

# A Risk Worth Taking

The single mom from Texas was dying. But the procedure that could cure her could also kill her.

BY LISA COLLIER COOL

AT FIRST, Emily Nitz Woods's symptoms didn't seem serious. Her rings didn't fit because her hands were a little swollen. So were her ankles. Then she noticed something strange: Sometimes her hands would turn blue or purple and briefly stiffen as if she had frostbite. She consulted one doctor, who thought it might be an allergic reaction, then another, but neither was able to give her a diagnosis. Meanwhile, Emily, who'd been riding in horse shows since she was five, continued to compete and placed in the top ten for a national event.

But her hands were still giving her problems, and soon she couldn't control the reins like she used to. A rheumatologist finally solved the mystery in 1999 through careful analysis of her symptoms, medical history and a blood test for certain antibodies: She had scleroderma,



a chronic autoimmune disorder. The then-29-year-old mom from Plano, Texas, didn't know how to react. She'd never heard of the disease, which affects an estimated 300,000 Americans, mostly women.

No one knows what causes scleroderma, but experts believe it's the result of the immune system triggering the body to produce too much collagen, a protein found in connective tissues. Theories to explain the gender disparity include links to hormones, differences in inflammatory response or fetal cells from previous pregnancies. There are two main forms of the disease, and Emily had the more serious, which attacks not only skin but also blood vessels, joints and internal organs, including the heart, lungs and kidneys. Due to the dangerous complications, about 50 percent of people with this type die within five years of diagnosis.

"That was very scary to learn," says Emily, "but I told myself it wasn't going to happen to me."

**F**OR TWO YEARS after the diagnosis, Emily's energy ebbed and her hands grew increasingly swollen and stiff. She was forced to give up riding, which was very hard for her: "Showing and competing were the passions I lived for." Her doctor prescribed several medications for her swelling and pain. Emily also tried acupuncture and Chinese herbs. Nothing brought complete relief, but for a time she was able to continue her advertising job.

In early 2002, she married her boss, Kevin Woods, and in September their daughter, Emma Alexandra, was born. She was six weeks early but in perfect health: a five-and-a-half-pound beauty with big brown eyes and a full head of silky hair. "Emma was such a good baby, I could take her anywhere," says Emily, who settled into life as a stay-at-home mom. "Everyone told me how lucky I was." She was glad to learn that scleroderma is not passed on from parent to child.

But Emily's luck didn't last. In 2003, the disease scarred her lungs, leaving her too short of breath to push a stroller very far. Joints all over her body became painfully stiff, severely restricting her range of motion. Emily and Kevin had to hire a full-time nanny to look after Emma.

By January 2004, Emily was so disabled, she couldn't drive a car, dress or feed herself, or walk more than 15 feet. To add to her misery, her marriage fell apart, for reasons unrelated to her illness. She and Emma moved to a ground-floor apartment, since Emily was unable to climb even a single step. Friends, relatives and members of her church came in shifts to help, while the nanny looked after Emma, then 16 months. "I could feel my body starting to shut down, and I realized I was dying," Emily says.

That's when a friend sent her an article about a risky treatment that might help: a stem cell transplant, using the person's own stem cells. A machine extracts the cells, which are frozen until needed, from the blood.

The patient is then given high-dose chemotherapy to kill the faulty immune system that causes the disease. The hope is that by then transplanting the stored stem cells, which have the unique ability to become other types of blood cells, the patient will generate a new immune system—one that won't attack the body. While the infection fighters are being produced, a process that usually takes eight to ten days, the patient is dangerously defenseless against germs. Complications can include infections, lung congestion, liver disease, kidney failure and heart problems. Because of the hazards, transplants are given only to patients who are at high risk of dying in the next five years but aren't too ill to tolerate the rigors of treatment.

At the time, about 30 Americans with scleroderma had undergone stem cell transplants, and three of them died of complications. To reduce dangerous side effects, doctors at Northwestern Memorial Hospital in Chicago were testing a stem cell transplant they hoped would be less toxic because it doesn't use radiation. However, their method was then so new, they'd treated only five patients in a clinical trial. While there had been no treatment-related deaths, researchers were still evaluating the results.

Still, Emily felt hope bubble up. "It sounded like the answer to my prayers. None of the safer options



At 18, Emily won a U.S. National Saddle Seat Equitation Championship.

were helping, so I knew I had to do something drastic or Emma would grow up without a mother." Although the doctors were willing to accept Emily, her health plan refused to cover the \$75,000 cost because the treatment was considered experimental. After two appeals failed, her parents, Don and Joanne Nitz, who breed show horses in Holland, Michigan, took a second mortgage on their home to help pay for the transplant.

In April 2004, Emily said a tearful goodbye to Emma before flying to Chicago. Babies weren't allowed in the transplant unit, so the little girl would stay in Texas with Kevin for several weeks. Since Emily was in no shape to



**One limitation of the treatment: Emily's hands remain swollen, rigid and curled.**

travel alone, her mom accompanied her. Emily was so stiff, her arms and legs didn't bend much, and it was very hard for her to sit down in the wheelchair or on the plane. She couldn't get up from a seat on her own; her mom had to lift her. Even getting into a cab was an ordeal. Emily's brother, who met them at the Chicago airport, says, "She was stiff as a board. We had to lay her sideways across the backseat. Mom and I sat up front with the driver."

At the hospital, the two women met with Yu Oyama, MD, then director of the immunotherapy program. "Emily was suffering horribly. Not only was her skin hard, like a stone, but her body was almost totally frozen in place," says Dr. Oyama.

After two weeks of medical tests

followed by removal of the stem cells, Emily received four doses of chemotherapy in as many days. That sparked hot flashes and severe vomiting. Her weight dropped from 110 to 87 pounds on her five-foot-five-inch frame. She also slipped while getting out of bed and suffered a broken jaw, further impairing her ability to eat. To lift Emily's spirits, Kevin sent videos of Emma. "There was one of her splashing in the pool and another of her sleeping in her crib. I watched them over and over, wishing I could be with her."

On May 18, 2004, she received her intravenous stem cell transplant, an occasion the nurses dubbed her birthday, because it

was the birth of her new immune system. At first, she'd be highly vulnerable to infections but would then gradually gain resistance. If the transplant was successful, her immune system would normalize and no longer stimulate the production of excess collagen. After that, it was hoped, progression of the disease would be stopped, her skin would soften and her energy would improve.

By the third week of June, doctors thought it was working: Emily's blood counts were better, and she had enough white blood cells to fight infection. So they said she could leave the hospital. She was jubilant but soon learned she had to return, as her kidneys were functioning at only a fraction of their normal level. "It was a

huge emotional and physical setback," Emily says. "I was hoping I'd be seeing signs of improvement, but I was even worse off."

In early July, doctors arranged for her to receive outpatient dialysis in Texas so she could go home to her daughter. Even in this bleak situation, she was elated to find Emma and Kevin waiting for her at the airport. Since Emily was too weak to get out of her wheelchair, Kevin put the toddler in her lap. Emily wasn't sure if her daughter would recognize her after three months apart, but Emma did. "Mommy!" she exclaimed, playfully pulling off Emily's hat. The little girl was surprised to see that her mother had no hair, then stroked Emily's head with a smile.

**O**VER THE NEXT few months, Emily's blonde hair grew back as she endured dialysis three times a week. Each session took four hours and left her so debilitated that she dreaded the next one. When someone asked what she wanted for Christmas, she replied, "I just want my kidneys back." In January 2005, she got her wish. Her kidneys improved enough for her to stop dialysis. The transplant was finally kicking in. Her skin wasn't quite as hard and tight. Little by little, it softened and didn't look as shiny. "A really good sign was when I saw creases and lines on my skin," she says. "People with scleroderma like to get wrinkles because that means we're getting bet-

ter." As her skin loosened, so did her joints. It was easier for her to sit down and stand up. Her knees and elbows became more flexible.

"I went from being pushed in a wheelchair to being able to walk for over an hour," she says. "And I could drive again. That was huge, because I could shop at the mall, visit friends and go on Emma's nursery school field trip, without relying on other people to take me everywhere. It was wonderful to have my freedom back." Doctors agree that overall, Emily has had a tremendous turnaround, and three years after the transplant, there's still no sign of the disease returning.

Recovering has made her more reflective. "Now I don't take anything for granted. It's a gift to be able to go anywhere I want, play with my daughter, see her looking angelic as she sleeps. I'm so grateful to have her in my life, to love and live for."

Recently, Emily's parents offered to give Emma a riding lesson. The little girl, now four, eagerly accepted. When they reached the barn, Emily felt a familiar yearning. "Hey, do you think I could ride?" she asked. Her dad helped her mount, then she wrapped the reins tightly around her hands so they wouldn't slip from her awkward grasp. A little nudge was all it took to get the mare moving, first in a sedate walk, then a brisk trot. Gaining confidence, Emily urged the horse into a canter, her face glowing with pride.

"I only rode for five minutes, but it felt so great," Emily says. "I was literally back in the saddle again!" ■