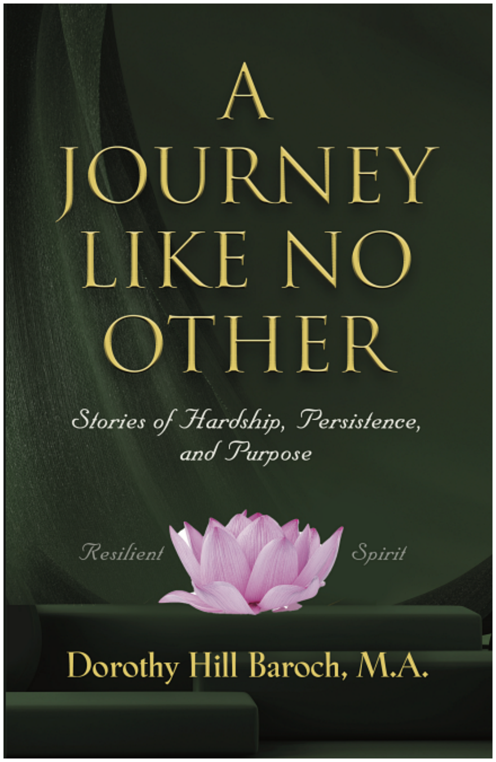

Each chapter in A Journey Like No Other highlights the unique approach to life taken by individuals and families who face challenging situations, situations that require persistence, creativity and belief in themselves.

A Journey Like No Other:
Stories of Hardship, Persistence and Purpose

By Dorothy Hill Baroch MA

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A JOURNEY LIKE NO OTHER

Stories of Hardship, Persistence, and Purpose

Resilient Spirit

Dorothy Hill Baroch, M.A.

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A Journey Like No Other: Stories of Hardship, Persistence, and Purpose

is dedicated
to the individuals who daily take risks,
who go where there are no guarantees,
and who stretch themselves to new heights,
even if it means being uncomfortable.
The road less traveled is sometimes fraught
with barricades, bumps, and uncharted terrain,
but it is on that road where one's character is truly tested.
*Katie Couric**

Think beyond restrictions.
Understand, dare, venture to lead
and to participate in all things good,
seeking to assess and cross over the trap of mental slavery.
Tanko Ahmed, Ph.D.

*Paraphrased from Katie Couric. (n.d.) AZQuotes.com
Retrieved June 05, 2023 from
AZQuotes.com Website

Note: The Dedication contains excerpts from comments by Katie Couric and Dr. Tanko Ahmed.

CONTENTS

CHAPTER THREE:
“A GUIDING LIGHT”

Written by Jennifer Fitz-Roy
Edited by Dorothy Hill Baroch

I was born with spina bifida lipomeningocele L1-2 in 1984 and, before my first birthday, had undergone an operation for tethered cord as well as a clubfoot casting. Most of my later surgeries were orthopedic and tethered cord.

Growing up with spina bifida, I spent a lot of time indoors. I had endless medical appointments, surgeries with lengthy hospitalizations, and recoveries that left me with precious little time to go outside and play. And once I was outside, getting around was difficult. The highlights of my year were my family’s beach trips in the summer. I’d stay in the water for hours, relishing the freedom of movement and pretending I was a sea creature whose home was the ocean. Often, I’d get in the kayak and feel the boat move underneath me as my sturdy arms propelled the oar through the water. I felt so strong and capable doing that, whereas the weakness of my legs often left me feeling inadequate. I soaked up the warmth of the sun on my skin and I played with my parents and cousins. I was happy, connected, and free.

Moments like these gave me hope and inspiration for my future. I struggled socially throughout middle school and high school, and I hated being different than everyone else. But I had the deep, secure, unconditional love and support of my family who fought for accessibility and my educational rights within our public school system. I learned to see the beauty in my differences, realizing that without them I would be a completely different person. When I was fifteen, my father was diagnosed with an aggressive cancer and passed away several months later. I was devastated; however, I continued to press on, gaining strength from the adversity. After high school graduation, I moved four hours away from home to attend school out of state.

Going to college opened up so many doors for me and I took new risks. I began writing, organizing, and public speaking with national disability groups. Yet the most unexpected risk I took was a camping and whitewater rafting trip with an organization that had knowledge and experience in adaptations for people with disabilities. I'd never done anything like that before, and indeed, I didn't know something like that was even possible for a wheelchair user like me. But it was, and I did it, and it was scary. I was hooked! I loved being outdoors with other people and trying new things. I loved that something I thought impossible was actually possible with some creativity and hard work.

I started to seek out other opportunities in my region for disabled people to get active and be outdoors. In high school, I had done a lot of swimming and used the indoor upper body rowing machine to try to stay in shape. Next, I began handcycling outside on the roads! I built up my endurance and eventually completed a 100-mile ride over three mountain passes in the White Mountains of New Hampshire. I learned how to cross-country ski, how to downhill ski, how to waterski, how to sea kayak, and how to canoe. I went on weeklong kayak and canoe camping trips in Lake Superior, the Boundary Waters, Yellowstone Lake, and so many beautiful, remote places I thought I'd never have the chance to see because I was born with spina bifida. I've literally had an entire world open up to me and I no longer place limits on myself or others. Being in the outdoors creates bonds with others in a truly magical way. It forces interdependence and problem-solving while simultaneously inspiring awe and wonder and humility.

Although my physical and mental health has improved so much from adaptive sports and outdoor activities, I'm not immune to all of the effects of spina bifida or other life challenges. After my mother passed away, very unexpectedly and traumatically, my mental health declined and my participation in the activities I loved started to decline as well. I struggled to stay connected and engaged and my depression made it hard to reach out. I needed an activity I could participate in with other people on a regular basis, and then train on my own.

I finally connected with the open para (adaptive) rowing program at my city's boathouse, and began winter training on a rowing machine for several months before rowing outside on the water in a single scull (a one-person boat). I never considered myself a competitor in any sport, but I had strong back muscles and I was determined. And I won my first race. On the water, I struggled with the stability of the boat, given my muscle imbalances and scoliosis caused by spina bifida. But I kept putting the hours in, working on my technique, going to camps and races, and showing up, even when it was scary or hard. Sometimes, I would grow frustrated when a more experienced teammate in a single alongside me would pass me but, when I took the focus off of her and focused on my own technique, I soon became more experienced and stronger, rising to her level of competence.

Rowing is difficult. It is a "suffer sport," which means pushing yourself to the point where you cannot breathe, where everything in you is screaming at your brain to stop, but you press on and force your body to keep going, and there's an incredible feeling of achievement after doing what you thought you could not. It's also very meditative and it's doing the same thing over and over again, staying focused on technique, staying focused on breathing, and paying attention to detail. It's showing up every day at practice, whether you feel like it or not, and learning to trust and depend on your coaches and teammates. It is spending time outdoors and connecting with nature.

Rowers practice in the cold, in the dark, and in the driving rain, not just in fair weather. Rowing taught me that I can push through uncomfortable moments and come out the other side okay and that I'm stronger than I think I am. I'm in control of my mind and how I respond to a situation.

Given the choice, I probably wouldn't have chosen to have spina bifida and the dozens of surgeries, hospitalizations and chronic pain that has accompanied it. Nor would I have chosen to experience the early deaths of my parents. I do choose, however, to accept—rather, to embrace—that this is the path in life that God has set out for me, and I try to walk it with joy. I don't always succeed. Sometimes I get angry, depressed, or anxious. But on the days that I do accept this path, life is much easier. For reasons my human mind does not yet understand, life is messy and imperfect. Life is filled with uncertainty, pain, and adversity and for that reason, it is also filled with sweet glimpses of peace, trust, joy, and love in a deep, meaningful way. For that, I am grateful.

* * *

Editor's Note: *In the Fall of 2022, Jen traveled to the Czech Republic to represent the USA at the 2022 World Rowing Championships. Making the national team was her primary goal and focus over the previous three years and throughout the pandemic. She trained twice a day, waking up at 5 a.m. on weekday mornings so she could walk her dog, Benson, before going to morning practice, and then doing strength training/CrossFit in the afternoons. Making the national team was a* *dream of hers, and she worked hard to improve her skills and strengths to qualify. Jen rowed the Women's PR2 single sculls, meaning that she would be in an individual boat in the para category with a fixed seat. She would use her trunk and arms to propel the boat.*

The outcome of this amazing European adventure…in Jen's words: "Yay—I survived! These past two weeks have been so difficult but if it's anything like most of my experiences in this sport it'll be worth it in ways I won't start to understand until later. There were so many cool moments—hearing my name and my country at the start, seeing my national team oars for the first time, and being at such a large international rowing event with the Jumbotrons and the huge audience in the stands cheering.

"I'm so grateful to so many, especially the para team PT @goffman who not only magically keeps pain at bay but also listens to me talk about what's on my mind, and my coach @enenoll.22 for helping me believe I could get there, taking such good care of me, and encouraging me through tough moments. I'll take some time off from rowing and then it's back at it with new knowledge and inspiration."

Unfortunately, this remarkable woman died unexpectedly in 2023, not fulfilling her dream to continue in the sport she had come to love. However, she reached a level of accomplishment that is a beacon, a guiding light for many.

Well done, Jennifer Fitz-Roy!

* * *

CHAPTER FOUR:
“AND THE DANCE GOES ON”

Written by Lourdes Mack
Edited by Dorothy Hill Baroch

INTRODUCTION

On my twenty-second birthday, I was already feeling older than my years!

I didn't have the same childhood as most other kids my age. I was constantly in and out of hospitals and rehab centers, with my body fighting as hard as my mind to stay healthy and alive. I remember the feeling of being ‘stuck’ in a hospital room multiple times. The only relief was the ability to watch the Disney Channel, especially my favorite movie, *Beauty and the Beast*. When I sang and laughed along with the movie, my mother knew I was feeling better and on the road to recovery.

I felt like I had to grow up a lot faster, partly because of all of the doctors’ appointments I had before and after the hospitalizations. My mom taught me to be as well-informed and as knowledgeable about my condition as I could be. But it was hard work, learning medical terms and procedures at such a young age.

The training in advocating for myself that my mother gave me helped as I grew older—both in doctors’ offices and at school. I started sitting in on my Individual Education Programs (IEPs) in middle school, and I realized that it was a room full of people trying to decide what was best for me *without me.* I've said this before at conferences; I have my mom to thank for teaching me that the individual who has the disability should be as involved as possible in decisions about class work or medical procedures. Because when it comes down to it, they are the ones who are going to go through those changes at school, and they are the ones who are going to have to go through those surgeries. No one knows what's best for the individual or what works best for them except for themselves…so let the individual be involved and have a say.

THE EARLY YEARS

I was diagnosed with selective mutism at an early age. While I had the ability to speak, in certain social situations I did not. My mom decided that if I couldn’t walk, we would do what was necessary to get me to talk.

When I was about six years old, I told my mom that I wanted to start acting in musical theater. She told me that I was very adamant at the time, and that this was something that I really wanted. Because I had selective mutism, she knew that if acting in musical theatre was something that I felt strongly about, then it was worth pursuing.

We began looking for possibilities. Some of the organizations would automatically say “no” m when they heard I used a wheelchair. One day, through an organization that is now called Inclusion Matters by Shane’s Inspiration, my mother found what would become my new theater place for years. She went to the location called Youth Academy of Dramatic Arts (YADA) and after an interview with my mom, they registered me.

At the last second, my mother told them that I used a wheelchair. That was not a problem for them, as long as someone else could help me up the stairs. My mother agreed and said, “OK, great, we will see you in a week.” And the rest is history. I was with this theater company from age six to thirteen years old.

When I was younger, I was never really good at expressing myself, especially when it came to a negative emotion. Being in theater gave me an escape. I wasn't Lourdes, who has a disability, uses a wheelchair, constantly needs surgeries and continually misses school. I was whatever role I had been given for that show and any worries that I might have about an upcoming surgery or doctor’s appointment would disappear during that time.

I believe that my artistic journey has gone hand in hand with how I have grown as a person. When I was younger, it was acting in musicals and theater and then eventually television and commercials that helped me mature. After that came dance. I danced for a total of six years, from age 13 to 19. I participated in two years of ballroom dance, and four years of hip-hop with American Sign Language in the routines.

When I was acting, it was me, Lourdes, escaping what was going on in my life. As a young child, I was unable to understand and fully face what I was going through and accept it. When you're acting, you're telling someone else's story, you're not you and you're showing someone else's emotions. When you're dancing, you get to tell a little bit more of your story, especially when you start choreographing your own routines. You pick the song, you pick the emotion and the type of movement and, even though there are no words, you tell a full story letting people know how you are feeling.

That's how I feel when I'm dancing because even now, in my 20s, I'm not the best at communicating my emotions. But when I'm dancing, when

I'm up on stage not saying a word—just moving—I feel like I'm getting to say everything that I can't say in words.

As I've gotten older, I have become more accepting of myself and forgiving of myself, in the sense of thinking, "I've been through a lot, but it's OK. I'm still here, I'm still fighting the good fight, and while there's a long way to go…I'm doing great."

I've gotten to a place where I want to tell *my story* through dance and theater instead of telling someone else's story.

And how will I do that?

After an initial interview, I was offered immediately—and accepted—an internship working in Orlando, Florida for The Walt Disney Company. That experience began in the Spring of 2024 and continued through February 2025. As a merchandise cast member, I received an hourly wage, lived in a villa with other Disney staff, and had numerous opportunities to experience the "World of Disney."

WHAT'S NEXT?

I am passionate about advocating for disability rights and look for opportunities to bring awareness to others, especially young people. For example, when I see teens staring at me in my wheelchair or hear them make a comment, I take a direct approach. "Hi, how are you? Are you wondering why I'm using a wheelchair?" If they seem to want to talk, I briefly tell them my story: "I was born with a birth defect that damaged my spine and I can't walk. The wheelchair has become my legs." I tell them I live independently and hope to attend a university." Sometimes the teens want to find out more, and we have a lengthy conversation.

Other times, their looks of disbelief as I pop a wheelie change to comments like, “Wow, that’s cool.”

Beyond all this, it’s hard to predict what my life will look like—from a medical, social, or employment standpoint. The more experiences I have, the more I am learning to believe in myself. The fact that I’ve worked my way through major medical challenges, and continue to learn, mature, and love life, gives me the confidence to step out on my own—but always with the loving support of family and friends.

* * *

CHAPTER TEN: “A PRAYER ON THE WIND”

As told to Dorothy Hill Baroch
by Jenni and Pukar Makani Lund

INTRODUCTION

On August 6, 2010, the United States suspended adoptions from Nepal. Jenni Lund, an American citizen from Washington State, along with 55 other American families, became stuck in the Nepal Pipeline. The U. S. government had, what turned out to be, unfounded suspicions of fraud and serious irregularities which were based on a poorly conducted 82-day investigation of 62 orphan cases. Because of this, the government postponed granting visas for all those pending adoptions, including the one for the little Nepalese boy Jenni had arranged to adopt.

Many children in Nepal are not put up for adoption—they are abandoned. A major contributor to this situation stems from the low status of women in the Nepali society, which leads to frequent abuse and abandonment of both wives and children. There are no social services and the per capita income of the average household is less than $350 a year. With adoptions halted and orphanages either closed or full to capacity, there is nowhere for these abandoned children to go. They are ignored by the Nepali government because they do not have a system in place to help them. Some children live on the street; still others die.[3]

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[3] https://housewithheart.org/aboutus/situationinnepal.html

Following the suspension of adoptions in 2010, *Both Ends Burning,* a non-profit, international adoption advocacy group, conducted an extensive investigation into the U. S. government's assertion that there was fraud. The results of the investigation determined that there was no evidence to prove the government's case.

"In the end, every child was able to go home with their new family because not a single shred of fraud was found. Nothing. Zero," said Jenni."

PART ONE

That was then….

"I started the adoption journey in 1998 on my second visit to Nepal. I knew then, that if I ever wanted to adopt a child, it would have to be from Nepal. However, had I known that I'd be filling out paperwork for seven months; waiting a year to be matched with a child; having to leave my entire life completely behind and live in Nepal for an indefinite amount of time; be given only five-days' notice to do so and then, still have no guarantee that I would be able to come home with my child—I would have said that was impossible. Yet, here I am."

After nearly four unplanned months away from home, and approximately $25,000 of unexpected costs, Jenni was able to return to the United States with her son on January 11, 2011.

PART TWO
This is now!

“Currently, I live in Central America with my beautiful teenage son. Since that time in 2011, when he was only 2 ½ years old, and we landed back in our then home of Washington State, an incredible journey has taken place. This life and journey that has unfolded is the innate expression of who he is as a human. As a child, he was insatiably curious and loved to have new experiences. As a teen, he has remained incredibly adventurous, and this inquisitive, intelligent side of him has emerged in full bloom, presenting itself in the form of a true love of travel and of learning.

“I fostered his joy for life by carrying him on my back as we hiked and biked in the forest, by hanging a rope-swing for him in the middle of our living room, and by teaching him to ‘powder sled’—a sport I invented on the ski hill behind our house. When the snow was deep, I would pull him to the top of that very steep hill, and we would ride the sled together all the way down, snow spraying wildly over our heads, screaming and laughing the entire way. The ride down always ended with “Mommy, can we do it again?” He learned to ski when he was only four and was on black diamond runs with me, in the right conditions, by the age of five. He had a love for airplanes (after all his Mommy came to find him on one), and therefore, at ages way below the ‘recommended age,’ he became quite good at flying drones. He has since become an expert at drone flying and continues to love it to this day.

“His intelligence was obvious from the moment I adopted him, and he was, at 2 ½, already quite verbose in his native language of Nepalese. He realized very quickly that I did not understand him. When we were walking around together through the streets of Kathmandu, him on my back in a baby carrier, it was a constant barrage of, '"Mommy, Mommy Tyō kē hō?"' while pointing at everything. Of course that meant, 'Mommy, what's that?' And this is the way we lived out our days stuck in the craziness of Kathmandu, while I awaited the fate the U.S. Government had placed upon us. Of course, it wasn't all chaos. There were beautiful moments with the elephants at the Chitwan National Park, his first plane ride to Pokhara where his eyes were as wide as saucers and he was gripping my hand with all the force his little body had, and visits to the gorgeous Buddhists Stupas where monks, for some unknown reason, always bowed to him in reverence. We also had our favorite Japanese restaurant where we sat on the floor together sipping tea and soup, a quiet park where we paid a fee to enter what felt like paradise to my rattled nerves, and sightseeing in various locations throughout the ancient valley.

"He faced health challenges at first, as he was malnourished, with barely any hair or nails at the age of two. He also had legs that were extremely bowed outwards, and the Medical Center in Kathmandu diagnosed him with rickets and recommended leg braces which I decided against. He had a really hard time walking when he was little and would trip or fall about every five steps. It didn't deter him, and he always had a smile on his face, even when he fell really hard. But it concerned me. Upon returning to the United States, Children's Hospital, in Seattle, Washington, ran tests and decided it was not rickets after all but yes, there was malformation that would hopefully straighten as he grew. This continued to cause problems with running and swimming and it was hard for him to play competitively without pain. We learned that sports like surfing and skateboarding were better for his body, but unfortunately his balance seemed to be compromised and he ended up with a severe concussion from skating (even with a helmet) and we had to stop that sport forever. One sport that he has picked up and has a real talent and passion for is Jiu-Jitsu. It has the combination of the physical and mental challenges that really suit him. Currently, he has been authorized by his incredible instructor in Mexico to teach children in Southern Costa Rica, where we live-part time, in a remote area at the end of a long dirt road.

"He struggled in the public school system with bullying and being misunderstood by teachers. He was often bored in class with lectures and sitting, so he would read under the table or go ahead on assignments and then be punished; a very frustrating situation. When COVID allowed us to attend school online, we never went back.

"Before COVID he attended the West Hawaii Explorations Academy. That was a truly wonderful experience. It was a Charter School that we won entrance to via lottery. It was there he thrived for the first time in a public education setting. Due to the alternative nature of hands-on learning, the excellent teachers and a more diverse group of children, he made real friends for the first time. His grades skyrocketed! He got his first round of straight A's and has never had a B since.

"This world of online schooling gave us freedom. I had chosen to raise him in Hawaii, where we were living at the time, but we have since moved on and spend most of our time in Mexico and Costa Rica. All are places where mixed race families are normal, and brown skinned people are the majority.

"He has learned to flourish in different environments and in different cultures. Though his culture was taken from him, he has learned how to adapt to, and appreciate, many different kinds of people and ways of living. Through his own struggles with his brilliant yet unique brain, he has developed a fascination with the innerworkings of our neural network and is studying hard to attend a top University where he can deepen his understanding and possibly bring that knowledge to medical school.

“Through our travels and experiences, he has learned about the medicine of plants and hopes to bridge this gap between indigenous healing and modern neurology. He has studied traditional plants with a medicine woman in Mexico, and is apprenticing online with an indigenously-trained curandera, a traditional or native healer or shaman. They provide their community with healing for mental, emotional, physical and spiritual illnesses.

“Had he been left in an orphanage in Kathmandu, I was told the best he could hope for would be a garbage collector. Many people who meet him find that he has a deep wisdom of the nature of the world and the cosmos far beyond his years. He was the youngest contributor whose work was published in a book called ***Noble Leadership in the Emergent Reality: Uplifting People, Planet and Prosperit***y. And, here he is, studying to be a leader in medicine.

“We have faced and overcome many challenges. Some we have been through together while others were lonely and personal. For my son, aside from medical and social challenges, there has been wading through the murky waters of incredible loss. The loss of a birth mother is a wound that heals slowly, if ever. The heartbreak of abandonment is another trauma that is seared deep into one’s psyche. As a young child and adolescent, he received therapy to process the pain and grief. There came a point when he thought that was no longer helpful, and we moved on from talk therapy to working with spiritual concepts and the cosmos at large in an attempt to bring understanding to a world where mothers have to make a choice to leave their babies under a bridge rather than raise them. I was told to convey the truth of this story from a young age, so he could process it as he matured. For a long time, he didn't want to even talk about Nepal, let alone visit. Now, the idea of returning is timidly emerging. Slowly, carefully, we peel off the layers in hopes of one day feeling peace.

"For myself, fighting the U.S. government as well as hiring attorneys and detectives while being trapped in Kathmandu, buried in a deluge of sound and chaos, felt like being dragged underwater. Being a new mom, in a foreign country, alone, added to this sense of barely surviving, clawing through one day at a time. Yes, I could have left my son in an orphanage and gone home, as the U.S. government loved to remind me. But that option felt worse than dying. I would never have been able to forgive myself for the irreversible trauma that choice would have caused him.

"Once I returned home, I was faced with extreme adrenal fatigue from the stress and overpowering burden of being trapped in Nepal and 'betrayed' by my government. Early on, there were many days I spent in bed, unable to move, while he stayed by my side, watching movies on his iPad, happy to just be next to his Mommy. When he started pre-school, though he loved being there, every single time I left he sobbed. I would drive away, watching him in my rearview mirror, standing in the window screaming and crying. Those tears never stopped in the few years he was there. The reality of abandonment was etched into his biology. Eventually we did find a rhythm and through careful diet, acupuncture, vitamins and herbal remedies, my energy returned and he grew strong.

"I believe this adoption was possible because it was rooted in a deep knowing that I was doing the right thing. I have learned to trust my intuition, to fight when I need to and, when things are really important, to just listen to myself. So many people told me so many different times, that I should not adopt as a single mother, that I was making a mistake and was embarking on an impossible journey of hardship and struggle. They were, simply put, wrong. And then there were those cheering for me from afar, raising money, donating, and alerting the media of our plight. I was buoyed by their love, and I do believe that the countless newspaper articles and radio interviews brought us home.

"I have learned time and time again that often the things that are our highest calling may not necessarily be easy. And that to experience the highest of highs we must intimately know the lowest of lows. The act of sitting with the pain, struggle, grief, and anger, has ultimately brought incredible joy into our lives. The hardships have been well worth every moment and are an integral part of the very fabric of our remarkable journey together. Through it, we have both learned how to face our fears, trust our heart, and adventure way beyond what we thought even possible in so many ways. Fortunately, we were able to find each other and to really, truly live a life that allows us to continue to follow our dreams."

And those dreams are coming true!

"Hi Pukar, Congratulations! You're in! Today we celebrate you. Tomorrow we'll make history."

Those were the words Jenni and Pukar received from Johns Hopkins University on December 13, 2024, at 1:59 p.m. Central Time. Early decision admissions were released, and Pukar was admitted to study neuroscience and interdisciplinary studies at his number one choice school!

His journey has been, and will be, like no other—a story of hardship, persistence, and purpose.

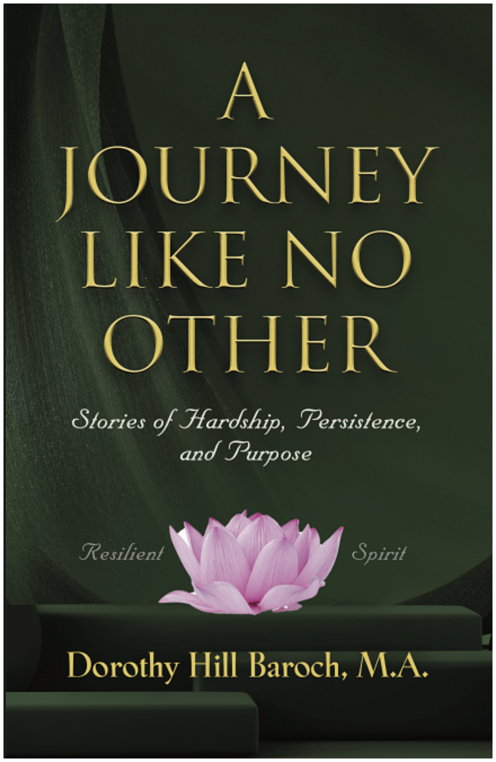
Namaste.

https://jennilund.com

Editor’s Note: Jenni explained that her desire to title her chapter, ***A PRAYER ON THE WIND***, is based on a meaningful and significant practice.

“The idea of prayers being carried by the wind is deeply symbolic in many Buddhist traditions and is prevalent throughout Nepal. Prayer flags are colorful cloths with written prayers; each representing different elements and are often used to spread good will and compassion. The wind is believed to carry the energy of the prayers to the world, blessing all beings. The deeply personal and spiritual journey of bringing my son home became my ‘prayer on the wind.’”

* * *



A JOURNEY LIKE NO OTHER

Stories of Hardship, Persistence, and Purpose

Resilient Spirit

Dorothy Hill Baroch, M.A.

Each chapter in A Journey Like No Other highlights the unique approach to life taken by individuals and families who face challenging situations, situations that require persistence, creativity and belief in themselves.

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