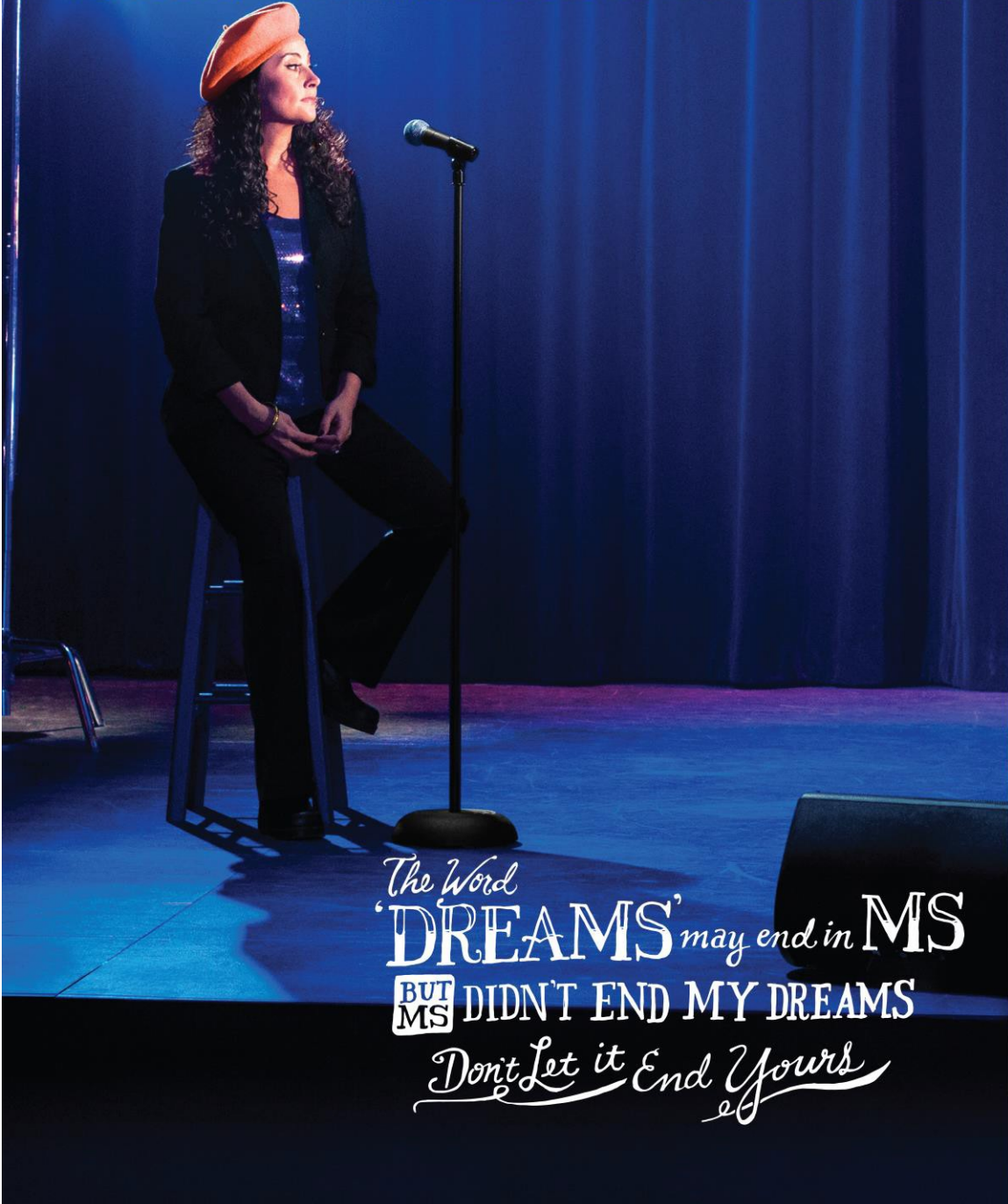


DREAMS

My Journey with Multiple Sclerosis, by Kristie Salerno Kent



The Word
'DREAMS' *may end in MS*
BUT MS DIDN'T END MY DREAMS
Don't Let it End Yours

DREAMS

My Journey with Multiple Sclerosis

By Kristie Salerno Kent

DREAMS: MY JOURNEY WITH MULTIPLE SCLEROSIS.
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Author's Note

I always dreamed of a career in the entertainment industry until a multiple sclerosis (MS) diagnosis changed my life. Rather than give up on my dream, following my diagnosis I decided to fight back and follow my passion. Songwriting and performance helped me find the strength to face my challenges and help others understand the impact of MS. "Dreams: My Journey with Multiple Sclerosis," is an intimate and honest story of how, as people living with MS, we can continue to pursue our passion and use it to overcome denial and find the courage to take action to fight MS. It is also a story of how a serious health challenge does not mean you should let go of your plans for the future. The word 'dreams' may end in 'MS,' but MS doesn't have to end your dreams.

It has taken an extraordinary team effort to share my story with you. This book is dedicated to my greatest blessings - my children, Kingston and Giabella. You have filled mommy's heart with so much love, pride and joy and have made my ultimate dream come true! To my husband Michael - thank you for being my umbrella during the rainy days until the sun came out again and we could bask in its glow together. Each end of our rainbow has two pots of gold... our precious son and our beautiful daughter! To my heavenly Father, thank you for the gifts you have blessed me with. May I continue to use them to do Your will. Thank you to Dr. Christopher LaGanke for helping me to BELIEVE!

To my fellow MS friends - you have given me courage, strength, and inspiration to pursue all of my passions. Although our MS journey might take us down a path of unknowns, may we always know that we don't walk alone.

- Kristie Salerno Kent

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INTRODUCTION

Finding Your Passion

It could be the bright lights or the hush over the audience. Maybe it's the rush of adrenaline that fills my body. Or the anticipation of an emotional connection that lasts for mere minutes but can provide inspiration enduring a lifetime. Perhaps it's the feeling of vulnerability and the relief of sharing my emotions, followed by the exhilaration of confronting an unpredictable reception.

Whatever it is, music makes me feel alive. I sing because I have to – it's almost like breathing. I have a built-in enthusiasm for music and performance that is deeply stirring and motivating. In my case, I was born with it. Life threw me a curveball and I lost it for a while. Then I found it again, and was able to get back on track in ways that are profoundly meaningful and satisfying, even though I have multiple sclerosis (MS). Through music I realized my soul can never be defeated, no matter what challenges come my way. Music gives me comfort, hope, and meaning. It helps me stay connected to my husband, children, and to the thousands of people I have met, many of whom are facing the challenge of MS themselves. Music is my passion.

I'm not an expert on humanity and don't pretend to have answers to life's most complicated and confusing dilemmas. But I do believe we are all driven by an intrinsic devotion to something. It could be an activity, an object, or an idea. Part of our journey is finding that something. Discovering your passion is so important in helping to realize your purpose and then pursue it.

While it's always important to find your passion, in times of struggle it can be even more important - and so much more difficult. It's hard to say exactly when my struggle began. In 1999 I was diagnosed with MS, but years before I heard those notorious initials I knew something wasn't right. Early on I started to feel my dream of being a performer slipping away.

While studying musical theatre at Syracuse University, I began to notice changes in my balance and coordination. I was fatigued and had numbness and tingling in my arms and legs. Following graduation my dreams were within reach. MS hadn't even crossed my mind. When I was eventually diagnosed I was in the middle of planning my wedding to my high school sweetheart. At that moment the spotlight went dark, and I let my passion slip away. It would be a long time before I got it back.

I spent many years in denial, hiding symptoms when they would flare and pretending I was all right. I refused to accept my diagnosis, but deep down I knew MS was changing me. I felt like I had lost control. Living with a chronic and rare medical condition can make you feel isolated. You lose hope. These feelings can rob us of the strength we need to fight and move forward. There are many different challenges that can cause these feelings, but MS is especially devastating because it is so variable.

Anytime I wanted to leave my house I'd think about "what ifs." I changed and cancelled plans to many social outings because I didn't want others to have to slow down for my sake. I only felt comfortable going to the same restaurants where I was familiar with the layouts. I avoided going to concerts and sporting events so I didn't have to deal with crowds. I could no longer wear the shoes I wanted to wear. My MS made me think about the simplest things,

like which chair I could hold onto for support while walking across the room. Even navigating around my kitchen was exhausting. It became so difficult to think about how I would structure my life and what I could accomplish in the future.

Following many years of sadness and fear, it was music that helped bring me back to life. Fate brought me a chance to sing for a live audience again, and that experience revived my passion and helped me to focus on what I could do, not what I couldn't. When I performed again, all of the exhilaration and inspiration I had felt so many times before came rushing back. Something inside me screamed for joy, and I felt hope and strength that had been missing for years. That first step led me to begin writing songs. I looked for opportunities to perform all across the country, and I found them. Audiences were kind and supportive and appreciative. From there, I went on to record my first album, filled with songs about hope and overcoming adversity. I found that when my heart was opened once again by my love for music, it freed my mind as well. I was not afraid. I really started to educate myself about MS, and I saw that there was much I could accomplish. I was finally able to accept MS... not as a devastating challenge that would stop me at every turn, but just another part of who I am today. Living with MS was the path I was given. It is not the path I would have chosen, but it is part of my journey. Music is helping me to enjoy the ride.

There are two things I've never heard people say they hate: food and music. Music has the ability to comfort and motivate, which is important at all times but especially when we face challenges. Go to the gym or watch people hiking or riding bikes. Many will be wearing headphones, listening to their favorite music. When I walk

on my treadmill I have a song list that motivates me. Certain songs push me to strive for more and work harder. There is real power in a melody and lyrics. It can reinforce for us that life has a rhythm and a tempo. Similar to the composition of a musical score, life has its ups and downs. I believe music helps protect the human spirit.

One of the more frustrating aspects of MS is the fact that symptoms are hard to explain. People who don't live with the disease have a difficult time really understanding what we're going through. It was a tremendous surprise for me to learn that music can be a vehicle to help family and friends understand what we are going through. And of course for other people living with MS, music can create a deep and meaningful connection, a way to express unity and compassion and hope. For many of us with MS, music is a coping mechanism, a therapy, and a motivator. It helped drive me out of denial and into action after my diagnosis. It showed me that I have a choice – I can face life's adversities with a smile or a groan. I do so love to smile.

Music is my personal passion, and it may be for many others. But all of us affected by MS have the opportunity to find our own passions and pursue them with all the energy we have. Whether it's painting, cooking, caring for your family, reading, or anything else that brings you pleasure. We can all use our talents to contribute, and we get so much in return when we do. First, we can see that MS can change our path, but we can still move forward. As we do it can be easier to find the strength to face MS head on, to take better care of our health and get the care we need. We can also find a way to make the journey easier and more rewarding for others. Our dreams don't have to end just because we have MS.

CHAPTER 1

Dreaming of the Spotlight

Mom used to make me two birthday cakes. One was for me, her youngest daughter, and the other cake said, “Happy Birthday Wonder Woman.” Growing up as the youngest of five children, I learned to hold my own in a crowded household. I believed I was *Wonder Woman*. She was my alter ego. I could achieve anything because I had super powers and nothing was going to stop me.

Wonder Woman is a great “girl power” super hero. She is strong and compassionate without discrimination. I admired her because she was fearless in her desire to conquer evil. I wanted to be like that. But instead of bulletproof bracelets and a lasso of truth, I was armed with my voice and a passion for performance. I might not stamp out evil, but I could do my best to make people happy.

My super powers were especially handy at our boisterous family gatherings in upstate New York. Mom’s Irish side and Dad’s Italian side of the family didn’t always visit at the same time, but when they did it was an epic clash to see who could be loudest. And there was always music. My Irish songwriting uncles, Rick and Terry, would bring their guitars and their own original compositions. My Grandpa Salerno provided his expertise on the guitar, although his repertoire was mostly limited to traditional Italian tunes. I remember asking to hear *Rudolph the Red-Nosed Reindeer* on Christmas Eve. It sounded suspiciously like *la tarantella*.

At family gatherings, we laughed and yelled and there was always a lot of drinking and food. In that beautiful family noise, I learned

to love the calming and harmonizing effect that a guitar could have. Once the playing started, the house would grow quiet and chaos was transformed into orderly and lovely sing-a-longs. From an early age I was inspired to test out my talents and those performances were the highlights of my childhood.

My oldest brother, Shawn, was always the rock star. My dad wanted Shawn to play sports, so he often kept his love for music hidden, except from me. We participated in our own mini-jam sessions, creating our versions of “head-banging” concerts with music from *Kiss* and *Rush*. Shawn may not have realized then, but he was bonding with his bratty little sister. We had a great connection, and music was to blame. In keeping with the music and the times, our mutual hair styles were, well, interesting.

During a basement renovation, I took advantage of the open space and concrete floor to make it my own Broadway stage. I’d sing at the top of my lungs and dance until my head was spinning. My sister Kim and I would write mini-plays and act them out together. The bathroom was my dressing room, and I wanted to paint a gold star on the door. I would practice acceptance speeches in the mirror. But it wasn’t all about me. It was more about connecting with people, and I craved an audience to do just that.

As I got a bit older, I started to focus on training for a career path I knew I would have to follow. I took voice lessons, joined youth dance classes, and performed in children’s theatre. At seven years old I absolutely knew what I wanted to do with my life. For some, standing in front of a live audience is terrifying. But even at that young age, for me it was soothing. At dance recitals, I distinctly remember feeling like I was making a wonderful connection with

strangers. I got to be somebody else on stage. I could be whoever I wanted to be. And I loved everything about it.

Then high school came, and with it the combined pressures of transitioning to adolescence and performing on a bigger stage. As I grew older my *Wonder Woman* super powers faded a little and I shied away from the spotlight. Many of my friends joined the cheerleading squad and I wanted to stick with them. Cheerleading diminished the time I had for other extracurricular activities, but I enjoyed the performance aspect and was having fun building relationships and meeting new people. I didn't stay out of the theatre for long, and dropped cheerleading when there was an opportunity to participate in school musicals. As a sophomore at East Syracuse Minoa High School in 1989 I joined stage crew, handling props and working behind-the-scenes. It wasn't until a production of *Oliver* during my junior year that I finally found the courage to audition. I was tentative and over-analyzed the situation. I decided to start with the chorus, and see how things went from there. I was more comfortable with the idea of supporting the vocals from the background then jumping into the bright and critical spotlight right away. It turned out that decision wasn't mine to make.

I was nervous but my instincts took over. My audition was one of those moments when everything falls in place. It just felt right, and the director saw it happen. I only wanted a spot on the chorus, so when he asked me to come back to audition for the leading role as Nancy, I was shocked.

My mom told me not to get my hopes up. And suddenly my fear and insecurity vanished. I said, "Why not? Remember I'm *Wonder Woman!*"

I got the part of Nancy and took on my first leading role - and in a wonderful turn of fate, that led to my most important role ever. A year prior I had met a cute boy named Mike in choir class. He was the silent bad boy type and I was the bubbly cheerleader. I'm pretty sure he joined choir class for the easy credits, but soon it was clear Mike had a great voice! We were given extra credit for trying out for the all-county and all-state choirs, and he made both. Our shared love for music is what allowed our opposite worlds to collide. We dated for a few months during my sophomore year, but he was older than me and we parted ways when he graduated from high school. When the curtains closed on my junior year performance in *Oliver*, Mike came back into my life. I hadn't seen him in months, but he surprised me back stage after the show. We've been making beautiful music together ever since!

My senior year I had the lead in a production of *Bye, Bye, Birdie*, working with the same director from *Oliver*. His name was Marshall Nye and he was my mentor who helped me take my passion to a new level. Marshall passed away suddenly soon after I left for college, but his inspiration continues to live on in my performances to this day.

In 1991 I decided to enter Syracuse University's musical theatre program, which allowed me to stay close to home. I had considered some other options including the University of Southern California and New York University, but Syracuse was in the process of rebuilding its theatre program, physically and theoretically. There would be new studios and a wonderfully renovated theatre. The school was searching for fresh talent to match the new facilities. Though I ran to college as a bundle of enthusiasm and energy, adjusting to the routine wasn't as easy as I

thought it would be. There was something holding me back, a feeling I could not explain but that I experienced every day.

Beginning my freshman year, a typical day started at the crack of dawn with what we called “core.” Early in the morning I’d make my way to the studio for dance, ballet, acting, and vocal training. I’d pause for a quick meal around 11:30 AM, and then make a mad dash to “The Hill” for academic classes - and it was called “The Hill” for a reason. My morning routine was tough. Several hours of dance and movement left me fatigued, and if I missed the shuttle bus I had to hike up that hill fast. It was steep and I often felt like I might not make it to class in time. I knew I was working hard but could not believe that my dance classes were slowing me down that much. Looking back now, that may have been the first time I noticed a change in my health. It would be years before any serious concern entered my mind. In college, I didn’t even know what MS stood for, let alone the signs and symptoms.

After academic classes I worked at the school bookstore, and then it was back to the theatre for stage crew work. Freshmen were not allowed to audition for performing roles, but I was learning a lot from experienced classmates. Taye Diggs, best known for his role in the original Broadway production of *Rent*, was incredible to watch in college. I was envious of his easy movement and natural flow on stage. I also learned from Vera Farmiga, who went on to appear on the big screen with George Clooney in *Up in the Air*. In her performances Vera was deliberate and effortless. So many of my peer performers at Syracuse provided wonderful examples for me to follow in the years ahead.

With their examples, though, came some surprising frustration. As I watched, I realized Taye and Vera and others moved in a precise

and natural way that I could not yet emulate. I knew what I wanted my body to do. I tried to work on the timing of my actions on stage and holding my posture steady, but there was a disconnection. I used to love how music connected me to my own body through movement. The rhythm would take over my body from the tips of my fingers to the point of my toes. In dance every movement had a purpose, whether it is the arch of your foot, a bend of the knee, or a roll of the neck. The music helped me to connect with every muscle, every bone, and every ligament. But now something was changing. In ballet and modern dance training my coordination was not as strong and precise as it used to be. When dancing alone it was bad enough, but it was especially difficult to dance with a partner. I found myself struggling with choreography that came so easy to me in high school, and I couldn't figure out why. My head felt clouded, almost like it was filled with cotton. I wondered if maybe I just wasn't as talented as my *Wonder Woman* years led me to believe. Or perhaps I was just training too hard.

By the time I was a sophomore I was finally experienced enough to audition for roles in school performances. But I didn't. My dancing in training classes thus far had left me with some doubts and I wanted to watch and learn more. I doubted my ability to perform on the same level as my peers, and I was scared. Something was missing. I was not on my game and I felt depressed, which certainly did not help matters. My struggles with coordination and balance had me convinced I was losing my talent. And I could always find an excuse. When my knee gave out, I blamed it on overtraining. When I missed a step, I was too tired. After weeks of feeling something was wrong, I finally decided to visit a physical therapist and was eventually referred to an orthopedic surgeon. They believed I was suffering from a dislocated kneecap. To

improve my stability, I used tape and wore a leg brace. To improve healing, I also sat out of performance training for a semester.

But the brace didn't help. If anything the restricted movement over time made things more uncomfortable. I missed performing and wanted to take another shot. I began training again, and soon it was time for the notorious sophomore evaluations. This is when the theatre faculty members gather to critique each student in the program. At this point many students who are not able to meet their standards are cut from the program. My anxiety rose waiting in line, watching peers leave in tears and wondering if this was the end of my dream too. I knew my physical ailments had limited my performance, but hoped my passion was apparent and believed it could carry me through.

In performing arts it's impossible to reach perfection. There's always room for improvement and the audience reception varies between each performance. I used to search for perfection. Waiting for my sophomore evaluation, I was mercilessly critical of myself. I wish I had known that it's not about perfection. It's about being profound.

While my performance was certainly not flawless, the faculty apparently saw that I could be profound, and that was enough. I passed my evaluation. Mike, who had remained my steady boyfriend since high school, didn't understand why I was so surprised. He reminded me about my director-mentor Marshall pulling me from the chorus for a leading role in high school. I began to see that maybe my performance was better than I thought, and I found renewed confidence that led me to audition again. First, I returned to the stage with an improv comedy troupe. It forced me to think on my feet and respond to the situation, rather

than worry about perfection. Then came another defining moment in my life.

During my junior year, my classmate Jay Falzone worked with his longtime friend Kevin Sturmer to write a musical called *That is to Love*. I auditioned for a role and recorded with the original cast. It was my first studio recording experience, which is in and of itself an accomplishment. But the inspiration from my work with the cast was much more personal.

The story followed a young couple preparing for their wedding, and their deepest and often darkest secrets are slowly revealed to each other and their families. It was a story about hiding painful truths and how it can affect relationships.

One song in the script, “Smile,” was particularly moving for me. It was about smiling through sadness and hiding trouble by keeping a happy exterior. I knew I was going through physical changes that were affecting me every day. But I was determined to just smile through it, hoping that this would make them go away. I kept everyone in my life, including Mike, at a certain distance to avoid any questions about my health. When I put on a smile, the emotional turmoil I was feeling would disappear for a bit. For me, it was worth hiding the truth. I would later learn that this strategy, taking great steps not to let the world see your pain, is so common among people living with MS and many other health problems.

Of course the physical reality of what was happening meant that I had to make some concessions. A fear of my inability to dance forced me to change from a musical theatre major to a theatre major. That way I could audition for productions that were less physically exhausting. It was certainly frustrating because there

were so many opportunities I wanted to pursue, but couldn't. At the same time, I was using my performance training to cover my health problems. I blamed my ailing knee for my limitations, and was determined to succeed as an actress in spite of it all. When they heard my story, friends were supportive. There was certainly no need for me to consider that the problem could be anything serious. I still had not heard of MS at this point in my life.

The top twelve seniors in the Syracuse theatre program are offered a chance to visit New York City and audition for casting directors. It's called the "Presentation for the Profession." In spite of my persistent doubt, and the fatigue and balance problems that continued to plague me, I was selected as one of the twelve students during my senior year.

There are many things I should remember from my presentation, including my partner, my memorized lines, the directors, and the thrill of being near Broadway. But all of that was overshadowed by one simple skirt.

Leading up to a five-hour bus ride to the Big Apple, I was completely preoccupied about what to wear. I coerced Mike into shopping with me, jumping between stores in search of the perfect outfit. This was the attire that would determine my future in performing arts, or so I thought. And it was a terribly difficult decision.

After hours of shopping I finally settled on a skirt, and even found some time to practice the scene with my partner. It's true, my priorities may have been off track, but I felt as ready as I could be for the audition of my life. My thoughts raced every minute we were in the city. We dodged angry cab drivers and lost tourists and

made it to the theatre. I headed for the dressing rooms. This was it, my dreams right there in front of me waiting for me to follow through with a break out performance. And I couldn't find my skirt.

I looked everywhere. On the bus, in my bags, on the floor in the dressing rooms and the theatre, but it was nowhere to be found. My presentation time was fast approaching. I looked at my jeans, riddled with holes for that college years, worn-out look. After all the work I had put in, the emotional struggles with doubt and fatigue, and the physical challenges with my balance and coordination that I tried so hard to hide, I felt like my dreams would be derailed by a missing skirt.

I called home in a panic and tried to reach Mike. We didn't have cell phones then, and I was left with the harsh reception of answering machines. I tried calling Mike at his office and his boss told me he called in sick. I was about to put my career on the line in a pair of highly distressed jeans.

Minutes before my presentation, I stood back stage with sweaty palms and a helpless anxiety. I hadn't introduced myself to the directors yet and I was already feeling defeated.

Then he tapped my shoulder and I heard a familiar voice say, "Did you forget something?"

I turned around and saw Mike with a giant, goofy grin, holding my dear skirt. He had made it, just in time. Mike found my skirt after I left that morning, skipped work, and drove to the city to make sure I had the outfit I felt I needed so much to chase my dreams. He understood how important the skirt was to me, even though I was perfectly capable of performing without it. He surprised me

backstage, just as he had after that performance of *Oliver* years before, and he gave me so much strength. If Mike believed in me that much, the least I could do was put on the performance of a lifetime. And that's exactly what I did.

Following my "Presentation for the Profession" in 1995, I returned to Syracuse and prepared to graduate. It was supposed to be the time in my life when my dreams were on the verge of coming true. And I couldn't have been any closer. My audition for directors in New York City had generated enthusiastic buzz, and I was called back to meet with a few casting agencies. At the same time the numbness in my legs was getting worse, and I was struggling with feelings of depression and despair. It was hard to explain, but even though so many things were falling into place for me, I felt like I needed a break. All the stress of planning what was next was becoming too much to bear.

Right before graduation, I returned to New York City to meet with agencies that had expressed interest. Mom made the trip with me. It was chaotic, racing from office to office hoping to find someone willing to take a chance on me. Even though Mom is 30 years older than me, I had trouble keeping up with her as we dashed through the city. Sure, Mom was always quick on her feet, but I could barely make it to each appointment. The busy intersections of the city reminded me of "The Hill" at Syracuse. I needed a shuttle bus to take me to the top. My legs weren't cooperating, and even though a chance at Broadway was staring me in the face, I was physically unable to take it.

I graduated with a Bachelor of Fine Arts degree, and told Mike I wanted a change in scenery. Maybe we could move somewhere with a slower pace. I was in a strange place mentally; even

concerned I was dealing with multiple personalities. This simply did not seem like the 'me' that I knew. I remembered *Wonder Woman*, and the bubbly and energetic personality that craved the spotlight. But when I looked in the mirror, all I saw now was fear. I no longer wanted to venture out, and stopped returning calls from casting agencies. I was tired of being scrutinized and judged. I missed the days when performing meant acting out another character and becoming someone else.

I took on a summer job directing local theatre near Syracuse. There were aspects of directing I truly loved. There are 'light bulb' moments when developing a theatrical performance, and I took pride in helping young actors reach those moments. I taught the choreography that was derailing my own performance career, and watched the cast find their personal talents. Helping others was a wonderful feeling, and I decided I wanted to find roles in theatre that allowed me to do so, even if I wasn't meant to be in the spotlight.

Once again I put on my smile, and told my family, friends, and colleagues I was interested in learning the whole entertainment business, rather than diving in to New York City immediately. I told them I didn't want to simply audition professionally. I refused to admit my physical problems were driving my decisions. Before the summer theatre performance I directed even had the opportunity to debut, Mike and I moved to Atlanta. Two of my sisters lived there, and it seemed like the escape I needed to rejuvenate and find my new passion.

CHAPTER 2

Searching for an Explanation

It was my great escape. To this day it's hard to explain why, but after college graduation I felt strongly that it was time for me to leave New York. I was going through periods of depression and fatigue that I could not explain or understand. My apartment lease was up, and I just wanted to sneak away and see if I could leave my health problems and depression behind by starting over someplace new. I made my decision during dress rehearsal for *Babes in Arms*, the summer musical theatre performance I was assistant directing. We were in the middle of coordinating all of the logistical needs for the show. Looking back, I think I was a bit conflicted and perhaps hiding my true feelings about performing. I enjoyed directing, and wanted so much for this production to be a success. But I also realized that it was not me onstage, doing what I loved most. Rather than being excited, I was a bit sad. Despite my health problems, deep down I knew that part of me still wanted to take a shot at a career in the theatre. At the same time, when I thought about how challenging that would be, I was not sure I could handle it physically. I decided to take a break, and see whether I could find satisfaction and joy working in the performing arts in other ways.

When I thought about the next chapter in my life, I knew I didn't want to move back home. I had to start someplace new. Two of my older sisters lived in Atlanta, and I loved the pace and quality of life there. There was something comforting about living in a lovely neighborhood that was just a few minutes away from an exciting urban area. It offered the tranquility and peace I thought I needed

to regroup, which was something I certainly wouldn't find in the hustle and bustle of chaotic Manhattan. I also liked the prospect of living in a milder climate compared to New York. I had always been an energetic and upbeat person and I hoped so much that a move to Atlanta could help me to be myself again. I wasn't planning to make this a permanent move. I was just looking for a chance to recuperate and feel healthy once more.

As I prepared to leave New York, I did not make any plans for a big goodbye. I worried that my family, friends, and theatre colleagues would see my decision to leave as a cop out. I felt sure that people could not really understand why I was leaving – especially since I was keeping many of the reasons hidden. I didn't want them to think I was running away from opportunity because I couldn't handle the pressure. I knew my problems were so much deeper than that, though I didn't fully comprehend them at the time. There were audition callbacks waiting for me, but I left them unanswered. I knew that others saw my potential, but I was constantly focused on hiding the changes in my mood and health and mobility. With all this going on, how could I explain a decision like this to anyone else, especially the people who knew me best?

One moment from that time has stayed with me to this day. I was sitting through a dress rehearsal of *Babes in Arms*. Grandma Vickery had always been a vital and important person in my life. It was a wonderful surprise when she walked into the theatre to see me. We only talked for a few minutes, and as I watched her walk away, it was like I was seeing her in a new light. I felt a terrible sadness. She was always a strong and active woman, even as she became older. She had earned numerous gold and silver medals for

swimming and biking in the Senior Games in New York, and was even asked to carry the torch one year. I watched her walk away and was in awe of the strength and grace in her stride. As I thought about her vitality, I wondered how the years would affect my own health. Would I have difficulty walking? Would my fatigue ever go away? I wanted to run after my Grandma and spend more time talking about her life and how she faced challenges and overcame them, to try to find the right path for myself. But I had my responsibilities with the play. As it turned out, that was the last time I saw Grandma Vickery in good health. She suffered a stroke soon after my move to Atlanta, and spent her final years partially paralyzed. Of course my heart broke for her, but I also saw so clearly how fragile life can be, and how changes in our health and independence at any age can affect us. I was afraid for myself, and more determined than ever to escape.

Mike and I packed everything we owned into a trailer and hitched it to his car. I was so anxious for a clean break that we finished the drive south in 16 hours, only stopping when absolutely necessary. Mike had always wanted to visit Washington D.C., but he felt my urgency to get away. As we drove we listened to music, pulled off at rest stops, and found ourselves crossing into Georgia before we knew it. We had made arrangements to live in the same apartment complex as my sister, Kim, and soon we were settled into our new home.

The first few months in Atlanta were spent jumping between temporary jobs to pay our bills. First, I found work as a nanny and took care of a baby who was sweet as can be, and I found quickly that I liked caring for children. Mike continued to encourage me to

be a performer, but I didn't feel secure in my ability to be on stage again.

Eventually I found a job that did involve performing, but it seemed very safe for me. I was hired to work as a storyteller at a local Border's bookstore. Reading for children of all ages, I was able to put my training as an actor and director to use. I did my best to bring the characters to life, and I found that I loved connecting with children in this way. People heard about my storytelling skills, and it didn't take long before I developed a significant following in the community. I was enjoying the work very much, and things were finally feeling on track, but through this transition the one change I wanted most still did not happen. Our move to Atlanta did not do as much to improve my spirits as I had hoped. I was still having strong feelings of depression, and I had developed a phobia of exploring new surroundings. I felt limited physically and was worried about what might go wrong with every new experience.

Fortunately, my enthusiasm for the job and the people I worked with kept me focused and helped me to move up the ranks quickly. I was soon made supervisor of the children's department, then sidelines buyer, and finally community relations coordinator. I was booking musical acts for the café attached to the bookstore and worked with many wonderful and famous authors on book signings and reading events. My responsibilities included marketing and publicity to promote each event. It was the first time I experienced that side of the entertainment business, and the hands-on education was very rewarding. As I dove into my new responsibilities, learning the ropes and meeting so many creative people inspired me to rekindle my own artistic aspirations.

After work I would come home each evening and express myself by writing short stories, plays, and poetry. I also practiced my singing, not on a stage but in the safety of my bedroom, reminding me of performances in my basement as a young girl. My neighbors may have been irritated, but I needed music in my life, even if it was just for my own enjoyment. This experience gave me a bit more confidence and helped me to realize that my passion for performing was still alive. It would not go away, no matter how far I moved from Broadway. Each time I booked performers for our small café, I thought about what they would go on to achieve and wondered, “Why am I not doing that?”

After nearly three years in Atlanta my health problems were present but relatively stable, and I built up some confidence and decided it was time for me to jump back into performing. I updated my resume, prepared my headshot and hit the ground running in the Atlanta performance scene. I took a voiceover class instead of acting. With voiceover work, no one could see me. I felt comfortable knowing my bizarre symptoms were hidden from the audience. It felt great. I was coming out of my depression, and the numbness and balance issues that derailed me in college actually seemed to be subsiding. I’ve since learned that the symptoms of MS can disappear and reappear without warning. It is one of the most devastating aspects of the form of the disease that I have, known as relapsing-remitting MS. You can go weeks, months, even years without experiencing symptoms. Every period of relief can create new feelings of hope, courage and strength. But when the symptoms return, they can tear you back down all over again. Back then I had no idea what I was dealing with, and my hopes were always crushed when my symptoms worsened. Despite this, I decided I had to audition again.

Sure enough, the confusing physical ailments came rushing back as I prepared for my first few auditions since college. It may have been caused by the stress and anxiety of getting on stage again, opening myself to potential criticism from directors and producers. First, I responded to a casting call by Kaiser Permanente's Educational Theatre Program and was asked to audition. It was a wonderful program that produced theatrical performances for elementary and high school students about health and nutrition, safety, and avoiding drug use. The troupe traveled all across Georgia and the Southeast, making stops to perform at different schools. I nailed the audition. My vocals sounded pristine and my monologue was moving. Then there was the dancing segment, in a full-body costume nonetheless. Inside the costume I was sweltering. Of course I didn't realize it at the time, but the heat was exacerbating my symptoms. Still, I was able to hide in the costume and put my clumsiness into the character I was playing. It worked. They asked me to sign on for ten months. I thought, "What the heck?" Children aren't as judgmental as professional directors and producers. I felt confident I could handle the physical challenge. I might as well give it a shot.

I also had an opportunity to audition for a show that was created by one of my idols, Debbie Allen, an award-winning actress, dancer, choreographer, and director. If cast, I would have worked under the direction of Debbie. Luckily, she wasn't on hand to see me audition. The show was called *Soul Possessed*, and I felt like my soul was possessed while trying to maneuver on stage. I walked out of Alliance Theatre that day with my head down after what was one of the worst auditions of my life. Thanks to my lack of coordination, the dance numbers were terrible, and I was mortified. There was no costume to hide in this time. I blamed

myself and questioned my own talents. I could not understand what was happening to me physically, and why it was happening again. Needless to say I didn't get a role in Debbie's production. Despite my poor performance someone in the audience that day saw something, or heard something, they liked. The casting agent at Alliance Theatre, Jody Feldman, continued to contact me and asked me to audition for several shows over the next few years, although I was never cast.

While auditioning I was still working at Border's bookstore. My boss granted me a temporary leave of absence to join Kaiser Permanente's Educational Theatre Program for the 10-month tour, and I was back to doing everything I loved; acting, singing, dancing, and writing. It was hard work. We would load our set and costumes into two vans around four in the morning, drive to the school, then unload and construct the set. Follow that with a one-hour live performance and the trip home, and it was about as much physical exertion as I could handle. At times I would have a pins-and-needles tingling in my hands, and I still had problems with coordination, especially in those giant, sweaty character costumes. But there was something so inspiring about performing for a good cause. We taught students important life lessons and dealt with sensitive topics, including HIV. It was work that was not just about being in the spotlight. It was about doing something to make a difference in the lives of the students in the audience.

I took a break from the tour to visit family in New York with Mike during the holidays in December of 1998. Mike wanted to make this return to NY a very special trip. His plans changed a few times while we were home, but the end result was perfect harmony. As I would soon learn, he was planning to ask me to marry him.

If you want to get married, you need a ring, right? Mike and I had been together since high school, and during this trip he was ready to take the dive and surprise me with a proposal - but the ring wasn't. He wanted to propose on Christmas, and a few weeks prior the all-important ring was still in Belgium at a jeweler for final touches. Long story short, the perfect ring didn't make it back in time, and Mike spent the days before Christmas racing around town to find a new set of presents for me so I wouldn't be suspicious.

A couple days after Christmas, when the ring did finally arrive, Mike wanted to take me on a visit to the church we attended while we were in college. In his mind, it was the perfect location for a proposal. He was literally planning on asking me, "Will you answer my prayers?" In my mind, I was busy! We had errands to run, my cousin's birthday party to attend, and a New Year's Eve party to prepare for. I could not understand why he wanted to say a prayer at the church so badly. Honestly, I was a little annoyed! Instead I convinced Mike to visit the courthouse on a family errand. He was stuck with the ring in his pocket, and awkwardly avoided walking through the metal detectors at the courthouse entrance. He said he'd catch up with me and waited outside. I still had no idea what was going on.

On New Year's Eve, we were preparing for a big night out. I was busy getting dressed at Mom's house, and before we left she asked Mike and I to pose for a photo. For Mike, this was the opportunity he had been waiting for. To plan for his surprise, he secretly took our dog, Barnaby, hostage. Mike looped a necklace around Barnaby's neck, with the late-arrival wedding ring attached. We gathered together for the photo, and of course Barnaby was front

and center. It was my mom who first noticed the necklace and ring on our precious pup, and she said “What’s around his neck? He’s got something dangling!” Before I realized what was happening Mike was on his knee, asking me to marry him. I have never been happier or more surprised. I always knew we’d get married someday, now it was really going to happen. Now it was really going to happen. My high school sweetheart had proposed, and it was time to plan our wonderful future together.

During the holidays my health had been fairly stable, and I was more optimistic about the future than I had been in years. It was the start of 1999 and I was on top of the world. I was performing in a way that was both manageable and rewarding. I had a wonderful fiancé who was making great progress in his own career. He had recently won a trip to Hawaii for leading his new company in sales over the past year. And so it was the perfect opportunity for us to plan a vacation and get away to celebrate.

In April, we traveled together to an island paradise in Hawaii. We spent the first few days just lying on the beach, snorkeling, and exploring waterfalls. For a while it was easy to forget about problems with my health or even the challenges of planning a wedding. But our happiness was cut short yet again. During this vacation in the sun my health changed, and it did so quickly. After just a few days my legs began to feel like Jell-O. I was overcome by fatigue and asked Mike if we could stay in at night instead of venturing out. When we were out and about I spent a lot of the time looking for my next place to sit instead of enjoying the beauty of the scenery. I didn’t tell him about the symptoms I was experiencing. I just said I needed to rest, and told him it was all

right to go out on his own. Mike would always respond, “I’m not going if you’re not going.”

Once again, I hoped that a change of scenery would erase my problems. But when we returned to Atlanta, the symptoms stuck around. My tour contract was up in May. I considered signing on to continue performing, but my health issues left me more confused and frustrated than ever. Once again, I had so much to be thankful for with my career, the love of my life, and a great place to call home. But something was clearly wrong with me physically, and once again I wanted to escape. It was eerily similar to my struggles after college graduation.

Border’s bookstore welcomed me back and put me in a new role as marketing manager in my district. The job involved organizing special programs for multiple stores in the area, and I had the opportunity to work on events with the likes of *Boyz II Men*, actress and author Jane Fonda, and *America Idol* host Randy Jackson. When I met Randy, *American Idol* was in full swing. Egged on by my colleagues, he asked me to sing something for him. I’m not sure if it was self-doubt creeping back into play, or if I just didn’t want to be discovered that way, but I declined. It’s one of those moments that I will always look back on and think, what if? Did I refuse because my health problems were making me afraid to reach for my dreams?

As I took on my new role with Border’s, the numbness and tingling in my hands became especially annoying. Typing, using paper clips, even getting dressed in the morning was a struggle. This time, though, I wasn’t dealing with feelings of depression. I was angry. Every day I realized that I had so much in my life that was hopeful and good, and I resented the fact that my health was

poking at me constantly, reminding me that all was not well. My friends and family would probably confirm that during this time I was often not a joy to be around. Still, I didn't talk to anyone about what was happening, because I couldn't explain it. My denial was a strong force that I thought was necessary to keep me going. I had no idea what was going on, and facing that fact was just too frightening. To cope, I closed myself off a bit from my family and even from Mike. I didn't want to complain or show my vulnerability. Our engagement was so new and I didn't want him to reconsider what he was getting himself into! Like so many people living with MS before and even after a diagnosis, I went to great pains to hide my symptoms. I avoided events that involved too much exertion or walking, and sometimes had to balance myself as I walked. I was no longer comfortable mountain biking, roller blading, and jogging with Mike because I didn't want anyone to notice how much I was struggling. I would exercise at home to *Billy Blanks Tae Bo* videos, or take walks with Barnaby in a private wooded area. I started to take an interest in nutrition and found it comforting to know that maybe I couldn't control what my body was doing, but I could control what I put into my body. And it worked for a while, until wedding planning was in full swing.

Mike and I wanted to be married in New York, and we quickly learned that planning a wedding remotely is a monumental task. We wanted our extended family to be able to attend. Grandma Vickery had suffered a stroke, and Grandma Salerno was one of the most important women in my life. Both would have struggled to make it to a destination wedding in Atlanta. Our families were also dealing with a bit of turmoil, so much of which can come to a head during a wedding! My parents were separated, and my dad wanted to bring his girlfriend to the wedding. There were long and

often painful conversations over who would walk me down the aisle and who would be seated where. There were so many phone calls to make. The whole ordeal made coordinating events for Border's seem like a cake walk. But our date was set for October 28, 2000, and we were determined to make it the wedding of our dreams.

As the saying goes, when man makes plans, God laughs. My life changed forever before our wedding date arrived. First, Grandma Vickery passed away. Then, in November of 1999, I woke up one morning and my hands felt like they were asleep. My feet went numb and cold. I had heard people talk about getting cold feet before taking the plunge, but they didn't mean literally, did they? It was difficult to dial the phone and I was dropping things left and right. The numbness spread down both my legs. I tried changing shoes, but my walking was slower than ever before. It was like I was dragging something along as I walked. Despite the fact that my symptoms were more severe than ever, I struggled through, and kept what was happening to myself. A week later I felt a tight squeezing in my mid-section and had difficulty breathing. I ignored that too, for as long as I could. There was just so much to get done. I felt I couldn't take a break. I also did not want to admit that something serious might be wrong with me.

A few days later hiding my symptoms was no longer an option. I woke up and couldn't move my legs. From my waist down I was completely numb, and I was very scared. Mike was already at work, but I was able to roll over and reach the phone to call him. He was shocked when I told him what was happening. For Mike, this came out of nowhere. Over so many years together I had not told him about my struggles, and this hit him like a ton of bricks.

He rushed home. There was panic in his eyes as he helped me get dressed. This was not the same Mike who was always the calm voice of reason. I could tell that he thought something was very wrong, and didn't know what to do. He helped me down the stairs. I had lost so much control I was banging into things on the way. We made it to the car, and Mike drove me to my doctor's office. By the time we arrived, I was able to walk a little, but still had a tingling, burning sensation down my legs. My doctor was also clearly concerned and sent me to the hospital for an MRI.

Lying on the table, strapped in and prepared for an MRI, I remember thinking it's a good thing I'm not claustrophobic. In fact, I found a strange comfort in the secure positioning. I didn't have to worry about walking or my balance. The lab technicians looked at my results, and called in other physicians for their opinions. They seemed to nod in agreement, but didn't tell me anything right away. Eventually they told me they would send the results to my neurologist, and that I'd need to schedule an appointment for a few days later.

The time between my MRI and my meeting with the neurologist seemed like an eternity. I continued to struggle more with my walking. I was given oral steroids that helped a bit, but took me on an emotional rollercoaster. I was unable to sleep. My family and friends all tried to help, researching natural remedies for muscle stiffness and exhaustion. No one had any idea I had been dealing with these symptoms for years. I decided to do the same thing I had been doing since college, and covered up my symptoms as best I could. I went back to work at Border's as if nothing was wrong.

A few days later I was at work. What started as a normal day turned into something almost surreal. I had booked an author to

read to a group of children in the afternoon. She wasn't returning our calls, and we worried she wouldn't make it as scheduled. Shortly before she was supposed to arrive, I got a fax in my office from the hospital where I had my MRI. I was shocked. From my understanding, the fax was supposed to go to my neurologist, not directly to me at work. It was difficult to hold my hand steady as I glanced over the form, looking for any information that would explain what was happening to me. I eventually found the information I was looking for:

Probable diagnosis: relapsing-remitting multiple sclerosis due to demyelination of the brain.

I was immediately overwhelmed with feelings of fear and panic and confusion. But at that very moment there was no time for me to process what it all meant. Several of my co-workers came to me with panic in their eyes, reminding me that we didn't have an author to read to the audience of families gathered in the children's section. With my diagnosis in hand, I still apparently had a performer's commitment in me – maybe it was my denial kicking in yet again! Either way, I said, "Fine, I'll do it." I grabbed the first book I saw on the shelf, "*The Jester Has Lost His Jingle.*" I opened the cover and started reading. I could barely control my shaking, but I put on my best stage face and acted like I have never acted before. I was not familiar with the book, and as I look back, in many ways this odd course of events felt a bit like destiny.

The book I chose was the story of a jester whose king no longer laughed at his antics. The king banished the jester from the kingdom, and he set out on a quest to find laughter again. The jester was confused and confounded. He thought he was no longer funny - how could this be? In his travels, the jester came upon a

hospital, where he met a young girl lying in bed with bandages on her head. The jester asked her why there was no more laughter in this world, and the girl said she has no reason to smile. She was fighting a tumor that had put her health in dire straits. She said she was tired and wanted to give up. The jester rallied and told her that when he faced serious hardship, he always decided to sing and play as much as possible. He performed and the girl laughed once again. The jester was able to tell the world that laughter was not dead. It lives inside all of us.

By the time I finished the story, I couldn't hold back my tears. The children were concerned and asked why I was so upset. Though I was sure they would not fully understand what I meant, I told them the moral of the story. As long as we keep laughter inside us, then we can get through anything.

Somehow I made it back to my desk and called Mike to tell him about the fax. He rushed over and picked me up to take me home. I was so upset that I couldn't drive myself. The car ride was so very difficult for both of us. We were mostly silent, neither of us really knowing what to say. We knew nothing about MS. When we got home we called family members and searched for information about MS online. What we found was petrifying.

I had an uncle in Kentucky who specialized in medical research as a librarian. When he heard about my condition, he put together a massive binder full of information about MS research and treatments. And once again my old friend denial showed up. I couldn't read it. I didn't want to have my worst fears about this disease confirmed. It all seemed so daunting and negative. I asked Mike if we should call off the wedding and told him this didn't have to be his path, too. He would always be my best friend, but I

wanted him to know that he didn't have to take on this challenge with me. Mike responded, "Are you kidding me?" He would never walk away.

We finished our plans for the wedding even with this terrible burden. Mike is nearly nine inches taller than me, and I was determined to wear heels with my dress. I settled for platform heels rather than full-on stilettos, and practiced walking in them before the wedding in the privacy of my home. This was a walk toward my future and I was not going to let MS take it away from me. When I did walk down the aisle in those heels, my vows to Mike and his in return held so much meaning. The words, "in sickness and in health," were never more poignant. I felt so lucky. Mike was determined to stand by my side, and I could only guess that many others living with MS might not be so fortunate. Mike made me feel like this was our challenge to face together, not mine alone. What a challenge it would turn out to be.

CHAPTER 3

Rediscovering My Ambition

London. Paris. Belgium. Mike has always been a romantic. Together we planned on experiencing the perfect European getaway for our honeymoon. I just wish I could have enjoyed every minute of it.

Instead I spent two weeks battling with myself. Whether it was climbing the Eiffel Tower or walking cobblestone streets under Big Ben as we tried to enjoy the honeymoon tour of a lifetime, my body did not cooperate. To put it simply, I was always exhausted. There were so many amazing places to explore and I tried my very best to push through the struggles. Still, most days after we got started I had to explain to Mike that I was too tired to continue. Once again he was my partner and my champion. He joined me for so many less taxing events like a picnic in a park or a bistro snack. I tried not to dwell on my struggles because I didn't want to dampen our time together. Deep down I was frustrated and angry.

Despite my fatigue, it was an amazing experience. But I sometimes wonder what it would have been like to celebrate our marriage with a more laid back trip, like relaxing at a vineyard. Then perhaps we could have visited Europe together later in life. I wondered how healthy newlyweds find the energy. Jumping from train to cab to hotel and museum was so very tiring. I also felt that the months of wedding planning had drained me physically and emotionally. Even at this point, I found a way to attribute my symptoms to something other than MS. It was all still so fresh in my mind that it was impossible to fully process my diagnosis.

When we got back to the U.S. and started our lives together as a married couple we resumed our daily routines, and that included denial. I spent the next three years pretending everything was all right, even as the numbness in my hands, feet, and torso persisted. When I would get overheated or stressed, it seemed like those symptoms would get a little more troublesome. I'd have difficulty bending my fingers and toes, and sometimes the pins and needles sensation was quite painful. By now I was a true expert at hiding it. Maybe I was a better actress than I realized! Most of the time people around me wouldn't have imagined anything was wrong with me. I compensated for symptoms by holding onto walls or chairs and by not participating in certain things that were too challenging for me. This is perhaps where denial is so sad and dangerous. I missed so much during these years, and it also kept me from seeking the medical help I needed. I had no interest in treatment to slow the progression of my disease, because that would confirm that it was a problem and that my MS was getting worse.

I was such a good actor that even Mike, the person closest to me in the world, rarely noticed my efforts to compensate. I constantly worked to handle any changes in my health by myself. I would have good days, then within an hour my condition would change and I wouldn't be able to get off the couch. I felt near constant fatigue, but wrote it off by claiming I needed more sleep or wasn't eating right. When Mike did notice, those times were especially difficult for me. I could tell it was frustrating for him, primarily because neither of us understood what was happening and we felt like we had no control. When he noticed changes in my health, it was much harder for me to avoid facing the truth. I often challenged Mike by pushing him away and putting up a wall. I

wanted to find out if he loved me for who I was, or if he simply felt sorry for me. Meanwhile, my family members, friends and neighbors who knew about my diagnosis rarely asked about it. I imagine they were trying to give us privacy, but it made us feel isolated and it was easier to continue to deny what was happening. It was like we were stuck in a bubble that was whisking us away from our life plans and dreams. Those feelings of isolation have had a major impact on how I approach friends and loved ones that are struggling through difficult times. I make a conscious effort to show my support rather than give them space because I remember how much I wanted to connect with someone on my most difficult days, and I never want people around me to feel like they've been left to deal with their problems alone.

When I did step back and try to analyze what was happening, there were many things I realized I took for granted. While I used to enjoy walks with our dear dog Barnaby, I found that I now preferred to walk in private wooded areas instead of public parks. I wanted to avoid having other people see my clumsy stride. I loved to cook, but as maneuvering around our kitchen became too difficult for me, Mike and I ordered take out dinners more often. Suddenly, fear was my motivator. The *Wonder Woman* years that were filled with infinite possibilities and tremendous courage had given way to hesitation and trepidation. I felt like a prisoner in my own body. Mike did everything he could to try to reduce the stress in our lives, hoping that this would improve my symptoms. Looking back I probably didn't have as many flare-ups as expected thanks to Mike's efforts, but my disease was silently progressing. His nurturing, as sweet and helpful as it was, also allowed me to stay in denial. By taking care of any tasks that had become too difficult for me, Mike was accommodating my ability to ignore my

disease and made it easier for me to brush aside symptoms that in reality were causing very serious changes to my body.

During this time I continued to think about performing, but I had more or less concluded that my days in the spotlight were over, and that was devastating. I'd have to find a different way to keep music and the arts in my life. I kept thinking, "Why me?" None of this was in my plan. I was on track to fulfill my childhood dreams. I had worked so hard to reach that goal, and now I wondered who I was without it. If I could not continue to pursue my dreams then who would I be? MS changes the path of your life; there is no doubt about that. As I would find out, figuring out what your new path will be is not easy.

More than anything, I just wanted to be normal again. Returning to New York never crossed my mind. Atlanta was my home now. Things were still going well for me at Borders Group Inc., and the normalcy was a welcome relief. I had joined Mike's health care plan, which was great on one hand because I would still have medical benefits if I couldn't continue to work. On the other hand, I dreaded becoming more of a burden, and wanted to find some sense of renewed independence. Right after my initial diagnosis in 1999 I approached my boss, Robert. There was no way to predict how my role as area marketing manager would be affected. It turned out I could not have been in a better situation. Robert told me not to worry about my job. He said I was secure at Borders and seemed so confident in that. I played devil's advocate. What if I can't do certain things like typing press releases or driving to events? Robert said it didn't matter, and then he explained why. His brother also had MS and lost his job at a radio station when his symptoms flared. Robert said he wouldn't let that happen to me.

Soon after my wedding I received a promotion to district marketing manager and began answering directly to corporate, working with multiple stores across Georgia. Robert was no longer my boss, but was still a caring and supportive peer. My main office remained in his store, and he often offered to assign his staff members to help me with my new job. I was so blessed to have Robert's support, and I know many people living with MS struggle to find a sense of understanding in the workforce. It was an early sign of how many people in this world are affected by MS in one way or another. A community of support is so vital. One day, that would become a driving force in my own life.

For now, driving was literally forcing changes in my life. Getting behind a wheel became a real issue for me, especially at night. The numbness in my hands forced me to watch the steering wheel instead of keeping my eyes on the road. The fleeting sensation in my feet caused me to manage the pedals with my heels. Robert understood and often designated late night events to someone else from our team at Borders. I'd simply provide a checklist to make sure all needs were met when I could not be there for an event in person. But there was one evening that I refused to relinquish my responsibilities. During the Masters golf tournament, we hosted Phil Mickelson for an event at Borders in Augusta, Georgia. Mike drove me for the two and a half hour trip. He continued to do all he could to make me feel like MS wasn't such a big deal. That night more than 300 people attended our event. I even made the local news for giving a fan the branded t-shirt off my back so he could have it signed by Phil!

Eventually my co-workers found out about my diagnosis, and they were just as supportive as Robert. They sent me articles and

information about MS. I would read until it was too scary or depressing. When facing challenges like MS, the saying is true; ignorance truly is bliss. In my mind I did not feel motivated to fight MS. I was determined to make do with what I had. When I had trouble typing thanks to numb, weak fingers and blurred vision, Robert offered to have one of his store employees assist me. I still tried to hide my symptoms as best I could and was determined not to use them as a crutch or an excuse. The network of support was comforting. I began to feel more secure around my co-workers than I did around family and friends. Borders provided an environment in which I still felt like I was in control and could manage everyday tasks. I had a flexible schedule and was able to work from home when there wasn't a major event to promote. I was immersed in an artistic setting. The effort to help other performers find an audience and pursue their passion was empowering, and I loved connecting with customers.

One customer in particular brought happiness into my life at a time when I desperately needed it. As an actor and as a fan, I was always obsessed with Kevin Spacey. One day, a woman named Kathleen walked up to me and asked if I could direct her to the section of Borders where she would find *People Magazine*. She said Kevin was on the cover, and I gushed over how talented he was. She said, "Thank you, that's my son!" I was a little embarrassed, but even more intrigued. Kathleen was a regular at our bookstore, and soon we grew close, chatting every time I ran into her. I told her about my passion for musical theatre, and she brought me a cassette tape recording of Kevin singing his heart out. Kathleen explained that Kevin was always such a great singer, but most people had no idea. Music was our connection. Kathleen was so kind and supportive that she even went a step further. As a

surprise she brought Kevin to Borders to meet me – but I wasn't there! I was visiting my family in New York and did not find out about the surprise until I was back in Atlanta and found a sweet personalized autographed photo waiting in my mailbox at work. I don't know if I've ever been filled with so much excitement and regret at the same time, but I will always remember Kathleen's kindness and the fact that Kevin is a great singer and a loving son!

By the end of 2002 Mike and I had settled into a comfortable routine that lasted for a while. Yes, the changes to my body had a significant impact on life around the house, but I was finding purpose and confidence at work. Pretending I didn't have MS seemed to be the right approach. Then, in December, Grandma Salerno passed away. And with this terrible loss I fell into a deep despair.

I've experienced a number of moments that felt like bottoming out, but the months following my grandmother's death may have been the darkest. She was such an important influence in my life. She taught me about enjoying the simplest things in life. I was asked to sing at her funeral and read a poem or say a few words. I decided not to sing because I was afraid of breaking down under the weight of my own sorrow, but I accepted the chance to say a few words. I was planning to simply read a poem. That plan changed in the middle of the night just hours before Grandma's funeral service. Her eulogy came to me in a rush of emotion. I just typed and typed and didn't stop until it was done. For those few hours, the trouble with my fingers disappeared as though someone else had taken over; almost as if Grandma wanted me to speak on her behalf in order to comfort our family. The wisdom she left behind came pouring out. As she lived her life Grandma Salerno often talked

about her legacy. She reminded us that when she was gone we would remember the little things we shared together, like our fantastic tea parties, crazy family gatherings, and the food she prepared as a labor of love. Of course, as children we didn't understand what she meant. When she was with us we didn't want to think about losing her. But once she was gone, I realized she was right. I can't hug her, but she is still with me to this day through those cherished memories. Grandma Salerno taught me to continue to create new memories with the people who are important to me at every opportunity, and not to let anything stop me from doing so. I wish I had sung at the funeral service and feel like I let my Grandma down. That regret has continued to influence me anytime I'm presented with an opportunity to take the stage.

The first few months of 2003 started in our new home with some funny mishaps and painful challenges. After our move we met new people in our neighborhood. We enjoyed a great friendship with another couple from New York that had moved to Atlanta like us, Brad and Cindy, though our first meeting was awkward to say the least. They initially purchased the land that we eventually built on, but instead opted for another property lot down the street. Before Mike and I moved in, we wanted to have a look around the house we bought and decided to "break in" through a window.

Construction on the house was in its final stages and we really wanted to check it out. Just at the moment when Mike was gracefully shoving me through an open bathroom window, Brad and Cindy drove up. They decided to play a little joke on their new neighbors.

"Hey, what are you doing breaking into our house?"

Brad's thick New Yorker accent made me feel right at home. We were confused and wondered if we had mixed up the lots. But they laughed and explained that their house was actually a few lots down. Their sense of humor matched ours perfectly and we were on a path to become great friends. We held regular poker nights together with a few other families in the neighborhood. In May, I was feeling exceptionally exhausted at one of our gatherings. It was overwhelming and I wanted to head out, but I didn't want to pull Mike away from the card table. We joked that I was leaving because I was losing. That was rarely the case; my acting skills lent themselves to a great poker face! I actually had a somewhat frightening need to rest. I couldn't find the energy to finish our game. I didn't want to stop the fun or share my fears. So I left alone.

Our home was only about a block away; a lovely stroll around a lake. It was after midnight when I ventured out into the darkness on my own. The lake was glistening under the glow of the moon. It was easy to get lost in the serene calm of our neighborhood, and I began to relax as I neared the cozy bed waiting for me. But without warning I hit the ground before I even knew what was happening. Lifting my head I turned my gaze to the sidewalk. Did I really just fall? What did I trip on? I was dazed and scared.

I quickly realized that I was numb on my left side. I started to panic because I couldn't get my body to help me stand back up. There was nothing wrong with the sidewalk. I was having my worst flare-up in years. It felt like I was a tree chopped from its roots and left helplessly on its side. If anyone drove by they would have thought I drank too much wine. Even in a crisis situation that's what I worried about most. I wondered what other people

might think of me, lying on the sidewalk down the street from my house in the middle of the night, unable to pick myself up.

Somehow I made it home. Through my tears I struggled to my feet, and then limped my way straight to bed. The next morning Mike noticed the scrapes on my arms and knees. I told him I fell and said it wasn't a big deal, but I still wasn't all right. I was struggling even more than usual to keep my balance and maneuver around the house. Mike could see I was walking strange and he felt terrible for letting me venture home alone the night before. He told me I needed to see a doctor. I had my excuses ready. I'm fine. There were no broken bones. It was just a few scrapes! But this time Mike saw right through me and insisted I needed to see a doctor, not for my fall, but because it seemed like my MS was progressing.

So I did. I saw several neurologists, and one-by-one they said yes, what you are experiencing is caused by your MS. Each time I heard those words it felt like being in a bright room and then suddenly the lights were switched off, leaving me alone in the dark. In my heart, I still hoped the original diagnosis might be wrong and that I was simply dealing with a virus. When my diagnosis was confirmed I felt like everything I had been preparing for my entire life died at that same moment. At my first appointment, I had another MRI. I brought my original MRI from my diagnosis in 1999, and the neurologist compared the new to the old. He used a red marker to circle the original six lesions, which are the marks that appear on the brain as MS progresses. Then he kept going. Seven, eight, nine... when he made it to 30 lesions on my brain and spine I begged him to stop. In the years following my diagnosis my disease had progressed at a rapid pace. Pretending I

was all right might have helped me to remain calm and pretend that nothing was different, but it hadn't changed reality.

The neurologist talked to us about disease-modifying therapies, drawing complex diagrams to show the differences between the various drugs available. He said the choice was mine, but he wanted me to start with an aggressive, high-dose and high-frequency therapy right away. He said my MS was already moderately severe. I was only 30 years old.

I wanted more opinions. My denial and fear made me want to get real, conclusive answers. In total I visited four neurologists in the late spring of 2003. Their bedside manners varied but their professional opinions did not. Whether it was the disheveled doc who kept leaving the room to take phone calls, or the buttoned-up veteran with an antique medical bag, they all said the same thing: I needed to start treating my MS. Mike and I pored over the piles of kits and information the neurologists provided. We went to each disease-modifying therapy's web-site and considered the options. I wasn't worried about the injection process. Needles didn't bother me. I was worried about the potential side effects.

In our searching we found an MS educational event in Atlanta and decided it was finally time to learn more about my disease. Actress Teri Garr was scheduled to speak. I remembered her performance in *Young Frankenstein* and *Mr. Mom* and was surprised to see she was dealing with MS too. At the event, Teri was entertaining. Although, I had a difficult time giggling about the destructive symptoms I was dealing with, it was nice to relate to some of the odd and embarrassing moments that MS can create. I approached her afterwards and joked about my favorite lines from her movies. I told her I used to perform, and she advised me to keep quiet

about my diagnosis for as long as I could, because if word got out she said I would never work another day in this business. It wasn't what I wanted to hear, though I understood what she meant and that she was trying to help.

At the same event there was another patient speaker; a woman who was forced to relinquish her role as CEO of a major company when her symptoms flared. Her words that day brought my own experiences to life. She was emotional on stage, and it opened me up. She was an average person facing real challenges. Then I noticed that I was surrounded by people facing similar challenges. I talked to other people at the event and had an epiphany; I wasn't facing this alone. All around me were people who could relate to the feelings of depression and isolation I was so used to hiding. In a way I felt that the bubble that kept Mike and me isolated finally popped and I found hope. Suddenly, we were part of a community.

After the event I decided to call the first neurologist I had seen and asked him for a disease-modifying therapy prescription. He told me I'd get a call from a nurse who would train me on how to administer the injection. Reality hit again. Was I going to have to inject myself for the rest of my life? The prescription arrived and I unpacked the materials in tears. The nurse called to set up a training appointment. But I was once again trapped by fear and found excuses. This was a huge step. Once I started treatment it meant I definitely had MS, and there was no turning back. I let my disease-modifying therapy sit idly in my refrigerator for weeks.

Then once again everything changed. Maybe it's true; you have to bottom out before rebuilding. While my therapy was continuing to chill in the refrigerator, opportunity came knocking. It wasn't uncommon for local musicians to send me samples of their music.

If they had a show at Borders or we stocked their album, it could be a launching pad for success. However the number of submissions was usually more than I could handle alone and most ended up in a box under my desk. My co-workers were instructed to put samples in the box and tell inquiring artists we would take a look. I rarely met them face-to-face, unless we decided to book them for a performance or sell their music. But songwriter Jayne Olderman was different. She was pitching a compilation album she had just finished recording with a few other artists, and was hoping we would consider selling it at Borders. A new co-worker of mine wasn't familiar with how we handled these types of inquiries, and she brought Jayne to my office to meet me in person. Whenever this happened I was always polite and went along with it, but in the back of my mind I assumed Jayne's album would end up in the box with the rest of them. I quickly saw that this was different. Jayne's passion was intoxicating. She seemed to be so dedicated to her work and was convinced this album needed to be on our shelves. Our connection was clear right away, and the way she interacted with me was almost motherly. I took a copy of the CD and wrote down her contact information.

On the way home from work that day I listened to the album. A song titled, "Whatever Makes Your Soul Sing," streamed through my speakers, and I was moved to tears. It was exactly what I needed to hear! The song talked about doing whatever makes you happy, and following your dreams and passions no matter how many challenging obstacles you face. It was all about courage and strength. Soon the song was on repeat at home, in my car, and at work. I booked Jayne and her fellow musicians immediately. We started selling the album and lined up a few shows in several of my Borders stores.

I decided to see Jayne and her group perform and stayed late at work one night to do so. When I walked up to Jayne to say congratulations and wish her luck, she was noticeably anxious.

“How well do you know ‘Whatever Makes Your Soul Sing’?”

I was a little confounded. Why was she asking me that? I told her I knew every word at this point. It had become one of my favorite and most inspirational songs.

“How would you feel about singing it with us tonight?”

Jayne was in a bind. One of the vocalists in her group wasn’t going to make it to the show. She needed someone to fill in, much like the day I was diagnosed with MS in 1999 and filled in for an absent author at a book reading. I hadn’t performed on stage since that diagnosis and had spent almost four years in hiding. There were about 80 people in the café waiting for the show to begin, including many of my co-workers, some of whom didn’t know I could sing. Honestly, at this point even I didn’t know if I could still sing. I was afraid, but didn’t have the time to think about it. If I had more time to over-analyze the situation, I may have talked myself out of it. But I took the stage, and for those few minutes I really heard my soul sing.

The response was phenomenal. A few people in the audience were repeat customers who had become familiar with me as marketing manager. Now they were seeing me as a performer, and suddenly I had a fan base. One of them held my hand and asked when I would sing again.

Stepping back into the spotlight that night was life changing. I realized that music was inside me. It was a part of me, and I was

invigorated. It helped me see great things in my future for the first time since being diagnosed in 1999. I knew at that moment that my future really could include my passion for music and the arts whether MS liked it or not. The next day I finally called back the nurse to schedule my injection training. I couldn't change my diagnosis, but I could manage how I dealt with it. What brought me out of denial was music.

At first Mike did the injections for me, and I think he had too much fun with it. At my first training the nurse told Mike to hold the syringe like a dart. He took a few steps back, raised his elbow and zeroed in on the bulls-eye before the nurse stopped him. During the first two weeks of treatment, Mike would count back from 10 at a snail's pace while injecting the medication for me. It drove me nuts. I just wanted to get the injection over with and go on with my life, so I soon took control. It wasn't long before the nightly injections were routine, and I was finally taking action to fight back against MS.

Jayne and I stayed in touch, and she invited me to her home studio to record a new version of "Whatever Makes Your Soul Sing." She played at a variety of coffee shops and bars in the area, and often asked me to come along. Jayne would pull me up on stage for one song, and my confidence grew with each performance.

Eventually I was contacted by an MS advocate I had met at the patient event where Teri Garr spoke. The advocate asked me to join her for lunch along with another co-worker, and I brought a recording of me singing Jane's song, "Whatever Makes Your Soul Sing." After listening to the track, they expressed interest in booking me to perform at a patient event coming up in Atlanta. The usual what-ifs began popping into my head again. This would

be a much bigger audience than the small coffee shops where I was performing. What if I drop the microphone because of my numb hands? What if I trip while standing on the stage? What if I forget the lyrics because I have a moment of cognitive dysfunction? What if I'm surrounded by people with wheelchairs and walkers? Would that scare me and make me too emotional to perform?

There I was, once again allowing fear and the what-ifs to paralyze me. I guess old habits die hard. But then I thought about *Wonder Woman*. She never backed down because of fear. I thought about my audience. Now they were my peers, and that gave me so much comfort. They would understand all of the what-ifs better than anyone else. I felt a responsibility to them and at the same time knew that I could be vulnerable in front of them. It was something I had never felt before in all my years of performing. The audience would be filled with people who were facing their fears by attending the event. They were leaving the comfort and security of their own homes in an effort to educate themselves about MS. We would all be learning together about our disease. I decided to say yes and perform at the MS event.

Words cannot express how amazing the experience was. While singing "Whatever makes your soul sing," my what-ifs disappeared. All I thought about was the audience. I looked out and saw bodies swaying, heads nodding, and toes tapping. I watched the mood in the hotel ballroom change from fear to freedom, and from despair to delight. When I walked off the stage I was immediately surrounded by my new MS family. One man struggled with all his strength to stand up out of his wheelchair just to hug me. Once again music had connected me to what I needed most: understanding, support, and hope.

When I was first diagnosed with MS, and even before the diagnosis when I had no idea why I felt tired and was unable to perform, I constantly asked, “Why me?” After that performance I had my answer. My lifetime of training was in preparation for a purpose after all. I had spent years seeking an external spotlight, but MS showed me that the beacon of light I needed was the one shining inside of me. Sharing my passion for music and the arts in my own way and with my new community would allow me to help others during their stormy days and maybe help to inspire them to do whatever made their souls sing.

I had a surge of energy and felt I was just getting started. Over the next two years I looked for other support groups, fundraisers, and MS programs where I could perform. I also realized that rather than just stopping my dreams cold, in fact MS had helped me to find a purpose and a passion. It was not the one I had planned originally, but it had the potential to be rewarding and fulfilling in ways I could not begin to imagine. I refused to let MS dictate my life, but I was still making concessions. At every performance I was worried about how my symptoms might affect me. I found myself needing to sit on stage, limiting my creative freedom. However, armed with a new outlook on life, the more I sang the more I wanted to sing. I saw a way to connect with people. I was coming out of hiding, and it felt great.

I also decided that it was important for me to share my thoughts and feelings about my MS journey through songwriting. Since 1999 I had been keeping a personal journal, and reviewing the entries struck a chord. I found that many of my lyrics were already on paper, just waiting to be set to music. It made me feel a little vulnerable to share my innermost thoughts, without a character to

play or a costume to cover my insecurities. But it also empowered me. I would be sharing my own stories and using my own words. They were messages of hope that I felt certain could help others. For so many years, if words went into my ears and touched my soul, they stayed in my head and influenced my music. Sometimes I worried that my own lyrics might not have the same impact that other songs had on me. But I knew I had to try. So many songs of hope were bottled up inside and it was time to release them.

One thing was clear. If I was going to do this, I needed to jump in with both feet. By 2005 I was already traveling to perform at numerous MS events across the country, and I was beginning to struggle with balancing my responsibilities at Borders. I came to the point where I could not do both. My work with Borders Group Inc. was great, but it wasn't nearly as rewarding as my new role as a patient advocate. I needed to take a leap of faith and resign from my day job. Everyone was understanding and excited but didn't want to see me go. I was sad to leave my wonderful co-workers, but in the end it was a weight off my shoulders. The freedom gave me the time to focus all my attention and energy into recording my first album.

The first step was to teach myself the business side of music. I had no managers, no producers, and no co-writers. I was a one woman show! I spent three months learning everything I could about the music industry, including how to copyright lyrics, how to protect recorded tracks from piracy, and how to market my music. It was a full-time job. I set up a regular work schedule in order to avoid lying around and watching daytime TV!

With my newfound knowledge of the intricate details within the music industry I created a business plan with a detailed budget and

a comprehensive marketing strategy. My timeline covered all the basics: who, what, when, where, why and how. It was a tight budget, and I didn't want to take out any loans, or borrow money from loved ones. In order to answer the "where" in my plan, I met with several music producers in Atlanta including Jan Smith, best known for her work as vocal coach for singers Rob Thomas and Usher. I remember walking into "Mama Jan's" studio. We got to know each other and I sang for her and one of her producers. Jan was interested in recording with me, but her fees would put me three times over my budget.

I went on to visit several other studios and even did a few practice demo recordings. Everyone I met with was interested in working with me, and they were all quite talented and skilled in their profession. However, I was waiting for a certain connection. I wanted to find someone who could help me discover my own musical thumbprint. At each meeting, I felt swayed from my original path a bit. Many of the producers had their own vision for my future in the music industry, but it didn't always align with my aspirations. That is, until I met J. David Leonard. He was a laid-back, wonderful listener. His personality reminded me of Mike. He was encouraging, supportive, understanding and I could sense he had a big heart. And I could afford his services.

The process of writing lyrics and recording my debut album was like peeling an onion. With each layer came tears. But those tears brought me closer to discovering my core. I would write at home by myself. Then I would take my lyrics and melody to David for recording sessions. My passion for music was driving me to the studio on a routine basis, even when physically driving the car was difficult. The recording booth was a soundproof room with padded

walls and a glass partition. It felt a little isolated until I closed my eyes and envisioned my audience. When I did, I realized I wasn't alone. Music would once again connect me to the rest of the world. Recording felt natural, and all my training came rushing back to me. For the first time in many years I was comfortable in my own skin again. There was safety in the studio environment. After six months of hard work, I had an album titled "Believe."

The photo shoot for the album cover art was an unforgettable experience. With the music recorded and the business plan set, I thought the hard part was behind me. I scheduled an outdoor shoot and woke up that day to blue skies and sunshine. The weatherman predicted pristine conditions, but to our surprise, as soon as I made it to the location clouds rolled in out of nowhere and the skies opened up. It didn't just rain, it poured. There I was with my hair done and makeup on waiting for the rain to stop. Instead, a raging thunderstorm knocked out the power inside the photographer's studio. I sat staring out the window and the photographer took some natural light shots. Initially it was disappointing, but after a moment of reflection, I realized I had come too far. Once the lightning and thunder stopped, we decided to proceed with the outdoor shoot. The rain was simply an added element, providing character and originality. I actually had fun stomping in puddles and smiling through the water with makeup running down my cheeks. Those outdoor shots were raw and revealing, and turned out to be my favorite images from the entire shoot.

I think that shoot had a lot of parallels to my experience living with MS. I could have chosen to avoid the situation, and cancel the shoot until the weather cleared. Instead I faced the storm, and used the rain to my advantage. It wasn't planned, but became a part of

the whole experience rather than a hindrance. I never planned on having MS, but once I accepted my own condition it became a part of who I am and led me to write original songs and record my music. I launched the album and started a new chapter in a lifelong dream to perform. A dream that seemed out of reach just a few years earlier was now coming true. Through a random chance to sing again, I had rediscovered my passion for performing and found a new purpose in my life. The question, “Why me?” was replaced with, “Why not me?”

CHAPTER 4

Facing MS Together

As I began to adapt to life with MS and rediscovered my passion for music, I still didn't realize just how much MS was affecting most of my personal relationships. Music helped me to reconnect and strengthen my relationship with my husband, family and friends by allowing me to sort out my own feelings and in turn communicate more effectively. I had closed myself off emotionally and music opened me back up. I knew it could do the same for others.

I was quickly immersing myself in a new community of people living with MS who really understood the physical and emotional challenges I was facing. The positive response to my album gave me the confidence to seek out new opportunities to perform. Each show helped me just as much as I hope it comforted and influenced the brave audience members who were there to learn more about the impact of MS on their own lives. They inspired me in so many ways. The more I shared my experiences through music, the easier it became for me to talk about the not-so-glamorous effects of MS. Music was a therapy that could change my mood by sparking memories and uniting me with people going through the same struggles. I needed to sing my heart out.

Mike always struggled to comprehend my symptoms, especially those that were subtle or invisible, and it was impossible to blame him. It had taken me years to face this disease honestly and without my own denial clouding the situation. As I accepted my diagnosis, I wanted to explain it all to Mike in a way he could relate to. Even if we could switch places, and Mike had MS and I

were his support, I wouldn't do it – and not just because I wouldn't wish that on Mike. Friends and family of people with MS have to shoulder so much responsibility, and it's often without any sympathy or support. Mike never told people how hard it had been for him to relate to my experience. But I knew I had to find a way to show him what I was dealing with on a day-to-day basis.

How can you explain numbness in your hands and feet? How can you demonstrate that seemingly small problems – trouble opening a jar or buttoning a shirt - can be a big deal? What about that feeling of walking through oatmeal when trying to get across a crowded room - how was Mike supposed to know what walking through oatmeal felt like? Despite these challenges, Mike seemed to understand when I gave him analogies to explain my symptoms. I used to tell him I sometimes felt like a bungee cord was strapped to my feet and pulled tightly up to my hip. I had this sensation of pushing against the tension of the cord every time I took a step.

Somehow I needed to try harder to help him understand. I wondered if there were things around the house I could use to help him feel what life was like in my shoes – though not literally because his feet are much larger than mine! An idea came to me one day after a conversation we had about shirts. I was keeping the shirts in my closet buttoned half-way so I could slip them over my head and would only have to handle a few buttons when I put them on. I was also wearing button-down shirts less frequently. Mike asked me about it – especially why I didn't wear some shirts he particularly liked. I went to the kitchen and grabbed a pair of heavy-duty rubber gloves I used to wash the dishes. It was time to put Mike to the test.

I told him to put on the rubber gloves and then try buttoning a shirt. As soon as he started - and struggled - I saw a light bulb over his head. He got it. He understood one of the challenges of MS in a way he never understood before. He said it was a strange experience to see the buttons in his hand, but not actually feel them, and minutes felt like hours as he struggled to perform a task he always thought was simple. I watched him fight with the zipper on his jacket and the laces on his shoes. I took it easy and didn't ask him to try some of the really hard stuff - like putting on make-up or clasping a bra! We talked about it for a while after I tested him. I told him about the feelings of frustration when you can't handle simple tasks on your own. I tried to explain that you are always worried about holding people up or being late or getting too tired to finish. Like so many other tasks, getting dressed can be a frustrating and complicated challenge with MS. Mike finally understood what that meant.

Helping him to understand what it means when your foot "drags" was a bit harder. Like so many people with MS, one foot would often drag behind the other when I walked. I had Mike try to walk while wearing a leg weight on his left ankle and a scuba-flipper on his right foot. I also asked him to walk while wearing one high heel to simulate wobbly balance. With his stylish and innovative footwear, he walked just a few feet in the comfort of our home and that was enough for him to understand. I watched as he tried to walk, holding on to walls and furniture as he made slow progress. I asked him to imagine what it would be like to shop for groceries or run to catch a plane. He was able to understand the challenges so well that he even identified some ways to rearrange our kitchen to make it easier for me to move around. He was seeing everything - including our surroundings - in a new light.

Using props and simple instructions to help Mike understand MS was amazing - for him and for me. I immediately wondered how they might affect other people. I was much more familiar with MS events after performing at more than a hundred of them, and thought a demonstration with props could make for a successful live workshop. People living with MS could show their loved ones how it felt to experience their symptoms. I was living with MS. I had performance training. And I was a marketing professional. All the pieces were in place to develop an intriguing plan of action to help spread the word.

I was working on a plan for a live workshop in August of 2007 when I came across a contest run by a patient advocacy organization. It was an opportunity to direct your own film about living with MS. They were calling for proposals and would be selecting five concepts for production and presentation at their national conference. I tried to picture the workshop as a film, which seemed like a great way to reach thousands of people at once. I decided that we could visit some public venues and ask people to take a moment to find out what it was like to live with MS in an educational but simple way. I would ask strangers to put on the dish gloves, scuba-flippers and high heels just like Mike did. It had potential, but I wasn't sure how it would play out.

I tried to find props that could recreate as many of my symptoms as possible. It wouldn't be a typical serious and somber educational piece about MS. I wanted people to laugh, cry, find hope and gain understanding and perspective. The film could be similar to segments on *The Tonight Show* where Jay Leno stops people at random on the streets to quiz them on current events. I'd find out if they knew anything about MS and see if they'd be

willing to use the props to really experience how MS can impact daily routines. I've always been comfortable conversing with strangers and didn't mind the thought of approaching people. Shopping at a mall and traveling through airports were two things I struggled with most, so I decided they would make the ideal locations for the film. I titled my proposal, "The Show Must Go On," and sent it in.

A few weeks later I got a phone call. Out of all the submissions the judges had selected mine as one of five winning proposals! I would soon begin working with a production company to bring my concept to life. They appreciated the business elements of my plan, and knew it could be used for marketing purposes on their end. They also saw my idea as an entirely new and compelling way to connect with patients, their friends, their family, and even people who had never heard of MS.

I was confident I could handle this project, even though I had only directed theatre, never film. It was my instinct to be very hands-on, to a point that was probably a little annoying for the producer, cameraman, and sound crew that helped me. Every step of the way I wanted to make sure we stuck to a vision of understanding and respect. The message of this film had to be delivered just right to help people living with MS. We picked a date to film and had a few conference calls in advance to discuss the production process.

To be honest, those calls didn't go so well. I was concerned that my vision for the film would not remain intact. The producer, Matthew Wachsmann, had a hard time grasping what I was trying to accomplish, and boy was I stubborn. Matthew suggested we act out scripted roles in a theatre in order to control for variables that would be unmanageable in a public venue with random

participants. But I wanted to capture authentic reactions from genuine people. Matthew said it would be difficult to gain the authorization needed to film in malls and airports. That didn't stop me either. It took a lot of phone calls and pleading, but Mike and I were able to secure a date and time to film at a local mall and even Atlanta's international airport. Poor Matthew was probably exhausted by me before we even met in person. He didn't understand why I felt that it had to be done this way, but he agreed to proceed. With every decision I was trying to keep the audience in mind, and after so many years of living with MS before and after my diagnosis, I felt I knew what would really work to help others understand.

While I was preparing for the film crew to meet in Atlanta, I also continued to perform songs from my album at MS events all over the country, traveling coast to coast three to four times a month. It was a stressful time, which can often lead to symptoms flaring. Just a day before we were scheduled to begin shooting I thought I was suffering from a relapse. I was feverish, having increased trouble walking, and Mike said my face was flushed. Soon I was in the emergency room for tests. We called Matthew and told him we may have to postpone the shoot, but he decided to keep the film crew in Atlanta for a few days to see if I improved. I was relieved to find out it wasn't a relapse, but a urinary tract infection that had spread to my kidneys. Sure, I was upset - once again everything was planned and on the verge of execution before a health issue got in the way. But this was nothing a round of antibiotics couldn't handle. I didn't care about my back pain or how exhausted I looked. I called upon my alter ego, *Wonder Woman*, and found the strength I needed. We were going to shoot this film.

The mall and airport staff agreed to let us reschedule for two days later, and this time the show did go on as planned. First, we filmed an introduction at a local theatre, but that's where the scripted part of the film ended. The rest would be a true reflection of real people and real life. We hopped in our cars and headed for the mall. After setting up the props, tripods and microphones, I started asking shoppers if they wanted to be in a documentary film. There was no shortage of people looking to get their big break! Then we explained that we were working on an educational film about MS, offering a first-hand experience to learn about what it's like to live with the disease. I still can't believe how wonderful, funny and willing people were during our shoot.

My main concern was that people would not want to try on the props. We had high heel shoes, scuba-flippers, rubber gloves and eyeglasses that distorted vision, and they could make you look pretty goofy. But after explaining the purpose of the props, people were more enthusiastic than I expected. My first question was always, "Have you ever heard of MS?" There was lots of misinformation. Some participants talked about Michael J. Fox or Muhammad Ali and their ailments. Some thought MS was a muscle disease. Many had never heard of MS at all. And none of this was surprising. Why would you know about MS if it's not a part of your life? For so many years I had no idea what I was dealing with. Some participants decided they wanted to contribute and offered to donate money to support MS research. One woman with rheumatoid arthritis said she understood what it's like when people just don't know how you feel on the inside. There was a man who had a family member with MS and knew all of the symptoms well, but had never thought about how he could use props to experience them for himself. I realized that this film was

positioned to connect with people in ways even I had not fully imagined.

Mike was a part of the team that day and it was his job to get anyone who agreed to participate in the demonstration to sign a legal waiver. It's against his nature to approach people he doesn't know, but he didn't let shyness get in the way. As my production assistant, it was also his job to help the participants into their "costumes" which came with some awkward moments! In an odd twist, I saw my fight with MS actually helping Mike to come out of his shell a bit and conquer his fears. He was learning more about me and finding his own courage in the process, and it was a beautiful sight.

Walking impairment turned out to be the hardest symptom for most people to understand. Without a cane or a walker I looked perfectly healthy. Many people that participated in my demonstration were shocked to learn that someone who looked like me could have MS. I provided them with background information, and once they put on the high heel and scuba-flipper, as ridiculous as they appeared, it really helped them experience what my symptoms felt like and how MS can impact the body. Simply walking in a straight line can be difficult. Quick motions and sloping floors can cause me to lose my balance. I've fallen many times, particularly in airports, which is why filming at the Atlanta hub - the busiest airport in the world - was a big deal. I hated the feeling when people would turn to see me struggling to get back on my feet, wondering what was wrong with me. I'd look back at the ground like I was trying to find out what I tripped on, even though I knew all too well there was nothing there. Rushing passengers, long lines, escalators and heavy baggage combine to turn airports

into living hells for many people with physical disabilities, including so many of us living with MS.

My only regret from the airport shoot was that we couldn't get approval to film at or beyond the security gate. Instead they set aside an area for us in the atrium for our demonstration. The props were still effective and for many of the participants it was an eye-opening experience. But the controlled environment did not simulate the real and often dangerous challenges I had faced so many times when I traveled. In total, about twenty people participated in our demonstration over two days. The response made me realize that even strangers care and want to learn about serious health problems. I was hopeful that the next time they saw someone parking in a handicap spot or using a wheelchair ramp, they would remember the day they walked through an airport in a flipper and a high heel, and would be able to better understand someone who might be struggling.

Over two days we shot almost 12 hours of footage, which we had to cut down to about eight minutes. Together we scoured the raw footage piece by piece and pulled out the segments that were most insightful, humorous, and inspiring. Out of the five winning films I was the only contestant to participate in the editing process. Once again, I had a clear vision for what this film should be, and I wanted to make sure it was right on target.

The film debuted at a national MS conference in Dallas and was posted on YouTube, and the initial screening felt like a full-on film festival. I was asked to take the stage and talk about why I wanted to create the film and how I hoped it would impact the MS community. When I first developed a business plan to be able to provide live workshops, I didn't do it for myself. It was a new and

unique way to help other people facing this disease. Even if it only affected ten people, those would be ten lives that could be improved because of our efforts. After the screening, people stopped me everywhere: in hallways, the bathroom, and at other conference events. Women often told me they also struggled to help their husband and family understand what they were going through. There seemed to be a critical need for what I was doing. The film helped people explain their condition in simple and understandable terms. Part of me expected the warm response because I had already seen how effective the demonstration and props were in helping Mike understand my symptoms. What I didn't expect was the longevity of the film. Years later it continues to be presented by MS groups across the country for fund raising and educational purposes. There are now *MS Experience* tents with demonstrations using similar props at annual walks in cities including Denver and Seattle. I still hear from someone about once a week saying they were influenced by the film. After a few years even Matthew acknowledged the impact of the film and admitted he was glad I stuck to my guns and pushed him during production.

At the conference in Dallas I met an older couple who had been facing these challenges together for decades. They were still so in love. It gave me a new sense of hope for my future with Mike. Just like the example I was trying to set for others, I thought, "If they can do it, so can we." Mike was starting to look at me like he used to in high school and college. If I could face MS, what else could life throw at me? He saw my renewed confidence and the strong woman he first fell in love with. The film production experience turned out to be a major spring board. It opened the door for me to build on the platform I had developed and reach new audiences with live workshops across the country which took my efforts to a

whole new level. After the film was released I set out as an MS ambassador, using the props to train patient advocates and family and friends of people with MS to help them understand MS symptoms.

A few live workshops in particular stood out to me. In Chicago, I met with a group of pharmaceutical sales representatives who were learning about the MS patient population in order to market a disease-modifying therapy. I was scheduled to present in a conference room at a hotel that was supposedly right around the corner from the airport. Traveling with a big bag of props, I arrived and soon realized just how out of touch the trainees were. Yes, the hotel was relatively close to the airport, but when the meeting organizer told me to just walk over, he clearly wasn't considering how my condition affects my mobility. What probably would've been only a ten minute trip for someone without walking difficulties, instead took me 40 minutes. By the time I dragged my bag to the conference room I was wiped out and irritated. The conference room itself was filled with luggage and was hard to navigate. I spoke for about 20 minutes about my personal experiences with MS, then set up for my demonstration and asked for a volunteer to try the props. When one trainee volunteered to walk around the room in a high heel and scuba-flipper, he asked everyone to move their luggage to the side and out of his way. I stopped them. At an airport, in a mall, or at any other crowded public venue people often don't move their belongings for me or anyone else, even for someone with a visible disability. Part of the challenge of traveling with MS is dealing with obstructions that most people can easily avoid. That moment was a game-changer for the group. The trainees grew quiet as they watched the volunteer stumble around the conference table and trip on nearly

every bag in his path. "By the way, can you imagine carrying a bag or other things and walking a mile to an airport hotel for a meeting when your walking is like that?" That seemed like a fitting way to end the workshop.

The focus of much of my work as an ambassador has been on adults, but it's another world entirely when meeting and learning from children facing MS. I had the chance to interact with families at the University of Alabama at Birmingham Center for Pediatric Onset Demyelinating Disease. Many of them had siblings there who didn't know what MS meant and how it affected their brothers and sisters. I went through my full demonstration with props and asked for volunteers who didn't have MS. One boy told me the gloves weren't too bad even though he was proceeding slowly through the tasks I gave him. Then I raised his anxiety level by shouting:

"You have to hurry! The bus is coming! Grab your books! Button your shirt, get your shoes on!"

When I applied the pressures of daily life, the boy looked at his brother who had MS and said, "Now I know why you're always late for school." I saw the relief on the faces of other children with MS in the audience. They were so happy to finally have someone understand. I also met ambitious kids who thought that maybe their dreams might not come true - and I saw myself. Some of them wanted to sing and perform. I tried to show them that they did not have to give up, and I saw sparks of excitement and inspiration. Parents also looked at me and realized a diagnosis does not have to mean the end of their dreams for their children as well. These moments will stay with me forever.

On a visit to an elementary school in Alabama, I was joined by a local news station and had a tough experience that reminded me that in all this good work there would still be challenges. The students listened to what I had to say, although I'm not sure it made much sense or had a significant impact at first. Some probably thought it was silly. But as I ran through my demonstrations with the props, they started to understand that I was dealing with real physical challenges, and they showed genuine compassion. They asked questions and compared my challenges to things they had seen in fellow classmates. The students also made a connection that gave me new insights, comparing the effect of MS on the nervous system to a video game that won't work if it isn't plugged in. It's an analogy that I've found very useful in talking about MS with children.

Unfortunately my visit to Alabama closed with a harsh reminder that I still had MS and would have to continue to deal with changes in my symptoms. We left the elementary school and headed to a local mall to set up an MS experience table for shoppers. After the demonstration, another TV station sent a crew to interview me as part of their special coverage during MS awareness month. It had been a long day, I was tired, and was suddenly unable to speak coherently. The camera was rolling and everyone was looking at me, but the words just wouldn't come out. I was talking gibberish, so much so I wasn't even able to apologize. The fact that MS can affect your voice has always been a nightmare for me. This episode lasted only about 30 minutes, but it shook me. I was only "back to normal" after I had a chance to sit down and relax.

In Florida in the spring of 2008 I hit another roadblock. I was doing a workshop at an MS event when I met a couple that

reminded me so much of me and Mike. The husband had trouble understanding why his wife's symptoms were so hard to manage. I asked him to put on the dish gloves along with a high heel shoe and scuba flipper on opposite feet. Then I had him pull some loose change from his pocket. He dropped the change and struggled to chase the coins that rolled away. Then he tipped over while trying to pick them up off the ground. His wife smiled and gave a sigh of relief and satisfaction that I had seen many times before. Finally, her husband truly understood what she was going through. A news reporter saw my demonstration at the MS event and asked to film a segment with me at a local mall. She tried on the high heel and scuba-flipper, but was completely unnerved by the stares she got from people passing by. She commented that many people were not helpful and even rude when she asked for help picking up a piece of paper. Overall the demonstration was again very effective, but I faced reality at the airport on my way home. While standing in line at security I had that walking-through-oatmeal feeling in my legs and started to panic. I was sure my legs would give out, and needed to get to the front of the line. People rolled their eyes and glared at me as I cut in line to reach the security agent. I had to tell them something was wrong. It wouldn't be long before my legs were completely numb. They called for a wheelchair, helped me get my shoes and belt off to get me through security and wheeled me to my gate. I felt stares from people around me who saw someone who "looked fine" being escorted in a wheelchair. That wasn't how I wanted to roll! When I landed in Atlanta I was again met with a wheelchair. Mike was traveling on business and fortunately our friend Dan was able to pick me up. Dan knew I couldn't drive, but was shocked to see me using a wheelchair. He had to physically help me into the car and into my house; he didn't even want to leave because he was so concerned. I downplayed

everything, but in reality I was terrified. I had to stay downstairs until Mike came home because I was frightened about navigating the stairs on my own.

This is around the time when my walking was most severely affected by MS. It took a month of physical therapy for me to regain feeling and strength in my legs after the incident in the Florida airport. I was fitted for forearm crutches, and Mike and I considered moving to a one story ranch home so I wouldn't have to deal with climbing stairs. Whenever I had flare ups my walking was affected and I was forced to abandon doing anything active. The unpredictability was often disappointing and even heartbreaking. I was afraid I would miss out on so much, but I was determined to move forward.

Mike and I talked frequently about having kids together, until my diagnosis. For a long time after that we did not bring it up. We were focused on our careers and enjoying our time together as newlyweds. Internally, I thought often about how MS might affect my dream of starting a family. I would give up any chance to perform to start a family with Mike. Children gravitated to him constantly. He would make a great father, but could I do it?

Mike and I would babysit my cousins and my niece and nephew together, and it was clear we made a great parenting team. It was almost like a make-believe family. I've never seen a man take care of children with so much love. For him it seemed easy and effortless. After we were married I knew Mike wanted us to have children, and I wanted so much to make that dream come true. I just didn't know if it was safe for me. I was taking a disease-modifying therapy and we would have to plan for me to stop treatment in order to get pregnant.

In 2007 I had started seeing an MS specialist named Dr. Chris LaGanke. We met through an MS support group in Alabama. I was asked to perform at a holiday MS event he attended and brought copies of my new album. Dr. LaGanke loved my performance and kept a few copies of the album to distribute to his patients and play in his office. When Mike met Dr. LaGanke and heard him speak he was convinced I needed to switch to him as my neurologist. His office was three and a half hours away from home and it was an impractical decision, but Mike insisted. Many neurologists don't specialize in MS, and Dr. LaGanke had an expertise that was beyond anything Mike and I had experienced in the past. His mother had MS, and he understood what life with MS was like. Mike even called and had my records transferred before I made a final decision!

When it comes down to it, the decision to work with Dr. LaGanke led to the birth of my son. I know that doesn't sound quite right, but it's true. Mike and I were hesitant and afraid before Dr. LaGanke stepped in. He told me he would do everything in his power to make sure my life was status quo. He truly wanted to help me manage my personal symptoms. Our shared goal as doctor and patient was for me to live my life to the fullest despite my MS.

During a routine visit with Dr. LaGanke in 2008 it was clear my disease was progressing. I had just recovered from the episode in the Florida airport, and while I was more determined than ever to conquer my symptoms, my body wasn't cooperating. Dr. LaGanke told me I was developing neutralizing antibodies that were hampering the efficacy of the disease-modifying therapy I was using. He was surprised by an increase in activity on my MRI and saw concerning inflammation. I told him about the time when I

was unable to speak on camera and that I had recently needed to use a wheel chair in the Florida airport. Based on my MRI, Dr. LaGanke thought I was at risk of experiencing even worse relapses, and he suggested it was time to switch to a more potent disease-modifying therapy.

In spite of the MRI, no matter the need for a stronger disease-modifying therapy, Dr. LaGanke wanted to know why Mike and I weren't starting a family of our own. Then he asked me, as straightforward as it gets, "What are you waiting for?" For the first time in my life I shared my fear of being a parent with MS. I told him how frightened I was about passing MS on to my children and questioned my ability to take care of a child. How could I when there were times I could not take care of myself? Would having a baby put an even heavier burden on Mike? What would happen if I go off therapy for a few months? What if it takes me a long time to get pregnant? What if? What if? What if?

Dr. LaGanke was the father of seven children, and he wouldn't have a part in any of my worries. He told me that if Mike and I were ready, "We'll make it happen." He promised to do everything he could to keep us safe. I'd have to stay off treatment for 30 days before it was all right to start trying, and then he would give me IV steroids to calm any potential inflammation. He also said that many autoimmune diseases become less severe, or go into remission during a pregnancy. He said the decision to have a baby was ours and it was within reach.

A few weeks later I spoke at another MS event in northern Florida. I told the audience that I had one major dream left unfulfilled. I wanted to be a mom. They all stood and cheered when I said I hoped to be back the next year to tell them my dream had come

true. Following my appearance, the person who had arranged for me to speak that day approached me and talked about a DVD that had been produced by a patient advocacy organization. It was a story about a couple that wanted to conceive a child in spite of an MS diagnosis. She sent the DVD to me at home, and I watched it with a waterfall of tears streaming down my cheeks. They followed the whole pregnancy, from the decision to try to conceive to birth. I realized the power of patient advocacy and saw how intense the impact was on my own life. It wasn't just about raising money for research. It was about bettering someone's life, helping them achieve their goals, and gaining strength and courage from others.

The DVD combined with Dr. LaGanke's reinforcement changed my life. For the first time I believed I could do it - and the time was right. Soon after I watched the DVD Mike and I put our plan in place to try to have a baby. Dr. LaGanke gave us the green light, and soon I was pregnant.

At first I saw the quick conception as a sign that I could do this. I had no fears and was confident I could take on the challenge. During the first few months I felt amazing. My symptoms subsided, but as they did some new realities set in. I started to think less about pregnancy and birth and more about raising a child and the things I would have to deal with as a mother with MS. I thought about climbing up and down the stairs carrying a newborn, and going for walks outside. Mike helped me order baby slings and strollers. I needed whatever tools were available to help me carry a child while remaining hands free so I could manage my own balance and coordination. I ran through so many scenarios in my head, like how I would bathe a newborn, carry him around a

grocery store, teach him how to walk, and take him to the playground. Of course it was too late for doubts. This time I could second guess myself as much as I wanted to, but it wasn't going to change the end result. Mike and I were having a baby!

In May 2009 I gave birth to Kingston. My baby boy was as precious and awe-inspiring a gift as I ever could have imagined. My biggest dream had come true and the MS monster couldn't stop this *Wonder Woman*. I was a mom! After Kingston was born, I had three days of IV steroids again to help calm any active inflammation that might occur. For the first few weeks getting up in the middle of the night was tough. Thanks to my poor night vision, Mike offered to handle the early AM wake ups. By four weeks in, Kingston was only waking up once in the middle of the night, and by six weeks in he was sleeping all night. We were so blessed. He was a relatively easy baby, and still I was exhausted. That was expected for a newborn mother, but there was something awkward in my caring for Kingston. I had trouble cradling him while walking like a healthy mother would, and I could tell that's what he wanted. I was always afraid of dropping him, and never felt as secure as I should have with him in my arms. The first time Mike went back to work and left me alone with Kingston I was petrified. My family wasn't around. My mom and my mother-in-law visited for the first two weeks of Kingston's life, but each went back home to New York soon after. I tried not to focus on what I couldn't do, and wanted to thrive on the things I knew I could accomplish.

Bath time was especially scary. Mike and I decided we didn't want to bathe Kingston in the sink, but the bathtub presented many challenges. Leaning over the tub while trying to manage the weight

of my dear child by myself wasn't easy. It wasn't just his weight that caused my struggle, but the difficulty I had balancing on my own body, coupled with his slippery squirms in the grasp of my unsteady arms. I'd often wait until Mike got home from work so we could bathe Kingston together. I wanted so badly to be able to do it on my own during the day so Mike could come home and relax. And it wasn't just bath time when I needed Mike's support. Snaps on Kingston's clothing and changing his diapers presented challenges as well. It was all so difficult when I couldn't feel my fingertips. I now realized I should have asked folks to change a diaper during those mall demonstrations! I was figuring out how to be a mom with MS, and was worried about whether I would be able to keep up with Kingston as he got older.

Six weeks after Kingston was born I visited Dr. LaGanke for a routine exam. Everyone at the office was so excited to meet my little boy. I went through another MRI and together we read the results immediately. "You're lighting up like a Christmas tree," Dr. LaGanke said, which means that there were active lesions appearing on my brain and spine. In spite of the IV steroids that I was administered just a few weeks earlier to prevent inflammation, my MS was gearing back up with a vengeance. With so much disease activity it was a wonder that I wasn't suffering from more intense symptoms. I had lost track of the number of lesions at this point. Dr. LaGanke again suggested I change disease-modifying therapies, but I wasn't comfortable with the risks associated with some of them. I started back on my old therapy and denial crept back in. It was hard to admit I needed something stronger to control my disease.

The following spring, about a month before Kingston's first birthday, MS was really limiting my role as a mother. I couldn't take him out to the store because carrying him in public was so hard. I would teeter side to side and was afraid people would think I was putting my child at risk. Being self-conscious, it was easier to stay home with Kingston, which is probably how he learned to read so fast. I also sang to him all the time and he loved to learn the lyrics. Music connected us, and it was safe. When we sang we were usually at home lying together on our sofa and I knew nothing bad could happen to him. From teething to reading, Kingston was always ahead of schedule, except when it came to walking. In retrospect I realize I probably had a lot to do with that as well. I preferred to keep him seated next to me or in a bouncer chair or playpen instead of letting him go off on his own to explore. I didn't want to have to worry about chasing him. But I also knew deep down that I couldn't keep him sheltered forever.

In April 2010 Dr. LaGanke once again discussed making some changes in my current treatments. He said it was time to take additional action to manage my disease. Another MRI showed progression was continuing, and he was particularly concerned about a large lesion on my spine that had the potential to cut off transmission completely, which meant I could lose my ability to walk for good. MS is different for everyone, and I'm lucky he spent so much time evaluating my personal symptoms. He'd have a nurse test my walking speed, then would conduct the same test on his own and compare the results. After the usual small talk about Kingston and life around the house, Dr. LaGanke started talking about a new treatment designed specifically to help people living with MS improve their walking. It was one of the first symptom management drugs approved for MS patients. He seemed excited

to tell me about the latest news in MS treatments, so I listened politely, as it wasn't at all unusual for Dr. LaGanke to give me these general updates. He then told me about the dosage and associated risks, and talked about why it might be right for me.

Me? Did he say for me?

I simply nodded my head and appreciated his thoroughness, but couldn't imagine why I would need such a specialized treatment. It's not like I was in a wheelchair at this point. But I didn't say anything more. Dr. LaGanke handed me a prescription. He said he wanted to see if we could have an impact on the symptom that was currently affecting me the most and go from there. Once again the choice was mine.

The activity on the latest MRI scared me, but I was struggling to understand why Dr. LaGanke was discussing my walking issues. I didn't fully realize that he was talking about me until he handed me a prescription. My cover was blown. I had spent so many years using my performance training to cover my symptoms and was always conscious of how others saw me, and that continued after my diagnosis. It was hard to admit that I needed help with walking, and even harder to accept that people around me were noticing changes in my ability to walk. Then Mike opened up. On the drive home he told me about all the situations I avoided or times when I changed my routine to manage my walking problems. He talked about how I stopped grocery shopping and the fact that I was using the stroller for support when I was out with Kingston. He said he understood why I wasn't cooking in the kitchen as often or cleaning up after dinners. I couldn't disagree with him, but all that time I was thinking that I was just slowing down a bit. I assumed a treatment for walking issues was for people in much worse shape

than me. I didn't realize how much walking problems were affecting my life and my family's life. Despite facing the realities that Mike was bringing to my attention, I still didn't take any action. It wasn't because I was afraid of the medication or that I had doubts in what my doctor and my husband were telling me. It was the realization that starting the treatment was proof that I could not manage my walking struggles on my own. I was back on the MS roller coaster with slow struggles to climb to the top and sudden, terrifying drops down.

It took a visit to the zoo on Kingston's first birthday to help me see the truth and finally fill the prescription for my walking medication. Several family members were there and it was impossible for me to keep up with them. It was embarrassing and frustrating. My legs were so sluggish. I had to face the facts, just as I did with the way MS was affecting my career. Now I could no longer deny that it was also affecting my life at home. As I watched Kingston at the zoo that day, I realized being smart about my treatments was an important part of parenting. I needed to set an example for my son and do everything I could to fight my disease, and that meant being diligent with my new treatment.

Soon after starting the treatment to help with my walking, I became more active – taking Kingston to the pool or the grocery store and spending time cooking in the kitchen. He was already taking an active role in my MS care, telling me to take my medication when he heard the reminder alarm on my phone go off. Having a mother with a chronic illness has taught him so much about being compassionate and understanding. He's dealt with things most kids don't see on a daily basis, and it's caused him to mature faster. Suddenly I was keeping up with my little toddler.

Mike was also seeing a difference. I could maneuver around the house and handle more things on my own. I was happier about the wife and mom I was becoming. Kingston knew I had MS from day one. I hid nothing from him. We used to read a book together, "My Mommy Has MS," and soon he could pronounce "multiple sclerosis" better than most adults. He's been to every single neurologist appointment with me since he was born. At Dr. LaGanke's office he would stop and try to read posters about the central nervous system, and sometimes the nurses would watch in awe as he sounded out complicated medical terms. When Dr. LaGanke asked Kingston what he wanted to be when he grew up, he would say he wanted to be a doctor because that way he could help people walk. He watched closely as Dr. LaGanke tested my own walking ability in his office, and assumed that's what all doctors do. Kingston also learned to pay attention to my health at home, and would ask if I was all right whenever I looked fatigued. In his second year, Kingston blossomed into a confident and independent little boy. And I know that seeing his mom improving and working to make a difference was an important part of his progress.

CHAPTER 5

Discovering New Dreams

When MS hands you a setback – as it inevitably will – it’s so important to keep a positive mindset. It took me a long time to learn that lesson, but having a passion to pursue made it easier to implement. That was the case in June 2010 when my battle with MS came upon a new hurdle and music helped me face my fears.

On my birthday Dr. LaGanke called. I thought he was going to send me his best wishes - instead, he needed to talk about a recent blood test of mine that caused him concern. The new treatment for my walking was helping with a specific symptom, but my disease-modifying therapy wasn’t slowing the overall progression of my MS. This time, Dr. LaGanke insisted it was time to change my therapy to something stronger. It was devastating news to hear on a day that should have been filled with celebration, and it felt like I was being diagnosed with MS all over again. Mike and I spent the next several days in a state of disbelief, researching the options Dr. LaGanke wanted me to consider. The associated risks we read about were intimidating. That same fear and denial that plagued me when I was first diagnosed came creeping back into play, but this time I was able to change course and face reality. It was music that saved me from falling victim to the uncertainty that had paralyzed me so many times before.

As I was struggling with what to do about my disease-modifying therapy, I got a call from a radio station manager named Bruce. I had met Bruce, whose wife also had MS, when I spoke and sang at an MS awareness event in Greensboro, North Carolina just a few days before my birthday. There was something special about my

connection with the audience that night. He said his listeners needed to hear my music and asked me to send him a copy of my album. I remember being filled with pride and excitement about the prospect of my songs being played on the radio. Bruce was calling to let me know he received my album and was playing it on his program. He was excited to tell me I cracked their top hits chart! People were calling his station on a routine basis to tell him they loved my music. It was good news that could not have come at a better time. He asked me if I'd like to join him for a live interview on-air that would be broadcast worldwide, even reaching American troops in Iraq and Afghanistan. I had the chance to talk about my experiences with MS and introduced two of my songs. It was a vulnerable feeling to share my personal thoughts with a global audience, but I knew my story could help others. The feedback had an incredible impact on me, and I found the strength and motivation to follow Dr. LaGanke's advice to change therapies. I was reminded of how music had earlier offered me that same strength, in 2003, when performing "Whatever Makes Your Soul Sing" gave me the courage to start my disease-modifying therapy in the first place. Soon I was on a new therapy, and was more determined than ever to fight back against my MS.

The following summer I attended my 20th high school class reunion in New York. Now that I had addressed my mobility impairments, I felt great and was able to keep up with my old friends. Some of my classmates with whom I was closer knew what I had been through and were delighted to see me so happy again. They told me that I seemed like "the old Kristie," full of energy and enthusiasm for life. I kept them updated on my work as an MS ambassador and told old theatre buddies about performing for the MS community and connecting with people in so many

wonderful ways. I told my classmates how amazing it was to feel like a part of a community of people who accepted me for who I was. I was fighting MS with a new family. Together we were sharing embarrassing moments and helping each other find courage and hope that could support us for the rest of our lives. I couldn't imagine a better job. Becoming an MS ambassador is the most rewarding of all the parts I have played. It may not be the Broadway stage I originally planned to take by storm, but I believed I was exactly where I was meant to be.

By the time Kingston was three, our wonderful though challenging experience having our first baby gave us hope that we might have another. It was important to Mike and me for Kingston to have a sibling. I always thought I would have a large family similar to what I experienced growing up. For Mike, it was even more important because he was an only child and longed for a brother or sister. He thought Kingston needed a buddy, a best friend. Mike focused on the important things, like amusement park rides designed for two. Based on his logic, clearly we needed an even number of children!

We already felt so blessed because things were going well with my treatment and with Kingston. I'm not sure I would have found the courage to have a second child if my walking hadn't improved the way it did. Kingston surpassed any dream I ever had about being a mom and surprised me in wonderful ways every day. He'd meet people and strike up conversations just like an adult. He was magnetic and always so happy. How could the experience be better? But we still had a desire to add another to the mix. A girl of course would be an amazing blessing. I pictured myself watching my little girl performing in the dance recitals that meant so much

to me during my childhood. Kingston confirmed our decision to proceed with his constant comments.

“If I have a baby brother or sister they can ride in the backseat with me.”

Mike and I felt it was important to discuss our plan to have another baby with my doctor, and I would advise anyone with MS who is thinking of having a baby to talk to their doctor as well. We were lucky yet again – within a few weeks I was pregnant. However, six weeks into the pregnancy I miscarried. It was a sad time but I didn't allow myself to be consumed by grief. My mindset had changed over the last few years and bumps in the road were just that. They were setbacks but they wouldn't stop me from moving on with my dreams. The next month we continued trying, and soon I was pregnant once more. The previous miscarriage led us to wait a bit before telling Kingston the news, but a few weeks before Christmas, while sitting on Santa's lap, Kingston asked for a baby brother or sister. To make sure Kingston remained excited and enthusiastic about adding to our family, we surprised him with the ultrasound and a t-shirt that said "Big Bro." We snapped some photos of that moment, which became the Christmas card we used to share the news with our family and friends. When we went to find out the baby's gender Kingston joined us.

“Is it a boy, girl, frog or robot?”

The physician smiled and asked Kingston to guess. He spent a few long minutes pondering the situation, and then finally guessed a girl. He was right! Kingston's baby sister was on her way, and he was already planning to share his toys and mentor her with all his love and affection.

Our beautiful Giabella was born in the summer of 2012. Kingston bravely held my hand during the delivery and he giggled with joy and excitement as his baby sister came into this world. His first words were, "I love her Mommy but she's kind of dirty and needs a bath." I was so much more comfortable and confident the second time around, and Mike was overjoyed. We knew we would be able to handle this new challenge and raise a wonderful daughter together. My role as parent fuels my fight against MS. My children need me, and I know that I need to be there for them. I can't just exist in passive indifference. In order to be the kind of mom I want to be, I need to remain active and vivacious. I have to keep moving forward, for myself and Mike certainly, but now so much of my drive is for our children. I remembered thinking that MS would make my dreams impossible. Instead, I channeled my inner *Wonder Woman* and am proud that I did not let that happen. In many ways my feelings now are even stronger. Now it's not just about my dreams. It's about being there to help make *their* dreams come true. I want to give them the love, support and guidance they need to be anything they want to be.

As I found new strength, of course there were constant reminders of my disease. Giabella is very strong for a tiny girl, and she's just as slippery as Kingston was in the bathtub. A few months after her birth I struggled to lift her out of the tub after her bath. She squirmed a bit and I lost my balance. As I fell instincts took over and I used my elbow to prevent her from hitting the ground. I cried out in pain. She just looked at me, wondering what all the fuss was about. I realized I needed to remain focused at all times and think about my actions carefully, even when I felt fine. Just because I had my second child didn't mean I was out of the woods.

I continued to take steps to protect my own health and started doing even more to reach out to others with MS. There's a critical need to help more people with MS focus on symptoms like walking. Many people have told me they did just what I did. They didn't want to talk to their doctor about walking problems or thought there was nothing they could do about it. As an MS ambassador I have continued to use my music and performances to help more people with MS find their passion. There is a large and wonderful community of support all across the country filled with caring and dedicated people who are always available to help others. As I made new connections, I kept my own struggles and denial in mind. There are thousands of people who are afraid to get the help they need from their doctor, a support group or even their families and friends because they think it will be a negative experience, or that somehow it will confirm what they already know but refuse to accept. I use my story to encourage anyone dealing with this disease to create their own MS family of support, because I am living proof that we can't do this on our own - and we don't have to.

One thing that continues to surprise me is that MS has taught me so much about my true character. It's not a "silver lining" and I don't want to make MS seem less frightening or challenging than it is. But I do know without a doubt that the light that shines for me today is brighter than any stage spotlight. I'm making all of my childhood dreams come true while living with MS. I wrote, recorded and released a solo album. I created and performed in a solo show. I produced a short film. I've been able to perform before thousands of people all across the U.S. And I realized my biggest dream of all: becoming a wife and mom.

Now I have a chance to come up with new dreams for myself and nurture the dreams of my son and daughter. I want anyone living with MS to understand how important it is to stop the denial. Nothing good comes of it. Hiding isn't a coping mechanism, and the longer you pretend that your symptoms are not affecting your life, the longer it will take for you to get the help you need and discover your own personal passion. At first I didn't accept the truth, avoided burdening anyone else with my pain and was afraid of showing weakness. I didn't want people to feel sorry for me. In taking my mask off and sharing my vulnerabilities, I found a greater sense of unity. Other people are dealing with many of the same symptoms and emotions. The most important thing to know is that you're not alone. Finding a support network can help so many people to overcome fear and keep dreams alive. We all have things in our life that we don't want to face, but when you do find the courage to do so you find out about who you really are.

I found my way through music and performance and sharing my story. For me, music has made it possible to join this amazing effort to help others facing MS. Music has been a companion that doesn't need anything in return from me. It heals me by triggering memories and connecting me to my own thoughts. It is so powerful, and helped me to fight for myself and my family. That is the message I most want to share – taking steps to rediscover your passion will not only help you, but can also have a positive impact on the loved ones in your life. Every one of us has an obstacle to overcome. Mine is MS. My passion for performing and singing for live audiences may sound exotic, but it breaks down to something so simple. I need music in my life because it makes me happy. People need to find out what their own passion is in life and stay focused on it. Finding your passion can be the foundation to help

build courage and strength. It could be painting, cooking, biking, volunteering or raising a family. Your dreams might not play out like you imagined they would, but if you stick to your passion, odds are you'll find yourself right where you're supposed to be. I'm so thankful to have been able to help people with music, and that's exactly what I thought about when I was a little girl singing in the bathroom mirror.

Years ago, after my MS diagnosis, I had a vision that I referred to as the "rocking chair." I pictured myself in my golden years reflecting on my life.

What if I had tried that, or challenged myself more? What could I have become if I didn't have MS?

The rocking chair was filled with regrets and abandoned dreams. But today my rocking chair vision is quite different. Now I picture Mike and myself with our children and grandkids, having sing-alongs like I used to as a child. I see myself sharing stories of a full and rich life. I will be able to look in the faces of my beautiful son and daughter and say, "I did it." I used all my God-given gifts to bring some hope into people's lives. I found my purpose, pursued my passions and made my dreams come true.

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Ms. Salerno Kent is a paid spokesperson for Acorda Therapeutics; she is living with MS and currently taking AMPYRA® (dalfampridine) Extended Release Tablets, 10 mg. AMPYRA is indicated to help improve walking in patients with MS. This was demonstrated by an increase in walking speed.

Important Safety Information

Do not take AMPYRA if you

- have ever had a seizure,
- have certain types of kidney problems, or
- are allergic to dalfampridine (4-aminopyridine), the active ingredient in AMPYRA.

Take AMPYRA exactly as prescribed by your doctor.

Before taking AMPYRA, tell your doctor if you

- have kidney problems or any other medical conditions
- are taking compounded 4-aminopyridine
- are pregnant or plan to become pregnant. It is not known if AMPYRA will harm your unborn baby.
- are breast-feeding or plan to breast-feed. It is not known if AMPYRA passes into your breast milk. You and your doctor should decide if you will take AMPYRA or breast-feed. You should not do both.
- are taking any other medicines

Stop taking AMPYRA and call your doctor right away if you have a seizure while taking AMPYRA. You could have a seizure even if you never had a seizure before. Your chance of having a seizure is higher if you take too much AMPYRA or if your kidneys have a mild decrease of function, which is common after age 50. Your doctor may do a blood test to check how well your kidneys are working before you start AMPYRA.

AMPYRA should not be taken with other forms of 4-aminopyridine (4-AP, fampridine), since the active ingredient is the same.

AMPYRA may cause serious side effects, including

- severe allergic reactions. Stop taking AMPYRA and call your doctor right away or get emergency medical help if you have shortness of breath or trouble breathing, swelling of your throat or tongue, or hives;
- kidney or bladder infections.

The most common adverse events for AMPYRA in MS patients were urinary tract infection, trouble sleeping, dizziness, headache, nausea, weakness, back pain, problems with balance, multiple sclerosis relapse, burning, tingling, or itching of your skin, irritation in your nose and throat, constipation, indigestion, and pain in your throat.

Please see the accompanying Patient Medication Guide on pages 88 - 93.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

MEDICATION GUIDE
AMPYRA® (am-PEER-ah)
(dalfampridine)
Extended Release Tablets

Read this Medication Guide before you start taking AMPYRA and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your medical condition or your treatment.

What is the most important information I should know about AMPYRA?

AMPYRA can cause seizures.

- You could have a seizure even if you never had a seizure before.
- Your chance of having a seizure is higher if you take too much AMPYRA or if your kidneys have a mild decrease of function, which is common after age 50.
- Your doctor may do a blood test to check how well your kidneys are working, if that is not known before you start taking AMPYRA.
- Do not take AMPYRA if you have ever had a seizure.
- Before taking AMPYRA tell your doctor if you have kidney problems.
- Take AMPYRA exactly as prescribed by your doctor. See “How should I take AMPYRA?”

Stop taking AMPYRA and call your doctor right away if you have a seizure while taking AMPYRA.

What is AMPYRA?

AMPYRA is a prescription medicine used to help improve walking in people with multiple sclerosis (MS). This was shown by an increase in walking speed.

It is not known if AMPYRA is safe or effective in children less than 18 years of age.

Who should not take AMPYRA?**Do not take AMPYRA if you:**

- have ever had a seizure
- have certain types of kidney problems
- are allergic to dalfampridine (4-aminopyridine), the active ingredient in AMPYRA

What should I tell my doctor before taking AMPYRA?**Before you take AMPYRA, tell your doctor if you:**

- have any other medical conditions
- are taking compounded 4-aminopyridine (fampridine, 4-AP)
- are pregnant or plan to become pregnant. It is not known if AMPYRA will harm your unborn baby. You and your doctor will decide if you should take AMPYRA while you are pregnant
- are breast-feeding or plan to breast-feed. It is not known if AMPYRA passes into your breast milk. You and your doctor should decide if you will take AMPYRA or breast-feed. You should not do both.

Tell your doctor about all the medicines you take, including prescription and non-prescription medicines, vitamins and herbal supplements.

Know the medicines you take. Keep a list of them and show it to your doctor and pharmacist when you get a new medicine.

How should I take AMPYRA?

- Take AMPYRA exactly as your doctor tells you to take it. Do not change your dose of AMPYRA.
- Take one tablet of AMPYRA 2 times each day about 12 hours apart. Do not take more than 2 tablets of AMPYRA in a 24-hour period.
- **Take AMPYRA tablets whole. Do not break, crush, chew or dissolve AMPYRA tablets before swallowing. If you cannot swallow AMPYRA tablets whole, tell your doctor.**
- AMPYRA is released slowly over time. If the tablet is broken, the medicine may be released too fast. This can raise your chance of having a seizure.
- AMPYRA can be taken with or without food.
- If you miss a dose of AMPYRA, do not make up the missed dose. Do not take 2 doses at the same time. Take your next dose at your regular scheduled time.
- If you take too much AMPYRA, call your doctor or go to the nearest hospital emergency room right away.
- Do not take AMPYRA together with other aminopyridine medications, including compounded 4-AP (sometimes called 4-aminopyridine, fampridine).

What are the possible side effects of AMPYRA?

AMPYRA may cause serious side effects, including:

- serious allergic reactions. Stop taking AMPYRA and call your doctor right away or get emergency medical help if you have:
 - shortness of breath or trouble breathing
 - swelling of your throat or tongue
 - hives
- kidney or bladder infections

See “What is the most important information I should know about AMPYRA?”

The most common side effects of AMPYRA include:

- urinary tract infection
- trouble sleeping (insomnia)
- dizziness
- headache
- nausea
- weakness
- back pain
- problems with balance
- multiple sclerosis relapse
- burning, tingling or itching of your skin
- irritation in your nose and throat
- constipation
- indigestion
- pain in your throat

Tell your doctor if you have any side effect that bothers you or that does not go away.

These are not all the possible side effects of AMPYRA. For more information, ask your doctor or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088.

How should I store AMPYRA?

- Store AMPYRA at 59°F to 86°F (15°C to 30°C).
- Safely throw away AMPYRA that is out of date or no longer needed.

Keep AMPYRA and all medicines out of the reach of children.

General Information about the safe and effective use of AMPYRA

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use AMPYRA for a condition for which it was not prescribed. Do not give AMPYRA to other people, even if they have the same symptoms that you have. It may harm them.

This Medication Guide summarizes the most important information about AMPYRA. If you would like more information, talk with your doctor. You can ask your pharmacist or doctor for information about AMPYRA that is written for health professionals.

For more information, go to www.AMPYRA.com or call 1-800-367-5109.

What are the ingredients in AMPYRA?

Active ingredient: dalfampridine (previously called fampridine)

Inactive ingredients: colloidal silicon dioxide, hydroxypropyl methylcellulose, magnesium stearate, microcrystalline cellulose, polyethylene glycol, and titanium dioxide.

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This Medication Guide has been approved by the U.S. Food and Drug Administration.

AMPYRA® is a registered trademark of Acorda Therapeutics, Inc.

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MXDAS® is a registered trademark of Alkermes Pharma Ireland Limited (APIL).

U.S. Patent Nos.: US 5,540,938; US 8,007,826; US 8,354,437; US 8,440,703; and US 8,663,685

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About the Author

Kristie Salerno Kent was diagnosed with MS in 1999 shortly before marrying her high school sweetheart, Mike. She spent years in denial, using her theatre training to cover symptoms and pretend her health was not an issue. She took an office job and stopped pursuing a career as a performer. It wasn't until she rediscovered her passion for music that Kristie found the courage to face MS.



After deciding to face her problems head on, Kristie recorded and produced her debut solo album, "Believe." Writing the album was a source of inner strength for Kristie during her day-to-day struggles with MS. She also produced and directed "The Show Must Go On," a short documentary designed to help others understand the emotions and physical symptoms associated with MS. Kristie has since fulfilled her biggest dream of becoming a parent. Her son Kingston was born in 2009 and her daughter Giabella was born in 2012. She has spent the last several years performing across the U.S. and hopes to inspire others living with MS to find the courage to continue following their own passions.

DREAMS

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Please see Indication and Important Safety Information on pages 86-87. Please see Patient Medication Guide on pages 88 – 93. AMP5573

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