

SAVED BY *Saints*

The Trip to Bologna that Healed a Life

BY MILES RYAN FISHER

"If I hadn't gone to Bologna, I'd be in a wheelchair."

Carrie Bennett was no stranger to pain. After all, she worked as a critical care nurse in the Emergency Room and Intensive Care Unit of St. Joseph Hospital in Fort Wayne, Indiana. A little more than two years ago, while walking down a stairwell at work, Carrie sustained a minor injury when she rolled her right ankle. At first, she didn't think much of it. She worked the rest of her shift and went home. In the morning, she awoke with intense pain coursing through her entire leg.

"It felt like somebody was sawing my leg off," she said. She went to the bathroom and began vomiting. She looked down and her leg was discolored.

Still, she managed to go to work. When her co-workers saw her, however, they forced her to admit herself to the Emergency Room, where she was given antibiotics and pain medication. Neither worked. Then a doctor told her, "I think you have RSD." Though she'd worked with patients suffering from all sorts of conditions, she'd never heard of the diagnosis. In fact, it was the first time that the doctor had ever issued it. Then Carrie's heart dropped at what the doctor said next: "It's incurable."



The Two Towers of Bologna (called Garisenda and Asinelli), which were constructed in the 12th century. Both towers lean, making the taller one—Asinelli Tower—the tallest leaning tower in Italy, at 318 feet. (Sergey Dzyuba)

According the McGill Pain Scale, what Carrie suffered from was some of the most excruciating pain one can experience.

Worse than unprepared childbirth.

Worse than amputation.

Worse than cancer.

It's a debilitating chronic pain called Complex Regional Pain Syndrome (CRPS)—formerly known as Reflex Sympathetic Dystrophy (RSD)—a condition in which the nervous system malfunctions and sends intense pain signals to the brain long after whatever injury precipitated it has healed. The pain grows disproportionate to that of the injury, making its sufferers writhe to the point that even a gentle touch is painful. In most cases, the pain remains localized, staying in the region of the body—usually a limb—where the injury occurred. The pain is so excruciating that some sufferers have had the affected limb amputated just to rid themselves of the pain. In Carrie's case, however, the pain spread through her body, incapacitating her.

"Your whole world explodes," Carrie said of CRPS. "It's horrific." She thought of her four children, her husband, her career. She even thought of ending her life—a thought that isn't uncommon for those suffering from CRPS. In fact, two individuals who Carrie met after being diagnosed have done just that.

But she continued searching for treatment, and even though nothing effective was being developed in the United States, she discovered the place where hope existed: Bologna, Italy. Carrie found reports of a breakthrough therapy involving a drug named neridronate that was being developed in Bologna at Policlinico Sant'Orsola-Malpighi—the largest hospital in Italy with more than



Dr. Nazzarena Malavolta and Case Manager

Gaetano Dioguardi, with Tanya, Marty, and Carrie.

1,500 beds and 5,000 employees. A doctor there named Nazzarena Malavolta and her team had begun developing effective treatments for individuals suffering from CRPS.

So Carrie sent a message to Dr. Malavolta in search of a miracle. And she received a message back: Come to Bologna and we will help you. After being evaluated by Dr. Malavolta to determine that the neridronate treatment was the correct treatment for her, Carrie began planning her trip to Bologna.

Of course, the trip to Bologna was not without expense. Carrie's healthcare company would not cover such a "radical" treatment in a foreign country. Never mind that the foreign country at hand was Italy and that Italy is ranked as the second healthiest country in the world¹ (and healthiest in Europe) by the World Health Organization. "The forward thinking that Italy has with their medical treatment—they want to address things," Carrie said. "They want their people to feel better."

Carrie and her husband began planning the trip—booking flights to Bologna and a Bed & Breakfast close to the hospital. The total cost for the trip would be \$5,000, which included the four treatments she would need at the hospital. Each of the treatments would cost just \$200 apiece, far less expensive than what such treatment—if it were available—would cost in the United States.

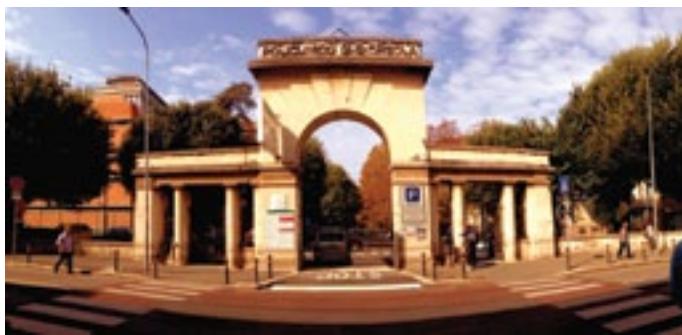
Just three weeks after contacting Dr. Malavolta, Carrie and her husband were on their way to Bologna. She was just the fourth American to go over for the treatment, which consists of four two-hour infusions of neridronate, which pulls fluid out of the bones to block the pain receptors and then coats the bones. It stays there for seven years. But as the doctor who'd diagnosed Carrie had originally said, there was no cure for what she had. In fact, there was no telling how much this treatment would help her—or if it would help at all, since every patient experienced differ-



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¹ The healthiest country, according to the World Health Organization, is Singapore. The United States, meanwhile, ranks 37th.



One of the entrances to Bologna's Policlinico Sant'Orsola-Malpighi, the largest hospital in Italy.

ent levels of improvement. Still, it was her only hope, and even if it helped ease the pain by twenty or thirty percent, it would dramatically improve her quality of life.

Carrie and her husband landed in Bologna on a Tuesday, two days before her first infusion. The moment she and her husband first walked into the hospital, “we felt like we were supposed to be there,” Carrie recollects. She met Dr. Malavolta, who was as friendly in person as she was over email. “She puts her heart into helping people,” Carrie said.

A Thursday-Monday-Thursday-Monday treatment schedule afforded Carrie and her husband some time to explore Italy while she underwent treatment. During the week, they walked the streets of Bologna, in awe of the “sheer magnitude of its history.” They visited the Towers of Bologna and walked beneath the many porticos.

The first weekend, they visited Rome, touring the must-see sites—the Spanish Steps, the Pantheon, the Colosseum, the Vatican. Carrie tossed a coin in the Trevi Fountain and made a wish to be healthy again. The second weekend—after Carrie had endured three of the infusions—they visited Venice. This trip however, proved to be too much for her, the treatment having depleted her energy. Though she was made it as far as the churches and shops in St. Mark’s Square, she spent most of the time horribly sick in bed. But in spite of this unfortunate way to see Italy for the first time, Italy’s beauty still overwhelmed her. “One day, I want to

bring my kids there,” she reflected. “I want to learn Italian so I can go there and enjoy it in a way that I couldn’t.”

After the four rounds of neridronate infusions, Carrie and her husband returned home and waited to see how her CRPS would respond to the treatment.

What Italy’s breakthrough therapy initially brought Carrie was hope.

What it left her with was a life reclaimed.

Just five months after receiving the treatment in Bologna, Carrie was back at her job, working first in the office until she recovered enough to go back to critical care nursing and 12-hour shifts. As the pain lessened, Carrie rediscovered a life that had been taken from her. She started walking without a limp. She began attending concerts and fireworks displays without the noise causing her pain to flare. And perhaps best of all, she was able to put away the pain pills, no longer having to rely on 98% of her pain medication.

But the fight hasn’t ended for Carrie. Not while others are suffering from the same condition that threatened to take her life. She launched and maintains a Facebook group called “CRPS Neridronate Study Support Group” that’s dedicated to helping others with CRPS by acting as a forum and providing information about the treatment offered only in Italy. “We felt like we belonged there,” she tells them about her experience in Italy. “They want us to get better.”

More than two years removed from the trip that gave her back her life, the trip that made her life worth living again, Carrie still finds it difficult to put this into perspective, tearing up when asked to talk about what Dr. Malavolta and her team mean for her and other CRPS sufferers.

“They are saints for what they did,” she says through her tears. “They give us hope.”

Author's Note: The neridronate treatment is not currently being offered at Policlinico Sant'Orsola-Malpighi in Bologna, but is currently being offered at Ente Ospedaliero Ospedali Galliera in Genoa.

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A panoramic view of Bologna, Italy. (GoneWithTheWind)