didn't yet know how badly our family needed to laugh together or how rarely those moments of laughter occurred. During the "weenie game" Samantha seemed to understand the humor, and the rising crescendo of her giggles made our whole family laugh harder, elevating the moment into a glorious concert.

### Treatment Options Before Google

In between quarterly visits to Dr. Greenspan, I researched all the interventions available in the early 1990s. (There weren't many.) But I was determined to try anything and everything with the very best doctors and therapists I could find. Some treatments were suggested by Dr. Greenspan, and others I found on my own—without the benefit of Google or the Internet. Each therapy and practitioner was a mini research project. Sometimes I'd find the number one in the field, only to be informed he or she had no time for us. Then I'd settle for the next best person who did have time. Afterwards, if Samantha didn't make enough progress, I'd wonder if she'd have done better working with the expert who'd been unavailable. Always, I called the star of the moment to beg, plead and badger. Almost as inconsolable as Samantha, instead of crying, I made endless phone calls.

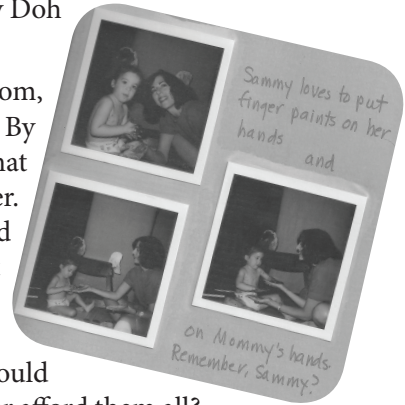


Finally we settled on a demanding regimen. From age two to five, Samantha had speech and occupational therapy twice a week and "floor time" (or play therapy) three times a week. Barbara Fields embraced the Greenspan floor time method of engaging a disinterested child. She was a warm-hearted, 50-something woman with a lilting voice and long gray-blond hair, who often wore loose flowery dresses. Sometimes Barbara asked me to join her and Samantha in the office, and both of us would painstakingly try to



involve my daughter in finger painting and Play Doh projects.

Other times I remained in the waiting room, available if Samantha needed a diaper change. By then I already knew there was no cure, and what worked for one child might not work for another. Sitting on the gold brocade couch, I mulled over possible treatments. What would be best for my little girl? Something reasonable and non-invasive, I hoped. It was clear we'd need a combination of treatments, but which ones would work best for Samantha? And how could we ever afford them all?



### Hearing Problems And The Bunny Rabbit

It wasn't just her language and motor delays which had me concerned. One day when Samantha was two and a half, I began to worry she might be hearing impaired as well. Not only was her eye contact minimal, but I was afraid she didn't hear me when I called her name, or notice the noise when the front door opened or closed. Often she didn't look up or turn her head in the direction of a voice or sound. When I finally took her for an audiology test, her hearing turned out to be normal. Dr. Greenspan suggested more sophisticated hearing tests to see if Samantha was a candidate for Auditory Integration Training. Auditory Integration Training (AIT) sometimes helped children with language processing problems improve expressive and receptive language, but not every child was a candidate.

"Samantha's hearing is within the normal range," the chief audiologist at Long Island College Hospital told us. "However, she is hearing phonemes unevenly, and that may be one of the reasons for her language delays."

"What's a phoneme?" I was starting to feel stupid.

The chief audiologist, who also ran the AIT program, said "A phoneme is the smallest contrastive unit in the sound system of a language." Behind wire rimmed glasses, her gray eyes were hyper alert.

"OK." I only partly understood. How would the doctor be able to determine such small and mysterious sound subtleties from watching my not-so-cooperative daughter? In the examining room, Samantha sat on my lap and listened to a variety of phonemes. At first these sounds came through a stuffed pink rabbit and later through headphones.

"I want the bunny rabbit," Samantha protested when she was first presented with the headphones. "These will hurt." She hurled them to the floor.

I stretched to retrieve them and put them on my own ears. “Look, Mommy’s wearing headphones. They don’t hurt at all. It’s fun to listen to the sounds.” After a few moments, I slipped them off my head and gently tried to position them over her ears.

“NO!” She yanked them off. “I don’t like them. They HURT.”

“Don’t worry, Mrs. Elisofon. A lot of kids don’t like them.” The audiologist turned to Samantha. “We really need you to wear the headphones for a short time. If you listen, you can have some M&Ms.”

“Will you let me put the headphones on?”

The deal was done. The doctor sat outside, watching my daughter’s face through a window, fiddling with dials on a sound system that emitted different frequencies. First there were low hissing noises and then high pitched whistles which rose slowly in volume until Samantha reacted by moving her head.

After the test, I learned more about the AIT program. “If you decide to do the treatment—and I definitely recommend it,” the Chief Audiologist told me “your daughter will come in five days a week for a month. She’ll spend two hours each morning with headphones listening to tapes; then she’ll take a two hour lunch break with you and come back to work for another two hours in the afternoon. The tapes will be individualized for Samantha with the goal of training her to hear sounds more evenly, so she can have an easier time distinguishing and processing words.”

“How will we know whether she’s improved at the end?” I had to ask. “What evidence can you give us?”

“We’ll do another hearing test and compare the results with what we got today.” She pointed at a graph that looked like a mountain range, with peaks and valleys in Samantha’s hearing. “Ideally, those lines should even out a lot.”

“Beyond those lines, though,” I pressed on, “what should we hope to see? Should I be noticing incremental differences in her speech over the course of treatment?” I couldn’t help wondering whether AIT would be a waste of time and money.

“You may notice longer sentences and phrases in bigger chunks,” the doctor responded. “I have to warn you, though, there may be some temporary side effects.”

“Side effects?”

“Some children become more aggressive and emotional from the stress of working so many hours, and they need to release energy.”

My heart sank.

“As you know, this treatment is fairly new, and we’d appreciate your feedback along the way as well as at the end.”

### **Auditory Integration vs. Potty Training**

Despite my misgivings, I set up appointments for June, after nursery school ended and when Matt would be in day camp. The AIT program meant briefly stopping Samantha’s other therapies, but even those specialists thought I should try it. I knew AIT would be a grueling experience for both Samantha and me. Spending six hours a day at Long Island College Hospital in Brooklyn Heights (plus the 40 minute commute each way in traffic) would be hell, but I felt it was worth a try.

At least the weather was warm and sunny most of the time, which made it possible to go to a nearby playground during her two hour lunch breaks. Samantha loved the swings, which were recommended by Greenspan to stimulate her nervous system. I pushed her until my arms ached before we switched to the seesaw.

The greatest challenge for me was continuing toilet training during AIT. Samantha was three and a half, and I still carried extra clothing, a potty seat and diapers everywhere we went. My daughter had used the potty seat at home with some success so I wanted to keep the momentum going. Starting over would be too arduous for both of us if I let her settle back into diapers. On lucky days, we made the 40 minute drive to LICH without accident, but it was a mad dash to the hospital restroom on the main floor and then a negotiation.

“I’m afraid.” Standing in front of the toilet, Samantha clung to me like a barnacle. “I don’t want to fall in.”

Fortunately, the hospital bathroom with its black stalls and toilets was clean and—more importantly—often empty.

“Mommy won’t let you fall in. We’ll use the potty seat like at home. I’ll even hold you.” Gently, I tried to place her on the toilet.

“Nooooo!” Her body went rigid, and her fingernails dug into my forearm.

“Please, Sammy. I promise not to drop you. I didn’t drop you yesterday or the day before. Don’t you trust me?”

“I don’t want you to drop me. You’re going to drop me!” she screamed in terror as a torrent of her urine splattered onto the white tiled floor.

Somehow we made it through the month. There were times when I didn’t know how I’d survive the tedium and loneliness of each day. I talked to other mothers with young children doing AIT, but that was depressing. All our kids had serious issues, and all of us were deeply worried. I recognized the forced smiles

and determined optimism, the guilty (and covert) competition when discussing our children's progress, and most of all, the sad, tired eyes which expressed the desperation motivating us to put headphones on our special needs kids four hours every weekday for a month.

As the AIT days passed, I noticed Samantha starting to string a few more words together and even speaking more than a single short sentence at a time. But she became extremely irritable. Then, at the end of the second week, during the ride home, there was a surprising change no one could have predicted. Sitting in the backseat of the car, Samantha began to rub her hand between her legs furiously. She was discovering the pleasures of her vagina. Despite the seatbelt, she rocked rhythmically against her fingers, faster and faster until her cheeks turned a sweaty, dark pink, and she appeared to climax.

I could not believe my developmentally delayed daughter was discovering masturbation at the age of three! This proved to be the most memorable result of AIT. The mountain range of lines on Samantha's final hearing test had significantly smoothed out, but I'll never really know whether the treatment helped her language processing. Masturbation, however, became Samantha's favorite game; she played eagerly anywhere and everywhere she could. Teaching her the word "masturbation" was easy, but convincing her to do it only in private was very difficult. Many years would pass before Samantha understood the meaning of embarrassment.

### The Blankie Game

Howard confided that her progress was like "watching grass grow," but giving up was never an option. Howard tended to be pessimistic but if we were going to have any chance of saving Samantha, I had to remain optimistic. However, in a rare, upbeat moment, Howard created the "blankie game" to engage both children. First, he took Matthew's blue blanket and tucked part of it behind a cabinet door in our bedroom so the blanket hung down just out of our son's reach.

Samantha laughed as Matthew stood on tip toe in his striped pajamas, straining to grab the elusive corner. "Give it back, Daddy. I want my blankie."

"Go get it. Jump for it."

"I can't, Daddy. You put it too high."

"Yes you can." Howard moved it a half inch lower, and Matt lunged for it.

"Your turn now, Samantha." My husband made sure Samantha's pink



blanket dangled a little lower than her brother's.

"Gimme blankie! Now. I want it." Samantha was outraged, where Matt had only been mildly frustrated.

"You can get it, Sammy. Just do what I did," Matt encouraged her.

"I can't."

"Stand on your tip toes. Just reach a little higher."

"You can do it, Sammy. Go on," all three of us urged.

She jumped about an inch and just managed to pull the corner down slightly. "I got it!" She flashed a triumphant smile.

"Okay, now we're going to see who can get their blankie back first." Howard put each blanket behind one of the doors.

"Not fair. Mine's higher," Matt complained.

"You're taller."

The twins looked so cute jumping side by side, Matt in his blue striped pajamas and Samantha in her fuchsia stripes. Howard was careful to position their blankets so they could take turns winning, and all of us laughed.

Unfortunately, these moments of shared laughter didn't happen often enough. More often it seemed like I was struggling with Samantha alone, while Howard had fun with Matthew, enjoying father/son conversations about sports. If Samantha sat down in the street and began screaming, Howard and Matt would keep walking and wait for us half a block away. Only if I couldn't handle her on my own would they return.

When we went to the park, Howard and I took turns pushing Samantha on the swing, but I was the one who waited with our daughter until a swing was available,



and I was the one who eventually had to persuade her to give up the swing so another child could have a turn. Usually Samantha refused, and then I was the one who strained to lift her while she clung stubbornly to the metal chains, screaming and kicking with all her strength. At the other end of the playground, Howard played catch with Matthew or watched him dig in the sandbox.

After the swings, Samantha wandered aimlessly while I tried to interest her in going down a slide or sitting in the sandbox with Matt. The sandbox was risky because she sometimes threw sand at her brother or

grabbed another child's shovel. I never felt comfortable talking to other mothers at the park; nor could I introduce my daughter to other little girls. Samantha didn't know how to make friends, and forced efforts left me feeling sad and embarrassed. Trapped in an exhausting and lonely vigil, my only real respite came when we sat down and she ate her Good Humor.





## Chapter 2

### Matthew's Heart



One sunny August day, Matt and Samantha posed on the deck of our rented vacation house, overlooking the bay. The photo in our gallery shows our three-year-olds in their pajamas; Matthew's hand grasps Samantha's forearm, but their gazes diverge. For once, Samantha looks at the camera while her brother seems distracted and offers a tentative smile. That was the last summer our son's innocence was still intact.

Howard and I already knew our son had been born with a heart murmur, but our pediatrician had always said that he'd "most likely outgrow this condition and the hole in his heart will close." In retrospect, Dr. Adams' prediction sounded much like previous reassurances that Samantha would outgrow her developmental delays. "Preemies sometimes take a while to catch up," we'd been told too many times. While Samantha's symptoms were loud and obvious, her brother's condition was invisible. Matt was an overactive little boy, running around the playground with no shortness of breath, no chest pains or bluish fingers from poor circulation. Nevertheless, his July check-up had been alarming.

Dr. Adams, a tall, silver-haired man, spent too much time circling Matt's pale, smooth chest with his stethoscope. My own heart palpitated as I watched.

"That heart murmur is not going away." The doctor's tone was gentle.

For a moment, I thought my own heart would stop dead. Then I forced myself

to take a deep breath and pay attention to what the doctor said next.

“At age three, if the hole hasn’t closed, you need to get it checked out.” He turned to his prescription pad and wrote down the name of a pediatric cardiologist.



“Mommy, what’s wrong with my heart?” Matt’s blue eyes were piercing.

“Nothing’s wrong right now.” I glanced at the pediatrician. “Your heart sounds the same as the last time. We just want to have an expert check to make sure everything’s okay.”

“Your mommy’s right,” Dr. Adams agreed. “We just want to be extra careful.”

I tried not to appear anxious because I didn’t want Matt to worry. If I could convince myself that my son’s heart was okay, then maybe it *would* be okay when we saw the cardiologist. But I couldn’t help wondering how big the hole was now. Had it been growing bigger instead of closing? What would happen if the murmur didn’t go away? I didn’t voice the questions that

kept springing to mind, not wanting to expand on bad news in front of my son. I wondered how a seasoned pediatrician could have spoken so openly in front of my savvy three-year-old.

“Don’t worry, old buddy, everything’s going to be okay.” Dr. Adams playfully ruffled Matt’s hair, but my son’s face looked as panicked and doubtful as I felt.

## The Second Opinion

The pediatric cardiologist was a middle aged woman with curly dark hair. Entering the examining room in her crisp white lab coat, she announced, “Hi, I’m Dr. Rosenstein and this is one of my residents.” She pointed to the petite woman who was trailing her. Turning to my son who was squirming in my lap, playing with a Power Ranger, she said “You must be Matt. Mind if we take a listen?”

For this doctor visit, despite the inconvenience, I’d brought Samantha and our babysitter along. They were sitting in the waiting room so Matt could go home with them after his examination. This time I planned to talk privately with the doctor and protect my son from overhearing any more upsetting news.

Dr. Rosenstein held her stethoscope, ready to go.

“Okay,” Matt mumbled, reluctantly handing me his Power Ranger.

The cardiologist placed her stethoscope on my three year old’s bare chest and then asked her resident do the same. I held my breath while each of them listened carefully.

Next Dr. Rosenstein explained that Matt needed an electrocardiogram and an echo test “to determine the size and location of the hole.”

“Don’t worry, Moose, it’s not going to hurt,” I exhaled slowly. “They’re going to put some sticky white circles on your chest, with wires attached to them.” I heard my own voice struggling to sound reasonable; I was on auto pilot. “The machine will record the pattern of your heartbeat and spit out a paper with squiggly lines.”

“I’m scared, Mommy.” Tears filled his blue eyes, the unusual tint of faded denim. “I don’t want them to find something wrong with my heart.”

I held his hand. “I know you’re scared, but let’s try not to think bad thoughts now.” I spoke to myself as much as my son. “How about if you squeeze my hand and think about whether you prefer pizza or fried chicken for dinner?”

By the time we’d finished the second test – “the one where they put goop on your chest and look at black and white pictures of your heart on a screen—” Matt had decided on pizza.

“Can I have lemon sorbet too?” He grinned, extracting the most he could from a bad situation.

I had one of the few three-year-olds on the planet who didn’t like ice cream, but loved all other icy desserts. I’d have let him eat the whole container of sorbet, if only it filled the hole in his heart. “You did a great job,” I told him. “Now it’s time to meet up with your sister and your babysitter and go for pizza and sorbet. I’m going to stay here to talk with the doctor for a little while.”

“Am I okay, Mommy?”

I crushed him to my chest in a tight hug. “Of course, you’re okay. I just need a grown up talk with the doctor to make sure you *stay* okay.”

After Matt left, six interns entered the examining room with yellow legal pads. They sketched my son’s heart and took notes while Dr. Rosenstein lectured: “Here we have a boy of three years and four months who presents with an ASD. As you can see from its location, there is mitral valve regurgitation from—”

“Wait a minute,” I interrupted the lesson. “What’s an ASD? What’s going on with the mitral valve?” Forcing the words from my mouth felt like spewing out hot sand. Surely, I couldn’t have one twin on the autistic spectrum and another with a serious heart problem?

“An ASD is an atrial septal defect. It means there’s a hole in the upper chamber of your son’s heart. You’re lucky because it looks as though he also had a ventricular hole in utero, but that one closed on its own.”

I did not feel lucky. “There’s a problem with his mitral valve too?” I felt like I might faint.

“Well,” explained Dr. Rosenstein, “the location of the hole caused a slight malformation of the valve. That means your son’s heart has to work twice as hard to pump blood through his body because of the regurgitation.”

My throat burned. I swallowed hard and tasted vomit.

“By regurgitation, I mean blood leakage,” she elaborated. “His heart is already slightly enlarged. He’s going to need surgery.”

*Blood leakage.* I tried to think, but my brain went numb. “I have to call my husband.”

### Howard Cross Examines A Cardiologist

Waiting for Howard in the reception area, I floundered and sank into bland décor; tan tweed industrial carpeting, eggshell walls with abstract prints, and the usual complement of framed medical degrees threatened to drown me. Half an hour later, my husband walked in, and I resurfaced. In Dr. Rosenstein’s office we braced ourselves, sitting side by side in stiff-backed chairs, while Howard conducted a cross examination that yielded much needed information about the meaning and implications of ASDs, mitral valves, and how quickly we needed to schedule our son’s surgery. I stared out the window at an overcast day and a view of the courtyard. There was no hope of escape.

“What would happen if he didn’t have surgery?” Howard was great in a crisis, but I could hear him balking at the idea of surgery. Neither of us wanted a surgeon to cut open our three-year-old son’s chest.

“If he doesn’t have surgery,” Dr. Rosenstein declared matter-of-factly, “his heart will eventually become enlarged and weakened from years of pumping twice as hard as a normal heart. He will end up needing a heart transplant by the time he’s 25.”

“It sounds like we have no choice,” I interjected, unable to bear the image of my son reaching the peak of his youth while desperately awaiting a heart donor.

“How soon do we need to schedule the surgery?” Howard loosened his tie.

“It’s not an emergency, but I would say the sooner the better.” The cardiologist glanced at her watch. It was past 5:00 PM, and I imagined she was weary of answering questions asked by shocked and worried parents—especially when one

of them was a lawyer.

“Would early September be soon enough?” Howard pursued. We needed time to seek a second opinion, research pediatric heart surgeons, and interview several before scheduling the surgery.

“Any time this year would be fine,” she assured us.

“What’s involved in the surgery, and how long will the operation take?” My husband soldiered on.

“About four hours. The surgeon will either sew or patch the hole and repair the mitral valve.”

“How risky is it—on a scale of 1 to 10?” Howard’s questions were relentless, but his tone remained polite.

“As heart operations go, an ASD is pretty much a cup of coffee to a cardiac surgeon.”

Wasn’t that good news? Then why did I feel like I couldn’t breathe?

“What’s the mortality rate on this type of surgery?” my husband asked.

I couldn’t possibly have spoken the word “mortality.” Even the most minuscule chance of Matt’s death was too high. Besides, we’d already had bad luck with percentages. In 1990, only one out of 150 children was born on the autistic spectrum, and only one out of about 2,000 had an ASD.

“The mitral valve repair takes it up a notch, but most pediatric heart surgeons will still tell you the operation’s pretty low risk,” Dr. Rosenstein concluded.

“Maybe it sounds stupid,” I had to ask this question, “but will his heart stop beating while they work?”

Dr. Rosenstein looked at me kindly. “Yes, they will stop your son’s heart and put him on a heart/lung machine. As soon as they finish, they will take him off the machine and restart his heart. All open cardiac surgeries are performed this way,” she added.

Leaving the office, Howard took my hand. “You can cry if you want to.”

I couldn’t help thinking he wanted me to cry for both of us.

During the weeks that followed, Howard resumed his whirlwind pace at his law office, while also frantically calling pediatric cardiologists, surgeons and hospitals. I continued my work with Samantha, going to play therapy, occupational therapy, and speech therapy. One day bled into the next as my life devolved into an endless series of therapists, doctors, and medical arrangements. Depressed and exhausted from my efforts to help my daughter, I didn’t know where I’d find the strength to deal with my son’s heart surgery. Fortunately, Prozac had recently come out, and it

proved to be a lifeline for me.

## Running The Gauntlet – Seeking More Opinions

Howard made appointments with pediatric cardiologists at Yale Medical Center, Children's Hospital in Boston, and Babies Hospital at Columbia Presbyterian in New York City. We traveled together to each city, asking each potential cardiac surgeon our questions and expressing our concerns. When we went to New Haven, we took Samantha with us to Yale for an echo cardiogram to make sure she didn't have a hidden heart problem too. If Samantha had a hole in her heart too, I thought I'd smash the casement windows at Yale and jump. Fortunately, she didn't. In addition to testing Samantha in New Haven, we also learned that we had to find two safe O+ blood donors for Matt, since neither Howard nor I shared our son's blood type. With the rampant fear of AIDS, no one relied on the hospital blood supply except in an emergency.

After Yale, we went to Boston Children's Hospital to see another surgeon. He was highly recommended, elegant with tall narrow hands and long, tapered fingers that looked way too big to work in my son's small chest on my son's small heart, an organ I now knew was the size of a nectarine. When Howard questioned the elegant Yale surgeon, he admitted to having "lost" one four-year-old boy. That was one too many for us.

Our last consultation was with Dr. Quaegebeur, known as "Dr. Q" at Babies Hospital; he was "the best in the country, if not in the world," we'd been told. In order to reserve a place in Dr. Q's schedule, Howard had actually booked the surgery before we met him. Originally from the Netherlands, Dr. Q was no more than 5'2", with a thick shock of silver gray hair and tiny, delicate hands. Arriving in Dr. Q's cubicle-sized office at the hospital, I took one of those hands in mine to shake hello. Looking into the doctor's intense, dark blue eyes, I saw intelligence, and I began to imagine how his child-sized hands would work on my little boy's heart.

Howard had been advised not to ask Dr. Q about his mortality rate. In his late 50s, the famous pediatric cardiac surgeon had operated on thousands of children all over the world, many of whom had





far more serious heart problems than our son's ASD. We'd been told Dr. Q usually didn't grant long interviews, and ours only lasted a few minutes.

"I know you're the best in your field." Howard smiled, but I knew what question he was about to pose. "So I hope you don't mind if I ask about your mortality rate. It's just that I'm a wreck over this, and I was hoping you could reassure me."

"So far, zero." His tone was unruffled, matter of fact.

### **Explaining Heart Surgery To "Question Man"**

After the interview, we received instructions about how to explain heart surgery to a three year old. Who could have imagined there was a children's book about a little boy who goes to the hospital because he was born with a hole in his heart? We were supposed to buy that book and read it with Matt, explaining how doctors fixing the little boy's heart with an operation would keep him healthy and strong. According to the storybook, the little boy sniffed something sweet and fell asleep before his operation. Later, he awakened and felt fine!? It was going to be a tough sell. We'd been advised not to go into detail about the operation unless Matt asked questions, and they assured us most three year olds didn't.

But we'd already nicknamed our son the "Question Man." No matter how many of his questions we answered, Matt kept on asking more until responding to him became impossible. When we tried following the storybook approach to explaining surgery on Matt, he burst into tears.

"That means they'll cut me open?" He honed right in on the first big "detail." "I don't want the doctors to cut me," he sobbed. "I'll fix it myself."

"You can't fix it yourself, honey," I explained with tears in my eyes. "You're three years old. Only a trained doctor knows how to do this kind of operation."

"But what if I don't want the operation?" He tossed the surgery book aside. "They're going to CUT me open with a KNIFE, right?" He translated the entire surgery fairy tale book to its bottom line; tears ran down his face.

"Matt, the doctors will put you to sleep so you won't feel anything. When you wake up, it will all be over, and we'll be waiting for you." Howard looked like he wanted to cry too.

"I won't let them hurt me! I won't."

"Mommy and I would never let anyone hurt you." My husband's tone was solemn, a sacred oath. His brown eyes met Matthew's blue ones as he spoke.

"Why me?" our son protested an instant later. "Why do I have a hole in my heart?"

"Just bad luck, Moose." I sighed, patting his arm, forcing myself to speak with

more confidence than I felt. “The good luck is we can fix it, and you will live a long healthy life.”

The good luck was that Prozac was keeping me upbeat. Sometimes I floated, but not because I was happy. Instead I felt dead inside, like a moviegoer, watching my Stepford-self speak while the real me was silent and invisible.

### **Samantha’s Separation Anxiety**

Explaining Matthew’s heart surgery to Samantha was something I dreaded, especially since Howard and I were going to be away for a week. Not only had we never left our daughter with a babysitter that long, but we’d also be taking Matthew with us. Since most three-year-old twins would have trouble dealing with their sibling’s heart surgery, I had no idea what behavior to expect from Samantha, who was used to being the center of my universe. I knew she’d feel angry and abandoned, but how much would she withdraw from me? Would she regress and undo all our efforts to save her?

One day, when Samantha seemed alert, calm, and connected to me, I told her about Matt’s surgery. We were walking home from the park, after a long period of being pushed on the swings, which the occupational therapist had told me both soothed and stimulated her. It was a dry 80 degrees, one of those crystal clear, blue sky summer days when the sun is so bright the sidewalk sparkles. Samantha was over her latest ear infection, and she’d just finished her Mr. Softee cone.

“At the end of the summer, your brother needs to go to the hospital and have an operation to fix his heart,” I began. “This means—”

“Am I going too?” she interrupted.

“Only Matthew is going because a doctor needs to sew up a hole in his heart. He’ll be fine but—”

“What about me? Do I have a hole in my heart?” She panicked, upset that she wasn’t included and afraid something was wrong with her too.

“Samantha your heart is fine, thank God. You’ll be home with Yvette, starting nursery school. You’ll continue seeing Barbara and your other therapists just like always.”

“Just like always?”

“Yes, everything will be exactly the same,” I emphasized reassuringly. “But your brother needs to be in the hospital for a week after his operation. Daddy and I have to stay in the hospital with Matt to make sure the doctors and nurses take really good care of him. But you can visit. After a few days, when Matt’s feeling better, you can come with Papa and Grandma to visit.”

"I don't WANT to stay with the babysitter all alone." Her voice rose to tantrum level. "WHY can't I be with you and Matthew?"

"Because three year olds are not allowed to stay in the hospital and bring in germs. You don't want to take a chance of getting Matt sick, while we are trying to get him well after surgery, do you?"

"It's NOT FAIR. I have to stay home ALL ALONE for a whole WEEK. All alone!" She burst into tears.

"I'm sorry, sweetheart. Daddy and I are sad too. But we will call you every day and kiss goodnight on the phone." I tried to hug her.

Samantha pushed me away with all of her strength. "You're leaving me!" she screamed. "You don't love me. You only love Matthew."

I wanted to cry. "You know that's not true!" My own volume rose. "Remember that song Barbara taught you? *Mommy Always Come Back*," I tried to sing in her therapist's soft, persuasive tone: "*Your mommy comes back. She always comes back. She always comes back to get you. Your mommy comes back, she always comes back. She never will forget you.*"

Samantha sniffled and sang the song back to me as a question. "My mommy comes back? She always comes back? She always comes back to get me? My mommy comes back? She always comes back? She never will forget me?"

We sang it together, and she allowed me to wipe her tears.

### Special Presents And Missed Kisses

Preparing Matthew was far more complicated. Before the operation, I'd promised him a present for every day in the hospital. Howard and I planned to surprise him every morning with a gift he could actually enjoy, depending on his level of recovery. The first gifts were videotapes and the last was a plastic fire engine with a siren. Howard had purchased doctor and nurse puppets for the third or fourth day. These felt hand puppets were smiling cartoon characters with canary yellow felt skin, rust colored yarn for hair, and marble sized plastic eyes—brown for the doctor and blue for the nurse. Matt's gifts offered some happy distraction, but even that was tainted by the impossibility of buying any present that would console Samantha. Nothing interested her.

We checked into the Babies Hospital the day before surgery on Thursday, September 12. Tests had to be done; blood had to be taken.

When the nurses brought out a catheter, Matt protested. "I don't want that thing inside my weenie!"

"All the scary stuff will be done while you're sleeping." I couldn't tell him the

catheter was the least of it.

“Will you be with me, Mommy?”

I squeezed his hand. “I will be with you until the moment you fall asleep. Daddy and I will both be there when you wake up.”

That night I sat by my son’s side in the hospital room and was relieved to see that—despite his fear—he fell asleep early just like any other three year old. The other mother in our semi-private room was not so lucky. Her nine month old daughter cried on and off all night, but luckily Matthew didn’t wake up.

One floor above us, Howard slept in the newly created wing of guest rooms for parents of children having heart operations. These tiny rooms resembled college dorms with their single beds, small bathrooms, and scratchy white towels. Here we would take turns sleeping—or trying to sleep—while Matt recovered.

At 8:00 PM we called Samantha as promised, but she wouldn’t come to the phone.

“Please put the phone next to her ear,” I told the babysitter. “Tell her we want to give a kiss her goodnight.”

“Okay Marguerite, but she says she won’t talk.”

“Samantha,” I began, trusting the phone was at her ear, hoping she could hear me. “Daddy and I are calling just like we promised. We love you and miss you. We’re sending you lots of hugs and kisses.” I made kissing sounds. “Can you send us a goodnight kiss?”

Silence.

Howard took the phone and held it next to both of our ears. “We’re going to call you again tomorrow after Matt’s surgery is over,” he said. “In a couple of days, when Moose is better we’ll have a party. You can go pick out some cupcakes, okay?”

“Okay.” Her voice was flat.

“How about a tiny kiss goodnight? Just a little tiny one?” He waited. “No? Then how about tomorrow night, Sweet Pea? You don’t want to make your mommy cry?”

“Maybe.”

Did “maybe” mean Samantha wanted me to cry? Or did it mean she’d kiss me tomorrow? Tears ran down my face. I was trying so hard to be the glue in my fragile family, but I was afraid my best efforts might not be enough.

### **Lemon Sorbet And Surgery**

At 8:00 AM the following morning, Matt got wheeled off on a gurney. Since the hospital only allowed one parent to accompany a child into the operating room, I

donned a gauzy yellow paper robe, cap and slippers and walked next to the gurney, holding my son's sweaty hand.

The anesthesiologist joined us. He was a reed thin man around 30, both brilliant and soft-spoken, one of the kindest doctors I'd ever met. Previously, Howard had taken the cardiologist aside because the anesthesiologist looked so young and inexperienced. We could never have guessed this young doctor had graduated Harvard at sixteen, finished medical school there at nineteen, and had already been practicing medicine for many years.

"Now, Matthew," the anesthesiologist coaxed, "you can choose your favorite flavor to sniff before you fall asleep. Would you like orange, lemon or cherry?"

"Lemon, please. I love lemon sorbet."

"Okay, my little man, lemon it is. Now we're going to put this clear mask on your face. You just keep breathing like you always do."

As he slipped the mask on, Matt's eyes darted from the doctor to me.

"Think about a big bowl of lemon sorbet," I suggested, and he squeezed my hand tight.

"Sorbet is for dessert," the anesthesiologist began in a soft, hypnotic tone. "But first I'm going to tell you a story about a little boy named Harry who went to McDonald's because he wanted to get a dinosaur toy they were giving away that week with a happy meal. Harry was hoping they wouldn't run out of Tyrannosaurus Rex, or else he'd have to settle for a Pterodactyl like his friend Charlie, or maybe even a dumb Brontosaurus who only eats leaves..."

Matthew's eyes slipped closed.

The doctor turned to me. "When he wakes up, it will all be over, and he won't remember anything. You'll see him in four hours, give or take. Please try not to worry. He's in great hands with Dr. Q and I'll be there with two other doctors assisting him. Tell your husband we'll come out and give you an update."

"Thank you. You've been wonderful." I wanted to hug him.

### Waiting Room Hell

Returning to the overheated waiting room, I found Howard sitting on the edge of a leather chair. "He's asleep now," I reported. "I guess they're starting. The doctor said surgery would take about four hours. They'll come out at some point to give us an update."

Four hours seemed like eternity. Jittery and exhausted from not sleeping, I had a headache from listening to the baby cry all night. It was time to take my Prozac.

“Let’s get breakfast.” Howard looked pale, like he hadn’t slept much either.

“Great idea.” I didn’t have much of an appetite, but we both needed to keep up our strength.

I’d thought eating might distract me, but the carrot muffins tasted like sawdust, and my coffee was bitter and tepid. Next to us in the waiting room, a family argued over whether their nineteen-year-old daughter should have a heart transplant. The daughter was crying, weary of waiting for someone to die and give her a heart, tired of hospitals and fighting to survive. Her mother was begging her to be patient and stay strong.

Strength and patience were what I needed too, but I’d never felt so tired—in every possible way. I tried to tell myself I was lucky because Matt would never need a heart transplant. His ordeal would be over in four more hours, even if four hours seemed like four years. Our family would probably never have the heartbreaking conversation I’d just overheard. We would, however, have other difficult conversations. Matt would recover, but what would happen to Samantha? Would there ever be a cure, or extremely effective treatments for autism? Would I have enough strength and love for both twins and their issues? Would Howard and I have enough love and energy left for each other, after dealing with the emotional and financial demands of our children?

Holding the *Post* in one hand, my husband said, “I feel so bad for Matt. I wish I could have the surgery for him.”

“The doctor told us this is an easy fix,” I tried to reassure him. “It will all be over in a few more hours.” In the long run, I was much more worried about Samantha. None of the doctors seemed able to save her, and even if they could help, it would take years instead of hours. I covered my face with my hands. “It’s a terrible thing to say, Matthew’s heart problem is a sprint. Samantha’s developmental issues are a marathon.”

“Don’t you understand I’m in agony?”

“Of course, I understand.” I summoned the energy to take Howard’s hand, and we both glanced at the clock. It was 10:18 AM, a little over an hour since the surgery started. “It’s going to turn out fine,” I heard myself say. “You did all the research and asked all the right questions. We found the very best doctors. Now we just have to let them do their job.”

At 11:48 AM, the anesthesiologist came out in scrubs to tell us the surgery had been successful, and an hour later Dr. Q walked toward us, without his surgical smock. “Your boy is going to be fine,” he told us. “The hole was quite small. We used a Kevlar patch to seal it, but the location required a bit of repair work on the valve. You can go see your son now.” He smiled.



Thanking Dr. Q, we ran down the hospital hallway to Matthew, who was on a gurney en route to ICU. Our son had tubes and wires all over his 34 pound body. He also had an IV and a catheter, and looked worse than he had as a preemie in NICU. I wanted to scoop him up in my arms, but that was impossible. His wrists were tied down to prevent him from pulling any of the tubes and wires out. I'd hoped he'd be drowsy, but instead he was wide awake.

### Post Op – A Mom Divided

“Mommy, can you hug me?” Tethered to the gurney, he looked completely miserable.

“I wish I could.” Glancing at Howard, I wiped away a tear. “How about a kiss for now?” I gently pressed my lips against his cheek and smoothed his damp hair. “I promise we’ll have lots of hugs later.”

Matt stayed in intensive care for two days. According to the nurse, he was “the healthiest one” in the ICU. While this remark was reassuring, I could see that my son was not getting much attention. When his little lips were cracked and he complained of being thirsty, no one brought him ice chips until I insisted. When he was finally allowed to have apple juice, I had to chase a nurse down to get some. I wanted so badly to run home and see Samantha for a few hours, but it was out of the question.

“Please, don’t leave me,” Matt begged Howard and me each night.

“We’ll wait until you get sleepy, but the nurses won’t let us stay in your room all night. We’re just one floor above you. You can call anytime, and we’ll come right back,” I reassured him.

As soon as his eyes closed around 9:00 PM, we called Samantha, and this time she came to the phone. “Great news,” I said. “Moose had his surgery, and he’s going to be fine.”

“When will you come home?” she asked.

“Probably Monday or Tuesday, depending on how Matt’s doing. Right now I have to watch over him the same way I watch over you when you’re sick.”

Silence.

“I promise to take you for strawberry ice cream, just the two of us. And after that, we can all visit Moose in the hospital with Grandma and Papa.”

“But I miss you. I miss you so much.” Her tiny voice shook.



"I miss you too." At least she was talking. "Will you blow me a kiss tonight?"

"Promise, you'll come home?"

"I promise. Cross my heart and hope to die." I blew her a big kiss and heard a smaller one come back.

Matthew was awake when we arrived at the ICU at 7:00 AM and excited about receiving his present: the latest Ninja Turtles videotape. (He'd watched *Free Willy*, yesterday's gift, over and over till he fell asleep.) Our son had exclusive use of the only portable VCR in the ICU because he was the only patient healthy enough to watch it.

Howard and I were thrilled with Matthew's progress and anxious to see him move out of intensive care. "Tomorrow they're going to move you into a regular room. You'll be able to eat real food," Howard said.

"Can you bring me Chinese?" he requested. "Cold sesame noodles and chicken with broccoli? Please?" This was music to a Jewish mother's ears.

"That's my boy!" Howard smiled.

It was amazing how resilient a three year old could be. When Matt moved into a regular room, all his tubes were removed except the IV and the catheter. He got out of bed and started walking down the hospital hallway only 48 hours after open heart surgery!

### **Reunited With Samantha**

Early the next night was our Chinese food party with Samantha, Grandma, Papa and the babysitter. Everyone sat around on red plastic chairs in one of the empty children's playrooms, balancing paper plates on our laps and trying not to drop noodles and rice all over the linoleum floor.

Samantha seemed happy to see us, or maybe just relieved. "I miss you, Moosie." She kissed his cheek. "Come home soon."

"I want to." He gave her a sad smile.

"We brought cupcakes." She snatched the bag from me. "Mommy, let me. Samantha wants to do it. Not you." Referring to herself as Samantha was "echolalia," a symptom of autism. Smiling at her brother, she pulled out a cupcake and licked the icing from her fingers. "I know you like vanilla. I got chocolate."

"Thank you, Sam," he tried to rally.

Matt was weak and tired easily; still, it was wonderful to watch him, slurping down noodles with peanut sauce dripping from his chin. I was also happy to see Samantha act so sweet and loving toward her brother. Most of the time they didn't

play together, and when they did interact, it was usually a fight. Had Samantha intuited the seriousness of her brother's situation? It certainly seemed that way. There weren't many silver linings in the cloud that seemed to follow our family, but I'll always remember Samantha's unexpected tenderness toward her brother in the hospital. And I also can still see Howard performing silly shows with the felt doctor and nurse hand puppets.

Alternating between the doctor's deep James Earl Jones and the nurse's squeaky Betty Boop falsetto, he enacted a silly seduction scene that caused the real nurses and doctors nearby to laugh out loud. Matthew laughed too, whether or not he understood the flirting jokes. Sometimes Howard was able to cut through the tedium and tension that hung over us like an invisible net.

Each day Matthew grew stronger. On Tuesday, he was almost running down the hospital hallways, and I was admonished to slow him down. By Wednesday, he was spending hours in the children's playroom, building a Lego fortress and pushing a truck around. On Thursday he motored around in a blue plastic cart, pretending to be a fireman, blasting the siren. Friday he was ready to be released.

Howard and I were also released— from our respective prisons of pain and worry. My husband escaped the hospital "guest" room (which he'd converted to a mini-office with paper, files, and empty FedEx envelopes strewn all over, and where he'd become increasingly attached to the phone as Matthew improved.) When we finally got home, I looked forward anxiously to being reunited with Samantha, now that my little boy was safe and healing.

When Samantha came home from nursery school that Friday afternoon, she did not hurl herself into my arms, yelling "Mommeeeeeeee!" as she usually did. Instead, she walked right past me. Deliberately, she hugged and kissed her brother before going into their room, lying down on her pink flowered bedspread and facing the wall.

I followed her into her room. "Hi, sweetheart, we're home," I tried, bending down to kiss her cheek. "I missed you so much."

Samantha slapped me in the face as hard as she could.

### Indelible Changes

That was the moment my daughter turned from a weirdly spacey three year old into an emotional fireball. Before Matt's surgery, she'd rocked and cried at the slightest deviation in scheduling, but otherwise she'd remained eerily detached. After the surgery, she became a continuously erupting volcano, spewing molten hot anger and frustration, emitting ear splitting screams, and issuing fierce, perseverating demands that sometimes escalated to violence, overflowing like

waves of lava into every area of our family life.

Looking back at the picture of our three-year-old twins on the deck of our summer house, both Matt and Samantha seem happy. But that was before Matt's surgery and before Samantha's first taste of separation. So much changed after that snapshot. There would never be another picture of Matt's chest without a long, vertical scar running down the middle. At first, our son's scar was red, raised and angry, but I knew it would gradually lighten and go flat. But what about Samantha's scars? I wondered. No one could see them in our family photos, where she always wore a blinding smile. My daughter's scars were invisible yet omnipresent, and I didn't know if they'd ever fade.



## Chapter 3

### Separate Cakes – A Grandfather’s Wish



My father never thought he'd live long enough to see one grandchild—let alone two. He was 43 when I was born, 75 when I married, and nearly 78 when Matt and Samantha came into the world. Shortly after the twins' birth, my dad was diagnosed with lung cancer. After losing half a lung, he bounced back from surgery to play with his grandchildren as fast as possible. I don't think he wanted to miss a moment of enjoying them. Although he tired easily, my dad seized every opportunity to visit "his" twins. I remember when Howard photographed Papa sitting in our den, proudly wearing his favorite sweatshirt. In the snapshot, "World's best grandpa" is emblazoned in looping green, blue and red script with a whimsical yellow sun above planet earth. I'm leaning into my father; his hand affectionately pulls my head closer. Like my dad, I'm wearing a sweatshirt, but mine sports the name of my favorite dance class. We are both enjoying the end of a visit with Matt and Samantha, and although I smile for the camera, we are both exhausted for different reasons. My father is exhausted from his recent struggles and the road he navigated over a lifetime, but I'm weary from looking ahead at the long road in front of me.

Blowing out the candles on my twins' fourth birthday was special for me. It was the last time they would share a cake or go the same school, although they'd continue to have birthday parties together for five more years. The twins' fourth birthday cake was a large vanilla rectangle with yellow flowers and "Happy



Birthday” in chocolate script. My dad would have loved watching Samantha in her plaid dress and black Mary Janes, trying to shoulder her brother away from the burning candles. He would have clapped when “his” twins extinguished the candles in one big breath. Instead, I applauded for both of us, especially appreciating this birthday ritual, which was one of the few activities my kids could succeed at together.

We were at Little Shop of Plaster, an arts and crafts store where children selected from a variety of unfinished ceramic items to paint. In the party room, sixteen “old threes” classmates surrounded them at a rectangular table. Everyone wore yellow plastic aprons and rolled up their sleeves. It was the perfect place for a winter party on a frigid December day and perfect for my two very different children. I’d learned from observing Samantha at other children’s parties that she could not understand or enjoy puppets, magicians, clowns or anything which involved pretend play or rapid verbal exchanges.



At a party like ours, helpers came around to offer paint colors, do touch ups and add sparkles.

Regardless of motor skills or artistic ability, every child at the party went home with a pretty party favor he or she could be proud to show Mom and Dad. Matt, like many of the boys, made a red Power Ranger. Samantha chose to paint a green Baby Bop, the girl dinosaur character in the Barney series. She tried to dab black dots for eyes and a pink bow on the head, but the colors smeared into a greenish brown. Still, she was happy with her creation, especially the many sparkles which gave the surface a coarse, grainy texture that she enjoyed rubbing repetitively.



For the first time, both sets of grandparents were absent from my twins' birthday party. Howard's father, Grandpa George, had died of liver cancer earlier that year. Although he wasn't particularly close to either of our children, Samantha seemed to feel his loss more than Matthew did. The last time she'd visited Grandpa George in the hospital, he'd had yellow eyes and a thin sheen of sweat on his face. She stood on tiptoes to reach for his hand and laid her pink cheek against his arm. A week later he was dead.

"Can I see Grandpa George again?" Samantha asked, rubbing her sparkly Baby Bop ceramic.

"No, but you can visit him in your memories."

She gave me a blank look.

"Memories are movies in your mind, like when you think of times in the past with Grandpa George. Remember when he came to your birthday party last year and gave you a pink teddy bear?"

Samantha stared into space, and I knew the conversation was over.

Matthew didn't talk about Grandpa George's death, but then again Grandpa George hadn't visited us much. Also, Matt's heart surgery had forced him to spend time in the hospital around sick people. I think my son intuitively understood death in a way that went beyond most four year olds. Or maybe he was just too scared to talk about Grandpa George. Matt didn't ask his usual litany of questions; in fact, he never brought up the subject at all.

Both Matthew and Samantha had a very different relationship with my parents, who often babysat. Matt liked racing toy cars with Papa and firing questions at him about being a soldier in the Korean War. Samantha preferred to snuggle silently in Grandma's lap, sometimes touching her face while staring into space. My parents also took the twins to many of the places they'd taken me as a little girl: the Children's Zoo in Central Park, the Empire State Building, F.A.O. Schwarz, and Serendipity for ice cream sundaes.

### **Marathon Emergency**

On the day of the New York City Marathon, a brisk and overcast October afternoon, we picked our way home around discarded cups and the detritus of a race that was over for most people. The phone was ringing as I walked in the door.

"Your father had a heart attack," my mother explained in a tight, controlled voice. "We're at Lenox Hill hospital."

"What happened?"

"We were walking home from Starbucks, and he started to complain of chest

pains radiating down his left arm. We both knew it was a heart attack. Somehow we managed to get home and call an ambulance.”

“How is he now?”

“Well, he’s awake, but it was pretty severe. He was DOA when we got to the hospital, but they were able to revive him. They’re telling me he’s lucky to be alive. If I hadn’t gotten him home and called right away, he wouldn’t have made it. You better come.”

“I’m on my way. Meet you in the emergency room.”

I looked at Howard. He’d pretty much guessed that my 82-year-old father had had a heart attack from overhearing my side of the conversation. Unfortunately, our children could also sense that something was terribly wrong. It was as though they’d seen a lightning bolt pass through me and felt the heat and electricity still hanging in the air.

“Dad had a heart attack,” I confirmed. “I better go.”

“I’m going with you,” Howard insisted.

“What about the kids?” I had to hurry, but I looked at them and felt paralyzed.

“Take them with us.”

“Aren’t they too young?” Wouldn’t Matt be terrified to go to the hospital after his recent heart surgery? Especially since Papa just had a heart attack. Samantha was still angry at me for leaving her when Matthew was in the hospital. Which would upset her more: leaving her home with Howard for a little while or taking her to the hospital where she might see my Dad die?

“You’re not going by yourself,” Howard informed me. “I’ll stay in the waiting room with the kids, and you’ll go in to your mother. Then we’ll switch and I’ll go talk to the doctors and ask questions. We can take turns with the kids.”

“Is Papa going to be okay?” Matthew asked. His blue eyes searched my face.

“I hope so.” I picked up his black leather bomber jacket. “Let’s go.”

“What’s wrong with Papa?” Samantha asked no one in particular. Her hazel eyes were glassy and distant.

“He had a heart attack,” I explained, gingerly sliding on her pink and white bomber jacket and praying she wouldn’t fight my help.

“Like Matthew?” She allowed the jacket to be snapped shut without resistance. But her hands retracted into their sleeves where they were unreachable. As usual, she didn’t want anyone to hold her hand.

“No,” I replied. “Not at all like Matthew. Heart attacks only happen to old

people, not to children like you.”

My own heart felt frozen and frantic at the same time. Would my dad survive? Would my mom cope? And how on earth would I find the strength to take care of everyone in my family? Right now I needed someone to take care of me. I felt trapped in a labyrinth where each path led to another problem instead of safety or some kind of solution. Thank God, I had Howard. Although the labyrinth seemed endless, I wasn’t alone. Knowing Howard would only be five minutes behind me, I was able to propel myself out the door and try to rush to the hospital.

On streets strewn with crushed paper cups and empty water bottles from the NYC marathon, it was impossible to find a taxi. All the exhausted marathon runners were cabbieing home, and the few who still trickled in were my competition. Dashing through the obstacle course of marathon litter, I wondered if I’d get to the hospital in time to see my Dad alive. Would my few minutes of hesitation make me too late? The sunlight faded, and I felt a cold wind behind me. It was only a few blocks to the hospital. If I could get there fast, Dad would be okay. Jumping over plastic water bottles, I reassured myself in much the same way I had when skipping over cracks in the sidewalk as a child.

Out of breath, I arrived at Lenox Hill’s emergency room, gave my name and situation to the triage nurse, and pushed through to the patient area. There I swam into the controlled chaos of nurses and doctors who circulated among patients in various degrees of illness and pain until I saw my mother.

My mom greeted me with a quick hug. “Dad’s awake now and you can see him.” She gestured to the white draped area where my father lay. “He suffered a very, very serious heart attack. The doctors have stabilized him for now, but he could have another one.” She spoke calmly; her face looked wan and strained. Normally a young looking 69, today she seemed suddenly aged, and her skeletally thin body reminded me of the branch of a tree ready to snap. “The doctors have suggested a few options, but we have to decide quickly. But I want you to see him first.”

Pulling back the curtain, I was pleasantly surprised to see my Dad awake and alert. Ironically, other than being pale, I thought he looked better than my mother.

“I’m still here, and the doctors tell me I’m lucky to be alive.” He smiled gamely, and his hand reached for mine. “Your mother did a terrific job.”

I kissed him. “Are you in pain?”

“Not anymore. But they’re telling me it will happen again unless I have some kind of surgery.” My father’s deep brown eyes glittered with terror at his near miss and the distinct possibility that his luck was running out. “I don’t know what to do.”

“Don’t worry.” I tried to sound calm and reassuring. “We’ll figure it out. Why don’t you rest now?”

“You’re not leaving, are you?” he asked, suddenly alarmed.

“No, of course not.” I squeezed his hand gently, happy to feel its dry warmth. “I just want to talk to Mom and the doctors. Howard is outside in the waiting room with the kids, and he wants to see you too. I promise I’ll come right back.”

After talking with my mother, the doctors, and Howard, it was time to choose the best of three alternatives for Dad. With heart medication alone, we were told he would probably die within the next six months. Open heart surgery would have been the best option, if Dad hadn’t been 82. Also, he’d just battled back from lung cancer surgery four years earlier. So we felt compelled to choose the middle ground: an angioplasty, followed by a Roto-Rooter procedure that would clear the blockage in his arteries. The doctors told us this was a relatively simple procedure, and Dad would be home in two days.

The doctors turned out to be wrong. My father had the angioplasty the next morning, but it didn’t go as planned. Instead of being awake afterwards, he was in a coma and on a respirator. After a frantic phone call from my mother, I rushed back to Lenox Hill in a driving downpour, chilled to the bone.

“What happened, Mom?” I peeled off my soggy black raincoat, horrified to see my Dad with the tube down his throat and attached to a machine that was keeping him alive. His face was as white and still as marble, and he appeared to be in a deep, dreamless sleep. It was hard to believe I was looking at the same man who’d recovered completely from having half a lung removed only a few years earlier. He’d been so brave and upbeat before his lung cancer surgery and had won that battle; it seemed so unfair that he might lose this one.

“I don’t know what happened! Did they botch it? Maybe we made the wrong choice. We should have gotten a second opinion—”

“Don’t you remember,” I interrupted. “I tried to reach my internist, but there wasn’t enough time.” My mother was miserable. Dark shadows circled her eyes, and she was wearing the same black sweater and jeans as the day before. It was obvious she hadn’t left his side.

“Maybe we should have tried to find a better heart surgeon.” She rubbed her gaunt cheekbones, and I wondered how long it had been since she’d eaten.

“Don’t blame yourself, Mom.” Even though Howard and I had suggested researching heart surgeons, the ER doctors at Lenox Hill warned that it was urgent to act right away. “Everyone said this was the best choice. The question is: why didn’t it work?”

“They’re telling me it was hardening of his arteries,” Mom said. “It was difficult to chip away the plaque.”

That afternoon Howard and I talked to the surgeon, a tall, plain looking woman with chin length black hair. I didn't absorb much of what she said. Her words sounded reasonable, but we knew we'd never get the full story. I found myself staring at the Band Aids on the tips of the doctor's right index and ring fingers. Had she been wearing those when she worked on my father? Had the Band Aids caused an instrument to slip in her hand?

After Howard went home, I stayed with my Mom for the rest of the day and took her to dinner before returning home to my family. It was the first of many days to come when I would sit with my mother by Dad's hospital bed, sharing her vigil to see if or when he'd wake up. During the first week I usually went for three or four hours, until it was time for my kids to come home from nursery school.

### Waiting For A Miracle

We kept hoping Dad would improve enough to go off the respirator. Instead we held our breath through a roller coaster ride of setbacks. First he suffered a hemorrhage from too much blood thinner, then kidney problems and dialysis, and finally sepsis, a serious blood infection caused by bedsores. One by one, he slowly (and it seemed valiantly) recovered from each battle just in time to face the next. After about six weeks, in early December, the doctors urged my mother to take Dad off the ventilator. They believed that he'd been on the machine too long and was too weak to ever come out of the coma.

My mother refused. Dad's brain was still healthy, and she believed he had a chance for a good quality of life if he woke up. She no longer trusted doctors, and she'd already caught nurses making mistakes in Dad's medications. She thought they probably would have killed him if she hadn't been there almost 24/7 to intercede.

I didn't know what to think. I wasn't happy with the doctors' advice either. I wanted to be optimistic and see Dad beat the odds the way he did with lung cancer. As always, Howard was pessimistic. He felt at some point my Mom should let go. But I understood her need to fight for his life, just the way I was fighting to help Samantha even when the odds were against us. On the other hand, I didn't want my father to stay in a coma indefinitely, or my Mom to fight a battle that might kill her too. In only two weeks, she'd lost 10 pounds, no matter how often we took her out to eat. She was 5'7" and now weighed 103. Her face was ghostly white, and clothing hung so loosely from her body that it seemed she was fading into her bones. She lived mostly on the hospital meals Dad didn't eat, and except for going home to shower, rarely left his side. Still, disconnecting Dad from the ventilator had to be her decision.

Mom continued her daily vigil, but as time went by, I spent fewer hours at the

hospital. Dad was in a coma; there was nothing I could do, and my children needed me. Sometimes I had to skip a day or two.

"You hardly come any more," my mother complained to me over the phone.

"I'm there almost every day."

"Even when you come, you don't stay long. You're always rushing away." She continued as if I hadn't spoken.

"I love Dad with all my heart," I said into the phone. "But I have a husband and two children at home. They need me too." I was desperately hoping my mom would not try to make me feel guilty and inadequate. I was having a hard enough time juggling everyone's needs.

"You have a babysitter who can stay with the twins," she insisted.

"Yes, I have a babysitter to HELP me, and God only knows what I would do if I didn't. But I'm still the mother, and no one can take my place." I was determined to put my kids first. I remembered how sad I felt when I was sick or lonely and Mom left me with a babysitter, in order to go out to dinner with Dad.

"You could stay with me longer while the kids are in school."

"You make it sound like I have nothing else to do. I MUST find a school for Samantha next year. Otherwise she'll fall even further behind. I've got hours of research, phone calls and school visits, plus fighting with the Board of Ed for funding, and that's only if we're lucky enough to find a good special ed private school with space for her."

"He's your father. Don't you want to be there when he wakes up?"

"Of course I want to be there. I love him too. That's why I stayed so much during the first two weeks. But now I have to put Howard and my children first, just the way you always put Dad first. And you know where I am if he wakes up or you need to talk."

"Are you planning to leave me here all alone on Thanksgiving?"

"It's just one day, Mom." We'd all been invited to Bob and Jane's house for Thanksgiving. But Mom had decided not to go. "I understand that you don't want to leave Dad. But what about the rest of my family?" I didn't remind her of the time she and Dad had left me alone on Thanksgiving to go to Florida for the weekend with friends.

"Fine," she snapped. "I won't call you if he wakes up, and I won't call you if he dies."

Stunned, I didn't know how to respond. Eventually I managed, "OK, if that's the way you feel I'll ask the nurses to call me." I was honestly devastated that my



mother could be so vindictive at such a terrible time. Early Thanksgiving morning, before my mother arrived, I went to Lenox Hill Hospital to kiss my Dad and leave my number with the floor nurse.

### Mother vs. Daughter

How much time could Mom expect me to spend with her if she was going to attack me? Was I supposed to buy her lunch at the coffee shop every single day? How many excruciating hours was I supposed to spend listening to each minuscule detail of Mom's hospital experience: Dad's urine output, his blood levels, and the lazy, rude nurses. Mom even insisted on reporting on the conditions of strangers, husbands of other women she'd befriended in the hot, airless, waiting room on the 11th floor. Worst of all were the digs about how her friends were so wonderful and attentive, while I was the uncaring daughter.

It wasn't as though I could talk with my Dad. He didn't know I was there, and my being my mother's babysitter wouldn't help him wake up. After a couple of hours in the hospital with Mom, I was drowning in a quicksand of memories. I didn't want to be angry or vindictive at a time like this, but how could I forget that she'd pressured my father to spend all of their income on jewelry, art, and month-long, first class vacations so that I almost couldn't finish college?

During spring break of my junior year, my mother left a notice from Vassar College on the kitchen counter that said I couldn't return to campus because my parents hadn't paid the tuition. How could I forget finding that? I had always tried so hard to make them proud of me, their only child...worked hard to get good grades, so I could get into a top school because they "didn't want to pay for a second rate school." Mom said, "Why stay at the Holiday Inn, when it costs the same to go the Plaza?" I knew she'd left the letter from Vassar because neither she nor Dad could face me with the news. Thank God, my elderly grandmother had just enough to pay the rest of the tuition.

In the early 1980s, after my parents went bankrupt, they still went out for fancy dinners but no longer invited me. Instead, I got five or ten dollars to eat alone. Even on my birthday, they went to dinner without me when I was sick, instead of staying home and keeping me company. I never told



Dad that Mom sometimes stole my allowance when she'd already spent her own. I clenched the phone, my hand now slippery with sweat.

"Look, Mom, I don't want to fight with you. I'll come as much as I can."

In the midst of my father's medical crisis, I also had to take care of my children. I had to keep my promise to Samantha to be the mommy who always comes back. I had to monitor her therapy and give her enough love to coax her out of her world into ours. Matthew needed attention from me too. Every week we had a "surprise day" when just the two of us did something together after school. He never knew whether I'd take him to the dinosaur exhibit at the Museum of Natural History, the Children's Museum, or Central Park where he could have me all to himself. My Dad had started the tradition of "surprise days" when I was in nursery school. If he ever woke up, I'd tell him about my surprise days with his grandson.

My mother had to understand that I loved my husband as much as she loved hers. I wanted time alone with Howard, to be there when he came home from work, to go out to dinner alone and just to catch my breath.

Last, but by no means least, I also needed a new school for Samantha. This was a research project that couldn't wait. Barbara suggested I look at Gillen Brewer, a nursery school on 92<sup>nd</sup> and First, which had just opened for children with developmental delays. At that time they had two classes, lower functioning and higher functioning, and they were planning to add one in between for the following year. The higher functioning class had eight kids pretending to be butterflies and bees. They were able to talk about bugs and clearly ahead of Samantha. The lower functioning group had spaced out kids standing around an industrial sink, splashing water together. They hardly talked at all. I couldn't put my daughter in either of these classes, and I didn't feel comfortable not knowing what the in-between class would look like. I also felt reluctant to gamble a year of her life on a start-up school.

The next school I looked at was AMAC, on West 17<sup>th</sup> Street in a dingy red brick building. It was 2:30 PM on a sunny, blustery day in early December when I entered a dimly lit waiting area. Once there, I watched a teacher with spiked black hair and pierced lips yank a boy's upper arm so roughly he almost fell down.

"You get back in this line NOW. I'm not going to tell you again," the teacher barked.

Not surprisingly, the boy started to cry.

I turned to two other mothers, waiting to pick up their children. "I'm here to look at this school for my daughter for kindergarten next year. Are the teachers always so rough with the kids?"

One of the mothers, a young, neatly dressed Hispanic woman, glanced over

her shoulder and leaned in closer to me. “This place is no good,” she whispered. “You don’t want to send your daughter here...unless you have no other choice. I’m getting my son out as soon as I can.”

“She’s right,” the second mother, a blonde in her 30s with a perfect manicure, quickly agreed. “This place has a terrible reputation. The teachers don’t really know what they’re doing. It’s all very disorganized. You’ll see for yourself,” she added.

Just then a frazzled looking psychologist in a wrinkled gray suit arrived to take me on a tour. “Sorry to keep you waiting. Jill, the director, got tied up on the phone and asked me to show you around instead. She’ll try to join us at the end to answer your questions.”

I wanted to leave, but my options were limited. Maybe it wasn’t as bad as it looked and sounded. It was important to keep an open mind and learn as much as I could about each school so I could make the best choice for Samantha. Following the frazzled psychologist down the first hallway, I noticed bare light bulbs hanging from the ceiling and walls in the process of being scraped.

“You’re renovating, I see...”

“Yes. It’s been taking longer than we expected.” He moved a bucket of plaster closer to the wall.

I didn’t need to ask if this was distracting and disruptive to the teachers and children.

“Tell me about the children who go here,” I said instead. “What are their disabilities?”

“Well, most of them are somewhere on the autistic spectrum. Some are emotionally disturbed.” He kicked an empty primer can out of our path. “There are also kids with language processing delays.”

“Where do you see my daughter fitting in here?” I asked, side-stepping a ladder.

“From what you’ve told me, Samantha would belong with the kids on the spectrum with language delays.”

“What reading techniques do you think would work for Samantha?”

“I don’t know exactly. Jill will explain all that.”

When we went back to the director’s office, I could see Jill was still busy on the phone.

“You could wait a few minutes. I’m sure she won’t be much longer.” He tried to cover his bald spot, smoothing down his coarse gray hair.

“That’s okay.” I edged away from the director’s office. “My dad’s in the hospital, and I’m already late to meet my mother. I’ll call another time,” I pretended to assure

him.

We shook hands, but he'd never hear from me again.

### Not Quite A Miracle

When I arrived at the hospital later that day, my Mom, though haggard, looked slightly hopeful. My father had been slowly weaned from the respirator, but he was still in a coma. His condition appeared otherwise unchanged.

"Maybe I'm crazy, but I could swear he's waking up," Mom's voice rose. "A little while ago, I squeezed his hand, and I felt like he was trying to squeeze back. Then I asked him if he loved me—and you know your Dad's sense of humor—it seemed like he shook his head slightly as if he was trying to say no."

"Wow, that's great!" I leaned over to kiss my Dad and squeezed his hand, but it was as limp as it had been on my last visit. "How about me?" I tried to tease. "Do you love me too?" I watched my father carefully and saw what I thought was a tiny, almost imperceptible nod.

"See what I mean?" My mom's red, tired eyes were starving for hope.

"I think I saw something too. Maybe it's the beginning...especially since we both saw it."

At the end of the day, Howard came from the office to visit. "Hi Jan." He kissed my Mom. "I hear Larry might be waking up." He peeled off his Burberry raincoat and collapsed into the green leather guest chair. "Long day."

"All my days are long," my mother replied competitively. "But I keep hoping and praying. You know me."

"Yes I do." Howard gave me a meaningful look before turning to my Dad. "Hey Larry, Marguerite told me you were getting ready to blow out of this place. Is that true?"

No response.

"You know," my husband continued, "the kids are going to celebrate their fourth birthday over at Little Shop of Plaster in a week. I hope you'll come help blow out the candles. They've been asking to see you."

Nothing.

"Well, I understand," he chatted on. "Maybe that's a little too soon? But how about the b'nai mitzvah? You're still planning to come to that?"

This time Dad nodded *twice*.

We all saw it.

Dad's eyes didn't open, but his face softened. He looked more like a healthy person who was exhausted and not quite ready to wake up.

Mom wiped a tear from her cheek, and I felt a glimmer of hope.

Maybe Howard's voice, familiar but different from ours, had begun to rouse him. Or maybe it was their shared sense of humor. My father had once told Howard he really wanted to go to Samantha's wedding and see how beautiful she would look as a bride. When Howard replied that he would be lucky if he made the b'nai mitzvah, my Dad had roared with laughter. Making it to the b'nai mitzvah had been a standing joke ever since. If Dad was nodding now, it seemed especially significant. Even for Howard, this was a tangible, positive response.

My father didn't open his eyes or speak that night, but he slowly emerged from the coma. While this was a joyous event, it didn't resemble anything I'd seen in the movies. At first Dad opened his eyes for short periods, speaking a few words at a time in slurred whispers that only my mom understood. He gradually became stronger and more alert, but the man lying in his hospital bed was very different from the father I'd known all my life. No longer was he joking and upbeat. Dad was still affectionate and kind sometimes, but he didn't *kibbitz* with the nurses and his stoic, can-do attitude was gone. Instead he complained constantly and lost his temper with everyone.

My warm, outgoing father had turned into a broken old man. The heart attack, his subsequent kidney failures, infections and more than two months in a coma had weakened Dad to the point where winning the battle to wake up was for him a pyrrhic victory. He wore a diaper which the nurses never came often enough to change, so my Mom had to do it. He'd lost 30 pounds and had trouble eating and keeping down food. He hated eating the hospital food and drinking the Ensure.

"How about if I bring you a Häagen-Dazs coffee milkshake? That's your favorite, right?" I asked him one morning, as I shook the snow from my umbrella.

"That's a great idea. Isn't it, Larry?" My mom sounded like a cheerleader as she stroked his white hair.

"I don't know," he replied without enthusiasm. "You can bring it if you want."

I returned with the milkshake after walking six blocks in a blizzard. "Here Dad, you'll love this. Finally, you can have all the calories you want!"

"Well, thanks," he mumbled.

My mom propped up the pillows and steered the straw between his cracked lips. "C'mon Larry. You've got to build up your strength."

Like an obedient child, he sucked it down quickly. Five minutes later he vomited.

“Maybe the milk shake wasn’t such a good idea after all.” Mom looked at me accusingly as she cleaned him up.

“Maybe he drank it too quickly. Maybe he shouldn’t have had it all at once.” I was determined not to get stuck in the blame game. “Hey, Dad, maybe it would cheer you up to see the kids.” I changed the subject.

“Definitely not. I’m too weak. I don’t want them to see me like this.”

“Okay. Maybe next week, if you’re feeling better?”

His dark brown eyes looked up at me sadly. “I really doubt it. You just don’t understand how tired I am.”

Dad went to physical therapy in a wheelchair with my mother. He screamed at her, at the therapists, at me, at whoever would listen. At every visit, he bellowed the same list of complaints: he couldn’t do the therapy; it was too difficult; he didn’t have the strength; nobody was listening to him. Everyone should just leave him alone and let him be.

I felt sorry for my mother, but there was another school to visit the next day. The Gateway School was also recommended by Barbara. Conveniently located in a church on Madison and 73<sup>rd</sup> Street, it supposedly had higher functioning children than those I’d seen at AMAC. Gateway had imposing white pillars and high ceilings. There were cream colored walls with crayon self-portraits of children taped next to their photographs. Thank God, the place looked like a kindergarten and not a construction site. Here I was greeted at exactly 2:00 PM by two middle-aged women, wearing tweed, Chanel-type suits.

### **Tweedle Dee And Tweedle Dum**

“Welcome to Gateway.” They both had firm, dry handshakes. “I’m Dr. Renwick, the director,” said the woman in the rose-pink suit. “And this is Dr. McMahon, our psychologist and head of admissions,” she introduced her virtual twin in the lime green suit.

Feeling as though I was escorted by Tweedle Dee and Tweedle Dum, I toured Gateway’s colorful classrooms. They were similar enough to Matthew’s homeroom at Epiphany Community Nursery School for me to recognize a high functioning environment. There were upper and lower case letters of the alphabet in primary colors on classroom walls, neatly stacked storybooks, and Lego projects in progress on plastic tables. The class here had eight children, instead of the sixteen in Matt’s class, and there seemed to be greater structure and less chaos at Gateway. Most of the kids looked reasonably engaged, although not as spirited and lively as my son’s classmates. So far I was impressed.

“What kinds of children do you accept here?”



“We look for bright kids with learning disabilities, some language delays and mild social and behavioral issues,” Dr. Renwick answered.

I wasn’t sure Samantha fell into that category, much as I wished she did.

“The most successful ones,” Dr. McMahon elaborated, “are usually those who are able to follow directions and take advantage of the extra support we offer.” Both doctors smiled and nodded at me.

But that could be any school, I thought. “OK, let me ask this a little differently. What kids don’t you accept? Who doesn’t fit in?”

“We don’t take kids with serious behavioral or emotional issues, or whom we feel would be disruptive or aggressive towards others,” Dr. McMahon explained.

“These issues happen more often when there are severe pragmatic language and social delays,” Dr. Renwick added. “Why don’t you come to our assembly and observe the children? See whether you think Samantha would fit in.”

At the assembly, the Gateway children quietly and obediently stood on top of chairs, talking about the animals they’d seen on their field trip to the zoo earlier that day. At the end, they waited silently for the director’s instruction to move the chairs against the wall and stack them in pairs. I wasn’t sure Samantha would or *could* climb on a chair, let alone articulate her experiences as well as these kids. I also knew that there was a strong possibility she wouldn’t help stack chairs and might just throw one instead. After the assembly, it was clear to me that Gateway would be the wrong place for Samantha. Despite my disappointment, I doubted that standing on a chair and obediently stacking it was the best goal anyway.

After crossing Gateway off my “to do” list, I went back to the hospital. Finally, at the beginning of February—after almost four months at Lenox Hill—my father decided he was well enough to see his grandchildren for a short time. The twins and I met him in an empty waiting room. He was sitting in a wheelchair with a thick, white blanket draped over his legs, though the room was stuffy and felt like 90 degrees.

When he saw Matt and Samantha, Dad broke into the biggest smile I’d seen since he entered the hospital. Slowly, he reached out his hand. “How are my two beautiful grandchildren?”

Both kids ran to Papa and Samantha would have jumped into his lap if my mother hadn’t restrained her.

“I miss you Papa. I miss you so much,” Matt said, placing one small hand on the white blanket over my father’s knees.

“You and Grandma didn’t come to my birthday,” Samantha said. She kissed my dad’s hand and allowed him to kiss hers. Her face lit as if somehow his warmth had

brought out hers.

My dad closed his eyes in bliss. "Believe me, I wouldn't have missed it for the world if I hadn't ended up here."

"Would you like to see a picture from the party?" I asked, handing him a snapshot. I'd suggested bringing a birthday photo to the hospital to Samantha, and she'd loved the idea. Together, she and Matt had chosen the picture of them blowing out their candles.

"That's some big cake you had there," Dad joked. "Maybe next year I'll get you each your own cake. That way you can have chocolate, Samantha, and Matt can have vanilla. Would you like that?"

"Yes, Papa, yes," they both answered.

"Will you come next year? I don't want you miss it again. Don't miss my birthday," Sam couldn't help repeating.

"I'll try, if I'm healthy." He didn't sound convincing.

"Are you feeling better now? Will you come home soon?" Matthew took my Dad's free hand.

"I'm better, but I still need to get stronger. It's up to the doctors." He looked up at my mother. "And to my boss over here."

My mom gave him a tight smile. "The boss needs you to do your physical therapy and cooperate."

"She's right," I said. "You've got to listen, if you want to get out of here. I know it's hard, but it's for your own good."

Dad rolled his eyes.

## Homeward Bound

He didn't go home until the end of February, after celebrating his 83<sup>rd</sup> birthday in his hospital bed, sitting up only long enough to blow out the candles on the mocha cake I brought. My mother took him home in a wheelchair, exhausted and worried that she wouldn't be able to care for him properly. My parents could only afford limited nursing, so the burden of caring for him fell heavily on her. Howard and I couldn't help much because of the bills from Samantha's therapy and Matt's heart surgery.

My father lasted 16 days at home. He was rushed back to Lenox Hill after passing out from dangerously low blood pressure. The last time I saw my father he was hooked up to a breathing machine and fully conscious, but he didn't make eye contact. Instead he stared intently at the ceiling, wide-eyed with terror.

Sometimes I wonder if it would have been better for all of us if he'd died from the heart attack on the day of the race, instead of suffering through a personal marathon he couldn't win. I don't want to remember the fear and resignation in Dad's face at the end. Instead, I want to focus on his bravery and determination, his sense of humor and warmth, and how—for him—I was the most beautiful little girl in the whole, wide world. I hope the best of my father can live on through me, Howard and our children. I'd keep up the surprise days with Matt for as long as possible, although by first grade he would prefer to play with friends. And I'd never stop telling Samantha she was the most beautiful girl in the world, even if she appeared conceited when she repeated my compliment to strangers. As for the twins' future birthdays, I'd give each child their own cake, the way my father would have done. Starting at age five, they would blow out their own candles and make their separate wishes.



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## ABOUT THE AUTHOR



Marguerite Elisofon is a New York City writer and the author of *My Picture Perfect Family*, a memoir about how her family navigated life with a child on the autistic spectrum before the internet and support groups existed. She also blogs about parenting young adults and disability related issues in *The Never Empty Nest*, which was featured on Fox 5 News. Her essays have been published in literary magazines such as: *Existere: Journal of Arts and Literature*, *Write for Light*, *Hobo Pancakes*, *Wild Violet* and *Kaleidoscope*. A Vassar graduate, Marguerite was born and raised in New York City, where she still lives with her husband, Howard, in their mostly-empty nest.