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MOMENTS OF VICTORY, MOMENTS OF CHANGE: Stories of Perseverance and Quiet Courage

By Dorothy Hill Baroch

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An abstract painting with a rich, textured background. The colors are vibrant and varied, including shades of purple, pink, orange, yellow, and teal. The brushstrokes are visible and expressive, creating a sense of movement and depth. The overall mood is one of energy and transformation.

*Moments of
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Moments of
Change*

Stories of Perseverance and
Quiet Courage

DOROTHY HILL BAROCH, M.A.

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CHAPTER FOUR

One Tough Old Broad Marge Hays

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As a septuagenarian, Marge Hays parasails, swims, boxes, snorkels, zip lines, and rides horses. That is quite an accomplishment for any able-bodied person. For a risk-taker like Marge, who has Spina Bifida, that is a major achievement.

Marge was born in 1947 at the Cleveland Clinic in Ohio. The doctors told her parents, Mary Louise and Francis Hays, that their little daughter would be mentally retarded and would never walk—if she lived. After explaining her medical problems, the doctors recommended that the family leave the baby at the hospital to die.

“Fortunately,” Marge says, “my mother saw things differently! She took me home and expected me to live. And I did, and I do—with enthusiasm.”

Her diagnosis included conditions secondary to Spina Bifida: a series of spinal and hip malformations, little feeling in the bottom of her right foot, and no feeling in her toes. She can’t always tell where her foot has landed. Because of that, three toes were amputated after being damaged. At birth, Marge’s vertebrae were fused to each other in a strange pattern. A couple vertebrae were fused, then a normal one, then more fusing. Now, in her older years, they are almost all fused together. She has no tailbone and only a partial right hip bone.

Childhood was difficult, not only for Marge but also for her parents and her sister, Mary Frances. She struggled to walk, since her right foot had no feeling. The doctors told her family that she must be protected from falling, because she had no tailbone. They put her into several layers of diapers to give her more padding and

spent a great deal of time holding her hands as she learned to balance. Eventually she could walk unaided, which led to more learning experiences.

“I was expected to perform all the things a non-disabled child could do,” says Marge. “I learned to put my own toys away, feed myself, make my bed, set the table and do other chores. “Mary Frances helped me a lot when I was young. She played with me, babysat me, towed me around the neighborhood in a little red wagon and, one day when I was about 5, she knocked a boy off his bike after he pushed me to the ground. As my Big Sister (she is 9 years older than I), she always watched out for me.

“At the end of kindergarten, the school wanted to hold me back because I couldn’t walk on tippy toes or backwards. My mom went to the school and had a ‘talk’ with them about my disability, explaining it was a miracle that I was alive.” Marge was promoted to first grade after that conversation!

The relationship between the sisters was not always amicable. “When I was a teenager, we had to share a bedroom and our schedules were completely opposite of each other. We fought constantly—I had to get up early in the morning and get ready for school, while she had to sleep during the day to be ready to work her night shift as a Reservations agent for United Airlines. Mary Frances’s benefits from working 30 years with United allowed me to travel extensively, for which I am very grateful!”

Marge had some reading issues during her school years, despite being an avid reader. After taking remedial reading classes in elementary school and high school, she completed a Bachelor’s Degree in Teaching, with a second major in Spanish. She added a Master’s Degree in Elementary Education and an Education Specialist’s degree in School Facility Planning to her list of credentials. Marge taught for 25 years in the Denver, Colorado Public Schools, one year in Lansing, Michigan, and

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Her mother, Mary Louise, searched for new and creative ways her daughter could complete her daily tasks. Marge was horse crazy and demanded a chance to learn to ride. Her mother found a stable that would teach her everything about horses from the ground up, hoping that she would lose interest after mucking out stalls. That strategy didn't work. Mary Louise finally had to agree with her strong-willed child and let the owners of the stable teach her to ride. She continues to ride to this day, even after a painful fall at age 67. "I shattered my clavicle and needed surgery, a plate, and seven pins. When I fell, my horse stopped immediately. She looked down as if to ask, 'What are you doing down there?'"

Instead of complaining or giving up riding, Marge posted a gratitude note on Facebook, thanking family and friends who helped her through the trauma. "I'm just glad I didn't slip on ice in the driveway and do the same thing. At least I was having fun at the time." That's a typical Marge Hays scenario—doing what she enjoys, despite the potential pitfalls.

Marge has been physically active all her life. "When I accomplish a challenge—physical or otherwise—I feel successful and confident. Why do I take the risks I do? I believe it's because I want to prove that I can do what people say I can't do. I want to prove others, and myself, wrong.

"I dated regularly and was married twice. I never had a boyfriend who was put off by my physical problems. My husband, Doug, helps me hike and I help him swim. I cook and clean, and he goes down the ladder into our crawlspace to get things from storage, or up ladders to paint. He does all the vacuuming because it hurts my back. We each do the things we can do. Our life is give and take, not just *take* because 'poor me, I have Spina Bifida and can't do stuff.'

“People have no idea how hard I work to look this good,” she says with a smile. “I work out in a gym, using t–rex straps, planks, weights, leg and pull–down machines, followed by shooting hoops. I have one rest/relax day, one stretch and mobility day for balance and core work, two swim days, and one day to take a walk outdoors. “All this for an aging person with Spina Bifida,” says Marge. “I’m getting stronger every day.”

Despite constant struggles with insurance companies, government agencies, and medical personnel to get the help and support she needs as a person with a major disability, Marge continues to advocate for herself. Her insurance company refused to pay for orthopedic shoes because she doesn’t have diabetes, citing Medicare rules. After fighting with Medicare for more than a year, she decided to discontinue her efforts when she was informed that the next step was Federal Court. Marge hoped to convince Medicare that Spina Bifida is a cause of neuropathy but was unsuccessful.

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“As someone with Spina Bifida, I learned early on that if you fall, you must get back up. Sometimes you’re lucky and there is someone to help but usually you must do it yourself! This philosophy has helped me throughout my life and not just with the actual physical falls—of which there were many. It gets ‘old’ sometimes, with all the surgeries and other problems, but I don’t believe in being bitter or whiny. Everyone in the world has some

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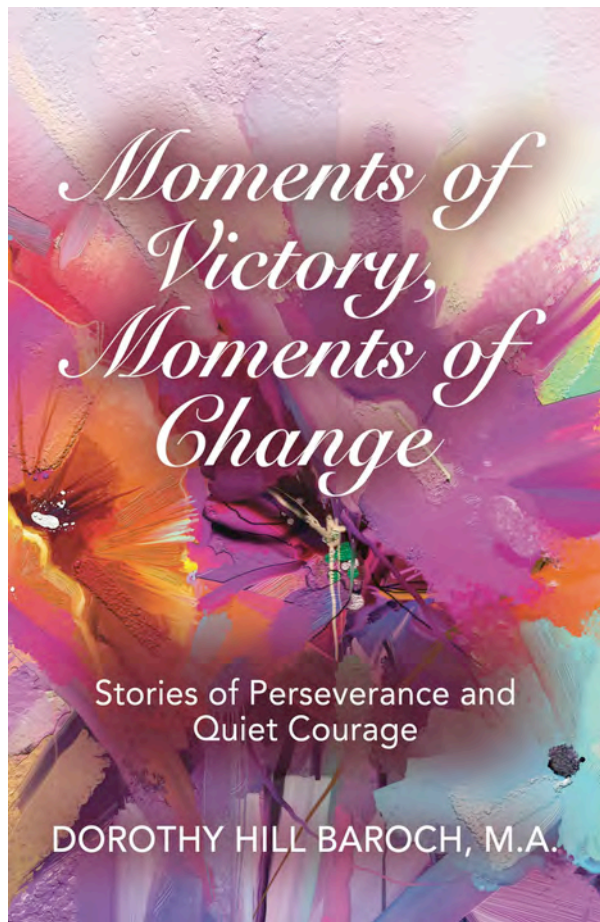
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“Although Mary Frances and I were always friendly, after our mother died in 1975, we became much closer. She was in a terrible car accident in her 50s—rescuers had to cut her out of her completely demolished car. Multiple breaks to all four limbs left her in a coma for 10 days and in the hospital in traction for six months. I have no idea how she survived all this. Since the accident, I have had more and more responsibility for her, even though I am in my 70s and she is an octogenarian—both of us getting closer to old age.

“I have a lot of control over what happens to me. Sure, I didn’t ask for Spina Bifida, but I have it and all the issues it includes. I take what I have and go for it, no holds barred. I take care of myself. I do the things daily that I need to do to keep healthy, and that means a lot more than swallowing a bunch of vitamins.

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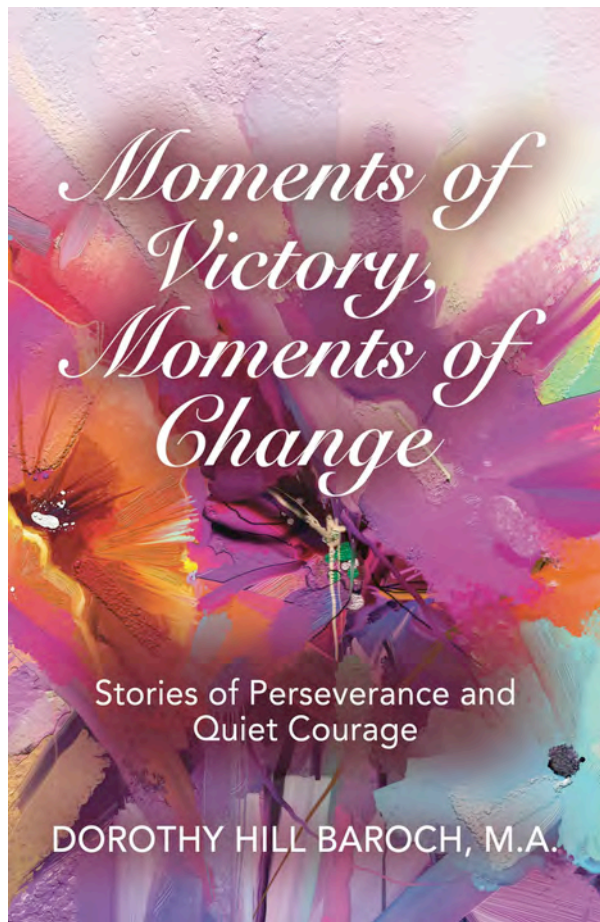
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