In the record books, Kristle Lowell is known as the USA Gymnastics Team athlete who won the 2013 world double-mini trampoline title. To her teammates, though, she’s known affectionately as “Icy Toes.” That’s because the 22-year-old tumbling and trampoline champion always wears leggings—and headbands and long-sleeved tops—during indoor practices. Kristle has Raynaud’s phenomenon (aka Raynaud’s disease or Raynaud’s syndrome). Her hands and feet become painful and numb when exposed to cold. “When your feet get numb and you can’t feel them, it’s dangerous,” the Chicago resident explains. “If you can’t use your toes to help balance, you can fall off the trampoline and get seriously hurt.” During competitions Kristle must be barefoot, but when practicing she undergoes an elaborate series of exercises to warm up, and she wears special shoes to stay warm but flexible. “All gyms are cold in winter,” she says, “about 60 to 65 degrees, which is normal for any athletic facility.”

**WOMEN AFFECTED FAR MORE**

Kristle is not alone. According to the Raynaud’s Association (RA; raynauds.org), a staggering 15 to 30 million Americans—5 to 10 percent of the population—have Raynaud’s. The vast majority of those diagnosed with the condition—90 percent—are women.

This painful and sometimes debilitating disorder causes spasms in the blood vessels that interrupt blood flow to the fingers, toes, nose, and ears. Exposure to cold triggers the episodes, typically causing the affected area to turn white, then blue and red. Emotional stress may also cause an attack.

According to the RA, an astounding 80 percent of sufferers do not even know they have the disorder and do not seek treatment. There is no formal test to diagnose it and no approved drugs to specifically treat it. “Too many Raynaud’s sufferers dismiss their symptoms as being due to ‘poor circulation,’” says Lynn Wunderman, founder and chair of the RA. “In a sense that’s true, but there’s a medical cause for poor circulation—and sometimes it can be serious.” Raynaud’s may be the first sign of an underlying disease such as scleroderma, lupus, or rheumatoid arthritis (“secondary” Raynaud’s), but most common is the “primary” form—not linked to another medical condition.

Simple blood tests, including an antinuclear antibody test, can help determine if Raynaud’s is primary or secondary.

Kristle recently learned that in her case, Raynaud’s is a symptom of an underlying disorder. In 2014 she was diagnosed with Ehlers-Danlos syndrome, a connective tissue disease that affects blood vessels, bones, skin, and other organs.

**CANCER AND RAYNAUD’S**

Researchers also have found that some types of cancer can cause secondary Raynaud’s, particularly those that develop in the blood, bone marrow, and immune system. These include lymphoma, multiple myeloma, and acute lymphoblastic leukemia. Secondary Raynaud’s can also be a side effect of taking certain medicines, including some types of
anti-migraine medications, such as Imitrex® (sumatriptan) and Ergomar® (ergotamine); beta-blockers (used to treat high blood pressure and heart disease); some chemotherapy medicines; decongestants; the contraceptive pill; medicines used in hormone replacement therapy; and some medicines used to treat high blood pressure, such as angiotensin-converting enzyme (ACE) inhibitors and Cata-

pres® (clonidine).

Like many other Raynaud’s sufferers, Lea Ann Andersen, a 59-year-old former member of the US Marine Corps, was diagnosed long before other health issues were recognized. The Texas resident initially sought medical treatment “because I was freezing all the time,” she says. She was diagnosed in 1990 with carpal tunnel syndrome and then, in 1993, with Raynaud’s. “I had ulcers on my fingertips from the Raynaud’s that would take months to heal,” she says.

When gastrointestinal problems arose, Lea Ann’s doctor said she had lupus. It wasn’t until 1997 that the lupus diagnosis was changed to scleroderma, a life-threatening autoimmune, connective tissue, and vascular disease that can affect skin, muscles, joints, lungs, kidneys, and other organs.

But more bad news was ahead. Ten years after the scleroderma diagnosis, Lea Ann was diagnosed with breast cancer—a triple negative, Stage IIA, invasive ductal carcinoma. She attributes the cause of the cancer to her time at Camp Lejeune, where she trained during the late 1970s. “While I was undergoing chemotherapy in 2008, I received a letter from the Department of the Navy informing me that the water at Camp Lejeune was toxic while I was there. It contained PCE [perchloroethylene], TEC [tetrachloroethylene], and other toxic chemicals that we drank, had our food cooked in, and showered in,” she says.

“They said it wasn’t likely, but there was a slight possibility that it could cause scleroderma, breast cancer, and 13 other diseases,” Lea Ann continues. “My oncologist said it could have taken 20 years for the cancer to mutate.”

During treatment for breast cancer, Lea Ann faced several complications related to Raynaud’s. The Neulasta® (pegfilgrastim) used during chemotherapy made the condition worse; and, to prevent the Adriamycin® (doxorubicin) she received intravenously from making her fingernails fall off, a nurse told Lea Ann to hold an ice pack until the IV was finished—not a practical solution for someone with Raynaud’s.

PRIMARY RAYNAUD’S MOST COMMON

Fortunately, most Raynaud’s is primary, not associated with an underlying disorder.

That is apparently the case for Barbara Gruen, PhD, a 66-year-old former school administrator from New York. “Early in my career, when I was working in a stressful job, I noticed that my hands and feet turned purple when I was under stress,” she recalls. “I didn’t think to see a doctor about it, but I mentioned it during my annual physical. As the doctor was leaving the exam room, he turned and said almost as an afterthought, ‘Oh, you have Raynaud’s. Stay out of the cold.’”

Stress, more than cold exposure, was the primary trigger for Barbara. When she developed breast cancer in 2006, the Raynaud’s returned with a vengeance. “My feet would turn black,” she says. Now that she is retired, stress-induced Raynaud’s episodes are rare, “but I am very sensitive to cold these days,” she says.

“I wear silk gloves under down mittens, I keep myself covered with a down coat and fur hat, I avoid heavily air-conditioned places, and I don’t shop in stores that are cold.”

Although avoiding the cold—and stress—is the first line of defense for Raynaud’s sufferers, it is not always practical to do so. To date there are no drugs for Raynaud’s that have been approved by the US Food and Drug Administration (FDA). Many sufferers find relief with off-label drugs, however, such as calcium channel blockers and phosphodiesterase-5 (PDE5) inhibitor drugs approved for erectile dysfunction (ED). Despite the efficacy of drugs earmarked for ED for Raynaud’s patients, getting access to them is proving to be a battle. They are expensive, and insurance companies usually won’t cover them.

Pharmaceutical companies have continued to conduct clinical trials and seek FDA approval for these drugs. The RA’s Lynn Wunderman says that there is a wealth of data, research, and articles in well-respected medical journals that conclude that ED drugs provide real benefits to patients.

While the search for effective drug treatments—and a cure—continues, the Raynaud’s Association is working to provide awareness and education via its website, Facebook, Twitter, video, quarterly newsletter, blog, discussion forum, and a comprehensive guide, The Cold Facts on Raynaud’s and Strategies for a Warmer Life (available at raynaudsguide.org).