

# FootSteps

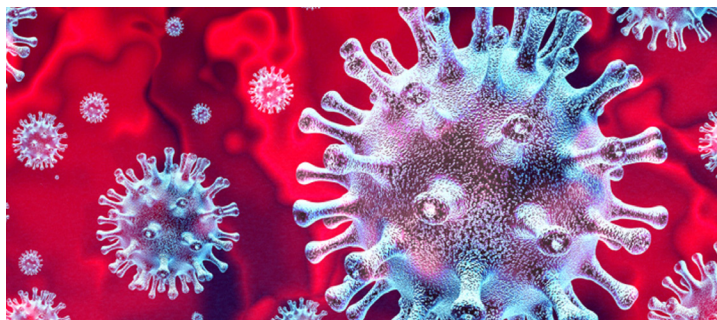
The newsletter for members of The Erythromelalgia Association  
*FootSteps* online: [erythromelalgia.org](http://erythromelalgia.org) or [burningfeet.org](http://burningfeet.org)

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## **NORD: COVID-19 should seem less threatening to people with rare disorders**

People with rare disorders know how to handle being sick. We're used to isolation. We're resilient. That's why the virus COVID-19 should seem less threatening to us, according to Marshall Summar, M.D., Director of the Rare Diseases Institute at Children's National Hospital, Washington, D.C. Dr. Summar spoke as part of a NORD webinar on March 31, 2020, with two other rare disease experts. COVID-19 is a respiratory illness, a coronavirus, the same sort of virus that causes the common cold. It spreads through tiny droplets created when an infected person sneezes or coughs. Should you develop cold-like symptoms, treat them as you would a cold or the flu. If you start running a fever with those symptoms, it's time to call your primary care provider. Many doctors and other primary care providers have started using telemedicine, which allows them to evaluate you without seeing you in person. If you need to go to a hospital to be treated, "don't panic," Dr. Summar advised.

People with EM or other rare disorders are no more likely to be infected with the virus than are members of the general public, but we should have a plan, in case, Dr. Summar said. Any plan includes knowing whom to call if we do get sick—usually our primary care provider, having a supply of prescription medicines on hand, find an activity you can tolerate for exercise, staying at least six feet away from other people and wearing a mask anytime we go out. Also in the plan should be shopping on off hours when the stores are less crowded and touching only the items we are going to buy. If possible have groceries



delivered and order other products online so they also will be delivered to your door.

"It's normal to have strong emotional reactions" when faced with abrupt change, said Albert Freedman, Ph.D., counseling psychologist and parent of a child with a rare disabling disease. When COVID-19 suddenly hit the news, our sense of safety was threatened and the first reaction for many was panic. But people in the rare disease community are adaptive, resilient and have experience with being isolated—exactly what we're being asked to do to keep the virus from spreading.

Dr. Freedman recommends that we focus on what is within our control:

- Taking care of ourselves by eating a good diet and getting enough sleep
- Staying connected to others
- Limiting time spent listening to the news
- Keeping a positive attitude

# FootSteps

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## The Erythromelalgia Association

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The intent and purpose of this publication is to inform those with EM or their friends and families—not, in any way, to provide medical advice.

## I am a caregiver

by Angela Demerle

My husband Ed became a “Man on Fire” in November 2005. Nothing has changed since then, and everything has changed since then. His case is severe—his feet burn every day, every hour of the day. His condition, woefully, has stayed the same. My life has changed profoundly; however, from that of average everyday spouse to caregiver, with a constant

emphasis on Ed’s wellbeing. As caregiver I have been at Ed’s side as he came to realize that his left foot would not stop burning even after three surgeries on the left great toe to “fix” the problem. As caregiver I came to the realization along with Ed that our active, travel-filled lives were seriously compromised by this condition. I planned the trips to the Cleveland Clinic and Yale Medical Center to get definitive diagnoses. I watched with love, hope and sympathy as Ed researched, e-mailed and phoned about alternative treatments that might help. None did. I rejoiced with Ed when we found a pain treatment doctor who could help.

As caregiver I admire the sheer will that Ed shows to live with EM every day. I wonder if I could cope with the loss of hobbies he loved that all involved physical activity. I am amazed at how he copes by adjusting to other more sedentary pursuits without feeling sorry for himself. As caregiver I sometimes feel down, but EM is all about adjustments, big and small. We golf in a cart rather than take hikes together. We go on vacations that are four hours’ drive, rather than a plane trip, away. We involve ourselves in groups that can give us support in our struggles. I look at others who don’t have these issues and am sometimes, but not often, envious. Others have their own kinds of problems. And I must always remember as a caregiver that as difficult as it may be for me, it is ever so much more difficult for Ed. Caregiver is a role that is so broad it is impossible to define. It is certainly not a role I took on voluntarily. Yet, I think a few words may suffice: I still have my husband by my side, burning feet and all, and for that I am so very grateful.





## National Geographic pain article discusses Yale research

"Nearly 50 million people in the United States and millions more around the world live with chronic pain," writes "A World of Pain" author Yudhijit Bhattacharjee in the January 2020 *National Geographic: Special Issue, Unraveling the Mysteries of Pain*. This comprehensive article explains what happens when we feel pain and where pain research is leading today.

Humans throughout the ages have felt agonizing pain and have had very few options for relief. In the late 1990s doctors began prescribing opioids like oxycodone for patients who experienced chronic pain—defined as pain that persists for more than three months. But the overuse and misuse of these drugs resulted in a spike in opioid drug addiction. Per *National Geographic*, in 2017, an estimated 1.7 million Americans had a substance abuse disorder stemming from the use of doctor-prescribed opioids. Since opioids were not the answer to chronic pain, the search for non-addicting pain relievers intensified.

"A World of Pain" asserts that the pain research being done at Yale, which is exploring the genetic origins of pain, may lead to novel therapies. Using inherited EM as a model, the Yale research group zeroed in on a protein—Nav 1.7. This protein powers nerve messages that travel along neurons, like messages sent from pain-signaling neurons in the skin, via the spinal cord, to the brain. Led by Stephen G. Waxman, M.D., Ph.D., the Yale researchers found that mutations to the EM gene yield malformed versions of the Nav 1.7 protein, a sodium channel. In IEM, the result is that pain-signaling neurons bombard the brain with pain messages constantly, causing burning sensations on the



Pamela Costa, Ph.D.

face, feet and hands. The article describes the constant burning Pamela Costa, Ph.D., experiences because of IEM. TEA member and clinical psychologist in Tacoma, Washington, U.S.A., Pam describes her pain as "inescapable."



Yudhijit Bhattacharjee,  
author of "A World of Pain"

"The discovery that Nav 1.7 can open or close the floodgates to pain signals has made Nav 1.7 an attractive target for researchers looking to develop pain medications that don't pose the risk of addiction," the article reports. Drug companies are on the hunt for substances that will block just Nav 1.7 and not the other sodium channels, one of which controls hearing. But such a compound has not yet been found, although Dr. Waxman remains confident that non-addictive pain medications will be developed.

"A World of Pain" also describes the findings of other pain research. A recent British study involved 300 patients with shoulder pain allegedly caused by a bone spur. Researchers divided the patients into three groups. One group had surgery to remove the spur, the second group was led to believe it had had the operation, and a third was sent home with no treatment. The group that had the surgery and the group that thought it did had similar levels of pain relief. One of the study's authors reports, "The pain relief the patients are getting is just driven by a placebo effect." Findings of still other research studies have shown how actual pain relief can occur if the patient is expecting reduced pain.



Electrophysiologist Brian Tanaka, Ph.D., analyzes data collected from pain-signaling neurons that carry EM mutations.

The full article is available online at [nationalgeographic.com](https://nationalgeographic.com), for those with a digital subscription.

The January 2020 *National Geographic: Special Issue, Unraveling the Mysteries of Pain* is available at your local library.





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**Raising Awareness.**

**Raising Research Funds.**

**Raising Hope.**

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## TEA FootSteps

### New TEA T-shirt spurs appeal donations

For the first time during an appeal, a gift of a new TEA T-shirt was sent to those donating \$75 or more. During this, the 2019 Annual Appeal, almost \$19,000 was donated and those who qualified by now have received their T-shirts. After subtracting costs for the T-shirts and postage and handling, TEA realized net donations of \$17,800. TEA thanks donors for their generous gifts. Now, just by wearing the T-shirts, we are raising awareness of EM—another way to support the mission of the organization.



TEA board member  
Deborah Mosarski  
modeling the TEA T-shirt