

Mystery disease unraveled by Stanford neurologist

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Safwan Jaradeh, left, diagnosed Laderriere with an autonomic disorder.

(Medical Xpress)—At first, Marc Laderriere thought that his decreasing energy was just age catching up to him—he was about to be 50. But something about that explanation didn't sit right.

"At one point, one of my doctors said, 'This is definitely a little strange. I don't know what you have, but it could be nerves,'" Laderriere recalled.

He was experiencing a set of symptoms that were unusual but did not strike him as significant: <u>Hot weather</u> sapped his strength and made him dizzy, but he was sweating less. In cool weather, he never got <u>goose</u> <u>bumps</u>.



As a young man growing up in France, Laderriere had always been active. "I did a lot of skiing, a lot of swimming," he said. When he came to work in the United States, as a director of wine sales for the Vina Robles Winery & Vineyards in Paso Robles, he said he became a workaholic. "I completely accepted that way of life," he said.

The more he traveled for his job, the less time and attention he paid to his health until he recognized, with some discomfort, that he was not in such great shape any more. He knew he should add exercise to his daily routine, but the fatigue he felt was overwhelming.

Laderriere, who lives in Paso Robles, started first with visits to local doctors. He had a variety of standard tests, with the thought that he might have developed diabetes. That was not the case. When one physician suggested it could be nerves, he went to see a local neurologist who sent him back to his original physician, still without a diagnosis. His symptoms continued and, finally, a local doctor suggested Stanford Hospital & Clinics.

During his first visit, he met with a group of physicians who asked him a lot questions,. "They were picking my brain," he said, "asking me, 'What's wrong with this?' I did not think to mention to them that I wasn't sweating, but my wife was with me and she did. One of the doctors said, 'Hmm, I think you may want to meet Dr. Jaradeh.'"

Knowing what to look for

Safwan Jaradeh, MD, is the director of Stanford's autonomic disorders program and a professor of neurology and neurological sciences. He is board certified in neurology, clinical neurophysiology, electrodiagnostic medicine and autonomic disorders. Worldwide, he estimates, there are only about 150 physicians with expertise in a biologic system most take for granted because its activities happen, when all goes well, without



conscious thought. Treatment facilities with laboratories set up to test for these disorders are even more difficult to find. With Jaradeh's arrival at Stanford, the tally of such labs on North America's West Coast doubled—to two.

The challenge for diagnosis and care begins with the complexity of the autonomic system. Only in the last 40 years has its biology, chemistry and interconnections become more known, yet it is the part of the nervous system that develops first. In addition, because the system affects more than one organ, its care requires special knowledge of each of those organs. "In a nutshell, it's responsible for your well-being," Jaradeh said. "It's the reason your heart beats. It's the reason why your stomach digests food. It's the reason you can hold your bladder if you're busy. It's the reason that you shiver if you're in a cold room and sweat if you're in a hot room."

Its functions are so ingrained to a sense of normalcy that when it begins to malfunction, regardless of which particular organ is affected, "people don't feel well," Jaradeh said. "They don't feel rested. They're completely drained. The inner balance is completely derailed."

The system reaches throughout the body and is especially crucial in the brainstem, where it connects the upper brain to the spinal cord and sends signals to the deepest parts of the brain. Dysfunction there can cause anxiety, depression and sleep disturbances. The range of symptoms might begin with something relatively small—like Laderriere's inability to sweat—or affect something like blood flow to the heart. "Sometimes patients present with unexplained arrhythmias where the heart palpitates like crazy," Jaradeh said, "and our cardiology colleagues cannot find a cause."

Because the autonomic nervous system has a significant presence in the digestive system, some patients develop major gastrointestinal issues,



Jaradeh said. "They can't eat very well or they feel bloated after eating a small meal, or they eat and pass out or they have constipation for days or they vomit in cycles." Heat intolerance, such as that experienced by Laderriere, means patients will develop heat stroke very quickly.

Half of those with autonomic disorders will have more than one part of the system affected, Jaradeh said. And, for a variety of reasons, including the lack of specialists who recognize the underlying systemic cause, people with such disorders may go for years without an accurate diagnosis. "Sometimes symptoms can't be well characterized," Jaradeh said. "A person will say, 'When I change position, I get dizzy.' The initial inclination is to say, 'There is something going on with your inner ear.' So that person goes to see the ear, nose and throat specialist—who can't find anything. Or it might be suspected that it's medication, so the medication is changed. Finally, somebody will realize that maybe it's the blood pressure that's changing. Then the blood pressure is measured by having the person gets up from a supine position, and that's when someone realizes that the blood pressure has dropped—and that there's something wrong with this person's autonomic system."

Finding a cause

Another confusing factor is the range of triggers for autonomic system disorders. They can be a secondary symptom of diabetes, Parkinson's disease and infections like tick-borne Lyme disease, or they can appear independently. Laderriere, it turns out, had had Lyme disease without knowing it. Jaradeh treated Laderriere's Lyme disease with an extended course of antibiotics to make sure that he did not still have an active infection.

Like many people who develop an autonomic system disorder, Laderriere had gone so long without diagnosis that he had begun to doubt what he felt going on in his body, Jaradeh said, adding: "He clearly



has something real, but he was beginning to be concerned that he was imagining his symptoms." Many patients may also go from doctor to doctor, looking for an explanation for a set of symptoms, which, like Laderriere's, seem simple and complex at the same time. "It is not uncommon for me to see patients who come with a large volume of medical records that when sifted through show a common thread," Jaradeh said. After a bit of education about what's going on, primary physicians and other types of specialists can become "great partners in care," he said.

Another frustration for patients can be the slow rate of recovery. The autonomic system's <u>nerve</u> fibers do not have a sheath that guides their growth and acts as a protective layer. Without that protection, they are more fragile; without that guide, they take longer to regain strength and normal behavior. "It doesn't mean that regrowth won't happen," Jaradeh said. "It's just a long tunnel before you get to the light."

There are yet no cures for autonomic system disorders. But recognizing that such a disorder is the source of a patient's symptoms allows doctors to treat those symptoms more effectively.

Trusting in the future

From the various tests that Jaradeh conducts with each visit, Laderriere is showing signs that his system is "on the slope of recovery," Jaradeh said. He has seen no further spread of disease within the autonomic system, and some areas have improved. "I think he will continue to regain function," Jaradeh said.

For others with similar issues, "the horizon is very promising," Jaradeh said. "The field is wide open, and the opportunities for interactions between physicians are very great and the choice of areas for research is unlimited." Possibilities include focusing on what neurotransmitters in



the brain are active in response to various levels of blood pressure, and connecting that to electrical activity in the heart. "Or you could focus on hormones," Jaradeh said. "We see patients who are sometimes misdiagnosed with early menopause who are actually having an autonomic problem. The ultimate future would be to see if we can figure out something in terms of the genetics of these issues—the sky is the limit."

Laderriere is willing to be patient. He is working with Jaradeh to see which medications will mitigate as many of his symptoms as possible. "I still don't sweat, so that's going to be the next stage of recovery," he said. "We're going to have to discover more with Dr. Jaradeh about what's to be done. He's so bright and has so much information. I feel I am in good hands—there's no doubt. We'll get there."

Provided by Stanford University Medical Center

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