The Erythromelalgia Association

Your EM Connection

TEA's Online Newsletter

September 2025

Two Powerful EM Stories

In this issue of TEA's EM Connection, we're proud to share the powerful stories of two brave and insightful women, Deborah and Sierra, who have generously documented their personal journeys with EM. We hope you find their experiences as inspiring as we do.

Deborah's story is told in a Q&A format, while Sierra's story is a personal narrative. We believe you will be moved by both.

Deborah's story:

Where were you born and raised?

I was born in California and raised in Boise, Idaho.

Where do you live now?

I live in Indian Land, South Carolina, just over the border from North Carolina.

Describe your immediate family.

I've been with my amazingly supportive husband, John, since we met in 1989. We've been married for over 34 years. Because of my erythromelalgia and neuropathy, we made the devastating decision not to have children, both due to my own suffering and the likelihood of passing on a terribly painful illness. It was one of the most heartbreaking decisions we ever faced. But we have two precious fur-babies that bring us immense joy. John and I often joke that we "must have used up all our luck finding each other". I'm deeply grateful for his love and unwavering support.

Describe your EM and how you were diagnosed.

Before 1991, I lived an active life, running, traveling, painting, ballroom and Latin dancing. I had just started my career as a flight attendant when I began having intense pain in both feet, which I initially thought was from overuse. It felt like walking on shards of glass. My doctor suspected a running injury and I went through multiple orthopedic surgeries. It wasn't until three years later that an intuitive neurologist recognized the symptoms of EM. He noticed the redness in my hands and face, not just my feet, and suspected something more was going on. At one point, we were seriously discussing amputating my foot just to get some relief. But thankfully my surgeon had good instincts. He believed the flushing condition would migrate and he was right. So, I'm thankful we didn't move forward with amputation.

How do you cope with your EM?

Honestly, it is still hard some days! Especially in the beginning, it felt impossible. I was so young, in my 20's, and active and ready to start a family when this strange horrible pain started. I couldn't accept how

strange horrible pain started. I couldn't accept how drastically and quickly my life was changing. Living in pain is very scary. I spent years looking for a cure, trying treatments, surgeries, medications, praying, and questioning everything. I didn't give myself space to grieve the life I lost.

But I also learned a lot about EM, and about myself. Over time, I learned I needed to make significant lifestyle changes alongside medical treatments. I also learned that immediate relief isn't always the best kind. For example, I used to soak in ice water for quick relief, but it damaged my skin, caused wounds and made the EM rebound flare so much more intensely painful. Now, I elevate my extremities, use a fan, and other gentler methods. It's not the quick relief ice water gives, but it's more sustainable and healthier.

Coping with a long-term illness is more difficult than people often realize. I've always been a positive person, and while I've had my fair share of "pity parties," I'm also genuinely grateful for what I still have. Not everyone knows how to support someone with a lifelong illness, and I don't fault them because it's impossible to relate unless you've lived it. That's why my husband's support has meant everything to me, and why being involved in TEA has been so healing. It connects me to others who truly understand.

Describe your involvement in TEA from the beginning to today.

I've been part of the community since before TEA even officially existed. Back in the mid 1990s, I connected with another person who had EM. He was part of a group email chain. We all exchanged stories, ideas, theories, and offered support to each other. Eventually one of those amazing people helped form TEA. I joined the board in 2003. I was nervous at first because I didn't feel qualified. But I came to realize that the desire to help matters more than any credential. Everyone on our board either has EM or loves someone who does. We are all volunteers, doing the best we can within our

volunteers, doing the best we can within our limitations. Being part of this group has given me a deep sense of purpose and connection.

What do you enjoy most about being a TEA Board Member?

That's easy! Making a difference and giving someone hope is one of the greatest gifts. When a person is newly diagnosed it is a frightening time for them. I was so grateful to have found supportive knowledgeable people before TEA, when I needed it most, and I wanted to give that back. Being able to listen, comfort, and share what I've learned means everything to me. Having this illness myself gives me a unique ability to empathize.

What do you do in your spare time?

I love spending time with my husband. While I'm not back to the active lifestyle I once had, I've found new ways to stay engaged. I jog in the pool with a float, and exercise in a cool room to help with my EM flares and improve my quality of life. I try to move every day, even if it's a different activity than what I loved doing before. I still paint occasionally. I also read a lot, usually medical articles, but I've come to enjoy audiobooks for pleasure.

What is your favorite book?

Speaking of audiobooks: The Comfort Crisis by Michael Easter. I like that he narrates it himself and approaches the topic from multiple angles. He shares statistics, data and research, he shares his personal journey, and also writes from a journalistic perspective. It's thoughtful, inspiring, and deeply human.

What is your favorite movie?

Collateral Beauty. It's one of those rare films that you can watch on a surface level or peel back like an onion and find layers of meaning in the writing. Each character has their own story, even the abstract ones: Love, Time, and Death. The character of Time speaks to me the most. As someone living with a painful chronic illness, these concepts take on a life

painful chronic illness, those concepts take on a life of their own. The film is beautifully written and incredibly moving. Bring tissues. My husband and I found it deeply healing.

What do you want people reading this to learn from it?

That life might not turn out the way you dreamed, but that doesn't mean it's over. If you give yourself permission to grieve, stay flexible, and keep faith, it is still possible to build a fulfilling life. Learn everything you can about your own situation so you can advocate for yourself or your loved one.

While there may not be a cure for erythromelalgia yet, there are many dedicated researchers, doctors, and organizations like TEA working hard to change that. One of my favorite lyrics once upset me, but now I understand it differently: "Feeling pain is a hard way to know you're alive, but someday, someone will make you glad you survived."

Pain is deeply personal and unique to each person. While I don't like it, and it's incredibly hard to live with intractable pain, it's also taught me compassion, patience, and empathy. So please: be hopeful, be proactive by educating yourself, be kind to yourself, lean into your faith, and allow yourself the grace you deserve on this bumpy path. And, know you are not alone.

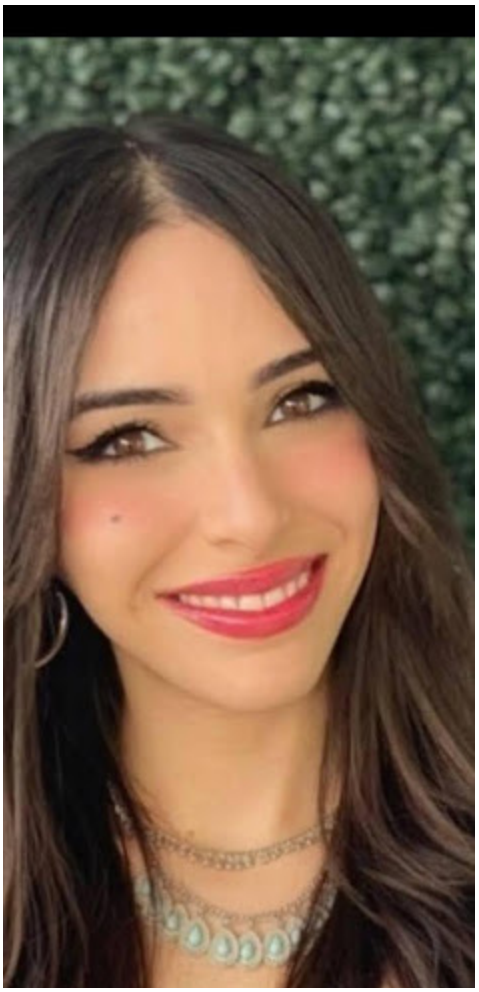
Favorite Quotes

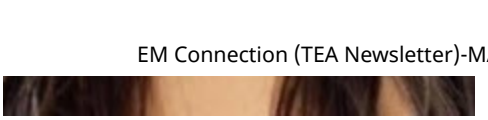
“Be kinder than necessary, for everyone you meet is fighting some kind of battle.”

And

“Life is not measured by the number of breaths we take, but by the moments that take our breath away.”

Sierra’s story:





My name is Sierra Domb, and I've lived with Erythromelalgia (EM) and co-occurring autoimmune issues since childhood. My symptoms include burning pain, swelling, redness, and heightened blood flow surging through my hands and feet. Although I enjoyed being outdoors and staying active, these activities were often difficult for me. Heat and movement increased my body temperature and blood flow, which triggered pain and discomfort.

I didn't have a name for what I was experiencing, and no one around me had heard of EM. When I tried to explain my symptoms, I was often met with bewilderment, and the visible effects EM had on my appearance were frequently met with shock and a lack of compassion.

Unfortunately, many children and adolescents with chronic conditions are not taken seriously. Their symptoms are often dismissed, and the difficulty of managing school, responsibilities, and social life while dealing with ongoing health issues is frequently overlooked. Instead of receiving support, pediatric patients are often misunderstood or told they are "too young" to have serious health problems, leaving them feeling unseen and isolated for not matching the expected image of a healthy, carefree young person. This expectation doesn't reflect the reality that anyone, regardless of age, can face health challenges.

It wasn't until young adulthood, while seeking medical attention for the sudden onset of Visual Snow Syndrome (VSS), that I was formally diagnosed with EM. During testing, doctors noticed the redness in my hands and feet, leading to further evaluation and tests that confirmed EM.

With a background as a neuroscience research collaborator and health communicator, I've focused on understanding how the brain and nervous system

influence EM. By supporting key brain systems, such as the hypothalamus, pituitary gland, and autonomic nervous system, I'm better able to manage heat sensitivity, pain fluctuations, hormonal changes, and autonomic imbalances that trigger flare-ups. Evidence-based practices that reduce stress, promote homeostasis, and harness neuroplasticity, like mindfulness, have also helped me decrease pain sensitivity and build resilience. I also manage my symptoms by staying cool whenever possible, consuming or gently applying chilled water as needed, portable fans, umbrellas for shade, and keeping my sleeping environment cool to prevent worse flare-ups and insomnia. Some medications have no effect, while others worsen symptoms or cause side effects, though experiences vary by individual. Although flare-ups are sometimes unavoidable and life doesn't always allow perfect management, I've learned what to expect and what helps me cope.

I'm sharing my story to raise awareness. If you're navigating EM, especially as a young person, and feeling discouraged, know that while you may face challenges others don't or need extra steps to stay comfortable, you can still find moments of happiness and lead a fulfilling life. I experience medical challenges, but the strength EM has required me to build has also made me more compassionate, knowledgeable, and resilient in managing my condition and navigating life. If anyone, including a doctor, lacks patience or compassion, they may not be the right fit for you. It can take time to find those who truly accept you as you are, but they exist. Do not try to be someone you're not or minimize your experience just to please others. In a world obsessed with productivity and the illusion of perfection, self-acceptance, authenticity, and self-care are actually some of the most productive things you can do. Life is hard enough, especially when facing a chronic condition. Whether you are struggling or not, whether you have EM or know someone who does, be kind to yourself and to others.

others.

Additions to TEA's Physicians List:

Do you have a physician who has diagnosed and/or treated your EM whose name you would like to share with other EM sufferers?

If so, please first ask your physician's permission to be listed on TEA's Physician Directory, and then submit their name, address, phone number and specialty to:

erythromelalgia.assoc@gmail.com

EM ZOOM Meetups:

The EM ZOOM Meetup meets on the 3rd Saturday of the month from 11:00 am to 12:30 pm PST (2:00 pm to 3:30 pm EST). Everyone is welcome!

Please contact pk.agarwal3@gmail.com to be added to the notification list.

Member Stories for TEA Newsletter:

Do you have a unique story about your life with EM to share with other EM sufferers? TEA is looking for member stories to publish in its online Newsletter, *Your EM Connection*. We have developed a suggested outline for submission.

Tell us:

- Your first name, age and area of US (or overseas country) where you live
- Describe your EM, when it began and how it was diagnosed
- In 500 words or less, tell us your story that will be of interest to other EM sufferers

Please e-mail your story to:

erythromelalgia.assoc@gmail.com