

Every Breath I Take

Ralph Rosa, stricken with multiple sclerosis,

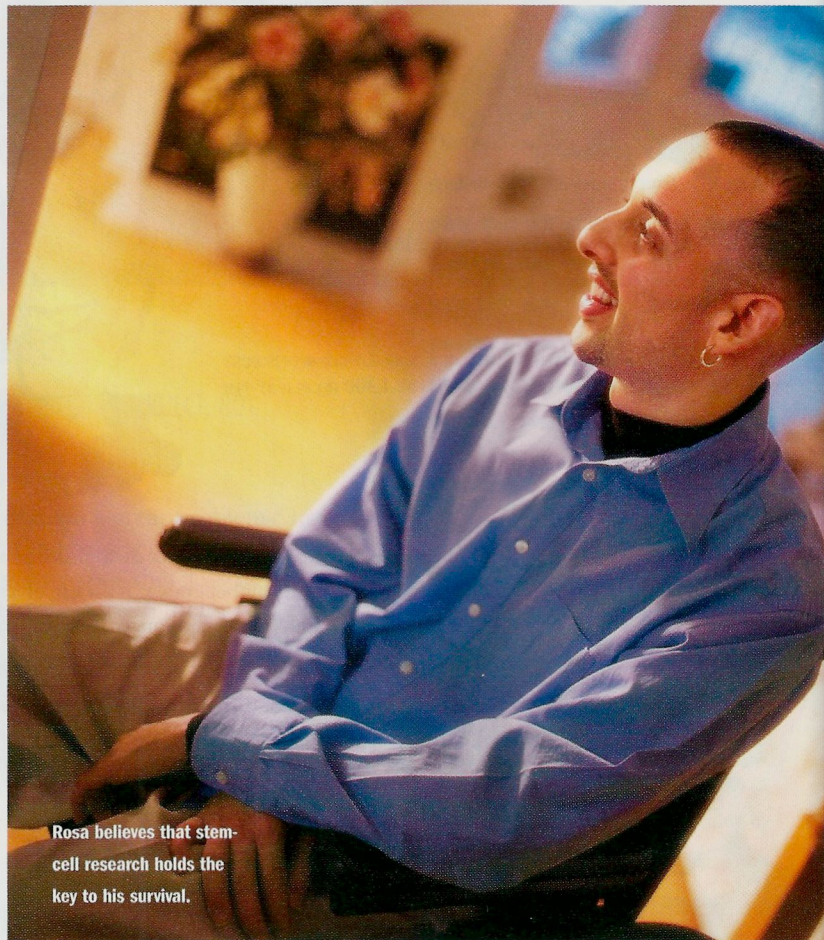
is determined to not go down without a fight *By Bill Glovin*

Ralph Rosa remembers the impact of seeing Van Halen on MTV as a 14 year old. "In that instant, I knew I had to learn to play guitar and join a band," he says. If he could also someday meet his true love and live in a house on the beach, that, he told himself, would be the perfect life.

He wasted no time chasing after his dream. Living in Puerto Rico at the time, Rosa began pestering his neighbor to give him guitar lessons. He practiced nonstop through his teenage years and eventually landed at the Berklee College of Music in Boston. When his family relocated to Perth Amboy from Puerto Rico in the early 1990s, he transferred to Rutgers College, where he sang in the Kirkpatrick Choir and played in a band called "Love Soup."

Soon after graduating in 1995 with a degree in music from Mason Gross School of the Arts, he headed back to Puerto Rico to visit old friends and joined a Latin rock band, "Causa Común." Within a year, they had signed a recording contract and began opening up for headliners at clubs all over Puerto Rico. When Rosa began dating someone that he thought he might marry, he couldn't help but feel that his dreams were within reach.

But then life threw him a major curve. In 1997, he suddenly collapsed. It wasn't the first time. Two years earlier at Rutgers, he had fallen on the stairs behind Brower Commons. Healthy and fit, he chalked it up to one of life's unexplained mysteries. His second fall, this time on a drum kit while recording a video in Puerto Rico, prompted him to visit a neurologist. A few days later, tests confirmed that he was suffering from multiple sclerosis (MS), a potentially fatal disease that strikes randomly.



Rosa believes that stem-cell research holds the key to his survival.

Fast-forward eight years to the family's Perth Amboy condo, where the 31-year-old Rosa lives with his mother and brother. Perched above a marina along Water Street, the condo offers a striking, panoramic view of Raritan Bay and the Arthur Kill. Staten Island appears close enough to touch on a clear, sunny morning. Seated in a wheelchair, Rosa wears a black and gray pullover

sweater and a baseball cap. The smile bordered by his close-cropped goatee is warm and genuine.

As Rosa begins his story, he suddenly leans in closer and brings his voice down to almost a whisper, "Let me tell you, this really sucks," he says. "I'm losing breath and energy all the time." The slight slurring of his words validates his claim. "What really gets me is that people see me in a wheelchair and think of me as useless. They don't realize that I was once a pretty good musician who was signed to a record deal. But I'm far from useless, and I'm not going down without a fight."

A foundation that Rosa launched in 1999 to advance MS research with funds raised through professional comedy shows and amateur volleyball games helps inspire him to drag himself out of bed in the mornings and lift weights three times a week. The foundation has also sponsored several MS information workshops in central New Jersey.

"I started the Multiple Sclerosis Research Foundation (www.msrf.org) because I didn't want to wallow in my own sorrow," he says. "There's a lot of putting on one of these shows: scheduling performers, promoting the event, turning a community center into a nightclub, and getting people to take tickets and wait on tables."

Rosa and his five-member board have raised \$65,000 to date, but sadly, his role in fund-raising is lessening. "By mid-afternoon, I don't have the energy to do much of anything," he says. Email, once a great way to recruit performers and volunteers, is now difficult due to paralysis in his right hand.

Several years ago, Rosa began to interview researchers specializing in multiple sclerosis. He was determined to make sure his foundation's money would be put to good use. "The idea was to find someone who I believed in," he says. "It took some time and effort, but I couldn't be happier with who I found."

In 2001, his search led him to Dr. Patrizia Casaccia-Bonnetil, an assistant professor at the University of Medicine and Dentistry of New Jersey. Casaccia-Bonnetil, who, as a neurologist in Italy had treated family members suffering from MS, decided to find a position at a research hospital in the United States to try to develop new and more effective therapies.

Literally translated, multiple sclerosis means "many scars." In the course of the disease, which afflicts a half-million Americans, white blood cells called T cells attack protein structures in the sheath of myelin that covers nerve fibers in the brain and spinal cord. One key to curing MS, Casaccia-Bonnetil believes, is to learn why the disease attacks twice as many females as males but progresses faster in men. By using stem cells from male and female mice in her experiments, she hopes to determine why estrogen seems to protect the myelin-forming cells, while testosterone appears to destroy them.

"The National Institutes of Health (NIH) rarely funds new approaches like the one I'm taking," says Casaccia-Bonnetil. "That's where Ralph's foundation comes in. Ralph is a firm believer that science will someday provide the answers, and the money he has raised helped me to present my preliminary data at an MS symposium

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in England in 2004. Now I'm hoping that new NIH money will enable me to take my ideas to the clinical stage. My hope is to develop new and effective gender-based therapies."

Where Rosa is concerned, Casaccia-Bonnetil is racing against the clock. The disease's symptoms can range from mild to severe, and Rosa's handpicked researcher sees his condition worsening. "NIH is trying to improve the rate at which scientific discovery moves into actual therapy; right now the average is 20 years," she says. "Ralph is the reason I'm obsessed with my work. His mission, his eagerness to meet with the students in my lab, his ability to stay cheerful and positive, these qualities remind me of Christopher Reeve." She pauses for a moment to collect herself and then adds solemnly, "With Ralph, I'm hoping for a miracle." □

Bill Glovin is senior editor of RUTGERS MAGAZINE.