

Emily Anew

By Emily Woods



People in their 20s do not worry much about health issues. Most are independent, and health is usually not near the top of their concerns. Health worries are for older people.

I was no different. Active best summed up my life. I became a U.S. National Champion horse rider, a springboard diver, played volleyball, kept in shape, and loved to shop. Then in the late 1990s health issues started climbing my list of concerns.

My hands and ankles started to show signs of Raynaud's, which was a minor worry. But by 1999 the swelling in my hands became noticeable. I was diagnosed with CREST. This little word transformed my life.

Soon, nothing seemed familiar. Scleroderma changed everything and I was angry about it. No more horse riding. No more competitions. No more exercising. And a lot less socializing. As the disease closed in I became deeply concerned about my future.

Advancing Symptoms

Symptoms in my ankles continued up the leg into my arms. My hands turned purple in the cold or if I became slightly emotional. My joints stiffened and the tissue inside hardened. Ligaments pulled tight.

By 2001 my fingers ulcerated, joints hurt, fatigue set in, and my skin got tight. I tried all common—and some uncommon—medications to relieve the symptoms. For a while these worked and I was able to continue at the advertising studio I worked for.

In spring 2002 I married my fiancé Kevin, and later that year I gave birth to Emma Alexandria. Doctors told me pregnancy could make my scleroderma worse, better or have no effect. I knew this was probably my only chance to have a child, so the uncertainty was

A young mother's scleroderma robbed her of an active life and would have robbed her of her daughter had she not aggressively sought a stem cell transplant. Today Emily Woods of Texas looks at life anew.

worth it. (After all, there was even a chance I could get better!)

However, my symptoms remained the same—and later advanced. My hands started to curl, range of motion decreased and organs were affected. My scleroderma had become diffuse.

Joy and Agony

My daughter was a joy. Scleroderma was the agony. The pain meds became more intense and my lung function decreased. Simple activities became harder and harder. We hired a nanny to help with Emma.

Before long I needed help almost around the clock. People from church, friends and family took shifts to help me at night and on the weekends.

By early 2004, I couldn't bend my elbows to feed myself, get dressed or pick anything up. I was emotionally defeated for a time. On top of this my marriage ended and I feared losing Emma and every ounce of independence I once had. My mother regularly flew back and forth from Michigan to take care of us. Kevin has remained a big part of Emma's life.

The Awakening

When I realized I would die unless something changed, I decided to aggressively fight back. My rheumatologist agreed to help. He said my fast-progressing, debilitating scleroderma made me a candidate for a stem cell transplant.

Stem cell transplants have been successful but insurance companies still consider this procedure experimental, meaning I'd need insurance company approval before moving ahead.

This would take a lot of time—maybe more than I had—so I got active, found Northwestern Memorial Hospital in Chicago and set up a consultation. (My insurance fears were real. It's been more than a year and half since the stem cell procedure and six appeals later and I'm still waiting to hear from them about reimbursement for costs.)

The Consult

I consulted with immunologist Dr. Yu Oyama and felt



confident putting everything in his hands. He did everything—the consult, the transplant procedure and monitored blood counts. I was shielded from the world because of the risk of infection.

The process was difficult, taking a couple months. My immune system was brought down to almost nothing through chemotherapy, even a common cold could create a serious problem. My weight fell to 88 pounds and I started having kidney problems toward the end of the procedure.

I was on dialysis for seven months. As the stem cells started to work, my kidney function went from six percent to 44 percent today. I am now off dialysis.

All the difficulty has been worthwhile because the results have been nothing short of a miracle. Besides the increased kidney function, my skin score test has dropped more than 50 percent.

Most importantly I can walk for hours (instead of a minute or less), get dressed, drive a car and—best of all—hold and play with Emma.

Those with a serious form of this disease should know there is hope. If anyone asks, I am always sure to mention a stem cell transplant may give your life back. It gave me mine—and I am grateful.

Emily Woods lives in Plano, Texas. She is glad to speak to anyone wanting an insider's perspective about stem cell transplantation. She encourages all patients to find a doctor who is proactive with their healthcare. "Lastly," she says, "don't throw in the towel. If I listened to some people I wouldn't be here now. Scleroderma is hard to conquer alone. My family and friends helped me through the challenges I faced at every stage of the disease. Don't try to go it alone." Her email is emily_annew@msn.com.

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