

It's So Good to Hear Your Voice

By Melissa Paris

INTRODUCTION

My sister Ali suffers from a form of pediatric epilepsy that affects the language center of her brain. She was born normal, but around age three had a series of 12 ear infections in three months. After that, Ali began to lose her language and soon after became completely mute. For three years, my family searched for a reason why Ali had lost her ability to speak. In 1995, she was diagnosed with Landau-Kleffner Syndrome (LKS). Since then, I've watched my sister change — and that affected my life profoundly. It was hard to grasp what was actually happening, and after she was diagnosed, Ali had to take medication after medication. I remember after her first round of steroids, which were aimed at making a pathway around what we think might be a virus in her brain, Ali would respond when someone called her name. Ali is now 14 and completely understands the world around her. Her language is coming in slowly, but she is making progress every day.

On April 11, 2002 I founded a non-profit organization called the Ali Paris Fund for LKS Research and Education. The goals of the foundation are two-fold: One is to raise money in order to fund medical research to find a cause and cure for LKS and further epilepsy research; the second is to educate the public on LKS, epilepsy, and the tolerance of people with disabilities.

Academy Scholars helped me cope with the aspects of my life that revolve around my sister. During my time at Germantown Academy, I had written poems and short stories about what it is like to have a sister who has disabilities. I had never, though, expressed my self on this scale. This program allowed me to write about my experiences and, in doing so, tell my story.

When I began my participation in the Academy Scholars program in my sophomore year of high school, I knew I wanted to do a project having to do with Ali, but I was not exactly sure how. I finally decided, after reading past English papers I had written on the subject, to write a memoir. My advisor, Mr. Peterson, first directed me to read a few memoirs before undertaking my project plan. I also read a diary to establish the difference between that and a memoir. Over the summer I read numerous books, visited many Web sites, and read up on the meanings of themes, moods, and non-fiction structure, so I would be well-versed for the fall, when I would begin my writing.

When I began my memoir, I first had to outline which memories I wished to include in it. After narrowing them down so they would all flow together with a common theme, I started writing. Not only was it academically difficult to compose a coherent, well-rounded, thematic piece of writing, but it was emotionally hard to admit some of the feelings I had about my sister. Each week, my memoir grew in length. Mr. Peterson and I had set up deadlines for when a certain number of pages or chapters were going to be due. At the end of December 2003, my memoir, in its preliminary stages, was complete.

In January 2004, Mr. Peterson reviewed and edited my memoir. After that was finished, I made Mr. Peterson's corrections. It was now ready to be viewed by teachers and other professionals. I wanted any type of reader to understand my memoir, so I asked a diverse group of people for their comments. By March 2004, those edits were complete. For the next month I devoted myself to reviewing my own memoir. This was the most difficult part of the entire process because I had to be critical of myself. I had to remind myself of the aspects that are crucial to a memoir, and edit out aspects that did not fit the requirements. After making my edits, I allowed my mom, dad, and Dr. Kollros, my mentor, to examine my memoir. I picked the people closest to me to delve into my work because I knew that their suggestions would be meaningful.

Following my memoir's completion, I plan on having it published, so I can distribute it to neurologists' offices across the country. By doing so, the doctors can pass my memoir out to siblings of brothers or sisters who have a neurological disorder. Those siblings then can realize that what they feel is not out of the ordinary and that I understand what they are going through. Writing this memoir has given me the opportunity to not only change my life, but I hope it will benefit the lives of others. This project has just given me a jump start to my future in continuing to write more about my life experiences and my sister Ali.

Music, Leather, and Sizzling Pork Chops

My sister Ali was born on December 19, 1989. We counted 10 toes, and we inspected her 10 fingers. Everything seemed to be there. I looked upon my sister, and I instantly fell in love. She was so small, yet Ali radiated so much warmth. Her face glowed and so did her family's faces as we looked upon the little bundle. No one ever imagined that Ali's body could be hiding a life-threatening secret. I was parked next to a motorcycle. It was painted orange and had lightening stripes racing down each side.

Attached to the bike was a side cart that sported the same orange hue. The license plate said "BIG BOB." The lingering breeze of old leather knocked me out as I got out of my car. I had arrived. This was the first time I had gone to *Lansdale's Bike Nite 2003*, and tonight I was selling raffle tickets for a homemade quilt. The Ali Paris Fund for Landau-Kleffner Syndrome (LKS) Research and Education display table was right next to the Boy Scouts, and I was thankful for their protection. Swarming around me were the typical biker stereotypes. Tattoos were as common as the letter "e," and the whole place smelled of roasting pig and leather chaps.

Chains jingled, making the atmosphere almost entertaining. People made music while they walked. The streets around me transformed not only into a bike show but an orchestra practice. The "show was about to begin," so I hurried back to my display table sure not to miss a beat. In just a few minutes, Bike Nite 2003 would officially commence. In an hour, we had our table covered with epilepsy literature and the auction item of the night was on prominent display. I started to get more comfortable with the whole situation unfolding before my eyes. I was smiling. The bikers smiled.

So far no violent Hell's Angels had arrived. The night was young, and I needed to sell at least two hundred raffle tickets. As the hours rolled by, my shoulders relaxed, so I figured I was now brave enough to start selling those tickets. I decided I would walk around the bike show and approach people asking them to buy tickets for the raffle. Knowing your audience is important when trying to sell a product. I felt that we should have been

auctioning off a Hooters' Wing Party instead of a homemade, "Log Cabin" quilt! Whatever the item may be, fundraising has taught me that what I am doing can change peoples' lives. I have to do everything in my power to make the money happen otherwise medical research on LKS would not be funded.

I founded the Ali Paris Fund for Landau-Kleffner Syndrome Research and Education on April 11, 2002. For two years, I have been raising money to find the cause and cure for Landau-Kleffner Syndrome (LKS), which is a pediatric form of epilepsy that affects the language center of the brain. My little sister Ali is afflicted with this life-threatening epilepsy. Ali was born normal and never showed signs of having a disability. When we were younger, Ali and I would pal around everywhere together. Although most siblings hated when their moms' made them dress alike, Ali and I did it until I was in fifth grade.

I look at pictures of us playing at the park, sleeping on the beach, and dressing up like princesses and wonder what that was like. When Ali was almost three, she experienced 12 ear infections in a three month period. My parents took her to the pediatrician's office each time, and the doctor never suspected anything to be out of the ordinary. Tubes were put in her ears to curb the frequency of Ali's ear infections, but they were too late. Ali, three years old, had unexplainably lost her language. In a matter of weeks, my sister became totally mute. I vaguely remember her talking. I try and think back to times when I do recall her speaking. These memories, locked and protected, are all I have of the 2-year-old Ali.

It gives me hope that I will hear Ali's voice again. I want to be flooded with memories of her talking someday, but for now, these are what I hold onto. In our video cabinet is a home movie of the day before my first day of kindergarten. I am dancing around with excitement as I explain to the camera that I am going to school tomorrow. My toothless grin plastered my face, and I could not have been happier. Sometimes I pull out that tape to watch, though not to reminisce about the first day of school. It is the only tape we have where my sister is talking. Ali runs around the living room in her red footie pajamas, also smiling like her big sister.

She was almost three, and the tape was shot just days before she lost her voice. Watching the Barney show contentedly, she merrily sings the "I love you" song. Throughout the film, I watch her say "hi" to Dad filming, and "I love you" to me. This video captures the past, and in the

present I feel like I am looking at a different family. In this tape is trapped my little sister and what she used to be. Ten years ago was the last time I heard my sister sing. Her sweet, innocent voice carries the tune, and up until a couple years ago, I used to watch Barney in an effort to recapture her voice.

Going up to strangers and asking for donations is always a trying task. Fear of rejection is part of the job, because for every "yes," there are two refusals. Walking the streets of Lansdale was no different. I was in my usual business attire: Ali Paris Fund t-shirt, black casual pants, and my crystal "Cinderella" shoes. Half the battle is presentation, and since the corporation is professional, I always try to look the part. Block after block I went up to people and explained my story. "Hi, my name is Melissa Paris, and I am raising money for children with epilepsy. Tonight I am selling raffle tickets for a beautiful handmade quilt. The tickets are a dollar a piece or six for five dollars. Would you care to buy one?" I felt vulnerable. I have told my story hundreds of times to thousands of people, and each time feels like the first. Raising money has become so embedded in my life that I consider it as one of my careers.

What drives me the most is the sight of my sister. When I was a little girl, first trying to understand my sister's illness, I would pray to wake up from the nightmare. LKS is extremely rare and very few doctors know about the syndrome. It took us three years of searching until Ali was diagnosed. Three years of developmentally priceless time was lost because no one knew what Ali had wrong inside. I always went to the doctor's appointments, and every time we were vainly promised answers. We went to doctors to find answers but eventually just lost trust. In spite of this, Ali and our family never lost hope. When a child has a disability that cannot be identified, families will fight for a diagnosis. What most families do not understand is that the diagnosis is only half the battle.

Just because the child's problem is identified, does not mean that the malady is cured. Ali was diagnosed with LKS in 1995 by Dr. Peter Kollros of Jefferson University Hospital. Prior to the Dr. Kollros' office appointment, my parents had to fill out a 20-page survey about Ali's medical history. I remember my mom and dad staying up late, slaving away at answering the survey questions. They had to be as specific as possible when answering the questions of the evaluation. The answers would ultimately determine the accuracy of Ali's diagnosis. Ali's future was dependent on those answers.

When we walked into Dr. Kollros' office, I saw other families clinging desperately to one another. Their faces were filled with fear, anxiety, and hope. I looked into the eyes of other brothers and sisters and saw my reflection in their eyes. All of us were looking for the same thing, but only some of us would leave feeling a sense of relief. The others would continue searching for their answer. Some might never stop the journey.

After many refills of water from the fountain, my family and I were called into Dr. Kollros' private office. We all sat in the stiff wooden chairs that circled around the doctor's desk. He explained to us the rarity of LKS and that only about one thousand people in the United States were afflicted by it. Then, Dr. Kollros gave us our salvation. He told us Ali had Landau-Kleffner Syndrome. She would soon be undergoing steroid treatment which would clear a pathway around the virus in her brain. After years of searching, Ali's voice seemed attainable again. At the age of seven, I barely grasped what was happening in my sister's brain. Ali took steroids for seven months. She gained 20 pounds, and I could barely recognize my sister anymore. She was and still is very petite. I used to think that a monster overtook her body. The real Ali was being suffocated underneath. When the seven months of treatment were over, I witnessed my first miracle.

Ali began to respond when you called her name. For hours I would call her name and watch her turn her head in my direction. Soon after, Ali would listen to our conversations at dinner. When I would tell a funny story, Ali would laugh at my jokes. It had been so long since I had heard my little sister laugh. Her laugh has always been a potent encouragement for me. Even today, I try to make her laugh by doing crazy, goofy things. I feel that if she laughs, at least she is not suffering. By being humorous, I also feel "normal" with her. All around me siblings are fighting, talking, or laughing with one another. Growing up has been hard, especially going to family reunions or to friends' houses, because it seems as if their lives are perfect.

It was always psychologically and emotionally difficult to see other sisters talking with each other. Even though I talk to my sister a lot about my life and take her on trips to the farm, zoo, and McDonald's, she scarcely talks back. I know she listens though. I have told Ali some of my darkest secrets. We may not talk to one another, but we communicate with our eyes, smiles, and actions. Ali's body language tells volumes about how she feels. She reacts differently to people she loves than to people she does

not, just as any child. Ali may not always voice that she loves me, but I know she does, and in her heart, she knows that I understand.

Bikers are the nicest people ever. The saying, "appearances can be deceiving" held true on *Bike Nite 2003*. I had already sold 50 tickets, and it was only half past seven in the evening. I was starting to get used to the crowd of leather that swarmed around me. When I passed the dew-rag stand, I was even thinking of buying matching pink ones for me and Ali who was coming later to the event. She had just undergone major back surgery, a result of the bone-weakening medicine she has to take daily. Once Ali got there, I planned to take a break from soliciting and walk around with her to see the various far-out bikes. Holding hands, together we would walk the streets of music, leather, and sizzling pork chops.

CHAPTER TWO

Bright Lights

The first day of camp was exciting for both of us. For eight weeks, we would spend every day together at camp. I was Ali's aide at Camp Kaiserman on the Mainline. Spending time with my sister is very important to me. I try to make "sister moments," in which we listen to music, dance, go swimming or just hang out. This summer, though, she was all mine. Everyday, we would take the bus to camp. It was a 45 minute ride, but it was the only time we rested during the entire camp day. Our schedule was packed with education and fun. I would take Ali swimming, to her speech and occupational therapies, lunch, and finally dance class at the end of the day. Our goal for swimming time was for Ali to learn how to use a kick board. The entire eight weeks of summer for the first 10 minutes Ali and I would swim laps.

Ali, holding onto the board with all her might, and I, swimming backwards trying to keep her arms out straight, were a humorous pair to watch. At lunch, we would sit outside with all of Ali's friends. I do not think we ever ate that much because we always ran around playing kick-ball or

braiding each other's hair. It was amazing to see these children connecting on a friendship level with my sister. Most of these children had never been exposed to a handicapped child, and their willingness to accept her made me feel that there will be a day when all people with disabilities will be tolerated.

We also squeezed in "education time" where I would instruct Ali for an hour. This summer I taught Ali the difference between the colors yellow and blue, how to identify the numbers 1, 2, and 3, and also how to draw a straight line. At first, it was frustrating because I wanted Ali to succeed right away. After some time though, Ali was beginning to succeed, and it was because of my teaching.

When I would ask her which stuffed animal was yellow, Ali eventually could pick out the one. I remember almost crying when she first began to show progress. Ali and I made a great team and both of us taught something to each other that summer. Ali taught a lot of people that summer. Counselors and campers were drawn to Ali because of her constant smile. I had never seen her so happy, and the people around her also became joyful at the sight of her. Specifically in Ali's dance class, she always brightened up the room. All the children were preparing for a dance recital where all their parents would attend. Ali and I were sitting in our usual spot, after stretching, watching Ali's friends practice their routine. I asked the dance teacher if Ali could somehow be incorporated into the dance recital too.

After that moment, Ali became the prima ballerina of the production. When all the children told their parents about the recital, they told them they had to come, not to see them, but to see Ali. The day of the performance arrived, and the entire camp knew it was Ali's day to perform. All the parents took their seats, and the music started. Ali and I stood on the corner of the stage waiting for the cue to send Ali on. She was wrapped in a beautiful gold sheet, which the other dancers would unravel when she got to her spot. The time came, and I directed Ali towards center stage.

Watching my sister walk out, and then be presented to the audience as the main star made me feel so proud. Ali looked like an angel in her gold outfit, with the bright lights illuminated around her. While Ali, holding one of her friend's hands, danced to the front of the stage, everyone clapped for her. Whenever I feel upset for Ali because we have either

received news she needs another surgery or that she has had more seizures, I close my eyes and picture Ali as that angel I saw on the stage. I smile and try to remind myself of how much she has given to me and how much I have taught her. That summer was the best time of my life.

CHAPTER THREE

Supporting Actress

Only five more minutes until the Academy Awards come on television. I cannot find my red, velour lipstick or my pink-beaded tiara. Under my bed, I scramble flinging to the bedroom floor, old, worn t-shirts and stuffed animals that have slipped through my bed sheets. Once they used to sit proud atop my purple-flowered bed spread, but that light of day is gone now. Things are not the same as they used to be and never will be again, for better or worse. Sliding down the banister, I tear my princess dress at the hem. Pink silk spills onto the ground, covering the wood and intertwining with the planks.

I don't have time to sweat the small stuff: the Oscars were coming on in only seconds, so I dashed to get my seat in the front row of the television. For the past three hours, Ali and I have watched the celebrities walk down the red carpet. We scrutinize the actors we do not like and comment on how some dare to wear last year's style. We gloat about the actors we did like: how beautiful they look and how I wish I could be there with Joan Rivers interviewing them. Ali's eyes are illuminated by the colors on TV. The sparkle in them dances from fashion model to stunt-double. I know she wishes she could be there too. As we sat there day dreaming about the time when we will finally take our place in the spotlight, our mom comes in to do our photo shoot.

Every year Ali and I dress up for the awards shows: the Oscars, Grammys, and even the Country Music Awards give us an excuse to be princesses for the night. To prove our devotion one could just look at our "photo shoots" that dated back to the 1990's. Photo albums are filled with our

glamour pictures, and this year is going to be no different. We pose, laugh, smile, and make silly faces for the camera. Modeling across the room, I hold Ali's hand because she still has her cast on.

Her cast is as glamorous as her gown. Pink and purple striped leg cast, yellow ball gown, with a crown and mink shawl is the fashion statement of the evening. If Ali were on the red carpet, I am sure the critics would love her. "Welcome to the 73rd Annual Academy Awards," the TV blares. Both bedecked and bejeweled, we are set for the show. I wrote on a piece of paper who I think the winners are going to be, and the entire family has taken bets on the best movie of the year. I always vote for the underdogs, the people in whom everyone had lost faith. In those people, I see the same magic and hope I see within myself. I am one of the supporting actresses helping the leading lady who takes the audience to exotic, enchanted places: places that go beyond everyday: places that introduce the world of desire and challenge, aspiration and knowledge, struggle and triumph.

CHAPTER FOUR

Life's Smiles

"How was your day? Did you have a busy schedule with therapies all morning? You look worn out now." I break the still silence with my questions. My words are harsh in the quiet and penetrate the stillness. I continue to talk even though there is no answer. During times like these, I realize my relationship with my sister is different from everyone else's. I would not trade our relationship for any other. Even though Ali does not always answer, I feel that she is communicating with me. By the look on her face I can tell she's had a rough day.

I see in her eyes that she's glad to be out of the house with me even if we are just going to get gas for my car. Ali sits next to me, looking peacefully out the window. Dusk wraps around the trees and blankets the remaining sunlight. Passing by at 45 mph, people and cars become blurs.

Inside the car it is hushed, except for the music from the radio which fills the car once again. With the windows down, we soak the night air in and watch the earth grow dark. Drifting back to my own thoughts, I analyze my school day. Classes, friends, and grades race through my brain.

Thoughts of college linger, and I allow myself to soar into my future. Goals that I want to achieve in my life surface to my consciousness. By the time I am 24 I want to have finished top in my class at Harvard Law School. At 30, I will be married with two children, and the Ali Paris Fund for LKS will have grown to international recognition. When I am 40, I will be close to retirement because I will have made partner in a law firm already. From age 50 and beyond, I will finally be able to live life peacefully. Things will have slowed down, and most of my life goals achieved. Ali? Does she have hopes and dreams as I do? Is she thinking about marriage? A career? Where does she see herself in 20 years?

Innocently, she peers out onto the world. Night has fallen, and the cool air from the outside awakens me. With darkness flooding the car, I put up the windows to keep the shadows away. "School was okay today. I had a math test. One of the problems was hard because I did not remember how to use the calculator. In English, Dr. Burke taught us about the World War I period. It was pretty interesting, you know?" Ali looks over at me. Her eyes reflect the lights from the oncoming cars. In them I can see my face shining back. Ali is 13, and everyday I observe her turning more and more into me at that age. When I was 13 I took my first exams, had my first boyfriend, and was Bat Mitzvahed.

My life was filled with firsts that began to give my life a distinct shape of its own. As much as I may try, I will never be able to recapture 13. Becoming a teenager is a significant rite of passage in a woman's life. Maturity is supposedly bestowed upon you by society, and you are instantly transformed into a young lady. Ali is growing into the young adult I once was. In spite of the fact that Ali has limited language, she brings out the best in her friends and family in so few words. In the future, I see her going to prom and graduating from high school, maybe getting a job, but hopefully just being happy. Within her is a strong power that drives her will to live. In the corner of my eye, I can still see Ali staring out the car window.

The light turns green, and I tear into the gas station. The car pulls along side the pump, and we wait for the gas tank to be filled. With the car in

park, I am able to look at Ali while I continue to chat with her about my day. A good song comes on the radio, so I turn it up. Ali and I bop to the tunes and I sing the lyrics loudly. People in other cars peer out at us, but Ali and I are too lost in the song to notice their stares. In my mirror, I can see the cute guy coming over to pump my gas. Quickly out of my purse, I grab my lip gloss and apply it freely to my lips until they are dazzling with shine. With eagerness in her eyes, Ali looks at the lip gloss that I grasp in my hand. Ali puckers her lips, like her big sister, and I put the gloss on her lips until they are silky pink.

"Fill it up with regular please," I say to the man. As the guy walks around to the other side of my car, Ali and I giggle about how cute he is. We decide when he comes back for the credit card that we will both give him our biggest, brightest smiles. Still rocking to the radio and snickering about our gas station hottie, my mind steps back from the situation. From a stranger's point of view, I would see two sisters laughing in the car together. The big sister is talking away as the little sister sits and listens intently. Both their eyes are sparkling, and they seem to be in their own happy place, separate from the busy world around them. The car glows with love, and affection illuminates the dimly lit gas station. No one could tell Ali had special needs and that is how it should be sometimes.

At this moment, the reality of the world seemed to slip away, and the entirety of the earth was within the car. The only thing that mattered was my sister. The guy was approaching, and we both got in "position." "Payment?" he asked. "Here's my credit card," I sheepishly replied. Ali flashed her pearly smile first. I admire her for her gusto. Within minutes he was back with my credit card, and Ali and I sped away into the night. I told her I could not believe she actually smiled. I joked how she had more courage than me because I did not smile. As we headed home, I went back to the thought I had earlier about Ali's dreams. I know Ali understands the world around her. I know how hard she works to stay in it. If only the world had more answers. Answers to release the bolt keeping my sister locked up inside.

A Crown of Curls

After a week full of pop quizzes, ugly gossip rumors, and a headache that scrapped at my skull, I just wanted a quiet Friday night. To my disappointment though, I came home to a house humming with anticipation and excitement. Sprawled across the leather couch were sparkly hair clips, cans of hairspray, beaded tube-tops, and glitter jean pants. The exotic forms on the couch lay scrunched and jumbled. I know my mom had already tried all of them on my sister. Earlier that week my mom informed me that she could not pick me up at school on Friday because my Ali had a school dance, which, by the way, started at seven o'clock.

This was Ali's first middle school dance and my parents were going to chaperone her. I could just see it now: my dad gettin' jiggy with it while my mom crooned the words to the songs. "I'm cool. I listen to young music," she would say to any suspicious onlooker. Because of my duty as a big sister, I could not allow this spectacle to go on. Earlier, I volunteered myself to be her chaperone but soon regretted it that weary afternoon. My head shrunk into the black pit that engulfed my mind, and I began to feel a cold coming on. I know I would not be able to bail that easily, so I lay on the fake cough routine pretty heavy. "Honey! How was school? Are you excited for—oh, are you sick?" My mom's elated face now bowed with a grimace. Frown lines punctured her mouth, and guilt swarmed into my heart. "Just a cough, Momma," I awkwardly replied. "Well maybe you shouldn't go tonight if you don't feel well. Go upstairs and get your sister now though. She's taking a nap before tonight." I trudged up the stairs and remembered the countless school functions at which I felt embarrassed by my parents. Now when I look back, I do not necessarily think that my parents were as humiliating as I thought they were.

As I have grown up and matured over the years I realized that my parents are very cool people, and it is socially acceptable to hang out with them. The stairs became more precipitous as I pondered the idea of telling my 13-year-old sister that taking her parents to the dance would be more *chic* than lugging her big sister around. I figured that Ali would not get it until she was older. So, I made up my mind to tag along with her after all. "We

only have two hours to eat dinner and get ready for the dance, so you guys up there need to get a move on it!" Mom informed us.

"Great only two hours, I'll never have enough time," I thought sarcastically. Even though I was not looking forward to an evening of teeny boppers and the Electric Slide, deep down I really wanted to go. Not to see all the girls huddled in their dance circles giggling at the boys across the room, but to be with my sister. Lately, I have not had much time for her between school, homework, and friends. I thought this would be a good way for me to score some brownie points with her. Ali's bedroom door opened jarringly. I was about to enter another world. I can hear Britney Spears singing softly as the spirals of blue light illuminate the metallic CD player. Neon stars dot across the ceiling. The pink carpet feels plush under my bare toes.

Even through the dim light, I can see my sister sleeping. Well actually, I can only see her black curly hair extruding from underneath the mountain of pillows and blankets. Gently, I touch her foot that is sticking out over her bed, to wake her. She knows I am in her room but makes no movement to acknowledge my presence. After five minutes of coaxing her out of bed, we walked downstairs for dinner. Twenty minutes later, the plates were being cleared, and it was off to our bedrooms to get dressed for the dance. I took the stairs two at a time, so I made it to the top first. Ali's clothes, that I had picked out earlier, were still arranged on her bed. The flower patterned peasant top, purple jeans, and a pink belt to match all embodied Ali's transformation from child to teenager. Before my eyes, I watched her go from my kid sister to a true friend.

I fixed her hair with butterfly clips and her curls adorned her head like a crown. Ali became a princess for this night and I have never seen someone so beautiful. The night was filled with magic, and the dance was more fun than I ever thought it could be. I held her hand and twirled her around. The colored lights illuminated her glossed smile. There were hundreds of other teenagers there crowded into the cafeteria. We were surrounded by smiles, giggles, arms waving, and hips shaking; but all I remember is Ali smiling, Ali giggling, waving her arms and shaking her hips. In a sea of people Ali and I had our own island. Eventually some of her classmates came, and we all danced together. I stepped back from the circle for a moment to allow Ali some freedom.

I have never seen her so carefree before, and it made me wish she

could always be this joyful. Guilt still hounded me for wanting to bail on chaperoning Ali earlier in the afternoon, but feelings of happiness and pride flooded my systems. Ali and I partied the night away, well into the nine o'clock hour. Our joy could have sustained us until morning. When my parents came to pick us up, they had to practically drag us away from the dance. Something special happened that night that bonded Ali and me in a different way. In a changed light, Ali was illuminated in my heart. I respected her more for all the things she endures and everything she goes through. With grace, Ali takes on the world, and I didn't realize it until this night. My whole life I saw Ali as my little sister, but at the dance I realized she meant more to me than that. Ali is my best friend and my hero but most of all, a beautiful young lady.

CHAPTER SIX

Again

Up until I was 10 years old, I never thought of my sister as having a disability. For all those years, Ali was mute. I would hear her laugh at most once a week. Each day I saw my sister grow weaker, but still didn't think anything could be wrong. To her, the world passed by. Minutes, days, and years swept over her body, and for all that time she never said a word. I just overlooked the fact that my sister was emotionally dying inside. At 10, I realized Ali and my family were different. It was hard, at such a young age, to admit your life is never going to be normal.

When you are 10, you try to just fit in with the people at your school and are just concerned about watching TV and playing sports. I felt I have always been mature for my age. When Ali was diagnosed in 1995, she took steroids, which made her understand language again. From that point on she made sounds and began to form words. Around this same time, I began coping with having a sister with disabilities. My parents told me that there was little research on being done on Landau-Kleffner Syndrome at the time. Knowledge concerning Ali's treatment outcomes

was limited according to her doctor. I remember Dr. Kollros telling me that he thought Ali might just wake up one day and talk normally again.

To an outsider that might sound outrageous, but I still believe she can. For my entire life I have wondered if she will wake up and say: "Good morning, Melissa." Living with open hope makes me feel even more vulnerable to everyday life. When I come home from school every afternoon, I wonder if my mom will be there to greet me. My heart pauses while the garage door opens in fear that my mom's car will not be there. So many times I have come home to an empty house. Minutes after I walk in, the phone ring and I know it is my mom on the other line. She is going to tell me Ali is in the hospital because she has had a seizure.

Ali's seizures are life-threatening, and she usually does not have just one. She has a condition called *status epilepticus* which means Ali has one seizure after another after another. For the few seconds before I pick up the phone, I am afraid that my mom will tell me Ali has died. I feel surrounded by my fears, stresses, and anxieties over death. When I look into Ali's eyes though, I see a fighter: someone who wants to live life to the fullest. It is hard to think about my life if Ali was not in it. Having a sister with a potentially fatal epileptic condition and a language disorder, changes the way I view life.

Though Ali is making progress, a black cloud still hangs over our heads. That one seizure could end her life and mine, but uncertainties in life are something I have learned to deal with. No one can understand the way I live my life unless they have a brother or sister with a life-threatening disability. When I was younger I used to think about having a "normal" sister, if there ever were one, and what that would be like. I dreamed about going to the mall with her, going to movies, and talking on the phone when I was away from home. Although, looking at my relationship now with Ali, I do not see such a big difference. We have found a way around the extraordinary obstacles.

I even feel that I am closer with my sister than some of my friends are with siblings. Without Ali, life would not mean as much. Memories would wash away easily. Each summer, we go on a family vacation for two weeks. On this vacation, our main goal is to relax, but it always turns into "how much can we get done." I always request to share a room with Ali so we can catch up on lost time. Sometimes, we get to go to the hotel pool by ourselves or sunbathe on the balcony together. These hours spent in the sun are precious to me. The regular activities we do together seem

perfectly normal to Ali and me. When it is just us, side by side, nothing in the world can bring us down. Without Ali in my life, I would never have these special times. Without Ali, for better or worse, I would not understand the hardships. I would take simple things for granted. I see how hard it is for my sister to walk up the stairs each day. Feeding herself is also a challenge at times. Though I have empathy for her, I cannot imagine living her life or trying to understand how it is for her. Everyday of my life I have watched Ali overcome daily obstacles. Challenges face her from the minute she wakes up, yet Ali still gets up every morning like the rest of us.

CHAPTER SEVEN

Inspiration, Admiration, Respect

“Place the table over here. We need to get this display set up before the store opens at eight.” The August 14, 2003 Whole Foods 5% Day sign hung above the sliding automatic doors. Within a couple of minutes, those doors would open and the store would be flooded with eager customers. One of our first community events for the Ali Paris Fund for LKS was about to take place. Ali has many allergies. She is severely sensitive to the smell of apples. Egg whites cause Ali to drool excessively, and monosodium glutamate (MSG), a food additive, gives her migraines. Any type of antibiotics can interfere with Ali’s seizure medications. Because Ali is seriously affected by such foods, we need to be hypersensitive about what she eats.

Whole Foods Market has offered an array of alternate options that fit Ali’s food needs. We began shopping at Whole Foods Market in 2000, after Ali had her life-threatening status epileptic episode that September. Some theories state that exposure to her allergies can heighten the chance of Ali having a seizure. By shopping at Whole Foods Market, we have been able to limit the encounter with her allergic triggers. Whenever I go into the grocery store and buy things for Ali, I feel that I am directly helping her avoid seizures. Since her seizures can be fatal,

it is very important to try to avoid them at any cost. Through Whole Foods, Ali is able to enjoy her favorite foods without running the risk of more seizures.

"Q102 radio station is set to arrive at noon time!" I shout to my mom across the storefront. By then the store will be packed with the cool hipsters that usually tramp in around lunch-time. It is now 9 a.m. Swarms of people have stopped by our table either to ask about our cause or to say they had seen me in the newspaper last week. My sister is sitting next to me. We appear like twins in our matching Ali Paris Fund for LKS t-shirts. Rolled at the cuffs and tucked into our shorts, the new shirts look great.

In an executive decision, we decided to put our motto on the front of them: "LKS takes away children's words. Help us bring back their voices." Stationed at the front of the store, we are able to observe everyone who comes in. A video tape of the Public Broadcasting System (PBS) documentary loops every 10 minutes. It features the Ali Paris Fund for LKS episode which was hosted by Olympic ice skater Peggy Fleming. Observers congratulate us on our fundraising accomplishments, but instead, I try to push the importance of knowing seizure first-aid. Ten-thirty: The next wave of new age mommies with their newborns starts to trickle in.

We watch the shoppers pass in front of our table. Everywhere I look, my eyes soak in the babies' mouths and teeth. My ears are swamped with moms' baby talk and babies' babble. I feel like the store had been swept over by a cuddly-wuddly tsunami. Babies talking have always fascinated me. Whenever my aunt or a family friend had a new baby, the idea of a toddler learning to talk captivated me. Vocabulary reflects a person's attitude and is a defining characteristic. The words someone chooses are unique. One event can be described in one million different ways, depending on the words chosen to describe it.

I cannot understand how one day a child babbled, and the next, spoke his/her first word. A week later it was three new words. By the end of that year the 1-year-old could sing his or her A, B, C's and speak in full sentences. This developmental phase of language I obviously do not remember in myself, and barely remember with my sister. There are only a couple of instances where I can recall my sister talking as a toddler. We were driving in the car. One of those Sunday afternoon drives in the

country, where you just go for hours on the twisted roads that carve into the hills. The reminders of daily chores and walking the dog slip away as the family car whittles its own path amongst the meadows of wild flowers. If you were to drive 10 minutes in any direction from my house when I lived in New Jersey, you would end up in places like these. I love just hopping in the car and picking a direction to follow. To me, that is freedom. Especially when traveling while the sun is about to set, and the world glows.

It was around 5 p.m. and the world was glowing now. Beautiful sunbeams caressed the car and cloaked everything in angel dust. My fingers waved in the cooling air outside my window. Out of the corner of my eye I saw my sister stick her hand out her window mimicking mine. Buckled up in the adjacent seat, Ali noticed the sinking sun too. The sun rays played with her hair, turning her Snow White locks into strands of rubies. Highlights from the summer sun illuminated on her head, and I did not recognize her for a second.

I leaned towards my window once more, saturated with the last beams of light. Then seconds later, the chilly night air filled the car, so I rolled up my window. Seeing goose-bumps on Ali's arm, I went to roll hers up too. My dad turned on the car radio. Notes of the latest song seeped into the car. Lyrics fell from my lips softly. Ali was singing too. Her voice carried the tune so loud. She zapped the tranquility. Louder and louder Ali sung. She was almost shouting. I shoved her in the arm and told her to be quiet. In my head now, I can see myself going to push her in slow motion. "B-E Q-U-I-E-T" dropped from my mouth. Today, I wish I could catch those words and take them back. Wishing is for dreamers though, and I live in reality. Reality does not let you rewind your life to take something back. Time travel is of the future, only apologies make instances better. It is true what they said: Life was not going to be easy.

"Thank you everyone for supporting the Ali Paris Fund for LKS at today's 5% Day. Miss Deana: you and your staff here at Whole Foods Market have worked hard, and we thank you from the bottom of our hearts. I know Ali especially appreciates the effort everyone has put forth to make this fundraiser successful." The day is done. Whole Foods Market will be closing in 20 minutes, and the raffle winners have already been drawn. The trunk is popped, and we begin to load all of our table clothes, epilepsy literature, and easels into the back. Posters are neatly laid on the back seats.

I hold the alligator-shaped bread the Whole Foods bakery made in honor of Ali on my lap. Waiting for my mom, I relax in the car with the air conditioner turned on full blast. Temperatures were at record highs this afternoon. The sun beat down on our heads while we all stood around outside with the Q102 radio crew. It was refreshing to finally feel the air blast on my face. Out in the sun today we auctioned off Q102 t-shirts and water-bottles to the eager crowd that had gathered around the Q102 bus. I felt proud to see all these people volunteering their time to help my sister and children like her. DJ Richie Rich, who had deejayed some of my teen dances before, was there. He went over to my sister when he saw her and gave Ali a big hug. We chatted about future dances the Ali Paris Fund for LKS was going to sponsor, and he volunteered his services again for anytime I wanted. Gestures like that are what count.

Still waiting, I think about all the interesting people I have met today, and how many of them said that I inspired them. Inspiration comes from admiration, respect, and heroism. It is hard to fathom that I could inspire other with all my work for the Ali Paris Fund for LKS. Ali is an inspiration. She was so well behaved today and waited patiently at our display when I went to answer questions of store customers. I saw her soaking in the sounds and sights of the world around us. Her eyes tell a story of the day, and they are tired now.

She went home with Dad just 10 minutes ago, and it has been a late night. I know she wants to get better and that is why she tried to stay at the store so long. In her is an insatiable burning that fires her up each morning for the day. Inspiration lives in her bones. I feel, whenever I hug her, the power she has inside. Ali passes on a little of her fire to every person she meets. No one can forget our Ali. My mom slides into the driver's seat and switches on the light beams. It is 10:45 by the time we pull out of the Whole Foods parking lot. As we drive away, the store lights shut off and everything becomes dark except for our car. On our way home, my mom and I talk about the successes of the 5% Day. I can only hear the tires rolling over the road.

The Volvo's headlights search over the street, reflecting off the street signs in the distance. Then sleepiness transcends the car, and half way home, silence rests upon our car. The light burns in my eyes, so I close them tight. The word "inspiration" flashes back into my head as sharply as a skater stops on the ice. This word sears onto my brain. Definition still eludes me especially as pertaining to myself. Before I drift off to sleep in

the car it is the last thought I think. Inspiration. Admiration. Respect. Heroism. Inspiration = Ali's love for life. Admiration = Ali's hard work in therapies and school. Respect = Feeding herself dinner without assistance. Heroism = Ali's courage to undergo 10 surgeries and not be confined to a wheelchair.

CHAPTER EIGHT

“... Yet so powerful...”

Looking in the mirror, I see a face painted over in the grays and greens of disbelief. Through the bathroom window, the colors of the sunset begin to glow making harsh realities appear soft. Blood trickles down my lip. I am brushing my teeth too hard. The adrenaline of the moment beats through my veins, and my hands begin to shake. Downstairs I hear my mom crying. “Why does this have to happen?” Fighting back my own tears, I try to stay focused. My stomach jolts up to my throat, but I have no time to think about anything else. My legs are sprinting, and my arms hurriedly grab at shirts, socks, and pajamas.

Where is the suitcase? I scramble under the bed pushing aside photo albums and old shoe boxes. It's in the closet. I get back up and run toward the closet shelves. Sirens sound outside. I heave it off the top shelf as the paramedics barge into the house. My mind detaches itself. When I look at my sister I don't recognize her. No way in hell is that her. Misplaced anger grows within me yet I still do not feel anything. Upset, confused and disappointment have not penetrated my mind's defenses. Watching her being loaded onto the stretcher is hard to watch. Rolled out the front door, down the lawn, into the back of the truck. And away she goes. She is unconscious of the people around her, the tubes in her nose and the heart monitor attached to her chest.

So small yet so powerful, her body shook the entire bed frame. During the car ride to the hospital, I still felt shaken up by what had just happened. Ali had been seizure-free for months. My fatigue was masked now with

my desire to beat the ambulance to the hospital. Even though Ali has had epilepsy for the past four years, I have or had never seen her have a grand mal seizure. At epilepsy information conferences, sometimes videos of people having seizures were shown for educational purposes. I remember this one conference where the video was in black and white.

People were strapped in their beds with wires strewn from their shaved skulls. I was disturbed by the footage. Even though my life has been centered on promoting the tolerance of people with disabilities through the Ali Paris Fund for Landau-Kleffner Syndrome Research and Education, I was scared of the people in the video. When I saw my sister having a seizure, I did not feel scared like when I saw the videos. A bizarre numbness overtook my body which drove me into an automatic mode. My emotions evaporated and sheer instincts pried their way out from the depths of my brain. After I ran down the stairs, her quivering leg was the first thing I saw. Back to reality: I took a wrong turn. Trying desperately to concentrate on the road and push back the horrors surfacing to my consciousness.

Every time Ali has a seizure could be her last day on this Earth. She has a condition called *status epilepticus* which is life-threatening because Ali does not have just one seizure but one after another. She takes emergency medication after her first seizure which can never be predicted. The day those pills stop working, though, will be the day we lose Ali. This intimacy with death lingers over my head as I drive. Not knowing scares me. Running through my mind are the wonders of whether I forgot my mom's toothbrush or Ali's baby doll. We had just unpacked the emergency suitcase just a week before. For the next three months, that bag would stay packed. Remaining strategically placed next to my dad's armoire, on the side, closest to the door.

It was visible as I walked up the stairs everyday. It thankfully collected dust, and I cleared it off when I helped out with the upstairs cleaning. Looking over at my dad, I could see that he was in disbelief, too. His crutches were thrown awkwardly in the backseat of my car. When we were still at the house, I moved the passenger seat back so his cast leg would fit in the car. Yesterday morning, he had knee surgery. We had thought it would just be a leisurely Valentine's Day this year. We all wanted a day of rest. I was home because of holiday break. I had just finished my exams the week before.

School was getting easier now that I was accepted to the University of Pittsburgh. The fall semester scramble was over. No more college applications, sending of transcripts, lunches in the library in order to work ahead in my classes. I was just beginning to feel relaxed again. Despite the fact my dad had to have knee surgery, overall everyone was healthy. My prayers for Ali to stay seizure-free seemed to be answered, for the time being. My mom and I were up the night before with my dad and had just laid down for a nap right before Ali began seizing.

Daddy was downstairs on the pull-out couch with her. Ten minutes later, we were jumping out of bed and running down the stairs to the sound of the knocking of the mattress against the bed frame. Covered still with the blanket, Ali's face wasn't visible. Instantly I darted to the kitchen where Ali's emergency medications are kept. Scurrying through the bottles of prescriptions, I finally found her pill container. Within 10 seconds, I passed my mom, who was on the phone dialing 911, and was back in the living room. Her seizure had stopped by that point and she now lay lifeless. When I talked about my feelings later with my parents I told them I did not think she was real.

We arrived at the hospital only minutes after Ali and Mom arrived. I dropped my dad off at the hospital emergency room entrance, and frantically scoped out a parking spot. Walking toward the hospital's automatic doors, the EMERGENCY sign pierced my heart with its red stinger. I hate hospitals. The smells, people, and sterilization all make me sick. I hold my breath as I walk in trying to hold onto my last gasp of fresh air for just one second longer. A nurse points me in the direction of Ali's room, but I already know where I'm going. Too many times have we been there. Too many long hours and lonely walks around the intensive care floor to count. I don't like to think about it. I go into Ali's room even though there are nurses huddled around her. My parents are sitting in chairs in the corner, unwillingly out of the way. I take a seat on the floor unaware of what I might be sitting in. Nothing mattered at that point.

I was wondering how long I would be able to take this constant cycle of hospital visits, or how long Ali could. Always hoping for the best, but waiting for the worst. It was six hours before we could all go home.

A Future of Roses and Violets

*Roses are red. Violets are blue.
Ali and I will be best friends for a lifetime
And love each other too.*

Often at night I think about my future. I wonder what it will be like to get married. After that, I think about having children one day. Dreams of the "perfect life" seem unrealistic, but I am willing to try for that ideal. I want to see my children get married and have babies of their own. I want to be the coolest grandmother ever by spoiling all my grandchildren to a fault. When I die, I want to pass knowing I was loved and I made a difference in this world. I feel I am at least entitled to that much. Every year I watch my parents get older.

Now they are in their 40's, but sooner or later I will have to let them go. I do not think of this morbid subject much, but inside, I feel a tremendous responsibility to always make them proud. Because of this and all my love for my sister, Ali will come live with my family and me when my parents are no longer here. I know that there will be adjustments having Ali live with me when she and I get older. She will not be a burden though because, after all, she is my only sister. People ask me what I would do if my husband did not like the idea of Ali living with us.

I say to them: I would never marry someone who was not prepared to marry me and my sister. Ali has been so much a part of my life that I could not stand being without her. Even though my life is different because of her, I would not trade it for another. This was the card I was dealt, and it only makes me stronger. "If you are going to do something," I always say, "do it all the way." Ali will never feel lonely or neglected. Just because she has a disability does not mean she should be shunned away. I am proud that I love Ali even if she has disabilities.

So many times I see siblings embarrassed of their brothers or sisters with a handicap. It is normal to feel embarrassed, but they need to realize the wonderful attributes in him/her. You cannot just sit at home and complain about it. You got to go out and live your life. Things happen for a reason.

and I believe Ali was sent here to make my family and me role models for other families going through the same issues. Understanding that life is not fair is the first step towards overcoming obstacles. Step two is realizing the power is within oneself to make a difference in this world. Whether a person has a sibling that does or does not have a disability is irrelevant for these lessons. I wish every sister had a relationship as strong as Ali's and mine.

I have never had a friend as close, and Ali and I do not even have the advantage of being able to have a "normal" conversation. Ali turned fourteen in December, 2003. I will soon be 17 years old. I have started applying to colleges, and I took into consideration the factor of distance from home. Leaving home will be hard next summer, but leaving Ali will be the most horrible. All Ali's life I have been there for her everyday, and next year she will see me only on school breaks and summer vacations. My life will never be the same and neither will hers. Deep down and through everything, we will continue to be close. I am planning to talk to her on the phone and write emails that my parents can read to her. We will both miss each other very much.

*Roses are red. Violets are blue.
Learning from one another
Is the best thing someone can do.*

Learn All Your Lessons

When I was a little girl before my sister was born, my mom taught me a poem. This poem shaped my life with its words, and its message guided me through rough spots in my life:

*“Learn all your lessons before you grow old
because learning is better than silver and gold.
Silver and gold may be washed away,
but a good education will never decay.”*

This compelling poem best describes my relationship with my sister. “Learn all your lessons before you grow old.” Life throws curve balls, so learn to bat them out of the park. Life with Ali has not been easy and undoubtedly the most trying times I have experienced. In the end, those hard times have made me a stronger person. Difficulties build character.

“Silver and gold may be washed away.” Materialistic objects do not compensate for learning life’s lessons. As demanding as they are sometimes, once lessons are learned, you remember them forever. Ali has taught me to treat people equally. My relationship with her proves to me that love conquers all, and hurdles that are high can be jumped with practice.

If I lost all my possessions, I would still have everything because I know the meaning of true love, and that lasts forever. “A good education never decays.” Thank you, Ali, for being my teacher and giving me a good education on life.