

## Monica & Helen Ramirez

### Scleroderma



In 2009, during a trip with my husband, I noticed my fingers changed color when I entered a cold room. I mentioned it to my best friend who was also my primary doctor at the time. As soon as she saw my hands, she saw it as a sign of Raynaud's phenomenon, ordered a test, and referred me to a rheumatologist. The rheumatologist diagnosed me with scleroderma and notified me of the life expectancy, which wasn't long.

When I was diagnosed, I was working as an operations manager in an international bank. I consider myself to be a warrior, and so I began to look for other options and specialists, who all gave the same diagnosis: chronic, degenerative condition, without a cure.

The second manifestation of scleroderma was my gastric reflux, which became so severe that I had to sleep sitting up, taking antacids, and not eating past six in the evening. I also avoided spicy foods, and anything heavily seasoned or acidic. I began to lose weight. No matter which precautions I took, I would still have gastric problems. Food would get stuck in my throat, and I suffered from abdominal inflammation, and vomiting. The gastroenterologist ordered exams that confirmed motility issues and gastroparesis. Medication helped the motility, but the gastric issues worsened. In 2011, after multiple hospitalizations and being otherwise confined at home, incapacitated and dependent on total parenteral nutrition and jejunostomy tube feedings, I weighed 70 pounds, and required a home health nurse in addition to assistance with activities of daily living. My prognosis was poor. All I could think about was my daughter, who had not yet graduated high school and how many dreams she had ahead.

Regardless of what happened, I continued having faith and believing in signs God sent me. In December of 2014 I was hospitalized due to an infection in my PICC line. During my hospitalization I had a cardiac pause of six seconds, which resulted in me getting a pacemaker.

A month after receiving the pacemaker, I had to see a cardiologist for a routine check. He happened to be married to a rheumatologist. I made an appointment with her, and my health began improving immensely.

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“For us this was not the final verdict, the doctors had only given a diagnosis but the one who had the last word was God.”

It's been 11 years since my diagnosis and I've had many complications, but I've found my new purpose in life, helping people with scleroderma. The Miami bilingual support group has given me energy and strength. It has blessed me. Though I have scleroderma, pulmonary fibrosis, Raynaud's phenomenon, gastroparesis, hypothyroidism, Sjogren's syndrome, Telangiectasias, and calcinosis, I have an entire medical team who stay up to date on research and make me feel like their favorite patient. On top of this medical team, I have my best friend and the best nurse in the entire world, my daughter, Helen. Helen graduated with a bachelor's degree in nursing last year and gives me 24/7 attention and care. I also have an angel who cares for me from heaven, my husband. He passed away in January 2021 from COVID-19. Most importantly, I have God.



**Helen:** Prior to my mom’s diagnosis I was a rather soft-spoken child, though my parents always encouraged me to be outspoken. At the time of the diagnosis, I was in high school. To say it was world-altering is an understatement. Because my parents had always encouraged me to speak up, I had a foundation that allowed me to not only be a caregiver but also her advocate.

At first the lack of information was panic inducing. There was nothing we could look up to see a prognosis. As my mother's health began to decline, I became her main caregiver. My aunt lived with us and she would cook and look after me. My father worked overtime trying to stay on top of the mounting medical bills.

I worked with her home health nurses so I could learn what to do to assist in her care. I changed her feeding tube dressings and did the feeds.



I also advocated for my mom when things didn't seem right. Once, a nurse came in, washed her hands, gloved up, and then proceeded to pick up trash from the floor. She threw it away and then attempted to touch my mother with those same gloves. I politely asked her to change gloves, and I guess it took her aback that a small, 17-year-old girl was correcting her behavior. She pushed back and said no. I remember my voice was shaking as I asked for her supervisor and requested a new nurse. On the outside I looked confident, but on the inside, I was shaking. I was so scared since I was always taught to respect my elders, but I knew I needed to advocate for my mom.

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Seeing my mother’s weight dwindle down, and hearing a physician suggest we take my mom home essentially to die, broke me. I just thought of all the things I would not have my mom for, like my birthday which was only a few weeks away, and then my high school graduation that spring, my college graduation, my wedding, and the birth of my first child. I remember as my mother prayed to God to keep her with me, I became angry. I remember telling God, “If you take my mom, you're not real and I hate you.” Being raised Catholic and being extremely involved in my religious community, this was rather odd. I remember my mom telling me “Regardless of what happens, I had you and that was my greatest gift. I love you forever, and I'll always be here watching you.”

It's been 10 years since that conversation. Though many things have changed, I am still constantly advocating for my mother. Starting the Miami bilingual support group has been a passion project for us both. I was able to share my nursing school graduation with my mom, as well as my engagement, and my wedding. I'm so grateful to have my father's voice always in my ear telling me what to do even though he isn't physically here with me anymore.

My mother has always been my best friend and I am eternally grateful to God to have shared these last 10 years with her. I'm looking forward to many more, and her meeting her grandchildren. I want families to know that this diagnosis is not a death sentence anymore. It's a rough journey, but there is always hope. ●

## Scleroderma

Scleroderma, or systemic sclerosis, is a chronic connective tissue disease generally classified as one of the autoimmune rheumatic diseases. The word “scleroderma” comes from two Greek words: “sclero” meaning hard, and “derma” meaning skin. Hardening of the skin is one of the most visible manifestations of the disease. The disease varies from patient-to-patient. Some facts about scleroderma are:

- Scleroderma is not contagious, infectious, cancerous or malignant.
- It is estimated that about 300,000 Americans have scleroderma.
- One-third of those people have the systemic form of the disease.
- Localized scleroderma is more common in children, whereas systemic is more common in adults.
- Female patients outnumber male patients about four to one.
- The onset of the disease is most frequent in people between the ages of 25 to 55.

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The Scleroderma Foundation

