

BEATING
MULTIPLE
SCLEROSIS

Empowering Stories of Self-Healing and Thriving

AGOTA NAWROTH
& PAIGE NEWSOME

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To my loved ones,

This book reveals the transformative path of my MS journey and daily dedication required for a healthy life. I'm taking care of myself, so you don't have to.

To the multiple sclerosis community,

May our stories empower and inspire, fostering understanding, compassion, and progress. Together, let's navigate the challenges of this journey, knowing that we are never alone.

With love and deepest admiration,
Agota Nawroth

ACKNOWLEDGMENTS

I would like to express my deepest gratitude and appreciation to everyone who has contributed to the creation and completion of this book.

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Lastly, I extend my gratitude to my followers, readers, and supporters. Your enthusiasm, feedback, and reviews inspire me to continue sharing my story and the knowledge I've acquired along the way with the world, raising awareness about diseases that can be prevented.

To all those mentioned above and the countless others who have contributed in various ways, your presence in my life has made this book a reality. Thank you for being a part of this remarkable journey.

With heartfelt appreciation,
Agota Nawroth

AUTHOR'S NOTE

Many individuals are searching for a diagnosis while struggling with various symptoms. For those of us already diagnosed, having answers can be a relief but also adds a lifelong burden. At times, this weight can feel overwhelming. I wish a book like this had been available when I was first diagnosed four years ago. It would have made a world of difference. Back then, I wouldn't have felt so alone and lost. I wouldn't have had to search through numerous books to connect the dots. My goal with this book is to provide you answers and give you practical guidance to regain control and steer your life back on track.

The stories in this book showcase the remarkable potential within us as human beings. We can heal our minds and bodies, making full recoveries from autoimmune diseases when we cultivate the right mindset and well-being practices. I haven't encountered anyone who thrives with a pessimistic outlook. Our minds are incredibly powerful. It's crucial to remember that the path to healing often begins there. While change can be a challenge, it's a necessary step for those seeking a healthier life.

So, who is this book for? It's not exclusively for people with MS. This book is filled with ideas to improve the lives of anyone, diagnosed or not, who is facing symptoms. Each chapter is a glimpse into someone's life, flourishing despite the diagnosis. My hope is that you'll discover a story or two that resonate with you. Please share this book, help us spread the message, and raise awareness about this complex condition. It doesn't have to lead to life in a wheelchair.

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Final Note

“Wellness is the complete integration of body, mind, and spirit – the realization that everything we do, think, feel, and believe has an effect on our state of well-being.”

– *Greg Anderson*

DISCLAIMER

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Story by

PARMJIT (PAM) KAUR

Diagnosed in 2008

Currently 39 years old

Lives in Las Vegas, United States

Instagram: @stemcells_n_dumbbells

Facebook: Parmjit Kaur (Jersey)

Growing up in a strict, low-income, Indian household, I was consumed by duty; duty to my parents to be a model child, duty to my siblings to be their protector and set a good example, and duty to myself to get good grades and, eventually, earn a livable wage. While all that can be overwhelming for any one person, it can be that much more difficult for a child, particularly a highly sensitive one, which I absolutely was.

As if the stress of life at home wasn't enough, I was being bullied regularly at school. I loved school, but the thought of being confronted by my bullies put me in a constant state of fear and panic. I rarely, if ever, felt safe. I rarely felt secure. Rather, I often cried myself to sleep, praying for an escape from my reality.

Slowly, the escalating pressure and my constant state of fear began to take its toll on me...and on my health. You see, in those days (I grew up

in the 80s and 90s), I hadn't heard anyone speak much about stress, mental health, and its sometimes-accompanying effects. I didn't know, nor understand, that the clinical depression I was eventually diagnosed with, and the regular stress, was introducing disease into my body. I first learned that lesson at only eighteen years old...

I was preparing for my first work trip to Las Vegas when I broke out with a painful, blistering rash on the right side of my chest and back. I writhed in agony as the blisters broke and stuck to my clothing. I fought a high fever, desperately wanting to see a doctor, but knowing I couldn't because I didn't have health insurance.

Eventually, the pain became so unbearable that I found myself in the Emergency Room (ER) at Trinitas Hospital in Elizabeth, New Jersey (NJ), where I was diagnosed with "Shingles". It wasn't until later in life, however, that I learned that Shingles usually presents in people who are in their fifties, or later in life. Shingles presenting before the age of forty is rare...

Rare. Rare. Rare. That word ruminated in my mind...over and over again. I couldn't quite understand how something that is said to be rare could've happened to me, an otherwise healthy, young female. But I soon learned that being an anomaly would be the running theme of my life.

One quiet evening, I sat with my brother and best friend, enjoying dinner at one of our favorite diners (NJ is well-known for having the most diners out of any state!) We sat with tears streaming down our faces from laughing entirely too hard, as we usually did, at the silliest of jokes that only made sense to us, when my friend asked, "What's wrong with your face?"

I assumed she was pointing at how red my face tends to get when I laugh too hard. It's something we've done since we were little girls—tease one another.

"HA-HA. You're so funny," I said, rolling my eyes.

"No, really!" She exclaimed. "You're talking, but only half of your mouth is moving!"

"Wait, what? You have to be joking," I responded.

I had to see this, so I walked over to a mirror and smiled. Sure enough, the right side of my face was motionless—almost frozen.

Soon after, I made another reluctant appointment to see a local doctor, who would eventually become my Primary Care Physician (PCP). I was astounded by yet another health event occurring so early in my life.

Upon entering his office, he knew almost immediately what I was dealing with. He looked at me with sympathy as he spoke my diagnosis, “Bell’s Palsy”. As for me, I wasn’t quite sure how to react, as it had been the first time I’d heard of this condition.

My doctor put me on a treatment plan that included taking an oral medication called Prednisone, a corticosteroid. And while the medication was effective in eventually healing me and restoring muscle function to my face, it was not without side effects, most notably the effects on my joints. As I attempted to stand or move my arms, I felt as though my limbs were going to give way, and the severe pain would throw me into a sobbing frenzy. I communicated these side effects to my physician and vowed, in that moment, to never—no matter how challenging the health event—put my body through that again.

While Bell’s Palsy was fortunately behind me, I needed to know more. I began looking into the age range that Bell’s Palsy is typically diagnosed with, the likelihood of recurrence, and more. Once again, as was the case with Shingles, I was shocked to learn that Bell’s Palsy most commonly affects those over sixty-five years.

Remember my life’s theme: Anomaly.

Years passed. While I hadn’t forgotten about my diagnosis (the mounting medical bills were a constant reminder of that harsh time), life forged on. I was in my early twenties and had landed a job with a mortgage company. I was thrilled, but my joy was short-lived. Around that time, I once again began experiencing unfamiliar symptoms.

My right hand and arm often became numb, and I regularly felt as though I was being poked with pins and needles. Perhaps, I should have been concerned, but I chalked it up to the way I usually slept, with my right arm beneath me. Soon after, I also began having trouble running up the stairs, but it wasn’t until I had trouble opening the door to my office one day that I knew something was very wrong.

I remember naively wondering if Bell’s Palsy had returned, not realizing that Bell’s Palsy only affects the face. Once again, I made an appointment to see my PCP, who then recommended that I get a computed tomography (CT) scan.

I think I lived in a dream world at that time. I thought I was invincible. It was this innocence that led me to believe that the CT scan would be fruitless and that the results would show that my unusual symptoms were nothing more than a fluke. I truly believed this...that is until I walked into work one day, and my then-manager, who happened to be a friend of my PCP's, told me news that I would never forget.

“Pam, you need to call your doctor back. He got your CT scan results, and he thinks you might have a brain tumor.”

Today, I know what a big HIPAA violation it was for my doctor to share my personal health information with someone other than me without my consent, but at that time, I could barely think. I was in shock. I was devastated. I called my doctor's office back and was told by one of his nurses that I needed to be seen ASAP. I made an appointment for the very same day. I called my fiancé at the time, choking back tears. I couldn't breathe and felt my chest tighten as I thought about the news I'd just received that I would soon share with him.

“Jaan (Punjabi translation for ‘life’), what happened? Are you okay?” he asked, full of concern.

“The test results came back,” I finally said, amid sobs that I could no longer control. He knew I'd had a CT scan prior. “Babe, the doctor thinks I might have a brain tumor. I don't want to die. Please, I don't want to die.”

And with that, we both cried. He'd previously lost a friend to a brain tumor, and my news brought back memories that he'd never thought he'd have to relive. Next, I called my best friend, Melody, and still sobbing, shared the news with her, too. She cried.

“Don't you worry, Pam. You are going to be okay!” She comforted me. “I am going to go to the doctor with you.” And she did.

She sat next to me and held my hand as the doctor pushed an image of a brain towards me, circling an area in which the CT scan had uncovered an unusual mass. “We will need to pursue further testing, Ms. Kaur, and I'm referring you to see a neurologist at the local hospital for follow-up.”

He was extremely sympathetic as he said the next few words, but they hit me like a ton of bricks. “Unfortunately, I suspect that you may have a brain tumor.”

I'd now heard that diagnosis for the second time in one day. I think I may have blacked out momentarily because my ears started ringing, and I don't remember what else he may have said.

I called the hospital to make an appointment with a neurologist; however, the earliest appointment available was a month out. I couldn't believe it. Here I was on the brink of death, or at least that's what I thought, and I was told it would be a month before someone would see me. So, I impatiently waited, each minute feeling like an eternity.

When it was finally time for my visit, a neurologist examined me, listening to my health history and making notes before ordering magnetic resonance imaging (MRI) of the brain. I felt claustrophobic and afraid as I laid in the noisy MRI machine. I no longer lived in a fantasy world. I no longer felt invincible. From that moment on, each test would bring with it an onslaught of panic and impending dread.

A couple of weeks had passed before my next appointment with the neurologist to review the results of the MRI. I showed up to my appointment, and he examined me, once again, asking a slew of questions. I sat on his examination table, the fresh paper beneath me, crunching every time I moved.

"Ms. Kaur," he said, "I have good news. The MRI results don't indicate you have a brain tumor."

I could hardly contain my joy and let out a long sigh of relief. Again, my excitement would be momentary.

"Rather," he said, "I believe you've had two silent strokes. We'll need to order more tests to rule out other possibilities." And with that, he ordered a series of tests, including an MRI of the spine, an electrocardiogram (EKG), and bloodwork. I was bewildered. It was 2008. I was twenty-four. How could this have happened?

More weeks passed, and it was time to visit him again to receive the results of the new tests. This time, another close friend, Kara, came to the neurologist with me. I felt more confident having her there because one, she'd always known how to make me laugh, and two, she'd worked in the medical field. I sat in front of the neurologist, with Kara to the right of me.

“Ms. Kaur,” the neurologist said, looking me in the eyes, “We will have to do one final test to say with 100% certainty, but we are confident in our conclusion that you have multiple sclerosis (MS).”

I didn’t have much of a reaction. I didn’t know what MS was. But I glanced over at Kara and noticed her mouth was agape.

“Okay. What’s that, and how do I get rid of it? My twenty-fifth birthday is coming up, Doc, and I don’t want to be sick on my milestone birthday,” I said, smiling. I’d thought MS was probably like a cold or maybe the flu—that I could just take medication for a few days, and it’d be gone. Oh, how innocent I was.

“Unfortunately, there is no cure for MS,” he explained. It is a chronic autoimmune disease, and it will be important to manage it through disease-modifying therapy via injections.”

“Oh. I’d prefer not to do injections,” I said, not understanding that it was the only option available at that time.

He smiled at me; his face filled with compassion. “Currently, disease-modifying therapies are only available via injection or infusion.”

I went home that day and began learning everything and anything I could about the disease, much of it alarming. I’d also learned that at that time, the highest incidences of MS were in Scotland, and that just so happened to be where I was born. A terrifying coincidence, perhaps.

The neurologist referred me to a different doctor in the same hospital, but one who specialized in treating patients with MS. This second neurologist ordered one last test, commonly called a lumbar puncture, or a spinal tap, to rule out a diagnosis of Lyme disease, which has symptoms similar to MS. During this procedure, a long needle was inserted between my vertebrae to remove a sample of my cerebrospinal fluid. It was pretty harmless, but the doctor instructed me to drink coffee if I found myself with a headache anyway. While that initial day went by like a breeze, the next day was like something out of a fiction novel. I woke up with an excruciating migraine that would only slightly lessen if I laid down. If I made the mistake of sitting or standing up, I would vomit profusely. It felt as though my brain was slamming against my skull.

I called the hospital, hoping for a solution, but instead was told, in so many words, to wait it out—that the pain would decrease over time, and

I had to be patient; that this was normal. It did not decrease. It was not normal. This went on for a couple of days, days that I spent curled up on a sofa, crying, feeling like I'd made the worst mistake of my life by agreeing to the spinal tap.

Melody and Kara would come over to try and cheer me up, but their sincere efforts were unfortunately futile. I couldn't bring myself to smile. I couldn't bring myself to laugh. I couldn't even bring myself to speak with my friends. They quickly saw the pain expressed on my face and described me as having become a shell of myself. I was becoming desperate, so I had my brother, the middle child, drive me to the ER. It was full, and I sat in the waiting room in tears, begging someone to see me.

Finally, after much pleading, I was seen by an ER doctor who inspected the site where the spinal fluid was removed and conducted another series of tests.

"I can't believe you were told to wait the headache out," he said, shaking his head after reading the test results. "You have a cerebrospinal fluid leak. This is very serious."

He immediately ordered an Epidural Blood Patch, a treatment that involved taking a sample of my blood and then injecting it into the spinal canal where the fluid was leaking. Although relief wasn't immediate, after the treatment and a short hospital stay, the horrific pain in my head went away. I then revisited the neurologist who'd ordered the test to hear the results.

"Ms. Kaur, your test results have confirmed that you have multiple sclerosis," she told me. "And we suspect you've had it for quite some time."

While I thought I'd be stunned, I was more so relieved—relieved to finally have an accurate diagnosis and relieved to have an answer to the mystery symptoms I'd been experiencing for years. While I wasn't thrilled about my diagnosis, I'd come to terms with the fact that I, Parmjit Kaur, at twenty-four years old, had MS, and my life was forever changed.

The first MS medication I started was Rebif, an injectable taken three times a week. From the first moment I injected myself, I felt happy and proud for having done it by myself. However, that feeling quickly dissipated as I began to experience the side effects of the medication,

side effects that I hadn't been warned about, nor prepared for. Side effects that included flu-like symptoms, hair loss, and perhaps the worst of them all—suicidal thoughts.

In addition to the horrid side effects, my balance, along with the strength in my right hand, was getting worse. I was beginning to fall and drop things more often. My once beautiful handwriting began looking like that of a toddler's, and climbing stairs was becoming impossible unless there was a railing available to grab hold of.

I began missing work and cancelling plans. Every day I mentally devised a plan as to how I'd end my life; my quality of life was rapidly waning. I wanted to live...but not like this. Never like this.

One night, I grabbed the same bottle of aspirin that had provided me momentary relief from my fever-like Rebit symptoms all those days that I'd injected myself, and drove to an abandoned parking lot. I sat, contemplating life and death. Sadly, the choice for me was obvious; and with that, I began swallowing pills by the handful. I laid my head back... and then, the phone rang.

I answered, crying. It was the youngest of the family, my fourteen-year-old baby brother. He'd known I was upset when I'd left the house and wanted to know where I was.

"I'm somewhere. And I'm probably not coming home," I said, trying to remain elusive.

"What did you do? Did you take those pills?" He asked. It turned out he'd seen me grab them. All I could muster amid tears was, "I'm sorry."

"NO!" He said. "Pam, drive yourself to the hospital RIGHT NOW!"

I heard the anguish in his voice. Suddenly, the reality of what I was doing hit me...I was abandoning my brother, the brother I'd raised like a son.

Perhaps, my answering the phone was a cry for help. Perhaps, I didn't really want to give up. Whatever the case, that evening I drove myself to the ER where I was admitted and made to drink liquid charcoal to remove the self-induced poison.

Following my suicide attempt, I decided I needed to try a new medication. This time, my neurologist suggested Copaxone. After almost a year on it, my doctor ordered an MRI to see how effective the

medication had been in slowing down the progression of the MS. Sadly, it had been ineffective, and the disease was still progressing, evidenced by frequent relapses. That news, coupled with several injection-site reactions, including the hollowing of my skin, was a clear indicator that we needed to go back to the drawing board. Except this time, I didn't agree with my neurologist's new direction: Tysabri, an intravenous infusion.

You see, Tysabri increases the risk of Progressive Multifocal Leukoencephalopathy (PML), a viral infection of the brain that usually leads to death or severe disability. That risk further increases if a patient has been infected by the common John Cunningham Virus (JCV), which a recent blood test had confirmed I'd tested positive for. My neurologist knew this, yet he was adamant that this was the best choice for me, and with that, my trust in my doctor began to wane. With limited options and feeling reluctant to experience the severe side effects that came with most MS medications, I decided to pursue a different route, one that didn't include medication.

I began looking into diets that would aid in healing, including the Wahls Protocol®, a modified paleolithic diet that focuses on eliminating grains, eggs, dairy products, etc., and a heavy emphasis on vegetables, fruits, meats, and fish. I also began working out more, particularly weightlifting, working hard to strengthen my legs. I was often heard saying that MS tried to take my legs, so I was building them up to take them back.

This approach worked well for me for a few years, but MS was relentless; unfortunately, the relapses continued. With each relapse, I lost a bit more function. I went from wearing four-inch heels to no heels at all, from wearing wedges to flats, from riding a bike and running to being unable to do either, and from walking up or down flights of stairs unaided to being forced to hold a railing when available. I was also falling more often, usually in public. Along with countless bruises, I was becoming a frequent flyer at the hospital. I even broke my ankle at my ten-year high school reunion. What was supposed to be a wonderful evening spent with friends turned into a night in the Emergency Room, surrounded by healthcare professionals.

I was shattered. With each month that passed, I found myself losing abilities that I once took for granted.

Then, a friend messaged me, telling me about Hematopoietic Stem Cell Transplantation (HSCT) for MS, a chemotherapy-based treatment for MS

that aims to “reset” the immune system by eradicating the T and B cells in your body that have essentially gone rogue, and then using your own stem cells to regrow it. T and B cells are types of lymphocytes (white blood cells involved in the immune response). However, I’d read about snake oil salesmen, touting different methods that claimed to effectively treat MS, and I was wary of yet another treatment that would supposedly heal me. While I should’ve paid heed to my friend’s recommendation, I put it out of my mind.

That is, until another patient I’d met through Facebook’s MS community and become close to, messaged me upon reading of my many struggles with the disease. She urged me to consider HSCT, sharing that she’d had the successful treatment herself. She had been part of Dr. Allan Burk’s clinical trial at Chicago’s Northwestern University Memorial Hospital. Dr. Burke is one of the leading doctors in developing the HSCT approach for MS and other autoimmune diseases.

However, I was afraid. Although HSCT is over 80% effective in stopping the progression of MS for patients that have Relapsing-Remitting MS (RRMS), which is the version of MS that I had, I didn’t want to put my body through chemotherapy. I also very wrongly equated femininity with long hair and the ability to bear children, both things that would be at risk if I went through chemo. So, I put-off having HSCT for two years. By then, not only had the clinical trial ended, but my prognosis was that I would soon have to use a wheelchair. While I still could’ve pursued HSCT at Northwestern, HSCT wasn’t an FDA-approved treatment for MS. Only a handful of insurance providers covered it. Another option was paying for the treatment myself, but at an overwhelming cost of \$100,000+, there was no way I could’ve afforded it. But with the MS rapidly progressing and not wanting to be trouble to my already burdened family, I knew HSCT was quite possibly the last chance at maintaining my independence.

My decision was made. I was going to figure out a way to get HSCT, and I was going to share this news with my neurologist, who I half expected to be supportive. Oh, how wrong I was.

I shared the news with him, and without so much as batting an eye, he told me I was taking a big risk, and I would probably die from the “experimental treatment”. The distrust I began feeling toward my doctor only increased because I realized that he was trying to instill fear in me. Despite what he’d said, HSCT was not experimental; rather, it had been performed on cancer patients since the 1950s. While there is absolutely risk with all treatments, HSCT was less risky than the alternative MS

drugs. But I didn't share all that with him. It wasn't my job to educate my physician about the best course of treatment. Instead, I asked him a question that he couldn't answer: "If you had multiple sclerosis, or any illness, wouldn't you also explore all credible treatment options?"

I began searching for additional locations that offered HSCT for MS and came across a forum for HSCT in Puebla, Mexico at a place called Clinica Ruiz. To my pleasant surprise, Clinica Ruiz was run by Dr. Guillermo J. Ruiz-Arguellas, an internist, hematologist, and one of the top twenty-five alumni out of Mayo Clinic. I read several positive reviews from patients from all over the world who'd been treated at Clinica Ruiz. That information, coupled with the treatment in Mexico being a fraction of what it would be in the U.S. (\$54,500 to be exact), helped me decide that Clinica Ruiz was where I wanted to be treated. So, I rushed to apply. The application process was pretty straight forward. Within two weeks, I was approved. I was elated!

With my application approved, I needed to raise money for the treatment. While the cost of HSCT was significantly lower in Mexico, I still didn't have that kind of money sitting around but that, too, proved to be a monumental hurdle. I started a GoFundMe page, but unfortunately, I only raised about \$7,000 of the \$54,500 that I still needed, and my treatment date was quickly approaching. With my fingers crossed, I applied for a personal loan and anxiously waited to hear back.

I will never forget the day I received my loan application results; they temporarily crushed my spirit. I read the results and felt like I needed a drink of water to wash away the knot in my throat. I walked into my kitchen where my father and stepmother had been sitting around chatting. They knew I'd applied for a loan and were just as eager as I was to hear the news.

"Did you hear back about the loan?" My stepmother asked me. I took a big gulp.

"I did...My loan was denied," I said, fighting back tears.

At that moment, my youngest brother walked into the kitchen, reading my solemn face. "What's wrong?" He asked. I've always had trouble hiding my emotions from him.

"My loan application was denied," I said...and with that, I began to sob. My brother hugged me, and he, too, cried along with me. He knew that without HSCT, there was a good possibility that I'd continue to get worse. My father, seeing how distraught my brother and I were, made a

grand gesture that would forever help to change my life. He offered to take out a loan against his existing life-insurance policy, so I could pay for my upcoming treatment. I can't put into words just how happy I was. And with that, I moved forward. In November 2016, I, along with twenty-five other patients, underwent a successful stem cell transplant in Puebla.

Even though HSCT was only meant to stop the progression of MS, almost immediately I noticed other improvements, starting with my balance. I no longer needed a railing to climb stairs. As the years passed, some of my lost abilities began returning. With this newfound strength, I also wanted to inspire other patients to continue pursuing their dreams, despite their disability. So, I set a new goal, and in 2018, I participated and placed in my very first bodybuilding competition.

Today, in 2023, I consider MS, for the most part, to be a distant memory. I'm running again, I can ride a bike again, I can wear heels again, and so much more! HSCT was a Godsend, and it truly gave me both a second chance and a new life, which I will never take for granted.

I've been asked if I am afraid about MS returning in the future. Truth be told, that's not something I've given much thought to as I've been very confident in HSCT's long-term effects. However, I recognize that to avoid introducing disease back into my body, I need to be in an environment conducive to healing. So, after getting HSCT, I moved out of my parents' home and away from the stress that came along with it.

These days I'm definitely much more cognizant of what I'm putting in my body. That is not to say that I always eat "healthily", but I do more often than not. I eat a balanced diet, paying attention to the ratio of carbs, protein, and fats in each meal. I've also taken advantage of supplementation and try to consume organic food whenever possible. My mindset and belief that HSCT treatment would work for me definitely contributed to its success! I'm a big believer in the power of the mind, of speaking things into existence, and of a positive mental attitude.

FINAL NOTE

"Before you heal someone, ask him if he is willing to give up the things that made him sick." -Hippocrates

As we reach the end of this book, I hope these stories have not only inspired you but also encouraged you to take a moment to reflect on your own life. The purpose of this book has been to shine a light on aspects that deserve recognition and change. It's not just about MS or autoimmune diseases; it's a call to awareness, an invitation to slow down and reevaluate our lives.

Our ancestors had wisdom we can learn from, and with today's technology and knowledge, we can create a healthier, more harmonious world, instead of heading down a destructive path. It's as simple as pausing to take a deep breath, enjoying the smell of flowers, and appreciating the beauty that surrounds us.

We hope you've found this book to be a valuable guide. In closing, remember that while healing isn't guaranteed, it's always within reach. The life you choose to lead is firmly in your hands. Join us on **www.BeatingMultipleSclerosis.com** to explore all the limitless possibilities together.