THE QUEST TO ENDURE

KENDELL KELTON AND SHANNON FARAR-GRIEFER HAVE NEVER MET, BUT THEY HAVE ONE THING IN COMMON—TEMPERING A TERRIBLE MEDICAL DIAGNOSIS WITH A PASSION FOR TRAIL RUNNING.

BY YITKA WINN

Shannon Farar-Griefer (white cap) of Hidden Hills, California, hugs her team before attempting her sixth finish of the Badwater 135, in Death Valley National Park, California, July 15, 2013.

LUCY NICHOLSON / REUTERS

Shannon Farar-Griefer after finishing the 2011 Western States 100, Auburn, California.

LARRY GASSAN

Kendell Kelton gets her trail fix on the Bluff Creek Trail, Oklahoma City.

ANDY CHASTEEN

IT WAS SPRING, AND KENDELL KELTON HAD RUN THIS LOOP A HUNDRED TIMES BEFORE. As she ran the nine miles around White Rock Lake in northeast Texas, she barely registered the docks, the picnic benches, the looming cypress trees, the rock doves and mallard ducks making slow circles on the surface of the water. She didn't see the way the Queen Anne's lace had bloomed since she ran here last, each flower a firework of white buds exploding out from a single green stalk.

The Dallas skyline nested on the tree-lined horizon, silhouetted against the setting sun. Dozens of other cyclists and runners and walkers were out that evening, too—but Kendell scarcely noticed any of them either. The only thing on her mind was the sentence her doctor had uttered to her earlier that day. The words she hadn't shared with another soul in the world. Not yet.

Though she'd heard of multiple sclerosis (MS) before, she knew very little about it. A few months earlier she'd turned 24. She wondered how much it had in common with muscular dystrophy, the hereditary disease she'd spent the last decade watching whittle down her father from a talented athlete to a man in a wheelchair.

She ran harder.

In a different time, in a different place—on the dusty, dry trails outside of Los Angeles, deep in the coastal sage scrub of the Santa Monica Mountains—Shannon Farar-Griefer, 54, was out for a training run as well. It, too, was a loop she knew like the back of her hand. Out in the mountains was where the mother and entrepreneur felt most herself, most free. Since she began running two decades ago, these trails had always felt like home.

As she came to a fork in the trail, she suddenly felt confused. Which way was home? From which way had she come? She wasn't sure. It seemed outrageous that she couldn't remember which way to go, but the more she looked around and weighed her options, the more confused she felt.

For the past 10 years, Shannon had been battling MS. It had wreaked some havoc on her body—unsteadiness that led to bad falls, fatigue that kept her bedridden some days. But this was the first time her mind had ever felt affected.

There was no one around on this particular run, and she didn't have a phone with her. She'd be sure to bring one next time, she thought. In the meantime, all she could do was choose a path, keep running and hope for the best.

MS is a chronic disease in which the immune system attacks healthy tissue in the central nervous system, impairing communication between the brain and the body. No two people experience the same combination of symptoms, which can include everything from muscle spasms, blurred vision and loss of balance to slurred speech, extreme fatigue, memory issues and, in about one third of all cases, paralysis.

The National Multiple Sclerosis Society estimates that 2.3 million people worldwide suffer from the disease. It comes in several renditions, the most common of which is called "relapsing-remitting." In this course of the disease, flare-ups are followed by periods of complete or partial remission. Most people with relapsing-remitting, however, will eventually transition to a more progressive form of the disease. And 10 percent are diagnosed right off the bat with primary-progressive MS, in which there are no remissions.

Shannon had gotten her first inkling that something was wrong after dropping out of the 2005 Javelina Jundred, a 100-miler in Arizona, when she felt what she describes as a "different weird pain in my legs."

"I just felt weak, with no balance. Within a couple of weeks, I was waking up every night at 2 a.m. curled up in the fetal position, in pain," she says. "I had just run all these races—Western States, Badwater, Javelina—and at first, I worried I'd maybe done nerve damage."

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She cancelled all of her upcoming races. She spent days undergoing medical tests and gathering second opinions from different neurologists. Every doctor she saw told her the same thing: she had MS. Her MS was so aggressive that new lesions were showing up in her brain each week.

Little is understood about what causes MS, though factors like stress, fatigue, infection and heat can trigger flare-ups. Although a complex menu of ever-evolving injectable drugs, infusions and oral medications can help people manage their symptoms, no true cure exists. The first suggestion many doctors offer is quite simple: exercise.

"Run more?" Shannon asked her doctor. She grinned. "Sure, I can do that."

In fact, she already had a race in mind: Badwater, the iconic 135-mile ultramarathon through Death Valley in the blistering heat of July. She had already run it once before, in 2001, as a "Badwater Double"—the entire course run twice consecutively. She asked her doctor for "permission" to run Badwater before initiating an aggressive drug regimen.

"Yes, go ahead," he told her. "But it will be your last race. You'll be in a wheelchair within a year."

A race notorious for heat so stifling it can literally melt runners' shoes might seem like an inauspicious place for someone with a heat-triggered medical condition, but Shannon learned that year that Badwater was actually one of the best places she could be. Her body stayed cooler than ever, thanks to the constant presence of a crew dressing her in icy layers, hosing her down and fanning her off.

To celebrate her finish that year, she and her husband took a trip to Tahiti. When they returned, she felt ready to begin drug therapy for her MS. But there was just one more little hitch.

At age 45, she learned she was pregnant.

Kendell Kelton was raised in the suburbs of Dallas, Texas. It was the kind of place where kids grow up under the assumption that they will play sports. Lots of them.

Shannon perseveres through extreme heat at the 2013 Badwater 135, Death Valley, California.

> “MY KIDS HAVE SEEN ME CROSS ALL THE FINISH LINES,” SAYS SHANNON, HER VOICE CRACKING, “AND I STILL WANT TO BE THEIR SUPER MOM. THEM SEEING ME LIKE THIS BREAKS MY HEART MORE THAN FEELING SICK.”

“I tried out for basketball, volleyball, soccer, and I was just awful,” Kendell says, laughing. “My dad had always been a super jock, a football and soccer player. Obviously, I did not inherit his hand-eye coordination. But I could always run.”

When her dad was diagnosed with myotonic muscular dystrophy, stress at home increased and family finances grew tight. Kendell’s mom went to work full-time to support the family—passing on a powerful message to Kendell and her sister, Rachel, about the value of hard work and perseverance in the face of adversity. Both sisters began working when they were 15, and both worked full-time to put themselves through college.

Also, as a teenager, Kendell was diagnosed with endometriosis—a painful disease affecting the uterus. This led her to suffer from bouts of heavy fatigue. Running soon became an emotional outlet: “I couldn’t control what was going on with my dad, I couldn’t control my disease, I couldn’t control work,” she says, “but I could control this.”

In her 20s, the chronic fatigue grew worse, though. At first, Kendell attributed it to the endometriosis, and when she began experiencing occasional muscle twitches in her arm, she wrote them off as symptomatic of living in Texas heat. Then, one day, she abruptly lost peripheral sight in her right eye. A trip to the emergency room pointed her to a neurologist. The ultimate diagnosis was relapsing-remitting MS.

She was presented with the usual litany of treatment options—drug and steroid therapies in the form of pills or intravenous (IV) infusions—all designed to help reduce frequency of MS flare-ups. Many of the treatments, which typically cost $4,000 to $5,000 a month, are experimental, constantly appearing and vanishing from the market. Most come with such an array of side effects that people quickly wind up on a complex cocktail of additional prescription medications to combat the nausea, inflammation, depression and other collateral damage from the heavy drugs.

At first, Kendell tried to ignore her diagnosis. But about a month later, on an otherwise ordinary afternoon, the weird tingling in her right shoulder progressed rapidly into uncontrollable muscle spasticity. Her arm burned and, as she describes it, flapped like a chicken wing. She was powerless to stop it. The pain went on for hours.

When she eventually agreed to a series of IV infusions, she sat for hours at a time in a clinic room filled with others receiving slow-drip treatments for various ailments.

LUCY NICHOLSON / REUTERS (BOTH)

Shannon cooling off at Badwater with help from her crew.

“You make conversation with the other people,” she says. “You ask someone, ‘What are you in here for?’ and they tell you, ‘I have stage IV pancreatic cancer.’ Then you feel like an asshole, because you’re like, ‘Oh … I just have MS.’”

It was at that clinic that Kendell met a woman with rheumatoid arthritis who confessed to harboring doubts about the value of the IV infusions. Kendell could relate. The chronic pain and spasticity in her right shoulder hadn’t gone away, and the infusions came with a host of new symptoms—painful bloating, facial swelling and bouts of unbearable depression.

Given the exorbitant cost of the drug therapies and their unsavory panoply of side effects, she began to wonder if there was a better way to fight her MS.

Shannon and her husband already had two sons, Moe and Ben, both approaching adolescence. The unexpected news of her third pregnancy came with a difficult decision. Carrying her baby to term would mean no drug treatments during that time, which would put her brain at risk for developing new lesions.

She would have the baby anyway. Four months after giving birth to a healthy boy named Jet, she went in for another MRI. Miraculously, the scan revealed no new lesions. Her pregnancy had put her MS into temporary remission.

For the next few years, things were good. Dutifully, she went in for MRIs every other month. She experienced occasional symptom flare-ups, but nothing that interfered too much with her life. During that time, she launched her own company, Moeben (a blend of her oldest two sons’ names), designing UV-protective arm sleeves for runners.

Kendell takes a break on the Bluff Creek Trail.

IN EARLY 2013, KENDELL DECIDED TO GO OFF IV TREATMENTS. SHE WOULD TRANSITION TO A PRIMARILY RAW-FOOD DIET, CUT BACK ON ALCOHOL, PRIORITIZE HER DAILY RUN, GET MORE SLEEP AND ESSENTIALLY DE-STRESS HER LIFE IN ANY WAY SHE COULD.

She also continued ticking off races—Angeles Crest 100, Miwok 100K, Rocky Raccoon, American River and several more Badwater finishes, shaving a few hours off her PR each time.

But when Shannon and her husband filed for divorce several years ago, the stress of that upheaval sent her MS into full-on rage mode. Fatigue came in to roost. She struggled sometimes to dress herself in the morning. She had to drop out of more of her planned races. Though she continued to run whenever she felt up to it, her doctors recommended she get a home nurse and initiate an aggressive drug-therapy regimen.

Shannon, a former fitness model, has always loved to tell her doctors, "I'm too vain for this disease." When they suggested she get a cane, she resisted, lamenting the lack of cool-looking canes available.

"Plus, after the cane comes the chair," she says jovially. "And, you know, in ultrarunning, the chair is the enemy!"

Her Instagram page is a mashup of running and trail shots, bikini-clad photos, endearing family pictures and an assortment of irreverently captioned images related to MS. Take this—Shannon photographing herself in the mirror, her hair wind-blown and supermodel gorgeous, her lips puckered duck-face style, a needle in one arm and her middle finger jammed skyward: "Doing #MS #selfies while hooked up on my IV steroid treatment the first of many over the next few days—hey I'm making the best out of a bad situation!"

Shannon wasn't sure how much benefit the potent drugs she began taking offered, and how much they might be exacerbating or even creating new problems. She felt that a year of especially heavy drug treatment she underwent in the wake of her divorce took a serious toll

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Kendell has found that trail running and a healthy diet can help her fight MS.

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on her body. Many of the IV injection sites had begun to bruise and atrophy.

When she asked her doctor why her welts weren't going away, he deadpanned, "Because they're permanent."

"No one told me that one ahead of time!" she says.

Against the emphatic urging of her doctors, she's taken several breaks from her drug regimen over the last couple of years. In hopes of managing her symptoms through diet and running alone, she focused on preparing fresh foods from her own organic garden.

"I'd rather decline with dignity, without putting toxic stuff in my body," she says. But one day at home last year, she started gagging, unable to swallow or breathe properly. Her son Jet, then 8 years old, came running over. Gently, he rubbed her throat and told her, "Mommy, it's going to be OK."

At the emergency room, the doctor looked at her from beneath furrowed eyebrows. "Your heart rate is at 40," he said, "your blood pressure is perfect, and your heart is in great shape. Are you an athlete?"

She smiled.

For Shannon, though, these have been the most difficult situations—her kids seeing her sick. "They've seen me cross all the finish lines," she says, her voice cracking, "and I still want to be their Super Mom. Them seeing me like this breaks my heart more than feeling sick."

Her doctor insisted she go back on aggressive drug treatments to combat her increasing breathing issues. The doctor added, "The path you're on, with breathing and swallowing problems—it's toward the end. You may need to get a feeding tube soon."

"But," he added, "your body is also very strong, physically. Most people are in a wheelchair before they get to this stage. Whatever you're doing, keep on doing it."

No one ever needed to tell Shannon that twice. When she left the hospital that day, she called up race director Jamil Coury.

"Can I come run Javelina this weekend?" she asked.

In her 20s, Kendell's love for running flourished. She completed her first road marathon and felt hooked. In 2008, a fellow runner named Charlie Brickman invited her to crew him and a few friends at the Rocky Raccoon 50- and 100-mile races in Huntsville, Texas. That introduction to the trail-running community in earnest left her inspired and intrigued.

But trails in the Dallas area were few and far between. When a new work opportunity took her to southern California several years ago, she relished the unprecedented trail and mountain access. Perhaps even more significantly, she found that her daily running habit on the local trails seemed to help mitigate the likelihood of MS flare-ups.

"I ran every day—Griffith Park, Malibu, Mount Wilson, Baldy," says Kendell, "and I started to feel so much better. I was nowhere near cured, but I wasn't struggling."

In addition to better trail-running opportunities, the first thing she noticed in California was a dramatic change in the prevailing local attitudes about how to treat chronic diseases like MS—a shift away from expensive, strictly pharmaceutical approaches to more natural and lifestyle-based strategies.

"THAT'S A GOOD THING ABOUT THIS DISEASE," SAYS SHANNON. "IT'S TAUGHT ME TO LIVE IN THE MOMENT, WHICH I'D NEVER DONE BEFORE. I'D ALWAYS BEEN THINKING AND PLANNING AHEAD ... NOW, I WAKE UP, AND IF I CAN WALK THAT DAY, I APPRECIATE THAT."

She stumbled on the work of a physician and clinical professor of medicine named Terry Wahls. Wahls had been a marathon runner before being diagnosed with relapsing-remitting MS that rapidly transitioned into progressive MS. After several years of being confined to a wheelchair and receiving chemotherapy, Wahls grew curious about the possibility of slowing the progression of her MS naturally, without drugs.

"As a doctor, I was compelled to find answers," Wahls wrote in her book, *The Wahls Protocol*. "As a patient, I was compelled to save my own life."

Wahls began eating nine cups of vegetables, fruit and leafy greens per day, along with grass-fed meats and fermented foods. Within a year, she ditched her wheelchair. She began going for long-distance bike rides again with her family. Today, to back up her personal experiences with science, she's busy conducting small-group clinical trials on others with progressive MS. Though far from conclusive, her preliminary findings look promising for the use of diet modification, exercise and stress-relief techniques to manage MS.

The more Kendell read, the more fascinated she grew. Wahls's experiences resonated. When Kendell was unable to find time (or was in too much pain from a round of IV infusions) to go running or make good food choices, she felt fatigued, depressed and more prone to MS flare-ups.

Inspired by the positive changes she experienced living in California, in early 2013 she decided to go off IV treatments for a six-month trial period. She would transition to a primarily raw-food diet, cut back on alcohol, prioritize her daily run, get more sleep (going to bed at 8:30 every night to wake up and run at 4:45) and essentially de-stress her life in any way she could.

This was a challenge, given her around-the-clock job as a high-stakes public-relations manager—but the link between taking good care of her body and feeling well was too obvious to ignore. If she let herself get dehydrated or too depleted physically or mentally, her MS flared up. Her shoulder once shook so intensely it dislocated while she was out on a trail. She soon learned that she had to be patient on her runs, extra careful to listen to her body and not overexert herself.

"That's what I love about the trail-running community," says Kendell. "There's not the same pressure as in road running to 'keep up.' It's OK to take breaks, or walk if you need to. You hear about runners, even as amazing as Tim Olson, who don't complete a race because they know their bodies' limitations."

Now, three years later, she's still managing her MS through lifestyle choices rather than drug therapies. On her 29th birthday last year, Kendell celebrated by running 29 miles. She also set her sights on running the 2015 Silver Rush 50 in Leadville, Colorado. Of course she hoped to be able to finish, but that wasn't her primary concern. She just wanted to have a goal to chase, an excuse to take a trip to the mountains and, perhaps above all, a way to prove that MS wouldn't hold her back from doing anything she set her mind to.

"Crewing for my friends and me at Rocky Raccoon may have started Kendell on her path as a trail runner," says Charlie, now her fiancé, "but the roles have definitely reversed in that she's become a daily inspiration for me. She's been through a lot and she just keeps on trucking. She's as mentally tough as they come."

One of the nastiest wiles of MS is its unpredictability. Some mornings, Shannon wakes up and feels too fatigued to get out of bed. She likens these days to being at mile 80 of a 100-mile race—everything hurts, but if you're patient enough and keep fighting, the pain eventually passes.

"As ultrarunners, we know our bodies so well," says Shannon. "We know how it's going to hurt, and how long. The scariest thing about MS is the unknown."

The morning of Javelina, Shannon woke up and felt hopeful that it could be a good day. She'd run this race many times before; its hallowed trails occupied a special place in her heart. She had no idea whether she'd be able to run one mile today, or five, or 100, but whatever she did, she knew it would be a way of saying to her MS, "I'm winning."

Things started off well, as she clicked off dusty miles under the Arizona sun and reveled in the time among friends. At the 50K mark, she took a break to self-administer a shot of Copaxone, one of her MS drugs. And then, as she's always done, she kept going.

Around 80K, she began having difficulty breathing. She called it quits at the 100K mark, and went home happy to have been able to run as far as she had.

"That's a good thing about this disease," says Shannon. "It's taught me to live in the moment, which I'd never done before. I'd always been thinking and planning ahead: 'OK, next month I have Leona Divide, then Western States, then Badwater ... .' Now, I wake up, and if I can walk that day, I appreciate that. Most people don't do that."

Last summer, she finished Badwater again—all 135 miles, her sixth finish. She says she has no idea how she pulled it off; she'd been on and off treatment yet again, unable to train consistently. Her breathing issues had worsened, leading to a recent diagnosis of "diaphragm dysfunction," meaning her respiratory muscles have begun to atrophy. And yet, running Badwater again this past year was the ultimate dream for her—the way to show the world and her children that it's still possible to be healthy, love life and fight the good fight.

"I don't know what the future holds for me," she says, "but I do know this: running is saving me from this disease."

For Kendell, the parallels between running long distances and MS are obvious. Each, in its own way, requires a certain tolerance for suffering. But the struggle to endure comes also with some unexpected gifts. In the same way the trail-running community is filled with people curious about how best to optimize their health and physical performance, having MS has forced Kendell to better tune in to her body's needs.

"I drank too much beer in college, like most people, and ate too many 2 a.m. burgers," Kendell says. "MS forced me to take a harder look at how I treat my body and how I can help it. I always liked running, but MS gave me another reason to pursue it more."

She's since moved back to Dallas for work, so when she arrived in Leadville last July to run the Silver Rush 50, the trails there felt like paradise. For the first 30 miles, she felt great. The cool mountain air, the slight breeze coursing over the trails, a sea of runners cheering one another on—it was one of the few days she could remember not feeling pain in her body. She was even far enough ahead of her time projections that Charlie, who was crewing for her, missed her at the halfway point. Fortunately, another runner with whom she'd been leapfrogging offered some extra food to tide her over until she could meet Charlie again.

In the last few hours, her stomach stopped holding down food. The altitude began catching up to her, too. A few fellow runners sidled up alongside her and told her, "We're not doing this race for time ... want to walk it in with us?"

And so they did, four friendly guys from Colorado and Kendell, taking it all in together under the soaring blue sky—the pine trees, the setting sun, the dirt beneath their shoes—as they made their way back to the finish line in Leadville. It was the longest distance Kendell had ever run.

The next morning, she got in the car for the 15-hour drive back to Texas in order to get back to her job. The fatigue that followed, and lasted for weeks, was immense. She took two full months off from running to let herself recover.

"My body hated me for a while," she says, "but at the same time, it also loved me, because I was just so happy. That is what really carries a person through physical pain.

"That's why I have to keep running. I still have this shitty disease that's always barking at me in the back of my mind, but I wouldn't be as healthy as I am without that. That's motivation alone to run, to just keep going."

Yitka Winn is a contributing editor for Trail Runner.